

## APPENDICES

### Appendix 1: Participant Information Sheet and Consent Form

#### Primary and Community Health Directorate

#### PARTICIPANT INFORMATION SHEET AND CONSENT FORM Participant

#### [Family Care Connect – a holistic first 2000 days model of care for women and families from migrant and refugee communities.](#)

##### Invitation

You are invited to take part in the Family Care Connect project. Family Care Connect involves child and family Hubs, where health and other agencies work together and you are supported to navigate these services. Our research is seeing whether these Hubs support the health and development of children, mothers and families from migrant and refugee communities.

##### Who is doing the research?

Tania Rimes  
Children and Communities Program Coordinator  
Primary and Community Health Directorate | South Eastern Sydney Local Health District (SESLHD).

Associate Professor Sue Woolfenden (Research lead)  
NHMRC Senior Research Fellow, Population Child Health Group | The University of New South Wales (UNSW). Senior Staff Specialist, Community Child Health | Sydney Children's Hospitals Network.

Before you decide if you want to take part in this research, we would like to explain what we are doing and why we are doing it. Please take the time to read the following information carefully. You can talk about it with a relative or a friend if you wish before deciding.

##### What is the purpose of this research?

We want to see if child and family Hubs help women and families from migrant and refugee communities move from pregnancy to Child and Family Health services. Also, we want to see if these Hubs support children's health and development in the first 12 months of life.

We will also look at how easy and cost-effective the Hub is for you and other women and families.

##### Why have I been invited to participate in this research?

You are eligible to participate in this research because you:

- are having your baby or recently given birth to your baby at **[INSERT HOSPITAL SITES]**
- live in the postcode of **[INSERT POSTCODE/S]**

- are at least 20 weeks pregnant, OR have recently given birth to your baby and have not been discharged home from postnatal ward
- are a newly arrived migrant (within the last 10 years) from a non-English speaking background; or a refugee (living in Australia for less than 10 years) from a non-English speaking background
- are 16 years of age or older.

### If I say yes, what will it involve?

If you decide to take part in the research and live in [INSERT SITE AREA] you will be in the **'FDCC Group'**. You will receive information about the child and family services in your area you can access after the birth of your baby. This information is given to all women, regardless of whether or not they participate in the study.

If you take part in the **"FDCC Group"**, you will also be contacted by a worker from the local child and family Hub who will give you more information on the services offered and assist you with accessing these services if you choose.

If you agree to take part, we will ask you to sign the Participant Information and Consent form below; OR sign the online consent found here [INSERT ONLINE CONSENT URL]; OR provide verbal consent over the telephone to the contact person for the research.

After you provide consent to take part in this research, we will ask you to:

- Complete a survey about you, your family, your support needs, and your wellbeing. This will take about 30 minutes. You can choose to do it online, by paper, over the phone, or in-person. **We can provide an interpreter to assist.**
- Complete another survey when your baby is 6 months and 12 months old. This will ask questions about you, what your needs are, and what services you have used. **We can provide an interpreter to assist.**
- We will also collect data from your local and state-wide hospital/s about you and your baby. This reduces the number of questions we need to ask you.

The data we collect from local hospitals includes:

- Information about you and your child such as country of birth, date of birth, gender, language spoken at home
- Information from routine questions asked to all women when they come to hospital about their health and wellbeing and their child's
- Information about the services you or your child has seen, for example the child and family health nurse.

The data we collect from state-wide hospitals includes:

- Information that is collected on all new mothers and babies in NSW
- Emergency Department presentations for you and your baby

**If you don't want us to collect data about you and your baby from state-wide hospitals, then we won't. Please let us know by checking the box.**

**I DO NOT want my state-wide hospital data included as part of this research**

**If you only provide verbal consent, we will not collect data about you and your baby from state-wide hospitals.**

As part of this research, we may also invite you to be interviewed. We will contact you at another time to discuss this process before the research is complete.

Any information we collect that can identify you or your child will remain confidential.

The total time you are involved with this project will be for 12 to 18 months, but you can choose to withdraw at any time.

**What if I don't want to take part in this research, or if I want to withdraw later?**

It is completely up to you whether or not you decide to take part. Saying yes or no will not affect your relationship with the care you receive, the services you access, or your visa status now or in the future.

If you wish to leave the research once it has started, you can do so verbally or in writing at any time without giving a reason. However, it may not be possible to withdraw your data from the research results once we have collected it and removed your identifying details. This is due to be done from March 2023.

**How is this research being paid for?**

The research is being paid for by NSW Health as part of the Translational Research Grant Scheme. More information about this scheme can be found here:

<https://www.medicalresearch.nsw.gov.au/translational-research-grants-scheme/>

**Are there risks to me in taking part in this research?**

There is very little risk to you, however if you become upset or distressed because of taking part in the research, the research team will arrange for counselling or other help. Any counselling or help will be provided by qualified staff who are not members of the research team. This will be provided free of charge.

Another risk in taking part in this research is the risk to your privacy as part of collecting data about you, your child, and your family. While this is a risk, we will take all the steps to ensure your information remains private and confidential. We do not collect you or your baby's name, or anything else that could identify you or your family. Instead, your name will be replaced with a number. Only people involved with this research will be able to tell that the information is about you.

**What happens if I suffer injury or complications as a result of the research?**

It is very unlikely that you will suffer any injury as we are only asking you to complete questionnaires. However, if you require treatment or suffer loss as a result of the wrongdoing of any of the parties involved in the research, you can seek compensation. The cost of your treatment must be paid by the compensation you receive.

**Will I benefit from the research?**

This research aims to determine how best to provide child health services for families and to improve how parents in the future access child and family health services, however it may or may not directly benefit you or your baby.

**Will taking part in this research cost me anything, and will I be paid?**

Taking part in this research will not cost you anything, nor will you be paid.

**How will my confidentiality be protected?**

Any information that is collected about you as part of this research will remain private and confidential and will be discussed only with your permission, except as required by law. This means the research team are Mandatory Reporters and may need to speak with NSW Department of Communities and Justice if they are told or are concerned that a child is being hurt or is at risk of being hurt e.g. if there is abuse or violence in the home.

If such a situation happens, we would discuss this with you in private and arrange for you to speak with another professional if required.

Only the researchers named above will have access to your details. All information will be stored on a secure drive within [INSERT LHD SITES] and UNSW. We will keep the information for 5 years after the research ends. After this time, it will be destroyed.

In line with Australian, New South Wales, and other relevant laws, you have the right to access and correct the information we collect and store about you. Please contact us if you would like to access the information.

**What happens with the results?**

If you give us your permission by providing your consent in written form, online, or verbally, we plan to publish the results in a report and in peer reviewed journals. We may also present results at professional forums and conferences to inform better ways of working and providing services.

We will also give a report on the research to the South Eastern Sydney Local Health District Human Research Ethics Committee.

In any report, publication, or presentation, information will be provided in such a way that you or your family cannot be identified.

**What should I do if I want to discuss this research further before I decide?**

When you have read this information, the researcher interviewer/project officer will discuss it with you and answer any queries you may have. If you would like to know more at any stage, please do not hesitate to contact Tania Rimes, Principal Investigator on (02) 9382 8696 or email her at [tania.rimes@health.nsw.gov.au](mailto:tania.rimes@health.nsw.gov.au). If you need an interpreter, you can contact Tania through the Translating and Interpreting Service (TIS) on 131 450.

**Who should I contact if I have concerns about the conduct of this research?**

This research has been approved by the South Eastern Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this research should contact the Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email [SESLHD-RSO@health.nsw.gov.au](mailto:SESLHD-RSO@health.nsw.gov.au) and quote HREC reference number: 2020/ETH03295.

The conduct of this research is at the [INSERT SITE NAMES]. Any person with concerns or complaints about the conduct of this research may also contact the [*details of the Research Governance Officer of the health district will be provided following SSA application*]

**Thank you for taking the time to consider this research.  
If you wish to take part in it, please sign the attached consent form.  
This information sheet is for you to keep.**

## Primary and Community Health Directorate

### CONSENT FORM

#### Family Care Connect – a holistic first 2000 days model of care for women and families from migrant and refugee communities.

1. I,.....  
of.....  
agree to take part in the research described in the participant information statement set out above and to have my data linked as outlined in the information sheet.
2. I have read the participant information statement, which explains why I have been asked to take part, the aims of the research and the possible risks of the research, and the statement has been explained to me to my satisfaction.
3. Before signing this consent form, I have been able to ask any questions relating to any possible physical and mental harm I might suffer as a result of taking part and I have received satisfactory answers.
4. I understand that I can withdraw from the research at any time without affecting my relationship with South Eastern Sydney Local Health District or service at the child and family hub.
5. I agree that research information collected from the results of the research may be published and presented, provided that I cannot be identified.
6. I understand that if I have any questions relating to my participation in this research, I may contact Tania Rimes on telephone (02) 9382 8696, who will be happy to answer them. I can call 131450 (TIS) for language support.
7. I have been given a copy of this Consent Form and the Participant Information Statement.

Complaints may be directed to the Research Support Office, South Eastern Sydney Local Health District, Prince of Wales Hospital, Randwick NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email [SESLHD-RSO@health.nsw.gov.au](mailto:SESLHD-RSO@health.nsw.gov.au) .

**Signature of participant**

**Please PRINT name**

**Date**

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**Signature of witness**

**Please PRINT name**

**Date**

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**Signature of investigator****Please PRINT name****Date**

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Investigator/officer taking consent to complete:

Check box if participant DOES NOT want their state-wide hospital data included as part of this research