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**Terms of Engagement for Working with Patients in a Person-Centred Partnership: A Secondary Analysis of Qualitative Data.**

Westlake, Debra; Lloyd, Helen

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## **Main Text File**

### **Title: Terms of Engagement for Working with Patients in a Person-Centred Partnership: A Secondary Analysis of Qualitative Data.**

#### **Abstract**

Evidence is emerging of the potential of person-centred approaches to create partnerships between professionals and patients, whilst also containing healthcare costs. This is important for enhancing outcomes in individuals with complex needs, who consistently report poor experiences with care. The shift towards person-centred care (PCC) is, however, a radical departure from the norm, with increased expectations of both professional and patient. While there have been studies on the ways in which health care professionals can modify practice to enhance PCC, not all patients welcome changes to their care delivery or understand the aim of the new approach. Without engagement and understanding from the patient, a PCC approach will fail to initiate. Few studies explore how, why and in what circumstances patients become more involved in their care and what professionals can do to enhance participation. We conducted a secondary analysis of qualitative data to examine this issue. Data were collected between 2014-2018 from primary-care based PCC projects across the Southwest of England. Supported by people with experience (practitioners and those receiving treatment), theory building workshops developed an explanatory framework that identified contextual factors and mechanisms likely to contribute to effective engagement. Our results show that engagement in a care partnership is achieved through trust and a patient's sense of candidacy. Shared understanding of purpose, clarity of expectations and power sharing were found to facilitate trusted relationships between professional and patient and encourage candidacy. Only then is it possible to develop goals that are meaningful to the patient. Our theory of engagement applies to professionals and patients alike, but places the initial burden of responsibility on those who hold the most power: the professional and the system. This theory has the potential to explain patient engagement in PCC and a range of other service interventions, treatments and intervention research.

**Keywords:** patient engagement, patient-centered care, patient-focused care, qualitative evaluation, realist theory, trust

### **What is known about this topic**

- Person-centredness is promoted in the UK to encourage patient participation in healthcare. Eliciting a patient's narrative and developing a care partnership are key to this approach.
- Evidence is building that PCC interventions can provide cost stability in healthcare systems.
- Little is known about how to enable patients and professionals to engage in this new way of working.

### **What this paper adds**

- A model describing conditions for active engagement between patients and professionals in pursuit of PCC.
- A sense of candidacy and trust are critical and are underpinned by mechanisms that develop shared understandings, clear expectations and power sharing.
- Skills training for professionals and organisations attempting to implement PCC should be focussed on these areas.

## **1. Introduction**

Person centredness is currently promoted across international health systems as part of a turn towards more participatory health care (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). This approach proposes a model of personhood beyond the biomedical features embodied in the role of 'patient'. Personhood values the individual's capacity, preferences, assets, and their power to co-create their own health, (Ekman et al., 2011; Sen, 2002). Self-responsibility in the management of long-term illness is viewed as an antithesis to patients as passive recipients of care. However, in the UK the concept of person centredness has been introduced within the context of fiscal constraint in statutory services. This has led some patients to believe changes in their care represent the neoliberal shrinking of public services in light of the costs incurred by growing numbers of people with long term conditions and multi-morbidity. There is, however, some promising evidence that person-centred initiatives can help to achieve cost stability within stretched health care systems, while also placing the person as the central figure in their own care (Hansson et al., 2016; Pirhonen et al., 2019). Definitions of PCC and participation have evolved and converged in recent years (Castro et al., 2016; Fumagalli, Radaelli, Lettieri, Bertele', & Masella, 2015). This has been facilitated by sustained investment, for example by the Swedish government (Ekman, Hedman, Swedberg, & Wallengren, 2015) and through the work of others (McCormack and McCance 2006, McCormack and McCance 2010). The Gothenburg Centre for Person Centred Care (GPCC) framework of routines to define and achieve PCC has been notable for leading the field (Britten et al., 2016; Ekman et al., 2011). The framework proposes a sequence of three routines comprising: (1) eliciting the individual's narrative (which includes all aspects of the person), (2) the co-creation of a plan of care including definition of individualised goals (3) safeguarding this plan by documenting it. Lloyd et al (Horrell, Lloyd, Sugavanam, Close, & Byng, 2017; Lloyd et al., 2017) have added a fourth routine: (4) an agreement to act in conjunction with the patient and other professionals to coordinate care.

Elicitation of the individual's narrative (Routine 1), is proposed as an anti-reductionism to the discussion of medical history and symptoms by encouraging an individual's sharing of their resources, goals and health concerns (Hydén, 1997; Mattingley, 2009; Sheaff et al., 2017). The narrative encourages voicing of the lifeworld: the ways in which people perceive and make sense of their illness in the context of their everyday lives (Barry, Stevenson, Britten, Barber, & Bradley, 2001). Incorporating, adjusting and amalgamating the lifeworld with important medical, clinical and other risk and treatment information is a complex activity requiring practitioner skills, training and resources; an art as much as a practical skill. If the routines are not grounded in the person's reality (Routine 1) the co-created plan (Routine 2) may embody non-specific goals that are not meaningful, achievable or relevant to the person (Naldemirci, Britten, Lloyd, & Wolf, 2019).

Primary analysis of evidence from our evaluations of PCC programmes in the Southwest UK found that some individuals experienced the new way of working as unusual, but welcomed it enthusiastically, while others were unwilling, or unable, to engage or simply did not understand it (Horrell et al., 2017; Lloyd et al., 2015; Westlake, Allard, Fosh, & Lloyd, 2017; Wheat, Fosh, & Lloyd, 2018). The programmes varied in their activities and titles, but shared the common principle of developing a broad narrative with the patient, via a guided, strengths-based conversation, from which holistic goals may be developed. Some of the programmes involved linking the individual to activities in their community, for example through a Community Connector or Wellbeing Advisor. The individual's response to the offer of engagement was critical to the outcomes of the new way of working, but little is known about what contexts and mechanisms might encourage individuals to share their illness or lifeworld narrative and participate in this new way of interacting with practitioners. These issues may be particularly pertinent for patients who struggle with high treatment burden, those with mental health issues, those who feel marginalised or seldom heard, or for whatever reason struggle to communicate fluently. This paper presents a theory-driven approach to analysing

how professionals can support engagement, and the contingent factors that influence why some individuals are more likely to engage than others.

## **2. Methods**

### **2.1 Secondary Analysis of Qualitative Data**

Primary data were collected between 2014 and 2018 during mixed methods formative evaluations of five primary care interventions. The evaluations assessed patient outcomes in health and wellbeing, implementation barriers and facilitators and addressed the research question of whether the interventions, which aimed to promote person-centred care (PCC) for individuals with multi-morbidity living in the community, were aligned with the GPCC routines (Close et al., 2019; Lloyd, Close, Wheat, Horrell, & Kirkpatrick, 2016; Sugavanam et al., 2018). Approval was obtained from the Health Research Authority to integrate and publish work from the five evaluations as part of our programme of work (Ref: Anonymised.). Individual participants gave written informed consent for their data to be collected and to be used in scientific publications. The original qualitative data set, used here for secondary analysis, is described in Table 1.

<Table 1 here> *Table 1: Sources of qualitative evaluation data from all sites*

The current paper forms a secondary analysis of the primary dataset by the principal investigator (Anon.) and a researcher on one of the evaluations, who was unfamiliar with the data from the other studies (Anon.) (Heaton, 2004). We sought to address a phenomenon observed in the primary data, but not addressed by the original research questions: that engagement in PCC could not be assumed – and indeed required practitioner and patient skills and dispositions to achieve. We wanted to understand from the data how and why and under what circumstances patients became engaged in the new way of working and how practitioners could best support engagement.

A Realist Evaluation approach (Pawson, 2013) was used to consolidate the findings of the five PCC evaluations in an overarching programme theory of the data, linking this to existing and new theories. Key terms used in Realist Evaluation are described in Figure 1.

<Figure 1 here> *Figure 1: Definitions of terms used in Realist Evaluation*

Theory was built from three sources: firstly, a re-reading of primary evaluation *reports* (evaluation reports, literature reviews and researcher diagrams and reflections), secondly, a secondary analysis of primary evaluation *data* (original transcripts and field notes) and thirdly, theory-building workshops (n=2) to test tentative theories and generate further theories with practitioners, researchers and people with lived experience. Ongoing dialogue between (Anon.) and (Anon.) further tested and refined initial formulations, using reflective memos to interrogate the emerging themes and build tentative Context-Mechanism-Outcome configurations (CMOs). To guide interpretation, illustrative diagrams were drafted and reworked to reflect the range of CMOs represented in the various data sources. This was continued until no new emerging theories or configurations were found. Figure 2 illustrates the development of the secondary analysis and the theory building process and is described in more detail below.

<Figure 2> *Figure 2: Steps used in theory development*

## **2.2 Step 1: Emergent Programme Theory (PT)**

A process of retroduction (Pawson, 1997) was used to build initial theories about contextual factors that influenced how the projects did, or did not, fulfil their aim of working in a PCC way and the mechanisms that were operating on this process. Specifically, we identified that some individuals failed to fully engage in PCC programmes, and it was this common finding across all of the evaluation projects that led us to generate an emergent PT (the Terms of Engagement). The theory constituted a *precondition* for person centred routines to commence. Without engagement, defined by our analysis, PCC would fail to initiate.

### **2.3 Step 2: Secondary analysis of primary evaluation data**

The emergent PT was tested by developing “If-Then” statements (Pearson et al., 2015) from the primary data reports and researcher reflections. These ‘micro-theories’ express a relationship between context and mechanism that lead to a particular outcome. The statements were organised into nodes in QSR Nvivo 12 and coded against a sample of the primary evaluation data to test researchers’ interpretations (Dalkin, 2015). Data were coded both deductively (from the initial programme theory) and inductively (exploring new aspects of meaning). This was refined until we had identified enough nodes to establish a framework to identify relationships that would later inform development of CMO configurations. The relationships were tested against the other data sets as described below, to reflect any disconfirming examples and ensure no relationships were missed.

### **2.4 Step 3: Stakeholder workshops**

Two stakeholder workshops were conducted to build co-produced “If-Then” statements. The first comprised six people with long-term conditions, two members of a university Patient and Public Involvement programme and four researchers (the authors and two other researchers with expertise in patient involvement). The second comprised three Wellbeing Advisors from the evaluation projects, a GP academic, and three researchers (the authors and a researcher involved in evaluation of person centred interventions). We firstly asked attendees to develop “If-Thens” from their own experiences and research in PCC. Secondly, they built “If-Thens” from vignettes that included elements of different cases from our evaluation data. In the second workshop, we also tested the consolidated theories from workshop one against practitioner experience. Statements were grouped under thematic headings, consolidated and tabulated by (Anon.).



## **2.5 Step4: Testing of consolidated “IF-Then” statements**

Consolidated “If-Then” statements were then back-tested against a set of previously un-sampled primary evaluation data (Gwernan-Jones et al., 2020). This allowed direct validation against the complete and original data source. Sampling of the evaluation data was purposive, with respondent cases selected to provide information about contexts, mechanisms and outcomes of interest and to test specific aspects of programme theory. Additional cases were sampled theoretically on the basis of their potential for confirming or disconfirming emerging statements.

## **2.6 Step 5: Consolidated “If-Then” statements developed into explanatory CMOs: building the final programme theory**

A process of constructing, exploring and refining led to a consolidated set of ‘If-Then’ statements (n=87) which identified relationships between context-mechanism-outcome (CMOs). These CMOs were then cross referenced with original source material (primary data, theory building workshops, researcher reflections) see Appendix Table 2. Working through this process, we identified a number of new CMOs. Each element of the configuration was assigned a letter (ie C= context, M= mechanism, O= outcome) and a numerical label to ease retrieval, based on their function within a causal chain. These are reported in findings as the below example (mechanism no. 13) in which a statement from a practitioner workshop was coded as a ‘shared understanding of purpose’ (M#13):

*If the practitioner is skilled and sensitive (M1= mechanism of programme resources) [they] make things manageable and achievable (M2= mechanism of reasoning) then patients are more likely to move towards their aims (O = outcome).*

These causal pathways were then drawn together with existing theories from the social science literature into a middle range (MRT) and final programme theory (PT) which is explored below.

### **3. Findings**

#### **3.1 Final programme theory**

Figure 3 represents our final PT, which describes the conditions necessary for a patient's engagement as a critical entry point to PCC.

<Figure 3 here> *Figure 3: Programme theory for Terms of Engagement for Person Centred Care*

We first begin by defining our outcomes and then build explanations backward towards context in the causal chain, explaining the mechanisms that caused those outcomes to be achieved and further elaborating the elements of our PT (Shaw et al., 2018). Relationships between contextual features and enabling and inhibiting mechanisms are considered and references to original data and "If-Then" statements are presented in Appendix Table 2 and referred to in the text.

#### **3.2 Outcomes explored:**

##### **Engagement and resistance**

Models of PCC may give the impression that all patients are willing and able to participate in shared responsibility for their care. Our findings show that this was not always the case. Engagement in the interventions comprised participation in *processes* (initiating contacts, making time for appointments, completing, storing and using documents, such as care planning tools) as well as engagement with the *philosophy* (development of relationships with practitioners, disclosure of lifeworld to enable meaningful goal development and belief in self-management of health (M#86). Where professionals were successful in engaging patients with the philosophy and processes of PCC, this transformative outcome became a fruitful starting point for the introduction of person centred routines.

Participants conveyed levels of engagement and resistance both explicitly and implicitly. While we can hypothesise that the ultimate resistance was expressed through declining to enrol in the projects, the primary evaluations did not recruit these individuals. Recruited patients could signal resistance by

questioning the relevance of, or failing to engage with, care planning tools and by expressing dissatisfaction with intervention professionals. Some patients circumvented the new way of working by approaching existing services instead of the new professional (M#100 #101). Implicit resistance was also expressed through a patient discourse of ‘*coping*’ or ‘*managing*’ that expressed irrelevance of the service to their needs or a lack of understanding of, or disregard for artefacts, such as care plans (M#66 #100).

However, engagement was not binary: the individual may engage with some aspects of PCC, such as having a guided conversation and developing a narrative, but show a lack of engagement with others, such as care planning. Engagement could also develop over time. Factors contributing to these outcomes are further explored below.

### **Existing theories of candidacy and trust**

Candidacy describes how a patient’s eligibility for services is conceived and negotiated in healthcare settings (Dixon-Woods, Cavers et al. 2006). Trust has been found to have significant impacts on healthcare relationships (Coulter, 2002; Mechanic & Meyer, 2000). These existing theories were found to be useful in developing our PT. If trust (O) and candidacy (O) developed, they then became a context (C) for the development of engagement (O). Shared understanding of purpose, clarity of expectations and sharing of power were theories of how contextual features could be overcome by programme resources and responses in order to develop candidacy and trust. This theory, embedded within our PT diagram, can be expressed in this way:

<Figure 4 here> *Figure 4: Middle range theory for Terms of Engagement for Person Centred Care*

Trust operated as a central theory throughout the causal chain, since it was also a *mechanism* enabling relationship-building with professionals and encouraged patients to feel comfortable in disclosing

elements of their lifeworld during narrative development. The mechanisms enabling development of candidacy and trust are explored below with reference to CMO configurations built from the data.

### **Establishing candidacy**

When patients were approached to participate in the new programmes, their responses ranged from gratitude and enthusiasm (positive candidacy (O #5, #38, #48, #59, #61-65) to confusion, uncertainty and scepticism (negative candidacy (O #31-33, #36,#37,#39, #47)). Where patients were not clear about why they had been approached or the criteria used to deem eligibility, they were more likely to be uncertain about enrolling in the programme (M #64). An example of this was a couple where both individuals had complex health needs but only one met programme eligibility criteria of having three or more long term health conditions (M, #56). The couple perceived these criteria as irrational since they saw their needs as overlapping and inherently connected.

Patient reasoning was influenced by a prevailing political discourse of austerity and responsible consumption of services. The political context induced suspicion about the real purpose of these projects (C#21) and triggered further reasoning about candidacy. But this depended on individual characteristics, beliefs and experiences (C #64, #99, #100). For example, patients with a political viewpoint suspected that the programme discourse of self-management was underpinned by neo-liberal attempts to shift responsibility back to the individual and cut their access to benefits and services (M #34).

Patients were surprised at time allocated for conversations when time as a commodity was restricted across most services (M#36). In one intervention, which provided a small health budget to achieve patient-defined health goals, patients felt guilty and believed it was *'too good to be true'* (M#32), particularly given the closure of a local community hospital (M#36).

Those who had a strong belief in enduring hardship without complaint (stoicism) tended towards a discourse of self-rationing of service use and promoted the prioritisation of those whom they considered more eligible or in need. These individuals were likely to decline offers of PCC (C #36, #37, #100). Where patients had integrated a strong behavioural norm of ‘how to be a patient’, which trusted in the expertise of professionals above their own self-determination, there was also resistance to the notion that they were eligible for a service that gave them more control (C #80,#98).

Conversely, individuals who had experience of patient involvement with traditional (NHS) or complementary health services or whose personal characteristics were disposed towards self-management of their health tended towards positive candidacy for the programmes. We have termed this a ‘rights and access’ mindset (C #38). These patients were likely to emphasise their eligibility and, in some cases, to fight for it. In other cases, carers promoted candidacy on behalf of the patient (M#65).

### **Building Trust**

Trust-building operated as context, mechanism and outcome during different stages of engagement. Patients who had poor previous experiences of services and relationships with professionals were less likely to trust in a new programme (C #87). If the new programme’s aims, rationale and processes were unclear to patients and coordination with existing trusted services was not transparent, they were more likely to favour existing services (O #87,#88) than place their confidence in the new initiative (M #88).

Trust through initial relationship-building was necessary, but not always sufficient, to secure engagement: the credibility of the new project was also based on tangible outcomes at an early stage of involvement (M #48). The delivery of material actions towards the patient’s goals, for example, through coordination with other services, linking to a community activity or taking the first steps

towards arrangement of a health budget, also enhanced confidence and trust (O#97). Such actions facilitated participation by affirming that practitioners were attentive to patients' needs and that the programme was credible (M#97).

### **3.3. Programme mechanisms disposed to overcome contextual limitations on candidacy and trust.**

Trust building and the establishment of candidacy by skilful, experienced professionals was able to enhance engagement through a series of mechanisms grouped under the theories of ; 'shared understanding of purpose' 'clarifying expectations', and 'sharing power'.

#### **Building shared understanding of purpose**

Some patients felt empowered by a relationship in which the traditional boundaries between professional and patient were challenged. They understood and were willing to take responsibility for the actions agreed to meet their health goals. Others did not comprehend why they were expected to engage in a new type of relationship with the professional (C #98). In some instances, a cognitive or mental health condition impaired ability to absorb and process information (C #33). However, a lack of understanding on the part of the patient was most often due to unclear professional narratives introducing the project, compounded by inaccurate or unclear explanatory materials such as leaflets and invitation letters (M #32). Our evaluations took place at the beginning of the cycle of service change. A lack of clarity in national policy and guidance for local implementation contributed to confusion at the coalface (C# 34). Professionals often lacked a sufficient understanding of the new project because they had not received adequate initial training in PCC and their approach was heuristically created by experience over time (M#91).

Where professionals were able to give a consistent project narrative, making it clear that the *shared* management of health and a partnership was key, participants could make informed decisions about

their candidacy and were more likely to trust the professional (M #86 #90). This was critical to engagement at first meetings with a patient (M #35).

Active and open listening to the individual, without judgement about what constituted a legitimate health, social concern or health behaviour was another key mechanism (M#35). Where participants had an unclear diagnosis or multiple conditions (C # 95), this conversation was experienced as particularly validating (M #96). Language that was not hierarchical, technical or value-loaded and which resisted expressing '*hidden agendas*' or pre-determined goals, was also important (M #12, 41).

Organisational policy and resources, such as appropriate training in PCC and proportionate caseload, enabled professionals to work in a way that provided sufficient time-allocation to consider important contextual factors of a patient's life (C#68, 69, 91). Time was considered essential to build practitioner-participant relationships (M#43, 82, 91, 94). Professionals and patients both believed that a lack of sufficient time resulted in over-simplification of the patient's situation ('*not knowing the whole history*') and often misaligned goals with the patient's aspirations (M #39).

### **Clarity of expectations**

Establishing a set of expectations between professionals and patients about frequency, length, and the location of future contacts, and the initiation of these contacts was particularly critical (M# 83, 84, 85). In one programme participants waited to be contacted by professionals, whereas the expectation was that patients would seek repeat appointments. Once an individual had been referred, swift follow up by the intervention professionals was important, so that momentum was not lost (M#63, 79). Face to face, rather than telephone contact (which felt like 'cold calling') also helped develop patient candidacy and trust (M #21, 22). Continuity of the relationship with a single professional was considered ideal, but there was value in knowing a second 'backup' professional who was trusted (M 23,#24, #26).

Misunderstandings about the new way of working led to patient confusion and, in some cases, disengagement (#C 32, #34-36). However, the development of a trusted relationship with intervention professionals could operate as a mediator mechanism by overcoming some programme limitations (M#4). This often involved the professional sharing some elements of their own lifeworld and working conditions (M#78). Patients tended to empathise with professionals who explained this was a new way of working and that programme resources, such as allocation of staff time, were still developing (M #78). Empathetic relationships with professionals resulted in patients feeling more engaged with the programme.

### **Sharing power – the role of the practitioner**

If a relationship of trust was built with a professional, a new type of relationship could be built in which patient preferences rather than professional concerns guided conversation (M #66, #86). Fundamental to this shift was the acknowledgement by professionals that they hold power and that the new programmes rested on their acceptance and encouragement of patients taking more control in the management of their health (M#16). Patients setting the type, time and location of their contact with professionals (M #84) were incremental but important steps towards partnership working and power shifting. More importantly, valuing and legitimising peoples' experiences through exploring their health beliefs supported the shift (M#15). The conceptualisation of healthcare as *relational*, rather than individual, with reciprocal sharing of responsibilities and obligations across a wider social network of family and community that *included* professionals, but that did not prioritise them, was also key (M #70).

Understanding and accepting the patient's intentions for managing their health and any associated risks was perhaps the most challenging shift. Professionals preferred to express this in the statement: 'I will honour the person's agenda *providing that there are no risks of harm or adverse implications*



*to that person or a member of the public* [our emphasis] (M#29). How far power is shared when professionals identify ‘unacceptable’ levels of risk and adversity is contentious (M #29, 30).

However, our data revealed acceptance of risk was an iterative process of assessment, negotiation and reflection between professional, patient and their social network.

The importance of practitioner skills in developing PCC cannot be overstated; their personal characteristics, beliefs and experiences were important contextual factors (C #63 #24 #25 #39, #40, #41) and training was a key mechanism of project implementation ( M#1, #3, #81, #15). Professionals with social care or voluntary sector experience, or who had received enhanced training in PCC believed they had an advantage (M #49).

Figures 5a and 5b give a worked example of a CMO configuration illustrating the importance of the practitioner role and summarising how mechanisms are related in our theoretical model. For clarity, this is shown as a two-phase process, but in reality was likely to be iterative and dynamic with trust and candidacy building over time.

<Figure 5 here> *Figures 5a & 5b: Worked Example of Context-Mechanism-Outcome configuration: Building Engagement for Person Centred Care*

#### **4. Discussion**

Engagement with the development of meaningful narratives, which share the patient’s lifeworld, are the foundation of PCC (Naldemirci et al., 2019). PCC interaction requires an understanding, however implicit, of how a ‘care partnership’ departs from previous patient-professional interactions and acceptance that the ‘norms’ of these previous relationships are challenged (Britten et al., 2016). For both patients and professionals this includes an acknowledgement of power dynamics and acceptance of power-shifting and sharing (Castro et al., 2016; Holmstrom & Roing, 2009; Pulvirenti, McMillan,

& Lawn, 2014). Accomplishing PCC is not only an enactment of the *processes* (the ‘know what’) but also requires the *mechanisms* (the ‘know how’) to create a space in which a patient is supported by professionals to take a more active role in their own health (the central *theory* of PCC). It is imperative to foster the conditions for the co-creation of this space. However, there is scant evidence in the literature supporting our understanding of how, why and in what circumstances patients become more engaged in this type of care and what professionals can do to support it.

A systematic review of Shared Decision Making (SDM) in older adults with multi-morbidity emphasizes that SDM is part of a wider culture change in which the ability of patients to participate is a key contextual factor (Bunn et al., 2018). In concordance with our analysis of PCC, successful cultivation of SDM is shown to be dependent on the creation of trust between those involved, which is related to shared understanding and expectations. The authors find a lack of evidence about interventions promoting SDM and conclude there is a need to understand more fully the factors that influence engagement. PCC, however, is much more than SDM. Whilst we acknowledge that SDM is a core step towards establishing person-centred interactions, greater shifts are required from professionals and the healthcare systems before this can be truly considered person-centred care. Such shifts require an understanding of the underpinning ethic of capabilities and personhood, appreciation of the lifeworld of the patient and actualisation of the care partnership across the healthcare continuum. We are therefore asking much more from systems, professionals, and patients than sharing decisions. Our theory of engagement applies to professionals and patients alike, but places the initial burden of responsibility of enhancing engagement in PCC on those who hold the most power: the professional and the system.

Trust has been shown to be fundamental. We explore the specific mechanisms that allow trust to develop (or conversely that lead to mistrust or scepticism). In accordance with other theories, we found that trust did not operate in a linear way, but showed iterative development over time, building

in a ‘ripple effect’ throughout the causal chain as context, mechanism and outcome (Jagosh et al., 2015). A trusted relationship as an outcome then creates a context for engagement. In turn, engagement - as an outcome constructed in the theory - becomes the context for the next set of explanatory theories about how person-centred programmes work.

#### **4.2 Summary of findings**

Our programme theory shows that professional and patient interaction takes place in the context of political discourse, organisational resources and individual patient and professional characteristics and beliefs. Trust, and the confidence it engenders, is one of the essential components of the relationship between professionals and patients. A patient’s understanding of why they are eligible for PCC (candidacy) is also central to engagement. Mechanisms facilitating shared understanding, clarity of expectations and the sharing of power are fundamental to the new way of working. These mechanisms, in turn, build trust and candidacy.

Professionals’ skills and competencies in PCC are the foundation for effective engagement and support in this radical departure from the healthcare norm. Healthcare systems need to invest in time, resources and training to help professionals flourish in their actualisation of PCC.

#### **4.3 Strengths and limitations**

This paper makes an original contribution by addressing a gap in knowledge about the factors that influence active engagement in person-centred care, with possible applicability to engagement in health care and interventions more broadly. The principles of realist theory building have enabled us to suggest both contextual features and mechanisms encouraging engagement in this radical shift towards PCC. Our theory of engagement originates from data collected during evaluations of person-centred interventions.

Healthcare projects or research studies of PCC could incorporate investigation of this theory in practice to test applicability and relationship to successful engagement. The data used for this secondary analysis originated from service evaluations across the southwest of England, the data may therefore not be representative of the experiences and practices of patients and professionals taking part in other interventions further afield.

### **4.3 Implications for research and practice**

The professional's role in supporting care partnerships is central (Beach & Inui, 2006; Bunn et al., 2018; Entwistle, Carter, Cribb, & McCaffery, 2010). Our theory identifies mechanisms by which professionals can mediate contextual limitations and encourage the engagement necessary to make person-centred interactions work. This is a new interactional space rather than a simple transition between medical history taking and structured goal setting and is dependent, in turn, on its own contextual factors. That context is often overlooked in introducing new ways of working. Where it is ignored this may lead to barriers to genuine meaningful engagement. Practitioner training and support is therefore fundamental to the success of these interventions in producing person-centred outcomes in people with long-term conditions (Foster et al., 2019). Considering this knowledge in PCC training is likely to support better patient engagement.

## **5. Conclusion**

'Terms of engagement' are a precondition for PCC. Where terms are met PCC is more likely to flourish since they encourage the person to develop authentic and elaborate narratives with a professional. Building this context is a complex activity dependent on relationships between practitioner and patient. It is also dependent on the organisations in which professionals are situated and national policy and discourses. The burden placed on practitioners to overcome the limitations of context and to facilitate new ways of experiencing the care partnership should be recognised.

Professionals should be supported by evidence-based policy direction and guidance, as well as resources, such as training, to achieve national goals of increasing patient participation in health care.

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