Article

Medication management in intellectual disability settings: A systematic review

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Abstract

There is a high level of medication usage among people with intellectual disability due to the presence of significant morbidity and co-morbidities. This review sought to explore medication management and administration in intellectual disability settings, identifying frameworks for practice, analysing whether collaborative practice led to better outcomes, identifying key processes associated with practice, locating tools to support practice and describing metrics for outcome measurement. A systematic review was conducted with analysis of 64 sources which remained following screening and appraisal. Limited evidence was identified with some insight into the processes underpinning medication management and administration. No assessment tools were found, but two potential outcome measures, adherence and errors, were noted. The paucity of guidelines and frameworks is concerning as this is a complex area of practice. There is a need for further practice development and research to be undertaken that takes note of the unique issues that can present in intellectual disability settings.

Keywords

intellectual disability, medication management, medication administration

Background

Individuals who have an intellectual disability have a high burden of illness (Baxter et al., 2006; Krahn et al., 2006; Sohler et al., 2009) often requiring the person to take multiple medications

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(Doan et al., 2013; Erickson et al., 2016). Medication use can vary from approximately 88% of people with an intellectual disability between 18 years and 39 years to over 94% of people over the age of 60 (Erickson et al., 2016). Types of medications prescribed are varied and complex but the most commonly prescribed medications to this group of individuals are anti-constipation agents, medications for peptic ulcer disease and gastro-oesophageal reflux disease, bronchodilators, antiepileptics, spasmolytics, hypnotics, stimulants, antipsychotics or anxiolytics and benzodiazepines (O'Dwyer et al., 2016; Zijlstra and Vlaskamp, 2005). The prevalence of polypharmacy increases with age and, within the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing, polypharmacy (use of 5 to 9 medications) was observed in 31.5% of participants and excessive polypharmacy (use of 10 or more medications) in 20.1% (O'Dwyer et al., 2016).

The safety of medication use within disability services is one that is a concern, not only for caregivers but also for practitioners. Medication management guidance has been developed to enable service providers to safely meet the medication needs of children, adults and older people with a disability living in residential care, thus minimising risk (Health Information and Quality Authority (HIQA), 2015; National Institute for Health and Care Excellence (NIHCE), 2014). This guidance ensures safe and effective care for individuals in keeping with legislative requirements.

The medication management process is complex (Erickson et al., 2016) and requires various interactions with the interdisciplinary team and division of roles within the medication process. Firstly, the person with an intellectual disability, along with the caregiver, usually interacts with the general practitioner (GP) or other consultant. Secondly, following this and the decision-making of treatment processes, a prescription may be completed and then medication is obtained from a pharmacy. The third step is then the taking of the medication and should include the individual's and caregiver's understanding of what the medication is for, how to take the medication and what to expect from the medication. Such information is suggested to enhance medication adherence (Erickson et al., 2016; Huneke et al., 2012). The fourth step in the medication process is ensuring monitoring to assess for the effectiveness of the medication as well as observing for side effects. The final step of the process is the re-evaluation of the medication by the person who prescribed it and encompasses feedback from the individual with an intellectual disability and the caregiver.

Medication management processes have been studied within acute hospital settings (Pham et al., 2012), nursing homes (Loganathan et al., 2011) and mental health settings (Maidment et al., 2006), but little or no attention has been given to intellectual disability settings. Furthermore, medication management processes are clearly outlined within policies and generally available for acute settings and nursing homes. In intellectual disability settings, however, it may differ as the nurse is only one of a number of individuals responsible for administering medications, and significant variability may be seen in different facilities' procedures and policies (Joos et al., 2014).

With regard to legislative requirements, standards and the rights of the individual with an intellectual disability, it is imperative that support staff employed by healthcare and social care providers (HSCPs) possess the requisite skills, knowledge and education in order to ensure a quality medication management process. There are a variety of assessment tools in operation to identify the supports individuals may require in the administration and management of medications, but these are primarily used in hospital and nursing home settings. Thus, for example, the Medication Management Ability Assessment (M1V1AA) and the Drug Regimen Unassisted Grading Scale (DRUGS) are standardised tools to assess medication management skills (Hutchison et al., 2006). A number of instruments were identified by Elliott and Marriott (2009) some of which may be useful in identifying physical and cognitive barriers to successful medication management.

While models of medication management are varied, many healthcare and social care settings adopt those set out in the NICE guidelines (NIHCE, 2014). This aims to ensure that medications provide the greatest possible benefit to people by encouraging medication reconciliation, review and use of decision aids. Despite the existence of broad, generic guidelines, there is a need for these to be further developed to find application in the complexity and uniqueness of intellectual disability settings. In such settings, medication management and administration may take place across diverse living situations (individual or group), formal and informal environments (service and family), differing locations (including residence, day centre, workplace and school), and will typically involve a people with varying levels of competency training, if any. Finally, there may be significant polypharmacy.

Aim and objectives

The aim of this systematic review is to explore the literature regarding medication management and medication administration in intellectual disability settings. In particular, it seeks to

- identify national and international models and frameworks that support medication management and administration for people with an intellectual disability in any setting;
- analyse whether collaborative practice between nurses, pharmacists, GPs and other HSCPs, in the administration of medications, achieves safe outcomes in populations with specific needs;
- identify key processes within medication management in intellectual disability services that require written guidance and/or protocols;
- identify whether assessment tools are available to support the person with an intellectual disability in the self-administration and self-management of medication; and
- describe potential metrics, outcome measures and performance indicators pertaining to medication management in intellectual disability settings.

Methods

Inclusion and exclusion criteria

This systematic review was designed and conducted based on the Cochrane handbook guidance for conducting systematic reviews (Higgins and Green, 2011). The selection criteria for each of the five research objectives are outlined in Tables 1 to 5, using the PEOS (Participants, Exposure, Outcomes and Study types) and the PICOS (Population, Intervention, Comparison, Outcomes and Study types) format as appropriate.

Search strategy

Initial scoping searches using the database thesauri were run in Medline, Embase, CINAHL and PsycINFO. These searches provided index terms, and a list of synonyms using MeSH terms and CINAHL subject headings, PsycINFO descriptors and Emtree terms.

Further scoping searches were run to select appropriate keywords contained in the title and abstract, author keywords and of index-terms used to describe the articles retrieved during the search. A keyword string was created for the two key concepts, 'Intellectual Disability OR Learning Disability' and 'Medication Administration/Management'. A double-strand search strategy was applied running the thesauri terms first and then keywords. These two searches were

Table 1. Study selection criteria for Research Objective 1.

Objective 1: To identify national and international models and frameworks that support medication management and administration for people with an intellectual disability in any setting, across the lifespan (e.g. campus, community group home, independent living and person's home)?	
Participants	People with an intellectual disability of any age Intellectual disability means 'a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development' (World Health Organization, 2019)
Exposure	Medication management and administration frameworks Medication management is defined as 'facilitation of safe and effective use of prescription and over-the-counter drugs' (Bulechek et al., 2013) Medication administration is defined as 'preparing, giving, and evaluating the effectiveness of prescription and non-prescription drugs' (Bulechek et al., 2013)
Outcomes	N/A (this question is descriptive in nature)
Study types	Descriptive studies, guidelines

Table 2. Study selection criteria for Research Objective 2.

Objective 2: To analyse whether or not collaborative practice between nurses, pharmacists, GPs, other HSCPs, PAs, keyworkers and informal carers in the administration of medications achieves safe and supportive outcomes in populations with specific needs.	
Participants	People with an intellectual disability of any age
Interventions	Collaborative medication management and administration between nurses, pharmacists, GPs and HSCPs, HCAs, PAs, keyworkers and informal carers
Comparators	Different collaborative and non-collaborative models
Outcomes	Safety, reduced risk and support
Study types	Effectiveness studies; descriptive and other observational studies

GP: general practitioner; HCA: healthcare assistant; HSCP: healthcare and social care providers; PA: personal assistant.

Table 3. Study selection criteria for Research Objective 3.

Objective 3: To identify key processes within medication management in intellectual disability services require written guidance and/or protocols	
Participants	Nurses, pharmacists, GPs, HSCPs, HCAs, PAs, keyworkers and informal carers
Exposure	Medication management and administration
Outcomes	Guidance and protocols
Study types	Descriptive studies; guidelines and protocols

GP: general practitioner; HCA: healthcare assistant; HSCP: healthcare and social care providers; PA: personal assistant.

then combined using the OR operator. This method was repeated for each concept and finally, the concepts were combined using the AND operand. The proximity operand of NEAR was also applied across the databases to increase precision of the search for medication management.

This strategy was initially created within Medline and then adapted for all other databases searched using keywords and database-specific subject headings where applicable. The reference

Table 4. Study selection criteria for Research Objective 4.

Objective 4: To identify what assessment tools are available to support the person with an intellectual disability in the self-administration and self-management of medication	
Participants	People with an intellectual disability
Exposure	Self-management and self-administration of medications
Comparators	Assessment tools
Outcomes	Safe self-management and self-administration of medications
Study types	Descriptive and observational studies

Table 5. Study selection criteria for Research Objective 5.

Objective 5: To describe potential metrics, outcome measures and performance indicators pertaining to medication management in intellectual disability settings	
Participants	Settings for people with an intellectual disability
Exposure	Medication management
Comparators	Performance models
Outcomes	Key performance indicators
Study types	Descriptive studies; effectiveness studies

lists of all included studies were reviewed for additional relevant studies. The searches were conducted during the week of the 12th–14th April 2018.

Six databases were selected for searching, Medline (1965–), CINAHL Complete (1937–), Embase (1990–), PsycINFO (1990–), IBECs and SciELO. This database spectrum ensured wide coverage of the literature ranging from journal articles to conference proceedings and monographs.

A comprehensive search methodology was undertaken for unpublished (grey) literature through extensive grey literature retrieval mechanisms. The search for unpublished or grey literature included ProQuest Dissertations and Theses (up to 14 April 2018), relevant key journals which report on conference proceedings, Internet searches/websites of relevant intellectual disability organisations (up to 2 May 2018) and service policy documents (up to 6 June 2018).

Language restrictions were not applied to the search strategy; however, given the timeframe available and challenges with securing translations, selection of relevant papers was restricted to English language. This enabled identification of the extent of potentially eligible additional papers, which, if not initially included, may be considered to have presented a source of possible language bias. Furthermore, study design delimiters were not employed, thus increasing the likelihood of finding relevant studies irrespective of design.

Study selection and risk of bias assessment

Selection of relevant studies and other documents was conducted independently by two reviewers. This involved initial screening of titles and abstracts. Full text versions of search results that remained were further independently examined by two reviewers and decisions reached regarding their inclusion/exclusion. Discrepancies were resolved through discussion. Two reviewers carried out independent assessment of risk of bias/methodological quality on all included reports using the tools listed in Table 6. If there were any discrepancies, consensus was reached by involving a third reviewer.

Table 6. Risk of bias/quality assessment tools.

Evidence category	Risk of bias/quality assessment tool
Descriptive and other observational studies	Adapted from the National Institute of Health checklist (National Institute of Health, 2013)
Protocols and guidelines	AGREE II tool (AGREE Collaboration, 2003)
Randomised controlled trials	Cochrane Risk of Bias (ROB) tool for intervention studies (Higgins and Green, 2011)

Data extraction and analysis

Data extraction from the included reports was undertaken by two reviewers, with one reviewer focusing on two of the research questions and the other reviewer on the remaining three. A third reviewer undertook independent random checking for accuracy of 25% of the data. No meta-analysis could be conducted due to methodological and clinical heterogeneity. Subsequently, extracted data were synthesised in research-objective specific evidence tables, and narrative accounts were developed in relation to the aspects of medication management and administration under question: frameworks, collaborative practice, processes, assessment tools; and metrics/outcomes.

Reporting this review adheres to, in as far as possible, the Preferred Reporting Items in Systematic Reviews and Meta-Analysis (Moher et al., 2009).

Results

The search (database and grey literature) yielded 4582 records. Following removal of duplicates ($n = 2$), screening for title and abstract resulted in 4452 records being excluded with 128 remaining for full-text assessment. Of these, 64 were excluded, leaving 64 records. The main reason for exclusion is related to the study/record outcome ($n = 31$) not being specifically focused on medication management and/or administration (Figure 1).

Research objective 1

The review sought to identify any models and frameworks for supporting medication management and administration for people with an intellectual disability across settings and lifespan. Seven studies were identified that were relevant to the research objective (Table 7).

Of these, only one, from Tasmania, explicitly described a framework (Department of Health and Human Services (DHHS), 2017), with two national guidance documents, from Ireland and the United Kingdom, respectively, addressing similar structural issues (HIQA, 2015; NIHCE, 2014). One further Irish report (National Federation of Voluntary Bodies (NFVB), 2009) highlighted areas to be addressed in the development of medication management policy and guidelines. There was significant cross-over in these documents with the following content included across two or more documents: statement of a clear purpose and scope (DHHS, 2017; NIHCE, 2014); delineation of roles and responsibilities (DHHS, 2017; NFVB, 2009); setting out of guiding principles (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014), such as person-centeredness, consent, choice, preference for self-management, quality and safety and systematic identification of how medications will be managed from prescription to disposal (including recording) (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); addressing

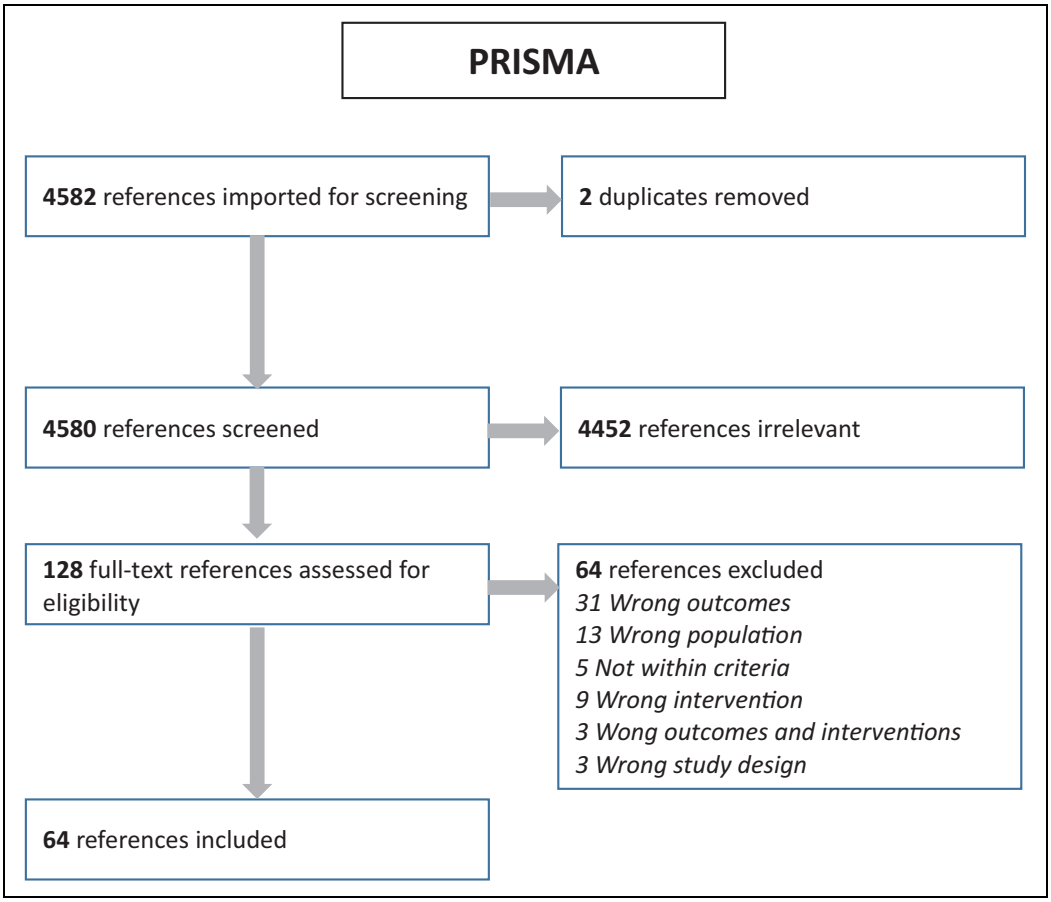

Figure 1. PRISMA diagram.

self-administration policy and application (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); management of refusal of medication (including covert administration) and of medication incidents/problems (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); policy on administration of medications by non-health professionals (DHHS, 2017; NIHCE, 2014); training for staff in this regard (DHHS, 2017; HIQA, 2015; NIHCE, 2014); undertaking of medication reviews at six-monthly (DHHS, 2017; NFVB, 2009) or yearly (NIHCE, 2014) intervals; guidance on the use of *pro re nata* (as required) and *stat*. (emergency) medication use (DHHS, 2017; HIQA, 2015; NFVB, 2009); management of non-prescribed product usage (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014;); adherence to controlled medications legislation (DHHS, 2017; HIQA, 2015; NFVB, 2009); and protection of the person's information (DHHS, 2017; NIHCE, 2014).

Halder et al. (2012), following the undertaking of their clinical audit, identified the need for clear policies and guidelines to be developed, particularly in relation to the assessment of a person's capacity to make decisions regarding their medication management. This was in the context

Table 7. Sources of data pertinent to models and frameworks.

Authors	Participants/population	Aim	Tool/approach	Results
Crossley and Withers (2009)	8 people with intellectual disability in community setting.	To explore people with intellectual disabilities' knowledge about their medication, their feelings about taking long-term antipsychotic medication, and develop a model to capture and reflect how they experience medication.	Grounded theory.	'Model of compliance' developed explaining how people with intellectual disabilities experience taking medication which could inform a framework.
Department of Health and Human Services (DHHS) (2017)	Staff and people receiving support from the Disability and Community Services in Tasmania.	To facilitate the best use of medication practices for those managing their own medications or those assisting with the process.	Framework for medication management.	Considers guiding principles and outlines clear roles and responsibilities in the administration process. It addresses self-administration and assessment of capacity and building towards capacity to self-manage.
Erickson et al. (2016)	30 caregivers of people with intellectual disabilities who take medications.	To learn from caregivers who are either family or support staff, what major issues they encounter throughout the process of managing medication and how these may be addressed.	Qualitative descriptive study.	Issues arising in medication management that may inform a framework; prescriber issues; continuity of care and recording accuracy; communication among people with intellectual disabilities, caregivers, and clinicians; compliance/adherence; knowledge and training of caregivers; and lack of inclusiveness in health system.

(continued)

Table 7. (continued)

Authors	Participants/population	Aim	Tool/approach	Results
National Federation of Voluntary Bodies (NFVB) (2009)	People with intellectual disabilities in services.	To provide comprehensive evidence-based information and guidance on the development of person-centred medication management policies and guidelines within member organisations.	Guideline on policy and guidance development.	Addresses all aspects of medication management and administration in an advisory, rather than prescriptive, manner. This is the source document for FVB member's policies and guidelines.
Halder et al. (2012)	62 carers of adults with intellectual disabilities in various settings.	To ascertain current covert administration practice against standards for best practice.	Quantitative descriptive audit.	Identifies need to develop clear policies/guidelines for capacity assessment and covert administration.
Health Information and Quality Authority (HIQA) (2015)	People with disabilities living in residential care settings.	To help service providers meet the medication needs of older people, children and adults with disabilities living in residential care.	National guidance document.	Identifies key issues such as person centeredness, person's choice and policies and procedures relating to medicine management: Considers many aspects for inclusion.
National Institute for Health and Care Excellence (NIHCE) (2014)	People living in care homes.	To provide recommendations for good practice on the systems and processes for managing medicines in care homes.	Best practice guideline on managing medication.	Addresses the development and review of policies for safe and effective use of medicines, supporting residents to make informed decisions; communication; record keeping; safeguarding, error management and reconciliation of medicines, prescribing, ordering, dispensing, supplying, receiving, storing and disposing of medicines; and self-administration, covert administration and staff training.

of covert medication administration. This requirement for guidance is supported by the efforts of service (NFVB, 2009), state (DHHS, 2017; HIQA, 2015) and clinical practice (NIHCE, 2014) agencies to set out comprehensive guidance for their users and staff. Whereas three research sources were identified in respect of frameworks (Crossley and Withers, 2009; Erickson et al., 2016; Halder et al., 2012), none of these directly addressed the development or, indeed, the content of such frameworks. One grounded theory study (Crossley and Withers, 2009) provided a model of how people with an intellectual disability experience medication management and these findings provide an important insight into the provision of accessible information to inform choice and decision-making on their part; an issue that was identified as central to the 'framework' documents presented. In their qualitative descriptive study of caregivers' perspectives, Erickson et al. (2016) similarly identified the importance of good and clear communication but also highlighted other concerns that may need to be addressed to ensure success of a framework. These included difficulties interacting with the medication prescriber; lack of continuity of care due to poor communication between clinicians, carers, agencies and people with an intellectual disability; problems administering medications; inadequate knowledge on the part of the caregivers; and fragmentation of clinical records leading to inadequate presence in the actual health system. Other potential components of a framework may address medication management away from home and how this might be planned for (DHHS, 2017).

Research objective 2

The concept of whether collaborative practice between nurses, pharmacists, GPs and other health care and social care professionals (HSCPs), in the administration of medications, achieves safe outcomes in populations with specific needs was considered. Eleven relevant studies provided evidence on collaborative practice specifically between nurses, pharmacists, GPs, other HSCPs, health care assistants (HCAs), personal assistants (PAs), keyworkers and informal carers in the administration of medications (Table 8).

Whether collaborative practice achieves safe and supportive outcomes in populations with specific needs was also contemplated. No effectiveness studies were located which specifically examined the outcome of collaboration between the various parties responsible for medication management. However, several sources referred to it, while focusing on other parameters and variables. The information extracted from these sources largely clustered on themes of complexity (Branford et al., 1997; Burrow and Rimmer, 1997), risks (Hom et al., 2015; Rasaratnam et al., 2004; Tan et al., 2015; Van Den Bemt et al., 2007) and team makeup (Ellenor and Frisk, 1977; Van Den Bemt et al., 2007; Venables et al., 2015) with repeated emphasis on education and training (Abbott et al., 2014; Bosner and Belfiore, 2001; Buelow and Shore, 2010; Rasaratnam et al., 2004).

In a descriptive mixed-methods study, Branford et al. (1997) identified the complexity of medication management, especially when it occurred across a number of locations (Burrow and Rimmer, 1997) as can be typical in intellectual disability settings. Describing the preparation, transport, storage, oversight and administration of this process, they highlighted the importance of collaboration and communication in minimising risk of medication errors. Such collaboration was not just between healthcare professionals but involved parents, bus drivers, reception staff and others. Burrow and Rimmer (1997) in an audit of medication records of 90 people with an intellectual disability noted inconsistencies across 30% of individuals' records. These variances were seen between the records of GPs, consultants and home care services, again highlighting the risks associated with there being several parties to medication management. Although risks

Table 8. Sources of data pertinent to collaborative practice.

Authors	Participants/population	Aim	Tool/approach	Results
Auberry et al. (2017)	12 staff supporting people with intellectual disabilities.	To determine whether augmenting direct support professional training with the use of simulation, debriefing and written reflection related to medication management would increase their skill level and confidence.	One-group mixed methods study with pretest/posttest.	Staff skill level improved significantly after hands-on simulations, particularly in respect of general and gastrointestinal medications. There was also a desire for staff education and training. Recommendations regarding continuing education with workplace simulations and debriefing with written reflective practice.
Bosner and Belfiore (2001)	1 person with intellectual disability.	To describe the effects of a system of least prompts to teach an adolescent with Down Syndrome and insulin-dependent diabetes to self-administer an insulin injection.	Single case posttest study.	Training with parents through behavioural task-teaching regimen on self-administration of insulin resulted in successful learning and increased self-confidence.
Branford et al. (1997)	167 people with intellectual disabilities' medication information. Across 13 day centres.	To characterise and quantify the implications for staff, carers and attenders of the need to administer medicines in day centres.	Mixed methods study.	Notes complexity of communication of medication information for those in day centres, with respect to times for administration, labelling, transport/storage, oversight and administration.
Buelow and Shore (2010)	Children with intellectual disabilities and epilepsy.	To address the management challenges of dual diagnosis (epilepsy and intellectual disability).	Opinion article.	Identifies ways that clinical nurse specialists may foster development of management skills in parents. Notes problems associated with the management of seizure and prescription management. By identifying problems related to living with epilepsy, the nurse can promote a partnership in healthcare by helping parents develop appropriate and effective action plans.

(continued)

Table 8. (continued)

Authors	Participants/population	Aim	Tool/approach	Results
Burrow and Rimmer (1997)	90 people with intellectual disabilities' medication records from GP, consultants and home managers (270 pieces of information).	Not stated.	Medication audit.	Audit shows discrepancies ranging from incorrect dosage to drug omissions. Highlights insufficient communication between all parties and implications of this. Recommends use of a home drug chart which would accompany each client for every medical contact and be regularly updated as well as good communication between professionals.
Ellenor and Frisk (1977)	208 people with intellectual disabilities and behavioural problems.	Not clearly stated.	Pretest/posttest study.	Pharmacist visits to people with intellectual disabilities led to a reduction in usage of antipsychotics, anxiolytics, antidepressants, sedatives, hypnotics and miscellaneous agents. The study shows that the pharmacist using a team approach can reduce the overuse of medications in those with intellectual disabilities.
Hom et al. (2015)	793 people with intellectual disabilities' medicine records.	To explore whether living arrangements might be related to anti-epileptic medication compliance.	Retrospective documentary review.	Highlights non-adherence rates for anti-epileptic medications. Significant differences according to living situation. Identifies need for education of people with intellectual disabilities and families on importance of medicine adherence.
Rasaratnam et al. (2004)	93 carers of people with intellectual disabilities who were prescribed neuroleptic medications.	To investigate the influence of attitudes of carers of people with intellectual disability towards giving medication.	Quantitative descriptive study.	Highlights health workers role supporting carers to make the correct decision about giving prescribed medications to individuals they care for. Negative feelings towards medications noted from family carers.

(continued)

Table 8. (continued)

Authors	Participants/population	Aim	Tool/approach	Results
Tan et al. (2015)	3905 people with intellectual disabilities' medication records. Community-based and person must have been on psychotropic medication.	To investigate oral psychotropic medication adherence among community-based adults with DD and MI and assess the association between psychotropic medication adherence and healthcare utilisation and health costs.	Retrospective cohort study.	Role of non-family caregivers may be associated with lower levels of non-adherence in psychotropic usage among people with intellectual disabilities. Recommendation for patients, caregivers and healthcare providers to work as a team.
Van Den Bemt et al. (2007)	Medicine administrations to 46 people with intellectual disabilities, living in an institution.	To identify the frequency of drug administration errors and determinants for these errors in an institution for individuals with intellectual disability.	Quantitative descriptive, observational, study.	Administration technique errors are most commonly cited and rated as being of intermediate seriousness. Clear protocols, teaching sessions and advice given by pharmacist may help prevent some types of errors. Using a distribution robot results in lower incidence of errors. While no association found between caretaker experience and the risk of errors, it is proposed that, in the absence of formal education and training, caretakers mainly learn by doing.
Venables et al. (2015)	Five nurses, eight medical practitioners and six pharmacists who provide support to people with intellectual disabilities.	To explore problems with oral medicines prescribed to paediatric patients from the perspectives of medical practitioners, pharmacists and nurses.	Qualitative.	Focuses on sensory and non-sensory problems with administering medicines to paediatric patients with intellectual disabilities. Issues pertaining to use and supply of 'special' medication are considered. Recommends collaboration between medical practitioners and pharmacists, making use of the latter as a resource.

DD: developmental disability; MI: mental illness.

associated with disparate documentation (Burrow and Rimmer, 1997) and complexity of processes (Branford et al., 1997; Van Den Bemt et al., 2007) have been noted, the problems of non-adherence were also identified in the literature (Hom et al., 2015; Rasaratnam et al., 2004; Tan et al., 2015). Interestingly, Hom et al. (2015) noted that, where there was adequate supervision, non-adherence rates reduced. In all of these sources, though, the importance of good communication between professional themselves, between professionals and carers and between professionals and people with an intellectual disability was repeated (Branford et al., 1997; Burrow and Rimmer, 1997; Ellenor and Frisk, 1977; Venables et al., 2015).

Potential solutions included that the use of a transportable medication chart (Burrow and Rimmer, 1997) would travel with the person with an intellectual disability and increased interaction between professionals, carers and people with an intellectual disability, perhaps mediated through an enhanced role for pharmacists (Ellenor and Frisk, 1977; Van Den Bemt et al., 2007; Venables et al., 2015) both within service settings and between the various parties. This more visible role for the pharmacist within the medication management team was allied with an acceptance that this 'team' is much wider than just the healthcare professionals and includes family (Bosner and Belfiore, 2001; Branford et al., 1997; Buelow and Shore, 2010; Hom et al., 2015; Rasaratnam et al., 2004), direct support staff (social care) (Auberry et al., 2017; Rasaratnam et al., 2004) and people with an intellectual disability themselves (Bosner and Belfiore, 2001; Ellenor and Frisk, 1977; Hom et al., 2015). The importance of education and training on medication management, across the members of this team, was a common theme (Bosner and Belfiore, 2001; Buelow and Shore, 2010; Rasaratnam et al., 2004) with the pharmacist (Ellenor and Frisk, 1977; Van Den Bemt et al., 2007; Venables et al., 2015) and clinical nurse specialist (Buelow and Shore, 2010) singled out as having important educational and training roles.

Research objective 3

In identifying key processes within medication management in intellectual disability services that require written guidance and/or protocols, 29 studies were sourced and 7 policy and procedural guidelines (Table 9).

A significant number of sources were located which provided an insight into the medication management protocols that may require written guidelines and/or protocols. The need for such guidelines was stated in a number of sources (Davis, 2016; Gadow and Kane, 1983; Halder et al., 2012; Heslop et al., 2005; Joos et al., 2014, 2015, 2016a, 2016b) with some acknowledging the need for guidelines to take account of the uniqueness of specific situations (Doyle and Cronin, 2017; Joos et al., 2016b) and the complexity of many intellectual disability settings (Branford et al., 1997) with transportation, receipt, storage, delivery and administration of medications often involving many people in many places (Branford et al., 1997). There was also a concern that irrespective of the generic nature of guidelines and protocols, there was also a requirement for person-centred and individualised planning (Davis et al., 2016; Donnelly, 2013; Doyle and Cronin, 2017; Epitropakis and DiPietro, 2015).

A review of the seven policy and procedural guidelines revealed 30 distinct medication-related processes. These have been collated into three process groupings: medication management processes, medication administrative processes and administrative processes.

Medication management processes. Medication management processes include those processes which are directly related to the procurement, safekeeping and disposal of pharmaceutical products (primarily medications). The identified processes are prescribing (Deb et al., 2006; DHHS, 2017;

Table 9. Sources of data pertinent to guidance and protocols.

Authors	Participants/population	Aim	Tool/approach	Results/comments
Branford et al. (1997)	167 people with intellectual disabilities' medication information. Across 13 day centres	To describe and quantify implications for staff, carers and attenders of the need to administer medicines in day centres.	Mixed methods study.	Identifies complexity of key medicine management processes related to attendees in day centres. Significant challenges and risk of errors highlighted.
Brasić et al. (2000)	Medication records of 767 people with intellectual disabilities in intermediate care setting.	To develop a screening procedure to identify serious errors in psychoactive medication administration.	Quantitative descriptive study.	Describes a procedure for pharmacists to continuously improve quality by assessing numbers and dosages of psychoactive medications administered to people, allowing identification of dosages of medications that are excessive or suboptimal, as well as facilitating identification and correction of polypharmacy.
Buckley (2013)	183 members of staff. Clinical staff supporting persons with disabilities and epilepsy in their homes and in the community.	Not clearly stated.	Educational initiative with pretest/ posttest.	Educational needs identified, and educational presentation delivered. Trends identified a need for improved specific knowledge in the area, recognition that this is a highly complex practice area, a need for advocacy, difficulty identifying and classifying seizures and treatment and management issues. Educational gains demonstrated after initiative after the presentation was given.
Burrow and Rimmer (1997)	90 people with intellectual disabilities' medication records from GP, consultants and home managers (270 pieces of information).	Not stated.	Medication audit.	Audit reveals inconsistencies involving 27 (30%) service users ranging from incorrect dosage to drug omissions. Demonstrates insufficient communication between all parties. Recommends a fail-safe system of ensuring that reliable updated information is always available on medication details. Proposes that home drug chart should accompany each client for every medical contact and should be updated.

(continued)

Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Cocks et al. (2016)	328 adults with intellectual disabilities and families/ support persons.	To describe the health status and medication use of adults with intellectual disabilities Western Australia.	Cross-sectional survey.	Highlights the importance of regular medication reviews for adults with intellectual disabilities, especially those taking more than five different medications. Process of medication reviews and oversight needs to be considered.
Dam et al. (2015)	10 residential services providing supports for people with intellectual disabilities.	To describe a programme providing staff with competencies to understand the residents' medication, observe and act on the effects of medicines and handle medicines in accordance with formal procedures and regulations.	Pretest/posttest study with an educational programme.	Describes education programme proposing the importance of engaging leaders of facilities, adjusting programmes according to needs and goals of the facilities and preparing teachers to employ appropriate pedagogical approaches.
Davis (2016)	People with intellectual disabilities and asthma.	To consider the management of asthma in people with intellectual disabilities.	Opinion.	Identifies shortcomings in management of asthma and the uniqueness of the issues related to achieving adequate inhaler technique and use. Notes the absence of clinical practice asthma guidelines that include specific recommendations for people with intellectual disability. Recommends collaborative approach to developing guidelines.
Davis (2014)	People with intellectual disabilities.	To call for action is relation to medical reviews for people with intellectual disabilities.	Opinion.	Recommends six-monthly medication reviews. Validated tools for healthcare providers to assess medication management skills need to be developed with associated education and training for pharmacists.

(continued)

Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Davis et al. (2015)	22 direct support professionals from governmental agencies and five staff from non-governmental service providers, supporting people with intellectual disabilities and asthma.	To explore direct support professionals' experiences, perceptions and needs in respect of asthma management for people with intellectual disabilities in supported accommodation.	Qualitative descriptive study.	Notes inconsistencies in staff training and instruction with lack of consistency in care given. Need for clear guidelines in respect of the person receiving the medication. Absence of a registered nurse left direct support professionals unable to recognise deterioration of respiratory function and need for *pro re nata* medications. The clinical assessment associated with this was not deemed by staff as being part of their role.
Davis et al. (2016)	17 adults with intellectual disabilities and asthma who self-administer their asthma medication. Various living situations.	To explore people with intellectual disabilities' understanding of asthma medication use, in order to inform future educational support.	Exploratory qualitative study.	Identifies factors that influence inhaled asthma medication use. Healthcare providers must provide information, training and support for self-management to maximise adherence. Recommends use of Written Asthma Action Plan (a decision support tool for early detection) prepared by health professionals, including nurses, to prevent or reduce the severity of an attack as well as information about avoiding triggers. Pharmacists could support self-management through medication reviews.
Deb et al. (2006)	People with intellectual disability and problem behaviours.	To provide advice on prescribing medication to manage behaviour problems among adults with an intellectual disability.	Guideline for medication prescription and usage.	Provides guidance on monitoring of treatment, the need for good communication among the team and sets out the key tenets of assessing capacity to consent/refuse treatment. Also identifies the main questions that should underpin medication audit.

(continued)

Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Deepak et al. (2012)	7 managers in care homes for people with intellectual disabilities who have epilepsy.	To identify the training status of staff in care homes for people with intellectual disabilities in relation to administration of emergency antiepileptic medications.	Qualitative descriptive study using survey.	Identifies a dearth in training among those who are responsible for administering emergency anti-epileptic medication despite arrangements being placed to train staff in their use. Highlights need for policies of training in such medication use.
Department of Health and Human Services (DHHS) (2017)	Staff and people receiving support from the Disability and Community Services in Tasmania.	To facilitate best use of medication practices for those managing their own medications or those assisting with the process.	Framework for medication management.	Considers guiding principles of medication management and outlines clear roles and responsibilities in the administration process. Discusses assessment of capacity and building towards capacity to self-manage and recommends what should be contained in a self-management plan.
Department of Social and Health Services (DSHS) (2017)	Staff and people with intellectual disabilities receiving service from the organisation.	To describe the procedures to be used by community residential service providers to support persons with intellectual disabilities who use medications.	Service medication policy.	Identifies procedures associated with self-administration of medications, consent, nurse delegation, storage and disposal of medicines and documentation. Part of a broader policy manual.
Dickens et al. (2006)	Prescription charts of 62 people with intellectual disabilities.	To introduce and evaluate an observer system in the medicines administration process.	Pretest/posttest with training.	The introduction of a trained HCA as an observer to medication administration, led to a reduction of medication administration errors. This has professional implications for registered nurses (perceived role erosion) as well as training implications for the observer. The use of an observer, focusing on the 'Five Rights' may be a useful process to reduce errors.

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Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Donnelly (2013)	8 local community pharmacists.	To describe a training session for pharmacists to encourage accessibility for people with intellectual disabilities living in the community.	Description of a training session.	Healthier Lives group identified the challenges they experience engaging with their local pharmacies and with self-management of medications. It was recommended that people with intellectual disabilities should be targeted for medication reviews and that information should be accessible and take cognisance of the cognitive ability of the individual person.
Doyle and Cronin (2017)	15 mothers of children with severe and profound intellectual disabilities.	To explore mothers' experiences of 'giving medicines' to children with severe and profound intellectual disabilities.	Phenomenological study.	Challenges for mothers include medicine refusal, difficulty in swallowing, masking, disguise and alteration of consistency. Timing of administration and its relation to eating and drinking is also a key factor for consideration. Recommended development of an education package for parents on best practice in giving medicines and tailored support packages that consider individual needs and adaptation of practice for the home setting.
Epitropakis and DiPietro (2015)	Paediatric patients with severe intellectual and behavioural disabilities.	To describe a medication compliance protocol.	Medication compliance protocol.	Describes the challenges of medication refusal in a neurobehavioural unit. A nurse-devised protocol resulted in improved compliance. This has involved the use of applied behavioural analysis. Individualised treatment plans with consistent protocol application is considered imperative.
Erickson et al. (2016)	30 caregivers of people with intellectual disabilities who take medications.	To learn from caregivers who are either family or support staff what major issues they encounter throughout the process of managing medication and how these might be addressed.	Qualitative descriptive study.	Identifies issues arising in medication management that may inform a framework; prescriber issues; continuity of care and recording accuracy; communication among people with intellectual disabilities, caregivers, and clinicians; compliance/adherence; knowledge and training of caregivers; and lack of inclusiveness in health system.

(continued)

Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Gadow and Kane (1983)	Teachers of 461 elementary pupils with intellectual disabilities who were on medications for seizure or behavioural issues.	To identify how medications are administered and stored in schools.	Quantitative descriptive study.	Highlights medication management in schools. Teachers were responsible for supervising this process in nearly half of cases under receipt of written permission from the doctor and parents. However, there was no daily record of drug administration in more than half of cases. Identified need for guidelines on medicine management and administration in school settings.
Halder et al. (2012)	62 carers of adults with intellectual disabilities.	To describe current practice of covert administration of medications against standards for best practice.	Quantitative descriptive study.	Of those who were administering medications covertly, over two-thirds were unaware of or did not have a policy in place to support this. A similar number had no written record of the patients' mental capacity or had written records of discussions with the patient's relatives or carers about covert use. Need for education and training of carers and for development of algorithm-based guidelines/policies to support covert administration.
Health Information and Quality Authority (HIQA) (2015)	People with disabilities living in residential care settings.	To help service providers meet the medication needs of older people, children and adults with disabilities living in residential care.	National guidance document.	Comprehensive guidance on key processes of medication management. The centrality of person centeredness and choice are identified. It notes that clear policies and procedures should be in place for medicine management based around the 10 rights of administration. Evidence to explicitly support/inform recommendations not provided.

(continued)

Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Heslop et al. (2005)	21 people with intellectual disabilities, who take psychotropics, from four different regions; 20 carers and 11 prescribers.	To explore people with intellectual disabilities', and their carers', knowledge of the persons' psychotropic medication treatment.	Qualitative descriptive study.	Findings note sketchy knowledge about why medication was prescribed, lack of knowledge about possible side effects, discrepancies between what people with intellectual disabilities thought their carers knew and what the carers actually knew, poor provision of information for carers, need for more information and limited access to alternatives to medications. Recommendations made to address these issues as well as proposing better training for carers about psychotropic medications, individually tailoring that information for each person.
Howseman (2013)	People with intellectual disabilities who have swallowing difficulties.	To provide guidance on the administration of medications to people who have swallowing difficulties.	Descriptive practice advisory.	Often different perspective on medication exist between formal and informal carers. Suggests that carers should be involved in care planning and management processes and guidelines for informal carers should be developed that take into account the subjective and objective realities of the carer in relation to the person receiving the medication. These plans should set out how people's needs will be met, how the management process will be evaluated and should be reviewed regularly to ensure that they continue to fulfil these purposes.
Joos et al. (2014)	34 directors, 45 unit employees, 42 nurses and 23 physicians providing support to people with intellectual disabilities in RCFs.	To describe medication management practices in RCFs and identify those aspects of the medication management process that can be improved to optimize care.	Cross-sectional, observational study, with interviews.	Notes discrepancies between the existence of SOPs for medication management and their use by staff. General absence of SOPs for most medication management processes. The development and use of SOPs as part of an overall medication management process is recommended, with an error reporting system, proactive evaluation and an expanded role for the pharmacist.

(continued)

Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Joos et al. (2015)	862 medication preparations and 268 medication administrations for 48 people with intellectual disabilities who receive medications via enteral feeding tubes. Settings were RCFs.	To collect direct observational data on drug administration practices via enteral feeding tubes.	Cross-sectional, observational study.	Differences in working methods for preparing and administering medications observed both between and within RCFs. These practices included the mixing together of two or more medications, failing to dilute liquid medication, not shaking suspensions and emulsions, crushing of modified release dosage forms and not flushing the enteral feeding tubes. The high variability in working methods suggests that there is a need for practical recommendations, guidelines and education programmes in relation to the administration of medications via enteral tubes.
Joos et al. (2016b)	356 staff across 9 RCFs for people with intellectual disabilities who administer medications through enteral feeding tubes.	To investigate staff knowledge on the safe administration of medications via enteral feeding tubes.	Quantitative descriptive study employing a questionnaire.	Findings demonstrate lack of knowledge among staff members. It is recommended that an educational intervention be developed and implemented which is setting-specific.
Joos et al. (2016a)	Medication records of 156 people with intellectual disabilities, who receive medication via enteral feeding tubes. Settings were RCFs.	To draw up an inventory of drugs that are routinely administered, via enteral feeding tubes, to people with intellectual disabilities in Belgian RCFs.	Cross-sectional, observational study.	Describes medication use and medication classes administered through enteral feeding tubes, among people with intellectual disabilities. Variety of medications administered raised the potential for drug–drug interactions. Recommends increased awareness when administering medications via enteral feeding tubes to people with intellectual disabilities as well as development of guidelines.

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Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Joos et al. (2016c)	24 staff members who provide medications via enteral feeding tubes to people with intellectual disabilities living in RCFs.	To identify barriers and facilitators administering medications via enteral feeding tubes.	Qualitative descriptive study.	Influencing factors on drug administration through an enteral feeding tube are identified. Poor knowledge of guidelines and clear administration instructions, lack of necessary material and practical issues and limited gastric fluid tolerance of some residents resulted in carers not complying with guidelines to avoid causing gastric discomfort.
National Federation of Voluntary Bodies (NFVB) (2009)	People with intellectual disabilities in services.	To provide comprehensive evidence-based information and guidance on the development of person-centred medication management policies and guidelines within member organisations.	Guideline on policy and guidance development.	Addresses all aspects of medication management and administration in an advisory, rather than prescriptive manner. This is the source document for FVB members' policies and guidelines on medication management and administration.
National Institute for Health and Care Excellence (NIHCE) (2014)	People living in care homes.	To provide recommendations for good practice on the systems and processes for managing medicines in care homes.	Best practice guideline on managing medication.	Addresses the development and review of policies for safe and effective use of medicines, supporting residents to make informed decisions.
National Health Service (NHS) Trafford (2013)	People living in care homes managed by the organisation.	To support practitioners in respect of covert administration of medications.	Guidance document.	Discusses some issues relating to covert medication and mental capacity using scenarios. Useful decision tool on same.

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Table 9. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Rasaratnam et al. (2004)	93 carers (formal and informal) of people with intellectual disabilities who take neuroleptic medication.	To investigate the influence of attitudes of carers of people with intellectual disability towards the giving of medication.	Quantitative descriptive study.	The study uncovers a significance difference between responses of family carers and professional carers, with negative feelings towards medications noted from the former.
Shaw and Hodson (2016)	95 people with intellectual disabilities across 16 residential and supported living environments.	To identify the number and type of interventions made by a pharmacist carrying out medication reviews for people with intellectual disabilities.	Quantitative descriptive, observational study.	A significant number of pharmacist-initiated interventions were made to support optimal medication management. Proposes clinical pharmacist led-medication reviews in care homes and supported living environments for people with intellectual disabilities.
Thurtle (2000)	17 people with intellectual disabilities' medication records, 16 care staff observations, 6 care staff scenarios and 12 medication plan reviews.	To describe the initiation and findings of an audit of drug administration procedures for people with intellectual disabilities in residential care.	Quantitative descriptive audit.	Stages of administration are identified and propose audits of medication management practice.
Van Den Bemt et al. (2007)	Medicine administrations to 46 people with intellectual disabilities, living in an institution.	To identify the frequency of medication administration errors and determinants for these errors.	Quantitative descriptive, observational, study.	Administration technique errors are most commonly cited and rated as being of intermediate seriousness. Clear general medication management protocols, teaching sessions and advice from pharmacists may help prevent some types of errors.

RCFs: residential care facilities; SOPs: standard operating procedures.

HIQA, 2015; NFVB, 2009; NIHCE, 2014); ordering (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); transcription of orders (HIQA, 2015); verbal and emergency orders (HIQA, 2015; NFVB, 2009); packaging and labelling (NFVB, 2009); dispensing and supplying (NIHCE, 2014); collecting and transporting (NFVB, 2009); receiving (NIHCE, 2014); storage (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); reconciliation (HIQA, 2015; NIHCE, 2014); and disposal (Department of Social and Health Services (DSHS), 2017; DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014).

Medication administration processes. Twelve medication administration processes were identified in the policy and procedural guideline sources. These encompassed administration of medications to people with an intellectual disability either by staff members, informal carers or by the persons themselves. Many documents referred to basic administration principles, such as the rights of administration (Dickens et al., 2006; HIQA, 2015; NIHCE, 2014). The identified processes are administration (via various routes) (DHHS, 2017; HIQA, 2015; NFVB, 2009); administration of 'as required' and emergency medication (DHHS, 2017; HIQA, 2015; NFVB, 2009); administration of schedule and high-alert medication (HIQA, 2015; NFVB, 2009); self-administration (DSHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); medication refusal (DHHS, 2017; DSHS, 2017; HIQA, 2015); covert administration of medication (HIQA, 2015; National Health Service (NHS) Trafford, 2013; NFVB, 2009; NIHCE, 2014); altering delivery form (crushing tablets etc.) (DHHS, 2017; NFVB, 2009); administration of over-the-counter and non-prescription medications (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); off-site administration of medications (DHHS, 2017); complex care and polypharmacy (Deb et al., 2006; DHHS, 2017; NFVB, 2009); safeguarding and monitoring for adverse reactions (Deb et al., 2006; DHHS, 2017; NFVB, 2009; NIHCE, 2014).

Administrative processes. Eight administrative processes were described. These pertained to actions, which either underpinned or met regulatory requirements related to medication management and/or administration. Some published sources noted the importance of these in the safe and smooth conduct of other medication processes. Thus, Burrow and Rimmer (1997) highlighted that poor communication can result in fragmentation of care while others (Brasić et al., 2000; Davis, 2014; Donnelly, 2013; Shaw and Hodson, 2016) identified the need for medication reviews to be undertaken at specified intervals. Many authors, though, recommended the provision of education and training to staff (Burrow and Rimmer, 1997; Dam et al., 2015; Davis, 2014; Davis et al., 2015; Deepak et al., 2012; Erickson et al., 2016; Halder et al., 2012; Heslop et al., 2005; Joos et al., 2015, 2016a), informal carers (Burrow and Rimmer, 1997; Doyle and Cronin, 2017; Erickson et al., 2016; Halder et al., 2012; Heslop et al., 2005) and people with an intellectual disability (Buckley, 2013; Burrow and Rimmer, 1997; Davis et al., 2016; Donnelly, 2013; Erickson et al., 2016; Heslop et al., 2005; Rasaratnam et al., 2004), with Rasaratnam et al. (2004) noting that lack of the same can lead to uninformed negative perspectives on medications among people with an intellectual disability and their carers. The administrative processes that were identified are undertaking medication review (Deb et al., 2006; DHHS, 2017; HIQA, 2015; NIHCE, 2014); recording keeping (DHHS, 2017; DSHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); communicating (DHHS, 2017); managing medication incidents/errors (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014); safeguarding and monitoring for adverse reactions (Deb et al., 2006; DHHS, 2017; NFVB, 2009; NIHCE, 2014); obtaining consent (Deb et al., 2006; DHHS, 2017; DSHS, 2017; NHS Trafford, 2013; NIHCE, 2014); assessing capacity (Deb et al., 2006; DHHS, 2017; NHS Trafford, 2013) education and training (Deb et al., 2006; NFVB, 2009; NIHCE, 2014).

Research objective 4

The review also considered assessment tools that are available to support the person with an intellectual disability in the self-administration and self-management of medication. Six sources were located, providing information on assessment tools to support the person with an intellectual disability in the self-administration and self-management of medication (Table 10).

While no sources were identified that definitively showed a link between support and successful self-management, several approaches were described (Bosner and Belfiore, 2001; Brickey, 1978; Davis et al., 2016). Two studies (Bosner and Belfiore, 2001; Brickey, 1978) focused on the employment of behavioural approaches to support skills teaching. Thus, specific medication management tasks were analysed and broken into steps, rewards provided to reinforce completion of a step, and fading to achieve maintenance. The medication management skills for example included self-administration of insulin (Bosner and Belfiore, 2001). Such approaches are useful in the learning and undertaking of specific behavioural tasks, but medication management, as noted in the previous section, encompasses more than discrete tasks; it also involves knowledge, reflection and judgement (Crossley and Withers, 2009; Davis et al., 2016). Davis et al. (2016) in their study of knowledge in relation to asthma medications noted the complex nature of self-managing medications (storage, administration, monitoring and reporting back) and proposed that written asthma action plans might be devised and used to support people with an intellectual disability to manage their own medications. Crossley and Withers (2009) in seeking to understand how people with an intellectual disability experience medication management identified the challenges they often have communicating issues, such as side effects, back to the prescribing clinicians. This may affect them taking ownership of the process and lead to poor compliance with the medication regimen.

It has been noted that self-management of medications requires judgement or decision-making (Crossley and Withers, 2009). While this issue did not emerge significantly from the published literature, one source specifically examined the use of information-giving on ability to provide consent to medications (Ferguson and Murphy, 2014), suggesting that the use of formatted information with associated training, build capacity in this regard (Brickey, 1978). The issues of capacity and consent are important as the Assisted Decision-Making (Capacity) Act 2015 (Government of Ireland, 2015) requires a starting point of capacity in relation to decisions.

Research objective 5

Five studies were sourced which addressed metrics, outcome measures and key performance indicators which pertained to medication management and administration. These are presented in Table 11.

No evidence was found which explicitly identified metrics or outcome measures in respect of medication management in intellectual disability settings, but two potential metrics of quality were noted. The concept of *adherence* was discussed in Dharmapuri et al.'s (2015) quantitative descriptive study and Tan et al.'s (2015) retrospective cohort study. Dharmapuri et al. (2015) identify the reasons for non-adherence to be multifarious in nature, though Tan et al. (2015), in their study, noted that rates of non-adherence were lower in intellectual disability populations than in the general population. They proposed that this pattern was due to the role of non-family caregivers in their lives. There is no strong evidence to support this but, in the absence of other outcome measures, adherence or compliance may be a useful proxy metric. It is noted that the

Table 10. Sources of data pertinent to assessment tools.

Authors	Participants/population	Aim	Tool/approach	Results/comments
Bosner and Belfiore (2001)	1 person with intellectual disability.	To describe the effects of a system of least prompts to teach an adolescent with Down Syndrome and insulin-dependent diabetes to self-administer an insulin injection.	Single case posttest study.	A 22-step routine is identified and task analyses within the routine developed. The results indicate that both tasks were completed successfully with partial participation and that self-confidence was enhanced. Demonstrates potential for partial self-administration.
Brickey (1978)	20 people with intellectual disabilities who took medications when attending a sheltered workshop.	To describe a programme for teaching self-medication for adults with moderate and severe intellectual disability.	Descriptive educational intervention study.	Describes a self-medication training program. Procedures were easy to implement and despite reservations by staff about ability to learn, the participants all learned how to self-medicate.
Crossley and Withers (2009)	8 people with intellectual disability in community setting.	To explore people with intellectual disabilities' knowledge about their medication and their feelings about taking long-term antipsychotic medication; to develop a model to capture and reflect how the participants with intellectual disabilities experience medication.	Grounded theory.	Model of how people with intellectual disabilities experience taking medication. Most had good knowledge of medicines they were on, when they were taken and an awareness of side effects. Questions raised on accuracy of self-report compared to daily notes in charts. Participants were not clear on why they were taking medications. Poor knowledge on contraindications. Most wanted more information. A minority had ever refused tablets. Lack of involvement of participants in decisions about medications.

(continued)

Table 10. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Davis et al. (2016)	17 adults with intellectual disabilities and asthma who self-administer their asthma medication. Various living situations.	To explore people with intellectual disabilities' understanding of asthma medication use, in order to inform future educational support.	Exploratory qualitative study.	Participants described factors that influenced inhaled asthma medication use: understanding of their illness and need for medication; self-management; and autonomy versus dependence. Healthcare providers must provide information, training and support for self-management to maximise adherence. Recommends use of Written Asthma Action Plan (a decision support tool for early detection) to prevent or reduce the severity of an attack as well as information about avoiding triggers. Pharmacists could support self-management through medication reviews.
Davis (2016)	People with intellectual disabilities and asthma.	To consider the management of asthma in people with intellectual disabilities.	Opinion.	Identifies the importance of providing education and training to people with intellectual disabilities and their support persons/caregivers.
Ferguson and Murphy (2014)	28 people with intellectual disabilities who take medications.	To investigate the capacity of individuals with intellectual disabilities to make decisions about their medications, and to evaluate whether the provision of training sessions on medications would increase their capacity.	Pretest/ posttest study.	Study finds that people with better verbal comprehension were more likely to be able to consent. Results show that provision of training (information) increased knowledge of medications.

Table 11. Data sources of related to metrics, outcome measures and key performance indicators.

Authors	Participants/population	Aim	Tool/approach	Results/comments
Dharmapuri et al. (2015)	138 school-going adolescents.	To assess the relationship between health literacy levels and medication adherence in adolescents.	Quantitative descriptive study.	Explores how to support people to adhere to their medication regimen. Having a chronic illness and intellectual disability were associated with poor medication adherence. Interrelation between age, sex, chronic illness, intellectual disability, health rating and health literacy on medication adherence. Worse medication adherence in adolescents with intellectual disabilities even if health literacy and chronic illness were not major issues.
Stupalski and Russell (1999)	Medication records of 41 people with intellectual disabilities located across 14 residences.	To identify and better understand the causes of medication errors and to initiate appropriate corrective action.	Retrospective quantitative descriptive study.	Examines medication errors and concludes that monitoring systems must be put in place, with an agreed and uniform definition of what constitutes a medication error and focusing on identifying systemic problems in care delivery. The introduction of a quality monitor is recommended collating information on relevant demographics, as well as data on medication error type, contributing factors, protocol and policy adherence. Finally, there should be planned approach to intervention and follow-up. The approach should not be punitive but involve all in identifying and solving problems at the point of care.

(continued)

Table 11. (continued)

Authors	Participants/population	Aim	Tool/approach	Results/comments
Tan et al. (2015)	3905 people with intellectual disabilities' medication records. Community-based and person must have been on psychotropic medication.	To investigate adherence to oral psychotropic medications in community-based adults with DD and MI; to assess association between psychotropic meds adherence and healthcare utilisation/costs.	Retrospective cohort study.	It is noted that levels of non-adherence to antipsychotics, while significant, are lower than in the mainstream population. This could be related to non-family caregivers. Recommends that people with intellectual disabilities, caregivers and healthcare providers work as a team.
Thurtle (2000)	17 people with intellectual disabilities' medication records, 16 care staff observations, 6 care staff scenarios and 12 medication plan reviews.	To describe the initiation and findings of an audit of drug administration procedures for people with intellectual disabilities in residential care.	Quantitative descriptive audit.	As part of an approach to reduce medication errors, the authors propose the use of signature lists for medication administration. They identify the key stages of such administration.
Zaal et al. (2016)	27 people with intellectual disabilities' medication records.	To evaluate the process of medication review using a STRIP in adults with an intellectual disability living in a residential care setting and the identification of drug-related problems.	Pilot study of STRIP tool.	Recommends that medication reviews/audits be conducted using STRIP tool. Identifies the main types of medication errors and proposes the use of a systematic tool for reducing these.

DD: developmental disability; MI: mental illness; STRIP: Systematic Tool to Reduce Inappropriate Prescribing.

contexts for adherence, as set out in aforementioned framework documents (DHHS, 2017; HIQA, 2015; NFVB, 2009; NIHCE, 2014), are capacity, consent, refusal and covert administration.

Several other sources examined medication errors (Stupalski and Russell, 1999; Thurtle, 2000; Zaal et al., 2016). Two of these were descriptive studies while one piloted a tool to reduce such errors (Zaal et al., 2016). The reasons for medication errors were noted to include polypharmacy (Zaal et al., 2016), monitoring issues (e.g. serum levels of medications or blood pressure) (Zaal et al., 2016), systemic issues (e.g. systems to monitor and improve supply, administration and prevent medication errors) (Stupalski and Russell, 1999) and communication breakdown during the processes of medication administration (Thurtle, 2000). Two sources proposed the collation of medication error data for the purpose of reducing their occurrence (Stupalski and Russell, 1999; Thurtle, 2000) while Zaal et al. (2016) recommended that such data should be collected systematically. While the literature does not provide evidence per se regarding the use of medication data as an outcome metric, it is notable that one (Stupalski and Russell, 1999) does propose the use of medication error data for the purpose of staff performance evaluation.

Limitations

This review has sought to set out the current status of knowledge on medication management and administration in intellectual disability settings. The dearth of strong evidence suggests that there is a need for research to be conducted to support practice. In particular, the lack of controlled trials and the preponderance of qualitative (including single case) studies have made it difficult to assess risk of bias. While the authors were aware of the existence of local guidelines and policies within intellectual disability services, services contacted expressed concern that any assessment of these could have negative consequences for their use. Thus, it was not possible to use these for the purposes of the review. The absence overarching frameworks or models for self-administration by people with an intellectual disability in the literature may be resulting in reactionary responses at local levels which have not filtered down to academic papers. Alternatively, this may be a consequence of self-administration not being considered for people with an intellectual disability.

Finally, it is acknowledged that sources in languages other than English may have been missed, due to an English language limitation at full-text level.

Conclusion

This review has sought to systematically examine the literature in respect of medication management and medication administration in intellectual disability settings. Five review objectives were put to the literature, examining frameworks for medication management, seeking evidence for the effectiveness of collaborative practice, describing the key processes requiring guideline development, identifying assessment tools to support self-management and administration and considering potential metrics to evaluate efficacy of medication management.

It is clear that the evidence in respect of these questions is limited and of questionable quality. Thus, even national guideline documentation fails to demonstrate a strong evidence base and appears to be grounded in traditional knowing and practice. This review does not suggest that the guidelines and proposed practices are unfounded, but rather that the absence of strong evidence leaves them open to question and potential challenge. Despite this, the review did identify policies and one framework that could form the basis for developing approaches that can be researched. A similar situation was found in respect of collaboration practice, with propositions that such

collaboration should be instigated within medication management practice. While this seems intuitively to be the case, particularly in the light of the complex and numerous processes, the efficacy of such propositions needs to be tested. Many processes were found to be associated with medication management, medication administration and ancillary activities. These may provide direction for policy and framework developers as to what processes need to be enacted in their services. Again, there is no clear evidence to support their use and if they are included, they should be subjected to audit.

In the light of greater emphasis on self-determination and human rights (Government of Ireland, 2015; NIHCE, 2014; United Nations, 2006), there has been increased attention given to self-administration of medication, with studies exploring skill development and service policies assessing capacity of people with an intellectual disability to manage their own medications. The evidence regarding assessment tools for supporting self-medication is scant and lacking quality. There is a need for research in this regard, both examining the effectiveness of education and training, while also considering the place, and indeed *role*, of consent in relation to the medication regimen.

Finally, no clear metrics were identified which have been used to demonstrate the outcomes of medication management. The only concepts that could be useful relate to adherence/compliance and medication errors. These, however, take no account of the experience of the people who are taking the medications.

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Supplemental material

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