

ACR Convergence 2022

Discovering ways to develop patient-included rheumatology research projects can prove a daunting task for both experienced and novice stakeholder groups. Some spend weeks, months, or even years struggling to develop a patient engagement in research model when many exist and in several contexts. Those experienced in patient-included research often look for ways to build on past successes or formulate new, innovative methods of engagement. Now there is a tool - The Pathway of Patient Engagement in Rheumatology Research (“Pathway”) -that can help all stakeholders that is specific to rheumatology and considers the unique participatory challenges of rheumatology patient partners.

This session introduced the Pathway, which can help those developing patient-included rheumatology research projects. It identifies existing engagement models and resources used in a similar research context and explains how to incorporate these into a project. Identifying initiatives and concepts of engagement already in practice avoids duplication of efforts and strengthens the ability across projects to measure engagement outcomes. Learning more about existing patient engagement models with those providing leadership in these efforts, will also increase the potential for future collaboration opportunities.

Action Council: Pathway of Patient Engagement in Rheumatology Research Review and Implementation.

Presented by Tiffany Westrich-Robertson (AiArthritis*), Cheryl Koehn (ACE*), Maarten De Wit (EULAR PARE), Dr. Linda Li (University of British Columbia and Arthritis Research Canada), and Kaleb Michaud (Moderator).

This session represented the first time since ACR started in 1934 that patient organisations have led a session with researchers on the panel. The presentation, by the Action Council (more on this below), was to introduce an amazing tool designed for researchers, pharmaceutical industry representatives, patient organisations, and those who engage patients in research. The tool is called the Pathway of Patient Engagement in Rheumatology Research (“Pathway”).

The tool was introduced by Tiffany Westrich-Robertson, who first discussed what patient engagement is. There are many types of patient engagement in research, but no single definition or model of engagement. Patient engagement can vary

from at worst, tokenism to at best, a full patient partnership. Tiffany referred to the many types of engagement as Concepts of Patient Engagement (COPIs). The Pathway tool is global in nature. Its goals are to really include patients in research projects by being a resource for those designing rheumatology research projects. It aims to build on past successes, to identify and incorporate existing COPIs, to develop novel methods of patient engagement, and to stay abreast of new projects globally in rheumatology.

We all know as patient leaders and advocates, that for many years now there has been a movement to engage patients in various ways in rheumatology research projects. But the Action Council recognised the lack of a standard patient engagement model and the lack of clear guidelines and resources for involving patients. The Action Council decided to act on these concerns and has developed the Pathway over the past two years. The Action Council is comprised of nineteen individuals selected on the basis of who could provide the most input to design the framework of the Pathway tool. They are global stakeholders representing the research community, including patient leaders and advocates, doctors, researchers, and academics.

The Pathway tool can be found at www.rheumactioncouncil.org/pathway. A short video was shown and Maarten De Wit explained its benefits. Cheryl Koehn emphasised that the tool had been the idea of patients and had been built by them. Tiffany commented that the tool, in identifying collaborators, tracing milestones, and finding other tools, avoids duplication of effort, improves value measurements, and increases the number of patient voices in rheumatology research.

In the next part of the presentation, Maarten showed everyone how to navigate through the Pathway. The best way for the reader to understand the navigation is to open the tool up (www.rheumactioncouncil.org/pathway) and play around with it. The Pathway tool includes a video on navigating the Pathway, stopping points on the Pathway (Resources to Improve Patient Involvement in Research; Novel 'Firsts' of Engagement; Historic Milestones), and a search function to access a large amount of information. Also included in the tool are four Glossaries, allowing users to search by Name (of patient organisation or collaborators), Context, Tools, and COPIs.

Following the introduction of Pathway, researcher Dr. Linda Li, presented work started in 2015 by Clayon Hamilton (Ph.D., Arthritis Research Canada), the PEIRS (Patient Engagement in Research Scale) project. PEIRS was driven by the idea that meaningful patient engagement in research is the planned, supported, and valued involvement of patients or their surrogates in the research, which facilitates their contributions and offers a rewarding experience. PEIRS reduces questions regarding a patient's involvement in research in eight areas (convenience, feeling valued, contributing, supported, the research environment, procedural requirements, benefits, and team interaction) to 22 items, divided into seven sections, with five-point Likert responses. The questions take about three to seven minutes to complete and the final score ranges from 0 to 100. The higher the score, the more satisfied is the patient with their involvement in the research project. The scale may be accessed and used freely at <https://www.clayonhamilton.com/peirs>

Linda stressed the importance of including the PEIRS project in the Pathway, because it is not enough to just include patients in a research team without assessing and improving the extent to which the engagement is meaningful.

Linda, speaking as a researcher, also addressed the question 'Why the Pathway?' Pathway gives a picture of the state of patient engagement in rheumatology research, allows for the quick identification of available tools for supporting patient engagement, is global in nature, and allows for the easy location of new initiatives. Everything is in one place and one can learn from the successes of others.

Cheryl then presented the value of Pathway from a patient organisation perspective, saying that Pathway is, at face value, an 'organisational memory' tool that knows, respects, and values the arthritis patient experience. It is this lived experience that is at the centre of a patient asking a question in research. Cheryl warned researchers not to underestimate the intelligence of patients, even if they cannot articulate something as the researcher would like. To the strengths of patients incorporated in Pathway, Cheryl asked the audience for more things that patients bring to the table. Answers included an impressive list: diversity, intersectionality, sensitivity, empathy, passion, creativity, and expertise.

The Pathway is a living record and tool for patient engagement in rheumatology research. It should be used, and it is important to spread the word about it. More importantly, if readers have been involved in a research project with patient involvement, please submit your case study, tool, guidance, etc. for inclusion on the Pathway. Please submit to <https://bit.ly/PathwaySubmissions>

*AiArthritis and ACE (Arthritis Consumer Experts) are both Members of ASIF.