

'Nothing about us without us': considerations for research involving young people

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Abstract

Research development in the adolescent health arena is increasingly called for, given the relative lack of robust data on the health of young people. However, specific issues need to be considered when researching this age group. Such issues include participation of young people in the research process, availability of adolescent-specific data, developmental considerations and the interface between paediatric and adult-orientated healthcare. The aim of this paper is to highlight the importance of participation of young people in research and to discuss the key areas for consideration for practitioners when conducting research involving young people.

Introduction

Research development in adolescent health is increasingly called for,¹ given the relative lack of robust data on the health of young people. There needs to be a greater distinction made in research between younger children, adolescents and adults so that important data are not lost nor findings overlooked. However, specific issues need to be considered when researching this age group. Furthermore, participation of young people is now recognised to be important from the outset of the research process and true participatory research is now advocated by professional bodies.^{2,3} The aim of this paper is to highlight the importance of participation of young people in research and to discuss the key areas for consideration for practitioners when conducting research involving young people.

Concept of participatory research

Young people can potentially be involved at any or all stages of research (see table 1) and can enhance the quality of the research.

At the same time their involvement can promote positive youth development, fostering key skills of communication,

planning, information gathering, problem solving and critical analysis. In a project to develop a participation strategy for a professional college, research was a key area young people wanted to be involved in.³

Setting the research agenda

From the outset, research questions should be relevant, resonant to the lives of young people and of importance to young people themselves. To ensure these questions are also representative of the views of the population in question, it is important to ensure that those involved come from a range of backgrounds.⁴ This includes young people with cognitive and/or communication impairments.^{4,5}

Funding bodies also have a responsibility to ensure that the views of young people are heard at this stage and considered when deciding research strategies and/or priority areas for study.²

Project development

Once the questions are defined, young people can work with researchers to develop them further, inform decisions regarding methodology to use, the choice of setting, the design of any intervention as well as the development of any informational resources, consent forms and so on.

Co-researchers

Reports of lay people as equal research partners are already available in the literature.⁶ There are currently several models of good practice supporting young people as co-researchers in the UK (see table 2).

Imperative to the engagement of young people as co-researchers is appropriate training for young people in consent, confidentiality, safe guarding, research methods and data protection. Young people will bring their unique perspectives to the interpretation of the data collected. Support from experienced, young people

Table 1 Involvement of young people in research

Setting the research agenda
Project development
Development of protocols
Design of interventions
Advisory Board membership
Co-researchers
Research participants
Dissemination

friendly researchers is vital. Arrangements for participation, supervision, support and training needs to be clearly defined in research protocols.

Dissemination of research findings

In adolescent health, it is vital that the results are disseminated to young people themselves whether they be participants, co-researchers or indeed members of the particular population being considered. Young people, in turn, can also be effective conduits for such dissemination.

Challenges of participatory research

Participatory research is still in its infancy and there remain significant challenges as has been the case with adults. Some researchers have reported some of these challenges⁴⁻⁷ including workload, recruitment, ethics, aspects of power and impact on research quality. Holland *et al*⁷ caution practitioners “against the assumption that participatory research per se necessarily produces ‘better’ research data, equalises power relations or enhances ethical integrity.” Research is also needed to explore how young people themselves perceive their potential roles as active research partners particularly in the context of chronic illness and limited energy levels. Participatory research can be an additional burden (as well as for their parents).

Specific issues for consideration in adolescent research

Data

A significant challenge for researchers is finding adolescent-specific data within data sources. If children are defined up to middle adolescence (0–15 years) and the rest of adolescence is incorporated into adult data, the impact of development during mid- and late adolescent years is ignored. Publications such as the Key Data for Adolescence⁸ have helped to redress this imbalance. The recognition of adolescent morbidity and mortality highlights the need for specific consideration of this age group. For example, in spite of improvements in childhood and adult cancer, similar improvements in adolescent-onset cancer mortality have yet to be reported.⁹ Likewise, loss of solid organ transplants are highest during adolescence.¹⁰ Whether such morbidity is related to adolescent behaviour, the impact of transition, the effect of physiological differences during

adolescence and/or the under-representation of this age group in clinical trials¹⁰ is as yet unknown.

Developmental considerations

Acknowledging the developmental status of young people is imperative in research. Chronological age is an imperfect marker of adolescent development. This is particularly pertinent when pubertal status is considered. Much is unknown regarding the process of normal puberty, let alone puberty in the context of illness.¹¹ Furthermore, pubertal assessment is poorly documented in routine clinical practice.¹² Self-assessment, although less accurate than formal Tanner staging¹³ can be a useful strategy and also engages young people in discussions regarding their changing bodies.

Another issue relating to adolescent development and research is the necessary inclusion of pregnancy testing in drug trial protocols. Such testing must be accompanied by appropriate safe guarding practices for young people found to be sexually active below the age of 16 years. Even if a young person is not yet sexually active, the assumptions of non-research staff, unaware of a research protocol, when they see serial pregnancy test results in hospital case notes can be prejudicial. In the case of those younger than 13 years, such assumptions may lead to unnecessary distress if child protection services are alerted. Centres taking part in clinical adolescent research need to ensure appropriate adolescent expertise and policies.

Brain development

Neuroscience is one of the most exciting areas of current adolescent health research. Longitudinal neuroimaging studies demonstrate that the adolescent brain continues to mature into the mid-twenties. Empirical evidence linking neurodevelopmental processes and adolescent real-world behaviour, however, remains sparse¹⁴ with ‘normal’ brain development yet to be fully delineated. Much of the discussion about adolescent brain development has focused on the late maturation of the prefrontal cortex, which coordinates executive functioning and the increasing ‘connectivity’ of the brain related to the neuromaturation processes of pruning and myelination.¹⁴ Researchers have proposed that the temporal gap between puberty and the development of the socioemotional system and the more prolonged development of the cognitive control system may be what underlies aspects of adolescent risk-taking behaviour.¹⁴ As neuroscience advances, researchers will need to consider the interpretation of data in the light of such progress. For example, how does their stage of brain development affect their perception of risk and benefits of research or the ratings of their own self-efficacy or independency?

Cognitive developmental status also relates to emerging capacity. Young people have, by definition, a limited life experience and may have unrealistic preconceptions of research and limited knowledge of the ethical guidelines underpinning research. More detailed

Table 2 Resources for involving young people as co-researchers

http://www.participationworks.org.uk
http://www.carnegie-youth.org.uk
http://childrens-research-centre.open.ac.uk
http://www.nya.org.uk/integrated-youth-support-services/young-researcher-network
http://www.ncb.org.uk/pear/home.aspx

information and specific reassurances may be necessary for research naïve adolescents. It is also important to acknowledge that emerging capacity is related to *both* developing cognition and life experiences. A young person with a congenital or early childhood onset condition may have greater life experience of hospitals and ill health than both their peers and adults, including professionals. Interestingly, young people with diabetes are more likely to self-classify themselves as adult compared with their healthy peers.¹⁵ Conversely, novel situations such as a new diagnosis or first admission to a new hospital, may tax an adolescent's cognitive and decision-making skills. Such lack of experience may lead to impulsive responses, overdependence upon adults or a limited ability to process information related to the risks and benefits of research participation. The latter is discussed further below.

Psychosocial development

Privacy is an important developmental consideration. From a physical aspect, young people have a heightened sensitivity to their body image particularly in comparison with peers. This should be taken into account in choices of setting and/or data collection format. Finding privacy in the parental home may be challenging so interviewers may need to explicitly request parents and siblings to stay out of a communal room during a research interview.

Confidentiality is reported to be important to adolescents within healthcare settings¹⁶ and research is no exception.^{17–19} Specifically addressing any concerns young people may have regarding disclosure to parents should be as routine in research clinics as standard clinics. Young people may not give full or accurate answers if they suspect parents or others in authority will find out. There may be ways of assuring anonymity, such as computer-based data collection. Similarly, adolescents may find conversations over the telephone easier than face-to-face discussions.²⁰ Just as in clinical practice, clarifying confidentiality and its limits to research participants, and assessing their understanding about such limits should take place during the initial introductory and recruitment phase of any project. It should also be clearly stated on consent forms and information leaflets, including those for parents. Further detailed discussion regarding strategies and specific techniques that facilitated the research interview process with young people can be found in the work by Mack *et al.*¹⁸

A key adolescent developmental task is taking increasing responsibility for one's own health including spending time alone with health professionals. Ensuring similar practices within research settings may be challenging. Continuity of professionals may be easier to ensure, but the presence of parents as well as research staff may be required. This is less of a concern if the research visit is additional to their routine clinical visit. However, if they are one and the same, consideration of how autonomy is respected is of prime importance. It should be acknowledged that combining routine clinical care with research may necessitate longer appointments. Research must never be detrimental to the usual healthcare of the young person in question.

Recruitment and retention

Informed consent is an integral component of recruitment incorporating adequate information, voluntariness and capacity to understand the information. During adolescence, the consent process itself can serve to enhance young persons' sense of control and decision-making capacity and provide an opportunity to assert their autonomy.¹⁷

Sharing power is a means of demonstrating respect for the young person. The process of informed consent and assent contributes to this. Young people should be reminded of the importance of their opinions, their right to refuse to participate or refuse to answer any question during an interview as well as their right to withdraw from the research at any time. In a study of just over a hundred 11–17 year olds with asthma being enrolled into a hypothetical above-minimal risk asthma clinical randomised control trial, there was 33% parent-young person disagreement.²¹ If young persons initially disagreed, they were also less likely to concur with the final decision, were less comfortable and less likely to feel they influenced the decision.²¹ As in clinical care, the overriding principle should always be to aim for parallel consent/assent with young person and family.

Another aspect of sharing power is establishing trust between the researcher and young person. Brody *et al.*²¹ reported that if there was initial disagreement regarding consent to a trial, enrolment was less likely if the doctor was unknown to the family. If research involves young people from diverse communities, there may be cultural influences around this issue.²² Finally, it is also interesting to reflect as to whether choice is truly being offered at time of recruitment. For example, if there are several research projects ongoing in a department, are individual young people given information about all the projects and the choice of which they would prefer to enter?

Adolescence, particularly mid-adolescence, is a time when young people need to 'fit in' and peer interactions gain in importance. Attempts to recruit young people for disease-related research may be unsuccessful

Table 3 Key areas to consider in research involving adolescents

Participation of young people in process
Availability of adolescent-specific data
Developmental considerations
Physical – puberty, pregnancy testing, brain development
Cognitive development
Psychosocial – including privacy and confidentiality, peer influences
Recruitment and retention
Consent, assent and right to refuse
Non-responders
Developmentally appropriate methods
Data collection
Choice of measure
Specific methods, for example, focus groups
Intervention design
Use of new technologies
Consideration of competing agendas
Young person
Parent and family
Clinical personnel
Research personnel
Potential of non-categorical approach
Issues arising at the paediatric-adult interface

simply because young people do not want to be reminded of their condition that is the basis of their eligibility for participation. Even the use of terminology such as ‘chronic illness’ may impact recruitment. Van Staa *et al*⁴ reported that young people refrained from participating in a survey about their long-term hospital care as they did not consider themselves ‘ill’. Recruitment strategies and protocol development need to be sensitive to such issues.

One ongoing concern is the frequent exclusion of young people with cognitive impairment, communication difficulties and/or those without English as a first language. These represent some of the most vulnerable young people seen in any health setting and therefore results of research which excludes them may underestimate need. Similarly, school-based studies will by definition exclude young people not at school, the latter which include vulnerable young people. Such limitations should always be discussed in studies.

Once recruited, retention is important to consider particularly as young people are less able to perceive longer-term consequences and health is likely to be of low priority to them. Strategies to optimise retention include provision of reminders in various formats – written, phone call, text and/or email. Consideration may be needed of innovative incentives within the limitations of ethical guidelines. In addition, young people, particularly in late adolescence and emerging adulthood, are a very mobile population and in order to ensure retention

and avoid a high drop out rate, it is important to be proactive and ensure multiple contact numbers.

As in any age group, there will always be non-responders. Adolescents who are non-responders to research involvement have been reported to have poorer health outcomes overall as adults.²³ Strategies to limit as well as identify characteristics of non-responders are integral to any research protocol.

Developmentally appropriate methods

Developmentally appropriate methods are key to minimise attrition and ensure success.²⁴ Multiple written questionnaires may be less acceptable to this age group who already face multiple examinations in education. Conversely, from a participant’s perspective, a questionnaire is easier to withdraw from than an interview! Likewise, an intervention’s apparent ineffectiveness may be due to its intrinsic developmental inappropriateness. Unlike previous studies of adolescent obesity with high, early attrition rates, the Loozit Study pilot reported a retention rate of 91% at 5 months, which the authors attributed to the fact that young people had been involved in the study design to ensure its developmental appropriateness.²⁵

An important methodological consideration is the choice of instruments/measures. Domains of interest are likely to be different between child, adolescent and adult measures. For example, an adult quality of life measure – the SF36²⁶ – does not incorporate important adolescent concepts such as activities with friends, self-esteem, behaviour, recreation, hobbies and sleep unlike the Paediatric Quality of Life measure.²⁷ Measurement in adolescent research often focuses on risk whereas of equal importance are aspects of resilience whether in terms of process and/or outcomes. Tools such as the adolescent edition of the CHIP (Child Health and Illness Profile) include a resilience domain as well as domains addressing comfort, risk avoidance and satisfaction.²⁸

Phrasing in instruments are important particularly in early adolescence when concrete rather than abstract phrasing is better understood. In qualitative research, open-ended questions are characteristically used in interviewing, and require abstract cognition to process and answer.¹⁸ Time allocation for questionnaires and interviews is important with more time required for questionnaire completion in early adolescence and longer time for interviews in later adolescence in recognition of their verbal skill development.²⁹ The classic ‘I don’t know’ response may have various meanings depending on whether the young person understood the question and/or has the verbal and cognitive skills to provide a response. Rephrasing questions is a necessary next step in such situations so that the older adolescent who is merely anxious will understand the same question with clarification whereas a younger adolescent may require more clarification and rephrasing before providing

adequate responses.¹⁸ Detailed pilots are thus important aspects of research protocols.

Examples of methods useful with young people include focus groups as they provide a permissive environment in which participants can raise issues of personal importance and pursue their own priorities. They provide 'safety in numbers' thereby allowing more confident participants to initially raise personal or sensitive issues. Online focus groups have also been reported in the literature.³⁰ However, focus groups may not be suitable for all research questions where exposure may be detrimental. Focus group methods must also remain flexible to suit a range of development-related capacities. A focus group of adolescents between the ages of 10 and 18 years will include a range of skills, life experience and maturity. Q methodology has been reported to be successful in enabling young people to speak freely and extensively about their own views and preferences.³¹ Other methods reported to be useful with this age group include visual story telling³² and video intervention assessment.³³

Selection of developmentally appropriate interventions is an important consideration. Web-based formats have obvious appeal and thereby may improve recruitment and retention. The potential of web-based interventions with this age group was explored in a recent review but the need for further research in this area was highlighted.³⁴ Rosen-Reynoso *et al*³⁵ reported on how participatory research was used in the development of an online transition curriculum with young people from diverse backgrounds. Recent examples of evaluations of web-based interventions include an online tool for the creation of a portable health summary from Toronto – MyHealth passport³⁶ as well as a web-based self-management programme in rheumatology.³⁷ Access (including confidential access) to electronic media is an important consideration to avoid exclusion of young people potentially most in need, for example, socioeconomically most deprived. Alternatively SMS- (text messaging) based interventions have been reported to have positive benefits in several chronic conditions.^{38 39} The exponential growth in this technology, however, needs to be borne in mind as what may be acceptable at the project conception may be out of date by the time the project is funded and ready to implement.

Need for acknowledgement of competing agendas in clinical research settings

From a practical perspective, awareness of the competing agendas within research-based clinics is important. There are potentially four competing agendas – those of research personnel, clinical team members, parents/caregivers and the young people themselves. As in routine clinic appointments, an assessment of who is actually choosing to be there and who has been and/or feels coerced is an important part of the consultation.

Likewise, in addition to the research agenda itself, there is the agenda concerning the usual care of the young person as well as that of transitional care. The potential for conflict between these various agendas is an ethical consideration and processes and settings, which limit any negative impact of such conflict, should be integrated into the research at an early stage.

Parents

It is important to identify and understand the relationship between adolescents and their parents as well as their perceived power differences. Adolescents who perceive themselves as less powerful than their parents will be less likely to exercise free will and may be reluctant to express their true feelings or concerns.

Parents however are important for many reasons including consent, adherence to research appointments, transport as well as supporting the research protocol. Parents can also impede research by, for example, influencing adolescent completion of questionnaires and it is always important to ascertain who actually completes the questionnaires. Parent proxy report is important when the young person is unable to self-report due to illness, willingness, cognitive impairment, emotional distress and/or verbal skills. However, interpretation of proxy reports must be made in the light of reported parent-adolescent disagreement, which includes both overestimation and underestimation.⁴⁰ Furthermore, parent proxy reports may fail to capture aspects of care that occur independently of the parent.⁴¹

Although the extent of disagreement may vary in different populations and/or with different issues, the overriding principle is that there are two equally important perspectives to consider – the adolescent and their care giver – which may be similar or different but equally important.

Potential of a non-categorical approach to research

In the study of chronic conditions of low prevalence, small numbers of participants may limit the generalisability of findings. One solution to this is adopting a non-categorical approach, acknowledging that many issues facing such young people are similar albeit with different consequences.⁴² What young people have most in common is that they are young people, first and foremost, and that their growth and development have major influences on their health and ill health. Examples of non-categorical approaches to research have been reported^{31 36 43} Such an approach may thus provide insights into the common challenges and effective solutions in designing and delivering care to adolescents and contribute to 'efficiencies of scale'.⁴²

Paediatric-adult interface

Finally, any discussion of adolescent research cannot ignore the bridge it represents between paediatric and adult research. Collaboration between these disciplines are imperative for success. Disciplines, such as social

science, that have considered adolescence as a distinct entity for much longer than paediatric and adult medical disciplines will further enrich such collaborative research.⁷

Issues concerning this interface include the relationship between child and adult measures particularly for prospective long-term follow-up studies. In such studies that commence in early childhood, there is an additional need to revisit the consent procedure once young people are competent to provide their own consent. Likewise, long-term follow-up studies should not impede effective transitional care as can occur if paediatricians 'hold on' to research participants for data collection purposes. Finally, funding of prospective research also needs engagement of paediatric and adult funding agencies to avoid the rejection of invaluable research because it spans different age brackets.

Conclusions

Young people are important to research from a clinical, epidemiological, ethical imperative as well as being distinctly different from children and adults. This paper has highlighted key areas in such research (table 3).

Current evidence suggests that more research about young people is needed as they have tended to fall out of the remit of paediatric research and not fallen into the adult research arena. The skills, behaviours and attitudes that are paramount in clinical practice with this age group are the same as those required in adolescent research. Research practitioners similarly need to be able to build a rapport with young people, have a flexible approach, be sensitive to verbal and non-verbal cues, and have a genuine interest in young people and their lives. Researchers need to ensure active participation of young people in research programmes and ensure that adequate time is resourced as well as employ researchers and clinicians with the appropriate skills in communication and engagement with this age group. If all this is in place, the likelihood for successful research, which actively involves young people and is resonant with their lives, can be assured.

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