

Principal Investigator: Catherine Pope

PARTICIPANT INFORMATION SHEET

COMPUTE QUAL

Research to understand views about the use of Artificial Intelligence (AI)/modelling in health care

Researchers from the Nuffield Department of Primary Care Health Sciences (NDPCHS) would 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 anything is unclear, or if you would like more information, please ask us.

What is the purpose of the study?

NHS care often focuses on preventing single conditions and specific diseases such as heart disease or cancer, with interventions delivered in isolation. Preventive services are often poorly attended, as many people do not recognise their own risk of disease, or how treatment or behaviour modification could reduce this. Providing more tailored information to patients and clinicians could support targeted screening and prevention services, with the knock-on effect of improving risk factor management, participation (e.g. with treatments, screening and prevention services), and long-term outcomes.

This study is part of a 5-year programme of research looking at whether using artificial intelligence* (AI) to analyse anonymised data from electronic health records can be used to predict those more likely to develop multiple long-term conditions (MLTC), and thus to get help sooner to those who need it and prevent people developing MLTC in the first place. Our aim in this study is to support other work in the larger programme for example by helping to identify what features of the AI/modelling approach help to convince clinicians and other stakeholders that the approach has merit ('works'), is 'safe', and is worth incorporating in care delivery.

Why have I been invited?

We want to understand how different healthcare stakeholders understand and think about AI/modelling, looking in particular at any concerns they have about the use of AI/modelling approaches within real-life pathways of care and service delivery. We plan to do this through Focus groups with GPs, practice nurses and allied health professionals, managers and commissioners involved in the care of or delivery of services to people with MLTCs. (We may also undertake some 1:1 interviews where this is more pragmatic.) We specifically want to include people who identify as digitally 'reluctant', i.e. those who dislike using computer algorithms or digital technologies in care delivery.

Principal Investigator: Catherine Pope

Inclusion/Exclusion Criteria

Adults aged 18 years and above who are UK based GPs, practice nurses and allied health professionals, service managers and commissioners. who have current or previous experience of caring for or providing services for patients with MLTCs.

Able to give informed consent for participation in the study and take part in a focus group conducted in English and audio-recorded.

What will happen if I decide to take part?

- If you are interested in taking part or have any questions, let us know by email or telephone using the contact details listed.
- We will ensure that you have read and understood the participant information leaflet, and have had an opportunity to have all your questions and concerns addressed.
- Your informed consent to participate in the study will be obtained by the researcher/facilitator prior to your taking part, and documented using a standardised informed consent form. A copy of this consent form will be emailed to you for your records, and the original stored securely by the research team.
- You will then be invited to attend one or more Focus Groups (focused on different topics)
 - The focus group, or interview, will be audio recorded and transcribed.
 - The focus group will take between 1 and 2 hrs of your time
 - (Where you are invited to interview, this will take 30-60 minutes of your time.
 - Meetings will be held online or in person.

What are the possible benefits and disadvantages of taking part?

- Taking part will involve you giving up some of your time.
- You will not benefit directly from the study, but many people find offering feedback a positive experience. The information gained may prove to be of benefit to HCPs and patients in the future.

Will I be reimbursed for taking part?

Participants will receive a certificate of participation for Continuing Professional Development purposes.

GP practices will be reimbursed for locum cover.

Participants attending a focus group or interview in their own time will receive a £30 shopping voucher, and will receive an additional £30 if they attend another focus group.

Where applicable, any reasonable travel expenses will be reimbursed. Accommodation may be provided where distance to a meeting is not practicable to travel in one day.

Principal Investigator: Catherine Pope

Do I have to take part?

No. You can ask questions about the research before deciding whether to take part. If you do agree to take part, you may withdraw yourself from the study at any time by advising us of this decision. This will not have any adverse consequences and you will not need to provide a reason.

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

If you withdraw during or after the focus group and before transcription it may not be possible to remove your data from the study due to the nature of a focus group discussion and recording, however the researcher will endeavour to do so. If you withdraw, when recordings or notes of the focus group have been transcribed and de-identified then the data will still be included in the study.

What information will be collected and why is the collection of this information relevant for achieving the research objectives?

The information you provide during the study is the research data. Any research data from which you can be identified (name, age, work setting, the original audio recording) is known as personal data.

All personal data (encrypted audio recordings, contact information, and any video recordings where applicable) will be stored safely and securely on the hard drive of a password protected computer in the Principal Investigator's University department (NDPCHS). Paper consent forms will be stored in a locked filing cabinet. Contact details will be used to invite participants to focus group/s, or where applicable an interview and to provide feedback between and after the focus group/s have taken place, and will be destroyed when your involvement is complete.

Any personal data relating to you (job title, work setting,) or contact details (full name, email, telephone number) will be stored securely and separately from research data, on a password-protected computers in the NDPCHS. Paper copies of expenses forms and/or honoraria will be stored securely in locked filing cabinets, and electronic copies will be stored securely on the hard drive of a password protected computer in the Principal Investigator's University department (NDPCHS). These will be destroyed when your involvement is complete.

Audio recordings will be encrypted and retained securely with the consent of the participants and audio files will be securely transferred, by way of the university file sharing system, to a NDPCHS-approved transcriber who has a contractual agreement with the University, which guarantees that information in the transcripts will remain confidential.

The transcripts will be returned to the researcher using a link to Nexus 365 OneDrive and password protection. On return to the researcher, the transcripts will be checked against the audio recordings. Any information that could identify you will be removed from the transcripts or changed to de-identify the participant before information is shared with other researchers or results are made public. Audio

Principal Investigator: Catherine Pope

files will be retained until the end of the study to facilitate checking and analysis. Audio files will be retained until the end of the study once analysis and publication of results is complete.

Online meetings may be video recorded for the purpose of transcript checking by the researcher only. Once the transcript has been checked the recording will be destroyed.

Deidentified data (written) may be uploaded into NVivo (data analysis software) which will be accessed by the research team on password-protected computers and these data may also be made available to other researchers or used in teaching.

Research data (including consent forms, interview notes, and transcripts) will be securely stored on the hard drive of a password-protected computer in NDPCHS and held 10 years following the completion of the study. Hard copies of consent forms or data notes will be securely stored in a lockable filing cabinet. The research team and transcriber will have access to the research data. Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research.

Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from the University's Information Compliance website at <https://compliance.admin.ox.ac.uk/individual-rights>.

Will the research be published? Could I be identified from any publications or other research outputs?

We plan to publish the study findings through journal articles, reports, presentations and conference papers. With your permission de-identified quotations may be used in research outputs. You will not be able to be identified in any written or verbal reports from the study.

Who is organising and funding the study?

The study is being organised by researchers at the University of Oxford. The study is funded by the National Institute for Health Research Programme Grants for Applied Research (NIHR PGfAR).

Who has reviewed this research?

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee: R95727/RE001.

Principal Investigator: Catherine Pope

Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this research, please contact Catherine Pope on **01865 289335**, and she will do her 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 University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

Further information and contact details:

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Study webpage: <https://www.phc.ox.ac.uk/research/groups-and-centres/medical-statistics/COMPUTE>

Thank you for your time and consideration.

***Artificial Intelligence:** *the theory and development of computer systems able to perform tasks normally requiring human intelligence, such as visual perception, speech recognition, decision-making, and translation between languages.*