

Adolescents in Research – The Challenges of Recruitment

The key role of the Research Nurse



UNIVERSITY OF OXFORD

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 Trial Units in order to identify effective interventions and reduce research waste" (1). A key agenda within the NHS 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 robustness of results; "small recruitment size produces decreased availability of sufficient evidence in order to inform decisions on health care"(2).
- The importance of improving the methods of recruitment, and identifying and addressing the challenges of recruitment to research, is in line with the NHS National Institute for Health Research strategic goals and objectives for the Clinical Research Nurse Workforce for 2015 – 2017 of: "Improved awareness, Improved standards of research delivery and practice, and Enhanced Patient experience" (3).
- The research nurse provides specific expertise to address issues concerning recruitment and holds a vital role throughout the research process, facilitating high quality research leading to the provision of an evidence-base for robust policy development and future global public health policies and programming.

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 massive portion of the world's population, 1.8 billion (2). Many studies have combined child and adolescent age groups, making it difficult to determine adolescent-specific outcomes, this neglects the uniqueness of the adolescent years, in which there are very specific and transient experiences which are sometimes not adequately captured. Habits, attitudes and physical morbidity that develop during adolescence set up trajectories that have a profound influence on health and wellbeing for the long term (4), an issue which is high on the government agenda (5). Yet this remains a population which present very specific challenges and remain amongst the most difficult to recruit and retain (6). There are a number of complexities in adolescent research, 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 find too personal, embarrassing or sensitive, other barriers to recruitment involve the complicated issues of assent and consent and parental/guardian consent. It is the experience and contribution of the research nurse that can provide a key role in overcoming these obstacles.

Adolescent medicine is relatively young, compared to paediatric or adult medicine. The Society on Research for Adolescence established in 1984, highlights the importance and uniqueness of this age group, it's goals are to advance understanding of adolescence and enhance the wellbeing of youth in a globalized world, and who see the adolescents' experiences and perspectives as "critical to a better future" (7). The Journal of Research on Adolescence, an International journal in publication since 1990, collates many research studies, using qualitative and quantitative methodologies, which specifically recruit this age group, and has significant impact in the knowledge in the field of adolescent research.

Involving adolescents in research studies, educating and raising awareness of personal and global impact of clinical research, all contributes to normalising involvement in research and increasing confidence to discuss trials with medical practitioners. In turn this may contribute to fulfilling the aspirations of the NHS to dramatically increase research involvement, a concept explored in a report in 2005 commissioned by Cancer research UK "Every patient a research patient? Evaluating the current state of research in the NHS" (8), and as highlighted in the NHS campaign in 2003/2004 "It's OK to ask" (9).

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, circulating in 18,000 healthy teenagers aged 15-19 years in the UK.

Overall Aim of the Study: To determine the relationship between meningococcal carriage and invasive disease in periods of high and low incidence of disease (comparing to a period of high disease incidence during 1999 – 2001).

A single oropharyngeal swab was used to sample meningococci from all participants, and a brief questionnaire administered to record the presence of siblings, smoking and social behaviour, which was completed by the participant.

Sponsored by University of Oxford, funded by the Wellcome Trust

18,000 healthy teenagers to recruit; where on earth do I start?

How did the research team at Oxford Vaccine Group approach this challenge?

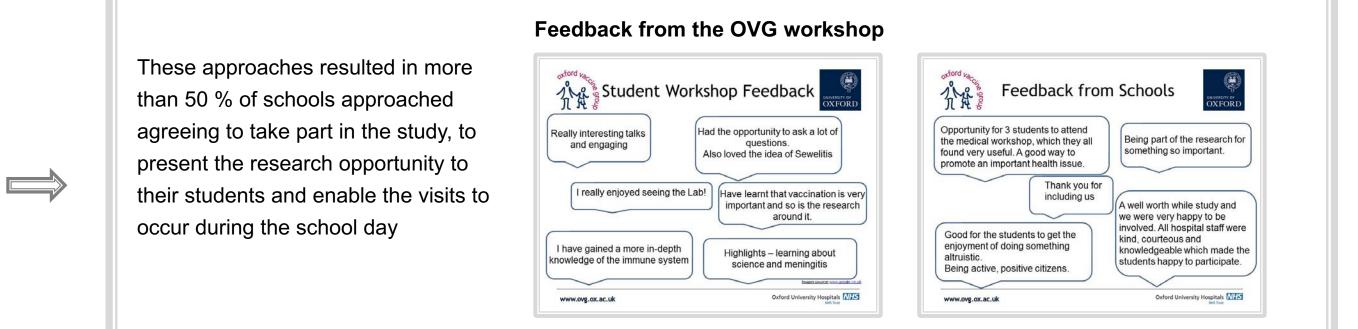
1. Engage the School

OVG research team offered to provide presentations in school assemblies, to broaden students knowledge and awareness of both meningitis and clinical trials

We provided a tailored service: the OVG team would be adaptable to requirements of individual schools, to best enable the research study to fit in with the school day with the least disruption to students and staff

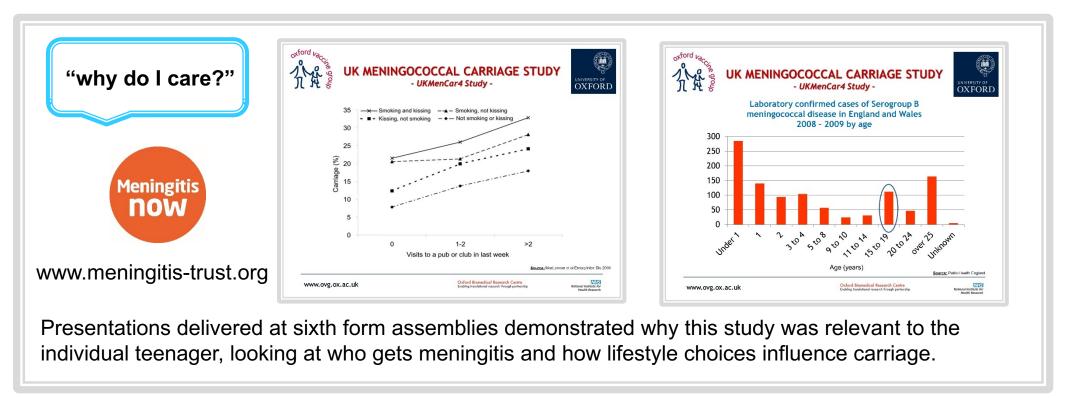


We offered the school an extra incentive of the provision of a day interactive workshop at the University of Oxford studying clinical vaccine trials for some of their most interested students, to provide a unique educational experience.

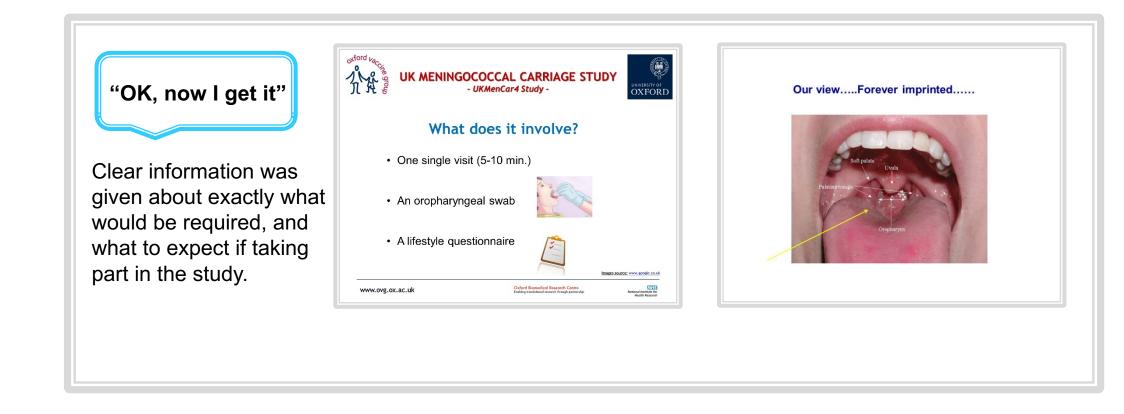


2. Engage, Inspire and Motivate the Adolescent

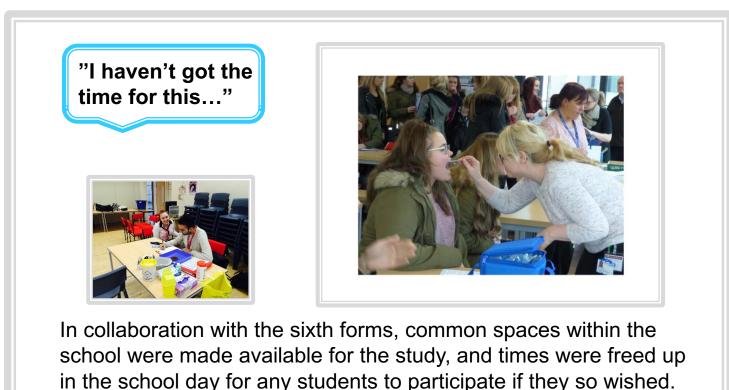
Relevant



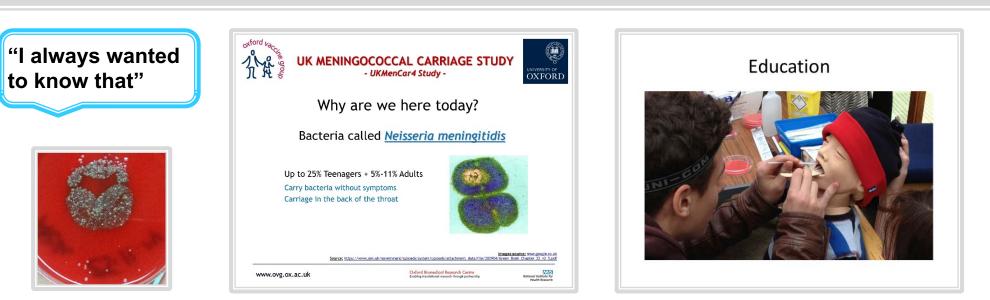
Understandable



Achievable

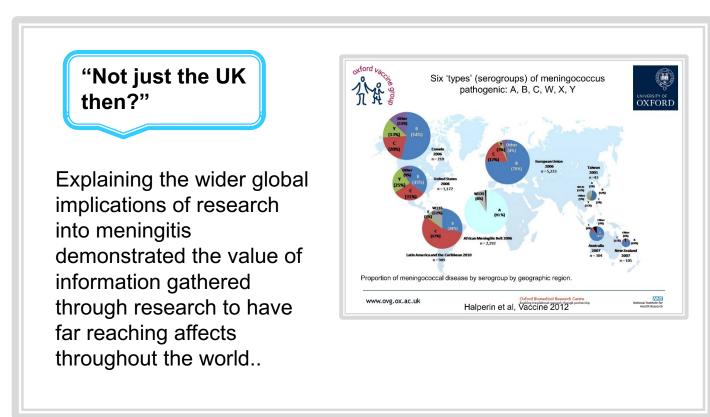


Interesting

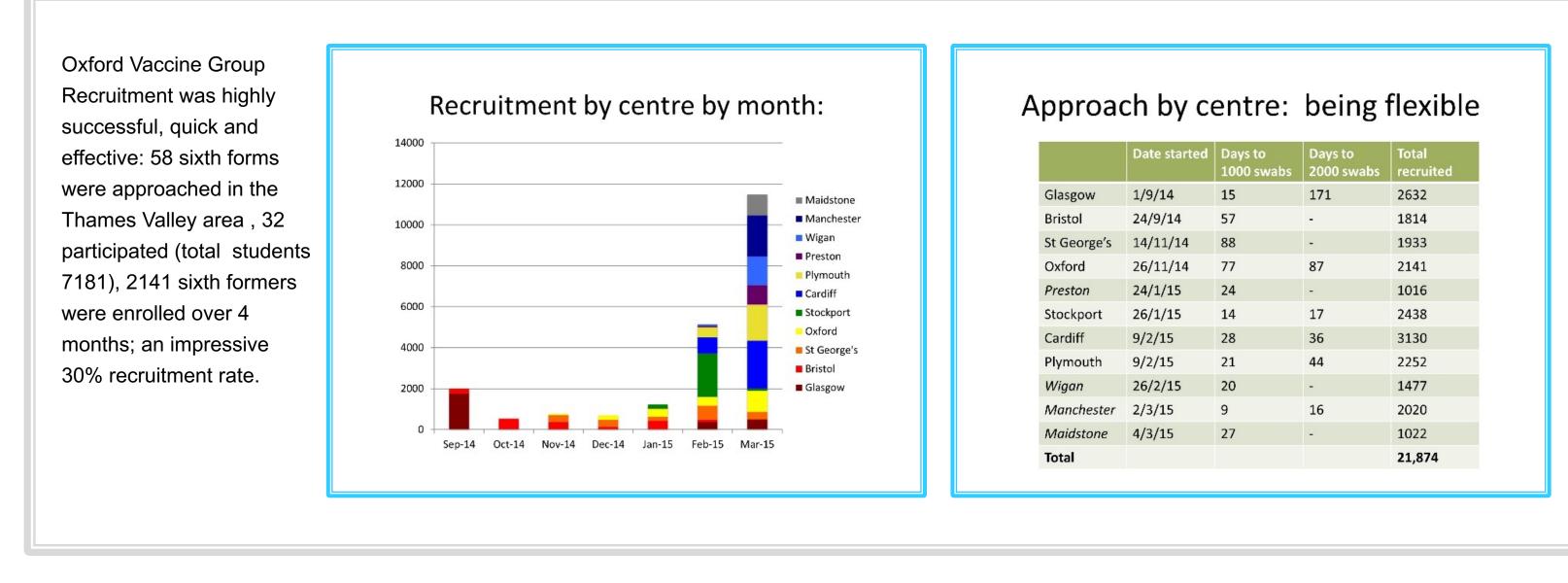


Interactive Public Engagement events, where sixth form students would be attending, were used to raise awareness and understanding of meningitis, and of the study. Explaining the science in terms that the sixth form students could relate to and having the hands on swabbing demonstrations with the model.

Valuable



How well did we do?



1. UKRCC Winter 2016, vol6, issue 4: (The ORRCA project (Online Resource for Recruitment research in Clinical triAls) supported by Medical Research Council (MRC) Network of Hubs for Trials Methodology Research

3. www.crn.nihr.ac.uk accessed 03/2017

4. Steinbeck K, Baur L, Cowell C, Pietrobelli A. Clinical research in adolescents: challenges and opportunities using obesity as a model. Int J Obes. 2009; 33: 2-7

5. DOH Children in Mind report; www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf

6. Amon KL et al ; Facebook as a recruitment tool for adolescent health research: a systematic review. Acad Pediatr. 2014 Sep-Oct;14(5):439-447.e4. doi:10.1016/j.acap.2014.05.049

7. http://www.s-r-a.org accessed in 03/2017

8. www.cancerresearchuk.org/sites/default/files/cruk every patient may2015 web.pdf

9. http://www.nihr.ac.uk/patients-and-public/documents/OK-to-ask-report.pd.

Pictures source: courtesy of ovg.ox.ac.uk

Produced by Caroline White Senior Research Nurse, and Rachel White Research Nurse, Oxford Vaccine Group, University of Oxford.

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-producers of research design, delivery and outcomes

Public Engagement events - public understanding of science is a good thing, we have a duty to educate, inform and entertain to accessibly present the modern picture of health and science. The research nurse can be that facilitator to enable the knowledge transfer to engage the public, to encourage ownership 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 unlocking 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 (a consideration if using social media to advertise and promote research is the minimum 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.

^{2.} www.thelancet.com Vol 379 April 28, 2012