

Community session: Diabetes and cardiovascular health – How to prevent heart complications in people with diabetes

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Background

The National Institute for Health and Care Research (NIHR) currently funds 20 Biomedical Research Centres (BRCs) across England. These are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics, and medical technologies. The Imperial BRC is a collaboration between Imperial College London and Imperial College Healthcare NHS Trust (ICHT) and is currently funded until November 2027. It has 14 research themes, four of which are cross cutting.

The Imperial Patient Experience Research Centre (PERC) is a core facility of the Imperial BRC undertaking research on research and supporting Imperial BRC researchers to undertake public involvement and engagement in research. PERC recognises that involving a diverse range of patients and members of the public in research is essential for ensuring that research is relevant, meaningful, and useful for improving healthcare experiences and outcomes for all. PERC is seeking to establish relationships with under-represented and under-served communities in North West London to engage a more diverse range of patients and members of the public in research. By working closely with these communities, PERC seeks to ensure that research is tailored to their specific needs and priorities, and that their voices are heard in healthcare decision-making.

Approach and purpose

EKTA Community is a mental health support group located in Harrow, catering to individuals aged 55 and above. Run entirely by a dedicated committee of volunteers, the group hosts bi-weekly social events featuring activities like yoga and painting. EKTA convenes monthly gatherings, complete with lunch, where members can enjoy informative sessions covering a wide range of topics, from health-related matters to finance and energy management. The group's mission is to offer assistance to South Indian mental health service users residing in Harrow. With a membership of 80 individuals, predominantly elderly residents of Harrow, EKTA plays a crucial role in providing a sense of community, facilitating knowledge exchange, and offering support to combat issues such as loneliness among its members.

In previous sessions with EKTA, diabetes was identified as an area of interest, and a topic that would be beneficial to members. PERC were approached by Professor Otavio Berwanger (Executive Director for The George Institute for Global Health, UK; Cardiologist-Professor of Medicine at Imperial College London; and Co-Lead of the Multiple Long-Term Conditions Imperial BRC research theme) and Jo Gambell (Operations Manager, Clinical Trials for The George Institute for Global Health, UK) who were preparing a stage 1 grant application. The research proposal was to conduct a clinical trial in which an existing drug would be repurposed to investigate its potential heart-protecting effects in people with type 2 diabetes. This provided the opportunity to deliver a health information session on diabetes and cardiovascular health, and to get feedback from EKTA community members on the research proposal.

Session overview

The session took place on Tuesday 12 November 2024, from 11am to 2pm at a community hub used by EKTA, and was delivered by Professor Otavio Berwanger and Jo Gambell, and supported by Dr Daphne Babalis (Director of Operations for the Imperial Clinical Trials Unit), Naima Adan and Naomi Asantewa-Sechereh.

The session was delivered in two parts:

1. **Health information on type 2 diabetes and cardiovascular health:** How to prevent heart complications in people with type 2 diabetes?
2. **Feedback on the research grant proposal:** How to generate high-quality research (clinical trials) that meet the needs of people living with type 2 diabetes and their communities.

Part 1 covered information on the following:

- What is diabetes?
- What causes type 2 diabetes?
- How high blood sugar affects your heart
- Types of complications in people with type 2 diabetes
- How is type 2 diabetes treated?
- Additional risk factors for heart complications
- How can we prevent heart complications?
- Q&A

Part 2 discussed the proposed clinical trial and asked attendees for their comments and feedback.

Attendee numbers

45 members of the public, primarily from the Harrow area and part of the EKTA community group, attended the session.

Discussion questions and comments from attendees

The discussion questions and comments from attendees are summarised below:

Can we reduce the chance of heart-related problems in people with diabetes?

Do you think this question is a problem worth investigating?

How important is this research question to you?

Comments:

- *Nods in the room indicating agreement*
- Attendees said 'Yes' and that this is '*very important*'

- One attendee shared that they have a heart condition. They had a pace maker fitted in March 2024 and have atrial fibrillation (AF). They had 3 ablations done which were successful.
- One attendee shared that they were told they are borderline diabetes. Within their family there is a history of heart related disease and high cholesterol in family. For those reasons they felt the research is important.

How should we invite participants to the study? (e.g. Receiving a text message from GP with a link)

Comments:

- Need to consider interaction between mental health conditions/medication/antidepressants and medication for diabetes: One attendee shared that they would be very interested in taking part in a study on high cholesterol to benefit future generations to come. They highlighted that some people with mental health conditions who are taking antidepressants or other medications may experience side effects from diabetic medication, and wanted to know what steps they could take to prevent them from relapsing.
- One attendee shared the best way for them was by email or text as they like to do things calmly and slowly. This attendee also asked about people that have learning difficulties or depression as well as diabetes, they may be interested to take part in this type of study and may have different needs.
- One attendee shared they often receive text messages from their GP surgery regarding surveys on their personal health; however, they don't receive feedback on the outcome of the survey and what is happening. This demonstrates the importance of keeping study participants informed throughout the trial.
- One attendee's wife received a text message regarding a specialist referral, but at the time she was receiving care for two different conditions and the message didn't mention which one the referral was about. This demonstrates the importance of making sure that messages are clear so that people understand what they are being asked and what it is in relation to.
- One attendee raised that not everyone is literate, so for some people getting an email, reading it and clicking on a link might not be as easy. There were also concerns around digital exclusion for the elderly or people who did not have English as their first language.
- One attendee said they would prefer a letter to enable them to study it and show it to their family members so they could discuss with them first.
- One attendee said they would want a text that is then followed up by an email, which would enable them to have time to digest what they were getting into. An email follow up 2 weeks after the text was suggested.
- For one attendee, they felt that they get so many text and emails, so from their perspective, letters would get more attention as they receive so few. They experience problems with their device so they don't always receive emails.

How should we invite people to take part, and tell them what they need to know?

Comments:

- A number of attendees expressed a preference for a video.
- One attendee commented that they are a visual person so would prefer a video. They would like to receive a letter in the post, which they could read and then watch the video so they could relate that information.
- One attendee receives surveys via their GP app 'Patient Access' and said they would prefer a video.

How can we make the research convenient for people?

Comments:

- One attendee shared that a questionnaire in the post would be more convenient for them.
- One attendee did not use a computer so they would prefer options that did not involve needing to use a computer.
- A letter or using WhatsApp were expressed a popular choices among attendees. Some attendees seemed more open to visiting links if they could be accessed via their mobile or WhatsApp if they used it.
- One attendee expressed a preference for paper as it gives them time to read it.

How should we collect the information we need to answer the research question?

Comments:

- One attendee commented that the purpose of the research is that individuals volunteer and say their information should be used, so they did not have concerns about their information being collected.
- One attendee would be happy for their information to be collected, as hopefully the researchers will be collecting information that is more relevant to them, so it would then directly benefit them too.
- One attendee was ok with information being shared as long as only the intended person gets the right information, as sometimes people's records can get mixed up.
- One attendee felt that as people's names wouldn't be mentioned in the information shared, they felt it didn't really matter if their information was shared.

Questions from attendees related to the trial:

- Do doctors select us for research, or do we sign up?
- How often would questionnaires be sent?
- Would there be any medicine involved to be taken?
- If you are starting someone on a new drug, will the participant's GP monitor their reaction to new drug as 6 month is too long to leave it.
- Does the trial involve visits to the hospital at Imperial?
- What would help people remember to take their medication? More people are getting familiar with WhatsApp. At a community centre in Brent they have been helping their elderly members get more familiar with using smart phone and WhatsApp.
- What about allergies or side effects of the medication?
- Doctors give us metformin for diabetes – is there a new one? Is metformin still ok?

Questions from attendees related to the general cardiovascular health/diabetes information:

- What is the normal sugar level we should have?
- Recently I had a sugar level test and they said it was 38 – I didn't know if that was good or bad.
- I am on two medications for cholesterol medication, but don't know how to reduce the medication I take.
- Rice and wheat are the two main carbohydrates that people consume worldwide. Have we found new strains of rice and wheat that contain less sugar?
- I don't have diabetes but have been told in the past that my fasting sugar levels are high – how do I maintain this?
- My doctor has asked me to take cholesterol tablets – I am health conscious, I don't eat fatty foods and my weight is right, so what is the reason for getting high cholesterol?
- I was on a trial for a cholesterol injection, which would last for 6 months, but I had to drop out – what has happened to this trial?
- Is it ok to take aspirin for heart problems? My GP said to take it, but one heart doctor online said not to take it.

Additional comments following the session received from feedback forms

Attendees were also given the option to provide additional comments by completing a paper feedback form (see **Appendix 1**). 10 forms were completed and their responses are displayed below.

Do you think the research is important?

Of the 10 attendees who completed the feedback form, all agreed the research was important:

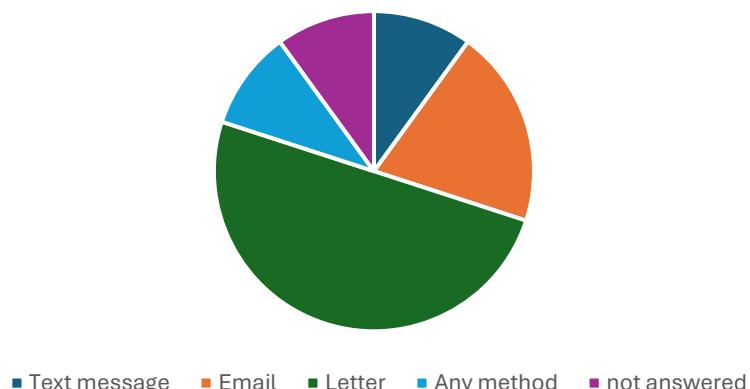
Yes – without research there will be no new medicines
Yes it is important, excellent
Yes, diabetics are more at risk
Yes very good to have more research
Very important for preventing future complications
Very important as it is connected
Yes, especially for parents with premature siblings who need support with healthy lifestyles
Yes this is important as they are connected
It is very important in this day and age
Yes, but I wanted to know more about the focus of your trial

How would you choose to be invited to take part in the research, if eligible?

Of the 10 attendees who completed the feedback form, 50% would like to receive a letter inviting them to take part in the research, when compared to an email (20%) or a text message (10%) option.

Text message	Email	Letter	Any method	Not answered
1	2	5	1	1

How would participants choose to be invited to the trial?

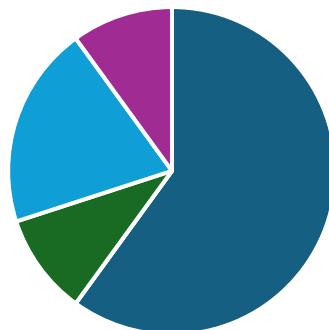


What method would be the most convenient for you for follow up during the research?

Of the 10 attendees who completed the feedback form, 60% would prefer the follow up during research to include both an online questionnaire and a phone call. Only 10% would like a video call follow up only, with 20% preferring a mix of methods.

Online questionnaire with phone call follow up	Phone call	Video Call	Mix of methods	Not answered
6	0	1	2	1

What would be the most convenient method for follow up appointments?



- Online questionnaire with phone call follow up
- Phone call
- Video Call
- Mix of methods

During the research, we would like to ask your permission to capture information from your GP and hospital doctors about any heart-related problems that happen to you. Would you be happy with this?

Of the 10 attendees who completed the feedback form, 90% would be happy for their routine data to be captured as part of the trial.

Yes	No	Not answered
9	0	1

Would participants be happy for their routine data to be used in the trial, with permission?



Please tell us about anything that you think is important about the research that we should consider:

It is important to let the patient know if there will be a serious reaction during the trial
Good to talk in all centres in different areas
None
We want to get rid of medication if something is better
<i>not answered</i>
Consider side effects with other medicines
Quality of life is important
<i>not answered</i>
Would have like to hear more about the trials I was eligible for in today's talk
<i>not answered</i>

Appendix 1: Feedback form to collect additional comments on the research proposal following the session

SESSION ON DIABETES AND CARDIOVASCULAR HEALTH RESEARCH

Do you think the research about cardiovascular health in people with diabetes is important? Please tell us what you think.

How would you choose to be invited to take part in the research, if eligible?

Text message from GP Practice Email from GP Practice Letter from GP Practice

What method would be most convenient for you for follow up during the research?

Phone call Video call Online questionnaire with follow up call if required A mix of all methods

During the research, we would like to ask your permission to capture information from your GP and hospital doctors about any heart-related problems that happen to you. Would you be happy with this?

Yes No I'm not sure

Please tell us about anything that you think is important about the research that we should consider:

Please give us your email address if you are happy to be contacted for more detailed feedback on this research:

THANK YOU FOR YOUR TIME AND INPUT

IMPERIAL

 The George Institute
for Global Health

Appendix 2: Photos

These are photos taken at the diabetes and cardiovascular health community session on Tuesday 12 November 2024.



