

PATIENT ENGAGEMENT IN HEALTH AND HEALTH CARE: A LITERATURE REVIEW.

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Introduction:

Patient engagement (PE) in health care is at the forefront of policy agendas globally and enshrined in legislation in several countries, e.g. the NHS Constitution DOH 2015 (Healthwatch,2018) and Swedish Patient Law 2015 (Bergerum et al, 2018). One part of engagement, enshrined as a right of all people in the 1978 Declaration of the Alma-Ata, requires engaging patients in their own individual medical decisions and also in the design and implementation of healthcare services (WHO, 1978). The World Health Organisation (WHO) state that patient, family and community “engagement has been realised as a core strategy for advancing universal health coverage, safe and quality healthcare, service coordination and people-centeredness” (pg 15) and are currently developing a comprehensive guide to implement meaningful engagement of patients and families at direct care, organisational and policy levels, and to advance patient and family engagement along the whole continuum of care from health to palliation (WHO, 2017).

The Health Service Executive (HSE) are consolidating and advancing the agenda of Patient Engagement in healthcare in Ireland. This review explores the literature to define what PE is and to identify the optimal conditions required to build on current practice and to implement meaningful, successful PE policy and practice.

There are several drivers for advancing the PE agenda:

- Serious clinical and service failings in the UK (Francis report) and internationally (WHO world alliance for patient safety forward programme) and European Union (EU) reports of the patients being unintentionally harmed in hospitals (Health and Social Care Regulatory forum, Ireland, 2009) have reinforced the urgency for gaining the unique perspective of the patient in addressing these patient safety problems (Ocloo and Matthews ,2016).
- The prevalence of chronic disease and greater longevity, and the challenges they present for a healthcare system originally designed to treat acute and transitory infections calls for new ways of working with patients to manage their care, (Pomey et al, 2015; Karazivan et al, 2015; Dent & Pahor, 2015). As current healthcare moves from disease-centred to patient-centred, the concept of PE has a significant role to play (Higgins et al, 2017).

- PE has been described as one of the most underutilised resources in healthcare and a potential “blockbuster drug” (Schneider, 2012, cited in Higgins, 2017) and has been referred to as the “holy grail” of health care as it may be revolutionary in guiding the planning of healthcare systems by enhancing how patients experience health services and by promoting patient-centred approaches to healthcare delivery (Carman et al, 2013).
- It is widely accepted that public engagement has the potential to be a widely transformative practice (Healthwatch UK, 2018), and that PE can be an innovative and viable approach to ensuring appropriate care in healthcare settings that are strained by limited resources (Pomey et al, 2015).
- Patients are being recognised as essential partners in the solutions to healthcare system problems, and central to health reform (Tritter et al,2009, cited in Ocloo & Matthews, 2016 ; Carman et al, 2013).
- Increased cost of medications and technology and subsequently healthcare has been a key driver for the challenge of moving from a traditional paternalistic model of care to one of partnership with patients, with cost containment being a key concern driving policy innovation (Dent & Pahor, 2015). Societal focus on healthcare quality, patient safety and patients’ healthcare experiences and growing rejection of paternalism drives efforts to involve patients, moving into the era of co-design and co-production, (Bergerum et al, 2018).
- Patient and Public involvement (PPI) is seen as a way to enhance democratic principles and accountability (Ocloo and Matthews 2016), is considered a moral and democratic right (Naas et al 2012, cited in Healthwatch UK, 2018), and introduces a higher level of transparency and accountability (Health and Social Care Regulation Ireland, 2009; Healthwatch UK, 2018). PE is driven by the ethical principles of enhancing agency and respecting autonomy (Moulton and King 2010, cited by Grande 2014).
- There is increased recognition and acceptance that users of health services have a rightful role, the requisite expertise and an important contribution to design and delivery of services, (Bradshaw, 2008, cited in Bombard et al, 2018). Health care systems around the world are responding to the demand of “nothing about me without me” (Baker et al 2011, cited in Fancott et al, 2018) and a shift from “what’s

the matter?” to “what matters to me?” (Roseman et al, 2013), as they attempt to operationalise patient-and -family-centred care in practice by more actively engaging patients in their care and policy decisions (Fancott 2018, Carman et al, 2013).

- In the US, federal government offers reimbursement for the use of health information technology to enhance patient engagement and many funding grants in research now require or promote patient and public involvement (PPI) in research, providing a further driver for PE (Hahn et al, 2013).
- Policy has also placed greater priority to involving patients and carers in the design, delivery and evaluation of services and provides the context for much subsequent policy and organisational developments (Forbat, Hubbard and Kearney 2009). Canadian Foundation for HC Improvement (CFHI), and the Quality Improvement Division in Ireland have identified patient and family engagement as drivers and key levers in improvement frameworks (Fancott et al, 2018; HSE, 2019). The importance of participation has been acknowledged in other Irish policy documents: Healthy Ireland Framework for Improved health and Well-being 2013-2025, HSE (2013); Office of Ombudsman learning to get better (2015); Report of the Commission on Patient Safety and Quality assurance DOH (2008); report of the Expert Group on Mental Health policy, DOH and C Dublin (2006). Several strategies have been developed to operationalise PE including a National Healthcare Charter (2012), the National Service User Strategy HSE (2013) and more recently the National Quality Improvement team “By all, with all, for all: a strategic approach to quality 2020-2024” strategy HSE (2020), the National Screening Service Patient and Public Partnership Strategy 2019-2023 HSE (2109) and the National Healthcare Communication Programme (HSE,2019).
- Globally health organisations, care delivery institutions and universities are striving to expand patient engagement beyond a token level (Pomey et al, 2015). Many healthcare organisations see PE as the right thing to do, with systematic public involvement in healthcare decision-making via regional or local health advisory councils, committees, boards or citizen juries now established in the UK, Canada, Australia and New Zealand. PE in health sector priority-setting has also been mandated or promoted in low income countries (Dukhanin et al, 2018). The Scottish Executive Health Department in 2003 indicated a move towards a more considered process of PE and involvement, requiring NHS Scotland to employ an approach which

allowed it to “recognise and respond sensitively to the individual needs, background and circumstances of people’s lives”. Similar policy directives are in place in North America, Canada and Australia (Forbat, Hubbard Kearney 2009). If patients have greater autonomy this will stimulate greater competition and efficiencies in health care and encourages the public to adopt healthier lifestyles potentially resulting in lower healthcare costs (Dent & Pahor, 2015).

Many benefits of PE have been reported:

Improvements in patient safety have been reported by several authors (Higgins et al 2017; Carman 2013; Institute of Patient and Family-centred care report IPFCC, 2017). Previously unrecognised areas of harm were detected by direct patient feedback and accordingly staff reporting of harm increased (Lachman et al, 2015 cited in Bergerum et al, 2015.) Efforts to communicate risk and involve patients in their care are considered critical to improving quality and cost of patient care (Grande et al, 2104).

The role of PE in improving quality of care has been reported. Patients have a unique perspective on healthcare that makes them valuable partners in Quality Improvement (QI) strategies (Roseman et al, 2013). QI initiatives that work to expand the patients’ and families’ ability to participate in care are a pathway to improving outcomes, an approach that is necessary and achievable (Hibbard and Greene, 2013). Globally, healthcare organisations have endeavoured to tap into the expertise and wisdom of patients and their families to use their experience to drive improvement in safety and quality of care (Fancott, 2018; Pomey, 2015; Carman et al, 2013). Promotion of the idea of patients, staff and government working in partnership further underlines the involvement of patients in service improvement. The policy in the Scottish Health Service (SEHD 2003) noted the importance of listening to patients and positioning them as equal partners in their healthcare. This invoked 3 parallel ideas of participation, empowerment and partnership as routes to improving services (Forbat Hubbard and Kearney, 2009). PE can inform patient and provider education and practice as well as enhance service delivery and governance, (Bombard et al, 2018). PE results in more relevant services and increased sense of dignity (Whiston et al, 2017). The impact of service user involvement in the NHS has resulted in new and improved services, development of information and dissemination of same, development of training sessions for service users

and Healthcare professionals, and working with service users changed healthcare staff attitudes, values and beliefs about the value of user involvement. Utilising individual's experience and knowledge of conditions to help others has been identified as a particular strength of user involvement (Mockford, 2012; Forbat et al 2009).

Better healthcare outcomes as a result of PE have been reported (Coulter, 2012 cited by Higgins et al, 2017; Hibbard and Greene, 2013; Carman et al, 2013). Patient- centred-ness results in fewer unexpected complications and deaths, reduced cost of end of life care without shortening it (Roseman et al ,2013, IPFCC 2013), reduced hospital admissions (Simpson and House 2002, cited by Bombard et al ,2018) and improved quality of life (Crawford 2002, cited by Bombard et al 2018).

Better care experiences and improved satisfaction have also been reported (Higgins et al 2017, Whiston et al, 2017). Patients who are more activated have better health outcomes and better care experiences than those who are less activated. Patients activation can be modified and increased through engagement interventions (Hibbard and Greene, 2013). It is recognised that actively involving patients and families in the design and implementation of improvements enhances experience and outcomes of care (Fancott et al, 2018; Ocloo &Matthews, 2016). Improved patient choice, self-care and shared decision-making also occur as a result of PE (Ocloo & Matthews, 2016). Engaging patients in QI efforts prompts changes that can include increasing engagement in their own care and improving their experiences with the Healthcare system (Roseman, 2013). Staff satisfaction is also impacted positively by PE. Job satisfaction increased and staff turnover reduced (Higgins et al, 2017; Roseman et al ,2013; IPFCC 2013) and there is a reduction in health care costs (Higgins et al, 2017).

Benefits of PE in research include more meaningful findings (Staley et al ,2013), with patient voice being heard (Ashcroft et al, 2015) while helping to shape study design and data analysis (Wykes 2014, cited by Whiston et al, 2017).

The agenda of patient involvement is broad and sometimes confusing, being driven by differing ideologies and positioning patients in quite distinctive manners. Although policies are seemingly aligned in their aim to increase Patient and Public Involvement, they

simultaneously invoke several different versions of what it means and what ideology underpins it (Forbat, Hubbard and Kearney, 2009). Furthermore, not all patients choose to be involved or should have to be responsible for monitoring care. Given their vulnerable condition it may not be the most reliable method (Ocloo & Matthews, 2016). Despite the public's demands for greater involvement in care and policy, greater engagement is not ideal for all people in all situations (Carman et al, 2013).

Given the number of drivers for and the benefits of PE, it is important that PE design and implementation result in meaningful and successful PE in order to attain the benefits outlined above for our patients, families, the public and our healthcare staff and services. With the launch of the Slaintecare Action Plan (DOH Ireland, 2019) which aims to provide "the right care, in the right place, at the right time", PE will play an important role in the design, delivery and evaluation of healthcare services into the future.

The following sections review the terminology and definitions of PE; models and methods of PE; challenges, barriers and enablers of PE; educational implications and evaluation of PE.

Terminology and definitions of PE

PE is multifaceted and complex. It has been described as both a process and a behaviour and is thought to be shaped by the relationship between the healthcare professional and the environment in which healthcare is delivered (Higgins, 2017).

PE has become a widely used term but remains a poorly understood concept (Higgins et al, 2017). Citations of the term have increased through healthcare disciplines, and definitions have varied over time and across contexts. (Higgins et al, 2012; Mockford et al, 2012). There is a lack of consistency in the terminology used for PE and the definition of the concept of PE (Gallivan et al, 2012; Hibbard and Greene, 2013; Grande et al, 2014; Finset, 2017, Madij & Gagliardi, 2019). Defining PE is very complex (Grande et al, 2014). No common definition renders the nature of the concept elusive (Higgins et al, 2017). However, the fact that the PE concept is referenced throughout the literature in a variety of disciplines, healthcare contexts, and a range of countries globally indicates that there is a shared effort to understand what PE means and how it can influence healthcare delivery (Higgins 2017).

Terms used to describe PE include person, patient, service user, patient and family, person and family, patient and carer, citizen, client, consumer, community, patient-centred, person-centred, patient and family centred, public, co-production, co-design, patients-as-partners, participation, consumer and peer leadership, involvement, active involvement, activation, empowerment, partnership, collaboration, cooperation and engagement. The concept of patient engagement is frequently referenced in a wide range of contexts, denoting a broader concept not proposed by other terms which are included within the breadth of PE (Hibbard and Greene, 2013; Higgins et al 2017).

Castro et al (2016) note that the terms used interchangeably in the literature had significant differences in their attributes on analyses of their application. Patient-Centred was partly used to indicate a general biopsychosocial perspective partly to demonstrate relationship quality, often referencing empathy. Patient Empowerment is more related to the individual process of taking responsibility for their own health, while Patient Participation is more related to active engagement, partnership and decision making in healthcare.

Although concepts may have many definitions, they all share key components which adds to the confusion regarding the meaning of PE (Gustavson, 2018).

PE may refer to the collaboration of patient, their families and or care representatives with healthcare professionals in health activities that design, deliver or improve health and healthcare (Carman et al ,2013) or working in partnership with service users to inform service redesign and improvement, policy, research and their own treatment or care (Forbat et al, 2009).The definition of PE varies from broad definitions such as “the actions people take for their health and to benefit from healthcare” (pg 3. Pomey et al, 2015), and “the process of actively involving and supporting patients in healthcare and treatment decision-making activities”(pg 281 Grande et al, 2014) or “ an activity that is done with or by patients rather than to, about or for them” (pg 627 Ocloo &Matthews, 2016) , to more comprehensive definitions such as “patient engagement is the involvement of patients and or family members in decision-making and active participation in a range of activities (e.g. planning, evaluation, care, research, training and recruitment). Starting from the premise of expertise by experience, patient engagement involves collaboration and partnership with professionals” (pg 13. Tambuyzer et al,2014 cited by Fancott et al 2018), and “a broad practice

of two-way interaction guided by a set of principles, processes and activities that provide an opportunity for stakeholders to be involved in meaningful interactions. Engagement considers and incorporates the values and needs of patients, clinicians and communities into healthcare decision-making to enhance transparency and accountability” (pg 2 Alberta Health Service, cited by Gallivan et al 2012).

Some of the terms and their meanings found in the literature included the following:

Co-production can be described as “user co-delivery of professionally designed services”. In principle it brings Healthcare (HC) professionals together with the patient as the “co-participants, co-designers and co-producers as part of the process of service production” eg expert patient programmes in the UK, but also in community-based projects and programmes (Dent and Pahor, 2015). Within the clinic coproduction equates to shared decision-making as well as the development of clinical guidelines (Dent & Pahor 2015).

Co-design approach facilitates democratic dialogue in the development and implementation of change interventions and service improvement (Boyd 2010, cited by O’Donnell et al, 2019) and places patient-centred outcomes such as dignity, identity, respectful communication and independence as key drivers for implementation (O Donnell et al, 2019).

Patient activation equates to understanding one’s role in the care process and having the knowledge, skill and confidence to manage one’s health and health care (Hibbard et al,2004 cited by Hibbard and Greene, 2013). Activation differs from compliance which is seen as the extent to which a patient follows medical advice.

Patient and family participation happens when the views of the patient and family are both sought and taken into account when designing, delivering and improving new and existing healthcare services (Whiston et al,2019).

Patient-centred care is “an overall philosophy and approach that ensures that everything individuals or organisations do clinically or administratively is based upon patient needs and preferences” (pg 9 Fooks et al,2015).

Patient experience is defined as “how patients perceive their care” (pg 9 Fooks et al 2015) or “the sum of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care” (pg 9 The Beryl Institute 2010, cited by Fooks et al 2015). It requires the organisation to hear what is being said, to measure experience and develop the ability to use this information to change practice, policies and rules.

Gallivan et al (2012), tabulated the terminology and definitions related to PE in their paper. 23 selected articles yielded fifteen different terms for “patient engagement” or related activities and they identified twenty-six definitions corresponding to the term.

A common definition of the concept of PE has been identified as being important to enable clinicians, healthcare administrators and researchers to design methods that guide behaviours and create settings that support the concept and influence the quality of care for patients. If the meaning of the concept of PE is explicit it will improve communication between healthcare professionals as there will be a shared understanding of the core aspects and variations in PE (Higgins et al, 2017). Conceptual clarification would assist in further developing PE in health care (Finset, 2017). Higgins et al (2107) identified four important attributes of PE. These are the personalisation of the approach; access to necessary care; commitment to pursuing quality care; and the therapeutic alliance. Majid & Gagliari (2019) highlight that limited understanding of the theory of PE can negatively impact the practical application of PE and add to the plethora of terms used by patients and healthcare professionals. The need for common language has also been identified as important to ensure all stakeholders have the same expectations and understanding of PE for meaningful and successful patient engagement to occur (Gallivan et al,2012; Grande et al, 2014, Majid &Gagliani, 2019).

Therefore, a glossary of terms of agreed definitions would be useful to clarify the meaning, purpose and aims of any PE activity. This would ensure clarity of expectations and the roles and responsibilities of all those involved in the engagement activity and create conditions conducive to successful and meaningful engagement. Also important is that the definition of involvement should be agreed by users and staff together. (Neech et al, 2018 cited by Healthwatch UK, 2018)

Models of Engagement

There is evidence that patients and the wider public can be involved and make a difference at most stages of healthcare and in service design and delivery (Coulter &Ellins 2006 cited by

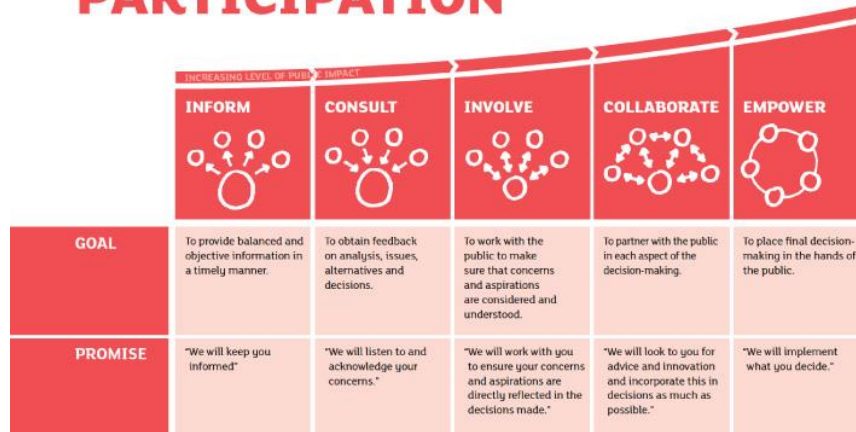
Ocloo&Matthews,2016), and can contribute to commissioning, monitoring, evaluation and research (Ocloo &Matthews 2016). PE can occur at all levels of healthcare including individual, organisational and policy making level (Carman et al, 2013). However, this does not mean that all patients choose to be involved or should have to be responsible for monitoring care as it may not be the most reliable way to do this given their vulnerable condition (Ocloo&Matthews,2016; Carman et al,2013).

Several models of patient and public engagement and participation are proposed in the literature. Traditionally, they have been defined and distinguished by the degree or power and level of involvement of patient and carers.

Arnstein's ladder of citizen participation (Arnstein, 1969) has been widely used as a theoretical framework to underpin developments in patient engagement and participation. It is an eight rung ladder extending from manipulation on the lower rungs to delegated power and citizen control at the top rungs. Charles and DeMaio (1993) adapted it in their model of lay participation in HC decision-making identifying 3 degrees of control that patients have ranging from consultation to partnership to dominant control. Hanley et al (2004) distinguish between consultation, collaboration and user-controlled involvement in a hierarchy of involvement (Forbat, Hubbard, Kearney2009). The concept of a linear progression towards more meaningful participation suggests that one should strive for the top rung of the ladder and in doing so may imply that meaningful engagement does not happen on the lower levels which is not the case. Meaningful engagement can occur at all steps of the theoretical ladders.

The IAP2 spectrum of public participation moves away from the notion of ascending steps and describes levels of participation along a continuum. These are inform, consult, involve, collaborate and empower with increasing impact on decision making denoted moving along the continuum. What happens at the various levels is explained in the context of the goal of participation and the promise to the public, and each level can be appropriately applied depending on the context in which it is being used. It also denotes the direction of information flow between the patient and the healthcare staff.

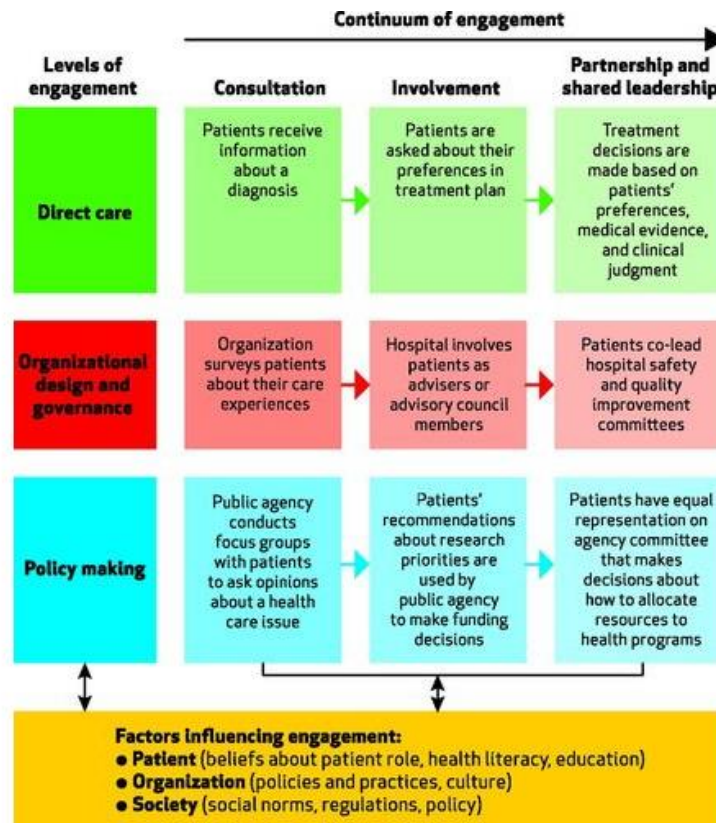
IAP2 SPECTRUM OF PUBLIC PARTICIPATION



Source: www.iap2.org

The Carman et al (2013) framework for understanding the elements of patient and family engagement and developing interventions and policies in healthcare denotes degrees of engagement along a continuum, characterises how information flows between the patient and healthcare provider, and how involved the patient or public become at direct-care, organisational and policy making levels. They also highlight factors influencing engagement. It suggests that by implementing interventions across multiple levels of engagement, a greater impact can be achieved than focusing only on achieving partnership and shared learning level. It is not suggested that the goal is always to move toward engagement at the higher end of the continuum. Such engagement is not necessarily better for every patient in every setting (Carman et al 2013).

This is consistent with Hahn et al (2013) who concluded that each level is considered to have its own value and that goals and objectives need to be clearly defined and the levels of engagement need to be consistent with the engagement activity goals (Hahn et al, 2013).



A Multidimensional Framework for Patient and Family Engagement in Health and Health Care. Source: Carman et al, 2013.

The Canadian Foundation for Health Improvement have encouraged more collaborative rather than consultative models/degrees of engagement, yet they also recognise that a full mosaic of methods to involve and engage patients is needed. A broader range of methods allows inclusivity of many voices and experiences that will influence thinking and understanding of patients' experiences of the healthcare system (Fancott et al, 2018).

Gustavsson (2018) proposes four levels of healthcare at which engagement can occur, namely Individual level, Group level, Governance and management level and lastly societal level.

Therefore, different models of engagement describe a variety of degrees of engagement and levels of the health system within which engagement can occur, and highlight factors that may influence engagement. Using theoretical models which acknowledge the value of engagement at all levels are more helpful when considering the design of PE interventions and policies.

Methods of engagement:

While the nature of PE may vary from including patients as members of a board to time-limited consultation with patients on service redesign, its aims should always be to improve the quality of care (Bombard et al 2018).

Direct-care or individual level:

There is an acknowledged growing consumer movement accelerating the shift from medical paternalism, in which the “doctor always knows best” towards a partnership where patients are engaged as stakeholders in their own care (Hahn et al 2013). Patients can engage in their own clinical care by using tools to decide a treatment option that aligns with their values and beliefs (Majid and Gagliari 2019). They can make decisions about their care pathways such as changes to medications (Whiston et al, 2017). Carman et al (2013) state that at the level of direct care, engagement integrates the patients’ values, experiences and perspectives related to prevention, diagnosis, and treatment including managing the patients’ health and selecting healthcare coverage and providers, and that PE at this level ranges from simply receiving information to being an active partner in the care team, setting goals, making decisions and proactively managing his or her health.

Involvement practices at the direct care level can have two focuses, one on making decisions about care, particularly treatment and the other on actively performing their own care. They share common ground as they both concern the involvement of patients as partners alongside the healthcare professional in care practice (Hanley et al, 2004 cited by Forbart, Hubbard and Kearney, 2009). Patient-Centred approaches put patients at the centre of the healthcare professionals work and concerns, whereas the patient-as-partner approach is considered to be a step further than patient-centred care as per Karazivan et al (2015) where the patient becomes an integrated member of the MDT bringing their experiential expertise to complement the expertise of the healthcare professionals. This approach supports co-design activities and involvement of patients much earlier in the process to determine organisational priorities based on patients’ needs and experiences (Fancott et al, 2017).

This integration hinges on the development and sustained use of competencies and practices by both patients and professionals. Patients make decisions with regard to their own care

based on their experiential knowledge, just as healthcare professionals apply their clinical and scientific expertise.

A patients' ability to establish meaningful interactions with professionals depends on their capacity to communicate their experiential knowledge (Pomey et al,2015).

Information+activation+collaboration engagement method is an interaction where two or more participants work together to share information, views and perspectives using tools that catalyse engagement. It adds a two-way communication process that supports engagement with this type of method sharing the goal of more and better conversations between a patient and a provider, facilitating communication of evidence and elicitation of patient preferences at the point of care.eg point of care engagement tools i.e. POCET (Grande et al, 2014).

Organisational level:

Patients can also engage in activities at organisational level such as strategic or operational planning, for example establishing an organisation's clinical priorities service delivery, serving as patient navigators, being a partner in a quality improvement team or co-executing a QI project. They can be involved in priority –setting, for example informing the direction of decision-making through storytelling, and they can also be involved in research by formulating research questions (Majid and Gagliardi ,2019). Patients can play a role in organisations as patient advisors or by participating in surveys and questionnaires (Fancott et al, 2018). Patients can be involved in decision- making about running a service, such as how appointment systems work (Whiston et al, 2017). Carman et al (2013) state that organisational design and governance level engagement integrates patients' values, experiences and perspectives into the design and governance of health organisations eg hospitals. Patients partner with organisational leaders, front-line managers and clinicians to plan, deliver and evaluate care. Patients also help design health care facilities; serve on hospitals' patient and family advisory councils; participate in the design and execution of quality improvement projects and assist with staff hiring, training and development. Patients are engaged early and meaningfully and are not token or single representatives.

Policy level:

At policy level, patients may be involved in decision-making about future plans for health policy (Whiston et al, 2017). Carman et al (2013) state that at policy making level, engagement focuses on developing, implementing and evaluating national, state and local health care policy and programmes. This is often described as citizen or public engagement and engagement at this level helps ensure that the health care system goals and focus is oriented around and responsive to patients' perspectives. At this level engagement may include individual patients as well as representatives of consumer organisations who speak on behalf of a general constituency. However, it is still rare for patients to have more than a token amount of power and influence at this level.

Patients, families and the public can be engaged at any level of the healthcare system. There are a myriad of methods described in the literature. No one size fits all when considering PE modes and methods, as there is a need to be sensitive to the context of the engagement. Engagement activities and strategies need to be tailored to the unique needs and circumstances and level of interest in engagement of patients (Grande et al, 2014; Higgins et al, 2017), as failure to adapt the activity appropriately would inhibit the engagement of the patient. Cultural competence of a system is an important ability in order for a system to provide care and engage people with diverse beliefs, values and behaviours, such as the patient's social, linguistic and cultural needs (Higgins et al, 2017).

Challenges, barriers and enablers of PE

There are several challenges, barriers and enablers of patient engagement discussed in the literature. Common themes which emerged are discussed in this section.

Lack of consistency and understanding of terminology and definition of PE:

Barriers to integrating patient involvement into health service, policy and research include the conceptual muddle of the articulation, understanding and implementation of involvement (Forbat et al 2009), a paucity of consensus regarding what exactly participation is, the best way to implement it and the impact of the participation (Whiston et al 2017), and the lack of a common understanding and interpretation of the concept of PE among stakeholders (Gallivan et al 2012). A lack of consensus and understanding about terminology, and subsequently the goals, expectations, roles and responsibilities of stakeholders are major barriers to achieving meaningful and successful PE and should be anticipated in the planning phase (Gallivan et al, 2012; Grande et al, 2014). Therefore, clarifying objectives, goals, roles and expectations of the engagement is crucial. Including all stakeholders in agenda setting, developing a shared mission and purpose from the outset of the process facilitates meaningful involvement (Fancott et al, 2018; Bombard et al, 2018). Providing training sessions to prepare staff and patients for engagement which provide clarity on roles and responsibilities aids all participants in understanding how they can optimally contribute (Bombard et al, 2018).

Time and resources, timing and location of engagement:

Effectively engaging patients requires a major investment of time and resources (Roseman et al, 2013; Forbat et al 2009). Competing resources and priorities are one of the biggest barriers to implementing PE (Ocloo and Matthews 2016). Timing of engagement is key. Engagement needs to occur prior to decision-making to ensure it is not tokenistic (Bombard et al, 2018). The location and physical environment influences participation e.g. cleanliness, and room set-up and the use of physical props and visual mapping have been shown to support discussion and interactions as well as demonstrate to patients and the public the value of their contribution (Thompson et al, 2015, cited by Bombard et al, 2018).

At the individual level:

At the individual level, patients' knowledge, attitudes and beliefs e.g. belief about their role or experience as a patient with the health service; their self-efficacy and confidence, education level, and their functional capacity, e.g. health status, and functioning all influence whether and to what extent they are able to engage (Forbat et al, 2009; Hibbard and Greene, 2013; Dent and Pahor, 2015, Ocloo and Matthews 2016). Vulnerable patient populations may face additional challenges (Carman et al, 2013) and some patients may be too unwell to be actively involved in their care (Bergerum et al, 2018). This highlights the need to tailor interventions to individual patients' variations and unique needs and circumstances, as failure to do so would inhibit their ability to engage (Higgins et al, 2017). Interventions that tailor support to the persons' level of activation and build skills and confidence have a positive impact on activation (Hibbard and Greene, 2013).

In the case of Patient partners, they do their part by acquiring knowledge and developing engagement practices. Patients therefore, need to have access to the relevant resources and information (Higgins et al, 2017). It is important to take into consideration patients' own engagement practices, their commitment to exploit the resources available and to tap into any potential synergy (Higgins et al, 2017; ,Pomey et al 2015). The patients' age, service satisfaction and level of education have an impact on support for greater participation (Whiston et al, 2017). Interventions which required high levels of patient work or have significant patient burden are deemed low feasibility (Grande et al,2014). Physical and organisational issues such as travel distances, transport and reimbursement for travel may also pose barriers to engagement (Forbat et al, 2009). Apathy was also perceived as a barrier with people not inclined to volunteer to go on committees (Forbat et al, 2009).

Mobile communications and learning technology are a key enabler of patients and families being more engaged with their care and to foster engagement efforts on a broader scale by linking patients across silos, thus augmenting their voices (Fancott et al, 2018). Even if a higher degree of involvement is not always appropriate for patients, many patients and their families will want to be more actively involved in healthcare activities (Carman et al, 2013).

At the organisational level:

Organisational policies or practices for engagement can enable patients to become active partners, such as rounding at the bedside or by creating patient advisor and partner roles in decision-making teams around quality improvement, patient safety committees and patient councils (Carman et al 2013, Ocloo and Matthews 2016). Traditional routines and other contextual standardisation combined with a healthcare culture that is resistant to change poses a barrier to enabling patient engagement (Batalden et al, 2016). Successful organisational support may lie in facilitating respectful and equal contexts where, for example a common language enabling common understanding between healthcare professionals and patients is promoted (Ocloo and Matthews, 2016). Motivational interviewing approaches have supported both healthcare professionals to employ a more personalised and collaborative approach and patients to become more engaged, representing a change in behaviour of both patients and healthcare staff (Bergeum et al 2018).

PE requires a practice culture that is receptive to making processes more transparent to patients while empowering them to suggest how those processes may improve. PE, therefore has its risks as it requires significant transparency, the yielding of some control and presents the possibility that patients and public will propose novel but unfeasible ideas. Practices need motivation and a clear understanding of the possible benefits of PE before committing resources to implementing it (Roseman et al, 2013). Encouraging PE as part of regular day to day team thinking and embedding engagement as part of the ethos of the service are core components of implementing PE. Tailoring engagement to specific local contexts influences and promotes engagement and improvement efforts at all organisational levels, and healthcare professionals should be supported by their organisation in partnering with patients in their clinical system (Bergerum et al, 2018). Mayben (2012) found that in a setting where healthcare professionals well-being is good, patient experience is also good which indicates that patients and healthcare professionals can influence each other in a positive way. A key facilitator of successful PE is the active involvement of leaders (Roseman et al, 2013; Bombard et al, 2018). Top-down and local champion led initiatives where leadership recognition, advocacy and commitment was given to implementing PE activities were instrumental factors in ensuring success. This is also required in order to ensure organisational sustainability of engagement, by leaders progressing engagement findings within

organisational strategic plans (Bombard et al, 2018). Active patient involvement requires continuous organisation preparation (Bergerum et al 2018).

At the societal level:

At a societal level, the broader social and political environment within which patients and healthcare organisations operate have an impact on engagement, which is influenced by social norms and local and national policies (Carman et al 2013, Ocloo and Matthews 2016). Issues regarding inequality, discrimination and social exclusion pose a barrier for inclusion of many groups and individuals having the opportunity to participate in PE (Ocloo and Matthews, 2016).

Opinions of stakeholders:

Opinions of all stakeholders in the engagement process can influence the amount of participation achieved. Lack of implementation of PE may be due to attitudinal, cultural, and behavioural barriers to participation, with healthcare professionals being required to do things differently and relinquish responsibility and power. Some healthcare professionals feel threatened by the notion of active involvement, and some feel the need to ensure that the professional roles are not compromised by patient participation (Ocloo and Matthews, 2016, Whiston et al, 2017; Forbat et al, 2009). Clinicians attitudes can limit participation (Whiston et al 2017). Yet, there needs to be a shift away from paternalism and toward collaboration (Forbat et al, 2009). Patients are also required to behave and think about their health and care (Whiston et al 2017) and the belief that healthcare professionals didn't welcome the input of patients and the public (Forbat et al 2009). A crucial factor in changing attitudes is participating in supported engagement work and the resulting subsequent experiential learning (Forbat et al,2009). Attending training sessions together built positive relationships between patients and healthcare staff which further served to resolve the key barrier of staff scepticism towards patient engagement and sharing power with them (Bombard et al, 2018). Despite healthcare professionals finding PE unfamiliar and challenging, collaborating in a structured project helped teams work together and resulted in a changed culture. (Roseman et al ,2013). Gaining a deeper understanding of patient partnership practices helps healthcare professionals feel less threatened and enables them to establish trust-based relationships with patients (Pomey et al, 2015). A therapeutic alliance which is a supportive relationship

between patients, organisations and healthcare professionals must exist to allow evaluation of healthcare services options in a collaborative way and sustain partnerships towards a shared outcome (Higgins et al,2017).

Representation:

Representativeness is an issue that poses a potential barrier to PE. There are concerns that those who are healthier, better educated, more articulate, have the time and can afford to attend are most likely to get involved and therefore may not be able to represent the concerns of the majority (Forbatt et al,2009). Handpicking of a narrow group of individuals and one or two appropriate or acquiescent representatives to be involved can occur, with many groups who may have greater or particular healthcare needs than the wider population often excluded from the involvement process. This can also curtail the pool of ideas for improvements and subsequently the opportunity to break cycles of suboptimal care (Ocloo and Matthews ,2016). It is important to ensure that there is diverse representation that is consistent with the broader population (Bombard et al, 2018). Using a variety of engagement methods across the spectrum from consultative to more collaborative lessens the expectation that just a few selected patients can represent the voice of all patients and addresses the tensions of representation versus representativeness (Fancott et al, 2018). Using a range of methods also ensures that a wide range of perspectives from many patients can be heard, collated, and used to inform developments of service delivery and policies designed in co-design teams (Fancott et al, 2018). The issue of naïve versus professional patients is also raised as a concern, where those with experience and knowledge of the health service are judged to have too much insider knowledge and therefore no longer bring a naïve perspective (Bairnes and Cotrell, 2012, cited by Fancott et al, 2018). However, a wide range of patient perspectives is generally sought (Bombard et al, 2018). When choosing recruitment methods, potential for introducing bias and inclusion of self-selected participants needs to be considered (Bombard et al, 2018). Methods of recruitment noted in the literature include recruiting participants through staff recommendations, social media or other marketing methods using a detailed job description (Roseman et al, 2013), or recruitment done by patients themselves employing a formal recruitment process and selection criteria to ensure the person's suitability (Karazivan et al ,2015). In some cases stipends, financial remuneration

or other incentives such as access to medical care or diplomas encouraged participation (Bombard et al, 2018).

Power gradients:

Concerns about power relations between patients and healthcare professionals were voiced (Forbat et al 2009), with dissatisfaction being expressed regarding the perceptible power hierarchies and imbalances between patients, families and healthcare professionals (Forbat et al,2009). Working together as equal partners was perceived as being important, acknowledging that patients' experiential expertise complements the healthcare professional's knowledge and experience (Forbat et al, 2009). Lack of integration of patients and healthcare professionals in participatory activities may have prevented mechanisms of mutual learning and evolution within the microsystem, thus limiting the developed guideline's relevance and quality (Pittens et al, 2013 cited by Bergerum et al, 2018).

The power gradient between the patient and healthcare provider is too steep to be overcome by methods of engagement that do not influence the actual communication process (Grande et al, 2014). Ensuring all stakeholders have an equal voice in all aspects of the engagement activity has been found to equalise the power. The use of techniques such as values and belief exercises and narratives to facilitate shared understanding helped level the playing field. External facilitation created a positive working environment of mutual respect and equal partnership (Iedema, 2010, cited by Bombard et al 2018). Having an external facilitator who is removed from the clinical area leading involvement encourages openness (Forbat et al, 2009). Co-design and co-production methods were also shown to promote successful PE and address the power imbalance (Batalden et al, 2016; Ocloo&Matthews, 2016; Bombard et al, 2018). Having a buddy system for patients and families also encourages participation in engagement activities (Bombard et al, 2018). Bringing patients into already established structures helps to create true partnerships as by doing so the relevant and valid understanding and expertise brought by the patient is recognised and can be incorporated immediately into processes (Karazivan et al, 2015). Although in general if PE is developed well at the formal level with extensive rights to voice opinions about services, the balance of power is still asymmetrical, with healthcare professionals holding more information than patients and informational barriers evident (Dent and Pahor, 2015).

Providing feedback on how suggestions were acted on increases the accuracy of the findings and also provides an opportunity for clarification or additional suggestions. Demonstrating to patients they have been listened to and that their input has been acted upon reduces the risk of the engagement being perceived as manipulation (Kvael et al, 2019). Building in regular updates to the support group also gives the opportunity to elicit further views and broaden the reach and involvement of patients (Bombard et al, 2018). This collective action through patient associations can often support active engagement (Dent and Pahor, 2015).

Health literacy:

Health literacy is “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions as well as cultural background, attitudes towards health interventions and availability of caregiver support services” (Higgins et al ,2017 pg 32.). It has an impact on a person’s ability to engage (Carman et al 2013). Interventions designed to improve patient and healthcare professional communication such as the point of care engagement tools are seen as essential to good patient-centred care (Grande et al, 2014).

Tokenism versus meaningful engagement:

Tokenism is defined as “the practice of making perfunctory or symbolic efforts to engage communities or patients” (pg 290, Hahn et al,2013) or “the difference between..... the empty ritual of participation and having the real power needed to affect the outcome” (Arnstien 1969, cited by Hahn et al,2013 pg. 291). Tokenism may have emerged due to a lack of resources, lack of practical support and strategies and a limited understanding of the theory underpinning PE (Rowland et al, 2017, cited by Majid & Gagliardi, 2019). It can occur at any level of engagement, therefore the level of engagement needs to be consistent with clearly defined goals for a given engagement activity (Hahn et al,2013). If the inclusion of patient as advisors or partners is tokenistic, if the engagement is not authentic and patients are included but not considered, then real danger exists that the engagement will be perceived as manipulation (Fancott et al, 2018).

Hahn et al (2013) have designed a table with activities mapped on a genuine-token continuum under three broad dimensions of methods/ structure of research, intent and relationship building. They concluded that what was most important was that “the intent to engage needs

to be genuine” which is demonstrated by collaboration in important decision-making points throughout the life cycle of the project. The methods/structures of engagement include group composition and management, scheduling of meetings and communication and feedback. Structures do not infer intent, as sophisticated structures which appear designed to engage stakeholders may be used with no intent to share power or use contributions. One distinctive difference between tokenism and genuine or meaningful engagement is the intent to be truly engaged, to be involved in a shared dialogue and shared responsibility. When this kind of partnership is achieved, engagement will be actual, real and true (Hahn et al, 2013).

The notion of meaningful engagement is a nebulous concept that is not well defined, yet widely used in the literature and is related to the degrees of engagement referred to in models of engagement such as the IAP2 spectrum of engagement (Black et al, 2018, cited by Madij &Gagliardi ,2019). It may refer to ideals of reciprocity, authenticity and partnership, and represent an ethical commitment and two- sided deliberation within the engagement process in the design, delivery and improvement of health services (Majid & Gagliardi, 2019).

Not all patient engagement is good:

The concept that having some patient engagement is good does not hold true. PE is much more contextually bound and complex than that and power imbalance and identity issues play a role in the quality of PE (Fancott et al, 2018). There are potential negative results of PE and to identify them it is necessary to consider the potential unintended consequences of implementing PE activities or extending PE policies (Dent and Pahor, 2015) particularly if the patient is disempowered by the process. For example, in instances of forced responsibility where a patient is incapable of or is forced to make a decision they don't want to; proto-professionalism where the healthcare professional focuses more on compliance than co-creation, and manipulation where patients are invited to be involved in forums to legitimise policies rather than engage the patient (Dent and Pahor, 2015). The tendency for manipulation is based on misassumptions that citizen participants will be more agnostic than deliberative in their approach (Dent and Pahor, 2015), they have an axe to grind, are too emotionally overwrought with their illness, will find technical details boring and won't have anything to add (Dr Robin McGee, cited by Eleanor Rivoire in masterclass 2019).

Creating engagement capable environments

The term “engagement-capable environments” refers to organisations who through the enactment of the three main pillars of 1. enlisting and preparing patients and families, 2. training and preparing staff for engagement and 3. ensuring leadership support of engagement activities by providing resources and infrastructure, (Baker and Denis, 2011, cited by Fancott et al, 2018) have enabled meaningful engagement and established the cultural change that is needed to support engagement efforts (Fancott et al, 2018). According to Wiener (2009), this concept of engagement-capable environments taps into the myriad of complex components that constitute organisational readiness for change, among which are the collective preparation and abilities of providers and patients to work together, and organisational leaders who can demonstrate and provide support for the commitment and value of engaging with patients and families. Distributive leadership, where there are leaders in PE across all levels of the organisation, provides strategic focus at the organisational level, and support for the implementation of engagement initiative and efforts to involve patients in activities and decision-making at local levels. This approach ensures that resources, structures and a common commitment are present at all levels of the organisation, and not simply a mandate from the top down and has been linked with service improvement and improved outcomes for patients.

Strong relationships among leaders and with their teams seen as a key factor to enable change (Fitzgerald et al ,2013, cited by Fancott et al, 2018). Patient engagement is about creating, maintaining and sustaining relationships and making human connections. The interactions, trust and respect that are developed in these relationships between patients, staff and leaders create the glue for engagement-capable environments (Fancott et al, 2018).

Strong relationships also ensure a shared understanding of the purpose, roles, responsibilities and expectations for the engagement activity and help to shift power relationships by developing more collaborative and distributive leadership that challenge current culture, remove barriers and create new structures that support teams which include patients to work in new and different ways and allow authentic partnership. It moves the engagement process to relational engagement and relational accountability that can result in partnered change and improvement across healthcare (Plamondon & Caxaj, 2018, cited by Fancott et al 2018).

Successful patient engagement is fundamentally a culture change within an organisation, incorporating an underlying philosophy of care that values and respects patients' perspectives and needs.

Some organisations have sought to develop infrastructures to support a mosaic of engagement activities (Fancott et al, 2018) as per the findings of Tritter and McCallum (2006) that using a range of methods recognises that different engagement methods are required for different purposes and reduces a hierarchy that assumes that one engagement activity is better than another. Some strategies bring greater numbers and diversity of voices into engagement and others lead to co-designed work. A combination of both allows greater representativeness while still ensuring an element of co-design in the process. Eg. The development of advisor and partner roles to support PE activities gives patients and families a voice and a visible presence, an important reminder of the centrality of patients in health care, while also providing the opportunity for patients and families be key players in the process of co-design of initiatives (Fancott et al,2018).

Despite the volume of policy referring to and supporting PE, operationalisation has proved challenging with progress to achieve greater engagement being slow and conducted with varying rates of success and consultation being the most frequently used model rather than collaborative (Ocloo & Matthews, 2016; Forbat, Hubbard and Kearney 2009). This gap between rhetoric and operationalisation further challenges implementation. However, experiential learning and behaviour modelling have potential to make a significant impact on how PE is operationalised (Forbat et al 2009). Local context application of PE may also positively impact on successful operationalisation.

Identification of the challenges and barriers to, and the enablers of PE informs the essential conditions which must be met in order to implement meaningful and successful PE.

The role of Education in PE:

Throughout the literature there is a common thread regarding the need for training for healthcare staff and patients, families and the public in engagement skills. It encompasses the concepts of capacity-building and creating readiness for the implementation of PE.

Staff need a foundational understanding that recognises the value that patients and families bring to improvement efforts and delivery of care. Staff need to be prepared in order to engage with their patients in their improvement efforts (Fancott et al, 2018). Staff at all levels of the healthcare system need to be both trained in engagement skills, as PE can occur at any level including policy level, and supported in the implementation of PE (Ocloo & Matthews, 2016). It is hoped that by receiving training healthcare staff will also be better prepared to recognise and encourage various engagement practices that may benefit the patient in the management of their care (Pomey et al,2015).

In preparing for PE there is a need for honest self-assessment of the state of engagement practices within teams and organisations (Finset,2017). Teams often realised that they had underestimated the need to support staff to learn how to engage and include perspectives of patients in meaningful ways in their initiatives. Organisations that invest time and resources to learn how to engage in meaningful ways become more mature in their efforts to engage, deepening relationships with patients and families (Finset, 2017). One of the key recommendations for implementing effective engagement is that staff understand and receive training on involvement (Neech et al cited by Healthwatch UK,2018).

Patients, families and the public will also need to be trained in engagement skills both at the direct care level but also at organisational and policy levels. D'Agosinto et al cited by Finset (2017) et al, reviewed 32 papers on how to promote patient participation in healthcare interactions by training patients in the use of effective communication skills. They found that many interventions had a positive effect on the patients' active participation in healthcare interactions. At an organisational level, Canadian Foundation for Health Improvement (CFHI) cited by Fancott et al (2018), have found that partnering experienced Patient and Family Advisors with newer recruits helpful to give support and to help them gain skills of effective engagement.

The faculty of medicine of the University of Montreal have established a group of patient trainers who participate in teaching medical students. This ensures they get experiential learning in PE from early in their professional training (Fancott et al,2018).

As discussed earlier in this review, patients, families and healthcare staff attending training together further helps to build engagement practices and level the playing field in the context of power gradients. This helps to negate the view of “us versus them”, blurs the boundaries of their defined roles, and reduces the potential to adopt dominant or subordinate roles. Being able to build relationships and learn together, respecting and valuing the expertise and experience that each brings to the team, begins to break down the current hierarchies that exist locally within teams and more broadly within the system (Fancott et al,2018).

Education and training of all healthcare staff, patients, families and the public is necessary as it has a role in capacity building and creating readiness for engagement which helps ensure the implementation of meaningful engagement.

Evaluation of PE

Evaluation of patient engagement is advocated for in the literature, to monitor the implementation and development of PE (Carman et al, 2013), to ensure the integrity of PE principles and practice (Boivin et al, 2018), and to demonstrate the value of PE beyond it being the right thing to do, to help understand what works, why it works and with what impact (Carman et al, 2013; Fancott et al, 2018). Both the process of PE and the impact or outcomes of PE can be evaluated using a qualitative or quantitative approach (Dukhanin et al, 2018; Boivin et al, 2018).

Process evaluation:

When evaluating process, it is important to assess the composition, cohesion or collaboration of the group, how equal the participation is and the level of deliberation (Bombard et al, 2018), and the representativeness, the value and the success of the process (Boivin et al, 2018). Process metrics enquiring into preconditions necessary for engagement, representativeness and accountability present a specific measurement challenge. Surrogate

engagement process metrics such as attendance may not always evaluate the engagement process in a meaningful way (Dukhanin et al, 2018). Faulkner et al 2015 cited by Ocloo and Matthews (2016) suggest using 4Pi national involvement standards (principles, purpose, presence, process and impact) to effectively evaluate processes of PE. Accreditation Canada (2016) have included client and family-centred care in their standards for accreditation to ensure PE is benchmarked against the highest standards. The Framework for Public Involvement in Clinical Effectiveness Processes outlines practices to consider or to follow when involving the public in the processes of developing clinical guidelines and clinical audit (DOH 2018). Finding effective ways to evaluate Patient and Public Involvement (PPI) processes are important to support good practice in the development of PPI approaches and interventions and also to gain an understanding of the effects of PPI (Ocloo and Matthews,2016).

Impact evaluation:

Defining the impact or outcomes of PE is complex given the fact that PE is dependent on a variety of factors such as the context, the purpose of the consultation, policy, resources and organisational and individual's culture (Mockford et al, 2012). Robust forms of measurement and specific constructs and variables are required to measure the impact and the extent of impact of PE/PPI strategies. (Carman;2013, Mockford et al, 2012; Higgins 2017). It is difficult to measure the outcomes of engagement as there may or may not be a proven causal effect between the engagement and outcomes of interest, and meaningful engagement is more than mere perception- real outcomes should be measured rather than perceived (Dukhanin et al, 2019). Outcomes that have been evaluated include the impact of PE on improved quality and safety of care, on the organisation or institution, e.g. the culture of staff and care settings; and the patients' experience of being engaged, e.g. time, energy and cost of being involved and whether they felt their involvement was worthwhile in the context of whether decisions were already made prior to their involvement and the changes in power in relationships that PE implies (Bombard et al ,2018; Karazivan et al, 2015). Measuring only healthcare quality and cost does not reflect the relational aspect of PE which in the opinion of some authors is key to successful engagement (Dukhanin, 2019).

Process and impact evaluation considerations:

- When evaluating PE activities, it is important to include an intent evaluation component which measures the extent to which activities were genuine or token (Hahn et al, 2013). Including assessment of patient experience can be useful in evaluating potential tokenism, while simultaneously providing data for patient-reported outcome measures (Hahn et al, 2013; Carman et al ,2013 Boivin, 2018).
- The timing of when any evaluation or engagement occurs can influence the results of the evaluation and ideally should occur as early as possible in the PE process and continue throughout and to the completion of the PE activity or strategy (Danis et al, 2019 cited in Dukhanin et al, 2019).
- Any evaluation of PE should be designed in accordance with the underlying theory and the intended goals or outcomes.
- To optimise relevance and meaningfulness of evaluation, patient and public input into developing and choosing outcome measures is advocated (Dukhanin at al 2019, Whiston et al 2019). Involvement of patients and public rarely extended to evaluation tool design, or the reporting of evaluation results Boivin et al (2017).
- According to Sofaer cited by Dukhanin (2019), the stage of maturation of a given organisation or engagement strategy should be considered in relation to evaluation and expected outcomes.
- Inclusion of assessment of the acquisition and development of skills against a taxonomy of competencies for engagement in healthcare of both patients and medical and health science students is useful to assess and monitor their development Karazivan et al (2015).

Choosing evaluation tools or methods:

Dukhanin et al (2018), have identified many tools with which to get started and provide observations and suggestions to help potential evaluators choose tools. Boivin et al 2018 provide an open-access repository of evaluation tools outlining their strengths and weaknesses to guide appropriate choice of tool for practitioner's specific context and evaluation needs. Hudon et al (2010) identified two instruments that measure enablement at the individual level in a hospital setting, one assessing enablement from the patients'

perspective and the other from both the patient and the nurse perspective. Carman et al (2013) suggest that existing measures of PE should be assessed for their usefulness, for example, in the case of the Patient activation measure (PAM). PAM is a validated measure across varying languages, health statuses, cultures and demographic groups. It gauges a person's self-concept as a manager of their health and health care and identifies the patient's activation level (PAL), of which there are four, ranging from low to high levels (Hibbard & Greene, 2013). There is evidence that links a person's PAL to their health outcomes and costs, and more positive experiences with treatment plans. It has been used to improve and personalise patient care by tailoring interventions to strengthen patient's role to the patients' specific level of activation. In doing so more efficient use is made of resources by using PAL measures to guide allocation of resources with more support given to those with at low levels and less to those with high levels (Hibbard & Greene, 2013).

It was noted in the literature that the engagement process was most commonly evaluated rather than outcome (Boivin et al, 2018; Dukhanin et al, 2018). Self-administered questionnaires and surveys were most common type of tool identified. The high level of literacy needed to be able to understand most tools has to be addressed given that patients and the public are the target users and because vulnerable population engagement is a frequent concern, Boivin (2017). Bombard et al (2018) highlight the need for the augmentation of traditional surveys and complaints processes to move towards a fuller engagement of patients in reviewing and improving the quality of health care service delivery.

There is no one standard approach identified for designing and reporting engagement activities, therefore development of evaluative frameworks and measurements for the process and outcomes of engagement is needed (Bombard et al, 2018). The need to include different strategies in different settings in the evidence base in order to gain insight into which interventions are the most effective or which might work best in a specific context was highlighted by Hibbard and Greene (2013). By identifying effective PE strategies, activities and the factors of the context which enables positive outcomes, the benefits of engaging patients in health care can be realised at organisational and system level, and the learning can be generalised (Bombard et al, 2018; Fancott et al, 2018). Boivin et al (2018) state that without adequate evaluation tools being utilised, ensuring the integrity of engagement principles and practice is difficult.

It can be concluded from findings discussed that evaluation of both process and impact of PE is both warranted and necessary.

Summary

PE is multifaceted and complex, being described as both a process and a behaviour and is thought to be shaped by the relationship between the healthcare professional and the environment in which healthcare is delivered. It is not a quick fix as it requires cultural change in order to move from a paternalistic clinical system to one that makes PE the way we do things.

Terminology describing PE is riven with lack of clarity of definition which results in confusion about what engagement is, what the goals, expectations, roles and responsibilities are and therefore being implemented in a suboptimal manner. Unless clarity is achieved about the different ways in which involvement is ideologically constructed, set outcome goals and careful planning for impact on patients, research and services are rendered problematic if not impossible. Also important is that the definition of involvement should be agreed by user and staff together at the outset of the engagement activity. A glossary of terms could be developed to achieve clarity and advance the agenda of PE in healthcare in Ireland.

Many models and methods of PE are described in the literature with the common message that not one size fits all and that employing multiple methods across all levels of the healthcare system is most likely to achieve optimal implementation. Tailoring the engagement to the context and the individual is important, including the concept of cultural competence.

Many challenges and barriers need to be considered such as the time and resources required for meaningful engagement. Timing of engagement needs to be prior to any decision-making. Relevant information needs to be accessible for patients and the public to enable engagement. Keeping the workload low also enhances ability of the patient to engage.

Organisations require leadership drive to address the cultural change required. Engagement should be specific to the local context to optimise operationalisation. Distributive leadership has been shown to be successful in the implementation of meaningful PE. Organisational policies and procedures can both support and advance the PE agenda.

National policies and legislation can also support the PE agenda. Legislation or policy requirements can support PE implementation but if organisations are not fully prepared to engage, legislative requirements to implement PE can result in tokenism.

Representation and representativeness pose potential barriers to PE. Ensuring diverse representation is important to ensure a wide range of perspectives are voiced by employing a myriad of engagement methods including those more vulnerable communities whose needs may be greatest and unmet. Recruitment processes with selection criteria and job specifications should be used when determining who to engage.

Education of patients, public and healthcare staff is required in order to build capacity for meaningful engagement and to create individual and organisational readiness for PE. Education not only about the benefits of PE but also how to implement engagement methods at all levels of healthcare is required. Attitudinal barriers also could be addressed through education. Education also assists in addressing the power gradients that exist between healthcare professionals and patients. Health literacy issues may be resolved through education.

It is crucial that tokenism is avoided by ensuring genuine intent to engage, and ensuring that PE has clear and agreed goals and objectives.

Creating engagement-capable-environments ensure organisational, staff and patient readiness which are imperative for meaningful engagement. Distributive leadership and subsequent strong relationships between leaders, staff and the community associated with engagement-capable environments are factors which facilitate meaningful and sustainable PE.

Evaluation of patient engagement is important to monitor the implementation and development of PE, to ensure the integrity of PE principles and practice and to demonstrate the value of PE beyond it being the right thing to do, to help understand what works, why it works and with what impact. Developing an evaluation tool would be central to ensuring robust and meaningful results.

Having a repository of context specific methods proven to be successful assist greatly in guiding how to do patient engagement well.

In conclusion:

Given the multifaceted and complex nature of PE, there are many factors to consider in order to implement PE in a meaningful and sustainable way. It is necessary to embrace and implement PE to meet the challenges of contemporary healthcare systems and to provide high quality, safe, appropriate and effective care to those who use our healthcare services.

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