

## Participant Information Sheet

**Study Title:** The Phage Collection Project – Phage Sampling Activity (Adults – UK)

**Researcher:** Ruweyda Sayid, Esme Brinsden, Dr Franklin Nobrega, Professor Saul Faust  
**ERGO number:** 100615

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

### What is the research about?

'The Phage Collection Project' is a citizen science initiative that wants to engage the public in phage therapy research, by providing individuals such as yourself with the opportunity to contribute to active scientific research. This aspect of our research involves members of the public collecting samples of water from the environment (e.g. rivers, lakes, ponds) or a toilet in the hopes that we (The Phage Collection Project) might isolate phages from them.

Any phages which the team isolate from the water sample you provide us with will be collected into the Phage Collection Project's biobank. This biobank will aid scientific research into these viruses. Therapeutically relevant phages in the project's biobank may also be used to produce phage therapies for use both within and outside of the UK. This commercial enterprise will be conducted in a non-profit manner, with all revenue funding the administration costs of the Phage Collection Project only.

### Why have I been asked to participate?

You have been selected to take part in this research because you have shown interest in the project by requesting a sampling pack through our website or at an outreach event that the project has attended.

We aim to recruit 1000 participants in this research over a 5-year period.

### What will happen to me if I take part?

The Phage Sampling Activity will run for a minimum of 5 years.

Each year citizen scientists like yourself will receive a sampling kit from the Phage Collection Project. Using this kit, you will collect a 50ml sample of water from your local environment or toilet and complete a sampling information sheet online. This sheet will ask for details about the sampling location (date of collection, name and GPS coordinates of the location) your name, email address and the name you would like to give to your phage if a member of the team isolates a phage from your sample. You may also upload a photo of your sampling location, but this is optional.

You will package and post your water sample to the Phage Collection Project following the instructions document provided in the kits.

You will receive an email confirmation from the Phage Collection Project thanking you for your participation in the research. In this email you will have the option to opt out to email updates from the Phage Collection Project about any research conducted on your phage. You can opt out of these emails at any time by emailing the Phage Collection Project at [phage.collection@soton.ac.uk](mailto:phage.collection@soton.ac.uk).

It must be noted that your water sample may not contain any phages.

To take part, you must sign a consent form to show that you have read, understood and agree to taking part in this research.

### **Are there any benefits in my taking part?**

Participation in the Phage Collection Project's Phage Sampling Activity will give you a more detailed understanding about antimicrobial resistance and phages.

You will be making a significant contribution to active scientific research and if we isolate any new phages from your water sample you will have the opportunity to name it.

### **Are there any risks involved?**

When collecting your water sample there are risks involved in relation to slips, trips and falls near water environments. There is the potential risk of drowning. Take care when collecting your sample and ensure you are wearing appropriate clothing and footwear. Collect your water samples in groups (or pairs) and go in good weather conditions.

There may be areas where you are legally not allowed to collect water samples. Make sure to investigate local, federal and provincial laws (where relevant) in the area you intend to collect water from. Do not trespass or infringe any laws during water sampling.

The water you are collecting may contain biohazardous material. Make sure to wear the gloves provided in the sampling kit to collect your water samples safely. The gloves provided in your sampling kit may contain latex. If you are allergic to latex, please source and use another pair of gloves that do not contain latex.

Use the sanitising wipe provided to clean your hands and the outside of the sampling tube after you have collected your water sample. Dispose of your gloves and used sanitising wipe in a general waste bin. Take sensible hygiene precautions; cover wounds/cuts/grazes etc; do not drink the water and wash your hands thoroughly with soap and water after collecting the sample.

Do not disturb or collect any vegetation or animals if you are collecting an environmental water sample. Make sure that you leave the environment as you found it, taking all materials (gloves, sanitising wipes, instructions etc) with you and disposing of them in a suitable bin.

If an emergency situation does occur that requires urgent attention, make sure to call one of the available services below.

999	When someone is seriously ill or injured, or a crime is in progress
101	To contact police in non-emergency situation
111	Non-emergency medical problem

### **What data will be collected?**

Your name, email address and home address will be collected in this research. This data will be collected and handled securely through a portal which participants access through the Phage Collection Project's website and will be stored electronically on a secure University server. Only members of the Phage Collection Project team will have access to this data.

You will provide your name and email address when you submit the sampling information sheet. The sampling information sheet will be scanned and stored electronically on the secure University server.

Any anonymised data collected during the study may be achieved in a data repository and may be used for future research and learning.

The project will keep the electronic copy of participants signed consent form on the University's secure server.

### **Will my participation be confidential?**

Your participation and the information we collect about you during the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential.

Consent forms, sampling information sheets and enrolment forms completed by participants through the Phage Collection Project's website will be stored electronically on a secure University server. Only members of the Phage Collection Project team will have access to the data.

### **Do I have to take part?**

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

If you wish to opt-out of email updates you receive from the Phage Collection Project you may do so at any time by replying to the email requesting to opt-out or by contacting the Phage Collection Project at [phage.collection@soton.ac.uk](mailto:phage.collection@soton.ac.uk).

### **What happens if I change my mind?**

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected.

You can withdraw from the study at any point by sending an email to the following contacts:

Ruweyda Sayid – [r.sayid@soton.ac.uk](mailto:r.sayid@soton.ac.uk)  
Esme Brinsden – [esme.brinsden@soton.ac.uk](mailto:esme.brinsden@soton.ac.uk)  
Dr Franklin Nobrega – [F.Nobrega@soton.ac.uk](mailto:F.Nobrega@soton.ac.uk)  
Professor Saul Faust - [s.faust@soton.ac.uk](mailto:s.faust@soton.ac.uk)  
The Phage Collection Project – [phage.collection@soton.ac.uk](mailto:phage.collection@soton.ac.uk)

If you withdraw from the study, your personal information will be destroyed by the Phage Collection Project.

### **What will happen to the results of the research?**

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

If participants do not ask for their personal data to be removed, it will be removed by the Phage Collection Project at the end of the study.

### **Where can I get more information?**

You may contact the following researchers below associated with the Phage Collection Project:

Ruweyda Sayid – [r.sayid@soton.ac.uk](mailto:r.sayid@soton.ac.uk)  
Esme Brinsden – [esme.brinsden@soton.ac.uk](mailto:esme.brinsden@soton.ac.uk)  
Dr Franklin Nobrega – [F.Nobrega@soton.ac.uk](mailto:F.Nobrega@soton.ac.uk)  
Professor Saul Faust - [s.faust@soton.ac.uk](mailto:s.faust@soton.ac.uk)  
The Phage Collection Project – [phage.collection@soton.ac.uk](mailto:phage.collection@soton.ac.uk)

### **What happens if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

Ruweyda Sayid – [r.sayid@soton.ac.uk](mailto:r.sayid@soton.ac.uk)  
Esme Brinsden – [esme.brinsden@soton.ac.uk](mailto:esme.brinsden@soton.ac.uk)  
Dr Franklin Nobrega – [F.Nobrega@soton.ac.uk](mailto:F.Nobrega@soton.ac.uk)  
Professor Saul Faust - [s.faust@soton.ac.uk](mailto:s.faust@soton.ac.uk)  
The Phage Collection Project – [phage.collection@soton.ac.uk](mailto:phage.collection@soton.ac.uk)

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head Research Ethics and Governance (023 8059 5058, [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)).

In the case of a medical emergency or non-emergency arising from participation in The Phage Collection Project's Phage Isolation Course contact:

999 – Emergency Services  
111 – Non-emergency Medical Services

### **Data Protection Privacy Notice**

#### **How will we use information about you?**

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, we will need to use information from you and your sixth form/college for this research project.

This information will include your initials. People will use this information to do the research or to check your records to make sure that the research is being done properly.

We will keep all information about you safe and secure.

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.

#### **What are your choices about how your information is used?**

- You can stop being part of the study at any time, without giving a reason, but we will keep all identifiable information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

#### **Where can you find out more about how your information is used?**

You can find out more about how we use your information:

- by sending an email to University's Data Protection Officer ([data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk)).
- by asking one of the research team or from our [general privacy policy](#).
- by sending an email to one of the researchers listed below.

Ruweyda Sayid – [r.sayid@soton.ac.uk](mailto:r.sayid@soton.ac.uk)  
Esme Brinsden – [esme.brinsden@soton.ac.uk](mailto:esme.brinsden@soton.ac.uk)  
Dr Franklin Nobrega – [F.Nobrega@soton.ac.uk](mailto:F.Nobrega@soton.ac.uk)  
Professor Saul Faust - [s.faust@soton.ac.uk](mailto:s.faust@soton.ac.uk)

The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

**Thank you.**

Thank you for reading the participant information sheet and for considering participation in the Phage Collection Project's Phage Sampling Activity.