PARTICIPANT INFORMATION LEAFLET

Feasibility trial of an intervention to improve attendance at diabetes eye screening

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. You can change your mind about taking part in the study any time you like, without giving reason.

WHY IS THIS STUDY BEING DONE?

The purpose of our study is to test a new way to promote attendance at diabetes eye screening. Over the past few months we asked doctors and nurses to remind people with diabetes about the importance of screening, either face-to-face, on the phone and by sending letters to people with diabetes. The doctors and nurses at your local practice tried out this approach to see whether it would work in the real world.

WHY AM I BEING ASKED TO TAKE PART?

You have been asked to take part because your local practice was trying out the new approach to improve attendance at diabetes eye screening and you may have received some of the reminders and information.

WHAT WILL HAPPEN TO ME IF I AGREE TO TAKE PART?

One of our researchers will arrange to talk to you for about 20 minutes at a time and place which suits you. The researcher will ask you about your experience of the efforts to promote diabetes eye screening at your practice. Beforehand we will ask you to complete a short questionnaire, so we have some information on the people who take part. You will be under no obligation to complete this questionnaire if you do not want to do so.

AUDIO RECORDING

With your consent, we will record our conversation. This recording will then be transcribed. You can request access to the transcript. You have a right to review the transcript to correct inaccuracies or to clarify points. If you would like to access the transcript, please contact one of the researchers using the contact details at the end of this information sheet.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

The aim is to find a way to increase the uptake of screening, which is an essential to prevent or delay the development of diabetic retinopathy. By taking part, you will have a chance to share your views and help us to find the best way to increase screening attendance.

WHAT ARE THE POSSIBLE CONSEQUENCES OF TAKING PART?

We don't think there will be any negative consequences for you and we would like to assure you that we are available to answer any questions throughout the study.

WILL IT COST ME ANYTHING TO TAKE PART?

No, it will not cost you anything. We will reimburse you for the cost of travel.

DO I HAVE TO TAKE PART?

No, participation in this study is completely voluntary. Even if you decide to take part, you can stop taking part at any time during the conversation. You can withdraw permission to use the information that you provide within one month of signing the consent form and the information you provide will be deleted.

WHO IS ORGANIZING AND FUNDING THIS STUDY?

This research is being carried out by researchers at the School of Public Health, University College Cork, in partnership with [GP practice]. A lot of our research is focused on health services and ways that services can be improved. The study is funded by the Health Research Board (HRB), a government agency that funds health research.

WILL TAKING PART BE CONFIDENTIAL?

Yes, your participation in this study will be private and confidential. The only people that will know you are taking part will be the researchers. All collected data will be pseudo anonymised after transcription and identifying information will be changed. A study ID number will be given to the transcript and any information linking you to the transcript and questionnaire will be removed. Hard copies of transcripts will

be stored securely in a locked filing cabinet in the School of Public Health, UCC. Electronic versions will be stored in a password protected computer in the School of Public Health, UCC. Your individual comments will not be identifiable. Anonymised results will be published in an international peer-reviewed journal and will be presented at research meetings and conferences. Everything you say during the conversation will be anonymised before the results are reported. We will ensure that your views cannot be personally identified in any public reporting of the study results.

DATA PROTECTION

We will be using the information from our conversation with you to understand patient experiences of this new approach. This study is being conducted in the public interest (General Data Protection Regulation 2016 Article 6(1)(e)); and for scientific research purposes (General Data Protection Regulation 2016 Article 9(2)(j)).

The data will be accessed, analysed and stored by researchers in the School of Public Health, University College Cork. Hard copies of transcripts will be stored securely in a locked filing cabinet in the School of Public Health, UCC. Electronic versions will be stored in a password protected computer in the School of Public Health, UCC. Your data will be stored for ten years, as per the UCC code of research conduct. We do not think that there will be any risks or implications that will arise for you as a result of collecting and storing your data.

You have a right to have any inaccurate information corrected. You have a right to request access to your data. If you wish to withdraw your consent, correct information, or access your transcript, you can contact Dr Sheena McHugh or Dr Fiona Riordan (details above). You have the right to lodge a complaint with the Data Protection Commissioner. You have a right to receive your data in a format which allows you to provide it to another party for analysis. Your data will not be used evaluate personal aspects relating to you i.e. analysing your performance at work.

Anonymised results will be published in an international peer-reviewed journals and will be presented at research meetings and conferences. We will ensure that your views cannot be personally identified in any public reporting of the study results.

All collected data will be anonymised after transcription and identifying information will be changed. Information provided by you will be strictly confidential. The recording of the conversation will be deleted after transcription. Only anonymised data will be used for analysis.

CONSENT TO FUTURE USES

In the future we may want to get in touch with you for different reasons. We may want to check something with you relating to the current study. We may want to know if you would like to learn more about our research studies. We may want to check if you would like to participate in any future studies that may be appropriate for you. By signing this consent form, you will allow one of our researchers to contact you in the future. You have no obligation to participate in any study. If you tick the relevant box on this consent form you are giving consent for our researchers to hold your contact details. Your contact details will be stored securely on a password protected computer in the School of Public Health, UCC. Your contact details will not be shared with anyone outside of our researchers. If another researcher would like to get in touch with you about a possible research opportunity, then we will contact you first to get your permission.

You may withdraw permission to be contacted at any time by getting in touch with one of the researchers. Whether or not you decide to tick this part of the consent form is completely up to you. Deciding not to consent to future contact will not influence your future care.

WHO SHOULD I CONTACT FOR FURTHER INFORMATION?

If you have any further questions, please do not hesitate to contact us:

Fiona Riordan

Address: School of Public Health, 4th Floor Western Gateway Building, University College Cork.

Tel: 021 420 5532 **Email:** fiona.riordan@ucc.ie

Principal investigator's name: Dr Sheena McHugh
Principal investigator's title: Lecturer
Telephone number of principal investigator: 021 4205526

Co-investigator's name: Dr Fiona Riordan
Co-investigator's title: Post-doctoral Researcher

Data Controller's/Joint Controller's Identity: Dr Sheena McHugh
Data Controller's/Joint Controller's Contact Details: 021 4205526

Data Protection Officer's Identity: Catriona O'Sullivan
Data Protection Officer's Contact Details: 021 4903949 | **foi@ucc.ie**

THANK YOU

CONSENT FORM

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Please tick

1. I agree to participate in this study ☐
2. I confirm that I have read and understood the information sheet for this study and have had the opportunity to ask questions. ☐
3. I understand that my participation in this study is voluntary. I am free to withdraw at any time during the conversation, without providing a reason. ☐
4. I understand that I can withdraw permission to use the information I provide within one month of signing this consent sheet, in which case the information I provided will be deleted. ☐
5. I agree that my anonymised data will be used in publications, reports, and presented at conferences and meetings. ☐
6. I agree to this conversation being audio recorded. ☐
7. I understand that the data I provide will be stored securely for 10 years, as per the UCC Code of Research Conduct ☐
8. I understand that under the freedom of information act, I am entitled to access the information I have provided at any time while it is in storage as specified above. ☐
9. I understand that I am free to contact any of the researchers to seek further clarification and information ☐
10. I agree that the study researchers may contact me about the current research project or future research opportunities and I confirm that they may hold my contact details for this purpose. ☐
11. I give informed explicit consent to have my data processed as part of this research study. ☐

Participant Signature	Name in Block Capitals	Date
Researcher Signature	Name in Block Capitals	Date