

What is research and why should patients and the public be involved?



Research is what we do when we have a question we want to answer or a problem we want to resolve. Health research aims to generate the knowledge that will allow health organisations to deliver better health care to population they look after.

The 3D's represent the types of activities patient research partners may do to promote and enhance Rheumatology research in Birmingham (see also the '[what is involved in being a R2P2 research partner](#)' ([/research/activity/mds/projects/ii/R2P2/partner/index.aspx](#)) section

2. The **delivery** of research (including the design and development of measures, sitting on steering committees, promoting strategies to enhance informed consent and patient understanding of research)
3. The **dissemination** of research (including the development of lay summaries, organisation of events to promote research and website design)

1. The **design** of research (including establishing research priorities and informing funding applications)

“ Professor Dame Sally Davies
Chief Medical Officer, Foreword in [Staley report \(http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/\)](http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/), 2009 "No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well"

INVOLVE, an organisation that supports greater public involvement in NHS, public health and social care research (<http://www.invo.org.uk/> (<http://www.invo.org.uk/>)), defines public involvement in research as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.”

A term you will often hear in relation to patient involvement in research is ‘Patient and Public Involvement’ (PPI). Examples of PPI within the RRG group are the patient involvement in both the DELAY (www.earlyarthritis.co.uk (<http://www.earlyarthritis.co.uk/>)) and RAPID ([/research/activity/mds/projects/ii/ra-rapid/index.aspx](#)) projects. The DELAY and RAPID projects are very much interlinked and the need for the RAPID project was identified through the involvement of patient research partners in the DELAY project. Research partners from both projects have been involved or are currently involved in the development of patient materials, lay summaries and surveys and are advising on the implementation of the various studies. Further details can be found on the project websites.