Engaging adolescents and young adults in a longitudinal health study: experience from the Top End cohort

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While young people are generally healthy, the silent progression towards chronic diseases such as diabetes and cardiovascular disease may have already begun in adolescence. Adolescence is often the stage of life when experimentation with health damaging activities such as smoking, alcohol and drug use begins and habits formed at this age often become entrenched. Despite increasing recognition of the importance of this phase of life, there continues to be a paucity of information on the health of this age group.

Described here is the successful engagement and recruitment of young people in a longitudinal health study. The Top End Cohort Study (n=195) was established to ascertain the current health status of a cohort of young people and to follow them through their life span. Participation was voluntary and eligibility was based on being born between 1987 and 1991 in the Darwin area and currently residing there. Darwin is home to people from many countries, allowing the recruitment of people from diverse cultural heritage. As there is a well-established study of Aboriginal people of the same age based in the Top End, the Aboriginal Birth Cohort Study, inclusion was limited to people born to non-Aboriginal mothers. Recruitment commenced in November 2007 and continued till September 2009.

Studies have found that young people dislike using health services because they think they will be embarrassing, lack confidentiality, and that health staff do not understand their needs and therefore the services provided are irrelevant. Previous research has highlighted specific barriers to engaging young people in health services such as cost, time and confidence in service providers. Strategies were incorporated both in the recruitment phase and in the delivery of health check in an effort to overcome these barriers.

The participants aged 16-21 years underwent a comprehensive health assessment which consisted of a wide range of procedures from anthropometrics, to ultrasounds of kidney, carotid and thyroid, blood and urine analysis and cognitive and emotional wellbeing assessment. A structured consent form was used allowing them the opportunity to either choose all procedures, or consent individually to each procedure that they wished to participate in. This allowed the participant a great degree of control over their health assessment and allowed them to opt out of any procedures which they might see as unpleasant, such as blood or urine collection.

There was a high level of participation across all assessment options. We believe that this can be largely attributed to the design of the consent form which allowed greater individual control. The majority (87.0%) consented to take part in all procedures. Blood and urine sampling were the two most often refused, but these still had high consent rates of 94.0% and 92.0% respectively. This highlights that the provision of information and allowing control and choice can achieve high participation rates even in procedures deemed unpleasant.

A questionnaire was sent to participants at the halfway point (n=74), requesting feedback on the effectiveness of recruitment strategies, the reason for their participation, their thoughts about the process and whether their needs were being met. The majority reported the health check was a positive experience; being inclusive, non-threatening and respected privacy. Respondents stated that what they most liked was the friendliness of staff, voluntary nature of the study and freedom of choice. The majority also placed high importance on the fact that explanations were provided for each test and that they were given the opportunity to decide what procedures they participated in. A typical response was: “The people were friendly and honest, they explained what they were doing and I wasn’t forced to take part in any test I didn’t feel comfortable with.”

Several respondents also appreciated having a free health check, which allowed them to learn more about their bodies and their health. Others also appreciated the fact that they were contributing to research for other young people. Negative aspects of the clinic related to the length of time taken to undertake tests due mainly to large group size.

This age group perceived themselves as healthy and did not otherwise attend health services. When asked to nominate a general practitioner (GP) where their results would be sent, only 48.2% could name a GP with even fewer actually using the service regularly. Given that more than half the participants did not use formal health services, but did participate in the current study, suggests that formal services are not attractive to young people.

This period of transition from school to work, adolescence to adulthood, is particularly important and may provide a window of opportunity to instil healthy lifestyle and nutritional choices to assist young people in maintaining a healthy lifestyle. The central factor in engaging young people is establishing confidence in the ability of the providers to maintain privacy of sensitive information. We found young people were interested in their health and would participate in health surveys and services if a model that suits their needs is used.
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References

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