INVENTIVE INVOLVEMENT | WITH PATIENTS & THE PUBLIC

Working with PPI contributors online

What this involves

Working online simply means communicating with PPI Contributors through a computer, computer network or the Internet e.g. via Facebook or Twitter or using Skype to facilitate meeting attendance.

What are the benefits of working with PPI Contributors online?

- It can be a fun way of getting people's attention and investment.

- It can be a good leveller, whether you are just working with PPI Contributors or whether you are working with PPI Contributors and staff together.

- It may challenge people to provide input that you would not elicit through more traditional methods encouraging creativity of thought

- It may appeal to reluctant speakers or more 'physical' learners

When this might be a useful/appropriate approach?:

- Working online is another tool in our broad range of communication options. What it offers as an alternative is a potentially broader audience, e.g. geographically broader

- The 'type' of recruit that you can reach, e.g. full time carers, may find that online they can be involved in your work at a time to suit them, but they would not be able to attend meetings.

- It may be a cheaper option, as you won't need to pay people's travel expenses and you can engage people from across the country. However, INVOLVE good practice guidance states that people involved in your work should be paid for their time even if working online.

- The anonymity of being involved online may enable you to work with people who would not attend a meeting, e.g. research into pregnant women who drink over the prescribed amount of alcohol , or any case where people may feel that their behaviour would be judged.

- Free online analytical tools can help gauge the level of interest and response to what you are doing. This can be helpful in demonstrating to a funder the reach of your involvement.

- Blogs work well if you post regularly and have built up a good level of followers.

- Any project that is national or international.

- To reach an audience that communicates largely online, for example under 25s. In this case ensure that you use the online media they currently use, which may change over time.

- Social media could be used to generate hypotheses by using publicly available information posted by the public. Then take the questions to a more structured discussion with a panel of public contributors. You can also use social media to identify potential contributors who post about your topic of interest.

How can you work with patients online?

The options are infinite, so this is a sample of some known and tested strategies:

- ***Twitter chat —*** a public Twitter conversation around one unique hashtag (#). This hashtag allows you to follow the discussion and participate in it. Twitter chats are usually recurring and on specific topics to regularly connect people with these interests.

- ***Closed Facebook Group*** — Facebook is a website where you can how information about yourself, and communicate with others. To protect the privacy of group members' posts, discussions, photos, or files, it is possible to make a closed group for a particular community. This can be done both when creating a new group, or by changing the privacy

> **An example of this was by Liz McDermott on a project called Queer Futures. She used Facebook to involve young people in the design and delivery of research about suicide and self-harm. The young people sent out the researchers' request to take part to their networks of LGBTQ young people.**

settings of an old group.

- ***Provide training for PPI Contributors*** — This can be done in any topic relevant to the volunteers that you are working with. It can be offered free or restricted to those who will pay. It means that PPI Contributors can undertake the training at a time to suit themselves and broken into sections that suit them too. If it is important to have interaction with others as part of the training this can be built in with online chat options.
  Examples include webinars and remote courses from Future Learn

- ***Interactive website or online fora*** — Examples include 'Cystic Fibrosis Unite' (cfunite.org) and the 'Cicely Saunders Institute' (www.csipublicinvolvement.co.uk)

- ***Blog to crowd source PPI*** — A blog is a regularly updated website or web page, typically one run by an individual or small group, that is written in an informal or conversational style. It is possible for readers of the blog to leave comments. An example of this was Louise Locock, of Oxford University, who got input to a potential research topic at: petsandhealthsite.wordpress.com/2017/02/01/pets-people-and-illness/

- ***Run a virtual PPI group*** — An example of this is the Behaviour management section's Weight Management Panel, a group of over 100 people across the country who are consulted on a range of issues, via email, on their topic of interest.

- ***Online surveys*** — You can use existing software tools for free (such as survey monkey) which enable you to run surveys asking for PPI into any aspect of your research.

- ***Skype calls to enable PPI in a meeting*** — Skype is having a spoken conversation over the Internet using the software application Skype, typically also viewing by webcam. This is often used to enable a meeting without the need to travel. Members can hear and speak in real time and often see each other too.
  A variation on this is Google hangouts, which also enables you to view documents on a shared screen.

- *Facebook Live (or equivalent)* — Facebook Live lets people, public figures and Pages share live video with their followers and friends. It enables you to interact with viewers in real time, fielding their burning questions, and checking out their Live Reactions to gauge how your broadcast is going? The video will be published to the Page or profile so that fans and friends who missed it can watch at a later time. The broadcaster can remove the video post at any time. Live broadcasts can last up to 4 hours.   https://live.fb.com/about/

- *Accessing social media you have not initiated* — At a very basic level, you can use social media to look at information that is not a product of questions directly asked. Instead, you can look at user-generated content.

Examples

- **Online hashtags and real time twitter comments to gauge general opinions of health issues. Chorus analytics allows you to take twitter hashtags and build up a picture of post content http://chorusanalytics.co.uk/**

- **Instagram - photo-sharing application**

- **Tumblr - microblogging and social networking website**

- **Flickr - Photo blogging platform**

- **Reddit - social news aggregation, web content rating, and discussion website**

You can also use other less obvious, publicly available information such as

What are the drawbacks of this approach?

- You will need to respond quickly to people's comments and feedback online. This is not necessarily a negative, but does need to be built into any timetable you have planned. You will also need to be open about monitoring out of office hours.

- You may need to handle negative or unpleasant things being posted online, and do so quickly to limit damage.

- You may get responses from people in other countries which may not be suitable to your research or from ineligible groups, which may be a drain on time when responding to these.

- Working online is just a communication tool – you will still need to consider how to publicise your involvement activity and ensure that the people you want are likely to respond.

- Depending on your audience there may be limitations in their ability to engage with the technology, either in technical ways or due to insufficient training or confidence. You may exclude some people as a result.

A combination of online and offline methods is likely to be the most suitable option to ensure you can include all eligible persons or groups.

Resources:

- e-Participation Toolkit: using online technology to involve patients, carers and communities
- 'Using digital technology and increasing engagement online'

Lucy Hose, East Midlands AHSN

- In this example a researcher at UCL is asking young cancer patients to comment on a website developed to support them — www.cancerresearchuk.org/about-cancer/cancer-chat/thread/test-a-website-for-young-people-with-cancer-and-distress
- The social network for health — healthunlocked.com
- UCL Institute of Health Informatics have an established Patient and Public Working Group and virtual panel — www.ucl.ac.uk/health-informatics/patient-public-involvement
- CRN Mental health Fast R service (Fast-r@kcl.ac.uk), a national service reviewing research protocols by mental health service users within seven working days.