Research Project exploring peer-to-peer Networking between people who Self Direct their Support

Information Sheet

Introduction

We would like you to help us with an upcoming research project organised by Open Lab, Newcastle University in collaboration with Disability North. You can get involved by participating in two workshops or an optional individual discussion. The project aims to shape design ideas for a local peer-to-peer exchange network tailored for your area for people with experience of self-directing their support. We will do this through workshops, individual and group discussions and design exploration. Two workshops are planned exploring how digital technologies could support exchanges of information or advice, skills or resources in a local context between people like you who have opted for more control over their support. The expected outcome is to create design ideas about how you think such a concept might work. It is envisaged there may be potential to develop design ideas further in a second phase. This information sheet provides you with more detail to help you decide whether or not you wish to take part in the project before you sign our consent form. Please read it carefully and if you wish discuss with others as you reach a decision. Should you agree to take part, be reassured you are free to withdraw at any time, there is no need to give a reason.

Who would we like to take part in the study?

We are looking for adults with experience of self-directing their support using a personal budget which they directly manage, who opted for control over how their support is organized. In particular we are keen to hear from individuals open to thinking about networking with others who made similar choices and who may live in the same area.

The primary researcher is Siobhan Macfarlane. She is undertaking the research as part of a Doctoral Trainee program in Digital Civics at Open Lab, Newcastle University. Siobhan and the research team plan to facilitate two workshops held at the Dene Centre/Disability North to explore what works well within your local network as you currently self manage your support and to uncover ways you might consider sharing your experience or ideas with others in a similar situation. We also want to understand aspects you think are lacking. In this way, we can start a discussion about practical solutions and collective ways to overcome obstacles or barriers to inclusion. The intention is to enrich options for each person to take part in their communities however they choose.

What will I be asked to do?

We would like you to take part in two half day workshops to be held at Disability North. The workshops will involve activities which are informal and easy to do. The aim is for people to feel relaxed and share ideas so your contributions can influence design outcomes. We would also like to meet some of you individually for focused discussion about how you benefit from self-directing your support, what this decision means for you and what knowledge, resources or ideas you might be prepared to share with other local people living with personalised support. Individual meetings can take place at Disability North, Newcastle University or a suitable place of your choice. Participants will be encouraged to raise questions throughout and discuss the work we do together. Our aim is that your contributions are valued.

Will my expenses be met?

Yes, we value your opinions and insights. A retail voucher for £20 will be available for taking part in an individual discussion and a retail voucher for £20 will also be available if you have given time to workshop attendance. We recognise not everyone will manage attendance at two separate workshops, however where possible we would appreciate participants aiming to attend both. Alternatively, you can opt to take part in an individual meeting only.
In addition, we will reimburse you for travel expenses incurred to attend the workshop or individual meeting, and refreshments will be provided for attendees during the sessions.

Will my taking part in this study be kept confidential?

Yes. All information collected during the course of this research, which might include our notes, things you write down or make during our workshops or meetings, and photos or audio recordings of our activities, will be kept confidential to the investigators and examiners of this project. Co-participants in workshops will also be asked to understand and respect workshop ground rules on confidentiality. All data will be kept securely at Newcastle University in a locked location or password protected on secure university equipment.
We would like to audio record workshops and individual meetings to aid recall of what has been discussed. After data collection is complete, it is anticipated insights and design ideas from the project may be shared with the project research partners including Disability North. These findings will be anonymised and in the event that we publish the work, any quotation or detail of contribution will be anonymously attributed using a pseudonym or participant number. At the end of the project a final report from the study will be available to read.

Will I be able to change my mind about taking part?

Yes. At any time you can withdraw from the project if you feel you no longer wish to take part. Please tell the lead researcher or a member of the project team or Disability North staff and arrangements can be made for any records of your contribution to be destroyed.

Contacts for further information

Should you wish to learn more about any aspect of the study, or about findings once the project has finished, you can get in touch using the contact details below:

Siobhan Macfarlane can be emailed on S.Macfarlane2@newcastle.ac.uk

or alternatively her supervisor Jennifer Liddle on Jennifer.Liddle@newcastle.ac.uk

Both can be contacted via the Research Group on: +44 191 20 84642 I 84630

This research project is undertaken as part of the Digital Civics Doctoral Trainee programme.

More information can be found at http://digitalcivics.io/. Digital Civics is part of Open Lab http://openlab.ncl.ac.uk based within Newcastle University.

Thank you for taking the time to read this.