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Arthritis research

AB1424-PARE EFFECTING A CHANGE AS A PATIENT INSIGHT PARTNER

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Background: In my patient advocacy work I had experience in every aspect except research. Through UCDs (University College Dublin) Centre of Arthritis Research (CAR) patient-research co-produced newsletter *News Rheum* I became aware of the Patient Voice initiative they had set up which is where I discovered the vasculitis research project I became involved with.

Objectives: My objectives to effect change were to be achieved by

- Sharing my knowledge
- Showing the value of patient involvement/engagement
- Learning how the research process works by being directly involved in the process

Methods: A personal perspective

Results: My formal involvement in this project started with my being invited to be a member of the interview panel choosing the postdoctoral researcher for the project. My remit was to ask the candidates about the impact of the project beyond just the science aspect, to try to figure out who just wanted a job, and who was interested and passionate about this project. I was not only choosing someone for the position but someone I was committing to work with for three years.

One of my first tasks was to act as a mentor in plain English to help the chosen researcher prepare a lay summary of the project. This helped both of us get to grips with the project and its objectives, as well as working out our working dynamic.

I work most closely with the project researcher, who has worked in rare disease but not in rheumatology. She has been very receptive and not only took an interest in learning more about the disease area but me as well.

I was introduced me to her first as a mentor, and second as a patient advocate. This helped us get to know each other and opened discussions including how PPI could aid her work and how invaluable it is from the patient perspective. This has given our relationship a great start and in a relatively short period we have built the great foundations for an excellent working relationship on a project we are both share a passion for.

For the researchers, to improve the process of PPI I would like some honest feedback on my performance as a patient insight partner. It may not be every patients ideal, but PPI is a knowledge exchange and we are all equal parties, I believe providing more robust feedback and sharing avenues for my improvement in a constructive way would be beneficial for my advocacy and future PPI work.

To prepare patient insight partners (PIPs) with no or limited experience of PPI there should be an opportunity to talk to another or former PIP about their experience or perhaps a leaflet detailing such experience which can be given to new PIPs. This is something not currently done within UCD, but, in response to my suggestion, Im working with UCD CAR to produce.

We are building the profile of our collaboration and showcasing the research by creating a blog together. The unique aspect of this blog is that it will represent both of our perspectives as researcher and patient advisor on specific topics. This is also an opportunity to inspire others involved in research projects to view other ways in which they can build on such collaboration, educate people about all aspects of the process

and learn from each other even more along the way. The reciprocal learning nature of this blog is the number one reason for its creation.

Conclusion: Anyone thinking about being a PIP should be aware of how important it is to share their expert knowledge in such as setting and shouldnt let their fear or perceived lack of knowledge hold them back. They should be willing to be an equal and expect to be treated as such and be willing to contribute fully to the knowledge exchange process including giving honest constructive feedback

Despite this relationship still being quite new we have plans to grow and build my PPI within UCD CAR.

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Patient information and education

AB1425-PARE FAMILY PLANNING IN CHRONIC RHEUMATIC DISEASES: UNMET NEEDS OF WOMEN AND MEN IN SWEDEN

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Background: Family planning (FP) in the context of chronic rheumatic disease (CRD) can be challenging for both women and men, with additional requirements for information and support.¹ However, it is unclear whether the needs of this population are being met by current clinical practice in Sweden.

Objectives: To gain insight into the perspectives of women and men with different CRDs on FP, and to assess whether they feel adequately supported to make informed decisions.

Methods: A 10-minute survey focusing on participants experiences and current needs around FP was designed. The survey was distributed (24 Aug 5 Sept 2018) via a web-based system to members of the Swedish Rheumatism Association; men and women aged 18-47 years were included. Data are reported for participants with arthritic or systemic CRDs (rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile idiopathic arthritis, systemic sclerosis, systemic lupus erythematosus, polymyositis, dermatomyositis). Participants with fibromyalgia, Ehlers-Danlos syndrome, other or no CRD were excluded.

Results: Of 944 participants, 542 (57%) women and 60 (6%) men with arthritic or systemic CRDs responded. Over a quarter of women (28%) who had/were expecting children felt their CRD had affected their ability to have children and more than half either believed that their CRD had influenced the number of children they had or were undecided (**Figure A**). Men were less affected by their CRD with respect to FP, with >60% reporting no impact on their ability to have children and/or how many. Of participants who did not want children/more children in the future, around a third attributed this to their CRD (women: 37% [n=86/232]; men: 30% [n=9/30]). Their biggest concerns were not being able to physically handle and/or cope with taking care of a child, and passing on their disease (**Figure B**). Womens concerns regarding disease activity after pregnancy were not unfounded, with 66% reporting disease worsening postpartum. The most common treatments reported by women with CRD while trying to conceive were DMARDs (20%), NSAIDs (18%), corticosteroids (14%) and anti-TNFs (13%). Of women on anti-TNF therapy (n=71), 68% discontinued treatment during pregnancy. Only around a third of women felt they had received adequate support and information about FP from their healthcare provider (HCP: 33%) and that this information was consistent between HCPs (28%). Men with CRD were even less satisfied with both the level of support (13%) and the consistency of information received around FP (13%).

Conclusion: The results of this survey suggest that in Sweden, CRD has a marked impact on FP for women, and to a lesser extent for men. Furthermore, the level of support and information on FP provided by HCPs to people with CRD, as well as the consistency of information received from different HCPs, were deemed inadequate. Providing better information on FP by HCPs, to both women and men with CRD, would help to support them on their journey to parenthood and overcome perceived obstacles to having children and continuing therapy.