**Title:**Exciting opportunity to represent patient and public voice onthe £12m MRC NIHR Rare Disease Research Platform Selection Panel

**Summary:**The UK Medical Research Council (MRC) and National Institute for Health and Care Research (NIHR) have released a call for proposals to form the UK Rare Disease Research Platform, with an investment of around £12 million over five years. This is an exciting opportunity for representatives of patient and public voice to be part of the selection panel, assessing proposals from research teams in response to this call and helping to reach decisions on which will be taken forward.

**Full description**:  The MRC NIHR Rare Diseases Research Platform will support the coordination of UK rare disease research and address tractable research challenges, with the ultimate aim of a step change in the mechanistic understanding, diagnosis and therapy of rare diseases. Up to twelve, thematic nodes will be funded. Full information is available on the [MRC website](https://www.ukri.org/opportunity/establish-an-integrated-uk-rare-disease-research-platform-nodes/). An initial set of outline proposals have assessed by an expert panel and successful applications invited to submit a full proposal for review.

The Platform intends to fully engage with the full range of crucial stakeholders in rare disease research, including patients and families, academic, clinical and industry researchers, policy makers and regulators.

We are seeking two representatives of patient and public voice to sit on this panel and contribute to assessing the proposals received. Representatives should ideally have lived experience of a rare condition and an interest in or experience of research. Representatives should be in a position to be able to broadly represent the shared interests of the rare disease community, rather than focussing on a particular disease or disease grouping. Experience of research funding is desirable, but not essential.

Expressions of interest are invited from potential representatives. Applications will be assessed on the basis of relevance of experience and two members selected to maximise diversity in the representation on the panel.

The expert panel meeting will be held on 22-23 March. Papers will be sent out at least two weeks prior to the meeting. There will be up to 29 full applications, including an application form, a 10 page case for support, and attachments (e.g. CVs, letters of support). Support will be provided in identifying a suitable route for the representatives to access the documents.

Each full application contains a dedicated section on patient and public involvement and engagement (PPIE) of around one page in length.

We are asking for representatives to provide brief comments at the meeting on the PPIE section of the applications. Each representative be asked to review around half of the applications (around 14 to 15 applications with the PPIE section comprising around one page). Representatives are then asked to participate fully in meeting discussion, including 1) assessment/scoring of applications and 2) developing an overall approach to PPIE for the Nodes and Platform.