CO-produced Mathematical Modelling of Epidemics Together (COMMET)

Community Engagement Workshops- Participant Information Sheet

We are inviting you to take part in a study

- Please take time to read the following information carefully. Discuss it with friends and family if you wish. Take time to decide whether you wish to take part.
- You are free to decide whether to take part in this study.
- You can stop taking part in any part of the study at any time, without giving a reason.
- Ask us if there is anything that is not clear or if you would like more information.

Important things that you need to know

- In this study, we are trying to understand mathematical modelling and its social context. We also want to understand how co-production methods can be used to improve mathematical models of infectious diseases.
- We are inviting to you to participate in three workshops to understand how lived experiences can inform the development of mathematical models of infectious diseases and be used to improve the mathematical modelling of the infectious disease mpox.
- It is up to you whether you take part in this study.
- We will use the information we gather in these workshops to inform a mathematical model for mpox. We will also use this information to help us develop tools to support co-production methods in mathematical modelling.
- Everyone involved in the study will keep your data safe and secure, and only approved members of staff will have access to your data. We will make sure no one can work out who you are from any reports we write about the project.
- The project is led by University College London (UCL). The Chief Investigator is Dr Elizabeth Fearon.

Contents

How to contact us

If you have any questions about this project, then please contact one of the researchers for this study:

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Bidborough House,
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London, WC1H 9BT
E-mail: sarah.barnes@ucl.ac.uk

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E-mail: e.fearon@ucl.ac.uk

1 Why are we doing this project?

COMMET is a two-year UK Research Innovation (UKRI) funded study which aims to develop methods and tools to support modellers, members of the public and key stakeholders to work together to co-produce epidemic infectious disease models. We believe that this will enable the co-creation of robust models that reflect diverse perspectives, values and cultural contexts, and are relevant and sensitive to the complexities of emerging and epidemic infections.

As part of this study, we are conducting a series of workshops with members of the public who are, or are part of the sexual networks of, gay, bisexual and other men who have sex with men (GBMSM). This includes trans and gender non-conforming people.

This is because we are using mpox, a disease that primarily affected GBMSM sexual networks in the UK, as a test case for our mathematical models. We would like to involve these groups of people in the development of a mathematical model of mpox to ensure it reflects real-world lived experience.

2 Why am I being asked to take part?

You are being asked to participate in these workshops because you have lived experiences relevant to the mathematical model we are developing as a test case of mpox.

If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to change your mind and withdraw at any time by leaving the workshop, however, once the workshop has started you won’t be able to withdraw your data.

3 What do I need to know about taking part in this project?

We invite you to take part in three workshops to explore how your lived experiences can help to improve mathematical models of infectious diseases. These will either be held in-person or online using video-conferencing software such as Microsoft Teams.

The first two workshops will last half a day each (approximately 4 hours), and the final workshop will be up to two hours online.

During the workshops, a facilitator will ask you to reflect on topics such as your experience of the UK mpox outbreak in 2022 and your attitudes to sexual health and science more generally. You will also participate in activities related to the development of mathematical models of infectious diseases, and share your feedback related to research questions and models being developed. No previous understanding of mathematical modelling is needed for this.

You do not have to answer any questions that you do not want to. You can also choose to leave the workshop at any time without giving a reason.

4 What will I need to do if I take part?

You do not need to do anything in preparation for the workshops except turn up at the appointed time.

A member of the team will send you a reminder before the workshops and give you specific instructions on how to join.

5 What are the possible disadvantages and risks of taking part?

During the workshop, it is possible that we will discuss difficult or sensitive topics related to your personal life, sex life and lived experience, particularly with respect to mpox outbreak in 2022-23. It is up to you how much information you would like to share, and you will be free to leave the workshop at any time.

If you find any of the topics difficult or upsetting, we will have a dedicated team member who will be able to support you, both during and after the workshop.

6 What are the possible benefits of taking part in this study?

You will be paid £25 per hour for taking part in these workshops, and your travel expenses will be paid. Beyond this, you are unlikely to benefit personally from taking part in this study. However, you might enjoy learning more about how mathematical models of infectious diseases are developed, sharing your experiences, and meeting other attendees.

7 More information about taking part

Do I have to take part?

No, it is up to you to decide whether or not to take part in the co-production workshops. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form.

If you decide not to take part in this study, this will not have any impact on you.

Can I stop taking part?

You can stop taking part in this study at any time, without giving a reason and without any consequences to you. You can do so by contacting the researcher named on this sheet.

If you stop taking part in this study before attending the workshop, we will delete any data we may have already collected. During and after the workshop, it will not be possible for you to withdraw your data due to the nature of the group discussion. However, you are free to leave the workshop at any point.

If you withdraw from the project after it ends, we will keep the information about you that we have already obtained.

What will happen to information about me collected during the study?

If you agree to take part, the following will happen:

- A consent form will be signed by you and a member of the research team. This form will contain your name and will be scanned immediately and stored in a password protected folder on the Data Safe Haven (DSH), which is a secure drive, at UCL. Alternatively you can complete a consent form online using a link provided by the researcher.

- We will ask for your permission, and the permission of other attendees, to record the workshops (sound only for in-person and online workshops). The recording will be held on an encrypted digital voice recorder until it is transferred to the DSH.
- The workshop facilitator or another member of the research team will make notes during the workshop. The audio recording will be deleted from the DSH once we have checked our written notes for completeness.
- Any notes taken during the workshop will only be identified by a project number, and not your name.

What will happen to information collected about me after the study?

This project is being undertaken by researchers based at University College London (UCL). Dr Elizabeth Fearon (UCL) is responsible for the project and all the data. We will be using information from you in order to undertake this project and we are responsible for looking after your information and using it properly.

Due to the nature of the group discussion, you cannot withdraw your data after the workshop.

Non-identifiable information for this study will be stored at a registered UCL archive facility for a minimum of 10 years after the end of the study.

If you have any questions about how data are handled in this study, please speak to the researchers listed on this information sheet. You may also contact the UCL Data Protection Office. The contact details for the researchers and the UCL Data Protection Office are provided at the end of this information sheet.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

UCL Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This ‘local’ privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our ‘general’ privacy notice.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the ‘local’ and ‘general’ privacy notices.

The lawful basis that will be used to process your personal data are: ‘Public task’ for personal data and ‘Research purposes’ for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk. More information on UCL's privacy notices are available at [https://www.ucl.ac.uk/legal-services/privacy.](https://www.ucl.ac.uk/legal-services/privacy)

What will happen to the results of the project?

Findings from the workshops will help us to understand how lived experience can inform the development of mathematical models of infectious diseases, and be used to improve mathematical modelling of the infectious disease mpox.

When the study is complete, we will present the findings at academic conferences and publish the results in academic journals. No sound recordings or names will be used. Any quotes will be anonymous. This information will not identify you and will not be combined with other information in a way that could identify you. You can ask the researchers for a copy of any future publications. Your identity and any personal details will be kept confidential. No named information about you will be published in any report of this study.

At UCL we use personally identifiable information to conduct research to improve health, care, and services. As a publicly funded organisation, we must ensure that it is in the public interest when we use personally identifiable information from people who have agreed to take part in research. This means that when you agree to take part in this project, we will use your data in the ways needed to conduct and analyse the work. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible.

Health and care research should serve the public interest, which means that we must demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer (research-incidents@ucl.ac.uk) who will investigate the matter. 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 complain to the Information Commissioner's Office (ICO) https://ico.org.uk/make-a-complaint/.

Who is organising and funding the study?

The study has been designed by researchers at University College London and University of Manchester. The project has been reviewed and is being paid for by UK Research and Innovation. UCL is Sponsor and has overall responsibility for the conduct of the group discussion part of the project. They are responsible for ensuring the discussions are carried out ethically and in the best interests of participants.

Who has reviewed the study?

All research at UCL is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by UCL Research Ethics Committee.

What if something goes wrong for me?

If you have any concerns about the way you have been approached or treated during the project, please talk to the researchers. If the problem is not addressed, you can email the UCL Research Ethics Committee on ethics@ucl.ac.uk

If you are harmed by taking part in the project, or if you are harmed because of someone's negligence, then you may be able to take legal action. The Sponsor of the study, University College London, holds an insurance policy, in case anything does go wrong.

8 Contacts for further information

If you want further information about this study, contact:

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UCL Data Protection Office
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Email: data-protection@ucl.ac.uk

Thank you for taking the time to consider taking part in this project.