|  |  |
| --- | --- |
| Application ID :  | SOA 16/63  |
| Application Title :  | An institutional ethnography of New Zealand's commitment to patient-centred care |
| Date of Submission :  | 26/09/2016 |
| Primary Investigator :  | Rachel Webster |

|  |  |
| --- | --- |
|  |  |
|  |  |

**Application approved by Massey University Human Ethics Southern A Committee, Wednesday, 21 December 2016.**

**Application**

**Initial Responses**

**Application Title**

An institutional ethnography of New Zealand's commitment to patient-centred care

**Campus of Chief Applicant**

Manawatu

**Project Type**

Postgraduate Student Research

**Project Summary**
*Please outline in no more than 2000 characters in lay language*

The New Zealand (NZ) government has prescribed a goal for health care at all levels to be patient-centred. Patient-centred care is recognised as an ‘approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families’ (Institute for Patient- and Family-Centred Care). It is a commitment to returning the power to the patient, not the health care system. Presently it is unknown the extent to which the existing health care systems in NZ supports or suppresses the ability to provide care which is patient-centred.

The aim of this project is to examine if NZ health care has a real intent towards and an understanding of what changes are required to support genuinely patient-centred care. This project will use Institutional Ethnography (IE) to explore the power and textual coordination present in the current health care structure that impacts on patient-centred care, to discover how things really work, and attempt to answer the question; what will help or hinder NZ achieving patient-centred care?

IE describes and tracks peoples work, seeking out empirical links, which are then able to be explicated to unravel the invisible, taken-for-granted, organisation of everyday practice. The IE will begin with the experiences of health service users; exploring their expert knowledge of receiving care, and their everyday work of being a consumer of the NZ health care system. While maintaining the standpoint of the patient, a wider network of health care personnel, texts and documents will be analysed. Through this analysis the project will attempt to illuminate the presence of power and ruling relationships that organise patient-centred behaviours which have not previously been visible.

**Describe the peer review process that has been used to discuss and analyse the ethical issues present in this project**

This project has been peer reviewed by Associate Professor Jean Gilmour following the School of Nursing research practices.

**List the ethical issues considered and explain how they have been addressed**

Just as the research method is emergent, so too are the potential ethical issues embedded within IE research, only the field researcher truly confronts the unanticipated aspects of research while the project is ongoing. The researcher RW is acutely aware of this, and while due consideration has been given to visible ethical concerns; RW is conscious of the need for effective on the spot ethical decision making and practices. As a registered nurse RW is attune to the unpredictable nature of ethical problems, RW has a strong connection to the nursing code of ethics, and the code of ethical conduct for research, teaching and evaluations involving human participants, which will enhance her abilities as a researcher in practice.

Many issues have arisen due to the nature of the methodology, in particular the challenge of proposing research where majority of participants are totally unknown until the research is well underway. Much attention has been paid to this in the consideration of ethical issues.

The following are the key known ethical issues identified for this project;

*Respect for Persons;*

Due to the unknown identity and circumstances of research participants, owing to the emergent methodology, it is appropriate to prepare for all possibilities. In saying that, it is entirely possible to carry out a well-rounded project without having to access overly vulnerable populations. For this reason, persons with diminished competence, children, and overly researched populations will be excluded from the participant population. Potential participants who identify as mental health service users will also be excluded as integrated care, which has strong links to this project, has been extensively researched with this population.

Participation in this research at all levels is voluntary, and participants may withdraw from the research at any time without personal or professional penalty.

*Minimisation of risk of harm;*

It is not expected that harm will come to participants from participation in this research. The researcher RW is aware that participants may feel uncomfortable talking to the researcher about a sensitive topic; however a study conducted by Decker, Naugle, Carter-Visscher, Bell, and Seifert (2011) found that participation in sensitive topic research seems less likely to cause distress than initially anticipated. Additionally, from other studies analysed, they found personal benefits to the participants were often reported as greater than the perceived negative effects. This is not to suggest there is no risk, instead that the risk is not likely to be sufficient to jeopardise the research. RW will remain alert for any signs of distress or discomfort, and make appropriate ethical decisions should the need arise.

As recommended by Mealer and Jones (2014), participants will be encouraged to engage in self-reflection following the interview, by way of either journaling, or discussing with a peer. Should any participant require further support due to the distress of the research, the researcher RW will refer them to appropriate professional support services.

Should a situation become overly distressing for a participant, the researcher will first turn off all recording devices and suspend the interview, following which an assessment will be made of the appropriateness of continuing after a intermission, or terminating the interview and seeking further support for the participant[ant if required. As an experienced clinician RW is well positioned to make such decisions.

*Risk of harm to researcher;*

Due to the potential sensitive topics discussed in the interview it is best practice to allow the participant to choose an interview location where they feel most comfortable (Elmir, Schmied, Jackson, & Wilkes, 2011; Mealer & Jones, 2014).

Interviewing alone poses potential risk to the researcher RW. Should an interview be arranged to be held at someone’s home, RW will make an assessment of the suitability and safety of the environment. RW will also ensure another person is aware of whereabouts and expected duration of the interview.

*Informed and voluntary consent;*

Consent from participants will be informed and voluntary, ensuring all four elements of informed consent are met. Potential participants will be given one week to consider the invitation. Consent will be written; copies of this will be stored securely. There are no foreseeable power relationship issues relevant to this project affecting the nature of consent.

*Risk of coercion;*

Phase one participants for this research will be chosen purposively. In order to mitigate for coercion, recruitment will be initiated by general practice nurses not related to the research. Potential participants who meet the criteria will be given a letter of invitation, from which it is up to the potential participant to engage with the researcher. The researcher will not be notified of any efforts to recruit, until a participant makes contact. If a potential participant chooses not to accept the invitation to participate they will receive no further contact and will not be penalised in any way.

*Respect for privacy and confidentiality;*

An assurance of confidentiality will be given to participants; RW will be pro-active in protecting confidentiality. Participants will be identified either by pseudonym or professional title where appropriate. For comprehension of the research, it will at times be important to understand the position of the informant, for contextual relevance. In these circumstances, as recommended by Norstedt and Breimo (2016), participants may be referred to as ‘registered nurse’, ‘doctor’ or ‘pharmacist’ etcetera. National organisations involved in this research exist in the public domain so will by nature be identifiable.

All data will be recorded and processed using pseudonyms or titles as appropriate. Consent forms will be stored in a separate location to the data. RW will be transcribing the data independently.

Decker, S. E., Naugle, A. E., Carter-Visscher, R., Bell, K., & Seifert, A. (2011). Ethical issues in research on sensitive topics: Participants' experiences of distress and benefit. *Journal of Empirical Research on Human Research Ethics, 6*(3), 55-64. doi: 10.1525/jer.2011.6.3.55

Elmir, R., Schmied, V., Jackson, D., & Wilkes, L. (2011). Interviewing people about potentially sensitive topics. *Nurse Researcher, 19*(1), 12-16.

Mealer, M., & Jones, J. (2014). Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse Researcher, 21*(4), 32-37. doi: 10.7748/nr2014.03.21.4.32.e1229

Norstedt, M., & Breimo, J. (2016). Moving Beyond Everyday Life in Institutional Ethnographies : Methodological Challenges and Ethical Dilemmas. *Forum : Qualitative Social Research*, 1.

**Full Application**

**Are you recruiting participants?**

Yes

**Project Details**

**Aim of the project**

The aim of this project is to examine if NZ health services have a real intent towards and an understanding of what changes are required to support genuinely patient-centred care.

**Background of the project**

The New Zealand (NZ) government has prescribed a goal for health care at all levels to be patient-centred. Patient-centred care is recognised as an ‘approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families’ (Institute for Patient- and Family-Centred Care). It is a commitment to returning the power to the patient, not the health care system. Presently it is unknown the extent to which the existing health care systems in NZ supports or suppresses the ability to provide care which is patient-centred.

**Outline the research procedures to be used, including approach/procedures for collecting data. Use flow chart if necessary.**

IE is a qualitative research approach, The premise of institutional ethnography is that our daily activities, or what we do in our lives, are coordinated by texts produced by the ruling relations or institutions (Smith, 1999, 2005). By exploring from the local situation and mapping actions and texts we begin to understand how things are put together, and therefore what could be changed to improve a particular situation. IE starts with a ‘small hero’ (Smith, 2006), in this research our small hero is the health care consumer. The small hero is the person, or group of people whom are in some way marginalised, subordinated or oppressed, possibly unknowingly, by textual organisation (including policies, documents, articles, media etc.). We use our small hero as the entry point into our research problem, by looking up and into our research problem from their standpoint, seeking out the complex social relations beyond their view.

The schematic below gives a visual guide of what may be seen looking up from the patient’s point of view – immediately visible is their everyday work, the texts and documents they engage with, and the health care professionals they have interactions with. Hidden behind these are the more invisible factors that may have a power/ruling effect on their experience of receiving care that is patient-centred. The concept of hidden powers is not intended in a covert way; rather it is not generally possible nor expected to see all aspects of how something is put together from simple participation such as being a health care consumer. We approach this research journey from where our small hero stands.

**Patient-centred care**

**National organisation**

**Local organisation**

Authors of texts and documents

Coordinators of healthcare

Texts and documents activated by health care professionals

Health care professionals encountered through using health care

Texts and documents activated when using

health

care

Organisation of everyday work of being a consumer of New Zealand health care

Using the above figure it is possible to explain the research approach and data collection procedures.

The research will begin with the small hero – the health care consumer, and explore their experiences, good and bad, of receiving health care in New Zealand. This will be achieved through a single interview with each consumer participant. The interview will be semi structured, and focus on the participant’s actual accounts of health service engagement. The interviewer will ask the participant to recall recent health care encounters, and guide the researcher through a time when they felt the care they received was not satisfactory, and their actions or work during this experience. How the participant’s actions are coordinated by text is fundamental to the inquiry. The interview will draw attention to texts and documents the participant has had interactions with during these times, perhaps a form they filled in, an information sheet they were given, a health promotion advertisement they saw. Questions will be aimed at establishing the influence of the text on the participant.

IE research is emergent; no two interviews will be the same, as one imperative of IE research is to seek new information at every interview to further inform the puzzle. Each interview could be considered as a puzzle piece from a puzzle which the final picture is not fully known, but each piece adds to the previous and informs the next. DeVault and McCoy (2012) explain this concept in another way; they suggest “the process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out. Institutional ethnographers know what they want to explain, but they can discover only step by step whom they need to interview or what texts and discourses they need to examine.” (p.383)

Once the social relations of the small hero have been explored through interview; transcription and mapping of the stories told and texts identified will take place. The knowledge gained through this mapping will inform the next series of interviews, working up from the small hero, into local and national organisation of health care, to explore the ‘hidden’ players in the small hero’s experience and investigate the institutional work processes. At each interview the standpoint of the small hero will be maintained, and the focus will continue to be on what people’s actions are and how their actions (or sometimes inaction) are coordinated by texts produced by institutions and organisations.

Smith, D. E. (1999). *Writing the social: Critique, theory, and investigations*. Toronto: University of Toronto Press.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Lanham: Altamira Press.

**Describe the experience of the researcher and / or supervisor to undertake this type of project**

The primary researcher – Rachel Webster (RW), is a recent graduate of the Massey University Master of Nursing programme, with successful completion of a research project. RW will be working under the supervision of Professor Jenny Carryer, an experienced PhD supervisor, examiner, and convenor.
Professor Carryer is well researched and published on the impact of nursing care, New Zealand health reforms, and primary health care. Professor Carryer is familiar with both patient-centred care and institutional ethnography, and is joined by Dr Mark Jones and Dr Luisa Toffoli. Dr Jones has extensive sector and industry experience in related areas to the topic. Dr Toffoli is an emerging expert on new public management and its impact on issues of safe staffing, patient safety, missed care and the challenges towards patient centeredness.

**Where will the project be conducted? – include physical location, setting**

The project will be conducted in NZ and involve multiple interviews at various locations.

Preliminary interviews are predicted to take place in Palmerston North, and will likely occur in participants’ homes, or in another local setting of their choosing.

Secondary interviews are less predictable, however given the assumption that secondary interviewees will be health care professionals; it is the researcher’s intention for these interviews to occur at their place of work.

IE includes the collection and analysis of texts and documents as an essential part of the research process. Texts may be physical or digital. The collection of these texts may occur at any time, from both physical and digital/network locations. Anticipated locations for text include health care settings and workplaces of participants, the homes of participants, and online databases.

**Describe the intended participants**

**How many participants will be involved?**

**How will potential participants be identified?**

**How will potential participants be recruited?**

(the above questions were answered collectively)

The first phase of interviews will be with adults (18 years or older) who have had recent extensive contact and multiple encounters with the New Zealand health care system across any setting, excluding mental health for reasons mentioned above. These participants will not be current in-patients of any service. These participants will likely be from the Manawatu region but may be from other areas.

Phase one participants will be chosen purposively from patients identified by general practice nurses, to whom they are well known.

In the first phase, the researcher is seeking between three and nine participants. The purpose of phase one interviews is to identify points of disjuncture within the participant’s experiences that will be the basis for explication. As people’s experiences are unique, despite purposive selection, the research process is reliant entirely on both their individual experience and what they choose to disclose within the interview. For this reason, it may take several phase one participants to reach sufficient entry points into the main body of the research.

Recruitment for phase one will be initiated by general practice nurses. Potential patient participants who meet the selection criteria will be given a letter of invitation and information sheet by the general practice nurse during a regular consultation. The researcher will not be informed of who has received invitations to participate. The first contact with the researcher must be initiated by potential participants after reviewing the invitation to participate. Following the first contact from the interested participant, RW will post or email further information including a consent form, and allow one week for the potential participant to consider their involvement, before following up with the participant in a manor agreed upon during the initial contact, e.g. by phone or by email.

It is important to note that within IE, participants are not the object of analysis, rather it is ‘how the participant’s experience was organised and controlled’ that is of interest, and is a means of acquiring and enriching our understanding of the institutional process (Rashid, Caine, & Goez, 2015). Because of this point of difference, there is no intent from the researcher to gather personal data such as age, ethnicity, and occupation, etcetera. Sex however will be disclosed. Lastly an interview date and time will be established in partnership with the participant.

Staying true to the IE methodology, the second phase participants will become known to the researcher only after the first phase is complete and the emergent issues are uncovered. These participants are identified as their particular role (e.g. ED registrar, district nurse) has been discovered through mapping of a patient participant’s story, to be of interest to the issue being explicated. It is the professional participant’s role, and how their work is coordinated that is of interest at this point. Specific experiences shared by patient participants **will not be discussed** at this stage; rather the research process starts afresh, exploring the professional participant’s experiences of *providing* care within the current health systems; however my questioning will be shaped by the **emergent issues** identified within the patient participant interviews.

The decision to trace participants by professional role, rather than follow the actual professionals from within the patient participants experience serves two purposes, and is supported by Norstedt and Breimo (2016). Firstly, patient participant confidentiality is protected, as they are not linked to the professional participants. Secondly, professional participants are not put in an uncomfortable position of risking disclosure of information protected by patient confidentiality, or of feeling personally scrutinised by the research.

It is likely this phase will include health care professionals, such as nurses and doctors, from both community and hospital settings, multidisciplinary staff, and members of management teams. Only those roles considered relevant to the issues being explicated will be approached for interview. This process of snowballing will continue until the problem has been explicated to the point where it is known what was ruling, organising and coordinating the first participant’s experience.

Phase two participants will be recruited by one of two methods, depending on their position. Clinicians, such as doctors and nurses will be recruited via snowballing; the researcher RW will begin with an initial clinician contact in either primary or tertiary settings as appropriate. The initial contact will be asked to pass on an invitation to participate and an information sheet to persons who hold professional roles that have been identified as being of interest. The researcher will not be informed who has received invitations to participate. Again contact with the researcher must be initiated by the prospective participant, after which the same process as with patient participants will be followed. Following the completion of the interview, once the next step is known, the participant will be asked to pass on a recruitment pack to the next identified position. Alternatively, potential participants will be approached directly by the main researcher RW, by email if available, or by appropriate channels of communication depending on the potential participant’s relationship to the research, using publically available contact information; for example through author details of a text, or publicly visible roles such as ministry employees. Initial contact will involve an introduction to the researcher and the project; Invited participants will be given an information sheet to consider. RW will follow up one week after initial contact with an email or phone call enable the potential participant to ask for further information or clarification, and discuss if the individual choses to participate or not, and negotiate an interview time and location if required.

The researcher will use due discretion to ensure sufficient knowledge is gained, without overly burdening participants. A generous estimate would be three second phase participants per first phase participant, and a further snowballing from these second phase participants to industry leaders, of which perhaps two or three will be approached.

Local and national organisations are anticipated to be included in the research in the final data collection stages, as identified through the texts located in earlier interviews. Organisations such as the Ministry of Health, in particular the authors of texts and policies such as the New Zealand Health Strategy and health targets, are predicted to be included.

Norstedt, M., & Breimo, J. (2016). Moving Beyond Everyday Life in Institutional Ethnographies : Methodological Challenges and Ethical Dilemmas. *Forum : Qualitative Social Research*, 1.

Rashid, M., Caine, V., & Goez, H. (2015). The Encounters and Challenges of Ethnography as a Methodology in Health Research. *International Journal of Qualitative Methods, 14*(5), 1609406915621421.

 **Who will make the initial approach to potential participants?**

General practice nurses

**Does the project include recruitment through advertising?**

No

**Does the project require permission of an organisation (e.g. an educational institution, an academic unit of Massey University or a business) to access participants or information?**

Yes

1. **list the organisation(s)**

Kauri HealthCare General Practice

1. **attach a copy of the draft request letter(s) to the application form, e.g. letter to Board of Trustees, PVC, HoD/I/S, CEO etc (include this in your list of attachments (Q5).**

**Describe any specific inclusion / exclusion criteria to select participants**

Phase one participants are the only participants who are subject to an inclusion/exclusion criteria, as subsequent participants are purposively selected based on their occupational link to the phase one participants experience.
Inclusion criteria for patient participants;
Adult (18 years or older)
User of health care services in the past 12 months
Extensive and multiple encounters with health care services
May have acute or chronic origins to their health care needs
Exclusion criteria for patient participants;
Users of mental health services
Person’s with diminished competence to provide consent
Current in-patients of any health care service
Residents of any long-term care settings
It is possible to carry out a well-rounded project without having to access overly vulnerable populations. Additionally, integrated care, a mental health concept which has strong links to this project, has been extensively researched with this population.

**How much time will participants have to give to the project?**

Initial contact will take no more than 10 minutes, and there will be a one week delay between initial contact and follow up to arrange an interview. It is expected that each interview will be between 45 and 60 minutes in length. It is possible that the researcher may need to return to the participant to clarify an answer or follow up on some information provided; this is expected to be either by email or as a phone call.
Following the interview, once the data has been transcribed, RW will contact each participant again to review a summary of their interview along with the transcribed data. This is estimated to take 15 to 30 minutes.

|  |
| --- |
| **Application Detail****Data Collection****Type of data collection**InterviewOther**Does the project include the use of participant interview/s?** |
| Yes |

**Does your project involve sound or image reporting?**

Yes

**Does the project require permission to access databases?**

No

**Recording**

**Does your project involve a non-researcher transcribing the recording?**

No

**Will you be providing participants with transcripts of interviews for editing?**

Yes

**If your project involves sound or image recording, describe how this will be undertaken and how consent will be given by the participant**

Participants will be aware the conversation is being recorded. Interviews will be sound recorded using a personal recorder. Consent will be gained in writing via the participant consent form and further confirmed verbally prior to the commencement of the interview. Recordings will be taken either in the room of the face to face interview, or via proximity to speakerphone or Skype device.

**Benefits and Risks**

**What are the possible benefits (if any) of the project to individual participants, groups, communities and institutions?**

Information used will help to produce a piece of research targeted at improving New Zealand health care’s commitment to delivering care that is patient-centred. Research demonstrates care that is patient-centred both improves the patient care experience, and creates public value for services (ACSQH, 2011), which suggests this research has potential to be beneficial for all parties involved.

The Ministry of Health have identified in The New Zealand Health Strategy (2016) a target of achieving this standard of care by 2026, making this research timely to their agenda. This is also aligned with other relevant New Zealand health care strategies, including the Māori Health Strategy.

**What discomfort (physical, psychological, social), incapacity or other risk of harm are individual participants likely to experience as a result of participation?**

It is not expected that harm will come to participants from participation in this research. The researcher RW is aware that participants may feel uncomfortable talking to the researcher about an unpleasant health care experience.

It is possible that an issue arising from the research may represent a breach of the Code of Health & Disability Services Consumers' Rights.

**Describe the strategies you will use to deal with any of the situations identified above**

As recommended by Mealer and Jones (2014), participants will be encouraged to engage in self-reflection following the interview, by way of either journaling, or discussing with a peer. Should any participant require further support due to the distress of the research, the researcher RW will refer them to appropriate professional support services.

Should a situation become overly distressing for a participant, the researcher will first turn off all recording devices and suspend the interview, following which an assessment will be made of the appropriateness of continuing after an intermission, or terminating the interview and seeking further support for the participant if required. As an experienced clinician RW is well positioned to make such decisions.

Should any potential breaches of the Code of Health & Disability Services Consumers' Rights be suspected, the researcher, as a Registered Nurse, is capable of supporting the participant to proceed with a formal complaint if they wish. One of the key competencies of Registered Nurses is patient advocacy; this will be upheld throughout the research process.

**Is discomfort (physical, psychological, social), incapacity or other risk of harm likely to be experienced by groups/communities or institutions as a result of this research?**

Yes

**Describe the strategies you will use to deal with this discomfit.**

It is possible that the findings of this research will reveal areas of care within the New Zealand health care system which are in need of improvement, and therefore may be uncomfortable for sector leaders. However, New Zealand health care has a learning culture, and will hopefully welcome these findings and embrace the opportunity to improve.

**Is ethnicity data being collected as part of this project?**

No

**Consent**

**Who will give information about the research to potential participants?**

General practice nurses from Kauri HealthCare General Practice

**How will the information be given to potential participants**

A letter of invitation and information sheet is to be given during a regular consultation

**How will consent be obtained?**

Written

**Are any participants under the age of 16?**

No

**Will the participants be proficient in English?**

Yes

**Pricacy / Confidentiality Issues**

**List any information that will be obtained from any sources other than the participant**

Texts are a source of data for this research. Expected additional sources of data include but may not be limited to; public record documentation from DHB’s, DHB policy and guideline documents, Ministry of Health publications, social media, websites, and academic journals.
Publically available texts will be collected by the researcher RW as they become relevant to the research. Permissions associated with these texts will be followed accordingly. Texts not publically available, but identified as relevant to the project will be requested from the respective authors or digital property owners. A separate information sheet and consent form will accompany this request.

**Identify any information that may be given to any person outside the research team that may describe participants.**

There should be no requirement to share any identifiable information with persons outside the research.

**Will participants identities' be known to the researchers?**

Yes

**How will the identities be confidentially maintained in the treatment and use of data?**

As discussed earlier, at the beginning of the interview, prior to commencing recording, a title will be agreed upon by which the participant will be addressed by the interviewer, e.g. a pseudonym. Participants will not be known to each other within the research.
Within publication the participant will be addressed by either pseudonym or title. Eg. Hospital nurse, community nurse, Registrar. No real identities will be linked to any stored data.
All data included in the final research, and subsequent publications will be thoroughly screened including supervisor checking, to ensure no identifiable factors are present to protect participants, with the exception of those who hold public national roles. In this instance, with consent, national public identities will be named.

**If an institution (e.g. school) to which participants belong is able to be identified, explain how you have made the institution aware of this.**

Although not identifiable, Mid Central Health will be made aware of this project by way of letter to the CEO outlining the proposed project, and the involvement of Mid Central DHB.

**Outline how and where data will be stored, particularly identifiable data**

Audio recording will be stored as an anonymous audio file. The audio file will be saved anonymously on a personal hard drive which is password protected and only accessible by myself (RW). The audio file will be transcribed within one month of the interview, and any paper copies kept in a locked cabinet in my office. Transcripts will be anonymous.

**Outline how and where consent forms will be stored**

Consent forms will be stored separate to all data in locked storage within the school of nursing for a period of 5 years

**Outline who has access to data and consent forms.**

The researcher – RW, and all supervisors - Professor Jenny Carryer, Dr Mark Jones, Dr Louisa Toffoli

**How will the data / consent forms be protected from unauthorised access?**

Electronic data will be stored on the personal hard drive of the computer of the researcher which is password protected. Paper transcripts will be kept in a locked cabinet in the researcher’s office at Massey University filed under pseudonym to protect any connection to consent forms; consent forms will be stored in a locked cabinet at the researcher’s home – accessible only by the researcher RW.

**How long will the data be kept?**

Following Massey University research protocol, all data will be kept for five years

**Who will be responsible for its safekeeping and eventual disposal?**

Lead supervisor, Professor Carryer, will be responsible for this.

**Will the data be transferred to an official archive?**

No

**Treaty of Waitangi**

**Does your research have a primary focus on Maori participants?**

No

**If your research involves the general population, outline how the involvement of Maori participants will be managed**

It is worth noting that the goals of patient-centred care are closely aligned with the inclusive Whānau-Ora model of health care delivery, where the core focus is on Whānau-centred care. The findings of this project will serve both patient and whānau-centred care as it can be predicted that barriers to the success of patient-centred care will also impact on whānau-centred care. With this in mind, where appropriate the research will attempt to include whānau-centred care concepts, and be attentive to this model of health care when interviewing participants who identify as Māori.

The focus of participant interviews is to locate points of disjuncture from a person’s experience, which serves as an entry point into the web of organisational ruling relations. It would be naïve not to consider the potential for such a disjuncture to be culturally centred. For this reason the researcher must be culturally aware and alert to such issues, and understand how to navigate the situation to achieve the best outcome for the participant.

Following consultation with Huataki Whareaitu (Cultural Advisor, Mid Central Health), the following considerations have been made for the research to proceed in a culturally appropriate manor;

Should the researcher uncover an unresolved issues relating to a Māori participant and their whanau requiring further investigation, the Māori Health Unit are best suited to manage this. The researcher is aware of formal referral processes to the Māori Health Unit to facilitate correct support for the participant.

Should the research path follow an issue relating to Māori culture and cultural safety, appropriate customs will be adhered to. Following the preliminary interview the research direction shifts towards organisational ruling relations, specifically texts and the power of these texts in organising the experience being explored. While this portion of the enquiry is independent from participants, the researcher will continue to respect Māori culture, and honour Māori research traditions where appropriate. In particular; recognition and application of Te Tiriti o Waitangi, and following the principle of Āta; growing respectful relationships when engaging with Māori.

In addition to consultation, the information sheet for patient participants has been reviewed by Huataki Whareaitu in keeping with best practice following 'Guidelines for Researchers on Health Research Involving Maori (2010)’, to ensure the document is readable and the information is appropriate should it reach a Māori audience.

The researcher is aware that further guidance may be required throughout the research process, and is thankful for the guidance of Huataki Whareaitu and the Māori Health Unit of Mid Central Health. It is intended that consultation will be meaningful and ongoing as required.

In conclusion of the advisory relationship, relevant findings of the project will be shared with the Māori Health team at Mid Central DHB in acknowledgement of their support of this project and their enduring commitment to a whanau-centred model of care.

**Cultural Issues**

**Does your research focus on any ethnic or social groups (Other than Maori)?**

No

**Sharing Research Findings**

**Describe how information resulting from the project will be shared with participants and disseminated in other forums.**
*Note that receipt of a summary is one of the participants rights*

A summary of the findings of the research will be sent to all participants, and the final dissertation will be publically available.
It is expected that the research will result in several publications to both peer reviewed and non-peer reviewed nursing journals and press. It is also anticipated that this research be presented at both national and international conferences relevant to both patient centred care and institutional ethnography.
A summary report will be sent to all groups consulted during this research, which will be followed up with an invitation from the researcher RW to present the findings in a formal or informal setting of their discretion. Sharing the knowledge gained from this research is a priority for the researcher, equally so being able to discuss current and future concerns with those who are positioned to facilitate change is a main concern.

Decker, S. E., Naugle, A. E., Carter-Visscher, R., Bell, K., & Seifert, A. (2011). Ethical issues in research on sensitive topics: Participants' experiences of distress and benefit. *Journal of Empirical Research on Human Research Ethics, 6*(3), 55-64. doi: 10.1525/jer.2011.6.3.55

Elmir, R., Schmied, V., Jackson, D., & Wilkes, L. (2011). Interviewing people about potentially sensitive topics. *Nurse Researcher, 19*(1), 12-16.

Mealer, M., & Jones, J. (2014). Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse Researcher, 21*(4), 32-37. doi: 10.7748/nr2014.03.21.4.32.e1229

Norstedt, M., & Breimo, J. (2016). Moving Beyond Everyday Life in Institutional Ethnographies : Methodological Challenges and Ethical Dilemmas. *Forum : Qualitative Social Research*, 1.

Rashid, M., Caine, V., & Goez, H. (2015). The Encounters and Challenges of Ethnography as a Methodology in Health Research. *International Journal of Qualitative Methods, 14*(5), 1609406915621421.

Smith, D. E. (1999). *Writing the social: Critique, theory, and investigations*. Toronto: University of Toronto Press.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Lanham: Altamira Press.