

# Information for Disabled Volunteers

### Introduction

The NIHR BioResource is an organisation that plays a crucial role in advancing research on various health and medical conditions. We are committed to bringing together researchers and willing volunteers to contribute to leading health research that will benefit everyone.

## Why volunteer with the BioResource?

We understand when it comes to entering a medical environment, some disabled people may feel certain anxieties. Here at the BioResource we want the health research experience to be welcoming, accessible and inclusive for all. Some reasons we would love you to volunteer with us include:

 Advocacy: Participation in health research enables people to advocate for improved healthcare, treatments, and support systems. By sharing your experiences and insights, you can help researchers and healthcare providers better comprehend the barriers you face, ultimately leading to the development of more inclusive and effective treatment solutions.



- shaping Inclusive Practices: The social model of disability underscores the importance of societal change to create inclusive environments. By volunteering for research with the BioResource, you become part of our mission to shape inclusive practices and policies within the healthcare system. You can also contribute to the BioResource's understanding of accessibility needs and highlight areas where improvements are necessary.
- Simplicity, Safety, and Security:
  The BioResource aims to make participating in health research simple, safe and secure. Volunteers can donate a blood sample at one of our 18 centres across England, or send a saliva sample via post. We adhere to the strictest guidelines and best practices for keeping your samples and data safe and secure.

When researchers request access to your data and samples, they must undergo extensive vetting and approval by our Governance and Ethics team and Steering Committee. Patients and the public are at the core of the BioResource, so applications are also reviewed by members of our Patient and Public Advisory Groups. You may withdraw your consent for us or researchers to use your information at any time, and request that we destroy any samples or data we hold.



### **Our Commitment**

The BioResource is deeply committed to ensuring that disabled volunteers have fair and equal access to participation. To achieve this, we have designed our facilities and materials with accessibility in mind, ensuring that everyone can engage comfortably. We understand that the needs of disabled individuals vary, so we offer flexible schedules and accommodations that cater to each individual's unique requirements. Additionally, our team consists of dedicated professionals who are readily available to assist and guide disabled volunteers, making their experience with us as seamless and fulfilling as possible. We're wholeheartedly committed to promoting inclusivity and ensuring that everyone, regardless of their abilities, can actively participate in our programme.



### **Our Processes**

- Read and sign a consent form.
- Provide your name, date of birth, NHS/
   CHI number and contact details and allow us to store them.
- Complete a questionnaire about your health and lifestyle.
- Allow us to collect, store and analyse health information about you, including accessing your medical records, other health-related records, (for example, through NHS Digital or other databases), educational (if required) and social care records.
- Donate a small sample of blood (3-4 teaspoons) or saliva; in the future, you may be invited to provide further samples.
- Agree to be contacted in the future about research studies, including clinical trials, which we believe you are suitable for based on the information we hold. You will be provided with information about any study you are eligible for, and you can decide whether you would like to take part. You are under no obligation to do so. We will monitor how often you are approached. We are happy to contribute towards any travel costs. Some research will not need any further input from you as the samples and data you provide will be enough.
- Agree to be contacted by the BioResource about updates, newsletters, invitations to open events, etc. You can choose not to receive these if you prefer.

#### Contact Information

- Website: https://bioresource.nihr.ac.uk
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