



Determinants of young Adult Social well-being and Health

A survey of young people from different ethnic groups in London

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



Protocol for tracing hard to reach DASH participants

1. Background

Participants who take part in all phases of longitudinal studies are likely to differ from those who are lost to follow-up. Differential attrition, or non-random loss of participants, can lead to bias in study findings by changing the composition of the sample so that it no longer represents the study population. This is particularly the case when response rates are low and there are large differences between responders and non-responders. Attrition also reduces sample sizes and decreases the statistical power to detect effects. Ethnic minorities are typically under-represented in epidemiological studies, thought to be due to uncertainty regarding their engagement and lack of appropriate sampling frames. In longitudinal studies attrition has been highest among ethnic minority and economically disadvantaged groups (Gore and Aseltine 2003).

The approach taken here to locate those currently untraced in DASH builds on a systematic review of retention strategies¹, reported retention strategies in DASH², experience of other large scale studies of ethnic minorities³, and current field experience in the DASH feasibility study. 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 multiple contact methods and flexible protocols, permitting file sharing among interviewers, engaging the target population at the outset of the project, and allowing an open-ended number of contact attempts¹. Studies of 'hard to reach' populations emphasise the need to design innovative and flexible tracking strategies that are able to engage and retain members of under represented groups such as ethnic minorities.

In 2012 following a telephone, mail, and web tracing exercise in 2010-2011, 81% of the 6643 participants in the first DASH survey ~~of DASH could be~~ were located (Table 1). This overall high retention rate reflects the use of strategies from the outset². Our retention strategies can broadly be grouped into five categories - community engagement, communication strategies, tracing, flexibility of data collection, and incentives – some generic to all ethnic groups and some culturally and age focused (Table 2). Typically, tracing of participants between data collection has been via letters/flyers, email and social networking sites such as Facebook. More intensive efforts involved telephone contact and database searches.

2. The DASH feasibility study

DASH started as a school-based study. Participants in 52 schools were first surveyed in 2002/03 (11-13y) and again in 2005/06 (14-16y) before they left

school. Participants are now 21-23y and a feasibility study is in progress (2012/13) to establish best practice for a face-to-face follow-up over the next few years. About 200 participants are taking part and different approaches are being tried including offering participants options of being seen in local GP surgeries, in pharmacies in local high streets, in clinical research centres and in their homes. Feedback of health screening results is currently proving an especially important incentive in the current Feasibility study as participants seem keen to receive the results of health measures such as accelerometry and blood test results.

This protocol describes the approach for locating those who could not be contacted in the Feasibility Study. The aim is to develop the protocol as we gain experience in the field and, if effective, to apply it to the rest of the untraced sample in the entire cohort.

Table 1. Percentage of Baseline Sample Traced 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	
• Advocacy	High-profile study champions, support from local community leaders e.g. religious leaders, teachers and community nurses. [AW] ¹
• Ethnic minority representation on study team	The ethnicity of researchers was key in engaging parents and pupils with the research. [AW]
• Lay representation on Steering Group	Head teachers and other lay people invited to be part of Steering Group. [AW]
• Study office in the community	DASH Study team set up a local office in a participating school. [W2]
• Advisory Group	An Advisory Group made up of 12 DASH participants set up to establish best methods for maintaining contact with sample. [FS]
• Community link worker	A dedicated person working to trace lost participants and

raise awareness of the DASH study in the community. **[FS]**

Communication strategies

- DASH study website (http://dash.sphsu.mrc.ac.uk/Young-people.html) Input into the study website design from PEAR (the Public Health, Education, Awareness, Research project supporting young people's contribution to public health research) to ensure user-friendliness for young people **[W2]**
- Social networking sites Facebook (https://www.facebook.com/dashlondon), Twitter, Myspace **[TEP; FS]**
- Feedback letters Annual feedback newsletters, seasonal greetings and calendar to participants and schools **[AW]**
- Local and national radio interviews PI gave interviews on local radio stations targeting specific ethnic groups e.g. Sunrise radio **[AW]**
- Posters in community locations Posters advertising the study results and key findings displayed in community locations e.g. places of worship, local libraries **[TEP]**
- Translation of study documentation Translation of information sheets & consent forms into 15 languages **[W1;W2]**
- Interactive science workshops Interactive science workshops run in schools to raise awareness of scientific aspects of study and encourage participation **[W1; W2]**.

Tracing

- Tracing questionnaire and electronic databases (Electoral Register, 192.com, Royalmail.com) Tracing questionnaire devised and electronic databases employed to trace participants and confirm addresses already held **[AW]** (see Appendix 1)

Flexibility of data collection

- Multiple school visits Multiple visits made to schools to accommodate absence, school timetables etc. **[W1; W2]**
- Various questionnaire options Participants offered various options to complete questionnaires i.e. online, telephone and postal questionnaire. **[W2?; TE]**
- Flexibility of locations Piloting of a range of locations e.g. GP surgeries, community pharmacies, Clinical Research Facilities, Kings College London, participants' homes. **[FS]**

Incentives

- Certificates Certificates used as an incentive to participation when participants were in schools. **[W1; W2]**
- Vouchers Monetary vouchers given on completion of questionnaires and physical measures. **[TEP; FS]**
- Feedback of physical and physiological measures Participants receive written feedback on their height, weight, BMI, BP, total and HDL cholesterol, and glycosylated haemoglobin. **[FS]**

¹KEY: W1 (Wave 1), W2 (Wave 2), **TEP** (Tracing Exercise ~~Postal follow-up~~), FS (Feasibility Study), AW (All waves)

3. Definition of 'hard to reach' participants:

Participants who could not be contacted by all possible modes – post, email, telephone (landline and mobile; different times of the day and day of the week), texting, contacting one or more link persons e.g. family member, friend, teacher.

4. Protocol to be employed for tracking hard-to-reach participants:

4.1 A 'tracking case' file to be developed for each participant defined as hard to reach to keep track of information and efforts to contact participant (see Appendix 1). All tracking activities to be documented and the outcomes of both successful and unsuccessful efforts noted. Tracking files to include details on: correspondence, records of outgoing and incoming telephone calls and contacts, community visits, requests to other participants for information, miscellaneous information etc.

4.2 To obtain key descriptors from data held to inform focused but multiple approaches at the individual, friendship and community level. For example this could include link person details, residential postcode, school attended, ethnicity, gender, socio-economic circumstances, area deprivation score, psychological well-being score, religion, place of worship attendance frequency, physical activities taken weekly, family members in household, number of other participants in the feasibility study that were in the same school/class, number with valid contact details who were in the same school or class.

4.3 Re-validate addresses using 192.com and address finder. If different from what is held on the DASH database then contact via post in the first instance. Allow 10 days for a reply before re-contacting and following the protocol for the untraced.

4.4 Map postcode to potential places for enquiry, using Google Streetview if necessary e.g. GP surgeries, markets, shopping malls, library, places of worship, and tailor approach accordingly.

4.5 Contact last school for information on current whereabouts. Request head teacher forward letter to the participant (see Appendix 2).

4.6 Request local GP forward a letter to the participant (if registered at that surgery). Use a similar approach for other potential sources with membership (e.g. religious leader at local mosque).

4.7 If a DASH participant in the Feasibility Study was in the same school/class as the untraced participant then enquire with the participant if they are in contact with each other. Ask if s/he could ask the untraced participant to contact the DASH Study community link worker. Feasibility Study participants to be give £10 voucher in return for providing details of untraced participants and recruiting them to the project.

4.8 Community visits

- a) If unable to contact the participant by phone, text message, email or post visit the address held to find out if participant still lives there. Conduct visits in the evenings or at weekends to optimise the possibility of finding people at home.
- b) If the participant is located in person and wishes to take part, obtain their current contact details (full name, address(es), phone numbers, including mobile, and email address) and those of up to three link persons. Give the participant a copy of the survey pack and inform them a member of the DASH will be in touch to arrange an interview.
- c) If the person declines to take part in the Feasibility Study, ask if we could contact him/her in the future for a health screen in a subsequent follow-up. Emphasise to all that their participation is completely voluntary and that we are very grateful for their continued interest and involvement in the study.
- d) If a member of the household answers the door and confirms that the participant is living at the address but not available request contact details for participant and/or those of up to three link persons (e.g. relative, friend). If possible arrange a time to call or visit. Document household member's name and contact details if they are willing to provide them. Give them the DASH office contact details and copy of the DASH survey pack and request they pass to participant.
- e) If participant is not located ask neighbours, corner shop owners, local place of worship if they know of the participant's whereabouts. For apartment blocks, some studies suggest starting on the top floor and working down, as residents who live on the upper floors glean greater knowledge of other residents by using the lift or stairs together.

5. Items to be taken on community visits:

- DASH introductory letters
- Advertising materials: DASH posters, banner and pocket cards
- Statement from community advocates
- Stamped envelopes
- Survey packs including introductory letters, information sheets, consent forms, and copy of questionnaire

6. Safety

- a) Always wear the MRC DASH ID and carry a Communicare mobile phone. Ensure it is fully charged before going out. Log in with details of visit with Communicare prior to visiting private homes and log out when finished following Communicare/MRC protocol.
- b) Never go into someone's house for an impromptu interview.

- c) Be familiar with local public transport and taxi numbers before leaving.
- d) If unsure about an area, arrange to visit with a member of the DASH study team.
- e) Avoid leafleting and door knocking in dark or secluded areas.
- f) If you don't like the feel of a doorstep interaction (e.g. individual is apparently intoxicated or making inappropriate comments), walk away without trying to update contact details or book an interview.

7. Documentation

- a) Document each visit using the tracking case file (see Appendix 1) including potential facilities that could be used to locate participant, participant outcomes (located or not, link person details, moved from area, interview to be arranged etc.), enquiries and requests for contact made and to whom (give name, location and contact details if available) e.g. pastor, head teacher, response to door-knocking and outcome, any safety issues. Document plans for follow up e.g. DASH project manager to arrange appointment, phone call, return visit. If participant wishes to withdraw then try to ascertain the reason(s) why.
- b) Pass on updated contact details to the DASH administrator, to be entered on SORD.
- c) As soon as possible inform Elli, DASH project manager, of contacts who have agreed to participate in follow up. Elli to arrange to contact participant for interview.

8. Ethics

All consent is voluntary and dependent on the goodwill of participants. Participants are free to withdraw at any time.

No participant should feel harassed or pressurised into taking part.

Emphasise the potential benefits of the project in terms of health promotion and reducing health inequalities, the confidentiality of the participant and any data obtained, and that they will be reimbursed for travel expenses and provided with a voucher following interview.

Maintain a friendly and polite manner in all interactions and respect the autonomy of the participant and their freedom to decline further contact.

Refs

1. Booker CL, Harding S, Benzeval M. A systematic review of the effect of retention methods in population-based cohort studies. *BMC Public Health* 2011; 11(1):249.
2. Harding S, Whitrow M, Maynard MJ, Teyhan A. Cohort profile: The DASH (Determinants of Adolescent Social well-being and Health) Study, an ethnically diverse cohort. *International Journal of Epidemiology* 2007; 36(3):512-17.

3. Sproston K, Nazroo J. *Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC)*. London: The Stationery Office, 2002.

Appendix 1 Tracking case profile

ID:	
Date:	Time:
Post Code:	
Details of possible link locations if known:	
<ul style="list-style-type: none">• Neighbour(s):• School:• Place of worship:• Library:• Leisure centre:• Corner shop:• Community club:• Refugee support centre:• Other:	
Participant seen	
Confirmed participant details:	
Name:	
Address:	
Phone:	Mobile:
Email:	
Participant seen in person?	yes <input type="checkbox"/> no <input type="checkbox"/>
Willing to participate?	yes <input type="checkbox"/> no <input type="checkbox"/>
Willing to be contacted in the future?	yes <input type="checkbox"/> no <input type="checkbox"/>
Reasons for not wanting to participate (if provided):	
Link person details e.g. member of household, family member, friend, neighbour, teacher, pastor etc:	
Person 1	
Name:	
Relationship to participant:	
Address:	
Phone:	Mobile:
Email:	
In contact with participant?	yes no
Person 2	
Name:	
Relationship to participant:	
Address:	
Phone:	Mobile:
Email:	
In contact with participant?	yes no

Person 3

Name:

Relationship to participant:

Address:

Phone:

Mobile:

Email:

In contact with participant?

yes

no

Participant not seen

Source of information e.g. link person (name, location):

Participant's whereabouts if known:

If relocated reason for move e.g. college/university, marriage, migration, work:

University details if applicable:

Employment details if applicable:

Other contact if applicable:

Left for participant:

Introductory letter? yes

no

no

Questionnaire and pre-paid envelope? yes

yes

no

Agreed action:

Contact participant by:

Telephone?

yes

no

Text?

yes

no

Email?

yes

no

Letter?

yes

no

To be completed post-visit:

Project manager advised of updated details? Date:

Follow-up phone call/text/email/letter completed? Date:

Link person contacted? Date:

Visit arranged to new address/contact? Date:

Tracking database updated? Date:

Other action:

Date:

Comments:

Appendix 2 Participant invitation letter



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«Name»

«Address1»

«Address2»

«Address3»

«Postcode»

Date

Dear (name),

Determinants of young Adult Social well-being and Health (DASH)

You may remember taking part in the DASH Study when you were at school. The first two stages took place in 2002/3 and 2005/6 and you were one of 6500 pupils from schools in the Greater London area who took part. DASH is an important study which will help us better understand how best to promote good health in young people like yourself.

We are preparing to start the next phase of DASH and we would be very happy if you could continue your participation. This will involve a health screen at a place convenient for you. You will be given some results as well as a £25 'Love to Shop' voucher. Travel costs will be reimbursed.

In order for us to contact you, we would be grateful if you could provide us with a telephone number (preferably a mobile) and a current email address. You can do this in a number of ways:

- a) Email your details to **dash@sphsu.mrc.ac.uk**
- b) Go to the DASH website <http://dash.sphsu.mrc.ac.uk> and click on the red writing at the top in the centre of the page to update your details
- c) Call us on the DASH freephone number **0800 389 2129**

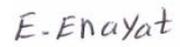
We look forward to hearing from you soon.

Yours sincerely,



Vivian Ibekwe

DASH Community Link



Dr Elli Enayat

DASH Project Manager



Prof. Seeromanie Harding

DASH Study Director

Appendix 3: Community Introduction Letter



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



«Name»

«Address1»

«Address2»

«Address3»

«Postcode»

Date

Dear Sir / Madam,

Re: Research study tracking the health and social conditions of young people in London - the Determinants of young Adult Social well-being and Health (DASH) study

Young people living in this neighbourhood took part in the DASH study when they were at school. They are now in their early 20s and we would like to see them again to assess their health.

DASH examines how social conditions in childhood influence health in later life. It has provided valuable insights about the diversity of family life, social support and neighbourhoods and the health of teenagers in London. DASH started in 2002/03 with about 6,500 young people living in 11 boroughs in London. Community support played a major role in engaging young people, families and schools with the study.

The DASH study is run by scientists from the Medical Research Council, Social and Public Health Sciences Unit in Glasgow, in collaboration with Kings College London.

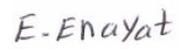
We look forward to your support to promote DASH and help us understand how best to keep London's young people healthy and happy, regardless of their background.

Yours sincerely,



Vivian Ibekwe

DASH Community Link



Dr Elli Enayat

DASH Project Manager



Prof. Seeromanie Harding

DASH Study Director