

## **Example 1: The Acne Priority Setting Partnership**

**Using Twitter, YouTube and mobile phone technology to involve people in identifying research priorities**

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### **About the research**

The [Acne Priority Setting Partnership](#) (PSP) was launched in 2013 by the [Acne Academy](#) in collaboration with the [James Lind Alliance](#). The aim was to put people with acne and treatment providers at the centre of deciding priorities for acne treatment research.

### **How have people been involved?**

Mick Mullane, the Patient Learning and Engagement Manager at the National Institute for Health Research (NIHR) Clinical Research Network and Dipaka Patel, the Communications Officer, worked with colleagues at the PSP to develop multiple ways for people with acne to suggest their priorities for research. Many people who get acne are young, so it was important to use social media.

The PSP team developed a survey that people could complete using a mobile phone or a PC. They then publicised the PSP and the link to the survey via:

- a poster with a [QR code](#) that enabled people to link to the survey
- two short films that were posted on YouTube
- tweeting about the PSP, again with a link to the survey and to the YouTube films.

The first stage of the process asked people about their priorities. Responses were then grouped into themes, and a second survey asked people to vote on these. Many people completed the surveys using their mobile phones. This meant that the PSP team were able to contact respondents via text message to:

- ask further questions
- tell people about the results of the first stage of the process
- invite them to take part in the second stage
- share the results of the project as a whole.

The use of YouTube as a complement to Twitter worked particularly well, as the films were something concrete that could be tweeted about, as opposed to just a link to the website and survey.

The team considered using Facebook but decided against it, because it requires you to post more information, and they did not want to influence people's suggestions for research. In contrast Twitter only allows you to send short messages, thus reducing the risk of influencing people.

No face-to-face involvement activities were undertaken at these stages in the PSP.

### **What resources were involved?**

It took about half a day to make each of the films, working in partnership with a filmmaker. Time spent tweeting and texting was minimal, especially as software was used to schedule the tweets and texts to go out at particular times. Texting is cheaper than posting a letter, and the NIHR has a central resource for this, which made it more affordable.

### **The impact of using social media**

Analysis of the second stage of the consultation showed that more people visited the PSP survey immediately after the YouTube films were released, and after the PSP's tweets were re-tweeted by the Channel 4 programme Embarrassing Bodies, Healthwatch groups and Patient.co.uk. In all, 4,000 people responded to the first stage of the PSP, with many of these doing so via mobile phones.

### **Advice to other researchers about using social media to actively involve people in research**

“Make sure the messages you send are engaging. Don't just send hollow tweets, asking people to complete surveys. Use things like YouTube films to stimulate people's interest. And make sure you feedback to people – otherwise you risk them not engaging with you in future.”

Mick Mullane, Patient Learning and Engagement Manager, NIHR Clinical Research Network

**Acknowledgements:** We would like to thank Mick Mullane for agreeing to share his experience, Bec Hanley for carrying out the interview and the project advisory group for their guidance.

**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement – The Acne Priority Setting Partnership: Using Twitter, YouTube and mobile phone technology to involve people in identifying research priorities