

VOCAL

Tweetchat
#Involvement
Preclinical



Appendix 3

“When we talk about public involvement, we mean all the ways in which the research community works together with people including patients, carers, advocates, service users, and members of the community. Excellent public involvement is inclusive, values all contributions, ensures people have a meaningful say in what happens and influences outcomes, as set out in the UK Standards for Public Involvement.”

[The Shared Commitment to Public Involvement](#)

**This work was commissioned by the
Medical Research Council**

VOCAL



Medical
Research
Council

Introduction and summary

Vocal was commissioned by the Medical Research Council (MRC) to undertake a review of public involvement in research (February–September 2022), with a specific focus on non-clinical health and biomedical research. This Appendix shares the findings from a public discussion on Twitter.

The #Involvement_Preclinical Tweetchat took place on 9 March 2022 and was a follow-up to a similar chat that took place in 2018. 85 contributors took part, with almost 400 tweets in total and around 35 people active in chat and adding comments.

Participants were mainly from UK, Ireland and Canada, many were patient advocates, some were public involvement leads from health services and research including people working in industry. There was a mix of people who often comment on the subject of public involvement on Twitter as well as some new people.

There was genuine interest, enthusiasm and commitment in the topic with some researchers mentioning their patient experiences as drivers for their work.

The Tweetchat helped with knowledge exchange as some significant reports and reviews were highlighted and shared. These are included in the Appendix 7.

Participants appeared to enjoy the opportunity to just come together, share ideas and develop our thinking.

The 3 questions asked were about why, what, and how do we actively involve patients and the public in the research landscape before, beside and beyond the clinical experience? For this review we have listed the comments from the 'why' question.

Why patient and public involvement (PPI)?

The question about WHY we need patient and public involvement with pre-clinical research produced the most valuable comments for this review:

- to understand the clinical impact
- to possibly flag priorities for preclinical research based on what would be useful in the clinical area
- to make sure research is relevant to public and patients, to guide relevance, to ensure dissemination of research results is accessible and tell public and patients what they want to know
- to ask the 'stupid' questions that no-one else dare ask.
- to ask some challenging questions e.g. why is much preclinical animal model work only done on males?

Summary

- to address gender bias in biomedicine; make more inclusive
- to make researchers think differently about their work – i.e. that it's funded by public money
- to ground folks doing this work who're often very removed from us and our experiences – we are more than biomarkers or a data point; not a collection of B cells.
- to keep the focus on what's important to patients
- to raise issues not thought of by others
- to keep research focused on an (eventual) end goal, it's interesting to lots of people and it's the right thing to do
- to fully understand the situation in which their research will be applied, even if that is very downstream
- to help avoid design flaws
- to help translate results into practice and make them meaningful and practical
- to help determine what people living with diseases deem important
- to make for better translation, more relevant research, connecting to people in a complex ethical area, sometimes it was more like outreach
- improve so much as well as the quality of the research – communication skills of the trainee, to add a new perspective that builds respect for the value of the work, understanding on what matters to patients etc. Wish universities had it as standard!

Legacy

All comments and content related to the Tweetchat remain on Twitter via searching for the #Involvement_Preclinical hashtag. Since the chat in March 2022, additional content relating to the subject continues to be posted.

MRC Review of public involvement in research (2022)

Complete list of documents

Looking forward: Working with the Medical Research Council towards a public involvement strategy (Main report & Executive Summary)

Appendix 1 Methodology of the MRC public involvement review

Appendix 2 Landscape review of public involvement in non-clinical research

Appendix 3 Tweetchat #Involvement_Preclinical

Appendix 4 A patient's desktop review of public involvement at the MRC

Appendix 5 Examples of MRC public involvement

Appendix 6 Public involvement in research survey

Appendix 7 References and toolkits about public involvement in research

Please see full list of acknowledgements in Main report

Photography

All photographs are from Vocal events and activities. They cannot be reproduced or used for any purposes. Copyright: Jill Jennings

Vocal

wearevocal.org

© UK Research and Innovation

Published by the Medical Research Council, part of UK Research and Innovation.

The text of this report and supporting data (excluding images and logos) is licensed under a Creative Commons Attribution 4.0 International (CCBY 4.0) License unless otherwise stated.

Any enquiries related to this publication should be sent to: publicengagement@mrc.ukri.org

This work was commissioned by the Medical Research Council

VOCAL



Medical
Research
Council