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Meaningful and effective patient engagement: What matters most to stakeholders

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Cover Page Footnote

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Meaningful and effective patient engagement: What matters most to stakeholders

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Abstract

To determine what resources, preparation, and support are needed for patients, providers, and leaders to meaningfully and appropriately engage in patient-centred health system redesign, researchers sought to learn what really matters to these three stakeholder groups. A qualitative descriptive design was selected using purposive participant sampling, focusing on ‘who’, ‘what’ and ‘why’ questions pertaining to stakeholder perceptions about patient engagement in their specific context as patients, providers or leaders. Four project groups were selected; each group was responsible for a strategic initiative within Alberta Health Services and represented one of three different levels of the healthcare system (i.e. program, site or governance). Semi-structured question guides were used to collect data. Thematic analysis of the transcribed participant responses revealed eleven major themes: understanding patient engagement; language, communication, information; level and timing of engagement; recruitment and retention; roles, responsibilities and expectations; reason for being; expense; time commitment; governance and structure; knowing who’s who; and evaluation. Patients, providers and leaders agreed to the importance of communication around the reasons for patient engagement including building trust through collaboration and clearly identifying goals, along with their roles and responsibilities. These stakeholder perspectives are needed to inform the development of tools, resources and education materials required to support patient engagement activities tailored to the needs, understandings and perspectives of stakeholders.

Keywords

Patient engagement, patient experience, qualitative, thematic analysis

Introduction

Engaging patients in the planning, delivery and evaluation of health policy and healthcare provision is becoming an accepted approach to improve healthcare delivery and increase decision-making transparency^{1,2,3}. Shared decision-making, described as a collaborative experience involving patients and providers, where patients play an active role in healthcare decisions, supports a healthcare system to deliver more prompt and safer care⁴. There are multiple methods and approaches to engage patients in decision-making that range from basic levels of involvement (e.g. completion of a survey) to meaningful and influential levels of engaged participation (e.g. membership on an advisory committee or council). The International Association of Public Participation (IAP2) has defined these levels on a spectrum of participation⁵. They demonstrate five levels of participation progressing from *inform* in which little or no active patient participation occurs (e.g. receiving information via a website, forum or other source) to *empower* in which the goal is to place the decision in the hands of patients (e.g. having an equal vote on decision-making committees)⁵. While no part of the spectrum is more important than the other, selection of

activities is dependent on the goal of patient participation or engagement.

Some approaches in service planning are considered by patients as being tokenistic, where, “most activities are limited to various forms of consultation, rather than interactive partnerships as are advocated for treatment decision making”¹. However, “if healthcare is to be truly patient-centered, patients must be provided with opportunities to influence the organization and delivery of services through involvement in services planning or evaluation”¹. This paper explores these views with various stakeholders in one large health system, Alberta Health Services (AHS) in Alberta, Canada. The perspectives of patients, healthcare providers and leaders are analyzed regarding what matters most to them about patients participating or being engaged in healthcare delivery decisions.

AHS defines engagement as “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 health service decision-making to enhance transparency and accountability^{7,6}. Within AHS, engagement is supported and advanced across the province by a Patient Engagement Department. To further support patient engagement within AHS, a study⁷ was conducted to gather stakeholder insights on what patient engagement means and what is required to make patient engagement successful. More specifically, the study sought to determine what resources (i.e. tools), preparation (i.e. education), and support (i.e. infrastructure) are needed for healthcare providers and leaders to meaningfully and appropriately engage patients in patient-centred health system design. What does patient engagement mean to patients, providers and leaders? What assumptions do they make about patient engagement? What do they feel is needed to make patient engagement successful and meaningful? And generally, what really matters to stakeholders?

Methods

Methodology

A qualitative research design was selected for this study to understand and describe the ideas, beliefs and experiences of three stakeholder groups – patients, providers and leaders. The study was pragmatic, used purposive participant sampling, focused on ‘who’, ‘what’ and ‘why’ questions pertaining to stakeholder perceptions about patient engagement in their specific context as patients, care providers or leaders and was conducive to flexible coding and thematic data analysis, as well as descriptive and interpretative analysis^{8,9}. Details of this methodology are described elsewhere¹⁰.

Setting

The study was conducted in AHS, Canada’s first province-wide, fully integrated health system. The organization employs over 104,000 staff members and is responsible for delivering health services to approximately 4 million people. The mission of the organization is to provide a patient-focused, quality health system that is accessible and sustainable for all individuals in the province. Research ethics committees from the University of Alberta, University of Calgary and the Community Research Ethics Board of Alberta approved the study.

Participants

Purposive sampling was used to select four project groups, each responsible for a strategic initiative within AHS. Participating project groups were selected based on the following criteria: have patient, provider and leader membership; hold regular meetings (continual patient involvement); and focused at a different organizational level (i.e. program, site, governance). Additional criteria included that group sizes would vary, as would their length of operation. All members of the groups were provided

with a high-level overview of the study and informed of the time and effort requested of them to participate.

Individual and Group Interviews

Patient, provider and leader participants were given the option to complete interviews individually or in a group setting with other similar representatives. Semi-structured question guides were used to collect data, allowing for several key open-ended questions while allowing the interviewer to probe for relevant topics that would elaborate on specific comments made by participants during the interviews^{8,9}. Questions focused on initiative purpose, individual and group characteristics, group dynamics (i.e. participation, interactions, power, influence), participants’ definitions of patient engagement including type or level of engagement, perceptions of supports and challenges related to patient engagement including resources and preparation, participants’ roles and responsibilities within each group and perceptions of evaluation of engagement of patients members in the group. Participant consent was obtained before each interview. The duration of individual interviews ranged from 30 to 60 minutes while group interviews ranged between 60 and 90 minutes. A trained interviewer carried out all interviews, which were audio recorded and transcribed verbatim.

Data Analysis

Interview data were coded by one of three members of the research team using a coding framework. The framework was developed through a series of steps that began with the researchers independently coding a few select interviews, with an eye to identifying underlying concepts. Next, the researchers met to compare and discuss the concepts they had identified and then, agreed on which of these would form the basis of the coding framework. All interviews were then coded using the coding framework. Subsequently, thematic analysis within each code allowed for an exploration of emergent themes and recurring patterns within each strategic initiative and across initiatives. Thematic analysis captures meaningful segments for comparing and contrasting across initiatives¹¹. To ensure trustworthiness of the data, two research team members reviewed each data set. Specifically, data were extracted and analyzed by one team member and a second team member validated the emerging themes. Discrepancies were reconciled through discussion between the two research team members.

Once the analysis of each stakeholder group was completed, findings were compared across the stakeholder groups as well as across the four initiatives to understand commonalities and differences. A final component of analysis included presenting an account of the analysis through a written summary and face-to-face discussion with the larger research team. This allowed for review and

revision of data analysis and contributed to further data synthesis.

Results

Project groups involved in the study ranged in membership size from 10 to 40 members; length of operation from six months to four years; and level of organization from program, to site, to governance. In total, 28 participants consented to be interviewed: 17 patients, three providers and eight leaders (see Table 1). Some participants spoke about the initiative they were directly participating in while others spoke about patient engagement generally and described past or ideal engagement experiences. Thematic analysis of the transcribed participant responses revealed a number of common sub-themes and eleven major themes: understanding patient engagement; language, communication and information; level and timing of engagement; recruitment and retention; roles, responsibilities and expectations; reason for being; expenses; time commitment; governance and structure; knowing who's who; and evaluation. The major themes and common sub-themes are shown in Table 2.

Understanding Patient Engagement

Participants provided their interpretations of what patient engagement meant to them using a variety of terms including, “*patient feedback*”, “*patient experience*”, “*patient and family centred care*”, “*involvement*” and “*meaningful engagement*”. Some participants used the terms interchangeably whereas others were very specific in their articulation of the definition and what assumptions and expectations they had of patient engagement. Patients generally described engagement as being free to identify issues or influencing decisions within the healthcare system and being involved in the development and evaluation of programs.

Providers viewed patient engagement as a partnership with patients across the organization and at multiple levels within the organization:

“It’s making sure that as an organization we systematically involve people who are receiving our services in all levels of planning, organizing and delivering at the point of care. So it’s working on all the different levels, having patients and families at all those levels. That’s to me what it is and doing that in a way that promotes really encouraging those partnership practices across the organization at all different levels”.

Leaders emphasized that patient engagement needs to be meaningful and not insincere or tokenistic, “... and not just giving lip service to setting up an advisory group, but actually integrating them into interviewing staff, being part of your strategic planning sessions, all of those kinds of things.”

Language, Communication and Information

Participants spoke about the use of jargon and the preferred mode, type and amount of information provided. Patients focused on the importance of meeting face-to-face and receiving information ahead of time to facilitate their preparedness for project meetings. They also commented on the use of appropriate language:

“Communication skills [are critical] because healthcare professionals talk in a language that’s sometimes very different... Very different than what the average [patient] can understand. They have to let go of the medical jargon and explain things to people”.

Provider comments focused on meeting individual needs when communicating and the importance of multiple forms of communication (e.g. in person, email, phone, etc.). Providers also spoke about the concept of confidentiality and discerning what is appropriate to share with patients:

“These [patient members] have all signed confidentiality agreements, but I think in the future, at some point, we’ll need to make a decision about what can we share with them and what we can’t share with them? Those are still untested waters in many respects”.

Leaders too, focused on confidentiality and restricting the use of “health” speak - that is not using jargon or rather, speaking in a way patients and family members can understand. They also focused on being conscientious of what is shared with patients.

Level & Timing of Engagement

Participants were asked about the level and timing of patient engagement in their project as outlined by the IAP2 Spectrum of Engagement⁵. Generally, comments focused on specific or clear expectations on the type and level of involvement to ensure engagement interactions are meaningful.

Patients focused on whether they felt the timing of their engagement experience was appropriate as they reflected on the stage, or timing of events during which they were brought into the discussions. In contrast, provider participants concentrated on the task at hand, or what they needed to have patient input on, before completing that task. Providers also communicated a concern for short project timelines, which they felt could contribute to tokenistic engagement:

“I believe that there are still pockets of being at the informing [level]. Rubber-stamping... Not on the part of the leaders involved in this initiative, but on the part of people trying to approach this group. The challenge is how to respectfully pushback and say ‘sorry you can’t just come

and expect a green light'; a tick box that you've done this [engaged with patients]".

Leader comments reinforced the issue of short timelines and affirmed the importance of being honest with stakeholders about how their input would be included in the final decision.

Recruitment & Retention

Participants remarked on the sub-populations represented within their committees including the individual characteristics and experiences of members. They also focused on the length of membership, ensuring that the work was meaningful and appropriate for the stakeholders involved.

Patients commented frequently on the demographic strength or gap of patient stakeholders such as their ethnicity, age, gender and healthcare experience:

"We know there are people who are not represented, such as the homeless, First Nations, different ethnic backgrounds, which doesn't have to mean race, but just different experiences (e.g. recent immigrants). So there is some cross-section missing. Although the group is not firm and fixed; there is some recruiting that they're still doing and that kind of thing".

Providers similarly suggested having a mixed representation of stakeholders of varying demographic background. They also made comments on recruitment approaches and being conscious of the patient's individual healthcare experience. Leaders also focused on recruiting a mix of members - while ensuring those members can meaningfully contribute to the issue. Leaders commented frequently on the need for members to be emotionally and physically ready to contribute to healthcare improvement:

"The biggest disservice you could do for someone is to onboard them in an advisory capacity when they are still really and truly in a grieving reflecting stage over a negative event that may have happened to them".

Roles, Responsibilities and Expectations

Patient, provider and leader participants spoke to the importance of knowing what was required of them and saw working together to meet a common goal as the key to the success of any engagement activity. Patients commented that they felt their role was to represent their personal opinion and the opinions of community members or the sub-population they were representing: *"[My role] basically boils down to my opinion; what I feel, based on what I've seen and how I think there's room for improvement."*

Providers perceived their role to be that of a facilitator or educator. However, they explained that their role continues to evolve as the organization learns more about

patient engagement. Providers also commented on the expectations they have for patients as advisors or in other engagement activities, suggesting patient members should be active participants versus passive ones who *"just show-up once a month and eat their sandwiches"*.

Leaders discussed their role with engagement as leading by example and referenced the IAP2 Spectrum of Engagement⁵ which AHS uses as a guide for patient and public engagement:

"Leaders have to model [patient engagement] and what [it] looks like. It's not something fluffy. We need to share the evidence with their teams to support them in engaging patients and families i.e. you get improved health outcomes by engaging patients and families. It's not just about people being happier. It's about better care and a better quality of work life".

Reason for Being

Comments on this theme focused on the *raison d'être* and using engagement as an opportunity to build confidence and relationships amongst stakeholders. Patients preferred knowing the purpose and intent of the engagement work as it supports working towards a common goal. They felt building collaborative stakeholder groups facilitates trust:

"This is the kind of thing that may build community confidence...People actually have a voice to say, these are our concerns. It's a real opportunity to be able to ask, 'do you guys know what you're doing? What is happening inside those doors?' The more there's transparency, the more there's trust".

Leaders agreed with patients, as they felt having terms of reference and organizational direction provides guidance.

Expenses

Expense-related comments centred on travel, lunch and parking and also touched on support required from an administrative perspective. Patients focused on factors of personal reimbursement; receiving compensation when participating in engagement activities. Providers identified personnel support as an expense, whereas leaders reflected on the benefits of involvement far outweighing the associated expenses.

Time Commitment

Participants articulated the importance of scheduling dedicated time to complete work associated with the activity (i.e. email, meetings and meeting preparation). Ensuring patients are aware of the time commitment is integral to the success of the engagement opportunity and expectation of participation. Patients relayed the value of the work and their willingness to take time away from work and family to contribute:

"It's still your own time. Myself, I usually take vacation time from work to do it, because it's generally during business hours that meetings occur. But again, if I want to have the input, then that's part of volunteering... there have been occasions for me where I was not able to get away from work and it just has to be that way".

Providers reflected on the time and commitment required of patient volunteers and the effect of short timelines on quality and inclusiveness. They also referenced the timing of engaging patients in project work and the pressures of project and initiative timelines:

"A lot of [patient engagement] has been here's what we developed, can I have your input and feedback and we'll come up with a new iteration and we go through a few rounds of getting their feedback... we need to get at "I've got a blank page. I need your help to build this".

Leaders expressed that meaningful patient engagement work does not occur off the side of one's desk.

Governance & Structure

Responses pertaining to governance and structure centred on participants' perceptions of why and how their committees operate and of recommendations for improvement (e.g. reduce committee size and reconsider committee recruitment approaches).

Patients made suggestions to how the committee should conduct the work. A patient recommended the formation of small breakout groups to discuss specific topics versus large committee debates to ease the sense of being overwhelmed. Providers commented on the ways in which they try to draw patients into the conversation and reinforced the importance of hearing from everyone:

"There's a vocal majority... but through the small group work and world café, you get to hear the less vocal [patients] point of view. From a true patient engagement perspective, if people are saying that they're going to give you their time, then we need to make sure that we put strategies and supports in place where we can hear everybody's opinion."

Leader comments identified the use of breakout teams to 'do' the actual work. Seen as a leadership role, chairing a committee was deemed important to help keep the committee on track, facilitate focused conversation and prevent "personal agendas" from taking the conversation astray.

Knowing Who's Who

Some participants wanted to know more about the other members; there was acknowledgement of the importance of building upon each other's strengths. Patients expressed a desire to have members share their names, experiences,

and areas of expertise. They also identified a need to develop meaningful relationships and meet the committee's mandate. Providers recognized that patient volunteers are devoted people willing to share their stories to improve the system. Providers also suggested that knowing the patient and their interests helps to determine the best fit when selecting patients for engagement opportunities. Leaders shared that large organizations struggle with "knowing who's who" within their programs and teams.

Evaluation

Participants discussed evaluation with a broad brush-stroke; from evaluating AHS as an organization to evaluating project committee work. Participants mentioned evaluation strategies including personal interviews, comment cards and surveys.

Patients focused on evaluating the clinical side of AHS as well as using formal evaluation strategies for the committee work they were engaged in:

"[By asking us these questions] you have raised a very interesting point. It's time we did an evaluation of our little group... I think it would be good to have an evaluation... Every year we go over our terms of reference and we revise or we talk about it, but to actually do some kind of evaluation, we haven't done that".

Similarly, providers spoke to the importance of doing evaluations within their operational context and patient engagement work. Leaders articulated the importance of evaluating patient engagement endeavours; however most leaders reinforced that evaluation was not anticipated nor planned.

Discussion

By conducting the study, we learned what patient engagement means to the participating stakeholders within AHS and what assumptions they make about it. Patients, providers and leaders articulated what really matters to them. The literature varies in terms of patient engagement perspectives but our study does confirm some of the same disparity or disconnect in terms of defining patient engagement as well as what activities are more meaningful in terms of patient engagement.

In this study, the 'patient engagement' term and definition was described in a variety of ways by patients, providers and leaders. Stakeholders used multiple terms interchangeably which is consistent with the literature as there is a clear absence of a common language for patient engagement or consistent understanding of its meaning¹². Patients used the words 'involvement', 'participation', 'patient engagement' and 'involved' when asked to describe their understanding of patient engagement. They

also articulated self-constructed definitions or used engagement examples to describe what patient engagement means to them; whereas, providers and leaders applied 'text book' like definitions when describing the same. Concerning the terms used to describe patient engagement, leaders applied similar terms to that of the patient group. Although using comparable terms, providers also spoke to 'partnership' amongst all stakeholders and across all levels of the organization. The term partnership has a different meaning when compared to involvement or engagement; partnership can be defined as a, "collaborative relationship between two or more parties based on trust, equality and mutual understanding for the achievement of a specified goal. Partnerships involve risks as well as benefits, making shared accountability critical"¹³. Essentially, partnerships are a higher level of engagement that closely resembles empowerment of participants with equal say in decisions⁵. Most of the findings in this qualitative study were confirmed by the literature. Gallivan et al. discussed definitions for patient engagement as vast and diverse, wherein over 15 terms were identified and used synonymously¹². Within the literature, there is also an assumption about the mindsets of stakeholders and the inhibition of successful collaboration. Van den Heuvel, quoted by Cahill, articulated that patients and providers have a differing understanding of involvement, where, "*one emerge[s] from the humanistic perspective and the other from the bureaucratic view of consumerism based on controlling costs, outcome and efficiency*"¹⁴. We expected participants to produce divergent views on what matters most for meaningful patient engagement, however this was not the case. Patients, providers and leaders supported collaborative approaches to health system and healthcare improvement. They all believed in a common goal; that being the success of the groups they belonged to and of the work they were participating in.

To support group success, representational and appropriate recruitment as well as defined roles and responsibilities were key factors identified by all stakeholders participating in the project. Patients suggested that they felt some members of the population were missing from their committee (e.g. homeless, war veterans, youth, First Nations and other ethnic groups and individuals with limited mobility, etc.). This sentiment is supported by the literature and further suggests that recruitment should be contextually based on the engagement goals and objectives. Bellows, et al. believe there are three promising practices for meaningful stakeholder recruitment, which include using multiple methods for recruitment, ensuring a diverse mix of participant and aligning the stakeholder with the engagement opportunity¹⁵. While agreeing that the recruitment process should identify a representational group, leaders also articulated the importance of seeking patient advisors who have dealt with and accepted their

healthcare experience and who are, therefore, emotionally ready to participate in health system improvement discussions and decisions in a meaningful way. Happell agrees that finding a person without 'an axe to grind' is a goal when engaging with patients and family members¹⁶. Once appropriate and mindful recruitment occurs, patients, providers and leaders can focus on the importance of enacting roles and responsibilities to enable the group's objectives. Some participants articulated that their project committee employs a terms of reference to guide individuals and group activities and provide structure. A patient member articulated that the first thing to do is to "*clearly outline the purpose and roles*" to help guide people; prevent member intimidation and limit the possibility of someone's personal agenda taking over the committee. A leader-participant mirrored this and also commented that the role of a committee chair is to guide and focus the discussion to prevent potential disengagement and scope creep.

Aligned with discerning the roles and responsibilities of individuals and groups, is the planned assessment of the groups' activities and achievements. Patients, providers and leaders described evaluating engagement efforts as something that was important, although missing from their group activities and plans. Leaders articulated the general support for evaluation, however shared that they had neither planned for an evaluation nor think their group is ready to be evaluated. Although the body of literature pertaining to engagement evaluation is new, Sheedy recommends evaluation be a step planned for at the beginning of an engagement endeavour, suggesting, "*It may be too late to properly capture key information and analyze/ evaluate the valued knowledge that has been generated. Integrating these considerations into the planning process at the outset will save time and frustration at the end and enable better learning from the process as it is taking place*"¹⁷. Evaluating committee activities resonated with the patient participants however, they also focused on the need to evaluate the healthcare system as a whole, suggesting that "*a simple survey like a patient satisfaction survey*" be used to gather feedback and determine if improvement gains have been made. However Coulter, referenced by Cayton, argues that it is the patient experience and not the level of patient satisfaction that matters, or more so that, "*what happened to them, rather than how satisfied they say they are, is a better measure of success*"¹⁸.

As originally stated, the AHS Patient Engagement Department set out to determine what resources, preparation and support are needed to meaningfully and appropriately engage patients and families. While gaining patient, provider and leader insights on those areas we explored some key questions about what patient engagement means to AHS stakeholders, their assumptions pertaining to engagement, what they feel is important in successful meaningful engagement and what really matters to them. Patient, provider and leader

responses identified a number of thematic codes or sub-themes, which were clustered under 11 key themes to inform the research question. In summary, the concepts included in Table 3 are what really matter to stakeholders. Several patients, providers and leaders consistently identified these concepts when asked what patient engagement is and what is required to make patient engagement meaningful. Supported by the Institute for Patient and Family Centered Care, stakeholders believe engagement is founded on transparency and partnership where accessible language free of medical jargon is utilized¹⁹. Legitimate patient engagement requires dedicated time and resources, which may elongate decision-making timelines. However, to effectively increase patient engagement within the health context and break down barriers to patient involvement, it is suggested that adequately resourced projects with expanded timespans be utilized²⁰. Patient representatives should be prepared and contextually representational to ensure meaningful contributions to engagement activities. Although little is known about patient engagement measurement and evaluation²¹, stakeholders reinforced the importance of comprehensive engagement evaluation and relaying how patients contributed to the decision-making process⁵. Reinforced by the literature stakeholder insights shed light on the commonalities and multi-factorial requirements of successful genuine patient engagement.

Limitations

Choosing the right type of projects to provide insights on ‘what really matters’ is important when evaluating projects for how effectively and meaningfully they engage patients. The study team utilized project committees that were already formed and available versus creating new committees involving a diverse group of stakeholders. Utilizing the IAP2 Public Participation Spectrum, a committee is one engagement method, which has a predetermined level of decision influence and impact. As there are multiple engagement methods that fall along the participation spectrum, choosing the right one to support the engagement objective is integral to achieving success. One way to address this limitation is to expand to other types of engagement methods (e.g. workshop, survey, citizens’ jury) and compare participant perceptions of these other types of engagement activities with those of committee participants.

Although the numbers of participants in the three groups – patients, providers and leaders – could be viewed as a limitation in deducing any conclusions or making inferences for generalizations, this sample size is not unusual for qualitative studies. It is more important to search for common theme saturation across responses. In this study, the findings of similar perspectives within groups and between groups suggest that there was saturation obtained in the responses and even with larger

sample sizes, there would only be stronger confirmation of these similar perspectives.

Conclusion

The intent of the project was to determine what stakeholders needed and wanted to meaningfully participate in or implement patient engagement. Informing the project with patient, provider, and leader insights supported by literature provide a strong collaborative foundation for future stakeholder engagement. We have found within this study and the literature, that a strong collaborative approach and foundation for meaningful patient engagement is required. This means that patient’ experiences and stories are not only heard but also acknowledged or appreciated and utilized to inform improvements or changes in care programs, practices and policies. This collaboration can only happen when there is a common understanding of what patient engagement means to all stakeholders within initiative contexts. This includes transparency regarding information shared and used, consideration of time and volunteer costs, patient engagement planning and evaluation and above all, providing stakeholders with what matters most to them – having the necessary orientation and education, supports and tools for patient engagement that results in positive outcomes for the patient and for all levels within the organization.

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Table 1. Project Group Descriptions and Interview Participants

Project Groups			
Initiative #1 (site level)			
Initiative Description:	A citizen advisory team made up of patients, family members and citizen who partner with planners and leaders to ensure input is included.	Study Participants (N)	
		Patients	5
Project Membership:	40 members	Providers	2
Length of Operation:	2 years	Leaders	3
Initiative #2 (governance level)			
Initiative Description:	To advise AHS (senior leaders, providers and clinicians) on policies, practices, & delivery of healthcare services.	Study Participants (N)	
		Patients	4
Project Membership:	25 members	Providers	1
Length of Operation:	6 months	Leaders	2
Initiative #3 (program level)			
Initiative Description:	The working group is responsible for developing a patient and family learning package to provide insights on the patient journey.	Study Participants (N)	
		Patients	1
Project Membership:	10 members	Providers	0
Length of Operation:	6 months	Leaders	2
Initiative #4 (site level)			
Initiative Description:	The advisory committee is to provide a mechanism for the integration of seniors' priorities into the planning and delivery of specialized geriatric services.	Study Participants (N)	
		Patients	7
Project Membership:	15 members	Providers	0
Length of Operation:	4 years	Leaders	1

Table 2. Themes and Sub-themes

Themes	Sub-themes
Understanding Patient Engagement	Meaningful Patient Engagement Tokenism Perspectives (attitudes and assumptions) Positive and negative experiences Benefits and Barriers to Patient Engagement General interest Patient Safety Councils Research Clinical Benefits – influencing system Levels of Engagement Methods of engagement - variety Importance of Relationships in Patient Engagement Roles and Responsibilities
Language, Communication and Information	Jargon and alternative choices in language Sharing information Information is timely and appropriate Multiple communication channels Collecting and Compiling Input Bringing people together Managing conflict Having and sending the right messages Patient engagement is important
Level and Timing of Engagement	The How-to of Patient Engagement Need a guide Patient Engagement Checklist Volunteer Involvement Toolkits for Patient Engagement Toolkits for Planning and Implementation Patient Engagement Toolkits in General Toolkits for Advisory Councils, Committees and Research Miscellaneous Patient Engagement Toolkits Readiness to Engage Assessing Patient Engagement Readiness Decision to Engage - assessment Attitudes about Patients and Families as Advisors Orientation Orientation Tools Patient Engagement Methods Methods and variety of Engagement Choosing appropriate Engagement methods Advisors on Operational Working Groups and Steering Committees Planner for Engaging Families Patient and Family Advisory Council Guidelines for Successful Involvement on Committees
Recruitment and Retention	Recruitment of Patients and Families Patient and Family Recruitment Strategy Diversity and representativeness Recruiting Hard to Reach Groups Qualities of Patient Advisors Being a successful or effective advisor Interview questions for potential advisor

	Retention
Roles, Responsibilities and Expectations	Terms of Reference Clear expectations Visible leaders – role clarity Setting boundaries
Reason for Being	Impact of group Role in defining scope of patient engagement Intention of member involvement
Expenses	Compensating expenses Patient participation made easier
Time Commitment	Flexibility Staff time and involvement Time for activities Learning skills
Governance and Structure	Understanding organizational context Leadership Group structure and dynamics Patient Engagement Department Committee and sub-committee structures Administration and IT support Budget
Knowing Who's Who	Shared biographies Telling stories Member relations Developing relationships Dialed-in staff
Evaluation	Impact Evaluation Satisfaction Outcomes Patient Engagement Evaluation Criteria Process and Outcome Evaluation Evaluation Tools and expertise

Table 3. Summary points of what really matters to stakeholders

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| <ul style="list-style-type: none"> • The way engagement is understood and executed – that it should be collaborative and transparent at all levels within the healthcare system; • The use of common or plain language and effective information dissemination; • The appropriateness of timelines or arranging adequate time to conduct genuine stakeholder engagement; • The representational nature of committee members; • The importance of documentation regarding patient experiences and engagement contributions and organizational leadership guidance and transparency in the use of patient responses; • The allocation of adequate resources (e.g. time, personnel and volunteers, monetary); • The evaluation of engagement efforts to know how and to what degree engagement is making a difference within the healthcare system. |
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