

# PATIENT VIEWS ON “LADDERS OF ENGAGEMENT”

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**On behalf of:  
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# Executive Summary

The Ontario SPOR Support Unit's Patient Partnership Working Group (PPWG) has commissioned a patient-led study to investigate patient views on "ladders of engagement" frameworks, using IAP2's Public Participation Spectrum (IAP2 Spectrum) as an example. Objectives of the study include determining what relevance such frameworks hold for patients and discovering if there is opportunity to reimagine a framework from a patient perspective. To gain insights into these questions, eight (8) patients were interviewed, the findings of which are discussed in this paper.

Conversations with engaged patients revealed diverse motives, preferences, and intentions related to engaging in research. The participants had differing understandings of key concepts such as partnership, meaningfulness, and what constitutes 'good' engagement. As a result, the interviewed patients did not relate easily to the IAP2 Spectrum. They felt it did not accurately reflect their experiences, and some thought it was not a desirable or helpful model from their perspective. Some patients were in agreement, however, that the IAP2 Spectrum may be useful in familiarizing newly engaged patients with researchers' views on engagement.

As a way to more easily talk about and analyze patient views, the participants were identified as belonging to one of three groups: patients who volunteer to provide their perspectives and feedback; patients with pre-existing professional-level research experience who volunteer their skills; and patients who seek to shape the practice of patient engagement by providing consulting to researchers and health institutions and organizations. Sorting the participants in this way was instructive as it helped to illuminate some of the tensions within the engaged patient community, particularly as they relate to the increasing "professionalization" of patients. In particular, participants were divided on whether meaningful contribution to engagement activities requires full partnership with researchers. In addition, there was concern among some participants that research-related training for patients may affect patients' abilities to maintain their unique patient perspectives, considering the intensive socialization into research practice that training provides. Another notable finding was that some participants felt that patients who advise on the practice of patient engagement do not necessarily represent the views and preferences of all engaged patients.

While there are no easy solutions to resolving these tensions, this study helps to shed light on patient views on engagement in research and offers ideas for further investigation.

# 1 Introduction

## 1.1 Context



In the Strategy for Patient-Oriented Research (SPOR) developed by the Canadian Institute for Health Research (CIHR), a goal is for patients to be involved in health research “as much and as meaningfully as possible” (Canadian Institutes of Health Research, 2014), which may include developing research questions, designing studies, recruiting patients, interpreting findings, and disseminating results. The guiding assumption is that patient engagement at these levels of research—with patients not as subjects but as collaborative partners—will ensure that patient priorities and perspectives are reflected in both study design and research outcomes, with the end goal of increasing relevance of health-related research to patients (Nass, Levine, & Yancy, 2012).

The Ontario SPOR SUPPORT Unit (OSSU) collaboration, funded by the Government of Ontario and CIHR, engages patients, researchers, clinicians, policy makers, industry representatives and other health system professionals to implement Canada’s SPOR within Ontario (“Ontario SPOR Support Unit,” 2018). The OSSU Patient Partner Working Group (PPWG), whose current membership includes ten (10) patients and caregivers, was formed to support OSSU-funded projects related to advancing patient-oriented research in Ontario. The PPWG has identified several projects of interest, including investigating “ladders of engagement” from a patient perspective.

## 1.2 Aim of this study



The aim of this study, as initially defined by the PPWG, is to understand patient views on current conceptualizations of engagement frameworks, colloquially referred to as “ladders of engagement.” IAP2’s Public Participation Spectrum (International Association for Public Participation, 2014)<sup>1</sup> is used as an example as it is commonly referenced by both patients and researchers to describe or explain patient engagement in research (Canadian Institutes of Health Research, 2015). The PPWG is interested in considering this framework from “a patient perspective,” which means finding out from engaged patients<sup>2</sup> their views on the framework, and by extension, their views on patient engagement in research.

The PPWG’s interest in this investigation stems from an understanding that frameworks like IAP2’s Public Participation Spectrum (IAP2 Spectrum) are used to describe, explain, and implement patient engagement activities within health-related research (Canadian Institutes of Health Research, 2015). Frameworks are often developed by researchers, academics, administrators, and others who oversee or advise on research projects (e.g. Ruco & Nichol, 2016; Shippee et al., 2013) . While frameworks co-developed by patients do exist (e.g. Hamilton et al., 2018), patient perspectives are not commonly reflected in engagement frameworks and patient views on engagement in research are not well-represented in the literature, with

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<sup>1</sup> See section 1.3 Background on “ladders of engagement”

<sup>2</sup> Engaged patients are patients who are or have been involved in research projects, not as research subjects but as collaborators or “patient-partners.”

the exception of a small number of process-focused studies (e.g. Finney Rutten et al., 2015). Increasingly, there is a call for “[g]reater data on what patients desire in research opportunities” (Bombak & Hanson, 2017, p. 41). Understanding patient views, then, may serve to inform and inspire new and improved directions for patient engagement in research, with patient perspectives integrally shaping not just research itself, but also the practice of engaging patients in research.

### 1.3 Background on “ladders of engagement”



An impetus for this study and a key interview topic is “ladders of engagement.” This colloquial term is in fact a misnomer which can lead to confusion or misunderstanding when left unclarified. The term is explained below as it relates to IAP2’s Public Participation Spectrum (See Figure 1).

Figure 1. IAP2’s Public Participation Spectrum

<b>IAP2’S PUBLIC PARTICIPATION SPECTRUM</b>						
The IAP2 Federation has developed the Spectrum to help groups define the public’s role in any public participation process. The IAP2 Spectrum is quickly becoming an international standard.		<b>INCREASING IMPACT ON THE DECISION</b>				
	<b>INFORM</b>	<b>CONSULT</b>	<b>INVOLVE</b>	<b>COLLABORATE</b>	<b>EMPOWER</b>	
<b>PUBLIC PARTICIPATION GOAL</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.	
<b>PROMISE TO THE PUBLIC</b>	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.	

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Although the term “ladder of engagement” is used generically to describe many kinds of frameworks, it is speculated that the IAP2 Spectrum and others like it are heavily influenced by a specific citizen participation model proposed by Sherry R. Arnstein (Brodie, Cowling, & Nissen, 2009, p. 18). Arnstein was then an employee at the Washington-based U.S. Department of Housing, Education, and Welfare. Arnstein’s “A Ladder of Citizen Participation,” an activist’s call to action, draws attention to power imbalances in civic activities and advocates for redistribution of power to citizens (Arnstein, 1969). Arnstein reframes citizen participation as citizen power: “[Citizen power] is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future.” (1969, p. 216) Although published almost 50 years ago, Arnstein’s ladder model continues to have enduring influence.

Arnstein’s model itself is presented as an illustration of an actual ladder<sup>3</sup>, with individual rungs representing different degrees of citizen participation within broader groupings. The lower rungs (Manipulation, Therapy) are grouped as “non-participation.” The middle rungs (Informing, Consultation, Placation) are grouped as “tokenism.” The upper rungs (Partnership, Delegated Power, Citizen Control) are grouped as “degrees of citizen power.” Arnstein concedes that this ladder conceptualization is likely too simple to convey the true complexity and nuance of citizen engagement but she offers it as a model nonetheless, imagining it can be applied to other arenas where “nobodies’...are trying to become ‘somebodies’ with enough power to make the target institutions responsive to their views, aspirations, and needs.” (Arnstein, 1969, p. 217)

Arnstein’s original applications of the ladder include U.S. federal programs such as anti-poverty initiatives and an initiative known as Model Cities; her additional suggested applications are focused on areas where those without power make demands for power, including in the church, colleges and universities, public schools, city halls and police departments (Arnstein, 1969). Interestingly, Arnstein does not mention healthcare.

Arnstein’s ladder, while influential in many spaces where citizen or public involvement is a factor, is not without its critics. Tritter and McCallum, in a critique of Arnstein’s ladder, point out that solely emphasizing power does not acknowledge that for some users (or patients) participation itself can be a goal (Tritter & McCallum, 2006, p. 156)—although some disagree that this ought to be case (e.g. Carman & Workman, 2017, p. 25). Tritter and McCallum also suggest that users need to “have agency and the ability to shape the methods used for their involvement.” (Tritter & McCallum, 2006, p. 157) They propose that Arnstein’s model may be missing some rungs (2006, p. 161) and that a single ladder model may in fact be missing more ladders (2006, p. 163). Notably, these same concerns are reflected by the patients interviewed for this study.

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<sup>3</sup> Arnstein’s Ladder of Citizen Participation is publicly accessible here: [https://en.wikipedia.org/wiki/Sherry\\_Arnstein](https://en.wikipedia.org/wiki/Sherry_Arnstein)

Despite the criticisms, Arnstein's ladder has inspired a multitude of variations and new models, adapted or edited to fit changing times and different communities, including health-related research (e.g. Crowe, 2017) and involvement in "care groups" (e.g. Attree, Morris, Payne, Vaughan, & Hinder, 2011; Lemmens et al., 2015). IAP2's Public Participation Spectrum is thought to be one of them (although it does not reference Arnstein's work) and continues to be referred to as a "ladder" model (e.g. NHS England, 2015, p. 7).

The IAP2 Spectrum is not a ladder but rather a simple grid with five columns and two rows (see Figure 1). The columns are labelled Inform, Consult, Involve, Collaborate, Empower. The rows are labelled Public Participation Goal and Promise to the Public. Inside the grid are corresponding descriptions related to each cell of the grid. For example, the Public Participation Goal for Consult is "to obtain public feedback on analysis, alternatives and/or decisions."

Some of Tritter and McCallum's critique of Arnstein's ladder could also be applied to the IAP2 Spectrum, as it, too, is a simplified representation of a complex idea. However, due to its frequent misnaming as a ladder, the IAP2 Spectrum can be misunderstood as a progression model, which it is not. The arrow pointing from left to right is not meant to indicate a step-by-step linear path but rather to represent increasing impact of patient input on particular research decisions. In other words, according to the IAP2 Spectrum, patients have the potential to have more impact on research projects if researchers "collaborate" with them instead of just "consult" them. This should be an uncontroversial idea if understood in this way. However, this is not the common understanding among patients interviewed for this study of what the model is meant to represent.

Regardless of whether one believes that it represents a progression model, the vocabulary and language choices in the IAP2 Spectrum suggest that it is meant to represent the point of view of a researcher or research entity. For example, the Promise to the Public under Inform is, "we will keep you informed," which means (in the context of patient engagement) the researcher ("we") will keep the patient ("you") informed. It is a reasonable assessment by the OSSU PPWG that the IAP2 Spectrum does not adequately account for, or represent, patient perspectives on engagement.

## 2 Asking Patients

### 2.1 Method



One-on-one interviews were conducted with engaged patients to elicit their views on patient engagement in research as well as their views on ladders of engagement, using the IAP2 Spectrum as an example.

In total, ten (10) people were invited to participate in this study—eight (8) of whom were nominated by PPWG members and two (2) PPWG members who volunteered to be interviewed. The PPWG members agreed in advance that people nominated for interviews would be patients involved in research to any degree – extensive or particular experience was not required. Ideally, there would be a mix of ages, genders, backgrounds, and socioeconomic statuses. One (1) person declined and one (1) person tentatively agreed but lost contact. In the end, eight (8) people, including the two (2) PPWG members, were interviewed.

Participants were contacted by email to set up a mutually agreeable time and were sent a briefing email ahead of time. Interviews were conducted by phone and audio-recorded (with verbal permission from each participant). Participants were not explicitly asked to provide their demographic details (e.g. gender, age, employment status); rather, these details were inferred from the interview responses.

Interview questions were organized to cover three general topics: the participant's experience participating in research projects, the participant's views on patient engagement, and the participant's views on IAP2's Public Participation Spectrum. Each participant was sent a list of questions and a copy of the IAP2 Spectrum in advance of their interview. In reality, while each interview indeed touched on each of these topics in some way, each interview took its own direction depending on the participant's particular experiences as well as their interests and personality. For example, some participants had more to say about their personal experiences than about their views or perspectives on patient engagement, while others shared their views but did not share their own experiences. The interviews proceeded in an open-ended fashion (Alshenqeeti, 2014) with occasional redirects or interjections by the interviewer to return to the interview topics.

The audio recordings of the interviews were transcribed and content analysis was conducted (Hsieh & Shannon, 2005).

Following the interviews, the PPWG reviewed the initial findings with the author and discussed their responses, impressions, and views. Their views on the findings were not originally slated to be included as part of this study. However, PPWG members' thoughts on the collected views of other engaged patients and their own experiences as engaged patients added valuable commentary and is therefore included in the Discussion section (Section 4).

## 2.2 Description of participants



The participants come from a variety of backgrounds and experiences related to engaging in health research. Three participants are very experienced, meaning they have overseen or acted as co-leads of research projects, have consulted to researchers about engaging patients, or, as in the case of one participant, held a variety of leadership roles in a multi-year community-based research initiative. Four participants are experienced, meaning they have participated in research projects in a variety of roles, are knowledgeable about processes and activities related to engaging in research, and are connected to a community of patients interested in engaging in research. One participant has limited experience but is familiar with terms and concepts, attends research-related networking and information events, and served on a Board of Directors at their local hospital for many years.

Table 1. Participant summary

<b>Gender</b>	6 women 2 men
<b>Age</b>	All are adults over 18 4 self-identify as retired
<b>Location</b>	7 in Ontario, 1 outside Ontario <sup>4</sup> 3 live in large cities, 4 live in medium-sized cities, 1 lives in a rural area

All of the participants have additional experience as engaged patients in organizational or institutional settings as members of operational committees, instructors in education and training programs, and advisors on special projects, to name a few roles.

Most participants are or have been patients with life-impacting chronic health conditions for which they have had intensive or sustained care within the healthcare system. Several participants are or have been caregivers to a friend or family member.

## 2.3 Participant attitudes to being interviewed



The participants were supportive of this project and willing to share their experiences and perspectives about patient engagement in research. Several participants wondered if they were experienced enough to warrant an interview. Some participants expressed a desire to answer the questions “correctly” and asked the interviewer to let them know if they “said something wrong”. One participant wanted to ensure they were not presenting any projects or project team members in an unfavourable light. Many participants expressed a desire to be helpful, both to this project and to the “cause” of promoting patient engagement in research.

<sup>4</sup> Although OSSU is a provincial organization it was acceptable to the PPWG to include a participant outside Ontario who is familiar with patient engagement practices in Ontario

## 3 Findings

### 3.1 Diverging views and inner conflicts



While some participants had similar backgrounds and experiences, and indeed some had similar views and opinions on particular topics, no two participants had exactly the same views, nor did any arrive at the identical conclusions or reflections about their experiences.

However, all of the participants thought that researchers should actively seek out the involvement of patients, and that patients who are interested in research should have access to meaningful engagement opportunities.<sup>5</sup>

On occasion, participants expressed confusion or inner conflict, or acknowledged paradoxes. For example, on the topic of compensation for engagement activities, some participants thought that while payment should be offered to everyone, they themselves would not accept it. One participant went further to suggest that people who request or accept payment may not have appropriate motives, yet still acknowledged that in some cases lack of compensation may serve as a barrier to participation. Conflicts or tensions are described in the sections below, where relevant.

### 3.2 Patient motives, preferences, and intentions



Despite some inconsistent and divergent views, analysis of the interview transcripts revealed patterns and similarities among participants based on their motives, preferences, and intentions as engaged patients – the reasons they were engaging in research, their preferred ways of engaging, and what they hoped to accomplish. To aid in finding analytical threads and ways to talk about these similarities (and differences), the participants were arranged into groups (see Weiss, 1995, p. 173 for a description of typologies as generalizations).

These groups are listed below in no particular order and with no intention to “rank” them in relation to one another. They are not meant to suggest that one collection of motives, preferences, or intentions is better or worse than another, and are not meant to represent a definitive, comprehensive, or prescriptive typology of patients.

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<sup>5</sup> The interviewed patients were not asked to differentiate between types of health-related research, such as basic research, clinical research, or population health research.

Table 2. Summary of Participant Groupings

Group	Description	# of participants
<b>Group A</b>	These participants are primarily interested in assisting researchers in a volunteer capacity by sharing their experiences, perspectives, and insights.	4
<b>Group B</b>	These participants, also interested in assisting researchers as volunteers, have professional-level research experience which predates their patient engagement experiences and are interested in utilizing their research skills.	2
<b>Group C</b>	These participants provide patient engagement consulting and occupy leadership or spokesperson roles, both in volunteer and paid capacities. Their focus is on shaping the practice of patient engagement.	2



### Group A

These participants are older and/or retired volunteers who divide their available time between family, friends, hobbies, part-time employment, and volunteer activities. While they may have multiple interests competing for their attention, they are generous and flexible when asked to help with projects. They believe that the primary value they bring to a research project is their experience as a patient (or caregiver) as well as the insights that experience brings.

These participants enjoy being part of a community of like-minded people who share an interest in contributing to research. They prefer to engage as volunteers with no expectation of payment. They place a high priority on how they are treated by researchers and other professionals during their engagement activities. They want to be listened to, taken seriously, given performance feedback if they are asked to perform a task (e.g. give a presentation, instruct a class, etc.), and treated respectfully (evidenced by tone of voice, eye contact, verbal affirmations, etc.) They value clear and frequent communication with project team members.

Some of these participants are skeptical about the role and motives of patients who provide consulting to researchers about the practice of patient engagement (like those in Group C). Underpinning their skepticism are their conflicted views on related issues of compensation, credentialization, and professionalization. They see their own engagement as altruistic and satisfying, and already feel they are treated by researchers as partners who make meaningful contributions. They do not wish to become paid patient engagement consultants or career-oriented professionals nor do they especially desire specialized credentials. (Some, however, have taken courses or received training as required for engagement in particular projects.)



### Group B

These participants are mid-career researchers with extensive research experience and/or credentials. They believe the value they bring to a project in addition to their patient or caregiver perspectives is their understanding of research process and protocols. One Group B participant referred to their own group as “Patients Plus.” While they consider themselves volunteers, they appreciate acknowledgement of their work through attribution credits, co-authorship of publications, or other formal recognition associated with a research project.

One participant expressed many of the same priorities as patients in Group A, including respectful interactions, receiving performance feedback, and clear communication. The other did not express the same priorities but implied that if partnership is “real” and mutual respect exists, appropriate behaviour and conduct are expected.

These participants think of themselves as well-equipped to contribute to research activities. One differentiates this group from other patient volunteers who are not trained in research and who need time to acclimatize to fast-paced or technical discussions. Both are supportive of patients pursuing patient-focused research training so that they may contribute more substantially and demonstrate (through credentials) their readiness to contribute.



### Group C

These participants are engagement advocates who support patient-researcher partnerships. They advise organizations and researchers on how best to include patients in their projects. While the two people in this group have different opinions on how patients ought to be included and have different employment contexts, they nevertheless share compelling similarities.

Both participants have decades-long experience as patients with chronic conditions. While their experience supports their authority and credibility, their personal histories as patients were not substantial topics in their interviews. Instead, their narratives were focused on the topic of patient engagement, not on how they themselves experienced being engaged patients.

These participants are employed or hire themselves out to advise on patient engagement. They provide counsel to researchers and organizations—through facilitation, consulting, coaching, framework development, curriculum development, and other professional, managerial, or administrative activities.

## 3.4 Patient views



The broad aim of this paper is to consider ladders of engagement from the patient's perspective. In considering this question, a number of challenges arise, including a reasonable suspicion that—given the range of experiences and backgrounds of patients—there is no single representative patient perspective (see Rowland, McMillan, McGillicuddy, & Richards, 2017). Indeed, the interviews reveal not only that there is a diversity of views but that individual patients also have contradictory or inconsistent views. This diversity of views pertained to the IAP2 Spectrum as well as a number of other key issues in patient engagement, summarized below.

### 3.4.1 The IAP2 Public Participation Spectrum



Generally, participants in Group A struggled to locate themselves on the IAP2 Spectrum and felt it does not represent their experiences. Some commented that it simply didn't apply—if they are part of a team and engaged in dialogue, the terms “consulting” or “involving” seem out of place. They also felt that any given element of the IAP2 spectrum could conceivably be the case at different times throughout a project or even in the course of a single interaction, making the differentiations meaningless. This view was shared by a participant in Group B, who was concerned that the sections (“boxes”) in the IAP2 Spectrum do not reflect how collaboration actually works. This patient also noted that such rigid ideas of involvement may in fact be problematic for patients, as researchers may limit patient involvement based on the sections, and point to the IAP2 Spectrum as implicit permission to do so.

In the IAP2 Spectrum, “empower” is presented as the most in-depth level of involvement for patients with the highest level of impact. Participants in Group A were skeptical that this was achievable or even desirable. Some proposed that it was not likely a good idea to place “final decision-making in the hands of the public” as professionals with appropriate training make educated and informed decisions. These participants did not feel that existing governance models needed to be corrected; rather, they were supportive of the idea that professionals should include patient perspectives when designing and conducting research. They did not feel that adding patient perspectives requires that patients take the lead on projects.

Participants in Group A reclaimed the word “empower” as something patients do for themselves. One participant said that empowerment meant being able to share one's story in a safe place. Another said that empowerment is evident in being able to decline opportunities, to be involved at one's own pace, and to choose one's desired level of involvement. The notion that a researcher or project team would bestow empowerment upon the patient did not resonate with these participants.

For one participant in Group C, the IAP2 Spectrum seemed to be in conflict with goals and principles of “true” patient partnership frameworks, which include: early engagement of patients in formulating research questions; continuity of patient engagement from beginning to end of the project; co-design of the entire project (not just occasional co-design activities); and equitable compensation for patients. Viewed from this participant's perspective, IAP2 Spectrum activities such as “focus groups” do not constitute patient partnership and would be more appropriately categorized as research activities.

Despite critiques that were shared by a majority of the participants, several expressed that the IAP2 Spectrum is inspirational and aspirational—a participant in Group B said it was helpful for newly engaged patients to see what might be possible in the future—and agreed that it might be useful for orienting new patients to being involved in research. These participants appeared to want to conclude the topic of the IAP2 Spectrum on a positive note. Another participant suggested that a true representation of patient involvement would be too complex to develop, and that a simple chart such as the IPA2 Spectrum, even if not entirely accurate in all situations, provides a good starting point for newly engaged patients.

### 3.4.2 Levels of engagement



In contrast to the IAP2 Spectrum, which identifies levels of engagement based on degrees to which a research team engages patients, participants talked about levels of engagement using their own markers and measures.

Participants in Group A evaluated their level of engagement by noting how much of their time is spent on project activities. Spending more time on project tasks – for example, reading a large amount of background material – means they are more engaged. Spending less time on a project – for example, attending an occasional meeting – means they are less engaged. Some of these participants consider themselves more engaged if a project is especially interesting or if a project team is especially cohesive. Engagement, in this case, relates to the degree to which engaged patients feel intellectually stimulated or emotionally satisfied. Participants in Group B, on the other hand, equated level of engagement with the degree to which they use their research training, knowledge, and skills in engagement activities. For example, designing questionnaires means they are more engaged, whereas sharing their patient experience with others means they are less engaged.

Participants in Group C did not comment on their own levels of engagement as engaged patients; however, a high level of engagement can be inferred from their interest in patient engagement as a practice or occupation. One participant wondered if levels of engagement might be defined as a patient's degree of understanding of a project and/or a project's relative complexity. In other words, patients become more engaged the more they are required to know about the research process and related subject matter (see Thompson, Bissell, Cooper, Armitage, & Barber, 2012 for a study on patient professionalization and credibility). It was also suggested that, because the same engagement frameworks are often applied to different healthcare spaces (e.g. policy, clinical, research, organizational), it may be appropriate to develop different taxonomies and terminologies for each.

### 3.4.3 Meaningfulness



Participants in Group A and B associated meaningfulness with feeling both valued and helpful. Their answers about meaningfulness, then, were related not to whether patient contribution is meaningful to research endeavours generally but to whether their personal contributions are meaningful to *themselves*, personally.

Several participants felt their involvement in a project was more likely to be meaningful if the fit was appropriate and they had something relevant to contribute. Project involvement seemed less meaningful if they felt their particular experience and interests were not a good match for project objectives or if they

had a sense that they were interchangeable with other patients. Participants in Group B also noted that making a tangible contribution, where the results of their work were visible in some way – for example, if a recommendation was implemented – added to the sense of meaningfulness due to feelings of satisfaction. Both groups felt that meaningfulness is individually defined.

Participants from both groups expressed the importance of specific behaviours from fellow research team members during interactions, including demonstrating good listening skills, stable eye contact during conversation, active note-taking when patients are speaking, nodding or otherwise indicating affirmation, and other signs of listening and paying attention. One participant preferred face-to-face meetings and appreciated efforts by researchers and project teams that seemed to go beyond administrative formalities. These efforts might include follow-up phone calls, personal conversations, and spontaneous expressions of appreciation. Not only are these efforts important to these two groups of engaged patients, the absence of these efforts signals “tokenistic” engagement and is therefore less meaningful. One participant defined tokenism as being included merely for their patient status and not for their specific experience or insights.

Participants in Groups A and B shared similar desires to be listened to, to feel seen and heard by project colleagues, and to have their time and contributions treated respectfully. Many also expressed appreciation for the opportunities for intellectual stimulation and social engagement.

Participants in Group C did not comment on what makes engagement meaningful to them personally, nor did they comment on what might or should be meaningful to other patients.

### 3.4.4 *Partnership and ‘good’ engagement*



For participants in Groups A and B, meaningfulness and partnership are deeply intertwined concepts. On a few occasions, variations of these terms were used interchangeably. Generally, participants “felt like partners” if they were treated in a way that demonstrated to them that both their presence and contributions were valued and helpful. The term “partnership” was used when describing collaborative interpersonal relationships where each team member had something unique to bring to the project. Equity-based considerations common to business partnerships such as shared decision-making, shared leadership, and equal pay and recognition were not mentioned by participants in Group A or B as essential elements to their notions of partnership. This view stands in contrast to the views of participants in Group C, whose perspectives on partnership are discussed below.

Both participants in Group C agreed that the term “partner” is most accurately used when patients and researchers are equals in a project, in all ways that equity might be measured (including pay, recognition, etc.) However, they were not aligned on whether patient engagement that occurred below this level of involvement was acceptable without also having patient partners at the helm of the project.

One participant in Group C thought patients should be invited to participate in activities, tasks, feedback sessions, etc. at any point where patient perspectives might be helpful in informing or shaping a project. While in many instances the word “partner” may not be an accurate reflection of the relationship between patient and researcher, broadly calling a collaboration “a partnership” signals that an interaction is not (or should not be) hierarchical. Partnership, in this case, is again used to indicate that a collaborative

interaction is taking place regardless of who is in charge. For this participant, the word “partner” is reflective of the spirit of teamwork and is not used literally.

Overall, this participant was wary of overly focusing on the word “partnership” and instead was interested in how patients can shift the course of a project through their involvement. In this participant’s view, good patient engagement occurs when projects are impacted in some way by including patient perspectives and feedback. Additionally, good patient engagement does not occur as a siloed or sequestered activity, where patients and researchers or other project team members meet separately with information mediated between the groups by a delegate. Rather, for this participant, good patient engagement includes direct contact between team members, ongoing dialogue, and continual adjustments to the project plan to recognize and accommodate patient feedback.

The other participant in Group C holds patient partnership as the primary goal. To them, full patient partnership requires patients as co-leaders and co-authors (“patient-partners”); continuity of patient leadership from the beginning to the end of a project; and patients to define or be involved in the defining of research questions and project design. For this participant, patient partnership ideally includes equitable pay and recognition for all project leads.

When describing patient partnership, this participant used terms and language that are commonly used in the context of organizational systems, often related to business or administration. Among terms used when discussing patient partnership included: sustainability, programmatic, systematic, capacity building, framework development, tools. This is notable as the only time patient engagement was described by a participant primarily through an organizational or administrative lens.

### 3.4.5 Patient representativeness



Most of the participants in Groups A and B shared the concern that the population of patients engaged in research was not diverse enough and that various interests were absent from or underrepresented in collaborative or decision-making forums. Of particular concern was diversity in socioeconomic status – participants in Group A noted critically that most, if not all, of the people in their own group were from middle-class backgrounds with enough time and financial resources to allow them to volunteer. Race, language, and culture were not generally noted as aspects that needed better representation, although some participants commented on the importance of including people with Indigenous backgrounds.

Some participants specifically stated they do not feel qualified to represent anyone but themselves while engaged in research and feel their role is to share their own perspectives and experiences. One participant, however, said they do indeed feel they are representing all patients and conveyed a sense of moral responsibility for those who are not present at engagement activities.

The participants in Group C agreed that engaged patients should not be seen to represent or speak on behalf of other patients. Similar to the views of some participants in Group A, these participants support the idea that engaged patients should be involved expressly to share their own personal experiences and perspectives.

One participant in Group C described patient-partners as having distinct expertise, on par with expertise provided by the other (professional) specialists on the project team. This participant noted that there is no requirement for representativeness in physicians and researchers, and therefore none should be required of patients. For example, physicians are not called “physician representatives” and are not thought to speak on behalf of other physicians. In this view, the patient-partner is and should be treated as an equal colleague to professionals on the research team, with shared goals and responsibilities and equally legitimate levels of expertise.

In contrast, the other participant in Group C did not mention the term “expertise” but rather described engaged patients as bringing fresh ideas that help teams move beyond standard thinking.

### 3.4.6 Patient compensation



Participants in Groups A and B consider themselves volunteers and do not wish to be paid for their work. Some agreed (when asked) that lack of compensation may be a barrier for others who wish to participate – in which case an honorarium may be appropriate. One participant expressed concern that discussion of barriers is overly focused on monetary compensation as many other barriers exist that compensation cannot address. For example, someone working full-time or at multiple jobs may not be able to attend daytime meetings, regardless of compensation offered.

Most of the participants in these two groups (A and B) were wary of the idea of “paying people to participate” as those who are paid may feel they cannot be truly honest or speak critically. When considering receiving payment themselves, many participants equated pay with having a job and expressed concern about possible lifestyle restrictions, including reduced flexibility, fewer choices, too much responsibility, and concerns of having to work “24/7.” Many stated they did not want to work in this field as a career.<sup>6</sup>

Reimbursement of expenses and modest per diem payments to cover incidental expenses were acceptable to (and indeed expected by) participants in Groups A and B. Considering payment for their time or effort, however, seemed to cause discomfort. One participant expressed feeling guilty upon discovering an honorarium had been included in a reimbursement payment for travel expenses. These participants differentiated between financial expenses (e.g. food, taxis, travel, accommodation) and expenditure of effort related to their own labour or time. In other words, hard costs can be reimbursed but time and effort are strictly volunteer. Most, however, were not opposed to receiving small honorariums, gift cards, and other thank-you gifts offered in appreciation.

Participants in Group B were forthcoming about the value of recognition for their careers and related pursuits. They did not require financial compensation for their engagement work as they felt they were being compensated already through feelings of personal satisfaction and altruism and through opportunities for formal recognition (e.g. public acknowledgment, authorship), referenceable experience, and a network of contacts.

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<sup>6</sup> Most of the patients in Group A are retirees, which may have influenced the degree to which they would embrace the thought of having a job at their current life stage.

Again, participants in Group C had differing views on compensation. One participant was supportive of volunteerism but thought payment was appropriate for professional tasks, such as consulting, framework development, and other similar work. The other participant, focused on patient partnership, thought that organizations and research teams are obliged to offer payment with the understanding that the patient-partner is free to decline payment. Where patients are co-leads with researchers, their pay should match the researchers' pay. This participant did not comment on compensation in situations where patients involved in projects are not co-leads. Both participants in Group C agreed that although current budgets may not have room to pay patients, new funding proposals should always plan for patient compensation. In terms of their own compensation: as one participant is a freelance consultant and the other holds organizational leadership positions, it is reasonable to assume they are paid for some or all of their patient engagement-related work. However, information about salaries or wages was neither requested nor offered.

Discussion about compensation brought forward comments from participants in Group A about the role and work of patients who advise on patient engagement as a professional occupation. They saw the work of what they called "professional" patients as disconnected from and unrelated to their own work as volunteers. The perceived career-related ambitions of patients like the participants in Group C seemed both opaque and somewhat worrying to participants in Group A, as "professional" patients are in a position to advise others on how they, the volunteers, ought to be engaged. Participants in Group A felt unclear as to who or what was defining the value of their work and on what basis recommendations were being made by patients in influential positions.

## 4 Discussion

### 4.1 Views on engagement and the IAP2 Spectrum



A key objective of this paper is to consider ladders of engagement—specifically, the IAP2 Public Participation Spectrum—from the patient’s perspective. The task is an important one: frameworks and models serve as “best practice” roadmaps for researchers and organizational leaders to follow when establishing funding and operational goals for research projects

(Canadian Institutes of Health Research, 2014). As the impetus for researchers to engage patients continues to grow, it is reasonable to attempt to both reflect current best practices and establish aspirational goals through an orderly conceptual graphic. As a result, one might expect instructive results from eliciting patient views on a commonly referenced framework such as the IAP2 Spectrum.

As it turns out, the IAP2 Spectrum did not resonate with the engaged patients interviewed for this study. When asked about the value of developing a new framework that would better reflect their experiences and views, the participants showed little interest; perhaps they knew intuitively that developing a graphic representation that reflects all patients’ perspectives would be difficult indeed (see Rowland et al., 2017).

It is unlikely that any single framework can account for the myriad ways in which engaged patients think about their own engagement. Even in this small study there were at least six ways participants expressed how they assess or contemplate engagement, including

- the amount of time a patient gives;
- the depth of experience a patient brings;
- the extent to which a patient feels connected to, or satisfied with, the project;
- the types of tasks or roles the patient performs;
- the level of training, knowledge, or skill a patient has;
- the degree of equality shared with research professionals on the team.

The conceptual frame of the IAP2 Spectrum does not account for these patient perspectives on engagement, which is consistent with the concerns of Tritter and McCallum already discussed. In addition, none of the participants seemed to connect to the concepts presented in the IAP2 Spectrum, nor did they identify in which “box” they might place themselves. The value of the IAP2 Spectrum to the interviewed patients (of those who expressed a positive opinion) was as “a form of acculturation” (Bombak & Hanson, 2017, p. 39) in training newly-engaged patients to conduct research according to validated parameters. It was a valid hunch of the PPWG, then, that the IAP2 Spectrum does not adequately include patient perspectives.

## 4.2 Intergroup dynamics



Participants were sorted into groups according to their stated motives, preferences, and intentions related to engaging in research. While these groupings provide a clearer sense of possible “types” of patients, they also provide insight into how engaged patients might relate to and think about each other.

One notable finding related to the groupings is that participants expressed no desire to become a different “type” of engaged patient, now or in the future. Participants did not view their own status as engaged patients (e.g. volunteer, consultant) as a link in a chain or as part of a progression of stages that patients move through to achieve a future goal. For example, participants who are primarily volunteers and want to support the efforts of researchers (those in Group A) did not state or hint at an interest in becoming patient engagement consultants (those in Group C).

Another notable finding is that participants in each group had opinions or views on one or both of the other groups. In fact, the idea to arrange participants in groups for analytical purposes was inspired in part by the extent to which they contrasted their views against the perceived views of “other types” of engaged patients as a way to describe themselves. For example, one participant stated they are not the type of patient who wants to make a career of advising about patient engagement. This statement (and others like it) emerged unsolicited and indicates that the participants had a sense that there are indeed “types” of engaged patients that are different from themselves.

## 4.3 Views of the PPWG



The PPWG agreed that indeed there are divergent interests among engaged patients, that certain terms (like partnership and meaningfulness) mean different things to different people, and that patients who offer consulting services about patient engagement have different motives, preferences, and intentions than volunteer engaged patients.

While the PPWG does not want to polarize or create tensions within the engaged patient community, they acknowledged that exploring a typology of engaged patients based on these differences may help explain why consensus on all fronts can be difficult to achieve and may provide clues as to how to move forward.

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The PPWG coalesced around a few key ideas:

- The IAP2 Spectrum and similar frameworks do not adequately reflect patients' experiences in engaging in research. The PPWG was undecided as to whether a new framework or model is required, and for what purpose;
- Research projects that engage patients will benefit more from their involvement if they include a diverse group of patients with varying degrees of experience, interests, and knowledge at all levels of the project;
- An "all or nothing" approach, which accepts engaged patients only as equal partners in research projects, may exclude contribution from patients who would otherwise like to contribute;
- As patient engagement advisors or consultants seek to shape how researchers engage patients, the degree to which the broader engaged patient population is a) aware of their objectives, and b) in alignment with their objectives remains unclear.

## 4.4 Representativeness



With one exception, participants agreed that engaged patients should not be seen to represent other patients. However, multiple (and sometimes contradictory) claims about representativeness emerged from the interviewees. For example, a participant in Group C who agreed with this idea in principle also expressed a desire to see more patient views

"represented" through increased numbers of engaged patients. They acknowledged that while it is impossible to engage all patients, they posited that engaging more patients is better than engaging fewer patients because the chance of assembling a more representative range of views is greater. This comment suggests a desire for statistical representation of patients where engaged patients are identified as reflecting an "average" patient (Rowland & Kumagai, 2018, pp. 2–3) or where the ratio of "types" of patients in the general population of patients is reflected in the engaged patient population. In addition, members of the PPWG occasionally emphasized the importance of including "the voice of the patient," a term that was used interchangeably with "patients." When patient engagement is described in this way, it conveys a sense of symbolic representation in which "authenticity of [patient] feeling or experience" is made manifest where it was previously absent (2018, p. 3). In this sense, engaging *any* patient, without special attention to skills, type, or background, may be valid.

Another interesting notion arose in discussions with participants about representativeness which speaks to potential challenges to achieving idealized conditions. One participant, also in Group C, compared the status of (who they called) patient-partners with that of researchers and physicians, noting that the former should not be held to a standard of representativeness that the latter is not. This idealized view, which is meant to suggest equality between engaged patients and researchers, does not account for the conceptual shift required of all parties to see the patient-partner not as a subject or informant but as a peer to researchers. Hierarchical "power dynamics and the status quo" complicate this envisioned notion of patient partnership (Crowe & Giles, 2016, p. 1). As well, exploration of the assumption that researchers or physicians do not or are not seen to represent their professional peers is outside the scope of this paper and is therefore not included; however, investigation of this idea may bring more insight.

In summary, participant responses about representation and representativeness underscore the complexity of these themes and reveal a potential need for further consideration of definitions and objectives.

## 4.5 Inclusivity



Most of the participants perceive engagement as a fluid, dynamic journey—a series of encounters in which they continually assess and reassess a number of factors, including: whether their contributions are relevant and valued; how much time and effort they are willing to spend at a given time; whether their experiences and interests are a good fit for the task or role; whether they are treated respectfully and with appreciation. The patient volunteers place a high priority on flexibility and choice. They value their freedom to spend more or less time volunteering depending on their current life circumstances and interests. They and the PPWG share the view that patient engagement in research should be open to all who are interested, regardless of whether the terms of their engagement are defined as “patient partnerships.”

This inclusive approach to patient engagement necessarily makes room for any type of contribution, whether volunteer or paid, novice or expert, inexperienced or experienced. Considering the patient community as a whole, which is arguably as diverse as any group of people can be, an inclusive approach seems appropriate. This requires that patient community members continue to accept, accommodate, negotiate with, and collaborate with each other to ensure that diversity does not give way to division.

This inclusive approach, however, does not easily reconcile with the uncomfortable reality that some patient views have the potential to affect other engaged patients or to shape the practice of patient engagement in ways that may not be acceptable to all patients. Tensions arising from differing or conflicting patient motives, preferences, and intentions can manifest in a variety of ways, including:

- Patients in leadership or influential positions may not be seen (by other patients) to represent the patient community, nor do they necessarily claim to. However, these influential patients advocate for definitions, roles, and terms of engagement that may not be aligned with what other patients want. Some engaged patients do not feel their preferences are taken into account by those who are shaping the practice of patient engagement.
- Increasing interest in patients to attain research credentials or specialized training has generated concern in the wider patient community, as only those with time and financial means may be able to access this training. This may have a homogenizing effect, which runs counter to efforts to diversify. This has additional implications as it may deter people from becoming involved if they feel training is a requirement for engaging in research.
- Intensive socialization of patients into research practice through specialized training or extensive engagement experience may complicate or colour the unique perspectives brought by patients. Some engaged patients feel that patients should resist “turning into researchers” so that they may continue to provide vital counter-perspectives when contributing to research projects.
- Key terms that are used to describe and explain patient engagement in research, such as partnership, expert, and even engagement itself have different meanings and uses among patients. Definitions for these terms are contested which may contribute to disagreement and confusion when attempting to resolve tensions, develop guidelines or frameworks, or envision the future of patient engagement in research.

The origins of these tensions and the factors that perpetuate them are multi-faceted and complex, including the paradox of a requirement for engaged patients to be both “ordinary” and “effective” (Learmonth, Martin, & Warwick, 2009). On one hand, patients’ everyday experiences with their own health conditions and the care they receive *are* why their contributions are seen as valuable to research; they are “ordinary” in that a) they are not researchers and b) they have gained their insights through personal experience, not professional training. On the other hand, engaged patients are increasingly expected to talk and act in ways that more seamlessly fit with an organization’s ways of doing things. This can happen through informal socialization as well as formal training. One possible outcome of the expectation for engaged patients to be “effective” is that, when they excel, they become obvious candidates to lead organizational patient engagement initiatives—which means they are less likely to be seen as “ordinary.” This is certainly a difficult balancing act for engaged patients to perform and may help to explain why some may feel, at times, they are not all standing on common ground.

There are no easy or simple ways to resolve these tensions. However, one can imagine that a concerted and sustained effort by engaged patients to refine and negotiate terms of engagement may lead to terms that are more widely acceptable and inclusive. Although it may be a winding path to get there, the diverse motives, preferences, and intentions of engaged patients can provide helpful signposts along the way.

## 5 Limitations

There are several known limitations in study design, implementation, and interpretation of findings, including:



Participants were recommended by the PPWG, which itself is comprised of experienced engaged patients. This means that the participants, as a whole, may be more experienced and more familiar with patient engagement practice than the average engaged patient. This was a known consequence of the PPWG recommending participants but was deemed acceptable nevertheless due to project time constraints. Future studies related to patient motives, preferences, and intentions may yield different results if participants are purposefully selected for maximum variation.



Findings of this study are based on telephone interviews with participants and a teleconference and email discussion with the PPWG, which has obvious limits as a single mode of data collection (Alshenqeeti, 2014). This study may have benefitted from an opportunity to employ additional qualitative research methods and techniques, such as field research, participant observation, and analysis of findings through a critical theory lens. These additional methods may have helped to contextualize patient accounts and add analytical richness.



There are many findings in this study that were not originally anticipated or planned for, such as groupings of patients by motives, preferences, and intentions; ways patients think about the practice of patient engagement; and differing definitions and understandings of key terms. While it is not surprising that such findings would arise from discussions about ladders of engagement, the participants were not given an opportunity to reflect directly on these tensions and potential conflicts. Returning to the participants to further explore these ideas may provide additional insights.

## 6 Conclusion



This study was commissioned to elicit and understand patient views on ladders of engagement, which at first appeared to be a straight-forward task. Discussions with engaged patients, however, led to consideration of a much wider range of topics and themes which revealed a diversity of motives, preferences, and intentions. This diversity helps to explain why “a patient perspective” is difficult to identify and articulate, as such a single or monolithic patient perspective simply may not exist. Any engagement model, including IAP2’s Public Participation Spectrum, cannot hope to represent or reflect something as elusive as a universal patient perspective. A new model could be developed by patients in an attempt to include a diversity of patient perspectives; however, it may prove to be an exercise in futility and one in which patients do not find much value.

What could be helpful to patients is further inquiry into what matters to patients when engaging in research and possible ways to resolve tensions within the engaged patient community, such as those identified in this study. Investigations could follow the methodology and form of community-based participatory (health) research which is participatory, locally situated, collectively-owned, transformative, and reflexive (Wright et al., 2013).

## 7 Ideas for further study



Although participants did not specifically recommend the development of a new patient engagement framework (and despite the author's skepticism about the value of such an attempt), there may be interest in replacing or supplementing existing frameworks with a patient-oriented version that is more inclusive and reflective of patient perspectives. A patient-developed engagement framework that accounts for patient preferences in engaging in research may be one such undertaking.

An unplanned outcome of this study is a proposal to consider a new typology of engaged patients based on motives, preferences, and intentions. Investigating and analyzing why patients become engaged, how they would like to be engaged, and what they hope to accomplish may help patients and researchers alike to better understand some of the tensions that inevitably arise when a diverse group of people work together on something they care about. The groupings discussed in this paper—A, B, and C—represent a good first attempt at sense-making regarding motives, preferences, and intentions. However, further study in this area is encouraged.

This study focuses on patient views and does not include the views of researchers or research project administrators. The PPWG expressed an interest in researcher views on ladders of engagement, as well as investigation of their motives, preferences, intentions—analyzed on their own and in contrast to patient views.

Some of the tensions between patients outlined in this study could be eased or resolved with a better understanding of what kind of engagement is most effective at accomplishing CIHR's stated goals of patient engagement. Then, engaged patients may more readily agree on definitions and terms of engagement. Comparative studies of research projects with different engagement approaches which aim to assess and compare levels of improvement of research relevance as a result of engaging patients may be helpful.

The PPWG is interested in seeing more patient-initiated/patient-led studies (such as this one) related to the value of patient engagement in research to both engaged patients and the wider (non-engaged) patient population, based on patient-defined research questions and goals.

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