



The National Development Team for Inclusion (NDTi) would like to invite you to take part in our project, Living on the Edge. Before you decide whether you are happy to participate, we would like you to understand why the research is being done and what it would involve for you. We will be happy to answer any questions you have. Please ask us if anything is not clear.

## **Purpose of the project**

NDTi wants to find out what life is like for people “living on the edge” with uncertainty or things that make life difficult. These are people who are not eligible for formal care and support from statutory services, but still need support. It’s the people who will fall through the gaps in communities, and society, if community organisations/individuals are not there for them.

People might be ‘living on the edge’ because they are going through a change or have multiple challenges.

We want to know more about the things that help people live well, and the challenges they face. This is so that we can understand how we could support the organisations that make positive difference in people’s lives. We think we could bring people together to learn from each other in the future.

We want to hear from people we often work with, including disabled, autistic, and older people. We're also keen to hear from those we work with less often including those from a variety of backgrounds such as refugees, people from different cultures, races, faiths, genders etc who live in the UK. We want to understand how people’s unique personal experiences and backgrounds affect the support they receive in their lives.

## **Why have I been invited to take part?**

You have been invited to take part as you are someone who is supported by a voluntary organisation or someone we know, or maybe someone told you that you might be interested in sharing your story. As part of the project it is very important that we hear from a range of people and we would like to hear your views and experiences.

## Do I have to take part?

It is up to you to decide whether to take part in. If you agree to take part, we will then ask you to sign a consent form. Whether or not you choose to take part it will not affect the support you receive from any voluntary or statutory services or organisations

## What will happen to me if I take part?

If you decide you would like to take part, you can do so in a variety of ways.

You could:

- Have a conversation with a member of the team
- Send us a short video of yourself
- Send us a voice note
- Write to us – send us an email, write a piece of poetry.
  
- Send us some pictures and have a chat with a member of the team to explain them
- Work with a member of the team to create a map of your life (a life map)
- Fill in a short online story form

We want to hear from you in a way that is comfortable for you.

We would like to know about the things that happened in your life that have been challenging, and what has helped, and what your life is like now. You might have support from a community organisation and could tell us how they have supported you.

If you choose to have a conversation with a member of the team, we can do this online, over the phone or in person. The conversation is likely to last no more than 45 minutes, or 1 hour 30 minutes if you are creating a life map. We will take written notes during the conversation, and may audio record it as well, if you agree. We will always let you know if you are being recorded and check with you first.

You can choose not to answer questions and you can choose to stop at any time.

## What will happen if I change my mind about taking part?

You can choose to withdraw your story for up to a month after sharing your experiences with us. You do not have to give a reason for withdrawing.

If you choose not to take part any more, you can then choose whether:

- we keep the information you have shared with us; or
- we destroy the information you have shared with us.

Please tell one of the NDTi team if you want to withdraw.

## How will you use the information I give you?

The contact information you give us will be used to make arrangements with you to take part in.

Everything you tell us will be kept confidential within the NDTi team. We may include things you say in our reports as quotes, but we will not use your name or any other information that will identify you. The exception to the confidentiality agreement is if you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else, unless we feel doing so poses a risk to anyone.

The information we get from you and other people taking part in the project will help us learn and better understand the things that are impacting people's lives and the things that can help. We hope that we will be able to use the learning to make changes in the future, through our work with organisations that support people. Findings may also be shared publicly, for example on NDTi website and through social media.

## What will you do with my personal information, and what rights do I have?

Your name, contact information and any other personal details you choose to share with us, will be stored electronically on NDTi's internal ICT systems and are compliant with the official level of the Government Security Classifications Scheme, meets the requirements as outlined within the Cyber Essentials Scheme and are compliant with the General Data Protection Regulations (2018). Access to the information will be restricted, and only key members of the team working on the project will be able to access it. Notes from conversations will be anonymised at the first opportunity to do so and kept separately from your personal information.

Your personal information will be stored for up to 12 months after the research ends, and then we will delete it.

Under General Data Protection Regulation (GDPR), we need to tell you what the legal basis for us processing your personal information is. This is 'consent' – through reading this information sheet, agreeing to participate and signing the consent form, you are consenting to us processing the personal information detailed above for the purposes of this research.

Your rights regarding your personal information are detailed below. You can exercise your rights at any time, by making a request to NDTi's Data Protection Officer either verbally or in writing.

**The right to be informed** - This Participant Information Sheet provides you with information about how we will process your personal data and keep it safe, how long we will keep your personal data and, if applicable, who we will share it with.

**The right of access** - NDTi have processes in place to ensure that we respond to a subject access request without undue delay and within one month of receipt.

**The right to rectification** - You have a right to have inaccurate personal data we hold about you rectified, or completed if it is incomplete. We have one calendar month to respond to your request. In certain circumstances we can refuse a request for rectification.

**The right to erasure** - You can ask that we erase your personal data.

## Expenses and payment

We are not paying anyone to take part in the research, however everyone who takes part will be put into a prize draw with the chance to win a £20 voucher.

## Risks or benefits of taking part

You may find sharing your experiences with us upsetting. Please only share what you feel comfortable sharing. You do not have to share anything you do not want to with us. If you choose to have a conversation with a member of the team, you do not have to answer any questions that you find too sensitive or difficult. You can also take time out of the conversation if you would like a break or you can stop at any time.

We hope that you will enjoy sharing your experiences. We also think that other organisations and individuals will benefit from hearing about your experiences.

### **Who is organising and funding the project?**

The National Development Team for Inclusion (NDTi) is the organisation leading this research. NDTi is a not-for-profit organisation working to enable people at risk of exclusion, due to age or disability, to live the life they choose. To find out more about NDTi please call 01225 255 268 or visit our website: [www.ndti.org.uk](http://www.ndti.org.uk)

The project is funded by NDTi. We have taken the decision to invest in this work as we think it is important to address.

### **Further information and contact details**

If you need any more information, or would like to talk about any part of the research, please contact Madeline Cooper the Project Manager [madeline.cooper@ndti.org.uk](mailto:madeline.cooper@ndti.org.uk), or Rebecca Krzyosiak the Project Administrator on [Rebecca.Krzyosiak@ndti.org.uk](mailto:Rebecca.Krzyosiak@ndti.org.uk)

### **What if I want to exercise my rights under GDPR around the personal information that is held about me?**

You can do this at any time, by making a request to NDTi's Data Protection Officer either verbally or in writing. NDTi's Data Protection Officer is Sally Richens, Director of Resources, NDTi, 4 Queen Street, Bath, BA1 1HE. Telephone: 01225 255 268. Email: [office@ndti.org.uk](mailto:office@ndti.org.uk).

### **How can I complain to the Information Commissioner's Office?**

Whilst we encourage that you discuss any concerns you may have about how NDTi hold or process your data with our Data Protection Officer, you have the right to complain directly to the Information Commissioner. The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF. Telephone: 0303 123 1113. Website: <https://ico.org.uk/concerns/>.

## Introducing the Team

The team who will be conducting the fieldwork include:



**George Evans**



**Gordan Waigand**



**Lyn Griffiths**



**Madeline Cooper**



**Vicky Mason-Angelow**



**Shameem Nawaz**