# Participant Plain Language Statement

# Research Project: Evaluation of the North East Melbourne (NEMA) Local Area Coordination (LAC) Service

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Thank you for your interest in participating in this research project.

This is a **Participant Information Sheet** for research. We call a person who takes part in research a participant.

These pages give some details about the project. Please take some time to read them.

We have set out the questions you might want to ask, with our answers, so that you can talk about them before you decide if you would like to take part.

You may ask questions about anything you don’t understand or want to know more about.

Please contact Amanda Pagan, by phone: 0416156500, or email apagan@bsl.org.au if you want more details.

### Why is the research being done?

To get access and funded supports through the NDIS, you would have some experience and exposure to Local Area Coordination (LAC).

Both the Local Area Coordination (LAC) service and the National Disability Insurance Scheme (NDIS) are new to The Brotherhood of St Laurence, and we want to keep improving over time.

So, the North Eastern Melbourne Area (NEMA) LAC Evaluation is designed to look at how LAC can better: improve its practice; support people with disability to implement their plans; and work with communities to be more inclusive.

### What will you be asked to do?

If you agree to participate, you will have a range of ways to take part. These include:

* Answering **Research Survey** questions sent to you by email (up to 5 emails) about your experience with: mainstream and community supports; planning; choice and control and other aspects of the NDIS (up to 20 mins per survey).
* Participating in **Themed Focus Groups** (up to 4) with other NEMA LAC participants to further develop opportunities that LAC could support communities to be more inclusive and/or provide opportunities for people to achieve their aspirations and dreams (up to 6 hours, including travel per focus group). Focus groups are themed around the key feature of LAC and the NDIS. You can choose one or more focus groups depending on your interests:
  + **Focus Group Theme 1: Community Inclusion** to discuss the mainstream services you use, the extent they meet your needs and if you face any barriers to getting what you need. We would like to know what Community Inclusion means to you.
  + **Focus Group Theme 2: Independence, Choice and Control** to talk about how you feel about your ability to advocate for what you want, either with a service provider or in life.
  + **Focus Group Theme 3: Planning, Choice and Control** to talk about how you feel about your ability to advocate for what you want in your plan.
  + **Focus Group Theme 4: Individual and Community Capacity Building** to talk about your experience of developing your plan with LAC. One of the roles of LAC is to support participants in the NDIS to develop capacity over time in relation to your plan. We would like to know what capacity building means to you.
* Participating in a **Panel Discussion** with fellow LAC participants and some staff to further develop actions that improve service delivery of LAC (4 hours, including travel per panel day).
* Participating in **Individual Interviews** to understand how you are experiencing LAC and the NDIS (3 hours, including travel per interview).

### Who will be in the research project?

We are hoping to hear from lots of participants. The Research Surveys will be sent to all participants by email. Each focus group will include up to 6 people with a disability who have an experience of the LAC service. The Panel Discussion will include approx. 12 people including those with a disability and some LAC staff. This panel will not include LAC staff who have a planning relationship with you or any other participants with a disability who take part in the panel. We are doing this to avoid any concern that you or others may feel about providing critical feedback on the NDIS and the planning process provided by LAC.

### Do I have to take part?

No. You decide if you want to take part in research or not. Even if you say ‘yes’, you can drop out at any time if you change your mind.

### Do I have to decide now?

If you are not sure about joining the research, ask for time to think about it. Most kinds of research can wait. You may want to talk to your family or friends before you decide.

### What will happen if I say ‘no’?

You may worry about saying no, if your Local Area Coordinator first talked to you about the research. We want to make it clear that even if you refuse, your Local Area Coordinator will go on giving you the best support that they can.

### Will doing the research help me?

We hope you enjoy talking to us. The main aim is to encourage participation of people with disability in all stages of the research and to create a sense of ownership and empowerment in your local region and the role of the LAC within the region;

Participation will provide you with the opportunity to:

* Have a say in the delivery and design of your local LAC service;
* Meet with other people with disability to make the NDIS better;
* Develop your experience and exposure with research and researchers;
* Be paid for sharing your expertise in Focus Groups, Individual Interviews and a Discussion Panel.

### What are the possible benefits for the community

We believe that the success of the NDIS in your community relies on the voices of people with disability being at the centre of developing LAC. This will mean more community ownership and help to find new ways to drive communities to be more supportive and inclusive, so that the dreams and aspirations of people with disability can be achieved.

### Could there be any problems for me if I take part?

We believe that the risks of participating in this research are low. A possible risk to you, that we will work hard to prevent, is that you may not feel empowered or heard as a result of participating in the research. To manage this, training and support will be provided by the research team throughout the evaluation period.

### Who will know if I am in the research or what I have talked about?

All information will be kept anonymous and confidential. At this stage we do not think the data will be reused for any other purposes or for future research. However, if this changes, we will seek your consent to use it.

### Will I know about the results of this project?

Yes. Our aim is to have the results of the evaluation made available at each LAC location in both report and visual format.

### What will happen next if I decide to take part?

If you agree, a member of the research team will phone you to arrange a meeting in person. This meeting is to make sure that you know what you are being part of and a time for you to ask a researcher some questions. Assuming that you still want to take part, the research team will write a letter confirming the research activities, dates and times.

The research project is funded by the Brotherhood of St Laurence.

If you have any concerns about the process please contact Janet Cohen, Chair BSL Human Research Ethics Chair, on telephone (03) 9438 1364, or email j.douglas@bsl.org.au.

**Thank you for reading this Participant Information Sheet.**

If you take part, please keep this leaflet with the copy of your consent form.