NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

UNIVERSITY OF OXFORD

PARTICIPANT INFORMATION LEAFLET – patients and carers

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information, and discuss it with others if you wish. If there is anything that is not clear, or if you *would like more information, please ask us.*

What is the purpose of the study?

Our team is evaluating a new smartphone and tablet app called the 'NHS App' which patients can use to digitally access NHS services. This app has been available to everyone in England from July 2019. Currently patients using the app can book GP appointments, view their medical records, order repeat prescriptions, set organ donation preferences, have online consultations and undertake other health and care-related tasks.

This study is looking to understand how people use the app, what they think about its different functions and how it helps them (or not) in accessing health services and support. We are also interested to find out about the impact of the NHS App on how care is organised and delivered in GP practices and across other parts of the service.

It is important to note that this is not the Covid-19 App, which has received much publicity of late but an app developed by NHSX (the digital arm of the NHS).

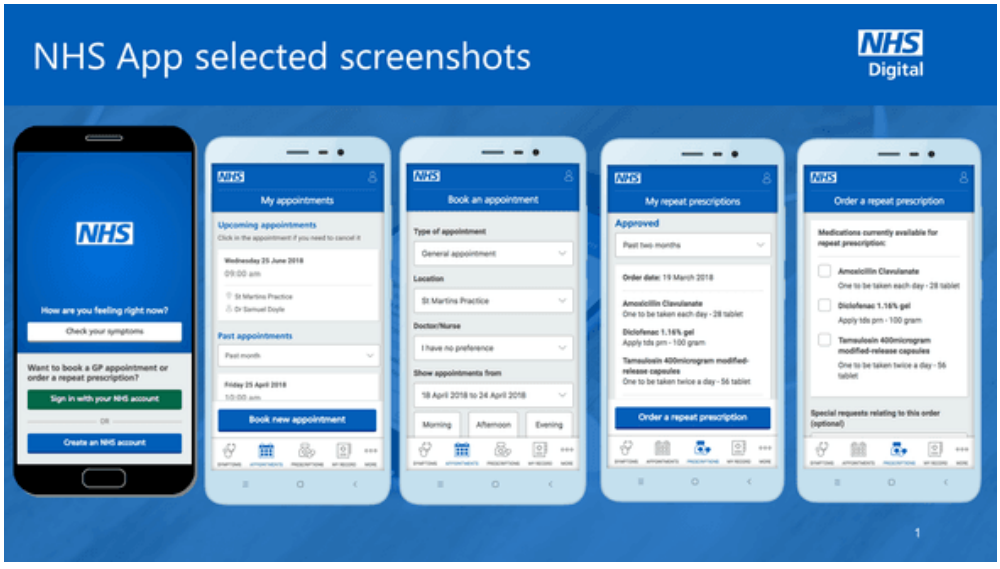

Figure 1: The NHS App

Why have I been invited?

You have been invited to take part in this research study because you are over 18, use NHS services, and have expressed an interest in participating. Altogether we plan to interview up to 30 patients, carers and members of the public about their views and experiences of the

NHS App over the course of the project and hold 4 discussion groups with up to 32 patients, carers and members of the public.

We will also be asking some participants if they would be willing to be interviewed twice over 12 months, to be able to reflect on changes over time.

Do I have to take part?

No, taking part is entirely voluntary and you can withdraw at any time if you later change your mind, without giving a reason.

What is involved in taking part?

If you are happy to take part in this study, a member of our research team will ask you to provide verbal consent. A copy of the consent record will be sent by email for you to keep in your records.

There are different ways in which you can choose to take part:

- Individual interview: we will do a 45-60 min interview with you, either by telephone, video or face-to-face at your home, your GP practice or another location of your choice (depending on Covid-19 social distancing restrictions). In case of face-to-face interviews, these will take place at your home, GP practice or another location of your choice. We will ask questions around how you are using the NHS App to manage your health (if you have indeed used it), in which ways you find it helpful (if any) and what difficulties you faced using the app (if at all). We may also ask you to demonstrate how you are using the app, by logging-in and talking us through the tasks you are undertaking.

- Video diaries: if you would like you could also capture a video diary (e.g. using the camera on your smartphone) to record how you manage your everyday activities, how you engage with the app, or how you are accessing healthcare e.g. ordering repeat prescriptions, checking symptoms, looking at GP records etc. and will describe and/or demonstrate how you accomplish each of these tasks and any particular challenges you encounter.

- Discussion group: you will participate in a 60-min discussion group with 6-8 other patients and/or carers, either by video or face-to-face (depending on Covid-19 social distancing restrictions). Face-to-face meetings will take at a location convenient to the group in community settings or existing patient organisations. The discussion, facilitated by an experienced researcher, will begin with a verbal explanation of the study and will explore participants' experiences using the app (or not) to access care: what the app is used for, what difficulties users are facing, and how it could be improved.

Please indicate during the verbal consent process whether you are willing to take part in one or more of the above options. The researcher will also ask if you are happy for the interview or discussion group to be recorded. You may be invited to participate in a follow-up interview 12 months later to understand if your views have changed.

What should I consider?

The main thing to consider is whether you are comfortable with researchers asking you questions and if you consent to the interview or discussion group being audio-recorded or video-recorded (or alternatively if you prefer researchers to take verbatim notes).

Are there any possible disadvantages or risks from taking part?

The main disadvantage of the interview or discussion group is we are asking you to commit some time on up to two occasions.

What are the possible benefits of taking part?

The main benefit of taking part is this is an opportunity for you to contribute to improving how technology enables access to care and understanding barriers to progress – whether practical, technical, professional, financial or other. If you raise issues about your personal experiences in this regard, we will incorporate these (anonymised) in our wider analysis.

Will I be reimbursed for taking part?

Yes, as a token of appreciation, we will offer you a £25 voucher to cover your time and travel expenses (if any).

Will my taking part in the study be kept confidential?

Yes. Video and audio recordings will have the audio written up word for word and all personal identifiers will be removed before the data is analysed, you will not be identifiable from the write up (transcripts) of the interview. Any video images will be pixelated to ensure anonymity. Recordings will be recorded directly onto an encrypted local University of Oxford laptop and downloaded straight away into a protected folder on a secure university drive which only approved members of the research team have access to. Audio-recordings will be transcribed by a professional transcriber under a non-disclosure confidentiality agreement and destroyed after the transcripts have been checked for accuracy.. In those stored data, you will be referred to only by a code name ('pseudonym'). We will keep a separate paper record in a locked cabinet of participants' real names and corresponding code names. All recordings will be destroyed at the end of the study.

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.

What will happen to my data?

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the data controller and is responsible for looking after your information and using it properly. If you consent, we will keep identifiable information about you including your name, and email address (or telephone number if you wish to have a telephone interview) - for 6 months after the study has finished, so as to contact you about the research study and feedback results of the research in future should you so wish.

The information that we collect from you will be the most minimal personally-identifiable information possible. We will store the de-identified research data and any research documents with personal information, such as consent forms, securely at the University of Oxford for 10 years after the end of the study.

The only people in the University of Oxford who will have access to information that identifies you will be people who need to contact you to conduct the research or audit the data collection process.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/.

You can find out more about how we use your information by contacting the project lead (contact details below).

What will happen if I don't want to carry on with the study?

You can stop at any time. Participation is voluntary and even if you originally said yes, you may change your mind at a later stage. If you withdraw from the study, unless you state otherwise, any interview or discussion group material that has been collected whilst you have been in the study will be used for research as detailed in this participant information sheet. You are free to request that your data are destroyed at any time during or after the study.

What will happen at the end of the study?

We will analyse the data and write some papers and reports, including a 'lay summary'. We will provide you with a summary of the findings if you would like us to. We will also publish a blog post on our departmental website and will share this with you. You will not be identified from any report or publication placed in the public domain.

What if you find something unexpected?

If anything you tell us in an interview or discussion group has a bearing on clinical governance (for example if you disclose to us that you have serious concerns about security or safety), we will alert the clinical director and/or other responsible individuals.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Professor John Powell by email: john.powell@phc.ox.ac.uk, or telephone: 07717695657. Alternatively, you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 616480, or the head of CTRG, email ctrg@admin.ox.ac.uk.

How have patients and the public been involved in this study?

People with different health conditions who do and do not use the NHS App were involved in helping design this study and with the participant facing documents.

Who is organising and funding the study?

The study is funded by the National Institute of Health Research (NIHR) Health Services and Delivery Research (HSDR) programme, which aims to produce rigorous and relevant evidence to improve the quality, accessibility and organisation of health and social care services. The study is sponsored by the University of Oxford.

The project is led jointly by Professor John Powell, who is an academic public health physician at the University of Oxford. The qualitative project team also consists of Dr Felix Greaves, who is also an academic public health physician at Imperial College London, Dr Chrysanthi Papoutsi who is a Senior Health Services Researcher, Dr Claire Reidy who is a Health Services Researcher and Dr Bernard Gudgin, PPI representative.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given

favourable opinion by West of Scotland Research Ethics Service Research Ethics Committee.

Further information and contact details:

Please contact the following individual if you would like further information.

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Thank you for considering taking part.