Department of Psychology

Maynooth University

Head of Department: Dr Michael Cooke

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Family-focused practice in mental health services in Ireland: exploration and implementation

PhD Scholar: Christine Mulligan, BA (Hons) in Psychology

Supervisors: Professor Sinéad McGilloway & Dr Mairead Furlong

Maynooth University Department of Psychology and

Centre for Mental Health and Community Research

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Acronyms

ACE	Adverse Childhood Experience
ACAMH	Association for Child and Adolescent Mental Health
ACOPMI	Adult Child of Parent with Mental Illness
AICAFMHA	Australian Infant, Child, Adolescent and Family Mental Health Association
AMHS	Adult Mental Health Services
CAMHS	Child and Adolescent Mental Health Services
CHO	Community Healthcare Organisations
COPMI	Children of Parent with a Mental Illness
COREQ	Consolidated Criteria for Reporting Qualitative Research
CSCs	Children's Services Committees
CYPSCs	Children and Young People's Services Committees
DoH	Department of Health
DoHC	Department of Health and Children
EIF	Early Intervention Foundation
EIP	Early Intervention Psychosis
FaPMI	Family Affected by Parental Mental Illness
FCS	Families, Carers Supporters
FFI	Family Focused Intervention
FFP	Family Focused Practice
FT	Family Talk
GDPR	General Data Protection Regulations
HSCB	Health and Social Care Boards
HSE	Health Service Executive
MHI	Mental Health Illness
MHS	Mental Health Services
MRC	Medical Research Council
MU	Maynooth University
NI	Northern Ireland
TFNI	Think Family Northern Ireland
PBCM	Preventative Basic Care Management
PMI	Parent with Mental Illness
PMHD	Parent with Mental Health Difficulties
PPI	Public and Patient Involvement

PSI	Psychological Society of Ireland
QoL	Quality of Life
RCADS	Revised Children's Anxiety and Depression Scale
RCT	Randomised Control Trial
RoI	Republic of Ireland
SCARED	Screen for Child Anxiety Related Disorders
SCORE	Systemic Clinical Outcome and Routine Evaluation
SDQ	Strengths and Difficulties Questionnaire
STV	Sharing the Vision
TFNI	Think Family Northern Ireland
UN	United Nations
VfC	Vision for Change

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salvaging loose lumps of coal, freed as the cart jerked over the cobblestones, left my father with a deep sense of shame. During her formative years, my mother lived in the tenements as her mother recovered from tuberculosis in St Mary's in the Phoenix Park. The countless adversities which they lived through robbed them of the opportunity to become aware of the importance of education. Before she died, mum took great pride in knowing that her daughter was the first of countless generations to achieve a degree and undertake a PhD. I wish she were here to see the final bound thesis.

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Research Summary

Background

An estimated one- to two-thirds of adult mental health service (AMHS) users have dependent children, while similar proportions of child and adolescent mental health service (CAMHS) users are living with at least one parent with a mental health disorder. Further evidence suggests that approximately 23% of children are living with parental mental illness (PMI) and have a substantial risk themselves (of 41%-77%) of developing a mental health illness. It is important, therefore, to advance family-focused or *'think family'* approaches within mental health services in order to address the needs of *both* parents and children.

Aims/Objectives

This research involved three separate, but related studies conducted as part of a larger project called 'PRIMERA' (**P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies). The overarching aims of the PRIMERA project were to identify, implement, and evaluate a family-focused intervention for families where a parent has a mental health disorder and more broadly, to begin to promote a *think family* care delivery agenda in Ireland. The specific objectives of the research reported here, were to: (1) understand the extent of, and commitment to, family-focused practice (FFP) within statutory mental health services in Ireland, contextualised with reference to the international literature **(Study/Publication One)**; and (2) to explore the experiences and views of family members and mental health practitioners who respectively took part in, or delivered, an evidence-based 6-8 week intervention called *Family Talk* (*FT*) which was identified as part of the PRIMERA project, for use in Ireland to support families with PMI **(Studies/Publications Two and Three).**

Method

An initial scoping study was conducted to: (1) establish, by means of an Expression of Interest 'survey', the nature and extent of family-focused practice (FFP) being undertaken in adult (N = 114) and child (N = 69) mental health services in Ireland; (2) review the international literature;

and (3) to identify and liaise with interested service sites to promote FT implementation. A primarily qualitative process evaluation was then conducted; this was nested within a Randomised Control Trial (RCT) undertaken as part of the larger PRIMERA project. Semi-structured interviews and focus groups were carried out with family members (n=45) who had taken part in the FT intervention, and a purposive sample of practitioners and managers (n=41) who had delivered or facilitated FT across the 10 participating RCT sites. All interviews and focus groups were audio recorded (with consent), transcribed verbatim, and analysed using constructivist grounded theory to identify key themes and subthemes.

Results

The results of the scoping study indicated a very low level of FFP within mental health services in Ireland. It was decided, therefore, on the basis of a subsequent review of the literature undertaken as part of the larger PRIMERA project, to implement and evaluate FT. Two-thirds of the participating sites which had initially agreed to implement FT (10/15), recruited families to the programme (and the research), albeit with varying degrees of success. The RCT findings, based on a total of 83 families at baseline, are reported elsewhere (Furlong et al., 2024).

The process evaluation findings indicate a high level of intervention acceptability among families and practitioners, with approximately two-thirds of both cohorts reporting substantial benefits, including reduced stigma, increased service-user confidence, and improvements in family communication/relationships. Interagency collaboration, coupled with strong organisational and managerial support, were significant enablers of change. Several challenges were identified, including difficulties in identifying/recruiting families, delays/stoppages due to the COVID-19 pandemic, and questions regarding the suitability of, and capacity to sustain the delivery of, a whole family intervention within services that are traditionally siloed and primarily driven by a biomedical model of care. These findings were used to inform the development of an initial programme theory to try to better understand how the *FT* programme led to the outcomes reported both here and in the RCT.

Conclusion

The findings reported here, provide important and useful insights into the experiences and attendant complexity of implementing, and participating in, a family-focused intervention for families with PMI, and especially in a jurisdiction that lacks the necessary national legislative and policy supports. Positive experiences were reported by the majority of families and mental health practitioners and managers in this research. Furthermore, the successful implementation of FT in several adult and child mental health services demonstrates the possibility of a 'no wrong door' approach for families where a parent has a mental health disorder. However, there remain complex and systemic barriers to implementing and sustaining a *think family* approach within mental health services in Ireland.

Author Contribution to the Published Studies: Chapters Four, Five, and Six

The PRIMERA research team was led by Professor Sinéad McGilloway (SMcG) as Principal Investigator, who conceived the project and who applied for, and secured, the funding. Dr Mairead Furlong (MF) managed the project on a day-to-day basis and co-led the design and implementation of the project. **Christine Mulligan (CM)** was the doctoral candidate who was primarily responsible for the process evaluation and who also contributed extensively to, and co-led, Phase One of the project (i.e. the scoping study). Other team members and their roles included: Sharon Lisa McGarr (SLM) (Fieldwork Co-ordinator); Dr Colm McGuinness (CMcG) (Statistician); Dr Siobhan O Connor (SO'C) (Fieldworker); Dr Nuala Whelan (NW) (RCT consultant); and Dr Fergal Rhatigan (FR) (Data Entry).

Publications for the PhD

Chapter Four:

1. **Mulligan, C**., Furlong, M., & McGilloway, S. (2020). Promoting and implementing family-focused interventions for families with parental mental illness: Scoping and installation. *Advances in Mental Health*, 18(3), 202–216. https://doi.org.jproxy.nuim.ie/10.1080/18387357.2019.1614466

Author contributions

C.Mulligan (Lead author) co-designed and co-conceived the design of the study. She conducted the majority of site visits and collated the findings. She also helped with the review of the literature and co-identified, and appraised, the Family Talk Intervention. She prepared initial drafts of the paper and prepared all boxes and figures.

M.Furlong (second author/reviewer) co-designed and co-conceived the design of the study. She undertook databases searches and led on the initial review of the literature and the co-identification and appraisal of the Family Talk intervention. She also contributed to the reviewing and drafting/editing of the paper.

S.McGilloway (Principal Investigator [PI] and co-author) co-designed and co-conceived the design of the study. She also supervised and advised on the co-identification and

appraisal of the FT intervention, the methodological approach, manuscript compilation and the reviewing, and drafting/editing of the paper.

(Advances in Mental Health is a journal for promotion, prevention and early intervention approaches to mental health.)

Chapter Five:

2. **Mulligan, C.,** Furlong, M., McGarr, S., O'Connor, S., & McGilloway, S. (2021). The Family Talk programme in Ireland: A qualitative analysis of the experiences of families with parental mental illness. *Frontiers in Psychiatry,* 12, 783189-783189. https://doi.org/10.3389/fpsyt.2021.783189

Author contributions

C.Mulligan, M.Furlong and S.McGilloway conceived and designed the study. C.Mulligan conducted interviews and coded transcripts, with 25% of transcripts independently coded by M. Furlong, S.McGarr and S. O'Connor. C.Mulligan prepared the initial draft, with subsequent drafts undertaken by M.Furlong with input from SMcGilloway, C.McGuinness and S.McGarr. All authors contributed to the writing of the article and approved the submitted version.

(Frontiers in Psychiatry publishes rigorously peer-reviewed research across a wide spectrum of translational, basic and clinical research. This edition was the second edition of a special interest research topic on parents-with-mental-andor-substance-use-disorders-and-their-children-volume-ii.)

Chapter Six:

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Author contributions

C.Mulligan, M.Furlong and S.McGilloway conceived and designed the study. C.Mulligan conducted interviews and coded transcripts, with 25% of transcripts independently

coded by M.Furlong, S.McGarr, and S.O'Connor. C.Mulligan prepared the initial draft, with subsequent drafts undertaken by M.Furlong, with input from S.McGilloway and S.McGarr. All authors contributed to the article and approved the submitted version.

The author's contribution to three additional papers are outlined in Appendix A.

Chapter One

1.1 Introduction

An estimated one in eight individuals, or approximately 970 million people worldwide, are living with a mental health illness/disorder, with studies suggesting a lifetime prevalence as high as 68% for women and 55% for men (Nicholson, 2010; Nicholson & Clayfield, 2004). Many of these individuals will, at some stage, require formal mental health intervention either through adult mental health services or primary care. Many service users are now parents (Rayner et al., 2021) due, at least in part, to significant improvements in aspects of mental health service (MHS) provision, such as the process of deinstitutionalisation from hospital to community care, and the development and greater availability of psychotropic medication; these kinds of changes have enabled services users to participate more fully in society, thereby also indirectly increasing their likelihood of having children (Brennan, 2014). Indeed, estimates from the US indicate that 33% to 65% of adult mental health service (AMHS) users are parents (Nicholson, 2010; Nicholson & Clayfield, 2004). More recently, a national census study conducted in Norway in 2013 found that 36% of AMHS users had children under 18 years old (Ruud et al., 2019), while the findings of an Australian study of service users receiving outpatient care, suggest that the proportion who were parents of <18s varied considerably from 12% to 45% (Maybery & Reupert, 2018); the factors underpinning such variation in PMI prevalence rates are discussed in more detail below.

In addition, estimates from the US indicate that 35% to 60% of those who attend Child and Adolescent Mental Health Services (CAMHS) live with a parent with a mental illness (Nicholson, 2010; Nicholson & Clayfield, 2004). A recent scoping review on the prevalence rates of PMI among CAMHS service users across a range of countries (e.g. Canada, France, Hong Kong, India, UK, and USA), found that approximately 36% are living with a parent with a mental health disorder (Campbell et al., 2021). Furthermore, a recent UK national retrospective study of children aged 0-16 years, found that over half (53%) were deemed to have a cumulative risk of

living with maternal mental illness by the age of 16 (Abel et al., 2019). While it is difficult to identify a direct linear causal relationship between PMI and child mental ill health, the existing evidence suggests that children of a parent with a mental illness (PMI), henceforth referred to as 'COPMI', have a significantly increased risk of psychopathology across the life course, thereby suggesting an association of some kind (e.g. Christiansen et al., 2019; Dean et al., 2010; Hosman et al., 2009; Kamis, 2021; Nurius et al., 2015; Patrick et al., 2022; Reupert et al., 2022; Ruud et al., 2019).

It is also important to note the challenges in establishing precise mental health prevalence rates for PMI and their children (where applicable). For example, there is considerable variation in the methods used to collect these data, including top-down (e.g. national population statistics), or bottom-up (e.g. service utilisation) approaches that are typically used to capture data across different time periods (Gatsou et al., 2016; Maybery et al., 2015b). For instance, a recent review by Maybery and Reupert (2018), based on nine studies conducted internationally, found that a number of different approaches have been used across studies to ascertain the overall prevalence rates of PMI. These include different methods (e.g. patient survey/clinician audit) and varying timeframes (e.g. ranging from one-day to two years) as well as the use of a range of demographic variables (i.e. relationship status, sex, gender) across different settings/contexts (i.e. inpatient and outpatient)

The challenge of establishing prevalence rates is compounded by the fact that not all individuals access services; for example, in the United Kingdom (UK), approximately one quarter (25.6%) of those attending primary care require support for common mental health difficulties such as depression or anxiety, yet almost one in five (17%) never seek professional help (Rayner et al., 2021). Furthermore, services do not routinely capture information on parental status for those who do seek professional mental health support (Golden et al., 2020; Reupert et al., 2018). For instance, the '*UK Adult Psychiatric Morbidity Survey*', which has been conducted every seven years since 1993, contains no details on the parental status of service users

(McManus et al., 2016). It is perhaps not surprising, therefore, that *"…up-to-date information about the numbers and ages of children and adolescents living with parental mental illness in the UK throughout childhood is scarce"* (Abel et al., 2019, p. 292). Likewise, the '*Annual Report on Irish Psychiatric Units'* in Ireland - which recorded over 16,000 mainly adult inpatient admissions in 2022 - provides data on age, sex, marital status, diagnosis, employment, and socioeconomic status, but no information is included on parental status or number of dependent children (Health Research Board [HRB], 2022). Despite the challenges of accurately establishing the proportion of families affected by parental mental illness (FaPMI), considerable research indicates that living with a parent with a mental health disorder can have a significant negative impact on both the service user and their families; this is described in more detail below.

1.2 Impact of PMI on the Family

A wealth of studies published since the late 1990s illustrate the significant impact of mental illness on the socioemotional/behavioural experience and wellbeing of parents who are living with a mental health disorder. For instance, a recent review undertaken by Andersen and Lund (2020) identified over 16,000 papers published on this topic over a 19-year period (i.e. 1999 to 2018). Adult service users who are parents often report living with stigma, fear, and guilt associated with parenting (Dolman et al., 2013; Rampou et al., 2015). While caring for children is a rewarding and valued social role, it carries with it many challenges, and the bidirectional relationship between parenting and mental illness may exacerbate a parent's feelings of inadequacy and guilt (Lacey et al., 2015; Montgomery et al., 2011; Radley et al., 2022). Other adverse outcomes for parents with a serious and enduring mental illness such as schizophrenia or bipolar disorder, include: self-preoccupation, irritability and distorted expectations (Smith, 2004); difficulties in finding and managing the most suitable medication (Spiegelhoff & Ahia, 2011); impaired psychosocial functioning and disrupted relationships (Campbell & Poon, 2020); and social withdrawal/loneliness due to a fear of being judged or

labelled as a 'bad parent' (Reupert & Maybery, 2009). All of these can lead, in turn, to poor coping skills/attachment, unemployment, and/or insecure housing (Dolman et al., 2013; Falkov, 2012; Luciano et al., 2014; Seeman, 2015). Help-seeking as already mentioned, may also be impeded by stigma and fear of interference by welfare services (McDaid, 2014; Jones et al., 2018; Rampou et al., 2015; Reedtz et al., 2019b; Reupert & Maybery, 2009; Tabak et al., 2016; van der Ende et al., 2016).

While knowledge of a parent's illness can be a protective factor for COPMI, evidence suggests that many parents lack the language, confidence or skills to discuss their disorder with family members (Reupert & Maybery, 2010; Solantaus et al., 2015). The, often-adverse, consequences of parenting with a mental health illness are further compounded in single headed homes where there is no partner to provide a 'safety net' for dependent children (Reedtz et al., 2019b). Stigma has also been reported by both co-parents and children because of their association with the service user parent, while family members often describe feelings of confusion at the service user's behaviour (Coates, 2017; Dobener et al., 2022; Gartstein et al., 2009; Gatsou et al., 2017). While there is a lack of data on the co-parent experience, the small pool of existing studies suggests that they bear increased financial and childcare responsibilities, an elevated risk of psychopathology/substance misuse, housing insecurity, loneliness, and conflict in the home (Bateson et al., 2017; Beardslee et al., 2007; Idstad et al., 2010; Iseselo et al., 2016). Furthermore, confidentiality guidelines and General Data Protection Regulations (GDPR[1]) within EU countries and the UK can limit, in part, co-parent involvement in treatment plans despite their often-important safeguarding role in the home (Oates, 1997). This kind of exclusion can, on rare occasions, have devastating outcomes such as familicide or

[1] https://gdpr-info.eu/

infanticide[2] (Naviaux et al., 2020). A need for more research on the experience of co-parenting with a partner who is living with a mental health disorder is indicated, while there have also been recent calls in an Irish context for greater involvement of co-parents/partners in mental health treatment plans (Butler, 2018).

1.3 Impact on Children

While no clear linear causal link has been established for the transmission of the risk of mental ill health from parent to child, the evidence indicates, as mentioned earlier, that COPMI face an increased risk of negative health outcomes (both physical and mental) due to the significant and now very well-documented social, emotional, and behavioural impact of living with an unwell parent (Pierce et al., 2020; Santvoort et al., 2015). It would appear that a complex interplay of genetic, prenatal, family and psychosocial factors mediate the relationship between the parents' symptoms and parent-child interactions (Abel et al., 2019; Campbell et al., 2021). This is discussed in more detail in the next section (Section 1.4). Importantly, research has shown that COPMI are 13 times more likely to develop psychopathology, with an increased risk of 41% to 77% of developing a moderate to severe mental illness themselves, as well as a greater likelihood of socioeconomic adversity (i.e. homelessness, unemployment) and low levels of school readiness (Bee et al., 2014; Bell et al., 2019; Dean et al., 2010; Hosman et al., 2009; Kato et al., 2015; Maybery & Reupert, 2009; Perrino et al., 2014; Pierce et al., 2020; Tabak et al., 2016). These children are also five times more likely to attend health and social services (including CAMHS) following prolonged exposure to PMI (Hosman et al., 2009).

Notably, a large recent review of CAMHS attendees, based on a total sample of over 14,000 parent/caregiver and child participants across 11 jurisdictions (e.g. Australia, Austria, Canada, France, India, and Kenya), found that 16% to 79% of those attending services were

[2] For example, in Ireland, Deirdre Morley killed her three children in January 2020 while suffering a psychotic episode that developed from a depressive illness. She was later admitted to the Central Mental Hospital in Dublin after being found not guilty by reason of insanity.

living with PMI, thereby illustrating the challenges and complexity of establishing precise prevalence rates as discussed earlier (Campbell et al., 2021). Another, albeit single stand-alone, study conducted in the Netherlands, reported rates of 36% and 33% respectively, for CAMHS users living with *maternal* and *paternal* mental illness (Wesseldijk et al., 2018). Typically, however, it has been suggested that 23% of children are living with PMI (Leijdesdorff et al., 2017; Maybery et al., 2009; Ruud et al., 2019), although the vast majority of studies focus on maternal rather than paternal illness, most likely due to the historic expectation of mothers as primary caregivers (Bowlby, 1979; Kamis et al., 2021; Ramchandani & Psychogiou, 2009). Mental illness can also present in various ways across the sexes (e.g. a higher incidence of substance misuse and lower depression among men), so the lack of research on paternal mental illness represents a clear gap in the literature (Santvoort et al., 2015). Likewise, much more research is needed to better understand the extent to which a parent's mental health disorder may trigger a transgenerational risk for COPMI and how this might vary by the sex of both the parent and the dependent child(ren) (Ramchandani & Psychogiou, 2009).

Children of PMI have described their experiences as "scary", "confusing", and "overwhelming" (Sherman & Hooker, 2018, p. 361). They also report feeling worried (McCormack et al., 2016:2017), fearful (Murphy et al., 2011), ashamed, and/or stigmatised by association with the unwell parent (Dam & Hall, 2016; Reupert et al., 2020). Stigma may also present differently within the FaPMI; for example, according to Dobener et al. (2022), some children may present with 'anticipated stigma', or the expectation of discrimination because of a parent's illness, while others report 'internalised stigma' which describes a negative self-perception as a result of living with an unwell parent. Temperament may also be a factor. A sensitive child may respond more negatively to a parent's chaotic behaviour which, in turn, may negatively impact a parent's confidence to parent (Manning & Gregoire, 2009). Parentification is yet another possible outcome (Cudjoe & Chiu, 2020; Dam & Hall, 2016; Hosman et al., 2009; Leijdesdorff et al., 2017; Patrick et al., 2022). First coined by Broszormenyi-Nagy and Spark

(1973), 'parentification' refers to the reversal of roles "*defined by the expectation from a parental figure that a child will fulfil a parental role within the family system*" (Earley & Cushway, 2002, p. 165). It has been suggested that parentification is more likely to occur in single headed homes where no co-parent is present (Cudjoe et al., 2022). All of these kinds of negative outcomes for children may also be exacerbated if a parent attempts, or dies by, suicide while an increased risk of child abuse has also been linked to living with maternal mental illness (Hosman et al., 2009; Moscoso et al., 2019; Nicholson, 2010; Nicolson et al., 2019).

It is important to note, however, that some COPMI may also report the development of positive attributes as a result of their experience of living with a parent's mental illness, including resourcefulness (Drost et al., 2016; Hughes et al., 2017), resilience (Gladstone et al., 2006), independence and empathy (Patrick et al., 2019). Outcomes may also differ according to the child's position in the family (where applicable). For example, older siblings and/or female children may be expected to perform caring duties for the unwell parent and/or siblings (Power et al., 2016). While having siblings can be a positive experience, others may find sharing a parent with limited capacity for caring for dependent children, an additional burden (Reedtz et al., 2019). Fear of a parent's unpredictability can also differ based on age/developmental stage, as younger children may not be as sensitive to the extent of dysfunction around a parent's illness (Gladstone et al., 2011). Older children may also wish to protect their younger siblings from any harm in the home (Östman, 2008). A number of authors have highlighted a need for further research to explore sibling experiences in more detail, as well as the impact of PMI across the lifespan (Foster, 2010; Hosman et al., 2009).

1.4 Longer-Term Impact of PMI

According to a recent study by Patrick et al. (2020), some adult COPMI report living with lasting negative emotions, including shame, loneliness, anger, fear, resentment of peers, and difficulties in establishing trusting adult relationships. Indeed, adults who have lived with maternal mental illness in childhood when compared to peers with no such experience, report

higher incidences of relational difficulties, lower self-esteem, poorer psychosocial functioning, greater poverty, higher rates of unskilled employment and alcohol misuse (Chen et al., 2023; Gladstone et al., 2011; Patrick et al., 2019:2020). Furthermore, adult COPMI may experience intrusive traumatic memories (e.g. of their parent's suicide/suicidal ideation) and ongoing dysfunction (e.g. volatile behaviour) in the parent-child relationship, lasting well beyond childhood (McCormack et al., 2017; Murphy, 2014; Petrowski & Stein, 2016). The transition from childhood to adulthood may also be impacted, as evidenced by one US study which found higher rates of depression and anxiety among COPMI who transition to college, when compared with students whose parent did not have a mental health disorder (Mitchell & Abraham, 2018).

Several conceptual and practice-based models have been developed to better understand and prevent the intergenerational risk and potential longer-term impact of mental illness on COPMI and to address the factors mediating its outcomes (Kristensen et al., 2022). For example, the '*Family Recovery Model'* (Nicholson & Henry, 2003) was initially designed to inform the development of evidence-based programmes for FaPMI; it aims to provide practitioners with an ecological model of family recovery and identifies targeted areas for intervention (e.g. child and parent overall wellbeing, and intrafamily relationships) when a parent is living with a mental health disorder. Likewise, the more recent '*Family Model*[3]*'* developed by psychiatrist Adrian Falkov, builds upon a previous '*Crossing Bridges'* framework to provide six key principles (and related questions) to guide mental health practitioners when working with, and supporting, affected families. These relate to: (1) the adult service user; (2) the child/ren; (3) parenting and intra-family relationships; (4) risk factors; (5) relationship(s) with MHS; and (6) culture and community context (Falkov, 2012).

[3] https://thefamilymodel.com/

A comprehensive conceptual model developed around the same time by Hosman, van Doesum and van Santoort (2009), provides an interesting '*Developmental Model of Transgenerational Psychopathology'* for COPMI, beginning in pregnancy. This multi-layered model, recently adapted by Christiansen et al. (2019), proposes that short- and longer-term outcomes for COPMI are compounded by a number of factors including: (1) severity/chronicity of the parent's illness; (2) family context/constitution (e.g. marital status and socioeconomic status); (3) available supports (e.g. social networks); and (4) the presence/absence of protective factors for the child (e.g. resilience, co-parent in the home).

1.5 Family-Focused Practice

All of the above models have in common, a strong emphasis on family-focused practice (FFP). Originating within the field of paediatrics in the 1950s (Foster et al., 2016; Maybery et al., 2016), FFP is usually (but not exclusively) implemented in AMHS to support service users who are parents and to minimise the negative impact of their mental illness in the home (Bee et al., 2014; Foster et al., 2016; Lannes et al., 2021; Maybery et al., 2016; Overbeek et al., 2022; Siegenthaler et al., 2012). While there is no agreed definition across both adult and child services, Lagdon (2021) provides a useful preliminary definition of FFP whereby *"professionals engage the service user within the context of their immediate connected family relationships and endeavour to meet the needs of both service users and family members"* (p. 414). Notably however, FFP is still understood and labelled in many different ways, having been variously described by authors and commentators in the field as a 'practice theory' (Hutchfield, 1999), 'programme' (Aubry et al., 2000), 'philosophy' (Malusky, 2005), 'model' (Mottaghipour & Bickerton's, 2005), 'paradigm' (Hall, 2005), or 'approach' (Foster et al., 2012). However, common to all of these is the notion of extending care beyond the individual to include family members (Foster et al., 2016; Grant, 2014).

Thus, within existing MHS, the introduction of FFP necessitates a paradigm shift from the individualised model of care that still tends to dominate most services across the world,

toward a more systemic, family-oriented approach (Biebel et al., 2016; Falkov et al., 2016; Hinden et al., 2006; Isobel et al., 2019). This includes family-inclusive activities and practices which have been variously described as 'family-focused,' 'family-centric,' 'family sensitive,' 'whole-family,' 'family minded', or 'think family,' (Clarke & Hughes, 2010; Evans & Fowler, 2008; Falkov, 2012; Maybery et al., 2016; McNeil, 2013; Social Care Institute for Excellence [SCIE], 2011). These terms describe a more holistic approach to mental health service delivery which goes beyond a focus on helping the individual service user to also supporting their immediate and extended family. This reflects an understanding that outcomes for the service user and wider family are more likely to be improved by recognising that individuals typically live in interconnected and interdependent relationships rather than in isolation (Falkov, 2012). The terms 'family-focused' and 'think family' will be used throughout this thesis to reflect, respectively, the commonly used 'FFP' acronym and also the wording in significant policy documents produced by the SCIE (2011) in the UK, and Barnardo's (2014) in Ireland, both of which highlight the importance of such approaches within mental health services.

Think family activities have been shown to be more effective if supported by a clear strategy which incorporates a number of key elements including: a focus on the whole family; upskilling the workforce; providing multiple pathways to services; care planning; interagency collaboration; and the provision of appropriate and effective programmes to prevent FaPMI from falling through service gaps (Grant & Reupert, 2016; Lauritzen et al., 2018; Leonard et al., 2020; Maybery et al., 2015b; Reupert et al., 2018; Tuck et al., 2023). According to Maybery et al. (2015), *think family* programmes tend to specifically "*target parents as the catalyst for facilitating change in their families"* (p.368). Interestingly, research also indicates that mental health practitioners who are trained in, and who deliver FFP, report higher levels of job satisfaction in the knowledge that the whole family and not just the service user is being supported (Gatsou et al., 2017; Grove et al., 2015; Maybery et al., 2015a). However, the available evidence suggests that the nature and extent of FFP and attendant policies vary

considerably (or are non-existent) across different countries and jurisdictions. A detailed overview of the family-focused literature and the range of programmes developed as part of FFP across the world, is provided in Chapter Two.

1.6 The Irish Context

Currently, Ireland does not have a *think family* policy or attendant initiatives, unlike a number of other countries and world leaders in this space. For example, Australia recognised the need for services for FaPMI as early as 1999 and a national COPMI programme (2001-2017) was established shortly thereafter to develop and produce online resources[4] to improve outcomes for FaPMI and to support practitioners championing their needs (Australian Infant, Child, Adolescent and Family Mental Health Association [AICAFMHA], 2004; Maybery et al., 2015a). Practice standards were also introduced for the mental health workforce (2010) to identify and support FaPMI (Goodyear et al., 2015; Tchernegovski et al., 2017) while later, the 2014 Mental Health Act was introduced in Victoria, Australia to "*recognize and support mental health consumers' children*", (Tchernegovski et al., 2017, p.1).Significantly, Australian academics have also played a central role in driving research in this field by, for example, establishing and leading since 2013, the 'Prato Research Collaborative[5]', a collaboration of international academics established to undertake and disseminate research to improve outcomes for families impacted by PMI (Reupert et al., 2022). A number of Scandinavian countries, including Norway, Finland, and Sweden, have also introduced important legal, practice and policy changes to identify and better support COPMI (discussed in more detail in Chapter Two) (Lauritzen & Reedtz, 2013:2016; Maybery et al., 2015c; Pihkala et al., 2012a:2017; Reedtz et al., 2019; Solantaus & Toikka, 2006; Solantaus et al., 2009). Closer to home, the T*hink Family Initiative* which was established in Northern Ireland (NI) and in five local authority sites

[4] https://www.copmi.net.au/
[5] Three members of the PRIMERA team, including the candidate, are members of this collaborative.

in the UK, has helped to increase practitioner awareness of the needs of families with PMI, leading most recently in NI to the recruitment of a number of family-focused social workers across each of the five Health and Social Care Boards (HSCBs) (Donaghy, 2022).

By contrast, the lack of clear policy or legislative attention on COPMI in the Republic of Ireland (RoI) means that we trail significantly behind many other countries in terms of FFP, and at a time of increased demand on CAMHS during and post the COVID-19 pandemic (O'Hagan et al., 2023). Furthermore, only one study (other than the current research) has been conducted in this field in the RoI, focusing on how psychiatric nurses (*n*=113) within one mental health service in Ireland were meeting the needs of COPMI (Houlihan et al., 2013). Reassuringly however, a number of significant policies have been developed over the last 20 years which have considerably improved outcomes for parents, children and families in general (Figure 1.1). Four of these, in particular, have helped, at least to some extent, to shift MHS toward more evidence-based programming and to re-orient services to better incorporate lifespan, recovery-focused and early intervention and prevention approaches (Higgins & McGowan, 2014; Higgins et al., 2020b; McDaid et al., 2023). These are discussed briefly below and highlighted in Figure 1.1 in the context of a timeline of key health policy developments in Ireland relevant to parents, children and families during the last 20 years (approximately).

Firstly, the *National Children's Strategy, Our Children - Their Lives*, launched in 2000, was the first comprehensive, inclusive strategy that called for a whole-child interagency approach across statutory, voluntary and community-based providers to improve outcomes for children in the RoI. Key goals were to encourage greater participation by children, improve research, and enhance services for children aged 0-18 years. Important elements of child development were also highlighted, including physical and mental health and wellbeing, peer relationships, identity, and self-care (Department of Health & Children, 2000). While the centrality of a stable family was one key domain, the potential lasting impact of adverse experiences in the home, such as PMI, were not directly addressed (Hughes et al., 2017).

Children's Services Committees (CSCs) (now called Children and Young Persons Service Committees [CYPSCs]) were subsequently established in 2007 to support a national interagency approach to improve outcomes for children and were later extended later to include young adults up to the age of 25 (see below).

The first ever mental health strategy in Ireland, *Vision for Change* (VfC), was developed six years later with key goals to, amongst other things, improve community-based service provision, promote recovery and encourage greater service user and carer participation in service development and delivery (Department of Health & Children, 2006). While not calling explicitly for a *think family* approach*,* it recommended a child-friendly ethos within MHS, and mental health promotion more generally, whilst also recognising that "*the safety and well-being of children whose needs may be compromised by parental illness needs to be carefully monitored"* (p.81). Adequate staffing, training and management structures were also key recommendations.

The goals for children and young people highlighted in both of the above key strategies were reiterated and expanded in the most recent *Better Outcomes Brighter Futures* strategy (2014-2020) which set out to improve outcomes for children and young people aged 0-24 years through: a coordinated, cross-government, interagency approach; better support for parents; earlier intervention and prevention; support of transitions for young people; involvement of children in service design and delivery; and, improvements in service quality (Department of Children & Youth Affairs, 2014). This framework again recognised the importance of parental well-being for a "*child's early social and emotional development"* (Department of Children & Youth Affairs, 2014, p. 54). Implicit in its goal to provide effective supports for parents, was to improve outcomes for children. It also led to the establishment of Tusla, (i.e. Irish for 'new beginning'), the National Child and Family Agency established in January 2014 with primary responsibility for improving outcomes for children.

The most recent relevant policy document, *Sharing the Vision - A Mental Health Policy for Everyone* (2020-2030), reiterates the importance of early intervention/prevention across the lifecycle (Department of Health, 2020) and the need to promote partnership and an interagency approach to MHS provision. An important addition to this latest framework is the inclusion of a specific implementation plan alongside a monitoring and management committee to oversee the introduction of key practice recommendations. A national programme is also planned to reduce stigma and discrimination for those living with mental health challenges. While this strategy has the potential to improve outcomes for all MHS users, it has been the subject of some criticism due to: its lack of recognition of the ongoing underfunding and under resourcing of services (e.g. mental health funding is less than 6% of the overall health budget); the exclusion of some key stakeholders (e.g. psychiatrists and allied health professionals) from the initial strategy consultation process; the absence of clear responsibility for implementation within the HSE; the under representation of severe mental illness; an over dependence on the biomedical model; and a lack of cohesiveness with the former VfC (College of Psychiatrists of Ireland, 2020; Social Workers in Adult Mental Health Services Special Interest Group of the ISWA, 2020). Notably however, the strategy aims to provide a *"renewed focus on partnership in care … to ensure service users and FCS* [families, carers and supporters] *are central in the design, development and delivery of services and take a lead role in recovery planning,"* (p.34). While this is a positive development, the strategy makes no specific reference to the increased risk of negative outcomes for FaPMI and remains individual- rather than family-focused.

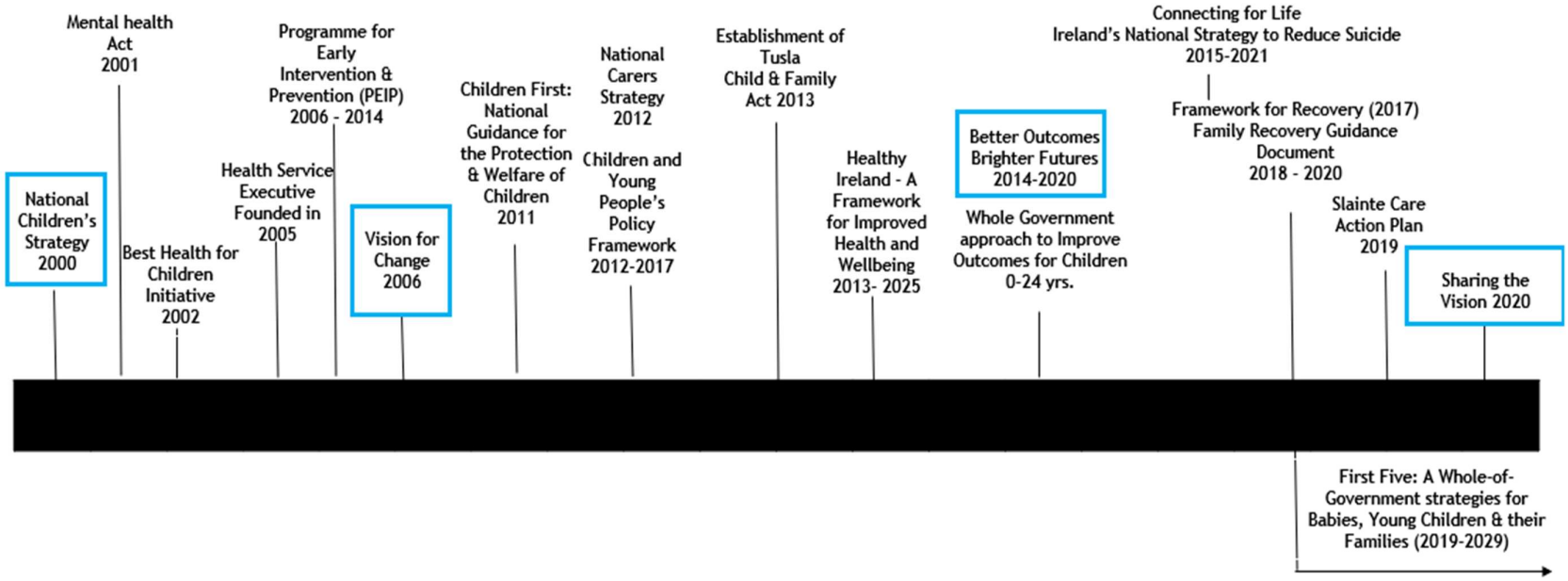
Nonetheless, there have been some interesting developments in Ireland in recent years, involving the delivery of three main programmes to support families affected by mental illness. The first of these, *Eolas* (the Irish word for 'knowledge'), was established in 2011 for families living with bipolar disorder and schizophrenia (Higgins et al., 2020a). This incorporates two companion psychoeducation programmes, one for service users and one for adult family/support members respectively, both of which are delivered by mental health

practitioners and by peers with lived experience. The programme is currently delivered in 15 MHS nationally, and a web-based version has been piloted recently with promising results relating to its online feasibility and acceptability among service users and their families (O'Sullivan et al., 2023). Since 2011, a total of 134 service user programmes and 124 family/friends' programmes have been delivered, involving over 2,000 service users and family members/supporters (personal communication with the Chair of the Eolas Steering Committee, Dr Patrick Gibbons, M.D.).

Evaluations of the Eolas programme, to date, show that while there were many barriers to implementation (Higgins et al., 2020a), service user confidence, knowledge of mental illness and overall wellness had improved following participation in the programme, while peer participation helped to normalise the lived experience of the illness for attendees (Higgins et al., 2020b). Similar positive experiences were reported by family members who described a greater sense of hope after attending the programme and enjoyed learning in a group setting (Higgins et al., 2022).

Figure 1.1

Timeline of key Irish Policies, Strategies and Initiatives Relevant to Parents, Children and Families in the Republic of Ireland (since 2000)



Note. *The four strategies most relevant to a family-focused approach to PMI are highlighted in blue.*

The second family-focused programme, *Behavioural Family Therapy* (BFT[6]), which launched its model of care in 2019, is offered as part of the national Early Intervention Psychosis (EIP) clinical programme designed to support service users experiencing psychosis. (The other three national programmes target self-harm and suicide, eating disorders, and Attention Deficit Hyperactivity Disorder (ADHD) respectively [HSE, 2019]). As a skills-based family intervention, BFT sessions involve a trained mental health professional working directly with a family for approximately 1 hour a week for up to 13 weeks. The overall aims of BFT, which is also delivered in a number of other countries across the world (e.g. Australia Canada, UK and the USA), are to improve communication around mental illness, provide psychoeducation to the family about the specific mental illness and improve treatment outcomes which, in turn, may reduce relapse rates (Bird et al., 2010). Available data from three of the five EIP teams who delivered BFT across Ireland in 2022, showed that half of the 174 service users who were taking part in the programme had completed it, while approximately one third (32%) had declined to attend; a further 14% were currently waitlisted for the programme. A peer support worker is also provided across all EIP teams (information provided in private communication from the Programme Manager of the Mental Health Clinical Programmes). Evaluations of BFT in both Ireland and elsewhere, indicate broadly positive outcomes such as reduced stress, fewer relapses, lower levels of hospitalisation and lower care costs (Bird et al., 2010; Pharoah et al., 2006), although delays in treatment due to, for example, the lack of BFT-trained staff, can negatively impact or hinder recovery (Darker et al., 2022:2023).

The third programme, *Family Connections,* is a multi-family, group-based treatment programme for family members of people living with borderline personality disorder (BPD) or emotion regulation disorder. This 12-week programme was developed and codesigned by Dr Alan Fruzzetti and Dr Perry Hoffman in 2005 in the USA (Courey et al., 2021). The programme

[6]https://www.hse.ie/eng/services/list/4/mental-healthservices/dsc/communityservices/behaviouralfamilytherapy.

is co-delivered by a mental health professional and a peer who has received training and comprises of six modules based around psychoeducation, relationships, and family skills (Courey et al., 2021). The first evaluation of the programme, conducted in 2005 (*N*=44 participants from 34 families), found that it successfully reduced family burden up to three months post-programme delivery (Hoffman et al., 2005). A 2017 study compared the 12-session *Family Connections* intervention (*N*=51) to a 3-week psychoeducation programme on BPD (*N*=29) and found comparable improvements which persisted up to 12-19 months post-programme (Flynn et al., 2017). Practitioner training for *Family Connections* is conducted annually in Ireland, but it was not possible at the time of writing to establish the number of programmes currently or previously delivered due to the lack of routinely available information (personal correspondence with the National Dialectical Behaviour Therapy Office).

Importantly, none of the above programmes specifically address the needs of the family where the service user is a parent and with children aged under 18 years of age. Furthermore, while the policies discussed earlier (Figure 1.1) go some way toward recognising the importance of a parent's mental health on children, they have not been fully implemented mainly due to a lack of support and funding (Darker et al., 2023; Higgins et al., 2020b). More specifically, MHS in Ireland are characterised by historic underfunding (as mentioned earlier), long waiting lists, lower than recommended staffing levels, a lack of ringfenced funding and importantly, considerable deficits in the provision of care for children already attending CAMHS (O'Connor et al., 2021). All of these are exacerbated by an increasing demand for services as a result of population growth and the recent COVID-19 pandemic which began in Ireland in March 2020 (O'Connor et al., 2021; Sicari & Sutherland, 2023). For these reasons, a number of commentators both in Ireland and elsewhere have argued convincingly that without a specific targeted and funded *think family* approach, COPMI will remain vulnerable and potentially 'invisible' despite their significantly increased risk of psychopathology in the short and longer term, while service provision remains patchy or non-existent (Barnardo's, 2014; Donaghy,

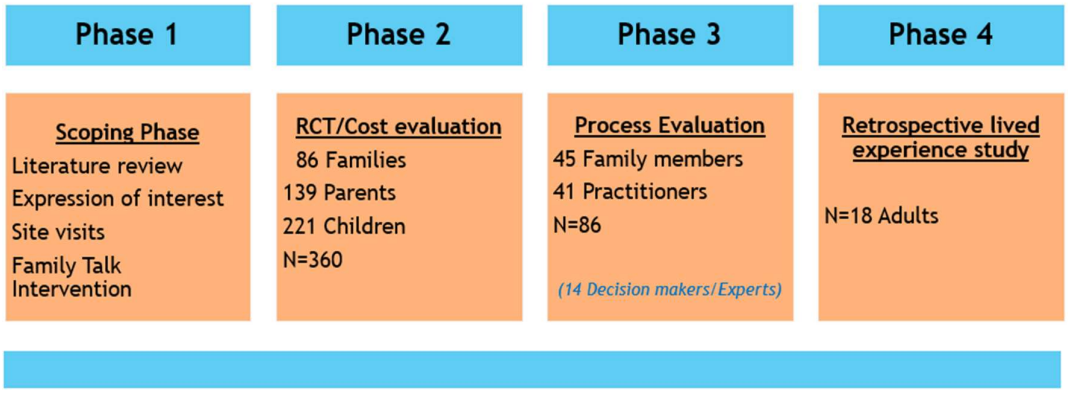
2014:2016; Falkov et al., 2016; Golden et al., 2020; Grant et al., 2018:2019; Grant & Reupert, 2016; Mental Health Commission, 2023). It was against this backdrop that the current research was conducted as part of a larger project to help identify, implement, and evaluate a family-focused programme in Ireland.

1.7 The Current Study: Aims and Objectives

The research presented in this thesis was conducted as part of a larger, mixed methods, multi-phase, 5.5-year project called PRIMERA (**P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies). The overarching aims of the PRIMERA project, which was funded by the HSE Mental Health Division (2017-2022) and implemented on a national basis, were to: identify, implement, and evaluate a family-focused intervention for families where a parent has a mental health disorder; and more broadly, to begin to promote a *think family* care delivery agenda in Ireland. The project involved four separate but related phases including: (1) an initial scoping study and literature review ***(Phase One)***; (2) a Randomised Control Trial (RCT) and cost analysis ***(Phase Two)****;* (3) a process evaluation ***(Phase Three)****;* and (4) a small study of the retrospective lived experience of PMI in childhood ***(Phase Four)*** (Figure 1.2). Specifically, the research reported here, involved three (published) studies which were conducted as part of Phases One and Three of the PRIMERA project (replicated in Chapters Four, Five and Six). Each of these is described briefly below, with more detail provided in Chapter Three. Further information on Phase Two is provided in Appendix B (i.e. published RCT paper). A summary of the findings from Phase Four, which are currently being prepared for publication, is also provided in Appendix C.

Figure 1.2

The National PRIMERA Research Project: An Overview of Key Phases



1.7.1 Study One: Promoting and Implementing Family-Focused Interventions for Families with Parental Mental Illness: Scoping and Installation.

The overall aim of **Study One** was to undertake a scoping study to inform the direction of the national project. The specific objectives of this study were to: (1) conduct a review of the international literature in order to: (a) identify and critically appraise the kinds of programmes/interventions developed to support FaPMI; (b) to identify measures which may be used as part of a subsequent RCT; and (c) to better understand international policies and practices in the field; (2) carry out a national mapping exercise to benchmark existing levels of, and interest in, FFP within AMHS and CAMHS in the RoI; (3) identify and work with specific MHS sites across the country to explore their readiness to implement a specific family-focused intervention; and (4) to help support programme implementation across selected sites.

This work led to the identification of the US-developed *Family Talk* (*FT*) programme which was deemed suitable for implementation in Ireland as part of the RCT conducted during Phase Two. Specifically, this programme was identified during the initial literature review as a promising, evidence-based, clinician-facilitated, whole-family complex intervention, initially designed for families where a parent has an affective disorder (Beardslee et al., 1987). This 7-session preventative programme uses psychoeducation to promote resilience as part of a

strengths-based approach designed to improve understanding and communication within the family regarding a parent's mental illness. For the purposes of this study, the term 'family' was defined by the participating families themselves; in other words, they decided for themselves whether participation in the FT programme should involve immediate and/or extended family members. However, in most cases, only immediate family members took part in the programme.

The available evidence, to date, demonstrates that *FT* may be used with families experiencing a range of mental health disorders, and the programme has led to statistically significant and sustained improvements in child mental health (i.e. both internalised and externalised behaviours) as well as improved parental symptoms, greater familial understanding around the parent's mental illness and lower levels of shame and stigma (Beardslee, 2019; Beardslee et al., 2007; Giannakopoulos et al., 2015; Pihkala & Johansson, 2008; Strand & Rudolfsson, 2017; Solantaus et al., 2010). The programme has also been implemented across several countries/jurisdictions, including the USA, Costa Rica, Colombia, the Netherlands, Greece, Scandinavia, Iceland, and Australia. A more detailed description of *FT* is provided later in Chapter Three (p.111). **Study One** was published in *Advances in Mental Health: Promotion, Prevention and Early Intervention*, on 16th May 2019.

1.7.2 Study Two: The Family Talk Programme in Ireland: A Qualitative Analysis of the Experiences of Families with Parental Mental Illness.

Following the completion of Study One and the identification of the *FT* programme for implementation in Ireland, the RCT and process evaluation (and attendant cost analysis) were designed and ultimately implemented across 10 MHS sites. The overall aim of **Study Two** was to undertake a primarily qualitative process evaluation to capture and explore the perceptions and experiences of a sample of families who had taken part in the RCT in order to better understand the mechanisms of impact which ultimately influenced programme outcomes. The specific objectives of this study were to: (1) explore the acceptability and accessibility of *FT*

amongst families across participating MHS sites; and (2) to assess their engagement with, and perceived effectiveness, of the programme. This study was published in *Frontiers in Psychiatry: Public Mental Health* (15th November 2021) as part of a special issue entitled *Parents with Mental and/or Substance Use Disorders and their Children, Volume II* (edited by Joanne Nicholson, Jean Lillian Paul, Anja Wittkowski, and Joanne Louise Riebschleger).

1.7.3 Study Three: A Family-Focused Intervention for Parental Mental Illness: A Practitioner Perspective

This final study was undertaken as the second element of the process evaluation which was conducted as part of Phase Three of the PRIMERA project. It was considered important to explore, not only family experiences and views of the new intervention as outlined above, but also to investigate practitioners' experiences of implementing and delivering *FT* across participating sites/services. Thus, the specific objectives of this study were to: (1) explore practitioner experiences and views of delivering *FT*; and (2) assess the acceptability and perceived effectiveness of the intervention across participating sites. This companion study/paper was also published in the special issue indicated above (i.e. in *Frontiers in Psychiatry: Public Mental Health).*

A number of one-to-one interviews were also conducted with 14 mental health experts and decision makers as part of Phase Three (Figure 1.2) to better understand the 'insider perspective' on implementing change within MHS in Ireland. However, a team decision was made to exclude these data from the third study and to focus solely on practitioners' and managers' perspectives and experiences of implementing/delivering *FT*. Some key points of interest from these interviews are summarised in Appendix D and it is hoped that these findings will be prepared for publication in due course.

1.8 Outline of the Thesis

Chapter Two of the thesis comprises two sections which reflect the findings of a two-part literature review. The first section focuses on identifying and appraising some of the main

programmes for FaPMI across the world, including those which involve parents only (e.g. mothers, couples), children and whole families as well as peer support interventions and a growing number of digital or web-based programmes. The second section briefly explores some of the factors that have been identified as influencing the successful delivery and implementation of these kinds of programmes within mainstream MHS provision in both a national and international context.

Chapter Three sets out the epistemological and ontological foundations underpinning the research reported here as well as, by way of context, an overview of the research design and methods employed in the larger PRIMERA project. More detailed methodological and other relevant information is then provided on each of the three studies described above, including the significant number of activities required to support the mental health practitioners during the early stages of implementation of *FT* across participating sites. A detailed overview of ethical considerations as well as a summary of the analyses undertaken in each of the three studies (and including a reflective piece), are also provided here.

Chapters Four to Six contain the published papers pertaining to each of the three studies described earlier, including the initial work in Study One which set the foundations for, and helped to inform, the larger project, followed by the two-strand process evaluation described in Studies Two and Three.

The final chapter, **Chapter Seven,** provides a critical synthesis and integration of the findings from all three studies (including comparisons with the literature) and discusses their implications in terms of both policy and clinical practice. In addition, an initial programme theory based on all of the collective findings reported here, will also the outlined. The strengths and limitations of the study are also discussed, followed by some key recommendations and directions for future research and practice.

Chapter Two

2.1 Introduction

As outlined in Chapter One, an initial rapid review of the literature was conducted during June-August 2017 during the first phase of the PRIMERA project, primarily to identify programmes that have been used across the world to support FaPMI. This early work, which was led by the PRIMERA Project Manager (Dr Mairéad Furlong), and which is described later in the paper included in Chapter Four (Study One), identified *FT* as the programme considered best suited for implementation in an Irish context.

This first review of the literature was later supplemented as part of the current research, the specific aims of which were to: (1) identify any additional studies of FFP programmes conducted during 2017-2022; (2) review the evidence for their effectiveness with a specific focus on review articles only; and (3) to explore some of the key facilitative and inhibitory factors influencing the implementation of FFP programmes in real world mental health settings in order to better understand the complex stages of practice change from identification/selection of a suitable programme to implementation. With regard to the last of these, it was considered helpful for the PRIMERA research team and the practitioners with whom they worked, to better appreciate some of the specific factors influencing the successful implementation of FFP in real world settings and especially as the project progressed.

This chapter is divided into two main sections to reflect these two separate but related reviews. First, an overview of the initial review (Section 2.2) of the literature conducted at the commencement of the study is provided. This is followed by a description of how this was later supplemented by the author as part of her research (Section 2.3). This second review of the literature also included a smaller piece of work conducted to address objective (3) above (i.e. to identify key factors influencing the implementation of FFP for FaPMI internationally).

2.2 Initial Review of Programmes for FaPMI

The initial review was conducted as part of the exploratory phase of the PRIMERA project (**Study One** – see Chapter Four). This involved a search of three main databases (i.e. PubMed, PsychInfo, MEDLINE) using the following search terms: [Parents with Mental Illness, Parents with Mental Health Issues/Difficulties] AND/OR [Children of Parents with Mental Illness] AND [Family-focused Mental Health]). A snowball search strategy identified a number of key systematic reviews and meta-analyses in the field and the reference lists of all included studies were also searched. Relevant papers written in English were included regardless of study design and if they incorporated a focus on programmes targeting families where parents had a range of mental health disorders including substance misuse (e.g. Huntsman, 2008). All were reviewed with regard to the targeted disorder(s), format, setting, and the outcomes assessed. As indicated in **Study One**, a number of narrative reviews totalling approximately 150 papers, were also identified and critically appraised.

The search identified six important and informative reviews which included most if not all of the studies that had been conducted in the field between 2000 and 2017 and which were conducted by teams in Australia (*n*=3) and the UK (*n*=3, two of which were co-produced in Switzerland and Austria respectively); all are described in Table 2.1 (along with their key findings). These included two systematic reviews (Bee et al., 2014), one of which also included a meta-analysis (Siegenthaler et al., 2012), and four reviews based on systematic review principles (Fraser et al., 2006; Huntsman, 2008; Reupert et al., 2012; Schrank et al., 2015). Total sample sizes were reported by Siegenthaler et al. 2012 (*N*=1,404 parents and *N*=1,497 children) and Fraser et al. (2006) (*N*=9 to 472). As outlined in **Study One** (Chapter Four), the approaches to FFP identified within the review, typically included psychoeducational, psychotherapeutic, and parenting programme elements designed to target parents and/or children. A small number of programmes were also based on what Bee et al. (2014) describe as 'psychosocial

extended care' which typically involves tailored strategies in the home or community which focus on the parent-child relationship.

All of the studies were published over a 10-year period and programmes were broadly categorised into those designed for: (1) parents only (e.g. mother/couple); (2) children/adolescents aged 7-18 years (involving mainly peer support groups); and (3) family-based or whole family interventions for both parent(s) and children typically aged 7-18 years (Bee et al., 2014; Fraser et al., 2006; Reupert et al., 2012; Schrank et al., 2015; Siegenthaler et al., 2012). Programme duration (when reported) ranged from six to eight weeks and in the case of one study, up to eight years (Crane & Totten, 2003). A small number of online programmes, which have become increasingly popular in recent years (e.g. Schrank et al., 2014), were also included in this initial review.

Overall, the findings from this first review suggest improved outcomes for FaPMI based on a wide range of interventions. However, there was considerable variation across studies and programmes due to differences with regard to, for example, the number and range of targeted disorders and the definitions used (e.g. 'mental health issues', 'mental health problems', 'mental illness', 'psychiatric illness', 'serious illness'). Many authors also highlighted the challenges involved in delivering complex interventions in clinical settings for vulnerable populations (e.g. Huntsman, 2008). However, a notable finding from the initial review was a 40% reduction in the risk of developing a mental health disorder for COPMI who had completed one of six family-focused interventions (including *Family Talk*), albeit the authors also suggest that the generalisability of this finding may be limited to interventions which are well structured and target a specific "*clinical problem*" (Siegenthaler et al., 2012, p.15). Notably, the cross-cultural generalisability of these findings is limited by a lack of data from jurisdictions beyond the UK, Europe, Australia and the US (e.g. Bee et al., 2014; Huntsman, 2008).

The collective findings from this initial review, however, support the provision of interventions for maternal mental illness given the positive results reported from a growing

range of programmes aimed at this cohort. The evidence for programmes designed to improve the quality of life (QoL) for COPMI is also promising despite being in its relative infancy and a growth in programmes targeting COPMI (Bee et al., 2014; Huntsman, 2008) and disorders other than depression (Bee et al., 2014), was indicated. However, a lack of economic evaluations and inconsistent reporting on programme uptake and adherence were also reported (Bee et al., 2014; Fraser et al., 2006), with calls for more rigorous research designs (Bee et al., 2014; Huntsman, 2008; Reupert et al., 2012; Schrank et al., 2015). Furthermore, the lack of information and standardised reporting on the number of individuals who do not attend, or drop out of, these programmes, represents an important gap in our knowledge around how to recruit and retain families with complex needs. A small sample of the more commonly reported programmes (based on both the initial and second review reported in the next section) and the key evidence underpinning each, are detailed in Table 2.2 (see p.54).

While it was not possible to confirm the extent to which all of the programmes identified and outlined in Table 2.2 are currently being delivered, they were developed and implemented across a number of countries (e.g. Australia, Finland, Norway, UK, and USA) and target a range of groups, including parents only (e.g. *Let's Talk About the Children [*henceforth referred to as *Let's Talk]*), mother and child dyads (i.e. EFFEKT-E), individual families (e.g. *Child Talk's /Child Talk's**+;** Family Talk; The Family Model*[7]) and family groups (e.g. *Kidstime; Family Group Cognitive-Behavioural; Family Options*). The duration of the programmes varies considerably from a minimum single session (i.e. *The Family Model*) up to 18-months (i.e. *Family*

[7] While the Family Model is not a programme of fixed duration like the others described here, it provides a framework to assist practitioners in the introduction of FFP for parental mental illness and has also helped to inform services for FaPMI in the UK (SCIE, 2012) and COPMI in New South Wales (Grant et al., 2020). The Family Model has been included here because it has been adopted in Australia and Northern Ireland as a training programme for mental health practitioners to enable them to use a family-focused strength-based approach to discuss a parent's mental health disorder with the family (Grant et al., 2020). An online foundational programme is available as well as a 322-page handbook (https://thefamilymodel.com).

Options). The newer *Child Talk+* programme (ranging between two to four sessions) which has been delivered in Norway and parts of Portugal and Italy, is reportedly suitable for parents with children aged as young as 12 months (up to 18 years) although no impact evaluation has, as yet, been conducted (van Doesum et al., 2021).

Table 2.1

*Six Reviews Included in the Initial Literature Review (Detailed in **Study One**, Mulligan et al., 2019)*

Author/Yr./Country	Type of study	Aim	No. of studies included and the countries where they originated	Sample sizes	Duration of programmes	Author Evaluation	Summary of Key Findings
Bee et al., 2014 (UK)	Systematic review	Synthesis and evaluation of Interventions to improve QoL for COPMI.	57 studies, 29 of which were RCTs; 26 addressed parents or COPMI; 26 studies reported on 38 interventions, at least one was provided online. (Countries were not specifically reported)	While not always reported, the number of parents with depression ranged from ~20 - 903 at baseline; community-based programmes for PMI included ~7- 60 participants.	~8 weeks - >1-year.	Trial quality reported as "poor or unclear" using Cochrane criteria for randomised/non-randomised designs, and Critical Appraisal Skills Programme (CASP) qualitative criteria.	Few programmes directly supported children (9/43) and most trials focused on parental depression. Evidence on the effectiveness of programmes to improve QoL in COPMI is in its infancy and more consistent reporting is needed, including economic evaluations and more robust trials with shorter and longer-term outcomes.
Fraser et al., 2006 (Australia)	Critical review	Interventions for COPMI, with 9 targeting families, 9 aimed at mothers and infants, and 7 for young people.	26 papers (8 RCTs) conducted in the USA (18), Australia (4), UK (3) and Israel (1). None delivered online.	Sample size varied from 9-472 participants.	Ranged From three home visits to one year.	Evaluated as strong (7), moderate (4), and weak (15) using the effective Public Health Practice Team (Thomas et al., 1999).	There is a need for programmes to consider the impact of broader social issues (e.g. housing, poverty) on mental illness. More data are needed on cost effectiveness and longer-term outcomes for COPMI across urban/rural settings, as

							well as improved research designs.
Huntsman, 2008 (Australia)	Literature review	Identify evidence for impact of PMI on families and effectiveness of interventions.	Unclear >100 Countries not specifically reported.	Range not specified	Not reported	Not reported.	The findings support early identification and intervention for maternal mental illness with positive results from psychotherapy, CBT, relationship building support postpartum and family-focused programmes involving mother-infant interaction, CBT, and family focused services. More COPMI-specific programmes are needed.
Reupert et al., 2012 (Australia)	Review	Identify interventions for COPMI.	21 studies conducted in Australia (5), Canada (1), Finland (1), Germany (2), Netherlands (3), UK (1), the USA (8); including FFI (7), peer support programmes for children 7-18 yrs., (12), online interventions (2) for ages 12-25 yrs.	Range not specified	Ranging from 6 sessions – 18 months.	Not conducted.	Educating COPMI on a parent's illness was a key element of the programmes identified. Six interventions focused on depression and anxiety. More validated outcomes and rigorous research designs are needed.

Schrank et al., 2015 (UK and Austria)	Systematic review	Identify interventions for parents with serious mental illness beyond the post-natal period.	18 articles based on 15 intervention studies conducted in the USA (10), Australia (2), Netherlands (1), Germany (1), and the UK (1). Programmes delivered online (3).	Range not specified	Not always reported but ranged from 6-8 weeks. The PACE family support programme however, helped families for up to 8 years (Crane et al., 2003).	One was evaluated as strong, one as moderate, and 16 (89%) of weak quality, assessed using EPHPP[a] (1998) qualitative assessment for quantitative research.	While 89% of the studies were evaluated as 'weak', outcomes for heterogeneous programmes were positive with regard to both parent and child outcomes. Only 20% of the participants in all included articles had a SMI (psychosis), so generalisability is limited. The authors recommend longer term studies to evaluate the effects on COPMI into adulthood.
Siegenthaler et al., 2012 (Switzerland and UK)	Systematic review and meta-analysis	Evaluate the effectiveness of interventions to prevent COPMI developing psychopathology.	17 articles reporting on 13 RCTs and meta-analyses, 6 focused on prevention; 7 evaluated internalised and externalised outcomes. Countries not reported.	Total of 1,404 parents, 1,497 children	Ranging from 1 to 32 sessions.	Reported as incomplete due to unclear allocations across control and treatment groups.	While sample sizes were small, preventative interventions appear to effectively reduce transgenerational psychopathology in COPMI by up to 40%. However, authors suggest that generalisability may be limited to similar structured programmes.

Note. COPMI, Children of parents with a mental illness, CBT, cognitive behavioural therapy, FFI, family-focused interventions, FFP, family-focused practice, RCT, randomised control trial, SMI, serious mental illness, QoL, quality of life. [a] EPHHP, Effective Public Health Practice Project, 1998 (National Collaborating Centre for Methods and Tools, 2010).

As outlined earlier in Chapter One, the findings of this initial review of the literature were used to inform the identification and selection of a programme for implementation in Ireland. Following discussions with the PRIMERA project Steering Committee, it was agreed that the *Family Talk* (*FT*) family-based intervention would be most suitable for the reasons outlined earlier in Chapter One (p.18-19), including its promising evidence base demonstrated across several clinical trials and meta-analyses for both parents and children (Beardslee et al.,1992:1997:2003; Giannakopoulos et al., 2015; Punamäki et al., 2013; Siegenthaler et al., 2012; Solantaus et al., 2010). The *FT* intervention is described in more detail in Chapter Three and in Appendix E.

Table 2.2

A Selection of the More Commonly Reported Programmes/Interventions for Families Where a Parent has a Mental Illness based on the Initial and Subsequent Review of the Literature (listed alphabetically by author)

Author/Region	Intervention	Target group	Duration	Primary content/method	Clinician training	Evidence
Beardslee et al., 1987:2007 (USA)	*Family Talk*	Whole family	7–8 sessions	Strengths based, psychoeducation	Online at https://emergingminds.com.au/online-course/family-focus/	In addition to the PRIMERA RCT, one rigorous RCT was conducted in Finland (Solantaus et al., 2010:2013). The programme was piloted in 1989 and a large clinical trial conducted in 1991 with a combined cohort of 100 families. The outcomes were evaluated at 2.5 and 4.5 year follow-up (Beardslee et al., 1992:1996:1997:2003). The safety and effectiveness of *FT* has also been demonstrated in a number of clinical trials and meta-analyses (Beardslee et al., 2003; Beardslee et al., 1992:1993; Punamäki et al., 2013; Siegenthaler et al., 2012; Solantaus et al., 2010).
Bühler et al., 2011, (Germany)	*EFFEKT-E*[a] Development support in families:	Mothers and children	6 sessions	Parenting and child behaviour modules. Based on an earlier Shure's programme	Fee charge for the EFFEKT in-person training programme.	This German website details evaluations on the programme in German (https://www.effekt-training.de/evaluation). A

	parent and child training			with a mother-child session added.		cohort control group design study involved 406 mothers (220 in the control group, 186 in the intervention group) with a child aged 4-7 yrs., delivered in 31 separate group-based settings (average 4-10 mothers). Parental confidence increased, stress levels reduced, and a significant effect was reported for children's emotional disturbance scores (Stemmler et al., 2013).
Compas et al., 2009; 2011:2015 (USA)	*Family Group Cognitive-Behavioural*	Whole family (group-based, up to four families in each group)	12-sessions program, 8 weekly sessions (4 monthly)	Cognitive behavioural strategies	Manualised	Children in the treatment group reported lower levels of anxiety and depression at 18-months follow up. Internalising symptoms were also lower at 18-months and externalising symptoms at both 18- and 24-months. Improvements were also reported in parents' symptoms except in cases of major depression.
Cooklin, 2004 (UK)	*Kidstime*	Multi-family group programme (6-10 families per workshop	Open-ended monthly meetings (2.5 hrs.)	Peer and group sessions, play, psychoeducation seminar, dramatized workshopping of children's stories	Licence to deliver the Kidstime workshop. Details at https://ourtime.org.uk/kidstime-workshops/setting-up-a-kidstime-workshop/	A recent evaluation of 12 workshops provided to 38 families, found that families felt better prepared to talk about mental illness and reported improved communication

						within the home (Merrick et al., 2023).
Falkov et al., 2012:2020; Grant et al., 2018 (UK/NI/Australia)	*The Family Model*	Whole family	Family-specific framework model (one session minimum)	Psychoeducation (framework and visual tool for supporting care planning and recovery for families)	Online free access to a foundational training programme https://thefamilymodel.com/e-learning/	A 2020 audit was conducted on levels of FFP in 4-5 Heath Social Care Boards, Improvements were seen in levels of interagency and FFP, but more work is needed. The *Family Model* training framework has been shown to improve levels of FFP.
Hinden et al., 2006; Nicholson et al., 2009 (USA)	*Family Options*	Whole family	12–18 months	Family coach potentially available 24 hrs; aims to develop a family-specific strength-based care plan for family, work, school, and housing.	Not specified.	Mothers reported significant improvements in symptoms at 12 months while a significant increase in social support was reported at 6 but not 12 months. Research indicates that changes are needed to the intervention as well as more rigorous evaluations (Nicholson et al., 2016).
Le et al., 2015 (USA)	*Mothers and babies' course* for English and Spanish low-income mothers	Mothers (Group based)	8 weekly sessions (3 booster sessions)	Cognitive behavioural strategies	Manual reportedly available online at no cost.	The programme aims to reduce perinatal depression in high-risk women. Preliminary findings are promising but still in an early stage of development.

van Doesum & Koster, 2008; van Doesum et al., 2021 (Netherlands & Norway)	*Child Talks and Child Talks+*	Whole family	2–4 sessions with parents and children (as young as 1-yr. old.)	Psychoeducation	English manual available at https://uit.no/prosjekter Two-day training recommended.	No impact evaluations have been conducted. According to Kristensen et al. (2022), "T*here has [sic] been no effect studies of the intervention,"* (p.2). It is described as a "*brief light touch*" programme but requires skills facilitators with a two-day training programme recommended. Child Talks has been implemented in the Netherlands, Norway and regions of Portugal and Italy. A Child Talks+ study protocol has been developed but to the best of our knowledge, no evaluation has been conducted to date (Farářová et al., 2022).
Pitman & Matthey, 2004; Pitman, 2010, (USA & Canada)	*The SMILES[b] program*	Group programme for COPMI 8-16 yrs.	3-day group programme (9am-3pm)	Psychoeducation, games and activities, stress reduction exercises	Not specified	The programme has been shown to improve outcomes for young people and increase their understanding of mental illness and coping skills.

Solantaus et al., 2015 (Finland)	*Let's Talk*	Parent-only family recovery intervention	2–3 sessions	Psychoeducation	Free online at https://emergingminds.com.au/online-course/lets-talk-children	5 RCTs, 3 quantitative and 5 qualitative studies have been conducted on *Let's Talk*, and it has been evaluated as a control comparison with *FT*. *Let's Talk* has been translated/adapted for implementation in Australia, Estonia, Greece, Japan, Norway, Sweden, Greece and the USA (Allchin & Solantaus, 2022; Nicholson et al., 2022). It was originally designed for practitioners with little or no experience or knowledge of child development and for services with limited capacity. It has been shown to decrease children's emotional symptoms and anxiety (based on parent reports) and improve prosocial behaviour for parents with a mood disorder (Solantaus et al., 2010). A recent study has commenced to train practitioners in *Let's Talk* in nine European Countries (see Section 2.4.2).

Notes: [a] SMILES, *Simplifying Mental Illness and Life Enhancement Skills,* [b]*Entwicklungs förderung in Familien: Eltern-und Kinder-Training* (*EFFEKT-E).*

2.3 Supplementary Review 2017-2022 – Part One: Family-focused Programmes

This section describes Part One of the supplementary review of the literature which was conducted as part of the current study in order to identify any additional studies on the effectiveness of FFP programmes for FaPMI published during 2017-2022.

2.3.1 Method and Overview

Part One of the supplementary review was based on a deliberatively broad, scoping-type, umbrella review which was conducted in line with some of the guidelines contained in the PRISMA-Scr checklist (Tricco et al., 2018). There was insufficient time within the scope of an already substantial, multi-publication PhD, to complete a full review of reviews. The same databases (i.e. PubMed, PsychInfo, MEDLINE) and search terms were used as in the initial review, but spanning the period from January 2017 to July 2022 and focused only on review articles. A similar snowball search was also conducted of the reference lists of key papers.

A total of 3,864 articles (Figure 2.1) were identified in the first instance and the titles screened, after which all duplicates or irrelevant papers were removed. The abstracts of the remaining 190 potentially eligible articles were then screened by the author and assessed for eligibility using the inclusion criteria below. While time constraints did not permit a double screening of abstracts (or part thereof), the principal supervisor/PI was consulted if there was any doubt about whether to include/exclude papers; the final selection of included studies and a critique of their findings, was also discussed at length and agreed with the PI.

Inclusion criteria

Articles were included if they were:

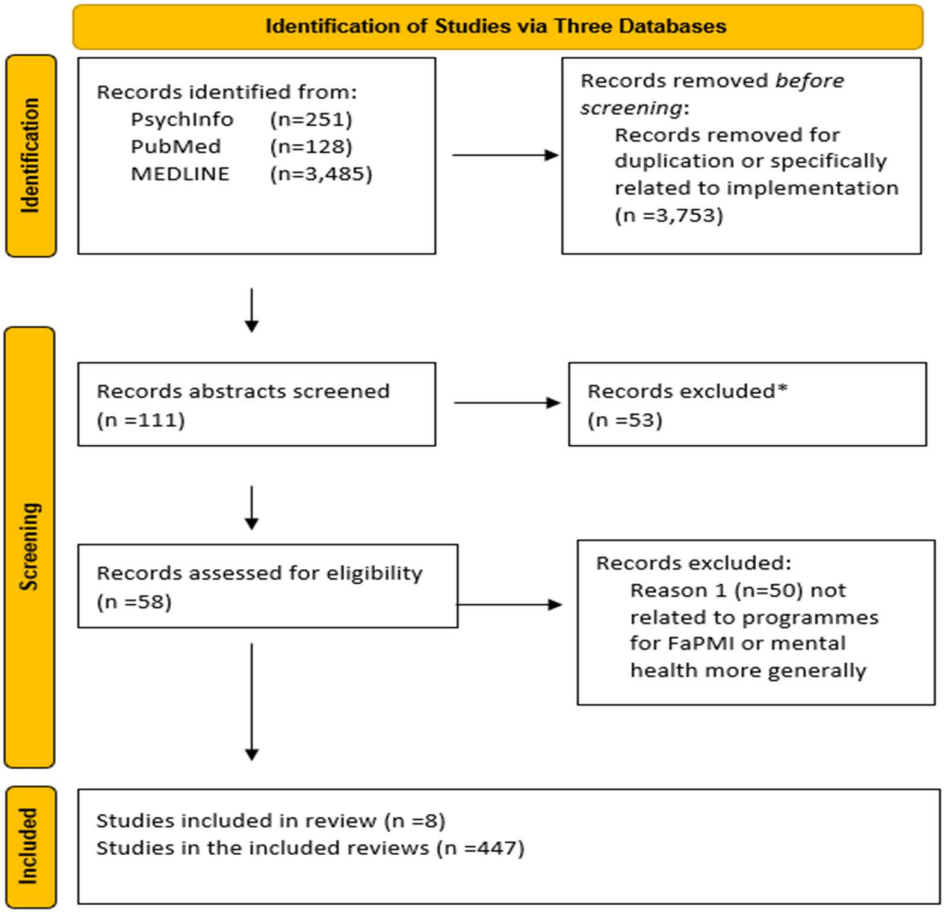
- Published in English
- Published between January 2017 and July 2022.
- Included any type of review of interventions designed to support FaPMI and including scoping, narrative, integrative, critical, and systematic reviews, as well as meta-analyses.

- Included any interventions for parents only OR children only OR whole families and any outcomes related to these interventions.

Eight eligible reviews were identified for inclusion, incorporating a total of 447 papers pertaining to 265 studies conducted across several countries (e.g. France, Germany, Netherlands, and Spain) and including a large number and wide range of programmes (approximately 160 in total, albeit with some overlap between the programmes included in this and the first review described earlier) (see Figure 2.1). The approximate overall sample size across all studies was 42,000 and comprised children (*n*=16,887), parents (*n*=20,420), clinicians (*n*=4,178), and families (*n*=363) (see Table 2.3). These studies focused solely on programmes for FaPMI, including, more specifically: defining FFP and identifying key programme components (Lagdon et al., 2021); evaluating programmes/interventions aimed at PMI and their children (Leonard et al., 2020; Overbeek et al., 2022; Radley et al., 2022); and investigating preventative programmes for COPMI (Lannes et al., 2021; Loechner et al., 2018; Tapias et al., 2021; Thanhäuser et al., 2017).

Figure 2.1

Flow Diagram for the Second Literature Search (2017-2022) of Programmes for FaPMI (Page et al., 2021)



Given the range of programmes included for both parents and COPMI, it was challenging to draw comparisons across studies owing to the heterogeneity of the programmes under investigation, the diversity of the samples (e.g. range of disorders, demographics and sample sizes), methodological/design variations, measurement of different outcomes, varying programme duration (and timing of follow-up assessments) and the variable search criteria used. For example, Radley (2022) included papers from the last 20 years while Overbeek (2022) had no start date limit but ended in February 2021. This variability across studies was compounded by the inclusion of some of the same programmes (e.g. *Family Talk, Family Group*

Cognitive-Behavioural Intervention and *Let's Talk*) across multiple reviews (both in this and the earlier review) as well as the use of different evaluation methods ranging from RCTs and quasi-experimental studies to pre-post designs and qualitative studies. Furthermore, recruitment and retention challenges, which are frequently associated with mental health prevention programmes (Ingoldsby, 2010; Van Doesum et al., 2016), raise the possibility of self-selection/retention bias as most families self-select to participate in these kinds of programmes. An overview and critical narrative on some of the more commonly used FaPMI programmes is provided below, including some web-based interventions which have grown in importance in recent years, particularly since the start of the COVID-19 pandemic (Falkov et al., 2020; Reupert et al., 2013; Woolderink et al., 2015).

Table 2.3

Eight Additional Reviews Identified in the Second Supplementary Literature Review (Listed in Alphabetical Order)

Author/Yr. Country	Type of study	Aim	No. studies included	Sample sizes	Duration of programmes	Evaluation	Summary of Key Findings and Author Recommendations
Lagdon et al., 2021 (UK)	Narrative review	To define FFP and identify programme components.	40 studies including 3 RCTs and quantitative and qualitative study designs. The exact number of interventions was unclear, with one online programme, and two with peer support.	Approx. 1,174 parents, 1,211 children, and 33 clinicians.	Programme duration ranged from a 64-minute DVD – up to weekly family support for alcohol and violence over a 7-yr. period (Dumaret et al., 2009).	Quality was evaluated using CASP[a] but was not reported.	While most family-focused components were similar across the included studies, this review also identified an additional component (part of some programmes) which involves ensuring/enabling participants to have access to community support services. The authors indicate that economic evaluations and an agreed FFP definition across adult and child services are needed. Family-focused outcomes beyond symptoms and deficits such as perceptions/expectations/priorities pre-post programme should also be used. More research is also needed to identify those FFP components best suited to COPMI.
Lannes et al., 2021 (France)	Systematic review and meta-analysis	Identify and evaluate preventative interventions for COPMI	31 articles, including 20 RCTS and 17 meta-analyses; 1 online programme.	30-316 children per study with a total of	Duration ranged from 6 – 33 sessions	14 (70%) rated as 'good' quality, 5 (25%) rated as 'fair', 1 (5%) rated as	The meta-analysis identified a significant risk reduction (47%) for COPMI of developing the same (or another) mental disorder as their parent, having

		with a disorder. At least one programme was offered online, with mention of online education programmes for parental mood or substance misuse disorder.		2,689 randomised children and 2,523 randomised parents in the narrative synthesis. 2,081 randomised children and 1,915 parents in the meta-analysis.		‘poor’. All were assessed using QUALSYST[b] (KMET et al., 2004).	taken part in a preventative intervention. A smaller but still significant effect was reported with regard to internalised symptoms. CBT and psychoeducation were the most common approaches employed at home or in outpatient settings. According to the authors, more research is needed to understand the complex factors impacting psychopathology in COPMI and the effect of different disorders.
Leonard et al., 2021 (UK)	Systematic review and meta-analysis	Evaluate the effectiveness of family focused home visiting for maternal mental illness.	14[e] studies including RCTs (9), (8 were included in a meta-analysis), quasi-experimental studies (3), cohort study/case series design (1). Components evaluated in the meta-analysis included CBT focusing on the mother-infant relationship. No online programmes were included; peer	A total of 5,540 participants, randomised to control and intervention groups ranging in size from 46-2,749 (families [8] professionals [91], parents [78], individuals and 5,512).	Programme duration ranged from 7 hrs. to 18 months.	Low to medium level quality reported from the non-randomised papers using a 15-point quality scale (National Institute of Health et al., 2014).	Family-focused home visiting programmes did not appear to improve depression or stress for mothers with a mental health disorder. More rigorous research is needed to evaluate FFP home visiting for disorders other than depression and to evaluate the effectiveness of family-focused programmes designed for home visiting.

			support studies were excluded.				
Loechner et al., 2018 (Germany)	Systematic review and meta-analysis	To evaluate preventive programmes for children of depressed parents.	14 studies incl. 7 trials of 5 heterogenous preventative interventions in USA (5), Canada (1) and Finland (1). Peer support components included in control groups (2).	935 (ranging in size from 24-316 children aged 6-18 yrs.)	6 weeks to 4 months	RCT quality, reported as high in 11 of the studies evaluated, assessed using a 10-item checklist for RCTs SIGN[c].	Preventative programmes for children of parents with depression were found to effectively minimise the risk of the children developing a mental disorder and reduced internalised symptoms across various interventions when compared with a control group. The authors suggest a need for further research outside of the US as well as longer-term follow ups.
Overbeek et al., 2022 (Netherlands)	Scoping review	Identify interventions for PMI.	127 studies including 73 RCTs, 25 pre-test, post-test and the remainder including quasi-experimental designs, group comparisons, group-based matching designs, sequential group, feasibility studies and pilot RCTs. Programmes were categorised by disorder including depression (62), substance abuse	Approx. 12,602 parents, 5,964 children	Length of a DVD – up to two years of home visits.	28% (36) of papers were rated good, 45% (57) fair, 27% (34) poor using a 26-item checklist developed to assess the methodological quality across randomised and non-randomised studies (Downs & Black, 1998).	While it was difficult to evaluate effective programme elements, those interventions which included family members were most effective for PMI along with the use of cognitive behavioural techniques. There is a lack of programmes for comorbidity, personality disorders and autism. An online education programme was effective in reducing parental stress. Most programmes target maternal mental illness (post-partum) and were developed for depression and substance

			(27), ADHD (9), PTSD (4), eating disorder (3), anxiety (2), bipolar disorder (1) and miscellaneous (18). Three programmes were offered online support and two provided peer support.				misuse. More research is needed on the long-term effectiveness of programmes for this cohort, particularly as the needs of children change as they age. Key enablers are strong parent-practitioner relationships and a non-judgmental attitude on the part of service providers.
Radley et al., 2022 (UK)	Scoping review	Understand the programmes developed for parents with psychosis.	110 papers reported on 38 studies of 34 interventions (8 RCTs, RCTs, 5 of which were protocols and 1 was a feasibility RCT) for 34 interventions developed/delivered in Australia (7), Denmark (1), Finland (2), Germany (5), Ireland (1), Israel (2), Netherlands (5), Norway (1), Portugal (1), Sweden (3), Switzerland (2), UK (6) and USA (5). Three were online, six included peer support.	Not reported	1-2 sessions - up to 2 yrs.	Not evaluated	No family focused intervention has yet been designed for parents with psychosis. Intervention components included psychoeducation, parenting skills, and strengthening parent–child relationships. Only 2 of the 34 interventions were evaluated using an RCT.

Tapias et al., 2021 (Spain)	Systematic review	Describe preventative programmes for asymptomatic COPMI.	16 studies were included, comprising 7 RCTs, 5 quasi experimental and 4 qualitative: 6 included peer support. No online programmes were mentioned.	Approx. 5 to 254 families	3-sessions – up to 18 months.	Of the quantitative studies, five were evaluated as strong and four rated as moderate using QATQS.[d]	Psychoeducation, resilience, problem solving, and coping skills are key components of COPMI preventative programmes while a family group-based approach is considered most effective. Many of the programmes used meals, drama, art, music and games as programme components. The majority of programmes showed positive outcomes with most demonstrating *significant* positive outcomes. Future research should explore the negative impact of parentification on the academic performance of COPMI.
Thanhäuser et al., 2017 (Germany & Italy)	Systematic review and meta-analysis	Evaluating the effectiveness of preventative interventions for COPMI.	95 articles from 50 samples, 34 studies based on 20 mother/infant samples, remainder based on 33 samples on child psychopathology. Included one online programme, and three included peer support.	Mother/infant 1,445 dyads 712/733 intervention, control group). Children aged 2-18 yrs. 3,020 children and young people (1,620/1,400	Mother-infant studies average ~11 sessions, youth studies ~16 sessions.	Mother-infant studies and quality overall was evaluated as moderate (4.8/8) on an 8-point scale.	The findings are consistent with earlier studies, such as those of mother/infant programmes, with a small but significant effect (Siegenthaler et al., 2012). Programmes which included both parent and youth were more effective in reducing psychopathology for COPMI. However, there was a more significant decrease in internalising and externalising

		intervention/ control group).	symptoms. More research is needed to identify and evaluate preventative programmes for COPMI.

Note. Children of parents with a mental illness (COPMI), cognitive behavioural therapy (CBT), family-focused interventions (FFI), family-focused practice (FFP), randomised control trial (RCT), serious mental illness (SMI), Quality of Life (QoL), [a] Critical appraisal skills programme (CASP) (2018); [b]QUALSYST, is a validated tool designed to evaluate qualitative studies based on 10 criteria (KMET et al., 2004); [c] SIGN, Scottish Intercollegiate Guidelines Network, (2015); Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004),[e] Leonard mentions 13 studies in the abstract but actually includes 14 studies in the paper.

2.3.2 Interventions for Parents Only

More than half of the programmes identified in the initial and second review of the literature, target maternal mental health using a range of individual/group, parent-infant/child, and family-based formats and programmes. This focus is perhaps best explained by the increased risk of depression related to pregnancy and the social cost of maternal mental illness given the (still) prominent influence of mothers in the home (Overbeek et al., 2022; Thanhäuser et al., 2017).

For example, almost three-quarters (72%) of the 127 studies included in Overbeek (2022) focused on women, while approximately one in five (21%, 27/127) were concerned with postnatal depression (e.g. *Keys to Caregiving* [Letourneau et al., 2011]); the remainder included parents more broadly and focused on improving outcomes for children and enhancing parent-child interactions. Likewise, Thanhäuser's (2017) review included a synthesis of 34 studies based on 20 samples which included mother-infant dyads (e.g. KOPP[8] [Van Doesum et al., 2005:2008]). Furthermore, over 80% of the parents included in Lannes' (2021) review and meta-analysis of 31 articles (based on 20 studies) were women. While Tapias (2021) reports that 75% (12/16) of the studies in their review included both mothers and fathers, fathers were only specifically identified in one of the 16 studies (Compas et al., 2015). Furthermore, only a small number of studies (*n*=9) in the remaining seven reviews, mentioned fathers (Casselman & Pemberton, 2015; Hanson et al., 2015; Kelley et al., 2017; Kelley & Fals-Stewart, 2002; Lam et al., 2008; Long et al., 2001; Stover & Kiselica, 2015; Tambelli et al., 2015; Thome & Arnardottir, 2013). Thus, there is a marked lack of paternal representation in FFP studies, and little is known about the impact of paternal mental health on COPMI (Fisher, 2016; Ramchandani & Psychogiou, 2009).

[8] This is a Dutch abbreviation of a programme for mothers with young children who are living with a mental illness.

Overall, the programmes included in this second review (Table 2.3) were delivered across a range of settings, thereby enhancing the overall generalisability of the findings. For example, nine trials included in the Lannes (2021) review, focused on psychoeducation for parents with mood, anxiety or substance misuse disorders in group, clinic, or home (online or home visits) settings. While the results relating to group-based programmes were mixed, home-based programmes which incorporated modelling, education, and support components (i.e. follow up phone calls) were "*most often associated with better maternal functioning, improved child functioning and parenting*" (Overbeek et al., 2022, p.10). Similarly, the use of psychotherapy to support mothers with children under two and with postnatal depression, was typically found to be effective, especially if it incorporated a psychoeducational component on child development and parenting skills (Overbeek et al., 2022). It is unclear, however, whether these effects were sustained if depression lasted beyond the postnatal period. Furthermore, according to Bee and colleagues (2014), pregnancy-related mental health disorders such as depression and anxiety, may resolve themselves more easily than other mental health problems and this should, therefore, be taken into consideration when evaluating interventions targeting maternal mental health and their attendant impacts. However, more data are needed on maternal mental health programmes to address questions such as the impact of household size (e.g. number/age of dependent children in the home), socio-economic status, and the presence or absence of a coparent.

Attachment-based interventions also appear to be generally effective for improving parent-child interactions (Overbeek et al., 2022) while cognitive behavioural therapy (CBT) (most often accompanied by psychoeducation), has been found to be particularly beneficial for maternal mental health and parental depression (Overbeek et al., 2022). Overall, programmes that incorporate multi-disciplinary, inter-agency, and/or community-based elements have been found to be generally preferred by parents and more effective for parental psychopathology and for improving family outcomes than single-agency programmes delivered solely within

clinic settings (Lagdon et al., 2021). Furthermore, according to Leonard (2020), it is important to take account of family composition because home-visitor-based programmes (i.e. delivered by specialist community public health midwives, nurses or other professionals in the home) did not appear to reduce levels of depression or maternal stress as they failed to account for complexities within the family and the multitude of factors (e.g. financial, house insecurities) which may compound symptoms of depression/anxiety for mothers experiencing post-partum psychopathology.

2.3.3 Peer Support Programmes (mainly for children and young people)

Some programmes identified here in the initial and second review of the literature, also incorporate some element of peer support and target mainly (but not exclusively) children and young people. Evidence suggests that peer support programmes for children and young people are typically designed to incorporate CBT and psychoeducation in order to enhance resilience and help normalise the young person's experience of living with PMI (Tapias et al., 2021). While formats vary, key components of peer support programmes include a group-based format involving a trainer or peer lead and age-appropriate information or skills training (e.g. problem solving) as well as opportunities for meaningful connection with individuals with a shared experience (von Doussa et al., 2023).

Of the eight reviews included here, Leonard (2020) excluded peer support studies, while Lannes (2021), Loechner (2018) and Thanhäuser (2017) did not explicitly highlight peer support, yet each of these three reviews (11, 2, and 3 respectively) included programmes that incorporated some peer or group support components. Peer or group support was also mentioned as components of control groups in at least two reviews (Lannes et al., 2021; Loechner et al., 2018). These findings support Tapias' (2021) observation that, while peer support is an important therapeutic component, only one third of the COPMI studies included in their review specifically mentioned peer support and yet, over two-thirds included multiple families and/or children's groups. This suggests that while peer support is not always explicitly

reported, it is often part of the therapeutic process, albeit perhaps on a more informal and implicit basis. Thus, more transparency is needed when reporting this aspect of programme provision.

Two interesting examples of peer support programmes are currently being delivered in Australia, both of which provide face-to-face prevention-focused peer support for COPMI (Hargreaves et al., 2008; Reupert et al., 2012; Tapias et al., 2021). The first of these, *CHAMPS* (**Ch**ildren **A**nd **M**entally Ill **P**arent**s**), is a strengths-based suite of programmes (i.e. including an afterschool programme, specialist programme [martial arts therapy], fun day and club day[9]) for primary school children (aged 8-12 years) that involves the provision of age-appropriate education and support to reduce isolation by building resilience and coping skills (Goodyear et al., 2009; Price-Robertson et al., 2019). The second programme, *PATS* (**P**aying **A**ttention **T**o **S**elf), is a peer support preventative programme designed to reduce the transgenerational risk of psychopathology for COPMI (aged 12-18 years). Both programmes have been found to reduce negative emotional outcomes in young people, improve coping skills, and decrease stigma around PMI within selective contexts (Goodyear et al., 2009; Price-Robertson et al., 2019).

Peer support has also been found to be an important and effective component in programmes involving adults, younger children and the family-focused programmes (discussed in the following section). For example, two such as *Family Options* and *Kidstime* (Table 2.2) incorporate a significant element of peer support within group settings which help to de-stigmatise mental illness (Radley et al., 2022). The first of these, *Family Options*, is a programme lasting 12-18 months based on a practitioner-family partnership to support the whole family across multiple areas (e.g. school, work, housing) and using various components including assessment, care plans and family coaching as well as peer support (Nicholson et al., 2009). The second, *Kidstime*, provides monthly whole family, group-based, workshops lasting two and a

[9] https://www.copmi.net.au/resources/vic-eastern-metropolitan-area-champs-programs.

half hours, which incorporate drama, psychoeducation, individual parent/child groups and joint family groups/sessions for FaPMI (Cooklin & Barnes, 2020; Spierling et al., 2019). Each group is led by a clinical or drama lead who meets initially with all families together (approximately 6-10 people per workshop) at the beginning of each session for 'fun' and for delivery of a presentation on a given topic. Adults and children then separate for peer support group work lasting approximately one hour. The children's group focuses on a given topic using games and drama exercises. The adult group is led by the clinical lead who facilitates discussion on the experience of PMI but maintains a focus on the needs of the children. To conclude, everyone gathers for pizza and a group discussion on the session.

A key strength of *Kidstime* is its multi-family structure which "*enables affected families to discuss mental health issues without one child, parent or family feeling exposed, judged or different*" (Spierling et al., 2019, p. 10). With regard to *Family Options*, the longer-term wraparound support for the whole family is an obvious strength. Positive outcomes reported for both programmes include a reduction in the loneliness and stigma often associated with mental illness and improvements in overall parent and child wellbeing (Overbeek et al., 2022). However, similar to many of the programmes reported here, more research is needed to better understand the effectiveness of each programme across populations, cultures and socio-economic familial contexts.

It is also important to note that, while peer support programmes have been found to improve well-being, younger populations may be at risk of developing a shared group identity of 'being different' or of receiving support while returning to an unchanged home environment (Foster et al., 2014). Furthermore, group settings may elicit anxiety in some younger attendees by leading to negative comparisons with peer group members (Letourneau et al., 2011; Overbeek et al., 2022). With regard to adult cohorts, Radley (2022) found that adult service users with psychosis were keen to receive peer support despite its use in only a small number of the reported interventions delivered to this group. In addition, Overbeek et al. (2022) found

that peer support was found to be particularly effective with ethnic minorities and for promoting engagement/attendance (Ericksen et al., 2018; Piedra et al., 2012; Porter et al., 2015). Indeed, more research among ethnic and cultural minorities may help us to better understand how FaPMI needs differ across cultures and among non-Caucasian cohorts. Overall, better reporting and more research are needed to better understand the benefits of peer support with cohorts of all ages.

2.3.4 Family-focused Programmes

Family-based programmes have been developed, as the name suggests, to support families and more specifically, families with dependent children (typically aged 7-18 years) who have the necessary cognitive skills to engage with the psychoeducational component of a given programme. Programmes that incorporate psychoeducation are important, as COPMI are typically not informed about a parent's illness (Tapias et al., 2021). Historically, family-focused interventions (FFIs) have focused largely on parental affective disorders such as depression or anxiety and/or substance misuse. As such, they have excluded a significant proportion of vulnerable service users living with different mental health disorders who equally require family-focused support. Notably, the most recent evidence suggests that COPMI who take part in preventative FFIs can potentially almost halve their risk of developing a mental health disorder. For example, Lannes' (2021) recent meta-analysis of five trials showed a substantial post-intervention reduction of 47% in the risk for COPMI of developing both the same or different mental health disorder to their parent; this represents a 7% increase in the risk reduction for COPMI noted by both Siegenthaler (2012) and Thanhäuser (2017) several years previously. Furthermore, it appears that programmes which include *both* parents and their children may be more effective in reducing psychopathology for COPMI than those which focus on either group alone (Thanhäuser et al., 2017). According to Loechner and colleagues (2018), the findings, to date, are promising although more rigorous evidence is needed to establish the

effectiveness of FFIs across a range of disorders and their suitability for *each* of the attending family members.

While family-focused programmes typically vary in terms of content (e.g. psychoeducation, coping skills, parenting skills, CBT) and duration (e.g. from a single session up to 18 months, see Table 2.2), many share common features, such as needs assessment, care planning, relationship and communication support, advocacy, problem solving, social skills training and a coordinated interagency care model to bridge service gaps (Devaney et al., 2020; Lagdon et al., 2021; Loechner et al., 2018; Nicholson et al., 2022). Family programmes are also typically delivered across a range of settings and contexts, including in-service, clinic, home, and online (Overbeek et al., 2022; Thanhäuser et al., 2017). Collectively, the evidence suggests that these kinds of family-inclusive programmes offer considerable benefits in terms of improved levels of wellbeing and communication in the home, a reduction in stigma for service users, a reduced risk of psychopathology for COPMI, lower levels of fear/worry within the family more generally, and improved parental capacity to meet the needs of the children (Radley et al., 2022; Tapias et al., 2021).

Loechner's (2018) meta-analysis of family-focused programmes further identified positive outcomes such as reduced depression and lower levels of internalised symptoms for COPMI, but notably, their findings also suggest that preventative interventions for non-depressed children of parents with depression, can "*prevent (or at least delay) the onset of depression*" (p.9). While more follow-up studies are needed to assess the longer term impact of these programmes on children, particularly families with complex needs (Lannes et al., 2021) two studies included in Lannes' (2021) review of interventions for children (5-18 years) identified a reduction in internalising and, to some extent, externalising symptoms, for COPMI at 12- and 24- month follow-up (Clarke et al. [2001] and Compas et al. [2009:2010:2011:2015]), respectively.

Family-focused interventions also appear to be more effective in cultures which value family (e.g. Chinese or Indian) when compared to parent-only programmes (Hinton et al., 2019). Despite their potential, however, a number of authors have suggested that the psychoeducational component should be ongoing rather than a one-off event, as the needs of children change over time and across key developmental milestones (Lannes et al., 2021; Tapias et al., 2021). Family and practitioner attitudes have also been shown to impact outcomes. For example, evidence suggests that, in general, an optimistic attitude toward participation in programmes by family members as well as their experience with services prior to attendance, also positively influence outcomes (Overbeek et al., 2022), while a non-judgemental practitioner-parent alliance has also been found to improve overall engagement (Lagdon et al., 2021). As mentioned earlier, more research is also needed from children and co-parents to ensure that the needs of each family member are met by any given programme.

2.3.5 Online Programmes

Nine papers included in the reviews listed in Table 2.3, incorporated web-based programmes, although this was not always made explicit (e.g. Lagdon et al., 2021; Lannes et al., 2021; Thanhäuser et al., 2017). The experience of the COVID-19 pandemic has highlighted the importance of digital technology such as online programmes, smartphones, chat rooms, blogs, and social media, to supplement and extend face-to-face interactions and interventions (Pierce et al., 2020), while simultaneously providing anonymous, de-stigmatising access to care (Tabak et al., 2016). The pandemic has also amplified the importance of remote treatment options in order to remove geographical access barriers to service provision (Overbeek et al., 2022; Radley et al., 2022). While more research is needed on how online and web-based programmes may, amongst other things, impact levels of connectedness and remote access to care (Ali et al., 2015) several programmes during the last two decades have been found to improve accessibility, eliminate travel time, and increase retention rates, all while offering a low-cost

service option and leading to positive outcomes for FaPMI (Overbeek et al., 2022; Radley et al., 2022).

For example, two interesting pilot online programmes were highlighted in the studies included here. The first of these, *NURTURE*, is an interactive 16-week forum for parents with an eating disorder who have children aged from birth to three years (Runfola et al., 2014). The second, *KopOpOuders (Chin Up, Parents*), is an online discussion group developed in the USA and the Netherlands for parents with a mental health disorder (van der Zanden et al., 2010). According to the authors, *Nurture* was well-received following a pilot with 13 mothers and importantly, there was no drop-off in participation, albeit the sample was very small (Runfola et al., 2014). Positive pre-post intervention outcomes showing moderate to large improvements in parenting skills, were also reported for 48 parents who took part in *KopOpOuders.*

An additional two programmes developed in the USA and the UK respectively, were evaluated using RCTs. The first is a 12-session *Parenting Educational Programme* which focuses on child development, parenting, and stress reduction and which incorporates psychoeducation, homework, and pre-recorded expert video content (O'Shea et al., 2019). The second *Netmums (Helping With Depression* [NetmumsHWD]), is a 12-session CBT-based programme designed for new mothers with postnatal depression (and with a child born within the previous 12-months) (O'Mahen et al., 2014). In addition to the 12-session programme, weekly support phone calls are made by a mental health professional and additional module options are also offered (e.g. 'Being a Good Mother') as well as access to a peer-support moderated chat room. The findings in relation to the evaluation of both programmes indicate more positive outcomes for intervention versus control group participants. The *Parenting Educational programme* reported lower levels of parental stress at 18-month follow-up (O'Shea et al., 2019) while women who completed *NetmumsHWD* reported improvements in depression, anxiety, work and social impairment when compared with the treatment-as-usual group (O'Mahen et al., 2014).

Lastly, universal access to digital programmes can be problematic as Wi-Fi and 'internet poverty' are common barriers reported by vulnerable populations (Pierce et al., 2020; Tabak et al., 2016). Digital interventions also raise questions about, amongst other things, the need for monitoring and/or clinical oversight for vulnerable participants and younger children (Grové & Reupert, 2017). Overall, much more research is needed to investigate the impact, acceptability, utility and cost-effectiveness of these programmes for various cohorts when compared to in-person face-to-face equivalents (Bond et al., 2023; Woolderink et al., 2015).

2.3.6 Summary

While the findings outlined here, indicate a range of potentially promising programmes for FaPMI, family-focused service provision across the developed world remains patchy or absent, with only a small number of countries and regions (i.e. Australia, Scandinavia, UK, the USA) regularly featured in the English language literature (see Tables 2.1, 2.2 and 2.3). The collective findings, including those from the initial review conducted as part of Study One (Chapter Four), highlight not only a continuing need for support for FaPMI, but also demonstrate the benefits (to a greater or lesser extent) of many interventions for both parents and children. Most studies of FFIs (including *FT*, the focus of this study) report positive outcomes related to parents' understanding of their mental illness as well as a deeper understanding of the needs of children (Lagdon et al., 2021); however, these programmes are typically challenging to implement given the complexity of addressing the needs of whole families with children across various developmental stages (Friedlander et al., 2011). While studies involving digital/web-based interventions found improved retention rates (Runfola et al., 2014), most report these kind of data in non-standardised ways, thereby making meaningful comparisons across studies difficult (Lannes et al., 2021; Loechner et al., 2018; Tapias et al., 2021).

Interestingly, Bee (2014), the initial review reported earlier in the chapter, identified a number of reasons for drop-outs/attrition more generally, including age (i.e. younger participants were more likely to drop-out), hospitalisation, change of employment, and/or

difficulties due to pressures of daily life (e.g. homelessness, single parenting). However, there is a need for more standardised reporting of recruitment, retention and drop-out rates across studies. There is also a need for much more high-quality evidence (Leonard et al., 2020; Schrank et al., 2015) on the longer-term impact of programmes and the sustainability of any positive outcomes over time, as well as the potentially reduced risk of developing psychopathology (47%) amongst COPMI who participate in family-focused programmes (Bee et al., 2014; Lannes et al., 2021). More preventative programmes are also needed for COPMI (Huntsman, 2008; Loechner et al., 2018) as well as greater inclusion of COPMI (including adult COPMI) and co-parents in research to ensure that their needs are met by currently available programmes. Strategies are also needed to address and reduce the stigma often associated with receiving mental health interventions and especially for those with those disorders considered more serious such as schizophrenia and bipolar disorder (Loechner et al., 2018; Radley et al., 2022; Tapias et al., 2021).

Finally, with regard to the reported quality of included studies, the more recent reviews suggest that study quality is improving, albeit more stringent protocols as well as randomised and economic evaluations are needed (Lagdon et al., 2021; Leonard et al., 2020). For instance, 70% (*n*=14) of the studies included in Lannes (2021), were rated as 'good' based on the QUALSYST tool (KMET et al., 2004) (Table 2.3). Likewise, all but 3 of the 14 studies reviewed by Loechner et al. (2018) were rated as 'high quality'. However, Thanhäuser's (2017) review of 95 articles (involving 50 samples) highlights a risk of bias in some of the lower quality studies which typically reported larger effect sizes. Based on the findings outlined, a number of recommendations were made by the study authors to help improve the overall quality of research and the generalisability of the findings while also addressing knowledge gaps in the field. Further information is provided below.

2.3.7 Key Recommendations for Future Research

Despite a growing body of evidence on the benefits of FFP for FaPMI, a number of authors have highlighted a need for methodological improvements to research in this field. More specifically, they recommend: more standardised outcome evaluations; an increase in RCTs and meta-analysis; more consistent reporting to objectively evaluate the growing evidence; and the inclusion of appropriate subgroup analyses to identify which programmes work best for whom and under what circumstances (e.g. across various disorders) (Lagdon et al., 2021, Overbeek et al., 2022; Radley et al., 2022). There is also a need for greater ethnic diversity as mentioned (e.g. non-Caucasian and low- and middle-income countries) and larger qualitative studies to address knowledge gaps within the research (Lagdon et al., 2021; Lannes et al., 2021; Loechner et al., 2018), coupled with more economic evaluations to assess the cost-effectiveness of programmes for FaPMI in real world settings (Lagdon et al., 2021; Loechner et al., 2018). The development of programmes to assist practitioners reduce the stigma associated with help-seeking, may also improve recruitment and retention rates (Lannes et al., 2021). These recommendations are summarised in Table 2.4 below.

Table 2.4

Summary of Key Recommendations for Future Research on Family-focused Interventions

- More research is needed to better identify the most effective programme components for all family members and especially the needs of children across developmental stages/milestones.
- Additional programmes are needed to address gaps in services for people with autism, personality disorder and comorbid issues, as well as the needs of younger children.
- Improvements are needed in the overall research design of studies, including more standardised reporting of recruitment and retention rates.
- An increase in ethnic diversity and the inclusion of low- and middle-income countries is considered to be important.
- Larger qualitative studies are required to address research gaps, with a particular need for more data on paternal mental illness.
- More research is needed on the benefits of web-based programmes and how they compare to face-to-face interventions.
- Many more economic evaluations are needed to better understand the cost-effectiveness of implementing FFPs in real world clinical settings.
- A need for flexibility is important, including additional components to suit the unique needs of services users and their families (e.g. parents with more serious disorders).
- Additional research is needed on the effectiveness of shorter FFIs to meet the needs of individuals with specific disorders.
- More programmes are needed to reduce stigma around mental health disorders.

Additional data are also needed on the utility and effectiveness of shorter FFIs for service users with serious mental health disorders such as psychosis. For example, Radley's (2022) scoping review which included 110 papers, identified only two, albeit very different interventions – *Family Talk* in Sweden and *Triple P* in the UK (originally designed to support parents of children with behavioural problems) which were delivered only to parents with psychosis. Parents who completed *FT* appreciated that their children had an opportunity to talk with a professional and found that the intervention improved family members' understanding of PMI (Strand & Meyersson, 2020). While both programmes were found to be effective and acceptable for this group, some of the *FT* participants expressed a desire for less sharing on the effects of their illness (Strand & Rudolfsson, 2017). Radley (2022) suggests a need for additional components within programmes, such as safety planning, to better prepare families for acute phases of illness, and for re-establishing self-esteem following an episode of psychosis. Therefore, while the programmes identified, were all deemed to be helpful (to a greater or lesser degree) and may also be effective for those with more severe mental health challenges, Radley (2022) argues that greater consideration must be given to the unique needs of the intended service users, their specific disorder, and the needs of their families. As already mentioned, more research is also needed to explore paternal mental illness as well as parenting with autism, personality disorder, or multiple comorbid issues, while there are also relatively few programmes for children aged seven and under (Overbeek et al., 2022).

With regard to the impact of PMI on outcomes, more information is needed on the influence of a parent's illness on children's school performance as well as the use of play to increase younger participants' enjoyment of, and participation in, interventions (Tapias et al., 2021). Future work is also needed to identify the components of programmes that are most important to families, including those which are most effective for children of different ages (Lagdon et al., 2021; Lannes et al., 2021), as well as the needs of co-parents (Leonard et al., 2020).

While a wide range of programmes have now been developed to support FaPMI, and with an increasing number of studies assessing their effectiveness, little is known about the implementation and embedding of family-focused interventions in services traditionally designed around an individualised or "*biomedical professional-centered approach that is focused on treatment in acute episodic care"* (Allchin et al., 2022, p.2). This next section considers this important question with reference to a second (smaller) body of literature.

2.4 Supplementary Review 2017-2022 - Part Two: Factors Influencing Implementation of FFP

As outlined earlier, the specific objectives of Part Two of the supplementary review were to identify: (1) key factors that facilitate the implementation of programmes for FaPMI and any attendant practice change; and (2) key barriers to successful implementation. Implementation has been defined as "*a specified set of activities designed to put into practice an activity or program of known dimensions"* (Fixsen et al., 2005, p.5). The science underpinning implementation was developed to increase the uptake of evidence-based programmes in real world clinical settings (Bauer et al., 2015). Implementation, however, is a complex process often involving non-linear, overlapping stages. For example, a recent review by Huybrechts and colleagues (2021) identified 28 different implementation frameworks referring to 90 components or elements (e.g. settings, contexts, intervention characteristics). However, these frameworks may be broadly categorised as relating to one of three key phases including: (1) implementation; (2) development/translation; and (3) sustainment. The first of these was the focus of this second element of this updated supplementary review.

2.4.1 Method and Overview

The approach to Part Two of the supplementary review was based on a deliberatively broad, scoping-type, exploratory review which was conducted in line with some of the guidelines contained in the PRISMA-Scr checklist (Tricco et al., 2018). Unlike Part One of the review, this focused on both review articles and primary research papers (i.e. based on single sample studies). The rationale for including the latter was based on an initial search which

identified a smaller number of single sample studies which indicated that the mental health workforce encounters significant challenges and barriers when implementing FFP for FaPMI (Vives-Espelta et al., 2022). It was decided, therefore, to extend the search to include these, but for purposes of simplicity, to present and discuss them separately from the review articles.

The same databases (i.e. PubMed, PsychInfo, MEDLINE) were used as in Part One (and also as used in the initial review). Search terms included the following: [Implement, Implementation OR Introduce, Introduction] WITH [Family-focused Practice, Family Focused Practice OR Think Family] WITH [Parental Mental- Illness Or Disorder] AND/OR [Adult-, Child-, Community Mental Health Services]. The following additional search terms were included to identify specific workforce-related papers as outlined above: [Practitioner OR Expert OR manager] experience of [Family-focused practice, Family Focused Practice OR Think Family] OR [Mandatory Family Focused Practices] WITH [Implementation, Implement OR Introduce Or Introduction].

A similar snowball search as before was also conducted of the reference lists of key papers. Special peer-reviewed journal editions on the topic of service provision for FaPMI were also used to identify relevant studies (e.g. *Parental Psychiatric Disorder: Distressed Parents and their Families*[10] [2015]; *Frontiers Research Topic articles on Parents with Mental and/or Substance Use Disorders and their Children*, Volume I[11] and II[12]) whilst selected grey literature was also searched (e.g. *Reaching out: think family. Analysis and themes from the Families At Risk* [Social Exclusion Unit Taskforce, 2008]; *and Family Minded: Supporting Children in Families Affected by Mental Illness* [Evans & Fowler, 2008]). As implementation science is a relatively recent field (Boulton et al., 2020), no limitations were placed on publication date or research design.

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[10] Edited by Andrea Reupert, Daryl Maybery, Joanne Nicholson, Michael Göpfert and Mary V. Seeman.
[11] Edited by Joanne Nicholson, Giovanni de Girolamo and Beate Schrank.
[12] Edited by Joanne Nicholson, Jean Lillian Paul, Anja Wittkowski, and Joanne Louise Riebschleger.

Approximately 1,159 review articles (Figure 2.2) were identified in the first instance and the titles screened, after which 947 were removed as irrelevant or a duplication. Once all duplicates or irrelevant articles had been removed, the abstracts of over 190 potentially eligible articles were screened by the author and assessed for eligibility using the inclusion criteria below. While time constraints did not permit a double screening of abstracts (or part thereof), the principal supervisor/PI was again consulted if there was any doubt about whether to include/exclude papers. As with Part One, the final selection of included studies and a critique of their findings, was also discussed at length and agreed with the PI.

Inclusion criteria

Articles were included if they were:

- Published in English
- Published up until July 2022 (no start date)
- Based on the implementation of either FFP or specific family-focused interventions for mental health service users and containing information relevant to barriers and enablers of service implementation.
- Based on specific workforce-related challenges of implementing FFP for FaPMI

A total of nine reviews published during 2009-2022 were included (Table 2.5). These incorporated: three systematic reviews, one with a meta-analysis (Gregg et al., 2021; Klaic et al., 2022; Novins et al., 2013); two integrative reviews (Maybery & Reupert, 2009; Vives-Espelta et al., 2022); a scoping review (Woodman et al., 2020); a consolidation review (Allchin & Solantaus, 2022); a qualitative synthesis (Shah-Anwar et al., 2019); and a review of family interventions for psychosis (Bucci et al., 2016). Collectively, the three systematic reviews accounted for over 460 studies (sample sizes were not typically reported) and focused on the implementation of FFP across a range of adult (Gregg et al., 2021; Maybery & Reupert, 2009), child (Novins et al., 2013) and mixed settings (Allchin & Solantaus, 2022; Bucci et al., 2016; Shah-

Anwar et al., 2019; Woodman et al., 2020). One involved a review of nurses' perceptions of FFP across various settings (Vives-Espelta et al., 2022). Four reviews originated in the UK, three in Australia (one co-produced with Finland), one in Spain, and one in the USA.

Figure 2.2

Flow Diagram Outlining the Literature Search of Review Articles on the Implementation of Family Focused Practices for FaPMI (Page et al., 2021)

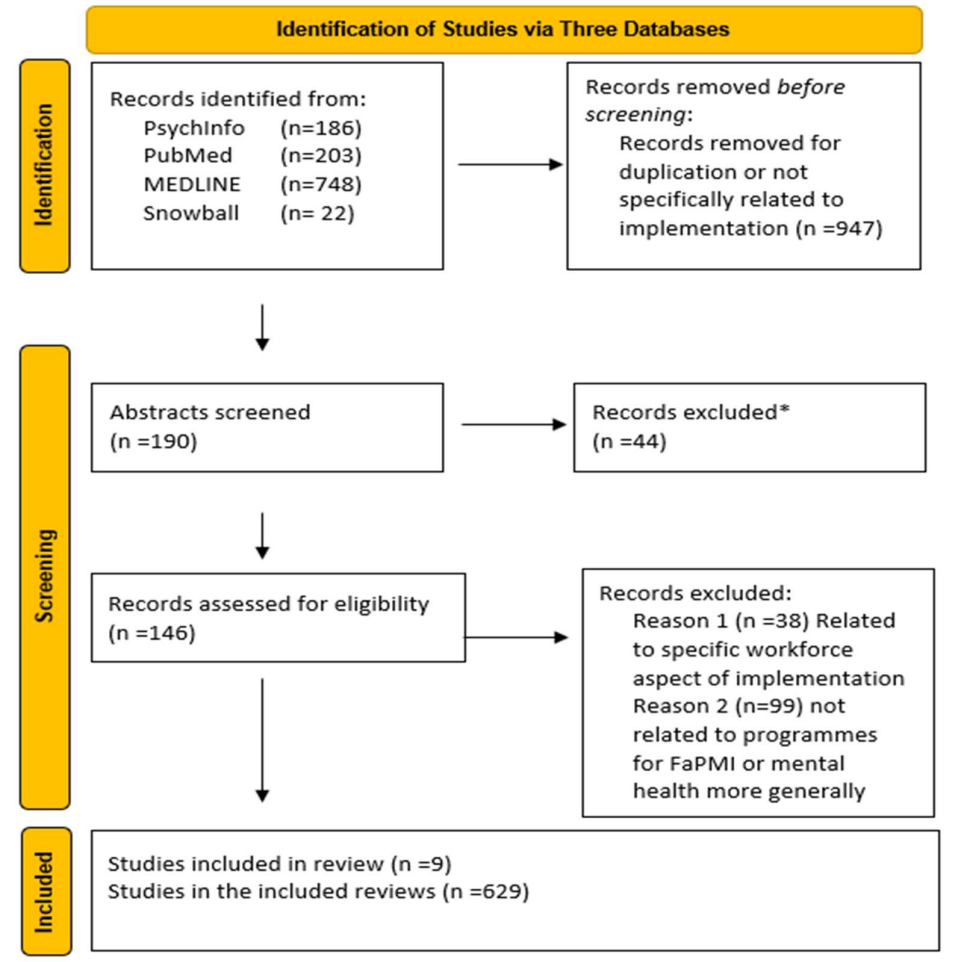


Table 2.5

Summary of Nine Reviews relating to the Implementation of Family-Focused Programmes for Parental Mental Illness

Author(s) and Country	Purpose of the study	No. papers included	Method	Sample Size	Setting	Analyses	Quality	Key findings
Allchin & Solantaus, 2022 (Australia & Finland)	Consolidation of the evidence on *Let's Talk* including one of the original programme designers (Solantaus).	26 papers including RCTs (5), quantitative studies (3), qualitative designs (5), mixed methods (7) and descriptive/ commentary (6).	Consolidation Review	Not specified	Mixed government and non-government adult, child and family settings.	Constant comparison analysis	Not evaluated	Studies incorporated a range of settings /jurisdictions, including AMHS, CAMHS, general psychiatry, across a range of mental health disorders. Four adaptations were found to be effective/suitable for service users and practitioners with similar outcomes. *Let's Talk* was translated/adapted for implementation in Australia, Estonia, Greece, Japan, Norway, Sweden, and the USA.
Bucci et al., 2016 (UK)	A review of the evidence and barriers to implementing family. interventions for psychosis in routine services (not specific to PMI).	~137 papers mentioned.	Review	Not specified	Mixed settings	Not specified.	Quality was not specified. Lack of clarity of papers included.	Implementation rates are low despite national (Australia) and international guidelines for family interventions for service users with psychosis. Unequal provision of services is a key barrier. More effective research methods and

								designs are needed with larger sample sizes and clear analysis protocols, as well as a greater understanding of the barriers in non-Western cultures (e.g. Asia, Africa, and India). Organisational, professional, and interagency change is needed to increase the effectiveness of the programmes introduced.
Gregg et al., 2021 (UK)	Identify factors influencing the implementation of FFP in AMHS.	19 studies based on 14 datasets Australia (8), qualitative (9) and quantitative and cross-sectional studies (10).	Systematic review	Sample sizes ranged from 6 to 349, (total 1,493).	AMHS	Narrative synthesis, quantitative and qualitative separately then combined.	Qualitative papers were of mixed quality with four rated as 'high' and, three as 'adequate'[13]. With two-thirds (6/9) not considering the researcher role. Quantitati	The components most likely to increase the use of FFP in AMHS include personal attitudes, beliefs about job role, ownership and management support for the implementation process.

[13] CASP, C. (2018). CASP qualitative checklist. *Critical Appraisal Skills Programme*.

							ve (3) were high, adequate (7) limited by missing data, and/or null findings. Possible selection bias in (6) studies. Quantitative papers were excluded.	
Klaic et al., 2022 (Australia)	Systematic review of healthcare interventions implemented to develop a framework.	252 publications, 30% of which included a meta-analysis, 19% mixed methods. Measuring fidelity (36), exploring fidelity (41).	Systematic review and meta-analyses	Not specified	Mixed settings	Systematic approach	No assessment of quality was conducted.	Elements essential for successful health service implementation include acceptability, fidelity and feasibility across all stages to achieve scalability and sustainability.
Maybery & Reupert, 2009 (Australia)	A Review of workforce barriers and enablers to supporting FaPMI.	28 publications including experimental and non-experimental studies from Australia, Denmark,	Integrative review	N/A	AMHS	Data was reviewed and categorised but no further data provided.	Paper written by expert academics in the field of PMI.	A multi-level approach is needed to address the workforce barriers to implementing supports for FaPMI across policy and management sectors. Effective change requires an inter- agency approach,

		Finland, Germany, Greece, Sweden, the UK, and the USA.						organisational supports as well as engagement from practitioners, service users, partners and children. More research is needed from COPMI and partners to better understand the impact of living in a FaPMI.
Novins et al., 2013 (USA)	Review of evidence-based implementation (not specific to PMI) for child and adolescent mental health services.	73 articles 44 unique studies evaluating exploration (2), preparation (19) implementation (60), and sustainment (8) phases of implementation. 23 focused on preventative interventions.	Systematic review – papers fitting the implementation phase focused on active implementation and scaling up the programme with 23/60 focused on prevention and the remainder on clinical interventions.	Not specified	CAMHS	An iterative coding procedure.	No quantitative meta-analysis was conducted.	Supporting programme fidelity and providing strong leadership were key to the successful implementation and sustainability of programmes, as well as practitioner retention. Training strategies and IT systems helped to strengthen organisational culture and are key to improving outcomes and sustainability. Better programme sustainability and outcomes require a good fit between the intervention and organisation culture.
Shah-Anwar et al., 2019 (UK)	Mental health perspectives of FFP across child and adult services.	Nine publications across Australia, Ireland, Hong Kong and the USA.	Qualitative Synthesis	143 mental health professionals	Adult and child settings	Meta-synthesis	Study quality was evaluated across 8 domains	Despite the broad range of FFP interventions, there is a lack of FFP policy. Organisational challenges (e.g. under resourced services, large workloads)

							(Walsh & Downe's, 2006). There was a lack of researcher reflexivity in studies (4) while the remainder lacked a rationale for the methods used.	were also common. Professionals were unclear where the responsibility lay for FFP. There are limited data on practitioners' views of FFP and limited organisational level data. There is a need to understand implementation differences across mental health disciplines.
Vives-Espelta et al., 2022 (Spain)	To understand nurses' perceptions and practices for PMI across various mental health settings.	23 Studies, (10 quantitative, 5 qualitative, 4 mixed methods and 4 theoretical) from Australia (3), Australia and Ireland (1), Australia and Finland (1), Australia, Norway and the USA (1), Finland (4), Germany, Israel, New Zealand, Thailand, all (1),	Integrative Review	4,054 practitioners	Various practices reported on	Constant comparison	Evaluated using the mixed methods Appraisal Tool (Hong et al., 2019). All studies were rated over 50%.	Various factors influence nurses' FFP with service users including gender and prior experience professionally or personally with mental disorders. Knowledge, skills, service, policies, standards and workload were all identified as important influential factors. The authors highlight a need for more mixed method studies to gain a broader understanding of the complex factors influencing the likelihood

		Ireland (4), and the UK (5).						of adopting a FFP approach to PMI across disciplines.
Woodman et al., 2020 (UK)	Scoping review of 'think family' approaches in healthcare settings to identify mechanisms of change.	62 studies, primarily focused on PMI, 59 focused on mothers and children's relationships (targeting mental health, substance misuse, domestic violence and physical health); 45 focused on improving parental capacity, 13 targeted parent/ children, and 5 children directly. Over half were USA based, 18% were UK based.	Scoping review	Not specifie d	Adult and child mixed settings.	Thematic analyses.	Quality is typically not appraised for scoping studies.	The heterogenous designs, outcomes and implementations were challenging. Key mechanisms of change related to screening, health promotion, relationships between parent(s) and professionals as well as effective communication. Supporting children via parental support is helpful, but a direct approach is also required. The evidence, overall, is limited, with some concern about the effectiveness of interventions to meet whole family needs and a risk of practitioners pathologizing /discriminating against parents with mental health disorders.

Note. AMHS, adult mental health services; COPMI, children of parents with a mental illness; PMI, parental mental illness; FFP, family-focused practice, UK, United Kingdom, USA, United States of America.

2.4.2 Workforce-Related Single Sample Studies

An additional 37 studies were identified in relation to workforce perceptions and experiences of FFP, all of which were based on single samples only. The abstracts of these papers were again screened by the author, after which 18 were excluded because they related to services for families, but were not specific for FaPMI (Appendix F). The remaining 19 studies (Table 2.5) were included because of their relevance to implementing FFP, or a specific FFP programme for FaPMI within MHS, and because they were useful in identifying factors that influence clinicians' willingness to engage in practice change. These incorporated six qualitative, seven quantitative, and six mixed methods studies conducted in Australia (*n*=8), Norway (*n*=3), Ireland (*n*=3), the USA (*n*=3), and the Netherlands (*n*=1); an additional study (Bauer et al., 2021) had 17 authors from 8 countries.

Eight of the nineteen studies examined one of the following three programmes (one for practitioners, two for families): (1) *Keeping Families and Children in Mind,* a course developed in Australia as a prerequisite for practitioners who are about to train in, and deliver, *FT* and comprising six modules to increase practitioner confidence working with families (Goodyear et al., 2015); (2) *Family Options,* a multifaceted programme (mentioned earlier) lasting 12-24 months and involving a wraparound support service provided by a family coach (Biebel et al., 2014:2016); and (3) *Let's Talk* (Allchin et al., 2020a:2020b:2020c; Karibi & Arblaster, 2019; Nicholson et al., 2022), also mentioned earlier, a two-session, parent-only programme to help FaPMI and which has been implemented in seven[14] countries to date (Allchin et al., 2022). This last programme (Table 2.2) was developed in Finland (described below) as part of a broader government initiative "*to incorporate promotive and preventative approaches to child wellbeing*" (Allchin & Solantaus, 2022, p. 5). Furthermore, a new project is also underway to deliver *Let's Talk* training to practitioners across nine European countries (i.e. Czech Republic,

[14] Australia, Estonia, Greece, Japan, Norway Sweden, and the USA.

Estonia, Finland, Greece, Poland, Portugal, Romania and Italy), as part of a EU4Health programme (2021-2027); this is being led by the Finnish programme developer, Dr Tytti Solantaus, and is being coordinated by the University of Turku in Finland. Mental Health Europe is partnering with the university to disseminate and evaluate the project (https://letstalk.utu.fi/blog/letstalk-kickstart-2023).

Seven of the included studies (Table 2.6) also investigated factors influencing practitioners' adoption of FFP for FaPMI (Everts et al., 2022; Goodyear et al., 2017; Grant et al., 2016:2019:2021; Leeman & Arblaster, 2019; Maybery et al., 2016) while three examined the longer-term impact of FFP legislation introduced in Norway in 2010 (Lauritzen et al., 2014:2018; Reedtz et al., 2022). One paper was also included because it outlines the first theoretical framework/programme theory developed by Bauer and colleagues (2021) to better understand the mechanisms needed to support the implementation of FFP within MHS. This framework was developed on the basis of a number of key components identified from interviews with 17 participants, most of whom were working in publicly funded MHS (e.g. psychology, psychiatry, occupational therapy and social work) across eight countries (i.e. Austria, Australia, Germany, Netherlands, Norway, Sweden, UK, and the USA). The framework combines resource inputs (i.e. from services, organisations, and practitioners) with appropriate support systems (e.g. financial, training, information technology) and context components which may significantly help or hinder programme development (e.g. stigma). Each stakeholder's knowledge, emotions and behaviour are also key elements to consider as these enable practitioners to more effectively deliver programmes (Bauer et al., 2021).

Table 2.6

Additional individual (Single Sample) Studies (n=19) on Factors Influencing FFP Implementation

Author	Purpose of the study	Method	Sample	Setting	Analyses	Key findings
Allchin et al., 2020a (Australia)	Assess managers' and programme implementors' perceptions on introducing *Let's Talk* (during a four-year RCT).	Qualitative	16 semi-structured interviews with service managers and implementation leads (9 male)	12 organisations, including AMHS (5), mental health disability services (2), and child and family services (5).	Thematic analysis using the Consolidation Framework for Implementation Research.	Organisational setting (funding, new policies, resourcing challenges) and stakeholder/organisational readiness were found to influence the implementation process. Practice, policy conflicts (e.g. medicalised/family-focused care model) and funding may help/hinder the process. Leadership attitudes, support and commitment to the new programme were reported to influence programme effectiveness. A dedicated implementor with organisational knowledge is a key driver. Readiness was also an important consideration for each stakeholder.
Allchin et al., 2020b (Australia)	How to sustain *Let's Talk* in AMHS.	Quantitative survey	73 mental health practitioners who took part in the implementation of *Let's Talk* as part of an RCT.	8 AMHS	Statistical analysis	Factors influencing practitioners' use of the *Let's Talk* intervention included training, gender, support, workload and time since training. Delays in delivering the programme after training reduced the likelihood of delivery. Over time, a decline in the use and delivery of the intervention was reported, which was negatively impacted by practitioners' caseloads and time-pressures. Practitioners were more likely to deliver the programme close to completing the training. Reminders and refreshers may be helpful.

						Programmes also need to be adapted for families. More research is needed to understand how practitioners should continue delivering programmes.
Allchin et al., 2020c (Australia)	Retrospective evaluation on the implementation and capacity to deliver the *Let's Talk* programme across 8 AMHS.	Mixed methods (survey and interview) retrospective study (12 months post RCT)	Telephone interviews with FaPMI coordinators (8) and semi-structured interviews with managers (5).	AMHS	Content analysis	Success was influenced by practitioner attitudes to both implementation and the intervention, programme and relational fit with the organisation, leadership support, and openness to change. Successful strategies for improving outcomes included the use of an implementation committee and plan, key personnel, and support which lasts throughout the implementation process.
Bauer et al., 2021 (Authors from 8 countries)	Understanding the elements influencing the design and implementation of FFP to develop a theory model for AMHS.	Qualitative	17 FFP research leaders across Austria, Australia, Germany, Netherlands, Norway, UK, and the US.	AMHS	Realist synthesis with complex systems thinking perspective and behaviour change theory	This is the first study to attempt to provide a programme theory to explain how and why FFP is effective. The design and implementation of FFP requires a strategic approach to consider available resources, tools for identifying COPMI, contextual barriers, reducing stigma, lack of policy and sustainable funding. Practitioners need support to address their concern regarding opening up conversations with service users about PMI. Service users need an understanding of the impact of PMI along with a sense of hope and readiness to open-up about their illness with children. Children require knowledge of the impact of PMI, support with help seeking behaviour and resilience to detach from issues in the home.
Biebel et al., 2014 (USA)	Shifting policy and building capacity for the implementation of the	Mixed methods	45 interviews conducted with staff (9), women (7),	Community based adult mental health service.	Constant comparative approach	Several elements were identified as essential to the successful implementation of FFP, included identifying complex families, and COPMI needs,

	Family Options intervention for PMI.		administrators (3), program directors (2), family coaches (3), consultant (1).			providing specific practitioner training and using a detailed implementation strategy.
Biebel et al., 2016 (USA)	Understanding the implementation of the *Family Options* intervention across a two-year timeframe.	Qualitative ethnographic interviews	Multiple interviews over many time points (100).	Community based adult mental health service.	Thematic analysis	Essential to the implementation process, was creating practitioner (i.e. identifying, recruiting and training staff with the necessary experience), and organisational (i.e. develop tools, arrange protocols and procedures for supporting FaPMI, including positive communication) capacity within the community (i.e. identify resources, build network capacity and partnerships). The training should address challenges specific to the service provider.
Everts et al., 2022 (Netherlands)	Evaluating respective files for the mandatory COPMI check.	Mixed methods	Four focus groups (sample size unclear) were conducted during routine meetings with AMHS professionals. Review of patient files also undertaken.	AMHS and CAMHS	Thematic analysis of open-ended questions.	Despite being mandated, parental status was not checked in over half of the files (14,469 files) examined. Practice improvements and redesigns are needed to clarify areas of confusion (e.g. the tool used to ID COPMI use of the term 'at risk' may limit some professionals' interpretation of *how* and *when* COPMI are 'at risk'). Recommendations included amending the tool to consider the *need/support* of COPMI rather than use a *safety* or a *risk* approach (e.g. suspicion of child abuse).
Goodyear et al., 2015 (Australia)	Cross sector implementation of the K*eeping families and*	Mixed methods pre-post training	55 responses to open ended questions on	Cross sector	Open-ended survey questions	Training helped to increase the number of opportunities to conduct FFP despite an initial decrease in clinicians' skill and knowledge to

	children in mind online training programme. Training was online with two-day face to face training and small group support for six-weeks.	and six-month follow up.	survey evaluating FFP pre and post training. (91% female), employed in child and family services and AMHS.		categorised (Braun & Clarke, 2006).	conduct FFP reported directly after the training. Levels of FFP increased at six-months post training. While an initial reduction in cross agency referrals occurred immediately post training, collaboration improved post-training at the six-month timeframe. Limited organisational support was a barrier to the use of FFP post training, with barriers to collaboration reported at both practitioner and organisational level.
Goodyear et al., 2017 (Australia)	Identifying characteristics of practitioners who engage with FFP.	Quantitative	307 AMHS practitioners	10 AMHS	Statistical analysis	Training, experience, sex, and setting all informed practitioners' likelihood to engage in FFP.
Grant et al., 2016 (Ireland)	Organisation and policy factors which influence FFP among Irish psychiatric nurses	Qualitative	14 psychiatric nurses across 8 services.	Acute inpatient and community setting.	Thematic analysis	The lack of mandated policy hindered FFP, while *Children First*[15] supports this approach. Home visits, consistent long-term work with families, FFP culture/collegial support and community-based services supported FFP. Training, strategic planning, and supportive management increased FFP practice.
Grant et al., 2019 (Ireland)	Identify factors influencing mental health nurses' use of FFP	Mixed methods	343 mental health nurses, 14 interviews	12 acute inpatient and community settings.	Thematic analysis	Knowledge, skill, confidence in parenting, experience of working with children, plus the opportunity for home visits, supported FFP. While community nurses obtained high scores (measured on a Family Focused Mental Health Practice Questionnaire) for knowledge and understanding of FFP, the majority were not actively applying FFP on a regular basis.

[15] Children First: National Guidance for the Protection and Welfare of Children Youth Affairs [DCYA], 2011)

Grant et al., 2021 (Ireland)	To understand levels of FFP among mental health professionals and parents.	Qualitative	30 adult mental health and children's services professionals social workers (21) and parents (21).	18 AMHS inpatient, addiction services	Thematic analysis	Enablers of FFP included the parent-practitioner relationship, respect for the service user, practitioners' parental status and personal experience with mental illness. Families' lack of readiness and concerns around child protection involvement in the home, were key barriers to participation.
Karibi & Arblaster, 2019 (Australia)	Evaluation of practitioners' experience of the *Let's Talk* training and implementation of the programme.	Qualitative	10 practitioners, social workers (5)	Adult, community mental health	Thematic analysis	Face-to-face training improved practitioners' experience of implementation and promoted a partnership approach while also improving stakeholder experience of the intervention.
Lauritzen et al., 2016 (Norway)	To understand practitioners' and organisations' response to the mandated introduction of child focused practitioners.	Quantitative	219 (2010), 185 (2013), and 108 (2015) mental health practitioners.	AMHS	Statistical analysis	Legislated change is not yet fully implemented. While some improvements have been made (e.g. introduction of child focused practitioners and increase in support and awareness of COPMI in AMHS), more work is needed to improve FFP roll-out.
Lauritzen et al., 2018 (Norway)	Understanding the 5 yr. follow up on the introduction of a COPMI assessment Form and the *Child Talks* intervention.	Quantitative	219 (2010), 185 (2013), and 108 (2015) practitioners.	45 hospital adult psychiatric units	Statistical analysis	While improvements have been made, the pace of change is slow, with most change occurring in the early years after legislation was introduced to identify and support COPMI. While more COPMI have been identified, there has been no substantial attendant increase in conversations with families.
Leeman & Arblaster, 2019 (Australia)	To understand mental health clinicians experience of FFP.	Qualitative	10 mental health practitioners	Community mental health	Thematic analysis	The combination of working with families with complex needs and workplace barriers, makes implementing FFP for FaPMI an ongoing challenge even with management and collegial support.

Maybery et al., 2016 (Australia)	To understand stakeholder factors mediating use of FFP.	Quantitative	307 adult mental health workers across Victoria.	10 adult mental health regions	Statistical analysis	Practitioners' perceived knowledge, skill and confidence are key predictors of FFP, but are dependent on understanding the role of PMI within the family.
Nicholson et al., 2022 (USA)	Adaption of the *Let's Talk* intervention.	Mixed evaluation and qualitative methods.	Multi-staged process of evaluating the adaption of *Let's Talk* during 2015-2019 involving 12 individual and group Interviews (70), video conferences (20) with experts and the adaptation team (4).	AMHS	Content analysis	Barriers to the implementation of the *Let's Talk* intervention included clinicians' desire for a flexible approach to practice. Recommended elements for change include a strengths-based, trauma-informed, culturally aware model which engages partners within families and addresses the unique needs of each family.
Reedtz et al., 2022 (Norway)	Evaluate practitioners' level of FFP 11-years after the introduction of legislation requiring the identification and support of COPMI within adult services.	Retrospective anonymised data study	Hospital data sample of 28,906 patient records.	Mental health and substance abuse unit of the largest hospital in Norway.	Statistical analyses	While the identification of COPMI has improved, the numbers are lower than expected. Several practitioners continue to fail to record the details of dependent children. Further changes were recommended to improve COPMI identification. Full implementation of legislated FFP practice was estimated to take until 2092 at the current rate of change. Making changes to the software used during service user intake could improve identification by requiring practitioners to address patient parenting status and number

	of dependent children before records can be completed.

Note. AMHS, adult mental health services; CAMHS, child and adolescent mental health services; COPMI, children of parents with a mental illness; FFP, family-focused practice; RCT, randomised control trial.

This next section describes several of the key components identified in this review that are considered to facilitate or hinder the successful implementation and overall sustainability of FFP.

2.4.3 Organisational and Practitioner-related Factors

Evidence suggests that a fundamental barrier to effective healthcare practices involving a family-based approach, is the dominance of the individualised biomedical model of care which persists due to, amongst many other factors, the nature of professional mental health training (Goodyear et al., 2017) and/or the lack of skills/knowledge/confidence to undertake family work (Bauer et al., 2021; Biebel et al., 2015; Maybery et al., 2014; Reedtz et al., 2022; Shah-Anwar et al., 2019; Skogøy et al., 2019). According to Bauer et al. (2021) and Reedtz (2022), support for COPMI in Norway remains inconsistent 11 years after legislation supporting FFP was introduced (Table 2.7) due, in large part, to a reluctance by practitioners to recognise the importance of, or to take ownership of, the need for FFP in AMHS. Reedtz (2022) goes on to suggest that this lack of support is "*ethically questionable*" (p.8) given the known impact of transgenerational psychopathology on COPMI. Evidence from the studies included here, also strongly emphasise the need for multidisciplinary participation when implementing FFP (Bucci et al., 2016; Shah-Anwar et al., 2019) as well as cross-disciplinary FFP education to improve the acceptability and sustainability of these interventions (Gregg et al., 2021; Klaic et al., 2022; Loechner et al., 2018; Maybery et al., 2014; Overbeek et al., 2022). Organisational buy-in is also critical to service or agency readiness to introduce new practices (Allchin & Solantaus, 2022) and maintaining longer-term change (Gregg et al., 2021); this should include consideration of the setting, an openness to practice change among staff, the availability of funding, and support from both management and colleagues (Allchin et al., 2020a; Bauer et al., 2021).

According to most review authors, practice change across health services is a challenging and time-consuming process, and also context-specific (Allchin et al., 2020a:2020c; Maybery & Reupert, 2009; Woodman et al., 2020). Unsurprisingly therefore, Klaic's (2022)

substantial review of generic health interventions (i.e. psychoeducation, technology-based and physical activity programmes), comprising of 252 papers (albeit almost two-thirds of which have no setting exclusions or settings reported), found very low rates of sustainable (4%), and scalable (9%) practice change. Acceptance and the perceived 'fit' of the new programme within the existing service were crucial to effective implementation in this, and other studies (Grant & Reupert, 2016; Gregg et al., 2021; Klaic et al., 2022; Shah-Anwar et al., 2019; Tchernegovski et al., 2018; Ward et al., 2017).

The collective findings reported here, clearly indicate that the scalability and sustainability of an intervention depends on the extent to which it is considered acceptable and feasible within the organisation's culture, *and* is accompanied by an appropriate implementation plan for sustainable change (Allchin et al., 2020a:2020c; Biebel et al., 2015; Lauritzen et al., 2016). Therefore, working *with,* and not *against* an organisation's culture is crucial (Novins et al., 2013). Key to practitioners' acceptance of FFP is training to address knowledge and skill gaps which often arise when practitioners work in traditionally demarcated adult and child services, along with the provision of ongoing supervision and peer support throughout the process of implementation (Grant et al., 2016:2019; Leenman & Arblaster, 2020; Reedtz et al., 2022; Skogøy et al., 2019; Vives-Espelta et al., 2022).

Furthermore, a number of factors such as gender and personal/professional experience with mental illness as mentioned earlier, can influence the extent to which a new practice is accepted (Golden et al., 2020; Goodyear et al., 2017; Grant et al., 2016; Gregg et al., 2021). Systemic family work is also more challenging when compared with the current individualised model of care, as it requires a dual focus (i.e. on the service user and family member[s]) which may be demanding for professionals with little or no experience of working with adult and child populations (Foster et al., 2012; Maybery et al., 2016; Maybery & Reupert, 2009; Tchernegovski et al., 2018). Discipline-related differences (e.g. professional training, work settings, jurisdictions) can also influence the acceptance of new practices (Gregg et al., 2021).

According to Novins et al. (2013), an implementation strategy informed by all disciplines, and which considers the skills, knowledge, and training of practitioners, is important in supporting the translation of FFP knowledge while also helping to sustain any positive change over time. The earliest identification and inclusion of FFP champions (i.e. a specific implementation lead) in developing and/or implementing a programme can further enhance the process (Allchin et al., 2022; Everts et al., 2022). According to a number of authors, long-term success is also more likely to occur if: all stakeholders 'own' the change needed; relationships between service-providers and service users are positive; and where there is confidence in the programme being introduced (Allchin & Solantaus, 2022; Gregg et al., 2021; Klaic et al., 2022; Woodman et al., 2020).

2.4.4 Intervention-specific Factors

As outlined earlier, while a number of service gaps have been identified in the literature, a wide range of interventions has been developed and implemented with promising, albeit mixed, results (Lannes et al., 2021; Siegenthaler et al., 2012; Thanhäuser et al., 2017). The variability in programme outcomes may be due to, amongst other things, stigma or family reluctance and/or readiness to attend/engage with programmes (Grant et al., 2021; Sreeram et al., 2022; Thornicroft et al., 2016). For example, the WHO (2017) report that an estimated two-thirds of those who need mental health support avoid seeking help due to stigma. Stigma as an access barrier, has also been associated with programmes specifically aimed at those with more serious and enduring disorders such as schizophrenia and psychosis**,** leading to recruitment and retention challenges as mentioned earlier (Dolman et al., 2013; Rampou et al., 2015; Reupert et al., 2021). However, a number of other factors must also be considered when selecting a 'good fit' intervention for a given service context, including: practitioner skills; the time and resources needed to undertake training (on top of an existing workload); programme duration; accessibility; organisational needs; the cost of delivering the intervention; and the availability of effective recruitment pathways (Allchin et al., 2020c; Allchin & Solantaus, 2022; Bauer et al.,

2021; Reedtz et al., 2022). Arguably however, given the range and widely varying impacts of mental health disorders, a continuum of programmes with appropriate practitioner training is needed to adequately support this population (Falkov, 2015).

For example, the previously mentioned *Let's Talk* programme was originally designed for adult mental health professionals with limited or no experience of working with children (Maybery et al., 2017); it has also been used as a two-session parent-only control group comparison with (the longer) *FT* (the programme adopted for the PRIMERA research) with 109 randomised families (Solantaus et al., 2010). Both interventions were found to be "*effective in decreasing children's emotional symptoms, anxiety, and marginally hyperactivity and in improving children's prosocial behaviour,"* (p. 883). While the lack of a control group was a limitation of this study, the absence of feedback from the child participants was also an important omission. A consolidation review of *Let's Talk* identified a suite of tools for FaPMI with various adaptations and modifications across a range of settings and jurisdictions (Allchin & Solantaus, 2022; Giannakopoulos et al., 2021; Punamäki et al., 2013; Solantaus et al., 2009:2010; Solantaus & Toikka, 2006). These include: *Let's Talk* (2-3 sessions between parent-practitioner); *Let's Talk Network Meeting* (discussion to extend the family's support session); *Let's Talk Information booklets* (self-directed booklets for parents with a mental health disorder or substance misuse); and *Let's Talk* 10-week peer support education group for parents and children (Allchin et al., 2022).

While it is considered ethically acceptable to implement interventions that have been shown to increase resilience and reduce levels of harm for a given population (Solantaus & Toikka, 2006), new programmes frequently come under scrutiny/criticism in what Fixsen refers to as the "*awkward*" phase of implementation (Fixsen et al., 2005, p. 16). The availability of high-quality evidence of impact helps, but 'drivers' are also important in terms of moving beyond this phase. Fixsen (2005) describes drivers as "*elements which positively support the implementation process as drivers or core implementation components, which include staff*

selection, training, and administrative supports," (p. 28). Drivers, in the context of FFP, may involve modifying training to suit the specific context, providing supervision/peer support, and/or changing recruitment pathways, all of which may be needed to advance a project beyond the initial *awkward* phase (Allchin et al., 2020a:2020c; Goodyear et al., 2017; Karibi & Arblaster, 2019). Furthermore, permitting service providers to adjust aspects of a programme to the needs of each family (e.g. by providing longer sessions, introducing icebreakers, or as mentioned, adding additional components for disorders considered to be more serious), has been shown to improve practitioners' acceptance of new programmes (Bucci et al., 2016; Nicholson et al., 2022).

In terms of practitioner training, it is also worth noting that several authors recommend supplemental face-to-face training for online programmes in order to more effectively address practitioner concerns, particularly during the initial stage of implementation (Bauer et al., 2021; Goodyear et al., 2015; Novins et al., 2013). Therefore, the 'fit' of a given programme must suit the needs of the intended recipient(s) (i.e. parent, child, and/or family, or practitioner), as well as the culture of the organisation, and the resources available to implement the programme effectively and sustainably (Allchin et al., 2022; Hinton et al., 2019; Novins et al., 2013).

While researchers and academics can help to evaluate the fit and/or effectiveness of a given programme and disseminate the findings, it has been suggested that "*sustaining family-focused practice is [*however*] the work of the healthcare setting*" (Allchin & Solantaus, 2022, p. 2) which, in turn, is significantly influenced by the broader socio-political context. A brief overview of the wider healthcare context is therefore necessary and is provided below, with a particular focus on societal factors that have influenced the introduction of practice change for FaPMI.

2.4.5 The Importance of Context

Responses to the needs of FaPMI internationally, as a public health issue, vary considerably and are influenced by a range of political/legislative and societal pressures, as well

as the nature and extent of collaboration across countries. Several of the countries referenced here in one or both of the reviews presented in this chapter, provide useful exemplars of the range of practice and legislative efforts introduced internationally to embed FFP for FaPMI. Table 2.7 illustrates and summarises some of the kinds of initiatives, practices, policies and collaborations that are in place (at the time of writing) to support FaPMI in a number of countries across the world. Arguably, as mentioned in Chapter One, Australia and the Nordic countries (i.e. Norway, Sweden, Finland), are world leaders in establishing national preventative programmes supported by legislation and policies to promote the identification and provision of services for FaPMI (Biebel et al., 2016; Falkov, 2012; Goodyear et al., 2015; Lauritzen et al., 2014; Lauritzen & Reedtz, 2013; Solantaus & Toikka, 2006).

As mentioned earlier, Sweden introduced legislation as early as 2001 to identify and support at-risk children. This was followed by the introduction of *Family Talk* in 2006 (Table 2.7) while later in 2010, legislation similar to that in Norway, was introduced to mandate services to, firstly, identify COPMI and children of parents with substance misuse disorder, and secondly, to identify and provide the necessary supports for this cohort (Pihkala et al., 2012a:2017). The evidence from other jurisdictions indicates that societal and political pressure may be necessary to drive implementation at a national level. For example, the *Think Family Northern Ireland* (TFNI) initiative received broad support, at least in part, because it constituted a practical response to two cases of familicide which attracted considerable media attention at a national level (Tew et al., 2015; Western and Eastern Health and Social Services Boards, 2008). This was implemented as part of a UK-wide pilot initiative and was deemed to be more successful than in other pilot sites because it was managed locally (Donaghy, 2014:2016; Grant et al., 2018; Tew et al., 2015). The *Family Model* training framework mentioned earlier in Table 2.2, was later adopted in Northern Ireland (NI) and is now available online to provide a framework for professionals working with FaPMI across both statutory and voluntary services (Falkov, 1998:2012; Grant et al., 2018; Tew et al., 2015). Recently (2020-2021), the TFNI came under the

remit of Children and Young Peoples Strategic Partnership (CYPSP) led by the Health and Social Care Boards, in order to support families living with mental illness and/or substance abuse using a '*no wrong door'* approach. This concept recommends that a person identified and presenting for help for mental health difficulties should receive the necessary support and treatment regardless of the referral or recruitment pathway (i.e. via adult, child or primary care levels of services) (Christie, 2017). Ringfenced funding was also provided in 2020-21 for one full-time family-focused social worker in four of the five HSCBs and one half-time post in the fifth in order to embed sustainable support for FaPMI in each region (personal communication with Mary Donaghy, the former Mental Health & Learning Disability Lead and *Think Family* NI Ireland Lead, HSC Board, Belfast).

Elsewhere in the UK, a number of key reports published between 2004 and 2015 (Table 2.7) encouraged efforts to support vulnerable families using a *think family* approach (Grant, 2014). For example, since 2015, local authorities (i.e. a form of local government tasked with running local services such as schools, social services and roads) in the UK are required to "*adopt a whole system, whole council, whole-family approach, coordinating services and support around the person*" (Department of Health, Local Government Association, Directors of Adult Social Services, & Children's Society, Carers' Trust., 2015, p. 7). More recently, a *Think Family-Whole Family Training Programme* has been developed in the UK to support practitioners working with FaPMI. This programme incorporates elements from two earlier programmes (*The Family Model* [Falkov, 2012], and the *Meriden Family Programme* [Fadden & Heelis, 2011]), as part of a two-day multi-agency programme to help practitioners work to improve outcomes for this cohort (Yates & Gatsou, 2021). However, a recent survey of 15 mental health trusts in England identified that "*less than half of practitioners engaged with the parenting experience, or the potential impact of parental mental health on children*" (Dunn et al., 2022, p. 335). Unlike the NI initiative which utilised regional champions to advance its *think*

family approach to FaPMI and despite calls for a 'no wrong door' approach, provision for these families in the UK still remains patchy (Grant et al., 2014:2018; SCIE, 2012; Tew et al., 2015).

Table 2.7

A Selection of Initiatives, Policies, Practices and Cross-country Collaborations Supporting the Needs of Families across the World who are Living with Parental Mental Illness

Country	Initiatives, policies, and legislative changes introduced to support families living with PMI	References
Australia	A strategy introduced in 2007 (in Victoria) set out to improve services for FaPMI. It was followed by the Mental Health Act (2014), requiring the identification and support of COPMI (Goodyear et al., 2015; Tchernegovski et al., 2017). A national COPMI initiative was funded between 2001-2017[16] to develop online resources for at risk families. Emerging Minds has been working for the last 20 years to advance the mental health of Australian families and now leads a National Workforce Centre for child mental health development to provide resources for all stakeholders. Australian practice standards were also established in 2010. Several important e-learning resources are located on the emerging minds website for PMI aimed at educating practitioners, including *Keeping families and children in mind* and *Family Talk.* The Prato research collaborative, officially known as the International Research Collaborative for Change in Parent & Child Mental Health, also began in Australia in 2013 (https://www.parentfamilymentalhealth.com/about-us). This international research group (e.g. with membership from Australia, USA, Northern Ireland, Ireland, Norway, Finland, Sweden) was established to research and publish papers to inform and improve services for families across the world.	Beardslee et al., 2007:2013; Foster et al., 2012; Goodyear et al., 2015; Lauritzen et al., 2014; Maybery et al., 2015a; Solantaus et al., 2010. https://www.copmi.net.au/; https://emergingminds.com.au/
Austria	While there is a lack of professional standards for COPMI, one resource was identified at https://village.lbg.ac.at/about which aims to support FaPMI and COPMI.	Zechmeister-Koss et al., 2020.
China	The 2019 National Action Plan for Child and Adolescent Mental Health requires psychiatrists to incorporate family-focused interventions for COPMI to reduce the burden of PMI on the family.	Yao et al., 2021

[16] https://www.copmi.net.au/about-copmi-2

Finland	A national approach (entitled the 'Effective Child and Family Programme 2001') was set up to implement preventive interventions for FaPMI. The national implementation of *Family Talk* began in 2006, with a lower threshold intervention option called *Let's Talk*, which was adapted for those without pre-existing disorders. Like the 2010 Norwegian legislation, the Finnish Child Welfare Act (2007) requires the identification of, and support for COPMI and children of parents with substance misuse issues.	Allchin & Solantaus, 2022; Beardslee et al., 2013; Solantaus et al., 2009; Solantaus & Toikka, 2006.
Ireland	Prior to the PRIMERA project, FFP for FaPMI was small-scale to non-existent with a small number of local champions delivering mainly locally developed programmes (e.g. *Families in Between* and *FT* at a very small, localised level). A more recent awareness-raising training programme was codesigned and piloted on a small scale by MHS and Tusla (in the West of Ireland) in order to inform health and social care professionals on the needs of FaPMI, but it is not currently in use. In 2022, a guidance document was also produced on FFP in AMHS (*Family Focused Practice in Adult Mental Health Care– A Guidance Document*) developed by the: HSE Mental Health Social Work Department in the Galway Roscommon Adult Mental Health Service). This was inspired, in part, by the PRIMERA research project as the team worked very closely with this site as part of the RCT.	Golden et al., 2020; HSE, Mental Health Services, 2022.
Italy	Currently, Italy has no national policy for supporting PMI, but following a European Family Association for Mental Illness Congress (2010), a COPMI initiative began in 2011 as an online support group and later became COMIP – Children of Mentally Ill Parents, (established in 2017). Italy has also been involved in the European Camille Project. In addition, an NGO was set up called, in English, 'children of mentally ill parents' to support families living with PMI (https://www.comip-italia.org/	Falkov et al., 2016.
Netherlands	The Netherlands first established preventative initiatives to support COPMI in 1987 and by 2000, all mental health services had incorporated a prevention team with a range of interventions to support FaPMI. Budget and legislative changes introduced in 2008 limited the implementation of FFP, but recent calls for a national COPMI initiative have been made. Mandatory identification of COPMI was added in 2013, with mixed results. A preventative programme, *Child Talks/Child Talks+*, were developed to support service users who are parents along with two online interventions, *Kopstoring* (https://www.koppsupport.nl/) for COPMI (16–25 yrs.) and *Survivalkid* (www.Sur-vivalkid.nl) for young people over 12 yrs.	Drost et al., 2011; Everts et al., 2022; Falkov et al., 2016; Grove & Reupert, 2015; Van Doesum & Hosman, 2009; Van Doesum et al., 2019; Woolderink et al., 2015.
Northern Ireland	Following the *Think Parent, Think Child, Think Family Guide* (SCIE, 2009), the 2007 O'Neill Inquiry (Western and Eastern Health and Social Services Boards, 2008; Health, Social Service & Public Service, 2008) Toner Report, the *Think Family Northern Ireland* (TFNI) initiative commenced as a pilot (2009), becoming core business for the Health and Social Care Boards (HSCBs) in 2012. The TFNI was deemed	Donaghy,2014 :2016; Falkov, 2012; Grant et al., 2018; McCartan et al., 2020; SCIE, 2012 ; Tew et al., 2015.

	more effective than its five sister UK pilot sites because efforts to advance the initiative were managed locally (SCIE, 2012). The SCIE report (2012) recommended an evaluation of the TFNI, increased involvement from lived experts and a better understanding of practitioners. Significant work has since been conducted to increase mental health practitioners' confidence to undertake FFP, including the development of educational supports to assist practitioners communicate more effectively with FaPMI and an aide memoire for *The Family Model* (Falkov, 2012). An audit review was conducted in 2020 to evaluate the embeddedness of FFP. This evaluation highlighted the complexity of sustaining practice change and the need to continue to promote and support the implementation of FFP for FaPMI.	
Norway	Amendments made to two acts, the Health Personnel Act, and the Specialized Health Services Act, resulted in the 2010 legislation which required practitioners to identify service users who are parents. Mandated child responsible personnel are now employed to coordinate and support COPMI, and a family assessment form was also introduced to assist with family identification. *Child Talks* was the family intervention implemented in northern Norway in 2010 for discussing a parent's mental health difficulties with the whole family. Subsequent improvements in COPMI identification have been reported, but change has been slow. *Adults for Children (Voksne for Barn)* (http://www.vfb.no) was also established to support practitioners working with FaPMI and provides training for *FT*.	Beardslee et al., 2013; Lauritzen et al., 2018; Lauritzen & Reedtz, 2016; Maybery et al., 2015a; Pihkala et al., 2012a; Reedtz et al., 2019.
Pan European	ENTER (European Network on Training, Evaluation and Research in mental health) is a collaboration of 16 members (June 2022) across 13 countries (i.e. Bosnia Herzegovina, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Lithuania, Poland, Slovenia, Spain, UK) involved in clinical services, and/or education or academia across 14 European countries to "*promote and defend the highest standards of mental health promotion, training and care in Europe*".	https://www.entermentalhealth.net
	Located within the ENTER research project, CAMILLE (Children and Adolescents of Mentally Ill Parents) developed training for professionals working with families as part of an EU project raising awareness of the needs of families living with PMI, and in the absence of pan European guidelines for working with COPMI. This programme is available in English, Finnish, German, Italian, Norwegian and Polish, with modules including: (a) 'Knowledge base' (Mental Illness and Substance Misuse, Child and Adolescent Development and Attachment); (b) 'Experiences and needs of families' (i.e. Living with PMI, being a parent, stigma); and (c) 'Methods for supporting families' (i.e. talking with children, resilience, successful services).	www.camilletraining.net
Pan European	EUFAMI was set up in Belgium to support family carers living with mental ill health across Europe. Their current website details seven projects (1) S.U.C.E.S.S (SUpporting family CaregivErs of adultS with mental health issueS); Interactive Playbook launched to help support Carers of People with	www.eufami.org/

	Schizophrenia; INVOLVE (for training family members in advocacy); Art4Me (promoting mental health through art); Share4Carers (mentioned below); Family project (explore risk, resilience in FaPMI to better understand the intergenerational risk of psychopathology); and the MENS project (connecting physical activity with mental health).	
Pan European	JEFpsy (acronym for Jeune Enfant Fratrie) established a website supporting young people (age 11-20 years) living in Belgium, France, Luxembourg, and Switzerland with a family member with a mental health disorder.	www.jefpsy.org/
Pan European	"*Share4Carers*'' was set up to address and advance support for PMI at a national level and involves a range of stakeholders (e.g. service users, academics, clinicians, and carers) in Belgium, Greece, Italy, and Turkey.	https://share4carers.eu/
Pan European	An EU project funded by the European Union under the EU4Health Programme (2021-2027) plans to deliver training in the *Let's Talk* short intervention across nine European countries (i.e. Czech Republic, Estonia, Finland, Greece, Poland, Portugal, Romania and Italy). The study commenced in Helsinki in February 2023.	https://letstalk.utu.fi/
Sweden	In 2001, legislation was established that required health care professionals to assess the needs of at-risk children. *Family Talk* was introduced in 2006 and followed by legislation (similar to Norway) introduced in 2010, mandating services to address the needs of COPMI and children of parents with substance misuse disorder. Implementation support was provided by the Swedish National Board of Health and Welfare in order to support the delivery of two interventions, *Family Talk* and *Let's Talk*. A website was also established (www.barnsomanhoriga.se) to support Swedish professionals working with COPMI.	Lauritzen & Reedtz, 2013; Pihkala et al., 2012a:2017; Strand & Rudolfsson, 2017.
UK	Various reports have been published in the UK highlighting the need to support FaPMI including *Reaching out: think family* (2004);*Think Family: Improving the life chances of families at risk (*2008); T*hink Child, Think Parent, Think Family* (2011:2012); *Family Minded: Supporting Children in Families Affected by Mental Illness* (Evans & Fowler, 2008); *Patients as Parents* (2002); and a joint Department of Health and local authorities response to *The Care Act and Whole-Family Approaches* (2015) to "*adopt a whole system, whole council, whole-family approach, coordinating services and support around the person*" (DH et al, 2015, p. 7; Tew et al., 2015). Notwithstanding, a recent survey of 15 mental health trusts in England identified that less than 50% of practitioners are attending to the parental status of service users (Dunn et al., 2022).	Dunn et al., 2022; Evans & Fowler, 2008; Grant, 2014; Morris et al., 2008; NICE, 2009; SCIE, 2012; Tew et al., 2015.

USA	The USA currently has no national strategy for the provision of services for COPMI, but various programmes (e.g. *Family Options, Family Talk*) have been developed for this cohort in a number of locations (e.g. Chicago, Boston).	Biebel et al., 2014; Falkov, 2015; Nicholson et al., 2015:2022.

Note. COPMI, children of parents with a mental illness; EU, European Union; FFP, family-focused practice; NICE, National Institute for Health Care Excellence; NGO, non-governmental organisation; PMI, parental mental illness; PRIMERA, **P**romoting **R**esearch, and **I**nnovation **in** Mental h**E**alth se**R**vices for f**A**milies; SCIE, Social Care Institute for Excellence.

At a pan-European level (Table 2.7), the lack of family-focused training for mental health practitioners led to the development of the two-day multi-country CAMILLE[17] (Children and Adolescents of Mentally Ill Parents) programme designed to improve practitioners' awareness of, and competence to undertake, family-focused work (Viganò et al., 2017). Elsewhere, while the USA has no national COPMI strategy, several programmes already mentioned (e.g. *FT*, *Family Options*) have been developed there and delivered at state level (Nicholson et al., 2009:2022). For example, *Family Options* described earlier, aims to support FaPMI over a period of 12-18 months to help them develop skills and to access additional supports for the whole family; this involves in-home visits and a 24-hour help line in the event of a family crisis (Nicholson et al., 2009). This programme is one of the most intensive and longest running of all those identified here and for that reason, it would be interesting to undertake a 'head-to-head' trial to examine how it compares to shorter programmes such as *FT* and others mentioned here.

While available evidence suggests that training and policy changes have had a positive impact on the provision of FFP internationally, sustaining change is clearly an ongoing challenge and there may be resistance to change even when the appropriate policies, standards and training are in place (Bertram et al., 2015; Falkov et al., 2016; Fixsen et al., 2005; Foster, 2015). While some authors suggest that at least two decades are required to "*get clinical innovations into practice*" (Bauer & Kirchner, 2020, p. 1), Norway provides an important exemplar with regard to FFP. Following its 2010 legislation, child-responsible personnel were mandated across services to coordinate and support COPMI across various points of contact, including clinics and hospital wards (Lauritzen & Reedtz, 2016). Lauritzen (2018) and Reedtz (2022) subsequently conducted 5- and 11-year reviews respectively, of the effectiveness of the legislation and

[17] https://mailtodawson.wixsite.com/camilletraining

practice change to embed support for COPMI across AMHS in Norway (Table 2.7). While both studies reported an increase in awareness of the negative impact of PMI on COPMI and a reduction in stigma, mandated child-focused personnel were not (at the time of writing) fully established across AMHS (Lauritzen et al., 2016:2018). It is perhaps reassuring to note since the introduction of the legislation, estimates of the number of COPMI identified, has increased from the initial 0.1% prevalence rate in 2010 to 56% in 2020. This increase highlights improvements in the identification of COPMI with over half of all service users (who were parents with dependent children) identified in 2020, compared with only .1% in 2010 (Reedtz et al., 2022). However, a decade on from enacting the legislation, FFP is not fully embedded across the country, with just under a third of those COPMI who are identified, actually receiving the support prescribed by the national programme (Reedtz et al., 2022).

As indicated earlier, the prioritisation of the biomedical model of care in Norway and indeed elsewhere, appears to have been an important barrier to the recruitment of mandated child-responsible personnel within AMHS (Bauer et al., 2021). This failure, despite significant high-level support in a national context, demonstrates the considerable challenges and complexity of effecting sustainable practice change within existing multi-layered systems, particularly when cross discipline buy-in is not forthcoming. Thus, legislation and policy change alone are insufficient to guarantee lasting transformation without a clear translation of the intended changes into clinical practice, including a sound rationale for why these changes are necessary (Isobel et al., 2019; Reupert et al., 2022; Tchernegovski et al., 2017). In summary, the socio-political context is a pivotal factor influencing the implementation of FFP and perhaps unsurprisingly, Isobel et al. (2019) caution that *"sustained change will be limited without significant shifts within broader political, cultural, and economic structures toward prevention and health promotion,"* (p.6).

2.4.6 Summary

Part Two of this review of the literature was based on a pool of over 620 studies, the findings of which highlight the complexity and challenges of implementing family-focused practice change within existing MHS. The evidence indicates that even with broad legislative and organisational support, sustained practice change may take years to achieve. The dominance of the biomedical and largely individualised model which guides most services across the world, remains a significant barrier to advancing FFP (Isobel et al., 2019; Reedtz et al., 2022). Each component identified above, including organisations, practitioners, programme-specific characteristics and wider societal factors/contexts, all interact in important and often complex ways to influence the successful (or not) implementation of FFP for FaPMI. The findings described here, provide a very useful and informative overview of many of the key facilitators of, and barriers to, the implementation of FFP, while they also offer a practical 'roadmap' for designing an implementation plan, including a number of key recommendations to promote advancement in the field. The collective findings highlight a need, in particular, for a multifaceted strategic approach to services for FaPMI that addresses key factors related to organisations, practitioners, intervention-specific features and broader societal issues.

Reupert and colleagues (2022) who are leading academics in this field, highlight a need for systemic change more broadly, and make several recommendations to help embed an interagency approach to FaPMI (see Table 2.8, Table 2.9). According to these authors, effective system change should incorporate a number of key elements including: policy and legislative changes to ensure that COPMI are identified and their needs addressed; interagency collaboration to address service gaps and develop appropriate referral pathways; cross-discipline education and training to understand the supports required by FaPMI; a recognition that no single programme is sufficient given the range of disorders and their impact on families; and finally, benchmarking and auditing to evaluate the changes introduced (Reupert et al.,

2022). Allchin (2022) also outlines the elements essential for a sustainable model of FFP in AMHS, including consideration of the broader context, practitioners, parents, organisations, and the importance of leadership by an internal implementer (Table 2.8). Given the global emphasis on the biomedical model of care, both Reupert (2022) and Isobel (2019) further highlight the importance of educating practitioners about the needs of this cohort, while Hanson et al. (2019) emphasise a number of essential principles for family inclusion and health and well-being including 'engagement' (e.g. developing a partnership approach to engage families in services) and 'stability' (e.g. valuing relationships and power dynamics within the home). Hinton (2019) further endorses family involvement throughout all stages of programme development (e.g. design and adaptation phase) and implementation, to ensure that the needs of all family members are met (Table 2.8).

Benchmarking should also account for skill levels where, for example, some practitioners may lack knowledge about the issues affecting COPMI, as well as practice gaps within an organisation, such as the ineffective recording practices of service users' parental status (Goodyear et al., 2017). Arguably, the Norwegian exemplar demonstrates the need for a realistic expectation of the pace of change towards a family-focused approach within services that are currently based on the biomedical model. Policy and/or legislative changes must also accommodate organisational culture in terms of the likely acceptability and feasibility of the intended programme (Bucci et al., 2016), while clear criteria should also be established from the outset for terminating/continuing any planned programme(s) (Klaic, 2022).

Table 2.8

Some International Recommendations on the Future Direction of Family-Focused Practice for Parental Mental Illness

Author/Country	Aim	Key findings
Allchin et al., 2022 (Australia & Norway) Prato research collaborative	Detail a model for sustainable FFP in AMHS.	Based on 30 years of implementing the *Let's Talk* intervention, six areas requiring action are set out to highlight key elements essential to sustaining FFP within AMHS. These relate to: practitioners (see below); parents (i.e. acknowledge skills, provide skilled practitioner, monitor results); organisations (i.e. align with organisation, integrate, tailor programmes and allocation of resources); leadership (i.e. drive implementation, communicate effectively, minimise conflict, provide feedback, adjust and adapt to the culture, make space for the programme); internal implementor; and the wider social and political context (i.e. integrate policies and funding, support prevention and collect data). For example, the actions needed with regard to practitioners include their appropriate selection, building their skills/confidence, pairing them with appropriate families. Tasks for the 'internal implementor' include support leadership, assistance with problem solving as it arises and the monitoring of implementation. Ultimately, leadership and organisational support are the two considered essential for the sustainable embedding of practice change.
Reupert et al., 2022 (Australia) Prato research collaborative	Set out the principles and recommendations for working with COPMI.	Change is required to move services towards early intervention and FFP for PMI, to include child and family focused practice to ensure that COPMI do not slip through service gaps or have their needs overshadowed by the unwell parent. Six principles for working with families: the parent-child relationship is bidirectional; early psychosocial intervention for children is necessary; parents need to be supported in their role; a whole family collaborative approach is needed; children and family members need to be involved in decision making; and a whole service approach is needed. Recommendations needed to inform the introduction of FFP for adult and child services, include: identifying and engaging parents; workforce/organisation (e.g. management support, identification procedures, child friendly environment, address issues of confidentiality, practice standards and professional training); along with system adjustments (e.g. benchmarking, policy introduction, supporting interagency collaboration, providing training), and the need for a pathway to services.

Hanson et al., 2019 (USA)	The need for a family-focused public health response.	Adopting a '*think family'* approach in prevention across all tiers of MHS is a necessary and valuable component of modern public health services to tackle the lifespan risk of PMI for dependent children. Essential principles for family inclusion include: engagement (e.g. developing a partnership approach to engage families in services); responsibility (e.g. supporting families in their roles and responsibilities); stability (e.g. valuing relationships and power dynamics within the home); and diversity (e.g. acknowledging and supporting variances across families and cultures) to improve quality of life and promote healthy development across the lifespan.
Hinton et al., 2019 (USA)	Incorporating families into global mental health research.	Family interventions appear to be more beneficial and effective in cultures which value family as an effective support when compared with individualised programmes, but are underrepresented in low-middle income countries (LMICs). While this paper focuses on family involvement in service users with neuropsychiatric disorders, the impact of culture on services is of note as family can be an important support for service users, especially in LMICs. A key recommendation here is the inclusion of families in all aspects of the design and implementation of programmes in a way in which balances the needs of the family with the potential added burden (economic, time, emotional) on the service user and family members.
Isobel et al., 2019 (Australia) 89 system change experts from 16 countries using a Delphi study (secondary analyses).	Narrative review of global change supporting families living with PMI.	The findings were based around Labov's (1973) model to include an 'orientation' (i.e. what drives a service to consider providing support for PMI), a 'complication' (i.e. once services begin, some issues will require more work), and a 'resolution' (i.e. what is the current status of the change needed and what additional change is required to bring about a solution for the change to be sustained). Various factors were identified to influence system change, including the introduction of standards/guidelines, national policies or a new intervention, and unknown factors. Change may require years of raising awareness of the needs of COPMI both within and outside of services. A one-size-fits-all approach will not be effective across various jurisdictions and while several countries have introduced new practices and services for this cohort, sustained support is essential.

Note. COPMI, children of parents with mental illness; FFP, family-focused practice; MHS, mental health services, PMI, parental mental illness.

According to a number of studies, effective planning also requires a dedicated service provider with local organisational knowledge and a commitment to FFP in order to expedite the process of identifying organisational and practitioner readiness and, therefore, overall levels of engagement (Allchin et al., 2020a:2020b:2020c; Allchin & Solantaus, 2022; Goodyear et al., 2017). Management and organisational support are also essential to support interdisciplinary workforce training (Maybery & Reupert, 2009), but it seems that support alone will not ensure successful implementation (Allchin et al., 2020c). For practitioners, a general awareness of their own limitations and experience with mental illness, and how it may influence their capacity for family work, may also be needed (Biebel et al., 2014).

Table 2.9

Key Recommendations Relating to the Implementation of FFP

- An effective lead implementor with local knowledge and a detailed strategic plan are key to the successful implementation of changes to practice.
- Implementation strategies would benefit from including a clear rationale and criteria for the discontinuing of a programme.
- Programmes are more likely to be accepted if they fit with the culture of the intended organisation.
- Implementors need to be persistent given the lengthy timeframe and non-linear stages of implementation within existing services.
- Embedding FFP is more likely to be effective when levels have been benchmarked, using a 'no wrong door', interagency collaborative approach, and ensuring that changes are audited so that problems are immediately addressed as they arise.
- Stakeholder (i.e. organisation, practitioner and family) readiness is key to the effective implementation of new programmes.
- Practitioner knowledge, skills and attitudes are important components which need to be supported by adequate training, a rationale for the change needed and adequate peer support and supervision.
- Key to achieving buy-in from families is minimising the stigma so often associated with mental health interventions.
- Strategies which incorporate a multi-disciplinary approach are more likely to be effective.
- Selecting a 'good fit' intervention requires consideration of several elements including: service context; practitioner skills; time and resources availability; effective recruitment pathways; programme duration; organisational needs; and the cost of delivering the intervention.

The findings reported here, clearly highlight the multiple challenges for services when implementing FFP for this cohort and therefore, why considerable time and energy are typically required to effect meaningful practice change. Similarly, the non-linear process of implementation across a range of real world settings preclude the possibility of any direct comparisons across sites which are normally at various stages of readiness and with different levels of managerial and organisational supports. Notwithstanding, the range of approaches adopted internationally in a growing number of countries and jurisdictions (Table 2.7) demonstrates a strong desire and willingness to address this important public health issue.

2.5 Conclusion

This chapter presented a two-part review of the literature designed to: (a) identify describe and summarise the range of programmes developed for FaPMI across the world (up until mid-2022) (building on the first review described earlier in the chapter); and (b) to explore some of the key barriers and enablers to implementing these interventions within MHS, and also taking into account workforce-related factors. While the need for FFP is clear, it would appear that a range of programmes is needed to help improve the outcomes for such a heterogeneous population of service users and their families. However, the wide range of contexts, settings and many other factors, pose significant methodological and other challenges for researchers in terms of generating consistent and high-quality evidence. Moreover, even when a programme has been found to be effective and supported by high quality evidence, the process of implementation and sustained practice change can be fraught with difficulty, as described in more detail in the two studies conducted as part of this research and described later in Chapters Five and Six.

Chapter Three: Methodological and Individual Study Overview

As outlined earlier, this chapter begins by describing the epistemological and ontological underpinnings of the research reported here. A broad overview of the design and primarily qualitative approaches to the three studies presented in this thesis, is then provided in separate sections dedicated to Study One and the overarching process evaluation (Studies Two and Three) respectively. A brief summary of the RCT within which the process evaluation (Studies 2 and 3) was nested, is also provided. The chapter concludes with a discussion of some of the overarching methodological considerations underpinning the three studies set out in Chapters Four, Five and Six. Some of the challenges encountered during the research process are also highlighted where applicable.

3.1 Epistemological and Ontological Foundations of the Research

According to Creswell and Creswell (2005), research is guided explicitly and implicitly by philosophical views on the nature of reality and how knowledge of that reality might be best understood. While a number of research paradigms exist on a continuum, three main approaches - positivism, pragmatism and constructivism - will be briefly discussed here, each with its own specific ontology or view of reality, and epistemology (i.e. the way in which knowledge is acquired about how the world works). This description of each paradigm is supplemented by further information provided in Table 3.1.

Historically, positivism, inspired by Descartes and Locke, began during the enlightenment period and as such, provides the foundation for all empirical inquiry. Positivism recognises a single independent reality, usually focused on the physical world, which can be observed and objectively measured using hypothetico-deductive logic (Park et al., 2020). Within this paradigm, *truth* is valued while, epistemologically, knowledge is acquired from the position of an outsider observing measurable facts (Table 3.1). Thus, the positivist researcher is a

neutral, objective, observer of experiments who uses solely quantitative methods to evaluate statistical data in order to verify predefined hypotheses.

Conversely, constructivism is a more recent philosophical development (attributed to early theorists von Glasersfeld [1974], Piaget, [1952:1968], and Vygotsky [1978]) recognises the richness of complex realities constructed by individuals and originating from unique contexts and personal histories (Charmaz, 2006:2016). As such, constructivism focuses on an individualised, deductive approach to research which aims to understand how context and lived experience inform knowledge (Kenny & Fourie, 2015). Researchers working within this paradigm are considered to be co-constructers who play an active reflexive role while using hermeneutics, dialectical and qualitative methods to gain a deeper understanding of each individual's worldview (Charmaz, 2005:2006; Creswell et al., 2007). Thus, constructivism involves the exploration of multiple views of reality using typically smaller samples sizes. When conducted with rigor however, constructivism effectively elicits multiple perspectives on a given topic with often rich and reflective findings yielding conceptual rather than numerical generalisability (Creswell, 2009; Creswell et al., 2007; Denzin & Lincoln, 2005).

Pragmatism, developed over the last century by proponents such as James (1890), Peirce (1905) and Dewey (1938), provides a middle ground on the philosophical landscape, thereby rejecting a simplistic demarcation between the single reality of positivism and the multiple realities of constructivism (Mead & Morris, 1997; Ormerod, 2006; Rorty, 1991). Instead, within this more recent paradigm, knowledge is useful when/if it can be practically applied and where *"beliefs are guides to actions and should be judged against the outcomes"* (Ormerod, 2006, p.892). While both pragmatism and constructivism acknowledge a socially constructed reality, the former also embraces the positivist view that truth is not solely dependent on human experiences and, therefore, exists outside of any one individual's unique experience. As a more flexible paradigm, research informed by pragmatism typically requires a

mix of both quantitative and qualitative methods. While pragmatism is considered by some to value only 'what works' (e.g. Bryant, 2017; Hall, 2013), it is nonetheless frequently required or expected by funders (and reviewers) in order to generate both quantitative (i.e. top-down hypothesis testing) and qualitative (i.e. bottom-up exploratory investigation) data on the topic under investigation (Denzin, 2012; Teddlie & Tashakkori, 2009).

Table 3.1

Comparison of Three Main Philosophical Paradigms: Positivism, Constructivism and Pragmatism

Points of divergence	Positivism	Constructivism	Pragmatism
Ontology (view/nature of reality)	Single reality where truth exists. An emphasis on the physical reality. Naïve realism.	Reality is relative, rich, and complex with multiple constructed versions. Truth is contextual; therefore, findings may not be generalisable. Individuals actively socially/(co)construct reality/knowledge, therefore meaning is subjective.	Flexible view of reality with an emphasis on what works. Reality is informed by experience and is therefore changeable/flexible.
Axiology (what is valued)	Truth and value free research.	Understanding individual experience, interactions, and context.	Knowledge is useful/valued when it can be practically applied.
Epistemology (nature of knowledge)	Dualist/Objectivist. Etic approach (knowledge acquired as an outsider) observable, measurable facts.	Relativist Emic (approach where knowledge is acquired as an insider) and/or Etic (informed by relevant theories).	Flexible approach to knowledge acquisition.
Methodology (how knowledge is gathered)	Experimental, observation, quantitative, statistical. Verification of hypotheses with objective measures leading to generalisable results.	Hermeneutical, dialectical, qualitative.	Mixed methods incorporating both quantitative and qualitative approaches.
Method of inquiry (Logic/Reasoning)	Hypothetico-deductive.	Inductive reasoning.	Research question dictates the use of indictive and deductive reasoning.

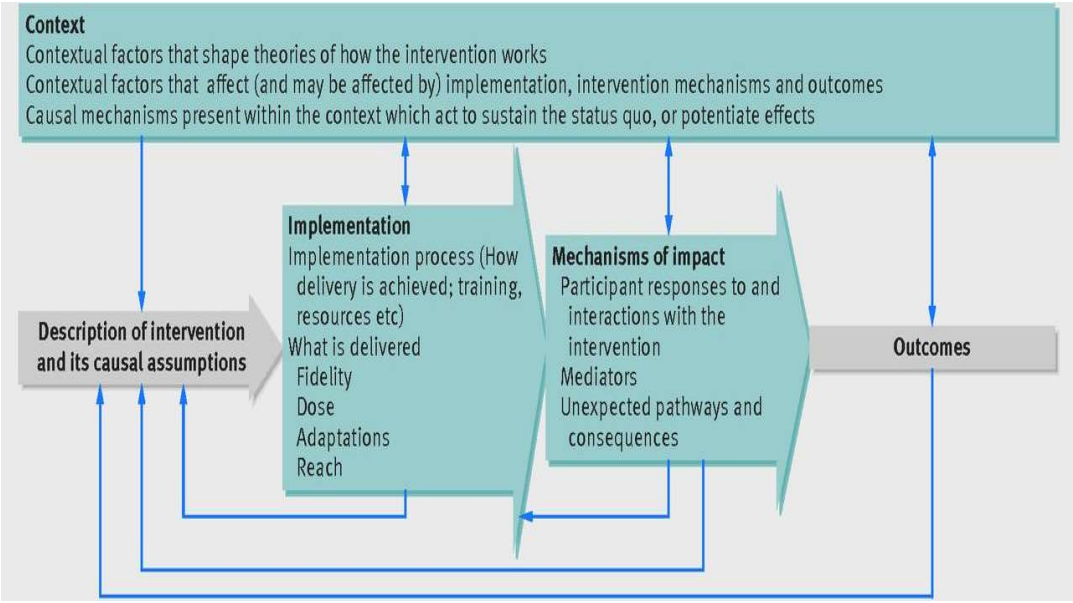
Researcher's position	Objective, neutral observer.	Active, plays a reflexive role within the research.	Concerned about real world and social applicability.

Note. Various sources were used to develop this table including Creswell (2009), Guba and Lincoln (2005), Hall, (2013), Kenny and Fourie, (2015), Pietkiewicz and Smith, (2014), and Tashakkori and Teddlie, (2009).

Thus, in this instance, the larger PRIMERA project was based on a pragmatic mixed methods approach involving an RCT to explore the effectiveness and impact of the FT intervention and a complementary process evaluation embedded within. The latter was the principal focus of the research reported here and involved the use of almost exclusively qualitative methods (with the exception of one brief fidelity questionnaire as described later). Therefore, the three-study research project reported here was conducted within, and guided by, a constructivism paradigmatic framework. The process evaluation, in particular, was undertaken to supplement and amplify the RCT findings and more specifically, to understand and explore: (1) programme implementation (e.g. programme identification, selection, fidelity, training and required resources); (2) mechanisms of impact (e.g. stakeholders' response to the programme, and potential mediating influences); and (3) how the broader context might influence the final outcomes (Moore et al., 2015) (although at the time of writing the papers included in Chapters 4 and 5, the RCT analysis was still ongoing). All three elements are considered essential when evaluating a complex intervention (in this case FT) involving "*multiple interacting components"* (Moore et al., 2015, p. 1). Indeed, the decision to conduct a process evaluation as part of the PRIMERA project was informed by the UK *Process Evaluation of Complex Interventions: Medical Research Council (MRC) guidance document* (Moore et al., 2015). As illustrated in Figure 3.1, these guidelines (which were updated in 2021 after this study began [Skivington et al., 2021]) recommend embedding a process evaluation within an RCT for the reasons outlined above. Thus, the design, administration and analyses outlined in **Studies Two** and **Three** below (both of which relied solely on qualitative methods), were informed by this framework. Further information is provided later in Sections 3.6 and 3.7.

Figure 3.1

Process Evaluation of Complex Interventions: Medical Research Council guidance (Moore et al., 2015, p. 2). (Reproduced by Permission from Moore in email dated 31st August 2023)



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3.2 STUDY ONE - Promoting and Implementing Family-focused Interventions for Families with Parental Mental Illness: Scoping and Installation

3.2.1 Identifying an Appropriate Intervention for Delivery in an Irish Context – Family Talk

Study One involved a range of activities conducted during the exploratory stage of the PRIMERA project, commencing with the initial literature review described earlier in Chapter Two. This preliminary work and especially the review of the literature, provided an initial useful and cost-efficient means of scoping out and understanding the field of research, while identifying important knowledge gaps at a time in the project when resource and time constraints precluded a more in-depth or rigorous review. As described earlier in Chapter One,

this work led to the co-identification and selection of *FT* for implementation and evaluation in Ireland.

As outlined in Chapter One, *FT* is a complex, strengths-based, early intervention and prevention programme developed in the late 1980s by Beardslee and colleagues and originally designed for parents with affective disorders (Beardslee et al., 1987:2013; Beardslee 2019). This intervention is a targeted, clinician-facilitated, 6–8-week manualised psychoeducation programme (Box 3.1) for the whole family where children aged 5-18 years have a parent with a mental health diagnosis and/or are in contact with MHS. The programme is delivered mainly in the home or in outpatient mental health settings and aims to support healthy parent-child relationships in the context of mental illness. The *FT* online training programme[18] is free to access and available online for practitioners who wish to deliver the programme to FaPMI. This training takes approximately 10 hours and includes a standardised programme manual. Further information on FT is provided in Appendix E.

A number of studies conducted to date, indicate that *FT* can reduce affective disorders for FaPMI by nearly a quarter (from 90% to 66%) at 4.5-year follow-up, and by 12% (43% to 31%) for non-affective disorders (Beardslee et al., 2007; Giannakopoulos et al., 2015; Solantaus et al., 2010). The safety and effectiveness of *FT* has also been demonstrated in several clinical trials and meta-analyses (Beardslee et al., 1992:2003; Punamäki et al., 2013; Siegenthaler et al., 2012; Solantaus et al., 2010), with parents reporting increases in the family's understanding of the parental disorder, enhanced parenting skills, and improvement of mental health symptoms both in parents and their children. While not intended to be therapeutic (Pihkala et al., 2011), *FT* is designed to promote resilience in the home by facilitating age-appropriate communication

[18] *Family Talk* training is available online at www.fampod.org and www.emergingminds.com.au/online-course/family-focus/

around the parent's illness. Psychoeducation is a key component and one which has been shown to improve communication, decrease child internalising symptoms, deepen parental understanding of the illness, and reduce shame and stigma which often accompany a psychiatric diagnosis (Pihkala & Johansson, 2008; Strand & Rudolfsson, 2017).

Box 3.1 *An Outline of the Benefits and Weekly Content of the Family Talk Intervention (**Study One**)*

Benefits of Selecting the Family Talk Intervention

- Incorporates a 'whole family' evidence-based approach
- Can be used with a range of mental health problems
- Freely available online training and resources
- Scope for flexibility in adding other relevant elements (e.g. additional CBT skills, crisis plan)
- Cross-site guidance and support
- Guidance and support available from the programme developer
- Involvement of many sites allows for a more robust evaluation.

Week 1: Practitioner meets with parents to take a family history.
Week 2: Psychoeducation & hearing the family story.
Week 3: Meeting the children.
Week 4: Planning the family meeting, practitioner meets with parents.
Week 5: Holding the family meeting. Practitioner meets with parents and children together.
Week 6: One-week follow-up where the mental health professional meets with the parents.
Week 7: Longer-term follow-up (3-6 months), practitioner meets with parents.

FT has been adopted as part of a public health approach to PMI across numerous jurisdictions, including Australia, the Netherlands, Finland, Norway, Sweden, the USA, Iceland, and Colombia (Beardslee, 2013; Christiansen et al., 2015; Gladstone & Beardslee, 2002; Solantaus et al., 2006). While programmes such as the parent-only *Let's Talk,* which is due to be implemented across nine European countries (as described in Chapter Two), were initially considered by the PRIMERA research team and steering group, *FT* was ultimately selected because it also included children living with PMI. Overall, the evidence underpinning *FT*, its whole-family focus, its potential suitability for a range of parental disorders, and the

accessibility and quality of its training, were all key considerations for its selection for implementation in Ireland as part of the PRIMERA project.

With regard to the Irish context, and as a direct result of the PRIMERA project, it is worth noting that *FT* was recently given a 3+ evidence-based rating (out of a maximum of 4) by the UK-based *Early Intervention Foundation* (EIF) following submission of a detailed application (in 2022) by the PRIMERA team. The EIF is an independent UK-based charity established to promote an evidence-based approach to early intervention and prevention, (it has since been renamed *Foundations* after merging in December 2022 with What Works for Children's Social Care [WWCSC]). This submission was in response to a call from the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) in Ireland (https://whatworks.gov.ie/hub-search-results) who had commissioned the EIF to set up a *What Works Evidence Hub* in Ireland (subsequently established in May 2023) for early intervention and prevention programmes designed to improve outcomes for children and families. Its role in the DCEDIY project was to review submissions for a range of programmes that are currently being implemented in Ireland to assess the nature and quality of the evidence underpinning them. The rating of *FT* provided by the EIF was based on two RCTs including, notably, the one completed as part of the PRIMERA project. Both RCTs were considered to be of sufficiently high quality (from a number conducted across the world) to be eligible for inclusion in DCEDIY's *What Works Evidence Hub* and also in the well-known EIF Guidebook (a regularly updated collection of information on over 100 early intervention programmes). [The 3+ evidence rating indicates that FT is evidenced-based because it has "*evidence from at least one rigorously conducted RCT or QED demonstrating a statistically significant positive impact on at least one child outcome*[19]."]

[19] https://whatworks.gov.ie/hub-search/report/3/Family%20Talk

3.2.2 Exploration: Assessing the nature and extent of (and interest in) FFP, in Ireland

As outlined later in Chapter Four, a national Expression of Interest (EoI) process was initiated by the research team at the beginning of the project (with the support of the, then Director of the HSE Mental Health Division). As part of that, an EoI form was developed and distributed to all 114 AMHS and 69 CAMHS throughout Ireland during August-September 2017 and with at least three reminders issued during that period (see Appendix H). This EoI was designed to assess the extent to which services were already providing FFP and if so, what were: (a) their service user target groups (e.g. adult/child/family); (b) the types of disorder(s) involved; (c) the programme components (i.e. psychoeducation, CBT, communication skills training); (d) the format used (i.e. individual, peer or whole family); and (e) the level of interagency co-production and co-delivery. If no FFP was being delivered, services were asked to indicate their interest in being involved in the PRIMERA research, a brief description of which was also included in the EoI.

A total of 37[20] completed EoIs were received (21% response rate), all of which were subsequently analysed and categorised according to three targeted cohorts: (a) parents with a mental health disorder; (b) adult service users with a mental health disorder; and (c) young people attending CAMHS (up to 18 years of age) and living with PMI. As outlined in the next chapter, programmes and supports being offered across adult and child services were typically small-scale, non-standardised and/or still in development, thereby limiting the possibility of conducting a large-scale evaluation of any programme already in operation.

[20] A number of late requests to participate in the research, were also received from additional sites and subsequently included in this total.

3.2.3 Installation: key drivers and activities

During the early exploratory and installation phases of implementing *FT*, as described in **Study One** (Chapter Four), a range of activities was undertaken by the PRIMERA research team, some of which might best be described within Fixsen's framework as 'implementation drivers'. As outlined earlier in Chapter Two, these refer to elements or components that support the process of implementation (Fixsen et al., 2005). More specifically, Fixsen describes three main categories of drivers including: 'competencies' (i.e. elements which increase the capacity of stakeholders to facilitate the programme with fidelity, such as staff training); 'organisational' (i.e. components which provide implementation support such as IT or administrative support structures); and 'leadership' drivers (i.e. the provision of effective leadership for the implementation process including appropriate decision making about the changes required) (Fixsen et al., 2015:2018). All of these were important in progressing the initial phase of *FT* implementation across participating PRIMERA sites (see Box 3.2).

For example, competency drivers included: the requirement for practitioners to undertake the *FT* training to improve their competency and skills to work with families; the organising and hosting of a number of training events designed to increase practitioners' knowledge around working with FaPMI (see Box 3.2); and developing and improving strategies for identifying and recruiting families such as designing and co-producing with site personnel, two trifold brochures, one for families and one for practitioners as well as an A4 poster to promote *FT* in clinic waiting rooms (Figure 3.2 and 3.3, see also Appendix K). Specifically, with regard to training events, a full-day Masterclass entitled '*Think Family – Opening Minds and Reaching Out',* held in Maynooth University (on 5th September 2018), was organised and hosted by the PRIMERA research team to support the recruitment of practitioners and increase competency around the needs of FaPMI and, in tandem, to help promote a *think family* approach to FaPMI amongst practitioners and other interested individuals or parties (Figure

3.4). Approximately 70-80 practitioners and other interested stakeholders (from a wide range of public and voluntary services) attended the event. A national media campaign was also conducted around this event to promote the research and highlight the importance of FFP (Appendix L).

Box 3.2 *Examples of the Competency, Leadership and Organisational Drivers used to Support the Early Stages of the PRIMERA Project*

Competency Drivers

- Clear selection criteria were co-developed for interested practitioners (Box 3.2).
- Clear expectations were outlined for each of the FFP site champions (Box 3.2).
- All practitioners were required to complete the *Keeping Families in Mind* online training (recommended prerequisite for FT training).
- All practitioners were required to confirm completion of the FT online training programme.
- The Masterclass, 'Think Family – Opening Minds and Reaching Out' and 'Family Talk Rally' were organised to increase awareness of the importance of FFP, to help upskill practitioners and to encourage participation in the PRIMERA RCT.
- A resource hub was established to supplement the FT training by providing a range of supplementary resources (see Study One).
- Family Talk brochures and a poster were co-designed to inform and assist practitioners in the recruitment of families for the RCT.
- An active feedback loop was maintained between the research team and participating sites to support the sharing of learning across sites and assist in the implementation of FT.
- The inclusion of experts by experience (of PMI and/or FT) in all MDT presentations, increased practitioners' knowledge and understanding of the needs of this cohort.
- The research team hosted a launch of the research findings in May 2022; one of the aims of this launch was to help increase knowledge and awareness of FFP and the PRIMERA research project.

Leadership Drivers

- The significant funding and leadership provided by the National HSE office provided an important incentive for practitioners to participate in a national project.
- An EoI was issued to all statutory MHS and agreed and signed by the former National Director of the HSE Mental Health Division.
- A letter encouraging support for the study was issued by Tusla and HSE managers in conjunction with the PRIMERA steering committee (Appendix M).
- The research team provided significant leadership throughout the project from identifying the *FT* programme in the first instance, to liaising extensively and regularly with sites, co-ordinating meetings, preparing, delivering and sharing presentations, securing the co-operation of experts with lived experience of *FT* to participate in site visits, organising training events and liaising with the national media, all of which were critical to securing buy-in from MDTs.
- Each site was required to have one FFP champion as a main point of contact to liaise with the research team and oversee the recruitment of practitioners and families to the study.

- *Family Talk* was raised as a topic by the FFP champions at weekly multi-disciplinary team meetings to encourage collegial support and facilitate recruitment of families.
- Champions were identified (and required) to provide peer support and supervision throughout the study.
- Some initial support and advice were provided to the research team by the programme developer (William Beardslee) and by some academics with decades of research experience as part of the Prato Research Collaborative (mentioned in Chapter One).

Organisational Drivers

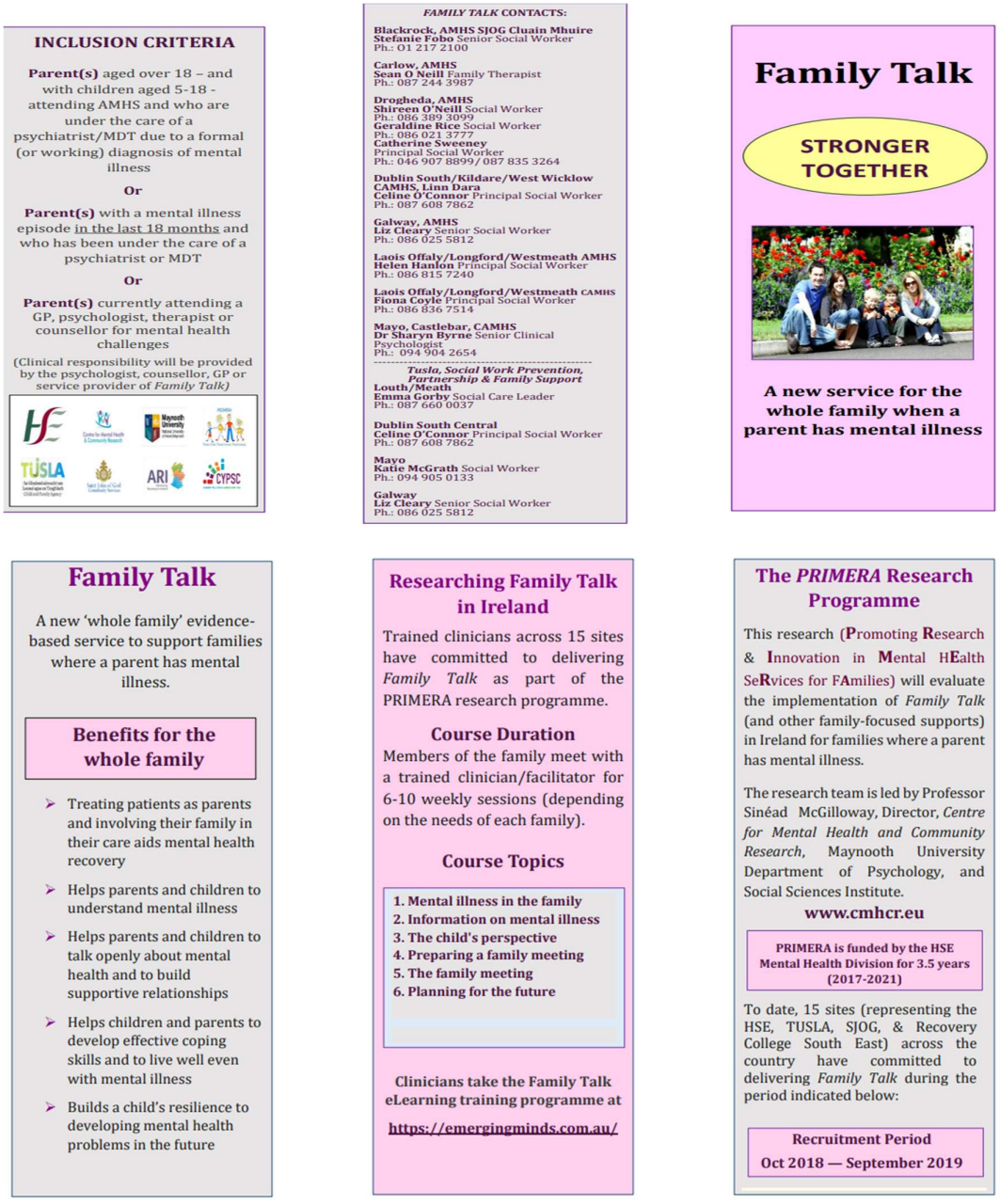
- Managerial support in the participating sites was important in terms of permitting practitioners to undertake the required training (i.e. *Keeping Families in Mind* and *Family Talk*).
- Administrative support was provided in some sites during the early stages of joining the study.
- Practitioners had access to their work office for phone calls and printing material (e.g. the *FT* manual), with permission from local managers.
- The HSE promoted *FT* in its quarterly staff magazine via e-zine to 100,000 HSE staff and 21,000 physical copies printed 4 times a year (see **Study One**) while its communications department also assisted in promoting *FT* via regional media.

A second training event, 'The Family Talk Rally,' was also organised by the research team and held at Maynooth University (14th October 2019) to help motivate practitioners to recruit families (Box 3.2). This event was attended by approximately 50 practitioners. The feedback from both events was very positive, as illustrated by comments included in the post-event Evaluation Form. For instance, one social worker commented: *"I was feeling deflated and defeated in trying to promote FT and a think family approach to my MDT. Today has revived my passion and motivation."* A second attendee commented: "*Great idea to bring the services together and hear about their experiences. Very well run and facilitators were excellent*".

Another key competency driver was the extensive 'resource hub' hosted on the PRIMERA webpage (https://cmhcr.eu/primera-programme) which was developed and maintained/updated by the research team and promoted regularly via an ezine to supplement the *FT* training (see **Study One**, Chapter Four, p. 155). This hub included, for example, *FT* training manuals, articles designed to support the training (e.g. 'How to Talk and Work with Children') and other helpful supports identified by the research team for managing issues such as, engaging fathers, writing child friendly care plans and identifying and engaging families.

Figure 3.2

A Copy of the A4 Trifold Family Talk Recruitment Brochure Designed to Support the Recruitment of Practitioners for the PRIMERA RCT (the Family Recruitment Brochure is attached in Appendix K)



INCLUSION CRITERIA

Parent(s) aged over 18 – and with children aged 5-18 - attending AMHS and who are under the care of a psychiatrist/MDT due to a formal (or working) diagnosis of mental illness

Or

Parent(s) with a mental illness episode in the last 18 months and who has been under the care of a psychiatrist or MDT

Or

Parent(s) currently attending a GP, psychologist, therapist or counsellor for mental health challenges

(Clinical responsibility will be provided by the psychologist, counsellor, GP or service provider of *Family Talk)*

***FAMILY TALK* CONTACTS:**

Blackrock, AMHS SJOG Cluain Mhuire
Stefanie Fobo Senior Social Worker
Ph.: 01 217 2100

Carlow, AMHS
Sean O Neill Family Therapist
Ph.: 087 244 3987

Drogheda, AMHS
Shireen O'Neill Social Worker
Ph.: 086 389 3099
Geraldine Rice Social Worker
Ph.: 086 021 3777
Catherine Sweeney
Principal Social Worker
Ph.: 046 907 8899/ 087 835 3264

Dublin South/Kildare/West Wicklow
CAMHS, Linn Dara
Celine O'Connor Principal Social Worker
Ph.: 087 608 7862

Galway, AMHS
Liz Cleary Senior Social Worker
Ph.: 086 025 5812

Laois Offaly/Longford/Westmeath AMHS
Helen Hanlon Principal Social Worker
Ph.: 086 815 7240

Laois Offaly/Longford/Westmeath CAMHS
Fiona Coyle Principal Social Worker
Ph.: 086 836 7514

Mayo, Castlebar, CAMHS
Dr Sharyn Byrne Senior Clinical Psychologist
Ph.: 094 904 2654

Tusla, Social Work Prevention, Partnership & Family Support
Louth/Meath
Emma Gorby Social Care Leader
Ph.: 087 660 0037

Dublin South Central
Celine O'Connor Principal Social Worker
Ph.: 087 608 7862

Mayo
Katie McGrath Social Worker
Ph.: 094 905 0133

Galway
Liz Cleary Senior Social Worker
Ph.: 086 025 5812

Family Talk

STRONGER TOGETHER

A new service for the whole family when a parent has mental illness

Family Talk

A new 'whole family' evidence-based service to support families where a parent has mental illness.

Benefits for the whole family

- Treating patients as parents and involving their family in their care aids mental health recovery
- Helps parents and children to understand mental illness
- Helps parents and children to talk openly about mental health and to build supportive relationships
- Helps children and parents to develop effective coping skills and to live well even with mental illness
- Builds a child's resilience to developing mental health problems in the future

Researching Family Talk in Ireland

Trained clinicians across 15 sites have committed to delivering *Family Talk* as part of the PRIMERA research programme.

Course Duration

Members of the family meet with a trained clinician/facilitator for 6-10 weekly sessions (depending on the needs of each family).

Course Topics

1. **Mental illness in the family**
2. **Information on mental illness**
3. **The child's perspective**
4. **Preparing a family meeting**
5. **The family meeting**
6. **Planning for the future**

Clinicians take the Family Talk eLearning training programme at

https://emergingminds.com.au/

The *PRIMERA* Research Programme

This research (**P**romoting **R**esearch & **I**nnovation in **M**ental H**E**alth Se**R**vices for FA**M**ilies) will evaluate the implementation of *Family Talk* (and other family-focused supports) in Ireland for families where a parent has mental illness.

The research team is led by Professor Sinéad McGilloway, Director, *Centre for Mental Health and Community Research*, Maynooth University Department of Psychology, and Social Sciences Institute.

www.cmhcr.eu

PRIMERA is funded by the HSE Mental Health Division for 3.5 years (2017-2021)

To date, 15 sites (representing the HSE, TUSLA, SJOG, & Recovery College South East) across the country have committed to delivering *Family Talk* during the period indicated below:

Recruitment Period
Oct 2018 — September 2019

Figure 3.3

A copy of the A4 Family Talk poster Designed to Assist Recruitment of Families for the PRIMERA RCT

Figure 3.4

Photographs from the PRIMERA Think Family 'Opening Minds and Reaching Out' Masterclass at Maynooth University held on September 5th, 2018

Note. Both photographs include Dr Adrian Falkov (who developed the Family Model mentioned in Chapter Two) who is a senior staff specialist in child, youth, and family psychiatry at the Royal North Shore Hospital in Sydney, Australia. The bottom photograph includes Sharon McGarr, the PRIMERA Fieldwork Co-ordinator. (Photographs were taken by Dr Rachel Kelly, MU Department of Psychology.)

An additional competency driver initiated to support practitioners was the establishment of an active and sustained feedback loop between the research team and practitioners, maintained via telephone calls and bimonthly ezines (see Appendix N). In this way, sites and practitioners who joined the study later, benefitted from the knowledge and experience of the first sites recruited, thereby helping to speed up their process of implementing *FT*. Furthermore, presentations prepared and delivered by the research team were shared with MDTs in each site and on some occasions, as outlined earlier, one or more service users who had completed *FT*, were invited to attend these meetings; these proved to

be very popular and helpful in encouraging more practitioners to become involved in *FT* delivery and, in parallel, to support the research.

As outlined earlier in Box 3.2, the installation of *FT* was also supported by leadership and organisational drivers. For example, leadership was demonstrated in a number of different ways including: the support, funding and leadership from the HSE particularly in the early stages of the research; the crucial role played by the research team throughout the project, from identifying the *FT* programme in the first place, to co-ordinating site visits and securing buy-in using a number of different approaches; and identifying *FT* champions who provided supervision and peer support to practitioners delivering the intervention. Some support and advice were also sought from experts in the field including Dr William Beardslee and Dr Adrian Falkov. Lastly, key organisational drivers included the provision of managerial and administrative support (to varying degrees) across sites as well as ongoing support from the HSE. For example, practitioners had access to their work phone and printers for materials (e.g. the *FT* manual) related to the project, while the HSE Communications department assisted in promoting *FT* via regional media.

As indicated in Box 3.3, a series of activities was also undertaken in parallel, to help with the recruitment of practitioners and families such as promoting *FT* and the PRIMERA research in local and national media (Appendix L). In terms of helping to recruit families, practitioners drafted letters which were then posted to families informing them about *FT* while direct telephone calls were also made by practitioners to inform existing service users about the study. The recruitment posters and brochures co-designed and co-produced by the research team and key site staff, were also placed in prominent locations in outpatient clinics/waiting rooms. All of these 'drivers' and attendant activities (Box 3.2 and Box 3.3) demonstrate the nature and extent of the support needed to maintain momentum throughout the lengthy and challenging

recruitment and implementation process, even prior to the delays caused by the COVID-19 pandemic.

Box 3.3 *Summary of the Activities Employed to Assist in the Recruitment of Practitioners and Families to the PRIMERA Research (RCT and process evaluation)*

Activities Adopted to Support Buy-in from Practitioners

- Nine 'responding sites' received follow-up site visits.
- All sites were emailed about Family Talk and issued with an invitation to participate.
- Family Talk was added to care plans for service users if needed.
- Several recruitment extensions were added to the project timeline.
- A number of presentations were delivered to national clinician conferences (e.g. social work conference- Family Focused Practice: The Role of Mental Health Social Workers 2020 at St Patrick's Mental Health Services Dublin 8 on 21st Feb 2020 (Full details in Appendix L).
- Word of mouth helped to recruit new sites.
- The research team (including the author) attended regular peer support meetings to provide support to practitioners.

Factors which Encouraged Buy-in/Participation from Families

- Letters were posted to families in some sites informing them about FT.
- Direct calls were made by practitioners to inform existing service users about FT.
- Recruitment posters and brochures were placed in prominent locations in outpatient clinics/waiting rooms.
- The project was promoted, when possible, through regional and national media outlets.
- FT brochures were added to all 'intake folders' to remind practitioners to consider the suitability of the intervention for service users during the intake process.
- All recruited families received a follow-up contact from the research team to address any questions they might have.
- Service users were invited to participate in PR events (including media interviews).
- Service users were involved in most presentations to MDTs (i.e. services users had to first complete the intervention and subsequently express an interest in participating in presentations.)

3.2.4 Summary of site and participant recruitment

In summary, approximately 100 visits were undertaken by the research team to 15 sites that had initially agreed to implement *FT* (the vast majority of site visits were made by the author). Following the EoI, Tusla, the national Child and Family Agency, Saint John of God (SJOG) (Hospitaller Ministries) and Primary Care Psychology approached, or were approached by, the research team and also joined the project. The site visits took place primarily to inform

multidisciplinary teams (MDTs) about the PRIMERA research and *FT*, and to assess the extent of their interest in, and readiness for, implementing the programme and taking part in the research (including the process evaluation).

A number of criteria were co-produced with site staff during this process to assess the readiness of each site and the eligibility of the staff for participation in the project (see Box 3.4). For example, all participating sites were required to have a lead practitioner/contact person with overall responsibility for delivering *FT* within the site and for identifying and supervising suitable practitioners to undertake *FT* training. The lead practitioners typically had a prior interest in conducting FFP and had first-hand experience of the generational impact of PMI in families. As such, they played a particularly important role in championing *FT* within their local services. The responsibilities of the lead practitioners and clinicians who delivered *FT* were outlined, agreed and documented by the research team (Appendix I & J). All of the mental health practitioners who agreed to participate in the research were also required to meet certain criteria (agreed in collaboration with clinicians) including, for example, three years' minimum experience of working in MHS and a willingness to participate both in regular peer supervision and in helping to identify and recruit families (see Box 3.4).

Box 3.4

Site and Practitioner Eligibility Criteria

Site Eligibility Criteria

- Availability of a lead contact person with the support of management, who is willing to coordinate clinicians, family recruitment, and point of contact with the research team.
- Availability of a contact person in the event of child welfare/protection issues.
- Ability to identify and recruit experienced staff to complete the Family Talk online training.
- Willingness to facilitate regular peer support for Family Talkers.
- Clear plan for identifying and recruiting eligible families for the RCT.
- Willingness of managers and practitioners to engage with and support the research project.

Practitioner Eligibility Criteria

- A minimum of 3 years' experience of working in mental health services.
- Completion of the FT (and 'Keeping families in mind') online training at https://emergingminds.com.au/online-course/family-focus/.

- Attendance at peer supervision meetings.
- Recruitment and/or delivery of FT to families.
- Participation in the research (e.g. interview and/or completing the cost diary for the RCT).

It is important to note that sites were characterised by variable levels of readiness and not all, therefore, were able to meet the site eligibility criteria. Staff in 10 of the 15 original sites went on to recruit families (albeit with varying degrees of success) for inclusion in Phase Two of the research (i.e. the RCT) and to subsequently train in, and deliver, *FT*. It should be noted here that MHS in Ireland are provided across nine distinct nationally funded Community Healthcare Organisations (CHOs), each of which is tasked with supporting the needs of their respective population. The sites who took part in the RCT and process evaluation were located across various regions in Ireland including the East, Midlands, Midwest, South-East and the West of Ireland and represented several CHOs including numbers two, five, seven and eight.

Prior to family recruitment (outlined in **Study Two**), it was also necessary to agree and co-produce the recruitment criteria with key stakeholders (e.g. the PRIMERA project Steering Group and senior mental health practitioners [see Appendix G]); the team also consulted with Dr Bill Beardslee, the programme developer. The subsequent recruitment criteria were informed by a number of specific factors including: (a) the information contained within the EoIs received from service staff; (b) a consensus amongst practitioners on the need for clinical governance for service users; and (c) consideration of the emotional capacity of children to engage with the intervention. Once agreed, recruitment for purposes of the RCT commenced in October 2018, but proceeded slowly initially due to a number of factors including: (a) the time required by FFP 'champions' to gain buy-in from managers; (b) practitioners' need for training; (c) the time required to identify/target and recruit relevant families on top of existing workloads; and (d) staff mobility issues and wider HSE recruitment difficulties.

3.2.4.1 COVID-19

A lack of readiness and delays due to COVID-19 lockdowns (see later) further extended the recruitment process thereby also delaying the process evaluation. The stay-at-home

requirement implemented on 27th March 2020 (ending in March 2022), led to some practitioner redeployment to COVID testing and/or the pausing/cancellation of face-to-face delivery of *FT* with families. Elsewhere, service users were discharged before commencing the FT intervention if the service user's needs were deemed non-urgent. Similar to the general population, practitioners and family members also became sick from virus infection. This appeared to be a major contributory factor to workload burnout and led to the withdrawal by some practitioners from the research. The lack of clarity around the ending of the lockdowns, which coincided with the final phase of the PRIMERA project, further limited each site's effectiveness and willingness to work with families, particularly those who joined the PRIMERA project at a later stage (see **Study Three**). These unavoidable delays led to three no-cost extensions to the project in order to mitigate the delayed completion of the research, including the process evaluation. For instance, at the original 'closing date' for the admission of new sites to the research (31st October 2019), only 41 families were recruited, and it was decided, therefore, to extend the closing date to 31st March 2020. This helped to increase the final total sample size to 83 families. Recruitment for the process evaluation was also delayed in parallel, commencing only after the six-month assessments within the RCT had been completed.

3.2.5 Public and Patient Involvement: A Collaborative and Engaged Approach

PPI was a key element of Study One and indeed, throughout the PRIMERA project. For example, the views of mental health practitioners were sought in relation to the selection and use of *FT*. The FT and research promotional materials developed during Study One, were co-produced with clinicians and some family members. All sites that agreed to take part in the research were also encouraged from the outset to adopt a collaborative interagency approach to delivering the intervention, while the research team also worked closely and collaboratively with all clinicians and site staff during every stage of the research (including Study One and the RCT).

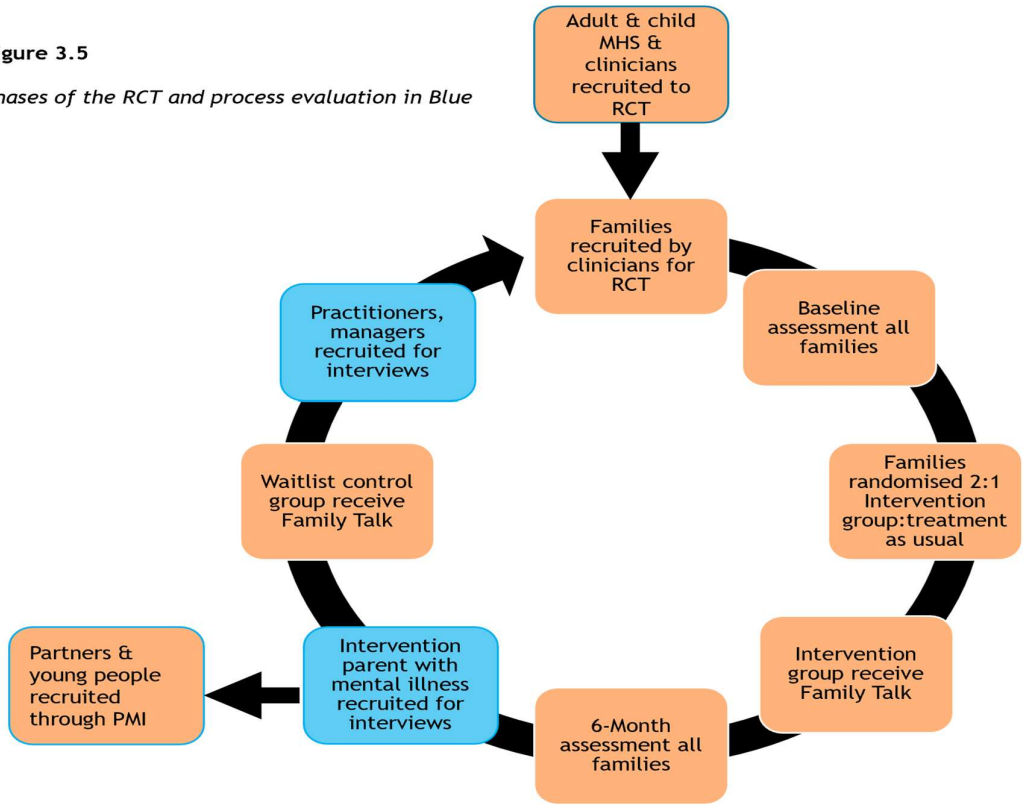
It is also worth noting that the most successful sites in terms of the number of participating families, were characterised by close and effective collaboration between a typically large number of statutory and non-statutory agencies/services. Several key agencies were also represented on the PRIMERA Project Steering Committee (see Appendix G) while all of our stakeholders, including families, were invited to take part in, and contribute actively to, all of the PRIMERA events. Family members were also invited to contribute to media promotion activities (e.g. participate in interviews with a journalist), to be actively involved in co-presentations to MDTs in participating sites, and to take part in the PRIMERA videos as part of the process of disseminating the findings from the project (see Section (7.4) in Chapter Seven).

THE PROCESS EVALUATION (Studies Two and Three)

This next section describes the methodological approach to the process evaluation and specifically, the two separate but related studies therein (Studies Two and Three). The different phases of data collection for the process evaluation relative to the RCT, are shown in Figure 3.5.

Figure 3.5

Phases of the RCT and process evaluation in Blue



3.3 STUDY TWO - The Family Talk programme in Ireland: A qualitative analysis of the experiences of families with parental mental illness

3.3.1 Participants and settings

Prospective parent participants were first required to fulfil a number of inclusion criteria for the RCT (see Box 3.5). Recruitment for this strand of the process evaluation was subsequently carried out using Maximum Variation Sampling (Coyne, 1997) which considered a balanced mix of participants across AMHS and CAMHS, urban/rural locations, and a range of demographic and background characteristics, such as age, gender, marital status, and diagnosis A total of 23 parents/families who were originally invited to participate in the RCT and who completed the 6-month follow-up assessments (i.e. once the group allocations were known), agreed to take part in this element of the process evaluation.

Box 3.5 *Family Participant Eligibility: Inclusion and Exclusion Criteria*

Family Eligibility Criteria	
Parent(s) aged 18 or over with children aged 5-18 years.	Attending AMHS under the care of a multi-disciplinary team (MDT) due to a formal (or pending) mental health diagnosis.
	Or
	Parent(s) with a mental health episode in the last 18 months who had been under the care of a psychiatrist or MDT.
	Or
	Parent(s) currently attending a GP for mental health issues.
Family Exclusion Criteria	
Family/parent in crisis (e.g. hospitalised, active psychosis/addiction [preventing participation]), contentious separation, and/or active custody disputes.	

Note. Children as young as five years participated in FT, but only young people aged 8-18 years took part in the research.

Approximately half (*n*=12/23) of the parents with a mental health disorder were recruited from AMHS, with the remainder (11/23) identified and recruited through CAMHS because their child was attending these services and the parent self-identified as having a mental health disorder. Indeed, it is worth noting here, that 42% of the children in the RCT families were attending either CAMHS or psychology/family services. Adult service-user participants in the process evaluation were typically aged in their early forties (*Mn*=41.6; *SD*=8.2), predominantly female (18/23), Caucasian (22/23), and socially disadvantaged (15/23); approximately half (11/23) were lone parents. Most had a formal diagnosis of anxiety/depression (14/23), followed by bipolar disorder (4/23), psychosis (n=3/23) or borderline personality disorder (2/23).

Seven partners of the 23 service user parents, plus 15 children (aged 9 to 18 years) also agreed to take part in the process evaluation. Five of the seven partners were male, four were recruited because their partner was attending AMHS and three because their child was attending CAMHS. Four partners were the sole earner in the home, and three also reported living with a mental health difficulty (i.e. anxiety, depression, and alcohol misuse). Ten of the

15 children were male and aged on average, 13.2 years (*SD*=2.8). Over half (8/15) were attending or waitlisted for CAMHS, while an additional three young people (two females and one male) reported mental health issues*,* two of whom had previously attempted suicide and one of whom had self-harmed*;* two (females) were attending counselling at the time of data collection. The children in the larger RCT tended to be more evenly distributed by gender and were also a little younger (*M*=10.3; *SD*= 5.3).

Fourteen of the families completed *FT*, four never started at all, while the remaining five left after one (*n*=1), two (*n*=2) or three (*n*=2) sessions due to, for example, a family crisis (e.g. family death, sexual assault, relapse), dissatisfaction with services, frustration due to COVID-19 delays, and/or a family member not wishing to continue. The nine families who dropped out of the RCT after completing less than three *FT* sessions, were interviewed for purposes of negative case analysis (King & Horrocks, 2010).

3.3.2 Interview schedules for Family Participants

The content of the initial interview schedules used in the study were informed by Fixsen's model, the MRC guidance mentioned earlier and by the initial review of the literature, with questions adapted as the interviews progressed. The content covered: experience of the recruitment process; prior experience of MHS; views of each aspect of the *FT* intervention including the content of the sessions; and any unexpected consequences of the programme. Specific interview questions included, for example: (1) *What do you remember about FT?* (2) *Tell me about your FT experience*; (3) *Would you make any changes to FT, and if so, what changes would you make?;* and (4) *What impact if any, has it had on you, or other family members?*

A post-FT questionnaire was also designed and planned for administration to parents (Appendix O) and children (Appendix P) after completion of the last session of the intervention. However, response rates were poor because the whole family were not in attendance. After

consultation with the research team, the fieldworkers (including the author) began administering the questionnaires to the families at the six-month assessment. Control group families were asked to complete the forms only after completing *FT* and a stamped addressed envelope was provided to facilitate returns, followed by text reminders (sent by the PRIMERA Fieldwork Co-Ordinator) to complete the forms. Only a small number (nine parents and eight children) were ultimately received.

3.3.3 Data Collection, Transcription and Analysis

As indicated earlier, families were initially recruited to the RCT by the mental health practitioners. Once identified, practitioners were required to explain *FT* to the parent (i.e. the parent with the mental health disorder) and its potential benefits, as well as an explanation of the PRIMERA project. Many practitioners, despite clear written instructions from the research team, struggled to explain the randomisation element of the RCT and indeed, this has also been observed in previous research (e.g. McGilloway et al., 2012). However, once prospective families were recruited to the trial, the research team provided further explanatory information as part of a two-stage process. The first stage involved a telephone conversation with the Fieldwork Co-ordinator; the second stage involved the fieldworker who would be conducting the baseline assessment with the parent, explaining in person, the process of randomisation and what the study involved. This parent was the primary access point to the family for the remainder of the study. Recruitment for the process evaluation as mentioned earlier, only began at the six-month follow up assessment (Figure 3.5). Prior to this, the researchers were blind to the RCT group allocation for each family. Once families disclosed their group allocation at the six-month follow-up, (see Appendix B), the parent, co-parent and their children (via the primary parent) were invited to take part in an interview for the process evaluation.

Once an invitation to an interview was accepted by a PMI, a text was sent confirming the agreed date/time and venue. On the day of the interview/focus group and prior to

commencement, the study information and consent forms were discussed in person with parents (Appendix Q), teenagers (Appendix R), children (Appendix S), practitioners/managers (Appendix T). Interview schedules and topic guides for each cohort can be found in Appendices U, V, W, X, Y and Z). The confidentiality guidelines were also gently reiterated. The Information and Consent Forms provided the rationale for the study, what was expected of the participant, details of ethical approval, how information was being anonymised, the benefits/risks of being interviewed, and contact numbers in the event of a problem arising. Due consideration was also given to the potential for bias (e.g. selection bias, Hawthorne effect) prior to and during the interviews (McCambridge et al., 2014). Where possible, interviews were conducted in participants' homes (unless otherwise requested) between August 2019 and March 2021, and remotely (via phone/video conferencing platforms) during the COVID-19 pandemic. Four children were interviewed with one (or both) parents present at the request of the parent/child, while the remaining interviews were conducted on a one-to-one basis with parents in a nearby room. Parents assented for children aged 16 years and under (*n*=14) to take part, but all children were also invited to give their verbal consent to participate. One 18-year-old participant provided both written and verbal consent. One couple was interviewed after completing *FT*, but had opted not to participate in the RCT.

All interviews were recorded with consent. A warm, person-centred approach (Rogers, 1951) was adopted throughout each interview while participant burden was monitored both verbally (e.g. *are you okay to continue?*) and visually (e.g. by observing participants body language). All but seven interviews (conducted by one team member, SMcGa, see **Study Two**) were conducted by the author who had no prior relationship with participants, although she had completed baseline and 6-month assessments with 87% of the families interviewed. A second interviewer was involved due to the risk of demand characteristics arising with a single interviewer and also to help reduce interviewer burden on this author (see Chapter Five). Family

interviews lasted approximately 30-40 minutes for parents and partners and 20 minutes for children. Each interviewee received a 'thank you' voucher for a well-known Irish shopping store (€10 for children and €25 for parents). Further information on the ethical considerations underpinning both this study and **Study Three**, is provided later in Section 3.5.1.

The format of the interviews (i.e. one-to-one, dyad/group) was decided in collaboration with the participating parents, and the interviews were concluded once saturation had been reached (Coyne, 1997; Glaser, 2002; Strauss & Corbin, 1998). The term 'saturation' in the context of CGT refers to the stage during data collection and analysis when no new categories or themes emerge, or can be identified, from the data (Charmaz & Thornberg, 2021). While efforts to increase the participation of co-parents and individuals who dropped out of the research were unsuccessful, data analysis ended and data saturation was reached when no new data emerged from the interviews with the 45 family members and 41 mental health practitioners and managers.

All Interviews were transcribed verbatim (by several team members including the author), uploaded to MAXQDA (VERBI Software, 2021) and each cohort was analysed separately (i.e. PMI, COPMI and coparents). Each transcript was rigorously read and re-read by the author in line with recommendations from the Consolidated Criteria for Reporting Qualitative Research (COREQ) framework (Guba & Lincoln, 1989:2005; Tong et al., 2007). For example, after the initial review of the transcripts (by the author), 25% were reviewed by PRIMERA team members, thereby enhancing the reliability and trustworthiness of findings, with any differences/disagreements discussed and clarified (Tashakkori & Teddlie, 2009). Voice and written memos were also recorded after each interview, including non-verbal behaviour (e.g. one interviewee uttered "*I'm tired,*" during a family interview as the parent spoke about their mental illness [see section 3.5.4. below]). Constant comparison within and across interviews also helped to identify key differences and similarities in categories, which were subsequently

read along with the secondary data (e.g. memos) until consensus was reached. The data were then analysed using Constructivist Grounded Theory (CGT) (Charmaz, 2006:2016). Further information on the analytical approach used in **both Studies Two** and **Three** is provided later in Section 3.5.2 along with information on researcher reflexivity.

3.4 STUDY THREE - A family-focused intervention for parental mental illness: A practitioner perspective

3.4.1 Participants and settings

Study Three involved a series of one-to-one interviews (*n*=14) and focus groups (*n*=5) conducted between June 2019 and February 2021 and designed to explore practitioners' experiences and views of delivering *FT*. The total sample (*N*=41) included 10 managers and 31 practitioners who had delivered *FT* to approximately two-thirds of the families (64%, 55/86) in the RCT. All stakeholders were approached by the author either face-to-face or via email and invited to take part in an interview or focus group to discuss their experience of *FT* and the research project more broadly. Practitioners who agreed to be interviewed, were predominantly female (87%) aged 31–50 years with approximately 15 years' (*SD*=6.7) work experience typically (77%, 24/31) across multiple settings (e.g. AMHS, CAMHS, and child protection services); 45% worked in AMHS and 45% in CAMHS, with the remaining 10% based in primary care or the Tusla Child and Family Agency**.** Half of the ten managers interviewed, were female, six were principal/senior social workers, two were senior clinical psychologists, one was a systemic family therapist, and one was a general manager; they were employed in AMHS (*n*=6), CAMHS (*n*=3) and in primary care psychology (*n*=1). Overall, most (73%, 30/41) of the managers/practitioners were employed as social workers with the remainder working mainly as social care workers (3/41), psychologists (3/41), clinical nurse specialists (2/41), family therapist (1/41), project leader (1/41) and general manager (1/41).

3.4.2 Measures

A brief 'Background Questionnaire' (Appendix Y) was first administered to all practitioners to elicit basic demographic information. The interview schedules and topic guides were devised, as with **Study Two**, on the basis of the literature, the MRC guidance and Fixsen's model. The content was open-ended to facilitate conversation flow in line with CGT (Charmaz, 2017) and was designed to investigate: (1) stakeholders' experience of facilitating/implementing *FT*; (2) key barriers and enablers to implementation and delivery; (3) factors moderating the longer-term sustainability of *FT*/FFP in their service/in Ireland; and (4) rates of recruitment and attrition.

A brief 'Fidelity Questionnaire' (Appendix Z) was also developed and administered online to clinicians (using Qualtrics) in order to elicit information that could be used to assess implementation fidelity. This survey included questions on, for example: (a) the number of *FT* sessions each family completed; (b) the percentage of overall material covered from the *FT* Manual; and (c) which material was not covered with each family and why. Practitioners were invited to complete the questionnaire if they: (a) had left the PRIMERA project earlier than anticipated (e.g. due to COVID-19 redeployment or movement due to a promotion); (b) were no longer delivering *FT* to families; or (c) had completed FT delivery (see Chapter Six). The response rate to the survey was disappointingly poor (28%, 14/50) due, in part, to the fact that it was administered during the COVID-19 pandemic, but perhaps more importantly, the administration of the survey coincided with a significant cyberattack[21] within the HSE which meant that practitioners were either too busy to respond to the request to complete the survey and/or reluctant to click on links. Both factors hindered practitioners' willingness to participate in the survey, but subsequent phone calls by the Project Manager and Fieldwork Co-ordinator

[21] https://www.hse.ie/eng/services/publications/conti-cyber-attack-on-the-hse-full-report.pdf

captured verbal responses to the survey (**Study Three**). Furthermore, it was not possible to complete follow-up interviews with practitioners due to implementation delays (which slowed recruitment), the COVID-19 lockdowns, and the redeployment of some practitioners during the pandemic.

3.4.3 Data Collection, Transcription and Analysis

Similar approaches to those described above were used for the collection and management of the practitioner data. All interviews were audio recorded with consent, transcribed verbatim (by several members of the team including the author) and uploaded to MAXQDA (VERBI Software, 2021) in preparation for analysis. As above, all transcripts were rigorously read and re-read in line with COREQ guidelines while a number of other approaches, as shown in Table 3.2 below (p.158), were also used to enhance the reliability and validity of the findings for both **Studies Two** and **Three** as recommended by the COREQ guidance and CGT (Charmaz et al., 2016:2017; Guba & Lincoln, 1989:2005; Tong et al., 2007). Further information on ethical considerations, data analysis, and researcher reflexivity, is provided in the next and final section of this chapter.

3.5 Overarching Methodological Considerations

3.5.1 Ethical Considerations

As the PRIMERA research involved a population deemed to be 'vulnerable', a comprehensive ethics application process was conducted with due consideration of a number of key documents and guidelines, including the Psychological Society of Ireland (PSI) (2019) Code of Ethics, MU Research Ethics Policy (2016), MU Research Integrity Policy (2016), MU Data Protection Act (1998:2003), and the *Children First: National Guidance for the Protection and Welfare of Children* (DCEDIY, 2017). Three agencies external to the university (i.e. HSE, Tusla, and SJOG) also required ethical approval from their own organisational ethics committees. This was a lengthy process due, in part, to the then new GDPR introduced in May 2018. Following

the preparation, submission, and review of the four detailed applications (i.e. MU, HSE, Tusla and SJOG), ethical approval (Appendix AA) was granted during late 2018 to early 2019 for all elements of the research, including the multi-site double blind RCT, process evaluation and cost analysis (i.e. from the HSE on 12/9/2018; MU 21/9/2018; Tusla 7/11/2018; and SJOG 7/1/2019).

Additional safeguards as part of the ethics process included oversight in the first instance by the HSE Steering Group and subsequently, by a smaller Expert Advisory Committee (Appendix G). Each researcher was also Garda vetted (an Garda Síochána is the Irish police force) and completed the *Child First* eLearning programme with the Tusla Child and Family Agency. Both verbal and written information and instructions were provided to all participants in order to obtain their written informed consent (Appendix Q, R, S, T, U). As mentioned above, GDPR data protection guidelines were also used to inform data management and storage throughout the project. All data collected from interviews and focus groups were coded with unique identifiers and anonymised at the point of digital recording to maintain confidentiality and anonymity.

Article One of the UN Convention on the Rights of the Child (1989) defines children as individuals aged under 18 and, therefore, consent to participate in the RCT was initially required from parents (as mentioned above), with subsequent verbal assent invited from each child in line with the Department of Children and Youth Affairs (DCYA) guidelines (2012). Interviews with young people were informed by Borger's (2000) guidelines on children's cognitive preparedness to answer questions, as well as relevant theories of cognitive development (e.g. Piaget, 1936; Vygotsky et al., 1978). For example, children aged five to seven years of age were permitted to take part in *FT* but were not interviewed for the process evaluation as logical thought, according to Piaget's four phases of cognitive development, begins at age seven. With this in mind, language and concepts throughout the interviews involving children, were kept simple, jargon was avoided at all times, and the familial language around mental illness was

mirrored throughout. The Information Sheets were also child friendly (Appendix R, S), based on simple open-ended questions to aid conversation flow. They were checked by the team for language accessibility and were adapted as interviews progressed in line with ethical and GDPR recommendations.

Procedures were also put in place to deal with any disclosure of harm, or behaviours observed which raised concern about a child's safety (DCYA, 2011). Interviewees were reminded that confidentiality was not guaranteed in the event of concern of harm or risk to children or vulnerable adults. A clear pathway for disclosures was established in line with *Children First: National Guidance for the Protection and Welfare of Children* (DCEDIY, 2017) and MU Child Protection guidelines. For example, the last of these requires, where applicable, includes completion of an *Incident Form,* discussion with the Principal Investigator, (Professor Sinead McGilloway), and a subsequent report to the university's designated liaison person who, if necessary, discusses concerns raised with outside agencies such as the HSE, and an Garda Síochána.

3.5.2 Analytical Approach

This next section details the rationale for the selection of the analytical approach used in the process evaluation described in both **Studies Two** and **Three**. A number of analytical approaches were considered, including CGT, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009), and thematic analysis (Braun & Clarke, 2006). A range of factors was also considered when determining the best approach including, the intended sample size, the research questions, the nature of the data generated for interviews and focus groups, and the author's philosophical stance and lived experience of PMI. For example, the intended sample size was much too large to permit IPA to be used, which is typically based on up to 12 participants (Noon, 2018). Ultimately an adapted version of the original Grounded Theory (GT) conceptualised by Glaser and Strauss in the 1960s (see Appendix BB) was selected for use in the

study. Based on an iterative process of data collection and analysis (Charmaz & Thornberg, 2021), GT was developed to reverse/reduce the theory-research divide in social science using rigorous methods to discover/uncover "*robust and astute hypothesis grounded in research"* (Kenny & Fourie, 2014, p. 2).

Specifically, CGT was used for a number of reasons. Firstly, it acknowledges the researcher as co-constructer of theory and encourages reviewing the literature throughout the research process. The CGT approach is also designed to reflect or capture a socially dynamic reality incorporating all language, actions, researcher interactions and research questions (Charmaz, 2016a; Kenny & Fourie 2014:2015). In classic GT, the researcher is viewed as an outsider who can obscure objective reality (Charmaz, 2006:2016a:2016b) whereas in CGT, reality is socially constructed, and as numerous as its constructors (Guba & Lincoln, 1989; Mills et al., 2006). Theory in classic GT 'emerges', whereas it is 'created' in the so-called Straussian CGT model (Charmaz, 2008). This difference in the researcher's role was key to selecting CGT given the author's lived experience of the topic under investigation and an awareness of how personal history can influence the research process.

Secondly, CGT was considered a useful approach for obtaining multiple perspectives from each individual within a family as well as the practitioners working within MHS but employed in different services and roles across the CHOs. For instance, while the CHOs provide services for similar populations, they are locally managed, employ different delivery models (i.e. community, hospital based), have variable resources (e.g. remote locations may find recruiting professionals challenging) and different loci of care (i.e. adult or child/adolescent services) as well as a range of geographical locations (i.e. rural, urban). In some cases, there are also legacy challenges where, for example, some CHOs are fiscally responsible for costly historic buildings being repurposed/decommissioned due to deinstitutionalisation. The levels of family

engagement with practitioners across sites also differed based on the temperament, skill, and confidence of the practitioner delivering *FT*.

Thirdly, the ongoing review of the literature required throughout each stage of the CGT analysis (unlike the classic GT variant) helped to scaffold the process of co-constructing data as well as identifying gaps in the literature (Charmaz, 2016a:2016b; Charmaz & Thornberg, 2021). For example, knowledge of the Scandinavian FFP legislation introduced in 2010 (Beardslee et al., 2012; Lauritzen et al., 2014:2018; Solantaus et al., 2010) informed the interview schedules for practitioners and managers in terms of the inclusion of questions on policy, practice, and/or legislation for FFP. Prior knowledge of the shorter parent-only *Let's Talk programme* introduced elsewhere (as previously mentioned), also prompted questions on stakeholders' perspectives on the inclusion/exclusion of children from mental health programmes. A priori knowledge further helped to facilitate a broad comparison of Ireland's mental health policy with those elsewhere, during the write-up phase of **Study One**. Overall, the researcher's role, the succinct coding process and the ongoing use of literature, were all aspects of CGT which made it particularly well suited to the analysis of the findings from the process evaluation described in **Studies Two** and **Three**.

3.5.3 Enhancing Validity and Reducing Bias

As briefly mentioned earlier, a range of techniques in line with CGT was used throughout the analysis to enhance the validity, reliability and replicability of the findings (Charmaz & Thornberg, 2021; Lincoln & Guba, 1985) (see Table 3.2). For example, all interviews were audio recorded and transcribed verbatim while an audit trail of code generation (Appendix EE) was also maintained to support the confirmability of the qualitative findings; this approach helps to verify that findings can be correctly tracked back through the analysis to the raw data and that interpretations of the data are rational and meaningful (see Bowen, 2009). A sample of the audit trail is provided in Appendix EE. A disconfirmation case analysis was also conducted.

Table 3.2

Summary of Approaches Used to Enhance the Reliability and Validity of the Findings from the Process Evaluation (informed by COREQ guidelines)

Project Stage	Methodological approach
Prior to Commencing PRIMERA	➢The author's training and experience as outlined in Table 3.3. ➢The interview process was discussed with stakeholders and followed up with a text confirming the details to ensure informed consent. A summary of the family demographics was provided by the PRIMERA Fieldwork Co-ordinator in advance of each interview.
Data Collection	➢Maximum (purposive) variation sampling was used to recruit stakeholders for each interview. ➢Interviewees were provided with a verbal and written overview of the PRIMERA study prior to providing their written informed consent. ➢All interviews were audio recorded and transcribed verbatim. ➢Upon invitation, the author attended all peer support meetings to understand practitioners' day-to-day challenges and to elicit their informal feedback on *FT* as well as identifying issues arising from delivering the intervention to families with complex needs. ➢Disconfirmation case analysis was conducted throughout (e.g. with regard to sites and/or families who withdrew from the study). ➢An iterative process was adopted to help inform all interview questions. ➢The author maintained a reflexive position throughout the project, discussing findings with colleagues and service users with lived experience (only after interviews were recorded). ➢Memos (verbal and written) were used to record non-verbal data.
Analysis	➢Data were triangulated from multiple sources within families and from practitioners across participating sites. ➢25% of transcripts were coded by three PRIMERA researchers. ➢The RCT assessments helped to detail stakeholders' context (i.e. demographic details, and work history). ➢Analysis was discussed with team members throughout the process. ➢An audit trail was maintained (see sample in Appendix EE). ➢Data collected until saturation was achieved.
Write up	➢Findings were discussed with practitioners after interviews were conducted to enhance validity, commonality, and reliability. ➢Findings were compared with studies from the international literature. ➢Findings were presented to funders/peers at conferences (e.g. Irish social worker conference: *Family Focused Practice: The Role of Mental Health Social Work, at the, It takes a village international conference for families experiencing substance use, mental or physical health problems,* Oslo, 13th- 17th May 2019). ➢Each of the three publications (**Chapters Four, Five** and **Six**) was submitted to peer-reviewed journals (e.g. a special edition of Frontiers in Psychiatry on PMI).

Considerations such as the researcher's self-awareness and training were helpful in terms of focusing on representing the authentic voice of the interviewees (Fossey et al., 2002). Thus, within CGT, the interviewer provides a self-reflexive space for the "*mutual exploration of the interviewee's experiences and perspectives*" (Charmaz & Thornberg, 2021, p. 317). Furthermore, while the studies presented in this thesis were conducted as part of the larger PRIMERA project, the findings from the process evaluation were analysed independently of the RCT findings (which were not available at the time of writing), thereby further ensuring that the outcomes of the process evaluation were not influenced by those of the RCT. While this separation of the RCT and process evaluation data minimised the risk of bias, it was not possible at the time of writing the papers presented in Chapters 4 and 5, to investigate the specifics of the relationship between the RCT outcomes and the process evaluation findings because the RCT findings were not available at that time.

3.5.4 Researcher Reflexivity

Researcher reflexivity is an important element of qualitative research and has been defined as "*a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself*" (Lincoln & Guba, 2005, p. 183). According to Charmaz, Thornberg and Keane (2017), CGT calls for "*strong reflexivity undergirding methodological self-consciousness*" (p. 316) and an openness to all methodological decisions. Thus, reflexivity was essential during the completion of the process evaluation given my own lived experience of PMI and its lasting effects, as well as a recognition on my part, of how personal history can lead to bias and influence outlook. The extent and timing of reflection (e.g. during data collection, developing interview questions, during analysis and/or write up phase) varies across the different variants of GT, but Charmaz's model encourages it (as with the current research) throughout the research process (Charmaz, 2016b; Gentle et al., 2014).

My own lived experience of a parent's mental health disorder during childhood and continuing throughout my adult life, were key factors which encouraged considerable reflexivity across each stage of this research (see Table 3.3), helping me to identify and address potential triggers, vulnerabilities, and/or biases prior to engaging with service users, and particularly those whose experiences most resembled my own (Lyle, 2009). A number of safeguards were put in place to address these. For example, I found myself triggered during a family interview when one child reported feeling "*tired*" as soon as his mother began discussing her illness which regularly involved self-harm. During this interview, I also found myself irritated by the service user's lack of insight/boundaries of the impact of her words on the child (an experience I myself regularly encountered), which left me concerned for that child and other children in the home. In talking through this interview thereafter with the Fieldwork Co-ordinator, a follow-up call was arranged to this family's *FT* practitioner to ensure that the children were being appropriately supported.

Prior to commencing the interviews for **Studies Two** and **Three**, I was also interviewed about my own lived experience of PMI during childhood as part of the retrospective lived experience sub-study which was conducted during Phase Four of the research (not part of this thesis). This provided me with an excellent opportunity to relate to my future interviewees. I recall observing my interviewer's changing facial expressions as I shared my experiences with them. I realised that, while time had dulled my feelings of helplessness, relaying my experience of observing a parent's suicide attempt, substance misuse and domestic violence, was upsetting for the interviewer to hear. This experience was important in shaping my desire to demonstrate empathy and objectivity during all of the interviews and to provide a 'safe space' for each interviewee to emote without fear of my response. Consideration of the power differential was also an important reflective point, especially for interviews with younger family members. Table

3.3 provides further details of the reflections I carried out before, during, and after conducting interviews with families and mental health practitioners for both **Studies Two** and **Three**.

Table 3.3

Relevant Interviewer Experience and Reflections Before, During and After Interviewing Stakeholders

Relevant training/experience prior to and after joining the PRIMERA research team.	Prior to commencing the research	During the interview process	After interviewing stakeholders
First Class honours degree in Psychology completed in 2017. Diploma in Counselling completed in 2007. Certificate in Applied Social Studies completed in 2000. Work experience as a job training manager teaching interview skills (1996-1998). Voluntary work experience working with vulnerable populations (e.g. inner-city youth work, helper on soup kitchen, Early Start assistant). Research experience conducting focus groups as part of a mixed methods research project funded by a Health Research Board summer scholarship award (2016). Lived experience of parental mental	Considered each point of contact with service users and how best to demonstrate empathy and to build rapport. Checked over and edited all documents (i.e. Interview schedules/consent forms) for readability. Prepared age-appropriate interview schedules/consent forms for family members. Reflected on the wording of the interview questions, considering how family members might understand them, and amended accordingly. Completed the *Child First* eLearning programme with Tusla Child and Family Agency (10th May 2018).	Read notes received by the Fieldwork Co-Ordinator from the mental health practitioner (and passed to the author) prior to meeting with families. Dressed appropriately for each meeting. Consciously avoided carrying paperwork into the home (i.e. looked like a casual visitor). Took time to connect-reconnect before commencing questioning (e.g. spent time explaining the research, answering questions and general informal chat about weather etc). Maintained appropriate eye contact throughout the interview process.	Sent a 'thank you' text after each meeting and reassured interviewees that I was happy to answer any questions about data protection, and confidentiality even after recording the interviews. Participants were also reminded again of their right to withdraw from the study. Wrote/recorded detailed personal notes after each interview. Spoke to a PRIMERA team member after each interview to discuss triggers experienced. Contacted mental health practitioner after family interviews requesting additional support as needed. Discussed findings with practitioners after the data were analysed (i.e. during the peer support meetings).

illness in childhood and as an adult. Awareness of my own Johari window (Taylor, 2005). This is a helpful approach for considering personal conscious and unconscious bias by reflecting on self-awareness in areas which are obvious or hidden to us (in this instance as a researcher) and those around us. It is a helpful reminder of the potential for blind spots in our understanding of ourselves and others. Completion of online training in General Data Protection Regulations (14th August 2018). Completion of the Emerging minds *Let's talk about the children* and *Family Talk* online training, prior to meeting families. Completion of an ethics module at Maynooth University in 2018 and completion of a qualitative training workshop on Qualitative Evidence Synthesis (QES) (20th May, 2019).	Obtained Garda clearance on 2nd July 2018.	Scheduled family appointments around service user's time/work/school constraints. Maintained an open-ended, flexible approach. Took time to introduce children to the audio recorder, showing them how it worked. Conducted test runs with children and the recorder so that they could hear how their voice sounded. Adopted a person-centred (Rogers, 1951) approach and considered the Hawthorne effect in advance (Mc Cambridge et al., 2014). Mirrored the preferred language used by each interviewee (e.g. avoided using the term 'bipolar' in one family).	Shared learning from sites at peer supervision meetings.

Reflexivity in qualitative research has sometimes been criticised as inadequate, overindulgent or unnecessary (Gentles et al., 2014). In this study however, I found the process

helpful because of my decades of lived experience of PMI. Consideration of the potential vulnerability of service users prior to each interview also helped me to better consider ways to avoid generating any distress during the interview process. For instance, the use of specific terms such as 'Schizophrenia' or 'Borderline Personality Disorder', as mentioned in earlier chapters, can often compound feelings of stigma, and for that reason, I opted to mirror the terminology and language used by interviewees at all times (MacLachlan et al., 2021). Each service user was also contacted after each interview by the Fieldwork Co-ordinator to 'check-in' with them and address any concerns they may have had (none were raised). The follow-up contact by the Fieldwork Co-ordinator provided an important safety check in the event of any concerns raised by families which related to me, as the interviewer. During the write-up phase, I was also aware of a growing frustration with the barriers faced by the families whom I had interviewed in terms of accessing appropriate, timely and effective support. However, this reflection encouraged me to honour each participant's narrative and unique context during the analyses and write-up phases of the research.

3.6 Conclusion

This chapter outlined, firstly, the constructivist paradigm within which the research reported here, was located, and specifically, the CGT approach employed for the analysis of the process evaluation data described in **Studies Two** and **Three**. Secondly, some key research design, methodological elements underpinning each of the three studies (**Chapters Four**, **Five** and **Six**) were described, alongside some important contextual information on the RCT (and associated activities) from the larger PRIMERA project within which the process evaluation was nested. This chapter concluded with a discussion of some of the overarching ethical and methodological considerations underpinning the research.

Chapter Four

Promoting and implementing family-focused interventions for families with parental mental illness: scoping and installation

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Abstract

Objectives: This paper outlines the findings from the first stage of a research programme called PRIMERA (Promoting Research and Innovation in Mental hEalth seRvices for fAmilies and Children). This programme aims to identify, help implement and evaluate family-focused interventions for families where a parent has a mental illness and promote a 'think family' service delivery agenda in the Republic of Ireland (RoI).

Methods: An initial scoping study was undertaken to: (1) assess the nature and extent of family-focused practice (FFP) in adult (N = 114) and child (N = 69) mental health services in the RoI; (2) review the international literature; and (3) undertake site/service visits to assess readiness for, and inform the implementation of, FFP.

Results: A national Expression of Interest (EoI) call led to 37 written submissions (20% response rate) plus six further requests for involvement from interested community services. Fifteen sites/ services (35%) were included in the research following critical appraisal and consultation. FFP across services/sites was small-scale or non-existent. Following a literature review and other strategic/resource considerations, all sites were invited to deliver the Family Talk (*FT*) intervention; 12 agreed to do so; three sites will deliver other programmes. A series of activities was undertaken by the research team to support early implementation.

Discussion: This first phase of the research provides a critical starting point for promoting, and assessing the development of, FFP in mental health services in the RoI. Some useful generalisable lessons are also identified in terms of building capacity and beginning to change practice in this field.

Keywords: Family-focused practice; family-focused intervention; parental mental illness; 'think family' approach; family mental health; family focused mental health practice

4.1 Background

Current experts in the field of mental health call for a family-focused or two-generational approach when treating an adult with a mental illness who is a parent. Family-focused practice (FFP) for families where a parent has a mental illness, commenced in the 1980s and is now part of several national initiatives in Australia, Finland and Norway (Falkov et al., 2016). FFP targets and supports the 'family unit' rather than just the individual receiving mental health support (Foster et al., 2016) and incorporates an interagency and strengths-based approach as well as some level of partnership between parents and mental health services.

Unlike many other countries (e.g. UK, Sweden, Norway, Finland, Australia), there is a lack of national guidance and service awareness in the Republic of Ireland (RoI), on the need to support families where there is a parental mental illness (PMI) (Grant et al., 2018). While recent policy developments indicate a need for interagency collaboration to promote positive child outcomes (e.g. Better Outcomes, Brighter Futures, 2014), mental health services do not attend to the parental status of adult service users and typically, do not attempt to meet the needs of children in these families (Barnardos, 2014). Current mental health service provision is characterised by: (a) an individualised approach to assessment/treatment; (b) a lack of collaboration between Adult Mental Health Services (AMHS) and Child and Adolescent Mental Health Services (CAMHS); and (c) competency concerns amongst mental health professionals who may feel ill-equipped for undertaking family focused work (Barnardos, 2014). Furthermore, mental health services remain under resourced due to the recent economic recession in the RoI (and elsewhere). For example, the most recent figures indicate that in 2016, AMHS staffing in the community was at 76% of recommended levels, whilst a 2017 review of five community CAMHS teams found staffing at 56% of optimal staffing levels as recommended in the 2006 VfC (HSE, 2016; Mental Health Commission [MHC], 2017). Failures in mental health care are also

frequently highlighted in the national media, particularly in relation to the provision of child mental health services.

A 'Think Family' approach has been adopted in Northern Ireland (NI) since 2009 (Donaghy, 2014, 2016) and whilst a recent evaluation indicated a high level of awareness of FFP among health and social care professionals, service provision was ad hoc and disjointed (Grant et al., 2018). A relatively recent study also compared FFP between two cohorts of registered psychiatric nurses in Ireland and Australia (Grant, 2014; Grant, Goodyear, Maybery, & Reupert, 2016), as well as the impact of organisational and policy-related factors on these practices (Grant & Reupert, 2016). A low level of FFP was reported, particularly among the Irish cohort, with only 15.6% trained in FFP. To date, no study has yet investigated the extent of FFP in adult and child mental health services within the Health Service Executive (HSE) (national health service) in the RoI.

For the first time in an Irish context, a research programme called 'PRIMERA' (**P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies and children) (2017–2021) was established with the following two overarching aims: (1) to identify, help implement and evaluate family-focused interventions for families with PMI; and (2) inform a 'think family' care delivery agenda within mental health services in the RoI.

The current paper describes the initial exploratory phase of the PRIMERA research programme, during which we: (a) conducted a rapid review of the international literature; (b) undertook a national scoping study to identify and appraise the nature and extent of FFP within the HSE in the RoI; (c) conducted (ongoing) visits with selected services/sites to explore site readiness for the implementation of FFP nationally; and (d) supported the early implementation of family-focused interventions across the country.

4.2 Method

Firstly, a rapid review was undertaken during June-August 2017 to critically appraise the literature on the effectiveness of interventions for families with PMI. Several mainstream electronic databases (PubMed, PsychInfo, MEDLINE) were searched using terms such as 'parents with mental illness', 'parents with mental health issues/difficulties', 'family mental health', 'children of parents with mental illness' and 'family-focused mental health practice'. A snowball search strategy was also used to identify key systematic reviews and meta-analyses. Each included review was examined to identify those interventions with the strongest evidence of effectiveness. References of included reviews were also perused (Greenhalgh & Peacock, 2005) together with grey literature (e.g. government reports and pan-European research detailed on the Enter Mental Health website -http://www. entermentalhealth.net/) and expert overviews and policy documents (e.g. Beardslee, Solantaus, Morgan, Gladstone, & Kowalenko, 2012; Social Care Institute for Excellence, 2011 'Think family' framework; and Australian COPMI (Children of Parents with Mental Illness) recovery frameworks.

Secondly, the scoping study involved administering, and collating the responses to, a national Expression of Interest (EoI) call issued by the, then National Director for Mental Health, during August-September 2017, to senior AMHS (N = 114) and CAMHS (N = 69) managers working in the HSE. This involved the use of a proforma which was prepared by the research team in consultation with the PRIMERA steering committee (PSC). Respondents were asked to respond to six open-ended questions requesting them to provide information on their services, including details on their existing/planned family-focused services for families with PMI (see Box 4.1). No quantitative data were collected. Submissions were then critically appraised on the basis of format and content of the programme, target population, and the scale of implementation (see Box 4.2), with follow-up phone-calls and emails undertaken as necessary. The scoping study was restricted to the HSE mental health services because: (a) the research is

funded by the HSE Mental Health Division; and (b) a change in practice is considered most desirable and urgent within formal mental health services.

Thirdly, a series of follow-up site visits subsequently took place following a critical appraisal of all EoI submissions, to ascertain the extent to which services were willing and able to consider FFP implementation.

Box 4.1. *Scoping Questions in the Expression of Interest Call.*

1) Demographic information.
2) Why are you interested in taking part in this research programme?
3) Are any services in your area currently delivering any family-focused services/approaches or following any particular family-focused model?
4) If 'yes, please name and describe these briefly below and then proceed to Question 6.

If 'no'/'don't know', please ignore Question 5 and proceed to Question 6.

5) Do you know of any other similar family-focused services that are currently being implemented in other regions within Ireland?
6) If 'yes', please name and describe these briefly below.

Box 4.2. *Criteria for Appraising Proforma Submissions.*

- Does the intervention address parental mental illness and impact on family?
- What mental health difficulties are targeted in intervention?
- Which members of the family are targeted in intervention?
- Intervention content and format.
- Interagency collaboration/delivery.
- Recovery-oriented/service users involved in co-delivery.
- Outcomes targeted in intervention.
- Evidence base of intervention.
- Site capacity to implement intervention.
- Willingness to engage in the research process.

4.3 Findings

4.3.1 Rapid Review

A large number of effectiveness and policy papers were identified in the rapid review (n = 150). Six systematic reviews of intervention effectiveness were found, involving studies

with sample sizes ranging from 13 to 57 (Bee et al., 2014; Fraser, James, Anderson, Lloyd, & Judd, 2006; Huntsman, 2008; Reupert et al., 2013; Schrank, Moran, Borghi, & Priebe, 2015; Siegenthaler, Munder, & Egger, 2012). The interventions included in reviews, had been evaluated using randomised controlled trials (RCTs), non-controlled trials and qualitative studies, and fell into three main categories: (1) parent-based interventions (involving parent(s), occasionally with infants 0–2 years); (2) peer-support groups for children (7–18 years); and (3) family-based interventions involving both parents and children (5–18 years). We appraised and compared these interventions across several key domains (e.g. target population, content, and outcomes) (see Table 4.1).

The pooled results across reviews indicate positive outcomes overall, for children and parents, albeit based on heterogeneous interventions (e.g. Bee et al., 2014; Siegenthaler et al., 2012). However, there was relatively limited evidence for any single intervention. Our goal was to identify a family intervention which: (a) involved both children and parents; (b) targeted child, parent and family outcomes; (c) was suitable for different mental health diagnoses; (d) targeted children across a wide age range; and (e) was replicable and capable of being implemented within services in the RoI. In this context, Family Talk (FT) emerged as an intervention with a potentially promising evidence base. This is a manualised, family-based (6–8 session) programme for which the evidence (based on several RCTs) indicates post-intervention increases in parent and child understanding of mental health, enhanced family functioning, improved mental health symptoms and greater resilience in both parents and children (e.g. Beardslee et al., 1992, 1997, 2003; Solantaus, Paavonen, Toikka, & Punamäki, 2010). Further information on the FT programme and its benefits, is provided in Box 4.3. A multi-family group (MFG) programme, involving one RCT and longer-term follow-up, was also identified as having generated positive family outcomes (Compas et al., 2009, 2011), but with less evidence to support it.

4.3.2 Assessing Existing Provision

Following the EoI call, 37 submissions/responses were received from services across Ireland (October 2017) (20% response rate), each of which was appraised according to the criteria in Box 4.2. Approximately 40% (16/37) of submissions indicated existing, planned or previously implemented family-focused services to address PMI and its impact on children, whereas the remaining submissions included references to family focused services either for adults with mental illness (9/37; 24%) or for children with mental health difficulties (12/37; 32%).

Following further interrogation and follow-up of all submissions (e.g. by means of phone calls and emails with relevant contact persons), 9 sites were identified as potentially promising.

Table 4.1

Comparison of Identified Family-focused Interventions Across Key Domains

Category	Family-based interventions	Child peer support	Parent-based interventions
Participants **Age of the child**	Parent and children 5-18 years generally, one intervention included children aged 4-7 years.	Children 7-18 years	Parent(s), sometimes infants Generally, 0–2 years; a few interventions with children aged 3–16 years.
Mental illness (MI)	Parents have depression, anxiety, bipolar, or substance abuse. Less robust evidence for schizophrenia/psychosis or personality disorders. Generally, children are not diagnosed with a MI.	Children typically are not diagnosed with a MI. Their parents typically have affective disorders; a few studies included parents with psychosis.	Parents generally have depression, but may also have anxiety, substance abuse, personality disorders and psychosis. Children are not diagnosed with a MI.
Format/setting	Primarily community setting individual and group-based format.	Community setting – group-based format.	Primarily community setting – individual or

	Occasionally inpatient setting.		group format. Occasionally inpatient setting.
Components	Varies among interventions. Psychoeducation, family communication, CBT, parenting skills, crisis plans.	Psychoeducation and CBT for child resiliency and peer support.	Varies among interventions. Psychotherapy for postnatal depression, parent skills.
Outcomes assessed	Child understanding and insight, resiliency, child internalising and externalising behaviours. Parental mental health and resiliency; family functioning and communication.	Child understanding and insight, child internalising and externalising behaviours.	Generally maternal depression. Occasionally parenting behaviours. In a few instances, child internalising and externalising behaviours.
Evidence base summary	Collectively, a good evidence base for improving child outcomes. No single family-based intervention has a very robust evidence base. Family Talk has most RCT evaluations and may be a promising intervention.	Collectively, quite weak given the number of uncontrolled studies. However, one-off RCTs of particular models indicate positive short-term child outcomes.	Collectively, good evidence for improving maternal depression and parenting behaviours. Little report on child outcomes. However, one-off RCTs of particular models suggest some impact on child outcomes.

These comprised of a mix of settings/services (community, inpatient) which were working with several target groups (parent, child and/or family) across a range of mental health diagnoses and different delivery formats (group, individual). These sites were subsequently included in a series of 'fact-finding' site visits undertaken in January-February 2018, during which the research team met with key staff to clarify their service elements/approaches and ascertain their capacity and willingness to implement FFP within their service. The questions outlined in Box 4.2 were used to guide the discussions and the information obtained was

entirely qualitative in nature, based on detailed notes taken by the research team. The 'results' showed that implementation was either non-existent (3 sites), in the planning stages (4 sites), or only small-scale (e.g. 5–10 families per year) (2 sites). For example, one site was planning to deliver systemic family therapy (SFT) whilst another was preparing to deliver a Multi-Family Group (MFG) programme. The latter has a strong evidence base in family mental health (McFarlane, 2016), although it is not specific to families with PMI. Systemic family therapy (SFT) is also underpinned by some evidence of effectiveness with regard to adults and children with a range of mental health problems (Carr, 2009, 2014).

There was a very high level of enthusiasm amongst all site personnel with regard to their willingness to be involved in a national study to promote and implement FFP. Most 'lead applicants' were social workers (80%), followed by family therapists (8%), psychologists (8%) and clinical nurse specialists (4%). However, clinicians reported several challenges in their experience in delivering/proposing to deliver FFP including: (1) low managerial priority reflected in the poor collaboration between AMHS and CAMHS; (2) a lack of resources to deliver FFP; and (3) difficulties in identifying and engaging families.

4.3.3 Adopting an Evidence-based Approach

While the cross-site enthusiasm for FFP was encouraging, the under-developed and small-scale nature of existing provision presented a challenge for the research team in terms of the robustness of any subsequent evaluation and a collective desire to generate interest and momentum in FFP across Ireland. Therefore, it was decided by the research team, in consultation with the PSC, that resources could be used more strategically and effectively to identify, implement and evaluate one model that was evidence-based, replicable and capable of being implemented across several sites in Ireland. The information gathered from the rapid review and the site visits, suggested that FT was the most promising intervention for the reasons outlined earlier in Box 4.3.

All 9 sites were subsequently invited to consider delivering this programme, 6 of whom agreed to do so in late March 2018. As outlined above, three sites were already planning their own interventions. Throughout 2018, word-of-mouth about Family Talk and the PRIMERA research spread, to the extent that six additional services/sites around the country contacted the research team and asked to be involved in the delivery and evaluation of FT (now 12 sites in total). These sites include HSE adult, child, and primary care mental health services, and several non-HSE organisations (e.g. Tusla (national Child and Family Agency), Saint John of God (Hospitaller Ministries), and Children and Young Persons' Services Committees). It was agreed by the PSC that non-HSE organisations could be involved in the research, in the interests of promoting inter-agency collaboration to support these families.

4.3.4 Supporting Installation and Early Implementation

Initially, a small number of key staff (typically social workers) in each site had expressed an interest in delivering FT. However, given the lack of collaboration between AMHS and CAMHS in the RoI – and in order to secure the buy-in and support of management and colleagues – the research team was required (and requested) to 'make a case' to each multidisciplinary team (MDT) in each site according to their locus of care (e.g. adult in AMHS, children in CAMHS and Tusla) and to indicate the potential benefits of FT for their target population.

Box 4.3. ***Benefits and Components of the Family Talk Intervention.***

Benefits of the Family Talk Intervention

- Incorporates a 'whole family' evidence-based approach
- Can be used with a range of mental health problems
- Freely available online training and resources
- Scope for flexibility in adding other relevant elements (e.g. additional CBT skills, crisis plan) Cross-site guidance and support
- Guidance and support available from the programme developer
- Involvement of many sites allows for a more robust evaluation

Components of Family Talk

Week 1: Clinician meets with parent(s) and takes a family history
Week 2: Providing psychoeducation & discussing the family story with parents

Week 3: Meeting with the children
Week 4: Meeting with parents to discuss a combined family meeting
Week 5: Family meeting with parent(s) and child(ren) together
Week 6: Clinician follows up with parent(s) after one week
Week 7: Longer term follow-up at 3–6 months with parent(s)

In adult services, we emphasised the benefits of FFP in helping to promote the recovery of the adult service-user. Therefore, supporting parents in their parenting role can help with their mental health, with additional benefits for the whole family who may, in turn, be involved in supporting the recovery of the parent (Falkov et al., 2016). We also emphasised the benefits of co-delivering *FT* with CAMHS/Tusla in terms of the experience of these organisations in working with families and children. With regard to sites where AMHS staff were already adopting a family-focused approach with some of their service users, we explained that *FT* complemented rather than duplicated their existing work because it specifically targets PMI and incorporates resources for working with both parents and children. Overall, the process of securing buy-in took approximately four months with considerable variation across sites. For example, the process of securing buy-in from CAMHS and Tusla was straightforward as they already believed, and understood, that supporting families with PMI can benefit a child's wellbeing in the short and longer term (Siegenthaler et al., 2012).

4.3.5 Equipping Staff Teams for FT Implementation

We subsequently initiated and supported a series of activities in 2018 to facilitate early *FT* implementation across participating sites, as outlined below.

- Project leads in each site recruited staff to complete the *FT* e-learning training programme.
- Some sites organised awareness raising workshops.
- Regular peer supervision has been put in place to support *FT* delivery.
- The research team developed a complementary eLearning resource hub (www.cmhcr.eu/primera) to: (1) assist AMHS staff in working with children and families; (2) support CAMHS/Tusla staff in working with parents with mental health issues; and (3) provide guidance on other elements of implementation, such as how to recruit families to *FT* (Box 4.4). This was an important element in securing buy-in from participating sites.
- The research team – in consultation with site personnel – drafted *FT* information brochures and posters (as well as research pamphlets) for families and clinicians.

- The research team met, and liaised, with key site personnel to discuss talking to families about *FT* and the PRIMERA research, whilst also providing them with supporting documentation.

Importantly, the research team also organised and facilitated access to several free FFP related events in order to promote learning and collaboration among relevant stakeholders. In particular, we organised and hosted a day-long masterclass in September 2018 (with Dr Adrian Falkov), which was widely attended by our site personnel (clinicians and management), as well as other services interested in FFP, service users, funders, senior HSE managers, national media, and researchers. The research team have also attended, and presented at, a number of local and national conferences and other related events (e.g. the Oireachtas Committee Meeting on the future of mental health; symposium in Belfast on 'Health and Social Care Professionals' Family Focused Practice with Parents who have Mental Illness, their Children and Families in Northern Ireland; and the Policy Forum for priorities in mental health in Ireland).

Box 4.4 ***eLearning Hub for PRIMERA Sites.***
(1) **Family** Talk & additions
i. *FT* training manuals
ii. Access to eLearning *FT* training
iii. Examples of crisis care plans (recommended for inclusion)
(2) Training needs
i. How to talk & work with children
ii. Psychoeducation of mental health disorders
iii. Explanation of recovery practices
(3) Recruitment considerations
i. Engaging fathers ii. Identifying & engaging families

4.3.6 Achieving Buy-in to the Research

It was also necessary to secure buy-in to the research and evaluation of *FT*. Our proposed design – incorporating an RCT with an embedded process evaluation and economic appraisal – was discussed at length and agreed with stakeholders. The other three smaller interventions will be evaluated separately using a mix of questionnaires and interviews. Clinicians and managers in all participating sites understood the importance of producing robust evidence to persuade funders to recognise and support FFP and as a basis for developing

national guidance in this area. The evaluation of *FT* will involve the identification and recruitment of approximately 80–100 families who will be required to meet a number of inclusion criteria (see Box 4.5) and who will be assessed at baseline, 6- and 12-month follow-ups along a number of dimensions, including child psychosocial functioning, family functioning, parental mental health, parent and child understanding of mental illness, parent and child resilience, and partner wellbeing.

4.3.7 Raising Public Awareness

In September 2018, the research team pitched the PRIMERA 'story' to the media (with the support of the university Communications Office) in order to raise public awareness of the need for FFP. We successfully attracted considerable media coverage from national radio, newspaper and social media platforms. Two national broadsheets (the Irish Examiner (6/09/2018) and The Irish Times (18/09/2018) carried articles on the research, with the latter producing a two-page feature. These were later circulated on social media platforms on Facebook, Twitter and relevant websites, with a potential readership of tens of thousands. The newspaper articles also generated interview requests from the national public service broadcaster (Raidió Teilifís Éireann (RTE)) on two (peak-time) programmes with over two million weekly listeners. The HSE communications office has also published an article in its regular staff magazine (available via e-zine to 100,000 HSE staff and 21,000 physical copies printed 4 times a year), whilst a recent article was also published in the Hospital Professional News (HPN), a professional journal circulated to all hospitals (public and private) in Ireland (10–12k physical copies and online version). We are also currently working with the HSE Communications Office to raise awareness of the FFP work in each site by harnessing local media.

Box 4.5 ***Family Talk Inclusion/Exclusion Criteria.***

Inclusion criteria

(a) Parent (over 18 years) with a child(ren) aged 5–18 years, who is attending AMHS

OR

(a) Parent(s) with a mental illness episode in the last 18 months and who had been under the care of a psychiatrist or MDT

OR

(b) Parent(s) currently attending a GP, psychologist, therapist or counsellor for mental health difficulties

Exclusion criteria

(a) Family/parent in crisis
(b) Active substance abuse/psychosis such that they cannot engage with intervention or research
(c) Parent in hospital
(d) Current acrimonious parental relationship (e.g. parental separation)
(e) Serious child protection issues

An outline of this phase of the research and a timeline of key milestones are shown in Figures 4.1 and 4.2 respectively.

4.4 Discussion

This initial exploratory phase of the research demonstrated that FFP in HSE mental health services in the RoI is extremely under-developed. While a response rate of 20% (37/183 HSE sites) indicates some awareness of the importance of using FFP to support parents with mental illness, the subsequent appraisal of submissions revealed a very low level of service provision. These findings are similar to those reported by Grant et al. (2016) in which a low level of FFP was evident among an Irish cohort of registered psychiatric nurses when compared to an Australian sample. Given the lack of a policy framework in the RoI to support families where a parent has mental illness (Barnardos, 2014), it is perhaps unsurprising that overburdened mental health services place little priority on FFP for this population.

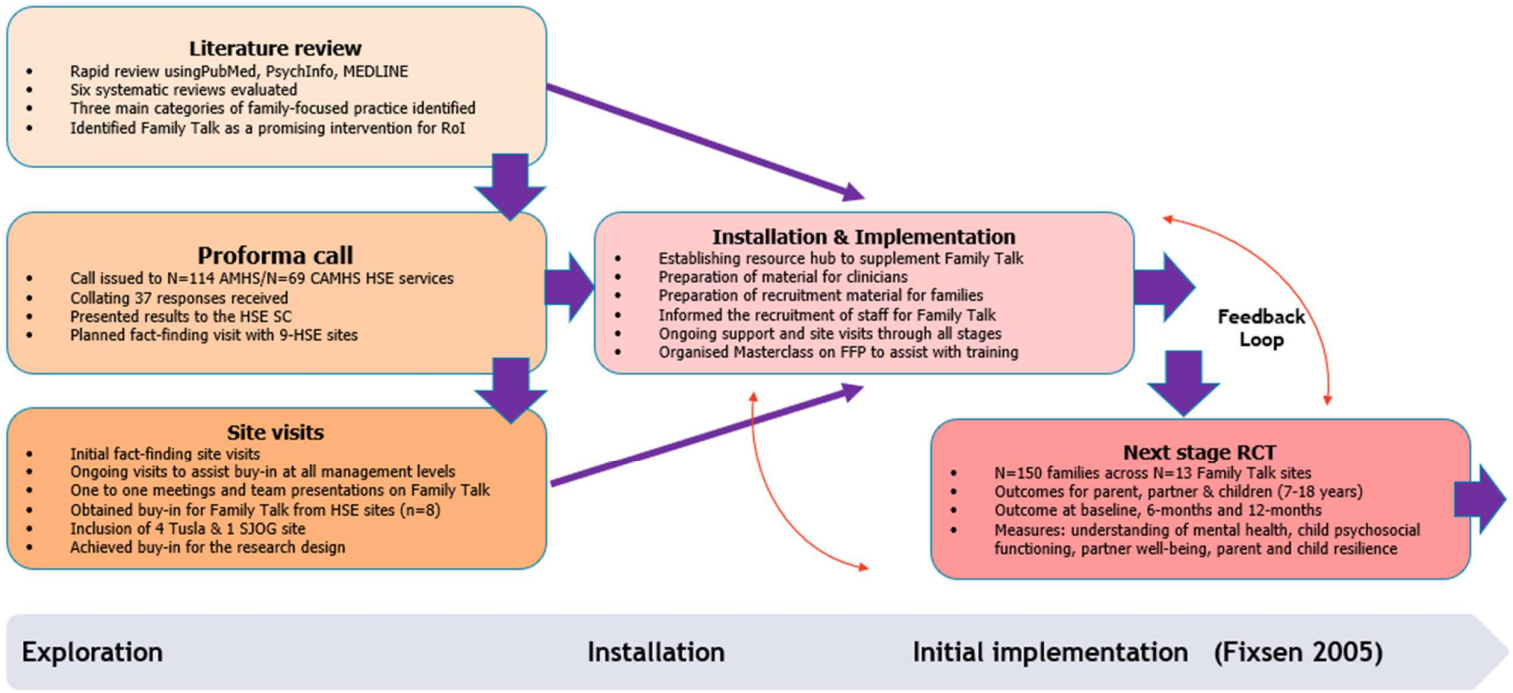
Nevertheless, this study showed that there was a significant appetite among clinicians to build capacity in FFP despite the challenges in so doing. Following a series of selected site visits and

based on evidential, strategic and resource considerations, there was a considerable level of buy-in to both the *FT* intervention and to the evaluation. The use of an evidence-based and freely available intervention should help to reduce the time involved for sites in developing FFP, whilst avoiding the kind of duplication that can often occur within, 'siloed', mental health services (MHR, 2012).

Furthermore, we know from implementation science that evidence-based interventions will not be effective if not properly implemented (Elliott & Mihalic, 2004; Fixsen, Naoom, Blase, & Friedman, 2005). Therefore, the research team invested considerable time and effort in ensuring that the factors required for successful implementation, were in place (insofar as possible) including: securing buy-in at local and higher management levels; developing a resource hub to assist implementation (e.g. guidance how to recruit and engage with families); helping sites to identify staff to deliver *FT*; raising awareness about referrals and cross-agency collaboration in delivering *FT*; producing recruitment materials; and utilising local and national media to raise public/service awareness about the need to support FFP. As noted by Fixsen et al. (2005), these kinds of 'implementation drivers' are essential for the successful introduction of new working practices. For example, identifying and supporting suitable clinicians is one of the key components in installing an evidence-based intervention within existing services. All of these activities should also help to promote a 'think family' care delivery agenda in the RoI. At the same time, however, the complexity and scale of the task that lies ahead should be acknowledged because it can often take years to effect a systems-wide change in practice (Falkov et al., 2016), and not least within the, often rigid and inflexible, structures of a national health system.

Figure 4.1

PRIMERA Research Programme: preparatory phase



The overall aim of the PRIMERA research is to promote, implement and evaluate FFP in the RoI, with a specific emphasis on evaluating the implementation, clinical and cost-effectiveness of *FT*. A robust evidence base should help to persuade funders to support FFP and to develop a national framework for working with families affected by PMI. However, we are aware, based on the experience of other countries, that while an evidence base and a policy framework are important, they are not necessarily sufficient to change practice (Falkov et al., 2016).

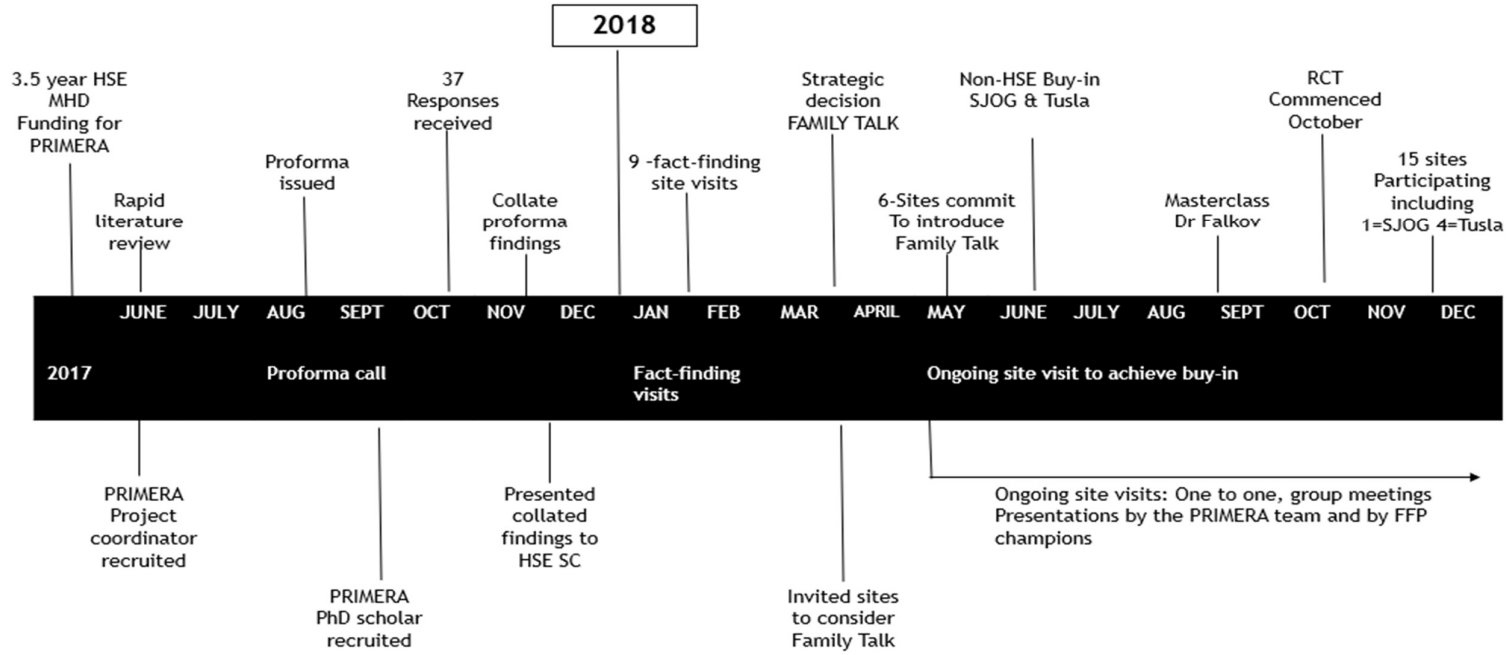
For instance, policy and legislative changes in the UK, Northern Ireland and Norway have increased service awareness of a 'think family' approach, but this has not necessarily translated into better 'on-the-ground' family-focused services (Grant et al., 2018; Lauritzen, Reedtz, Van Doesum, & Martinussen, 2014). Once again, this highlights the many challenges of implementing and routinely embedding FFP within mental health services in the community. For instance, 'Think Family' in NI joined with the larger UK Social Care Institute for Excellence (SCIE) initiative to inform an implementation plan to engage service users, review screening and assessment methodology and to develop an adult and child partnership protocol to assist cross agency work (Donaghy, 2014). A recent evaluation, conducted to assess the levels of FFP among health and social care professionals (n = 868) across all five NI Trusts, reported a good awareness of the Think Family initiative (Grant et al., 2018). However, despite the fact that one third of those surveyed, reported working with families impacted by parental illness on a daily basis (60% on a weekly or monthly basis), low levels of FFP were identified and service provision was somewhat disjointed (Grant et al., 2018).

Norway also introduced legislative changes in 2010 requiring the mandatory identification and assessment of children living in families where a parent is hospitalised with mental health difficulties and substance abuse. A recent report found that while identification of this 'hidden' population had increased, new practices were not yet consistent across all

disciplines (Lauritzen et al., 2014). All of these indicate that the implementation of any new practice is a non-linear, recursive process which often requires considerable time (Fixsen et al., 2005).

Figure 4.2

PRIMERA Preparatory Stage Timeline



Given these systemic difficulties, it is not surprising that the RoI lags behind international counterparts (Reupert & Maybery, 2016). Australia, as world leaders, introduced FFP 25 years ago (Grant et al., 2018), while specialist service and professional training in mental health has also been introduced elsewhere (Beardslee, Solantaus, Morgan, Gladstone, & Kowalenko, 2012; Lauritzen et al., 2014; Solantaus & Toikka, 2006). For instance, the concept of a 'whole family' policy for PMI was introduced in the UK in 2007 (Evans & Fowler, 2008).

Consequently, this research programme has adopted both a bottom-up and top-down approach to developing FFP in the RoI. The bottom-up element has involved investing in the early implementation of FFP and monitoring implementation throughout the lifetime of the research, whilst the top-down aspect has entailed assessing the evidence, liaising with decision makers/other key stakeholders and, in the future, informing and helping to develop national guidance/policies. Thus, the current development of FFP in the RoI has, uniquely, been very much research-led and informed, but undertaken in close collaboration with stakeholders at all levels. Experts in the field endorse the benefits of policy maker-researcher-service-provider collaborations in creating and sustaining change, although challenges remain (Nicholson et al., 2015). Recently, Falkov was quoted as saying that it typically takes at least five years of awareness raising before practice changes, but that 'what is happening in the Republic [of Ireland] is a much quicker move from awareness into action' (2018, Irish Times). Thus, the evaluation of *FT* (and the three other smaller interventions) is an important first step in building awareness and capacity in an attempt to ultimately change practice within the Irish mental health (and other) services in Ireland. However, much more will be needed. For example, complementary supports/activities could include child peer groups, working with parents alone (especially with regard to younger children), and raising service and public awareness of FFP.

4.4.1 Strengths and Limitations

This is the first study to investigate existing FFP among statutory adult and child mental health services in the RoI. This began with a review of the evidence base in order to inform the

strategic decision to invite sites to implement Family Talk, thereby avoiding duplication and expediting delivery of FFP. Buy-in was successfully (and relatively quickly) secured within 12 sites across the RoI to deliver *FT* using a range of 'top-down' and 'bottom-up' levers (Nicholson et al., 2015), whilst we believe there is also merit in evaluating the work of the three other participating sites. In line with implementation science (Fixsen et al., 2005), considerable time and resources were invested by the research team in facilitating and supporting sites in the cross-agency implementation of *FT*. Lastly, *FT* will be evaluated using an RCT design with an embedded process evaluation and economic appraisal, all of which are relatively rare in this field (Bee et al., 2014).

However, the study was (necessarily) limited in its focus only on HSE AMHS and CAMHS services, thereby potentially excluding existing FFP within Tusla and the community and voluntary sector. While some Tusla and non-HSE sites later became involved in the study, this was more by accident than design. In addition, the rapid review lacks the rigour of a systematic or full rapid review, but it was not possible within the study timeframe to conduct a more detailed review. Nonetheless, we have identified an evidence-based intervention (with the assistance of the programme designer, William Beardslee) that has proven to be attractive and intuitively appealing to the many stakeholders with whom we are working.

4.5 Conclusion

This research is the first of its kind in RoI to address the important issue of PMI and its impact on children and young people within HSE services. The scoping study showed a marked lack of FFP, but also, encouragingly, strong multi-site support and a desire amongst frontline and managerial staff to change the status quo. We successfully established a research-led collaboration – in the spirit of engaged research – with service providers, managers and policy makers to encourage, support and facilitate 15 sites across Ireland to implement cross-agency FFP, 12 of which will be involved in an evaluation of *FT*.

The staff and agencies across the 12 *FT* sites have agreed to: undertake the 10-hour online training; arrange additional MDT and peer-supervision meetings to support delivery; work through their existing waitlists to identify eligible families; liaise/work with other agencies; deliver the *FT* to eligible families; and to do this whilst already carrying heavy workloads. This amply demonstrates a clear recognition of the importance of this work and a strong commitment to tackle the needs of these vulnerable families in the RoI, despite the challenges that may lie ahead. With an estimated 30–40 clinicians now engaging in family-focused training, liaison and delivery, the work of building capacity has commenced. Our preparatory work provides a critical starting point and hopefully a strong basis for developing FFP in the RoI, while yielding key generalisable lessons to inform 'think family' research, practice and policy in Ireland and elsewhere.

References for Chapter Four (Study One) can be found in Appendix CC

Chapter Five

The *Family Talk* Programme in Ireland: A Qualitative Analysis of the Experiences of Families With Parental Mental Illness

Mulligan, C., Furlong, M., McGarr, S., O'Connor, S., & McGilloway, S. (2021). The Family Talk programme in Ireland: A qualitative analysis of the experiences of families with parental mental illness. *Frontiers in Psychiatry*, *12*, 783189.

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Abstract

Background: Parental mental illness is common, costly, can lead to children developing mental disorders and impaired lifetime outcomes, and places a substantial burden on caregiving partners. *Family Talk* (*FT*) is a widely implemented, 7-session, whole-family programme, with promising evidence of effectiveness in targeting the intergenerational transmission of mental illness. However, to date, very little qualitative research of family experiences of *FT* has been undertaken. The objectives of this study were to: (1) investigate the experiences of families attending *FT*; and (2) explore the key facilitators and barriers to engagement in mainstream mental health settings.

Methods: This study was nested within a randomised controlled trial (RCT) of *Family Talk* [*N*= 86 families (139 parents, 221 children)] implemented in 15 adult, child and primary care mental health sites in Ireland. Semi-structured interviews were conducted with a purposive sample of 45 participants, including 23 parents with mental illness (PMI), 7 partners and 15 children/young people aged 9 to 18 years. Interview data were transcribed verbatim and analysed using constructivist grounded theory.

Results: Over two thirds of families across sites reported substantial benefits from participation in *FT*, including reduced stigma, giving children and partners a voice, increased service-user confidence, and improved family communication/relationships. Key facilitators identified by families included: programme delivery by a competent, non-judgmental clinician; the whole-family approach; and family readiness to engage. Barriers to engagement included stigma, family crises/relapse, service constraints, impact of COVID-19, and a need for further child, family and follow-up sessions/supports.

Conclusion: This study is the first qualitative analysis of family experiences of *FT* to be conducted within the context of an RCT and national programme to introduce family-focused practise for families with PMI. The findings illustrate that *FT* is beneficial across cultural/policy contexts, different mental disorders and can be implemented across adult and child mental

health settings, including children with existing mental health challenges. Key barriers and facilitators to implementation were identified by families, all of which should help to inform the future implementation of *FT*, and other similar interventions, both in Ireland and elsewhere.

Keywords: children, COPMI, Family Talk, mental health, mental disorder, mental illness, parents, qualitative research

5.1 Introduction

It is estimated that 23% of all families have at least one parent who has, or had, a mental illness; this has been shown to increase the risk of children developing a mental disorder during their lifetime (range 41 to 77%), whilst multiplying five-fold their utilisation of health and social services, and placing a substantial emotional, financial and parenting burden on caregiving partners (1–3). In the Republic of Ireland (RoI), 20% of adults experience a mental health illness—the third highest incidence across 36 countries in Europe—costing the Irish state €11 billion per year (4). Furthermore, it is estimated that 280,000 children in the RoI are dependent on parents who have a mental illness (5).

The transmission of risk from parents to children involves a complex interplay of genetic, prenatal, family and environmental/social influences and is significantly mediated by the impact of parental symptoms on parent-child interactions (e.g., insensitive and erratic attunement) (2). Worryingly, these vulnerable families are often not identified or supported by mental health professionals in the RoI, or in other jurisdictions, due to: a lack of policy/practise guidance; little or no collaboration between Adult Mental Health Services (AMHS) and Child and Adolescent Mental Health Services (CAMHS); an individualised, crisis-oriented approach to assessment/treatment; competency and confidentiality concerns amongst mental health professionals who may feel ill-equipped to undertake family work; and parental stigma/fear of social services and losing custody of their children (6, 7).

Although the prevalence and burden of parental mental illness (PMI) is a cause for public concern, there is increasing evidence that integrated prevention and early intervention family-focused programmes/practise (FFPs) can help decrease the risk of developing mental disorders for children by up to 40% (8) and reduce referrals to child protection services (9). The *Family Talk* programme, in particular, has been identified in several systematic reviews (8, 10, 11) as a key intervention with promising evidence of effectiveness in improving parent and child

understanding of mental illness and child internalising symptoms (12–16), with one study indicating enhanced family functioning and parental mental health recovery 4.5 years later (14).

Family Talk (*FT*) was developed by William Beardslee and colleagues in the USA in the 1980's and is a manualised, 7-session, strengths-based, psycho-educational, whole-family approach designed to enhance family understanding and communication about parental mental illness, improve family interpersonal relationships, and promote family resilience and utilisation of social supports (12). The intervention involves a clinician meeting with each individual family, i.e. with parents (sessions 1, 2, 4, 6, 7), with each child individually (session 3), and with the whole family (session 4) (see Figure 5.1). Sessions typically last 60–90 min. The current evidence base for *FT* is limited by the small number of RCTs conducted to date and within only three countries (USA, Finland, Germany), generally small sample sizes, and mixed support for effectiveness in improving child externalising symptoms, parental mental health and family functioning (14, 15, 17, 18).

Due to its small but growing evidence base, *FT* has been implemented in recent years in several countries to support families where a parent has mental illness [e.g., the USA (Chicago), Costa Rica, Colombia, the Netherlands, Greece, Scandinavia (Norway, Sweden, Finland), Iceland, and Australia (Victoria)] (19). Internationally, there has been a growing trend, informed by the United Nations Convention on the Rights of the Child, to introduce legislation mandating support for children when a parent suffers from serious mental illness [e.g., the Swedish Health and Medical Service Act (20, 21)]. This legislation means that psychiatric services are obliged to take patient's children into consideration, including meeting their needs for information and support, and discussing issues of parenthood and the children's well-being (21). However, the continuing stigma around mental illness, especially as a parent, coupled with service provider constraints, often means that these policies are not implemented in practise (22).

Within the Irish context, whilst national practise guidelines have recently re-oriented toward a recovery,[22] strengths-based model of care that recognises the needs of family carers and the value of family-focused mental health practise (23–25), there is no specific policy/practise guidance to support families with PMI in the RoI. Consequently, the national Health Service Executive (HSE) provided funding for the current research programme— called "PRIMERA" (**P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies and children), the primary aims of which were to: (1) identify/develop, implement, and evaluate family-focused interventions for families with PMI; and (2) inform a "think family" care delivery agenda within mental health services in Ireland. Following an initial scoping study that demonstrated a lack of structured support for this population in the RoI, it was agreed with stakeholders that clinicians across 15 AMHS, CAMHS and child protection/welfare service sites would deliver *Family Talk* as part of a randomised controlled trial (RCT), with embedded qualitative and economic analyses (6, 26). *FT* was chosen for implementation as it: incorporates a structured "whole family" evidence-based approach; can be used with a range of mental disorders; provided freely available and high quality online training/resources[23]; and was replicable and capable of being implemented across sites in Ireland (6).

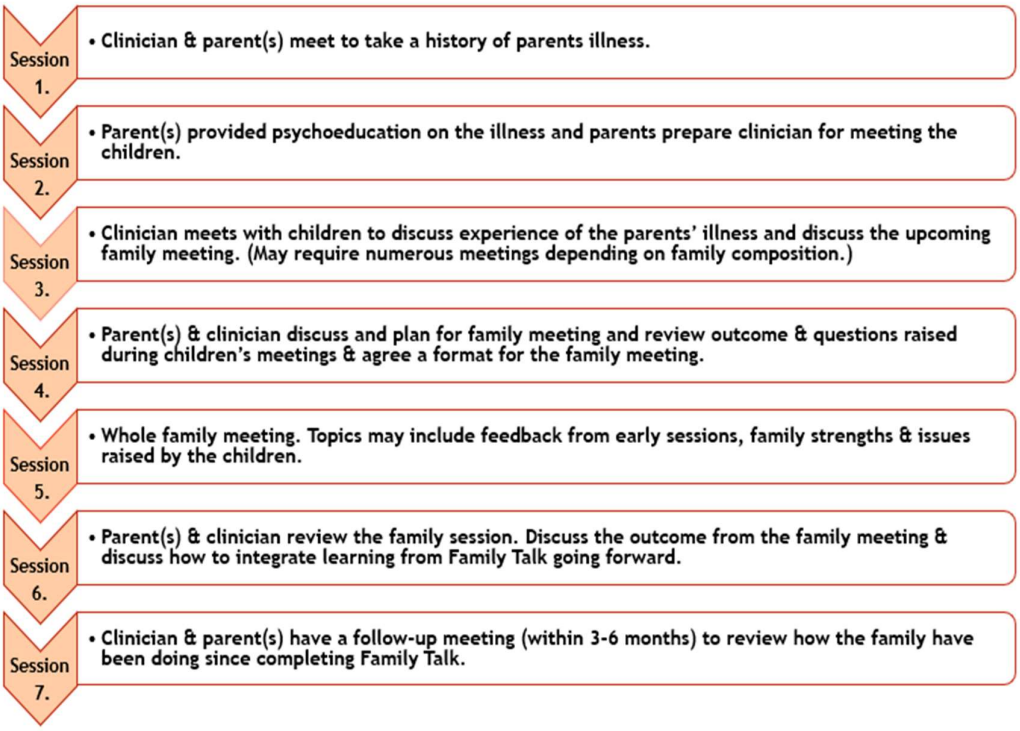
Despite the growing number of trial evaluations of *FT*, very few qualitative studies to date have investigated the experiences of families in attending *FT*. This means that little is known about the barriers and facilitators of change, intervention characteristics or contextual factors that may influence implementation and trial outcomes, particularly when delivered in real-world service settings (27). Indeed, the voices of service users, their families and particularly children, are rarely heard in controlled evaluations of FFPs (10, 28). Previously, it

[22] The approach argues against just treating or managing symptoms but focusing on building the resilience of people with mental illness and a change in outlook that is related to leading a meaningful, purposeful life, with or without ongoing episodes of illness (23).
[23] http://emergingminds.com.au/online-course/family-focus

has been found that children may have a different perspective on "what helps" compared to parents and mental health practitioners (29). In addition, partners of service users have reported feeling uninvolved in research, which compounds their experience of feeling unsupported in their care burden by mental health services (30, 31). Thus, eliciting the views of children and other family members regarding *FT* delivery is important for informing the future development and refinement of this, and other similar, programmes.

Figure 5.1

Family Talk Sessions



Five qualitative studies eliciting family experiences of *FT* have been conducted, to date, all undertaken in Sweden, three within outpatient psychiatric settings (32–34), one within a substance misuse clinic (35), and another in an open care psychosis unit (36). With regard to the last of these, a companion study of clinician reports of family experiences of *FT* was also conducted (37). Table 5.1 summarises the participant characteristics across these studies. Collectively, the findings from these studies from both parents and children show that: the

silence around mental illness in their home had been broken, they had greater understanding of mental illness, and more open family communication and closer relationships, although the level of improvements varied across and within families (32–36). Service-user parents felt more equipped and empowered in their parenting role and children expressed relief from fears, less monitoring of their parents, less care work in the home, and being able to spend more time with friends and other interests (33, 35, 37).

Arguably, these findings are potentially biased in that they did not interview families who refused to attend or disengaged from the programme. High rates of refusal and attrition have been noted elsewhere, often due to competing needs for daily survival and fear of judgement (15, 37). A limited range of informants (e.g., mostly PMIs with depression, limited data from partners or those who disengage from *FT*), small sample sizes, and an overall lack of cultural diversity, underscore the need for qualitative analyses to be undertaken across a wider variety of settings and contexts. For instance, *FT* is not always delivered in countries with specific policy/practise guidance for this population.

This qualitative study was nested within an RCT of the *Family Talk* intervention in Ireland for families with parental mental illness and children aged 5–18 years; the aim of the RCT was to assess the nature and extent of any pre-post intervention changes in child and family psychosocial functioning (26) and data analysis is currently underway. The objectives of the current study were to: (1) investigate the experiences of families attending *FT*; and (2) explore the processes of change, contextual factors or intervention characteristics that may influence trial outcomes in mainstream mental health settings (26).

Table 5.1

Qualitative Studies of Family Talk

References	Cohort Interviewed	Recruitment Agency	Parental Diagnosis	Methods & Analysis	Country
Pihkala et al. (32)	10 service-user parents (SUPs)	Adult psychiatry	Depression	Qualitative interviews, grounded theory	Sweden
Pihkala et al. (33)	14 children from 9 families, aged 6-17 yrs.	General psychiatry	6 depression, 1 psychosis, 1 anxiety and ADHD, 1 with PTSD	Qualitative interviews, content analysis	Sweden
Pihkala et al. (34)	17 SUPs & 8 partners from 18 families	General psychiatry	11 depression, 2 personality disorder, 2 bipolar, 1 anxiety and ADHD, 1 psychosis and PTSD	Qualitative interviews, grounded theory	Sweden
Pihkala et al. (35)	7 SUPs, 7 partners & 10 children, aged 8-15 yrs.	Clinic for substance use disorder	All 7 parents diagnosed with substance misuse comorbid with depression, anxiety and/or bipolar disorder	Qualitative interviews, content analysis	Sweden
Strand and Meyersson (36)	8 SUPs & 7 children, aged 8-15 yrs.	Open care psychosis units	4 schizophrenia and 4 schizoaffective disorder	Qualitative interviews, content analysis	Sweden
Strand and Rudolfsson (37)	11 *Family Talk* clinicians	Open care psychosis units	Parental psychosis	Qualitative interviews, thematic analysis	Sweden

Notes. ADHD, attention deficit hyperactivity disorder; PTSD, post-traumatic stress disorder; SUP, Service-user parent

5.2 Methods

5.2.1 Participants and Settings

The larger RCT included 86 families (139 parents, 221 children) in 15 sites across the RoI, involving adult, child, and primary care mental health services, and Tusla child protection services (26). Families (parents and children aged 5–18 years) were recruited by clinicians in each site from their existing waiting lists, and written informed consent/assent was obtained for their participation in the research (26). *FT* was delivered in a mental health outpatient clinic and/or in the home by a mental health professional, typically a social care worker, social worker, or psychologist. Families were eligible where a parent had a formally diagnosed mental disorder, with 80% of service-users attending AMHS for various mental disorders and 20% receiving antidepressant medication or primary care psychological support under the governance of a General Practitioner (26). Due to the high risk of intergenerational transmission of mental disorders (2), and a desire among stakeholders to increase family-focused collaboration between traditionally segregated adult (AMHS) and child mental health services (CAMHS) (6), we included families where children attended CAMHS or primary care services for mental health issues, as well as families where children were not involved with mental health services (26).

Participants were block randomised, on a 2:1 ratio, to the *FT* intervention (n = 56) or to a treatment as usual control group (n = 30). Assessments were carried out at baseline and at six-month follow-up periods. At six-month follow-up, attrition was 37%, the rate of which doubled due to the impact of the COVID19 lockdown restrictions (22.8 vs. 45%). More details on study parameters can be seen in the study protocol (26). The flow of participants from recruitment through the RCT to the qualitative studies is shown in Figure 5.2.

7	AMHS	Female	Divorced	Schizophrenia	52	None identified	3	Not in services	1:1 with PM	Left after 3 sessions
8	CAMHS	Female	Married	Depression	48	Depression symptoms	3	Eldest in CAMHS with depression and youngest with behavioural difficulties	1:1 with eldest child; group interview with other family members	Completed FT
9	AMHS	Female	Married	Depression	36	None identified	3	Eldest in CAMHS, feeling suicidal	1:1 with PMI	Completed FT
10	CAMHS	Female	Married	Anxiety/Depression	40	None identified	2	Eldest in CAMHS with depression	1:1 with both parents & eldest child	Completed FT
11	CAMHS	Female	Widowed	Depression	37	N/A	3	Eldest in CAMHS, suicidal	1:1 with PMI	Did not start FT
12	AMHS	Male	Separate	Depression	43	N/A	1	Not in services	Dyad with father & son	Completed FT
13	CAMHS	Female	Single parent	Bipolar/ADHD	39	N/A	2	Eldest in CAMHS for stress/ADHD	1:1 with PM	Completed FT
14	CAMHS	Male	Married	Depression	50	None identified	5	Three children in CAMHS – all with anxiety	1:1 with PM	Completed FT
15	CAMHS	Female	Single parent	Depression	44	N/A	5	Two children in CAMHS – depression/anxiety and ADHD/ASD	1:1 with parent & youngest child	Completed FT

improved family communication, problem solving, and warmer relationships. A total of four sub-themes were identified here.

Benefits to PMI

Three quarters of service-user parents (12/16) reported a reduction in shame, stigma and worry about being a "bad parent" following the intervention, which helped to improve their sense of well-being and parental confidence. Labelling was a common source of stigma. One service-user parent, for instance, agreed to participate only on the condition that the term "bipolar" was not used with his children. Another parent recalled the pejorative names used by his wife, such as "crazy" or "mentaller". Such labelling encouraged the PMI not to share their suffering and to try to appear "normal."

> "I became very good at hiding things, trying to adapt and fit in and mirroring other people that were deemed to be socially acceptable." (PMI 5)
>
> "After coming out and saying it to them, and talking to them about it, there is nothing to be ashamed of." (PMI 13)
>
> "It was hard. But it was very relieving because there was a lot of stuff that I would have been fearing to talk about or say out loud." (PMI 12)

Table 5.3

Qualitative Themes and Subthemes of Family Experiences of Family Talk

Theme 1: Benefits and experience of *FT*	
Sub themes	***Sub-Sub themes***
From fear and silence to sharing and empowerment	**Experiences of service-user parents** - Reduced stigma and worry - Deeper understanding of impact of MI on children - Better family relationships (communication, support) - Parental confidence and enhanced wellbeing **Hearing the child's voice** - Disclose hidden concerns and burdens - Better understanding of PMI - Relief and less worry - Warmer, more open family relationships **Partners' experiences** - Relief at having burden validated - Enhanced team approach to supporting PMI - Closer family relationships
Facilitators of change	-Clinician skill -Whole-family approach -Timeliness/readiness
Theme 2: Key barriers to participation	
Sub Themes	***Sub-Sub Themes***
Initial engagement phase	Parental stigma and beliefs Lack of clarity for children on purpose of *FT* Service constraints
Intervention phase	Emotionally challenging, but in a good way Varied within-family experiences Covid complications Disengaging from *FT*
Concluding Phase	More child, family and follow-up sessions Need for additional supports

Notes: FT, Family Talk; MI, Mental illness; PMI, Parental mental illness.

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All partners described relief at having their experiences validated by the *FT* clinician and acknowledged by the PMI. While heated discussions and angry outbursts were common in the initial sessions, they were seen as worthwhile as it increased understanding and empathy between parents on the burdens that each was carrying. Five partners indicated that their relationship with the PMI had improved following *FT*. Partners also expressed to the PMI that they wanted to know how best to support them and wanted to be involved in their care plans. The dialogical approach of *FT* sessions helped to encourage a team approach to supporting the PMI, helping both parents feel more connected.

> "It's an opportunity for him [husband] to hear me voicing the impact that it has on me in a very calm manner, because I'm in front of somebody else. It also takes away some of the guilt or the blame for me on his side. . . when you are more involved in the treatment." (Partner 3)

> "These sessions were great because we were both able to see where the other person was coming from." (Partner 1)

> "I think it [*Family Talk*] is 100% needed. As I said, there was nobody out there for me or the kids that I knew about. . . I can't compliment it enough. It's just the best thing that happened." (Partner 4)

Facilitators of Change

[This subtheme, within Theme 2 represents those elements of the programme which when present, significantly influenced family members' positive experience of the intervention including clinician skills, the inclusion of the whole family, the timeliness of the intervention and each family's readiness to attend the programme.[25]]

Clinician Skills

The majority of PMIs and partners indicated that it was the skill of *FT* clinicians that mediated the benefits for families. Parents welcomed the non-judgemental and strengths-based approach adopted by clinicians, and their skill in facilitating multiple perspectives across

[25] This text was added following a request from the examiners.

several developmental ages. In addition, the PMIs (12/16) appreciated the clinician-led, psycho-educational aspect of the programme, which led to a deeper understanding and normalisation of their mental health challenges.

> "*Family Talk* was very positive because there was somebody, a trained professional who had seen this before-it was in a way normalised. The kids were worried they were the only family in Ireland who had this problem." (PMI 5)

> "Everything that I talked about and went through, I had full support from her [*FT* clinician]. I can't even tell you how good she was. I can't say it enough. She was unbelievable." (PMI 12)

> "Everyone can say how they felt without any fear...Everyone felt very good afterwards and it was like a weight lifted. . . It's like a friendship with someone [clinician] that knows what you're talking about." (PMI 13)

Whole Family Approach

All family members believed that *FT* worked because it involved the whole family, and allowed multiple, often hidden, stigmas, concerns and burdens to be revealed and shared, thereby validating each person's lived experience, whilst also empowering them to be more supportive of each other. Participants indicated that the focus on the family unit had helped them to look beyond their individual burdens and to feel deeper understanding and empathy for each other.

> "It [*FT*] opened up the family and they talked about what they wanted to say and everything and you knew exactly where you stood, and it was up to you then to change the wrong things to try change them to the right things...It was brilliant because it brought out everything, the good and the bad, which was good." (Partner 7)

> "I just remember it was good for our family to actually talk properly without any kind of aggression, without any blame. . . everyone could just say how they saw things and people would put in their input without anyone kind of being upset about it. It was good to have like outside influences making sure everything was just calm." (Eldest child, 16 years old)

Timeliness/Readiness

Parents also indicated that timing, setting and their readiness for *FT* were important factors in engagement. If approached too early, they said that they might have denied the impact of their illness on their family/children. They also required a lead-in time to build up the

> "I just don't think we got a whole lot from it. It is very one sided to be honest. . . when an issue did come up, if there was something with regards to myself or my husband, they just constantly kept bringing it back to "well, how does that affect [child]?" (PMI 10)

> "[The PMI] was getting so emotional because of her own opinions about things and stuff… I wasn't going to start dumping my own out there because it could have got messy and emotional. I didn't want to escalate any kind of like… emotions. It was emotional enough. I was just kind of dealing with what was being brought up by [partner] and [child]." (Partner 1)

Figure 5.3

Challenges to Participation in Family Talk During the Engagement, Intervention and Concluding Phases

The COVID-19 pandemic restrictions have been shown to have had a considerable impact on population mental health and on those with pre-existing mental illness, both in Ireland and internationally (41–44). Seven families in this study were interviewed during the COVID-19 emergency, with three reporting sustained benefits from *FT* and that they were coping well with pandemic stresses, while four families reported increased mental distress and challenging child misbehaviour as a result of the restrictions; two of these families had disengaged from *FT* due to stigma/relapse issues and two indicated that *FT* delivery had been

suspended due to the restrictions. Therefore, it appeared that the level of prior vulnerability and ability to engage with *FT* predicted how well families had coped with the stresses of the COVID-19 restrictions. In addition, one parent reported attending online sessions of *FT* for PMIs, partners, and older teenagers (16+) but these were not considered suitable for younger children or for family sessions and they had to wait until it could be delivered safely again in person and in line with COVID-guidelines.

> "I don't think we could have dealt with months of isolation if we hadn't done *FT*. We make time for each other now at this stage. We watch family films or to sit down for dinner, meals." (PMI 13)

> "It wasn't the same but we were able to talk with him [clinician] on zoom. It was a while before the children could be seen so it wasn't ideal." (PMI 5)

Disengaging from FT

Families who disengaged from *FT* after three or fewer sessions (n = 5) gave the following reasons. One said that *FT* was too emotionally upsetting, with another feeling a sense of blame for causing her children's mental health issues. A number of other factors also contributed to disengagement including family crisis, relapse in symptoms, and having too many competing priorities. Additional delays/disruption in *FT* delivery due to the COVID-19 restrictions also led to some degree of disillusionment and disengagement from mental health services. This was more common in areas where mental health clinicians were partially redeployed to frontline COVID-19 duties and could only provide minimal telephone support to service users (41). Interestingly, those who disengaged from *FT* were almost twice as likely as "completers" to be lone parents (6/9 vs. 5/14)–suggesting that the stresses of lone parenting may also have been a barrier to engagement.

> "With Covid, we are far less a priority for them. I don't know when or if we're ever going to get it." (PMI 22)

> "It felt like she was attacking me and it was my fault how the girls are...I don't need that." (PMI 19)

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Similarly, child programmes that exclude parents may reduce the likelihood of mutual understanding as parents lack the opportunity to discuss their stigma concerns, to gain insight into the impact of their mental illness on their children, and/or to build parental confidence. Enhancing parental confidence and competence has been identified as key to shaping the quality of parent-child relationships (52). Significantly, the involvement of partners is less common in the implementation of FFPs (3). The findings from the current study indicated that *FT* provided a forum, usually for the first time, for partners to express their burdens and stresses and to communicate with the PMI about how they can better support them. Given the level of burden and stress reported, and the protective boundary provided by a healthy second parent (2), it is imperative that services/FFPs help to strengthen the "safety net" that co-parents provide in families with PMI. Recent filicide tragedies in Ireland (e.g., McGinley case) highlight the ultimate cost of not involving family members in the service user's treatment (53).

Significant barriers to participation were also reported in the current study. Most family members, including both completers and drop-outs, indicated that they had experienced challenges in engaging with *FT* in the initial phase. Parental fears and stigma around mental illness were the most commonly reported barriers to participation. Children also expressed reservations about attending, indicating that they were uninformed about the purpose of *FT* and wanted prior contact with the clinician prior to commencing *FT* sessions. Other family barriers to engagement were also noted, including relapse in symptoms and family crises. Previous qualitative studies have similarly highlighted that fear of judgement and/or competing needs for daily survival may impede family engagement (32, 37). These findings suggest that clinicians may benefit from the development of *FT*/FFP training videos/protocols to promote effective engagement strategies and address potential barriers to participation and retention. For instance, addressing issues of stigma, readiness/timeliness, consent and confidentiality during the recruitment process and including quotes/videos from previous *FT* attendees may help to improve engagement (54). In addition, a child-friendly recruitment approach that used

age-appropriate marketing literature and involved a meet-and-greet session with the facilitating clinician might help to address children's concerns about attending. Lastly, low functioning PMIs may benefit from additional psycho-educational sessions and complementary group supports to promote engagement (37).

Service constraints were also an inhibitive factor in family engagement with the programme. The capacity of *FT* clinicians to build rapport and familiarity with the family beforehand was undermined by high turnover of personnel and under resourced mental health teams. In addition, a small number of families were discharged from AMHS/CAMHS before they could start *FT*, while several other families disengaged due to their unhappiness with long waiting lists, and delays/disruptions due to the COVID-19 lockdown restrictions. These difficulties reflect general underfunding of mental health services in the RoI, alongside a lack of policy/practise priority given to supporting this population in an Irish context (26, 45, 55).

Some challenges were also noted during the intervention phase. Firstly, while most families reported that *FT* was ultimately worthwhile, it was also seen as emotionally challenging at times. Many reported difficulties in speaking openly in sessions and/or listening to other's experiences and indeed, this was also shown in research by Pihkala et al. (33) in Sweden. The clinician's skill in facilitating multiple perspectives was instrumental in ensuring that family members could listen to each other without becoming overly defensive or upset. Secondly, there was some evidence that children within two families did not receive sufficient time in their individual child session (e.g. 20 min each). Moreover, while children largely reported benefits from *FT*, there was little mention of fun within sessions. Therefore, children may benefit from the inclusion of some light relief at the beginning or close of sessions (e.g., ice breakers, child-friendly videos, closing "fun" take-home exercise), as used in, for example, the *Kidstime* intervention (56).

Thirdly, the COVID-19 lockdown restrictions had implications for the delivery of *FT*, including blended adaptation (both in-person and online sessions), as well as family

disengagement following repeated delays to delivery. Notably, there was considerable variation in the capacity of sites to deliver *FT* during the lockdowns with some mental health staff partially redeployed to frontline COVID-19 duties and providing minimal phone support to patients while clinicians in other areas were able to continue home visits and outpatient clinics, following COVID-19 guidelines (41). Reassuringly however, it is likely that the future implementation of *FT* will be conducted in person in view of the >90% uptake of vaccination in the RoI (57).

Lastly, while most families benefitted from *FT*, they indicated a desire for additional child, family and follow-up sessions, thereby suggesting that some of their needs had not been met. This was also noted by *FT* clinicians working with lower functioning psy eesis pa t tsin

experiences of *FT*

in developing and evaluating training videos that teach recruitment strategies to see whether they improve engagement. In addition, qualitative analyses may inform RCT evaluations of *FT*/FFPs; for instance, RCTs could include as outcome measures, benefits identified in qualitative analyses, such as reduction in stigma, parental confidence/competence, service user mental health, partner well-being, and family functioning. Moreover, facilitators and barriers to implementation identified in qualitative studies could be tested as moderator/mediator variables in quantitative research.

References for Chapter Five (Study Two) can be found in Appendix DD

Chapter Six

A Family-Focused Intervention for Parental Mental Illness: A Practitioner's Perspective

Furlong, M., Mulligan, C., McGarr, S., O'Connor, S., & McGilloway, S. (2021). A family-focused intervention for parental mental illness: A practitioner perspective. *Frontiers in Psychiatry*, *12*, 783161.

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Abstract

Background: Parental mental illness (PMI) is common and can lead to children developing mental disorders. Family Talk (*FT*) is a well-known and widely implemented intervention designed to reduce the risk of transgenerational psychopathology. However, given the research to practise "gap," very little qualitative research, to date, has investigated practitioner experiences in implementing *FT*. This study aimed to explore the practitioner-perceived barriers and facilitators to the implementation and sustainability of *FT* within mainstream mental health settings.

Methods: This qualitative study was nested within a randomised controlled trial (RCT) of Family Talk [*N* = 86 families (139 parents, 221 children)] within 15 adult (AMHS), child (CAMHS), primary care mental health, and child protection sites in Ireland. Semi-structured interviews and focus groups were undertaken with a purposive sample of clinicians (*n*= 31) and managers (*n*= 10), based on their experiences of implementing *FT*. Interview data were transcribed verbatim, analysed using constructivist grounded theory, and informed by Fixsen's implementation science framework.

Results: Service providers highlighted a number of benefits for approximately two thirds of families across different diagnoses and mental health settings (AMHS/CAMHS/primary care). Sites varied in their capacity to embed *FT*, with key enablers identified as acquiring managerial and organisational support, building clinician skill, and establishing interagency collaboration. Implementation challenges included: recruitment difficulties, stresses in working with multiply-disadvantaged families, disruption in delivery due to the COVID-19 global pandemic, and sustainability concerns (e.g., perceived fit of *FT* with organisational remit/capacity, systemic and cultural barriers to change).

Conclusion: This study is only the second qualitative study ever conducted to explore practitioner experiences in implementing *FT*, and the first conducted within the context of an

RCT and national research programme to introduce family-focused practise (FFP) for families living with PMI. The findings illuminate the successes and complexities of implementing FFP in a country without a “think family” infrastructure, whilst highlighting a number of important generalisable lessons for the implementation of *FT*, and other similar interventions, elsewhere.

Keywords: family talk, implementation, mental disorder, mental illness, parents, qualitative, COPMI, children

of recommended staffing levels (37, 38). In the earlier phase of this research (2017–2018), we conducted a scoping study of FFP across adult (*n* = 114) and child (*n* = 69) mental health services

and organise themes, and informed by Fixsen's implementation science framework and the Medical Research Council (MRC) guidance for complex interventions (18, 41, 42). Details of the RCT protocol and registration can be seen at the following link https://trialsjournal.biomedcentral.com/articles/ 10.1186/s13063-021-05199-4; (40).

6.2.1 Participants and Settings

A purposive sample of mental health clinicians (*n* = 31), and managers (*n* = 10) were identified and recruited for participation in the study, based on their experiences of delivering *FT* to 55 families within the RCT.

The larger RCT included 86 families (139 parents, 221 children) in 15 sites across Ireland, involving AMHS, CAMHS, primary care psychology, and child protection/welfare services (40). Families were block randomised, on a 2:1 ratio, to the *FT* intervention (*n* = 56) or to a treatment as usual control group (*n* = 30), and assessed at baseline and 6-month follow up. At follow up, attrition was 37%, the rate of which doubled due to the impact of the COVID-19 lockdown restrictions (23 vs. 45%). Eligible families were those with a child aged 5–18 years and a parent with a formally diagnosed mental disorder. Eighty per cent of service-users were attending AMHS and 20% were receiving antidepressant medication or primary care psychological support under the care of a General Practitioner (40). Due to the high risk of intergenerational transmission of mental disorders (2), and a desire among stakeholders to increase family-focused collaboration between traditionally segregated adult (AMHS) and child mental health services (CAMHS) (4), we included families where children attended CAMHS or primary care services for mental health issues, as well as families where children were not involved with mental health services. Families were excluded if the parent/family was in a state of crisis/instability (e.g., hospitalised, active psychosis/addiction, contentious separation) (40). The 55 families included in service provider reports, had a similar profile to the larger RCT sample in terms of age, gender, mental disorder, and site/location (Table 6.1).

Participating sites were eligible to participate in the research if they had secured managerial support to implement *FT*, and had identified a lead person to coordinate clinicians, oversee training, plan family recruitment, organise regular peer supervision and be a point of contact with the research team. Clinicians delivering *FT* were required to have at least 3 years' experience in working within adult, child mental health and/or protection services; have completed the online training in *FT* (www.emergingminds.com.au), attend monthly supervision, and recruit families and/or facilitate *FT*. Families were recruited by clinicians in each site from their existing waiting lists. *FT* was delivered in an outpatient clinic and/or in the home by an *FT* clinician (40). Ethical approval (for both the RCT and qualitative study) was obtained from four research ethics committees including the research institution where the research was carried out [name withheld for anonymous peer review], the HSE, Tusla child protection agency and Saint John of God's Hospitaller Services. The flow of participants from recruitment through the RCT to the qualitative studies is shown in Figure 6.1.

Clinicians and managers were selected for interview based on service setting (e.g., AMHS, CAMHS, primary care, Tusla child protection agency), professional discipline (e.g., social work, psychology) and site location. All 15 sites were approached and interviews were secured with participants from five sites that recruited 10+ families each, from 3/5 sites that recruited ≤3 families, and from 1/5 sites that did not recruit any families. Three sites could not be contacted and three declined interview due to *FT* clinicians either leaving the service or having competing demands on their time due to the COVID-19 pandemic. Most of the 31 clinicians interviewed were female (*n* = 27), parents (*n* = 25), aged 31–50 years (*n* = 26), with 14 employed in AMHS, 14 in CAMHS and 3 in primary care and the Tusla child protection agency. More than three quarters were employed as social workers, three as social care workers, and the remaining five as clinical nurse specialists and psychologists. On average, they had been employed as practitioners for 15 years (SD = 6.7), with most (24/31) having worked in multiple settings (e.g., AMHS, CAMHS, and child protection services).

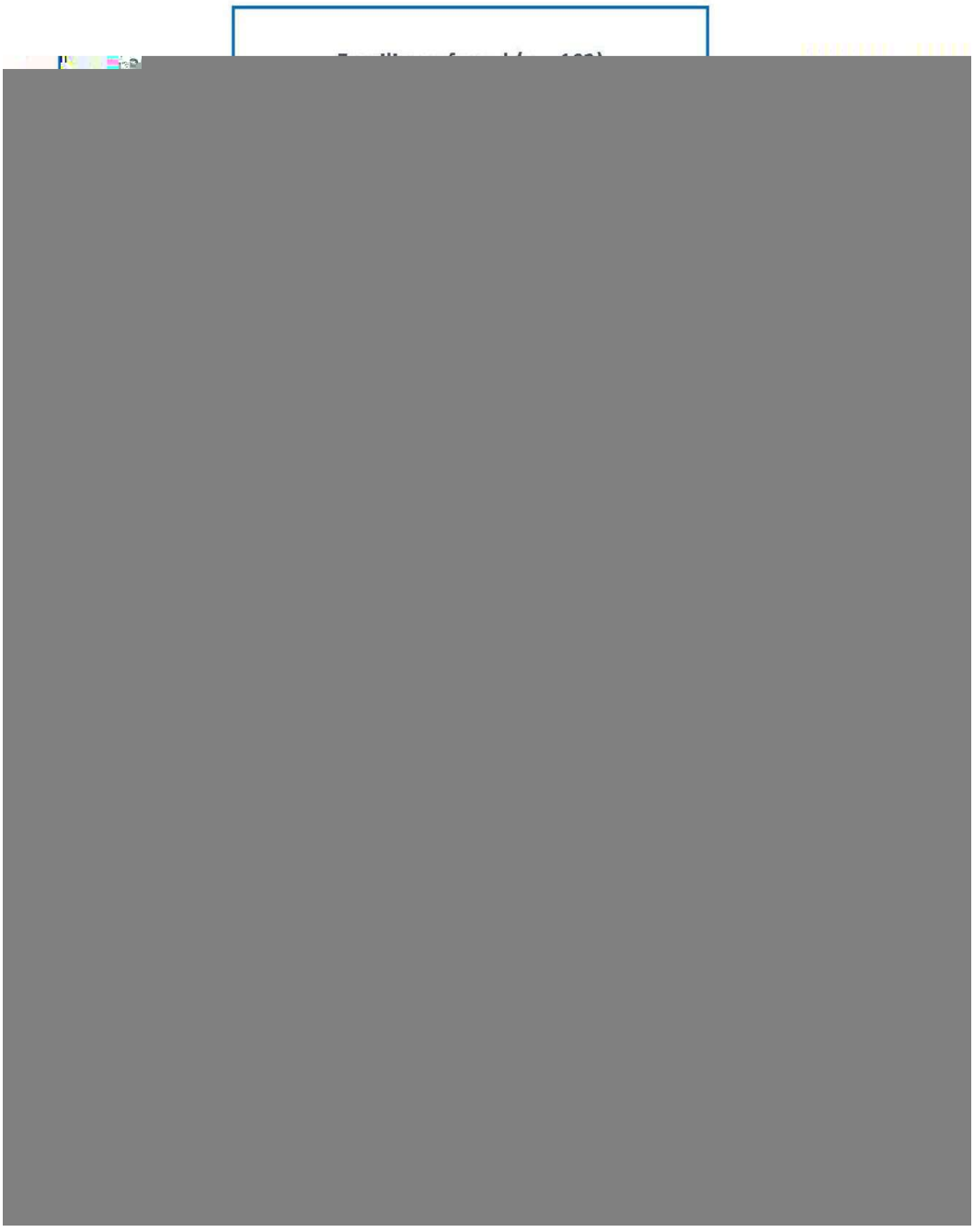
6.2.2 Data Collection and Analysis

All participants provided written informed consent to participate in a one-to-one, semi-structured interview or focus group. Eight managers and eight clinicians participated in an individual interview while two managers and 23 clinicians were interviewed across five focus groups. The focus groups typically lasted 1.5 h (with a break if so required), while one-to-one interviews with clinicians and managers lasted 30–45 min. Most interviews were conducted using online platforms (all managers, 24/31 of clinicians) due to the COVID-19 pandemic restrictions. An interview schedule/topic guide was devised to investigate: (1) stakeholders' experiences of facilitating/implementing *FT*; (2) key barriers and enablers to implementation; and (3) factors mediating the longer-term sustainability of *FT*/FFP in their service/in Ireland. The interviews were conducted by CM, who had met with all service providers several times previously during the exploration and installation phases of *FT* implementation (4). Interviews were audio recorded and transcribed verbatim.

The data were uploaded to MAXQDA software (44) and analysed using constructivist Grounded Theory in order to identify and organise themes (41). Analysis was informed by Fixsen's implementation science framework and the MRC guidance for complex interventions (18, 42). Data were analysed using line-by-line and focused coding, constant comparison of codes to find similarities and variations within categories and hierarchical linking of categories to generate super-ordinate (or overarching) themes. All of the interviews were read by CM and MF, CM coded and analysed all of the data, while three authors (MF, SMcGa, SOC) independently assessed the reliability of coding on 25% of the transcripts, with more than 90% inter-rater agreement. Disagreements were resolved by discussion. Trustworthiness of the analytic process was also enhanced by audiotaped interviews, verbatim transcription, an audit trail of code generation (Appendix EE), clear description of sampling procedures, participants and settings, theoretical saturation, and seeking disconfirming cases. Reporting adhered to COREQ guidelines (Consolidated Criteria for Reporting Qualitative Research) (45).

Figure 6.1

Study flow diagram from RCT to qualitative studies.



> affected, so having this model of working on those cases, I'll be working with that going forward." (Clinician 11, Tusla, Site 1)

Seeing the Benefits of the Programme: Benefits to Families

An important and frequently reported implementation driver for clinicians/managers, was the benefits they had witnessed in approximately two thirds of the families with whom they were working; these included: reduced worry and stigma, a greater understanding of the impact of PMI on family members, a new family narrative around the parents' illness, and improved family communication. Clinicians indicated that parents/partners were typically surprised/upset by how much their children had been affected by tense/volatile home situations, and had hidden their worries and concerns to avoid burdening parents. For children, having their reality acknowledged, was significant as children were usually told nothing was wrong. As parents became more cognisant of their children's needs, family members were motivated to reduce levels of anger/arguments, and to relate to each other in more warm, caring and fun ways, thereby leading to reduced stress and increased family well-being. Clinicians further indicated that the improved family interactions/relationships assisted the PMI's personal and parental confidence and wellbeing.

> "I think parents being able for the first time to hear their kid's opinions, and that they have opinions on it, they do have questions, and they're not in the dark–that does have a positive impact. Parents can become upset. I have had parents who cry in the feedback session. They can't believe they [children] knew what was happening, but there is some motivating factor in that for recovery. One parent I was working with for over a year had not shown a massive shift, but whatever it was about hearing feedback from her kids, and questions about her mental health, it seemed to motivate her. It did make a difference to her recovery." (Clinician 4, AMHS, Site 3)

> "Their life is totally different. The mum had a lot of guilt and shame around her being a mental health patient. It was the first time she talked to the girls and they talked about the frustrations of mum not being available. She's able to speak to both the girls now. Mum is able to cook every day when she couldn't before so life has become a lot more predictable, which is exactly what they wanted–so hugely beneficial for them." (Clinician 10, AMHS, Site 1)

> "For the kids themselves, just to be given that space to talk and have their own voice heard is huge... Because the kids know without maybe knowing what the words are for it, but they know that there's something going on in the household...Takes a huge weight off their shoulders...In one family, both girls were actually blaming themselves for mum's illness because their aunt had told them it was their fault that mum was having relapses." (Clinician 1, CAMHS, Site 3)

> "That was the best thing he [service user] had done he said and because of the communication with his family, he's doing quite well again. He's more aware of the need to communicate." (Clinician 15, AMHS, Site 1)

Benefits for Clinicians and the Wider Service

Most clinicians also believed that *FT* was beneficial for themselves and for their service. *FT* was reported to be enjoyable and rewarding and had helped to allay long-held ethical

posters to recruit families; hosting/facilitating access to FFP workshops/masterclasses; co-delivering presentations to site managers and MDTs; providing regular updates by e-zines; and promoting the study through local and national media to raise public and service awareness on the topic (4). Thus, the early installation and implementation of *FT* was a joint collaboration between the research team and site stakeholders (4).

> "What attracted it to us was the fact that it was supported by research, it was multi-site, it was a broader 'Think Family' agenda which appealed to us... The sense of being part of something bigger. There was a support structure there and we wouldn't have done this in a systematic way unless we were part of the research study." (Manager 9, AMHS, Site 5)

> "More recent referrals have come from team members, and that has a lot to do with a few more of the talks by the research team coming into the service." (Clinician 3, CAMHS, Site 3)

> "It was great to be part of the research. I feel it was a very exciting time and you guys are doing such an incredible job...I definitely intend to keep going. I would absolutely love to see it more evolved in Ireland. I'm a big believer in it." (Clinician 4, AMHS, Site 3)

Theme 2: Barriers to Implementation

Engaging and Retaining Families

Engaging and retaining families was the primary challenge faced by service providers and was one which was exacerbated by the COVID-19 restrictions. Clinicians indicated that three to four families had to be approached for everyone successfully recruited, and in ten sites there were three or less families recruited (Table 6.3). Overall, 16% (16/102) of referrals to the RCT were withdrawn before randomisation due to their unsuitability for *FT* (e.g., child protection issues, parent relapse, family crises). Of the 56 families allocated to the intervention group, 6 did not start *FT* and 5 disengaged after attending <3 sessions, with 53% attending all sessions [mean attendance was 4.4 sessions (Sd 1.2)]. Participants identified a range of barriers to engagement and retention covering multiple family, clinician, organisational, pandemic, research, and systemic/cultural levels.

professional training. Other barriers included: slow referral processes; difficulties in identifying PMIs; needing to re-secure buy-in with new consultants who rotated on a 6-monthly basis; and colleagues being supportive in theory but not in practise as demonstrated, for example, by their unwillingness to train in *FT* or to refer families, a tendency to discharge suitable families without notice, and being risk adverse in balancing service-user confidentiality/data protection concerns with family needs.

7) but not as part of the RCT and, despite support from the research team, struggled to communicate to families the value of taking part in the research.

> "The main challenge was recruitment. It's because they [colleagues] didn't explain it properly to the parent." (Clinician 31, CAMHS, Site 3)

> "We have been hugely affected by COVID... And after so much work put into it [FT]. That's been hugely challenging." (Manager 6, AMHS, Site 1)

> "We had a certain amount of time to complete it because of the [research] timelines so there's that added pressure to find families and get them seen. Once that is gone, it will be very good to see this as an integral part of AMHS. I really hope that happens." (Clinician 12, AMHS, Site 1)

Variation Across Sites

Ten sites recruited three or fewer families, only one of which (site 11) withdrew from the research; they did so because clinicians did not see *FT* as being a fit with the type of systemic family work which they wanted to undertake. The remaining nine sites were all characterised by limited resources (e.g., few *FT* clinicians with little dedicated time), ideological differences, lack of a champion or practical support from colleagues, and

> the families to see what social work can do. Within the team, the role of social work was a very basic view of the role of social work [e.g., form filling and applying for benefits/services rather than engaging families in interventions]." (Clinician 26, AMHS, Site 7)

> "Mum has mental health problems, a lot of trauma from her background... The family would really benefit from it [*FT*]. But Tusla said, no, it doesn't meet our threshold as Dad's a protective parent." (Clinician 28, Tusla, Site 13)

Delivery Challenges

A small number of clinicians indicated that the family meeting, in particular, was stressful, due to the emotional content being shared, and the requirement to support parents and children spanning a broad age range.

> "What I found difficult was the family meetings, you were sitting with mum, a 16-year-old, an 11-year-old and a six-year-old in the room. You speak differently...You're still getting the essence across, but you're not being as frank about certain issues, or you're making it more child friendly because a child is there." (Clinician 4, AMHS, Site 3)

Fidelity to *FT* protocols was also a challenge, with frequent delays/disruptions due to the COVID-19 restrictions. In a small number of cases, clinicians adapted *FT* using online platforms, which facilitated individual parent and older teen sessions, but was not considered suitable for younger children or family sessions, and therefore completion of *FT* was delayed. In addition, for families with more complex needs, one third of clinicians indicated that they provided additional parent, child and family sessions beyond the 7-session model, and referred families to further services (e.g., individual/relationship counselling, family supports). As *FT* was frequently the first (and perhaps only) time parents and children spoke about living with PMI, parents/partners were often angry/upset during initial sessions, while some service users needed time to adjust to not being the sole focus of care. Child meetings were also extended (if time permitted) when complex issues or concerns were raised.

> "Due to the pandemic, I was unable to recommence Family Talk. It was impossible to start the individual meetings again and it just didn't flow straight into the family meeting. Otherwise, I feel the Family Talk would have been very successful." (Clinician 7, AMHS, Site 2)

> "A couple of families had a lot of issues, and they needed time–one session with the kids wasn't going to be enough... And they needed follow-on supports that I was able to refer them to." (Clinician 11, CAMHS, Area 3)

Theme 3: Sustainability of FT/FFP in Ireland

Site Continuity Plans

Despite the disruptive long-run impact of COVID-19 (e.g., increased waitlists), six sites have continued to deliver *FT* beyond the research programme, while the remaining areas hope to use its principles in practise, subject to resource limitations. The top five recruiting sites (Table 6.3) appear best placed to sustain *FT* as managers/clinicians have: (1) introduced practise guidelines for engaging families to *FT* as part of routine service provision (e.g., during initial patient assessments); (2) promoted *FT* using service-user feedback; (3) encouraged new staff/colleagues to train in *FT*; (4) continued to deliver *FT* to families; and (5) held regular *FT* peer supervision.

> "We have continued receiving referrals for Family Talk and are continuing to deliver it to families. I am delighted that staff want it to become embedded in practice and our peer supervision group has become an established forum." (Manager 6, AMHS, Site 1)

> "We still continue here in CAMHS. I still fly the Family Talk flag as much as I can." (Manager 4, CAMHS, Site 3)

> "We are going to continue using it in CAMHS. I think it's a very useful service. But definitely the challenge is the recruitment." (Clinician 21, CAMHS, Site 4)

> "I still use it. I use it in everyday work now." (Manager 10, AMHS, Site 8)

> "The intervention is really great so it's definitely something that we're going to continue to do with families. It should have been here a long time ago." (Clinician 29, AMHS, Site 5)

FT "Fit" With Service Remit and as Part of FFP Suite of Supports

A key sustainability issue concerned the perceived "fit" of *FT* with service remit; while many stakeholders expected AMHS to be the most natural fit for *FT*– and with CAMHS/Tusla perceived as being more proficient at family work–success in implementing *FT* appeared to be mediated more by local site resources, organisational culture and the availability of a strong champion. A small number of CAMHS clinicians within one site viewed *FT* as a mid-level

with little benefits for families or clinical practise. Rather, participants emphasised the benefits of providing training in FFP, such as *FT*, and having managerial support to deliver FFP to families.

> "I think if you make this kind of thing mandatory or legislative, it adds a little bit to the scary factor, both for families and us working with them... I think a better investment is to train clinicians in it [FFP/*FT*] and then support them to do it, allow them time. But you need to move beyond the
> individual, medical model for that." (Manager 1, Primary Care, Site 4)

Figure 6.2

Multi-level Approach to Embedded FFP

6.4 Discussion

Service providers highlighted a number of benefits for the majority of families, while several key facilitators and barriers to implementation and sustainability were also identified. The benefits noted here corroborate those reported by a sample of family members (*n* = 45 from 23 families) who participated in a second qualitative study which is reported in a companion paper (Mulligan et al., 2021). The findings are also consistent with those of studies of clinicians and families who experienced delivering/attending *FT* in psychiatric settings in Sweden (30, 47). Perceived benefits for families in this study included: feeling heard and

validated, reduced worry and stigma, a greater understanding of mental illness; improved parental confidence; and better family communication. Benefits were reported across different mental health settings (e.g., AMHS/CAMHS) and types of mental disorders and highlighted that *FT* was capable of being implemented in a country without a "think family" policy or dedicated FFP funding infrastructure.

Within the current study, clinicians/managers identified a number of facilitators and barriers to implementation, which build upon those identified in (the few) previous qualitative studies of *FT* delivery (28–32, 47), and which should help to inform the future implementation of *FT*/FFPs across countries. These might also usefully be tested as mediators/moderators within controlled trials. Five of the 15 sites recruited 90% of families (Table 6.3) and participants from these sites provided important insights into key facilitators. These included: the availability and drive of an FFP champion with managerial support; promoting interagency collaboration among AMHS, CAMHS, primary care, and child protection services in the area; engaging in regular awareness-raising and buy-in efforts with management/colleagues (e.g., *FT* on weekly MDT agenda and offered as part of care plan during initial assessments); encouraging clinicians to participate in *FT* training; setting up referral and supervision structures, and allowing clinicians sufficient time to engage in *FT* promotion, recruitment, and delivery activities. The use of multiple modes of recruitment (e.g., brochures, in-person invitations, phone-calls) also appeared to be linked to better family engagement. These findings are important in reinforcing the enablers of successful FFP implementation identified elsewhere, including building community capacity and interagency collaboration (5, 19), as well as targeting management, organisational policy, and professionals' attitudes, skills, and knowledge (5).

Another key facilitator to implementation was the structured, manualised approach of the intervention, and its freely available online training, which greatly increased its accessibility for busy professionals working across different geographical areas. Nevertheless, some clinicians indicated that they would have welcomed supplementary face-to-face training with

Mediating factors in the current study were less related to type of service than to the availability of a champion and local site resources as well as organisational culture, and interagency collaboration. In Australia, where a range of FFP supports have been established for over 20 years, AMHS and primary care are the most common provider settings (24), but in general, there is a consensus that FFP is the responsibility of all services, whether adult- or child focused (54).

6.4.1 Strengths and Limitations

This study is just the second qualitative analysis of practitioner experiences of implementing *FT*, and the first conducted within the context of an RCT and national programme to introduce FFP for families with PMI across AMHS, CAMHS, primary care and child protection settings (in Ireland). A large and diverse sample of stakeholders (*n* = 41) was interviewed including clinicians and managers across a number of sites, including those that struggled with recruitment. The findings identified a number of barriers and facilitators to implementation and mirror the family experiences of *FT* reported here in our companion paper.

Limitations include the generalisability of the findings across different cultural contexts and settings. Unlike other jurisdictions where *FT* was longer established and/or there was prior legislation/FFP practise standards, *FT* was implemented in Ireland as a catalyst for a paradigm change in mental health provision for families with PMI. In addition, most sites involved AMHS or CAMHS staff so caution is advised, therefore, in generalising to other mental health/family support settings. Furthermore, most of the clinicians/managers were social workers and 80% had previous experience in working within AMHS, CAMHS and/or child protection settings, thereby potentially limiting generalisability to other disciplines and those without cross-agency experience.

Importantly, there was some evidence that *FT* implementation (e.g., site buy in) had taken place because it was the focus of a national research programme funded by the HSE in Ireland. While some clinicians indicated that the RCT timeline also impeded recruitment, all

and delivered at a cost of €761.50 per family (including one-off costs), and €415.31 per family when recurring costs were included. The cost rating for *FT*, as determined by the EIF on the basis of the PRIMERA cost analysis, was given a 'low to moderate' when compared with other similar programmes.

The above findings were supported and amplified by the data from the family interviews which, as outlined in **Study Two**, were conducted with 23 of the RCT families. The results of the process evaluation indicate a high level of intervention acceptability among both families and practitioners, with approximately two-thirds of both cohorts reporting substantial benefits. Similar to findings reported from a study in Sweden, users reported a reduction in stigma, increased confidence and (consistent with the PRIMERA RCT results), improved understanding of the impact of their disorder on the family (Strand & Meyersson, 2020). Unlike the Swedish cohort, however, over half of the children interviewed as part of the PRIMERA project were already attending (or waitlisted for) CAMHS, most of whom also reported benefiting from the intervention. The facilitation of a whole-family conversation around the parent's mental health disorder also reportedly reduced children's fears regarding their parent, and improved the service users' self-reported well-being. Similar positive outcomes were also reported in an earlier Swedish study for families who attended an adapted version of *FT* for parental substance misuse (Pihkala et al., 2017). Despite an initial reluctance amongst some families to participate in *FT*, large and almost equal proportions of parents and practitioners reported benefits for families. Importantly, this was also the case for children, many of whom were already attending CAMHS or exhibiting psychological distress (see Appendix B). Collectively, these findings demonstrate the benefits of facilitating a shared narrative around PMI as part of a structured manualised programme delivered by experienced mental health professionals.

Another key finding from **Study Two** is consistent with Overbeek's (2022) assertion that attitudes, motivation, and expectations prior to undertaking a new intervention are key to

shaping participants' level of engagement and commitment to a programme, regardless of whether they are a family member or practitioner. All of these were identified as key facilitative mechanisms in the process evaluation reported here. Furthermore, as also noted by Strand and Meyersson (2020) and Pihkala et al. (2008:2012), a positive service user-practitioner relationship is important for providing a safe non-judgemental space that allows families to open up about their thoughts and feelings. While some of the younger participants and co-parents in the current research were also initially anxious about attending the intervention, overall, they reported reduced concerns about the unwell parent as well as improved intra-familial communication following their participation in the programme.

However, the sometimes-mixed feedback from some family members illustrates that members of a family may perceive the same programme differently. Thus, some parents reported that they benefitted less than their child(ren), and on at least one occasion, unlike the child and co-parent, the service user parent disliked the focus on their mental health disorder and expressed a desire for more discussion on what they described as the 'child's issue'. This difference in perspective may reflect not only a diagnosis-related issue, but an underlying difficulty in the parent-child relationship and attachment that goes beyond the scope of the *FT* programme. This to some extent supports Strand and Meyersson's (2020) assertion that *FT* in its standard 6-8 session format may not be suitable for all families and especially where a parent has a serious mental health disorder (e.g. psychosis or schizophrenia); hence, additional components specific to the disorder or the family may be required (Radley et al., 2022). A need for more research on intra-family differences in how *FT* is perceived, in line with Beardslee's recent recommendation (Beardslee, 2019), is indicated.

Most of the families in the current research were also keen to receive additional support after completing *FT*, a finding also reported elsewhere (Maybery et al., 2019). While *FT* typically offers a booster session three to six months post completion, it was not possible to incorporate this within the timescale of the RCT, but many practitioners successfully delivered

this session when not hindered by the COVID-19 pandemic. Several studies described by Lannes (2021) describe programmes that provide booster sessions to maximise their impact, while Loechner (2018) also recommends the use of such sessions and/or additional supports (e.g. extra sessions during difficult periods or electronic reminders of topics covered during a programme) to help sustain positive outcomes. Overbeek (2022) also identified at least one study (i.e. Ammerman et al., 2015) which suggests the need, in some instances, for additional parent training component s

screening for PMI. Indeed, the more effective project sites in terms of the number of families recruited, were also characterised by strong interagency peer support and supervision which helped to motivate practitioners to train in, and deliver, *FT* for the duration of the project; these have also been identified elsewhere as important drivers and mechanisms of successful programme implementation (Gregg et al., 2021; Isobel et al., 2019; Maybery & Reupert, 2009; Reupert et al., 2022; Vives-Espelta et al., 2022). Substantial funding from the, then Director of the HSE Mental Health Division (Dr Anne O'Connor), with support from FFP champions across MHS, and academics with decades of research experience with vulnerable populations, were also key to the success of this research-led collaboration. Whilst psychologists, social care workers, and clinical nurse specialists were critical to the participation of the 10 MHS sites in the project, systemically trained social workers were lynchpins to its overall success.

While it was not possible at the time of writing, to confirm the extent to which all participating RCT sites are continuing to deliver *FT* (in part because of ongoing reallocation of staff due to redeployment, promotions, and leaving the service or maternity leave), we are aware that *FT* delivery is ongoing in the most successful RCT site (i.e. in terms of number of families recruited and the nature and extent of interagency collaboration) located in Galway-Roscommon AMHS (in the west of Ireland). Importantly, the FFP champion in this site, a Principal Social Worker, has been instrumental in establishing an inter-agency 'Crosslinx Forum' which meets monthly to support *FT* delivery and a FFP ethos within the service; this comprises of Mental Health Services, CYPSC, Jigsaw, TUSLA Family Support and Child Protection Services, and National Counselling and Addiction Services. This may be considered a best practice exemplar in terms of the level of organisational support and buy-in, which were identified in the findings reported here and also in the wider literature (e.g. Grant et al., 2014:2018; Reupert et al., 2022; SCIE, 2012; Tew et al., 2015) to be important drivers of successful programme implementation.

It is worth noting here that the above social worker also developed and co-authored a new HSE guidance document (Chapter Two, Table 2.7) entitled *Family Focused Practice in Adult Mental Health Care* (HSE, Mental Health Services, 2022), which sets out a number of important recommendations for advancing FFP in AMHS in Ireland and which was inspired, at least in part, by this site's participation in the PRIMERA research (Box 7.1). Key recommendations in this report include, employing dedicated FFP co-ordinators for specific regions, an awareness-raising campaign around the needs of FaPMI, an interagency/cross disciplinary approach, cross-sector training/continuous professional development, and peer supervision for practitioners (Golden et al., 2020; HSE, Mental Health Services, 2022). Again, most of these, also seen in the wider literature (Grant et al., 2014:2016:2019; Gregg et al., 2021; Leenman & Arblaster, 2020; Maybery & Reupert, 2009; Reedtz et al., 2022; Reupert et al., 2022; Skogøy et al., 2019; Vives-Espelta et al., 2022), were identified by practitioners in the process evaluation interviews as central to successful *FT* delivery and important, therefore, in promoting successful outcomes for families.

Box 7.1 *Summary of the Recommendations to Embed Family-Focused Practice in AMHS in Galway/Roscommon (HSE, Mental Health Services, 2022)*

- Three dedicated co-ordinators to advance FFP in MHS in the Galway/Roscommon area.
- Training for personnel in current policies around the inclusion of family members, the needs of FaPMI, and the benefits of a *think family* approach.
- Equip, train and support the supervision of practitioners' delivering FFP.
- Evaluate and measure the programmes, thereby contributing to the evidence base.
- Facilitate interagency and inter-disciplinary support and training for FFP for FaPMI.
- Collaborate with the Recovery College[1] on recovery training models.
- Implement an awareness-raising campaign around the needs of FaPMI.
- Provide peer supervision for practitioners providing FFP programmes.

Note.[1]The first Recovery College was established in Ireland in 2013 and since then, seven colleges have been established to support the personal recovery of service users, informed by the principles of co-production and a collaborative approach to training (Hayes et al., 2023). Personal recovery is seen as distinct from clinical recovery (typically based on a medical model of care) and centres on living well with hope in spite of living with a mental health disorder. These practices are supported by the Recovery Framework introduced in the HSE in 2017 (Chapter One, Figure 1.1).

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pathways and a discussion on Family Talk as an intervention" (Golden et al., 2020, p. 5). A total

mechanisms. Additional family-related mechanisms are outlined later in Section 7.3 and in Figure 7.1.

7.2.3 Wider Economic and Socio-political Drivers and Mechanisms

It is worth noting that more than three quarters of the families (77%) involved in the PRIMERA RCT were socially and economically disadvantaged (Appendix B) when compared with the average Irish population (Central Statistics Office, 2023). This group, therefore, would typically have complex and challenging needs (e.g. early school leaving, unemployment, low paid jobs, unstable housing) which may explain, at least in part, the hesitation of some families to attend or complete the *FT* intervention in the current research.

Other factors related to the wider economic and socio-political context are also important when it comes to implementing the changes needed to support the delivery of a new programme and enhance FFP for FaPMI in Ireland and elsewhere. As outlined earlier in Chapter One, these include, in an Irish context, the considerable pressures on existing services, historical under-funding, inadequate levels of personnel, and long waitlists for services. Furthermore, any available MHS funding (and support of FFP) may be subject to a number of wider societal and global changes, compounded by the continuing cost (and other) implications of the COVID-19 pandemic, and including the impact of Brexit (February 2020), Russia's invasion of Ukraine in February 2022 and the current cost of living crisis. Each of these unparalleled events, combined with national HSE issues (e.g. the cervical cancer scandal[27], and the more recent ransomware attack) have important implications for Ireland's fiscal budget considering that 15 years on from the 2008 global financial crash, the effects of the subsequent HSE recruitment embargo still affects staffing levels today (Barrett et al., 2015; Furlong et al., 2021; Health–Europe, 2022; McEwen & Murphy, 2022).

[27]https://www.irishtimes.com/news/politics/oireachtas/government-comes-under-criticism-in-dail-over-health-service-scandals-1.4804493

At the same time, the potentially devastating impact of PMI for some families has gained national public attention in recent years and the role of the media cannot be underestimated when it comes to 'spotlighting' issues of public interest. Similar to the impetus for the *TFNI initiative* (Donaghy, 2016; Grant et al., 2018; SCIE, 2012), two cases of filicide in Ireland have drawn national attention to the increased risk to children when a parent has a significant mental health disorder. While mercifully rare events, the tragic murder by the MHS service user Deirdre Morley of her three children in 2020 (she was eventually found not guilty by reason of insanity), and the earlier murder of Zoe and Ella Butler by their father in Cork in 2010 (and his subsequent death by suicide), demonstrate the potentially devastating cost of PMI on dependent children (Butler, 2018). This kind of national attention can be an important impetus for change.

In summary, any plan to implement a new programme and to enhance FFP for FaPMI may have significant practical and socioeconomic implications across every level of service. Thus, for change to be sustained, it may require *"…significant shifts within broader political, cultural, and economic structures toward prevention and health promotion; as well as recognizing the importance of family within models of health and illness"* (Isobel et al., 2019, p. 6).

7.3 The Development of an Initial Programme Theory for Family Talk

The findings from the process evaluation, coupled with the activities conducted during Study One and the subsequent findings from the RCT, were synthesised by the author (in collaboration with the supervisory team) to develop an initial programme theory or logic model for *FT* to help us better understand the 'hows' and 'whys' of its implementation across a range of service contexts, and taking into consideration the many contextual challenges in a jurisdiction in which *think family* practice was largely absent (Figure 7.1). This initial 'PRIMERA model' was informed, methodologically, by the CGT approach used here (Charmaz et al., 2017) and by work on programme theory development more generally (e.g. Aarons et al., 2011;

possible due to time/resource constraints and the already substantial amount of work undertaken in the completion of this research, to adhere fully to the PRISMA-Scr guidelines (e.g. the absence of double review).

Secondly, the timing and duration of the RCT unfortunately coincided with the COVID-19 pandemic (as mentioned earlier in Chapter Three), thereby negatively impacting the recruitment of families and the delivery of *FT*, both of which also affected the timing of the process evaluation, although the sample size therein was still substantial. The timeframe for this project also, unavoidably, coincided with significant structural changes and public criticism of the HSE (e.g. HSE cyber-attack[30], and Look-back review into CAMHS[31]). The planned 12-month follow-up assessment for the PRIMERA RCT was also not possible due to COVID-related delays.

Thirdly, during the group interviews, several factors influenced family members' capacity to engage in the interview process. During one whole-family interview, a service user shared potentially upsetting details in front of the children about her experience of ongoing self-harm while later the co-parent cried about feeling helpless. Managing individual needs during *whole* family interviews was often emotionally challenging given the vulnerability demonstrated, and the complex needs of each family. It was also difficult to ascertain how well children were prepared for the interview process, evidenced by one child who told his mother, after his one-to-one interview, that he had said nothing because of his school's '*stranger danger'* training. Details of the intervention were also deliberately withheld from children in another home which only came to light during the interview (i.e. as an attempt by the service user parent to prevent her children from refusing to attend the intervention).

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[30] https://www.hse.ie/eng/services/publications/conti-cyber-attack-on-the-hse-full-report.pdf accessed October 29th, 2022.

[31]https://www.hse.ie/eng/services/news/newsfeatures/south-kerry-camhs-review/report-on-the-look-back-review-into-camhs-area-a.pdf accessed October 29th, 2022.

Fourthly, as outlined earlier, five focus groups involving five participating sites were conducted, each with practitioners from the same site to encourage robust and extensive discussion about *FT.* However, these findings may not be entirely representative. While practitioners in all sites were invited to be interviewed, not everyone responded to the invitation and indeed, a similar finding has been reported by Green et al. (2015). Two focus groups were also hampered by technology (e.g. participants joined late due to access issues or called in on a mobile phone with poor connectivity) leaving gaps in the audio recordings. Nevertheless, clarifying questions were later emailed as follow-up interviews were not possible. Given that 80% of the practitioners who were interviewed, had prior work experience across AMHS, CAMHS and/or child protection services, the findings may not be wholly generalisable to other practitioners who lack such cross-agency experience. The potential for self-selection and self-reporting bias, was also present, as in any qualitative research (McCambridge et al., 2014).

Lastly, many attempts were made to increase the involvement of additional co-parents, children (via the service user) and also service users/practitioners who refused to take part in the RCT and process evaluation. Nine families who completed less than three sessions (**Study Two**) of *FT* were interviewed here, but in general, more is needed to understand how services can best support this cohort. Furthermore, while the sample of co-parents was small, most reported benefiting from taking part in *FT* and all asked for follow up resources. The findings here, indicate the important safety net provided by co-parents in the home and, therefore, the need for them to be also supported by MHS. Future studies would benefit from considering strategies for including this cohort during the design phase of a research project in the hope that their voice could be heard. Brainstorming new and quick ways for collecting fidelity data from extremely busy mental health practitioners might also be worth considering given the challenges experienced here.

Furthermore, not all families are willing to be involved, although it is essential to invite family members where possible, to participate in all phases of programme design, development, and delivery to increase the acceptability of programmes. While several of the mental health policies introduced in Ireland over the last two decades (Figure 1.1) support the inclusion of family members, Delaney (2019) insist that COPMI should be viewed as unique individuals and not merely the 'property' of their parents, thereby requiring more targeted support. According to McGorry and colleagues (2022), "*despite having the greatest level of need, and potential to benefit, adolescents and emerging adults have the worst access to timely and quality mental health care,"* (p. 61). This is consistent with recommendations from the Prato collaborative which recommends that both a *child*

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Abstract

Background

FT in order to enhance the evidence base for its use with a wider range of mental health disorders. Furthermore, we know little about which populations may benefit most from FT. Longitudinal studies indicate that variables such as severity of parental mental illness, socioeconomic status, and availability of familial and service supports may moderate the risk of children with PMI developing a mental disorder [2, 20]. Similarly, attritional analyses from recent quantitative and qualitative studies of FT also suggest that socioeconomic status and/or severity of PMI may influence intervention effectiveness [13, 21]. Lastly, costs are a critical consideration for governments when allocating funding and resources [6] but there is an absence of costs analyses in informing the implementation of FT, and indeed family-focused practice more generally, within routine mental health settings.

Ireland lags behind most European countries and Australia as it does not have a legislative framework and/or a national "think family" policy/practice guidance to identify and support families with PMI [22, 23]. Consequently, the funding provided by the national Health Service Executive for the current 'PRIMERA' research (**P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies and children) was crucial in supporting the first endeavour to systematically implement FFP for families with PMI in Ireland. The overarching aims of the multi-strand PRIMERA project were to identify/develop, implement, and evaluate a family-focused intervention for families with PMI and, by so doing, help to inform a "think family" care delivery agenda within mental health services in Ireland. The project involved three key phases including: (1) an initial scoping study and literature review *(Phase 1*); (2) an RCT and cost analysis *(Phase 2);* and (3) a process evaluation *(Phase 3).* This paper focuses only on Phase 2. The findings from Phases 1 and 3 are reported elsewhere (References withheld for blind review).

In the first phase of this research (2017–2018), we conducted a scoping study of family-focused practice (FFP) across adult (n = 114) and child (n = 69) mental health services in Ireland, and found that support for families was either non-existent, in the planning stages, or *ad hoc* and small scale [Reference withheld for blind review]. It was subsequently decided on the basis of a review of the literature and in conjunction with stakeholders, to implement FT. This intervention was selected because it: incorporates a structured "whole family" evidence-based approach; encourages collaboration between traditionally segregated adult and child mental health services; is freely available; has high quality online training/resources; and was considered to be replicable and capable of being implemented across sites in Ireland [Reference withheld for blind review]. The objectives of the study reported here *(Phase 2)* were to conduct a randomised controlled trial and costs analysis to assess the effectiveness of FT, compared to usual services, in improving child and family psychosocial functioning in families with PMI in Ireland.

Methods

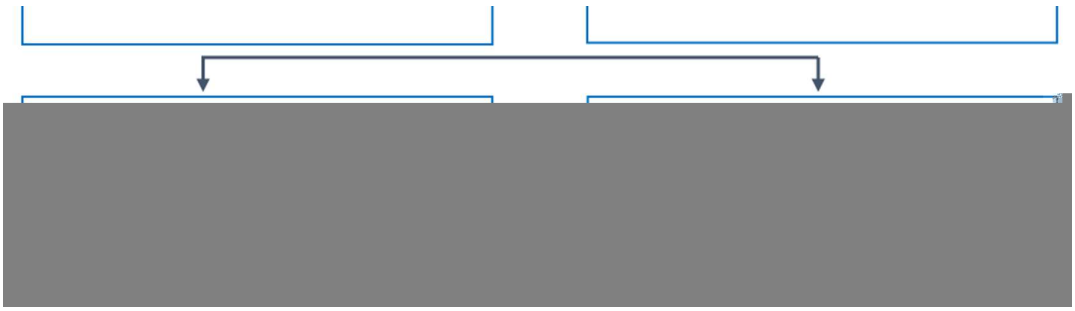
Participants and settings

FT was installed and implemented in 15 sites in Ireland between 2017 and 2021. Ten of the 15 FT sites recruited eligible families for the trial, including five Adult Mental Health Services (AMHS), one Child and Adolescent Mental Health Service (CAMHS), one site affiliated to the statutory child welfare and protection agency in Ireland (called 'Tusla'), and four interagency networks involving liaison among AMHS, CAMHS, Tusla and primary care services (Five sites did not include families in the trial due to ineligibility of recruited participants, staff deficits and/or the impact of COVID-19 restrictions.). FT was delivered within community outpatient clinics in both rural and urban areas, with a minority (< 15%) taking place in the home setting. Families were eligible for inclusion in the study if parent(s) were aged over 18, had children aged 5–18 years, and were either (a) attending AMHS due to a formal (or working) diagnosis of mental

illness, and under the care of a consultant psychiatrist/multi-disciplinary team; or (b) attending their general practitioner (GP) for mental illness. The parents' symptoms had to be relatively stable to allow them to engage with the intervention and the research.

Figure 3

Study Flow



Randomisation, Allocation Concealment, and Blinding

Families were blindly randomised within each site area on a 2:1 basis to FT or to a services-as-usual, wait-list control group. This ratio, while it leads to a small reduction in statistical power, is ethically more desirable as it allows for the inclusion of a larger intervention group. Randomisation and allocation took place following family recruitment and baseline assessment, and was conducted by an independent consultant (unconnected to recruitment, data collection, or data analysis), using the SNOSE (Sequentially Numbered Opaque Sealed Envelopes) method [25]. The independent consultant privately informed practitioners of the family's group allocation, and concealed the randomisation and allocation sequence from the research team. Due to the nature of the intervention, neither family participants nor practitioners were blind to allocation. However, the researchers involved in data collection and statistical analysis were blind to treatment allocation. Participants and practitioners were requested not to disclose their group allocation to the research team at the follow-up assessment. Practitioners who delivered FT were not involved in delivering services to the control group (and vice versa) in order to avoid contamination between the intervention and control groups.

Procedure

The trial received ethical approval from the institution where the research was conducted, as well as from an additional three ethics committees linked to collaborating organisations, including the Health Services Executive Research Ethics Committee, Tusla Ethics Review Committee, and the Saint John of God's Research Ethics Committee. Families (parents and children 5–18 years) were recruited by practitioners in each site from their existing waiting lists. Sites had a prior installation/ implementation period in order to allow practitioners to train and gain experience in delivering FT, and each site also had a designated lead person responsible for promoting referrals to FT and the RCT. Recruitment brochures and posters were designed by the research team in collaboration with a number of site personnel and used to inform families and practitioners about FT and the study. Recruitment commenced in March 2019 and was carried out by referring practitioners on a staggered basis. Once practitioners assessed the suitability of the family for FT and the RCT, and secured consent from parents for their contact details to be passed in confidence to the research team, parents were then contacted by the fieldwork coordinator via telephone to arrange for one of the research team to visit them to explain the research. Researchers met with parents in the family home, or, if preferred, in a local family/health care centre. At each data collection point (T0 and T1), families were given information sheets and their written informed consent was obtained. Data were collected from one parent only (71 mothers, 12 fathers). For measures of child functioning, the parent had to select a child aged 5 to 18 years old to report upon. Families were provided with a small 'thank you' for their participation in the research, in the form of a shopping voucher worth €20 at each data collection visit. Practitioners informed families of their allocation within two weeks of the baseline assessment, and arranged a suitable time for FT sessions.

Prior to the COVID-19 pandemic in mid- March 2020, the follow-up assessment (T1) took place six months after the baseline assessment (T0). However, due to intermittent periods of COVID-19 public safety restrictions in 2020-2021, both delivery of the intervention and data collection had to be paused for 4-6 months (i.e. from mid-March to July 2020, November 2020, and January 2021). Therefore, assessments affected by the restrictions were collected 4-6 months later than originally planned. Taking the pause into account, we still considered the follow-up assessment time for these families to also be at 6 months. We compared outcomes in the analysis for assessments conducted before and after the COVID-19 restrictions. It was not possible to conduct the planned 12-month assessment within the funding timeframe. Data collection ended in December 2021.

Measures

A 'Profile Questionnaire' was developed specifically for purposes of the study in order to elicit demographic and background information on participating families. This provided important data for describing participant characteristics, testing the equivalency of the control and intervention groups, and conducting attrition analyses. A number of psychometrically robust, parent-report measures were also administered to assess primary and secondary outcomes as described below.

Primary outcomes

Our two primary outcomes were family functioning and child psychosocial functioning, both of which represent key objectives of the FT programme [17]. *Family functioning* was assessed with the Systematic Clinical Outcome and Routine Evaluation (SCORE-15), a 15-item, reliable and validated parent-report measure of family communication, relationships, and functioning [26]. The SCORE-15 has three dimensions or subscales including: 'Strengths and adaptability'; 'Overwhelmed by difficulty'; and 'Disrupted communication', with lower scores on each

indicating better family functioning. The clinical cut-off score is 39 for adults, with population norms of 26.

Child psychosocial functioning was measured by the 25-item Strengths and Difficulties Questionnaire (SDQ) [27], a parent-report, psychometrically sound questionnaire designed to assess child conduct problems, hyperactivity, emotional symptoms, peer problems, and pro-social behaviour for 3–18 year-olds. Higher scores indicate more emotional and behavioural difficulties. The clinical cut-off point is 17, with a borderline score of 14.

The following secondary outcomes were also assessed.

- *Child depression* was assessed using the 10-item, psychometrically robust, parent-

calculate the per-family cost of delivering the intervention (including and excluding one-off, non-recurring costs). This enabled us to provide an indication of the approximate costs involved in preparing for, and delivering the intervention, as well as the approximate proportions of time spent on various activities, which should be useful for service planning in implementing FFP.

Results

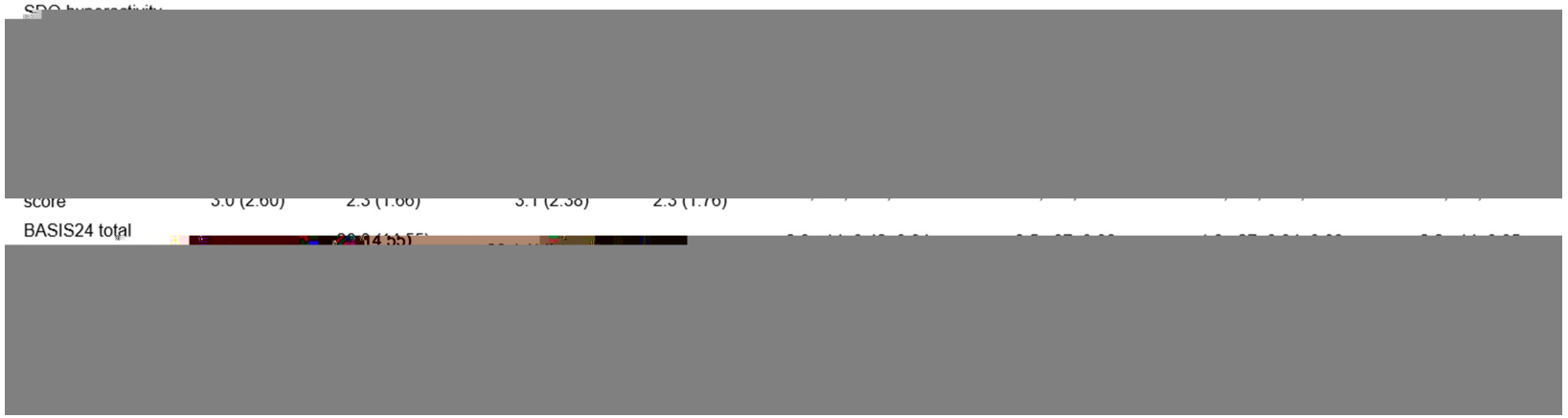
Participant characteristics

Parent participants were predominantly female (86%), with a mean age of 40.5 years (SD = 6.81) (Table 1). Most parents, at baseline, had been diagnosed with anxiety/depression (57%), followed by Bipolar Disorder (20%), Borderline Personality Disorder (12%), PTSD (8%) and psychosis (2%). Nearly half (48%) were in their current episode for more than two years, 12% for 1-2 years, 14.5% for 6-12 months and 17% for < 6 months duration. The vast majority of parents (< 80%) were attending AMHS, with the remainder under the clinical care of their GP. Most of the index children were female (60%) with a mean age of 13.85 years (*SD*=4.44). More than half of children (53%) were attending CAMHS or a psychology/family support service. More than three-quarters of families (77%) were socially disadvantaged when compared with average Irish norms [40] (Table 1).

Statistical analyses (Chi-square and two-sample t tests) indicated no significant differences between intervention and control group participants with respect to baseline characteristics or measure scores, with the exception that control group parents and children were slightly younger (parents: 38.5 years [6.51] vs. 42.5 years [7.10]; children: 12.2 years [4.62] vs. 14.5 years [4.25]) (Table 1). No statistically significant differences in participant characteristics were found between those retained in the study and those lost to follow-up. Overall, the rate of attrition at follow up was 37%, but this doubled following the COVID-19 restrictions (23% vs. 45%). While similar reasons for attrition were given across both groups (e.g. impact of COVID-19, family crisis, relapse), the higher rate of attrition from the intervention group (42% vs. 29%) may be related to family disengagement from the research process due to disillusionment in delays/disruptions in attending FT as a result of the pandemic restrictions (Figure 1).

Intervention outcomes

The intention-to-treat (ITT) analyses revealed statistically significant between-group differences in two of the primary outcomes at 6-month follow up: family functioning (SCORE-15) and child behaviour (SDQ conduct scale), with both indicating medium effect sizes. There was also a statistically significant between-group difference in parental understanding of mental illness (PUMI total score), in that those who reported lower levels of mental-health literacy at baseline significantly improved at follow-up. No statistically significant between-group mean differences were found for the other outcomes, although positive trends favoured the intervention (Table 2, Figures 3-5). The per-protocol analyses yielded similar results (Table 2). Interestingly, while the SDQ total score (overall child psychosocial functioning) was not statistically significant in the main analysis, exploratory post-hoc testing across a range of baseline values in the per-protocol analysis indicated that children who reported baseline SDQ scores in the 'borderline' region (14.9-16) achieved statistically significant changes at follow up when compared to those with baseline scores in the 'normal' or 'clinical' regions (Table 3). We found no statistically significant differences between those whose attendance/assessments were delayed by the COVID-19 restrictions and those who attended/were assessed before the pandemic. No harms were indicated either from the intervention or from the conduct of the RCT.


SDQ hyperactivity
score
3.0 (2.60)
2.3 (1.66)
3.1 (2.38)
2.3 (1.76)
BASIS24 total

80
Control
SCORE15 Total

Table 4 Impact of covariates on outcomes

CES total	F(3, 49) = 2.624, p=.061, η_p^2 = .14	F(1, 49) = 1.487, p=.229 d = .35, η_p^2 = .03	F(1, 49) = 5.305, **p=.026** *, d = .66, η_p^2 = .10	F(3, 41) = 7.360, **p<.001** *, η_p^2 = .35	F(1, 41) = .104, p=.749, d = .10, η_p^2 = .00	F(1, 41) = 13.992, **p<.001** *, d = 1.17, η_p^2 = .25

* p < .05 is statistically significant.

Table 5 Costs of implementing Family Talk

Salary per hour (mean €, SD)	31.27 (7.37)
[redacted]	
- Recruiting families	2.74 (3.34)
- FT sessions	10.14 (5.85)
- Travel to family hom[redacted]	[redacted]
[redacted]	
Total mean cost per clinician	1464.42 ([redacted])
[redacted]	

Discussion

The findings from the current RCT indicate that, across different mental health settings and diagnoses, Family Talk (FT) led to improved family relationships and functioning and fewer child conduct problems and, where mental health literacy was lower at baseline, improved parental understanding of mental illness and its impact on children. There were additional improvements in the per-protocol analysis in overall emotional and behavioural functioning for children who scored in the borderline range on the SDQ at baseline. There were no statistically significant improvements within the main analyses (ITT or per protocol) for child depression, anxiety, or parental mental health symptoms although there were trends favouring FT. Interestingly, however, we found that parents with less severe mental illness at baseline, and families with more partner and socioeconomic supports, derived additional benefits from FT, including improvements in child depression/anxiety and prosocial behaviour and in parental mental health symptoms and resilience. This was particularly the case where families attended all sessions, underlining the importance of engagement and implementation fidelity for positive treatment outcomes [41].

Enhanced family functioning and communication is a key objective of FT [16] and research indicates that these are very important in protecting children from developing mental health problems [42]. However, this outcome has not been commonly assessed within independent evaluations of FT. The current RCT included family functioning as a primary outcome in our protocol [Reference withheld for blind review], and found that FT significantly improved family cohesion, communication and ability to deal with stresses. This is consistent with the positive changes in family functioning reported in studies conducted by Beardslee and colleagues [9, 10, 16] and also within a recently completed RCT conducted in Greece [13]. In addition, we found significant improvements in the related, more proximal outcome of family understanding of, and communication about PMI within parents with lower levels of mental health literacy at baseline. Previous studies that assessed mental health literacy have similarly reported positive results [9-12]. Interestingly, Giannakopoulos et al. (2021) found that improved family functioning was associated with the greatest changes in children's psychosocial outcomes [13], thereby suggesting that a focus on family relationships should be an important active ingredient in interventions for children of PMI.

Most previous RCT evaluations of FT have indicated improvements in child internalising and externalising symptoms [9-11, 13-15], although some mixed results have also been reported, with one study showing improvements in externalising but not in internalising symptoms [12], another finding improvements in neither [18], and a third indicating improvements in child but not parent report of child psychosocial functioning [16]. Our study found improvements in child externalising (conduct) symptoms within the main ITT analysis, but only found improvements in overall child emotional and behavioural symptoms (SDQ total scale) for those who scored in the borderline region at baseline and whose families attended all sessions (per protocol analysis). Moreover, improvements in child depression/anxiety in the current study were also linked to families with better partner and economic supports, indicating that improvements in child internalising symptoms were only experienced by some subgroups.

Likewise, we found improvements in parental mental health symptoms only for the higher functioning family subgroups that had more partner and economic supports, and/or reported less severe parental mental illness at baseline. A small number of earlier FT evaluations have reported improvements in parental mental health at the overall group level, albeit at 1.5 and 4.5 year follow up [10, 13, 16], so it is possible that a longer-term assessment would capture benefits for more parents in the current study that were not realised in the shorter term. Interestingly, there have been mixed results from previous studies that investigated the link between child outcomes and the severity of PMI. For example, two studies conducted in Finland and Sweden found no link between child outcomes and baseline severity of parental depression/change from baseline [14, 15] while, conversely, Giannakopoulos et al. [13] reported that improvements in depression in a sample of Greek parents, were associated with enhanced child psychosocial functioning. Therefore, the nature of the relationship between severity of PMI and child outcomes remains unclear.

Little research, to date, has investigated the influence of socioeconomic status or partner mental health on intervention outcomes. A small number of previous studies of FT – two RCTs and a qualitative analysis – noted that disadvantaged families were more likely to disengage from FT [12, 14, 21]. The findings reported here suggest that families with more socioeconomic and/or partner supports derived additional benefits with regard to improved child internalising symptoms. Moreover, the process evaluation undertaken during Phase 3 of the project and conducted alongside the RCT, showed that socially disadvantaged families, and particularly those without a supportive partner and with more enduring mental illness, were more likely to withdraw from FT due to family crises, relapse in symptoms, and stresses in daily living

and that considerable time, resources and collective will are required to move away from the traditional biomedical and siloed approaches to treatment [22, 50].

Future research should focus on producing more large-scale, high quality, independent evaluations of FT across different cultural, policy, and mental health settings, and with a range of mental health diagnoses. These should also include, where possible, longer-term follow-up assessments and consideration of a range of outcomes relating to family functioning, child internalising and externalising symptoms, and parental wellbeing. The qualitative analyses also revealed benefits for sub-categories of parent and child wellbeing, including reduced stigma and feeling heard and validated, thereby highlighting outcomes that could be usefully assessed in future RCTs [References withheld]. In addition, further research is required to investigate for whom the intervention works best and which variables most influence intervention effectiveness. While we explored the influence of several factors including baseline severity of parental mental illness, partner mental health and socioeconomic status, our qualitative analyses identified a range of organisational and family factors that might be usefully tested as moderator/mediator variables in quantitative research; these include presence of a local champion, awareness-raising activities, adequate staffing, referral and supervision structures, family readiness to engage and treatment integrity [References withheld]. Larger-scale studies could model the influence of such variables. Lastly, more sophisticated cost-effectiveness and/or cost-benefit analyses are needed to inform the mainstream implementation of FFPs within routine mental health services.

Conclusion

The findings from the current study demonstrate that even in a country that lacks a national "think family" policy/practice framework to support families with PMI, a low-cost, structured, whole-family intervention can be effective in improving family functioning and child behaviour. Additional benefits in child and parental mental health were noted for higher functioning families, indicating that a continuum of supports may be required to meet the many and often complex needs of families. The RCT (and the accompanying qualitative analyses) demonstrate that FT can be successfully implemented with different mental health disorders and across a range of adult, child and primary care mental health settings. These findings are important in adding to the growing evidence base for FT, whilst also providing a robust basis to inform practice and policy development for families with PMI, both in Ireland and elsewhere. However, multi-level, public-health responses are required across jurisdictions, not only to promote the longer-term sustainability of FFP, but also to address the enduring political, cultural, organisational, and family barriers to change.

Abbreviations

AMHS: adult mental health services
BASIS-24: Behaviour and Symptom Identification Scale 24
CAMHS: child and adolescent mental health services
CI: Confidence interval
CONSORT: Consolidated Standards of Reporting Trials
CSE: Coping Self-Efficacy questionnaire
FFP: family-focused practice
FT: Family Talk
GP: General practitioner
ITT: Intention to treat
MDT: Multi-disciplinary Team
MM: Mixed modelling
PMI: parental mental illness

PRIMERA: **P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies and children
PUMI: Parental Understanding of Mental Illness questionnaire
RCADS: Revised Children's Anxiety and Depression Scale
RCT: randomised controlled trial
SCARED-5: Screen for Child Anxiety Related Disorders 5
SCORE-15: Systematic Clinical Outcome and Routine Evaluation 15
SD: Standard deviation
SDQ: Strengths and Difficulties Questionnaire
SES: Socioeconomic status
TAU: Treatment as usual
T0: Baseline assessment before intervention
T1: First follow-up assessment

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Conflict of interest

None

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Table 1. Participant characteristics at baseline
Table 2. Intervention outcome analyses
Table 3. SDQ total
Table 4. Impact of covariates on outcomes
Table 5. Costs of implementing Family Talk
Figure 1. Study flow diagram
Figure 2. Family Talk sessions
Figure 3. SCORE-15
Figure 4. SDQ conduct problems
Figure 5. PUMI

	1a	Identification as a randomised trial in the title	P1
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	N/A
	6b	Any changes to trial outcomes after the trial commenced, with reasons	P7
Sample size			

		assessing outcomes) and how	
	11b	If relevant, description of the similarity of interventions	N/A
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	P9-10

*We strongly recommend reading this statement in conjunction with the CONSORT 2010 Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials

		b. Describe the impacts and mitigating strategies, including their rationale and implications for the trial. The impacts are outlined above and below. Mitigating strategies involved: • Seeking additional funding to extend the trial by 10 months to allow time for intervention delivery, data collection and data analysis • Working with services to try and stay in contact with participants where possible using online platforms • Analysing the data we collected even though we did not reach the required sample size and attrition was doubled • Conducting analyses to compare results between families whose attendance/assessments were delayed by the COVID-19 restrictions and those who attended or were assessed before the pandemic • Not being able to conduct the planned 12-month follow-up assessment or the full cost effectiveness analysis within the funding timeframe	(see below) P5-7, 9, 10, 13, 14
		c. Provide a modification timeline. Funding for an additional 10 months was secured. All data collection was completed in December 2021.	P6
III.	Responsible Parties	State who planned, reviewed and approved the modifications. The modifications were planned by the PRIMERA research team, extra funding was secured from the Maynooth University Higher Education Authority COVID-19 Costed Extension Fund, and approval was obtained from the Health Services Executive and Maynooth University.	P16

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6	Methods: Outcomes		The pandemic restrictions delayed/disrupted the delivery of the intervention and the collection of data from families.	We secured extra funding to be able to complete the 6-month data collection and to try to recruit more participants to the trial. We were unable to conduct the planned 12-month follow-up assessment or the full cost effectiveness analysis within the funding timeframe However, we collected and analysed costs data from practitioners to estimate the costs of delivering the intervention to families.	P6, 7, 10, 14
7	Methods: Sample Size		The restrictions greatly impacted recruitment to the trial	We analysed the data we collected even though we did not reach the required sample size for one of our primary outcomes.	P4, 5, 13, 14
8-10	Methods: Randomisation	✔			P5
11	Methods: Blinding	✔			P5
12	Methods: Statistical methods	✔			P8, 9
13	Results: Participant flow	✔			P5

14	Results: Recruitment		The restrictions greatly impacted recruitment to the trial	We analysed the data we collected even though we did not reach the required sample size for one of our primary outcomes.	P5
15	Results: Baseline data	✔			P10
16	Results: Numbers analysed		Attrition doubled after the pandemic compared to beforehand.	We made every effort to collect follow-up data from as many families as possible.	P5, 11
	Results: Outcomes and estimation	✔			P11
18	Results: Ancillary analyses	✔			P11
19	Results: Harms		There were no indication of harms but there was a higher attrition rate from the intervention group compared to the control group, most likely due to disengagement from the service when the intervention was delayed multiple times.	We reported what happened in the study flow diagram and followed up on experiences of participants in our qualitative analyses.	P11
20	Discussion: Limitations		The limitations are outlined above.	The limitations are reported in the paper.	P13, 14

21	Discussion: Generalisability		Generalisability is possibly comprised by some families having the intervention disrupted/delayed, the higher rate of attrition, and that the pandemic and restrictions may have affected mental health beyond the effect of the intervention.	Generalisability limitations are outlined in the discussion. Nevertheless the findings have implications for policy, practice and research	P13-15
	Other information: Registration	✔			P2
24	Other information: Protocol	✔			P18, ref 20
25	Other information: Funding	We sought additional funding to extend the trial to allow time for intervention delivery, data collection and data analysis			P16

*Aspects of the trial that are directly affected or changed by the extenuating circumstance and are not under the control of investigators, sponsor or funder.
**Aspects of the trial that are modified by the study investigators, sponsor or funder to respond to the extenuating circumstance or manage the direct impacts on the trial.

Appendix C: Abstract for Retrospective Study of living with PMI in Childhood

Background

Evidence has accumulated over the last three decades to highlight the important role of

makes it challenging to hold the government and management accountable for what/where money is being spent.
- Funding is piecemeal, not frontloaded and never ring fenced. E.g., even the clinical programs are rolled out without adequate guaranteed funding which impedes lasting implementation at a national level.

Resource challenges fiscal & staffing

- Mental health reform: National budget is over 1 billion. WHO recommend 12% to be spent on mental health, Slainte care recommended 10%, but current funding is still only at 6%. The HSE also has a long history of spending money badly (80's 20% of MH budget spent on in-patient hospitals). Also, the largest cohort of staff are nurses with an over reliance on agency staff nurses who cost 2/3rd more than normal staff.
- Fourteen years since the VFC, staffing levels continue to be inadequate.

Interagency barriers

- The lack of resources fuels competition and mistrust between services. (e.g., CAMHS provide wraparound services for individuals but this cannot be replicated in AMHS. Some level of mistrust was also expressed about CAMHS referring individuals with multiple complex needs to AMHS where mental illness is only one in a long list of issues. This led to the suggestion that funding should follow the individual and not the agency.

Lack of political will

- With only a Junior minister for mental health, there is a clear lack of priority for mental health as demonstrated in the funding percentages mentioned earlier.
- Without sustained public pressure on mental health, it will not be valued on the political agenda especially as children have little impact politically and are therefore easily ignored.

International experience of and barriers to FFP

- Despite legislative change in Norway in 2010, FFP has not been embedded. Practice changes have not been implemented because they were introduced as an extra task for the adult mental health services without any extra resources. As it is not a task that is measured, (or if measured, without consequences if not completed), clinicians can easily opt out of the task.
- In most cases, if a child friendly person is tasked with the role of assessing children of parents admitted to adult wards (required by law), they invariably burn out. Therefore, multiple people are needed who will *equip* staff to do the tasks rather than carry sole responsibility for the task themselves.
- Change has not been systematic.
- Norway also has an issue with the lack of an integrated IT systems making it easy for staff to avoid necessary FFP tasks.
- A drop off in FFP is experienced once the research team pull out.

<u>Possible steps forward</u>

- The FFP implementation plan must be realistic given that it requires approximately 20-25 years to change thinking, practice, and culture.
- Change agents (champions) need access to senior management to effect change at frontline, operational, and strategic levels while strengthening guidance/policy/procedures/pathways.

Appendix E: Summary of the Family Talk Intervention Briefing Paper

Helping to inform a 'Think Family' approach to mental health service provision in Ireland:

The Family Talk Intervention

Briefing Paper

PRIMERA Research Team

Centre for Mental Health and Community Research

Maynooth University Department of Psychology

PRIMERA

Promoting **R**esearch and **I**nnovation
in **M**ental h**E**alth se**R**vices for f**A**milies

(b) Identify discussion points for the family meeting

(c) Role-play family meeting discussion points

Week (5) Holding the family meeting - Worker meets with parents and children together

(a) Parents or worker provide information on depression and anxiety

(b) Support family discussion

Week (6) 1-week follow-up Mental Health professional meets with parents

(a) Check-in to ensure that everyone is ok

(b) Support parents to plan next steps for the family

Week (7) Long-term follow-up (3-6 months) Worker meets with parents

(a) Check-in with families every six to nine months

(b) Be available for continued follow-up

It is recommended that practitioners also look at Keeping families and children in mind as a prerequisite course to *Family Talk*. It is a short eLearning resource to help practitioners in establishing a 'family-sensitive' approach.

Practitioners should also usefully consult with the links below which all provide excellent online resources which will inform the implementation of *Family Talk*.

https://fampod.org/

https://emergingminds.com.au/about/

http://www.copmi.net.au/

Family Talk: Online training resource for clinicians

An eLearning resource for mental health professionals working with families where parents experience mental health issues such as depression and/or anxiety.

Aim: Train the clinician to assist the family to understand the impact of depression/anxiety on a child and to develop resilience.

Duration: 10-20 hours (includes videos and assessments)

Resource: PDF handbook available for download

Cost: No cost

Seven eLearning modules:

(1) Working with the family

(2) Introducing family talk

(3) Building understanding

(4) Dialogue with the child

(5) Partnering with parents

(6) Resilient families

(7) Enabling the future

Parent Talk: Module for parents

Parent Talk[34] is an online programme for interested parents to provide information about depression/anxiety and build resilience for children and parents (available on the COPMI website).

Format: Online resource

Cost: No cost

B. European sites

The links below may also provide useful information.

Enter Mental Health

The mission of 'ENTER' is to promote and defend the highest standards of mental health promotion, training and care in Europe based on collaborative research'. Of particular note is the free manual 'train the trainer' resource for professionals working in the area of mental health.

The manual can be found here: EMILIA

Emilia (part of ENTER MENTAL HEALTH) provides a number of training modules for mental health professionals working to promote social inclusion (those living with mental health issues) and includes a family module which can be found here: http://mailtodawson.wixsite.com/emilia-training/families

CAMILLE **(part of the ENTER site)** used EU Daphne III funding to design training to upskill professionals working with parental mental illness.

This training component includes:

Components include:

(1) Introduction
(2) Knowledge base (attachment theory, coping strategies, legal regulations)
(3) Parental/family needs (child-related skills and parent/adult-related skills)
(4) Supporting the family
(5) Evaluation & certificate of attendance.
(6) Includes necessary training resources including OHPs, handout and supporting documents.

C. Additional training resources from Emerging Minds & COPMI sites:

[34] http://www.copmi.net.au/find-resources/resource-library/item/family-talk-tips-and-information-for-families-where-a-parent-has-a-mental-health-problem-or-disorder

- A 'whole family', family-centred approach, involving both parents and children in the intervention (including adherence to any kind of family-focused model)
- Inter-agency collaboration/coordination among key services (e.g. Adult Mental Health, Child and Family agency, CAMHS, primary care, community organisations)
- Utilisation of interventions such as psycho-education, cognitive-behavioural therapy and/or counselling to help reduce the impact of poor mental health on parents and on their children and to help improve parenting competencies, child coping and resilience skills
- A focus on recovery-oriented care and working collaboratively with families.

Who is conducting the research?

The programme of research is being undertaken by a research team led by Professor Sinéad McGilloway, Director of the *Centre for Mental Health and Community Research*

PRIMERA Expression of Interest Form

1. Name:

2. Location/name of service:

3. Address:

4. Contact details:

Please answer the following questions:

5. Why are you interested in taking part in this research programme?

6. Are any services in your area currently delivering any family-focused services/ approaches or following any particular family-focused model?

Yes □ No □ Don't know □

7. If 'yes, please name and describe these briefly below and then proceed to Question 8. If 'no'/'don't know', please proceed to Question 8.

As stated earlier individuals in most of the services represented on the sub-group are delivering psycho-education interventions with families they are working with.

8. Do you know of any other similar family-focused services that are currently being implemented in other regions within Ireland?

Yes □ No □

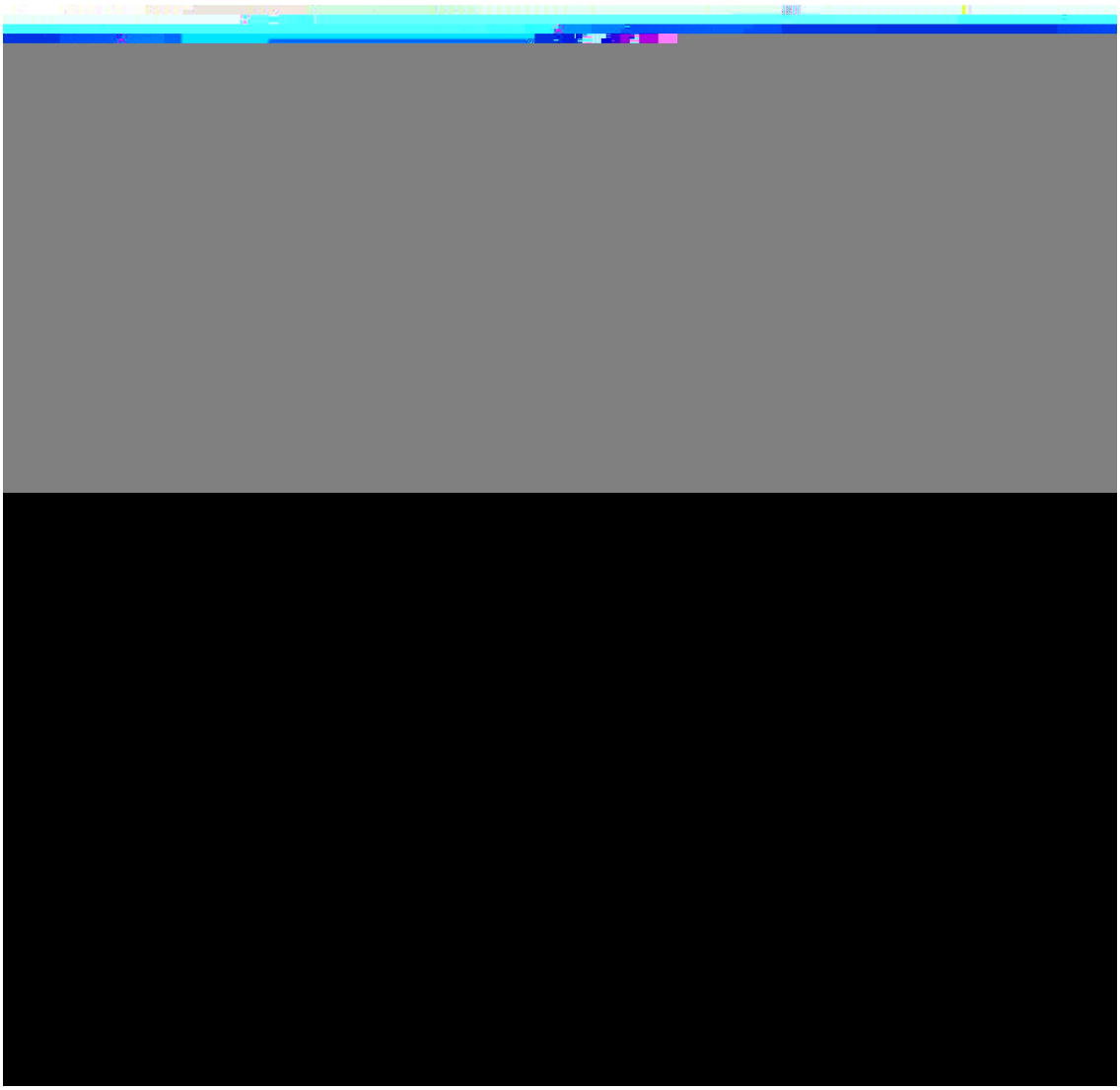
9. If 'yes', please name and describe these briefly below.

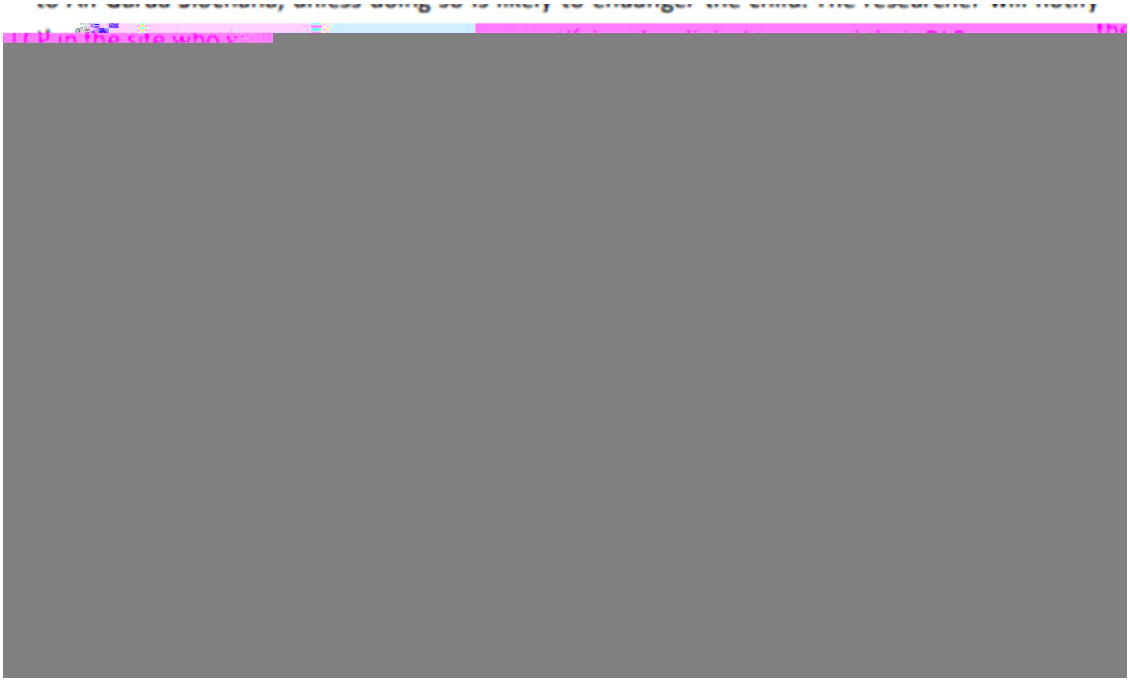
NB. Please email this completed document to Mairead.Furlong@mu.ie before 22nd September 2017.

THANK YOU FOR YOUR INTEREST

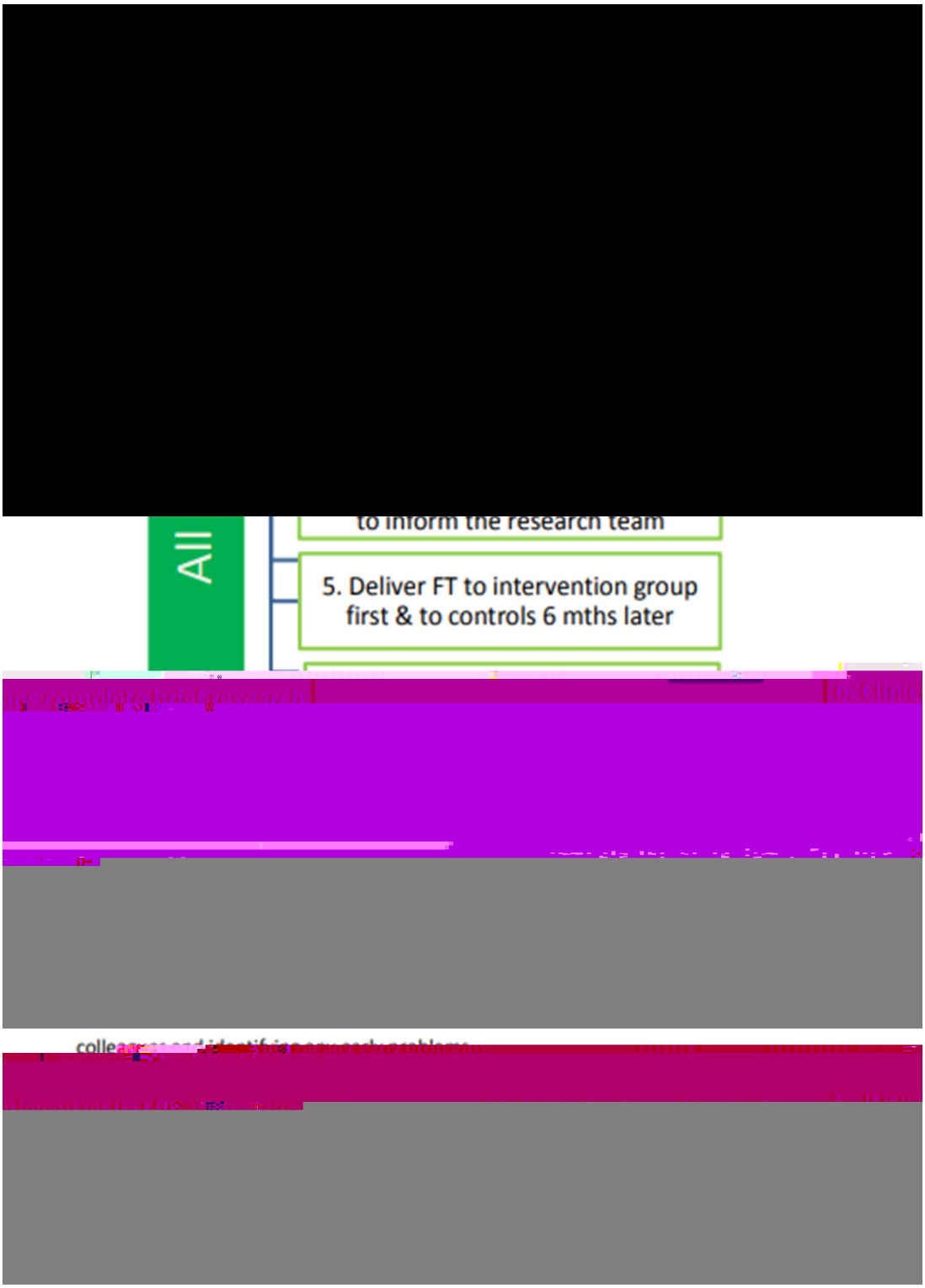
Appendix I: PRIMERA List of Responsibilities for Lead Clinician at each Site (PDF)

Responsibilites of lead contact person in each site *



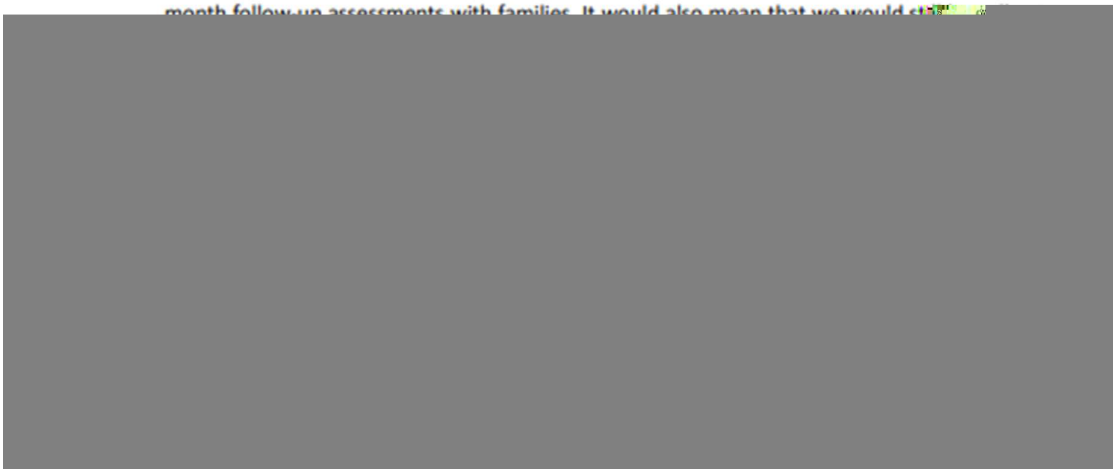


Appendix J: Responsibilities for All Clinicians Delivering Family Talk as part of the RCT (PDF)

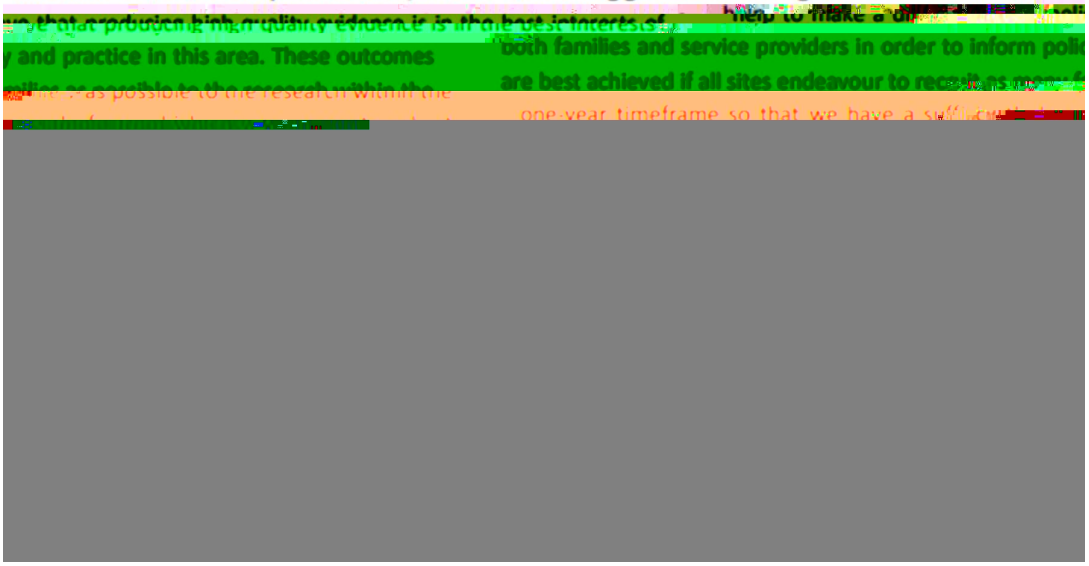


4. Family leaflets have been provided to help clinicians explain FT to families using plain language

- The funding for the study ends in early 2021. If most of the recruitment is left towards the end of 2019, that leaves a very limited period of time for the research team to conduct 6- and 12-month follow-up assessments with families. It would also mean that we would st

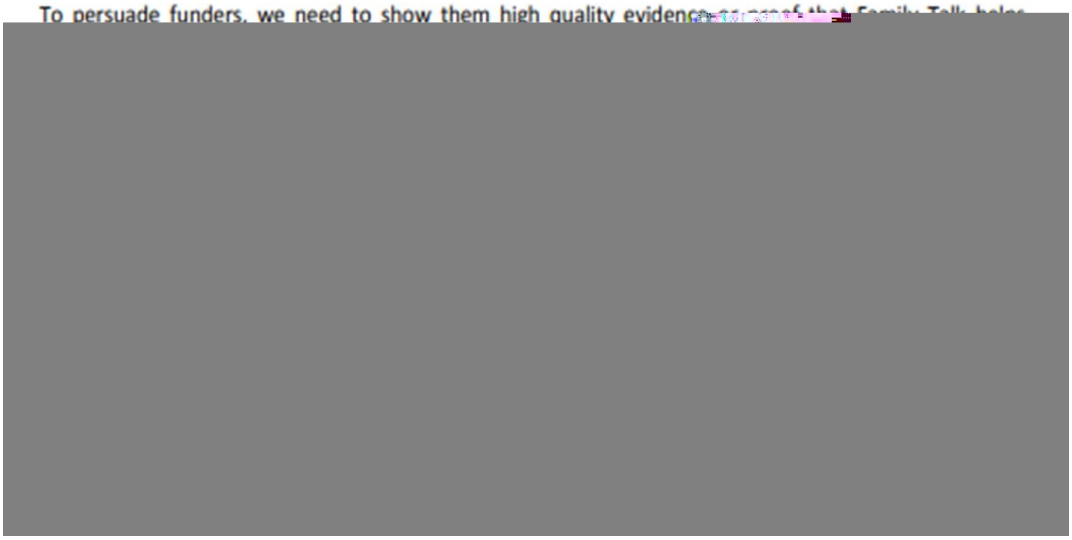


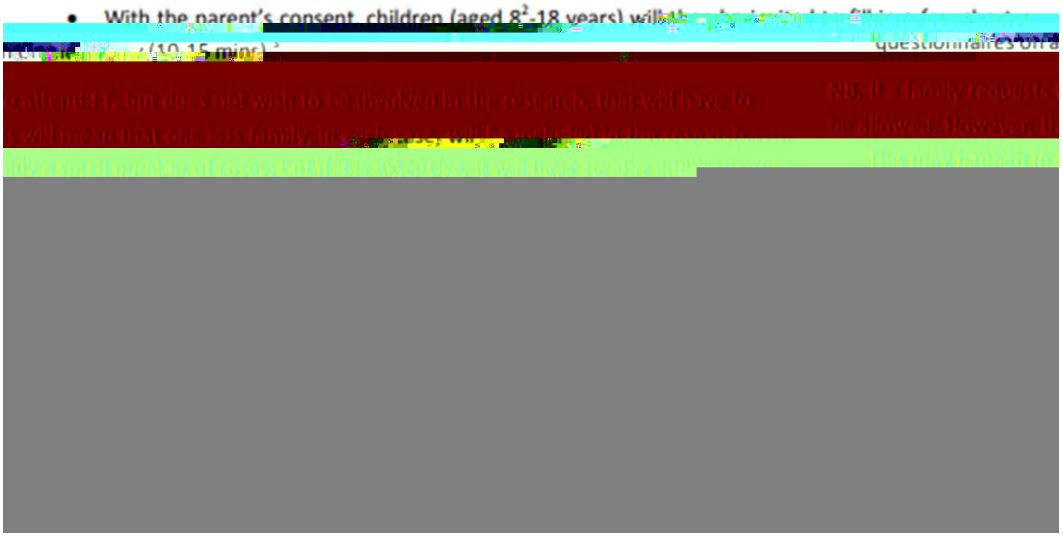
the research team are required to work, and our overarching goal to conduct rigorous research that will

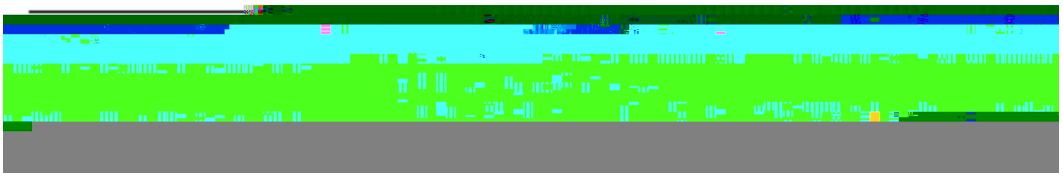


2:1 chance of getting Family Talk now or in six months

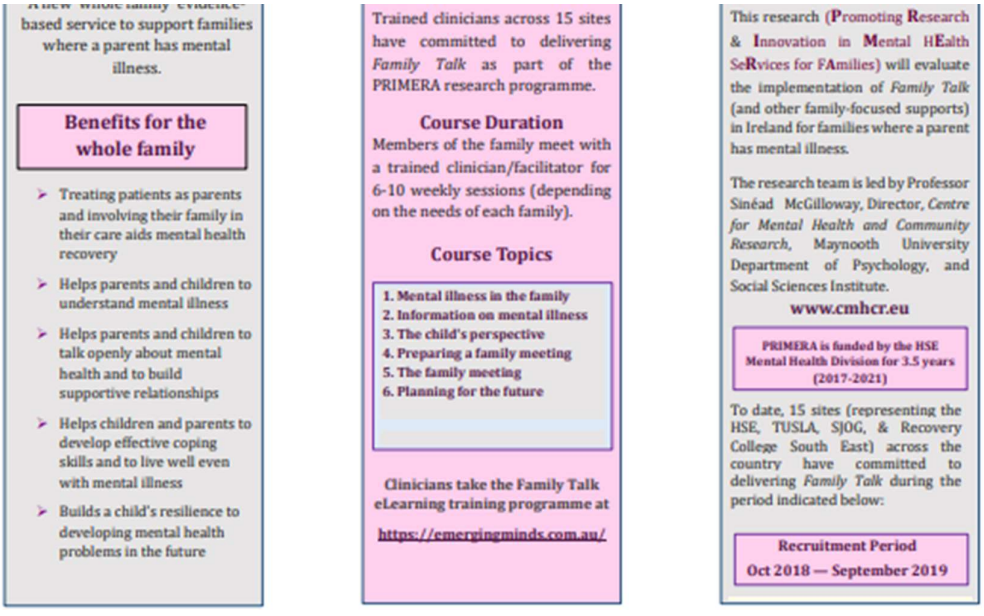
To persuade funders, we need to show them high quality evidence [redacted]







Appendix K: Trifold Brochure to Inform Mental Health Practitioners about PRIMERA (PDF)



based service to support families where a parent has mental illness.

Benefits for the whole family

- Treating patients as parents and involving their family in their care aids mental health recovery
- Helps parents and children to understand mental illness
- Helps parents and children to talk openly about mental health and to build supportive relationships
- Helps children and parents to develop effective coping skills and to live well even with mental illness
- Builds a child's resilience to developing mental health problems in the future

Trained clinicians across 15 sites have committed to delivering *Family Talk* as part of the PRIMERA research programme.

Course Duration

Members of the family meet with a trained clinician/facilitator for 6-10 weekly sessions (depending on the needs of each family).

Course Topics

1. Mental illness in the family
2. Information on mental illness
3. The child's perspective
4. Preparing a family meeting
5. The family meeting
6. Planning for the future

Clinicians take the Family Talk eLearning training programme at

https://emergingminds.com.au/

This research (**P**romoting **R**esearch & **I**nnovation in **M**ental H**E**alth Se**R**vices for F**A**milies) will evaluate the implementation of *Family Talk* (and other family-focused supports) in Ireland for families where a parent has mental illness.

The research team is led by Professor Sinéad McGilloway, Director, *Centre for Mental Health and Community Research*, Maynooth University Department of Psychology, and Social Sciences Institute.

www.cmhcr.eu

PRIMERA is funded by the HSE Mental Health Division for 3.5 years (2017-2021)

To date, 15 sites (representing the HSE, TUSLA, SJOG, & Recovery College South East) across the country have committed to delivering *Family Talk* during the period indicated below:

Recruitment Period
Oct 2018 — September 2019

Appendix L: List of Presentations and Media Promotions Conducted during the Study

Presentations

Mulligan, C. Presentation as part of the CMHCR 'Against the Odds' event held as part of Research Week (and on World Mental Health Day), 10th October 2018.

Mulligan, C. Introducing PRIMERA. Maynooth Psychology 20th birthday event, 30th January 2019.

Mulligan, C., Furlong, M. and McGilloway, S. "Growing pains" - developing family-focused practice for families with parental mental illness in the Republic of Ireland. "It takes a village" International conference for families experiencing substance use, mental or physical health problems Oslo, 13th- 17th May 2019.

Mulligan, C., Furlong, M. and McGilloway, S. Adult children: The presenting past: living in a home with parental mental illness, Family-focused Symposium, Drogheda, 3rd Sept 2019.

Mulligan, C., Furlong, M. and McGilloway, S. Series of PRIMERA research presentations at academic meetings. These multi-disciplinary educational gatherings involved broader mental health teams on new practices/papers and provided PRIMERA with the opportunity to present to professionals not directly linked to PRIMERA. Carlow 7th May 2019; Letterkenny 28th June 2019; Galway, 8th, and 22nd October 2019.

Mulligan, C., Furlong, M. and McGilloway, S. PRIMERA: Promoting Research and Innovation in Mental hEalth seRvices for fAmilies, Annual Irish Social Work Conference, at St Patrick's Mental Health Services, James's Street, Dublin 8 on February, 21st 2020 entitled, *Family Focused Practice: The Role of Mental Health Social Work.*

Poster presentations

McGilloway, S., Furlong, M., **Mulligan, C.,** McGarr, S., and O'Connor, S. Implementing family-focused practice through engaged research & collaboration in the Republic of Ireland: Clinicians' perspectives. Poster presentation for the Symposium to celebrate Think Family initiatives (November 2022).

Furlong, M., **Mulligan, C**., McGarr, S., O'Connor, S., McGilloway, S. Developing and evaluating a 'Think Family' care delivery agenda within mental health services in the Republic of Ireland: A national scoping study. Poster presentation for the Symposium to celebrate Think Family Initiatives (September 2018) in Northern Ireland.

Lectures

Mulligan, C., McGilloway, S. Parental Mental Illness: Two 2hr guest lectures were delivered on the need to support PMI in DCU on 10th & 17th April 2019.

Media promotion of PRIMERA

The Irish Times on 1st June 2022 https://www.irishtimes.com/life-and-style/health-family/parenting/breaking-the-cycle-of-intergenerational-mental-illness-1.4887160 Published 1st June 2022

The Irish times published on 17th May 2022 https://www.irishtimes.com/news/health/study-calls-for-family-focused-approach-to-mental-health-treatment-1.4879932

Irish Independent published on 16th May 2022 https://www.independent.ie/irish-news/health/nearly-one-in-four-families-has-at-least-one-parent who-has-or-had-a-mental-health-disorder-41654522.html

The Bridge (Maynooth University magazine) published December 2018
https://www.maynoothuniversity.ie/daro/events/archive?page=2

The Irish Examiner published on 6th September 2018
https://www.irishexaminer.com/news/arid-30867014.html

The Irish Times on 18th September 2018 Reflection on this authors' lived experiences of growing up in a family where there were mental health difficulties. The other PRIMERA team members, Professor Sinéad McGilloway, and Dr Mairead Furlong, also discuss the research within this article. https://www.irishtimes.com/life-and-style/health-family/parenting/my-mummy-didn-t-wake-up-this-morning-1.3625624

Radio Interviews

Professor Sinéad McGilloway
Kildare Today with Clem Ryan on 18th May 2022
https://www.kfmradio.com/on-air/podcasts/kildare-today/episode/wednesday-18th-may-2022-hour-1/

Connemara FM with Marian Herriot on 23rd May
https://www.connemarafm.com/podcasts-for-connemara-community-radio/

Drive time with Mary Wilson on 6th September 2018
https://rte.ie/r.html?rii=b9_10931049_83_06-09-2018_

Dr Mairead Furlong
Kilkenny Carlow FM Radio with Sue Nunn's mental Health segment on 23rd May 2022
https://kclr96fm.com/the-way-it-is-with-sue-nunn-wednesday-18th-may-2022/

Christine Mulligan
Interviewed on the 'The Ray D'Arcy radio show' on 25/9/2018.
https://www.rte.ie/radio/radio1/clips/21437306/

Interviewed for the 'Walk in her shoes' in St Patricks Hospital on 5/10/2018.
Clip no longer available online.

Interviewed on the Galway Bay FM radio show promoting PRIMERA regionally.
https://galwaybayfm.ie/galway-bay-fm-news-desk/mental-health-family-support-programme-rolled-out-in-galway/

Podcast Took part in a podcast on 20TH March 2023 with Professor Sinéad McGilloway detailing findings from the PRIMERA study for the Association for Child and Adolescent Mental Health (ACAMH) https://www.acamh.org/author/acamh-podcasts

Appendix M: Letter issued on behalf of Senior HSE and Tusla Managers

11 March 2019

Dear managers and practitioners

Re: Delivery of Family Talk as part of the PRIMERA research programme

As you may already know, the PRIMERA[35] research programme at Maynooth University's *Centre for Mental Health and Community Research* is currently working with 15 sites across the Republic of Ireland in implementing and evaluating family-focused practice for families where a parent has mental health difficulties/illness (https://cmhcr.eu/primera-programme/). The sites are listed below. This research is of considerable national and international importance in promoting a 'think family' agenda in the Republic of Ireland. Many commentators have highlighted that these families often do not receive the supports they need, and have called for the provision of more holistic, integrated, evidence-based and family-focused interventions for families where a parent has mental health difficulties (Barnardo's, 2014; Bee et al. 2014).

The aims of the PRIMERA research are to: (1) identify, implement, and evaluate family-focused interventions for families where a parent has mental health difficulties (and has children 0-18 years); (2) promote a 'think family' care delivery agenda in supporting such families in Ireland; and (3) develop national practice guidance in working with these families.

Currently, 12 sites are involved in delivering Family Talk (FT) (a 6-8 session evidence-based model), which will be evaluated as part of the PRIMERA research. Collaborating organisations within the 12 FT sites include: HSE Adult and Child and Adolescent Mental Health Services, HSE Primary Care, Tusla Child and Family agency, Saint John of God Hospitaller Services, Children and Young People's Services Committees, Recovery College Southeast, and the community/voluntary sector.

Family Talk participating sites

- Carlow AMHS & Recovery College Southeast
- Cherry Orchard AMHS/CAMHS
- Galway Roscommon AMHS/CAMHS (Crosslinx West)
- Louth AMHS/CAMHS
- Longford/Westmeath, Laois/Offaly AMHS/CAMHS/Primary Care
- Mayo Mental Health Services
- St John of God AMHS Cluain Mhuire Blackrock
- Tusla Dublin South Central and Kildare
- Tusla Galway Roscommon
- Tusla Louth Meath
- Tusla Mayo
- Clare Children and Young People's Services Committee

Sites delivering an alternative family- focused intervention

- Kilkenny Mental Health Services
- Letterkenny Mental health Services

[35] PRIMERA - **P**romoting **R**esearch and **I**nnovation in **M**ental h**E**Alth se**R**vices for children and f**A**milies

- North Dublin AMHS

We recognise, and are grateful for, the time, energy and dedication invested by clinicians and managers in all participating sites in introducing family-focused practice as part of this important research programme. However, the success of the programme and the accompanying research rely hugely on the number of families who can be identified and recruited to the study. Given the funding timeline, **the deadline for enrolling families into the research is September 2019**. Therefore, we would request that all clinicians and managers make a focused and concerted effort to identify as many families as possible to enrol into the research by this date.

We believe that producing high quality evidence is in the best interests of both families and service providers in order to inform policy and practice in this neglected area. These outcomes are best achieved if all sites endeavour to recruit as many families as possible to the research so that the research team have a sufficiently large sample from which to generate robust findings.

This is a unique opportunity to try and make a real difference for vulnerable families in Ireland and possibly beyond.

Many thanks for your help and support.

We look forward to continuing to work with you all.

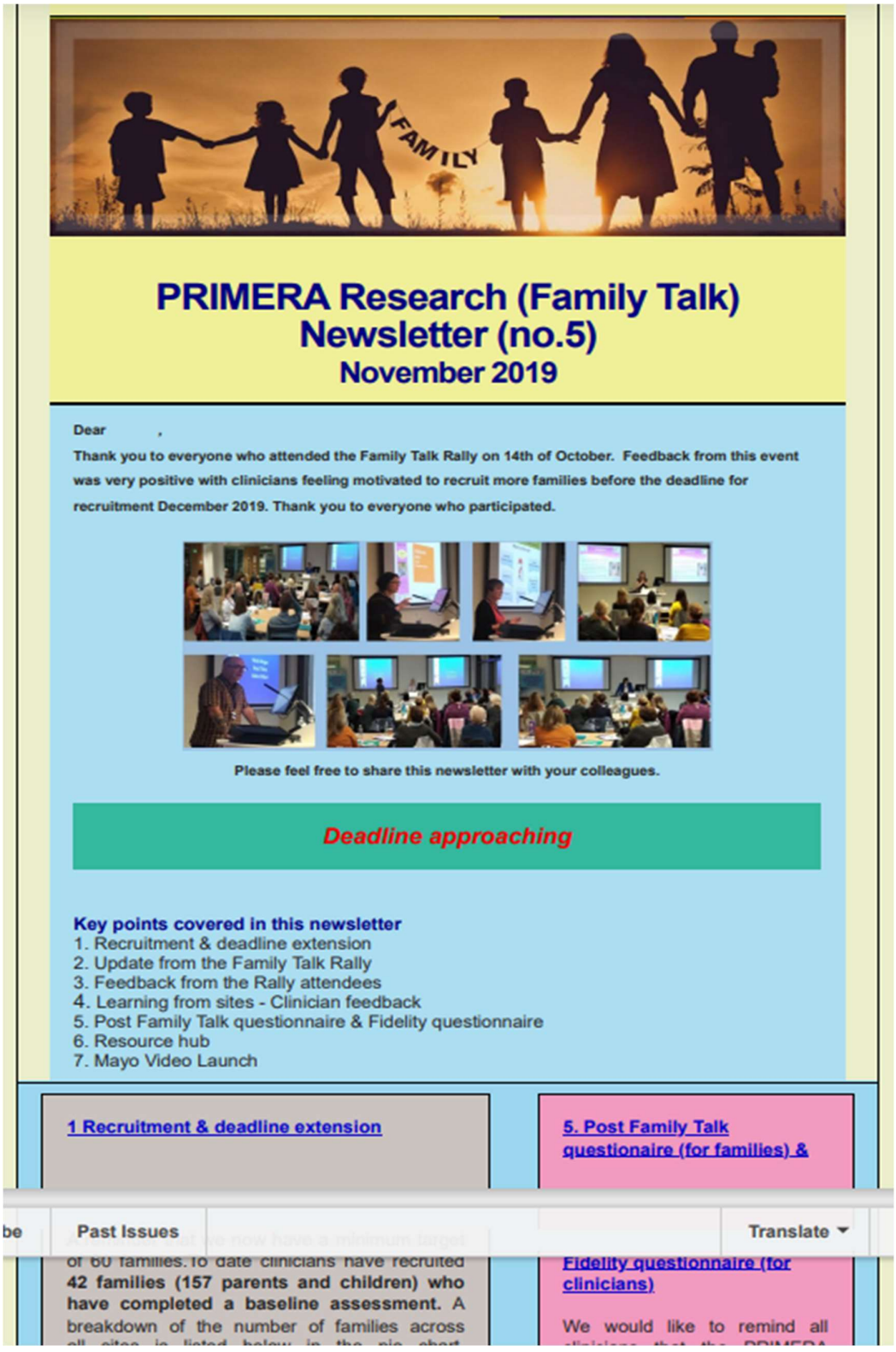
Yours sincerely,

Dr Sinead Reynolds, Chair of the PRIMERA Steering Committee, HSE national Mental Health Operations and Performance

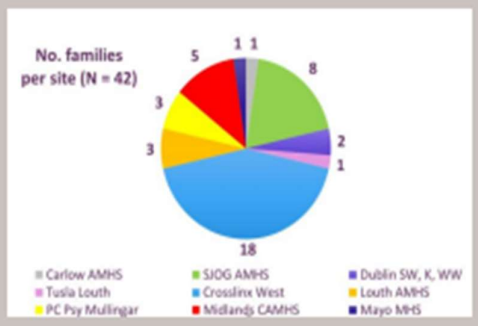
cc PRIMERA Steering Committee and Research Team

- Mr Jim Ryan, Head of Mental Health Operations
- Mr Gerry Maley, Business Manager to the Head of Mental Health Engagement, National Mental Health Division, HSE
- Mr Gerry Lowry, Tusla Commissioning, Tusla Area Manager Cavan, and Monaghan
- Dr Shari McDaid, Director of Mental Health Reform
- Ms Kate Mitchell, Senior Policy and Research Officer, Mental Health Reform
- Prof Agnes Higgins, Professor in Mental Health (School of Nursing and Midwifery, Trinity College Dublin
- Prof Sinead McGilloway, Director, Maynooth University Centre for Mental Health and Community Research, Principal Investigator PRIMERA research programme
- Dr Mairead Furlong, PRIMERA research programme manager, Maynooth University
- Ms Christine Mulligan, Doctoral fellow, PRIMERA research programme, Maynooth University

Appendix N: Sample Ezine Issued for the Feedback Loop (PDF copy/format from Mailchimp)



have completed a baseline assessment. A breakdown of the number of families across all sites is listed below in the pie chart. Eight service users have also completed a 6 month assessment with the research team.



To date **77 clinicians** have completed the Family Talk online training with an additional 10 staff training in Cork and the Midwest.

2. Update on the Family Talk Rally

I was feeling deflated & defeated in trying to promote FT and a Think family approach in my MDT. Today has revived my passion & motivation. Thank you!

Great idea to bring the services together and hear about their experiences. Very well run and facilitators were excellent.

The Rally was very well received and attended by 50 clinicians who were welcomed by Professor Sinead McGilloway, principal investigator of PRIMERA and Dr Sinead Reynolds, senior manager in national mental health operations. Gina Delaney, the National Engagement and Recovery Lead, set out the Framework for Recovery in Mental Health, 2018-2020 which focuses on supporting Families in Recovery. Mary G Killion, principal

We would like to remind all clinicians that the PRIMERA researchers are asking Families to complete the Post Family Talk questionnaire at the 6-month assessment (with stamped addressed envelope). We would also ask you to remember to keep a record of the number of hours involved (and costs incurred) in recruiting families and delivering Family Talk. This data will be required xxxxxxxx.

6. Resource hub

Below is a reminder of the resources available on the PRIMERA resource hub which can be found here.

7. Mayo Launch Irelands first online resource (WITH project)

Maria Walsh MEP and Dr Sharyn Byrne (senior clinical psychologist CAMHS) of CAMHS in Castlebar launched the WITH Project (Wellbeing In The Home) on October 11th. This programme

The complete presentation from the Family Talk Rally can be downloaded here xxxxxx

3. Feedback from Rally attendees

84% of attendees of the Rally strongly agreed that the event was useful and 87% left the event with a better understanding the importance of Family Focused practice for families impacted by parental mental illness (PMI). Attendees report that the most helpful elements on the day included lived experience by Shay O'Brien who talked on the inter-generational impact of PMI and Aideen Millard who recently completed the Family Talk intervention. The shared learning across PRIMERA sites and Northern Ireland on the challenges faced by clinicians, presented by Mary G Killion, principal social worker Galway/Roscommon and Mary Donagh,social care commissioning lead within Adult Mental Health and Learning Disability, and regional lead for Think Family NI was highly rated.

To date **77 clinicians** have to date completed the Family Talk online training with an additional 10 staff training in Cork and the Midwest.

4. Learning from sites - Clinician Feedback

Mairead presented on important factors for keeping clinicians motivated and supported in their efforts to engage families to Family Talk. These include:

- Leading 'from the front' with a **local champion** promoting Family Talk (FT) at local levels
- Getting **buy-in from all relevant disciplines**
- Allowing **sufficient time to engage families** (secured through good relationships with clients)
- Carve out **dedicated time** in your diary to recruit families for Family Talk
- **Include Family Talk on the agenda** of weekly team meetings to highlight the issue of family-focused practice on a regular basis.

Do remember to access the Family Talk resource needs or contact the PRIMERA team at PRIMERA@mu.ie

to parental mental health produced in Ireland.

Photo by Michael McLaughlin published in Mayo News on 15th October 2019

Access to these excellent resources can be found on the PRIMERA resource hub and here www.mindspacemayo.ie (YouTube Channel)

A youth led panel at the launch included Christine Mulligan (Maynooth University), Chloe Moyles, Niamh Lusson, Sarah Moran and Maria Walsh, MEP. Back, from left: Peadar Gardiner (Mindspace Mayo), Dean Kenny and Dr Sharyn Byrne (psychologist, HSE).

Appendix O: Post Family Talk Questionnaire for Parents

INFORMATION SHEET, CONSENT FORM AND POST-FAMILY TALK QUESTIONNAIRE FOR PARENTS/GUARDIANS

Post Family Talk Questionnaire

Administered by the Family Talk Clinician to parent(s)

Thank you for taking part in the *Family Talk* course. We hope that you found it helpful. This short questionnaire is to help the research team to understand your experience of the service. Your feedback is crucial in informing delivery of *Family Talk* for families in the future.

There is no right or wrong answer to any question. When you have finished, we ask you to give this form to (clinician's name)_____who will pass the form to the research team. If you want to write any other comment, simple write on the back page of the question and answer sheet.

All of the answers you give here will be kept confidential. You can withdraw or amend your data at any time (before November 2019). All research data is stored with a password and kept at Maynooth University for a period of ten years. After this time they are all destroyed. By signing your name on this page, you are giving consent for your questionnaire to be included (anonymously) in the PRIMERA study. If you are unsure of any item, or want to ask a question, do ask for help.

Signature: _____

Blocked signature: _____

Date: _____

Clinician: _____

This short questionnaire will assist us to determine your satisfaction with the Family Talk Intervention.

(Administered by the Clinician to parents on completing the course)

Please state the extent to which you agree or disagree with the following statements, where 1 is Strongly Agree and 5 is Strongly Disagree (tick one per statement).	**Strongly Agree**	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**
	1	**2**	**3**	**4**	**5**
Date course completed: *Site:* *Clinician:*					
1. I felt understood by the course facilitator.	○	○	○	○	○
2. The Family Talk course was worth attending.	○	○	○	○	○
3. The duration of Family Talk course was just right for me.	○	○	○	○	○
4. This course improved my understanding of mental health difficulty.	○	○	○	○	○
5. The course motivated me to change my behaviour.	○	○	○	○	○
6. I want to tell other families about this course.	○	○	○	○	○
7. The Family Talk course was interesting.	○	○	○	○	○
8. I know where to go to get help for my family.	○	○	○	○	○
9. The individual child meetings met my children's needs	○	○	○	○	○
10. I have a better understanding of the impact of parental mental illness on a child	○	○	○	○	○
11. I believe this family has improved our communication as a family	○	○	○	○	○
12. The information supplied during *Family Talk* was upsetting at times.	○	○	○	○	○
In what way was the course upsetting?					
13. Is there any way in which Family Talk did not meet with your expectations?					
14. If you could improve the course what changes would you make?					
(Only complete Q.15, Q.16, Q.17, Q18 if they are relevant for you)					
15. The handouts/supporting material/homework were useful.	○	○	○	○	○
16. The care plan was very helpful	○	○	○	○	○
17. The cognitive behavioural therapy sessions were helpful.	○	○	○	○	○
18. I believe the *Family Talk* Course has improved my relationship with my husband/life partner.	○	○	○	○	○

Appendix P: Post Family Talk Questionnaire for Children

INFORMATION SHEET, ASSENT/CONSENT FORM AND POST-FAMILY TALK QUESTIONNAIRE FOR CHILDREN (8-18 YEARS)

Post Family Talk Questionnaire

Administered by the Family Talk Clinician to child(ren)

Thank you for taking part in the *Family Talk* course. We hope that you liked doing the course with your family. On the next page we have a few questions to ask you. We would love to know what you liked about the course and what you did not enjoy. This will help the researchers to improve this course for other families. There is no right or wrong answer to any question. When you have finished, give these sheets back to (clincian's name) _____ who will pass the form to the research team. If you want to say anything else and need more space, write on the back page.

We will not share your answers with anyone, not even your Mam/Dad. All of your information will be confidential. You do not have to answer every question. You can also withdraw your information if you change your mind later. In that case, you can ask your Mam/Dad to contact the research team (PRIMERA@mu.ie) and we will not use your information. All questionnaires are kept under lock and key at Maynooth University for ten years. After this time they are all destroyed. By signing your name below, you are saying you are happy for the research team to use your answers (without mentioning your name) in our study.

Signature: _____

Blocked signature: _____

Date: _____

Clinician: _____

Date course completed: _____

Please answer the following questions with the answer which best describes (circle your answer).			
1. Did it help you to talk about the mental health of your Mam/Dad?	**Yes**	**Mixed**	**No**
2. Did you feel that the therapist understood you?	**Yes**	**Don't know**	**No**
3. Do you think it was good to talk to a therapist without your parents?	**Yes**	**Don't know**	**No**
4. Do you think it was good to have a family meeting?	**Yes**	**Don't know**	**No**
5. After Family Talk, how were things for you?			
a. After Family Talk, I felt	**Better**	**No change**	**Worse**
b. Talking to my mam/dad became	**Better**	**No change**	**Worse**
c. Asking about my parent's problem became	**Better**	**No change**	**Worse**
d. What I know and understand about my parent's problem became	**Better**	**No change**	**Worse**
6. After Family Talk, my understanding of my mam/dad and their mental health issues became	**Better**	**No change**	**Worse**
7. After Family Talk, I feel that my Mam's/Dad's understanding of me became	**Better**	**No change**	**Worse**
8. Sometimes children are worried about their parents when they have mental health issues. After Family Talk, I felt	**More Worried**	**No change**	**Less Worried**
9. Children might feel that their parent's problems are their fault. Do you ever feel it was your fault?	**Yes**	**Don't know**	**No**
10. Would you recommend that other children take part in these family meetings?	**Yes**	**Don't know**	**No**

11. What, if anything, would you change about Family Talk?

_____

_____

_____

12. Is there anything else you would like to say?

_____

_____

_____

Appendix Q: Information and Consent Form for Parents

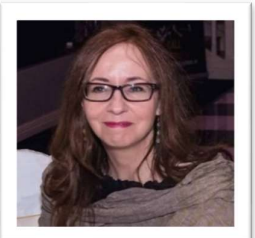
PRIMERA Research Programme
Promoting Research and Innovation in Mental hEalth seRvices for fAmilies

Information Sheet and consent form for Parents

Purpose of the study

My name is Christine Mulligan, and I am a PhD student with Maynooth University, in the Department of Psychology. I am working as a researcher on the PRIMERA Research Programme under the supervision of Professor Sinead McGilloway and Dr Mairead Furlong. The study is funded by the HSE Mental Health Division.

The aim of the PRIMERA study is to help improve services in Ireland for families where a parent has a mental health challenges (such as depression, bipolar, anxiety or schizophrenia). As part of the study, we would love to meet with parents and partners who have attended the *Family Talk* service.



Mairead Furlong
Mairead.furlong@mu.ie
Ph.: 087 XXX XXXX

Christine Mulligan
PRIMERA@mu.ie
Ph.: 087 XXX XXXX

Sinéad McGilloway
sinead.mcgilloway@mu.ie
Ph.: 708 XXXX/XXXX

What will the study involve?

You have already completed questionnaires as part of the study, for which we are grateful. In this part of the study, you are being asked to participate in an interview (30-40 minutes) in order to discuss your experience of the *Family Talk* programme and the extent to which you think that it helped you and your family. Your feedback will be crucial in informing the future delivery of Family Talk to families.

- We will arrange a time and place that suits you.
- The interview will be audio-recorded so that the researcher will not forget anything that is said on the day.

Who has approved this study?

This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee, as well as the ethics committees from the HSE, Saint John of God, and Tusla. You may have a copy of this approval if you request it.

Why have you been asked to take part?

You have been asked because you and your family attended the *Family Talk* service.

Do you have to take part?

No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to participate in a one-to-one interview with me. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form and given a copy and the information sheet for your own records. If you decide to take part, you are still free to withdraw/amend your data at

any time without giving a reason and/or to withdraw/amend your information up until such time as the research findings are analysed. A decision to withdraw at any time, or a decision not to take part, will not affect your access to services.

What information will be collected?
As part of the interview, it is likely that personally sensitive information may be shared, for instance, in relation to your mental health and contact with mental health services. However, we assure you that all information will be kept confidential and anonymous.

Will your participation in the study be kept confidential?
Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time. All hard copy information will be held in a locked cabinet at Maynooth University (MU), and electronic information will be encrypted and held securely on MU servers and will be accessed by password only by the PRIMERA research team.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

The only time confidentiality is not guaranteed is if the researcher is concerned that someone in your family is being hurt (e.g., a child). In this case, we may have to report our concern. If we have concerns, we will discuss first with your child and with you. Researchers follow very strict guidelines and only breach confidentiality when it is absolutely necessary.

'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'

What will happen to the information which you give?
All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the Principal Investigator [PI] Sinead McGilloway). Manual data will be shredded confidentially, and electronic data will be reformatted or overwritten by the PI in Maynooth University.

What will happen to the results?
The research will be written up and presented in summary reports, as part of my PhD, presented at national and international conferences, and may be published in scientific journals. It will not be possible to identify participants in any results that are presented. A copy of the research findings will be made available to participants upon request. Outputs will be put up on our study website https://cmhcr.eu/primera-programme/

Future research studies
If you agree to do so, we would like to place an anonymised version of data on the Irish Qualitative Data Archive (IQDA). This archive has been created to store anonymous data

produced as part of social research projects conducted in Ireland, so that other researchers may be able to access and use these data in subsequent projects. This means that research data can be used on more than one occasion and for more than one project/purpose.

What are the benefits of taking part?

We also hope that you will find it empowering to provide feedback on your experiences of attending the service, and to recommend improvements for future delivery. Your data and feedback will be essential in providing better supports for other families in Ireland when a parent has mental health difficulties.

What are the possible disadvantages of taking part?

We do not believe there are risks to you if you agree to take part. However, it is possible that talking about your experience may cause some distress. I can pause or stop the interview if you feel too distressed to continue.

What if there is a problem?

At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you experience distress following the interview, we ask you to contact your mental health support professional _____at Ph. _____. You may also contact me, Christine, at 087 XXX XXXX who will advise you what to do next. If you need help right now, some excellent website resources and support groups include:

- **Mental Health Ireland** - https://www.mentalhealthireland.ie/need-help-now/
- **Childline** - https://www.childline.ie/ Phone 1800 66 66 66 24hr a day (Under 18s only - Free)
  Text BULLY or TALK or HELP to 50101 from 10am to 4am, Tel: 01 6767960 (For Parents)
- **Samaritans Ireland**- https://www.samaritans.org, Freephone: 116 123. Text: 087 2 60 90 90 (standard text rates apply**),** Email: jo@samaritans.ie (RoI)
- **Emerging Minds** - https://emergingminds.com.au/

You may contact my supervisor Dr Mairead Furlong (Mairead.Furlong@mu.ie) if you feel the research has not been carried out as described above.

Alternatively, you may contact the Principal Investigator, Prof Sinéad McGilloway, at 01 708 6052/4765 (office hours) or write to her at the Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare, Ireland (email: sinead.mcgilloway@mu.ie).

Making a complaint

If you are unhappy with any aspect of the research and want to make a complaint, you should contact (1) your mental health professional or (2) Tusla Tell Us/HSE Complaints and Feedback Procedure.

Families attending a Tusla service should make their complaint at https://www.tusla.ie/about/feedback-and-complaints/making-a-comment-compliment-or-complaint/

Families attending a HSE service should make their complaint at https://www.hse.ie/eng/services/yourhealthservice/feedback/complaint/

Any further queries?

If you need any further information, you can contact me: Christine Mulligan at 087 XXX XXXX or christine.mulligan.2015@mumail.ie

If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this.

INFORMED CONSENT FORM

Parent/Partner Consent Form

1. I confirm that the purpose of this research project was explained to me verbally face to face and in writing. All of my questions were answered. ☐

2. I confirm that I am taking part in this study voluntarily. ☐

3. I agree to an audio-recorded interview for the purposes of the research. ☐

4. I understand that I can withdraw from the study (or withdraw my information) at any time. I am aware that my withdrawal will not affect my access to any current or future services or supports. I also understand I can withdraw my data any time before the final reports (or thesis) are written up in January 2020. ☐

5. I understand how my information will be managed and that I can ask to see it and amend it. ☐

6. I understand the limits to confidentiality as described in this form. ☐

7. I consent for my data, in an anonymous format, to be placed in the Irish Qualitative Data Archive where it may be used in further research projects. If any future research projects are conducted using my anonymised data, then the project will require approval from a research ethics committee. ☐

a) I agree for my data to be used for further research projects. ☐

b) I **do not** agree for my data to be used for further research projects. ☐

c) I agree to quotation/publication of extracts from my interview. ☐

d) I **do not** agree to quotation/publication of extracts from my interview. ☐

Signed (Parent/Partner): _____Date: _____

Signed Block letters (parent/partner) _____

I the undersigned have taken the time to explain in full to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed (Researcher): _____Date: _____

If during your participation in this study, you feel the information and guidelines that you were

given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a confidential and sensitive manner.

For your information, the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix R: Information and Consent Form for Adolescents 17-18 years for Interview

PRIMERA Research Study
Promoting Research and Innovation in Mental hEalth seRvices for fAmilies

Information Sheet for Adolescents 17-18 years

Purpose of the study

My name is Christine Mulligan, and I am a PhD student with Maynooth University, in the Department of Psychology. I am working as a researcher on the PRIMERA Research Programme under the supervision of Professor Sinead McGilloway and Dr Mairead Furlong. The study is funded by the HSE Mental Health Division.

The aim of the PRIMERA study is to help improve services in Ireland for families where a parent has mental health challenges (such as depression, bipolar, anxiety or schizophrenia). As part of the study, we would love to interview children/teenagers who attended the *Family Talk* service.

Mairead Furlong
Mairead.furlong@mu.ie
Ph.: 087 XXX XXXX

Christine Mulligan
PRIMERA@mu.ie
Ph.: 087 XXX XXXX

Sinéad McGilloway
sinead.mcgilloway@mu.ie
Ph.: 708 XXXX/XXX

What will the study involve?

You have already completed questionnaires as part of the study, for which we are grateful. In this part of the study, a selected number of children/teenagers are asked to participate in an interview (about 30-40 minutes) in order to discuss their experience of the *Family Talk*

programme and the extent to which they think that it helped them and their family. Your feedback will be crucial in informing the future delivery of Family Talk to families.

- We will arrange a time and place that suits you (this is usually in your home).
- The interview will be audio-recorded so that the researcher will not forget anything that is said on the day.

Who has approved this study?
This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee, as well as the ethics committees from the HSE, Saint John of God, and Tusla. You may have a copy of this approval if you request it.

Why have you been asked to take part?
You have been asked because you and your family attended the *Family Talk* service.

Do you have to take part?
No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to participate in a one-to-one interview with me (Christine). It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form and given a copy and the information sheet for your own records. If you decide to take part, you are still free to withdraw/amend your data at any time without giving a reason and/or to withdraw/amend your information up until such time as the research findings are analysed. A decision to withdraw at any time, or a decision not to take part, will not affect your access to services.

What information will be collected?
As part of the interview, it is likely that personally sensitive information may be shared, for instance, in relation to your parent's mental health and contact with mental health services. However, we assure you that all information will be kept confidential and anonymous.

Will your participation in the study be kept confidential?
Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time. All hard copy information will be held in a locked cabinet at Maynooth University (MU), and electronic information will be encrypted and held securely on MU servers and will be accessed by password only by the PRIMERA research team.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

The only time confidentiality is not guaranteed is if the researcher is concerned that someone in your family is being hurt (e.g., a child). In this case, we may have to report our concern. If we have concerns, we will discuss first with you and with your parents (if appropriate). Researchers follow very strict guidelines and only breach confidentiality when it is absolutely necessary.

'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'

What will happen to the information which you give?

All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the Principal Investigator [PI] Sinead McGilloway). Manual data will be shredded confidentially, and electronic data will be reformatted or overwritten by the PI in Maynooth University.

What will happen to the results?

The research will be written up and presented in summary reports, as part of my PhD, presented at national and international conferences, and may be published in scientific journals. A copy of the research findings will be made available to participants upon request. Outputs will be put up on our study website https://cmhcr.eu/primera-programme/

Future research

If you agree to do so, we would like to place an anonymised version of the data on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it. This archive has been created to store anonymous data produced as part of social research projects conducted in Ireland, so that other researchers may be able to access and use these data in subsequent projects. This means that research data can be used on more than one occasion and for more than one project/purpose.

What are the benefits?

We also hope that you will find it empowering to provide feedback on your experiences of attending the Family Talk service, and to recommend improvements for future delivery. Your data and feedback will be essential in providing better supports for other families in Ireland when a parent has mental health difficulties.

What are the possible disadvantages of taking part?

We do not believe there are risks to you if you agree to take part. However, it is possible that talking about your experience may cause some distress. I can pause or stop the interview if you feel too distressed to continue. See also below.

What if there is a problem?

At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you experience any distress following the interview, it may help to discuss with your Mam/Dad. You may also contact me (Christine) at 087 XXX XXXX and I will advise you what to do next. In a very small number of cases, it may make sense to contact your GP or the Family Talk mental health worker _____at Ph. _____.
Some excellent website resources and support groups include:

- **Mental Health Ireland** - https://www.mentalhealthireland.ie/need-help-now/

- **Childline** - https://www.childline.ie/ Phone 1800 66 66 66 24hr a day (Under 18s only - Free)
  Text BULLY or TALK or HELP to 50101 from 10am to 4am, Tel: 01 6767960 (For Parents)
- **Samaritans Ireland**- https://www.samaritans.org, Freephone: 116 123. Text: 087 2 60 90 90 (standard text rates apply**),** Email: jo@samaritans.ie (RoI)
- **Emerging Minds** - https://emergingminds.com.au/

You may contact my supervisor Dr Mairead Furlong (Mairead.Furlong@mu.ie) if you feel the research has not been carried out as described above.

Alternatively, you may contact the Principal Investigator, Prof Sinéad McGilloway, at 01 708 6052/4765 (office hours) or write to her at the Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare, Ireland (email: sinead.mcgilloway@mu.ie).

Making a complaint
If you are unhappy with any aspect of the research and want to make a complaint, you should talk first with your Mam/Dad. Then, either you or you parent can contact (1) your mental health professional or (2) Tusla Tell Us/HSE Complaints and Feedback Procedure.

Families attending a Tusla service should make their complaint at https://www.tusla.ie/about/feedback-and-complaints/making-a-comment-compliment-or-complaint/

Families attending a HSE service should make their complaint at https://www.hse.ie/eng/services/yourhealthservice/feedback/complaint

Any further queries?
If you need any further information, you can contact me: Christine Mulligan at 087 XXX XXXX or christine.mulligan.2015@mumail.ie

If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this.

INFORMED CONSENT FORM

Teen Consent Form

1. I confirm that the purpose of this research project was explained to me verbally face to face and in writing. All of my questions were answered. ☐
2. I confirm that I am taking part in this study voluntarily. ☐
3. I agree to an audio-recorded interview for the purposes of the research. ☐
4. I understand that I can withdraw from the study (or withdraw my information) at any time. I am aware that my withdrawal will not affect my access to any current or future services or supports. I also understand I can withdraw my data any time before the final reports (or thesis) are written up in January 2020. ☐
5. I understand how my information will be managed and that I can ask to see it or amend it. ☐
6. I understand the limits to confidentiality as described in this form. ☐
7. I consent for my data, in an anonymous format, to be placed in the Irish Qualitative. ☐

Data Archive where it may be used in further research projects. If any future research projects are conducted using my anonymised data, then the project will require approval from a research ethics committee.

e) I agree to quotation/publication of extracts from my interview. ☐

Signed (Teenager): _____Date**:** _____

Signed Block letters (Teenager)_____

I the undersigned have taken the time to explain in full to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed (Researcher): _____**Date:** _____

If during your participation in this study, you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a confidential and sensitive manner.

For your information, the Data Controller for this research project is Maynooth University,

Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix S: Information Consent/Assent Form for Parents/Guardians of Children (7-16 years) for interview

PRIMERA Research Study
Promoting Research and Innovation in Mental hEalth seRvices for fAmilies

Information Sheet and consent & assent form for Parents/Guardians of Children (7-16 yrs.)

Purpose of the study

My name is Christine Mulligan, and I am a PhD student with Maynooth University, in the Department of Psychology. I am working as a researcher on the PRIMERA Research Programme under the supervision of Professor Sinead McGilloway and Dr Mairead Furlong. The study is funded by the HSE Mental Health Division.

The aim of the PRIMERA study is to help improve services in Ireland for families where a parent has mental health challenges (such as depression, bipolar, anxiety or schizophrenia). As part of the study, we would love to interview one of your children who has attended the *Family Talk* service with you. To conduct the interview, we need your consent and your child's assent (Children over 16 years can provide their own consent and do not require parental consent).

Mairead Furlong
Mairead.furlong@mu.ie
Ph.: 087 XXX XXXX

Christine Mulligan
PRIMERA@mu.ie
Ph.: 087 XXX XXXX

Sinéad McGilloway
sinead.mcgilloway@mu.ie
Ph.: 708 XXXX/XXXX

What will the study involve?

Your child has already completed questionnaires as part of the study, for which we are grateful. In this part of the study, a selected number of children are being asked to participate in an interview (about 15-30 minutes) in order to discuss their experience of the *Family Talk* programme and the extent to which they think that it has helped them and their family. Your child's feedback will be crucial in informing the future delivery of Family Talk to families.

- We will arrange a time and place that suits your child (usually your home).
- The interview will be audio-recorded so that the researcher will not forget anything that is said on the day.

Who has approved this study?

This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee, as well as the ethics committees from the HSE, Saint John of God, and Tusla. You may have a copy of this approval if you request it.

Why has my child been asked to take part?

Your child has been asked to take part because you and your family attended the *Family Talk* service.

Does my child have to take part?

No, your child is under no obligation whatsoever to take part in this research. However, we hope that they will agree to take part in a one-to-one interview with me (Christine). It is entirely up to you and your child to decide whether or not they would like to take part. If you decide to do so, you will be asked to sign a consent form and given a copy and the information sheet for your own records. Your child will also need to agree to take part. If your child decides to take part, your child is still free to withdraw/amend their data at any time without giving a reason and/or to withdraw/amend their information up until such time as the research findings are analysed. A decision to withdraw at any time, or a decision not to take part, will not affect your access to services.

What information will be collected?

As part of the interview, it is possible that personally sensitive information may be shared, for instance, in relation to your mental health and contact with mental health services. However, we assure you that all information will be kept confidential and anonymous.

Will your participation in the study be kept confidential?
Yes, all information that is collected about you and your child during the course of the research will be kept confidential. No names will be identified at any time. All hard copy information will be held in a locked cabinet at Maynooth University (MU), and electronic information will be encrypted and held securely on MU servers and will be accessed by password only by the PRIMERA research team.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

The only time confidentiality is not guaranteed is when the researcher is concerned that someone in your family is being hurt. In this case, we may have to report our concern. If we have concerns, we will discuss first with your child and with you. Researchers follow very strict guidelines and only breach confidentiality when it is absolutely necessary.

'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'

What will happen to the information which you give?
All the information your child provides will be kept at Maynooth University in such a way that it will not be possible to identify you or them. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the Principal Investigator [PI] Sinead McGilloway). Manual data will be shredded confidentially, and electronic data will be reformatted or overwritten by the PI in Maynooth University.

What will happen to the results?
The research will be written up and presented in summary reports, as part of my PhD, presented at national and international conferences, and may be published in scientific journals. A copy of the research findings will be made available to participants upon request. Outputs will be put up on our study website https://cmhcr.eu/primera-programme/

Future research
If you and your child agree to do so, we would like to place an anonymised version of the data on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it. This archive has been created to store anonymous data produced as part of social research projects conducted in Ireland, so that other researchers may be able to access and use these data in subsequent projects. This means that research data can be used on more than one occasion and for more than one project/purpose.

What are the benefits?
We hope that your child will find it empowering to provide feedback on their experiences of attending the service, and to recommend improvements for future delivery. Their data and feedback will be essential in providing better supports for other families in Ireland when a parent has mental health difficulties.

What are the possible disadvantages of taking part?

We do not believe there are risks to your child if they agree to take part. If it emerges that you child experiences some distress or discomfort in talking about their experiences, I can pause or stop the interview if they feel too distressed to continue. See also below.

What if there is a problem?

At the end of the interview, I will discuss with your child how they found the experience and how they are feeling. If your child experiences any distress following the interview, we recommend that they talk with you, their parent, in the first instance. If appropriate, you could contact your mental health support professional _____ at Ph. _____. You may also contact me (Christine) at 087 XXX XXXX and I will advise you what to do next. Some excellent website resources and support groups include:

- **Mental Health Ireland** - https://www.mentalhealthireland.ie/need-help-now/
- **Childline** - https://www.childline.ie/ Phone 1800 66 66 66 24hr a day (Under 18s only - Free)
  Text BULLY or TALK or HELP to 50101 from 10am to 4am, Tel: 01 6767960 (For Parents)
- **Samaritans Ireland**- https://www.samaritans.org, Freephone: 116 123. Text: 087 2 60 90 90 (standard text rates apply**),** Email: jo@samaritans.ie (RoI)
- **Emerging Minds** - https://emergingminds.com.au/

You may contact my supervisor Dr Mairead Furlong (Mairead.Furlong@mu.ie) if you feel the research has not been carried out as described above.

Alternatively, you may contact the Principal Investigator, Prof Sinéad McGilloway, at 01 708 XXXX/XXXX (office hours) or write to her at the Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare, Ireland (email: sinead.mcgilloway@mu.ie).

Making a complaint

If you or your child are unhappy with any aspect of the research and want to make a complaint, you should contact (1) your mental health professional or (2) Tusla Tell Us/HSE Complaints and Feedback Procedure.

Families attending a Tusla service should make their complaint at https://www.tusla.ie/about/feedback-and-complaints/making-a-comment-compliment-or-complaint/

Families attending a HSE service should make their complaint at https://www.hse.ie/eng/services/yourhealthservice/feedback/complaint/

Any further queries?

If you need any further information, you can contact me: Christine Mulligan, phone number, 087 XXX XXXX christine.mulligan.2015@mumail.ie

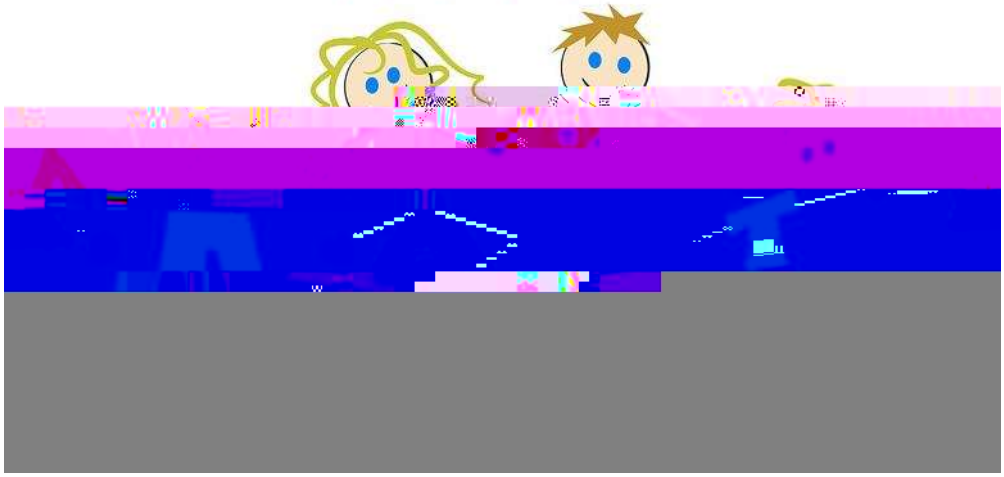
If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this.

Information & Assent Form

Children & Teenagers (7-16 years)

PRIMERA



Note: Please ask your Mam or Dad for help in reading the sheet below if you do not understand anything that is being said

- A researcher called Christine would like to chat with/interview children in families where a Mam or Dad are sometimes unwell with mental health problems, for example, depression, anxiety or bipolar.
- Christine would like to chat to you about what you thought of the Family Talk service that you and your family attended and whether it helped you or not.
- The chat is arranged for a time and place that suits you (usually in your home) and will last 15-30 minutes.
- The chat is audio recorded to make sure Christine does not forget anything that you say. Later, Christine will type out everything said during the interview.
- You do not have to answer any questions that you do not want to. You can also draw your answers if you would like to do that.
- If you feel like this, (a little confused), or just need a break during your chat with Christine, tell her and she will know what to do.

- You can have your Mam/Dad in the room during the interview if you like; whatever makes you feel most comfortable.

- If you feel upset following the interview, you should talk with your Mam/Dad who will advise what to do.

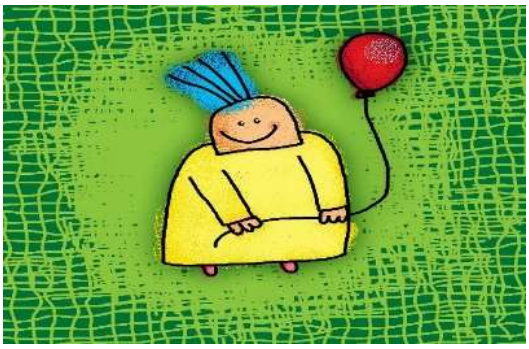
- All information you give us is anonymous and confidential. Nothing you say to Christine during your interview will be discussed with anyone else unless Christine is a little worried about your being hurt in some way. If you say anything that makes Christine a little worried about you or someone else being hurt, she will have to tell another person because it is the law. If we have concerns, we will discuss first with you (and your Mam/Dad). As a researcher, Christine has to follow the rules (just like you in school). The rules she follows are called **Children First: National Guidance for the Protection and Welfare of Children (2011).**

- We never tell anyone your name in the reports we write. No one will know that we had a chat unless you tell them yourself.

- All information you give us is kept securely in Maynooth University and no-one has access to this data outside of the PRIMERA research team.

- You can withdraw or change your data at any point up until the research is published. Withdrawing some or all of your data will not affect your access to future care.

- If you are unhappy with the research and how you have been treated and you want to make a complaint, you should talk to your Mam/Dad who will advise what to do next. Your Mam/Dad should contact (1) your mental health professional or (2) Tusla at Tell Us/HSE Complaints and Feedback Procedure.



WE HOPE YOU CAN HELP.

IF YOU WANT TO HELP YOU CAN TELL CHRISTINE NOW

Parent and Child Consent/Assent Form

	Parent	Child
1. Both parent and child agree that the purpose for this research project has been explained both face to face and in writing here on this form. All questions have been answered.	☐	☐
2. Both parent and child agree to take part in this study voluntarily and agree to an interview with Christine.	☐	☐
3. Both parent and child will write their names below to show their permission (consent/assent) to be interviewed (Child must be 7 years or older).	☐	☐
4. Both parent and child agree to their interview being audio recorded for this research.	☐	☐
5. Both parent and child understand that they can say they want to STOP being in the interview. Both can also say, do not use my answer (up until the reports are written). This will not affect access to any future care.	☐	☐
6. Both parent and child understand everything said during the interview is confidential unless Christine is worried that someone is hurt. Both parent and child know mam/dad can sit in on the interview if that makes (child) more comfortable.	☐	☐
7. Both parent and child understand that names are never mentioned in any reports.	☐	☐
8. We consent for the interview data, in an anonymous format, to be placed in the Irish Qualitative Data Archive where it may be used in further research projects. If any future research projects are conducted using the anonymised data, then the project will require approval from a research ethics committee.	☐	☐
f) We agree to quotation/publication of extracts from the interview.	☐	☐

Signed (Parent): _____Date: _____

Block writing (Parent): _____

Signed (Child): _____Age _____Date: _____

Block writing (Child): _____

I the undersigned have taken the time to explain in full to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed (Researcher): _____Date: _____

If during your participation in this study, you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process,

please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a confidential and sensitive manner.

For your information, the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix T: Information Sheet and Consent Form for Service Providers of Family Talk for Interview/Focus group

PRIMERA Research Programme
Promoting Research and Innovation in Mental hEalth seRvices for fAmilies

Information sheet and consent form for service providers of *Family Talk*

Purpose of the study

My name is Christine Mulligan and I am a PhD student with Maynooth University, in the Department of Psychology. I am working as a researcher on the PRIMERA Research Programme under the supervision of Professor Sinead McGilloway and Dr Mairead Furlong. The study is funded by the HSE Mental Health Division. The aim of the PRIMERA study is to help implement and evaluate family-focussed services in Ireland for families where a parent has mental health challenges (such as depression, bipolar, anxiety or schizophrenia). As part of the study, we would love to meet with service providers involved in the implementation and delivery of the *Family Talk* service.

Mairead Furlong
Mairead.furlong@mu.ie

Christine Mulligan
PRIMERA@mu.ie

Sinéad McGilloway
sinead.mcgilloway@mu.ie

What will the study involve?

We are inviting you to participate in an interview (30-60 minutes) OR focus group (approx. 60 minutes) in order to discuss your experience of implementing and delivering *Family Talk* within your service/area. Your feedback will be crucial in informing the future delivery of *Family Talk* to families.

Topics of the interview/focus group will include your experiences of recruiting and engaging families, working with families in Family Talk, identifying key outcomes and enablers and barriers to delivery; level of managerial support and buy-in, among other implementation issues.

- We will arrange a time and place that suits you.
- The interview will be audio-recorded so that the researcher will not forget anything that is said on the day.

Who has approved this study?
This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee, as well as the ethics committees from the HSE, Saint John of God, and Tusla. You may have a copy of this approval if you request it.

Why have you been asked to take part?
You have been asked because you were involved in the implementation and delivery of *Family Talk*.

Do you have to take part?
No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to participate in a one-to-one interview with me (Christine). It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form and given a copy and the information sheet for your own records. If you decide to take part, you are still free to withdraw/amend your data at any time without giving a reason and/or to withdraw/amend your information up until such time as the research findings are analysed. A decision to withdraw at any time, or a decision not to take part, will not affect your access to services.

What information will be collected?
As part of the interview, it is possible, although very unlikely, that identifying sensitive information will be shared. All information will be kept confidential and anonymous.

Will your participation in the study be kept confidential?
Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time. All hard copy information will be held in a locked cabinet at Maynooth University (MU), and electronic information will be encrypted and held securely on MU servers and will be accessed by password only by the PRIMERA research team.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'

What will happen to the information which you give?

All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the Principal Investigator [PI] Sinead McGilloway). Manual data will be shredded confidentially and electronic data will be reformatted or overwritten by the PI in Maynooth University.

What will happen to the results?

The research will be written up and presented in summary reports, as part of Christine's PhD, presented at national and international conferences, and may be published in scientific journals. A copy of the research findings will be made available to participants upon request. Outputs will be put up on our study website https://cmhcr.eu/primera-programme/

Future research

If you agree to do so, we would like to place an anonymised version of the data on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it. This archive has been created to store anonymous data produced as part of social research projects conducted in Ireland, so that other researchers may be able to access and use these data in subsequent projects. This means that research data can be used on more than one occasion and for more than one project/purpose.

What are the benefits?

We also hope that you will find it useful to provide feedback on your experiences of delivering the Family Talk service, and to recommend improvements for future delivery. Your data and feedback will be essential in providing better supports for other families in Ireland when a parent has mental health difficulties.

What are the possible disadvantages of taking part?

We do not anticipate any risks to you if you agree to take part. However, if you experience any distress during the interview/focus group, the interview/focus group will be stopped and possibly rearranged for a later date.

What if there is a problem?

You may contact my supervisor Dr Mairead Furlong (Mairead.Furlong@mu.ie) if you feel the research has not been carried out as described above.

Alternatively, you may contact the Principal Investigator, Prof Sinéad McGilloway, at 01 708 6052/4765 or write to her at the Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare, Ireland (email: sinead.mcgilloway@mu.ie).

Making a complaint

If you are unhappy with any aspect of the research and want to make a complaint, you should contact (1) the lead contact person within your site for the PRIMERA study or (2) Tusla Tell Us/HSE Complaints and Feedback Procedure.

Tusla service providers should make their complaint at https://www.tusla.ie/about/feedback-and-complaints/making-a-comment-compliment-or-complaint/

HSE service providers should make their complaint at https://www.hse.ie/eng/services/yourhealthservice/feedback/complaint/

Any further queries?

If you need any further information, you can contact me: Christine Mulligan at xxx xxx xxxx or christine.mulligan.2015@mumail.ie

If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this

INFORMED CONSENT FORM

Clinician Consent Form

1. I confirm that the purpose of this research project was explained to me verbally face to face and in writing. All of my questions were answered. ☐
2. I confirm that I am taking part in this study voluntarily. ☐
3. I agree to an audio-recorded interview for the purposes of the research. ☐
4. I understand that I can withdraw from the study (or withdraw my information) at any time. I am aware that my withdrawal will not affect my access to any current or future services or supports. I also understand I can withdraw my data any time before the final reports (or thesis) are written up in January 2020. ☐
5. I understand how my information will be managed and that I can ask to see it. ☐
6. I understand the limits to confidentiality as described in this form. ☐

7. I consent for my data, in an anonymous format, to be placed in the Irish Qualitative Data Archive where it may be used in further research projects. If any future research projects are conducted using my anonymised data, then the project will require approval from a research ethics committee. ☐

g) I agree to quotation/publication of extracts from my interview ☐

Signed (Clinician): _____ **Date:** _____

Signed Block letters (Clinician)_____

I the undersigned have taken the time to explain in full to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed (Researcher): _____**Date:** _____

If during your participation in this study, you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a confidential and sensitive manner.

For your information, the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix U: Interview Schedule: Management Interview Schedule

A semi-structure (20 minute) Skype/phone with Managers

Questions will be selected from the options below depending on the management level.

1. What do you see as the key socio-political factors influencing levels of mental ill health in your geographical area?
2. There have long been calls for systematic data collection and interagency collaboration to identification of needs of service users and their families. What barriers have delayed this process?
3. What are the key drivers to effective implementation of core services in your organisation?
4. What are the key barriers to effective implementation of core services in your organisation?
5. What do you see as the key service user barriers to the uptake of core services (such as BFT)?
6. In 2010, Norway became the first country to introduce mandatory assessment for all new admissions to psychiatric care/substance-abuse where physical health fields must consider children's needs for information and follow-up when the parent is unwell. Do you see a place for this type of legislation in an Irish setting?
7. In your experience what drives change at CHO levels, policy or practice?
8. A two generational approach has been recommended when addressing mental ill health (NRC National Research Council & IOM Institute of Medicine, 2014). How does this fit the current service provision in your organisation?
9. How would you rate your organisations policy and actions on the continuum of family focussed activities (above & below the line)?
10. What role do you see for selective prevention children of service who are impacted by parental mental illness in your service?
11. With the reorientation towards localised control, what can researchers do to inform your decisions core services?
12. What is your opinion on the move towards eHealth in treating mental ill health?

Appendix V: Interview Schedule for Parent, Coparents, Parent who Dropout of FT, Longer-term follow up.

Interview Schedule for Parent/partner

Remember, there are no right or wrong answers to any of these questions

Family Talk

1. Tell me about your experience of the *Family Talk* service.
2. What did you like about it?
3. Was there anything you didn't about it?
4. How did you first hear about Family Talk?
    - What did you think first when you heard about it?
5. In what ways, if any, did Family Talk help you and your family?
    - E.g., improved parent/partner wellbeing/mental health, improved parenting skills, child behaviour and wellbeing, family understanding and communication about MI better, better relationships, better coping, and planning (crisis care plan)?
    - How has doing the *Family Talk* course improved your understanding of how mental ill health affects children?
    - How has *Family Talk* affected your *relationship/communication* with family members (partner, children)?
    - To what extent was Family Talk more helpful for parents, children, partner?
6. What were the most useful things/skills you learned on the programme?
7. To what extent do you think the course might influence how you deal with future mental health challenges?
8. To what extent are there things that you and your family might need help with?
9. What changes would you recommend if the Family Talk course was to be delivered to other families?

Mental health, parenting, and service user

10. To what extent do you think that services, before Family Talk, have helped you/your partner with parenting and/or talking to your children about your/their mental health?
11. To what extent are you happy about how services have helped you/your partner deal with your/their mental health in general?
12. Before Family Talk, what has been your experience of parenting when you/your partner are not feeling mentally well?
    - How did you cope when you/they were unwell?
    - If applicable, how did you/your partner cope when you/they were unwell?
    - How did your children cope when you/they were unwell?
13. Do you/child/partner cope differently now that you have done Family Talk?
14. *Family Talk* is promoted as a prevention programme for children; do you think a course like this might have helped you as a child/other family in similar situations?
15. Is there anything else you would like to add?

Interview Schedule for Parent who dropped out from Family Talk

Remember, there are no right or wrong answers to any of these questions

1. Can you tell me why you decided to stop attending *Family Talk*?
2. In the short time that you and your family attended, what was your impression of the course?
3. What was your relationship like with the clinician?
4. Was there anything positive you/your children/partner found in the short time of attending?
5. Would you be interested in completing the *Family Talk* programme at a future date?
6. Is there anything else you would like to say about Family Talk?
7. Is there anything you would like to add?

Interview Schedule for Parent (service user & non-service user) – longer-term follow up

Remember, there are no right or wrong answers to any of these questions

1. Tell me how you have been since our last meeting?
2. How the issue of your mental health come up within the family since we last talked? If yes, can you tell me about it?
3. What parts of the *Family Talk* course do you remember the most now?
4. What parts of the course have you used since we last met?
5. Tell me how your family are doing since we last talked.
6. Have there been any significant changes since the last time we talked?
7. How confident do you feel now talking to your child(ren) about mental health issues?
8. Looking back now, is there anything you could change about the *Family Talk* course?
9. Would you recommend the course to other families in a similar situation?
10. If there anything else, you would like to add?

Appendix W: Interview Schedule for Teenagers and younger children

Remember, there are no right or wrong answers to any of these questions

Family Talk

- Tell me about your experience of the *Family Talk* service.
- What did you like about it?
- Was there anything you didn't about it?
- How did you first hear about Family Talk?
- What did you think when you first heard about it?
- In what ways, if any, did Family Talk help you and your family?
- To what extent do you think Family Talk has helped you to understand more about your Mam's/Dad's mental health challenges?
- To what extent do you think Family Talk has helped your Mam/Dad to understand more how their mental health affects their children?
- To what extent has Family Talk helped you and your family talk more openly about your parent's mental health issues? Are family relationships any better?
- To what extent do you think you cope better as a result of going to Family Talk? Describe things that help you cope.
- To what extent do you think your Mam/Dad cope better as a result of going to Family Talk?
- If applicable, to what extent do you think your siblings cope better as a result of going to Family Talk?
- Is there a care plan in place in case your Mam/Dad becomes unwell in the future?
- What were the most useful things/skills you learned on the programme?
- To what extent do you think Family Talk might influence how your family deals with future mental health challenges?
- To what extent are there things that you and your family might still need help with?
- What changes would you recommend if the Family Talk course was to be delivered to other families?

Mental health, family, and service use

1. How long has your Mam/Dad suffered from mental health difficulties?
2. In the past, how have your Mam's/Dad's difficulties affected your life (at home, in school, other activities)?
    - How did you cope when they were unwell?
    - How did your Mam/Dad cope when they were unwell?
    - How did your siblings cope (if applicable)?
3. Do you think you cope differently/better now that you have done Family Talk or is it much the same/worse?
4. Do you think your siblings/Mam/Dad cope better now that you have done Family Talk or is it much the same/worse?
5. Prior to Family Talk, to what extent do you think services have helped the family in coping with your Mam's/Dad's mental health difficulties?

6. To what extent are you happy about how services have helped your Mam/Dad with their mental health?
7. To what extent would you recommend that other families attend Family Talk?
8. Is there anything else you would like to add?

Appendix W: Interview Schedule for Younger Children

(Questions were adapted based on the age of younger children)

Remember, there is no right or wrong answers to any of these questions.

Family Talk

1. Tell me about your experience of the *Family Talk* service.
2. What did you like about it?
3. Was there anything you didn't about it?
4. How did you first hear about Family Talk?
    - What did you think when you first heard about it?
5. In what ways, if any, did Family Talk help you and your family?
    - To what extent do you think Family Talk has helped you to understand more about your Mam's/Dad's mental health challenges?
    - To what extent do you think Family Talk has helped your Mam/Dad to understand more how their mental health affects you/siblings?
    - To what extent has Family Talk helped you and your family talk more openly about your parent's mental health issues? Are family relationships any better?
    - If applicable, to what extent do you think your siblings were helped by Family Talk?
6. What were the most useful things/skills you learned on the programme?

Appendix X: Schedule for one-to-one clinician interviews and background questionnaire

1. Describe your work experience in mental health.
2. What sparked your interest in a family-focussed approach to parental mental illness?
3. What other services in your location support the needs of families impacted by parental mental illness?
4. Describe some of the recruitment challenges with families for Family Talk. Can you give an example of families who said no to the intervention?
5. Which element(s) of Family talk did you find (a) most, and (b) least helpful?
6. Can you identify non-specific intervention components (e.g., facilities, time flexibility, contextual factors and therapeutic alliance) which should be considered if rolling out Family Talk?
7. In your opinion what was the level of engagement of service users/partner/children with FTI?
8. If you could improve the Family Talk eLearning training, what changes would you make?
9. Can you describe one family that comes to mind when you think about the impact of PMI on children?
10. What are the barriers/enablers to addressing the impact of parental mental difficulty on children?
11. How would you rate your organisations policy and actions on the continuum of family-focussed activities (above the line)?
12. How would you rate your organisations work force practices on the continuum of family focussed activities (below the line)?
13. Describe your experience of being involved in the PRIMERA study.
14. Is there anything else you would like to add?

Appendix X: Background Questionnaire for Mental Health Practitioner Interviews

PRIMERA Focus Group/Interview

Location: **CHO Area:**

Date:

1. **Gender:** **Male** **Female**

2. **Marital status:**

   _____

3. **Circle your age range:** **20 -30** **31-40** **41-50** **51+**

4. **Have you ever been a parent?**

   _____

   _____

5. **Current job title** _____

6. **My relevant work experience includes (circle all relevant):**

   AMHS CAMHS Child protection Family Work Social Work Other_____

7. **Number of years in each area (if relevant):**

   A. AMHS ___Yrs. B. CAMHS ___Yrs. **C**. Child protection ___Yrs. **D**. Family Work ___Yrs.

   E. Social work ___Yrs. **F.** Other _____ Yrs.

8. **Number of families involved in Family Talk at this site.**

   a. How many families have you brought through Family Talk? _____
   b. Detail below any additional referrals for families as a result of families attending Family Talk.

   _____

   _____

Appendix Y: Focus Group Topic Guide for Practitioners

1. Introduction - outline your current role; give a brief overview of your experience in mental health and describe how you heard about the PRIMERA study.
2. What were the key challenges to introducing Family Talk at your site?
3. To what degree was it necessary for you to change the programme for your families?
4. Describe the recruitment methods which used best with service user/partner/children.
5. What are the barriers/enablers to addressing the impact of parental mental difficulty on children?
6. In your opinion who holds the key to improving the lived experience of mental health in Ireland?
7. If you could improve the eLearning training, what changes would you make?
8. How often did you provide/utilise supervision within your site, with other sites?
9. Which element(s) of Family talk did you find (a) most, and (b) least helpful?
10. What non-specific intervention components (e.g., facilities, time flexibility, contextual factors and therapeutic alliance) should be considered if rolling out Family Talk?
11. In your opinion what was the level of engagement of SUers/partner/children with FTI?
12. How would you rate your organisations policy and actions on the continuum of family-focussed activities (above the line)?
13. How would you rate your organisations work force practices on the continuum of family focussed activities (below the line)?
14. A two generational approach/programme has been recommended to address the impact of parental mental difficulty on families (NCR National Research Council and IOM Institute of Medicine 2014). In your option, how realistic is this within the current Irish mental health system?
15. Describe your experience of being involved in the PRIMERA study.
16. Is there anything else you would like to add?

Appendix Z: Practitioner Fidelity Questionnaire (Qualtrics – PDF Copy below)

Family Talk Delivery Survey

Ethics & work Experience

Q1.

Thank you for taking part in the PRIMERA research study. In this short survey, we ask you questions about your delivery of Family Talk to families (e.g. number of sessions attended by families, amount of Family Talk material covered in sessions, etc.). Your **confidential** information will be very helpful for us in finding out if Family Talk is helpful for families and clinicians. We appreciate you taking the time to complete this survey.

This survey is expected to take no longer than 5-10 minutes to complete. By completing and submitting the survey, you are confirming your voluntary consent to **anonymously** participate in this part of the PRIMERA research project.

NB: Four questions at the end of the survey, relating to your recommendations about Family Talk, will require an answer in order to complete this survey.

Ethical approval has been received for the PRIMERA study from the HSE scientific research ethics committee, Maynooth University ethics committee, St John of God's ethics department and Tusla research ethics committee.

Q2. My gender is

- ○ Male
- ○ Female

Q3. My age range is

- ○ 20-30
- ○ 31-40
- ○ 41-50
- ○ 51+

Q4. Are you, or have you ever been a parent of children (0-18 years)?

Q5. My current occupation (job title) is

Q6. The site I **currently** work in is (list the full name including target service users e.g. HSE AMHS / CAMHS)

Q7. My mental health **training** includes the following qualifications (i.e. Certificate, BA, MS, PhD followed by the field of study e.g. BA social care).

Q8. My years of mental health **work experience** include the following areas (i.e. Adult MHS, Child & Adolescent MHS, Suicide protection, Child protection services, Social care work, or **Other**). Please also specify where and for how long (i.e. HSE AMH 2 years, CAMHS 3 years).

Q9. How many families did you approach about the Family Talk Intervention?

Q10. How many families started Family Talk with you?

Fidelity Questions

Q11. Select the number of Family Talk sessions **each** family completed (i.e. if the family completed Family Talk select session 6. If they only attended 3 sessions select session 3).

	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6
Family 1	○	○	○	○	○	○
Family 2	○	○	○	○	○	○
Family 3	○	○	○	○	○	○
Family 4	○	○	○	○	○	○
Family 5	○	○	○	○	○	○
Family 6	○	○	○	○	○	○
Family 7	○	○	○	○	○	○
Family 8	○	○	○	○	○	○

Q12.

*The next **seven questions** relate to how families responded to Family Talk, (i.e. how many sessions, were completed, what material was not used and why, how family members responded and if families were signposted to other services)*

What percentage of the overall material (in the Family Talk Manual) was covered with each family?

	0-20%	21-40%	41-60%	61-80%	81-100%
Family 1	○	○	○	○	○
Family 2	○	○	○	○	○
Family 3	○	○	○	○	○
Family 4	○	○	○	○	○
Family 5	○	○	○	○	○
Family 6	○	○	○	○	○
Family 7	○	○	○	○	○
Family 8	○	○	○	○	○

Q13. **What material (from the Family Talk programme) was not covered with each family? Please explain why?**

- ☐ Family 1
- ☐ Family 2
- ☐ Family 3
- ☐ Family 4
- ☐ Family 5
- ☐ Family 6
- ☐ Family 7
- ☐ Family 8

Q14. **What changes or modifications of Family Talk were needed with each family (specify the modifications below)? e.g. additional sessions were needed with parents and/or children**

- ☐ Family 1
- ☐ Family 2
- ☐ Family 3
- ☐ Family 4
- ☐ Family 5
- ☐ Family 6
- ☐ Family 7
- ☐ Family 8

Q15. **How engaged was each family member in the Family Talk course? (Please slide across to answer this question for parent, children and partner (if relevant) for each family)**

	Parent with mental health difficulty			Child(ren) in the family			Partner/Support person (if applicable)		
	Yes	Somewhat	No	Yes	Somewhat	No	Yes	Somewhat	No
Family 1	○	○	○	○	○	○	○	○	○
Family 2	○	○	○	○	○	○	○	○	○
Family 3	○	○	○	○	○	○	○	○	○
Family 4	○	○	○	○	○	○	○	○	○
Family 5	○	○	○	○	○	○	○	○	○
Family 6	○	○	○	○	○	○	○	○	○
Family 7	○	○	○	○	○	○	○	○	○
Family 8	○	○	○	○	○	○	○	○	○

Q16.

If family members did not engage, please briefly describe and explain for each family.

☐ Family 1

☐ Family 2

☐ Family 3

☐ Family 4

☐ Family 5

☐ Family 6

☐ Family 7

Q17.

Detail any additional services offered to each family as a result of completing Family Talk (i.e. signposted to OT/ Child referred to CAMHS).

- [ ] Family 1
- [ ] Family 2
- [ ] Family 3
- [ ] Family 4
- [ ] Family 5
- [ ] Family 6
- [ ] Family 7
- [ ] Family 8

Q18. Indicate here which of the families listed above were in the intervention group and which families were in the control group.

Recommendations

Q19.

THE NEXT FOUR QUESTIONS REQUIRE A RESPONSE IN ORDER TO COMPLETE THE SURVEY.

What elements of the Family Talk intervention could be improved?

Q20. What changes would you make if you were delivering Family Talk in the future?

Q21. To what extent did your organisation support you in delivering Family Talk?

Q22. Is there anything else you would like to say about the Family Talk intervention or the PRIMERA research project?

Q23. If you are willing to take part in a short qualitative interview about your experience of Family Talk, please insert your email address below.

f you have any questions about this research contact Christine at PRIMERA@mu.ie.
You will receive a response within 24 hours.

Maynooth University Ethics Committee can be contacted at research.ethics@mu.ie or +353 (0)1 708 6019.
Maynooth University Data Protection officer is Ann McKeon who can be contacted at ann.mckeon@mu.ie.

Tusla staff that are unhappy with any element of the research should make their complaint to Tusla's Tell Us Complaints and Feedback at https://www.tusla.ie/about/feedback-and-complaints/tell-us-publications/

Appendix AA: HSE Ethics Application Form with Letter of Approval (one of four submissions)

STANDARD APPLICATION FORM

For the Ethical Review of
Health-Related Research Studies, which are not Clinical Trials of Medicinal Products For Human Use
as defined in S.I. 190/2004

DO NOT COMPLETE THIS APPLICATION FORM
IF YOUR STUDY IS A CLINICAL TRIAL OF A MEDICINAL PRODUCT

Title of Study: PRIMERA Research Programme - **P**romoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies

Application Version No: _____

Application Date: 8th August 2018

For Official Use Only – Date Stamp of Receipt by REC:

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This Application Form is divided into Sections.

*Sections A, B, C, D, E, J and K are **Mandatory.**

(Sections F, G, H, I and L are optional. Please delete Sections F, G, H, I and L if these sections do not apply to the application being submitted for review.)

IMPORTANT NOTE: Please refer to **Section I** within the form before any attempt to complete the Standard Application Form. **Section I** is designed to assist applicants in ascertaining if their research study is in fact a clinical trial of a medicinal product.

IMPORTANT NOTE: This application form permits the applicant to delete individual questions within each section depending on their response to the preceding questions. Please respond to each question carefully and refer to the accompanying *Guidance Manual* for more in-depth advice prior to deleting any question.

PLEASE ENSURE TO REFER TO THE ACCOMPANYING GUIDANCE MANUAL WHEN COMPLETING THIS APPLICATION FORM.

SECTION A GENERAL INFORMATION

SECTION A IS MANDATORY

A1 Title of the Research Study:

Promoting **R**esearch and **I**nnovation in **M**ental h**E**alth se**R**vices for f**A**milies (The PRIMERA Research Programme)

A2 (a) Is this a multi-site study? Yes

If you chose 'yes' please delete questions A2 (e) and (f), If you chose 'no' please delete Questions A2 (b) (c) and (d)

A2 (b) If yes, please name the principal investigator with overall responsibility for the conduct of this multi-site study.

Title: Professor **Name:**Sinéad McGilloway
Qualifications:BSSc,PhD, CPsychol, CSci, AFBPS
Position: Professor and Director, *Centre for Mental Health and Community Research*
Dept: Psychology
Organisation: National University of Ireland Maynooth
Address: Maynooth University Department of Psychology, John Hume Building, National University of Ireland Maynooth, Maynooth, Co.Kildare, Ireland.
Tel:+353 1 708 4765 **E-mail:**Sinead.McGilloway@mu.ie

A2 (c) For multi-site studies, please name each site where this study is proposed to take place, state the lead co-investigator for each of these sites and state if you have got an outcome from the relevant research ethics committee(s).

Note to committee:

Thirteen sites across the country have confirmed their participation in the PRIMERA research programme (8 HSE, 4 Tusla and one Saint John of God [SJOG] site – see table below). Of these, 11 sites (6 HSE sites, 4 Tusla and one SJOG) will be involved in delivering Family Talk (sites 1-11 in table below). Two HSE sites will be involved in delivering systemic family therapy or multi-family group as these services were being delivered/developed at the time of the Expression of Interest call in 2017 (sites 12-13 in table below). Separate ethical approval will be sought from Tusla and SJOG.

There are no co-investigators as such in each site as defined in section A3 below. Instead, we have identified a lead contact person(s) in each site; these individuals are service providers/practitioners who have agreed to work with the research team. Thus, they will not be undertaking any research, but will be working closely with the research team in a service co-ordinator/liaison role. Given that this is a national study funded by the HSE, we have been advised to seek HSE ethical approval at a national level rather than from each of the local HSE sites.

Site:	**Lead Contact person for each site:**	**Research Ethics Committee Outcome**
1. HSE Letterkenny Mental health Services	Mairead Gallen	Approval letter forthcoming from national HSE ethics committee
2. HSE Crosslinx West Galway	Mary G Killion	As above
3. HSE Mayo Mental Health Services	Sharyn Byrne	As above
4. HSE Louth Adult Mental Health Services	Shireen O' Neill	As above
5. HSE Cherry Orchard AMHS/CAMHS	Celine O' Connor	As above
6. HSE Carlow AMHS with Recovery College South East	Sean O' Neill	As above
7. Tusla social work and Prevention, Partnership and Family Support (PPFS), Galway	Morgan Mee	We are seeking separate ethical approval from Tusla
8. Tusla social work and PPFS, Dublin South Central	Loretta Scanlon	As above
9. Tusla social work and PPFS, Mayo	Sharyn Byrne	As above
10. Tusla social work and PPFS, LouthMeath	Orla Hughes	As above
11. Saint John of God, CluainMhuire Community Mental Health Services, Blackrock	Adele Kane	We are seeking separate ethical approval from Saint John of God's
Systemic family therapy and multi-family group		
12. Kilkenny Mental Health Services	Sean Boland	National level HSE
13. North Dublin AMHS	Mary Kelleher	National level HSE

A2 (d) For multi-site studies, please provide details of the Lead Co-Investigators at each site.

* As outlined above, there are no lead co-investigators at each site. Therefore, we have listed below the names of each of our **main contacts/collaborators**at each site.

1. Letterkenny Mental health Services – FAMILY TALK
Title: Ms. **Name:** Name removed
Qualifications: Clinical Nurse Specialist, Family Therapist
Position: Clinical Nurse Specialist, Family Therapist
Dept : Adult Mental Health Services (AMHS)
Organisation: HSE
Address: The Willows, Carnamuggagh, Letterkenny, Co. Donegal
Tel : Details removed

2. Crosslinx West Galway/Roscommon – FAMILY TALK
Title: Ms. **Name:** Name removed
Qualifications: Principal Social Worker

Position: Principal Social Worker
Dept : AMHS and CAMHS
Organisation: HSE
Address: Woodview/Unit 9A, Merlin Park University Hospital Campus, Galway
Tel : Details removed

3. Mayo Mental Health Services – FAMILY TALK
Title: Dr **Name:** Name removed
Qualifications: Clinical Psychology
Position: Senior Clinical Psychologist
Dept : CAMHS
Organisation: HSE
Address: CAMHS, St. Mary's, Castlebar, Co. Mayo
Tel : Details removed

4. Louth Adult Mental Health Services – FAMILY TALK
Title: Ms. **Name:** Name removed
Qualifications: Social Worker
Position: Senior Social Worker
Dept : AMHS
Organisation: HSE
Address: Singleton House, Saint Lawrence St., Drogheda, Co. Louth
Tel : Details removed

5. Cherry Orchard AMHS/CAMHS – FAMILY TALK
Title: Ms. **Name:** Name removed
Qualifications: Principal Social Worker
Position: Principal Social Worker
Dept : CAMHS
Organisation: HSE
Address: Linn Dara Child & Adolescent Mental Health Services, Cherry Orchard Campus, Dublin 10
Tel : Details removed

6. Carlow AMHS with Recovery College South East – FAMILY TALK
Title: Mr. **Name:** Name removed
Qualifications: Removed
Position: Removed
Dept : AMHS
Organisation: HSE and Recovery College
Address: St Dympna's Hospital, Athy Road, Carlow
Tel : Details removed

7. TuslaLouthMeath social work and Prevention Partnership and Family Support (PPFS) – FAMILY TALK
Title: Ms. **Name:** Name removed
Qualifications: Social Worker
Position: Senior Social Worker
Dept : Tusla social work
Organisation: Tusla
Address: Tusla, Enterprise Centre, Trim Rd., Navan, Co. Meath

Tel : Details removed

8. Tusla Dublin South Central social work and PPFS – FAMILY TALK
Title: Ms. **Name:** Name removed
Qualifications: Social Worker
Position: Senior Social Worker
Dept : Social work
Organisation: Tusla
Address: Church House,78BDonore Avenue, Dublin 8
Tel : Details removed

9. Tusla Mayo social work and PPFS Mayo – FAMILY TALK
Title: Mr **Name:** Name removed
Qualifications: Social Worker
Position: Removed
Dept : Tusla
Organisation: Tusla
Address: Tusla, 2nd Floor, Mill Lane, Bridge Street, Castlebar, Mayo.
Tel : Details removed

10. Tusla Mayo social work and PPFS Galway Roscommon – FAMILY TALK
Title: Mr **Name:** Name removed
Qualifications: Social Worker
Position: CYPSC Coordinator
Dept : Tusla
Organisation: Tusla
Address: 13 FanaBurca, Western Distribution Rd., Knocknacarra, Galway. Tel: Email:
Tel : Details removed

11. CluainMhuire Community Mental Health Services, Blackrock
Title: Ms. **Name:** Name removed
Qualifications: Social Worker
Position: Senior Social Worker
Dept : AMHS
Organisation: Saint John of God
Address: CluainMhuire Community Mental Health Services, Newtownpark Avenue, Blackrock, Co. Dublin
Tel : Details removed

12. Kilkenny Mental Health Services – SYSTEMIC FAMILY THERAPY
Title: Dr **Name:** Name removed
Qualifications: Removed
Position: Name removed
Dept : AMHS
Organisation: HSE
Address: St. Canice's Hospital, Dublin Rd., Kilkenny
Tel : Details removed

9. North Dublin AMHS – MULTI-FAMILY GROUP
Title: Ms. **Name:** Name removed
Qualifications: Social Worker

Position: Senior Social Worker
Dept : AMHS
Organisation: HSE
Address: St. Francis Centre, Station Road, Raheny, Dublin 15
Tel : Details removed

A3. Details of Co-investigators:

N/A – Our collaborators will not be conducting research analysis although they will facilitate contact between the families and the research team. Their contact details are provided in section A2 (d) above.

Name of site (if applicable): Answer
Title: Dr. / Ms. / Mr. / Prof. **Name:** Answer
Qualifications: Answer
Position: Answer
Dept : Answer
Organisation: Answer
Address: Answer
Tel: Answer **E-mail:** Answer
Role in Research e.g. statistical / data / laboratory analysis: Answer

A4. Lead contact person who is to receive correspondence in relation to this application or be contacted with queries about this application.

Name: Prof Sinead McGilloway
Position: Professor and Director, *Centre for Mental Health and Community Research*
Organisation: Maynooth University
Address for Correspondence: Maynooth University Department of Psychology, John Hume Building, National University of Ireland Maynooth, Maynooth, Co. Kildare.
Tel (work): +353 1 708 4765 **E-mail:** Sinead.McGilloway@mu.ie

A5 (a) Is this study being undertaken as part of an academic qualification? No
However, one part of the study (the process evaluation of the *Family Talk* intervention) will form the basis of a PhD for Christine Mulligan, Doctoral Fellow on the PRIMERA Research Programme. Details of this process evaluation are provided in Section B8.

A5 (b) If yes, please complete the following:
Student Name(s): Christine Mulligan
Academic Course: PhD in Psychology
Academic Institution: National University of Ireland Maynooth

A5 (c) Academic Supervisor(s):

Main Supervisor

Title: Prof. **Name:** Sinéad McGilloway
Qualifications: BSSC,PhD, CPsychol, CSci, AFBPS
Position: Director, *Centre for Mental Health and Community Research* **Dept:** Psychology
Organisation: National University of Ireland Maynooth

Address: Maynooth University Department of Psychology, John Hume Building, National University of Ireland Maynooth, Maynooth, Co.Kildare, Ireland.
Tel: +353 1 708 4765 **E-mail:** Sinead.McGilloway@mu.ie

Co-supervisor

Title: Dr. **Name:** Mairead Furlong
Qualifications: PhD, MA Counselling Psychology
Position: PRIMERA Research Programme Coordinator **Dept:** Psychology
Organisation: National University of Ireland Maynooth
Address: Maynooth University Department of Psychology, John Hume Building, National University of Ireland Maynooth, Maynooth, Co.Kildare, Ireland.
Tel: Removed **E-mail:** Mairead.Furlong@mu.ie

SECTION B STUDY DESCRIPTORS

SECTION B IS MANDATORY

B1. What is the anticipated start date of this study?

September/October 2018

B2. What is the anticipated duration of this study?

The study is funded by the HSE (Mental Health Division) for 3.5 years (2017-2021)

B3. Please provide a brief lay (plain English) description of the study. Please ensure the language used in your answer is at a level suitable for use in a research participant information leaflet.

Mental disorders are "…one of the greatest public challenges in the European Region" (European Mental Health Action Plan, 2013; p.1). Children of parents with mental health difficulties are at increased risk of a range of negative mental health, social, physical, and educational outcomes (Perrino et al. 2014). Yet they are amongst the most vulnerable 'hidden' groups in society. Research indicates that up to one in five young people may live in families where a parent has mental health difficulties (Reupert et al. 2012). Due to the current organisation of mental health services in Ireland (and internationally), the complex needs of these children and families often go unrecognised and untreated.

In 2017, the HSE Mental Health Division funded a 3.5 year (2017-2021) programme of research at the *Centre for Mental Health and Community Research* (at Maynooth University) called PRIMERA (**P**romoting **R**esearch and **I**nnovation in **M**ental h**E**Alth se**R**vices for children and f**A**milies) (https://cmhcr.eu/primera-programme/)**.** PRIMERA aims to: (1) identify, help develop/implement and evaluate family-focused interventions for families when a parent has mental health difficulties (and has children aged 5-18 years); and (2) promote a 'think family' care delivery agenda in supporting such families in Ireland.

Following an initial scoping study - based on a national Expression of Interest (EoI) call to HSE mental health services in 2017 - 8HSE sites across the country were identified (using agreed criteria) as eligible for inclusion in the PRIMERA research programme. In due course, 4 Tusla sites and one Saint John of God site joined the study. Thus 13 sites

have confirmed their involvement in the research. At the same time, the research team undertook a review of the international research literature in order to identify the use of, and evidence underpinning, family-focused mental health interventions across the world. An intervention called *Family Talk* was identified as the intervention with the most promising evidence base, whilst it is also similar to some previous and existing/proposed services in Ireland.

Eleven of the thirteen sites agreed to deliver *Family Talk*, while the remaining two sites will deliver systemic family therapy and a group multi-family programme, as these were already in the planning stages at the time of the EoI call. All services will be evaluated by the PRIMERA research team, but with a particular focus on a robust evaluation of *Family Talk*. A series of studies (based on a mix of quantitative and qualitative methods) will be conducted in parallel to assess the impact of the intervention as well as the experiences, processes and costs involved in their implementation and delivery.

B4. Provide brief information on the study background.

Recent years have seen a growing recognition of the need for more integrated and effective service responses to families when a parent has mental health challenges. Currently, most mental health services in Ireland (and internationally) do not attend to the parenting status of service users due to individualised approaches to assessment and treatment, segregation of adult and child and adolescent mental health services, and professionals' competencies around child welfare concerns (Barnardos, 2014). As a result, many commentators have called for the identification and evaluation of more holistic family-focused interventions when a parent has mental health difficulties (Bee et al. 2014).

Internationally, clinical trials and meta-analyses indicate the safety and effectiveness of various family-focussed interventions in helping parents and children cope with parental mental illness (Siegenthaler et al. 2012). In particular, four clinical trials of *Family Talk*, a 6-8 session intervention for parents and children, reported increased understanding of mental health, enhanced family functioning and parenting skills, and improvement of mental health symptoms and resilience in both parents and children (Beardslee et al. 2013). Moreover, *Family Talk* is attractive to service providers due to its freely available online training and resources. Accordingly, *Family Talk* has been adopted within several national initiatives – Australia, Finland, Norway, Greece – that have been established in recent years to support children and families when a parent has mental health difficulties (Beardslee et al. 2013).

Following a nationwide scoping survey of existing family-focused practice within HSE Adult Mental Health Services and Child and Adolescent Mental Health Services in 2017, the PRIMERA team identified *Family Talk* as a strong candidate for implementation and evaluation in an Irish context. Amongst other things, it has an evidence base, is implemented in a number of countries throughout the world and is similar to the work being conducted in several sites across the country. Eleven sites across the country have agreed to deliver *Family Talk* as part of the PRIMERA evaluation (6 HSE, 4 Tusla and one SJOG site).

The PRIMERA scoping survey also revealed two other HSE sites that deliver an alternative service for families when a parent has mental health difficulties. One site is developing a multi-family group approach run across two weekends. Multi-family group work has a strong evidence base in mental health family work (McFarlane, 2016: NICE, 2014), although not specific to families where a parent has mental health difficulties. Therefore, we believe that this service merits some investigation in an Irish context. The other site is using systemic family therapy

(SFT) which is also underpinned by some evidence in working with adults and children with a range of mental health problems (Carr, 2009, 2014), although, similar to multi-family group work, this evidence base is not specific to our target population. Therefore, we are interested in investigating the extent to which 6-8 sessions of SFT can produce positive outcomes for family members where a parent has mental health difficulties. Each of the interventions is described later in Section B8.

B5. List the study aims and objectives.

The overarching aims of the PRIMERA research programme are to: (1) identify, liaise and collaborate with mental health services in Ireland that currently deliver, or are interested in developing and delivering, an inter-agency, family-focused intervention (FFI) for families where a parent has a diagnosed mental health problem (and their children aged 5-18); (2) investigate the implementation and clinical and cost-effectiveness of a selected intervention (Family Talk); (3) to explore the effectiveness of two smaller interventions currently being implemented in Ireland (Systemic Family Therapy and Multi-Family Group); and (4) to help inform a 'think family' care delivery agenda, more broadly, within mental health services in Ireland (e.g. by critically appraising and providing relevant resources for clinicians, delivering workshops[36]/stakeholder events, participating at other events/meetings when required).

The specific objectives of the study are to:
1. Examine the clinical effectiveness of the selected intervention (Family Talk) in addressing key family, parent and child outcomes.

2. Explore the experiences of families/stakeholders in receiving/delivering Family Talk including in particular, the barriers and facilitators to implementation. We will also investigate the extent to which 'think family'/family-focused practices have become more embedded within mental health services in Ireland during the PRIMERA research;

3. Examine the cost effectiveness of Family Talk. To date, no evaluations of Family Talk (or other family-focused interventions) have reported costs data.

4. Assess the effectiveness of Systemic Family Therapy (SFT) as well as experiences of its delivery and receipt;

5. Explore the initial perspectives and views of the newly developed multi-family group (MFG) intervention; and

6. Resources permitting, we hope to develop a national guidance framework on working with families where a parent has mental health difficulties. **NB.** It may not be possible to achieve the latter goal in the time available due to the large amount of work involved in achieving the other study objectives, but we will keep this under review.

B6. List the study endpoints/ measurable outcomes (if applicable).

[36] For example, the PRIMERA team are hosting a Masterclass in Maynooth University on the 5th of September

1. Family Talk
Parents, partners (where applicable) and children will complete self-report questionnaires at baseline (pre-intervention) and at 6- and 12-month follow-up.

Parents will complete self-report measures on: child mental health and wellbeing, family functioning, parental understanding of the impact of their mental health on children, parental mental health symptoms, parental resilience and coping, parenting competencies and service utilisation. Partners (where applicable) will be invited to complete a simple measure of their own mental health and wellbeing.

Children aged 7-18 years will be asked to complete a number of brief self-report measures online using the secure Qualtrics software package (more detail provided below). Measures include: child mental health and wellbeing, child resilience and coping, family functioning, and child understanding of parental mental illness.

2. Systemic Family Therapy
An identical approach to that described above will be taken with the exception of the 12-month follow-up assessment.

3. Multi-Family Group
No outcomes will be assessed in the analysis of the multi-family group. Only qualitative data will be collected from participants in order to assess their views and experiences of the intervention.

B7. Provide information on the study design.

Different study designs will be utilised in the evaluation of the different interventions:

1. *Family Talk* – a randomised controlled trial (impact evaluation) alongside an embedded process and costs evaluation. *FT* will be evaluated as a multi-centre, randomised, controlled, investigator-blinded superiority trial with two parallel groups and a primary endpoint of child and parent mental health and wellbeing at six-month follow up. Data will be collected at 12-month follow up for the intervention group but not for the control group as they will have received Family Talk by then.

The process evaluation of FT will involve interviews with service users and service providers and other stakeholders to investigate their experiences of attending/delivering the FT service. In addition, families (parents and children) will be asked to complete a *Family Satisfaction Questionnaire* at the end of service delivery. Implementation fidelity and the extent to which family-focused practice has become embedded in service delivery will also be assessed using online surveys within the process evaluation. The process evaluation of Family Talk provides the basis for the PhD which will be conducted as part of this programme of research by Christine Mulligan.

2. *Systemic Family Therapy* – outcomes measured at pre- and post-intervention (no control group) as well as a brief qualitative analysis of the experiences and perspectives of service users and service providers.

3. *Multi-family Group* – a qualitative study design to assess the experiences and views of service users and clinicians/service providers.

B8. Provide information on the study methodology.

Participants and settings

For each of the interventions, participants will include families (i.e. parents and children aged 5-18 years) in our selected sites where a parent has mental health difficulties. Parents will be a current or previous patient of Adult Mental Health Services or will be currently receiving medication/treatment from their GP for their mental health issues (e.g. anxiety, depression). The vast majority of parents in the sites will be a current patient of AMHS and will be under the clinical responsibility of the consultant psychiatrist, multi-disciplinary team (MDT) or clinician who is delivering the family-focused intervention. In some cases, a child may be in CAMHS or the family is in contact with Tusla services, but the parent must have recognised mental health issues and should be receiving treatment/medication from their GP. Clinical responsibility will be provided by the GP and the service provider of the family-focused intervention. We will recruit only children aged five years and over because the interventions are targeted at children who are able to verbally express their experiences.

Participants will also include other stakeholders such as those delivering and coordinating the intervention (e.g. clinicians, managers). In addition, we hope to include staff in mental health services who are not a site in the evaluation as well as national and international experts and policy makers.

Interventions

1. *Family Talk*

Intervention arm

Family Talk (FT) is a manualised, strengths-based, 6-8 session programme for families where a parent has mental health difficulties. *Family Talk* uses an individual family format and the trained clinician(s) meets with parents, children and the whole family. The first two sessions involve the clinician and parents and includes a discussion of the family's experience of mental illness and psycho-education, as required. In session three, the clinician meets with the children alone to conduct an assessment and to identify any questions which the child(ren) may have in relation to their parent's mental health difficulties. Next, a planning meeting between the clinician and parents is held, after which a whole family session is organised to support family discussion and provide information on mental disorders as needed. The intervention concludes with follow-up meetings (after one week and after 3-6 months) to check in and support the family going forward.

Waitlist control group

The waitlist control group will receive services as usual. This will mean the parent will still receive individual treatment in AMHS for their mental health difficulties or, in a small number of cases, will be receiving medication/treatment from their GP. Importantly however - and as in most RCTs in the community (e.g. McGilloway et al, 2012) - waitlist families will be offered the FT intervention following the 6-month follow-up assessment period.

With regard to the delay of treatment to the waitlist control group, we recognise the need to balance duty of care to participants with the need to conduct a robust (unbiased) methodology that will allow us to evaluate whether FT is of value to families. In order to reduce the number of families for whom the FT intervention is delayed, families will be informed by both clinicians and researchers that they have a 2:1 chance of receiving FT now or in six months' time. We have used this approach successfully in our previous research which also involved many vulnerable

and disadvantaged parents (McGilloway et al. 2012, 2014, 2016). In addition, care is provided for waitlist families in that they will receive usual services (parent attending AMHS). Furthermore, if clinicians judge that the family must receive FT now and cannot wait, then the family will receive the intervention, but will be removed from the RCT.

2. Systemic Family Therapy

Family therapists work with parents attending AMHS and their families (e.g. partner, children 7 years and older, significant others). In some cases, family therapy may be preceded by couples' therapy. Family therapy in this instance involves 6-8 sessions, delivered fortnightly for 1-1.5 hours at each session. Each family member has an opportunity to talk about their experience of the parent's mental health and their role in the family. Therapists will attend to the type of language used and the level of expressed emotion in sessions and will utilise a range of techniques to improve communication and problem-solving skills within families. These techniques include: genograms, reframing problems, identifying strengths, relabelling negatively labelled behaviour in positive non-blaming terms, and presenting multiple perspectives.

3. Multi-Family Group

This intervention is for families where a parent is attending the HSE adult mental health service. The intervention aims to facilitate families in talking together about a parent's mental health diagnosis and to explore ways of supporting the recovery of the whole family. The intervention includes three to four individual family meetings with the project facilitators and two full day multi-family workshops that will include members of four to five families. Invitees will include parents, dependent children, adult children, and other significant adults in the children's lives. During the workshops, the families will work together in their own family groups and will also work separately in peer groups of parents, children and other adults in the family. Group work will include discussions and art therapy. Each of the families will be invited to preparatory and follow up meetings with the project facilitators.

The project facilitators will include mental health social workers working in the mental health service and HSE mental health peer support workers employed in the mental health service. The advisory group for the intervention includes social work staff, peer service user supporters and researchers from the PRIMERA team. There will be three workshop cycles with delivery to take place in late 2018 to mid-2019.

Measures

1. Family Talk

This section will outline the measures used in the (a) Impact (RCT) evaluation; (b) the Process evaluation; and (c) the Cost evaluation of *Family Talk.*

(a) RCT/Impact evaluation: Outcome measures

A battery of measures/questionnaires will be used to provide a comprehensive and rigorous assessment of child, parent and family outcomes. Measures have been identified and selected based on age-appropriateness, relevance, psychometric robustness and our previous work (e.g. McGilloway et al. 2012, 2014). In addition, we have consulted with service users during several of our site visits who have given feedback on the selected measures.

Care will be taken to minimise participant burden, and assessments with parents will take 30-60 minutes, depending on levels of literacy. Assessments with children (7-18 years) will take approximately 15 minutes. While children 5 years and older are suitable to attend Family Talk,

the questionnaires are only suitable for children 7 years and older. Parents, partners and children will complete self-report questionnaires at pre-intervention, and at 6- and 12-month follow-up periods. Appropriate (ongoing) informed consent and assent will be obtained prior to each assessment (please see Appendices 1-3).

Child outcomes

Once prior parental consent and child assent has been provided, the child participants will be invited to complete a few self-report measures using the secure Qualtrics online software package (Qualtrics, 2017). The online survey will take 10-15 minutes and will include voice-recorded files in order to assist comprehension. No personal identifiers of children will be collected using Qualtrics and Qualtrics does not share data with third parties. We have consulted with the Data Protection Officer in Maynooth University (Ann McKeon) who has advised us that Qualtrics provides excellent data security. Service users have advised that the online survey will appeal to children.

A preview of the draft survey can be found at the following link:
https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_4Py9emeB7WYr13f?Q_SurveyVersionID=current&Q_CHL=preview
A pdf of the Qualtrics survey can be seen in Appendix 4.

1. Child mental health and wellbeing - *Strengths and Difficulties Questionnaire (SDQ)*

The SDQ (Goodman, 1997) is a 25-item, widely used and psychometrically sound measure of child wellbeing and behaviour for 3-18 year-olds. The SDQ has a parent and child version; in the former, the parent reports on the child's behaviour whilst in the latter version, the selected child (7-18 years) reports on their own behaviour. Both parents and children will complete the SDQ in the current evaluation. The SDQ comprises five subscales which assess conduct problems, hyperactivity, emotional symptoms, peer problems, and pro-social behaviour. Both subscale and total scores may be obtained (Appendices 5-6).

2. Child resilience - *Child and Youth Resilience Measure 12 (CYRM-12)*

The CYRM-12 (Liebenberg et al, 2012) is a brief validated 12-item child report measure of the child's resilience and assesses individual traits, relationship to caregiver(s), and contextual factors that facilitate a sense of belonging, all of which have been found to influence resilience (Appendix 7).

3. Child's understanding and experience of parental mental health challenges

There are currently no validated measures of a child's understanding of (parental) mental health difficulties. However, a key objective of *Family Talk* (and most family-focused interventions) is to improve knowledge and understanding of parental mental health difficulties, and to promote empathy and communication among family members. Therefore, a brief age-appropriate questionnaire has been devised in collaboration with service users and practitioners in our sites to assess the child's understanding and experience of parental mental health challenges and the extent to which their understanding and experience may have changed following the intervention and in comparison to a control group (Appendix 8).

Parent outcomes

Parent measures will be completed in person with a researcher either in the parent's home or in another suitable venue (e.g. a local mental health or community centre). We have used this approach successfully in our previous research.

4. Parental mental health - *Behaviour and Symptom Identification Scale (BASIS-24)*

The BASIS-24 (Harvard Medical School) is a 24-item self-report questionnaire which provides a comprehensive assessment of mental health functioning in clinical populations (aged>18) across six major areas (during the previous week): depression/functioning, relationships, self-harm, emotional lability, psychosis, and substance abuse. BASIS-24 is ideally suited to the present study as it is not diagnosis-specific, but is designed to cut across diagnoses to reflect the wide range of symptoms and problems that occur across the diagnostic spectrum. It is designed to assess change during or following mental health treatment (Appendix 9).

5. Parent's understanding and experience of mental health challenges
There are currently no psychometrically robust and user-friendly measures of mental health literacy, and particularly to assess a parent's understanding and experience of how their mental health affects their children. Therefore, similar to above, we have devised a 20 item questionnaire that measures the parent's mental health literacy (e.g. awareness of common myths about mental health), their experience of mental health challenges as they relate to their children, and their perceived level of social and service supports. The questionnaire has been devised in response to, and in collaboration with, service users and practitioners (Appendix 10).

6. Parental resilience and coping - *The Coping Self-Efficacy (CSE) scale* and the ***Connor-Davidson Resilience Scale 2 (CD-RISC2)***
The CSE scale (Chesney et al. 2006) is a 26-item self-report measure of a person's confidence in performing coping behaviours when faced with life challenges, as well as a way of assessing changes in CSE over time in intervention research. The scale measures problem-focused coping, ability to stop unpleasant emotions and thoughts, as well as receipt of support from friends and family (Appendix 11).

The CD-RISC2 (Mandleco et al. 2000) is an abbreviated two-item (self-report) version of the CD-RISC which captures the essence of resilience (i.e. the ability to spring back and successfully adapt to change). This brief measure assesses resilience or progress after treatment or interventions (Appendix 12).

7. Parenting competencies - *Parental Sense of Competence scale (PSOC)*
The PSOC (Johnston & Mash 1989)is a 16-item, self-report scale designed to assess parent self-efficacy in parents of children aged 0-18 years. It is one of the most commonly used tools for measuring parental self-efficacy and comprises two subscales related to parent satisfaction and parent self-efficacy. A total parent competence score may also be calculated (Appendix 13).

Partner outcomes

8. Partner mental health - *Warwick-Edinburgh Mental Well-being Scale (WEMWBS)*
The WEMWBS (Tennant et al, 2007) is a 14-item, psychometrically robust, self-report measure used to assess mental health and wellbeing in the general population (during the previous two weeks). This assesses both hedonic (e.g. life satisfaction) and eudemonic (e.g. psychological functioning and self-realisation) perspectives and also incorporates positive affect (e.g. optimism) and positive functioning (e.g. energy) (Appendix 14).

Family outcomes

9. Family functioning – *Systematic Clinical Outcome and Routine Evaluation 15 (SCORE 15)*
The SCORE 15 (Stratton et al. 2010) is a 15-item reliable and validated self-report measure of family functioning. It is suitable for clinical populations for adults and the child version is suitable for children over 7 years. The SCORE 15 has three dimensions: strengths and adaptability,

overwhelmed by difficulty, and disrupted communication. A total score may also be calculated (Appendices 15-16).

Background characteristics

10. The Profile Questionnaire

Demographic and background information on families will be collected at baseline from parents using an adapted version of the *Profile Questionnaire (PQ)* used in our current and previous research (McGilloway et al. 2017). This will include information on the physical and mental health of family members, perceived social support, and socioeconomic status (related to parental income, employment, education and living circumstances). We will collect the minimal amount of personal data necessary to conduct our analyses. The *PQ* will provide important data for purposes of attrition analysis and for testing the equivalency of the control and intervention groups. A brief follow-up version will be used to assess any changes at follow-up (e.g. change of partner, new children etc.) (Appendix 17).

(b) Process evaluation of Family Talk

The process evaluation will run in parallel to the RCT and will involve the application of mixed methods to investigate the experiences and contextual factors related to receiving/implementing FT in an Irish service context. This will include: (1) assessing the experiences and views of key stakeholders involved in the organisation and delivery of the intervention; (2) monitoring and appraising service implementation including identifying the need for change, securing managerial buy-in, establishing necessary resources for implementation, implementation fidelity and organisational/cultural change; and (3) assessing referral rates and engagement of participants and service providers with the intervention and their overall experiences, views and levels of satisfaction.

The study and analysis will be informed by the MRC guidance for complex interventions (Medical Research Council, 2015) and will be located within an implementation science framework (e.g. Fixsen et al. 2009; the Consolidated Framework for Implementation Research, 2009). The process evaluation of Family Talk provides the basis for the PhD which will be conducted as part of this programme of research (by Christine Mulligan).

Written informed consent/assent will be obtained from all participants involved in the process evaluation. Interviews will be audio-recorded where consent is provided. The different elements of the study are outlined below.

Qualitative element: Interviews and focus groups

Interviews with parents and partners

We will conduct semi-structured interviews with a subsample of parents (n≈15-20) and partners (n≈ 10) involved in the RCT in order to explore their experience of participating in FT and to learn to what extent it met their needs. We will employ a maximum variation sampling strategy in order to recruit a heterogeneous sample across different site locations and with different demographic characteristics (e.g. age, marital status, SES, and so forth). Interviews will be conducted at 6-month and 12-month follow ups. The interviewer will adopt a warm person-centred approach (Rogers, 1951). Interviews will take place in the participant's home (unless otherwise requested) and will last approximately 30-45 minutes. A brief interview will also be carried out with parents who dropped out of FT (n≈10) (see Appendix 18 for information and consent form and interview schedules).

Interviews with children

Semi-structured interviews (15-30 minutes) will also be conducted with a small sample of children aged 12-18 years (n≈10) at the six-month follow up in order to explore their experience of the FT programme and the extent to which they think it helped themselves and other family members. In addition, we will use an alternative interview story approach for interviewing the younger children (7-12 years) (n≈10).

The interview story (15-30 minutes) involves a family imagined by the child in which a parent has mental health difficulties. The child is encouraged to build up a picture of the house, location and family members who live in the home. Picture cards are used to help the child identify emotions. The child is also asked to imagine that the family attends FT and to relate the family's experience of the programme (e.g. what helped, what could be improved). The interview story approach has been used successfully in previous research (Furlong et al. 2018) to discuss sensitive issues with younger children (e.g. children who have experienced domestic abuse). The indirect approach allows the child to externalise the issue and talk about it in a more objective fashion, thereby offering emotional protection to the child. Occasionally, children may slip into 'I' language during the course of an interview rather than use the name of the character they have chosen. If that happens, the researcher mirrors the language used by the child. The researcher (CM) is a mature, female interviewer, trained in psychotherapy, and has experience of families where a parent has mental health issues. She will be attuned to the verbal and non-verbal cues of the child and will pause/stop the interview if the child shows signs of distress.

More details on ethical procedures with children are outlined in sections C and D below (See Appendices 19-20 for information and consent/assent forms and interview schedules).

Interviews /focus groups with clinicians and managers

Further one-to-one semi-structured interviews and/or focus groups will be conducted with FT clinicians/service providers across all sites (n≈40). Individual interviews will last 30-60 minutes and focus groups will last approximately 60 minutes. Topics will include the experience of implementing and delivering *Family Talk* within services; key outcomes and enablers and barriers to delivery; rates of recruitment and attrition, and organisational support, amongst other issues (See Appendix 21 for information and consent form and interview schedule/topic guide).

A small number of in person/skype/phone interviews (15-30 minutes) will also be held with managers/decision makers within sites where possible (e.g. line managers, Executive Clinical Directors, consultant psychiatrists) (n≈10). The purpose of the interview will be to elicit their experience/views of FT within their service and to assess to what extent the intervention fits with their policy and practice objectives (See Appendix 22 for information and consent form and interview schedule).

Interviews with national and international policy makers and experts

In person/skype/phone interviews (15-30 minutes) will be held with national and international policy makers and experts (n≈5) to elicit their views on family-focused practice in Ireland, how it compares to international policy and practice, and to provide recommendations for the future (see Appendix 23 for information and consent form and interview schedule).

Documentary analysis

A documentary analysis of minutes from meetings with sites (if available) and other relevant documentation, will also be used to help map the development of family-focused mental health practice over the duration of the PRIMERA research programme.

Quantitative element: surveys and questionnaires

Questionnaire with families who attend Family Talk

A *Family Satisfaction Questionnaire* will be given by clinicians, to families (parents and children) following the intervention. The questionnaire will be administered to approximately 80 families, allowing for an approximate attrition rate of 20%. The parent version of the FSQ has 18 items and the child version has 12 items. Participants will be asked to evaluate the extent to which FT was a positive experience for families, has helped with family functioning and understanding of mental health, and to provide suggestions for improvement. Parents and children will be asked for consent prior to completing the form (Appendices 24-25).

On-line (Qualtrics) fidelity survey with clinicians

An online Qualtrics survey will be administered once to clinicians following FT delivery in order to assess fidelity to the implementation. The survey takes approximately 15 minutes to complete and asks about therapist adherence to session checklists as well as family attendance and engagement to the intervention. Clinicians must provide consent online prior to completing the survey (although completion of the survey is tantamount to consent) (Appendix 26 for survey pdf). A preview of the survey content can also be seen at:https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_bxzwIJb0oHAcBvv?Q_SurveyVersionID=current&Q_CHL=preview

On-line (Qualtrics) survey with sites and non-sites

The *Family-Focused Mental Health Practice Questionnaire* (Maybery et al. 2010) will be administered to sites and non-sites (n≈80) to compare the extent to which services have become more family focused as a result of the PRIMERA research. The items relate to family-focused policy and practice for families where a parent has mental health difficulties (Appendix 27 for survey pdf). A preview of the draft survey content can be seen at:
https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_6xxe36VeGppHy6x?Q_SurveyVersionID=current&Q_CHL=preview

(C) Cost evaluation of Family Talk

Service Utilisation Questionnaire (SUQ)

The SUQ is an adapted version of the Client Service Receipt Inventory (CSRI) (Beecham & Knapp, 1992) and has been used in our previous research (Furlong et al. 2018; O' Neill et al. 2013). The form will assess the type and number of contacts families have had with healthcare, social care and educational services in the 6 months prior to completion. The form will be administered by means of a face-to-face interview carried out by researchers with parent participants. The form will be administered along with the other psychometric inventories (Appendix 28).

Cost diaries

Cost diaries will be developed based on our previous research (e.g. McGilloway et al. 2018) and discussions with programme facilitators/service providers. The latter will complete the diary. Items will include time taken to recruit and engage families, preparation time, time to deliver the course, and so forth. Time will be multiplied by salary/wage costs to calculate the approximate cost of delivering Family Talk.

2. Systemic Family Therapy (SFT)

The outcomes measured at pre- and post-intervention to evaluate SFT with children and parents will be identical to those used to evaluate FT, as outlined above (Appendices 4-15). However, no control group will be included in this evaluation and a much smaller sample will be involved (n≈20 families).

Interviews will also be conducted with a subsample of service users (*n*=5) and service providers (*n*=4) in order to investigate their experiences of receiving/delivering the intervention. Topics with service providers will include: experiences in setting up and delivering the interventions, referral pathways, extent of buy-in from management and colleagues, and experiences in engaging and retaining families in interventions.

We will use virtually identical information and consent forms and interview schedules to those used in the FT evaluation (See appendices 1-3, 18-22). The main difference is that we will insert 'Systemic Family Therapy' in place of *Family Talk*. We will remove the paragraphs in Appendix 1 that outline the RCT methodology. We will also remove reference to SJOG as it is not relevant to this site and intervention.

3. Multi-Family Group (MFG)

No questionnaires will be used to assess the multi-family group (MFG) intervention. As this intervention is only in development, the service providers do not wish to measure outcomes, but instead prefer to collaborate with families to tailor the intervention to their needs. Therefore, a small amount of qualitative data will be collected from families and service providers using semi-structured interviews (*n*=15). This data will investigate experiences of receiving/delivering the intervention. Reflection on each workshop cycle will inform the delivery of the next cycle.

As above, we will use adapted versions of the information and consent forms and interview schedules used to interview FT service users and service providers (See Appendices 18-22). We will insert 'Multi-family group' instead of *Family Talk*. We will also remove reference to SJOG as it is not relevant to this site and intervention.

Data analysis

Quantitative data

1. Family Talk RCT: The RCT data analysis will be led by the team statistician and will include: a baseline analysis; an attrition analysis at each time point involving a comparison of 'stayers' and 'leavers'; and a strict intention to treat and per protocol analysis of outcomes (and calculation of effect sizes using Cohen's (1988) guidelines); this will involve using a linear mixed model approach to repeated measures data including condition, baseline value, area and time, together with predictors of missing values to allow the 'missing at random' assumption to hold. Regression analyses will examine the impact of covariates on intervention outcomes.

Clinicians/service providers in each of our sites will be invited to complete the *Family-Focused Mental Health Practice Questionnaire (FFMHPQ)* at two different time points. Depending on the number of staff who complete the measure, a Wilcoxon Signed Rank Test or a repeated measures ANOVA will be performed as appropriate. We will also compare the level of family-focused practice between our sites and a sample of other services (non-sites) using between groups ANOVA/Mann-Whitney U test, as appropriate.

We will use descriptive statistics to analyse measures of fidelity (therapist adherence, family attendance), and the Family Satisfaction Questionnaire. Frequencies, medians, interquartile ranges, means and standard deviations will be reported as appropriate.

2. SFT - Pre-post intervention analysis (without control group): In the evaluation of SFT, approximately 20 families will be recruited. Given the small sample size, the Wilcoxon Signed Rank test will be used to assess any changes in outcomes from pre- to post-intervention for families. Frequencies, medians, interquartile ranges, means and standard deviations will be generated as appropriate.

Qualitative data (FT, SFT and MFG):

The qualitative data (e.g. interviews, focus groups, meeting minutes) gathered as part of all three evaluations will be transcribed in full and analysed using standard thematic analysis (Braun et al. 2006) and Framework Analysis (Pope et al. 2000). The qualitative analysis will be informed by the MRC framework for process evaluations (MRC, 2015) and located within an implementation science framework (e.g. Fixsen et al. 2009; the Consolidated Framework for Implementation Research, 2009).

Costs data (Family Talk)

The cost effectiveness analysis (CEA) will compare the cost-effectiveness of receiving Family Talk versus a control group receiving services as usual. The CEA approach will be identical to those undertaken in the Incredible Years Ireland study and the ENRICH study (O' Neill et al. 2013; Furlong et al. 2018). The CEA will calculate:

(i) The cost of delivering Family Talk

(ii) A comparison of service utilisation for the intervention and control conditions; and

(iii) An incremental cost-effectiveness ratio (ICER), to give the cost of obtaining a one unit decrease on the clinical outcome measures employed in the RCT (i.e. SDQ, BASIS-24) when comparing Family Talk versus usual services.

The ICER will use a 1000 replication bootstrap to provide a 95% confidence interval accompanied by appropriate sensitivity analyses. The CEA will adopt a multiagency, public sector, analytic perspective and will use official sources to provide estimates of unit costs separate from frequencies of resource utilisation. In addition, a cost-benefit analysis (CBA) will be conducted to investigate the differential impacts of the intervention on later costs, such as generating savings in relation to reduction in health and mental health service utilisation, and improvement in education.

B9. Provide information on the statistical approach to be used in the analysis of your results (if appropriate) / source of any statistical advice.

The main statistical approaches to be used are outlined above in Section B8 (in the section entitled 'Data analysis'). These will vary according to the study design for each intervention.

B10 (a) Please justify the proposed sample size and provide details of its calculation (including minimum clinically important difference).

FT evaluation

The precise number of participants for inclusion in the RCT will be based on a full power analysis for an intention-to-treat trial using the SDQ and the BASIS-24 as the primary outcome measures for child and parent participants respectively. We estimate that complete data would be required from approximately 100 families in the intervention arm and 50 in the waitlist control group (assuming a 2:1 allocation ratio) to allow over 80% power to detect a difference in mean outcome of 0.5 standard deviations or a Cohen's d of 0.5 (modest effect size) (Sullivan and Feinn, 2012) between the intervention and control groups on our primary outcomes (and allowing for approximately 20% attrition). We would consider these numbers to be achievable

based on discussions with our eleven confirmed sites. Previous RCTs of *FT* have indicated statistically significant improvements in child and parent wellbeing with sample sizes of 37, 66, 105 and 119 families respectively (Beardslee et al. 1992; 2003; Christiansen et al. 2015; Punamaki et al. 2013).

SFT and MFG evaluations
A sample size calculation is not applicable in either of the evaluations of SFT and MFG as an RCT study design is not being used here. It has been estimated by service providers that a maximum of 20 families will receive SFT and 15 families (involving 4/5 members per family) will receive MFG.

B10 (b) Where sample size calculation is impossible (e.g. it is a pilot study and previous studies cannot be used to provide the required estimates) then please explain why the sample size to be used has been chosen.

Not applicable

B11. How many research participants are to be recruited in total?

Family Talk – Approximately 150 families. Thus, at least 150 parents will complete measures. Given that more than one child per family may complete measures, the number of children may be larger than 150.

Systemic Family Therapy – 20 families will be targeted and will be invited to complete measures. Similar to above, more than one child per family may complete measures, and so the number of children may be larger than 20.

Multi-Family Group – 15 families will be targeted and recruited. Given that more than one child per family may provide data, the number of children may be larger than 15.

A sample of service providers (n≈40) and other stakeholders (e.g. managers, decision makers, experts - n≈15) will also be invited to participate in the above studies.

B12 (a) How many research participants are to be recruited in each study group (where applicable)? Please complete the following table (where applicable).

We are not clear what exactly is being asked in this question. In terms of the RCT evaluation of Family Talk, 100 families will be recruited for the intervention group and 50 families to the control group. B13 below provides details on numbers in each site.

Name of Study Group:	**Name of Study Group:**	**Name of Study Group:**	**Name of Study Group:**	**Name of Study Group:**
Number of Participants in this Study Group:	**Number of Participants in this Study Group:**	**Number of Participants in this Study Group:**	**Number of Participants in this Study Group:**	**Number of Participants in this Study Group:**

Name of Study Group:	**Name of Study Group:**	**Name of Study Group:**	**Name of Study Group:**	**Name of Study Group:**

Number of Participants in this Study Group:	**Number of Participants in this Study Group:**	**Number of Participants in this Study Group:**	**Number of Participants in this Study Group:**	**Number of Participants in this Study Group:**

B12 (b) Please provide details on the method of randomisation (where applicable).

RCT (Family Talk)
Baseline assessments will be conducted once suitable families have been identified, are considered eligible and have agreed to participate in the study. Participants will then be block randomised by site location (using family as the unit of randomisation) and blindly and randomly allocated on a 2:1 basis to the intervention and control arms of the trial. Randomisation will be undertaken by a senior statistician using computerised random allocation procedures; an independent collaborator will conceal the allocation sequence until the grouping has been assigned. The use of block randomisation means that FT can be delivered in a staggered manner, with some participants beginning the intervention while further recruitment continues.

B13. How many research participants are to be recruited at each study site (where applicable)? Please complete the following table.

Site:	**Number of Research Participants at this site:**
FT sites	
1. Letterkenny Mental health Services	15 (10 Intervention, 5 Control)
2. Crosslinx West Galway	20 (14 Intervention, 6 Control)
3. Mayo Mental Health Services	10 (7 intervention, 3 control)
4. Louth Adult Mental Health Services	30 (20 intervention, 10 control)
5. Cherry Orchard AMHS/CAMHS	50 (33 intervention, 17 control)
6. Carlow AMHS with Recovery College Southeast	10 (7 intervention, 3 control)
7. CluainMhuire Community Mental Health Services, Blackrock	20 (14 Intervention, 6 Control)
8. Tusla social work and PPFS Galway	5 (3 intervention, 2 control)
9. Tusla social work and PPFS, Dublin South Central	15 (10 intervention, 5 control)
10.Tusla social work and PPFS Mayo	10 (7 intervention, 3 control)
11.Tusla social work and PPFS Louth Meath	10 (7 intervention, 3 control)
TOTAL NUMBER OF FAMILIES	**195 families**
SFT and MSG sites	
12. Kilkenny Mental Health Services	20
13. North Dublin AMHS	15
TOTAL NUMBER OF FAMILIES	**35**

SECTION C study PARTICIPANTS

SECTION C IS MANDATORY

C1 PARTICIPANTS – SELECTION AND RECRUITMENT

C1.1 HOW will the participants in the study be selected?

The primary participants in all three studies will include families (parents and children) in selected sites. Parents with mental health difficulties will be identified by clinicians who are working directly with clients in each site; eligible families will be targeted and selected using the inclusion criteria described below in Section C1.3 (and agreed by all sites).

Other participants will include service providers (e.g. clinicians, managers) as well as national and international experts and policy makers, all of whom will be identified by the research team in collaboration with each site (where applicable). In addition, resources permitting, we hope to include staff from HSE mental health services who were not successful in their bid to become a site in PRIMERA.

C1.2 HOW will the participants in the study be recruited?

Family participants

Families (parents and children) will be recruited by staff in the selected sites. The MDT, as well as the wider area management team in each site, have been informed about the intervention and the PRIMERA research, and they have agreed to make referrals to the key contact/liaison person in each site. In the case of the FT evaluation, the research team have drafted recruitment brochures for clinicians and families respectively, as well as a poster aimed at informing both families and professionals about the intervention and the PRIMERA research (see Appendices 28-30). These have been developed in consultation with service providers from each site as well as service users from the Recovery College Southeast. The steps in the recruitment process are outlined below.

1. In the first instance, the clinicians/service providers in each site will verbally inform the service user parent about the intervention and about the PRIMERA research. They may use the family brochure as a means to initiate a conversation about the intervention and the research.

2. Once the service provider has secured agreement from the parent that they are interested in participating, they will ask for their consent (on the family recruitment leaflet) for their contact details to be passed in confidence to the research team.

3.Parents will then be contacted by the research team via telephone to arrange for one of the research team to talk to them in more detail about the study and to arrange to visit them to tell them more about the research and obtain their written informed consent in person. All children aged 7-16 years are eligible to participate and their written assent will be obtained once their parent has provided prior consent for their child's participation. Children over 16 years old do not require parental consent and can give their own consent (Appendices 1-3).

NB. Written informed consent/assent will be obtained at each data collection time point (e.g. baseline, 6- and 12-month follow up, and also if a parent/child is asked to participate in a qualitative interview (See Appendices 1-3, 18-20).

Service providers

Service providers (clinicians, management) within each site will also be invited to participate in semi-structured interviews/focus groups and will be asked to provide written informed consent (see Appendices 21-22). Service providers will also be asked to provide their informed consent before completing two brief online surveys on: (a) implementation fidelity and (b) family-focused practice in their service (Appendices 26-27).

See link for fidelity survey at:
https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_bxzwIJb0oHAcBvv?Q_SurveyVersionID=current&Q_CHL=preview

See link for Family Practice Questionnaire at:
https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_6xxe36VeGppHy6x?Q_SurveyVersionID=current&Q_CHL=preview

Other stakeholders

We will also recruit policy makers and experts through our network of contacts, involving, for instance, PRIMERA Steering group, psychiatrists, international academics and policy influencers in the field (e.g. Dr Adrian Falkov, Prof Andrea Reupert). All will provide written informed consent prior to participation (Appendix 23).

Resources permitting, we will recruit staff from HSE mental health services that were not successful in their bid to become a site in PRIMERA through our email contact list of received Expression of Interest submissions. Staff that provide consent will complete a brief questionnaire on family-focussed practice in their service so as to compare experiences with sites selected as part of the PRIMERA study. The link to this is for the Family Practice Questionnaire (see link above; Appendix 27).

C1.3 What are the inclusion criteria for research participants? (Please justify, where necessary)

The research team have discussed the inclusion criteria with all sites and it has been agreed that eligible family participants will fulfil one of the following:

1. Parent(s) aged over 18 – and with children aged 5-18 years - attending AMHS and who are under the care of a psychiatrist/MDT due to a formal (or working) diagnosis of mental difficulty;

Or

2. Parent(s) with a mental difficulty episode in the last 18 months who had been under the care of a psychiatrist or MDT;

Or

3. Parent(s) currently attending a GP for mental health issues (clinical responsibility will be provided by the GP and FT clinician/service provider)

In all of the above cases, the parents' symptoms should be relatively well maintained (i.e. not in crisis), unless the parent can be supported by staff to engage in a relatively stable manner with the family-focused service.

Each site has discussed the above criteria and has selected the category which is likely to apply to the families with whom they work routinely. For example, HSE and SJOG sites will typically include families in the first category. Tusla/CAMHS sites may occasionally accept families in categories two and three where the parent is not currently in contact with AMHS, but is attending their GP for treatment for mental health issues. [Separate ethical approval is being sought from Tusla, Saint John of God and Maynooth University].

C1.4 What are the exclusion criteria for research participants? (Please justify, where necessary)

Exclusion criteria include the following:
(1) parents/children with active psychosis or active substance misuse and/or a life threatening physical illness; and (2) cases where there is a dispute over child custody or an urgent need for child protection services. Families (parents and children) have to be relatively stable and able to engage with the intervention and agree to take part in the research.

C1.5 Will any participants recruited to this research study be simultaneously involved in any other research project? Not to our knowledge

C2 PARTICIPANTS – INFORMED CONSENT

C2.1 (a) Will informed consent be obtained? Yes

C2.1 (b) If no, please justify. You must provide a full and detailed explanation as to why informed consent will not be obtained.

N/A

C2.1 (c) If yes, please outline the consent process in full. (How will consent be obtained, when, by whom and from whom etc.)

Service users

As outlined above, eligible families (parents and children) will be identified and recruited by staff in participating sites. The clinicians/service providers in each site will verbally inform the service-user parents about the intervention and about the PRIMERA research. They may choose to use the family brochure as a means of initiating a conversation about the intervention and the research. Families will be informed by the clinician/service provider that, as well as taking part in the intervention, they will be asked to complete a number of questionnaires and that some parents (and children) may be invited to also participate in an interview to discuss their experiences and views of the service.

As outlined in Section C1.2, once the service provider has secured verbal agreement from the parent that their family would be interested in participating, they will ask the parent if they consent to their contact details being passed in confidence to the research team. Parents will then be contacted via telephone to arrange for a member of the research team to talk to them in more detail about the study. With the parent's verbal agreement, the researcher will arrange a meeting with the parent in order to obtain their written informed consent in person and to administer the questionnaires. Written informed consent will be obtained by the researcher either in the participant's home or in HSE/service offices, depending on which location is preferred by the participant and can be arranged.

Once the researcher meets the parent, the researcher will discuss the research and seek the parent's written informed consent before the assessment (or interview) takes place (Appendix 1). Parents will also be asked to provide their written informed consent for their child (7-16 years) to complete a small number of measures as part of an online (Qualtrics) survey. Parents will be shown a copy of the survey if so desired/requested. The child's written assent will be obtained to complete the measures. The parent and child will agree to provide the parent's or child's email address to the researcher and then the link to the Qualtrics survey will be sent to the parent's or child's email address. The Qualtrics survey will also inform children of their ethical and data protection rights and will ask them to provide assent before they can participate in completing the measures (Appendix 2, see link below to Qualtrics survey). Children over 16 years can provide their own consent and do not need their parent's consent to participate (Appendix 3).

All survey responses will be completely anonymised with no identifiable data collected using this platform. All data collected on Qualtrics will remain under the ethical governance of Maynooth University (MU) and will be stored on encrypted MU computers. Qualtrics (Provo, UT, 2018) never shares data with a third party. The survey can be found at the following link: https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_4Py9emeB7WYr13f?Q_SurveyVersionID=current&Q_CHL=preview

All participants in the study (including parents and children) will be assured of confidentiality (including the limits of confidentiality) and the anonymity of data throughout the research process, including their data protection rights and secure storage, processing and deletion of their data. Participants will also be informed that they may withdraw from the study and/or withdraw/amend their data if they wish, and that withdrawal from the research will not affect their future access to services. Participants will be informed of their right to complain to the Data Protection Officer and Ethics in Maynooth University (contact details provided). The information sheets also provide guidance on what to do in cases where questions may possibly cause distress. Consent/assent will be obtained for each data collection time point (e.g. baseline, 6- and 12-month follow up, and if the parent/child is asked to participate in a qualitative interview) (Appendices 1-3, 18-20).

Service providers

Service providers (clinicians, management) within each site will be invited, following delivery of their intervention, to participate in a semi-structured interview/focus group to discuss their experiences and views of implementing and delivering the service. They will also be asked to provide their written informed consent prior to the interview (see Appendices 21-22) and also before completing a brief online survey on implementation fidelity and family-focused practice in their service (Appendices 26-27)

See link for fidelity survey at: https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_bxzwIJb0oHAcBvv?Q_SurveyVersionID=current&Q_CHL=preview

See link for Family Practice Questionnaire at: https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_6xxe36VeGppHy6x?Q_SurveyVersionID=current&Q_CHL=preview

Other stakeholders

Policy makers and experts will be invited to a telephone/skype/face-to-face interview and will be asked to provide their written informed consent prior to participation (Appendix 23).

We will email staff from HSE mental health services who were not successful in their bid to become a site in PRIMERA and ask them to complete a brief questionnaire on family-focussed practice in their service. The online survey/questionnaire will ask for informed consent prior to participation.
https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_6xxe36VeGppHy6x?Q_SurveyVersionID=current&Q_CHL=preview

As with service users, service providers and other stakeholders will be informed of data confidentiality, anonymity, data protection rights, and their right to withdraw from the study without giving a reason (Appendices 21-23, 26-27, links to Qualtrics surveys above).

C2.2 (a) Will participants be informed of their right to refuse to participate and their right to withdraw from this research study? Yes

C2.2 (b) If no, please justify.

N/A

C2.3 (a) Will there be a time interval between giving information and seeking consent? Yes

C2.3 (b) If yes, please elaborate.

Prior to meeting with a researcher, all participants will have discussed the study with their clinician and have received verbal and written information about the study (e.g. family brochure). Participants must provide verbal consent for clinicians to pass their contact details to the research team. All participants will have an opportunity to speak with a researcher on the phone and then in person to seek further detail if so required. Written informed consent will be sought in person prior to completion of questionnaires, or participation in an interview.

C2.3 (c) If no, please justify and explain why an instantaneous decision is reasonable having regard to the rights of the prospective research participants and the risks of the study.

N/A

C3 adult participants (AGED 18 or over) - CAPACITY

C3.1 (a) Will all adult research participants have the capacity to give informed consent? Yes

C4 participants under the age of 18

C4.1 (a) Will any research participants be under the age of 18 i.e. Children? Yes
If answer is No, please delete remaining questions in Section C4

C4.1 (b) If yes, please specify:
Persons < 16 Yes
Persons aged 16 – 18 Yes

Children in care No

C4.1 (c) If yes to persons < 16, please specify:
Pre-term neonates No
Full-term neonates No
Infants and Toddlers 0 - 4 No
Children 5 - 8 Yes
Children 9 – 12 Yes
Adolescents 13 -15 Yes

C4.2 Is this research of such a nature that it can only be carried out on children? Please elaborate.

One of the key aims of the PRIMERA research programme is to help implement and evaluate safe and effective interventions for families in Ireland where a parent (with one or more children aged 5-18) has mental health difficulties. Therefore, it is of the utmost importance that we can assess the views of both parents *and children* in order to ascertain if the interventions are indeed safe and effective and to also learn how they might be improved. We know that children can be seriously impacted by their parent's mental health, that they have a right to express their views and experiences, and to be consulted in decision-making with regard to developing family-centred interventions for this population (United Nations Convention on the Rights of the Child, 1989).

C4.3 Is the purpose of the research to generate knowledge about the health or social care needs of children?

Yes. The quantitative analyses will produce evidence on whether family-focused interventions improve child mental health and wellbeing, child coping and resilience, and enhance family functioning. The qualitative analyses will explore to what extent the interventions are meeting the needs of children. The experiences and views of parents and service providers will also provide key information on the health and social care needs of these children.

C4.4 Is the research expected to provide direct benefit to child participants, or if there is no prospect of direct benefit, are the risks no more than minimal? Please elaborate.

Based on previous studies in the field, we hope that participating children will enjoy direct benefits as a result of receiving the interventions (e.g. improved child mental health and wellbeing, enhanced family functioning). We do not anticipate adverse effects and indeed, the therapeutic benefits of taking part in community-based research are widely acknowledged (Castillo et al. 2012; Hutchings et al. 2013). Our qualitative work will investigate whether any unintended harms occurred as a result of the interventions.

Qualtrics survey with children
In the FT and SFT evaluations, children can assent/consent to complete a few brief questionnaires on the secure Qualtrics online platform. Considering the sensitive nature of some of the questions, the Qualtrics survey will be designed to provide guidance and support to children in case of emotional distress. For example, children will be advised in the first instance to discuss their concerns with their family. They will also be provided with the contact details (name, email, phone number) of a researcher (Christine Mulligan) with whom they can discuss any concerns or pose any questions. In addition, they will be provided with the contact

details of the clinician/service provider who informed their family about FT and the PRIMERA research. They will also be provided with contact details of Samaritans/Childline and other relevant support resources and websites if so required (Appendices 2-3, link to Qualtrics child survey at https://maynoothpsychology.eu.qualtrics.com/jfe/preview/SV_4Py9emeB7WYr13f?Q_SurveyVersionID=current&Q_CHL=preview

Qualitative interview with children

We also intend to conduct one-to-one interviews with a subsample of children in order to explore their experiences of participating in the interventions. There is a small possibility that a child may experience discomfort or emotional distress during the course of an interview as a result of the potentially sensitive nature of the issues discussed. However, based on our previous studies, children often find it useful to provide feedback and discuss their experiences in an interview (e.g. Furlong et al. 2018).

Before the interview starts, children will be informed that they can stop the interview at any time without giving a reason and assured about their right to confidentiality, anonymity and to withdraw their data at any time without giving a reason. Any display of distress by a child will be dealt with sensitively by the researcher and, if necessary, the interview will be stopped. The parent/guardian can be present in the room if the child is comfortable with that. In the event that a child suffers emotional distress following research participation, we will state in their Information Sheet that they should discuss with their family in the first instance. As with the Qualtrics package, we will provide contact details for the mental health professional who informed them of FT/PRIMERA (name, phone number and email address will be provided) and the contact details of a specific researcher (name, phone number and email address of researcher provided). Further information will be given on relevant support organisations (e.g. Samaritans/Childline) and other relevant websites (Appendices 19-20).

C4.5 Will each child receive information about the risks and benefits of the study according to his/her capacity to understand? Please elaborate and provide copies.

The Information Sheet for children will briefly outline (in simple accessible language) the risks and benefits/uses of the study. With respect to benefits, we will explain that their data and feedback will be essential in providing better supports for families in Ireland when a parent has mental health difficulties. Although we do not anticipate any risks for children in participating in the study, there is a small possibility that a few children may experience a degree of emotional distress given the sensitive nature of some of the questions. The information sheet will advise what they should do if they experience emotional distress, as outlined in section C4.4 (Appendices 2-3, 19-20).

C4.6 Will the explicit wish of the child who is capable of forming an opinion and assessing information to refuse to participate or to be withdrawn from the study be considered by the investigators? Please elaborate, outlining the assent process in full. (How will assent be obtained, when and by whom etc.)

With regard to the participation of children (7-16 years), written informed consent will firstly be sought from those who are legally responsible for the child (i.e. the parent/guardian of the child) on behalf of that child, in line with the 2012 guidelines set out by the Department of Children and Youth Affairs (DCYA). Child participants will also be informed of the research and required to give assent. Children over 16 years can provide their own consent. Both parents and children will be informed that the child's participation is entirely voluntary and that they can

withdraw their data. It will also be clearly explained to parents and children that withdrawal from the research will carry no penalties and, in particular, will not affect their access/future access to services and supports (Appendices 1-3, 19-20).

C4.7 Please comment on the involvement of parents / legal guardians of the child in the consent process.

As stated in C4.6, written informed consent will be firstly sought from the parents/legal guardians of the child (7-16 years). Then, the child participants will be informed of the research and will provide their assent. Also, parents (as well as children) will be informed that their children can withdraw from the research at any point and that future access to services will not be affected. Children over 16 years can provide their own consent (Appendices 1-3, 18-19).

C4.8 Please explain your approach to reviewing assent where research subjects reach the age of 18 during the course of the study.

In cases where participants reach the age of 18 during the course of the study, we will go back to them and ask for their written informed consent to still retain and analyse their data within the study.

C4.9 Please comment on what will occur if the researcher discovers that a child is <u>at risk</u> during the course of this study?

Where a child discloses that s/he is at risk of harm, or where the researcher observes behaviour or receives evidence of incidents considered likely to cause serious harm to the child, the researcher has a duty to take steps to protect the child and/or other children (DCYA, 2011).Therefore, all children participating in this research will be told from the outset that confidentiality cannot be guaranteed if information is divulged regarding a risk of serious harm to the child. The researcher will explain that; "*Whatever you have to say in this interview is confidential unless you tell me that you or somebody else are in danger of serious harm. If that happens, I would need to report that to someone who might be able to help."* The above information is recommended to ensure that the child is fully aware of the situation and the steps that are going to be taken in order to protect them. If during the course of research it becomes necessary to report a child protection concern in line with the Children First national guidance, every possible effort will be made to keep the child's parents/carers informed of the situation, except in circumstances where doing so might place the child at further risk. In reporting these concerns, the researcher is protected in law by the Protections for Persons Reporting Child Abuse Act 1998 (Government of Ireland, 1998).

If a researcher becomes concerned about either the safety of a parent or child, the researchers will follow Children First guidelines and Maynooth University's Child Protection Procedures. All researchers and fieldworkers have completed the Children's First e-learning programme. In addition, the researcher/fieldworker will be required to complete an *Incident Form* and discuss the issue with the Principal Investigator (Prof Sinead McGilloway). A report will also be forwarded to the Designated Liaison Person within Maynooth University who will process any reports of child abuse and will liaise, where necessary, with outside agencies (HSE/Tusla/An Garda Síochána). The parents/carers of the child in question will be informed if a report is to be submitted to Tusla, or to An Garda Síochána, unless doing so is likely to endanger the child.

All research involving individuals under 18 years will be carried out in line with the Children First: National Guidance for the Protection and Welfare of Children (DCYA, 2017), Children First

Act (2015), the DCYA (2012) Guidance for Developing Ethical Research Projects involving Children, and Maynooth University's Child Protection Procedures (2017). All researchers/fieldworkers engaged in data collection have been informed of these guidelines, which will also form the basis of a pre-data collection consultation session for the team.

The research will be conducted in strict accordance with the ethical codes of conduct of the British Psychological Society and the Psychological Society of Ireland. All researchers and fieldworkers who will be in contact with children (and/or their parents) have been Garda vetted.

C5 PARTICIPANTS - CHECKLIST

C5.1 Please confirm if persons from any of the following groups will participate in this study. This is a quick checklist to assist research ethics committee members and to identify whether study participants include persons from vulnerable groups and to establish what special arrangements, if any, have been made to deal with issues of consent. It is recognised that not all groups in this listing will automatically be vulnerable or lacking in capacity. Please refer to the HSE's National Consent Policy, particularly Part 3, Section 5.

Committees are particularly interested to know if persons in any of these groups are being targeted for inclusion, as per the inclusion criteria.

(a) Healthy Volunteers Yes

(b) Patients Yes

Most of our parent participants will be attending mental health services and therefore are outpatients.

- **Unconscious patients** No
- **Current psychiatric in-patients** No
- **Patients in an emergency medical setting** No

(c) Relatives / Carers of patients No

(d) Persons in dependent or unequal relationships Yes

- **Students** Yes
- **Employees / staff members** Yes
- **Persons in residential care** No
- **Persons highly dependent on medical care** Yes Some parents may be on medication for their mental health issues.
- Also, **children** are dependent on their parents and so are in an unequal relationship

(e) Intellectually impaired persons No

(f) Persons with a life-limiting condition No

(Please refer to guidance manual for definition)

(g) Persons with an acquired brain injury No

C5.2 If yes to any of the above, please comment on the vulnerability of the research participants, and outline the special arrangements in recognition of this vulnerability (if any).

Service users include parents who have mental health challenges and dependent children who have a parent with mental health issues. We have outlined in section C4 how we will deal with risks to child wellbeing and welfare during the research process.

Similar to children, parents with mental health issues may be potentially vulnerable in terms of the sensitivity of the issues discussed in data collection and may feel emotionally distressed as a result. In addition, there is a possible risk that parent welfare concerns may arise during the discussions; for instance, it may emerge during the interview process that a parent may need to link into services with regard to their mental illness (e.g. as indicated by their score on the BASIS-24). If a parent welfare concern arises during the interview process, that person will be directed by the researcher to the service provider of the intervention, who will refer the person to their GP, mental health professional, or consultant psychiatrist, as appropriate. All information sheets provide advice and contact supports in case parents need supports following the research. In addition, parents are informed that they may make a complaint to HSE/Tusla Complaints office, lead contact person in their site, MU ethics committee, MU Data Protection Officer, supervisors (Sinead McGilloway and Mairead Furlong) of the PhD candidate, Christine Mulligan, as appropriate (Appendices 2-4, 22-24).

Furthermore, service providers in sites will act as gatekeepers and select suitable parents and children for the research. Service providers will have clinical responsibility for patients and families involved in the intervention. Therefore, these organisations will also act as safeguards for participants, in addition to the safeguards provided by researchers.

C5.3 Please comment on whether women of child-bearing potential, breastfeeding mothers, or pregnant women will be included or excluded in this research study.

Service users may possibly involve parents who are of child-bearing potential, or who are currently pregnant or breastfeeding.

SECTION D RESEARCH PROCEDURES

SECTION D IS MANDATORY

D1 (a) What activities, procedures or interventions (if any) are research participants asked to undergo or engage in for the purposes of this research study?

Interventions
Selected families will be invited to attend a family-focused intervention - FT, SFT or MFG depending on site location. The interventions were described earlier in section B8. Clinicians/ service providers have agreed to deliver the intervention as part of the research and will have undergone training in their respective interventions prior to delivery.

Research activities
All research participants (service users, service providers, other stakeholders) will complete different elements of the research as described in detail in section B8. These are summarised briefly below.

Service users
In evaluating FT/SFT, children and parents will complete questionnaires at baseline and 6-month follow up to assess outcomes. A 12-month follow up assessment will also be conducted with FT families. Parent measures will be completed in person with a researcher (30-60 minutes

at each data collection point). Child measures will be completed online with Qualtrics (10-15 minutes at each data collection point). FT families (parents and children) will be asked to complete a *Family Satisfaction Questionnaire* at the end of service delivery. For all three interventions, a subsample of parents and children will be invited to participate in a semi-structured interview/interview story to discuss their experiences of the intervention.

Service providers
In all three evaluations, a sub-sample of clinicians and managers will be invited to participate in a semi-structured interview/focus group to discuss their experiences in organising and delivering the interventions. In the FT evaluation, service providers will be asked to complete a brief online survey about implementation fidelity. They will also be asked to complete the 'Family Focused Practice Questionnaire' to assess the extent to which their practice has become more family focused.

Other stakeholders
Sites that were not successful in becoming a site in PRIMERA will be asked to complete the *Family Focused Practice Questionnaire.*

We also hope (resources permitting) to conduct a semi-structured interview (phone/skype/in person) with selected policy makers and national and international experts in the field in order to assess and compare family focused practice and policy in different countries, including the Republic of Ireland.

D1 (b) What other activities (if any) are taking place for the <u>purposes of this research study</u> e.g. chart review, sample analysis etc.?

As outlined earlier in Section B4 (p.9), staff in the 7 FT sites are required to complete (and have now completed) the 10-hour (free) online training and are starting the process of recruiting families to the research.

D2. Please provide details below of any potential harm that may result from any of the activities, procedures, interventions or other activities listed above.

Based on previous studies in the field and on our previous (and current) work, we do not anticipate harm for families in participating in the intervention or research activities. Nevertheless, our safeguards are outlined below.

Harm from interventions
Service providers will have clinical responsibility for the welfare of families during their participation in the intervention and will stop the intervention if clinically required and/or requested by the family (e.g. the parent experiences relapse in mental health symptoms and must be hospitalised).

Harm from the research process
As outlined in sections C4 and C5 above, there is a small possibility that a child or parent may experience discomfort or emotional distress during data collection as a result of the potentially sensitive nature of the issues discussed. However, based on our previous experience, participants usually find the research process to be helpful rather than harmful. The researcher will deal with any distress in a sensitive manner and, if required, will refer participants to an appropriate person. This process is outlined in more detail in sections C4 and C5.

D3. What is the potential benefit that may occur as a result of this study?

We hope that service users will benefit from a range of outcomes as a result of receiving the intervention, including improved child and parent mental health, resilience, family functioning, and a better understanding and awareness of the impact of mental health on families. We also hope that service users (parents, partners and children) will find it beneficial and empowering to discuss and provide feedback on their experiences of attending the service, and to recommend improvements for future delivery.

Furthermore, we believe that a number of other benefits have accrued, to date, as a result of the PRIMERA research. These include the following.

1. The research has provided an important impetus for clinicians/service providers in our selected sites to think more deeply and at both a collective and strategic level, about the complex and challenging issue of family mental health.

2. The work which we have undertaken, to date, has also been important in identifying suitable interventions for delivery by mental health professionals, whilst also providing access to training (in *Family Talk*), and helping to secure buy-in and support from mental health professional colleagues and management to deliver the intervention.

3. The PRIMERA research team compiled a resources hub to facilitate sites in delivering their respective interventions.

4. We have identified relevant events of interest and encouraged staff in our participating sites to attend; for example, we have encouraged staff to attend (free-of-charge) events in Belfast and in Drogheda. We have also organised a Masterclass with world-renowned expert Dr Adrian Falkov which is due to take place in Maynooth University on 5th September 2018. All of these activities are important in helping to promote a 'think family' service delivery agenda in Ireland.

5. We believe that a number of different outcomes and outputs from our evaluations will be invaluable in informing a guidance framework on best practice and issues in working with Irish families where a parent has mental health challenges.

D4 (a) Will the study involve the withholding of treatment?
Yes

D4 (b) Will there be any harms that could result from withholding treatment? No

D4 (c) If yes, please elaborate.

We do not believe that any harm should result from delaying treatment for the control group in our FT evaluation but nevertheless, there is an ethical issue involved in delaying a promising treatment, which should be highlighted.

With regard to the RCT evaluation of FT, we recognise the need to balance a duty of care to participants with the need to conduct a robust (unbiased) methodology that will allow us to evaluate whether FT is beneficial for families. Families will be informed by clinicians and researchers that they have a 2:1 chance of receiving FT now or in six months' time; therefore, families are twice as likely to receive the intervention sooner rather than later while still allowing the research team to investigate if FT is more effective for families than services as usual. In the

interim waiting period, wait list control families will receive usual services (e.g. parent attending AMHS/GP). If clinicians judge that the family must receive FT now and cannot wait, then the family will be removed from the RCT. Service providers and researchers will also take care to select families which are suitable for the intervention (i.e. families who are relative stable and able to engage), thereby minimising the likelihood of any harm arising from the delay in treatment. At the same time, it must be recognised that services as usual represent all that is (and has been) available until now in an Irish context.

D5 (a) How will the health of participants be monitored <u>during</u> the study, and who will be responsible for this?

It is not within the remit of the study to monitor the physical health of participants. However, if it is clear that there is a concern about the physical or mental health of a service user (parent or child), the participant will be directed by the researcher to contact their GP.

Clinical responsibility for the mental health of the parent as client/patient will be overseen by their consultant psychiatrist, MDT, service provider of the intervention, or GP, as appropriate.

D5 (b) How will the health of participants be monitored <u>after</u> the study, and who will be responsible for this?

It is not within the remit of the study to monitor the physical or mental health of participants per se. In the unlikely event that participants may suffer emotional distress following their participation in the research, we will state in their Information Sheet that they should contact the mental health professional who delivered the FT intervention.

Some families may continue to be involved with mental health services following this study. In those cases, the mental health of the parent/child will be the clinical responsibility of their consultant psychiatrist, MDT, or GP, as appropriate.

D6 (a) Will the interventions provided during the study be available if needed after the termination of the study? Don't know

D6 (b) If yes, please state the intervention you are referring to and state who will bear the cost of provision of this intervention?

It is hoped that our selected sites will continue to deliver their interventions as part of routine service provision following the termination of the study, although that may be influenced by the outcomes of the evaluations. The resources required for service delivery will be borne by the respective organisation, namely HSE, SJOG, and Tusla.

D7. Please comment on how individual results will be managed.

It is highly unlikely that, following the administration of questionnaires and interviews, that analysis of scores/themes will reveal a negative result that was not identified during the in-person interview with the parent. In general, the selected instruments do not measure outcomes indicating high risk welfare/health concerns. If a possible risk for parent welfare arises during interviews (e.g. their score on the BASIS-24 indicates an area of concern), then that person will be directed by the researcher to the service provider of the intervention, who will refer the person to their GP, mental health professional, or consultant psychiatrist, as appropriate.

Therefore, participants will not be automatically informed of the scores/themes that emerge from their data (from questionnaires/interview/focus group). Data will be analysed and reported on a group basis. However, the information sheets will make participants aware of their right to access their own personal data and, if requested, see the transcript and themes that emerged from their data. Contact details will be provided for participants who wish to access their data.

D8. Please comment on how aggregated study results will be made available.

The research will be written up and presented in a series of summary reports, presented at national and international conferences, as part of a doctoral thesis, and may be published in scientific journals. A copy of the research findings will be made available to participants upon request. Outputs will be put up on our study website https://cmhcr.eu/primera-programme/

D9. Will the research participant's general practitioner be informed that the research participant is taking part in the study (if appropriate)? Yes

Yes, for type 3 parents, where the parent is not attending AMHS and is not under the clinical responsibility of a consultant psychiatrist, but is instead receiving medication/treatment from the GP for their mental health issues. The Family Talk clinician will inform the GP that the family is attending Family Talk and engaging in the PRIMERA study (The recruitment brochures may be useful in providing information to the GP).

D10. Will the research participant's hospital consultant be informed that the research participant is taking part in the study (if appropriate)? Yes

Consultants of service users will be aware as part of the treating MDT if the parent is hospitalised for mental health issues during the study. However, parents who are hospitalised for mental health issues are not eligible for inclusion in the study. If a parent suffers relapse while attending the intervention, the intervention will be discontinued until symptoms can be relatively well maintained.

The issue is not applicable where service-user parents are not attending AMHS but are attending their GP for medication for their mental health issues.

SECTION E data protection

SECTION E IS MANDATORY

E1 data processing - consent

E1.1 (a) Will consent be sought for the processing of data? Yes

E1.1 (b) If no, please elaborate.

N/A

E2 data processing - GENERAL

Note: We have completed a Data Protection Impact Assessment (DPIA) for both Saint John of God and Maynooth University (Appendix 30). The MU DPIA assessment was drafted in consultation with the Data Protection Officer in Maynooth University (Ann McKeon, Ph. 01-7086184 or email: ann.mckeon@mu.ie).

E2.1 Who will have access to the data which is collected?

Only the PRIMERA research team at Maynooth University will have access to the collected data.

E2.2 What media of data will be collected?

Paper copies of questionnaires with parents Online questionnaires with children (7-18 years) using Qualtrics package Online survey and questionnaire for service providers using Qualtrics package Digital audio recording of interviews/focus groups with services users, service providers and other stakeholders.

E2.3 (a) Would you class the data collected in this study as anonymous, irrevocably anonymised, pseudonymised, coded or identifiable data?

Coded - To ensure all information remains confidential, participants will be assigned a unique study number (identifier) at recruitment by the Project Coordinator. This number will be used on all database files, instead of names, for the duration of the study. Anonymised research data and personal identifier information will be held separately. While the three core members of the research team (SMcG, MF and CM) have access to anonymised data, personal identifying information (such as a name or address) will be stored in a separate, password-protected file on the MU server to which only the Project Coordinator (MF) will have access. We will collect the minimum of identifying information required to conduct the study. We will not collect any personal identifying information on children using the Qualtrics online platform. We will not destroy the personal identifiers until the study is completed as we may need to go back to a family to verify info for some reason. Also, we have to keep personal identifiers until the end of the study as a participant may look to amend, access or withdraw their data. For further information, please note that we have completed a Data Protection Impact Assessment as part of this ethics application.

E2.3 (b) If 'coded', please confirm who will retain the 'key' to re-identify the data?

Only the Project Coordinator will have access to identifiers and will retain the key to re-identify data at a later stage if so required.

E2.4 Where will data which is collected be stored?

All data files will be uploaded onto a central, password protected, secure site at Maynooth University. This will be maintained as part of the university network, but will be accessible only to the project researchers. Database files will be held on the Project Coordinator's PC and will also be uploaded to a secure server.

E2.5 Please comment on security measures which have been put in place to ensure the security of collected data.

The study will adhere closely to the GDPR and data protection guidelines on research in the health sector by the Data Commissioner of Ireland (Data Protection Bill 2018). All forms will be anonymised through the allocation of a unique identification number and will be stored under lock and key throughout, and following completion of, the study. These will be accessible only to the research team. Consent forms will be stored separately from the research data.

All computers will be password-protected and the transfer of any information from laptops to the secure network will be carried out with extreme caution. A separate (password protected) database of names and contact details will be stored away from the other data and there will be no means of linking the two. As well as being stored on a password protected computer, encryption software will be used to encrypt sensitive data which are stored electronically. Encrypted data will be accessible using a key which will only be known to the research team members.

E2.6 (a) Will data collected be at any stage leaving the site(s) of origin?

Yes

E2.6 (b) If yes, please elaborate.

Data collected from service users and providers and users (e.g. questionnaires, audio recordings) will take place in participants' homes/service offices and will be transferred to a secure server in Maynooth University.

E2.7 Where will data analysis take place and who will perform data analysis (if known)?

Data analysis will take place in Maynooth University. The research team will perform data analysis which will be led and supervised by the Project Coordinator (Dr Mairead Furlong) and the Principal Investigator (Prof Sinead McGilloway).

E2.8 (a) After data analysis has taken place, will data be destroyed or retained?

Data will be destroyed 10 years after the completion of the study in line with MU ethics policy.

E2.8 (b) Please elaborate.

Ten years after the completion of the study, all data will be destroyed by the Principal Investigator. Manual data will be shredded confidentially and electronic data will be reformatted or overwritten by the PI in Maynooth University.

E2.8 (c) If destroyed, how, when and by whom will it be destroyed?

As in E2.8 (b), all data will be destroyed by the Principal Investigator ten years after the completion of the study. Manual data will be shredded confidentially and electronic data will be reformatted or overwritten by the PI in Maynooth University.

E2.8 (d) If retained, for how long, for what purpose, and where will it be retained?

Where participants provide consent/assent, an anonymised version of their qualitative data will be placed on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it (Appendix 1, 17-22).

E2.9 Please comment on the confidentiality of collected data.

All information that is collected about participants will be kept confidential. Consent forms and identifiers will be stored separately from the research data. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on MU PCs or servers and will be accessed only by the core PRIMERA research team (Prof Sinead McGilloway, Dr Mairead Furlong, Christine Mulligan).

No information will be distributed to any other unauthorised individual or third party. If participants wish, the data that they provide can be made available to them at their own discretion.

Research publications will not include any personal information that can identify the individual. Participants will be told in their information sheet that publications will not include any detail that could identify them as an individual.

Where participants provide consent/assent, an anonymised version of their qualitative data will be placed on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it.

Participants will also be told: 'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'

E2.10 (a) Will any of the interview data collected consist of audio recordings / video recordings? Yes

E2.10 (b) If yes, will participants be given the opportunity to review and amend transcripts of the tapes?

The information sheets will make participants aware of their right to access their own personal data and, if requested, see their transcript. Contact details will be provided for participants who wish to access their data.

Participants will also be informed that they can withdraw/amend their data, or parts of their data, at any time.

E2.11 (a) Will any of the study data collected consist of photographs/ video recordings? No

E2.11 (b) If yes, please elaborate.

N/A

E3 ACCESS TO HEALTHCARE RECORDS

E3.1 (a) Does the study involve access to healthcare records (hard copy / electronic)? No

If answer is No, please delete remaining questions in Section E3

SECTION J INDEMNITY and insurance

SECTION J IS MANDATORY

J1 Please confirm and provide evidence that appropriate insurance/indemnity is in place for this research study at each site.

Given that the investigators are all employed by Maynooth University, no insurance/indemnity is required at each site. Maynooth University has a professional indemnity insurance policy which will cover all aspects of this research as carried out by the research team across all sites. This policy has a limit of indemnity in excess of €6.5million for any one claim and in the aggregate. The university also has public and employers liability insurance in place with a limit of indemnity on each of not less than €13m for any one event (Appendix 35).

J2 Please confirm and provide evidence that appropriate insurance/indemnity is in place for this research study for each investigator.

As above

J3.1 Please give the name and address of the organisation / or individual legally responsible for this research study?

Maynooth University

J3.2 Where an organisation is legally responsible, please specify if this organisation is:

A pharmaceutical company No
A medical device company No
A university Yes
A registered charity No
Other No If yes, please specify: N/A

J3.3 Please confirm and provide evidence of any specific additional insurance / indemnity arrangements which have been put in place, if any, by this organisation / or individual for this research study?

N/A

SECTION K COST AND RESOURCE IMPLICATIONS, funding and payments

SECTION K IS MANDATORY

K1 COST AND RESOURCE IMPLICATIONS

K1.1 Please provide details of all cost / resource implications related to this study (e.g. staff time, office use, telephone / printing costs etc.)

The main resource implications for staff involved in this research will be: (a) their time involved in service delivery (but it is hoped that this will be helpful to them in their role when working with vulnerable families); (b) the time invested by the main site contacts/liaison co-ordinators;

and (c) the (small amount of) time allocated by staff (upon invitation) to take part in a one-to-one interview and/or to complete the online surveys.

K2 funding

K2.1 (a) Is funding in place to conduct this study? Yes

K2.1 (b) If no, has funding been sought to conduct this study? From where? Please elaborate.

N/A

K2.1 (c) If yes, please state the source of funding (industry, grant or other), the name of the funder, the amount of funding and duration of funding.

Source of funding (industry, grant or other):
Grant
Name of Funder:
HSE Mental Health Division
Amount of Funding:
€500,000
Duration of Funding
3.5 years (2017-2021)

K2.1(d) Please provide additional details in relation to management of funds.

The grant is administered by the Research and Development Office at Maynooth University and is managed on a day-to-day basis by the PI (Prof Sinéad McGilloway). The PI signs off on all expenditure relating to the grant and reviews budget expenditure on a regular basis. External audits of all MU research grants are also frequently carried out.

K2.1(e) Is the study funded by a 'for profit' organisation? No

K2.2 (a) Do any conflicts of interest exist in relation to funding or potential funding? No

K2.2 (b) If yes, please elaborate.

K3 payments to investigators

K3.1 (a) Will any payments (monetary or otherwise) be made to investigators? N/A

K3.1 (b) If yes, please provide details of payments (including amount).

K4 payments to PARTICIPANTS

K4.1 (a) Will any payments / reimbursements (monetary or otherwise) be made to participants? Yes

K4.1 (b) If yes, please provide details of payments / reimbursements (including amount).

Parents will be given a shopping voucher to the value of €25 for the family at each data collection point as a small token of thanks and appreciation for the family's participation in the research. Given budget restrictions, instead of giving separate vouchers to each parent and child within the RCT, we have decided to give the voucher at the 'family' level so that we can afford a number of children (7-18 years) in the family to complete the Qualtrics survey (If we opted to give a separate voucher to each participating child, we could only afford to select one child per family to complete the survey, which has negative ethical and scientific implications). Both parents and children will be informed that the voucher is for the family. We have discussed with service-user parents and with clinicians who have indicated that the voucher given to the family as a whole is the preferred option. As there will be a smaller sample of parents and children interviewed in our qualitative (process) study, we will be able to afford to give a separate voucher to each participating parent and child (€15 and €10 respectively). In our previous research with vulnerable families, participants have appreciated the voucher and the value that researchers have placed on their time (e.g. the Incredible Years Ireland study and the ENRICH research programme (please see www.cmhcr.eu).

Details of gift vouchers are provided in participants' information sheets (Appendices 1-3, 18-20).

Clinicians/service providers and stakeholders will not be reimbursed for their participation in the research.

SECTION l additional ethical ISSUES

L1 (a) Does this project raise any additional ethical issues? No

If answer is No, please delete remaining questions in Section L.

PLEASE ENSURE THIS APPLICATION FORM IS FULLY COMPLETED AS INCOMPLETE SUBMISSIONS WILL NOT BE REVIEWED.

Copy of the HSE Study Approval Letter

Náisiúnta um Meabhairshláinte
Ospidéal Dr. Steevens' BAC 8, DO8 W2A8
T 01 8976108 R: mentalhealth@hse.ie
National Director, Mental Health Service
Dr. Steevens Hospital, Dublin 8, DO8 W2A8
Tel: 01 6352596Email: mentalhealth@hse.ie

September 17, 2018.

Re: HSE National Mental Health Ethics Approval for the PRIMERA research programme

Dear Dr Furlong,

Thank you for submitting your ethics application for PRIMERA research programme - Promoting Research and Innovation in Mental hEalth seRvices for fAmilies .

I am happy to inform you that we are now in a position to grant research ethics approval based on the information submitted. We are aware that you intend to carry out this research in HSE mental health services and this approval covers this work. We are also aware that you plan to seek additional approval as appropriate and necessary from various research ethics committees.

I wish you every success in your research endeavours.

Yours Sincerely

Dr Sinead Reynolds
Office of the HSE National Director Mental Health

Appendix BB: Similarities and Differences across Three Grounded Theory Variants

Variations & Similarities within Grounded Theory Adaptations (Kenny & Fourie, 2015; Mills et al., 2006)			
Grounded Theory Variant	Classic (traditional)/Glaserian	Straussian	Constructivist
Proponent	Glaser, 1967:1991:1998	Strauss & Corbin, 1990:1994	Charmaz, 2006:2016
Techniques used by all three variants.			
Theoretical sampling	Data collection is a dynamic process requiring initial sample plans which adapts as 'gaps' are identified during coding/concept development or as the theory begins to appear. Collecting, coding, and categorising are conducted simultaneously.		
Saturation	Analysis ends when no new data emerges. Saturation applies to new, emerging categories and not population (Charmaz & Thornberg, 2021).		
Constant comparison	Data is coded line by line, constantly comparing (a) code with code, (b) code with categories, and (c) categories with categories.		
Memos	Recording of reflections made by the researcher throughout the data collection and analysis process culminates in the development of a theory.		
Theory substantive or formal.	The theory generated may be substantive (i.e. not generalisable beyond the setting being studied) or formal (i.e. transferrable across other settings).		
Differences across each adaptation			
Philosophy	Unspecified by Glaser but as (pre-existing) theory is objectively discovered, Classic GT is broadly considered to be founded on a positivist philosophy (Charmaz, 2006; Madill et al., 2000).	Strauss & Corbin asserted a post-positivist & symbolic interactionism.	Charmaz's adaptation is distinguished by a constructivist and symbolic interactionist philosophy.
Epistemologically Ontology	**Objective** Naïve realist	**Varied** Relativist (Mills) Critical realist (Kenny & Fourie, 2015)	**Subjective** Relativist
Coding procedures	1. Substantive 2. Theoretical 3. *Discover/emergence* of a Grounded theory **(Holton et al., 2010)**	1. Open 2. Axial (5 stages) 3. Selective (5 stages) 4. Conditional matrix (frames & summaries stages 1-3)	1. Initial, open 2. Refocused 3. Construct of Grounded Theory **(Charmaz, 2008)**

		5. *Create* a Grounded theory **(Strauss & Corbin, 1990)**	
Researchers Relationship with the Theory	Independent	Active	Co-constructor
Use of literature	No a priori research conducted.	Permits review of the literature throughout the research process but not to the extent that it limits the analysis process.	Like the Straussian adaption, Charmaz recommended reviewing literature throughout the research project but delaying the literature review write up until analysis is complete.

Appendix CC: Reference List for Study One (Chapter Four)

Promoting and implementing family-focused interventions for families with parental mental illness: scoping and installation

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Appendix DD: Reference List for Study Two (Chapter Five)

The *Family Talk* Programme in Ireland: A Qualitative Analysis of the Experiences of Families With Parental Mental Illness

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Appendix EE: Sample Audit Trail of Interview with Service User

Interview transcript 111 – Service user Male (mid 40s)			
This family live in the west of Ireland. At the time of the study, the father had experienced depression for a four-year period following a work accident and had been unable to work. This eventually put additional strain on the coparent which led Dad to request support for his wife who reported feeling overwhelmed from the strain of his illness over four years and feeling like she was carrying the whole family. The children in the home were 15, 13 & 8 years of age during the initial assessment for participation in the PRIMERA RCT. This author completed the 6 month assessment with service user (father) after which, he was invited to participate in an interview as part of the process evaluation and an invitation was extended to the whole family. All but the youngest family member took part and were interviewed individual on the same evening, in their home. Regarding some comments made by this interview, this service user had felt he overshared about his depression during this initial assessment as he was very emotional as he recalled the years since becoming unwell. This was reported to me prior to the 6 month assessment (by the field work coordinator) so I was prepared to put his mind at ease if the issue was raised. Based on his concern, prior to the interviews, the coparent (wife) requested that I avoid all question about his mental illness and just focused on each person's experience of the Family Talk Intervention. The atmosphere on the evening of the interviews was very warm and the family were grateful for the opportunity to share about their positive experience of FT. Comments from each of the interviewees mirrored those outlined below and while no one found the process of the family meeting easy, each reported finding it beneficial for the whole family. Wife and two of the three children in the home were also interviewed.			
Int = Interviewer M 111 = Interviewee	**Open coding/Initial**	**Refocused**	**Theory – final themes, sub themes.**
Int: How did you hear about it first? **M 111:** I think it was through [wife] and it was offered by [social worker?]. As something they were talking about. Starting to offer. It was a pilot or a trial. And they wanted to see if it would be any benefit to us and if we would be of any interest to us and we said yes. **Int:** Okay. **M 111:** So, that's what happened. **Int:** Yeah. Had you thought about needing something for the family before that, [name], or had you the head space to even think about that?	First approach – who, when how? Levels of awareness of the need for FFP.	Initial recruitment – positive.	T1ST2: Benefit of FT. Facilitators of change. ***Clinician skill*** T1ST2: Benefit of FT.

M 111: Personally, no. Like, [wife] was the one who was saying like, um, that brought it to my attention that needing this- Saying "Right, we'll get you fixed, and you get sorted over time and you heal. But what kind of damage have we done to the kids?" **Int:** Okay. **M 111:** So, she was aware of the family as a whole. I was very aware of myself, never mind anyone else around me at the time. **Int:** Sure, yeah. **M 111:** I think I even frightened…was it [different social worker?]? **Int:** I think it was [another social worker]. Is it [another social worker?] that came down? **M 111:** I can't remember. **Int:** Anyway. **M 111:** I'm- head like a sieve. **Int:** You said it last time. You know, I said it to [different social worker?] and she said, "Not at all. It was nothing at all." I think they were just worried that it was a difficult- **M 111:** (overlapping) It was a difficult time. **Int:** Taking in all the information from you. **M 111:** But at the time it was just- headspace wasn't great at the time. **Int:** Yeah, yeah. **M 111:** There was a lot going on. **Int:** Thank you for doing it even despite that. **M 111:** Yeah, that's… Hopefully it will help someone else.	Parental differences – children too? Coparent conscious of the impact on the kids. Strengths of two parent homes. Interviewee felt he overshared during the initial baseline assessment – needed reassurance that he had not. He had also mentioned it again at 6-month baseline assessment when recruited for this interview. Psychological wellness prior to recruitment? Impact on response? Illness, symptom? Depression. Motivation for attending FT or/or the research.	Skill of practitioner to normalise feelings around MH disclosure. Symptoms impact daily life & memory. Positive experience with MH services. How presentation of MH impacts recruitment opportunities. Opportunity to give back has a positive impact on MH.	Facilitators of change. ***Timeliness, readiness*** T1ST2: Benefit of FT. Facilitators of change. ***Whole Family approach*** T1ST2: Benefit of FT. Facilitators of change. ***Clinician skill***

Int: Yeah. **M 111:** I don't see it as a… I'm trying to give back. **Int:** Yeah. **M 111:** You've helped us, so we want to help back. **Int:** Great. Brilliant. **M 111:** So, that would be my angle on it. **Int:** Okay. So, what do you- When did you finish the course? Do you remember? [Wife] was thinking about 3 or 4 weeks ago? … **M 111:** Maybe 2 and a half months, something like that. I'm not great with time either (laughter), but I think it's a little longer than that. **Int:** No problem. And would you have known- What kind of relationship did you have with [social worker?] beforehand? **M 111:** I wouldn't have had. It would have um… [social worker?] appeared on the radar for [wife] when I asked and I reached out to my own um, mental health team in Athenry that, "Look, my wife has been trying to hold things together on her own the last four years and I think she needs someone independent from me to talk it out." **Int:** Okay. **M 111:** Because sometimes I'm not there for her to talk things out. I'm just barely hanging on myself sometimes so I kind of kept her at arms distance and I have to be honest with them, I can't. Like, she would come to me with family things, and I would just go, "I can't do this." So, I knew, I could see that she was going, "I need to be able to talk it out with someone." **Int:** Yeah. Brilliant.	Altruism Positive experience of research & FT? Simply opportunity to share? Duration since programme important to consider going forward? (Double blind research). (Kids and coparent also interviewed) Wife attending services after husband asked for support. Aware of the toll his illness was taking on his spouse. Asked for help prior to FT. Impact of illness on marriage – level of parental burden.	Prior relationship with MHS. Safety net of having a two-parent household. Eventually the coparent needs support. Timely access to the services.	T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. ***Parental confidence & enhanced wellbeing.*** T1ST2: Benefit of FT. Facilitators of change. ***Timeliness, readiness***

M 111: So, I asked. And I think I asked once or twice. And it took them a couple weeks, but they organised. They were very good. They organised it. And [wife] had her own time then, with her own counsellor who was [social worker?] and [social worker?] was the one who helped her through that and let her unload her worries and fears and the crap that she had to put up with. (laughter) You know that kind of way. **Int:** Yeah. **M 111:** So, that was great. And I think she really needed that. And I think it was very unfair for her to kind of have to hold everything together. The way I say it is like, she was battling away and had been for, I mean, I was ill for the guts of 4 years. So, she had been battling to try and keep us as a family together for 4 years. So, the strain, I mean, I don't know how she did it. I don't think if I was in her shoes, I don't think I could have held it together as well as she did. **Int:** Yeah, yeah. **M 111:** But the strain was showing on her. So, when you were in a bad spot, you can see where everyone else is. It's the only way I can say it. Like, at the moment, my form, apart from being sick at the moment with a chest infection, the mental form is fairly good, so I can be oblivious to other things going on around me. (laughter) But when I was down, I could see when people were coming down to my level, were at my level, or lower than my level. I don't know how that makes sense. **Int:** Yeah. **M 111:** But I could see that she was starting to struggle, and it wasn't easy on her. And I felt very sorry for her. Even though I couldn't- Usually the husband's thing is to go in there and try to- You're supposed to support, you're supposed to help. Try to take the weight. But I wasn't able to, and I knew the only way I could do it was to try to ask for help for her, because it's just unfair. **Int:** Yeah.	Experience with the practitioner conducting FT. Speed of referral helped. Ultimately both parents were attending MHS – duration of husband's illness took its toll. Symptom of illness? Prior relationship with MHS? Parental differences in experience? Differences in perception of need for services? Strain on relationship prior to FT. Feelings of guilt at the burden he felt not being able to support his wife. Impact of illness on the marriage and family life. What happens if support comes too late? Spouse needs services.	Benefit of having two parents in the home. Additional stress on the service user when support is not forth coming for the whole family. Helplessness of not being able to heal self or family member. Safety net of second parent. Asking for help for spouse reduced some of the feelings of guilt.	T1ST2: Benefit of FT. Facilitators of change. ***Clinician skill*** T1ST2: Benefit of FT. Partners experience ***Relief at having burden validated.*** T1ST2: Benefit of FT. Facilitators of change. ***Clinician skill*** T1ST2: Benefit of FT. Facilitators of change. ***Timeliness, readiness*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. ***Deeper understanding of the impact***

M 111: I'd say like, anyone that has someone with mental health issues in a family, the partner, spouse, whatever, would probably over a period of time struggle as well. And they do need help, they do need support to try to keep the family or keep the relationship or keep whatever on the road or else everything would just fall apart. Because it does take a toll on them. There's only so much that one person can take as well. And I didn't want her to end up following. Like I literally come out of my thing, and she would be going down that rabbit hole after I was coming out of it. **Int:** Yeah. **M 111:** So, I was saying no, I was afraid. And I felt like I wasn't healing quick enough. And I didn't want her to, yeah. So, yeah. It's complicated but I'm trying to get the nuances of you can see where I'm coming from with that. **Int:** Yeah, absolutely. So, what do you remember about the- Now, this is not a test. (laughter) … **M 111:** Uh, I remember the honesty. Um…You know, the kids, in fairness to them, they were very open, and I wouldn't say brutally honest, I wouldn't call it brutal, I would just call it pure honesty. So…they kind of told you from their heart or their head what was going on in their lives and how they were trying to deal with it. Like, um, youngest lad we were the most worried about because he was, we thought he would be the biggest sponge, taking in everything. **Int:** Yeah. **M 111:** But he seemed to be oblivious to most of it and he just plodded away. At the time he reacted the worst and he played out in school, and I suppose he was…angry. He was 6. He was 5 sorry. He was only starting national school and Daddy wasn't there and he acted out in the first month or so. **Int:** Okay. **M 111:** And that kind of flagged that, right, something not right here. I think he sort of settled into things and we had different teachers and things improved and we got help. Well, to a degree and indirectly. The school kind of realised what was going on	Feelings of guilt, worry, anxiety – compounded by the MI? Bidirectional impact of the relationship? Personal limits. Capacity to consider the impact of his illness in time. Wife needed treatment. Fearful - worried Feelings of guilt. Shame? Overarching memory of FT. Hearing the impact on the kids. Different concerns depending on the child. Age/stage of development? Opportunity to find out -opportunity to speak and ask questions. Power of honesty. Surprised by responses. External support from school.	Impact of PMI on the whole family. Need for whole family approach. Cost of ignoring the burden on the spouse. Supporting the whole family reduces PMI fear which helps the family. Sibling differences. Honestly easier together with a known practitioner. Sibling differences = different needs as it relates to the mental illness.	***of MI on children.*** T1ST2: Benefit of FT. Facilitators of change. ***Whole Family approach*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. ***Reduced***

in the home situation without probing too much which was very good, very thoughtful. **Int:** Brilliant. **M 111:** And they helped him. But it took about a year for that to settle down. And the first year, when he was in Junior, in the original class that he had, didn't want to know, didn't care and was quite difficult to deal with. The next year the teacher was very intuitive, very good. Realised what was going on. **Int:** Okay, yeah. **M 111:** Without digging. And he settled down really. So, it was a better… You know, things were starting to settle for him. While the older guys are quite sensitive as well. They- I didn't realise that 2 years into my illness that my oldest was being bullied in school. And kept it to himself. And he was also at the time worried about me going to kill myself. **Int:** Okay. **M 111:** And he was quite worried about that, and it was bothering him, and he was keeping it inside. So, that came out. **Int:** Was that the first time you had heard the, was it? **M 111:** Yeah, he would never tell us himself. So, when he opened up, he…it was very sad to hear that. And kind of from our point of view, I felt very bad that I made him feel…afraid almost or made him worry about these things at 16. I know he's 16 now but at the time he was 14 or 15 and that's a lot of worry for someone that age on their shoulders. So, yeah, I wasn't aware of it at the time but now looking back, you go, "Oh god." (laughter) So, that, it helped with that, and we were able to be as honest as we were. We told him everything. But um, at the time I probably wasn't telling him everything to kind of save him, but he already knew. And I should have been more honest with him- **Int:** Was that surprising for you, [name], that he knew? That he was picking up on stuff?	Did they talk to the school or did the school pick up on it? School helpful. Surprised to find out the oldest was being bullied and was fearful PMI was at risk of suicide. Had kept it hidden. Oldest more awareness based on his age? Hearing the child's emotional reality – sadness. Guilt on hearing the needs. PMI thought not telling the child was a way of protecting him but actually left them both in silence.	Importances of context & accessing external support. Development age of children at the time of parent's diagnosis and duration of the illness. Hidden worries. Older siblings may see and know more and therefore worry more. Children seek to protect the parent. Opportunity to share burdens knowing dad was okay. Lack of parental attunement during the	***stigma & worry.*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. ***Deeper understanding of the impact of MI on children.*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. Service user parents. ***Deeper understanding of the impact of MI on children.*** T1ST1B: Benefit & experience of FT. From fear & silence.

M 111: It was. He comes across sometimes as, "I'm a teenager, I don't care, go away." (laughter) **Int:** (laughter) Okay. **M 111:** So, I know it's not a defence mechanism- **Int:** (overlapping) Yeah, the push-pull, yeah. **M 111:** So, if you try to push him sometimes, he'd almost walk away. Kind of "What do you know." (laughter) You know, the standard teenager reacts. So, I didn't realise he was, um, he had perceived as much as he did. **Int:** Yeah. **M 111:** And the middle guy then was also very sensitive, and he was also more worried that, "Will Daddy be okay?" He understood enough that he was in a bad place and will this ever be okay. And we always tell him, it's like a process, it's like an injury. Sometimes it can take a while for it to heal. But it will. To varying degrees but it will. And time will help. But it can be a rollercoaster until it gets... It's not like a broken bone, I said, you know, a broken bone you can set it, you're away. Mental health is a bit of a nuanced thing, you have to trial and error. And there was a lot of trial and error with medication and kind of me having to deal with the baggage of my injuries and my burns at the time and trying to figure out what... Do you know, denial would have been a part of that too. Um... **Int:** But that's part of the grief process isn't it, [name]? **M 111:** It probably would. **M 111:** Thinking back now, maybe that could have been it too. But I was so kind of wrapped up in my own little murky world, I can't remember what. Misery really. That's all I can remember. **Int:** But, so for the course, was it hard hearing the feedback from the kids or?	Relationship prior to FT? Challenging parent – child phase as child seeks more autonomy. Parents unaware what children knew. Each child has a unique awareness of response to the parents' illness. Each child had different concerns. Hidden worry. (parents worried about kids, kids worried about parents) Process of illness a rollercoaster. Illness – kept dad in his own world,	presentation of the illness may challenge ability to meet/understand each child's unique development stage. Relationships in the home. Parental attunement and skill before and after FT. Increased PMI self-awareness.	Hearing the child's voice. ***Disclosing hidden concerns & burdens.*** T1ST1B: Benefit of FT. From fear & silence. Experience of service user parents. ***Better Family relationships.*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. Service user parents. ***Deeper understanding of the impact of MI on children.*** T1ST1B: Benefit & experience of FT. From fear & silence. Hearing the child's voice.

M 111: I think it was um… It was but it also drew a line under it. So, it helped us as a family see what we went through. See what the kids, from their vantage point what they could see. How it affected them. And try to give them what they wanted to try to move on. And I think for that it brought us into a room together and we had to talk about the white elephant or ghost or whatever it is, you know, the skeleton in the closet. Whatever way, I don't know what the right euphemism is, but you understand that kind of way. (**Int:** laughter – Yeah). We were all kind of dancing around this, but it wouldn't go away, and we wouldn't talk about it directly. So, this kind of made us face it. So, our biggest issue it appears, or it was drawn to my attention from [wife]. [wife] is very perceptive, very good that way. But that I was still kind of, starting to turn a corner. And I think it was part of the fact that I could see she had so long held it together and I had to step up a little bit. And that helped. She helped jar me into the position of, "Come one, get out of this." **Int:** Okay. **M 111:** So, it did help. I don't know how it helped, but it did. Or maybe it was because I was feeling better at that time and- **Int:** Of course. The timing was right. **M 111:** Exactly. So, it seemed to have just kind of play her out. So, I know that different people have different ways, different things happen to them, so they heal at different paces. But you know, it made us face their fears and we could tell them with honesty what was going on, where we were, and how this is going to be... I wouldn't say fixed but how we're going to move on from this and- …I suppose. Honesty is better than fear. We're afraid that it will affect them into their 20s and 30s and they'll bottle this up and come their 30s or 40s or 50s they, the old way of saying it, they would have a nervous breakdown, or they'd face the ghost and they didn't want to. You know what I mean, and their world coming down on top of them or it will affect their own families when they have them. So, we didn't want that, we didn't want them completely and utterly damaged or scared later on in their lives. I know everyone has things and we all carry scars from life, but we didn't want it this being...life changing. **Int:** That's very perceptive, [name], because the research shows that when kids, because they are perceptive, they do see. And there's a difference because	unaware of the needs of the kids. Difficult hearing honestly from the kids but helpful too. Elephant in the room. Not knowing what to say or if it was needed. Turning a corner – ready to attend? Roll of coparent in seeking help? Benefit – timing of the intervention? Fearful of the longer-term impact on the kids. Wanting to support the kids now in the home of minimising any long-term impact.	Importance of providing a safe space for honest communication about the mental illness. A whole family honest conversation helps.	***Disclosing hidden concerns & burdens.*** T1ST1B: Benefit of FT. From fear & silence. Experience of service user parents. ***Better Family relationships.*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. Service user parents. ***Deeper understanding of the impact of MI on children.*** T1ST1B: Benefit of FT. From fear & silence. Experience of service user parents. ***Better Family relationships.***

sometime the older kid sees more than the younger kid because the younger kid is maybe protected a bit. It depends, different families are different. **M 111:** But um, it did help give them a place to try and sound out or verbalise, I guess. So, yes, you're right, find the words would be a great way to put it. **Int:** Yeah, yeah. **M 111:** But um, that helped an awful lot because it took a lot of pressure off the two older boys anyhow where they were- Once they realised that I'm not going to be a, what do you call it? A bloody mess all the time. (laughter) That helped an awful lot. And as I said, I am healing, there will be blips here and there, but it's not going to be bad, you know what I mean? You know, we were honest with them, we told them what I suffer from, we told them how it was trial and error, we told them about the medication, we gave them my background so they could understand why I was okay some times and then all of a sudden I wasn't. You know what I mean? So, they kind of...it made some sense to them. But they didn't seem to be too bothered once they got some of the answers and we gave them a little bit of the background they were like, "Oh, sound." And that was it, like, they just moved on. **Int:** Yeah. [Wife] was saying that, because she said, "Do you want to ask more questions?" and they said, "no, no, that's it, we're happy now." **M 111:** They got what they wanted to hear. And they kind of- I presume, like, one of them came back "It's okay if we ask questions again?" "As many times as, you want to. We're going to be, we're going to honest." I don't know, I don't want to use the word brutally honest, but we will be honest. We'll try not to sugarcoat it too much, but we will try not to horrify them either. (laughter) **Int:** Yeah. Age appropriate. **M 111:** Yeah, that kind of thing. So… I wouldn't be the most perceptive in the world. (laughter) To a lot of things. Like, I can be quite blind to a lot of things but my wife it very perceptive. Like, as you said, there's strengths. There are certain things that I'm kind of good at and there's certain things that my wife, especially this, she's very good at. Very, very perceptive.	Safe space for kids to talk honestly. Hidden worry removed. Hidden fears removed.		T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. Service user parents. ***Deeper understanding of the impact of MI on children.*** T1ST2: Benefit of FT. Facilitators of change. ***Whole Family approach*** T1ST1B: Benefit of FT. From fear & silence. Experience of service user parents. ***Better Family relationships.*** T1ST1: Benefit of FT. From fear & silence to sharing & empowerment. ***Reduced stigma & worry.***

Int: Yeah, brilliant. So, [wife] was mentioning that having it in the house with someone that she knew was helpful? **M 111:** Well, she knew [social worker?] and she trusted her, and she understood what we were trying to do. I was just going on [wife] at the time. And if her gut instincts were good, I was happy enough with it because I wasn't quite ready to go and make decisions on my own, so it was like, "Should I do this?" and she would be like, "Yes." and I'd be, "Fine, I'll do this." So, you know that kind of way? Does that make sense? Yeah, I wasn't willing- I wasn't able to take responsibility for nearly anything at that stage. I was getting there but I wasn't quite there yet. … **Int:** Yeah, absolutely. Is there anything else? Was it long enough, too long, could it have been longer? Was there anything you would have changed about it? **M 111:** Um, no. It worked. For what we needed. It was enough, it was perfect. Now, I can't speak for any other families and whatever other issues they could be dealing with. Some of them could be very, very complicated.			T1ST1B: Benefit of FT. From fear & silence. Experience of service user parents. ***Parental confidence & enhanced wellbeing.*** T1ST2: Benefit of FT. Facilitators of change. ***Whole Family approach*** T1ST1B: Benefit & experience of FT. From fear & silence. Experience of the service user. ***Parental confidence & enhances wellbeing.*** T1ST1B: Benefit & experience of FT. From fear

			& silence. Hearing the child's voice. ***Better understanding of PMI*** T1ST2: Benefit of FT. Facilitators of change. ***Clinician skill***

Appendix FF: Reference List for Study Three (Chapter Six)

A Family-Focused Intervention for Parental Mental Illness: A Practitioners Perspective

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PhD Scholar: Christine Mulligan, BA (Hons) in Psychology
Supervisors: Professor Sinéad McGilloway & Dr Mairead Furlong
Maynooth University Department of Psychology and
Centre for Mental Health and Community Research