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## **Exploring Mediating Factors of Long-term Collaborations in Health Data Sharing between Government and Academia**

### **PARTICIPANT INFORMATION SHEET**

Central University Research Ethics Committee Approval Reference: **MS IDREC 1111309**

#### **1. Introductory paragraph**

You are invited to participate in a research project led by Ghita Benjelloun Benkacem in the context of a dissertation project part of the MSc in Applied Digital Health at the University of Oxford. Ghita will be the lead researcher, and Dr Elspeth Davies, the lead supervisor, will be the Principal Investigator for the study.

Before you decide, it is essential for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if anything is unclear or if you would like more information. Take time to decide whether you wish to take part.

#### **2. Why is this research being conducted?**

Existing academic literature primarily addresses short-term Government and Academia Collaborations in Health Data Sharing (GACiHDS) initiatives, many of which are COVID-19 responses. Factors mediating the establishment and implementation of **sustainable** GACiHDS, which result in long-term public health solutions, have received **limited attention**. JS Lee and colleagues<sup>1</sup> have identified several areas to guide researchers interested in conducting studies like this one to generate evidence of those mediating factors.

Through a scoping review and interviews, we would like to explore a range of GACiHDS and, for each, consider the most relevant **areas such as how the agreement to access data was set up, what were people's roles, stakeholder involvement/frictions, timeline and key learnings from processes related to funding or data infrastructure, to respond to crisis periods and other challenges faced to maintain them.**

**The project aims to get insights from real-world GACiHDS initiatives, their specific contexts, and how some of these areas above impacted project establishment, implementation and maintenance.**

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<sup>1</sup> Lee JS, Tyler ARB, Veinot TC, Yakel E. Now Is the Time to Strengthen Government-Academic Data Infrastructures to Jump-Start Future Public Health Crisis Response. *JMIR Public Health Surveill* [Internet]. 2024 [cited 2024 Oct 27];10:51880. Available from: <https://publichealth.jmir.org/2024/1/e51880>

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### 3. Why have I been invited to take part?

You have been invited to participate because you are a research team member involved in setting up a Government and Academia Collaboration in Health Data Sharing (GACiHDS). We aim to contact 10 to 20 other researchers also involved in GACiHDS.

We aim to **get insights from your experiences that can help draw lessons from, and enhance understanding of, strategies that could apply to new GACiHDS in a similar context** to encourage establishment and sustainability of these initiatives.

To be included in the study, you will need to:

- Have been involved in developing a Government and Academia Collaborations in Health Data Sharing (GACiHDS) initiative
- Be 18 years and over and be able to provide informed consent
- Be based in the UK

### 4. Do I have to take part?

No. It is up to you to decide whether to take part. You can withdraw yourself from the research, without giving a reason and without negative consequences associated with it, by informing the researcher of this decision via email at [ghita.benjellounbenkacem@phc.ox.ac.uk](mailto:ghita.benjellounbenkacem@phc.ox.ac.uk).

The deadline by which you can withdraw any information you have contributed to the research is 08<sup>th</sup> June 2025. If you decide to withdraw, any data that has already been collected (related to the research and personal data) will be deleted from any database where it had been stored.

### 5. What will happen to me if I take part in the research?

#### Location and Scheduling

To confirm you would like to participate, you can reply to the email through which you were initially reached. If you have been contacted through an alternative method, you can directly email the researcher at [ghita.benjellounbenkacem@phc.ox.ac.uk](mailto:ghita.benjellounbenkacem@phc.ox.ac.uk) until **01<sup>th</sup> June 2025** to mention you would like to participate in the study.

You will receive a follow-up email within a week to arrange a time for the interview. Remember that you can withdraw at any time until 08<sup>th</sup> June 2025.

The research interview will take place online (via MS Teams); after a time has been agreed upon, you will receive a meeting invitation via email.

#### Providing Consent

Consent will be collected verbally at the start of the interview. The researcher will go through the consent statements, complete a paper consent form on your behalf, and sign it if you agree with all statements. After the interview, the researcher will scan and email you a password-protected copy



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of your signed consent form for your records while retaining a secure copy on the University of Oxford servers in a dedicated SharePoint for the study created by the researcher and with protected access.

### Interview Details

The interview will last around 30 minutes and no longer than 1 hour. You can ask to pause or stop at any time during the interview.

With your consent, we would like to transcribe and audio record the interview to make accurate notes of our conversation. Personal information, interview transcript and audio recording along with notes will be stored securely and separately. Details on storage are further down in this document. Before the recording starts, we will ask you to turn off your camera so that you can record the audio without the video. Note that you can still participate if you do not wish the discussion to be transcribed/audio recorded.

The interview will be structured to ensure research questions are addressed, and open-ended questions will also be used to diversify and enrich the insight gathered. Please note the study will not involve revealing any patient information at any time.

### After the Interview

The researcher will produce notes from the transcription of the interview, anonymise yours and the project names (along with additional personal data provided). Within one week after the interview, the research will send you the resulting notes over email. You will be able to approve the use of the notes as qualitative data for analysis, but you will not be able to make any changes to their interpretation... If you do not reply within two weeks, the researcher will assume you approve the use of the notes in the study. If you do not wish to use the notes in the study, you can withdraw until 08<sup>th</sup> June 2025.

## **6. What are the possible disadvantages and risks of taking part?**

Any insights you provide will be anonymised, and project names will not be displayed to prevent direct identification. However, we would like you to be aware that contextual information might still make participants recognisable.

We try to mitigate this risk by enabling you to request reasonable modifications on which, and/or how, notes will be reported in the study within 2 weeks of receiving them. You can also choose to withdraw from the study if you think the risk is too significant.

## **7. Are there any benefits to taking part?**

While there are no direct benefits for those participants in this research, it is hoped that it will bring benefit to the research community by being a first step in factors mediating sustainable GACiHDS, in this case, by initially reflecting on actual world case study, how those were approached and the consequences different approaches had. Further research will be recommended from the elements gathered through this study.



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## 8. Expenses and payments

As this is a student-unfunded project in the context of an MSc dissertation, reimbursement for taking part in the project is not possible.

## 9. What information will be collected, and why is the collection of this information relevant to achieving the research objectives?

We are interested in understanding your experiences and perspectives of working on your GACiHDS, perspectives. By interviewing you and analysing resulting data, we can meaningfully address the research questions mentioned above. In particular, we will collect:

- Your consent form record as evidence confirming your agreement to take part in the study,
- **Your** contact and personal details (name, project names, institution, roles, and professional email) to manage scheduling and communication in relation to your interview and participation in the study
- **Your** interview transcript to **create summary** notes from it capturing your insights and perspectives.
- **Your interview audio recording** to check the accuracy of the transcription and ensure notes represent the discussion that happened during the interview.

Once collected, all of these data will be securely stored in a dedicated folder for this study on the University of Oxford SharePoint server, accessible only to the researcher and their supervisors. Participant consent form records—scanned using the researcher's local devices—will be moved into this folder immediately after the interview. Contact and personal details will be recorded in an Excel database, each participant will be identified by a unique Participant ID, and interview transcripts and notes along with audio recording will also be stored under these IDs rather than by personal name. Data stored on devices at the time of collection will be deleted as soon as it is transferred to SharePoint), and email correspondence will be deleted from the researcher's University Outlook inbox at the end of the study when the dissertation grades are released in September 2025.

Data will not be shared with any third parties, nor will they be transferred outside the UK. They will be used for this specific study's objectives and may be used for any future research. Hence, all remaining data (consent form records, contact details, interview transcripts and audio recording, and notes) will then remain in SharePoint until 01<sup>st</sup> October 2030, at which point they will be permanently deleted from the University servers. However, please note that under no circumstances will the data be identifiable. Instead, anonymity will remain.

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Your participant ID number will be allocated to you during the interview. This ID number will be the only way to associate your interview data (stored in the folders) with your personal data (stored in a separate database). Within the secured SharePoint, **separate** passwords will be required to access each folder and the personal information database. This approach ensures the data can be collected as required while ensuring it is stored and protected to preserve anonymity where required.

Only the researcher and necessarily members of the University of Oxford will have access to the entirety of the data, and they will require relevant passwords and permissions to access them. Data will be retained until 1<sup>st</sup> October 2030 per usual research standards. No data will remain on local devices and will automatically be deleted once transferred to the dedicated SharePoint on the University server. Only the audio recording will be deleted from the SharePoint once the transcription has been judged accurate, notes produced and approved for use. The choice of location of data storing and how long it will be retained will ensure the availability of the data if the study gets published and will lead to future research projects.

#### **10. Will the research be published? Could I be identified from any publications or other research outputs?**

The findings from the research will be written up in a dissertation and may later be refined for publication in an academic journal. As insights will be shared anonymously in the study and project names will not be displayed, you may not be directly identifiable. However, participants may still be indirectly identified through contextual information and direct quotes – though anonymous - shared about a specific project. If you do not feel comfortable with this, you can withdraw from the study until 08<sup>th</sup> June 2025.

A copy of my dissertation will be deposited online in the [Oxford University Research Archive](#), where it will be publicly available to facilitate its use in future research.

#### **11. 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>.

#### **12. Who has reviewed this research?**

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee. (Ethics reference: **MS IDREC 1111309**).

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



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If you have a concern about any aspect of this research, please contact Ghita Benjelloun Benkacem ([ghita.benjellounbenkacem@phc.ox.ac.uk](mailto:ghita.benjellounbenkacem@phc.ox.ac.uk)) or Elspeth Davies ([elspeth.davies@phc.ox.ac.uk](mailto:elspeth.davies@phc.ox.ac.uk)) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and indicate 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](mailto:rgea.complaints@admin.ox.ac.uk) or 01865 616480.

#### **14. Further Information and Contact Details**

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

University of Oxford, Nuffield Department of Primary Care Health Sciences

Radcliffe Observatory Quarter, Woodstock Road, Oxford, OX2 6GG

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