



Are patients ready for integrated person-centered care? A qualitative study of people with epilepsy in Ireland

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ABSTRACT

The National Clinical Programme for Epilepsy (NCPE) in Ireland aims to deliver a holistic model of integrated person-centered care (PCC) that addresses the full spectrum of biomedical and psychosocial needs of people with epilepsy (PwE). However, like all strategic plans, the model encompasses an inherent set of assumptions about the readiness of the environment to implement and sustain the actions required to realize its goals. In this study, through the lens of PwE, the Irish epilepsy care setting was explored to understand its capacity to adopt a new paradigm of integrated PCC. Focus groups and semi-structured one-to-one interviews were employed to capture the qualitative experiences of a sample of Irish PwE ($n = 27$) in the context of the care that they receive. Participants were from different regions of the country and were aged between 18 and 55 years with 1 to 42 years since diagnosis (YSD). Highlighting a gap between policy intent and action on the ground, findings suggest that patient readiness to adopt a new model of care cannot be assumed. Expectations, preferences, behaviors, and values of PwE may sustain the more traditional constructions of healthcare delivery rather than the integrated PCC goals of reform. These culturally constituted perceptions illustrate that PwE do not instinctively appreciate the goals of healthcare reform nor the different behavior expected from them within a reformed healthcare system. Recalibrating deep-rooted patient views is necessary to accomplish the aspirations of integrated PCC. Patient engagement emphasizing the meaningful role that they can play in shaping their healthcare services is vital.

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1. Introduction

Internationally, integrated person (patient)-centered care (PCC) is a key feature of current healthcare reform policies [1–13]. Integrated PCC involves a shift from a disease-centered approach that goes beyond simply addressing the individual's diagnosed condition and treatment to a more holistic view of their needs [14]. This includes integrating knowledge and practice within and across organizational, disciplinary, professional, and sectoral health system boundaries [15]. The aim of integrated PCC is to create a more interpersonal collaborative partnership between a person, their healthcare practitioners (HCPs), and care networks [13,16] and to recast care as respectful, holistic, empowering, cost efficient, and condition and lifetime spanning [6,8,10]. Potential benefits include improved access to care, personal health outcomes,

health literacy, patient and practitioner satisfaction, and overall cost containment [17].

Despite the unequivocal aspirations of integrated PCC, what it is in practice proves more difficult to describe [2,18–20]. Using a practice-based lens [14] to explore the point where theory meets the practicalities of placing the person at the center of care is fundamental to understanding the challenge of moving from statements of intent within policy to meaningful implementation of integrated PCC [15,19]. Like all strategic plans, healthcare policy encompasses an inherent set of assumptions about the readiness of the environment to implement and sustain the actions required to realize its goals [14,21,22]. Written policy in this case has a tendency to assume that stakeholders, such as, HCPs, patients, and families, have relevant expectations and understanding of what is expected of them, that necessary operating processes are in place or doable, and that the healthcare system has capacity to adapt its practices as needed to deliver on its stated aims. Furthermore, those invoking the integrated PCC vision may assume a level of homogeneity in both the patient and HCP population that is at odds with its

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main tenets of individuality [23–25]. Thus, without explicit identification and assessment of such assumptions, a realistic roadmap for attaining the strategic vision cannot be developed.

In this study, the readiness of the Irish epilepsy care ecosystem to realize the benefits of an integrated PCC model is explored from the viewpoint of people with epilepsy (PwE). Ongoing healthcare reforms have seen the Health Service Executive (HSE) in Ireland establish the National Clinical Programmes (NCP) (from 2010) to drive service improvements in specific clinical domains [26,27]. Within the NCP, epilepsy care was one of the areas targeted for reform [26]. To address the spectrum of on-going biomedical and psychosocial care needs, particularly for those with difficult to control or drug-resistant epilepsy [28,29], the National Clinical Programme for Epilepsy (NCPE) describes a model that aims to achieve holistic integrated PCC [15,27,30,31]. The core objectives of the model are to improve quality of and access to specialist care for PwE while at the same time delivering on value by, where possible, moving from hospital to community-based care. Although there is a consensus among various stakeholders regarding these objectives, their capacity to implement the changes required to realize the ambitions of the NCPE model is unclear.

Using a qualitative approach, this study aimed to understand how the outlooks, behaviors, and competencies of PwE as they interact with the health service concur or conflict with the aspirations of a new model of integrated person-centered epilepsy care [30–32]. This exploration of the emergent healthcare experience of PwE aimed to identify factors that may enable or impede practical implementation of the model. As such, it is an appraisal of policy assumptions, the ultimate goal of which is to inform a pathway to integrated PCC for PwE in Ireland.

2. Methods

2.1. Study design

This study is one part of a wider ethnographic exploration of the epilepsy care ecosystem in Ireland, which was conducted to understand both PwE and HCP experiences of integrated PCC in practice [15]. In this paper, using focus groups and interviews, the everyday practice and nature of transactions in epilepsy care was explored through the lens of those receiving care. The HCP perspective is reported in a previous manuscript [15].

2.2. Participant sample

Participants with a clinical diagnosis of epilepsy were recruited via Epilepsy Ireland (EI), the national nongovernmental organization (NGO) representing PwE or via one of four hospital-based epilepsy centers across Ireland. Twenty-seven individuals (17 female, 10 male) ranging in age from 18 to 55 years participated in the study (Table 1). Encompassing a range of 1 to 42 years since diagnosis (YSD), participants present a wide breadth of experience living with epilepsy and engaging with epilepsy services. At the time of the study (between December 2015 and March 2017), four participants had been seizure-

free for more than a year, and 25 participants were currently taking antiepileptic drugs (AEDs).

2.3. Data collection

To accommodate individual participant preferences regarding engaging in group discussions or individual conversations, a combination of focus groups and one-to-one interviews were employed in this study. This approach also allowed an enhanced richness to the collected data as issues emerging during interviews could be further explored or clarified during focus groups and vice versa.

2.3.1. Focus groups

Researchers conducted three focus groups with 16 participants in total, a male only group ($n = 5$), a female only group ($n = 7$), and a young adult focus group (3 females, 1 male). It was hoped that homogeneity of the groups would result in participants being comfortable with their peers and therefore likely to contribute to discussion. For example, PwE can have specific gender-based needs; therefore, by grouping according to gender, it was hoped that participants would feel safer during discussions. Furthermore, the focus groups were designed to consider women with epilepsy and needs of young adults who have recently transitioned from pediatric to adult services as these are among a range of specific groups identified in the NCPE model of care for particular attention [27]. Each focus group met twice to encourage increased engagement between participants and to allow the conversation to evolve. The focus groups were moderated by a postdoctoral researcher and took place in a meeting room on either university or hospital campus and lasted between 90 and 120 min.

2.3.2. Interviews

To capture information about the lived experience of PwE, one-to-one in-depth interviews were conducted. The interviews allowed participants to tell their stories in private without being concerned about expressing their views in the presence of others as may be the case during group discussions.

Thirteen participants (7 female, 6 male) engaged in semi-structured interviews with a postdoctoral researcher. The interviewer employed an open, conversational style to allow interviewees to emphasize experiences and learning of importance to them. Interviews lasted between 60 and 90 min and took place in either a university meeting room, hospital meeting room, or cafe. Two participants took part in both the interviews and focus groups.

During the interviews and focus groups, an iterative conversational approach was adopted to allow issues of importance to participants to emerge. To initiate conversation, researchers used open-ended opening questions to explore key PCC dimensions [13,16,17,32,33] (Table 2). As reported in a previous manuscript [15], both the focus groups and interviews were audio-recorded.

2.3.3. Research team

Data collection was conducted by three postdoctoral researchers: a female with a PhD in anthropology who is also a registered nurse, a male with a PhD in anthropology, and a male advanced nurse practitioner (ANP) with a PhD in health services research. A fourth postdoctoral researcher (male, PhD in qualitative sociology) assisted with data analysis.

2.4. Data analysis

To protect the confidentiality of each participant within the data collected, they were each assigned a unique study identifier. Recordings of interviews and focus groups were transcribed verbatim, deidentified, and imported into NVivo for data analysis management. All data were analyzed using Braun and Clarke's [34] six phases of thematic analysis. This included (i) becoming familiar with the data by reading and

Table 1
Participant details.

Summary participant overview				
Sex	Participation type	Years since diagnosis	Seizure-free (1 year +)	AEDs
Female (17)	Interview (13)	0–5 (8)	Yes (4)	Yes (25)
Male (10)	Focus Group (16)	6–10 (2)	No (23)	No (2)
	Both (2)	11–15 (7)		
		16–20 (5)		
		20+ (5)		

Table 2
PCC dimensions and opening questions.

Overview of interview and focus group topics	
PCC dimension	Opening question
Holistic healthcare	How are both your nonmedical concerns about the impact of epilepsy on your daily life and your medical needs such as use of antiepilepsy drugs addressed during your epilepsy care?
The expert and autonomous patient	How is your experience as a person living with epilepsy taken into consideration when you interact with the epilepsy care services?
Patient-clinician partnership	How would you describe your involvement in, or contribution to, discussions with healthcare providers such as doctors and nurses about your epilepsy care?
Dignity and respect	What way do you feel before during and after you attend the epilepsy clinic?
Use of information and communication technology	What is your experience of the use of computer technology such as electronic health records to aid your epilepsy care?

rereading the interview and focus group transcripts, (ii) coding and collating data systematically across the entire data set, (iii) organizing codes and collated data into potential thematic areas, (iv) reviewing and refining themes at the level of the coded data extracts and the entire data set, (v) ongoing analysis to finalize the specifics of each theme and the overall analysis story, and (vi) producing a final analysis report including selection of data excerpts. Throughout each phase of the data analytic process the research team reached consensus on generated themes and validated interpretations through ongoing discussions and continued reference back to the original raw dataset.

2.5. Ethical considerations

Ethical approval for the project was granted by the Research Ethics Committees of participating sites (universities and clinical sites). Informed written consent was obtained from all participants.

3. Results

The findings (results) suggest that patient readiness to participate in and adopt a new integrated PCC paradigm cannot be assumed. They show that when PwE enter the healthcare arena they can occupy a position or act in ways that are sometimes more aligned with a traditional model of healthcare delivery than with healthcare modernization goals. These ingrained practices of PwE shape their transactions with HCPs and the healthcare system as illustrated under 4 key overlapping rather than discrete themes that emerged from the data: (i) patient expectations, (ii) patient preferences, (iii) patient behaviours, and (iv) what patients value when engaging with the health service. In the findings, while excerpts are used to illustrate a distinct theme, some could be attributed to multiple themes. For example, a patient behavior might also be indicative of what that patient values. Similarly, patient expectations could be reflective of their preferences. The following excerpts are credited to interviewees using participant number 1–27 and M or F to indicate sex (e.g., 3M indicates participant number 3 who is male) whereas focus group extracts use a collective identifier of either FGM (male only), FGF (female only), or FGYA (young adult).

3.1. Patient expectations

The data revealed that when PwE engage with specialist services, they have understandable expectations of good interpersonal communication with their HCPs, that their agenda for care or services is appropriately addressed, that there is continuity and coordination of care over time, and that they will be seen by the most expert clinician. For

example, one PwE felt reasonably disillusioned by poor communication skills of the HCP:

“He barely looked up from his notes when I walked into the room... barely listened...I felt that a lot of the consultants...barely talked to me at all...their patient care was awful...lack of speaking to me, lack of addressing me”. (9F)

Meanwhile, another participant highlighted that during relatively time-limited clinical encounters patients want to feel their healthcare priorities are addressed:

“my condition is obviously connected with every aspect of my life... what else is there to talk about besides my condition ... It was just really awkward...me and my mum were like ‘we don’t need to know this,’ and then it was taking up lots of time...You’d think he was more concerned about himself than you...it was so unnecessary... it takes up time”. (FGYA)

Repeated clinical consultations are a feature of living with a chronic condition, such as, epilepsy; hence, PwE emphasize the importance of continuity of care over time.

“they’re looking like they’ve never met you before...but I’ve never met you before either. It’s always a different person...and if you have no consistency, to me it’s just like they look at my paperwork”. (5F)

Despite specialist epilepsy clinics being staffed by a mix of HCPs including consultant epileptologists, advanced (epilepsy) nurse practitioners (ANP), and nonconsultant hospital doctors (NCHDs) participants still privileged meeting with the consultant at clinical encounters. This serves to reinforce the assumption that the consultant is the expert and the key practitioner to drive their medical care.

“You really felt that the number one man should have been there to speak to you...not a registrar who you’ve never met”. (3M)

“I was waiting an hour...when I finally got to see someone it was [consultant’s] understudy that I didn’t know...had to ask my whole medical history...you have explained probably ten different times”. (13F)

3.2. Patient preferences

The findings illustrate that while PwE want the holistic care promulgated by integrated PCC policy, they simultaneously have a preference for care led by the expert consultant epileptologist within the hospital-based specialist setting. This dichotomy is somewhat contrary to policy objectives for holistic care that fundamentally require interconnections that go beyond the specialist epilepsy clinic frame of reference. Nonetheless, in this regard, one PwE noted that their consultant had been overly biomedically focused:

“my previous neurologists ... just kept on medicating, medicating, medicating until I said to him, ‘I can’t do this, I can’t talk [as a side-effect of AEDs]’”. (FGF)

Issues regarding information sharing and exchange between different HCPs involved in an individual’s care were considered by PwE participants to diminish a sense that holistic care is being delivered:

“I had to explain it all to them...they didn’t communicate at all with [the other hospital]”. (FGYA)

Despite their desire for holistic care, the data illustrate poor comprehension of integrated care policy aspirations on the part of PwE. The expression by multiple PwE participants of the primacy of the consultant

epileptologist, together with the belief that primary care cannot cater for PwE poses a barrier to better shared intersectoral epilepsy care services:

“Epilepsy is a bit strange. Your doctor [GP] can't deal with it, it has to be a specialist...I can't think why I would ever see the GP”. (15M)

“I personally think the hospital and the consultant is the primary thing”. (FGM)

“I don't want to be mean, but I don't want to see anybody who isn't a consultant”. (FGF)

3.3. Patient behaviors

As evidenced by the data, the experience of living with the condition and navigating the healthcare service can lead to some PwE becoming self-advocating experts over time, where they adopt active strategies for managing clinical encounters with HCPs and develop their own communication tactics in order to influence clinical decisions. These behaviors can coalesce with the supported self-management aims of integrated PCC policy [27,35], and affords the healthcare system an opportunity to encourage such behavior beyond episodic clinical encounters. The following extracts demonstrate that for some PwE it becomes important to prepare for the clinical consultation, to ensure a full picture of their condition is presented to the consultant:

“... (now) I do my homework when I go and meet the consultant and rather than verbally telling him I give him the piece of paper and it is not an enjoyable experience to be sitting there for five minutes when the consultant is reading, looking at his own notes and looking at what side effects ... if he had got my homework before we met, there would be a lot more dignity in face-to-face interaction rather than taking notes”. (FGM)

“I did a big Word document ... he takes the page, so I was sitting in silence, which was great, and he was reading, reading, reading. So, this is how you work, [I said] you want figures and times. That appointment was a bit of a turnaround then”. (FGF)

“You have to stand up to be heard or you will just sit there...and accept what they say is the right decision, when sometimes you feel that they are not, from your own previous history...you kind of take yourself more seriously...it was not just the hospital or the team, it was myself...I could take control myself by learning more about medication myself rather than being told”. (3M)

“I certainly feel an expert in my own knowledge...I know my epilepsy”. (FGF)

“You live inside your own head: you are the only person who does that, so you are an expert”. (FGF)

Other PwE admitted to being conflicted at consultations with regard to how much information to disclose about their condition:

“I don't think I was being honest enough with myself ...not all the time...you need some straightforward questions...to see if I'm being honest enough with the amount of seizures I've had... I wouldn't let on as to how bad it was...you just don't want it to be any worse.

You're afraid to change your medications...Maybe you want to be a good patient...it's hard to tell them that it hasn't worked”. (FGF)

Conversely some PwE became strong advocates for themselves and could use the consultations to assertively express their needs:

“So, I said an increase of medication would have more serious consequences than one more seizure, so I would wait...so I can make my own choices regarding my condition...I then didn't have to cope with adjusting to a higher dosage, that meant that I could continue in my studies and remain largely unaffected.... if I keep taking my medication and control my lifestyle aspects there is nothing really much to fear”. (12M)

3.4. What patients' value

It was clear from the data that the key factors that matter to PwE as they engage with the health service include being treated as a person not just a condition, that their expertise as a person living with epilepsy is respected and considered in clinical decision-making, and the development of a bond/relationship with their clinician. To enable these conditions, time is an extremely valued feature of their healthcare experience. Nonetheless, at times PwE do report feeling treated more like a medical case than as a person:

“... I think I had one MRI ... and they put you in and they pull you right back out again and they kick you out. I think that needs to be changed ... treat you like a person and not just about what is going on in your body”. (FGYA)

Correspondingly, another PwE explained how receiving the news that she should no longer be driving because of her condition exposed a gap between clinicians' biomedical focus and patients' quality of life concerns:

“... he was like, 'leave your car in the car park' ... I had kids to collect from school ... they literally rip the end out of your world when somebody tells you that ... what will I do with my kids? Do you tell them you're not going to horse riding or you're not going to football ... you're a mother ... I couldn't go to work, there is no bus to my job, what am I supposed to do ... my husband used to bring me to work ... and my parents-in-law, they would actually bring me home from work? I think that was the most upsetting part of anything”. (FGF)

Participants also spoke about how their experience of living with epilepsy is a key asset within the care process:

“(clinicians) are trained in science and medical information...they can't get that compassion with the patient”. (13F)

“they are not actually living with it: we are actually living with it”. (FGM)

“I am the person telling them, giving them the feedback of the impact it is having”. (FGM)

Other PwE felt that developing a familiar, professional, and empathetic relationship between themselves, and the HCP(s) was crucial to the quality of care:

“A bond... would help in so many ways...to develop a relationship rather than a name”. (FGM)

“I suppose I would like to feel comfortable when you are in the appointments...I think that is really important when you have got

epilepsy because it is something that is so complex and personal...it is sometimes hard to talk about such personal information especially with someone that you feel like you don't really know properly... you're not going to say extra bits that actually could really matter...". (FGYA)

Time is an extremely valued and contested feature of the PwE healthcare experience; participants valued time with the consultant epileptologist within specialist epilepsy centers. With limited time available, however, this intensifies the pressure to maximize the value of the consultation:

"they are so quick, and it is like they want to get you out the door... they don't really care how you feel". (FGYA)

"How are they going to help you without seeing them that long". (6M)

"There was a time when you couldn't ever see him for more than two minutes...Yesterday I actually had time and he was actually listening...The time they give you is basically nothing". (14F)

Nevertheless, some PwE seemed to understand time constraints as a constituent part of how the health service works and either accepted the situation as is or developed their own behaviors to work within this:

"I... generally think you are a name on a page and that is probably more to do with the fact the health service is so busy. I wouldn't really be blaming the doctors". (5F)

"you only have ten minutes with him once a year: you need to make it count". (FGF)

4. Discussion

In the context of healthcare reform in Ireland, this study examined the perspectives of PwE, their motivations, values, and expectations, and how they align with a recommended new model of integrated person-centered care [27]. The findings illustrate the complexity of healthcare when it is embodied by different individuals who are continuously adapting as they learn how to navigate a healthcare system, which is itself in a state of constant change. They demonstrate that the challenge of translating reform policies into practice involves undoing and resetting a range of entrenched formal and informal, conscious and unconscious, witting and unwitting, everyday interactions that shape healthcare services and the experience of those who interact with it [14].

While demonstrating that the expectations, preferences, behaviors, and values expressed by participating PwE are not particularly in conflict with the principles of integrated PCC, the findings simultaneously highlight a gap between policy intent and actions on the ground [19]. In other words, as yet there is a considerable difference between the ideal of integrated PCC expressed in the NCPe model [27] and the reality as experienced by PwE. Despite the holistic aspirations within policy, there is still an overwhelming, perhaps unconscious cultural conditioning, driven by the health system and HCPs to treat the diagnosed condition rather than the person. In some ways, the person may also be complicit in this, as their similarly culturally constituted lived experience has emphasized the primacy of the consultant epileptologist. Moreover, little about how the health system currently operates helps to enlighten PwE that their care can be shared between different HCPs and still meet their needs. For example, the data did not show evidence

that PwE fully understand the ANP-led expert epilepsy services now available across Ireland [30,31] or a role for GPs in epilepsy care. These findings imply a lack of healthcare system and patient readiness for integrated PCC rather than their disinterest in the concept.

Perspectives of the PwE captured in this study indicate that interdependent features of relationships, consistency, expertise, and time are most important to achieve high quality care. Not seeing a familiar HCP (particularly at consultant level) at consecutive encounters can be deemed a barrier to the development of an effective patient-clinician relationship, which considers the individual needs of PwE. Weak or underdeveloped communication skills on a consultant's part can lead to sensitive information being imparted in a somewhat thoughtless manner (e.g., advised not to drive because of seizures). Hurried clinical consultations can lead to a PwE feeling disrespected as a unique person with specific preferences, who wants a meaningful engagement with the clinician's medical *expertise*. These factors are at odds with the concept of PwE as "expert patients" with agency and experience who can guide the treatment of their condition in partnership with HCPs [36]. They highlight that "time for care is precious" [36] to allow for a focus on effective communication [24,37] between HCPs and patients, that reinforces the need for patients to be listened to, and where patient involvement in shared decision-making is supported and encouraged [38]. Enhanced communication could also play a part in recalibrating the patient outlook so that they adopt the role expected of them in policy.

In the journey from policy to practice, meaningful engagement between the healthcare system and patients is so far absent regarding: the development of new models of care [27]; new roles, such as, ANPs within healthcare delivery [30,31]; shifts away from hospital-centric models of care [35]; and strategies that will engender confidence in primary care and community-based services. Importantly, this engagement must support patients and emphasize the meaningful role that they can play in understanding and shaping their healthcare services, to ensure the highest quality of safe and timely care while avoiding an unintended shift from patient rights to obligations [38]. The engagement must be ongoing, and care itself conceived of as less a box of discrete techniques and more a suite of distributed capacities, in the hospital and beyond, that can be tailored to evolving individual needs.

4.1. Limitations

This paper is limited to reporting only on a study of the PwE perspective of the Irish healthcare system's readiness to adopt a new model of integrated PCC. However, the study is part of a wider program of research where the viewpoint of other stakeholders was explored. For example, in Byrne et al. [15], the HCP perspective on transforming policy into action is reported, and a further manuscript on intersectoral hospital-community collaboration is currently under review.

While many of the participant comments recorded during this study seem negative, it is important to note that these were more a criticism of the "tone" of the interactions that deliver epilepsy care than complaints about its quality. As previously reported [15], HCPs similarly agonize about how the relatively brief encounters they have with PwE may not appropriately meet their needs. This highlights the relevance of HCPs, patients and other stakeholders working together to collaboratively create the conditions to realize the benefits of an integrated person-centered model of care.

Although the study participants included PwE of different ages, YSD, seizure control, and came from different regions across Ireland, the sample does not fully represent the complex and varied needs of multiple diverse patient subgroups, such as, children with epilepsy, older people with epilepsy, AND those with intellectual disability and epilepsy [27]. In addition, as participants were recruited via specialist epilepsy services and EI, and the sample is limited to those who were willing to engage, information bias cannot be ruled out. Similarly, to mitigate the potential influence of the researchers on the study output, post

fieldwork team meetings were held to validate interpretation of the collected data and discuss emerging themes.

In future studies, more in-depth examination with stratified cohorts of well-defined PwE groups may highlight additional factors for consideration in terms of implementing a model of integrated PCC. Likewise, by recruiting participants from different settings (e.g., community or primary care), the voice of those who do not have easy access to specialist services may also enrich the understanding of the readiness of the health system for the integrated PCC paradigm.

5. Conclusion

Healthcare reform policy assumes ahistoric homogenous patients who want holistic care integrated across a range of boundaries addressing both their biomedical and psychosocial needs. However, in this study, PwE privilege the role of consultant epileptologists and view hospital-based specialist services as the place to receive expert care. At times, they also favor a biomedical model of care. These culturally constituted perceptions of PwE that have built up over a long period illustrate that patients do not automatically possess the knowledge of healthcare reform objectives [39] nor do they spontaneously understand that a reformed health system expects different behavior from them. Deep-rooted patient views must be recalibrated if the NCPE aspirations of integrated PCC are to be accomplished. However, it is not the responsibility of patients to learn and ensure success of reform initiatives. Rather the healthcare system must partner meaningfully with patients when designing, developing, and implementing new models of care.

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Declaration of competing interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

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