1. **What is the research study about?**

You are invited to take part in this photovoice research project.

**Photovoice** is a participatory photographic research method. It will involve People with Intellectual Disability (PwID) taking photographs that visually represent how they contribute to family, friends, community and our planet.

The research project aims to:

* Develop an understanding of what contribution means to PwID.
* Gather content that can inform the creation of an assessment that measures contribution.

We are also interested in what community members think about the contributions of PwID.

1. **Who is conducting this research?**

The study is being carried out by the following researchers:Dr Samuel Arnold (UNSW), Prof Keith McVilly (University of Melbourne), Prof Julian Trollor (UNSW), Adjunct Prof John Walsh AM (The University of Sydney), Prof Gigi Foster (UNSW), Prof Karen Fisher (UNSW), Dr Suzy Green (The Positivity Institute).

**Research Funder:** This research is being funded by Endeavour Foundation Disability Research Fund

1. **Inclusion/Exclusion Criteria**

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

* Adults aged 18+ years old
1. **Do I have to take part in this research study?**

This information sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about.

Participation in this research is voluntary. If you do not wish the person you support to take part, they do not have to

If you decide you want to take part in the research study, you will be asked to:

* Read the information carefully (ask questions if necessary);
* Sign and return the consent form if you decide to participate in the study;
* Take a copy of this form with you to keep.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with professional staff or your relationship with UNSW.

1. **What does participation in this research require, and are there any risks involved?**

If you consent to participating in this study, you will be asked questions about your attendance at a gallery event.

The **gallery event** will present the photographs and contribution story of PwID. You will be asked to answer questions about your experience at the gallery event.

You will be invited to have one-on-one discussions with the researchers during the gallery event. With your permission the research team would like to audio and/or video record these discussions. If you agree, your comments will be recorded during this discussion. The researchers will be able to withdraw or destroy your individual response if requested.

**Additional Costs and Reimbursement:** There are no costs associated with participating in this research project.

**Psychological Distress:**

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may tell us they wish to skip it and go to the next question, or may stop immediately.

If you become upset or distressed because of your participation in the research project, the research team will be able to recommend counselling or other appropriate support. E.g., we can assist you in contacting your GP to discuss the possibility of attending sessions with a psychologist. Please contact a member of our research team, Dr Samuel Arnold, on 02 9385 0620 or samuel.arnold@unsw.edu.au, who can help to arrange this support.

Alternatively, a number of free contactable support services are included at section 9.

1. **What will happen to information about me?**

By signing the consent form, you consent to the research team collecting and using information about you for the research study. Their information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

Electronic data collected will be stored on UNSW servers that require UNSW staff authorization and a password to gain access. Individual logins must be used to access files. Access levels are set by UNSW IT. Data will be stored in adherence to UNSW IT Security Standards and Guidelines Policy.

Hard copies of consent forms collected will be stored in a locked cabinet at the Department of Developmental Disability Neuropsychiatry, UNSW Sydney, 30 Botany Street, UNSW Sydney, Sydney 2052. Access to this data is restricted to research team members.

Audio or video recordings of you will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators. It will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed. Separate photography and videography release forms seek consent for photos’ and / or videos taken to be used in public gallery events, publications or websites.

Data will be retained for 5 years post publication of resulting manuscripts. After this time, electronic data will be permanently deleted from all storage devices and paper-based data will be shredded.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [**UNSW Privacy Management Plan**](https://www.legal.unsw.edu.au/compliance/privacyhome.html).

1. **How and when will I find out what the results of the research study are?**

The research team intend to publish and/ report the results of the research. Identifiable information (photographs / videos) will be published or disseminated publicly only once the people identifiable in the photographs or videos have signed release forms.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

1. **What if I want to withdraw from the research study?**

If you do consent to participate, you may withdraw at any time. You can do so by completing the ‘Withdrawal of Consent Form’ which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

1. **What if I have a complaint or any concerns about the research study?**

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

**Complaints Contact**

|  |  |
| --- | --- |
| **Position** | UNSW Human Research Ethics Coordinator |
| **Telephone** | + 61 2 9385 6222 |
| **Email** | humanethics@unsw.edu.au  |
| **HC Reference Number** | HC201962 |

1. **What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

|  |  |
| --- | --- |
| **Name** | Dr Samuel Arnold |
| **Position** | Research Fellow |
| **Telephone** | 02 93850620 |
| **Email** | Samuel.arnold@unsw.edu.au |

**Chief Investigator**

|  |  |
| --- | --- |
| **Name** | Dr Samuel Arnold  |
| **Position** | Research Fellow |
| **Telephone** | 02 93850620 |
| **Email** | Samuel.arnold@unsw.edu.au |

**Support Services Contact Details**

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

|  |  |
| --- | --- |
| **Name/Organisation** | Beyond Blue  |
| **Telephone** | 1300 224 636 |
| **Email** | [www.beyondblue.org.au](http://www.beyondblue.org.au)  |

|  |  |
| --- | --- |
| **Name/Organisation** | Lifeline Australia  |
| **Telephone** | 13 11 14 |
| **Email** | <https://www.lifeline.org.au/> |

**Consent Form – Participant providing own consent**

**Declaration by the participant**

* I understand I am being asked to provide consent to participate in this research study;
* I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
* I understand the purposes, study tasks and risks of the research described in the study;
* Recordings: I understand that the research team will audio/video record the gallery event. I agree to be recorded for this purpose.
* I provide my consent for the information collected about me to be used for the purpose of this research study only.
* I have had an opportunity to ask questions and I am satisfied with the answers I have received;
* I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect their/my relationship with any of the named organisations and/or research team members;
* I understand that I will be given a signed copy of this document to keep.
* I understand that the results of the research will be made available on the 3DN website.
* I provide my consent for the information collected about me to made available to other researchers as described at section 6 of this document.
* I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

**Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Email Address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* Optional - I provide my consent to be identifed in publications relating to this research
* Optional - I provide my consent for my name and contact details to be retained in a register so I can be contacted about other research projects in the future.

**Participant Signature**

|  |  |
| --- | --- |
| Name of Participant (please print) |  |
| Signature of Research Participant  |  |
| Date |  |

**Declaration by Researcher\***

* I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

**Researcher Signature\***

|  |  |
| --- | --- |
| Name of Researcher (please print) |  |
| Signature of Researcher  |  |
| Date |  |

**+An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

**Note: All parties signing the consent section must date their own signature.**

**Form for Withdrawal of Participation**

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales.

* I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
* I am withdrawing my consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.
* I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

**Participant Name**

|  |  |
| --- | --- |
| Name of Participant (please type) |  |
| Date |  |

**The section for Withdrawal of Participation should be forwarded to:**

|  |  |
| --- | --- |
| CI Name: | Dr Samuel Arnold |
| Email: | Samuel.arnold@unsw.edu.au |
| Phone: | 02 93850620 |
| Postal Address: | Department of Developmental Disability Neuropsychiatry, 30 Botany St, UNSW Sydney, 2052 |