Designability Privacy Notice – User Engagement and Research Participants

About This Notice

This privacy notice can be made available in alternative formats, including Easy Read, large print, audio, or BSL supported formats, by contacting research@designability.org.uk or calling us on 01225 824103.

About Us

Designability is a national charity that creates innovative products and services with and for disabled people, removing barriers and helping them to live with greater independence.

For us to carry out our activities, we often need to collect information about your lived experience of disability. We recognise the importance of your privacy, and Designability is committed to ensuring that your privacy is always protected.

This notice indicates what kind of personal information Designability collects from people who help us carry out research, why we need it, how we use it, and what measures are in place to keep it secure. For this notice, Designability is the *"data controller" meaning* we alone, or jointly with others, determine the purposes and means of the processing of personal data.

Data Protection Principles

When you take part in our research, we will:

- **Be clear and honest about how your information is used.** We will explain how we use your information, the lawful bases we rely on, and your rights. Where we rely on consent, we will ask for it clearly and separately, and you can withdraw it at any time. Where we process special category information, such as information about your health, disability, ethnicity, religion, sex life or sexual orientation, we will only do so where the law allows and appropriate safeguards are in place.
- **Only collect information that we genuinely need.** We will only ask for the minimum personal information necessary to carry out the research and understand people's experiences.
- **Only use your information in the ways we have explained to you.** If we ever want to use your information for something new, we will tell you and ask permission, where required.
- **Take reasonable steps to make sure your information is accurate and up to date.**
- **Only keep your information for as long as it is needed for the research, or where we are legally required to keep it.**

- **Keep your information safe and secure.** We use appropriate safeguards to protect your information and make sure it is not lost, misused, or shared in ways you would not expect.

Our research is carried out in line with UK data protection laws, including the UK GDPR, the Data Protection Act 2018, and the Data (Use and Access) Act 2025 where applicable. Where we use special category personal data for research, we do so only where a valid condition applies and with appropriate safeguards designed to protect participants.

What Do We Collect?
Our research aims vary by project. This means we may ask for different information from you for each project. For every piece of research, there will be clear information outlining the purpose of the work and the information we wish to collect from you, how it will be collected, and how we will use it.

Where a project requires your agreement to take part, we will explain this clearly before participation. We will also explain the lawful basis we rely on for processing your personal information for that project.

Type of information we may collect	**(Some examples of what this might include)**
Information about you	Name, address, age, nationality, ethnicity, religion, gender, sex, details of any disability, and its impact on your day-to-day life. Job role, whether you have parenting / caring responsibilities. We collect this information in line with best practice wording used by national surveys, like the Office for National Statistics and Scope, who campaign to transform attitudes to disability, tackle injustice and inspire action. We do not routinely use solely automated decision-making, including profiling, to make decisions about you that have legal or similarly significant effects. If this changes, we will update this notice and explain your rights.
Contact information for you	Name, address, telephone numbers, email address.
Emergency contact information / accompanying person	Name, preferred contact method.

Information needed to pay agreed expenses	Bank account details, email address.

When And How We Collect Your Data

We collect data about you in a variety of ways, e.g. surveys, interviews and workshops. In some cases, we will collect data about you from third parties, such as other organisations undertaking relevant research. These third parties will ask your permission before they share your information with us, and formal data sharing agreements will be in place between parties.

Why We Collect And Use Your Data

We only use your personal information where we have a lawful basis to do so under UK GDPR. Depending on the nature of the research activity, this may include your consent, our legitimate interests in carrying out charitable research and user engagement, compliance with a legal obligation, or processing that is necessary for reasons of substantial public interest or for scientific or statistical research purposes where the law permits this and appropriate safeguards are in place. Where we process special category personal data, such as information about your health or disability, we will identify a valid condition under Article 9 UK GDPR and Schedule 1 of the Data Protection Act 2018 where required. E.g.

- Scientific research / statistical purposes with safeguards
- Substantial public interest
- Explicit Consent

We will not use your personal information for other purposes within Designability unless we have told you about this and, where needed, obtained your consent. For example, if you choose to work with our Marketing and Communications team to help share the research or raise awareness of our charitable work, this would be covered by a separate privacy notice.

Reason for collecting your personal information	**Some examples of what this might include**
Research and participation	• To help us choose individuals to take part in research projects • To contact and communicate with participants about research activities • To arrange and carry out interviews, surveys, workshops, and co-design activities • To provide accessibility adjustments or support needed to help people take part

	• To analyse research findings and identify themes, trends, and insights • To produce research reports, publications, and recommendations (information is anonymised unless you have given explicit permission otherwise)
Participant wellbeing and safeguarding	• To support safe and ethical participation in research • To respond appropriately if wellbeing or safeguarding concerns arise during participation • To ensure participation is voluntary and appropriate for all
Payments and reimbursements	• To process participant payments, incentives, or reimbursements such as travel expenses • To maintain financial records and audit trails
Legal and regulatory obligations	• To comply with our legal obligations, including maintaining financial records in line with requirements from HM Revenue and Customs • To comply with charity, safeguarding, insurance, or regulatory requirements • To respond to lawful requests from regulatory or public authorities where required
Funded research requirements	• To meet contractual or reporting requirements linked to grant funded research projects • To comply with funder-specific data retention or monitoring requirements
Improving our services and charitable work	• To help us understand barriers people face and improve products, services, and design guidance • To evaluate the impact of our research and charitable activities • To improve how we design and deliver inclusive research and engagement
Communications and storytelling (only with consent)	• To share participant experiences, case studies, or content that helps raise awareness of barriers and promotes our charitable aims • This will only happen where explicit consent has been given

Consent

Where we rely on your consent, we will ask for it clearly before you take part and, where relevant, separately for additional uses such as future contact or communications activity. You can withdraw your consent at any time. If you decide to withdraw, there will be no penalty for doing so and it will not affect your ability to take part in future projects.

Withdrawal will not affect processing that has already taken place lawfully before your consent was withdrawn and, in some cases, we may need to retain limited information where this is required by law or to maintain the integrity of research records.

You should not share another person's personal information with us unless it is both necessary for the research or activity and you are legally authorised to act on their behalf, e.g. have parental responsibility or legal guardianship.)

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Sharing Your Data

To support our research work, we may share personal information with a small number of trusted organisations and service providers where this is necessary for the relevant project.

These may include survey and form providers, secure data storage and IT providers, payment processors, accessibility support providers, transcription or analysis providers, partner organisations involved in the research, funders where reporting is required, and professional advisers or regulators where the law requires this. We only share the minimum amount of information necessary for the specific purpose.

Where possible, your information will be processed in the UK. If personal information is transferred outside the UK, we will ensure that an appropriate safeguard is in place, such as an adequacy decision or approved contractual safeguards, and we will provide more information on request.

Designability is a charity and not a support, benefits, or statutory decision-making service. We do not share information you provide for research, or the fact that you later withdraw from a project, with organisations that provide support or benefits unless you ask us to do so or we are legally required to do so.

Designability does not sell your information to any third parties.

How We Protect Your Data

Appropriate controls are in place to store and protect personal data. We have security procedures in place to guard against unauthorised access, improper use, alteration, destruction or accidental loss of personal information. Information is only accessible by personnel authorised to do so as part of the research project, and data is stored and transmitted securely using methods such as encryption, anonymisation, or password protected files on data sets, held in secure password management systems.

Anonymised data that falls outside of the scope of data protection legislation (as it contains no identifying or identifiable information) may continue to be stored by Designability for the purposes of statistical analysis.

We use systems and processes designed to protect research participant information with appropriate technical and organisational measures. All staff at Designability receive regular training in information governance and handling personal data, including the requirements of the UK GDPR and the Data Protection Act 2018. We also consider our duties under equality and accessibility legislation when designing and delivering research.

How Long We Keep Your Data

In line with data protection principles, we only keep your personal data for as long as it is necessary for the relevant research purpose, to meet legal, accounting, insurance, safeguarding, or funding requirements, or to establish, exercise, or defend legal claims. The

retention period may vary depending on the nature of the study and any funder or regulatory requirements. We will explain any project-specific retention period at the start of the project where this differs from our usual approach.

Data will be securely destroyed when no longer needed, or anonymised.

Your Data Protection Rights

Under data protection law you have legal rights concerning personal information held by us, including

- The right to be informed
- The right of access
- The right to rectification
- The right to erasure
- The right to restrict processing
- The right to object
- The right to data portability, where applicable
- Rights in relation to automated decision-making, where applicable

We aim to ensure that the information we hold about you is accurate and up to date. You can ask for a copy of the personal information we hold about you, ask us to correct inaccurate information, and in some circumstances ask us to delete or restrict the use of your information, object to processing, or receive a copy of information you provided to us in a portable format where that right applies. Some of these rights may be limited where an exemption applies under data protection law, including certain exemptions for research, statistics, or archiving where appropriate safeguards are in place.

Similarly, at the point a deletion request is made, personal data may already have been incorporated into anonymised or aggregated analysis. Whilst anonymised analysis cannot usually be altered or removed, we will delete associated identifiable personal data, wherever possible.

If you wish to exercise any of your rights or ask questions about how we handle your personal information, please contact a member of the research team in the first instance. If they are unable to assist, or if you wish to raise a complaint, please contact Designability's Data Protection Officer using the details below.

Requests and complaints

If you submit a subject access request or another data protection request, we will respond within the time required by law. If we need further information from you to identify the information requested or to confirm your identity, the time for responding may be paused until we receive the clarification we reasonably need.

If you raise a concern or complaint with us about the way we have handled your personal information, we will acknowledge it as soon as possible, but no later than 30 days from

receipt, and will investigate it in line with our complaints process. We will respond without undue delay, in line with our legal responsibilities.

We keep a record of data protection complaints so that we can investigate them properly and explain the outcome and any available escalation options.

You can change how we contact you, discuss our use of your personal information, or raise a concern or complaint with us using any of the contact methods below

By email: DPO@designability.org.uk Tel: **01225 824103**

In writing to: **The Data Protection Officer, Designability Charity Ltd, Wolfson Centre, Department D1, Royal United Hospital, Combe Park, BATH, BA1 3NG**

If you wish to make a complaint, you may also use our online form, in addition to the other contact methods listed above. Data Complaints Form – Fill in form

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office https://ico.org.uk/global/contact-us

Designability is registered with the Information Commissioner's Office under number Z6810677, is a Registered Charity under number 256335, and a Registered Company limited by guarantee under number 933932 (England and Wales)

Changes To Our Privacy Notice

Designability may update this Privacy Notice from time to time to reflect changes in the law, our research activities, or the way we handle personal information.

This Privacy Notice is the latest published version. We will make updated versions available through our usual channels.

Date of Update	Reason
16/06/2025	To comply with the Data (Use and Access) Act 2025