

Exploring Your Options (User Analytics)



School of Arts and Creative Technologies

Participant Information Sheet: Anonymous Research

Project background

The University of York would like to invite you to take part in the following project: Exploring Your Options (User Analytics). Before agreeing to take part, please read this information sheet carefully and let us know if anything is unclear or you would like further information.

What is the purpose of the project?

Exploring Your Options is an interactive film that has been designed to guide women who have been diagnosed with cancer through fertility preservation options before the start of cancer treatment. In this project, we are interested in finding out how people use Exploring Your Options and its interactive features. This will help us learn how to improve it and inform the development of similar resources in the future.

Your participation in this project will involve providing us with permission to collect some data about how you have watched the film and used its interactive features. This data will allow us to understand things like: how many people have watched our film, how many times do they watch it on average, which sections of the film are watched the most, and do people use features like the opportunity to save questions for later. The data we collect will be anonymous and won't include any identifying information about you. For example, while we would like to collect data about whether you used the question log feature in the film, we won't collect any data about the actual questions you asked. If you have any questions or concerns about the data we are asking for your permission to collect, please raise these concerns with the researcher named below.

This project is being led by Jonathan Hook, who is a Professor of Interactive Media at the University of York (jonathan.hook@york.ac.uk). The work is being conducted according to restrictions that have been subject to approval by the ACT Ethics committee. The Chair of the ACT Ethics committee can be contacted on ACT-ethics@york.ac.uk.

Your participation in this project is voluntary. If you would like to learn about the results of this project and how it has led to the improvement of Exploring Your Options, please keep an eye on our website (<https://exploringyouroptions.info>) where we will provide a copy of a research report to view once this project has been completed.

Why have I been invited to take part?

You have been invited to take part because we think that you are someone who has used the Exploring Your Options film. Seeing data about how people use our film will help us improve it and design similar resources in the future.

We are interested in collecting data about the use of film by a variety of different users of our film, including: people who are in the process of making choices about their own fertility preservation, those who are supporting someone else in making a decision (e.g. partners, parents, carers, friends), medical professionals, or other interested people (e.g. other researchers). If you are in any of these groups, we would appreciate your permission to collect data about how you use the film.

Do I have to take part?

No, participation is optional. You can choose to take part or not choosing “consent” or “do not consent” on a pop-up box that appears when you first visit our website. A picture of this pop-up box is provided below for your reference.

Help us to improve this film

The University of York asks for your consent to collect non-identifiable data about how you use this film, and to set analytics cookies that make this data accurate. You can learn more by reading our [research information sheet](#) and [privacy policy](#). By clicking consent, you confirm that you have been given the opportunity to read the information provided about how we will use and process your data, and understand that (expand each for details):

- ▶ **Your data will be used for research and technical improvements**
- ▶ **Your data may be shared anonymously in outputs and a repository**
- ▶ **You have rights over your data, including to have it deleted**

If you choose not to give consent for this data collection, you will still be able to access the film and all of its features will still work in full.

Consent

Do Not Consent

If you do decide to take part, you will not have to do anything else other than use the film as you normally would. We will then collect data automatically while you use it. If you decide not to take part, then the film will work in full and your user experience will not change.

If you change your mind at any point, you can withdraw your participation without having to provide a reason. If you would like us to stop collecting data about your use of the film, you visit our [privacy page](#) and follow the instructions to reset your consent choice. If you would like us to delete any data that we have already collected about you, you can also follow instructions on this same page. You will be provided with a code that you can email to the

lead researcher (jonathan.hook@york.ac.uk). We will then use it to find and delete the data we have collected about you as soon as possible. Please note we can only guarantee full deletion within 14 days of collection. After this period, data may be aggregated into research outputs or publications, making it impossible to identify and remove your individual record. If you would prefer to request the deletion of your data without contacting the research team, you can alternatively contact the University of York's Data Protection Officer (contact details in the final section of this document).

Will I be identified in any outputs?

No. Your participation in this research activity will be treated anonymously and you will not be identified in any outputs.

Privacy Notice

This section explains how personal data will be used by the Exploring Your Options project at the University of York.

For this project, the University of York is the [Data Controller](#). We are registered with the Information Commissioner's Office. [Our registration number](#) is Z4855807.

What is our legal basis for processing your data?

Privacy law (the UK General Data Protection Regulation (GDPR) and Data Protection Act 2018) requires us to have a legal reason to process your personal data. Our reason is we need it to perform a public task.¹

This is because the University has a public function, defined in [our charter and statutes](#), which includes carrying out research projects.² We need to use personal data in order to carry out this research project.

Information about your health, ethnicity, sexual identity and other sensitive information is called "[special category](#)" data. We have to have an additional legal reason to use this data, because it is sensitive. Our reason is that it is needed for research purposes.³ All research projects at the University follow our [research ethics policies](#).

¹This refers to [UK GDPR Article 6 \(1\) \(e\)](#): processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

² [Our charter and statutes](#) states: 4.f. To provide instruction in such branches of learning as the University may think fit and to make provision for research and for the advancement and dissemination of knowledge in such manner as the University may determine.

³This refers to [UK GDPR Article 9 \(2\) \(j\)](#): processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

How do we use your data?

We will use your data to understand how people use and experience Exploring Your Options and its interactive features. To achieve this, we will analyze your and other people's data together to explore things like: how many people have watched our film, how many times do they watch it on average, which sections of the film are watched the most, and do people use features like the opportunity to save questions for later.

If you choose to participate in other research surveys that we advertise on our website, we may ask you to provide a code that links your data with your survey responses. This will allow us to conduct further analysis that lets us understand whether people who use the film in certain ways respond to survey questions differently (e.g. do people who find the film helpful watch it more times). We will only ever link your data to other survey responses with your explicit additional consent and we will provide you with a further information sheet explaining how this will be done and why before we ask for your consent.

We intend to use the results of the analysis of your data to make our film better and inform the design of similar films in the future. We also may use our results for other purposes like demonstrating the positive impacts the film has had so far as part of applications for funding to support its further development.

Will AI be used to analyze my data?

We will not use AI to analyze your data.

Who do we share your data with?

Your data may be shared with other members of our research team as part of the analysis process. These people include Dr Simona Manni and Professor Bob Philips from the University of York and Professor Georgina Jones from Leeds Beckett University.

As well as this, we use computer software or systems to hold and manage data. Other companies only provide the software, system or storage. They are not allowed to use your data for their own reasons. The most relevant example of a software system used in this research is the Google Analytics platform, which we will use to gather and perform some elements of analysis of your data. We want you to know that we have taken all steps required to guarantee that your data is not accessed or reused by Google for any reasons other than those described in this information sheet.

We have agreements in place when we share data. These agreements meet legal requirements to ensure your data is protected.

How do we keep your data secure?

The University is serious about keeping your data secure and protecting your rights to privacy. We don't ask you for data we don't need, and only give access to people who need to

know. We think about security when planning projects, to make sure they work well. Our IT security team checks regularly to make sure we're taking the right steps. For more details see [our security webpages](#).

How do we transfer your data safely internationally?

If your data is stored or processed outside the UK, we follow legal requirements to make sure that the same level of privacy rules still apply.

How long will we keep your data?

The University has rules in place for [how long research data can be kept](#) when the research project is finished. Your information will be kept for no longer than we require to keep it for the purposes described in this information sheet, and at most 10 years. After this time an anonymized version will be kept in the University of York's secure data repository [Research Data York](#). As this will be fully anonymous, it will not be possible to identify you in any way from this data.

What rights do you have in relation to your data?

[You have rights over your data](#). This sheet explains how you can stop participating in the study, and what will happen to your data if you do. This information is in the section 'Do I have to take part?'.

If you want to get a copy of your data, or talk to us about any other rights, please contact us using the details below.

Questions or concerns

If you have any questions or concerns about how your data is being processed, please contact the project leader Jonathan Hook by email (jonathan.hook@york.ac.uk).

If you have further questions, the University's Data Protection Officer can be contacted at dataprotection@york.ac.uk or by writing to: **Data Protection Officer, University of York, Heslington, York, YO10 5DD.**

Right to complain

If you are unhappy with how the University has handled your personal data, please contact our Data Protection Officer using the details above, so that we can try to put things right.

If you are unhappy with our response, you have a right to [complain to the Information Commissioner's Office](#). You can also contact the Information Commissioner's Office by post to **Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF** or by phone on **0303 123 1113**.