

“You can help people”: Adolescents’ Views on Engaging Young People in Longitudinal Research

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Abstract

Introduction: Determining how best to recruit and retain adolescents has proven difficult for many projects. We sought to discover adolescents' thoughts about and understanding of participation in longitudinal research and to identify recruitment and retention strategies that were meaningful to them.

Methods: We conducted seven focus groups with 10-15 year olds (mixed and single gender) in two large rural centres in the state of New South Wales, Australia. All focus groups and interviews were digitally recorded, transcribed verbatim and analysed by the research team.

Results: Adolescents discussed both external and internal factors that were salient to their involvement in the present focus groups, as well as factors that may influence their involvement in a larger longitudinal study. Adolescents had a generally positive view of research at the outset of the focus groups but were reluctant to engage in research that involved collection of biological specimens. However, through discussion of the research aims and methodology, most adolescents wanted to participate in the proposed longitudinal study at the end of the focus groups.

Discussion: Effective recruitment of adolescents requires an appreciation of motivators, as well as time and resources to extend potential participants' understanding.

Introduction

Published literature on recruitment of adolescent research participants is largely based on opportunistic debriefs. A review of published examples of adolescent involvement in school-based prevention and intervention programs found that most articles did not report on processes for recruiting and retaining adolescents. Moreover, most of the studies that had high rates of recruitment did not report their strategies (Blom-Hoffman et al., 2009). The few strategies that were reported did not seem feasible for most research projects that were working with restricted budgets (Blom-Hoffman et al., 2009). Thus, determining how best to recruit and retain adolescents has proven difficult for many projects. We sought to discover adolescents' thoughts about and understanding of participation in longitudinal research and to identify recruitment and retention strategies that were meaningful to them.

The current research is a preliminary stage of a planned longitudinal study of the relationships between hormones and adolescent health and wellbeing (known as the ARCHER study, or the Adolescent Rural Cohort study on Hormones, Health, Education, Environment & Relationships). The ARCHER study will document relationships between the biochemical markers of puberty in blood and urine, social and psychological wellbeing, and mental and physical health in young people between the ages of 10 and 15 years. As noted by Jones & Broome, "It is clear investigators need more information from adolescents themselves to develop meaningful, valid, and reliable designs that will maximise recruitment and retention of adolescents in research" (Jones & Broome, 2001, p. 89). Understanding how to recruit young people to longitudinal research and motivate them to continue to participate are essential to the success of research which seeks to understand and promote the health of adolescents.

Background

Australian young people have low mortality and morbidity when compared with other age groups and health indicators in many areas have improved over recent years. Nevertheless, there are continuing areas of concern. Mental health disorders, including depression, anxiety and drug and alcohol use account for half of the disease burden in young people. Injury, transport accidents and self-inflicted injury, in particular, continue to be the leading cause of death in young people. Also of concern are the increasing rates of disorders such as obesity, sexually transmitted infections, risky alcohol use and some chronic illnesses (AIHW 2007).

Our current understanding of adolescent health and morbidity relies mainly on successive cross-sectional data providing 'snap-shots' in time of the prevalence of an indicator of interest and how that prevalence varies by demographic, social or other factors. While informative, cross-sectional research has limited capacity to demonstrate causal relationships between, for example, risk behaviours and health outcomes. There is increasing recognition of the importance of early exposure(s) and behaviour on youth and adult health outcomes (Steinbeck, Baur, Cowell, & Pietrobelli, 2009). However, few longitudinal studies have successfully involved adolescents, and these few rarely include biological data collection and sensitive topics such as puberty, body changes and sexuality (Nicholson & Rempel, 2004). Adolescence is a time of rapid physical, psychological and social changes (Jones & Broome, 2001; Lamb et al, 2001). For this

reason, intensive data collection in longitudinal research is required to identify changes in protective and risk factors over time and how they relate to adolescents' health. Such research allows examination of multiple exposures, identification of potential determinants and outcomes, and to measure relationships over time.

Resource and methodological challenges have restricted the scope of longitudinal research focussing on the critical adolescent years. Particularly challenging areas for researchers conducting longitudinal studies include: (1) ethical issues preventing use of incentives; (2) lack of relevance to adolescents' interest; and (3) recruitment and attrition during middle adolescence (Steinbeck, Baur, Cowell, & Pietrobelli, 2009). This is likely most pronounced in populations of vulnerable, marginalised adolescents such as those not attending school, those with mental health problems, and homeless youth, though retention of such groups is possible (Solorio, Rosenthal, Milburn, et al., 2008). Retention is also difficult when participants have not provided links to family or partners who may serve as alternate contacts, as some adolescents have transient lifestyles (Seed, Juarez, & Alnatour, 2009). While many of these issues also exist in research in other age or sub-groups of the population, they are particularly pronounced in adolescent research. It is recognised that adolescents are relatively under-researched and are therefore disadvantaged in terms of potential health benefits from research (Sanci et al., 2004).

Engaging young people in longitudinal research is a daunting task. This is particularly so when research asks about sensitive issues such as sexuality (Bagnoli & Clark, 2010) or requires the collection of biological specimens such as blood (Broome & Richards, 2003). Yet data on social, psychological, physiological and biological influences are critical for research that aims to fully understand the complex causal pathways to health and morbidity in adolescence and adulthood. Learning from young people about the best way to respond to their reluctance is essential (Bagnoli & Clark, 2010).

The aims of the study were to inform research techniques by gaining greater knowledge of: (1) adolescents' understanding of and attitudes to research (2) ethical and methodological issues around more sensitive research areas such as puberty, sexuality and collection of blood and urine samples, and (3) engagement strategies appropriate for adolescents involved in longitudinal research.

Methods

This was a qualitative study where data were collected through focus group interviews with adolescents aged 10-15 years. The decision to use focus group discussions as a means of engaging young people was not accidental. Focus groups provide a less formal, less structured, not as "heavy" environment in which to explore young people's experiences (Clark-Jones & Broome, 2001; Bagnoli & Clark, 2010). They also have the potential of engaging with young people's enthusiasm and energy in a more social setting (Darling, 1993, cited in Clark-Jones & Broome, 2001). Among the research team, there was a clear desire to create a respectful space in which young people's voices and opinions were valued. Bagnoli & Clark argue that focus groups "can provide participants with a space in which they define their own categories and labels, and unmask ideas and opinions through dialogue and debate with others" (2010, p. 104).

Setting and Participants

We conducted seven focus groups with 10-15 year olds (mixed and single gender) in two large rural centres in the state of New South Wales, Australia. The 2009 population estimate for these two towns was 38,685 and 41,211 (ABS website, 2010). Under the Rural, Remote and Metropolitan Areas Classification (RRMA), both Dubbo and Orange are classified as large rural centres. This locality-based index was developed by the Department of Primary Industries and Energy, and the Department of Human Services and Health and used nationally for the Australian census (Department of Primary Industries and Energy and Department of Human Services and Health, 1994). The RRMA index reflects distance from both service centres and from other people (Australian Institute of Health and Welfare, 2004). Eligible participants were individuals aged between 10 and 15 years, with signed parental consent and individual assent.

Recruitment

Various recruitment processes were implemented until the target number (of 3-4 focus groups, each with 5-10 adolescents) was reached in both locations. Steps for recruitment included direct approach by the researchers to parents, distribution of flyers in two schools, and a one-day advertisement in local newspapers. The advertisement was placed once in a local Saturday newspaper in Dubbo (circulation n=4750) and Orange (circulation n=8870). Each potential participant was asked if they were enquiring about the focus groups as a result of seeing the advertisement. One participant responded in Orange as a result of seeing the advertisement; none of the participants in Dubbo were recruited through the advertisement.

Flyers were also placed on community notice boards including paediatrician surgeries, libraries, sporting facilities, shopping centres, and take-away food shops. Additionally, information about the focus groups was distributed through selected email distribution lists. These lists included members of youth inter-agencies, which are a forum for local government and non-government organisations to meet, share ideas, resources, and provide networking and support opportunity for local youth workers and services. Thus, the individuals on these email lists would have contact with many potential focus group participants.

Despite these processes, there was a strong reliance on word-of-mouth recruitment. Many of the participants knew someone connected to another study or the University of Sydney in some way. This resulted in a number of focus groups in which the majority of participants knew each other. While this might be perceived as a limitation, other researchers have found that focus groups are most successful when participants come from similar backgrounds or know each other (Bagnoli & Clark, 2010).

During recruitment, parents were given the opportunity to complete an expression of interest (EOI) form to consent to placing their details on a study register to be re-contacted regarding other ARCHER research studies. Of the 58 participants, 30 participants' parents completed the EOI.

Focus group interview procedures

Four single sex focus group interviews were held (2 male and 2 female) as well as three mixed groups. The focus groups were conducted at the University of Sydney School of

Rural Health campuses in the rural centres of Dubbo and Orange on a weekday after school. The average focus group interview duration was 62 minutes and ranged from 52 to 70 minutes. Group numbers ranged from 5 to 11 participants and were conducted by a moderator, assistant moderator, and observer.

As an ice-breaker, focus group participants were asked to brainstorm and/or draw their ideas about what research was and what research meant to them. Then, focus groups explored the notion of motivation for participation in research in two ways. Participants were asked what prompted them to come to the focus group, allowing us to explore their motivations based on their actual behaviours in attending the focus group. Secondly, participants were asked what would motivate them to participate in research over time. Both recruitment and retainment strategies were discussed.

Students were able to choose either a \$20 department store gift card or \$20 mobile phone credit at the conclusion of the focus group as a token appreciation of their involvement.

Data Analysis

All focus groups and interviews were digitally recorded, transcribed verbatim and analysed by the research team. NVIVO (a qualitative data analysis program) was used to assist in managing the data. The first two authors performed separate content analyses and then discussed identified themes and concepts. No major discrepancies were identified.

The study was approved by the University of Sydney Human Ethics Committee.

Results

A total of 58 students were recruited equally across both sites (males 46 %). Primary school (aged 10–12 years) and secondary school (aged 13–15 years) students made up 46% and 54% of the sample, respectively.

Table 1: Participants by location, gender and level of school

	Dubbo		Orange		Total	
	Male	Female	Male	Female	Male	Female
Primary	5	11	5	5	10	16
Secondary	3	10	14	5	17	15

See Figure 1 for a pictorial view of the results.

(Insert Figure 1 here).

Opinions and Feelings Prior to Focus Group discussions

To the adolescents, research often meant homework, books, the Internet, and working on computers. Many adolescents also mentioned that research was “good” or “helpful” to both themselves and the wider population.

Despite these positive feelings, many adolescents were originally sceptical of longitudinal research that involved providing several biological samples. At the beginning of the focus group, adolescents often indicated that research such as the ARCHER study would not be acceptable to them and that they would not engage in a project that required that type of commitment.

"I got a bit stunned when she mentioned needles... she said, like, taking a bit of blood.

--facilitator: Don't worry, we're not taking any blood today.

--She said you might!

--facilitator: We'll talk about it. That's all we're going to do..." (Boy, Dubbo, 10-12 years).

However, through the process of the focus group, a change occurred.

Recruitment to the Focus Group: Motivation for participation

External factors

Parental encouragement. For younger participants (10-12 year olds) parental encouragement was quite important in their participation in the focus group. Parental engagement with the purpose of the research was important, as noted by one participant:

"[I'm here cause] Mum told me to.

--Your mum told you to?

--Exactly, she thought everyone ought to be here"

(Girl, Dubbo, 10-12 years).

While parents were still supportive, the older participants (13-15 year olds) exercised a greater choice in participation than younger participants ("*Yeah, Dad showed me the paper but I decided to come along*" compared to "*I'm here because mum signed me in and I didn't even really know*").

Peer influence. While parents were a motivator for many younger adolescents, peer encouragement was the main reason many focus group participants attended. Many adolescents invited a friend or two to attend the focus group with them.

F: "I'm almost fourteen and I came because she [indicating friend] wanted me to.

F: I'm fourteen and I came because she [indicating friend] asked me to.

M: I'm fourteen years old and I came because I heard there was a pizza supper and my friend [name omitted] told me to." (Mixed, 13-15, Orange).

Incentive. Initially, most of the adolescents did not know that they would receive snacks and acknowledgement of their time in the form of a \$20 phone credit or gift card, but many adolescents were very appreciative and one male said: "*I didn't even know [there was] going to be food!*" (Mixed, 10-12, Orange). In later focus groups, some adolescents had heard from friends or siblings that an incentive was involved, and commented that

the promised reward increased their desire to participate.

Internal factors

Making new friends. Most adolescents cited external factors as reasons for being involved in the focus group. However, internal factors resounded more strongly with some participants, with making new friends, or meeting new people of interest to some of the adolescents.

Experience/Just because. Other adolescents mentioned that they wanted to experience a focus group or wanted to be involved because it sounded like fun. *"I came here [to the focus group] to see what it's like because I haven't done it before"* (Girls, 10-12, Dubbo).

Large Study Engagement: Motivation for participation

External factors

Incentives. Financial incentives were most strongly endorsed by a younger boys' focus group. However, over the course of the discussion, this group identified a range of non-financial motivations (*"because it was a good thing"*). Among the older participants (both boys and girls), financial incentives were seen as a "bonus" rather than the driving force behind participation in research. Most of the young people supported modest incentives such as phone cards, music downloads and movie passes. Participants also felt that the financial rewards should be age sensitive:

"I think you would have to have different age groups get different prizes because you give some six to eight year olds an iPhone for instance, they're not going to use it very well, but then again the littler kids will probably do it for less. Also I don't think they have to be things. I think a good way of doing it would be get recognition of some sort, because lots of people would do something like for a big certificate" (Girl, 10-12, Orange).

A number of the focus group participants expressed individualistic values in relation to incentives. In general, they felt any rewards given should be to those directly involved. This individualism may reflect the intimate nature of the participation (i.e. repeatedly providing biological samples), with one participant commenting, *"The town didn't pee in a bag"* (13-15 year old boy, Orange).

When pressed, some participants felt that schools involved in recruitment, could be rewarded by, for example, sponsored excursions. A few adolescents also spoke about rewards that could be shared among their whole family.

Peer influence. Similar to reasons for being involved in the focus group, many adolescents voiced that they would like to be part of a research study of which their friends were a part. They also mentioned that they would like to be able to recruit friends into a study in which they were involved.

Internal factors

Interest/Social Good. A strong thread among the focus groups was the notion of participation as a social contribution (*"I'd just do it cause it was a good thing to do"* and

"it could save somebody's life"). "You can help each other; you can help people learn about research" (Girls, 10-12, Dubbo). When asked about possible incentives, some adolescents indicated that incentives weren't necessary: "I'd just do it for free," "I would just do it" (Boys, 10-12, Dubbo), or that they'd participate to "help Australia" (Mixed, 10-12, Orange).

Study Engagement/Acknowledgement. Connected to this desire to make a social contribution was a desire for acknowledgement, with a number of people identifying formal acknowledgment, such as a certificate or public announcement, as a motivation for participation. Some adolescents were interested in contributing directly to the study by designing newsletters, planning social events, or even driving researchers to collect samples as they reached driving age.

Making new friends. Another strong thread among the focus groups, particularly among girls, was the socialising opportunities created by participation. Many talked about participation being motivated by a desire to meet new people, as the following comments reveal:

"You get to be with new people..."

"Maybe every, end of the month, not individual prizes but everybody comes in to a big party and they have competitions..."

"All the people who, everybody who's close and who participated in it, could come and we could all have a big party and stuff..." (Girls, 10-12, Dubbo).

Learning about themselves. Adolescents also wanted to be a part of research to learn about themselves. They expressed interest in receiving feedback and newsletters during the course of the study that were personalized with their feedback. Older participants indicated this would act as a motivator to continue in the study as they would learn about how to "take care" of their bodies. The preferred method for receiving this information was via the postal service.

Opinions and Feelings After Focus Group discussions

Enjoyment of the Focus Group. At the conclusion of the sessions, participants in these focus groups were asked to confidentially rate their experience of participation and were overwhelmingly positive, with comments like:

"That was great!

--We should have this once a week.

--Have a group like this whenever you have to do it so it would keep kids coming if they had a meeting to look forward to.

--I was hesitant coming here because I thought it would be boring... so I think if you're developing groups like this sort of thing, it wouldn't be as bad.

--I'd come back; it was fun.

--Yeah I think it was good because we had people that we know though.

--I'd come if there was pizza again."

Focus Groups as Recruitment. The use of research methods that value young people
You can help people!

(such as focus groups) is likely to increase successful adolescent engagement. Adolescents in these focus groups were more inclined to join a longitudinal study involving biological sampling at the end of the focus groups compared to the beginning.

Facilitator: "The last thing we want to do it just talk about what you think of participating in a project like this... any last ideas about whether you would want to do it or not, or what you think about it, or anything else?"

--I'd do it.

--I'd do it.

--I'd do it. It could be interesting to see what the results came out.

--Yeah.

--Yeah.

--Yeah.

--And to be part of the results would be cool.

--Yeah" (Girls, 13-15, Dubbo).

Facilitator: "So when you guys came in and I said would you guys be a part of the study, most of you said no or maybe... so if we're talking about now we've kind of gone through all these... and now I said would you be a part of the study, what would you say?"

M: Yeah.

Facilitator: Yeah? Everybody says yes?

M: Yeah

Facilitator: That's amazing. So if we talk about it and we talk about how these things actually happen they don't seem that bad is that accurate, would you agree with that? (everyone is nodding heads) Yeah? Okay" (Mixed, 13-15, Dubbo).

Discussion

Our research found that young people's motivation to engage in research varies by age and gender. Parental engagement with the research was more important for younger participants than older ones. Parental recruitment has been identified in past research as important to a sample of adolescents with chronic illnesses (Broome & Richards, 2003).

While incentives were important to the adolescents we interviewed, they did not need to be financially based; altruism was found to be an important motivator for participation. Stanford and colleagues (2003) also found altruism to be an important motivator, though their research was within a very different population: older adolescents, over half which were HIV positive. Moreover, the adolescents in Stanford's research were retrospectively asked about their reasons for joining a study with which they were currently involved. Their research was based on a measure that had thirteen items that allowed adolescents to rank the factors most important to their study participation. Another study that asked about reasons for staying involved with a study found that a desire to help friends and family was important to adolescents (Villarruel, Jemmott, Jemmott, & Eakin, 2006). However, this questionnaire was given to adolescents who had remained engaged after a large drop off in the study's retainment. While both previous studies cited found altruism to be important to adolescent participation, our results are in a novel population, and emerged from qualitative data,

without prompts.

Peer recruitment and the social opportunities possible through research participation were also important recruitment motivators to adolescents in our study. Past research has found that peer relationships are also important to retention (Clark-Jones & Broome, 2001).

Even though computers are used for much of our lives, the adolescents in our study said they would prefer personalized information or updates to be sent in the mail, rather than by email. While many researchers may believe that young people prefer to do everything electronically, the excitement of having something arrive by mail seemed to be a novel incentive to the adolescents involved in this research. This finding highlights the importance of knowing the specific participants involved in a research project and of not assuming that the research team knows their preferences.

Our study found that detailed explanations of the research purpose and methodology appeared to increase interest in participation through the process of the focus group. It is likely that participants' underlying altruistic feelings and attitudes (i.e. "research helps people") were a strong foundation for building the attractiveness of research for young people. Establishing and then building on adolescents' good will toward research will likely contribute toward high levels of adolescent engagement.

Among researchers, there is a growing awareness of the need to engage young people in research in a meaningful way and to position young people as experts in their world (Bagnoli & Clark, 2010; Clark-Jones & Broome, 2001). However, this raises ethical challenges for researchers (Bagnoli & Clarke, 2010, Lamb et al, 2001). Weithorn & Campbell (cited in Lamb et al, 2001) found that adolescents over 14 years were mentally competent and able to provide informed consent while those under the age of 14 were more vulnerable. Thus, care needs to be taken that adolescents are not coerced (by researchers or parents) or induced (via monetary incentives) to participate. One method of increasing levels of informed consent is by having young participants explain the research process back to researchers in an interactive forum (Lamb et al., 2001). This interactive process is reminiscent of a focus group interaction, which the current study found to be a method with potential for successful adolescent research recruitment. Further, explanatory focus groups may be an effective recruitment strategy, with one study documenting one in five adolescent participants engaging with the ongoing research project after focus group engagement (Bagnoli & Clark, 2010).

Our focus groups mainly consisted of participants from independent or private (non-government) schools. This was likely due to the limitations of the recruitment process: we were not able to approach adolescents through government schools due to the restrictive research approval processes for these schools, and we relied strongly on word-of-mouth recruitment. Accordingly, the findings may only reflect those of higher socio-economic background. Additionally, the findings about attitudes toward future research engagement do not necessarily indicate future behaviour and require caution in interpretation.

The New South Wales Commission for Children & Young People and The Australian Research Alliance for Children and Youth (ARACY) have identified a number of "key

operating principles” in undertaking research with young people (2009), including: respectful engagement with children and young people; trust and relationships; choice, flexibility and adaptability in research design, approach and implementation; reflexive research designs; transparency and accountability in research processes; and benefits to children and young people.

Incorporating these strategies must be done in concert with an understanding of the targeted adolescent population. We believe that effective recruitment of adolescents requires an appreciation of motivators, as well as time and resources to extend potential participants’ understanding. Recruitment and retention strategies that respond to aspects that young people have identified as important are more likely to be successful in adolescents’ engagement.

Figure 1. Visual Representation of Themes



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