Adolescents in Research – The Challenges of Recruitment

The key role of the Research Nurse

Why recruitment is high on the agenda

- In December 2016 the UK Clinical Research Collaboration announced that Methodological research addressing recruitment challenges has been identified as a priority for UK Clinical Trials Units to meet and identify effective interventions and reduce research waste (1). Any agenda within the MRC is to increase public participation in research, and the efficient recruitment of the required number of participants within a study is vital to the quality and volume of data collected. A number of barriers are associated with effectively recruiting participants to clinical research that have been widely described in the literature (2). The importance of improving the methods of recruitment, and identifying and addressing the challenges of recruitment to research, is as true with the Medical Research Council (MRC) Health and Biomedical Research Unit, as with any other health research strand (3). Thus, the MRC has stepped up its recruitment efforts to develop innovative methods that involve and engage potential participants across the whole research process. This is not only an ethical imperative but also a strategic goal for the Clinical Research Nurse Workforce for 2015 – 2017 (4). The value of research and the role of the research nurse in addressing and overcoming these challenges and barriers to effective recruitment is in line with the NHS National Institute for Health Research (5) on health care” (2).

Why adolescents?

Participation of healthy adolescents in research is highly valuable as a specific population group: children, adolescents and young adults aged 10-24 years make up a reasonable portion of the world’s population, 1.9 billion (3). Many studies have combined child and adolescent age groups, making it difficult to determine adolescent-specific outcomes. The heterogeneity of the adolescent years, in which there are very specific, and transient experiences which are sometimes not adequately captured. Initials, attitudes and physical maturity that develop during adolescence set up important themes that have a profound influence on health and wellbeing for the long term (3). Adolescents are a population with very specific characteristics and values amongst the most difficult to recruit and retain (3). There is an increased need for alternative adolescent-specific recruitment, and recruitment and retention can be affected by a variety of factors, whether recruitment methods, study content or accessibility. Some studies address issues that the adolescent may not feel personal, embarrassing or sensitive, other barriers to recruitment involve the complicated issues of assent and consent and parental agreement (3). It is the experience and contribution of the research nurse that can provide a key role in overcoming these statistics. Adolescent medicine is relatively young, compared to paediatrics or adult medicine. The Society of Research for Adolescents established in 1994, highlights the importance and uniqueness of the age group, its role is to advance understanding of adolescence and enhance the wellbeing of youth in a globalized world, and who see the adolescent developmental experiences and perspectives as being a ‘feature of the future’ (4). The Journal of Research on Adolescence, an international journal. It can be less expensive and have a lower burden on the population that wants to participate in research, which can be equated to a lower burden of research and cost. Recruitment was highly effective: 58 schools approached in the study; 30% recruitment rate. In total 30% recruitment rate.

Case study: “Understanding meningococcal carriage and disease”

A multi-centre cross-sectional study of meningococcal oropharyngeal carriage, with a questionnaire, to obtain a representative collection of meningococcal isolates from asymptomatic carriage at a time of low disease incidence, recruiting 18,800 healthy teenagers aged 15-19 years in the UK. A single asymptomatic evenly used to sample meningococci from all participants, and a brief questionnaire administered to record the presence of symptoms, including and social behaviour, which were completed by the participant. Recruitment was highly effective: 58 sixth forms were approached in the study; 30% recruitment rate.

Overall Aim of the Study: To determine the relationship between meningococcal oropharyngeal carriage and incidence of disease in periods of high and low incidence of disease. Pneumococcal meningitis is a period of high incidence (1988 – 2017). A single asymptomatic evenly used to sample meningococci from all participants, and a brief questionnaire administered to record the presence of symptoms, including and social behaviour, which were completed by the participant. Recruitment was highly effective: 58 sixth forms were approached in the study; 30% recruitment rate.

1. Engage the School

OVG research team offered to provide feedback on school assemblies, to broaden students knowledge and awareness of both meningococcal and meningitis. The interventions used in this case study have international applicability and are likely to be enhanced through the consideration of novel approaches which acknowledge the uniqueness of adolescents and their world. We offered the school an extra incentive for their students and staff.

2. Engage, Inspire and Motivate the Adolescent

Achievable

“Why do I care?”

www.meningitis-trust.org

Interesting

Interactive Public Engagement events, where school students would be attending, were used to raise awareness and understanding of meningitis, and of the study. Exploring the science in terms that the students would be able to understand and having the hands on working demonstrations with the models.

Valuable

“Not just the UK Fast”

Exploring the wider global implications of research, explaining the value of research amongst the global community.

Relevant

“OK, now I get it”

Clear information was given about why it would be required, and expectation of timing part of the study.

Understandable

“OK, now I get it”

Clear information was given about why it would be required, and expectation of timing part of the study.

How well did we do?

Oxford Vaccine Group

Recruitment was highly successful: 58 sixth forms were approached in the study; 30% recruitment rate. The feedback from the OVG workshop was positive and constructive. We offered the school an extra incentive for their students and staff.

Feedback from the OVG workshop

These approaches resulted in more than 50% of schools approached agreeing to take part in the study to prevent the research opportunity for their students and enable the visits to occur during the school day.

Blue Sky Thinking

The interventions used in this case study have international applicability and are likely to be enhanced through the consideration of novel approaches which acknowledge the uniqueness of adolescents and their world. Researchers need to increase the amount of Patient and Public Involvement, leading to an environment where patients, and communities become active partners and are co-shapers of research design, delivery and outcomes. Public Engagement events - public understanding of science is a goal that we have a duty to educate, inform and entertain to successfully present the modern picture of health and science. The research nurse can be that facilitator to enable the knowledge transfer to the public, to encourage awareness of research.

As research nurses we need to embrace digital technologies and become more digitally confident. Researchers are increasingly using social media to recruit participants, in particular using the potential value of Twitter and Facebook. A systematic review (6) investigating Facebook as a recruitment tool for adolescent health research, demonstrated that it was a very successful in engaging young adults, which is also cost-effective in comparison using social media to advertise and promote research the maximum age requirements for the adolescent to sign up - 13 years). Recruiting via the use of an online platform has the potential to reach a wider network of eligible participants.

Every nurse is a research nurse, all nurses are making an important daily contribution to the advancement of science. As a professional body we can be a well-educated, well-prepared workforce which understands research as a core activity which is critical to developing new solutions. As a professional body we are part of an international health research system and our work has Global influence.