PARTICIPANT INFORMATION SHEET

Study Title: Public's views about Artificial Intelligence uses in healthcare

This information sheet provides some information to help you decide whether to take part in the above study. Please take time to read it carefully, and discuss it with the research team, friends, or family if you wish, before deciding whether to take part. If there is anything that you do not understand, or if you would like more information, please contact me using the details below.

What is the purpose of the research?

Artificial Intelligence (AI) is a technology that allows computers to carry out tasks that require human reasoning and problem-solving skills. Healthcare software has been in use for many decades in medicine, and traditionally is designed to follow rules created by humans. In recent years, there has been significant development in the field of machine learning (which is a type of AI technology), advancing how computers learn from information to generate outcomes by themselves, often without rules written by humans. AI advancements in healthcare and medicine require a massive amount of health and medical information to learn from. Additionally, rolling out AI in healthcare is subject to ethical and regulatory processes.

The uses of AI in healthcare and for wellbeing may bring about benefits to society through supporting medical decision-making, the development of new treatments, and improved health outcomes. However, there is little awareness about how it may be used in healthcare among members of the public. Therefore, it is important to understand people's feelings about uses of AI in healthcare to maintain trust and confidence in healthcare provision.

This project aims to identify:

- How ready different stakeholders (public and healthcare professionals) are for the uses of AI in healthcare and for wellbeing
- Public perceptions around the risks and benefits of using AI in healthcare
- Public preferences for involving stakeholders in decision-making about how AI is developed and used in healthcare

We want to understand where information gaps exist, and what risks and benefits people think there will be for different AI uses, and who might be affected by these. A major part of this is to engage with members of the public as stakeholders in the ethical and regulatory debates about AI in healthcare. We will explore when you consider the uses of AI in healthcare to be appropriate, the factors that influence your judgement, and how you would value systems that enabled you to play a role in decision making about AI roll-out in healthcare and for wellbeing.

Why have I been invited?

You have been invited to take part in this research because you are at least 18 years of age and understand and speak English fluently. We will be recruiting around 24-100 participants in total to participate in one of 8-10 focus groups, with potentially 7-10 people per group.

Do I have to take part?

No. It is your choice if you want to take part in this study. If you do agree to take part, we will ask you to consent, this will be formally recorded on a consent form, a copy of which will be sent to you to keep. However, you would be free to withdraw from the study at any time, without needing to give a reason. You can withdraw by notifying a research team member through the contact details provided, or on the day of the focus groups. This would not affect your legal rights.

You would also be able to withdraw your consent, which would mean that any responses you have given will not be used in the data analysis or be published. Your ability to withdraw your consent continues after the focus group, up until the data is analysed, however, after that point aggregated (grouped) data will be published in the form of anonymised quotes (meaning identifiers have been removed) which cannot be withdrawn.

What will happen if I do take part?

We will arrange a focus group involving 7-10 participants to discuss topics about using AI in healthcare in different circumstances. The focus group will be held virtually, unless there is the opportunity to run an in-person focus group. If you do not have access to digital services to join a virtual meeting (accessible on most smartphones, computers, and tablets) but would still like to take part in the study, please let us know. The focus group will last approximately 2-2.5 hours including set-up and break times. With your consent, an audio recording will be made of the focus group (for transcription and analysis purposes). If you do not wish to be audio recorded, unfortunately you cannot participate in the focus group.

A researcher will run through some made-up situations about how AI might be used and pose questions to the group for you to consider and share your views. All participants will be given a chance to provide answers to these, including personal opinions. **There are no right or wrong answers, just your perspectives about the discussion topics**.

On the day of the focus group, before we start the focus group, we will ask you to complete a short, optional, survey asking about your background.

Are there any risks in taking part in this study?

We do not anticipate any risks to your participation, but you will be sharing your time and information, and giving your opinions. The focus group also aims to generate discussion between participants, and you may disagree with what others have to say, potentially because of differences in personal values and opinions. Please be respectful of this, and do not repeat what is said in the focus group to others, to maintain confidentiality. Remember that participation is voluntary, and you do not need to give or expand on any information if you do not wish to do so.

Are there any benefits from taking part in this study?

As a participant, you may get more knowledge about what AI is and how it may be used in healthcare by having the opportunity to reflect on the issue. Otherwise, there will not be any direct benefits to you. Indirectly, through our work with standard setters, oversight bodies, clinical researchers, and industry, the research may inform the development of future guidance, and decision-making approaches for AI in healthcare, helping to ensure that they are responsive to the stakeholders they are designed to protect.

Will my time/travel costs be reimbursed?

Yes. As a token of our appreciation participants will be offered £30 for participating in the study. If you are invited to an in-person focus group where possible, you would also be able to claim back your travel costs up to the value of £30, and we will ask you to retain any receipts.

Who has reviewed this study?

All research studies are checked by an ethics committee to ensure the research is conducted safely and to the best standards. This research has been reviewed by and received favourable opinion through a subcommittee of the University of Oxford Central University Research Ethics Committee (CUREC). The research is funded by and has been favourably reviewed by the Economic and Social Research Council (part of UK Research and Innovation) grant number: ES/T007214/1.

What will happen to the results of this study?

The group discussions will be recorded, audio recordings will be transcribed, and transcripts analysed. The results will be presented at scientific meetings and published in scientific journals. Details of all outputs and information relating to this research will be publicised on the project website: www.aideproject.web.ox.ac.uk

Will my taking part in the study be kept confidential?

Any information collected about you during this study will only be accessible to members of the research team and will not be shared with anyone else without your prior explicit written permission. This includes your name and contact information, which are used for purposes of study administration and will be kept separately from the survey data, interview audio recording and transcripts. No identifiable data will be shared with third parties. Responsible members of the University of Oxford [and the relevant NHS Trust(s)] may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

If you agree to your details being held to be contacted regarding future research, we will retain a copy of your consent form until such time as your details are removed from our database but will keep the consent form and your details separate.

Identifiable data (including audio transcripts, but not consent forms) will be anonymised at the earliest reasonable point and will be deleted as soon as no longer required for the research. When processing the data, your name will be replaced by a code so that you as an individual cannot be identified and transcripts will be reviewed for removal of any potentially identifying information.

De-identified study materials, where any personal identifiable information has been removed, will be retained, and may be submitted for archiving to the UK Research Data Service, or a similar database/repository, through which access will be limited only to approved researchers, and the Oxford University Research Archive (ORA).

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 sponsor for this study, based in the United Kingdom, is the data controller and is responsible for looking after your information and using it properly.

We will be using information from the background survey, the focus group, and your contact information in order to undertake this study and will use the minimum personally identifiable information possible. The transcription of the focus groups will be conducted by an external transcriptionist approved for the study.

We will keep identifiable information about you for a minimum retention period of three years in accordance with university policies. Beyond this, all project data will be destroyed once it is no longer needed unless there is a compelling reason to keep it for longer (e.g. if a query about conduct arose). Paper documentation will be sent for shredding by a university approved service and all electronic files, including back-ups, will be deleted. This excludes any research documents with personal information, such as consent forms, which will be held securely at the University of Oxford for three years after the end of the study, unless you agree to be contacted for future research (see 'Participation in future research' below).

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
https://compliance.web.ox.ac.uk/individual-rights

You can find out more about how we use your information by contacting Nisha Shah (nisha.shah@law.ox.ac.uk

What if something goes wrong?

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 have a concern about any aspect of this project, please speak to the researcher Nisha Shah (details below) or the Chief Investigator Professor Jane Kaye (Email: jane.kaye@law.ox.ac.uk) and we will do our best to answer your query.

We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford, who will seek to resolve the issue as soon as possible:

Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Oxford, OX3 7GB.

Participation in future research

If you agree to us contacting you in relation to future research, your contact details would be held separately from this study in password protected files on a secure location at the University of Oxford, accessible only to the research group conducting this project. Your consent for would also be retained. All contact will come from the HeLEX research team in the first instance. Agreeing to be contacted does not oblige you to take part in future research, and you can withdraw from this register at any time they wish, upon which your personal data will be deleted.

Have patients and the public been involved in this study?

Yes. This study is part of a wider project funded by the ESRC called AIDE (AI in healthcare for all: Designing a platform for sustainable stakeholder Engagement). The AIDE project has a Patient and Public Involvement Panel (PPIP) made up of members of the public, who have helped to design the themes and questions to include in the focus groups. (For more info see www.aideproject.web.ox.ac.uk)

What if I have further questions?

Please contact **Nisha Shah on Tel. 01865 281 266 or Email Nisha.shah@law.ox.ac.uk** who will happily answer any further questions you may have.

Thank you for reading this sheet and considering whether you would be willing to participate.