

Example 6: Children of the 90s

Using Facebook and Skype to involve young people in a long-term research project

About the research

The Children of the 90s study, also known as the Avon Longitudinal Study of Parents and Children (ALSPAC), is a long-term health research project based in Bristol. More than 14,000 mothers enrolled during pregnancy in 1991 and 1992, and the health and development of their children has been followed in great detail ever since. In recent years, the project has expanded to include the fathers, siblings, children and grandparents of the original children (now aged 21 to 23), making it a unique four-generational study.

How have people been involved?

There is an advisory panel made up of young participants in the study. It was set up when the study participants were teenagers. The panel meets face-to-face at least six times per year to advise on various aspects of the study, for example to review documents related to new research projects before they are submitted to an ethics committee. Social media is used to complement this face-to-face involvement.

Facebook

It was agreed that a [secret Facebook group](#) would be the best way for panel members to communicate with each other and with the ALSPAC participation team and researchers outside meetings.

Facebook was seen as an easy way for panel members to get in touch with the participation team, because they are using it anyway. It also offered a place to communicate securely.

Facebook is used to arrange meetings and to continue discussing issues that are raised during meetings. The Facebook group enables members to continue the discussion and allows the researchers to see how the discussion develops.

Skype

The panel uses Skype to enable young people who no longer live near Bristol (where the study is based) to join meetings. Around five young people currently call into meetings via Skype.

What are the challenges?

With the Facebook group, the main challenge has been ensuring that members see messages and posts as not everyone looks at the page regularly. So Makaela (a

member of the ALSPAC participation team) sends an email to panel members if she wants to ensure that they see a post. It can also be a challenge to keep things clear, and to ensure that the most relevant posts are at the top of the page; however this can now be overcome by 'pinning' important posts to the top of the page.

Using Skype at meetings can also be a challenge. The free version of Skype only allows one person to join on a video link, so the audio-only format is used. That means that people joining by Skype can't see what's going on at the meetings and don't know when they can contribute vocally. The participation team, researchers and panel members have got round this by having a verbal discussion amongst people who are actually in the room, with those joining by Skype typing in their comments. The Skype messages appear on a large screen in the meeting room so that everyone can see them. The chair is then responsible for ensuring that the points are brought in to the discussion. There is 'Skype time' as part of each agenda item to ensure this can take place.

What resources are involved?

The Facebook group is free and has saved time in arranging meetings and continuing discussions. It's also more effective than using emails as you can see all of the discussion.

It has taken time to get used to Skype contributions at meetings but this is now working well.

The impact of using social media

Social media has been really beneficial in enabling people who no longer live in Bristol to remain involved. It has saved time and enabled the participation team, researchers and the advisory panel to work more effectively. It makes the research more accessible to those who are actively involved and means people can contribute if they can't attend a meeting and see first-hand what's being said. Previously, the emphasis was on discussion in meetings but now the discussion can continue over a longer period if needed. This gives people more time to reflect and is particularly useful if the panel are discussing more controversial research methods or proposals.

The future

ALSPAC plans to use Twitter (@CO90s), YouTube (<http://www.youtube.com/user/children90s>), SoundCloud (<https://soundcloud.com/children-of-the-90s>) and Imgur (<http://co90s.imgur.com/>) to involve and engage young people in the future. At the moment YouTube and Twitter are used to engage participants – alerting them to new publications, and giving them access to talks and podcasts whilst Imgur is a useful tool to disseminate research findings in an accessible manner.

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

"Keep it simple. It's important not to bombard people with lots of posts, and to be clear about what you're asking. Don't over-burden people, and don't ask things too often.

“Social media is most effective when it’s combined with other forms of communication, so it should be used alongside face-to-face meetings and other means of communication.

“The Children of the 90s study is growing and increasingly young people are using social media to interact with us. So if you’re trying to communicate with participants, it’s a good avenue to use.”

Makaela Jacobs-Pearson, ALSPAC

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Reference: INVOLVE (2014) Examples of the use of social media for active public involvement - Children of the 90s: Using Facebook and Skype to involve young people in a long-term research project