

CASE STUDY



Bath Institute for
Rheumatic Diseases

BIRD'S PATIENT ENGAGEMENT PROGRAMME

Our Patient and Public Engagement initiative works closely with patients to get them involved in research and deepen their understanding of their rheumatic disease.

BIRD runs an extensive programme of patient engagement and education events. Our live events have grown to over 500 patients attending every year and our patient network reaches many thousands every year. During the COVID pandemic we switched to offering patients support via podcasts instead of our established disease-specific patient information days and these have attracted over 6,000 listens. We know that both types of learning interaction, involving Consultants, researchers and healthcare professionals, help to give people a deeper understanding of their condition, medications, treatments and research news. Patients value this and are able to use it to help them increase confidence and better self-manage their condition.



H's story...

H is 57 years old and has lived with Psoriatic Arthritis for 28 years. Her symptoms first emerged in her late 20s when she had painful feet and toes but she wasn't fully diagnosed until several years later when she was referred to a rheumatologist for swollen finger joints. She was initially diagnosed with seronegative arthritis and later given a Psoriatic Arthritis (PsA) diagnosis. Psoriatic arthritis has had such a significant effect on H's life over the past 28 years that it impacts her physical ability to perform day to day activities at home and work. During flare ups, she struggles to walk far and needs to take regular rests whilst the fatigue, pain and discomfort limits normal activities with her family. She cannot open bottles and jars or reach up to

things above shoulder height, she has difficulty with basic tasks such as chopping vegetables despite having a number of kitchen aids. H feels fortunate to have the support of family and friends but knows they haven't always understood how fatigued she can become. She often masks or plays down her symptoms and it frustrates her to have to ask for help. A number of adjustments have been made to her home such as extra handrails and bathroom support equipment installed. H does most of her shopping online and severe pain and mobility issues means she now relies on a blue disability badge to enable her to park closer to places she needs to be. Her neck, shoulders, ankles, wrists and spine are so affected she struggles to enjoy gardening –

something she has always loved - and can only enjoy her creative hobbies of sewing and painting on a 'good' day when her hands are not too sore. H changed from hospital-based nursing to community nursing a few months before diagnosis as shift work became too exhausting and painful. Part time hours allowed her to continue nursing for some time. Her understanding of the impact of long-term health conditions and disability and has been an asset in terms of supporting others in her work. Shielding through the pandemic led to her mobility deteriorating further and she made the difficult decision to retire from her nursing role of 38 years.



Help is at hand...

H heard about the work of BIRD and the PPE Programme through an online group and was pleased to get a place at one of the PsA information day events - she felt excited at the prospect of learning more and meeting others with the condition.

The programme was great and I learnt so much. The wide range of knowledgeable experts available and the talks given were really informative

In addition, H found hearing about the latest research and new medications interesting and reassuring and was grateful to have the chance to join in with discussions. She picked up new self-management tips from a physiotherapist speaker and telling her family and friends what she learnt helped them to understand her condition better too. H stays connected to BIRD and says she thoroughly recommends the programme and events to people, whether they are recently diagnosed or have had their condition for many years.

My experiences as a patient participating in the programme have all been positive, I am constantly learning more about PsA and have surprised myself at how much I have gained from my participation, despite my nursing background

The information days have sparked H's interest in research and patient involvement and she has been inspired to read a number of research papers linked to professionals who presented or who were referenced during the events she attended. Further, she has since participated in research herself and feels it's a way of helping current and future patients and service development – both of which are really important to her.

The more we as patients understand about PsA, the more effectively we can manage our condition

We know that our patient audiences benefit from our programme. All of our events include feedback with response rates exceeding 67% and information is compiled and analysed and made available to all.

We aim for at least 85% of people engaged with information through the Patient Engagement programme to describe their knowledge as improved or really improved since attending, and for our reach to reflect the needs of the general population in terms of age, gender, socio-economic group and ethnic background.

Bath Institute for Rheumatic Diseases,
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