DEAR EDITOR, Patient and Public Involvement and Engagement (PPIE) is a critical part of research, from early study design through to dissemination of results. The importance of PPIE input in the early phases of research design is significant and increasingly recognized throughout the research community, with most funders now requiring evidence of meaningful PPIE in grant applications [1]. Benefits include more patient-oriented research goals and creating a communication network for dissemination of study findings to the public. Thus, PPIE forms a fundamental part of delivering effective, impactful research.

Several approaches have been developed to involve patients closely in research [2, 3]. Previous publications have proposed key factors to consider when developing patient involvement plans [4]; however, mechanisms for how best to achieve this are less clearly defined. There remains a need for step-by-step practical guidance for researchers to follow when working with patients and lay partners to reduce an imbalance of understanding, to recognize the value of non-scientific participants, and to ensure the voices and views of patients are represented. Here we describe the approach taken within the CLUSTER Consortium.

CLUSTER is a UK-wide multi-disciplinary consortium focused on precision medicine research for JIA [5]. It brings together researchers in JIA and associated JIA-uveitis, with bioinformaticians and industry partners, in partnership with a patient and parent network.

From its inception, CLUSTER developed a dedicated UK-wide PPIE group, the CLUSTER Consortium Champions, hereafter referred to as ‘The Champions’. These individuals have lived experience of JIA and/or JIA-uveitis, typically being patients or parents [6]. Several of the Champions also represent JIA charities thereby forming a wider patient and parent network, helping to diversify patient views and experiences that they bring to CLUSTER. The Champions worked closely with the Consortium’s research partners to develop an innovative PPIE policy (Fig. 1). This sets out the process to support involvement at the earliest possible stage of project design and grant applications, whilst acknowledging the real-world context of time pressures. This process integrates feedback forms (Supplementary Data S1, available at Rheumatology online) for researchers and PPIE participants to complete, facilitating a feedback loop to both capture the value of patient involvement (impact of implementation) and inform ongoing
improvements. The CLUSTER Consortium has internal funding calls which were used to test and refine this policy. Through implementation, all researchers applying for internal funding were required to involve the Champions early in discussions, prior to submitting formal funding applications. For specific projects, typically a subset of the group take part, depending on their availability and the specific skills and interests that different individuals bring.

The positive impact of implementation is evidenced by survey data collated following each application cycle. In 80% of cases, the Champions involved scored the process 10/10 when asked how satisfied they were with their involvement. Similarly, in all cases researchers reported extremely positive experiences and cited significant changes to their proposal as a direct result of consultation with the Champions.

Two example cases demonstrate the impact of involvement facilitated by this policy. The Champions contributed to complementary projects titled ‘Gut-derived metabolites and modulation of pathogenic B-cells in Juvenile Idiopathic Arthritis’ and ‘Immunomodulation of pathogenic B cell responses by gut-derived metabolites in Juvenile Idiopathic Arthritis’, which were subsequently funded as part of highly prestigious awards from the Kennedy Trust for Rheumatology Research and Foundation for Research in Rheumatology (FOREUM). Their input had a significant impact on project design, notably on the patient-facing aspects including qualifying the patient impact and methods to increase the accuracy of the dietary assessment. Most significantly, this led to the Champions being included as co-applicants on the FOREUM proposal, with ongoing involvement in experimental design.

Early involvement in a second project entitled ‘Unlock PsA: Stratifying the Impact of Psoriatic Arthritis in Children and Adults’ was also critical. The primary research question was co-developed with PPIE, identifying the right treatment from the outset of disease. The group then co-designed the project in greater depth, including which experiences should be studied, identifying a specific drug (methotrexate) as a key focus, and highlighting the importance of comparing disease in childhood and adulthood. This proposal led to a prestigious Fellowship from the Medical Research Council. With a defined process, this policy supports Early Career Researchers, many of whom have no patient-facing experience, in successful patient involvement and embeds good practice in the future leaders of Paediatric Rheumatology research.

The importance of involving patients and parents or carers early in the research process cannot be overstated. This makes it more likely that relevant research questions are asked and that the intended outcomes respond to patients’ unmet needs, informed by lived experience. This clearly defined strategic policy has enabled systematic incorporation of PPIE into the early phases of research planning in CLUSTER and high-quality patient involvement has been demonstrated throughout

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the project. Ultimately this approach will strengthen research outcomes, maximising benefit for patients with JIA and JIA-Uveitis.

**Supplementary material**

Supplementary material is available at *Rheumatology* online.

**Data availability**

The data underlying this article will be shared on reasonable request to the corresponding author.

**Contribution statement**

R.B., A.M., F.L.F., Z.W., L.R.W. and K.H., in partnership with all of the CLUSTER Champions, developed and refined the policy and procedures referred to in this paper. R.B. and F.L.F. prepared the draft paper. E.C.R. and S.J.W.S.-W. were among the initial users of the new policy and provided feedback to refine it. All authors reviewed, edited and commented on the manuscript. All authors approved the final revised manuscript.

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**CLUSTER Co-Investigators:** Prof Lucy R. Wedderburn (UCL GOS Institute of Child Health, London and Great Ormond Street Hospital NHS Foundation Trust); Prof Andrew Dick (UCL Institute of Ophthalmology, London); Prof Michael W. Beresford (University of Liverpool and Alder Hey Children’s NHS Foundation Trust, Liverpool); Prof Athimalaipet V. Ramanan (University Hospitals Bristol and University of Bristol); Prof Michael Barnes (Queen Mary University, London); Prof Stephen Eyre (University of Manchester); Prof Kimme Hyrich (University of Manchester); Prof Soumya Raychaudhuri (University of Manchester); Dr Chris Wallace (University of Cambridge); Prof Nophar Geifman (University of Surrey).

**Members of the CLUSTER consortium are as follows:**

Prof Lucy R. Wedderburn, Dr Melissa Kartawinata, Ms Zoe Wanstall, Ms Bethany R Jebsen, Ms Freya Luling Feilding, Ms Alyssa McNeese, Ms Elizabeth Ralph, Ms Vasiliki Alexiou, Mr Fatjon Dekaj, Ms Aline Kimonyo, Ms Fatema Merali, Ms Emma Summer, Ms Emily Robinson (UCL GOS Institute of Child Health, London); Prof Andrew Dick (UCL Institute of Ophthalmology, London); Prof Michael W. Berestof, Dr Emil Carlsson, Dr Joanna Fairlie, Dr Jenna F. Gritzfeld (University of Liverpool); Prof Athimalaipet Ramanan, Ms Teresa Duerr (University Hospitals Bristol); Prof Michael Barnes, Ms Sandra Ng (Queen Mary University, London); Prof Kimme Hyrich, Prof Stephen Eyre, Prof Soumya Raychaudhuri, Prof Andrew Morris, Dr Annie Yarwood, Dr Samantha Smith, Dr Stevie Shoop-Worrall, Ms Saskia Lawson-Tovey, Dr John Bowes, Dr Paul Martin, Ms Melissa Tordoff, Ms Jeronee Jencynloss, Mr Michael Stadler, Prof Wendy Thomson, Dr Damian Tarasek (University of Manchester); Dr Chris Wallace, Dr Wei-Yu Lin (University of Cambridge); Prof Nophar Geifman (University of Surrey); Dr Sarah Clarke (School of Population Health Sciences and MRC Integrative Epidemiology Unit, University of Bristol); Dr Victoria J. Burton, Dr Thierry Sornasse (AbbVie Inc.); Daniela Dastros-Pitei MD, PhD, Sumanta Mukherjee, PhD (GlasoSmithKline Research and Development Limited);
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