

## **Sign up to be contacted to become a research volunteer: Privacy Notice – Version 1, 20.05.2021**

### **About this Privacy Notice**

This privacy notice relates to the website <https://cityofresearch.org/> and service described in this privacy notice, which is provided by the City of Research partners to enable members of the public to give permission to be contacted by researchers about taking part in UK-approved health and social care research studies. This service is referred to in this document as the 'Service'. The City of Research partners are Bradford Teaching Hospitals NHS Foundation Trust, Bradford District Care NHS Foundation Trust, Airedale NHS Foundation Trust and Bradford and Craven Clinical Commissioning Group (CCG). Over time, we anticipate new partner organisations will join the City of Research collaboration and this may include non-health and social care organisations, for example, higher educational institutions, the Bradford Council and charities. In this privacy notice, 'we' or 'us' means the City of Research partners. 'You' or 'your' means you, a member of the public who is using the Service.

This privacy notice tells you what information the City of Research partners collect and how it is used to provide the Service, including your rights and how to contact us.

### **What is health and social care research?**

Health and social care research may be exploring prevention, diagnosis or treatment of disease, which includes health and social factors in any disease area. Research may be sponsored by companies developing new medicines or medical devices, NHS organisations, universities or medical research charities. The research sponsor decides what information will be collected for the study and how it will be used.

All NHS organisations are expected to participate and support health and social care research. The Health Research Authority in England and government departments in Northern Ireland, Scotland and Wales are committed to an environment where patients, service users and the public (including carers, relatives of patients and service users and healthy volunteers) are given, and take, the opportunity to participate in health and social care research and to get involved in its design, management, conduct and dissemination, and are confident about doing so; they set standards for NHS organisations to make sure they protect your privacy and comply with the law when you are involved in research. Independent research ethics committees review research studies to make sure that the research uses of data about you are in the public interest, and meet ethical standards.

For more information on how patient information may be used for research:  
<https://www.hra.nhs.uk/information-about-patients/>

## The Service and who we are

The Service allows you to:

1. Give your permission for the City of Research partners to share the details you have provided through the Service with researchers of UK-approved health and social care research studies for the purposes of researchers contacting you about taking part in their research studies.
2. Give your permission to be contacted by the City of Research partners about
  - the progress and outcomes of the research studies; and
  - future developments in the Service, including to provide opportunities for you to take part in other types of research.
3. Withdraw your permissions to be contacted.

Using the information you provide to the City of Research partners through the Service, we will share your details with researchers of relevant studies so they can contact you to ask you to take part in their studies.

You are not providing permission to **take part** in these research studies through the Service – the researchers will ask for your permission to take part once they have contacted you. There is no obligation for you to take part and you can change your mind at any time.

## General Data Protection Regulation Legal Basis

Bradford Teaching Hospitals NHS Foundation Trust is the Data Controller for the personal information collected and processed about you and held by Mailchimp in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 (DPA18). There is more about Mailchimp below under 'Where we store your personal information'. Bradford Teaching Hospitals NHS Foundation Trust will grant access to your personal information held by Mailchimp to the other City of Research partners in order that they too may process the information you have provided for the purposes of the Service.

Our legal basis for collecting, analysing, and sharing your personal information is:

*GDPR Article 6 (1) (e) – processing is necessary for the performance of a task carried out in the public interest.*

Our legal basis for processing the information you provide about your ethnicity under GDPR is:

*GDPR Article 9 (2) (g) – processing is necessary for reasons of substantial public interest*

*GDPR Article 9 (2) (j) - processing is necessary for scientific research and statistical purposes*

## **How we use your personal information and why**

### **To share your details and permission to contact with researchers**

The personal information you have provided to us through the Service will be used by us to identify whether you may be suitable for a particular research study. When researchers ask us for your details, we will first check, using the information you have provided through the Service, if their study is likely to be suitable for you, for example, age, gender/sex classification, etc. If a study is not likely to be suitable then we will not share your details. If a study is suitable, we will share your details provided through the Service. There is more about this below under 'Who we share your personal information with'.

### **To help researchers plan their studies and to monitor and improve the Service**

We will use the information you have provided to help researchers plan their studies. For example, we will analyse:

- the number of people who have signed up to the Service;
- where they are located
- their age group
- their ethnicity
- their gender/sex classification
- their areas of interest

This analysis will also support us, our pharmaceutical industry partners, our academic partners, the NIHR and other relevant stakeholders and our NHS partners to promote UK-approved research studies to under-represented groups.

Anonymous statistical data produced from this analysis may be shared with researchers, the Department of Health and Social Care, the NIHR and other stakeholders and other relevant organisations. It may also be published. This statistical data will not identify you.

### **To contact you**

If you give us permission, your personal information will be used by the City of Research partners to keep you informed about the progress and outcomes of research. We will also keep you informed about developments in the Service to provide opportunities for you to take part in other types of research. This would include, for example, letting you know and about any changes to the Service, including any significant changes to this privacy notice. We will keep you informed by email via Mailchimp. There is more about Mailchimp below under 'Where we store your personal information'. These emails will be general, for example, newsletters, and will not be targeted to you as a result of any of the information you have provided. You can unsubscribe at any time from receiving these emails by using the unsubscribe functionality in the email, or newsletter, but, in doing this, you will also withdraw your permission to be contacted by researchers about UK-approved research studies.

## **To withdraw your permission to be contacted**

If you change your mind and would like to withdraw your permission to be contacted by researchers about UK-approved research studies, you can unsubscribe by using the unsubscribe functionality in the emails or newsletters we send you. This will withdraw your permission to be contacted by those researchers and by the City of Research partners; it will not withdraw your permission to participate in any study you may already have agreed to participate in. In order to withdraw your permission from a research study you have already agreed to participate in, you will need to contact the research team associated with that research study directly.

Where you withdraw your permission to be contacted by researchers about UK-approved research studies, the information collected about you through this Service will no longer be shared by the City of Research partners with researchers. Where your information has already been shared with a researcher, you may, therefore, still be contacted by researchers during this time. You will not be contacted by the City of Research partners.

When you have withdrawn your permission to be contacted, the information you provided through the Service, including the withdrawal of your permission to be contacted, will be retained by Mailchimp for legal reasons for 8 years. There is more about this below under 'How long we keep your personal information for'.

## **Updating your details**

If you need to update any of the information you have provided through the Service, you will need to use the unsubscribe functionality in an email or newsletter we have sent you and re-register for the Service with your updated information.

## **The types of personal information we use**

We will collect various types of information about you through the Service. As you go through the Service you will be asked various questions. We have summarised below why we need this information:

Full Name & For contact purposes only  
Telephone  
Number

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Address & We're asking this so researchers can contact you about research  
Postcode studies in your area.

Where you live will also help us to identify studies that may be more suitable for you.

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E-mail

We will share your email address with researchers working on UK-approved research studies, so that they can contact you about their study if it is suitable for you.

We will use your email to contact you about the progress and outcomes of research and future developments in the Service.

We may also use your email address to contact you about specific studies you might be interested in via a newsletter.

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Age Groups

We're asking this so we can make sure there is the right mix of people of different ages taking part in research studies. This is so we can make sure any outcomes developed will work for everyone. We may also wish to target certain age groups.

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Ethnicity

We're asking this so we can make sure there is the right mix of people of different ethnicity taking part in research studies. This is so we can make sure any outcomes developed will work for everyone. We may also wish to target certain ethnic groups.

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Gender/Sex Classification

We're asking this so we can make sure there is the right mix of people taking part in research studies. This is so we can make sure any outcomes developed will work for everyone. We may also wish to target different groups.

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Areas of interest

We're asking this so we can use your choices to provide you with information for a particular research study that falls within your areas of interest. We may also wish to target individuals with certain areas of interest, for example, diabetes research, cardiovascular disease research, stroke research, etc.

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\*There is a requirement for you to be over the age of 18 years old. If you are under 18, you will not be able to use the Service.

## **Who we share your personal information with**

The personal information you provide will only be shared with researchers working on UK-approved research studies, so that they can contact you about their study if it may be suitable for you. They will only be passed your details once they have completed the application process detailed below.

The researchers will only use your information to contact you by email, letter or telephone to invite you to take part in their study. They will contact you using their place of work's official email address. You should carefully check the email address from any email which looks to come from a researcher of a study to make sure it is genuine. You can find further information on how to spot the obvious signs of a scam/phishing attempt by visiting the [National Cyber Security Website](#), or [Action Fraud](#).

If you receive an email which is not from the researcher's work's official email address, for example, @bthft.nhs.uk, @nhs.net, or you have concerns that the email may not be genuine, you should contact us by email [bepartof.cityofresearch@bthft.nhs.uk](mailto:bepartof.cityofresearch@bthft.nhs.uk) .

Researchers will want to agree a time to discuss the study with you in more detail. If you decide to participate in their study, the researcher will ask you to give further permission to take part in that study. You may also be asked to provide identification to the researcher so that they can verify who you are.

Researchers of UK-approved research studies will be required to apply to City of Research partners to obtain your details, including your email address, to contact you. This Service makes sure that the researchers have a legal basis under the General Data Protection Regulation and Data Protection Act 2018 to use your information, the application is relevant to health and social care research and that it will be used safely, securely and appropriately for their study.

## **How long we keep your personal information for**

We will retain your information for legal purposes for 8 years when we will review the situation and either destroy or retain your information for further use. If we decide to retain your information we will contact you and inform you of the legal basis for continuing at this time.

If you have agreed to participate in a research study, the research study will need to keep your information for longer than this. The researcher for the study will tell you how long they need to use your information for when you agree to take part in their study. This will also be in their privacy notice.

In the meantime, if you withdraw your permission to be contacted through the Service before the end of 8 years, the personal information you provided will be retained by Mailchimp for legal purposes for 8 years from the date you withdrew your permission.



Eight (8) years is the time period recommended for keeping standard care records under the [Records Management Code of Practice for Health and Social Care 2016](#).

## Where we store your personal information

The City of Research partners process your personal information for this Service in the United Kingdom. We subscribe to a third party marketing tool called 'Mailchimp' to hold your information on our behalf. Mailchimp servers are located in the United States. Mailchimp's privacy notice is available at <https://mailchimp.com/legal/privacy/>

Your personal information will only be shared with researchers of UK-approved research studies. They may store data outside of the UK but this will only be permitted where this complies with the General Data Protection Regulation (GDPR). The City of Research partners will ensure this is allowed under GDPR when we are considering their application for access to your information. Anonymous data, for example, statistical data, which does not allow you to be identified, may be stored and processed outside of the UK by those with whom we have shared anonymous data and when it is published by us.

## Your rights over your personal information

You have the following rights in relation to your personal information obtained through the Service:

- the right to be informed about how your personal information is being used **(be informed)**;
- the right to access the personal information **(get access)**;
- the right to request the correction of inaccurate personal information **(rectify or change)**;
- the right to request the erasure of your personal information in certain limited circumstances **(erase or remove)**;
- the right to restrict processing of your personal information where certain requirements are met **(restrict or stop processing)**;
- the right to object to the processing of your personal information in certain circumstances **(object to processing or use)**;
- the right to request that elements of your data are transferred either to you or another service provider in certain circumstances **(move, copy or transfer)**;
- the right to object to certain automated decision-making processes using your personal information **(know if a decision was made by a computer rather than a person)**; and
- the right to raise a concern with NHS Digital and the [Information Commissioner's Office](#) at any time **(raise a concern)**.

More information about your legal rights can be found on the [Information Commissioner's website](#).

Please note that some of these rights do not apply in relation to the processing of your personal information by us through this Service due to the specific requirements and exemptions which apply to them. The rights which do apply in relation to the

personal information we process as part of this Service are set out in summary form below.

## Summary of your rights

Summary of your rights over your personal information

<b>Rights</b>	<b>Where we are relying on public task (Article 6(1)(e) of GDPR above)</b>	<b>Where we are processing for scientific research and statistical purposes in relation to anonymous statistics (Article 9(2)(j) of GDPR above)</b>
Be informed	Yes	Yes
Get access	Yes	No
Rectify or change	Yes	No
Erase or remove	No	Yes
Restrict or stop processing	Yes	No
Move, copy or transfer	No	Yes
Object to processing or use	Yes	No
Know if a decision was made by a computer rather than a person	Yes	Yes
Raise a concern	Yes	Yes

If you decide to participate in a research study, you will be provided with a privacy notice by the researcher before agreeing to participate in their study. This will explain how the researcher will use your personal information and your rights in relation to this. Your rights may be different from those above.

## Contact us

If you have any queries in relation to the use of your personal information in connection with the Service, or if you want to exercise any of your rights above, please contact [bepartof.cityofresearch@bthft.nhs.uk](mailto:bepartof.cityofresearch@bthft.nhs.uk) . Bradford Teaching Hospitals NHS Foundation Trust's Data Protection Officer is Jennifer Pope, whose duties include monitoring internal compliance and advising the organisation on its data protection obligations. You can contact her at [dataprotectionofficer@bthft.nhs.uk](mailto:dataprotectionofficer@bthft.nhs.uk) .



## Contact the Information Commissioner

If we are unable to resolve any queries or concerns in relation to the use of your personal information in connection with the Service, you can raise your concern with the Information Commissioner. You can contact the Information Commissioner's Office:

- using the online [Contact Us](#) service
- by calling 0303 123 1113
- by writing to the Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF