

# From small seeds...

(Matthew Ridd & Julie Clayton,  
EBI Seed Fund project 2019)

## [Themes]

Improving Funding Bids  
Experience Informing Research  
Patient & Public Involvement (PPI)

**Early engagement with patients in health research (enabled by a small seed fund) informs and improves grant applications, by incorporating expertise from the population most impacted by future research**

*"Shingles does not discriminate, so language should not be a barrier for people with experience of it to come together with researchers to share their stories and experiences to help in making healthcare better for all concerned."* Rosa Hui, Bristol & Avon Chinese Women's Group

**[Aim & Approach]** Prof. Matthew Ridd (Healthcare Researcher into skin conditions) & Dr Julie Clayton (PPI & Engagement Coordinator) carried out a small project investigating people's experiences of shingles and subsequent chronic nerve pain (post-herpetic neuralgia), as part of planning for a new research study. It provided a better understanding of the condition and uncovered what aspects of research mattered most to patients.

**[Practical Details]** A small grant of £500 from the Elizabeth Blackwell Institute for Health Research (EBI) Seed Fund covered workshop costs, including participants' travel and time (attendees were reimbursed at £20 per hour for their input), and paid for an interpreter.

**[Key Partnerships]** Bristol Black Carers and Bristol & Avon Chinese Women's Group assisted with participant recruitment. These organisations provide culturally appropriate support and assistance for carers and families within Black and Minority Ethnic communities across Bristol.

**[Activity & Outcomes]** Around 20 people with lived experience of shingles and post-herpetic neuralgia, including a number from ethnic minorities and with English as a second language, took part in two informal workshops. Patients and carers talked with researchers about the condition, its effects and how the proposed research was relevant to them. They highlighted stereotypes about shingles, and revealed how some groups can feel excluded from, or suspicious of, academic research. Details of the research question and trial design were also discussed, such as medication dose; intervention duration; recruitment and retention of participants and how to allay worries about potential side-effects from trial medication. Researchers gained a much greater insight into the condition; its effects on sleep and mood; and the difficulty of describing post-herpetic pain; as well as the importance of using culturally appropriate images of skin conditions in trial recruitment.

**[Support]** Grants for very small engagement projects, which provide vital opportunities to try out ideas, can be hard to find. EBI Seed Funding made a big difference by enabling pre-award engagement to take place. The fund was open to any Bristol University health researcher to pilot a new project, enhance an activity, or deliver a one-off event.

**[Impact]** The workshops informed a successful £1.9m bid to the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme for a large trial starting in 2021 - the ATHENA study. Matt said *"We gained a much better understanding of issues that affect the perceived relevance of the study to potential participants and of the findings to patients. We also now have a group of people willing to be involved on-going research"*. Such insights usefully inform grant applications, ensuring researchers are working closely with people who have knowledge of living with a particular condition, and that research proposals are meaningful to patient communities.

## Public Engagement

Strengthening research with conversations that count