**Participant Information Sheet:  
Community Member**

**INTUIT:** Interaction Design for Trusted Sharing of Personal Health Data to Live Well with HIV

**We are inviting you to take part in a   
Group Survey study**

* Please take time to read the following information carefully. Discuss it with friends and relatives if you wish. Take time to decide whether or not you wish to take part.
* You are free to decide whether or not to take part in this research study. If you decide to take part you can pause or stop at any time, without giving a reason.
* Please ask us if there is anything that is not clear or if you would like more information.
* Thank you for reading this information. If you decide to take part you will be given a copy of this Information Sheet and asked to give your consent by completing an online form.

**Important things that you need to know**

* The Group Survey is an online survey that involves you being asked to respond to three rounds of questions.
* The survey will be sent to both people living with HIV and healthcare professionals, who will be invited, remotely and anonymously, to answer questions about HIV care.
* We are interested to hear about your personal experiences of receiving HIV care. We are not testing any new medication.
* Taking part in this study is voluntary.
* We will only use information about you that we need for the research study. The research team members will keep data that we collect from you safe and secure; and only the research team members will know your name and contact details. We will make sure that no one can work out who you are from the reports that we write.
* The study is led by the INTUIT Research Team at Newcastle University (NU), in partnership with University College London (UCL), and is sponsored by The Newcastle upon Tyne Hospitals (NUTH) NHS Foundation Trust.

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**How to contact us**

If you have any questions about this study, please talk to a member of our research team:

**Professor Abigail Durrant**

Chief Investigator, INTUIT Study

Newcastle University

Telephone: 0191 208 7972  
[Abigail.Durrant1@nhs.net](mailto:Abigail.Durrant1@nhs.net)

For further information about how research data is processed, please contact:

**UCL Data Protection Office**

Telephone: 0203 108 8764

Email: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

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| 1 | **Why are we doing this study?** |

This study is trying to find out how we can improve information sharing between people living with HIV and their healthcare providers (including doctors, nurses, psychologists and health advisors).

Through effective treatment, HIV has been transformed into a *long-term condition* with normal life expectancy for the majority of people. This has also meant that for many patients, their clinic visits have become less frequent, often only once or twice a year.

This is why it is important to think about ways of making the most of these appointments. Patients should feel fully informed about their medical condition, and supported to keep their health and wellbeing the best it can be.

An important part of clinic appointments is the sharing of information between patients and their healthcare providers.

New digital technology (e.g. smartphones and Fitbits) can help people record information about their own health and lifestyle. In this study, we would like to understand how such technology could be better designed to help people living with HIV communicate with healthcare professionals.

In the surveys, we will ask about your clinical consultations, what information is important for you, as an expert in the lived experience of HIV, to share with your clinician, and what information you would like them to be able to share with you. We would like to understand any challenges to sharing personal information in the context of routine care management, and also to identify ways for improving sharing of information with the aim of facilitating communication between patients and healthcare professionals.

This is a Group Survey where responses from both people with HIV and healthcare professionals will be collated, analysed and shared anonymously with participants in subsequent rounds to prompt further contribution and reflection. Taking part involves completing a three-round survey (up to 30 minutes each) remotely in your own time.

This study will help us understand how the design of new technology could be used to improve the care and self-management of HIV, both in the UK and around the world.

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| 2 | **Why am I being asked to take part?** |

You are being asked to take part in this study because you have already engaged with the INTUIT research project and gave permission to be invited to take part in further INTUIT studies, or because you have expressed an interest in taking part. It is up to you to decide whether or not to take part.

If you do decide to take part, you will be given this Information Sheet to keep and be asked to give your consent to join in the study. If you decide to take part, you are still free to change your mind and withdraw at any time and without giving a reason.

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| 3 | **What do I need to know about the procedures in this study?** |

The INTUIT Study Team will contact you via email to provide information about the study and guide you through the process of providing your consent. You will have time to review information about the study and, if you decide to take part, you will be asked to give your consent signing an online Consent Form at a provided link.

A researcher will then send you a Study ID Number to use for completing an online pre-study demographic questionnaire via a provided link. The demographic questionnaire will help us interpret the data collected. After completing this questionnaire, you will receive a link to the first survey to be completed and submitted online (Round 1). You will be asked to give your Study ID Number when completing this form.

Approximately three weeks later, you will receive a link to a second survey that you are asked to complete (Round 2). The questions asked in the second survey will be devised by the researchers based on participants’ responses to the first survey.

Approximately three weeks later, you will receive a link to a third survey that you are asked to complete (Round 3). For the third survey you will be asked for feedback and comments on participants’ responses to the first and second surveys.

You are not required to answer any questions that you do not wish to, and you do not need to disclose any personal information if you do not wish to. If you wish to pause or stop taking part in this study at any point, you just need to let the researcher know by telephone or email (see contact details below).

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

You will be asked to complete the three online surveys at weblinks sent to you by a researcher. Each survey should be completed and submitted online, at your convenience during a two-week period. Participation in the study is over a three-month period of time in total.

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

We think that it is unlikely that you would come to any harm through taking part in the study. However, it is possible that the questions might ask you to talk about difficult experiences, which could be upsetting for you. The researcher will be responsive to your needs and concerns, and will try to make sure that you feel at ease and comfortable during the study. You are free to pause or withdraw from the study at any time without the need to give an explanation.

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

You will be given a £20 shopping voucher in recognition of your time. You may also enjoy knowing that you are contributing to the potential improvement of HIV care. We hope you will find this to be rewarding.

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| 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. If you decide to take part, you will be given this Information Sheet to keep and you will be asked to give your consent by reviewing and signing an online Consent Form at a provided link.

Can I stop taking part after I’ve joined the study?

You can pause or stop taking part in this study at any time and without giving a reason.

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

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

* We will ask you to complete a pre-study demographic questionnaire on a computer via a weblink that we will provide via email. In this questionnaire, we will not be asking you for your name, date of birth or contact details. We will ask you questions about your age, gender identity, ethnic group, sexual orientation, your health and your digital technology use. The completed questionnaire will help us interpret research data that we collect.
* The researcher will then send you a link to an online survey, for you to complete at your convenience and pseudonymously within two weeks.
* This survey is the first of three online surveys to complete (Round 1 of 3).
* You will be asked to provide your Study ID Number each time that you complete these online surveys, so that your responses do not reveal your real name.
* After each survey round, we will collect all participant responses and qualitatively analyse them to produce a summary of key themes that collectively represent the responses, supported by direct quotes from participants (associated with their Study ID Number).
* We will share with you the summary from Round 1, and then the summary from Round 2, when we send you the link to the next survey.
* For the survey in Round 3, you will be asked for feedback on the responses from Rounds 1 and 2.
* After all responses from all rounds have been analysed, the researchers will share, via email, a final summary of study findings with all participants.

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

NUTH NHS Trust is the sponsor for this study based in England, and Newcastle University (NU) and UCL act as joint data controllers. We will be using information from you in order to undertake this study and we are responsible for looking after your information and using it properly.

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.

If you withdraw from the study before it ends, we will remove any information about you. If you withdraw from the study after it ends, we will keep the information about you that we have already obtained.

The other universities collaborating on this study will only receive information from the study without any personally identifying information about you. This information will not contain your name or any other identifying details.

The research team keep identifiable information about you from this study for two years after the study has finished. Non-identifiable information for this study will be transferred to a registered UCL archive facility and stored 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 Chief Investigator for this study, Abigail Durrant, or the Data Protection Office at UCL. Contact details are provided at the end of this information sheet.

What will happen to the results of the study?

When the results are presented, any quotes used by the researchers will be anonymous.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

When the study is completed, we will present the findings at academic conferences and publish the results in academic journals, so that other healthcare professionals and researchers can see them. You can ask a member of the research team 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.

We will also put the results on our website: <https://intuitproject.org/> and on our Twitter Account: @INTUIT\_project

We use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to 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 a research study, we will use your data in the ways needed to conduct and analyse the research study. 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 have to 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 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).

Who is organising and funding the study?

The study has been designed by the INTUIT research team. The study has been reviewed and is being paid for by the Engineering and Physical Sciences Research Council (EPSRC). NUTH NHS Trust is Sponsor and has overall responsibility for the conduct of the study. They are responsible for ensuring the study is carried out ethically and in the best interests of the study participants.

Who has reviewed the study?

The study has been reviewed and authorised by a Research Ethics Committee, the Health Research Authority (HRA), and by the Joint Research and Development Office for Newcastle University and NUTH NHS Trust.

What if something goes wrong for me?

If something goes wrong for you whilst taking part in the study, please feel free to contact the research team and/ or alternative contacts using the details given below.

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

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| 8 | **Contacts for further information** |

If you want further information about this study, please contact:

**Prof. Abigail Durrant**

Chief Investigator, INTUIT Clinical Study

Newcastle University

Urban Sciences Building, 1 Science Square

Newcastle upon Tyne, NE4 5TG

Tel: 0191 208 7972

Email: [Abigail.Durrant1@nhs.net](mailto:Abigail.Durrant1@nhs.net)

**UCL Data Protection Office**

Tel: 0203 108 8764

Email: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

For further information about your rights related to the processing of personal data, please visit the website for Information Commissioners Office (ICO): <https://ico.org.uk/>

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