

PARTICIPANT INFORMATION SHEET – PROXY/INFORMAL CARER (v0.2 – 02/05/23)

Title of Study: TINA study: How can the language of a virtual receptionist (chatbot) be optimised to increase access to cervical screening appointments?

IRAS ID: 318801

REC reference:

PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

Section 1: Taking Part

We would like to invite you to participate in a research project about a virtual method of scheduling cervical screening appointments at the GP surgery. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. If you have any questions you can contact us using the contact details at the end of this information sheet.

What is the purpose of the study?

Cervical screening is a health test that aims to identify whether people with a cervix are at risk of developing cervical cell changes or cancer. In the UK, all patients who are registered as female and aged between 25 and 64 are invited by their NHS GP practices for regular cervical screening. Research shows that around a third of those invited do not attend screening, with a higher number of people from ethnic minority backgrounds failing to schedule and book appointments. Clerkenwell Medical Practice is currently testing a new WhatsApp based virtual receptionist for scheduling cervical screening tests. This virtual receptionist uses Chatbots which imitate human conversation and allow patients to interact as if they were communicating with a real person. We are interested in understanding how patients use the Chatbots and how the language they provide can be improved to increase the uptake of cervical screening. The findings of this research will help the development of the virtual receptionist in the future and may also improve engagement with cervical screening by patients at the practice.

Who is responsible for this study?

This study is the responsibility of Dr Doris Dippold, Senior Lecturer in Intercultural Communication at the University of Surrey and also involves and also involves Dr Freda

Mold, Senior Lecturer in Integrated Care (co-investigator). We are closely working with spryt.com who have developed the digital receptionist and will be responsible for its technical implementation, and Islington GP Federation who are supporting this project and will implement recommendations made from it.

Why have I been invited to take part?

You are invited to participate in this study because you are a friend/relative/informal carer of a patient who is eligible for cervical screening. We are asking for your involvement because you may provide language/interpreter support that helps your friend/relative book GP practice appointments or you help with translation when they receive health care. As your views about scheduling and booking cervical screening appointments are also important, we would like to know what you think about the virtual receptionist.

Do I have to take part?

Participation is voluntary and you do not have to take part. We will describe the study in this information sheet and will give you at least **3** days to read this, so you can decide whether you wish to take part. You are free to withdraw from the research at any time without giving a reason. Your decision about this will not affect the standard of care your friend/relative will receive in future. Please contact us if there is anything that is not clear, or if you have any questions, or need more information.

What will happen to me if I decide to take part?

If you decide to take part, you will be asked to provide some information about your age, gender, ethnic background and first language and to sign a consent form to confirm your agreement to participate. You will be given this information sheet and a copy of the consent form to keep. We will then invite you to undertake an interview with an experienced researcher from the University of Surrey at a time that is convenient for you. You will be asked about your experiences and expectations of booking cervical screening tests for your friend/relative during the interview, which will be conducted either online using MS Teams or by telephone and will take around 40 to 50 minutes. If you have not used the virtual receptionist before we will ask you to try it out. Interviews will be audio recorded on MS Teams or by telephone before being transcribed by a member of the University research team into word documents. Any identifying information such as names, places and/or events that may be discussed during the interview will be removed before the transcripts are analysed.

What happens if I do not want to take part or if I change my mind?

You do not have to take part in this study. If you do take part in this study you are free to withdraw from it at any time, without giving a reason. This will not affect your care in any

way. You will receive a payment of £15 in the form of an e-voucher no more than two weeks after the interview.

What happens to my data if I want to withdraw?

If you wish to withdraw from the study, data already collected can only be withdrawn up to two weeks after the date of the interview. Following this time, because information collected will not be linked to your name or personal details, it will not be possible to remove it. If you wish to withdraw from the study, you must contact us using the details provided at the end of this information sheet within two weeks of your interview.

What are the possible benefits in taking part?

There are no direct benefits for you in taking part. However, the information from this study will help us understand how we can best adapt the virtual receptionist to assist patients with scheduling and booking cervical screening in the future.

Are there any potential risks involved?

In the interviews we will ask you about your general use of technology, and your experiences of booking GP practice appointments in relation to cervical screening. We will also ask you about the virtual receptionist if you have used it, and if you have not, we will ask you to try it. Our questions will not focus on your friend or relative's specific health conditions or experiences of having cervical screening actually performed. However, a possible disadvantage to taking part in this study for some people is that discussing cervical screening in general may feel embarrassing. Your interview will be undertaken by an experienced researcher from the University of Surrey, and all information you provide about screening will be treated with strictest confidence and will not be shared outside the research team.

How is the project being funded?

This research is being funded by a University of Surrey Economic and Social Research Council (ESRC) Impact Acceleration Account award.

Will my participation be kept confidential?

All information collected during the course of the research will be kept strictly confidential and personal data will be managed in line with current Data Protection Laws. Your name and where you live will not be identified within the findings of the research. Identification codes will be assigned to the data to maintain your anonymity. All project data related to the administration of the project (e.g. consent form), will be held for at least 6 years and all

research data for at least 10 years in accordance with University policy. Data will not be shared outside the research team or transferred outside the UK.

We are responsible for making sure your participation is kept confidential and any data is kept secure and used only in the way described in this information sheet. Your information may be reviewed for monitoring and audit purposes, by the University of Surrey and/or regulators who will treat your data in confidence.

Will my data be shared or used in future research studies?

At the end of the study, all data will be de-identified and combined into one dataset. All personal information that could identify you will be anonymised. We would like your permission to use anonymised data in future research studies. Data will not be shared with researchers external to the University of Surrey and will be kept within the UK.

What will happen to the results of the study?

We will produce a final report summarising the main findings of this research. We will share this with spryt.com and the Islington GP Federation. The findings of this research may be published in scientific journals, newsletters and presented at conferences. Any published findings and quotations will use pseudonyms and will maintain your confidentiality and anonymity. You will not be personally identified in any reports or publications. You can contact the research team to find out the results of this research using the details at the end of this information sheet.

Who has reviewed this study?

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion by the xxxxxx

Section 2: Your personal data

What is personal data?

‘Personal Data’ means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your initials, name, age, gender, NHS number, contact details (email address and/or telephone number), educational qualifications, employment status, and age which is regarded as ‘personal data’ and your

ethnic origin, religion and first language which is regarded as a 'special category personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

Who is handling my personal data?

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your personal data on behalf of the controller and is responsible for looking after your information and using it properly. This information will include your:

- Initials
- Name
- Age
- Gender
- NHS number
- Contact details (email address and/or telephone number)
- Educational qualifications
- Employment status

People will use this information to do the research or to check your records to make sure that the research is being done properly.

What will happen to my personal data?

As a publicly funded organisation, we must only use **identifiable personal** information from people who have agreed to take part in research and process this data fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the **public interest** and special category data is processed on an additional condition necessary for **research purposes**. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for the duration of the study. All anonymised data will be held for 10 years. After completion of the project, data will be transferred to <https://ukdataservice.ac.uk/> for public access free of cost.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways or the research to be reliable and accurate. If you decide to withdraw from the study, we may not be able to withdraw your data. We will keep and use

the minimum amount of your personally identifiable information that we have already collected in order to complete the study.

If you wish to complain about how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter (dataprotection@surrey.ac.uk). If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can contact the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

You can find out more about how we use your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting dataprotection@surrey.ac.uk.

Section 3: Further information

What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)
Research and Innovation Services
University of Surrey
Senate House, Guildford, Surrey, GU2 7XH
Email: rigo@surrey.ac.uk

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have concerns about how you have been treated during the course of this study, then you should follow the instructions given above.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Dr Doris Dippold

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Sources of support

There are several organisations who can provide support for any concerns or questions about cervical screening: The Eve Appeal: <https://eveappeal.org.uk/gynaecological-cancers/cervical-cancer/>); Jo's Cervical Cancer Trust: <https://www.jostrust.org.uk/get-support>, <https://eveappeal.org.uk/gynaecological-cancers/cervical-cancer/>.

Thank you for reading this information sheet and for considering taking part in this research.