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Igniting intersectoral collaboration in chronic disease management: a participatory action research study on epilepsy care in Ireland

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ABSTRACT

Models of care developed to improve the lives of people with chronic diseases highlight integrated care as essential to meeting their needs and achieving person (patient)-centered care (PCC). Nevertheless, barriers to collaborative practice and siloed work environments persist. To set in motion some groundwork for intersectoral collaboration this study brought two expert groups of epilepsy care practitioners together to engage in participatory action research (PAR). The expert practitioner groups were hospital-based epilepsy specialist nurses (ESNs) and community-based resource officers (CROs). The PAR highlighted, that while the participants share a mutual interest in caring for people with epilepsy, underdeveloped CRO-ESN relationships, arising from unconscious bias and ambiguity can result in missed opportunities for optimal care coordination with consequent potential for unnecessary replication and waste of finite resources. However, through dialogue and critical self-reflection, a growing emotional connection between the disciplines evolved over the course of the PAR. This allowed for buds of collaboration to develop with CROs and ESNs working together to tackle some of the key barriers to their collaboration.

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Introduction

Globally, integrated care is a core concept within current healthcare reform agendas (Angus & Valentijn, 2018; Barry et al., 2017; Burke et al., 2018; Gauld, 2017; Ireland, 2017; Myers, Cleary, Johnson, & Schmied, 2015; Robinson, Varhol, Bell, Quirk, & Durrington, 2015; Willis et al., 2014; World Health Organisation, 2016). The aim of integrated care is the realization of cost-efficient coordinated care that puts the person (patient) at the center (Håkansson Eklund et al., 2018; Naldemirci et al., 2018) and envisions a breadth of care spanning basic health promotion all the way toward dignified end of life care (Angus & Valentijn, 2018; Burke et al., 2018; Ireland, 2017; Kodner & Spreeuwenberg, 2002; Sturmberg, O'Halloran, & Martin, 2012; Willis et al., 2014). Integrated care can be achieved through interdisciplinary or interprofessional collaboration within a single organization (intraorganisational) or across organizational boundaries and health-care sectors (interorganizational, intersectoral).

Integrated care is of particular relevance in the context of chronic disease (Karam, Brault, Van Durme, & Macq, 2018; Kodner & Spreeuwenberg, 2002; Norbye, 2016; Young et al., 2017), where an individual's healthcare needs can be ever changing requiring input at different times from a variety of health-care providers across various health-care settings. For example, episodes of exacerbation may necessitate timely access to in-patient or out-patient hospital-based specialist services whilst

at times where the condition is stable an individual's needs may be more psychosocial in nature and be addressed in community or primary care settings. Hence, within healthcare reform strategies (Lyngso, Godfredsen, & Frolich, 2016; Winters, Magalhaes, Kinsella, & Kothari, 2016) the requirement for intersectoral or interorganizational collaboration is identified as fundamental to meeting people's ongoing needs and achieving holistic integrated care (Auschra, 2018; Kodner & Spreeuwenberg, 2002). Nonetheless, "collaboration is neither obvious nor easy" and is "fraught with duality and underlying assumptions" (Kaats & Opheij, 2014, p. 35). Barriers include a lack of knowledge by one or more parties about other parties and their role in healthcare provision (Auschra, 2018), and a dearth of methods to enable shared work and communication across sectors (Sohi, Champagne, & Shidler, 2015). As it is mostly not possible to enforce collaboration, Kaats and Opheij (2014) note the importance of stimulating potential partners to collaborate.

Background

In Ireland, as part of the national healthcare reform agenda, the Health Service Executive (HSE) established the National Clinical Programmes (NCP) in 2010 to drive clinical service improvements and realize the triple aim of improved patient care, improved access and better use of resources (Darker,

Nicolson, Carroll, & Barry, 2018). The NCP initiative includes a number of acute and chronic health-care domains bringing together clinical and management health-care professionals to design strategies for standardized models of integrated person-centered care (PCC). Epilepsy is one of the chronic care domains targeted by the NCP for reform (Health Service Executive, 2016; Higgins et al., 2018, 2018).

Characterized by recurring unprovoked seizures, epilepsy can have a significant effect on the quality of life of people with epilepsy (PwE) (Laxer et al., 2014). Approximately two-thirds of PwE can have seizures stabilized with antiepileptic drugs (AEDs). However, those with difficult to control or drug-resistant epilepsy have ongoing chronic care needs with increased likelihood of comorbidities, cognitive effects, reduced quality of life, social stigmatization, decreased life expectancy and increased mortality risk (Fisher et al., 2014; Laxer et al., 2014). Consequently, in the National Clinical Programme for Epilepsy (NCPE) model of care, the life-impacting nature of the condition is recognized. The NCPE acknowledges the need for holistic intersectoral service provision that spans a spectrum of medical and psychosocial care, enabling health-care providers to work together across boundaries and sectors to deliver safe and effective PCC (Health Service Executive, 2016; Higgins et al., 2018, 2018). Yet, this does not mean that the necessary partnerships will be established or, if they are, that they will run smoothly (Kaats & Opheij, 2014).

The study presented in this paper was conducted to kindle intersectoral collaboration in the epilepsy care domain in Ireland. It brings together a key expert group from each of two distinct sectors, namely hospital-based and community settings, to consider opportunities for and challenges to a meaningful collaborative healthcare partnership that can result in driving improvements in quality, safety and efficiency, patient satisfaction and better access to care (Auschra, 2018; Burke et al., 2018; Gauld, 2017; Holt, Rod, Waldorff, & Tjørnhøj-Thomsen, 2018; Ireland, 2017; Rämgård, Blomqvist, & Petersson, 2015; Willis et al., 2014). This study was one part of a wider ethnographic exploration on the readiness of the Irish epilepsy care ecosystem to realize the benefits of a person-centered model of care (Byrne et al., 2019).

Methods

Research design

The study employed a contextual and practice-oriented participatory action research (PAR) approach. In PAR, researchers work collaboratively and reflexively with practitioners and stakeholders with a goal of creating new knowledge or new practice (Bennett et al., 2016; Cordeiro & Soares, 2018; Holter & Schwartz-Barcott, 1993; Huang, 2010). Consequently, PAR has an orientation toward recalibrating organizational culture and “empowering stakeholders” (Huang, 2010, p. 93). PAR is cyclical in nature and includes interactional nonlinear looking, thinking and acting (see Figure 1), to create new understanding or ways of knowing (Hegney & Francis, 2015; Rämgård et al., 2015). As a rudimentary explanation, looking cycles allow definition and clarification of problems; thinking involves further work on interpreting and analyzing the

problem; acting involves devising ways to resolve the problems and move forward (Rämgård et al., 2015).

Study setting

This PAR study arose from a wider ethnographic exploration of the epilepsy care ecology in Ireland where interviews, focus groups, workshops, and observations were used to understand health-care providers, and people with epilepsy’s experiences of PCC and integrated care in practice (Byrne et al., 2019). Throughout this wider exploration, a lack of well-functioning intersectoral collaboration between hospital-based services and the community was revealed. A specific example was in the underdeveloped intersectoral relationship between hospital-based epilepsy specialist nurses (ESN) and epilepsy community resource officers (CRO) which was deemed an inhibitor to effective PCC. To address this, a representative sample of experienced ESNs and CROs were enrolled to the PAR study to provide and exchange perspectives on epilepsy care in Ireland. They each had been involved in the prior ethnographic research and had expressed interest in advancing collaborative practice.

Participants

Six ESNs who are employees of the Irish health service took part. Four of these are employed in different hospital-based epilepsy centers across Ireland, another works in both a hospital-based and community setting, and the sixth works in a residential care setting for people with intellectual disability. Four CROs employed in different regions of the country (rural and urban) by Epilepsy Ireland (EI), a charitable non-government organization which is the national advocacy service for people with epilepsy, also took part. All the CRO and ESN participants were female, and collectively had many years’ experience working in the epilepsy care domain (Table 1).

Whilst the professions differ in terms of education, training and practice, they serve a complementary function with the ESN supporting more biomedical clinically oriented needs and the CRO role supporting everyday experience and psychosocial needs of people living with epilepsy. ESNs are skilled nurses who have undertaken advanced training and

Table 1. Participant characteristics for PAR.

Profession	Gender	Years of Practice	Work Setting	Employer	Region
ESN	Female	16	Community	Epilepsy Ireland	Region 1
ESN	Female	10	Adult Intellectual Disability Services	HSE	Region 1
ESN	Female	6	Hospital	HSE	Region 2
ESN	Female	6	Hospital	HSE	Region 3
ESN	Female	3	Hospital	HSE	Region 4
ESN	Female	4	Hospital	HSE	Region 5
CRO	Female	5	Community	Epilepsy Ireland	Region 2
CRO	Female	17	Community	Epilepsy Ireland	Region 3
CRO	Female	2	Community	Epilepsy Ireland	Region 3
CRO	Female	12	Community	Epilepsy Ireland	Region 4
Researcher	Male	12	Academic	RCSI	Region 1

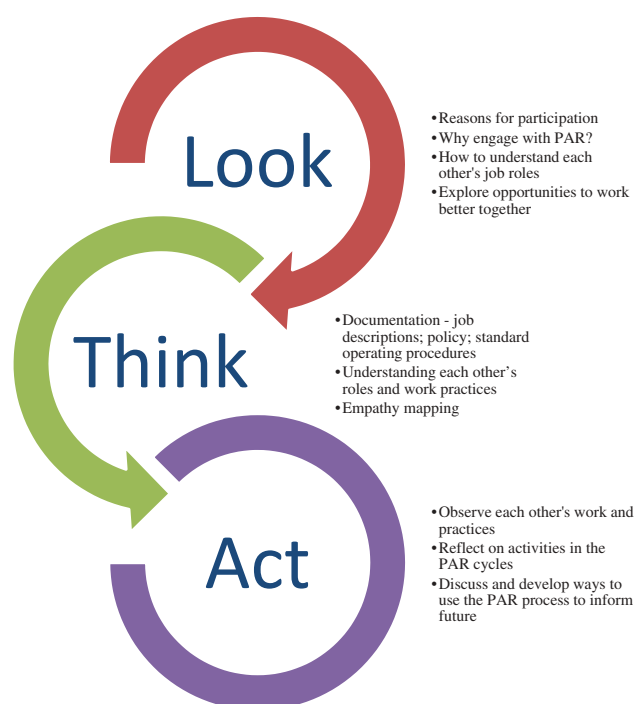


Figure 1. PAR discussion topics and progression over time through looking, thinking and acting.

education in clinical epilepsy care. Their role spans the management of a range of in-patient, out-patient and outreach epilepsy services; coordination of care; and “providing information, education, and support to people with epilepsy and their families” (Higgins et al., 2018, p. 86). CROs are trained and educated community health professionals. Their role involves offering information and advocacy to people with epilepsy and their families in the community setting, delivering a myriad of services including “one-to-one support, self-management training programmes, online support groups, regional support groups, talks and seminars, training to health-care professionals, and epilepsy awareness talks in schools” (Epilepsy Ireland, 2017).

Latest figures available from the HSE indicate that there are 16.5 ESNs currently employed in different centers across the country (Health Service Executive, 2017). Epilepsy Ireland reports that there are 11 CROs employed throughout Ireland presently (Epilepsy Ireland, 2018). Therefore, for each group, our representative sample included 36% of people currently working in these roles.

Researcher

In PAR the researcher is seen to be participant as well as a facilitator, likewise the participants are seen as co-researchers (Hegney & Francis, 2015; Rämgård et al., 2015). In this study, a post-doctoral research fellow with a background in advance nursing practice and expertise in health services qualitative research facilitated the PAR process. The researcher focused on creating a sustained safe research environment for the participants aimed at developing a shared understanding of the PAR objectives, to challenge emerging ideas and interpretations, and

to foster a culture of critical self-reflection and transparency as the process evolved.

Data collection and analysis

The purpose of the PAR was to facilitate the ESNs and CROs in gaining a greater understanding and appreciation of each other's professions, work practices, and circumstances. Exploring the impact of their own and each other's roles, and the culture within their professions and care settings, the PAR group would identify opportunities for mutuality. Later they would devise and potentially implement changes within services to enhance intersectoral collaboration and consequently quality of patient care.

Starting in December 2016, the PAR group met six times, at intervals of four to 6 weeks, over a ten-month period. At the outset, participants were advised that the process would involve a series of meetings that each would last approximately 4 h, and successive meetings would build on the previous encounter with the overarching focus of *'Finding common ground in epilepsy care'*. To consider this, participants reflected on the following questions as the PAR series progressed:

- How do CROs and ESNs, respectively, describe the purpose of epilepsy care and services?
- How well do these two perspectives converge?
- Does this convergence uncover potential for greater collaboration that puts the person with epilepsy at the center?

The date, time and location of each PAR meeting were scheduled by the researcher in consultation with the participants.

The schedule and interval between meetings allowed participants to reflect upon the previous, and prepare agreed work for the next, meeting. To accommodate participants' travel arrangements, meetings started at 10am, finished at 3 pm and included refreshment breaks. They were held at various regional locations in appropriate secure settings (e.g., hotel conference room; public education buildings). Travel costs to meetings and refreshments were provided.

All PAR meetings were audio-recorded and transcribed verbatim. The de-identified transcriptions were imported into NVivo which was used for data coding and analysis purposes. To ensure the analysis remained close to the experiences of those involved, no specific frameworks were used at the initial coding stage. Inductive thematic analysis (Braun & Clarke, 2006) was undertaken on the data whilst ensuring constant recourse to the experience and reflections of ESNs and CROs.

Ethical considerations

Ethical approval for the project was granted by the Research Ethics Committees of participating sites: 23rd November 2015, Ethics (Medical Research) Committee, Beaumont Hospital, REC Ref 15/87; 12th November 2015, Galway University Hospital Clinical Research Ethics Committee, Ref C.A. 1380; 24th November 2015, SJH/AMNCH Research Ethics Committee, REC Ref 2015-11; 19th April 2016, Clinical Research Ethics Committee, Cork Teaching Hospitals, Ref ECM (jj) 4 12/04/16. Informed written consent was obtained from individual CROs and ESNs prior to becoming PAR participants.

Findings

While facilitated by the researcher, the evolution of the PAR process was wholly led by the CROs and ESNs. At least eight participants were present at each meeting. Phases of the PAR developed organically in line with the groups growing appetite to know and learn more. The topics discussed in each meeting and how these progressed over time are illustrated in [Figure 1](#). Building on dialogue that took place over the initial stages of the PAR engagement, the participants progressed to sharing and jointly reviewing documents relevant to their respective roles. These included ESN and CRO job descriptions, NCPE model of care and associated standard operating procedures. This subsequently led to an empathy mapping exercise to afford greater insight into each other's lifeworld (Zuber & Moody, 2018). Individual ESNs and CROs then arranged observational shadowing sessions to experience the other professions' everyday work practices. Learning from the shadowing was reflected on in a subsequent meeting.

Although the study followed a chronological order, the findings are presented as a set of emergent themes and evolving commitment to collaborative action that traversed the series of PAR events. The themes which illustrate both the challenges to and opportunities for intersectoral collaboration are (i) Underdeveloped relationships; (ii) Fragmentation of

care; (iii) Unconscious bias and ambiguity (iv) Learning about and with each other; (v) The power of empathy.

Underdeveloped relationships

Although a working relationship between the hospital-based ESNs and community-based CROs was in existence prior to the PAR, participants acknowledged that it was not sufficiently developed. Therefore, the benefits for PwE that could be achieved through more meaningful collaboration were not being realized.

I think essentially we are all doing the same thing, but we are just not doing it together. There (is) just a lot of gaps. [ESN]

The underdeveloped relationship was further illustrated in a conversation about the seemingly arbitrary process for patient referrals from ESNs to CROs:

... I (CRO) just find very little referrals from the hospital and that is not a reflection on ... anyone or anything, it is just how it is ... it would be great to see more people (with epilepsy) ... who may need help with issues in college or getting employment ... [CRO]

ESNs similarly recognized this deficit in coordinating care across the hospital-community boundary:

No to be honest I forget (about referring patients to the CRO) ... Sometimes they (patient) say they will think about it (contacting the CRO) so I always print off the (CRO telephone) number and give it to them ... and (say) go in in your own time. So, it isn't (a standardised process) ... I suppose why we don't get the number of referrals, I am still giving them your (CRO) number to contact you and encourage them. [ESN]

Nevertheless, from the outset of the PAR engagement, the participants demonstrated a shared ambition and an aspiration to turn learning with and about each other into actionable quality improvements in epilepsy care.

... I suppose I would like to find out how we can deliver better services for people ... [ESN]

... what is nice today is being able to meet some of the girls that I wouldn't have met before, the nurses in hospitals ... my hope for these meetings is that what does come out is thinking of the person and not thinking what we think the person wants [CRO]

... Anything I can learn from others to help improve our (epilepsy) service ... [ESN]

Fragmentation of care

Through the PAR dialogue, it became apparent that structures and processes were lacking regarding collaborative monitoring and review of the existing (albeit underdeveloped) CRO-ESN alliance, and the impact on patient care. There is no opportunity to jointly assess what does and does not work well, and how things can be improved through enhanced complementarity. An example is an expressed frustration with limitations around information sharing and exchange in the patient referral process.

... I think to refer somebody (patient) to Epilepsy Ireland and not tell them (CRO) that something is complicated ... where there are lots of issues going on ... I think it is very unfair ... [ESN]

... we (CROs) don't have access to medical notes. So, what we get is a referral comes to us ... we ring a person (with epilepsy) with no knowledge of what is going on ... [CRO]

Similarly, a deficit in communication with consequent lack of understanding of respective roles and further fragmentation of patient care was articulated. This emerged through discussions about the need for CROs and ESNs to meet more regularly to discuss patient cases, and to experience how patient needs are heard and interpreted differently by different people.

... the first thing I wrote was CRO and ESN meetings to discuss cases. That is the first thing I wrote down this morning ... because to me we don't communicate enough ... from the very outset, when I came into my role first it was like Epilepsy Ireland ... why would you be referring to them ... And I know that that is not true, and I know how hard the girls (CROs) work. [ESN]

... (a young man with epilepsy) was told by a doctor not to play rugby anymore because of the implications of him now having epilepsy. And his mood had deteriorated, so all the medical people were blaming the mood deterioration on the medication. And I was thinking, hang on a second if this guy played rugby, loved playing rugby, captained teams playing in finals and all of a sudden stopped playing rugby, are we missing what is actually going on here. So I think people in the community hear one thing and I think people in hospital hear another [CRO]

Through this dialogue, the PAR team recognized that the current referral process, although designed to protect patient privacy, had not undergone any review since its inception. While they identified this as an opportunity for a collaborative quality improvement, they similarly believed they should not rush to a solution before more fully understanding the problem. An agreed action was to continue to learn more about each other and their lived experience of caring for people with epilepsy.

Before we go to a referral process can I just say I think a big problem is the communication. So, before we start any of these tasks or how we can go about fixing things or integrating things or knitting together the services I think we should be communicating more effectively with each other. That is the first thing we should do. [ESN]

Unconscious bias and ambiguity

Unconscious bias occurs when individuals or groups hold beliefs or prejudices (either positive or negative) about another individual or group (Glicksman, 2016). Such biases which are deep-seated, and often transpire involuntarily, serve to influence people's behavior. For example, a reluctance of hospital-based clinicians to refer patients to primary or community care may arise if they believe that the required competence and standard of care will not be available to patients in those settings.

... there is a barrier there and I think it is probably historic ... you have different clinicians with different views of CROs ... and the authority comes from the clinician (doctor) down ... as good as the nurses are, we (ESNs) are trying to break down those barriers, it is hard to change your mind-set ... but you have to see both sides ... [ESN]

Likewise, a perception regarding territorial protection may also give rise to hesitation in progressing intersectoral cooperation.

I (CRO) would say they (ESNs) are concerned about the duplication of the CRO role and the epilepsy nurse specialist role and I think that would be a major concern of theirs, it would maybe affect their behaviour in ... work that could be referred ... [CRO]

Nevertheless, the PAR engagement also revealed a seemingly contradictory ESN-CRO interdependence arising from limited access to allied health-care services.

... there is a seven-month waiting list for neuropsychology in our hospital ... very selective patients get in ... there has to be something a bit different about you, like we have one guy who is gifted ... he got in ... so it is hit and miss ... your average person doesn't get in and they need to get in ... [ESN]

The examples here from the excerpts suggest how a scarcity of neuropsychology services results in ESNs referring patients to CROs for psychosocial support as a stopgap.

... the volume is phenomenal, and we have no way of treating them (patients) so they keep coming back and keep coming back. You (ESNs) are sending them to the community ... you are getting some degree of counselling (for the patient) but it is not a specialist service ... [CRO]

Without a proper collaborative structure, no forum existed for CROs and ESNs to interrogate assumptions about and expectations of each other's roles. The PAR group identified a need to more fully appreciate the potential for improved patient care through collaborative action.

... for the benefit of the person with epilepsy CROs must understand what the nurse's (ESN) role is and the nurse must understand the role of the CRO ... thinking of things like this can benefit each other's role [ESN].

Learning about and with each other

The PAR group reflected on how the separate care settings (hospital-based and community) might enhance or inhibit patient participation and the quality and outcome of care.

... going to the hospital is anxiety provoking and maybe from previous experience if you got news you didn't want to hear. And also, in a hospital you receive the information, this is what you are told to do, which is not a two-way education ... if it was in a community setting, a non-hospital environment (maybe) people would feel that they had more autonomy or that it was more of an exchange ... [CRO].

The care environment factor was also considered in the context of delivering patient education. The participating ESNs had recently commenced hospital-based patient group education sessions. As this is something the CROs have long experience of providing in the community, this presented opportunity for learning from each other as to how their respective patient education endeavors could be mutually beneficial and further enhance PCC. The following excerpts from a detailed discussion on this topic illustrate the missed opportunity for ESN-CRO collaboration.

... they (educational sessions ... are having low numbers and (we) cannot figure this out ... I (ESN) think that one person (patient)

might dominate a lot of it so it meant that other people were going along and listening to somebody else's story which they weren't getting value from ... so while I think they (ESNs) felt that there was a need for it (educational sessions) they couldn't really tell whether people (patients) were happy with what they were taking away ... [ESN]

... support groups are a difficult thing to run ... and yes there are individuals who dominate it but we have to have very strong facilitation skills to deal with that in a nice way ... somebody who is very depressed or very low can bring the whole tone down and you have seven people leaving worse than when they came in ... [CRO]

... I (ESN) am wondering then (about) group education events ... how is it like or different to what CROs might do in the community with a group of people. And if it is the same for example, does that mean there is some sort of replication (of work) or if it is different does it mean it is complementary? ... [ESN]

Referring to the Support and Training in Epilepsy Self-Management (STEPS) programme, a CRO shared their approach to developing effective patient education.

... in our STEPS programme (delivered over 12 weeks) we (CROs) start from a factual base about epilepsy and what it is ... so it is totally non-threatening ... as the programme progresses and you get into stress, anxiety, negative thinking and negative thoughts and it becomes deeper ... we ask you (patient) to commit to everything, to the 12 modules, so you build up a rapport with your group and they build up a confidence level to speak up about how it affected them ... they are actually fabulous to be part of ... [CRO]

This led to an ESN attending a CRO delivered community education session to see things in action and subsequently sharing their reflections on it with the PAR group:

... the (educational) session was welcoming, relaxed and afforded all participants to contribute equally ... the presenter (CRO) was empathetic, professional, and knowledgeable in the subject area and had excellent communication skills ... she (CRO) was clear, concise and the presentation was very simple explaining the subject area in very simple terms ... the group session allowed the parents to share their story ... [ESN]

The power of empathy

As the PAR process progressed, evidence of a deepening emotional connection between participants emerged as ESNs and CROs identified more with each other and appreciated more fully what they experience in their delivery of care to people with epilepsy. They each articulated what they understand regarding the scope of the other role, recognizing the demanding nature of the job, the professionalism entailed therein, the training involved, the self-development undertaken, and so on.

... making patients aware that the (ESNs) can actually do the consultation ... they (patients) don't realise that the epilepsy specialist nurse is actually as qualified ... it is our culture ... we perceive that the consultant is the be all and end all ... we (CROs) need to tell them (patients) that they are not just ringing for the nurse who will talk to the doctor, they are ringing to say that the nurse might actually change the medications themselves ... (CRO speaking about ESN role)

... hard working, demands, almost a fight to prove ... be it for funding or be it for recognition or be it a fight to achieve targets,

that constant need to meet targets, achieve things, pressure ... meeting the individual needs ... but it is a little bit different when it moves ... the day moves, the hour, the situation, the environment, the person. I suppose for me (ESN) I have the security of being in the hospital, I know where A, B and C is but if I was put in their [CROs] shoes and just sent off for a week I don't know how I would survive ... [ESN speaking about CRO role]

The participants empathized with each other in terms of their work environment, for example, ESNs work in a hospital-based setting with colleagues near at hand, whereas the CRO role covers a wide geographical spread and can sometimes appear a little isolated.

I (ESN) wonder do they (CROs) see a secure environment. I had a few incidents recently ... like I think their door is pretty much open and people can walk in, even angry people so I think they are probably quite vulnerable actually whereas in the hospital ... there is security ... [ESN]

A theme common to the CROs and ESNs empathizing about each other's role was how their roles are appraised within their respective organizations. The participants felt that this does not necessarily capture or appreciate the nuance of care for individual patients.

Everything these days seems to be measured in terms of how many people walk through the door but there is no actual measurement of the quality of the work that is to be done. That is across the board, that is just a general observation ... community, medical, everything, it is all about how many people come in but not actually what are these people getting out of the service. And there is a difference between the amount of people walking in the door and ten people walking out after getting a good quality of service. But there is no way of measuring that and I think that is a big failure ... [CRO]

To further develop their embryonic emotional connection, ESNs and CROs took action and engaged in shadowing exercises to observe each other in their typical work environment and practices. These shadowing exercises involved ESNs and CROs spending a working-day with each other. Reflections were shared with the PAR group in a subsequent discussion.

CROs on ESNs

... multi-tasking ... not just an office job ... they can be called to wards, AMU (Acute Medical Unit), ED (Emergency Department), maternity cases ... they (ESNs) must be patient, flexible, have good organisational and clinical skills, knowledge of epilepsy and medications ... people skills, empathy and understanding ... [CRO]

... the clinical environment is very busy and it's a very busy job ... the ESN is called upon by many and there is lots of administrative work ... [CRO]

... both of us build relationships to improve the quality of care for people with epilepsy either in the hospital or community ... linking with other disciplines ... some of the similarities include office administration, telephone line support, educating patients even seizure management but in different environments ... [CRO].

ESNs on CROs

As an ESN I thought I was holistic in my approach to patients and their families however what I observed ... makes me question this and question if the approach I take is still too complex and

medically orientated not facilitating sufficiently the feelings of the PWE ... [ESN]"

... I (ESN) observed that (CRO) and (administrator) worked very well together and work in partnership ... I listened to her (CRO) (telephone) calls, this was very informative ... I identified that listening skills, clear communication, voice pitch and tone are vital for the (CRO) role. The CROs deal with all age groups, I just deal with over 16's ... [ESN]

... The shadowing task has been invaluable in building a relationship between the CRO and ESN. I will be referring and recommending the services of Epilepsy Ireland and the CRO considerably more in the future. They are a valuable asset to the epilepsy services in Ireland ... [ESN].

Discussion

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 (Holt et al., 2018; Liberati, Gorli, & Scaratti, 2016; Naldemirci et al., 2017; Young et al., 2017). For example, an integrated care aspiration may assume that the workforce clearly understands what is expected of it, 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 the stated strategic aims. However, without explicit identification and assessment of such assumptions, a realistic roadmap for attaining the strategic vision cannot be developed.

This PAR study brought together representatives from community-based (CROs) and hospital-based (ESNs) epilepsy care sectors to explore their readiness for collaborative practice to drive integrated care and to simultaneously catalyze its development. As evidenced by the findings, while CROs and ESNs share mutual interest in caring for people with epilepsy, the conditions for meaningful collaborative practice were not in place at the outset of the study. Underdeveloped CRO-ESN relationships, arising from uncertainties, biases, and misunderstandings gave rise to missed opportunities for optimal intersectoral coordination of patient care with consequent potential for unnecessary replication and waste of finite resources. However, as participants recounted and shared experiences of caring for people with epilepsy, a growing emotional connection and desire to learn more together developed between the CROs and ESNs as the study evolved. Additionally, empathy mapping and observational shadowing embedded in the PAR process helped ESNs and CROs to suspend preconceptions about each other's roles and open their minds to the potential of improving PCC for epilepsy care through collaborative practice. Building emotional connections through this work helps practitioners to develop a PCC culture (Bokhour et al., 2018).

The PAR process provided a safe space for the CROs and ESNs to engage in constructive dialogue and critical self-reflection from which they could gain a greater understanding of their shared ambition, each other's roles, and to consider ways in which they could work better together. Everyone involved was open and willing to share their opinions and experiences truthfully throughout. Such reflective dialogue aids the positive

transfer of knowledge and is integral to creating the conditions for effective collaboration between professions working in health systems (Huzzard, Hellström, & Lifvergren, 2018; Rämgård et al., 2015). To allow the dialogue to mature, for trust to develop, and for a deep understanding about the need for intersectoral collaboration to evolve, the PAR process involved a series of six events conducted at intervals over 10 months. Taking this time, encouraged participants to engage in "design thinking" (Zuber & Moody, 2018) and to avoid premature development of solutions before fully appreciating the coexisting CRO and ESN realities. Kaats and Opheij (2014) note that where partnerships rush to set up a joint venture without meaningful dialogue they almost without exception hit a deadlock.

Buds of ESN-CRO collaboration have emerged as a residue of this PAR study. For example, conversations about the sometimes anxiety-provoking nature of the hospital-based clinical environment for PwE together with an identified need for better communication between the ESNs and CROs are leading to recalibrations of practice in response. Some of the CROs and ESNs who work in the same geographical region have begun delivering joint information and education sessions for PwE in a local community setting. A rethinking of the referral process from hospital-based ESN to the CRO has also been instigated. Furthermore, the participants have become ambassadors for intersectoral collaboration by sharing their PAR experience at local team meetings, and dissemination at relevant (epilepsy and nursing) national conferences. These activities are a legacy of the PAR work and illustrate how the process has upskilled practitioners in a way that can immediately impact on quality and safety of patient care.

Limitations

This PAR was limited to a study of the CRO and ESN roles and their interprofessional relationship. The need to focus specifically on the CRO-ESN relationship arose from a prior ethnographic examination which identified limited intersectoral collaboration between hospital and the community-based epilepsy services. Strengthening the ESN-CRO partnership was seen as core to driving hospital-community intersectoral epilepsy care. However, we acknowledge that creating the appropriate conditions for effective collaboration between actors in the healthcare system requires "getting the whole system in the room" to stimulate the necessary dialogue and develop a systems mind-set (Huzzard et al., 2018). This is essential to avoid privileging clinician-centric perspective and to ensuring that other stakeholder-critical issues and experiences are not missed. Consequently, future PAR initiatives should include *inter alia* the voices of the patient, family members and carers, allied health professionals, doctors, primary care practitioners, health-care managers and policymakers.

Although this study involved a seemingly small sample size, the participants represent 36% of all CROs and ESNs currently employed in the epilepsy care ecosystem in Ireland. Consequently, they represent a significant opportunity to become influencers of their coworkers and to build on the intersectoral collaboration foundations laid

down by the PAR process. While the context of the study is epilepsy care in Ireland, the approach and learning are transferrable to similarly complex chronic conditions in other jurisdictions.

Concluding comments

If health-care provider commitment was sufficient for achieving meaningful integrated care, it would be widespread in the healthcare system. Throughout this study, the respective dedication of ESNs and CROs to delivering and continuously improving high-quality PCC for PwE was evident. However, before engaging in the PAR process much of their efforts lacked a deep understanding of the breadth and complexity of each other's roles. While commitment is necessary, it is not sufficient for achieving intersectoral collaboration.

Concepts such as integrated care and patient-centeredness are key aspirations of current international and national healthcare reform policy (Health Service Executive, 2016; Ireland, 2017; World Health Organisation [WHO], 2016). However, this does not mean they will automatically translate into frontline health service practice. Advancing integrated care requires meaningful attempts to nurture and develop relationships between diverse roles and sectors to participate in intersectoral collaboration. Such a project does not tend to organically develop from a top-down structure perspective. Rather, a more considered approach to achieving this needs to be instigated from the bottom up.

The contention of this article is that reforming health systems toward integrated care requires incremental steps and staff engagement in innovation to be successful (Bokhour et al., 2018; Liberati et al., 2016; Naldemirci et al., 2017). Investment in interventions such as the PAR study presented here is required to stimulate the development of integrated health-care systems.

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Declaration of 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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