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Study title: Exploring British Asian people's views about type 2 diabetes and support from brief mobile phone messages

Ethics Approval Reference: R50751/RE001

Participant Information Sheet

You have been invited to take part in this study because we would like to talk to people who are living with type 2 diabetes. We would like you to help us with our research by coming to a focus group discussion. This information sheet explains what the research is about and what we are inviting you to do. Please read this information carefully and talk about it with a friend or relative if you wish. We will answer any questions you have and explain anything that is not clear. Take your time to decide if you want to take part. It is up to you if you want to do this. If you don't, then that's fine too.

The eligibility criteria for the study are

- Participant is willing and able to give informed consent for participation in the study
- Male or female, aged 18 years or above
- Self-reported South Asian ethnicity
- Ability to speak English, Punjabi, Urdu, Bengali or Gujarati
- Diagnosis of type 2 diabetes
- Taking oral glucose lowering treatment
- Has access to a mobile phone (shared access is allowed with permission of phone owner)
- Knows how to use SMS (it is okay if participant needs help to send or retrieve SMS)

Who are we?

My name is Suman Prinjha and I am a researcher working at the Health Experiences Research Group, at the University of Oxford. I will be working with a facilitator from the East Midlands Centre for Black and Minority Ethnic Health to run the focus group.

What is the SuMMiT-D study about?

This study forms part of a wider programme of work that aims to understand how mobile phones and other digital devices can be used to provide information and advice about medicines and their best use for people with type 2 diabetes. In the future, new communication and computing technologies will play a key part in health care. The research team, working with people with diabetes, is developing a system to do this. This work has included looking at the sort of information and advice that people might find helpful, finding ways to make the information personally relevant, and looking at the design



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of the system so it is easy to use. We want to test this system with a large number of patients in a research study.

For this study we are very keen to find out your views and experiences of type 2 diabetes and taking medicines (tablets) for it. This also includes views about getting brief mobile phone messages to help with diabetes medication. To find out more, we want to have a group discussion called a “focus group”. We will be asking 8 people to come to the focus group discussion to talk about their experiences of living with and taking tablets for diabetes.

What will you have to do if you choose to take part?

Eight people will come to the focus group, which will take place in a local venue. We will let you know where and when the focus group will take place nearer the time. I will come to the group with the facilitator and we will ask some questions to get the discussion going. The discussion will last no longer than 2 hours.

Do I have to take part?

No. It is entirely up to you. If you do decide to take part, we will ask you to sign a consent form to say that you agree to take part. You will be given a copy of the form to keep. Consent forms will be stored securely and confidentially on University computer systems accessed only by members of the research team, and in a safe, lockable place at University premises. Only the researchers on this research project will have access to them. Consent forms will be stored for at least 5 years after publication or public release of the work of the research.

What if you change your mind about taking part?

If you decide to take part, this is your voluntary decision so you are free to stop taking part any time without giving a reason, without any questions being asked, and without penalty, by advising the researchers of this decision.

If you take part it will not be possible to withdraw anything you have said from the focus group records once the group has started, because it is a group discussion (comments made by an individual are part of the discussion and are likely to influence the comments made by another participant).

What will we talk about?

We will talk about:

- what is it like living with diabetes?
- what problems you have with your medicines (tablets)?
- what do you think about getting short messages on your phone to help you with your diabetes medicines?
- what sort of messages would work best for you?

It is up to you how much or how little you say in the focus group, you don't have to answer any questions you don't want to.

How will we record what you say?

We would like to audio record the focus group, and we will ask you if this is OK first. This is so we don't forget what you have said. Only the researchers of this study and the person who types up the recording will hear it. All names or personal details made during the focus group will be removed by the researcher when read through the typed up copy of the recording (transcript). We keep the recording and the typed up copy securely at the University of Oxford and only the researchers and the person typing up the recordings will see them. After the study is finished, we will archive the transcript at the University of Oxford, and the recording will be destroyed three years after the study ends.

Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Will anyone find out what you have said?

No. We will not use your name in anything that we write. Your details will be kept confidential (private). Quotations from the focus group may be used in the report we write but these will be anonymous.

What are the benefits/risks of taking part?

People who have taken part in similar focus groups often say they found the experience rewarding. You will also have the opportunity to contribute to this study that aims to help improve healthcare for people with diabetes. Apart from having to give up some of your time, we do not expect there will be any disadvantages to you taking part.

Will you get anything for helping?

Yes. We will give you a £20 shopping voucher to say thank you for your time and effort. We will cover any travel expenses you may have for getting to and from the focus group.

What will happen to the information from the focus group?

We will use the typed up recording from this discussion and other discussions to write a report for the SuMMiT-D study. The SuMMiT-D study will develop and test a way to send brief messages to help people taking medicines for diabetes.

Who is organising and funding the research?

This research study is organised by the Nuffield Department of Primary Care Health Sciences and the Institute of Biomedical Engineering at the University of Oxford. Collaborators include the University of Manchester.

The research is funded by the NIHR Programme Grants for Applied Research. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

What will I have to do if I would like to take part in the study?

If you would like to take part in the focus groups, you can let the person who contacted you from the East Midlands Centre for Black and Minority Ethnic Health know, email bmehealth-em@leicester.ac.uk OR phone 0116 258 8969.

If you do not want to take part in the study at all, you need to do nothing more.

Who has reviewed the project?

This project has been reviewed by and received ethics clearance through the University of Oxford Central University Research Ethics Committee (ref: R50751/RE001).

What if there is a problem?

If you have a concern about any aspect of this study, you can get in touch with the researcher here:

Suman Prinjha

☎ Tel: 07774 629 231 ✉ E-mail: suman.prinjha@phc.ox.ac.uk

Or

Professor Andrew Farmer on phone: 01865 617942 or email:

patoandrewfarmer@phc.ox.ac.uk

The researcher should acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the relevant chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter in a reasonably expeditious manner:

Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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Nuffield Department of Primary Care Health Sciences
Radcliffe Observatory Quarter
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☎ Tel: 07774 629 231 ✉ E-mail: suman.prinjha@phc.ox.ac.uk

Thank you for taking the time to read this.

Suman Prinjha

This study is being conducted by the University of Oxford. We will only use your email for the purposes of this study.