

# 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 initiative works closely with patients to get them involved in research and deepen their understanding of their rheumatic disease.

In phase III of the programme, we have placed an enhanced focus on our aim to encourage patient participation in research. It is important that we capture, assess, and evolve the experience they have had. This case study reflects the experience of a patient who volunteered to work within our new Patient Research Panel and the positive impacts they have experienced from getting involved in research.



## Case Study Background

Lesley is 73 years old and first became ill in her late twenties. She was sent to various rheumatology departments hoping for some respite from the pain caused by Rheumatoid Arthritis. Some twenty years later, she asked to be referred to Bath, where she was given a diagnosis of Psoriatic Arthritis.

Lesley was invited to a BIRD information day for Psoriatic Arthritis at the former Royal National Hospital for Rheumatic Disease (RNHRD), in central Bath (known as the Mineral Water Hospital). She remembers 'an excellent day's programme' where different specialists presented latest developments, medications, research updates and advice on how to best self-manage disease. This was before podcasts and webinars had been introduced. She found the events were very valuable and enjoyed meeting with other people, discussing things like pain management and sharing information with others.

## MOTIVATION TO JOIN BIRD'S VOLUNTEER PATIENT RESEARCH PANEL

Lesley felt that treatment and advice from the RNHRD and information from BIRD really helped to get her life on a more even balance. She was keen to 'give back' with the hope more people could gain improved quality of life. She was happy to complete clinic questionnaires and took part in a study about medication that asked for feedback, such as why people stopped their medication and why others kept going, the pros and cons. Lesley also volunteered for a bio-bank study which involved keeping a food diary, review meetings and having various samples taken for research.

A first call out for a new 'Patient Research Panel' was sent by Patient Engagement Programme Director, Mel Brooke, via BIRD's patient network in early 2020, just before the Covid pandemic. Lesley was quick to respond, feeling it essential to engage patients in research to gather insights to inform choices and future developments.

*"a layperson can offer an insight from a different perspective to medical knowledge based on their personal experience"*

## ENGAGEMENT AND INVOLVEMENT EXPERIENCE THROUGH THE PATIENT RESEARCH PANEL

BIRD is well connected to a wide range of researchers and organisations and had already been helping to find patient volunteers to participate in various projects and research engagement opportunities. The Patient Research Panel (PRP) was developed as a conduit for deeper engagement and involvement, made up of people with a diverse range of experience or simply a desire to learn. Mel, a patient engagement expert, uses her knowledge to support and liaise with researchers to identify mechanisms for involving patients in research and helps to explain and guide PRP members along the way.

Lesley very much enjoyed being connected to the panel and the opportunities BIRD has shared. She has participated in a variety of research activities such as evaluating medicines, participating in online meetings, lay reviewing e-surveys and questionnaires. She was very pleased to take part in a Psoriatic Arthritis research priority setting project, another opportunity that BIRD had been able to share.

Lesley says: 'What's nice about the PRP, is that there is no pressure, you can look through requests and opt in if you have the time. You can also choose topics which you feel most able to contribute towards. For me, the bigger project opportunities were most enjoyable as they involved yet more engagement and took place during the pandemic when I was shielding and home alone with plenty of time to participate.'

## SATISFACTION FOR RESEARCH ENGAGED PATIENTS

Lesley tells us the most enjoyable types of involvement are those with interaction such as workshops and zoom meetings although she is happy to help lay reviewing documents and papers too. She sums up by saying:

*"Personally, I just feel so happy I can give something back. I know how hard life is with that level of pain, and how much the RNHRD and BIRD have helped me. Being involved with PRP has made me collate information on my own experience and medications, compile a diary of events, all of which I can draw on to help other people. The workshops have helped me be more open-minded and reflect on other people's experiences too. It has been an eye-opener and has increased my understanding. The podcasts and webinars have also added to my knowledge and have been useful to pass on to others. I have been able to support a local lady who is starting on her journey and overwhelmed by the whole thing"*

Lesley strongly recommends becoming involved in research, she feels the benefits are many for the patient, for the experts and for future patients.

*"I have been through all the drugs now and feel my 40+ years' experience is valuable!"*

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

