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Reciprocity: combining youth involvement, engagement and participation in health research



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Abstract

Children's participation in research has been driven in part by an understanding of children's rights, in part by the new sociology of childhood and in part by funders' requirements to engage young people as participants. However, two enduring challenges are the tension between top-down demands for involvement and meaningful participation; and the time that participation demands from both researchers and participants. This paper describes one approach to addressing these challenges through involving young people in research during work experience at a University. Young people (aged 14-18) were engaged in a reciprocal arrangement, whereby they took part in a structured work experience programme whilst also contributing to three ongoing research projects. This had benefits for both the young participants and the research teams, and created a deliberative space where the young people's contributions could be valued.

Introduction

Recent decades have seen what Hill *et al.* call an "explosion of research activities that endeavour to engage children" (2004, p.77), an explosion which has reflected two trends. The first was the reframing of young people's agency in the light of drivers such as the United Nations Conventions of the Rights of the Child (Alderson 2001). The second was a growing emphasis on *engaging* the public as a research audience, and *involving* the public as research partners, with young people identified as one key group (NCCPE 2011, RCUK 2011). Funders increasingly expect and encourage public involvement "wherever possible in the design, conduct, analysis and reporting of research" (Department of Health 2005, p.8), including research concerning young people (Kirby and Bryson 2002, Alderson and Morrow 2004).

By engaging and involving young people in research, UK Research councils hope to “enhance the experience of contemporary research [...] encouraging more young people from a diversity of backgrounds to pursue [...] scientific] careers, and enabling more to act as informed citizens” (RCUK 2011, p.6). The importance of such policies is underscored by research in the UK and other European countries indicating that young people have become less positive about science in school and more likely to feel that a science career is ‘not for them’ (Millar 2007). The case for engagement and involvement also draws on the principle that citizens have the right to influence publically-funded research and on the argument that both scientists and the public may benefit (Entwistle, Renfrew et al. 1998, Thompson, Barber et al. 2009, NCCPE 2011).

Yet while researchers generally accept that public engagement and involvement are laudable and potentially beneficial (Burchell, Franklin et al. 2009, Thompson, Barber et al. 2009, Bauer and Jensen 2011), a recent Royal Society report suggests that most do not pursue these activities in practice (The Royal Society 2009). Several tensions persist which reduce the possibilities of meaningful and inclusive participation. At a practical level, ‘lack of time’ is a common reason given by researchers (The Royal Society 2009), and this may be one reason why researchers sometimes exclude ‘harder to reach’ young people from their activities (Curtis, Roberts et al. 2004). Young people can likewise find heavy time-commitments off-putting (Anderson, Stackhouse et al. 2011, Kleinman, Delborne et al. 2011), meaning that those who do find the time may be dissimilar in a whole range of ways from their peers. Such time constraints may partly explain why practical suggestions for engaging young people often involve brief, school-based activities such as delivering a science lesson (e.g. Bauer and Jensen 2011, NCCPE 2011). Similarly most involvement of young people in research consists of relatively brief consultations at the start or end of a project, rather than longer-term participation or participation in ongoing research (Stafford, Laybourn et al. 2003, Faulkner 2009).

Researchers wishing to pursue engagement activities may also face dilemmas arising from the 'top-down' directives of research funders, which typically oblige researchers to engage with the public but which also require pre-determined study protocols. Such protocols give little space for young participants to have meaningful input once a project has been funded, yet require input at a point months or even years before a study can begin, with no firm expectation that this input will be utilised if the study remains unfunded (Franks 2011). For young people, a long gap between participation in design and (possible) meaningful participation in research is unlikely to be appealing. As several commentators have noted (Curtis, Liabo et al. 2004, Sinclair 2004, Roberts 2008, Franks 2011), transparency is often lacking regarding the ways in which young people are engaged in research studies or regarding the extent to which these processes yield concrete outcomes. More examples are needed on engaging young people in realistic, meaningful ways which can reflect the timescales of typical funded projects, and the timelines of young lives.

This paper makes a contribution to addressing this gap, and describes one method for creating a space which can enable meaningful participation as 'research apprentices' in the middle of a real-world research project. We argue that this approach can be used to integrate engagement, involvement and even participation in research in a way which provides benefits to both the young people and the researchers.

Context: the 'Young Scientists Programme'

The London School of Hygiene and Tropical Medicine's (LSHTM) 'Young Scientists Programme' offers work experience and related activities to students from local schools, focusing on schools from deprived areas. This Programme was initiated in 2001 and has been run by AG since 2007: more details, and a short recent podcast, are available from www.lshtm.ac.uk/aboutus/volunteering/ysp/

Most young scientists come to LSHTM during the one- or two-week work experience placements which form part of the UK national curriculum for Key Stage 4 (age 14-16). During their placements, young scientists work in pairs to carry out independent research projects (e.g. designing and conducting a small survey), supervised by LSHTM staff and student volunteers. These projects can cover anything from local to international health issues, and form the basis for presentations by the young scientists on their final day. Where possible we take students from multiple schools simultaneously and form pairs across schools, with a typical total group size of 10-12 students. We also run occasional half-day workshops for school classes, either at LSHTM or in the schools themselves. This paper describes the reciprocal arrangement whereby young scientists participated in three 'real-life' research projects based at LSHTM in the Transport and Health research group.

The case study: participation, engagement and involvement of 'young scientists' in three ongoing studies

A reciprocal approach to recruitment

The Young Scientists Programme originally focussed on providing an educational experience, and young scientists made only occasional, brief contributions to research (e.g. providing feedback on the design of recruitment materials). In 2010, AG decided to experiment with forging a deeper connection between the programme and an ongoing study, *On The Buses*. This study (2010-2012) was a mixed-method evaluation of the public health impact of giving under-18 year olds in London free bus travel (Wilkinson, Edwards et al. 2011). AG was collaborating on the study's qualitative research strand, and initially used the Young Scientists Programme to invite past and current young scientists to participate in qualitative interviews. She also adapted a half-day 'What is public health?' schools workshop to include *On The Buses* as a case study. This became the basis for a reciprocal approach to recruitment, offering the workshop to two schools that had previously participated in the Young Scientists Programme, and asking for permission to conclude the workshop by inviting students to participate.

Integrated work experience in one qualitative study

AG then started to engage and involve young scientists in the qualitative research strand of *On The Buses*. In spring 2010, when the qualitative research was still at an exploratory stage, she gave one young scientist an 'open brief' to conduct a project inspired by the study's aims. In spring 2011, when qualitative data collection and analysis was well underway, AG wrote more focussed briefs suggesting the young scientists choose between a number of specific emerging questions (see Box 1). She gave these focussed briefs to 12 young scientists attending LSHTM in two separate work experience sessions (one group of two and one of ten). At the end of their placements, these young scientists were invited to participate in in-depth interviews about their research in their project pairs. These 13 young scientists came from 4 schools and were all 14 or 15 years old. Four were girls and four identified as White British.

Box 1: Research questions selected by the 13 young scientists during integrated work experience for the *On The Buses* study¹

1. How does free bus travel affect the mental and social health of children under sixteen?
2. Would it matter if young people's travel stopped being universally free?
3. Does free bus travel affect young people's attitudes towards cars?
4. Does free bus travel make young people feel more like London citizens?
5. Do buses represent 'public space' for young people?
6. What does free travel let young people do that they wouldn't do otherwise?
7. How does free bus travel affect under 16's physical activity?

¹ Research presentations available at <http://www.lshtm.ac.uk/php/hsrp/buses/youth/>

Integrated work experience in two quantitative studies

AG subsequently employed a similar approach in two quantitative projects. In April 2013, she commissioned two young scientists to work with her to pilot and help implement a data collection protocol for a direct observational study examining the use of cycling clothing (e.g. helmets or Lycra) among London's cyclists. In July 2013 she commissioned three young scientists to pilot a protocol for identifying how much coverage cycling fatalities receive in the London media. These five further young scientists came from three schools and were 17 or 18 years old. Two were girls and none identified as White British. Two had previously participated in the qualitative study in 2011, and at their request had returned to LSHTM.

All three studies received ethical approval from the LSHTM research ethics committee, and all young people provided written informed consent for in-depth interviews.

Data analysis

This paper draws on a range of data sources, including: fieldnotes by the authors; the research presentations generated by the young scientists; comments made by young scientists in two focus group sessions discussing the first draft of this manuscript, and verbatim transcripts of the interviews which AG conducted with the young scientists. These data were analysed qualitatively to identify themes in young people's accounts of their participation, benefits to the research team, and benefits for the young people. The analysis was lead by AG and, like similar studies (Curtis, Liabo et al. 2004, Phillips 2011), represents a reflexive analysis from inside a project rather than a detached gaze from the outside. NVivo 8 was used for coding and data management, and quotations are presented with identifying details removed and with young scientists identified by their gender and a number.

Findings

Benefits for the research team: a reciprocal strategy of recruiting participants

The Young Scientists' Programme proved a relatively productive and efficient means of recruiting participants for interviews in the first, qualitative study. This was particularly useful in generating initial data early on in the study, before we started to sample purposively. We approached 30 current and former young scientists, of whom 16 agreed to be interviewed (10/15 current young scientists, 6/15 former young scientists). Our two school workshops generated a further five volunteers, out of around 40 students. These school workshops were especially useful in accessing a wider age range than the young scientists (mostly aged 14-16 years), as AG was able to request to run the workshops with a younger (11-12 years) and an older (17-18 years) class.

Integrated work experience as a basis for in-depth engagement in the research process

All 13 students completing work experience at LSHTM in 2010-11 were very positive about their placements, and seven subsequently asked to come back during their holidays – bringing with them three friends and two siblings! This included two boys who have currently arranged to return to LSHTM for three further work experience placements, and have in more recent sessions started, at their own request, to act as mentors to the younger students.

A key aspect to this positive response seemed to be the fact that young scientists lead their projects themselves (albeit with significant steering from AG). This control was repeatedly linked by young people to a new perception of science as creative. For example, during one group discussion the young scientists agreed that the best thing about the work experience was being able to 'choose how you're going to do it and then give your opinion', in contrast to a perception of school

where 'science is just facts and you can't argue' (AG fieldnotes). This last comment echoes previous research indicating that school students can be put off science by fact-driven curricula which focus upon consensually-agreed and essentially indisputable 'safe science' (Miller 2001, Millar 2007). By contrast the young scientists were designing small-scale studies for themselves where the results were not known in advance. Several described this process as exciting, even when the results themselves were as they expected:

M4: I was not *that* surprised [by the findings] but I just found it, because it's nothing I do daily to be honest, it's out of the ordinary to be able to research things like that so yeah I found it kind of interesting.

The two-week work experience therefore gave the students some research control and, crucially, more research time than is possible in most school science projects. This opportunity for in-depth engagement seemed key to uncovering the potential interest of topics that might initially seem boring:

M5 One last thing, I really didn't expect that the topic of public health and public transport would be so interesting because I just thought [...] it's not going to link to anything, but I actually really enjoyed the whole two weeks.

This account highlights one advantage of work experience over other forms of public engagement and involvement: because one starts with a 'captive audience', one does not necessarily need to have an initial line or 'hook' to spark people's interest (NCCPE 2011). The quote also highlights what seemed another important feature in engaging the young scientists, namely the links they could make between the topic and their own lives. This contrasts with some school students' complaints that science curricula are too 'disconnected' from their concerns (Millar 2007) and indicates the potential for research involvement to help young people see the world in new ways:

M8: Before I used the bus as like a social outlet but I didn't really think of it in my mind as a public space, maybe because I didn't really understand, but now I could see how it would be a public space ...[like yesterday when] I was coming back from work and I saw my friends on the bus.

Moreover young scientists from the large group of 10 students working on the qualitative study were also able to make links between each others' projects. This holistic perspective was evident at the end of the placement when each pair was asked to describe their own research:

F2: You see [names] presentations they're looking at when young people use buses as public spaces where they can meet, talk and stuff. But that's also what affects our research when it says, "do you feel safe on the bus?" Because most people said they don't feel safe at all times especially when a large group of youths gets on the bus and so yeah they're all really linked together.

Similarly students from the smaller groups seemed particularly to enjoy discussing their findings with other study scientists:

AG fieldnotes: [The three boys] have just met with four of the scientists working on that project and discussed how their findings could be understood with the framework of systems dynamics. Together we drew lots of flow diagrams and tried to tease out the implications for cycling policy. They seemed really captivated by seeing how their research could fit in a much bigger picture.

Finally, the experience of two boys who visited LSHTM multiple times provided some evidence that, in line with other reports (NCCPE 2011), a link with a real research study could be an important motivator for the students. These two boys were among the initial cohort of 13 students working on the qualitative study in

2010-11, and at the time they and the others never spontaneously raised their projects' connection with a real study as being of importance to them. Instead it was fact that their projects were substantially under their own control which seemed of significance to them, and which marked those projects out from previous school work. Subsequently, however, the two boys returned at their own request for three further work experience sessions, working on projects of their own devising in the first two sessions and then working as research assistants on an ongoing LSHTM study (on cycling fatalities in the media) in the third session. During this final session, both boys spontaneously commented that it was good again to be working on a "proper and actual" research study, because it felt more meaningful to be doing "something that is going somewhere" (AG fieldnotes). As such it seems plausible that young scientists gain motivation from working on a real study, but may not articulate this if they have never experienced an alternative.

Collecting the data and 'being' the data: young scientists as both research apprentices and potential participants

Besides acting as a platform for engaging young people, the integrated work experience made a real contribution to the three ongoing LSHTM studies. In the two quantitative projects the students made welcome contributions to data collection, with supervision and support from AG. In the study of cyclists' clothing, the students collected around 15% of the data subsequently used to address the study's main hypotheses (Goodman, Green et al. In press). In the study of media coverage of cycling fatalities, the students collected around 50% of a dataset which is being treated as a pilot for a larger, multi-city study.

As for the qualitative study, the contributions of the young scientists stemmed not only from their own small research projects but also from the opportunity which the integrated work experience offered for observation and interview. For example, one specified aim of *On The Buses* was to examine whether increased bus use among young people might decrease their future dependence on cars, and two young scientists chose this as their research focus (Box 1, project 3). This pair

conducted a survey of 94 students aged 11-16 across their two schools in East and West London and found that a large majority (72/94) reported wanting a car before they turned 20. This finding fit with the observation in our own qualitative data collection that most younger teenagers still report wanting to drive in the future (although older teenagers are less positive about driving as a mode of transport in London). This conclusion was further reinforced by observations of the young scientists themselves. For example, at the final presentation "all the [12] young scientist presenters said they hoped to buy a car when they could!" (JG fieldnotes) and during the placement some young scientists were incredulous that this research question could even be considered worth asking:

M3: Yeah he [another young scientist] practically kept on asking us why we wanted, why anybody would not want a car? But we were, well if the Mayor has introduced this [free bus travel scheme] maybe there are people that are actually affected by this and actually want to use public transportation. So it's not a reasonable question what he asked.

The young scientists also contributed to developing and testing lines of enquiry in ways which had not been anticipated. For example, one hypothesis of the *On The Buses* study was that the universal nature of the free bus travel entitlement for young people in London would mean that was not stigmatised. A discussion with one young scientist gave AG the idea that a useful way to test this might be to compare attitudes between free bus travel and free school meals, the latter of which are generally means-tested. As well as following this approach up in qualitative interviews with *On The Buses* participants, AG told a subsequent pair of young scientists about this idea and gave them a related research brief (Box 1, project 2). This pair surveyed 58 students aged 11-16 from one school in East London and analysed their free-text answers to questions including 'What would you think if bus travel was only free for poorer kids?'. Reflecting on their findings and their own experiences, they helped AG crystallise two reasons why current attitudes towards free school meals might not be as informative as she had hoped. The first reason

was that parents might be less willing to pay for 'unnecessary' travel (e.g. bus hopping with friends) than they would be willing to pay for lunch: "That's the only trouble, you don't, it's not essential that you get travel and you get to where you want" (M2). The second revolved around the potential differences between *taking away* a benefit versus setting it up as targeted from the beginning:

M1: There'd be a massive hole to fill, there'd be a lot of children that would be used to having something for free and now they don't. [...] Whereas with free school meals it's not as like prominent, because free school meals have been around for ages, everyone's used to the idea.

In examining the potential importance of universally free bus travel (Goodman, Jones et al. 2013), AG was thus able to draw upon both the reflections of young scientists and their personal experiences. This combination of participant and researcher roles was also apparent in the young scientists' accounts of benefitting from their insider status while also seeking to step outside their personal experiences and represent a variety of perspectives:

F4: It was different [doing the research compared to when we were earlier interviewed as participants] because OK, you'll be able to answer for yourself, but you don't have the thoughts of what other people are thinking [...]. With the survey we got a range, a range of different views, and it allowed us to develop routes of different ideas we had [...]. You've got to know that there's other different perspectives, rather than in an interview room you only get your own.

Furthermore it was not only the young scientists who found themselves simultaneously acting as observers and being observed. One young scientist commented to AG after she conducted an in-depth interview that it was 'funny to see you being all like "Researcher" all of a sudden' and they went on to discuss the reasons for AG's interview manner and how they might help one obtain good quality

qualitative data. Thus even the young scientists' contributions as participants could potentially be educational for them, one unexpected mutual benefit of seeking this participation in the context of a work experience placement.

A final unexpected mutual benefit occurred when one of the 13 *On The Buses* young scientists met Deputy Prime Minister Nick Clegg, after winning a prestigious youth award. This is the highest direct political access *On The Buses* is likely to have, and without any coaching our young scientist was brilliantly 'on message' in explaining why she had been nominated for the award by us: "I did a research project about something very important to you, Nick, which is fairness..." (AG fieldnotes). In one sense, this impromptu advocacy was clearly a one-off incident, and we would hesitate to suggest it had any direct effect on Clegg's support in July 2013 for introducing free bus travel for young people nationwide (The Independent 2013). Nevertheless, it does illustrate one of the ways in which public involvement can open up the space for the unforeseen to happen.

Discussion

This paper describes how, during an ongoing public health research study, we initially recruited 21 participants (age 12-18) using a recruitment strategy which involved approaching schools and young people to whom we had previously offered workshops and work experience. We then involved 13 young people (aged 14-15) in the qualitative strand of the study in more depth, using 'integrated work experience' to combine research engagement, involvement and participation. Subsequently, we involved five students (aged 17-18) in piloting a data collection protocol and then collecting data for two quantitative studies. These reciprocal approaches all proved productive ways to generate data, and the integrated work experience produced significant and sometimes unexpected mutual benefits.

It has previously been noted that public engagement and involvement can increase access to research participants if service users involved in the study help to recruit their peers (Hanley, Bradburn et al. 2003). This paper exemplifies that this

can also be achieved by offering workshops to schools in exchange for permission to invite their students to participate. In AG's experience, this reciprocal strategy involved less time and effort than when 'cold-calling' schools in former studies. Although we had the benefit of working through LSHTM's Young Scientists Programme, other researchers could perhaps offer services to schools via national organisations such as STEMNET which work to bring scientists into schools (<http://www.stemnet.org.uk/>).

As for our integrated work experience, to our knowledge this was novel in its use of national curriculum work experience and in its experimentation with an integrated approach. We believe that key advantages of using work experience are that it exacts comparatively low opportunity costs, and can help to overcome time constraint barriers. For us as researchers, the dedicated infrastructure of school work experience coordinators greatly reduced the administrative burden associated with arranging placements. For young people, taking part did not represent time lost to other activities because work experience has a dedicated slot in the school calendar. A 'captive audience' reduced the pressure on us to capture young people's imagination in advance (NCCPE 2011).

Moreover, these comparative low costs met with a good return in terms of concrete mutual benefits. As researchers we were able to meet our engagement and involvement goals while simultaneously generating some useful data, side-stepping the single most commonly-reported barrier of 'needing to spend more time on research' (The Royal Society 2009). In addition, in contrast with the tendency for public engagement to be more common among senior scientists (Bauer and Jensen 2011), this model allowed more junior academics such as AG to take a lead role.

As for the young scientists, they were able to bolster their CVs, learn new skills and see what life is like in higher education. These benefits are particularly important given that the young scientists' schools were generally in disadvantaged areas and often struggled (the schools told us) to find high-quality, 'aspirational' work experience for their students. The young scientists were also given the space to engage in a research project outside the context of their school or the family. We believe this space potentially provides what Cockburn (2007) has called an

'intermediary realm' where young people can have a less ritualised encounter with scientists than is common in engagement activities such as school councils. By engaging young people as 'apprentice researchers' within a formal work experience programme, we were able to treat their research contributions as part of a team effort; and they in turn could respond to both their peers' and our contributions as relatively equal research partners, at least in the space where 'their' projects were discussed.

We believe that this combination of relatively low costs and concrete mutual benefits may represent a more realistic and sustainable basis for engagement and involvement than strategies which depend heavily on altruism or a sense of duty among researchers, institutions or members of the public (Pearson 2001, Kleinman, Delborne et al. 2011). We therefore suggest that integrated work experience may be a useful approach for other studies generating qualitative data about young people or collecting quantitative data in straightforward ways. Nevertheless, it is also important to recognise the limitations of this approach. First, the qualitative data generated through the work experience would not have provided sufficient range or depth to be the sole basis for our research, and was only one of a number of ways we used to access young people's views (Jones, Steinbach et al. 2012). We are also aware of the need for reflexivity as to our own role in influencing the young scientists' research topics and interpretations. Secondly, although we took their contributions seriously, they were inevitably junior partners in the relationship. This particularly applied to the quantitative studies, during which AG took final decisions when it came to designing and implementing the research protocols. Young scientists are very much 'apprentice' researchers but, like all early career researchers, their contributions were valued, and provided a number of insights for the research team.

Finally, we recognise that the potential benefits of the strategies outlined in this paper need to be balanced against ethical considerations. We would not want the possibility of mutual benefit to displace the altruism which currently motivates participants to take part in research, and motivates researchers to take part in

LSHTM's Young Scientist Programme. For example, we do not want researchers to start offering work experience consisting solely of menial research tasks that are no longer interesting or educational for the young scientist. We likewise do not want young people to feel obliged to participate in research in order to get workshops and work experience. We therefore always tried to stress the voluntary nature of the in-depth qualitative interviews, and believe this is reflected in our modest-to-moderate participation rates (16/30 among young scientists, 5/40 among workshop students).

Conclusion

We describe one reciprocal approach to engaging young people in research which addressed two much-debated tensions: time constraints, and meshing top down directives with meaningful input. This approach provided both a relatively efficient way to recruit young people and also a means of integrating engagement, involvement and (in some cases) participation in ongoing qualitative and quantitative studies. Our 'integrated work experience' approach will not work for all researchers or for all research projects, but may prove useful for some. Reporting by other groups, including problems and failures as well as triumphs, will provide a sound basis for further improvement.

Conflict of interest

None

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