

THE PATIENT VOICE

in ARTHRITIS RESEARCH

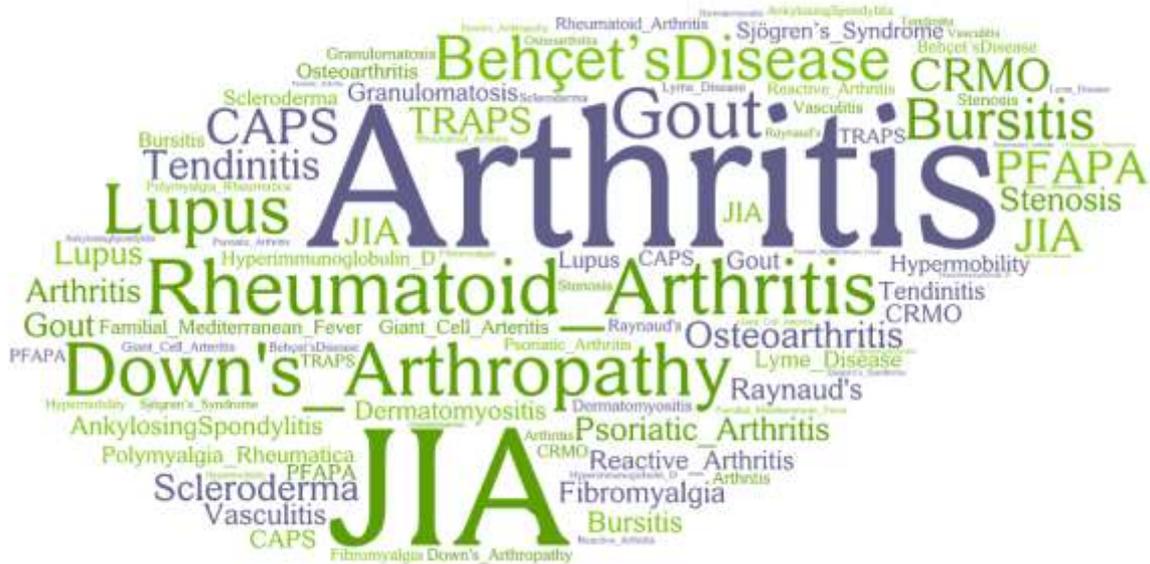
Embedding patient views in arthritis research

**Report of the Inaugural Discussion Forum to Develop
Public and Patient Involvement (PPI) Strategy**

*UCD Centre for Arthritis Research
UCD Conway Institute, Belfield, Dublin 4*



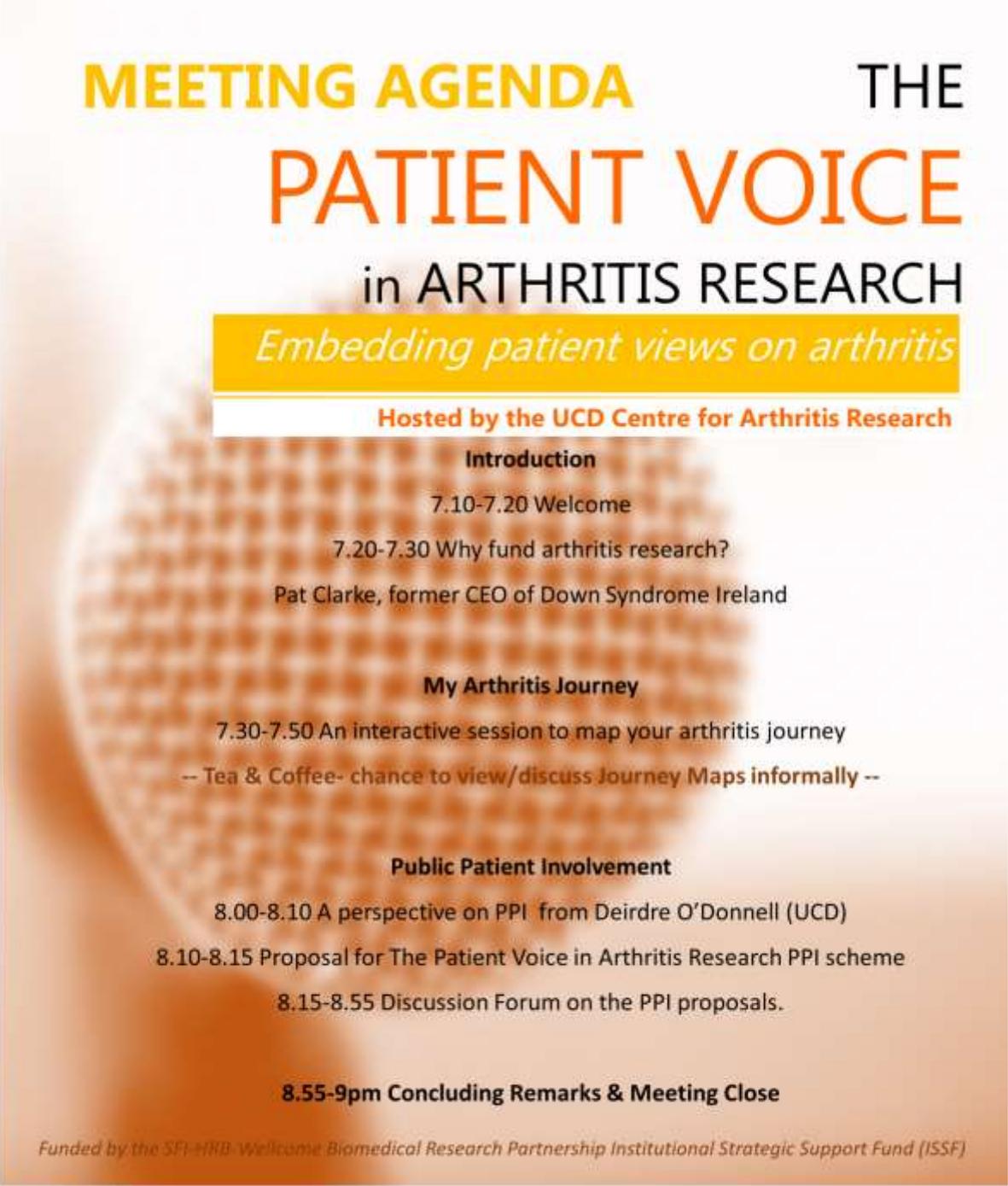
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Meeting Agenda



MEETING AGENDA **THE**
PATIENT VOICE
in **ARTHRITIS RESEARCH**
Embedding patient views on arthritis

Hosted by the UCD Centre for Arthritis Research

Introduction

7.10-7.20 Welcome

7.20-7.30 Why fund arthritis research?
Pat Clarke, former CEO of Down Syndrome Ireland

My Arthritis Journey

7.30-7.50 An interactive session to map your arthritis journey
-- Tea & Coffee- chance to view/discuss Journey Maps informally --

Public Patient Involvement

8.00-8.10 A perspective on PPI from Deirdre O'Donnell (UCD)
8.10-8.15 Proposal for The Patient Voice in Arthritis Research PPI scheme
8.15-8.55 Discussion Forum on the PPI proposals.

8.55-9pm Concluding Remarks & Meeting Close

Funded by the SFI-HRB-Wellcome Biomedical Research Partnership Institutional Strategic Support Fund (ISSF)



The UCD Centre for Arthritis Research aims to incorporate public and patient involvement (PPI) into their standard research process.

Three PPI schemes were proposed for discussion at The Patient Voice in Arthritis Research inaugural discussion forum.

1) Formal Participation.

The creation of a steering committee, with patient members, that would review outputs, grant proposals and develop longer term strategies for arthritis and rheumatic disease research.

2) Casual Participation.

The formation of patient panels, who will give input into specific research plans, as and when required, in a manner that suits the patient.

3) Patient educators

Patients set challenges to our graduate students. The graduate student must consolidate the patient needs and clinical feasibility and develop a research strategy to address this challenge. The primary goal is not to achieve a solution to the problem (although it may), but rather to train the graduate to understand and account for the patient perspective within their research.

These three schemes have the capacity to grow with demand and offered a range of flexible ways that patients could be involved dependent upon their individual interest and availability.

Attendees were asked to discuss the interest, barriers and facilitators of the proposed schemes.



Meeting Overview

At the outset of the UCD Centre for Arthritis Research's Patient Voice in Arthritis patient consultation session, project lead Dr Emma Dorris gave an introduction, providing an overview of the Centre's research, explaining how it fits within a wider PPI scheme within UCD; it is the second initiative of its kind following The Patient Voice in Cancer Research. Dr Dorris outlined the aims of this initiative i.e. to embed the patient view in research through patient consultation in the design process. This will be implemented through a collaboratively-designed framework and starts with the peer-to-peer nature of the dialogue within this first consultation session. A booklet introducing the UCD Centre for Arthritis Research, their research and collaborators was given to every attendee.

Following the introduction, Pat Clarke from Down Syndrome Ireland talks about the organisation's involvement. Following this an interactive session 'My Arthritis Journey', where patients are given an opportunity to visually map their experiences with arthritis and share these with the room. This concludes with a short break, followed by UCD researcher Deirdre O'Donnell who speaks to attendees about her experience with PPI (Public Patient Involvement). The main group discussions begin: all attendees (researchers, patients, and patient advocates) are split into three groups discussing: a) patient member(s) of a formal steering committee b) casual patient engagement and c) the patient educator.



Snapshots from the inaugural Patient Voice in Arthritis Research Discussion Forum.

(From Top Left, Clockwise: Our attendees, Deirdre O'Donnell, Pat Clarke and Emma Dorris.

A Charity View as to Why they Support Arthritis Research

Pat Clarke, former CEO of Down Syndrome Ireland.

Pat Clarke, recently retired as CEO of Down Syndrome Ireland (DSI), spoke about the reasons for the organisation's involvement in arthritis research. Clarke, through his role and as a parent of an individual with Down syndrome, spoke about the link between Down syndrome (DS) and arthritis and why this needs funding: "Going way back, DSI would have seen the benefit of research but there was a very limited amount of medical research being done on physical ailments that people with Down syndrome were afflicted with".

"In about 1993 or 1994 we had a partnership with the National Children's Hospital, Harcourt St., where we screened over 500 (DS) children and arrived at the first research-based medical management guidelines for children with DS and they were internationally recognised and approved."

Since then, DSI has funded several other research projects and in 2013 Down Syndrome Ireland worked with clinicians in Our Lady's Children's Hospital, Crumlin to investigate "the increased incidence of arthritis occurring amongst children with Down syndrome in Ireland"¹. A national screening programme, the first of its kind in Ireland, led to significant data on what is referred to as Down's Arthropathy.

It was identified that there is an increased risk in what is known as juvenile arthritis in children with DS, and that there were often "significant delays in diagnosis, leading to other problems in the child's life," explained Clarke. It also led to findings including the prevalence of Down's Arthritis being 18-21 per 1,000, greater than previously estimated.

For these reasons, DSI is keen to raise awareness of Down's Arthritis through its newsletters and e-zines, as well as contributing to further research on arthritis, leading to its co-funding of this initiative.

¹ Down Syndrome Arthritis <https://downsyndrome.ie/information-centre/health/dsi-involved-in-life-changing-research-into-arthritis/>

The Patient Journey

Before the three group discussions, an interactive segment took place where all attendees were asked to take part in an exercise to visually map their individual arthritis journey (anonymously). The aim was to identify their biggest challenges by picking a point pre-diagnosis (negative or positive) and creating a graph plotting the journey from this point onwards through different stages of the diagnosis and how the patient was feeling about this e.g. a point where there was access or lack thereof to information, a treatment or intervention, and how this impacted upon their emotional and physical wellbeing. Researchers were asked to take part, mapping patient involvement in their research and where this worked or did not work out for them.

The end result was a compilation of graphs charting the ups and downs of these arthritis patients, which will be collated into a series of digital Patient Journey Maps that will be released in summer. These maps will highlight the individual nature of arthritis and rheumatic disease experiences.

During the coffee break, patients were encouraged to look at all the graphs and use them as inspiration for informing their own experience.

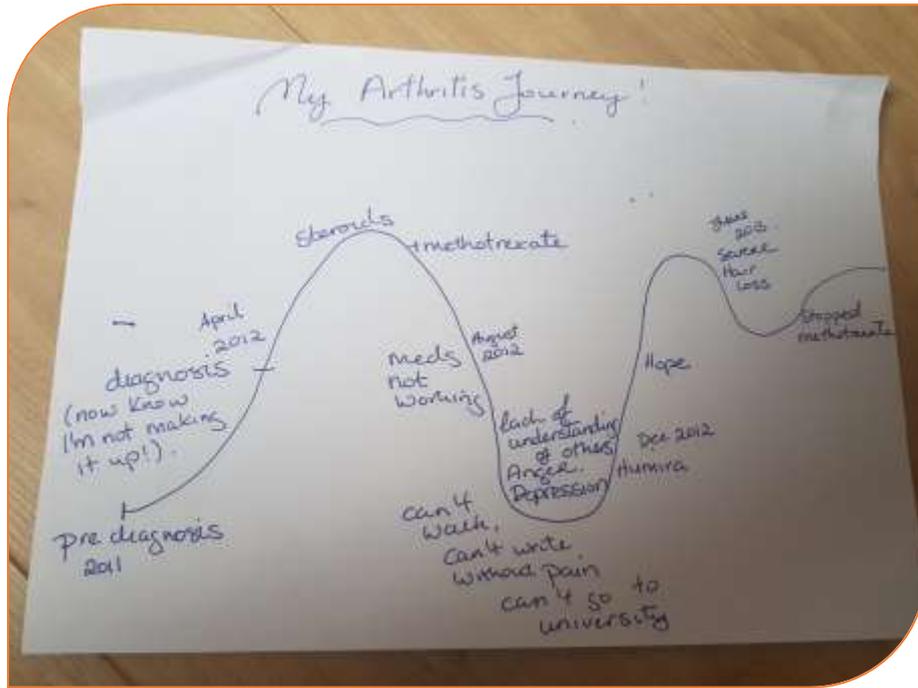


Fig. 1: Example of a Patient Journey Map

(+) Positive; (-) Negative

- 2011: Pre-diagnosis
- April 2012: Diagnosis (feeling/relief that “now I know I’m not making it up”) +
- Steroids and Methotrexate +
- August 2012: Medications not working -
- Lack of understanding of others, anger, depression -
- Can’t walk, can’t write without pain. Cannot go to university -
- December 2012: Humira +
- Hope +
- June 2013: severe hair loss -
- Stopped Methotrexate +

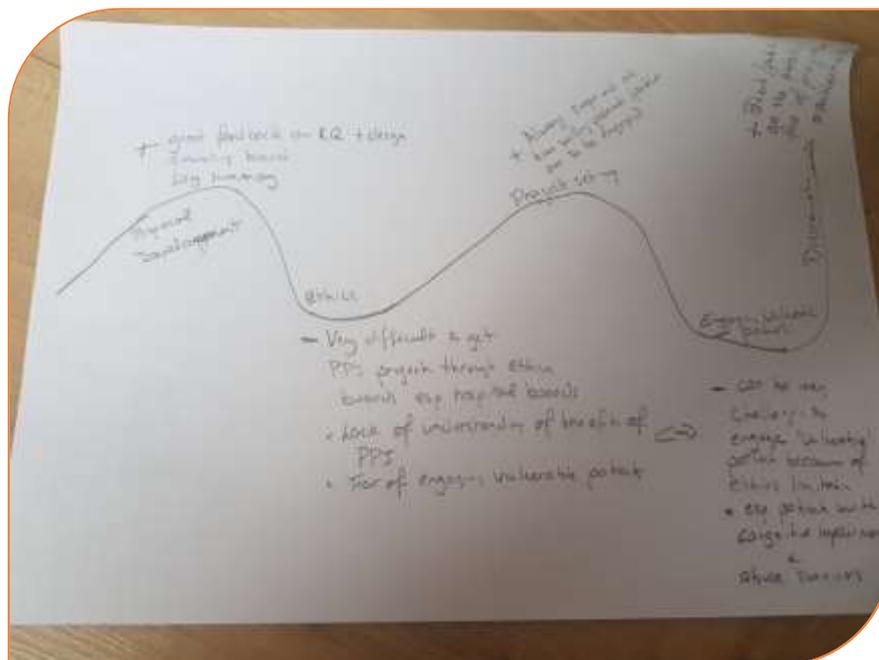


Fig. 2: Example of a Researcher journey map

(+) Positive; (-) Negative

- Proposal development. Great feedback on RQ and design, sounding board, lay summary +
- Ethics: very difficult to get PPI project through ethics boards, especially hospitals boards; lack of understanding of benefits of PPI; fear of engaging vulnerable patients -
- Project setup: Always surprised at how willing patient/public are to be engaged +
- Engaging vulnerable patients: Can be very challenging to engage 'vulnerable' patients because of ethics limitations and especially patients with cognitive impairments and abuse survivors -
- Dissemination: Patient/public are the 'public face' of the project = authenticity +

Deirdre O'Donnell, an example of PPI (Public Patient Involvement) within UCD Research

Deirdre O'Donnell, researcher and lecturer in Health Systems in UCD, talked about her work on applied research in the area of improvement of the health system. O'Donnell says: "All of our research would be very focused towards developing interventions and reforming the health system from the perspective of the patient". O'Donnell's particular focus is on ageing and frailty with regard to safe-guarding vulnerable adults in relation to cognitive capacity and assisted decision making. Her public and patient-focused research encompasses three different projects within UCD: 1) a HSE-funded project in conjunction with the NCPOP (National Centre for the Protection of Older People), 2) HRB-funded Safe project, 3) HRB-APA-funded PADMACS (Promoting Assisted Decision Making in Acute Care Settings) study.

The NCPOP project was centred on elder abuse with regard to prevalence studies and prevention, intervention development, and work with survivors of elder abuse. "I knew I couldn't do this research without talking to survivors of abuse and the public."

"They were not only the public face but also the authors My role was to facilitate rather than lead"

O'Donnell talks about ethics as the biggest block to developing PPI research, leading to working with representatives of older people "who are not necessarily vulnerable and who have not experienced elder abuse" rather than the abuse victims themselves. This led to the co-development, with this public working group, of an intervention called Keep Control.

"They were not only the public face but also the authors of [the intervention]. My role was to facilitate rather than lead. The benefit was an intervention that had older people speaking to other older people about how to protect themselves. It was hugely empowering." explains O'Donnell.

As a result of working with patient representatives of the same age-group, the benefits included sensitivity to the language used and the medium in which it was delivered (videos, website, printed materials, stickers).

“The working group really felt that they owned this intervention and willingly became the public face when we launched the public campaign. They travelled around the country, speaking in libraries and parish halls, and I believe it had a greater impact than me standing up there talking.”

“The benefits included sensitivity to the language used and the medium in which it was delivered”

O’Donnell’s second project is the Safe project: developing a pathway for frail, elderly people through St. Vincent’s Hospital. PPI has been a strong aspect of this project from the beginning.

“Critically, the public patient group are heavily involved in shaping the outcomes used to measure the effectiveness of the pathway.”

Due to the experience-based design developed by the group, O’Donnell notes that it is completely different to what was envisioned at the outset: “The things that HCPs think are important are completely different to what the public patient group thinks is important.” For example, healthcare professionals (HCPs) are used to the hospital layout but the group felt the much more signage was needed for older patients to find their way around and back out again.

Another outcome was improvements in communication. Prior to the PPI research, HCPs would walk in, deliver a treatment plan and leave, which often resulted in the patient forgetting what was said. There is now documentation for the care plan as a part of the consultation process.

HRB's 10-15 year plan for meaningful patient engagement within all health research in Ireland right down to reviewing grant applications, proposal developments, and through to dissemination of research.

The PADMACS (Promoting Assisted Decision Making in Acute Care Settings) study is the most recent PPI project led by O'Donnell, beginning in December 2017. "We are quite proud of the PPI element of PADMACS: we brought them in at the proposal-writing stage."

The aim of PADMACS is to enhance or promote understanding of what assisted decision making is, and for HCPs, reflect on how it might impact their practice, with the aim of improving delivery of acute healthcare services to older people.

Finally, O'Connell summed up the key lessons she learned:

- Effective PPI only happens when you have meaningful engagement and involvement of patients from the earliest point possible
- Tokenism: you cannot have one patient representing all patients on a steering group in a room with 10 physicians and 6 researchers. Critical mass is 20-30% of the group
- Every group discussion must be non-hierarchical: first name only basis, rotating the chair or co-chairing
- Expert knowledge must be communicated in an accessible way
- Try to have PPI group as public face of the project: gives authenticity, better intervention uptake
- Ethics and ethics boards are a key challenge: blocked through lack of understanding of value of PPI, lack of understanding of what vulnerability is and how vulnerable patients can engage without increasing vulnerability

Group A: Patient Members of Formal Steering Committee

Overview

The task for Group A was to discuss the possible structure of a formal steering committee that incorporates one or more patient members: what this role might involve, external structures that might support this role, and potential barriers to participation. It was suggested that the patient representative(s) on the formal committee come from a wider patient group(s) and that this would feed back into a plenary meeting updating all participants of the patient group(s) of committee meeting outcomes. Group A had six participants: four patients (one of whom was a facilitator), one facilitator/researcher and, additionally, one researcher.

Barriers to Participation

Formality of committee structure

“If it’s very formal, I think that would be very intimidating.”

“To feel like you’re not just being interrogated.”

“Not just one patient and 30 researchers, you know?”

“To say things and not feel stupid because you have others saying: no, no, I have the same experiences.”

“You might have a surgeon sitting here in this group [and] there would be things I wouldn’t want to say to him.”

Three of the four patients expressed a desire to have a less formal structure; the idea of one patient attending a meeting with many researchers was seen as intimidating whereas meeting with a patient majority was seen as more desirable. Patients expressed a reluctance to share problems or experiences with researchers in the absence of a “supportive” environment.

A Three-Tier Structure: Patient Focus Group; Steering Committee; Plenary Meeting

“A plenary type of idea as well, maybe bring everyone together.”

“The other point of that plenary is maybe people coming back to present, to give people an opportunity to see what’s been happening, if you’ve been involved in a trial or you gave blood, or did a survey: it gives a chance to come back with ‘this is what we’ve found’.”

“A feedback loop to us.”

This led to a discussion on the possibility of a patient focus group with a representative who then reports to the committee. With this three-tier structure (the third ‘tier’ being a plenary meeting) patients can feel supported and comfortable enough to share their experiences of arthritis with each other in an informal group setting. This can then be taken as a collection of views, opinions, concerns and reported to the committee. These group participants had been briefed on the other discussions but may have forgotten that Group B’s discussion was centered on an informal patient engagement forum that might feed into the formal review committee, however, this is a different approach combining a focus group and follow-up plenary meetings, something to consider alongside or in place of the informal engagement proposal.

‘Behind the Scenes’: Keeping Patients Informed

“I think what would frustrate patients would be the delay between the start of the research and when you actually see the results.”

“[Knowing] how long it takes for something to come from an idea to a clinical setting.”

While not directly related to the role of patient representative on a formal review committee, group members expressed a desire to be kept informed throughout the progression of a project they are involved in. Following on from the discussion around a

plenary meeting was a common thread of being kept informed: rather than being frustrated with the time it takes to see results, as one researcher suggested, the patient members of this group indicated that they would like to be updated, even if it was not with concrete results e.g. being updated on current phase or a projects, expected or projected delays, etc.; being kept “in the loop”.

Patient Focus Group: Balancing Representation and Structure

“It’s going to help to have it facilitated by someone who knows the background, who knows what the outcomes should be, what outcome they want. Otherwise you could ramble for hours.”

“Just because we’re patients doesn’t mean we’ve no skills.”

“From experience, if it’s an identified patient rather than an imposed outsider, it tends to work better.”

“There [can be] too much that is their own personal points of view and that’s where the group is very powerful for research.”

“The idea that you’re representing a group [...] that you’re conscious you’re doing that. In some ways it’s training your discussion to make sure you’re going in as a representative of that group but not just [for yourself].”

Choice of representative was also important: while this group wanted patient representation, they also noted the need for someone who can steer towards a clear set of outcomes. There is also a concern that with too few patients, the patient voice is one or a few individuals who are voicing their own personal opinions and points of view rather than progressing the conversation towards a clear set of outcomes, to benefit all patients.

One proposed solution was a rotating chair, in order to give everyone in the group an opportunity to guide the discussion. Another idea, in order to keep the conversations on track in between meetings, was to have discussion points that members would be asked to brainstorm on outside of meetings and *“next time they come they’ll have some maybe answers to that. Sometimes you have to sit with the idea for a while and think about.”*

It was loosely agreed that the representative would be a “semi-professional” while noting that all perspectives should be taken into account: *I think you’re right that maybe one of the patient representatives should be that kind of person: a patient but also with those skills [to steer, facilitate etc.]. But the other patient representatives might be there in a supporting role. But also because they have things to say and a contribution to make.”*

Diversity/Representation

“Every patient has a different experience. Everyone is different, so it’s good to have more of them rather than a couple of them because everyone experiences the disease differently so it’s important to have a critical mass of people to actually, really get [...] enough information.”

“Everyone experiences the disease differently”

“I don’t know if you’d need [a representative] for every type [or arthritis] but I think you’d need someone who had an appreciation of the different types and also I think that’s where your idea of the focus groups is really important, that actually, right, I need to make sure I’ve spoken to someone with juvenile arthritis, I need to make sure I’ve spoken to the rheumatoid groups.”

“You have to make sure you [as a representative] have met with [all types of arthritis patients] because I’ve been to other young women’s groups for arthritis and the main thing is having children. How it is affected by the disease and they’ve got time running out and all these other pressures going on so that would be an area we definitely need to have space for.”

“If you have someone who is elderly and alone and suddenly diagnosed and is scared and doesn’t have anyone to share with - so it is important to cover all different ages.”

The importance of the patient focus group was also compounded with the issue of representation: one patient on a formal committee was seen as too narrow to fully represent the patient voice. It would be desirable that the patient sitting on the committee is a) bringing multiple perspectives from the focus group, and b) has an understanding of the broad spectrum of patients with arthritis i.e. disease type, progression as well as gender, age, socioeconomic background, education level.

Practical Barriers/Flexibility

“You’d probably have to give [this] a lot of time, which I wouldn’t have. If you had Skype or something it would be easier. Say if you couldn’t make it off your sofa today because you’re knees are terrible or something like that.”

“I think that might be useful if you want a meeting, say if there’s a group of patients who could get to Galway or Cork, Letterkenny, and you’re based in Dublin. It means that you’re not just going to be relying on the patients living in Dublin.”

One possible practical barrier that was common amongst all group discussions was that of meeting times: being able to meet at regular intervals at specific locations. More than one patient expressed concern that due to illness or other commitments, there may not be a desire on the part of many patients to take part in such a formal committee structure.

Ways around communicating regularly in a face-to-face manner with researchers and other patients were discussed: online fora; WhatsApp groups, Skype, GoToMeeting, and other online/e-conference software and platforms that would not necessarily be a substitute for face-to-face discussions, which were deemed essential, but rather as an occasional substitute for patients who could not make a meeting on a particular day. It was also suggested as a way to feed more diversity into group participation rather than relying on

patients in the Dublin area, where most of this UCD research will be carried out, at least for the initial project.

Group B: Casual/Informal Patient Involvement

Overview

The aim of this group discussion was to explore what ways casual patient engagement could be carried out, potential barriers to these forms of engagement, and how they might feed back into the other proposals of patient educator and patient representative on a formal review committee. This group had two co-facilitators, one being a member of a patient support group and the second a researcher. This group had a slightly different make up: there was one patient who was also a researcher, and two patient advocates (an official AI representative and an iCAN representative), as well as two researchers. In this respect, while Group B came up with novel ideas, insights, and proposals for how this casual engagement might work, it was tackled mainly from the point of view of the (engaged and concerned) researcher and the carer point of view.

Casual Engagement Format

“Even if you had a casual group it would take work to maintain. It’s not just a mailing list that sits there. There would still need to be a lot of behind the scenes work.”

One recurrent discussion topic was the format that this engagement might take. While the facilitator started with the assumption that it would mainly consist of remote involvement, perhaps beginning as a mailing list, the other group members teased this out and discussed barriers to patient involvement with a mailing list (or online participation) alone.

This was expanded to discuss the value of other forms of online engagement including survey and questionnaires as well as informal interviews and informal group settings. While the purpose of this group meeting was not to definitively choose one particular method of engagement, it was proposed that a combination of the above might work, with the knowledge that patients might dip in and out of these engagements depending upon time commitments or interest.

“I put [this patient voice event] on a private forum and I have 800 members on that and I’m still the only person here. And yet I come from Tipperary. I know lots of families in Dublin and I asked them if they would come...”

The usual issues around mailing list responses (generally very low), survey response (can also be quite low), and commitment (patients may drop out if they have to engage online on more than a once off basis) will need to be further addressed. One researcher suggested more directed, specific topics and initial meetings with researchers in order to make the patient feel interested and engaged enough to take part.

Accessibility

Accessibility was discussed in relation to remote involvement. Concerns were raised about technical expertise and knowledge: would enough patients have access to a computer and internet connection? Would enough patients have the expertise to navigate the required online interactions? This may not be an issue for younger patients but more arthritis patients fall into the bracket of 65+ and, as such, may require training, access to equipment, or perhaps prefer not to take part in this form of patient engagement.

“Even when certain words are said [at meetings], we’re taking about jargon, I used to write them down and Google them later because I’d be so embarrassed to ask.”

“Consistency of language so you are not using different terms for the same thing. That you are using similar language and terms consistently.”

Accessibility was also discussed in terms of accessible language, perhaps the development of a form of jargon-free arthritis research dictionary that would be made available to patients (and researchers).

Other barriers to participation

“If you were to have a meaningful engagement with patients and the public they have to be involved from the beginning. If you haven’t got funding yet so you’re still developing your proposal for the HRB, you have no money, you are writing your proposal and you have to engage the public in a way that does not cost any money. How do you do that?”

Budgetary constraints were cited as a possible roadblock to early researcher involvement. It can be the case that researchers are on a small or non-existent budget and still need a form of patient engagement. This connects back to the discussion on online engagement, whereby the right mix of online recruitment (Twitter, Facebook) and survey tools (SurveyMonkey) could potentially work for some research projects.

Representation

“But it’s good too that you’re not just a token person. I did find I was always the token person [...] I felt that I didn’t speak up much, they didn’t value my opinion, I was nervous at the doctor’s.”

In terms of patient representation, previous groups had discussed the idea of being a broadly representative as possible i.e. representing arthritis patients of all ages, gender, background. A second definition of representation was used in this group: the idea of the patient as a “token person” within a research group. The individual involved in patient advocacy spoke of feeling like a token person who was there to “tick boxes” and felt that it was too intimidating to speak up.

Authenticity/Veracity

“There could be an issue of authenticity. If you have a big group or a survey is it the same as sitting down and talking to someone involved in the project?”

The question of authenticity was raised in relation to comparisons between online group participation and face-to-face group discussions: a) is online a suitable equivalent and b)

how do we determine that participants are genuinely arthritis patients? This led to a discussion on a form of pre-screening or meetings with patients before the online study/project begins. This was also proposed as a solution to deeper patient involvement: patients who have had the opportunity to sit down with a researcher and discuss the remote engagement format/topic are more likely to participate and become repeat participants or perhaps go on to volunteer for a patient educator role or to sit on the formal review committee.

Ethical Considerations and Transparency

“I would be happy to answer your question, even 10 questions, today, but I would like to know exactly how that information is going to be used.”

“Ethics is a pain but I think it is useful for that because you get to see information.”

“If it was mapped out clearly for both researchers and patient, that there are rules on [where] the information might go.”

“Some kind of feedback loop. I don’t just go away and redesign my proposal, I come back to the group and say: you know what, it is important that you gave me that information. I’ve changed my proposal to whatever.”

While it was acknowledged that ethical approval can be difficult to obtain for research projects like this, i.e. involving patients, especially from a hospital ethics board, it was also noted that ethical guidelines were crucial to accountability and transparency. It was agreed that patients should be able to access their own personal information that they have volunteered but also see where the information is being used and be updated of any research proposal, grant application, study design changes that were the result of a beneficial interaction between patients and researchers. This is not only responsible research and innovation; ***it empowers the patient and allows them to feel that they are part of the solution rather than being seen as a patient to be treated, with no valuable role to play.***

Researcher Perspective: Reservations and Opportunities

Given that researchers dominated this group discussion, it was a good opportunity to gauge any caveats or reservations on the part of researchers to take part in this sort of informal research platform. One researcher mentioned on several occasions that the casual engagement platform, by itself, would not constitute an entire PPI project and would only work if it was one of three strands, alongside the preceding projects. Even then, she voiced concerns about its overall usefulness to a wider research project.

However, towards the close of the group discussion, all researchers noted the potential benefits of such casual patient engagement including flexibility: *“People that sign on, that have a medium level of involvement if they are available: they could be consulted about a leaflet or they could be consulted more in depth about the research question.”*

It was also proposed that the learning process between the patient and the researcher as they take part in varying forms of casual patient engagement could be part of what one group participant termed a “graduation process” whereby:

“You get a casual group who are participating in a few surveys, opting in for this, opting out for that, but actually that means that over time you’re learning more about the process and you could become a permanent patient educator or part of the formal panel or whatever, be part of a broader stream of input.”

“It [potentially] builds a partnership. It builds trust and you might be raising awareness in that way, it’s valuable that people listen.”

“It becomes a success breeding success, the more you reach success, you breed success. The more feedback you get that your input is having some sort of value, the more you get involved again, and it’s that sort of iterative type of process.”

Group C: Patient Educator Role

Overview

The task of Group C was to discuss the possibility of creating the role of patient educator – an arthritis patient who would interact with and advise an early stage researcher – and the challenges around and the barriers to creating this role. Group C had eight participants: two patients, five researchers, one of which was a facilitator, the second facilitator being both an arthritis patient and volunteer for Arthritis Ireland.

Patient voice/depersonalisation

One recurring theme that emerged from this discussion was the idea of the patient voice as a means of restoring personhood and respect when they feel depersonalised as a result of engaging with medical professionals. This was in response to the feasibility of being paired with a researcher to provide a patient perspective.

P1 (patient 1) noted her positive experiences at the Rheumatic and Musculoskeletal Disease Unit at Harold's Cross as distinct from other interactions with medical professionals: *"From the day I walked in, they would look at me as a total person. Not just as an elbow, not just as an arm, not as a leg, but they were they were looking at me from the head to the toe; they were looking at me mentally, physically emotionally and fitness."*

"When [I] went to Harold's Cross suddenly [I was] a person, a complete total person."

From a researcher perspective, this idea of looking at the patient holistically was of importance to pairing a patient with a graduate student:

"The key point is that a patient can bring an awful lot more to the discussion than their disease."

“I actually think that what would be important for me is just that I would be believed and understood and listened to. And if I was treated with respect I don’t see any barriers [to participation] at all.”

Patient/Researcher Relationship

Aside from giving the patient a voice, it was noted that the patient educator role could have a two-way function. One patient voiced her desire to engage on the practicalities of coping with arthritis: information around medication options, dosage, side-effects. This may be one patient’s opinion but, while the researcher is not medical professional and should not be treated as such, it is likely that arthritis patients will expect the researcher to having good knowledge of existing arthritis treatments. This is the anchor point from which patients are likely to relate to research in the idea, lab or clinical stage. While this is not specific to the role of patient educator, it does point to a *reciprocal relationship between the researcher and the patient, where information is bidirectional and the patient is kept informed.*

“It has to start with research: the effects of the drugs, the actual sitting down with somebody, having someone sit down with you and discussing what drugs you should be put on, what the side effects are when you come off them, how long to let it go into your system before you come off them, and, more important than that is also that you actually know that you’re actually able to weigh the pros and cons of being on the medication.”

Motivations for Involvement

Being informed: *“Knowing that [progressive illness is] coming down the line and trying to avoid it by getting information and just getting nowhere. And not getting referred to anyone, not getting any information. I got a set of x-rays, that was my highlight. They sent me for x-rays and I thought, oh my goodness, am I being cured or something? And they came back and said: ‘you’ve arthritis,’ and I said, yeah, I kinda knew that.”*

Helping self/others: *“If you can turn around and find something that mightn’t work for me but that might work for my grandchild, or might work for someone starting off, Jesus, go for it.”*

Diversity/Representation

The group facilitator voiced concerns about representation of all arthritis patients in the face of self-selection: more confident patients are likely to come forward for the patient/research collaboration while less confident or more vulnerable individuals may not choose to do so. One of the patients noted that this form of self-selection may be dependent upon *pre-existing notions about what kind of interactions will take place during this initiative*. She noted the language describing the Patient Voice event included “panel of researchers”, which may be off-putting for potential participants. This is something to possibly take into account when designing literature, online campaigns for recruiting future participants.

“You say ‘coming in to meet a panel of researchers’ and you think, square table, cold room, brick walls, six people behind this.”

Gender balance was also mentioned but not addressed directly other than noting that arthritis predominantly affects more women.

Barriers to Participation

While the facilitator and researchers voice concerns about travel as a possible barrier to taking part in the patient educator role, this group consisted of patients from the Dublin area so further sampling would need to be undertaken to assess.

A more significant barrier was accessibility: as these patients all have arthritis, the range of mobility will vary, but factors including stairs, seating, and location will have to be taken into account.

“It was quite obvious that it wasn’t any of you that put out the chairs, it was the hotel. Because anyone with arthritis, to get in between those rows of chairs, even for me and it’s very mild.”

Pre-study Briefing

Patients were queried as to whether the age or stage of progress of their researcher was a factor; whether working with younger or early stage researchers would be a barrier. This led to a comment that patients may prefer to meet the researcher before they agree to sign on for the study. This aspect of the interpersonal relationship between the researcher and the patient, who will be working together for a significant period of time, is of note. It may be advisable to incorporate a pre-study briefing to have the researcher and potential participant sit down in an informal setting and discuss the project.

Patient Recruitment

Various platforms for patient recruitment were mentioned including social media and doctor's offices. *A novel way of reaching out, as suggested by one of the patients, was **community groups***: Age Action, Irish Countrywomen's Association, library groups and senior citizens groups.

"At some stage [members of women's groups have] had some little form of arthritis or whatever and at this stage in the women's groups they would be about 60. It's a way to meet and have coffee. And 95% of them, I remember one saying 'we'd love to have someone to have a chat'. Tell us what to do and whatnot."

Appendix

I. Guide for Facilitators



Guide for facilitators

Your role is to document the discussion and to guide it. Below are the questions we would like answers to. Allow the conversation to flow, but try to direct it such that the below topics are covered.

The aim of this discussion forum is to receive input into:

1) How feasible is the proposal

- a. Are there barriers to participation?
- b. Can they be overcome?
- c. Can they be circumvented?

2) How interesting is the proposal

- a. Would you like to be involved?
- b. Can we improve its attractiveness?
- c. Can we develop it to be more inclusion?
- d. What would make you interested and keep you interested in participating?

3) How accessible is the proposal?

- a. Are there strategies/technologies/communication pathways that would allow you to participate more easily?
- b. Are there terms/language that need clarification?
- c. How can we make more people engage with the scheme?

Scope of the discussion forum

The three areas of PPI that we would like to initiate are as follows:

1) Formal Participation.

The creation of a steering committee, of which patients will be members. Meeting 3-4 times per year, this committee would review outputs, grant proposals and develop longer term strategies for arthritis and rheumatic disease research.

2) Casual Participation.

The formation of patient panels, who will give casual input into specific research plans, as and when required, in a manner that suits the patient. No formal commitment is required. Using surveys, telephone interviews or tele-conferences, it is a way to allow patients to have their input as the need arises.

3) Patient educators

Starting with a pilot scheme, we would invite patients to set challenges to our graduate students. The graduate student must consolidate the patient needs and clinical feasibility and develop a research strategy to address this challenge. The graduate would liaise with the patient during the short project. The project will then be presented on a research day, and both patients and researchers would evaluate it together. The primary goal of the patient educator proposal is not to achieve a solution to the problem (although it may), but rather to train the graduate to understand and account for the patient perspective within their research.

Each group will have a single proposal to discuss. We have commissioned the journalist and science communicator Marie Boran to attend the meeting, record it and prepare a report. Your notes will be collected and directly fed into the report and the terms of reference for the PPI scheme that will arise from it.

Sincerest thanks for agreeing to participate.

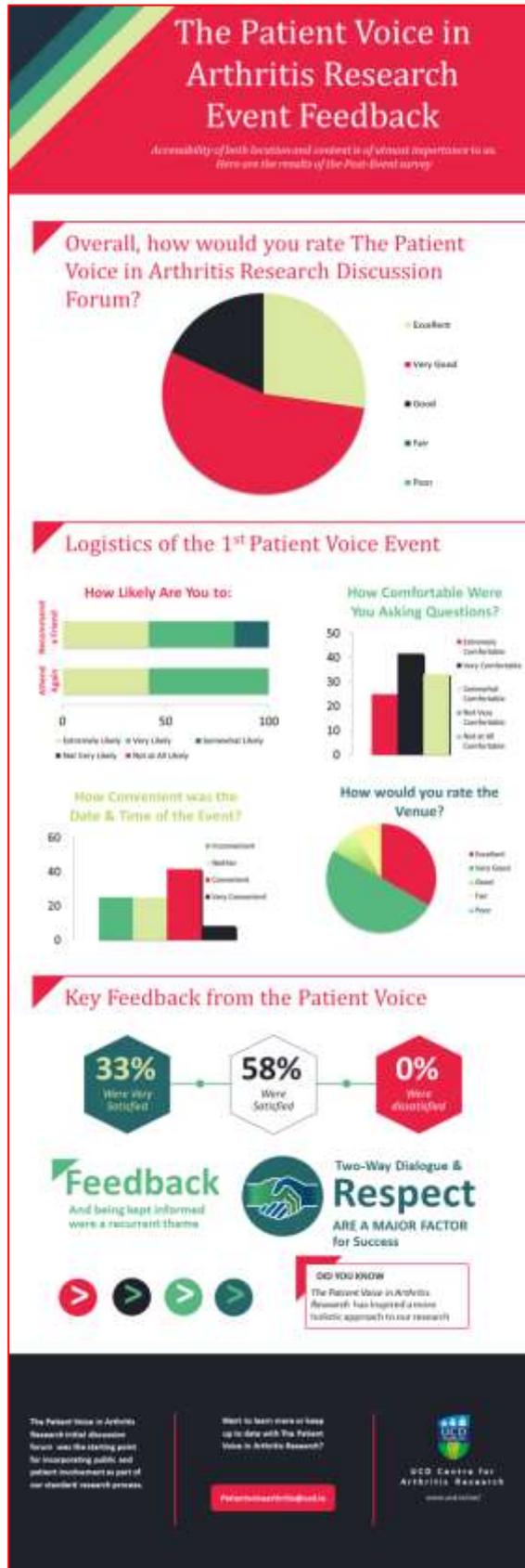
II. Event Feedback

We continually strive to improve upon our communications and events.

Following The Patient Voice in Arthritis Research Discussion Forum, a survey was sent to all attendees. We received a 50% response rate.

This infographic highlights attendee responses to the event.

All values are % of total responses to each question.



III. Funding

Funding for *The Patient Voice in Arthritis Research* inaugural discussion forum was provided by UCD and the SFI-HRB-Wellcome Trust Biomedical Research Partnership Institutional Strategic Support Fund (ISSF).

