

# Examples of projects using social media for public involvement

## About this project

These examples are part of a project that looked at the use of social media for active public involvement. The project advisory group developed a [guidance document](#), which can be downloaded, and also wrote up the interviews that were part of the project as examples.

The examples each include a summary of the research project; how members of the public were involved; challenges; resources used; the impact of using social media; and advice for others. You can view the examples by clicking on the individual links below or by downloading this [pdf document](#)

## List of examples:

**[Example 1:](#) The Acne Priority Setting Partnership – Using **Twitter**, YouTube and mobile phone technology to involve people in identifying research priorities**

Mick Mullane, The Acne Priority Setting Partnership

**[Example 2:](#) Salford Research and Development (R+D) and NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (PCPSTRC) – Using **Twitter** to find people to involve in a research advisory group**

Philip Hammond, Salford R+D and NIHR Greater Manchester PCPSTRC

**[Example 3:](#) International Centre for Mental Health Social Research – Using **Twitter** and a **blog** to identify and prioritise topics for research**

Martin Webber, International Centre for Mental Health Social Research

**Example 4: Queer Futures** – Using **Facebook** to involve young people in the design and delivery of research about suicide and self-harm

Liz McDermott, Queer Futures

**Example 5: NIHR Clinical Research Network Children Specialty Rheumatology Clinical Studies Group** – Using **Facebook** to ask parents and families about their priorities for research

Sharon Douglas, Scottish Network for Arthritis in Children (SNAC) Trustee, NIHR Clinical Studies Group (CSG) Consumer Champion

**Example 6: Children of the 90s** – Using **Facebook** and **Skype** to involve young people in a long-term research project

Makaela Jacobs-Pearson, Avon Longitudinal Study of Parents and Children

**Example 7: Cystic Fibrosis (CF) Unite** – Using an **interactive website** to involve people with cystic fibrosis in discussions about research

Matt Hurley, CFUnite

**Example 8: Greater Manchester Kidney Information Network** – Exploring the impact of social media on patient information provision, networking and social support using an **interactive website, Twitter** and **blogs**

Cristina Vasilica, Greater Manchester Kidney Information Network

**Example 9: West Midlands Collaboration for Leadership in Applied Health Research and Care (CLAHRC)** – Using an **interactive website** to involve people in dialogues about

CLAHRC research.

Jo Sartori, CLAHRC West Midlands

The guidance document and the examples are the first step in helping people to navigate this new type of interaction, and we will look to revise and add to them over time. If you are using social media to actively involve people in research, especially if you are using a type of social media not mentioned in any of the examples, please contact us at [involve@nihr.ac.uk](mailto:involve@nihr.ac.uk) and tell us your story.

**Members of the project advisory group were:**

Bec Hanley (TwoCan Associates), Louca-Mai Brady (INVOLVE advisory group member), Tina Coldham (INVOLVE advisory group member) and Marisha Palm (INVOLVE Coordinating Centre)

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