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## Participant Information Sheet

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| **Study title:** | Patient and whānau values, perspectives and experiences related to decision making about haemodialysis vascular access | |
| **Principal investigator:** | **Name: Kate Richards**  **Department: Medicine**  **Position: PhD Student** | Contact phone number:  Email macka823@student.otago.ac.nz  Or call Christchurch Hospital Switch Board on 03 364 0640 and they will put you through |

**Introduction**

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

**What is the aim of this research project?**

We want to know about patients and their whānau/caregivers experiences of the fistula, graft or line they use for haemodialysis. Most particularly, we are interested in the factors that influence your preferences for what you use for dialysis. This may include the effects on you, your family, community, environment, or other things. We will use this information to design research that is useful to patients who have kidney failure and their whānau*.*

**Who is funding this project?**

This project is part of the PhD work of Kate Richards. She has funding from a Health Research Council Clinical Training Research Fellowship.

**Who are we seeking to participate in the project?**

We want to talk to adult patients (age over 18) and their whānau/caregivers who have experienced a line, fistula or graft and can talk with us in English. We are looking for people from a range of age groups, ethnicities and dialysis experiences.

**If you participate, what will you be asked to do?**

If you participate we will arrange for a time and location to talk with you (and your whanau/caregiver if you wish). This can be face to face, over the internet or by phone. The interviewers identify as Pakeha. Māori and Pasifika patients and whānau may wish to have Māori or Pasifika support people present, which we can organise. Interviews will take about an hour, and will be audio recorded then transcribed. All recorded and written information about you won’t have your details on it, which means it won’t be able to be traced back to you. Interviews will be confidential, like when you talk to your medical teams.

Whether or not you participate will not affect the care you receive at your kidney unit, and nothing you say will be reported back to anyone in your treating team. If you have any medical concerns that come up in the interview, the interviewer will ask you to discuss them with your treating team.

At the end of the interview we would like to offer a $50 petrol or grocery voucher in appreciation of your time and sharing of your experiences with us*.*

**Is there any risk of discomfort or harm from participation?**

The main risks to you are that you may feel upset when discussing some of your experiences. We will have details of people you can talk these feelings through with if you would like to after the interview. We can also stop the interview at any time if you need a break, or have had enough.

**What information will be collected, and how will it be used?**

The information we collect will be about your experiences of haemodialysis vascular access (fistula, lines or graft), and what your values and priorities are about this. We will record interviews, and the recordings will be transcribed in to word documents. These will not have any details which could be used to identify you, and will be kept secure on password protected University of Otago computer systems. Only the research team will have access to these records, which will be kept for 10 years. The recordings will be deleted after they are transcribed. If other researchers want to access the records for future research they would need an ethics committee to say its ok, and your personal details would not be provided.

**What about anonymity and confidentiality?**

Your interviews will be kept confidential. We will allocate each participant a different study number, so that none of the written records from the interviews will contain any information that could be used to identify who you are. A professional who has signed a confidentiality agreement will be used to transcribe the interviews. Only the research team will have access to these transcriptions, and they will be stored on a password protected computer. When we publish the results of our research we will ensure that any quotes used from the interviews will not include details that could be used to identify you. We will separately have a document which contains your contact details and your study identification number. This means we can return the transcript of the interview to you if you want to see it.

**If you agree to participate, can you withdraw later?**

You may withdraw from participation in the project at any time before or during the interview, until publication of the study.

**Any questions?**

If you have any questions now or in the future, please feel free to contact either:

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| **Name: Kate Richards**  **Position: PhD Student**  **Department: Medicine** | Email macka823@student.otago.ac.nz  Or, call Christchurch Hospital Switch Board on 03 364 0640 and they will put you through |

*This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.*