

CASE STUDY



Bath Institute for
Rheumatic Diseases

BIRD'S PATIENT ENGAGEMENT PROGRAMME

BIRD exists to support arthritis research, healthcare professional education and patient engagement. We strive to put patients at the centre of our work, recognising and encouraging the importance of their voice. Our Patient and Public Engagement programme (PPE) initiative works closely with patients to get them involved in research and deepen their understanding of their rheumatic disease.

In phase III of the PPE programme (2022) we have placed an enhanced focus on our aim to encourage patient participation in research. It is important, therefore consequently, that we also understand and review the experience from a researcher's perspective. This BIRD case study reflects the experience of a researcher who worked with Mel Brooke, BIRD Patient and Public Engagement Director and our new PPE Volunteer Patient Research Panel.



Case Study Background

Dr Frankie Brown, PhD. and Postdoctoral Research Associate at the Department for Health at the University of Bath working with Dr Raj Sengupta, Consultant at the Royal National Hospital for Rheumatic Diseases (RNHRD) secured a grant from BIRD's research grant funding committee to develop ideas generated by a previous remote consultation project. In that project the team had interviewed rheumatology patients and staff and subsequently developed two further research project ideas.

Working with Mel Brooke, BIRD Patient & Public Engagement Director as the lead consultant advisor for patient engagement in research the projects were as follows:

Project 1: Build a pilot algorithm to triage rheumatology patients and determine who is most suited to remote instead of in-person consultations, utilising both subjective and objective data. Part of the work would involve sending surveys to patients, to determine whether they had attended any remote consultations and exploring perceived benefits and barriers.

Project 2: To produce a resource for both patients and staff to help them prepare for remote consultations.

SURVEY DESIGN AND OVERCOMING BARRIERS

Having agreed on the importance of involving patients in research and these projects, Frankie initially wanted to explore if BIRD could help her test out some surveys on a group of patients. While the project was still in the preliminary design stage, Mel made some additional suggestions, such as involving a patient in the design of the survey and linking the project rationale to that of other findings and recently published papers – both of which were welcomed.

Mel enquired if patient involvement had been budgeted for during the funding application process as this helps to widen potential inclusivity (overcoming cost barriers for things like patient time) and follows the National Institute for Health and Care Research (NIHR) advice. The initial project seed funding was limited however and did not include scope for this but Frankie was working on a protocol and accompanying documents for a fuller NHS ethics application with the aim of submitting it shortly. Time was of the essence and she was keen to get patients involved as soon as possible so help was offered via BIRD's voluntary patient research panel.

USING BIRD'S VOLUNTEER PATIENT RESEARCH PANEL

Project 1:

Following the introductory discussions, Frankie emailed the draft patient questionnaire. Mel reviewed and approved it before discussing this new engagement opportunity with members of the patient research panel.

A participation invite was sent to the panel members and those who volunteered to help were sent the draft document, issued with some review guidance and a timeframe in which to respond. Seven panel members responded with comments which Mel collated and summarised into a single document for Frankie. Frankie was extremely pleased with the panel's help and said the feedback provided would be incorporated into the trial protocol and other trial documents.

"Thank you so much for this, I will certainly be back in touch about where the survey goes, so that you can update the participants. Please thank the participants on my behalf and I look forward to working with them again!"



PROTOCOLS AND WORKSHOP

Project 2:

Later in the project development Frankie came to BIRD to say she was putting the Patient Involvement (PPI) section in the protocol document, asked for suggestions on what to include from a patient engagement perspective, as well as help in getting a group of patients together for a workshop to look at and discuss the resources available to help patients prepare for remote consultations. The research team wanted to identify gaps and what the patients considered most important.

Workshop insights were fed back to a second project workshop with clinicians from the rheumatology department. The outputs of the two workshops combined would help develop a resource to help patients and clinicians prepare for remote consultations.

Initially, Mel reviewed and suggested edits to the draft PPI segment of the protocol and offered to help set-up and host the patient workshop. As things progressed, Mel initiated the 'patient information sheet' which she helped to review and outlined what was needed for the workshop invite wording. Feedback on progress following the first survey was also requested for the panel members.

Mel raised a discussion on the question of whether or not formal participant consent would be needed for the workshop. Frankie sent a query about this to the Research Development Service at University of Bath who helped clarify and resolve this particular case.

Mel sent out the participation invite to the patient research panel and began liaison to find a best date to maximise the number of people attending. A date was set and six panel volunteers were sent pre-meeting documents, meeting links and instructions. Afterwards, Frankie said she felt the workshop was a success and the insights very useful. The participants enjoyed contributing and each was sent a personal thank you email by Mel on behalf of BIRD and the research team.

"Thanks again for getting the participants together and facilitating the workshop on Tuesday, it was excellent." (Dr Frankie Brown)

Frankie got back in touch again later to say ethics had approved the Participation Information Sheet for the project and that she had set up an e-survey which Mel agreed BIRD could share in the e-newsletter to their patient network. The team are still currently trying to embed the use of the resource at the hospital but as Frankie says: 'the input from the patients (to get this far) has been invaluable'.

LAST YEAR OVER 2,600 PATIENTS WERE INVITED TO PARTICIPATE IN RESEARCH BY BIRD AND 251 RESPONDED.