**PARTICIPANT INFORMATION SHEET**

**Project title**: Exploring the Social Effects of Neurodiversity on Indigenous African migrant families in Aotearoa New Zealand

**Name of Principal Investigator/Supervisor (PI)**: Dr. Anneka Anderson

**Name of Co-investigator**: Dr. Karen Brewer

**Name of Student Researcher**: Rachel Tapera

**Researcher introduction**

My name is Rachel Tapera, I am a Doctoral student at Te Kupenga Hauora Māori in the Faculty of Medical and Health Sciences. Dr. Anneka Anderson and Dr. Karen Brewer are my supervisors in this research project.

**Project description and invitation**

 I would like to invite you to participate in a research study. I am exploring the social effects of neurodiversity on Indigenous African migrants families. Neurodiversity refers to people with the conditions of Attention Deficit Hyperactivity Disorder, Autism, Dyspraxia, Dyslexia and other related ones. I would like to learn from your experience of raising and caring for a neurodiverse child.

**Who can participate in this study?**

This study is for people who;

* Self-identify as Indigenous African.
* Have raised or cared for a neurodiverse child.
* Reside in New Zealand.

**What will I have to do?**

I (Rachel), will interview you about your experience of raising and caring for a neurodiverse child (I expect the interview to take 60 to 90 minutes). In some cases, a second interview or a longer interview may be required. We can do the interview wherever you prefer, e.g. in your home, school or public library. You can choose if you want to be interviewed by yourself or with a family member or support person. Interviews can also be held virtually on Zoom or over the phone.

Your participation in the study is entirely your choice (voluntary) and I will not tell anyone whether you choose to participate or not. If you do agree to take part in this research, you are free to withdraw from the study at any time without giving a reason.

Some people find it helpful to talk about their experiences but you might also find it difficult or sad as you reflect on your situation. If you are feeling uncomfortable or upset during the interviews, we can stop. Referrals to healthcare support will be provided if necessary.

You will receive a koha ($30 supermarket voucher) for each interview in appreciation of giving up your time for the study (even if you decide to withdraw from the study after the information is collected).

**Data storage/retention/destruction/future use**

 Before we start the interview you will need to give your consent to participate. You can give written or verbal consent. The written consent forms will be stored in a locked cabinet on University of Auckland premises, separate from research data, for a total of six years. The verbal consents will be audio recorded and the electronic consents will be stored in a folder, separate from the research data on the UoA managed storage for six years. . After this time, all electronic data will be destroyed by deletion and consent forms will be destroyed by a disposal company that provides security for confidential documents or the documents will be shredded.

Interviews will be audio recorded. You can ask to turn the device off at any point during the interview. All the information collected from this research will be stored on a password protected University of Auckland computer, backed up by a server.

**Right to Withdraw from Participation**

You can withdraw from participating in the interview at any time without giving a reason. You can withdraw your data from the research up to two weeks after the interview date. If there is more than one person in your interview you will not be able to withdraw your individual data.

**Anonymity and Confidentiality**

Any information that you share in this research will be kept confidential and no material that could personally identify you (let other people know who you are) will be used in any reports on this study. We will try hard to ensure confidentiality during this study, but we cannot absolutely guarantee it given the small population of neurodiverse Indigenous African migrants in New Zealand

**Contact details**

If you have any concerns or would require more information about this research please contact;

|  |  |  |
| --- | --- | --- |
| Rachel Tapera,Researcher,Te Kupenga Hauora Māori,Faculty of Medical and Health SciencesThe University of Auckland,Private Bag 92019,Auckland 1142, New Zealand. Email: rtap016@aucklanduni.ac.nz  | Dr. Anneka Anderson,Principal Investigator,Te Kupenga Hauora Māori,Faculty of Medical and Health SciencesThe University of Auckland,Private Bag 92019Auckland 1142, New ZealandEmail: a.anderson@auckland.ac.nz Tel: +64 9 923 3373 | Professor Papaarangi Reid,Tumuaki,Te Kupenga Hauora Māori,Faculty of Medical and Health SciencesThe University of Auckland,Private Bag 92019Auckland 1142, New ZealandEmail: p.reid@auckland.ac.nz Tel: +64 9 923 4853 |

**UAHPEC Chair contact details**:

For any queries regarding ethical concerns you may contact;

The Chair,

The University of Auckland Human Participants Ethics Committee,

Office of Research Strategy and Integrity,

The University of Auckland,

Private Bag 92019, Auckland 1142.

Telephone: 09 373-7599 ext. 83711.

Email: humanethics@auckland.ac.nz

**APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 21/04/2020 for three years. Reference number 024459.**