Title of article

Participant Engagement in Longitudinal Studies: Current Practice,
Opportunities and Challenges

Abstract

Drawing on presentations given at a workshop sponsored by Cohort and Longitudinal Studies Enhancement Resources (CLOSER), this article reviews the range of participant engagement strategies used by longitudinal studies in the UK and around the world. Studies are evolving traditional approaches like mailings and materials, using websites and social media, tailoring monetary incentives, and using different forms of face-to-face interactions with participants like social events and advisory groups. We present what these studies have found to be best practice, discuss key learnings and similarities and differences between studies as well as proposing avenues for future research.

Introduction

Longitudinal studies use a variety of strategies to maintain interest, encourage participation, increase commitment and otherwise engage sample members over the lifetime of a study. This reflects a desire to minimise attrition over time, but can also stem from a belief in the broader value of participant engagement to the design of the study and to benefit study members for their participation. Many studies are using a range of participant engagement strategies, including holding events for study members, engaging with the arts and taking advantage of technologies to communicate with participants in new ways.

Based on presentations given at a January 2016 workshop (https://www.closer.ac.uk/event/participantengagementkew/) by CLOSER (Cohort and Longitudinal Studies Enhancement Resources, 2016), a consortium of eight leading longitudinal studies in the UK, this article reviews the range of engagement strategies currently used by longitudinal studies in the UK and around the world. We present what these studies have found to be best practice, discuss key learnings and similarities and differences between studies as well as proposing avenues for future research.

Background

Approaches to participant engagement can be seen as lying on a continuum. One end is typified by strategies which require a fairly passive role from study members. Examples of these include the various types of materials that studies aim at their participants, including letters (some offering incentives to participate) and postcards, websites and social media activity such as Twitter. The other end is typified by approaches that require participants to play a more active role. Examples of this approach would include participant advisory groups or consultations, Patient and Public Involvement (PPI) or participatory action research. Engagement

strategies have evolved - and continue to evolve - over time, with digital technologies playing a particularly prominent role in how new approaches are developing.

Several factors influence which forms of engagement strategies may be used. Study disciplinary background is one factor; participant advisory groups and PPI (both at the more active end of the engagement continuum) are more commonly found among biomedical than social science studies. There are also disciplinary differences in whether studies use strategies which involve participants' identities being revealed with their consent to each other and/or publicly. Social science studies (whose data is often more easily obtained than that of biomedical studies) avoid such approaches. . Sample characteristics make a difference, with key considerations including the homogeneity of the sample, its geographic spread, the age range of participants and overall sample size. Practical considerations such as survey budget and the mode of interview will also shape the strategies used. More generally, all studies have to operate against a wider backdrop of public confidence and trust in research and how personal data is stored and used, and these contexts can change over time and vary between countries. Finally, the choice of engagement strategy may reflect its perceived effectiveness, with some but not all approaches having been evaluated in terms of their impact on attrition.

Prior to hosting a workshop focused on participant engagement, CLOSER conducted a short survey in 2015 to better understand what longitudinal studies are doing to engage their participants. Overall 26 international longitudinal studies took part; 14 were based in the UK, 8 elsewhere in Europe, and 4 were non-European. The survey showed that a variety of strategies are used on any single study. As expected, most use traditional strategies like feedback mailings and monetary incentives; however, many studies are also using more novel forms of engagement including study websites and social media, participant advisory groups and events/conferences. To date, little is known about the effectiveness of these less traditional forms of engagement (Park and Calderwood, 2016).

Following the survey, CLOSER held a workshop in 2016 at which longitudinal studies from around the world shared the many different kinds of engagement strategies they used. In this article, we describe how these studies are evolving traditional approaches like mailings and materials; how they are using websites and social media; the tailoring of monetary incentives; and different forms of face-to-face interactions with participants. We include information about its effectiveness where this was available from the presentations, and also include some references to published research in these areas. We describe what these studies have found to be best practice (as presented at the workshop), and discuss key learnings and similarities and differences between studies. We also propose avenues for future research in this area.

Participant engagement strategies

Materials and content of mailings

The 2015 CLOSER survey showed that the use of mailings remains the most common type of strategy reported by the 26 longitudinal studies that responded. Of

this group 23 use newsletters, leaflets or bulletins, 21 use traditional letters or postcards, 19 send change of address cards, and 19 send birthday or Christmas cards (Park and Calderwood, 2016). Every participating study used at least one of these methods, with the majority (23) using three or four. The prevalent use of these traditional approaches reflect well-established evidence about their effectiveness. Advance notification is positively associated with participation in cross-sectional studies (see e.g. De Leuuw et al, 2007 for a review), but there is less evidence about the impact of mailings on response rates and retention in longitudinal studies. There is some recent evidence regarding the effectiveness of targeting communication messages (Lynn, 2016; 2017). Much of the research in this area has focused on between-wave mailings, showing that they are effective overall at reducing attrition, and that targeted content, incentives and professionally-designed materials may be effective at boosting response, including from certain sub-groups (McGonagle et al, 2011; McGonagle et al, 2013; Fumagalli et al, 2013; Calderwood, 2014).

Studies use mailings in strategic and targeted ways, often using images to enhance both aesthetics and relevance. For example, in the annual feedback mailing for the 1958 and 1970 birth cohort studies at the Centre for Longitudinal Studies (CLS), cohort members are informed of updates and research impact via three to four carefully selected stories and images with a variety of themes and show both positive and negative results from research. They have found short articles (250-300 words) written in plain English and the use of simple infographics to be effective at communicating research findings to participants. Images are carefully chosen to show people engaged in an activity with natural poses and smiles and to cover a range of ethnicities at an appropriate age (Rainsberry, 2016a).

In addition to mailings, studies are innovating the types of physical materials given. Two studies of children use a medium with appeal to both children and their families: photography. The Born in Bradford study, which tracks the health of children (and their parents) born in Bradford, UK between 2007 and 2010, has worked with a social documentary photographer since its launch in 2005. Photos taken of fathers with their babies and of the children as they have grown were compiled into "chapbooks" for participants and displayed at a Family Festival event (Barratt and Andrews, 2016). Photography has also been important as a form of research reciprocity for Young Lives, a longitudinal quantitative and qualitative study of childhood poverty that has followed 12,000 children in four different countries – Ethiopia, India, Peru, and Vietnam - over 15 years. It oversampled the poor, and 60% of its participants live in rural areas. One of the most valued forms of feedback for Young Lives participants has been albums of photos taken of the children and family in front of their home at each visit and photos taken of the children doing daily activities (Knowles, 2016). The sentimental value of these photo albums well exceeds its monetary costs. The ways in which studies customise content in mailings and materials given to respondents show that 'traditional' methods are evolving to better suit the needs and wants of their subject populations. The strategic and creative use of images of participants are especially important not only as a form of feedback for some groups, but also as a way of highlighting content, personalising the study and connecting participants to the survey's human impact. However, such approaches would likely not be acceptable for social science studies as they involve the participants being identified.

Online communication and social media

To some extent, online communications can be seen as an extension of more traditional forms of engagement like letters and postcards. Similar to mailings, websites, email and social media are used to feedback to participants, seek updated contact information and inform them of upcoming survey activities. Online communications also provide new opportunities to engage participants in cost-effective ways and share news and interact 'in real time', especially as internet usage has become increasingly widespread. Nearly three-quarters of respondents to the CLOSER survey reported that their studies communicate with participants online in some form: 19 have a participant-facing website, 16 use email and ten use social media (Park and Calderwood, 2016).

Many studies use several internet or social media outlets concurrently. As presented by Burton et al (2016), the website is a key engagement tool for Understanding Society, a UK-wide study whose diverse study participants range from the age of ten to 102. Sample members can contact the study through the site, find study news and examples of impact, view copies of past mailings and see FAQs. The study also posts study news on Facebook, Twitter and Instagram. Similarly, the Avon Longitudinal Study of Parents and Children (ALSPAC), a birth cohort study of families in the Bristol, UK area (also known as Children of the 90's), has a lively social media presence with several Facebook pages for different subgroups. Facebook posts include pictures and news about events, research findings, invitations to events and information on what to expect. Unlike on Understanding Society, ALSPAC's Facebook pages allow for one-to-one communications between participants and with the study, and they use it to elicit involvement and feedback. ALSPAC also has a YouTube channel, Instagram account and Twitter account (O'Hare and Jacobs-Pearson, 2016).

The use of this technology does not come without challenges, however. It is well known that internet and social media use varies among different age groups and other subgroups (Ofcom, 2017), in particular with higher use shown among younger people. So opportunities to engage via the internet or social media may only apply to a proportion of the study sample or to particular age cohorts. Even among younger generations that have grown up with this technology, important nuances exist between teens' and young adults' engagement with social media content.

The Millennium Cohort Study (MCS), a longitudinal study of about 19,000 children born in the UK in 2000-01, and Next Steps, which follows the lives of around 16,000 people born in 1989-90, had both recently relaunched their communications programmes. Both were at key transitional points within the survey; MCS cohort members were about to become the main respondent for interview for the first time at age 14, while the Next Steps survey was to be relaunched under the management of the Centre for Longitudinal Studies (CLS), following an up to ten-year gap in contact with participants. Following audience research (described later in this article), both studies created new websites and launched Facebook and Twitter accounts.

The studies found that both the level of engagement and the preferred content differed between the two age groups. Online engagement was more effective for the

14-year old MCS members and their families than Next Steps' 25-year old members, who showed low levels of engagement over Facebook and Twitter overall. Further, for MCS members, real-time updates made for good social media content (more 'likes'), news was more popular than summaries of findings on the website, and mailings were effective at driving website traffic. Next Steps' members, on the other hand, 'liked' findings and impact information on social media, and email was more effective at driving website traffic than post (Rainsberry, 2016b).

Using social media also raises ethical concerns around study members' privacy and confidentiality. In order to mitigate risks to privacy and confidentiality as well as the risks that members would post or share false or negative information on social media, MCS and Next Steps use protected Twitter accounts with disabled photo-tagging; disable timeline posts, ratings and photo-tagging in Facebook; provide 'staying safe online' information on the website; monitor social media accounts daily; and set the profanity filter to 'strong' (Rainsberry, 2016b).

There are different approaches to the use of social media between biomedical studies such as ALSPAC, and studies in the social science tradition such as Understanding Society, Next Steps and MCS. The former encourage interaction on social media between participants and are not concerned about participants revealing their identities to each other; the latter primarily use social media to disseminate information and minimise or discourage interaction between participants. This difference is likely to reflect a number of issues, including disciplinary differences in data access.

As the effectiveness of social media and websites can vary by study and at various stages of a study, further research is needed on the impact of online engagement, as well as on differences in usage and preferred content among various subgroups. Empirical evidence is also needed on cost-effectiveness in terms of time investments and effects on attrition or other study outcomes for both social media and websites, which differ in the quality of engagement. Social media requires more recurrent updating and monitoring than websites; it is important not only to keep accounts lively through frequent postings, but also to monitor for potential safety or confidentiality issues around social media interactions. Moreover, the attractiveness of particular social media sites to different age groups will change over time. Websites, on the other hand, tend to function as more passive forms of engagement, but are able to provide much more information than social media outlets and may require less continual maintenance.

Monetary incentives

The CLOSER survey found that monetary incentives were the third most commonly used engagement strategy after online communications and mailings. Ten of the 26 studies used monetary incentives or a mix of monetary and non-monetary incentives (Park and Calderwood, 2016).

It is well-established that incentives are effective at boosting response rates in both cross-sectional and longitudinal studies (e.g. Singer, 2002; Jackle and Lynn, 2008). In the longitudinal context, unconditional incentives have a larger long-term

effect than conditional incentives (Jackle and Lynn, 2008), and higher value incentives tend to reduce attrition at the subsequent wave (Rodgers, 2002). Further, reducing incentive amounts at later waves does not seem to have a negative impact (Jackle and Lynn, 2008).

At the CLOSER workshop, several household panel studies shared how they are adapting monetary incentives to suit their specific study design and how they are tailoring incentives for specific populations over subsequent waves. The Longitudinal Internet Studies for the Social Sciences (LISS), a household panel study in the Netherlands that administers its questionnaires online every month, keeps their respondents 'happy' by providing monetary incentives of €15 per hour and free internet access and computer loan if necessary (Janssen, 2016).

Both Understanding Society and the Panel Study of Income Dynamics (PSID) used unconditional incentives initially, but now find conditional incentives to be effective at boosting participation among certain subgroups. For example, Understanding Society offers a £10 voucher per adult for those whose household responded in the previous wave and £20 for those whose household did not respond in the previous wave (if they respond, the incentive reverts back to £10 in the subsequent wave). In addition, ad hoc incentives are given for additional tasks, like completing a time diary or qualitative interview as part of the study or returning change-of-address cards (Parutis, 2016). PSID, currently the world's longest running national household panel survey of about 10,000 families, interviews by telephone every other year. The use of incentives has been a longstanding plan, and they devote a lot of resources to monetary incentives (approximately $1 per interview minute). Additional incentives include small payments for returning an address update postcard and reimbursements for cell phone minutes, child care or meals. PSID has recently begun to use incentives more strategically due to lower responses among certain subgroups, periods of low activity, lagging or burdensome study components, high-cost activities where cooperation is essential (e.g. keeping an appointment for in-person visits in remote areas) or when there are challenges in achieving response rate goals (e.g. end-of-study incentives that double in the final month - $75 to $150) (Sastry, 2016).

A traditional strategy to reduce attrition and boost response rates, monetary incentives remain effective. Unlike other forms of engagement, the effect on survey participation is more direct and easier to quantify. The aforementioned household panel surveys suggest that tailoring monetary incentives to account for greater respondent burden or to persuade more difficult-to-engage subgroups can help counteract reluctance to participate and potentially save on other costs.

Participant involvement in study design

Some studies actively engage participants by involving them in the design and management of the study itself. Of 26 studies, eight studies have participant advisory groups, and six have carried out some form of participant consultation, according to the CLOSER survey (Park and Calderwood, 2016). More common among studies from a biomedical tradition, this strategy provides an opportunity for intimate engagement and impact on the survey. Two different models were used by studies:

ongoing advice for various stages or parts of a survey or singular consultations to solicit information for specific issues.

Brightlight and ALSPAC use ongoing advisory panels and focus groups to inform their study design. The 2012 TYA Cancer Cohort Study, a cohort of 1000 teenage and young adult (TYA) patients that has been followed for three years is central to Brightlight, a national evaluation of teenage and young adult (TYA) cancer services in England.. The design of this study was informed by work with young people acting as co-researchers in a Youth Advisory Panel. Brightlight reports that the benefits of working with the advisory panel were higher than expected in terms of uptake and retention. The youth participants also had important insight into the recruitment process. Those in the Youth Advisory Panel continue to work with researchers to consult on study conduct (e.g. recruitment, retention, frequency and content of newsletters) (Fern, 2016). ALSPAC set up an Advisory Panel in 2006. Members are recruited and re-enrolled annually; they advise on study documentation, data collection proposals and study design and sit on the study's ethics committee to share their opinions about the future of the study. Several other focus groups were established, including a smoking study feedback group and family newsletter focus group. Participants were also involved in the design and content of the 21st birthday book sent to study members as a Christmas present (O'Hare and Jacobs-Pearson, 2016).

Other studies have used one-time consultations to solicit opinions on aspects of study design like informed consent and communication preferences. The Nord-Troøndelag Health Study (HUNT), a longitudinal population health study in Norway, held a workshop to consult participants on how they wanted to be contacted, as well as to discuss issues around dynamic consent. As a result of the meeting, the study found that participants wanted to have access to their individual information and that 'once and for all' consent was 'good enough' (Stuifbergen, 2016). MCS conducted qualitative and survey research with parents and 12/13-year old members, and also other non-cohort members, to inform the study design for the Age 14 survey. Participants were asked about what has driven or prevented involvement, the dynamics of family decision making about participation, the experiences of taking part and communication preferences. These findings informed practice in the form of MCS communications (mailings and online) and in their content. As a result of this activity, a relaunch mailing was sent via post directly to cohort members with information on how and why their participation was important; a joint mailing was sent to families (with separate envelopes for the parents and young person); and as described earlier, a study Facebook page and Twitter account were created (Calderwood, 2016).

Whether a singular event or continuous, participant involvement in study design can be considered a reciprocally beneficial investment. The studies learn how to best recruit, retain and communicate with participants, which is particularly valuable when the survey population is a specialised one. In turn, involvement in these advisory groups and consultations seem to increase participants' commitment and understanding of the survey process and its impact on society (although of course this will only apply to a very small proportion of study members). Such approaches have not, to our knowledge, been empirically evaluated for their impact on attrition, although this is seldom the main reason for involving participants in

engagement activities of this nature. Although some of this learning could certainly be achieved by using non-study members in the same age group, it is certainly true that participants themselves have unique insights and experiences.

Face-to-face events

At the CLOSER workshop, several studies described using face-to-face events to make respondents feel special and valued, to share research and to show the impact of their participation. As was the case with advisory groups and consultations, these approaches were less common than other forms of engagement, and more common in locally based studies (which were more likely to be biomedical). This no doubt partly reflects the fact it is more feasible and cost-effective to put on events at a local rather than a national level. Of the studies that responded to the CLOSER survey, seven held social events for participants and six held participant conferences or talks (Park and Calderwood, 2016).

Those that engage participants face-to-face tend to do so through a variety of events. ALSPAC is a good example of this approach. Their main event is ResearchFest, a conference for participants that showcases 'Children of the '90s' research as part of a year-long events programme. Bringing together researchers, participants and staff, the conference is a mix of scientific talks and hands-on activities; participants are trained to work with researchers to deliver high-quality lay posters and a film. In addition to this conference, ALSPAC held a summer lecture series (158 participants); a Children of the Children of the 90's party at Bristol Zoo; coffee mornings for parents of similar-aged children to meet up; holiday parties and creative workshops for study mothers (O'Hare and Jacobs-Pearson, 2016).

Understandably, studies whose participants live in a smaller geographical area have greater opportunities to organise face-to-face events. These types of studies are also mindful of the importance of sharing the impact of the studies as well as sharing educational or even material resources with the community. The Lothian Birth Cohort 1936 study, whose members are surveyed every three years, hold 'tea' events and share how members' participation has impacted important research. Further, they endeavour to make their members feel special by sharing members' stories through "Life Portraits" in the news media and through a four-star-rated play, "Still Life Dreaming", seen by over 700 people (Morton, 2016). In Young Lives, a longitudinal study of childhood poverty in Ethiopia, India, Peru and Vietnam, community members (peers, caregivers, and community representatives) are interviewed along with the children who are the primary subjects. Therefore, in an effort to build trust with the community as a whole and to be sensitive to cultural issues around reciprocity in their survey sites, Young Lives have not only given 'community gifts' such as a cupboard for a school staff room, but have also held community events and workshops. Successful meetings with local officials, researchers and NGO's and a participatory theatre event were held in India. In Vietnam, they found it was important to involve commune leaders and structures and to hold a meeting to report back before leaving the community. Participatory activities with children have also been held, but to varying degrees of success (Knowles, 2016).

Studies are also creating opportunities to educate or provide services for participants through face-to-face events. The Cork Babies after Scope: Evaluating the Longitudinal Impact Using Neurological and Nutritional Endpoints (BASELINE) Birth Cohort Study, the first birth cohort study in Ireland, provides health assessments as part of their study. BASELINE held a well-attended parent information evening, and participants receive allergy testing and follow-up, neurodevelopment assessment with follow-up and health care advice on topics such as eczema, weight gain and feeding (Cobbe, 2016). The Southampton Women's Survey (SWS), the only birth cohort study in Europe in which mothers were recruited before conception of their child, found that educational interventions reciprocally enhanced the original study by raising overall enthusiasm and engagement. For example, some participants (or their siblings) of SWS are involved in LifeLab, an effort to engage 13- and 14-year olds on how to improve their health and the health of their future children through increased health and science literacy. Their excitement in seeing how SWS findings are being used in LifeLab materials has supported both retention in SWS and recruitment to LifeLab (Inskip, 2016). Education is also an important form of engagement and feedback in the Young Lives study, particularly because many communities involved in the study have poor infrastructure and services and low levels of education. Parents in Peru, for example, received immediate feedback on children's nutrition and education and opportunities to participate in workshops (Knowles, 2016).

In general, although events can be resource- and time- intensive, studies find that they increase participants' pride and enthusiasm for continued participation. Studies that use face-to-face events do not rely on a singular occasion; rather, they offer a program of various types of experiences for study members, their families or their communities. Yet, rather than diluting participation across events, successful events tend to raise engagement overall. They connect individual participation experiences with the research impact on the wider community. However, by their nature, a relatively small proportion of study participants attend these kinds of events. Some would argue that the value of these events cannot be measured by attendance rates because they are building a culture of community and commitment between researchers and respondents, and fostering the relationship with the community in which the study might be located. In addition, studies can then report on the event as part of their communications with the whole study community, helping with their wider engagement activities.

Therefore, the effect of these events may be especially difficult to quantify. Such approaches have not, to our knowledge, been empirically evaluated for their impact on attrition, although as discussed above, there are many other reasons for involving participants in engagement activities of this nature. Nor does there appear to have been any exploration of the impact that taking part in events like these might have on participants' subsequent responses to survey questions.

Conclusion

Longitudinal studies must not only encourage initial participation, but also engage participants over many years in order to reduce attrition over subsequent waves. Therefore, studies carefully select strategies to foster this long-term

relationship. The wide variety of participant engagement strategies described here show how studies have adapted to participants' needs and to changing cultural and technological environments to help study members feel they are taking part in something interesting and impactful.

Several lessons can be learned from the various approaches. First, studies underscore the importance of making participants feel valued and irreplaceable by showing them that they are making real life positive impact in society. They do this through creative event planning, opportunities for participants to assist in study design and impactful feedback materials. Second, online communications can be an effective tool for participant engagement, but it is important to consider how different groups use the internet and interact with social media. Third, traditional methods like mailings and monetary incentives are still effective, especially when tailored to the needs of respondents. Fourth, there are some notable differences between studies from the social and biomedical science traditions, particularly regarding the acceptability of identifying study participants. Finally, a multi-pronged approach seems particularly successful in raising enthusiasm and increasing commitment to the study because strategies are mutually enhancing. For example, photos taken at events are used as content for websites or social media, and mailings or emails can boost website traffic.

Although there is some evidence to suggest the positive impact of various engagement methods, empirical evaluation of their impact on response and attrition is often not carried out. In addition to the difficulty of ascertaining the impact of a particular approach on attrition (since multiple strategies are often used in combination), longitudinal studies are often concerned about longer term impacts and motivated by other factors than minimising attrition alone. Moreover, robust evaluation often requires experimental allocation to different engagement strategies, which is also challenging. However, there is certainly more that can be done. Specifically, relative cost-effectiveness has yet to be assessed over the long term: what is the effect on response rates over time, to what degree do these strategies help to convert refusals or nonresponse? How online communications and social media usage might be tailored for different subgroups is also an important area of research, as well as the identification of solutions that address privacy and confidentiality concerns. Future research should explore the degree of impact on participants' involvement in study design and for which design areas it is most essential to seek feedback. More generally, the impact of different participant engagement on responses given to survey questions, data quality and respondent behaviour (or panel conditioning) is also an important area for future research.

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