

It IS about us!

## Patient Engagement in Health Research

*A report on interviews conducted with members of Arthritis Research Canada's Arthritis Patient Advisory Board for a Qualitative Research Study of Arthritis Patients' Views and Experiences on Engaging in Health Research*

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## Executive Summary

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Patient engagement in health research is broadly understood to occur when patients are meaningfully and actively involved at any stage of the research process, from setting the research agenda to designing the research project, collecting data, and disseminating results. The guiding motto of “Nothing About Us Without Us” is central, embodying the democratic belief that people who are most affected by research have a right to have a voice in what and how research is undertaken if they choose. Although patient engagement in research is increasingly desired by patients, researchers and funders, there are a lack of resources developed from patients’ perspectives in order to guide the cultivation and sustainability of meaningful patient engagement in research.

Jointly developed by researchers and patient partners from Arthritis Research Canada’s Arthritis Patient Advisory Board (APAB), the *It IS About Us* study aims to: 1) explore patients’ views and experiences of patient engagement in health research, 2) understand the barriers and facilitators to patient engagement in health research, and 3) develop a user-friendly resource to support patient-researcher partnerships based on our findings for objectives 1 and 2. In 2016, we conducted 22 in-depth interviews with current and past members of APAB. Interviews were audiotaped and transcribed verbatim, and participants were invited to review and modify their transcripts. Our thematic analysis followed an iterative process using aspects of grounded theory.

The current report summarizes the findings of the preliminary analysis. Four preliminary themes were identified, including 1) *empowering patients: having the patient voice heard*, 2) *engaged patient as occupation: “adding another spinning plate to an already busy life”*, 3) *building social relations*, and 4) *demonstrating “there’s respect”*.

Our preliminary findings explore:

1. Participants’ views of their engagement in research as an opportunity to empower patients’ perspectives. A major barrier and facilitators to sharing perspectives as an APAB member are also identified.
2. Participants’ experiences of the added work involved in engaging in research as an APAB member, as well as the main barriers and facilitators to juggling this work amidst multiple priorities.
3. Participants’ perspectives on building social relations as a facilitator to cultivating ongoing engagement in research as an APAB member.
4. Participants’ perspectives on the importance of demonstrating respect within patient-researcher interactions as a facilitator to cultivating ongoing engagement in research as an APAB member.

Our next step is to conduct further analysis using an ethics lens to unpack ethical issues that are emerging from our preliminary themes. Preliminary themes also support further analysis of power dynamics within social relations between researchers and patients, and among patients.

A participatory approach will continue to guide our analysis, with meetings held with APAB patient partners to share perspectives on verifying, modifying or refuting emerging themes. Based on our findings for objectives 1 and 2, we will develop a resource in partnership with APAB patient partners to address objective 3. A half-day meeting will be held with APAB members to obtain feedback to refine the final resource.

## Introduction

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Underpinning patient engagement in health research is the motto of “Nothing About Us Without Us”. [1] Adopted by the global disability rights movement, it reflects the principle of participation and wider societal developments toward realizing citizen empowerment. [2] [3] Similarly, the emergence of ‘patients as partners’ is integral to patient-centred care and shared decision-making in healthcare. [4] [5] [6] These developments have laid a foundation for patient engagement in health research.

Support for patient engagement continues to increase. For example, research funding agencies in Canada, the United States (US), United Kingdom (UK) and elsewhere recommend patient engagement as a means to improve research relevance and quality. [7] [8] [9] [10] Not all forms of engagement are considered equal, but exist on a continuum varying from consultation to more participatory collaboration and shared leadership. [9] A 2014 systematic review found, however, that research dedicated to identifying the best methods and outcomes in achieving successful patient engagement is lacking and clearly needed. [11]

While several models are available to facilitate patient engagement in health research, it should be noted that many have been largely developed by researchers for researchers. For example, researchers have led the development of the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research’s (SPOR) Patient Engagement Framework, and the Patient-Centered Outcomes Research Institute’s (PCORI) Patient and Family Engagement Rubric in consultation with patients. [12] [8] Another example is Hewlett’s FIRST (Facilitate, Identify, Respect, Support and Train) model, which provides a practical guide to building researcher-patient collaboration based on the combined experiences of four researchers and three patients collaborating in rheumatology research. [13] Also in the U.K., INVOLVE has provided guidelines for researchers who are new to public involvement in research, which were developed with the support of an advisory group consisting of health researchers, a care-giver, and a public and patient involvement manager at the National Institute for Health Research. [14] In addition, Oliver et al. draw upon research and scholarship, and direct experience of researchers to develop a framework for distinguishing between different methods for public involvement in research, and the ensuing interactions and potential for impact. [15] There is currently a lack of resources grounded in systematic research from the patients’ perspective in order to support patients as they engage in health research.

To cultivate and sustain patient engagement, it is critical to better understand patients’ views and experiences of engaging in the research process. Despite growing attention toward the vital role of engaging with patients in research, little is known about the challenges they encounter, and how sustainable development of patient engagement can be achieved from patients’ perspectives. Without a better understanding of what patient engagement is, how it can best be put into practice, and what difference it makes from patients’ perspectives, the practice of patient engagement is vulnerable to tokenism (i.e. researchers making perfunctory or uninformed gestures towards engaging with patients) and failure to achieve outcomes that are feasible and desirable to patients.

### **Arthritis Patient Advisory Board of Arthritis Research Canada**

Founded in British Columbia by Arthritis Research Canada in 2001, Arthritis Patient Advisory Board (APAB) is a group of volunteers with at least one form of arthritis, whose goals are to bring their experiences and arthritis knowledge to collaborate with scientists at the research centre, and to serve as a bridge in disseminating research to the public. [16] A key accomplishment of APAB has been to publish

a quarterly newsletter written from the perspectives of people living with arthritis, which aims to keep the public informed of advances in arthritis research conducted at ARC. Originally, APAB was established with five members. To date, it consists of 21 members and 12 emeritus members (28 women; five men), aged 26-68 years. Most APAB members have been involved in at least three research projects led by Arthritis Research Canada scientists, while long-term members have been involved in up to 20 projects. As research partners, APAB members participate in identifying research topics, shaping the research, co-authoring scientific papers, writing lay summaries, attending conferences, and participating in grant applications. Furthermore, they mentor other patients, as well as researchers, trainees and research staff, in patient engagement in the research process. The majority of APAB members reside in BC (in urban and rural areas), one member is based in Toronto and five live in Quebec.

### **The “*It IS About Us*” Study**

The purpose of this study is to address an important gap in patient engagement in health research, namely a lack of evidence-based resources to guide individuals and organizations (i.e. patients, researchers, decision-makers, funders) in the development and sustainability of patient engagement processes that reflect patients’ perspectives. Specific objectives are to: 1) explore APAB members’ views and experiences of patient engagement in health research, 2) understand the barriers and facilitators to patient engagement in health research, and 3) develop a user-friendly resource based on APAB members’ perspectives. The project was conducted in partnership with four APAB patient partners (listed as co-authors). A memorandum of understanding was developed to represent an agreement between APAB patient partners and researchers at Arthritis Research Canada to collectively own all data (subject to a participant’s approval), results and research outputs generated by the project. In this report, we discuss the preliminary findings.

## **Methods**

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### **Study Design**

Data collection and analysis was guided by a qualitative design informed by aspects of constructivist grounded theory. [17] This approach is suitable to gain an interpretive understanding of processes, social settings, and human behaviour from participants’ perspectives. Semi-structured, in-depth interviews were conducted with a purposive sample of past and present APAB members with varying degrees of experience in engaging in research. Our aim was to better understand how participants viewed and experienced their engagement in health research. Peer checking and member checking enhanced the rigour of our emerging analysis.

### **Participants**

Eligible participants were past or present members of APAB. From August 2015 to November 2015, participants were recruited via an email invitation and word of mouth. Interested individuals were invited to contact the lead research trainees (either by email or phone) who provided details about the study and screened for eligibility. Informed consent was obtained from all participants.

The University of British Columbia’s Behavioural Research Ethics Board granted ethical approval for the study (#H15-00217).

## Interviews

The interview guide was devised in partnership with APAB patient partners to enable participants to contribute their perspectives regardless of their degree of experience with engaging in research. Interviews were conducted at a time and place convenient for the participant. The interview guide (see Appendix A) was organized into three separate but overlapping sections: 1) experiences/benefits/downsides of being a patient engaging in research; 2) interactions with researchers; 3) perspectives on APAB's development. Open-ended questions were asked, and probes and prompts used for elaboration. Consistent with a grounded theory approach, questions were modified as data from preceding interviews were analyzed. Interviews were conducted by the lead research trainees and supervised by a researcher with experience in qualitative research. Field notes were taken to aid interpretation and validity of the data-driven claims. The interviews were audiotaped to ensure accuracy.

## Data Analysis

Audio recordings were stored on a secure server at Arthritis Research Canada and transcribed verbatim. All transcripts were de-identified by the lead research trainees. Each participant was invited to review and modify their de-identified transcript, and provide permission for their transcript to be used for analysis. Our analysis followed an iterative process using constant comparison methods informed by grounded theory. [17] Coding was carried out predominantly via paper-based methods, and NVivo 10 was used for storage and management. No preselected codes were identified prior to data analysis. Three research staff/trainees with backgrounds in qualitative research independently read and coded a selection of transcripts, and met to identify emerging issues for discussion and develop an initial coding scheme. Codes were then compared and contrasted between the remaining transcripts, with similar and deviant cases being sought. This process was followed by clustering codes into thematic categories. These preliminary categories were verified, modified or refuted in research team discussions with a supervisor experienced in conducting qualitative research, and meetings were held to gain the perspectives of APAB patient partners. No participant names were used in the reporting, and all quotes were presented with pseudonyms.

## Results

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Thirty-three eligible individuals were identified from membership records provided by APAB. Of those, 22 (67%) consented to participate. Twenty-one (95%) were female, with a median age of 60 years (see Table 1). Of note, 14 (64%) participants had completed a degree or above. Twelve (55%) participants were in paid employment, 9 (41%) had retired, 2 (9%) were receiving disability benefits, and 2 (9%) were students. Sixteen (73%) self-reported a diagnosis of inflammatory arthritis (including rheumatoid arthritis, lupus, Sjogren's syndrome, ankylosing spondylitis, scleroderma, psoriatic arthritis, polymyositis, Raynaud's, vasculitis, and seronegative undifferentiated spondyloarthropathy), and 9 (41%) self-reported a diagnosis of osteoarthritis (OA). Four (18%) self-reported a diagnosis of both inflammatory arthritis and OA, and 15 (68%) reported at least one additional ongoing health condition. Sampling ensured inclusion of past (n=4) and current (n=18) members of APAB, and time spent as an APAB member varied from 1 month to 10 years (the median amount of time was 3 years).

From analysis of the transcripts, 4 preliminary themes are emerging: 1) *empowering patients: having the patient voice heard*; 2) *engaged patient as occupation: “adding another spinning plate to an already busy life”*; 3) *building social relations*; 4) *demonstrating “there’s respect”*.

### **Theme 1: Empowering patients: having the patient voice heard**

Many participants viewed their engagement in research as an APAB member to be “empowering”, perceiving APAB to offer opportunities for them to have a voice in the research process. For example, Chloe commented:

*“I was really interested in the idea that patients can have a voice and that it’s valued, and that they’re not just sitting on the sidelines as okay, we have a new medication, let’s just give that to patients and not get their feedback on it... feeling that I could have a voice heard was very powerful and empowering”.*

Having a voice in the research process was perceived as central to “empowering” themselves as a patient as it was seen to mark a shift away from a patient as “*somebody who’s consuming something but not contributing back to it or influencing or shaping it*” (Olivia). Julie’s engagement in research as an APAB member was also:

*“quite driven by having the patient voice included in research. As in about things that matter to patients, is it easy for us to understand or are the outcomes strong outcomes that are important to patients? Is the methodology the best methodology? Could we improve the methodology? Can we help get the word out to the public?”*

More than one participant viewed their engagement as an APAB member to involve upholding a responsibility to have a voice in influencing or shaping the research process. For example, Victoria commented:

*“I think APAB brings the person to the table, brings all of us as individuals and our experiences to the table... by participating in the research is that I think that we bring the person’s perspective to this stuff to improve quality... when [Researcher] first came to the group, I just kept looking at it and thinking, “There’s something wrong here. This just doesn’t...this isn’t ringing”... You also have a responsibility, I think, to the group, not to rubber stamp something if you don’t feel strongly about it... that’s responsibility to my ideals but it was also a responsibility to the group that all of us didn’t keep our ideas to ourselves and said, “Well gee, she’s a doctorate person, she must know what she’s doing”.*

Some participants (particularly newer APAB members) found, however, that feelings of uncertainty were a major barrier to sharing their perspectives as an APAB member. For example, Laura commented:

*“We went through the agenda and they were talking and the question was, you know, above my head because I didn’t know what went on prior to that. So I just sort of sat and listened and I got some things but I was still, you know, quite overwhelmed... I would have to, you know, Google the acronyms to see what they all stood for and that so, ya, I felt a little, a little lost”.*



Participants perceived researchers to play an important role in facilitating patients to share their perspectives. For example, Jessica reflected:

*“patients sometimes need encouragement and reinforcement that their views are not, they themselves may be worried that their views are not as important or lesser... or less valid and I think the academic members of the research team can really help the patient to contribute even more by reinforcing that their perspectives are equal, if not, greater... patients are going to be reticent to contribute if they feel it’s tokenism. If they feel it’s really valued then that’s going to encourage them to speak and contribute more freely without fear that they should only say something that they think, you know, that they wouldn’t remain silent if there was an opportunity to present an idea even if it was really far out”.*

Lori described her experience of researchers and research staff putting her “at ease” to speak freely through actively listening and taking seriously what patients had to say:

*“the researchers and research coordinators put you at ease immediately, so you are able to relax and that enables you to speak and comment freely... we [APAB] members talk about this a lot. We never felt like any question we asked or any feedback we gave was ever discounted. They really listened without judgment so that you quickly felt at ease”.*

Participants also described taking time to equip themselves with new knowledge as another key facilitator to influencing or shaping the research process as an APAB member. By doing so, many participants felt they were on a “quest to also be professional” (Jessica). David described how he approached his role as interviewer for APAB’s quarterly newsletter:

*“I try to be as professional as possible... I need to inform myself about the issues before I even ask a question... by being professional for interviewing and writing, it means for me to start with the end in mind... So by being professional for interviewing and writing, it means for me I start with the end in mind. In other words, I kind of have an idea in my mind where it’s going, what it should look like at the end of it and then all of my questions and all of my comments are geared toward getting the interview subject to go there, to go along that, that route... So when I say professional, it’s not just a question of I just walk in and sit down and say okay, well, what do we wanna talk about? No, I am... I try to be really, really prepared and knowledgeable”.*

As well as taking time to equip themselves with new knowledge, some participants also drew upon existing skills and experience to facilitate sharing their perspectives in the research process as an APAB member. Norma explained:

*“for someone like myself it was easy... because, I mean, I have a background in science so that does kind of help. I’ve been involved since my undergrad so, ya... for me it’s the understanding of what’s occurring with the studies, designs and the explanation, the technical terms, those are quite familiar to me. So for me myself it’s been easy”.*

Although many highlighted that they had no or limited experience being engaged in research as a patient, they often had previous educational or professional backgrounds that they perceived to facilitate them in sharing their perspectives as an APAB member.

## **Theme 2: Engaged patient as occupation: “adding another spinning plate to an already busy life”**

Participants were experiencing a substantial amount of work being added to their existing priorities in being engaged in research as an APAB member. Many viewed their engagement as “volunteer work” that brought added demands on their time. Julie commented:

*“the burden is just the time involved. It’s everyday managing something or writing something, responding to something, planning something, doing something, engaging someone, looking for help with something, providing feedback on something, starting something, finishing something, and so it can be very busy and it can be intrusive into my life”.*

Barriers to continuing to volunteer were described by participants as the emotional and physical impacts of juggling between multiple priorities. Sarah, for example, was experiencing a:

*“...constant guilty, nagging feeling that I’m not doing enough... I have no personal time... I have a national role in my job... which has been very time consuming. So between all those things, um, it gives me very little time um for my husband [laughs] [...] as much as it’s adding to my plate and making me feel stressed out that I’m not doing enough, it’s been nothing but a positive experience other than the time commitment... I’m being pulled in different directions... I’m not doing anything a hundred percent”.*

Others also described experiencing stress, tiredness, or not having done enough with tasks that were “*hanging over my head*” (David; Irene). Other barriers (related to employment status, skill building and experience, disease stability, access to funding, level of enjoyment, changing schedules, and symptoms including pain and fatigue) also impacted participants’ ability to volunteer as an APAB member, causing it to fluctuate over time and from day to day. Heather highlighted: “*when you have a chronic and crippling disease... it’s sort of the guardian at the gate, it shapes and interferes with and constrains your relationships with the world*”, while Norma described:

*“I’m on the [research project] now just taking over for [other APAB member] ... there were a couple of meetings coming up... I was actually given the Monday and then the Saturday. So I actually made sure I didn’t book any shifts on those days and then Friday ended up being the date for the meeting... so I couldn’t attend... I have a crazy all over the place schedule that’s not predictable”.*

While participants emphasized that their “*willingness to put in some homework and some work to participate is important. You can’t just sort of show up or not show up*” (Marie), many also described the accommodating approach taken by other patients in leadership positions within APAB to facilitate them in continuing to engage in research. For example, David emphasized:

*“there is a lot of empathy on the board and a lot of understanding of, of the fact that other people are struggling with this disease... about a year ago I came very close to just stopping and uh I thought you know I had a conversation with the Chairs... told them how I was feeling. And they said you know you do what you need to do and we’ll support you either way. And so I went away and I thought about it for a while... I said no, I’m going to do this, so that’s where I, when I basically decided to commit.*

Lori also highlighted:

*“I had the option not to attend meetings if I wasn’t feeling well... the chairs are very encouraging... one of the chairs that I deal with the most, comes to my home so that I don’t have to drive to town. We’ve done a lot of projects together at my place... She goes above and beyond to help members continue to volunteer”.*

Participants also described looking to other members to “cover for some things that were important” (Marie) as a facilitator to their own continued engagement. More than one participant highlighted the value of being supplied with someone in a paid position of administrative support by Arthritis Research Canada, who could offer “more continuity, so that people can disengage but you’re still confident that things will go on” (Julie). Participants also emphasized the importance of planning ahead and learning to say no as ways to mitigate the challenges of juggling multiple priorities and facilitate their ongoing engagement as an APAB member.

Participants’ perception that the benefits of being engaged in research outweighed negative impacts was also identified as a facilitator to continuing engagement as an APAB member. For example, Lori reflected:

*“...I have a hard time saying no and so sometimes, there was a point where I was just, it was becoming a full time job and so I think that’s, that can be a downside because you can, you can end up, it can end up sort of taking over but it’s, at the same time it’s just so gratifying because with arthritis what happens is you, some of us had to quit our jobs or leave our careers behind so, you know, there was a real sense that, you know, that I was to utilize some of my skills, right, and find purpose again in my life so for me it was more upside than down”.*

Others also spoke to how “gratifying” they found their engagement to be. They viewed their engagement as a way of “helping others”, and also described how being engaged offered opportunities to learn more about how to manage their disease, which facilitated their ongoing engagement as an APAB member. Dekka commented:

*“Sometimes when you have a chronic disease you feel like you’ve lost control... So when I say that you feel empowered means you are able to make choices that can minimize your symptoms or your flares or just you’re able to have a better quality of life. So, you know, learning from the OT about ergonomics, learning from [Researcher] ... I think a lot of that over the years, you know, is important to, you know, help us deal with it on a daily basis... It is kind of neat to hear what all the other APAB members were doing... Others work with researchers, we attend conferences and other seminars, so there are always opportunities to learn and I think it’s neat to give back. I benefited from so many other people sharing their knowledge and their life experiences. It’s nice to be part of this group because you feel like you’re giving back and helping others. I remember what it was like in the early years of being diagnosed and struggling to find information, now I am helping people find resources, find solutions to their problems, and helping them navigate all the information out there”.*

### **Theme 3: *Building social relations***

Many participants described their experiences of building social relations through their interactions with researchers as an APAB member. For some participants, these experiences marked a change in power dynamics. For example, Irene described her experiences of interacting with researchers who sought to consult with APAB members about their research:

*“we have a guest speaker come to a Board meeting and ask for our help. I mean the first time that happened I was like whoa... it’s like a culture shock as a patient... because you’re not used to them asking you for help. You’re used to asking them for help... So for them to ask you for help was, is like wow, they were in, they want to know what we know”.*

Phoebe described how building social relations with researchers through informal interaction could lead to changes in power dynamics and thereby facilitate her comfort level in engaging as an APAB member:

*“Everybody was on a first-name basis and right away that, that power, that power hierarchy is dismissed. It no longer exists... So when you’re sitting across the table from [Researcher] and he’s just talking about his research as casually as if he was at a Sunday picnic, all of a sudden your comfort level as a consumer goes up... there’s a little bit of discomfort because do I look stupid, ill-informed, unstudied when compared to them. But that, those feelings were eradicated by meeting the researchers one on one... We felt quite comfortable passing them in the hall and saying hi. We knew a little bit about their families. They knew about ours”.*

Based in their experiences, participants also described the dynamics of their social relations with other APAB members. Madeleine commented that an introductory meeting was held “so that I would get a sense of the responsibilities and you know the expectations and all of that, but also if our personalities meshed”. Participants felt other APAB members were welcoming and encouraging, and they often experienced a sense of solidarity “built on camaraderie” within the group (Olivia). Many participants viewed relations they had built with other APAB members over time as a facilitator to continuing their engagement within APAB. Jan explained “the atmosphere as well is really nice and friendly... it’s non-judgmental, you can say, say silly things that you’ve tried and, and not really feel uh [you’re] being judged... it’s just a nice group of um, uh patients that uh you know once you’re in there you don’t want to quit”. Lori also highlighted:

*“it’s nice to have somebody in your life that is facing the same challenges and with whom you can share experiences. I have met members that have become very close personal friends... as it relates to [APAB], it sometimes forced me to go out when I was having a bad day, coming home from the meeting on those nights, I was always very thankful that I had attended. The camaraderie can be good medicine. Coping with arthritis can make you retreat from social activities; being a member forces you to get out of your comfort zone, and being with supportive people who understand is the real reward”.*

Although many participants formed friendships over time, some felt “isolated” (Sarah). Among these participants, joining monthly group meetings remotely was identified as one barrier to building social relations. Marie highlighted the role that patient leaders within APAB played in addressing this barrier:

*“it’s more difficult to get into the conversation. It requires the people who are leading the meeting, chairing the meeting to actually make a point of making sure that you’re part of it... And you miss the social part of it cause I think that’s part of, a big part of this group too, is getting to know other people who have similar interests and also have arthritis”.*

In addition, some participants also described how building social relations among patients by holding social events facilitated the growth of new patient engagement initiatives. Victoria explained:

*“we have our two social meetings a year... And we just get together for dinner and talk about what we’re going to do and stuff like that... this one was just in June and again we were on the patio of the [restaurant], which was really nice and then [other APAB member] and I took [patient] out from [location], that’s started APAB out there... if you know somebody then you’re not so unlikely to ask them for a favor or two, to ask them for information. For example, for her now, she has two people that she knows really well so I don’t think she’ll be afraid to ask us if she runs into any problems...”*

#### **Theme 4: Demonstrating “there’s respect”**

Participants viewed respect in their interactions with researchers to play an important role in facilitating their engagement in research as an APAB member. Phoebe emphasized *“respect for the patient’s viewpoint. That was the most important because if there wasn’t any respect for that viewpoint, there’d be no point in us being there. So don’t ask us to the table if you are going to dismiss what we have to say”*. Respectful interactions were often seen to involve patients and researchers indicating sincerely that each other’s contribution was valued. Laura explained:

*“I don’t need any accolades or anything like that, that’s not why I’m doing what I’m doing, you know, but I find that, I think when people feel appreciated they’re willing to even do more and so I think that’s with anything you do. If there’s an appreciation, you know, that your voice matters, that your input matters and yes we hear you, I think that’s really important”.*

Based on their experiences, some participants described how researchers had demonstrated their contribution was valued by making an active effort to seek out and act upon their perspectives, by taking a flexible approach to accommodate patients’ time constraints and priorities while asking for help, and by treating patients “like a colleague” in their interactions. For example, Jessica described being:

*“sent a draft of the newsletter. Would you have some time to review it before I send.... So I think that’s really nice, first of all, that you’re not just sent something without a warning and then expected to be able to find time in their deadline to do it. Then when I reply back in the affirmative, then I’m sent the material when it’s ready with a request for a time period in order to provide the feedback and inevitably, you know, the change are incorporated which is really important for a patient to see... you’re being listened to... you’re being valued... it’s not tokenism again it’s actually incorporated. In the same way I received one of those e-mails at the end of last week saying could I do it this weekend... I replied back that I have a number of commitments, was the deadline flexible and therefore could I receive it at the end of the week rather than the beginning of the week and right away the response was yes, of course, which, again, the communication indicates that there’s respect”.*

Marie also emphasized:

*“we also have researchers come and present at most of our meetings and they have been really good to come and, not only share information but actually get feedback from us. So there have been some research projects where our feedback has made a difference in how the research was designed just from some of the questions and comments that we had the researchers took that and actually said oh, ya, let’s, we can look at this, we can make some changes here. So to me that’s showing respect to the patient perspective... I’ve felt very welcome that the researcher has been very, have treated me like a colleague in terms of sitting and talking and asking questions and interacting. So I don’t feel like I’m being treated as a second-class citizen”*

Participants also highlighted the importance of giving recognition to researchers, thereby demonstrating respect. For example, Olivia commented:

*“people who have, you know, 5, 10, 20 years of research training, I think that their voice should be heard as well. You know, they should still have an important say in what is feasible or doable. So some of the pro-patient in research language that I hear seems to really discount the researcher and I don’t agree with that... I think patient engagement goes both ways. The patient is just as important as the researcher, and the researcher is just as important as the patient”.*

More than one participant viewed their engagement in research as an APAB member to be a demonstration of respect for researchers. David commented: *“the newsletter is a, has a real patient voice uh but it also uh shows a great deal of um I guess respect and a great deal of admiration for, for the people that are actually doing the research”*. Julie described how she indicated her respect for researchers by considering their perceived time constraints in her interactions:

*“so I had emailed [Researcher] and said, “I think you should really showcase this on a slide by itself and talk to it a little bit,” and then he just emails back one word, “Done!”... you have to, you know, respect the researchers that are often also clinicians, that their time is valuable but if you have a valuable patient perspective to add to their work”.*

## Discussion

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The early findings provide more in-depth insights into patients’ perspectives of engagement in health research as an APAB member. As we have seen through the first preliminary theme, participants viewed their engagement in research as an APAB member to be “empowering” on account of opportunities they perceived to influence research through sharing their perspectives. Feelings of uncertainty were experienced by many participants as a common barrier to sharing their perspectives as a patient. Researchers’ actions to encourage patients that their perspectives would be heard and taken seriously were perceived to be a key facilitator. In addition, participants also found that their existing skills and experience, as well as taking time to inform themselves with new knowledge, often facilitated them in having their voices heard and taken seriously as an APAB member.

The second preliminary theme explored how participants described their experiences of engagement in research as an APAB member to add “volunteer work” to their “already busy lives”. A potential barrier

to cultivating and sustaining engagement was identified as emotional and physical impacts experienced by participants in juggling this work amidst other priorities. One facilitator to sustaining engagement described by participants was patient leaders, as well as other members of APAB and ARC, taking an accommodating approach toward participants' fluctuating ability to volunteer. Another facilitator was participants' perceived benefit of their engagement (i.e. finding purpose in the added work).

The third preliminary theme highlighted how participants perceived building social relations between patients and researchers, and among patients, to facilitate the development and sustainability of patient engagement in research. Changes in power dynamics were commonly perceived to support building social relations between patients and researchers, while patient leadership was identified to have a key facilitating role in building social relations among patients within APAB.

Demonstrating respect within patient-researcher interactions was also perceived by participants as a major facilitator in their engagement in research, as explored by the fourth preliminary theme. Emphasis was placed on researchers and patients indicating mutual respect by sincerely valuing each other's contributions. Ways in which researchers and patients demonstrated that they valued each other's contributions were also explored.

Our next steps are to:

- Conduct further analysis to gain a more in-depth understanding of preliminary findings, meeting with APAB patient partners to gain their perspectives on emerging themes. The preliminary findings also support using an ethics lens to further analyze the potential benefits and harms of patient engagement in research from participants' perspectives. This is consistent with a recent report by the BC Support Unit which addressed a need to identify ethical considerations when patients are engaged in health research. [18] Our preliminary findings highlight ethical considerations specifically within patient-researcher and patient-patient relations and interactions, which further analysis using an ethics lens will aim to unpack. Power dynamics within these relations and interactions will also be further explored, particularly with emphasis on patient leadership roles as a facilitator in cultivating patient engagement in research.
- A participatory approach will be taken to develop the online resources proposed for objective 3 of the 'It IS All About Us' study. The resources will address priority areas for cultivating and sustaining patient engagement in research, as well as strategies to facilitate action within each priority area in ways that reflect patients' priorities.
- The research team (including researchers and APAB partners) will decide how to disseminate the final online resources beyond the narrow scope of arthritis and musculoskeletal stakeholders to include research leaders in cognitive health research, patient advocacy organizations and community organizations. Due to the spectrum of existing patient engagement in research in chronic conditions (such as asthma and chronic obstructive pulmonary disease, diabetes, spinal cord injuries and HIV), we propose the resource to serve as a discussion point that can inform the potential for future implementation in relevant contexts beyond the scope of arthritis and musculoskeletal stakeholder organizations. [11] Given our source of data, the resource is unlikely to be suitable for supporting patient engagement in research in vulnerable and marginalized populations.

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## Appendix A: Interview Guide

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**1. To begin, please tell me about yourself.**

Probes:

- Tell me a bit about your health.
- Please walk me through how you first became involved with Arthritis Research Canada's Arthritis Patient Advisory Board.
- What role(s) have you played in research?

**2. How easy or difficult have you found being involved in research? Please elaborate.**

Probes:

- What do you like or dislike about being involved in research?
- Thinking about your experiences, could you tell me what helps you take part in research?
- Have you found there are any downsides to being involved in research? Could you give an example?
- Can you describe what leads you to continue to be involved in research?
- Can you talk me through what led you to leave APAB? [Emeritus APAB members only]

**3. Could you describe your interactions with researchers at Arthritis Research Canada?**

Probes:

- To what extent do researchers partner with you in research?
- To what extent do you feel that your contributions are valued by researchers?
- Have there been any changes in your interactions with researchers over time? Please elaborate.

**4. Could you describe what you think is/has been important for APAB's development?**

Probes:

- Thinking back, what was important for APAB's development in the early years? Has this changed over the years? [More Experienced Members only]
- What can/does/should APAB do that no other organization does or can do as well?
- Can you describe where APAB has most impact?
- Could you describe what you like or dislike about the culture within APAB?
- Can you describe what you like or dislike about how APAB operates?
- Can you talk me through how APAB has secured funding?
- How do you hope to see APAB develop in the short-term/long-term?
- To what extent does ARC support you to engage in research?

**5. Are there any benefits to being involved in research at Arthritis Research Canada? If so, please elaborate.**

Probes:

- To what extent do you feel that your involvement is recognized?
- Has being involved in research affected the way that you manage other priorities/manage your health? If so, to what extent?

**Thank you very much for your time. We really appreciate you sharing your experiences.**

**Table 1: Participant Characteristics**

<b>Participant Characteristics (n=22)</b>	
Age range (median)	26-68 years (60 years)
Female	21 (95.5%)
Employment status:	
- Retired	9 (40.9%)
- Employed full-time	4 (18.1%)
- Employed part-time	4 (18.1%)
- Student	2 (9.1%)
- Self-employed	2 (9.1%)
- Permanent disability leave	2 (9.1%)
- Employed Casually	1 (4.5%)
- Freelance	1 (4.5%)
Current APAB member	18 (81.8%)
Self-reported diagnosis of:	
- Osteoarthritis	9 (40.9%)
- Inflammatory Arthritis	16 (72.7%)
Diagnosis of chronic joint disease:	
- OA	9 (40.9%)
- RA	9 (40.9%)
- Lupus	2 (9.1%)
- Sjogren's syndrome	2
- Ankylosing Spondylitis	1 (4.5%)
- Scleroderma	1
- Juvenile Rheumatoid Arthritis	1
- Psoriatic Arthritis	1
- Polymyositis	1
- Raynaud's	1
- Vasculitis	1
- Seronegative undifferentiated spondyloarthropathy	1
Level of education:	
- Post-doctoral	2 (9.1%)
- Master's degree	7 (31.8%)
- Completed college	5 (22.7%)
- Some college, no degree	4 (18.1%)
- Completed high school	3 (13.6%)