



Determinants of young Adult Social wellbeing
and Health

 <http://www.facebook.com/dashlondon>



Retention and attrition in longitudinal cohort studies.

Report on culturally-appropriate retention strategies in an ethnically diverse cohort: lessons from the DASH Study

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1.0 Introduction

Longitudinal studies offer a valuable resource to the public health community, but their results can be limited through sample attrition. Losing study members through failure to locate due to residential mobility or failure to participate at follow-up waves is a major concern in the conduct of all longitudinal studies. Selective attrition of sub-populations with a greater likelihood of ill health can lead to biased estimates of association and reduce the generalisability of findings (Marcellus, 2004; Patel et al. 2003; Booker et al. 2011). Certain groups have been reported as more at risk of selective attrition, particularly ethnic minorities, those with low family income or low education and those living in urban areas (Patel et al. 2003). This report details the methods used to minimise attrition in the Determinants of young Adult Social well-being and Health (DASH) study - a longitudinal cohort with a focus on ethnic minority health.

1.1 DASH

The DASH study started in 2002/03 with 6643 school children, then aged 11-12 years, 80% from ethnic minorities. Wave 2 took place in 2005/06, when they were 14-16 years (school years 9 and 10). In 2010/2011, when participants were aged 19-21 years a postal follow-up was conducted complemented by telephone interview and on-line questionnaires. A feasibility study is in progress (2012/13) to establish best practice for a face-to-face follow-up over the next few years with about 200 participants taking part.

The cohort is culturally diverse, with over fifty languages spoken and many religions represented. DASH is unique in that it includes a range of longitudinal social, psychosocial, and health measures, and has the largest longitudinal samples of ethnic minority young people in the UK. It examines the influence of social circumstances (e.g. economic disadvantage, family life, neighbourhoods) on a range of health outcomes (health behaviours, physical and physiological measures).

Key findings already published from the study include better mental health of ethnic minority young people compared to their White counterparts, *despite* greater socio-economic disadvantage (Bhui et al 2012); emergence of ethnic differences in blood pressure among boys in late adolescence (Harding et al 2010), and the influence of family lifestyles on overweight status (Harding et al 2010). These findings led to the initiation of a prevention study, the DiEt and Active Living study ([DEAL](#)), using places of worship to nurture healthy lifestyles in communities (Maynard et al 2009; Rawlins et al 2012).

1.2. DASH sample retention

Contact has been maintained with a high proportion (81%) of the original DASH sample (Table 1), from what are conventionally thought to be 'hard to reach' populations. The strategies that have contributed to this high retention rate were informed by our systematic review of retention strategies (Booker et al, 2011), experience of other cohort studies and field experience from the current feasibility study, and are described below.

2.0 Retention strategies

The key strategies used fall under the following five categories: 1) community engagement, 2) communication strategies, 3) tracing, 4) flexibility of data collection, and 5) incentives.

2.1. Community engagement

A number of methods were used to engage with local communities. Firstly, the study benefited from the support of a network of community 'advocates' or study champions – local community leaders, head teachers and parent governors, community nurses, local religious leaders and well-known public figures – who promoted the study and its importance to the community. The study was championed by several notable Black Britons including, for example, Dame Jocelyn Barrow, a founding member of the Campaign Against Racial Discrimination. Well-known public figures and respected local voices raised the profile of the study and encouraged participation by schools and by pupils. Teachers referred directly to this strategy as being influential in persuading parents of the importance of the study. A second factor boosting participation and community engagement

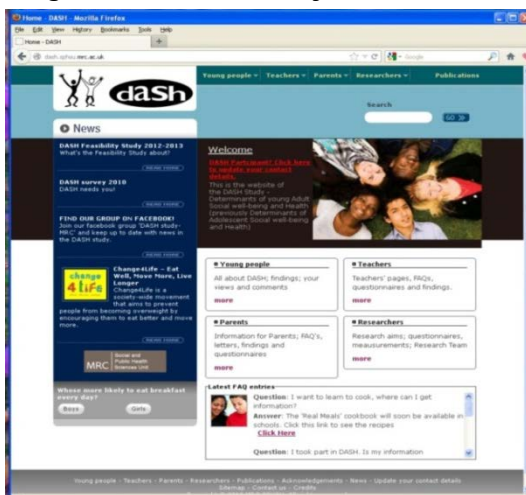
was ethnic minority representation in the research team and on the DASH steering group. The ethnicity of researchers was found to be key in engaging parents and pupils with the research. It lent credibility to the research and also acted as a recruitment and retention strategy for many schools who promoted ethnic minority researchers as role models for their pupils. Thirdly, the second wave of the study was run from an office in one of the participating schools, strengthening ties with the school and local communities.

Two more recent initiatives build on experience from other cohort studies such as the Avon Longitudinal Study of Parents and Children (ALSPAC) (http://www.euconet.com/?page_id=234t). Twelve DASH participants have been invited to form a participant advisory group (PAG) with members of the DASH study team. The PAG will advise on best practice for retention, survey methods in the field, questionnaire content and appropriateness of measures, and feedback to communities. A community link worker has joined the team and will explore the use of culturally focussed approaches to locate participants whom we have failed to contact. Community engagement has been instrumental in promoting trust in the science underpinning DASH and the value of participation in DASH.

2.2. Communication Strategies

A variety of strategies have been used to communicate with the sample in ways which are convenient and meaningful to them.

Figure 1 The DASH Study Website



During the surveys in schools, information was communicated to study members and their parents by way of information packs, workshops and Q&A sessions. Information sheets and consent forms were translated into over 12 languages. This strategy was more for family members than the young people themselves, and enhanced relations with families, especially older family members. However, there were many instances where ethnic minority parents appeared to place more importance on oral communication with researchers than on the information packs. This links back to the value of having the study office in schools, where parents and relatives could easily contact the study team to ask questions and resolve queries. The DASH study team also conducted

Figure 2 The DASH Study Facebook page



interactive science

workshops in schools and local communities. The workshops fulfilled a dual function of an incentive to schools to promote engagement with science and to encourage participation. The high attendance at workshops and positive feedback from various stakeholders testifies to the usefulness of these strategies.

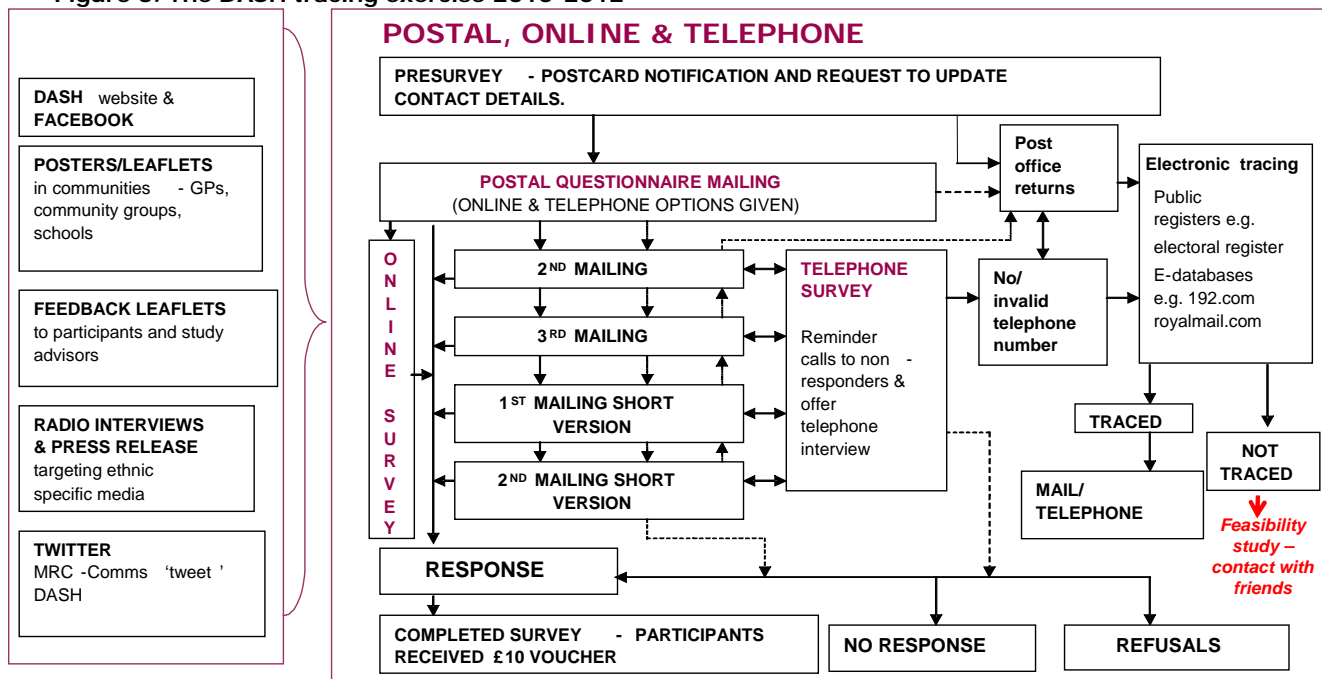
DASH researchers have done interviews on local and national radio stations, including specifically ethnic minority targeted radio stations e.g. Sunrise radio (Asian), to keep the study in the public eye. Posters have been displayed in community locations, for example places of worship, local community centres and libraries. Key results from the study are also communicated to participants via regular newsletters and the website.

Given that the participants are currently in their early twenties, it is important to use the digital communication methods which they use themselves. The DASH study has its own dedicated website (<http://dash.sphsu.mrc.ac.uk/>; see Figure 1), designed in conjunction with PEAR (the Public Health, Education, Awareness, Research project which supported young people's contribution to public health research) to ensure user-friendliness for young people. The website contains a summary of the study and its findings for different users (young people; parents; teachers; researchers), publications, and all study written materials i.e. information sheets, questionnaires, etc. It also has a 'contact us' section where participants can update their details and post queries. Social media such as Facebook (<http://www.facebook.com/dashlondon>; Figure 2) and Twitter are also used to communicate study results and to highlight new stages of the study to participants. In the current feasibility study, participants have been asked to update their details using Facebook, and are sent text reminders of appointments and email is used to arrange appointments.

2.3. Tracing

In 2010-12 a large-scale tracing exercise was conducted to trace those who had lost touch with the study. Figure 3 shows the methods used.

Figure 3. The DASH tracing exercise 2010-2012



Promotional methods included announcements on the DASH website and Facebook page, posters in prominent community locations, press releases to local press and radio interviews (see above). The pro-active methods of tracing included a postal questionnaire requesting participants to confirm their contact details. The option to respond via the web was also offered at this stage. The questionnaire was re-sent three times in total followed by a shorter version of the questionnaire which was sent out twice. At every stage, non-responders were contacted by a specially recruited and trained telephone team who offered a reminder to complete the questionnaire as well as the option to complete it over the phone. All post-office returns from each of the mailings were recorded and participants were then entered into electronic tracing. Electronic tracing methods included using electronic address databases such as 192.com and royalmail.com as well as checking public registers such as the electoral register. In total, 1025 of 2256 formerly untraced participants were located using these methods. The feasibility study is providing new opportunities for tracing the remaining 19% (n=1231) of the sample currently untraced. A 'snowballing' approach is being used - i.e. feasibility participants are asked to refer friends in DASH that they

are still in touch with. In addition to the community engagement methods above, indications are that snowballing will be an effective tool in locating some of the untraced participants due to the maintenance of social networks initiated at school.

2.4. Flexibility of Data Collection

Being flexible and adaptive in the face of challenging environments has always been key to ensuring high participation and retention rates in DASH. In the waves conducted in schools (Waves 1 and 2), multiple school visits were carried out to accommodate absence, absenteeism and school timetables. As these were inner-city London schools, being flexible and responsive to the school environment and working with the schools was crucial to ensuring the highest possible participation rate. In some schools multiple short visits enabled schools to accommodate the study around certain lessons (e.g. Physical Education). As a result of this strategy, retention increased by 26%, 6% and 2% after the second, third and fourth visits respectively (Harding et al 2007).

As detailed in section 2.3, flexibility was employed in the tracing exercise by offering multiple questionnaire response options. Participants were able to respond to the questionnaire using the web, telephone or the traditional postal return. At ages 19-21 years, response rates to postal surveys are usually low. In DASH, using postal questionnaires *as well as* the web and telephone options gave a better yield than postal questionnaires alone. Twenty seven per cent of those with an eligible address confirmed their address via mail, 34% of those with eligible telephone numbers via telephone and only 1% via the web. Consistent with the literature in this area (Booker et al. 2011; Boys et al. 2003; Michaud, 2005) using options other than just postal survey increased response rates. In a meta-analysis, offering a telephone option was associated with one of the highest increases in cohort study retention rates (Booker et al. 2011). In DASH, offering a telephone option increased retention by 32%. Direct contact with researchers was possibly preferred due to a sense of being part of a study for the last 10 years in addition to competing priorities preventing use of other methods.

In the current feasibility study, flexibility in terms of location for data collection is being piloted. Participants have the option to be seen either in their home or at a range of locations across London, including GP surgeries, community pharmacies, clinical research facilities, and King's College London. Providing a choice of venues offers convenience to participants and this flexibility also allows participants to fit the study in around their work or studying commitments – particularly useful for this age group. The option of having a home visit is proving useful for participants with children.

2.5. Incentives

Incentives are commonly used in population-based cohort studies and have been shown to be effective in improving retention rates (e.g. Doody et al. 2003; Laurie & Lynn, 2009; Olsen, 2008; Booker et al. 2011). Incentives (both monetary and non-monetary) have been used in each phase of DASH. During data collection in schools, completion certificates were given, and in more recent contact monetary vouchers have been used. Completion certificates were popular and at Wave 2, three years after the Wave 1 baseline survey, many brought along their original DASH certificates.

Monetary vouchers have been given for updating contact information/completion of questionnaires during the postal and telephone follow-up (£10 voucher) and currently in the feasibility study (£25 voucher) for completion of questionnaire and physical assessments. Monetary vouchers are also given for referring friends who are participants and, for those with children, to cover childcare costs over the duration of the interview.

The current feasibility study also includes the additional incentive of individual feedback on selected physical and physiological measures taken in the study e.g. BMI, body fat, blood results etc. This is proving to be a strong motivator to participation as participants are keen to receive feedback in the form of a 'snapshot' of their health in their early twenties.

3.0 Conclusion

There is a critical need to identify and document effective retention strategies to maximise the value of cohort studies, ensuring they are representative of ethnic and/or disadvantaged sub-populations in society, particularly since they tend to carry a heavier public health burden. Although few studies have formally evaluated retention methods, the literature suggest that the following are useful strategies - offering incentives to study participants, implementing tracking procedures with flexible protocols, engaging the target population at the outset of the project, and allowing multiple contact attempts (Booker et al 2011). All of these techniques have been effectively used in the DASH study. Studies of 'hard to reach' populations emphasise the need to design innovative and flexible strategies that are able to engage and retain members of under-represented groups such as ethnic minorities. We have found that engendering positive relationships with participants and their families, particularly through the community engagement methods outlined above, is proving to be equally important as the standard retention tools for DASH, where ensuring high retention rates relies on a high level of trust and loyalty to the study.

Questions often arise about the lack of engagement of ethnic minority populations in scientific studies. DASH demonstrates that a mixture of focused and culturally appropriate strategies can successfully engage diverse communities. Future research could usefully include the cost effectiveness of multiple strategies.

4.0 References

- Bhui KS, Lenguerrand E, Maynard MJ, Stansfeld SA, Harding S (2012). Does cultural integration explain a mental health advantage for adolescents? *Int. J. Epidemiol*; 41: 791-802.
- Booker CL, Harding S and Benzeval M. (2011). A systematic review of the effect of retention methods in population-based cohort studies. *BMC Public Health*, 11: 249.
- Boys A, Marsden J, Stillwell G, Hatchings K, Griffiths P, Farrell M. (2003). Minimizing respondent attrition in longitudinal research: Practical implications from a cohort study of adolescent drinking. *Journal of Adolescence*, 26: 363-373.
- Doody MM, Sigurdson AS, Kampa D, Chimes K, Alexander BH, Ron E, Tarone RE, Linet MS. (2003). Randomized trial of financial incentives and delivery methods for improving response to a mailed questionnaire. *American Journal of Epidemiology*; 57: 643-651.
- Harding S, Whitrow M, Maynard M, Teyhan A. Cohort profile: The DASH (Determinants of Adolescent Social well-being and Health) Study, an ethnically diverse cohort (2007). *Int. J. Epidemiol*; 36: 512-517.
- Harding S, Teyhan A, Maynard M, Cruickshank JK. Ethnic differences in overweight and obesity in early adolescence in the MRC DASH study: the role of adolescent and parental lifestyle (2008). *Int. J. Epidemiol*; 37: 162-172.
- Harding S, Whitrow M, Lenguerrand E, Maynard M, Teyhan A, Cruickshank JK, et al (2010). Emergence of ethnic differences in blood pressure in adolescence: The Determinants of Adolescent Social Well-Being and Health study. *Hypertension*; 55: 1063-9.
- Laurie H, Lynn P (2009). The use of respondent incentives on longitudinal surveys. In: Lynn P (Ed) *Methodology of Longitudinal Surveys*. West Sussex, UK: John Wiley, 205-233.
- Maynard MJ, Baker G, Rawlins E, Anderson A, Harding S (2009). Developing obesity prevention interventions among minority ethnic children in schools and places of worship: The DEAL (DiEt and Active Living) study. *BMC Public Health*, 21; 9: 480.
- Marcellus, L. (2004) Are we missing anything? Pursuing research on attrition. *Canadian Journal of Nursing Research*, 36(3): 82-98.
- Michaud DS, Midthune D, Hermansen S, Leitzmann M, Harlan LC, Kipnis V, Schatzkin A. (2005). Comparison of cancer registry case ascertainment with SEER estimates and self-reporting in a subset of the NIH-AARP Diet and Health Study. *Journal of Registry Management*; 32: 70-75.
- Olsen RJ. (2005). The problem of respondent attrition: Survey methodology is key. *Monthly Labor Review*; 128: 63-70.
- Patel M, Doku V and Tennakoon L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment*; 9: 229-238.
- Rawlins E, Baker G, Maynard M, Harding S. Perceptions of healthy eating and physical activity in an ethnically diverse sample of young children and their parents: the DEAL prevention of obesity study (2012). *Journal of Human Nutrition and Dietetics* doi: 10.1111/j.1365-277X.2012.01280.x. [Epub ahead of print].

5.0 Tables

Table 1 Traced DASH sample (percentage of baseline), by ethnicity

	Total baseline sample	N (% baseline) traced, 2012
White	1236	1050 (85)
Black Caribbean	946	753 (80)
Black African	1107	887 (80)
Indian	493	445 (90)
Pakistani & Bangladeshi	631	544 (86)
Mixed Black Caribbean / White	568	453 (80)
White Other	725	549 (76)
Other	937	731 (78)
Total	6643	5412 (81)

Table 2 Summary of Retention Strategies

Strategy	Details
Community Engagement	
<ul style="list-style-type: none"> Advocacy Ethnic minority representation on Study team 	<p>High-profile study champions, support from local community leaders e.g. religious leaders, teachers and community nurses. [AW]¹</p> <p>The ethnicity of researchers was key in engaging parents and pupils with the research. [AW]</p>
<ul style="list-style-type: none"> Lay representation on Steering Group Study Office in the community Advisory Group 	<p>Head teachers and other lay people invited to be part of Steering Group. [AW]</p> <p>DASH Study team set up a local office in a participating school. [W2]</p> <p>An Advisory Group made up of 12 DASH participants set up to establish best methods for maintaining contact with sample. [FS]</p>
<ul style="list-style-type: none"> Community link worker 	<p>A dedicated person working to trace lost participants and raise awareness of the DASH study in the community. [FS]</p>
Communication Strategies	
<ul style="list-style-type: none"> DASH study website Social networking sites Feedback letters Local and national radio interviews Posters in community locations Translation of study documentation Interactive science workshops 	<p>Input to the study website design from PEAR (the Public health, Education, Awareness, Research project supporting young people's contribution public health research) to ensure user-friendliness for young people [W2]</p> <p>Facebook, twitter, myspace [insert links] [P; FS]</p> <p>Annual feedback newsletters, seasonal greetings and calendar to participants and schools [AW]</p> <p>PI gave interviews on local radio stations targeting specific ethnic groups e.g. Sunrise radio [AW]</p> <p>Posters advertising the study results and key findings displayed in community locations e.g. places of worship, local libraries [P]</p> <p>Translation of information sheets & consent forms into 15 languages [W1;W2]</p> <p>Interactive science workshops run in schools to raise awareness of scientific aspects of study and encourage participation [W1; W2].</p>
Tracing	
<ul style="list-style-type: none"> Tracing Questionnaire Electronic database searches (Electoral Register, 192.com, Royalmail.com) 	<p>All used to trace participants and confirm addresses already held. [AW]</p>
Flexibility of Data Collection	
<ul style="list-style-type: none"> Multiple school visits Various questionnaire options Flexibility of locations 	<p>Multiple visits were made to schools to accommodate absence, school timetables etc. [W1; W2]</p> <p>Participants offered various options to complete questionnaires i.e. online, telephone and postal questionnaire. [W2]</p> <p>Piloting of a range of locations e.g. GP surgeries, pharmacies, clinical research facilities, Kings College London, homes. [FS]</p>
Incentives	
<ul style="list-style-type: none"> Certificates Vouchers Feedback of physical and physiological measures 	<p>Certificates were used as an incentive to participation when participants were in schools. [W1; W2]</p> <p>Monetary vouchers given on completion of questionnaires and physical measures. [P; FS]</p> <p>Participants receive written feedback on their height, weight, BMI, BP, total and HDL cholesterol, and glycosylated haemoglobin [FS]</p>

¹KEY: W1 (Wave 1), W2 (Wave 2), P (Postal follow-up), FS (Feasibility Study), AW (All waves)