# Navigating abandonment – elective surgery cancellation from the patient perspective

2019

Health and Environmental Studies, Clinical Science / Nursing

A thesis submitted to Auckland University of Technology

in partial fulfilment of the requirements for the degree of Master of Health Science

# Abstract

Elective surgery cancellation creates significant cost to both patients and organisations. To date, the majority of research has been from the hospital perspective, with a focus on decreasing the numbers of cancellations, improving productivity and saving money.

The question of what happens for the patient when elective surgery is cancelled has not been asked. Qualitative grounded theory endeavours to establish strong, consistent theory in places where little is known about a phenomenon of interest. The constructivist grounded theory of Charmaz was the approach chosen. Constructivist grounded theory is rooted in pragmatism, which aligns with the researcher's world view of focusing on 'what works.' By exploring what happened to participants when elective surgery was cancelled, from their perspective, and what actions they took to make sense of what happened to them, it was possible to construct interpretive meanings to these actions and develop theory to direct health professional responses.

Participants who had experienced elective surgery cancellation followed by rebooking and completion of their surgery were recruited via a mailed invitation leaflet. The experience of elective surgery cancellation was explored via in-depth interview and analysed through a theoretical lens of co-constructionism of participant and researcher. The core category of this study, '*Navigating Abandonment*', was composed of four major categories; readying, waiting, being let down and rebuilding fragile trust.

The findings of this research contribute new knowledge and insight into the patient perspective of this highly stressful event. Further research has the potential to improve patient satisfaction following elective surgery cancellation, through improved patient education and clear guidelines in the event of a hospital-initiated cancellation.

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# Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

09/11/2019

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Signature                                                                          Date

# Acknowledgements

# Ethics Approval

11 December 2017

Shelaine Zambas
Faculty of Health and Environmental Sciences

Dear Shelaine

Re Ethics Application:     **17/416 Elective surgery cancellation**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 11 December 2020.

Once locality authorisation has been received, please forward to AUTEC.

**Standard Conditions of Approval**

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.  Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only.  If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
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# Chapter 1  Introduction

A significant proportion of surgical procedures in New Zealand occur as elective procedures. Approximately 6% of 12,000 elective surgical patients in 2014-2015 experienced cancelled surgery within the Waitemata District Health Board (WDHB) catchment area (Waitemata District Health Board, 2017). Cancellation of elective surgical procedures is recognised as a major cause of emotional distress to the patient and their family/whānau (Herrod et al., 2019). To date, the focus of research into the cancellation of elective surgery has been from a hospital and administration perspective. Little is known about the cancellation of elective surgery from the patient perspective.

In this chapter I explore the aim and context of this study, including departmental targets and previous WDHB initiatives to reduce elective surgery cancellations. I will also situate myself within the study in terms of my professional role as a nurse specialist within the anaesthetic department.

## Aim

The aim of this thesis is to capture what happens when elective surgery is cancelled from the patient perspective, with the purpose of deepening the understanding of healthcare professionals, family members and significant others, about how best to support the cancelled person. This study focuses on the patient and how they construct the reality of what is happening to them, investigating cues and events in what is happening around them, that informs what they already know. I have limited this study to elective surgical procedures only. This represents a more controlled environment of minor to moderate surgery, as opposed to acute or trauma surgery, which happens suddenly, and is often life-threatening. Similarly, I have broadened this study to include any elective surgery cancellation as opposed to only day of surgery cancellation, thereby providing a greater pool of potential participants.

## Thesis structure

This thesis has been organised in the following way. Chapter one focuses on providing the introduction and background to the study. Chapter two is a review of the available literature published relating to the research question. Chapter three includes the

methods and methodology used for this study. Included in chapter four are the research findings. Chapter five focuses on discussing new insights arising from the study findings, the strengths and limitations, implications for practice, future recommendations, the study significance, and the conclusion.

## Background

My current role is located within a public hospital anaesthetic department, where I am one of three specialty nurses, working alongside our clinical lead consultant anaesthetist and supporting sixty-two full/part-time consultant anaesthetists. This is a desk job, making clinical decisions, talking on the telephone, data input, consulting and liaising and with some time spent in outpatient clinics. Our service has a primary Key Performance Indicator (KPI), to avoid and/or minimise day of surgery cancellations for elective surgical procedures, due to any anaesthetic reasons. This KPI is underpinned by the Ministry of Health (MOH) Elective Services Patient Flow Indicators (ESPI). There are six ESPIs that measure whether DHBs are meeting the required performance standard (Ministry of Health, 2019).

The anaesthetic service works collaboratively with all surgical specialties to ensure that we particularly meet the MOH target number four, being the delivery of treatment within four months of First Surgical Assessment (FSA). I receive weekly data reports from across the WDHB outlining cancellations, reasons why if known and the location of the cancellation, across the three separate sites. I gradually became aware of the patient experience of cancellation when I received telephone calls from patients who had had an elective surgical procedure cancelled and were wondering when the surgery would be rebooked. During these telephone conversations I began to hear some of the distress and frustration that the patient was experiencing. I developed an awareness that for the patient, this journey of waiting to be rebooked was not a pleasant experience. While my role was to reduce elective surgery cancellation, more time was spent on service delivery being something we could control and there was not much time or attention paid to what was happening for the patient.

Over time I struggled to do anything about this KPI and the reports I was receiving. Initially alone in this role, I did not have the time or resource to allocate to investigating day-of-surgery cancellations. Once our team was boosted with two

further specialty nurses and after discussion with the clinical lead, I was supported to research elective surgery cancellations.

I began a preliminary literature scan which showed there was no research currently available on the topic which sparked more enthusiasm as there was a case to answer. Many studies reported that surgery cancellation was a problem, and many had focused on service delivery initiatives to decrease cancellation numbers. But no study had asked the patient 'what happened when surgery was cancelled'? I began preliminary conversations with other clinicians, theatre administration staff and surgical booking staff to find out what happens when elective surgical procedures are cancelled and how these procedures get rebooked within WDHB. I became concerned regarding the lack of a clear process for clinical staff to follow. There appeared to be no clearly defined process and it was left up to whoever was around at the time to do something about it. Often it was left to non-clinical administration staff to follow-up with the patient, with various levels of finesse and success. In order to develop an appropriate process for elective surgery cancellation and rebooking, it seemed important to understand what happened to the patients when they are cancelled and the journey they take to get rebooked.

I recalled a personal experience of major elective surgery. If I had been cancelled and therefore experienced a delay in surgery, I believe I would have been devastated. I was in so much pain. Whatever the reason for the cancellation I would have been very unhappy. I would have become very demanding, as I desperately sought to be rebooked as soon as possible. Amongst the patients that telephoned me, wanting to know when they would be rebooked, there was the same level of desperation for information, the demand to know what was happening and/or to speak to the person who knew what was happening. As patients described worsening pain, loss of function and physical conditioning, I was left with a sense of helplessness as a clinician, there was really nothing I could do to help them. I knew there was an identified gap here, not only in our knowledge of what happens to the patient but also a gap in our service provision because of this lack of knowledge. Thus, a personal and professional drive was birthed to do something to fill this knowledge gap and bring help to patients following elective surgery cancellation.

## Outside Influences

### Departmental Targets

As mentioned above the WDHB has the MOH ESPI to avoid and/or minimise cancellations for elective surgical procedures. Elective surgical procedures number approximately 12,000 per year across all sites (North Shore Hospital (NSH) and Waitakere Hospital (WTK) and the Elective Surgical Centre (ESC)). In comparison, to other District Health Boards, WDHB equates favourably with a less than 2% cancellation rate; these statistics were provided to me (WDHB, personal communication, August 28th, 2018) and more recent statistics are unavailable at this time. Therefore on average 240 patients experience elective surgery cancellation at WDHB every year.

In 2018, the anaesthetic service commenced a pilot study, aimed at equipping and educating specialty nurses to assess the anaesthetic requirements of patients in clinic. This assessment would occur at the time the offer of surgery is made, and the specialty nurses would case manage the patient through to surgery completion. This initiative was introduced due to the identification of gaps in the current process with the aim of improving patient experience by decreasing the number of clinic visits required, providing consistent medication advice and improving pre surgery optimisation of chronic conditions, all of which would assist in reducing elective surgical cancellations. This initiative, to some extent, overlaps with my research in that a percentage of patients managed by the specialty nurses will have their surgical procedure cancelled. There is potential for the nurse to prepare the patient for the possibility that their surgery could be cancelled.

The knowledge gained from my research has the potential for immediate application by the specialty nurses when speaking to cancelled surgery patients. Importantly, it will allow the nurses to gain understanding of the patient's construction of what it means to have surgery cancelled and the rebooking process. This study has the potential to fill the knowledge gap and inform nursing practice.

### Previous WDHB Initiatives

In my current role, I have been asked to participate in several initiatives to resolve issues that have a direct impact on elective surgical patient outcomes and their

experience. Firstly, there is a proposal for E-booking forms for elective surgery, streamlining theatre list planning and bed capacity assessment. Currently the list duration is based on the time entered on a form by the booking doctor. This is notoriously inaccurate and results in both under booking of lists and over booking with subsequent staffing issues. This has often led to the cancellation of elective surgery and directly affects the anaesthetic specialty nurses' ability to accurately assess patients for anaesthetic risk, as they rely on the accuracy of the list information. Better booking systems will ensure improved accuracy and reduce elective surgery cancellations.

A patient's journey for an elective surgery, an automated approach towards prioritisation and perioperative assessment, is the second initiative. This was an international research project funded through Orion health and WDHB supported this research by providing information about 'what we do'. This is specific for the anaesthetic department as perioperative physicians and the specialty nurses are primarily involved in perioperative assessment. A pertinent key finding was: currently there is no patient interaction with their own elective surgery and that greater patient access to anaesthetic and surgical information is required (A Patient's Journey for an Elective Surgery, Nov 2017 – unpublished). This initiative emphasised the reality of what we do as opposed to what we think we do. It brought a stark reminder to interact better and inform more fully with our surgical patients, thus improving patient satisfaction.

Due to my involvement in these initiatives, I realised that while hospital initiatives are improving and ongoing, I sought greater understanding of elective surgery cancellation from another direction, that being the patient. We could ask what is the frame of reference of the patient when their surgery is cancelled? What is their interpretation of events? What is their outlook, position or stance? How do they approach the problem? What is their attitude or frame of mind? These are all questions that will inform the construction of their reality.

## The Research Approach

As I began to identify the research question that I wanted answered, I explored a number of research methodologies. I wanted to understand how patients responded

to and made sense of the cancellation of their elective surgery. Grounded theory seemed to be the most appropriate choice. There are a number of grounded theory approaches, however constructivist grounded theory argues that we exist in a world that is acted upon and interpreted by our research participants and ourselves, as well as being affected by other people and circumstances (Morse et al., 2009). Constructivists study how and sometimes why participants construct meanings and actions in specific situations. They view data as constructed rather than discovered. According to Charmaz (2009), constructivist grounded theorists move two steps from classic grounded theory and simultaneously take a large step forward into interpretive social science. Constructivist grounded theorists also take a reflexive stance towards the research process. Charmaz (2014) states we consider how our theories evolve, meaning that both researchers and research participants are involved with interpreting meanings and actions. The constructivist approach acknowledges that the resulting theory is an interpretation. The theory depends on the researcher's view; it does not and cannot stand outside of it (Clarke, 2007). Classical grounded theory would not have been appropriate for this research as, according to Glaser, the researcher must maintain an open mind and enter into an area of study as an impartial blank slate (Glaser, 1992). Thus constructivist grounded theory was a good fit for the researcher, due to professional involvement and existing knowledge of the surgical pathway. By using the grounded theory method, to answer the research question of elective surgery cancellation from the patient perspective, the final product is a comprehensive grounded theory that explains a process associated with a phenomenon (Birks & Mills, 2015).

## Summary

This chapter has provided the background to the research study, what is included in this thesis and why. This study will make a significant contribution to understanding what is happening for the elective surgical patient when their surgery is cancelled, either on the day of the planned surgery or sometime beforehand. This contribution will inform practice, so that changes can be initiated to improve the patient experience. Understanding acquired will enable future elective surgical patients and their families to have knowledge about elective surgery cancellation from the patient

perspective and to provide solutions to the problems identified by the participants in this study.

# Chapter 2  Literature Review

## Introduction

In this chapter the literature relevant to elective surgery cancellation is examined and discussed, opening with the search strategy used and a brief overview of the role of literature in a grounded theory study. An overview of the sociocultural and political context of healthcare in New Zealand follows. There is also a critique and evaluation of the available literature related to elective surgical cancellation, with focus from the patient perspective and how they have been included in the ongoing processes, with the main areas examined being: cancelled surgery, patient perspective, patient satisfaction, and nurse-led clinic.

## Search Strategy

To access national and worldwide information, relevant to this research study, PubMed, CINAHL, MEDLINE and Scopus were searched using the following search terms: elective surgical cancellation, operating rooms, patient experience, cancelled or cancellation, general surgery. Due to the small number of articles matching these search words, a combination of words were used, such as, cancellation and surgery; operating rooms and cancellation. As the number of articles remained small, a decision was made to broaden the search words to include; surgery, operations, surgical procedures, patient attitude and combinations of patient experience and surgical procedures.  I commenced this search in 2017 and due to the scarcity of patient centred research, examined articles published as far back as 1991. Additional searching for relevant literature was undertaken up until finalising this study in 2019. The literature presented in this chapter was chosen for its relevance to this study.

## Literature Review in a Grounded Theory Study

Within classical grounded theory methodology, existing literature is typically referenced after the theory has emerged, not before. Glaser and Strauss (1967a) claimed, that to discover something new the data should speak to the researcher. They advocated for delaying the literature review until after completing the analysis, not wanting the researcher to see their data through the lens of earlier ideas (Charmaz, 2014), with the purpose of keeping the researcher as free and as open as possible to

discover and interpret emerging data (Mills & Birks, 2014). Many contemporary grounded theorists reject Glaser and Strauss's original position and Glaser's continued devotion to it, although he does present a strong case. Glaser (1998), states that pre-research literature reviews are detrimental to generating grounded theory, due to researchers becoming distracted by perceived professional concepts that are irrelevant. They may also be exposed to speculation, while theoretical sensitivity is eroded to rhetorical jargon and lastly the relevant literature may be far away from what is actually going on (Glaser, 1998). Further to this, Glaser does advise that where a literature review is required prior to a study commencing, the researcher should treat the literature as data (Mills & Birks, 2014). Grounded theorists increasingly recognise that a lack of familiarity with relevant literature is unlikely and unsustainable.

Reviewing the literature on a topic of the proposed study, can provide an indication to the researcher as to the extent of current knowledge and what work has been previously done. Urquhart (2012) argues that it is an effective way to orientate the researcher to the field of study, without necessarily prejudicing them in any way. Constructivist grounded theorists acknowledge the relevance of the literature review and that the researcher will enter into a study with a broad range of knowledge about their proposed area of research (Charmaz, 2014; Mills & Birks, 2014). Furthermore, as described in the previous chapter, I had some involvement with people who had had their elective surgical procedure cancelled and were waiting to be rebooked, resulting in preliminary understanding of the research topic.

In this literature review I have followed Charmaz's approach. This approach is underpinned by a constructivist philosophy which acknowledges the researcher and participants co-construction of knowledge. In order to do this, the researcher needs some preliminary understanding of where to focus the research question. Originally, the focus of the study was to be day-of-surgery cancellation, however, on reviewing the literature, it was noted that surgery cancellation does not only occur in hospital on the planned day of surgery. Surgery cancellation can also occur at home a few days prior. The purpose of the literature review was to frame and justify the research question and identify the knowledge gaps. Grounded theory is an appropriate approach when little is known about a topic, but knowledge of gaps in the literature

cannot be obtained unless at least a preliminary review of literature is undertaken (McGhee, Marland, & Atkinson, 2007).

## Culture of Healthcare in New Zealand

The predominant medical culture draws many conclusions about patients and how they journey through the health care system, based on the erroneous assumption that all patients have common experiences, values and expectations (Barbazza, Langins, Kluge, & Tello, 2015). Currently, in New Zealand's healthcare system, there is the belief that the patient must take responsibility for themselves - change resides within the individual, and unfortunately healthcare is most accessible to and effective for patients who are verbal, articulate, assertive and able to express their feelings (DeSouza, 2008). Also, healthcare providers are viewed as the "expert" or the "authority", and patients are often not viewed as partners in the process (Wepa, 2015). An understanding of the existing health culture is relevant as the focus of this study is how patients process surgery cancellation and how they make sense of it. There are very few researchers who have undertaken to study exclusively the patient perspective on this topic.

## Elective Surgery Cancellation

### Cancelled Surgery

Previous elective surgery cancellation research has relied heavily on the use of retrospective studies employing a single point of data collection from hospital records, for example, electronic records, chart review and theatre lists (Caesar, Karlsson, Olsson, Samuelsson, & Hansson-Olofsson, 2014; Chalya et al., 2011; Dimitriadis, Iyer, & Evgeniou, 2013). Although research has been undertaken to understand elective surgery cancellation, the majority of studies have focused on cost effectiveness, improving efficiency and reducing length of stay (Kaddoum, Fadlallah, Hitti, Fadi, & El Eid, 2016; Rymaruk, 2011; Wang, Samaranayake, & Tout, 2013). Existing research indicates three broad reasons for why elective surgery cancellations occur. These are hospital related, patient related, and administration related. Hospital related reasons include: shortage of adequate resources (Kumar & Gandhi, 2012; Lankoande et al., 2016; Rymaruk, 2011), operating room schedule overrun (Coady-Fariborzian, Anstead, Lawler, & Pagan, 2016; Kumar & Gandhi, 2012), surgeon availability (Al Talalwah & McIltrot, 2019), and a lack of postoperative resources (Dimitriadis et al., 2013). Patient

related reasons include: medically unsuitable (Dalton, Kelly, Murphy, McCoy, & Glynn, 2016; Dimitriadis et al., 2013), poorly communicated information regarding date and time of surgery (Lee, Rodgers, Oh, & Muckler, 2017), inadequate medication advice (Caesar et al., 2014), nervousness or panic, transportation issues (Kaddoum et al., 2016; Lee et al., 2017; Wang et al., 2013) and patients changing their mind (Coady-Fariborzian et al., 2016). Finally, cancellation occurs due to administrative and scheduling errors (Chalya et al., 2011; Kaddoum et al., 2016; Leslie, Beiko, & Janet van Vlymen, 2013; Rymaruk, 2011).

Most studies concluded that more research was needed and offered generalised statements about possible solutions, concluding that it was important to recognise and monitor elective surgery cancellations. Several discussed strategies for innovation, for example, improving preoperative screening by implementing nurse-patient call log, (nurses call patients two times prior to day of surgery) and patients being given an easily understandable booklet containing specific patient information (Coady-Fariborzian et al., 2016; Haufler & Harrington, 2011; Lee et al., 2017; Rymaruk, 2011). Another strategy was to attempt to involve patients in the planning of their care (Caesar et al., 2014; Lankoande et al., 2016). Other hospital related strategies included increasing operating theatre spaces, improving scheduling and admission procedure, increase in equipment and manpower, improving communication between specialists and the use of information technology (Chalya et al., 2011; Dalton et al., 2016; Hovlid, Bukve, Haug, Aslaksen, & von Plessen, 2012; Kumar & Gandhi, 2012). Limitations of the research were clearly stated, for example, bias in categorising cases where there was some ambiguity (Caesar et al., 2014) or where multiple factors may have contributed to the cancellations (Kaddoum et al., 2016), incomplete patient records (Coady-Fariborzian et al., 2016; Dalton et al., 2016) and undocumented communication between specialists (Dalton et al., 2016). A number of studies emphasised the limits of generalisability and advised other institutions to do local assessments before employing any strategies (Al Talalwah & McIltrot, 2019; Dimitriadis et al., 2013; Kaddoum et al., 2016). Having outlined the obvious causes of cancelled surgery, it was clear the starting point for many health care institutions worldwide was to look at hospital processes, healthcare real estate and staffing. These recommendations resonated with current critique of healthcare, that new processes and services are

introduced without asking for the recipients' views (Lanchester, 2017; Rodgers & Milton, 2013).

## Patient Perspective

There have been some studies which have explored the patient perspective. Leslie et al (2013), explored day of surgery cancellations beginning with a prospective study using the theatre database. The researchers confirmed the documented reasons for cancellation, across three specialties of general surgery, gynaecology and urology, dividing causes of cancellations into structure, process and patient-related factors. Data was gathered from their database by chart reviews and they conducted a quantitative survey with a subset of cancelled patients, stating that the survey results merely confirmed the emotional and financial impact of surgery cancellation (Leslie et al., 2013). Hovlid et al (2013), undertook a qualitative study to measure patient experiences with interventions to reduce surgery cancellations. The aim of the study was to explore the patient experience of the redesigned pathway, using a qualitative design with semi-structured interviews. One criticism of this study was, from the patients that were interviewed, all proceeded to surgery. Thus no information was gathered on the experience of patients who had surgery cancelled (Hovlid et al., 2013).

Reducing orthopaedic elective surgery cancellation, due to patient related factors, was the main focus of a study conducted by Singhal et al (2014). The aim was to determine the impact of administering a questionnaire to patients over the telephone the week prior to surgery, to try and identify potential factors that could lead to surgery cancellation. There were five questions based on patient-related reasons for cancellation. This study concluded that perioperative staff should take the initiative to contact patients near to the date of surgery and combat any factors that could result in cancellations. Again, this study focused on the patient factors causing cancellation rather than cancellation due to service factors as noted previously (Singhal et al., 2014). Such approaches, while attempting to include patient responses and/or opinions, have restricted questions to the processes under review. There was no attempt to identify what happened to the patient when surgery was cancelled, how knowledge was constructed about this or how patients made sense of what occurred. Despite this, progress has been made to advance the patient experience through quality initiatives designed to improve patient satisfaction.

## Patient Satisfaction

Many hospital systems have sought to improve patient satisfaction and research around quality initiatives designed to improve the patient experience within the hospital setting. Henderson (2004) interviewed twenty patients to explore the patient perspective of what was important to make their hospital stay satisfactory. Sixteen patient satisfaction themes were identified across the data. The greatest number of themes recognised by any one patient was eleven and the lowest was three. The most consistently discussed themes were 'medical outcomes' (patients were concerned about the physical outcomes of their surgery, they wanted it to go well and be free of complications), provision of information (information about their illness and treatment), alongside clinical care (competent and compassionate care delivery). Overall, the satisfaction themes reflected real life issues for patients. They wanted to be comfortable, receive competent and compassionate care and leave hospital with improved health (Henderson et al., 2004).

A descriptive study was conducted within an Istanbul Faculty of Medicine, with orthopaedic patients who were planned to undergo surgical procedures (Dadaş & Eti-aslan, 2004). A questionnaire was developed including twelve questions about the personal characteristics of the patients, and patients and families' reactions to surgery cancellations. The purpose of the study was to identify the causes for cancellations of surgical interventions and to identify the reactions of patients and their families. Upon being informed of their cancellation, 54% of the patients were noted to cry, 18% seemed silent and calm, 16% became nervous and had difficulty speaking, 6% were extremely upset and refused to talk, 4% cried and displayed bad attitudes, later offering apologies and 2% were pleased with the decision. Reactions of the patient's families following the cancellations were: 30% waited helplessly, 30% tried to conceal their sadness, 22% started to quarrel with staff and 18% chose to discuss the cancellation with the surgeon. Interestingly, "Why weren't we told about the possibility of a cancellation?" was found to be the most frequent question asked by the patients' families (Dadaş & Eti-aslan, 2004). While priorities varied somewhat between individuals, core themes recurred. The suggested initiatives from this study include: better pre-operative assessments and preparation, such as, defining health problems that may delay surgery; better communication between clinicians and the realistic

preparation of surgery lists (Dadaş & Eti-aslan, 2004). The above studies highlight the importance of communication for patients and their families. It appears the receipt of information pertinent to what is happening is of great importance and to receive this in a timely manner.

### Lack of information causing anxiety

Communication is critical for providing efficient care to patients. This is especially important for patients waiting for elective surgery, as they experience a variety of unknowns before the procedure as mentioned above. These patient priorities are further confirmed by Chan et al. (2012) who conducted a systematic review of eleven studies on patients' experiences before surgery. This review identified four themes relating to patients' experience of preoperative communication with health professionals: need for information, involving relatives, the need for control, and professionalism (Chan et al., 2012).

Communication surrounding cancellation did not meet with patient expectations in a prospective survey by Mehta et al. (2014). Orthopaedic patients were surveyed the morning after their surgery had been cancelled, ensuring there was every opportunity for medical staff to discuss the cancellation with the patient. This study found patients preferred to be notified of surgery cancellation by a doctor as opposed to a nurse, suggesting that patients have preferences and expectations about the manner in which information is imparted to them regarding their operations. This highlights that physicians are the preferred source of information provision and illustrates the importance of communication in the doctor-patient relationship (Mehta et al., 2014).

Dell'Atti (2014), studied the effect of cancelling elective procedures within a urology department. The study purpose was to analyse the number of elective surgical cancellations, as well as identifying and comparing potential emotional trauma and satisfaction between older (>65years) and younger (<65years) patients (Dell'Atti, 2014). Patient surveys and local anxiety and depression scales were used to assess patients, finding significantly lower patient satisfaction following elective surgery cancellation in elderly patients compared to younger patients. The researchers concluded that, due to an ageing population, it is a priority to take into consideration the psychological consequences of surgery cancellation (Dell'Atti, 2014). The

importance of communication between doctor to nurse and doctor or nurse to patient is the principal finding in the studies above. Ensuring communication is of a high standard has been shown to reduce the patient suffering through the emotional trauma of surgery cancellation.

## Financial and psychological burden

Alongside the emotional anguish of cancellation is the financial loss experienced by patients and their families. Two recent studies sought to identify the financial and psychological burden of cancelled surgery. Firstly, Lankoande et al (2016) explored the causes of cancellation, financial cost (to the patient and the hospital) and the patient's emotional response. Cancellation caused a negative emotional reaction in 85.7% of patients and 'sadness' was the most frequent emotion identified (Lankoande et al., 2016). Secondly, Herrod et al.'s (2019) study was conducted due to the 'Winter National Health Service Crisis'. Non-cancer elective surgeries were cancelled throughout December 2017 and January 2018, in order to free resources for emergency admissions. Cancelled patients were sent a survey. The cancellation of elective surgery during the winter months had an adverse effect on patients, including lost working days and health-related anxiety. Of the participants, 30% reported extreme levels of sadness, disappointment, anger, frustration and stress. Moderate concern about continued symptoms was reported by 70% and 59% expressed moderate concern about their deteriorating condition (Herrod et al., 2019). The above studies call on management to deal with the avoidable costs by improving both management and efficiency and recommend policy changes. Change at policy level, however, takes time.

## Nurse-led Clinics

In response to the challenges of minimising surgery cancellations, many hospitals worldwide have maximised the existing 'Pre-Admission Clinic' (PAC) model by, introducing nurse-led clinics for elective surgery patients. Pre-admission clinics have been successful in sending early warning of potential risk factors possibly delaying elective procedures and have improved the patient satisfaction through effective communication. Ivarsson et al. (2002) introduced a nurse-led PAC, as a means of avoiding organisational and medical problems that are instrumental in causing elective surgical cancellations. Furthermore, this group of researchers, continued with the pre-

admission clinic and introduced other initiatives, such as a change in the planning, waitlist system and patient support via follow-up telephone calls and internet-based support system (Ivarsson, Larsson, & Sjöberg, 2004; Ivarsson et al., 2002).

A hermeneutic phenomenological research approach was utilised by Gilmartin (2004), to explore participants' experiences of a nurse-led PAC. Data was collected using face-to-face interviews of thirty patients undergoing day surgery in a large hospital. Findings suggested that the nurse-led clinic appeared to function effectively, with most patients feeling they were adequately assessed and prepared for surgery. The majority reported receiving comprehensive information about procedures, they appreciated the health education and had the opportunity to ask questions. A few patients reported deficits in information giving, indicating their individual needs were not met and leaving them feeling anxious. Others alluded to problems associated with unexpected cancellation of procedures, causing disequilibrium. The findings indicated that the giving of information, psychological support and patient centred care could be strengthened in the preassessment preparation for patients undergoing elective surgery (Gilmartin, 2004).

A further example of decreasing surgery cancellation, using PACs, is explored in a retrospective cross-sectional descriptive study carried out by Emmanuel and Macpherson (2013). Although the most common reason for surgery cancellation was termed non-preventable misadventure, such as acute upper respiratory infection, non-adherence to fasting and medication guidelines were the next most common reasons for surgery cancellation. As previously suggested, such cancellations could potentially be reduced via clear communication and provision of unambiguous information at a nurse-led PAC (Emanuel & Macpherson, 2013).

Although nurse-led PACs are being increasingly implemented worldwide, Conny (2016) advocates for the development of clinical guidelines, pathways and protocols. In a systematic review, ten research studies were critically appraised. The specific objectives were to produce evidence on the impact of PACs for elective orthopaedic patients on health service outcomes which included surgery cancellation, length of hospital stay and waiting time for preassessment and surgery. Also, to examine the effectiveness of PACs on patient levels of satisfaction, postoperative complications and

recovery, and levels of fear and anxiety before surgery. Results showed that nurse-led PACs can reduce surgery cancellation rates, by nurses serving as effective coordinators, assessors and educators, which was found to greatly improve the level of patient satisfaction (Conny & Wan-Yim, 2016).

## Summary

In this chapter literature related to elective surgical cancellation, particularly from the patient perspective has been reviewed. For many of the qualitative approaches employed by the above researchers, the patient perspective has been stated as being valuable and important. Yet the patient and their families' experiences, no matter how well documented, appear to be sparsely included within the ongoing plans for improvement to current processes. Quality initiatives, including patient satisfaction, are embraced by healthcare organisations worldwide and although patient satisfaction within the elective surgical pathway is acknowledged, little real traction has been made to incorporate the patient experience in solutions, such as nurse-led clinics. The implementation of nurse-led PACs is thought to improve the patient experience and decrease elective surgical cancellations, through risk identification and reinforcement of preoperative instructions. However, a better understanding of what is going on when surgery is cancelled and how patients make sense of what happens, will assist healthcare professionals to provide the information and support that patients really need. There is a gap within current knowledge of the experience for patients when elective surgery is cancelled. The question 'what happens when elective surgery is cancelled from the patient perspective?' has not been asked previously. This research attempts to respond to that question. The following chapter explains the methodology underpinning the research and the research methods undertaken to collect and analyse the data.

# Chapter 3  Methodology and Methods

## Introduction

This chapter discusses the methodology and methods used in this research. The chapter begins with an overview of qualitative research and its relevance for this research topic. This is followed by an overview of the philosophical understandings of grounded theory methodology with specific attention to how this aligns with this study's research question and aims.

The second half of this chapter focuses on the process of implementing grounded theory methods. Included are participant recruitment, data collection and analysis. Discussion includes the key tenets of grounded theory research (purposive sampling, coding, memoing, theoretical sampling, storyline and theoretical saturation) and how they are applied in the methods. Following on from this is a discussion of rigour and the criteria used to ensure trustworthiness of the research.

## Selecting a Methodology: Grounded Theory

As discussed, in Chapter two, previous research involving surgery cancellation has been from a largely quantitative approach, predominantly looking at the hospital systems and what improvements can be made to these to ensure a decrease in the number of surgery cancellations. Very little research has focused on the patient who has been cancelled, what happened for them and how they navigated through the experience. Therefore, a qualitative research approach is needed. The term "qualitative research," means any type of research that produces findings not arrived at by statistical procedures or other means or quantification (Strauss & Corbin, 1998). This can include research about peoples' lives, lived experiences, behaviours, emotions and feelings. A methodological challenge occurs when we consider whether grounded theory should be considered a quantitative or qualitative methodology (Alammar, Intezari, Cardow, & Pauleen, 2019). Glaser (2003) argues that grounded theory is neither a quantitative of qualitative research approach and in fact borrows from both methods. While the methodology is widely recognised and used as a qualitative methodology (Charmaz, 2006; Strauss & Corbin, 1990), classical grounded theorists consider grounded theory holds a middle territory between qualitative and quantitative approaches. This middle territory is unique and offers researchers an

alternative that is of the greatest practical use. It firmly grounds the explanatory theory in the data, is likely to offer insight and enhance understanding, thereby providing a meaningful guide to action (Simmons, 2011; Strauss & Corbin, 1998).

Elective surgery cancellations will continue to occur. With the best intentions of all parties involved, cancellations are inevitable. Considering how this is dealt with, how people are treated, how the communication occurs and by whom, are examples of some of the questions that arise prior to the implementation of changes that seek to improve the experience. Who better to answer these questions than the participants who have experienced elective surgery cancellation and for the researcher to discover what helped them to cope through this. Grounded theory endeavours to establish strong, consistent theory in places where knowledge is absent. The knowledge gained enables people to explain and act to change situations.  Breckenridge et al (2012), advocated a constructivist version of grounded theory; constructionism asserts that reality is constructed by individuals as they assign meaning to the world around them. Grounded theory is most suitably employed in studies where little is known about a phenomenon of interest (Birks & Mills, 2015) and where action is sought.

Conversely, the methodological choice for a research study must be informed by the philosophical underpinnings of the chosen approach. The epistemology, being how we construct knowledge and the ontology, being what we know, should be the best fit with the methodology, the research question and the researchers' world view (Yilmaz, 2013). The researcher, coming from a nursing background beginning in the 1980s, steeped in evidence-based practice, initially struggled with determining a worldview that was an accurate representation, having never questioned the positivist approach. Thus, a personal research journey began through post-positivism, to the emergence of new interpretative models of research, like grounded theory and to the epistemology of constructionism. The next section will explain why constructivist grounded theory following Kathy Charmaz (Charmaz, 2006), is the closest reflection of the researcher's world view and is the most suitable methodology employed to answer the research question of this study.

## Philosophical Understandings

In 1967, sociologists Barney Glaser and Anselm Strauss published their seminal book "The Discovery of grounded theory: Strategies for qualitative research" (Glaser & Strauss, 1967b), laying the foundation for one of the most prominent and influential methodologies. Glaser and Strauss brought together their two contrasting philosophical and methodological traditions: respectively, Columbia University positivism and University of Chicago pragmatism (Charmaz, 2009). The positivist tradition assumes that reality exists 'out there' and it is observable, stable and measurable. An unbiased observer can discover theoretical generalizations that explain experiential phenomena. Facts and values are separate. In contrast, the pragmatist view believes reality is a fluid unknown process. It assumes that reality is socially constructed; that there is no single, observable reality. It acknowledges multiple perspectives emerging from people's actions to solve the problems they face in their world.  Researchers do not 'find' knowledge, they construct it (Loftus & Rothwell, 2010).

Quite soon after their joint publication in 1967, Glaser and Strauss developed grounded theory in different directions and started to argue their own understanding of grounded theory methodology and methods apart from each other (Vollstedt & Rezat, 2019). Glaser worked primarily on his own and Strauss together with Juliet Corbin. In contrast to Glaser's classical approach, Strauss and Corbin gave a very detailed outline of data analysis, emphasising ongoing validation, combined with induction, and then deduction at the theoretical sampling stage (Heath & Cowley, 2004). This emphasis contributed to the view that there is a step-by-step formula that must be followed in order to produce a grounded theory (Charmaz, 2000).

Students of Glaser and Strauss further developed different interpretations of grounded theory to form a second generation of grounded theory researchers namely Juliet Corbin, Adele Clarke and Kathy Charmaz (Morse et al., 2009).  Charmaz maintains the process of construction of knowledge, the role of the participant and the researcher generating knowledge, makes grounded theory development a co-constructed endeavour. This was a key development, using a different philosophical approach to Glaser, Corbin and Strauss, which becomes manifest in opposing frameworks and criticisms of coding and data analysis (Kenny & Fourie, 2015). For Charmaz, the

pragmatist foundations of grounded theory encourage us to construct interpretive rendering of the worlds' studied, rather than an external reporting of events and statements (Charmaz, 2014).

As mentioned, constructivist grounded theory is rooted in pragmatism, which aligns with the researcher's world view of focusing on 'what works.' By studying what happened to participants when elective surgery was cancelled, from their perspective, and what actions they took to make sense of what happened to them, it was possible to construct interpretive meanings to these actions. This approach answers the research question.

## Research Design Methods

The purpose of a grounded theory study, whether classical, evolved or constructivist is to inductively generate theory from data (Mills & Birks, 2014). As a novice researcher, structure was needed; therefore I began to draw on the strengths of the separate scientific and interpretive research traditions of the two sociologists who developed the methodology (Glaser & Strauss, 1967b).

Grounded theory methodology is predicated on the following eight assumptions:

1. The need to get out into the field and discover what is really going on.

2. The relevance of theory, grounded in data, to the development of a discipline and as a basis for social action.

3. The complexity and variability of phenomena and of human action.

4. The belief that persons are actors who take an active role in responding to problematic solutions.

5. The realization that persons act on the basis of meaning.

6. The understanding that meaning is defined and redefined through interaction.

7. Sensitivity to the evolving and unfolding nature of events (process).

8. An awareness of the interrelationships among conditions (structure), action (process) and consequences

(Strauss & Corbin 1998, p. 9-10).

To begin with, these eight assumptions were very helpful towards understanding the participant's behaviour and establishing meaning through the participant's experiences, and how the contexts and conditions impacted individually.

## Accessing the Field

This study was conducted within the location boundary of the Waitemata District Health Board (WDHB), Auckland, New Zealand (Appendix A). This location was chosen for two reasons. Firstly, the researcher was an employee and research partner of the WDHB, being the main source of recruitment for participants. Secondly, data gathering was self-funded using a private car, therefore sampling was restricted to an easily accessible geographical area.

The initial contact with potential participants occurred via a mailed invitation leaflet. The contact details of potential participants were collected from a WDHB database report by a nurse other than the researcher, who then applied the inclusion and exclusion criteria. Potential participants were invited to participate via the invitation leaflet mail-out which included the researcher's contact details (Appendix B). The potential participants had two weeks to consider the invitation. If there was no reply, potential participants had one follow-up telephone call from a nurse other than the researcher. Potential participants responded to the invitation via telephone or email. Once potential participants indicated an interest, the researcher emailed each a copy of the Information Sheet and Consent Form (Appendices C and D). Potential participants gave consent via two ways. Firstly, electronically via email and secondly, face to face with the researcher after the information sheet had been read by participant and questions answered. There was the opportunity for follow up invitations for potential participants if necessary. Upon receipt of the completed consent form, the researcher contacted the participant again and arranged a time to meet for an interview. The recruitment and data gathering occurred over a three-month period.

## Purposive Sampling

Grounded theory methods involve purposive sampling, then theoretical sampling coupled with theoretical sensitivity (Strauss & Corbin, 1998). Purposive sampling technique is the deliberate choice of a participant due to the qualities the participant

possesses. Simply put, the researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue of knowledge or experience (Etikan, Musa, & Alkassim, 2016). In this study, the purpose of initial participant selection was to recruit those patients who have experienced elective surgery cancellation and have agreed to be interviewed. The estimated number of participants to be recruited was approximately 4-8, based on the analysis approach used of constant comparison and the time limits of the study. The timing of the interview was after the cancelled surgical procedure had been rebooked and completed. The timing decision was a clinical observation, made on the basis of a conversation between the researcher and a senior medical officer. He was of the opinion it was morally appropriate for the researcher to approach prospective participants after completion of surgery, thereby maintaining independence as a researcher. If the approach was made while surgery was pending, the researcher may have felt obligated by the participant to speed things along and the participant may have felt obliged to consent to ensure completion of the surgery.

Grounded theory is characterised by the initial analysis occurring almost immediately. This means that each data collection event is followed by analysis of the data that has been collected (Mills & Birks, 2014). In this study, the first three participant interviews occurred close together thus providing the opportunity for initial coding only of the data between interviews one and two, and interviews two and three.

## Participant Selection

To be eligible for inclusion in this study the following criteria had to be met:

1. Adults who are fluent in conversational English

2. Who have experienced cancellation of elective surgery

3. Who have had surgery rebooked and surgery is completed

4. Who agree to being interviewed

In setting the first criterion, adults who are fluent in conversational English, related to the suitability of respondents to the research question and avoidance of complex consent issues if a child were to be interviewed (child being under the age of 16 years). Conversational English was deemed most appropriate to this study, as it is the primary

language of the researcher, who had no access to interpreters for this study and no funding to support this.

The second criterion related directly to the participant having experienced elective surgery cancellation, aside from acute or trauma surgery, thereby having first-hand experience of the very phenomena under study and who would be able to share their story.

The third criterion, of the participant having the cancelled surgery rebooked and completed, has been previously mentioned. As stated, maintaining authenticity throughout the researcher and participant relationship was deemed of paramount importance. As a novice researcher, focus was to be centred on the cancelled surgery experience and not getting distracted by the participant's attention focused on how they could get their surgery rebooked.

The last criterion, agree to be interviewed, communicates to the participant how the data will be obtained and the researcher's expectation of participant commitment. In total three women and two men were interviewed.

## About the Participants

As stated, four participants were interviewed in the initial data collection. Two of the participants were in hospital when they had surgery cancelled, one participant was cancelled at home on the day of surgery and one was cancelled at home two days before the day of surgery. The fifth participant, who was recruited later, was in hospital when surgery was cancelled, and he was cancelled twice.

## Data Collection

When generating data within a constructivist grounded theory, the researcher co-constructs with the participant (Corbin & Strauss, 2015; Mills & Birks, 2014). They may work directly with the participants by conducting interviews or facilitating focus groups and/or generate data in the form of personal memos, field notes of observations, and gather information from records and reports. The kind of data the researcher pursues depends on the topic and access. Researchers can generate strong grounded theories with rich data (Charmaz, 2006).

In this study semi- structured interviews were favoured. This type of interview was used to enable participants to direct the discussion, to pace the interview to suit them, in what order and to what depth (Corbin & Strauss, 2015). The researcher developed general questions designed to open conversation about the topic and used audiotape to record each interview. Interviews provided the opportunity for the researcher to learn about the process of surgery cancellation, directly from the participant's perspective and what this meant to them.

The participants were given the option to be interviewed in their own homes or a place of their choosing. One participant chose to be interviewed at work, one at a local Community Centre and the remaining participants chose to be interviewed in their own home. See (Appendix J) for the researcher safety protocol, for an interview that is conducted within the participants' private residence.

Each interview followed a similar format. The researcher began by introducing herself and confirming the participant's identity. Then ensuring the participant was comfortably seated, this was followed by a brief conversation about the research topic and consent form and answering any questions. The participant was reminded that if they did not want to answer any question or needed to take a break, they just had to say so.

Permission was sought to make notes of nonverbal responses and reactions if any and to audio record the interview. Then the researcher asked if the participant would like to begin the interview. Once the participant was ready, the audiotape was turned on and the interview started. Interviews lasted between 40-60 minutes.

The interview questions (Appendix I) consist of three phases: initial open ended questions, intermediate and ending questions, adapted from Charmaz (2006, p.30-31). Within the three phases are differing prompt type questions depending on what the answer was that preceded it. The researcher used these prompts during the interview as a guide, when it appeared the preceding question had been fully explored and answered. The researcher made a real effort not to be drawn into hospital process type questions, for example, when the participant experience did not make sense from the researchers professional perspective. Towards the end of the interview, participants were given the opportunity to add any comments they wanted to, if there

was anything else the participant thought the researcher should know, and if they had any questions for the researcher.

As previously stated, grounded theory is characterised by the initial analysis occurring almost immediately. To fully understand the research problem it is possible interview questions will need modification, due to study progression and emerging categories (Creswell, 2013). For example, the researcher added to the existing questions to aid in exploring the emerging subcategory of 'acknowledgment and apology'. For example: other participants have placed importance on receiving acknowledgement that surgery was cancelled. Was this important to you? And if not, why was it not important? Can you remember being given an apology? Was this important for you? Thus, interview questions become more refined to explore these emerging categories.

## Data Analysis

Grounded theory analysis has two main rules: firstly, everything is a concept, which is to say all is data (Glaser & Strauss, 2009) and data analysis needs to proceed immediately following the first data collection. Data is initially analysed for recurring actions, characteristics, experiences, phrases or explanations which are labelled with a code. Codes become categories and these are compared with future categories. It is the constant comparison of codes and categories that drives theoretical sampling and the ongoing collection of data (Mills & Birks, 2014).

## Coding

Once the interviews have been transcribed, the first analytical step in grounded theory is coding. The researcher used the three level system of initial coding, focused coding and theoretical coding (Charmaz, 2006, 2014). Excerpts from transcripts will be used to illustrate this process.

Initial coding consisted of examining each line of data and defining the actions or events the researcher could see are occurring or were represented. This line-by-line coding kept the researcher close to the data and keeps away any motives, fears or unresolved issues the researcher may bring. It was the beginning of studying the data analytically (Charmaz, 1996).

Table 1: Initial coding

| Raw data | Initial coding |
|---|---|
| **P: umm and then I got told that it wasn't going to happen umm so yeah it was kind of that whole I don't know I can't I can't even explain it I cried let's put it that way umm because my kids were geared up for it as well my husband was geared up for it and then bang it's finished there's nothing happening that's it so umm then it was actually rescheduled for the following week which was even harder because I perceived it to be maybe the next day or a couple of days later** | being told<br>not knowing<br>feeling overwhelmed<br>recruiting family<br>involving spouse<br>abruptly stopping<br>nothing happening<br>coping with unexpected time frames |
| **I: ohh okay** | adjusting timetable and expectations |
| **P: but it was the next week so again another week off work and everything else umm but yeah I guess it was the the (sic) surgeon that that (sic) phoned was really lovely about it they were very apologetic but umm it was just that whole then it just stops you don't you don't hear anything else** | feeling work pressure due to more time off<br>accepting apology that was given<br>struggling with non-communication<br>feeling excluded |

Initial codes help the researcher break the data into categories and begin to see processes, leading to focused coding.

Focused coding refers to taking earlier codes that continually reappear in the initial coding. Thus, deciding which of the earlier codes make the most analytic sense and the categorising of data most accurately and completely (Charmaz, 2006). In the example below I select the codes *recruiting family* and *feeling excluded* to capture and explain the main process in the participant's statement. Focused coding allowed the researcher to try out categories to develop the analytic framework, thus *recruiting family* became a sub-category of the first category *Readying* and *feeling excluded* became a sub-category for the third category *Being Let Down*.

Table 2: Focused coding

| Initial coding | Focused coding |
|---|---|
| **being told**<br>**not knowing**<br>**feeling overwhelmed**<br>**recruiting family**<br>**involving spouse**<br>**abruptly stopping**<br>**nothing happening**<br>**rescheduling time frame unexpected** | recruiting family |
| **adjusting timetable and expectations**<br>**feeling work pressure due to more time off**<br>**accepting apology that was given**<br>**struggling with non-communication**<br>**being excluded** | feeling excluded |

## Theoretical Sampling

Throughout the process of focused coding, the researcher employs a technique called theoretical sampling. Engaging in theoretical sampling prompts the researcher to predict where and how to find needed data to fill gaps and saturate categories. This ensures the construction of robust categories and leads the researcher to clarify relationships between categories. This is important when exploring new or uncharted areas and helps to develop the emerging theory (Charmaz, 2006; Corbin & Strauss, 2015). In this study, the interval between interviews three and four provided the necessary time to construct ideas about the data and then examine these ideas through further enquiry. For example, the memo below demonstrates the emergence of a strong category *acknowledgement and apology* from the data collected from participant one and two, but it was not mentioned by participant three. When interviewing participant four, the researcher specifically asked for a response about *acknowledgement and apology*, to gauge importance.

Memo:

Katie spoke about and hinted throughout that she would have liked some recognition or acknowledgement that she had had surgery cancelled. She wasn't particular about who should acknowledge her or when. But towards the

end of the interview she spoke a number of times that this was lacking in that no-one had given any acknowledgment. She at one-point thought that the surgeon could have said something when she returned for surgery, but then realised that he would be busy… then thought that someone else could have reminded him. She didn't think it would take very much to do this. I didn't really notice this at the time, perhaps because she emphasised it at the end of the interview and being my first ever interview, I was tired.

Anna mentioned that the communication wasn't very good amongst hospital staff and then from staff to patients. She mentioned her husband had said the surgeon had apologised for the day. This seemed to satisfy her, as she didn't mention it again and I didn't pick up on this as being important.

Des didn't mention acknowledgment or apology at all. I didn't think to ask him about it.

Then during the fourth interview Teresa mentioned, right at the beginning, that it would have been nice if someone had sat with her after she had been "told" surgery was cancelled. I immediately thought I've heard this somewhere before and could this be related to receiving acknowledgement or apology? Further into the interview, when she was talking about being rebooked for surgery, I asked her if anyone had said anything to her about the cancelled surgery? Did anyone acknowledge her as previously being cancelled or express an apology? Her negative response was when I thought that this is an important step in the process. That someone gives cancelled patient's first acknowledgement and second an apology.

## Memoing

Memo writing is the process of free writing by the researcher. They are spontaneous, not mechanical, written records of the researcher's thinking, analysis, interpretations, questions and directions for further data gathering, during the process of the grounded theory study (Charmaz, 2006; Mills & Birks, 2014; Strauss & Corbin, 1998). They are meant to be analytical and conceptual rather than descriptive. In this study the researcher found memoing a struggle but combined with storyline and diagrams, showed improvement with the process. Memos evolved and have grown in complexity, clarity, density and accuracy, keeping the research grounded and maintaining awareness of the researcher (Strauss & Corbin, 1998). Each memo written in this study was saved with the date and title, which assisted greatly during analysis.

## Theoretical Sensitivity

Sampling is closely related to the sensitivity that the researcher has developed towards the emerging concept (Charmaz, 2006). Theoretical sensitivity is a multidimensional concept; including the researcher's level of insight into the research area, how attuned

they are to the nuances and complexity of the participants words and actions, the ability to see, define and express phenomena and the capacity to separate what's relevant from what is not (Charmaz, 2006; Glaser, 2003; Strauss & Corbin, 1990). Within this study the researcher's development of theoretical sensitivity remains ongoing and is growing with time. In the early stages of this study the importance of the category of "acknowledgement and apology" was overlooked. With the development of more sensitivity the researcher was able to return to the data and recode them in the light of this new insight.

## Constant Comparative Analysis

One of the key tasks of coding is the linking together of categories, using the method of constant comparative analysis, to make comparisons at each level of analysis (Glaser & Strauss, 1967b). Firstly, comparing data with data, finding similarities and differences, then categories and sub-categories are compared with each other, leading to a core category (Mills & Birks, 2014). Through the process of constant comparative analysis, the importance of memoing is clearly seen as mentioned above. As the researcher becomes more analytical, certain codes become conceptual categories (Charmaz, 2014). For example, the first category of *readying* includes the process the participants had to move through of *making space* in their busy and full lives. They appeared to be unable to do this by themselves, perhaps beginning to feel their diminished control over this process, with the outcome being the necessity to recruit family members to help and support. All the while *enduring* multiple clinic visits and appointments with different specialists and all the tests and investigations that went with this. But all through this process is the feeling that they are not in the driver's seat. They think they are making things happen and they are not. They are being led all the way, being told when to come and what to do; they are essentially lacking control over this whole experience. They are *readying* themselves and at the same time being readied by someone else.

## Storyline

The technique of Storyline was used to aid the analytical processes, thus attempting to reach the highest level of abstraction while staying true to the data (Strauss & Corbin, 1998). It is a form of writing that is undertaken away from the data. It is free writing as an expression of a version of events, thus facilitating the explanatory power

characteristic of theory grounded in data (Vaismoradi, 2016). On reaching the later stages of analysis, the researcher admits to feeling overwhelmed with the amount of material generated through initial coding. Theoretical sensitivity was then enhanced by the action of moving away completely from the previous data immersion. This did appear to be counter intuitive at the time, but the process of not looking at the data and allowing a space of free writing really emphasised the developing storyline which is the story of the coding. The three techniques of Storyline being stepping back, refining and evidencing, assisted the researcher to move the analysis from description to abstraction. Abstraction is the theoretical extraction of concepts that capture the essence of the substantive data (Bryant & Charmaz, 2019). In this study, the researcher struggled with memoing and was encouraged by supervisors and colleagues in a Grounded Theory support group, to use the technique of Storyline to contrast and compare codes, to ask questions of the data and in this way move the analysis towards category identification.

## Theoretical Development

To advance the emerging theory development, Charmaz (2014) advocates the use of theoretical sorting, diagramming and the integration of memos. Theoretical sorting occurs via memos becoming more precise, analytic and incisive around the links between categories and subcategories. Diagramming offers a visual representation of the emerging theory and this often displays the processes more accurately, allowing the researcher to supply connections between categories. Integration of memos is achieved by sorting existing memos and writing new ones when analysis brings developments and change. In this study, these three methods were used alongside one another to not only support the researcher's analysis, but to enable diagrammatical presentation of the emerging theory to others, see Figure 1. in Chapter 4.

## Theoretical Saturation

Theoretical sampling continues until theoretical saturation is achieved. Categories are saturated when the gathering of data no longer sparks fresh theoretical insights nor adds to core theoretical categories (Charmaz, 2006; Strauss & Corbin, 1990). During the iterative process in the research, it became apparent that more information was needed to saturate the categories under development. Hence further theoretical sampling was planned, and a fifth participant was interviewed. This participant was

chosen due to his experience of having surgery cancelled twice, thereby being able to add rich data to the emerging theory. As this is a master's research project, it is limited by the restricted time of the master's programme. Although the categories appear dense and have good explanatory power, the researcher acknowledges that more data would likely have been collected to add to the developing categories, if time and funding had permitted.

## Ethical Considerations

Ethical approval to proceed was sought from the Auckland University of Technology (AUT) Ethics Committee and was granted 11th December 2017 (Appendix E). Next approval was sought from the Research and Knowledge centre, WDHB; Locality Process and Māori Review, and was granted 28th February 2018, Registration #: RM13827 (Appendix F). Dr Helen Wihongi, Research Advisor – Māori/Senior Research Fellow, He Kamaka Waiora, WDHB and Auckland District Health Board suggested the researcher present the proposal to the Mātauranga Māori Committee, AUT; thus, fulfilling the consultation with Māori aspect of research conducted within the WDHB (Appendix G). The recommendations and comments made by the Mātauranga Māori Committee and Dr Wihongi were included in the research methods thus approval was given for the research.

Cultural considerations are important when undertaking research and in New Zealand these considerations are firmly embedded within Te Tiriti o Waitangi principles of partnership, participation and protection. Treaty principles are primarily concerned with the way in which the Crown and Māori behave in their interactions with one another. Both emphasise the need for recognition and respect in the treaty partnership and stress the parties' shared obligation to act reasonably, honourably and in good faith towards each other (Hancock & Gover, 2001).

The Treaty is an integral part of New Zealand's constitutional framework and its status will continue to evolve along with other constitutional principles and norms (Hancock & Gover, 2001). For this reason, immediate and ongoing consultation with cultural advisors is essential for research involving Māori; it is of paramount importance to have awareness and respect for cultural protocols. The generalisability of research findings is more successful if all population groups are represented in the study,

particularly for Auckland city as a large multi-cultural city. Attention needs to be given to the possible lack of recruitment of certain ethnic groups, and why some groups will be underrepresented, or decide not to participate.

## Treaty Principles: Partnership, Participation and Protection

The participant and researcher work together to generate theory grounded in data, thus implementing the principle of Partnership in their interaction. This relationship is reciprocal, meaning, there is a sharing of knowledge, or a sharing of stories, rather than the taking of knowledge and taking of stories (Smith, 2013). The researcher will take something to give, in the form of a koha (gift), before asking for information (a koha was given to those participants who were interviewed in the form of a petrol voucher to the value of $20). Consultation with a Māori reviewer, in this case Dr Helen Wihongi (WDHB), ensured connection and engagement and was all that was required due to the small numbers of Māori participants expected. No Māori participants were recruited in this study, but if they had been then a summary report would be given at the end to participants and those who offered consultation.

The principle of Participation was implemented through the participant information leaflet, which clearly outlines what the study is about, what the participant is being asked to do, who is doing the study and withdrawing from the study. Being part of the study was the participants' choice and they can choose not to take part, or to withdraw from the study at any time. Principal involvement of participants is one of sharing information of an experience, a form of storytelling. Possibly participants may be asked to read transcripts of their interview for accuracy and approval. Whānau were excluded from the study, which conceivably may impact negatively for the inclusion and access of Māori to the study.

This study implements the principle of Protection from the very beginning. At the invitation to participate stage, the purpose of the study is fully disclosed. No pressure was placed upon participants to sign consent forms. The researcher has experience with how to interview a participant in a culturally safe manner, including, having respect for the cultural knowledge and values of others, having an awareness of one's own way of seeing others and being able to analyse the effect of their decisions on the knowledge that is collected. "Me whakatika te matatika ki roto i te tikanga kia tika ai" -

For ethical frameworks to be authentic they must be shaped by our cultural values (B. Smith et al., 2009). Emphasis was placed on building trust, respecting any power imbalances that may arise and respecting privacy. During data collection, the interviewer avoided leading questions and refrained from disclosing personal impressions/judgements. Confidentiality was maintained by only the researcher and supervisor handling the data and analysis. Consent forms and data were kept separately. As transcription services were used, completion and adherence to the confidentiality agreement was required (Appendix H).

## Criteria for Ensuring Rigour

Researchers strive to be honest and sincere, to generate theory grounded in data. Developing criteria to ensure this is reassuring to the reader that a study was of significance and value (Glaser, 2003; Lincoln & Guba, 1985). Of course, any attempt to define a single set of criteria for all research is fruitless. We will limit our discussion to the grounded theory approach, which uses a systematic set of procedures, as discussed above, to develop inductive theory about a phenomenon. These procedures offer a rigorous orderly guide to theory development, that at each stage is faithful to the area under study  (Glaser & Strauss, 1967b; Strauss & Corbin, 1998). Further demonstration of a rigorous approach in this research needs to be considered. Discussion of the four criteria conferred by Nicholls, originally proposed by Lincoln and Guba (1985), that being credibility, transferability, dependability and confirmability will follow (Lincoln & Guba, 1985; Nicholls, 2009b).

## Credibility

Credibility, within qualitative research, refers to those activities that increase the likelihood of credible discoveries compatible with participants' perceptions (Corbin & Strauss, 2015; Glaser & Strauss, 2009). This can be achieved through choosing a methodology that fits the research question. As described in this chapter, a grounded theory methodology was selected and the procedures of data gathering, and analysis were followed. As theory emerges, the researcher facilitating this process must be accountable for the actions taken and decisions made, therefore writing reflexive memos is one of the most truthful and methodologically consistent ways to achieve this (Mills & Birks, 2014). Member checking was used to establish credibility, drawing on a peer panel after analysis, to ensure that analysis is valid and a legitimate

representation of the phenomenon (Finlay & Ballinger, 2006). The researcher achieved this in three ways; firstly, by presenting early findings to a research group as part of a study day. This was well received with insightful questions and encouragements. Secondly, presenting one storyline to a grounded theory group, including post graduate master's and PhD students and several supervisors. This was very useful, with one group member describing her experience of cancelled surgery and how the storyline matched her experience. Thirdly, presenting to the same grounded theory group a draft of the final diagram, where much discussion followed with one supervisor editing the diagram on a whiteboard.

## Transferability

The second criterion, transferability, is the evidence that it is possible to relate developed theories from one context or group to another (Lincoln & Guba, 1985; Nicholls, 2009b). Within this study, the researcher will clearly show the sub-categories and categories and will detail this with a diagram depicting how the categories relate to each other. A description outlining the breath, depth and variation will follow. It is the researchers hope that the core category is sufficiently broad so that it can be used to study other populations and similar situations beyond this setting (Corbin & Strauss, 2015; Glaser & Strauss, 2009). It is noted that the sample size is small, therefore further research is required, including a larger sample size gaining theory saturation, before the findings can be applied to others.

## Dependability

Within qualitative research, dependability is the evidence of consistency and accuracy in data collection and analysis (Glaser, 2003; Nicholls, 2009b). Using the iterative process of grounded theory, the researcher returns again and again to the data constantly comparing earlier assumptions. Throughout the research process the maintenance of an audit trail is an essential requirement. Including recording any decisions made during research activities, changes in research direction and the rationale for the choices that were made. The tools of memoing and storyline were helpful in providing detailed information during analysis and were an important feature of safeguarding dependability. This trail of decision making built my confidence as a researcher and was helpful in preventing the "second guessing" of the decisions

that were made during the research process (Corbin & Strauss, 2015; Mills & Birks, 2014).

## Confirmability

Confirmability is defined as an active process of increasing insight into one's work to guide future actions. At the beginning of this study the researcher's supervisors felt it was useful to do a presupposition interview of the research question, thereby ensuring a critical review of the involvement of the researcher in the research and how this impacted on processes and outcomes (Mills & Birks, 2014). This is briefly mentioned in chapter one, under background. Any categories that emerged from the analysis that did not fit with the overall findings have been acknowledged and discussed in the finding's chapters.

## Summary

Within this study the maintenance of written memos and storyline, previously mentioned under dependability, provide a written record of reflexivity. Noting the actions and feelings and the influences these had on the researcher's thinking were incorporated in the analysis as to the impact and outcome. Coupled with the audit trail, this demonstrates a transparent decision trail (Corbin & Strauss, 2015; Mills & Birks, 2014; Nicholls, 2009a). While not exhaustive, the above referenced criteria used as a guide, being credibility, transferability, dependability, and confirmability will be enough to establish quality and applicability of this research.

This chapter has discussed qualitative research and its relevance to the research question. An overview of constructivist grounded theory, as portrayed by Charmaz, was provided as the chosen methodology, as the epistemology of pragmatism 'fit' with the study and the researcher. In addition, a discussion around the philosophical aspects of grounded theory is included. All the methods applied to gather data and then form the analysis were outlined. Followed by the ethical considerations that were considered, how rigour was ensured and the criteria that were used are included. The research findings as presented in the next chapter.

# Chapter 4  Findings

## Introduction

This chapter represents the findings of this study. The core category, categories and subcategories are outlined in Table 3 below. Each category captures what happened to participants and how they managed what happened as they moved through the process of elective surgery cancellation. To assist with making sense of the relationships between the core category, categories and subcategories a table has been inserted at the beginning of each findings section. The core category, categories and subcategories *appear in italics* within each section that they relate to. Excerpts of the interview transcript will be used to illustrate the findings. Each participant has been given a pseudonym. At the end of each excerpt there is the pseudonym and a number detailing where in the transcript the excerpt comes from, such as, (Des 58-60). Where one excerpt contains two or more sources within one transcription, this will be noted as follows (Des 12-14, 23-25).

Table 3: Categories

| Core Category | Categories | Subcategories |
|---|---|---|
| **Navigating Abandonment** | Readying | Making space<br>Recruiting family<br>Enduring |
| | Waiting | Struggling with hesitating<br>Wondering<br>Accepting distress |
| | Being Let Down | Suffering delay<br>Being excluded<br>Resigning |
| | Rebuilding Fragile Trust | Repeating and adjusting<br>Understanding cancellation<br>Expecting acknowledgement |

## Navigating Abandonment

*Navigating Abandonment* is the core category that informs the developing theory within this study. This core category captures the common experiences of the participants as they moved though elective surgery cancellation, with

acknowledgement given to the individual responses as they deviate from the common experience. As shown in Figure 1, *Navigating Abandonment* is depicted as a cyclical process of interlocking cog wheels, with some of the properties that influence each cog rotating around the outside. Cogs were chosen as they reflect movement and hint at the organisational machine behind the process. Each participant moved through this cyclical process at their individual rate, some moved between the cogs backwards and forwards, some lingered longer than others and some did not experience the process of moving through each cog as the others did.



Figure 1. Navigating abandonment: Elective surgery cancellation

Navigating is the process that happens throughout the experience, through all four categories, as each participant's makes sense of what is happening. But abandonment does not start to creep in until the second category and continues through to the fourth category. Abandonment is a very strong word, which initially was questioned by

the researcher's grounded theory peers. If you are abandoned you do not come back, therefore if your surgery is abandoned how can you come back. Upon discussion and reflection the decision was made by the researcher to keep abandonment because of the strength of the experience described by participants. The participant was the one that was abandoned, for a time and a place, by part of the organisation and it is the surgical procedure that is re-established by another part of the organisation, thus allowing the participant's abandonment to end. Each of the categories and subcategories of the process of *Navigating Abandonment* are described below.

## Readying

Table 4: Readying

| Category | Subcategory |
|----------|-------------|
| **Readying** | Making space |
| | Recruiting family |
| | Enduring |

When each participant spoke of surgery cancellation, they included the time before surgery, detailing the preparations they needed to make and the events leading up to the time when surgery was cancelled.  The category of *readying* was about how each participant went about the process of getting ready; what they did to organise themselves, their work, their families. They needed expert advice because, to a certain extent, they did not know what was involved. As the advice was given and followed, they start to work their way along. This included *making space* for this event in their lives, because adjustments had to be made and new demands dealt with. To assist with these adjustments' participants began *recruiting family* to provide support and encouragement. Once this part of the process was established, the *readying* was understood, the participants spoke of entering a time of *enduring*; such as, enduring the multiple interactions with hospital staff and the many details that were scrutinised then added to the plan or discarded.

## Making Space

Conditions influencing the process of *making space* included learning the regime of certain medications and supplements that some participants were instructed to take on specific days the week prior to surgery. For others their skin preparation was a vital

part of getting ready and had to be completed on day three before, day two before and on the day before surgery. There was information to comprehend on why this skin preparation had to happen, what was the benefit and what are the consequences if the information was not adhered too. Other physical concerns were the management of constantly waking up at night due to pain and for some, pre-surgery medications also interfered with sleep patterns.

> … I knew they wanted my leg as clean as they could get it and understanding if it wasn't clean, I could get an infection. I was pretty careful … (Des 17-19).

> … I was unwell but managing at work so in that sense I had probably umm brought my life in a bit to manage umm there was a a (sic) whole lot of space between work took a lot of energy and ill health which also took a lot of energy and the surveillance that we need over ourselves when we are in ill health I you know you get sick of all this stuff you need around you in your own life and sleep doesn't come easily umm and medications interfere and there were nights when I just want to chuck it all in let it be… Teresa (105-112).

All participants, while progressing through the *making space* process were aware that they need expert guidance, but conversely felt as if everyone was telling them what to do. They said 'yes' to surgery when it was offered and that felt like the last decision they made. Participants were told when to come to clinic appointments to see the surgeon and the anaesthetist and other clinicians. When appointments were not convenient, they felt obliged to take them, thinking that things would be delayed if they did not.

> … I was like okay I'll ring them and see if they can give me an idea (of a surgical date) like is it gonna be closer in the first couple of months or am I literally looking at a date in my last couple months and I kinda knew they can't give you an exact… gotta be able to give me something… and the lady on the phone was like ohh no you're gonna be closer to the to the (sic) end of your four months so I know I was at the beginning of it then I was like right four months plenty of time over Christmas I can take all these bookings for work perfect and then yeah then a week later a week later and that's the other thing it wasn't it wasn't even a decent time later it was literally a week or two later I got a letter saying "ahh can we book you here" and I was like I just rung are you telling me you didn't have any i.. yeah any idea?... yeah and just a bit dismissive… (Katie 313-321, 323-326, 328).

It appeared to be of little influence on the process if prior knowledge or experience of elective surgery existed.

> … I get really nervous I I I (sic) had a lot of surgeries I get really nervous… (Katie 42).

> … I'm very accustomed to surgery surgery itself doesn't make me nervous but there's a few procedures that make me very nervous and when I go in that is all I'm like stressing about … (Katie 120-124).

It is interesting that Katie early in the interview stated she got really nervous prior to surgery and then later in the same interview clarified this by saying it wasn't the surgery she got nervous about it was the procedures that came beforehand that caused her the most stress. If this was her first surgical experience, she wouldn't have had this prior knowledge to get nervous about. Des also talked about previous surgeries as did Sonny, but the process of *making space* still had to be completed by everyone regardless of any pre-existing understanding.

Participants have entered into a verbal contract, an agreement to accept the surgery that was offered. As they allowed surgery to take over more space, they start to see how its impact builds and builds and how their control over the process diminishes.

> … you do feel a little bit out of control of the situation and when it's something happening to you physically you kind of wanna have a feeling of control just a little bit … umm yeah just like I suppose you've got control and saying yes or no that you want to have it it (sic) was elective surgery I chose to have surgery to have it done umm but in saying that I've you kind of you just throw yourself in there… (Anna 468-472).

## Recruiting Family

*Readying* for surgery involved *recruiting family* participation, to take over tasks and responsibilities that the participant was or would be unable to fulfil, and for emotional support. For each participant this was necessary as none lived in isolation. There appeared to be enormous family participation for the day to day practicalities and picking up the slack left by the person having surgery. There were husbands that took time off work. Grandparents who travelled down to help look after young children. Children who were briefed on what was happening and who would take over what and

where. A son travelled up to help, a sister took a month off work and travelled from overseas to help.

> … so my husband took two weeks off work [chuckle] yeah guys I'm this surgery on my legs I can't do everything I've got six dogs … [laughter] mate there's no way that my husband wasn't going to be able to to take the time off work umm thankfully he's in a job that he was able to … (Katie 511-517).

> … my husband took time off work… my kids were geared up for it as well my husband was geared up for it …  umm my parents came down from Kerikeri to look after the kids for us … (Anna 15, 25-26, 249).

> … I have a son who lives umm out of Auckland in the Taranaki area he travelled up I had a a (sic) sister who had taken a month off to come for the help … she only had a month and I would need her for that month because my family have work and have children … I had brought in things to just manage and family family (sic) were just wonderful in in (sic) many many (sic) ways … (Teresa 20-21, 30-31, 117-118).

For Katie and Anna this close family participation and support was something they relied upon and they appear to be expectant of this level of involvement, which perhaps as wives and mothers was a product of their reciprocal relationship. Teresa also valued and was humbled at the love and support from her immediate family but found that her extended family involvement was not always positive or helpful. This tended to impede her process of *readying*, describing how a family member used to watch her and make assumption about how she was coping. Other extended family had perceptions about what was going on for Teresa with the result of adding to her distress. There appeared to be family that were kept informed and other family that were not aware of any details. Teresa described a conversation that one of her sons had with an extended family member:

> … I was at a family gathering extended family gathering umm on the other side of the family and a someone had asked him how I was and he said you have no right to know… he said to me okay I want you to know that I will not be talking to people about you if you want some help I I (sic) I'm very willing to give it he said but I'm gonna wait for you to ask … and I had another member of the family he used to watch me ohh you're not doing too well and make assumptions

about how I was going and I didn't find that very helpful either …
(Teresa 119-123, 128-130).

The *recruiting family* happened before surgery while the participant was moving through the process of *readying*, with the expectation that the family participation and support would continue after surgery. Participants spoke of degrees of incapacitation that existed before surgery, where supportive assistance was required and there was the future incapacitation that required some anticipation and planning. For some, the longer the time period was before they had surgery, the more physically debilitated they became.

> Memo 15: There were degrees of incapacitation that existed before surgery, for the participant to endure through this was part of the mental preparation. To cope with the incapacitation supportive assistance was required and this was provided for the most part by family members.
>
> By allowing surgery to enter their lives, the participants received hope and a way to alleviate the incapacity. There was also the immediate postoperative period where maximum support would be needed, and this was planned for and the responsibility shared out amongst the willing.

*Readying* for surgery affected the participants and their families: spouses, children, parents and siblings. It did not matter how young or old the family members were, such as, some of the children were at Primary School, some were married with their own families, they were all affected differently. The extent and type of reaction of individual family members appears to depend on how involved they were in the participant's life and/or emotionally cared about them.

> … you don't always realise in the day to day life how much your family loves you until you become unwell. Something that you should have known in your heart all along and you don't know, so that was the ambivalence and the resolution the decision that I would get better… (Teresa 149-154).

## Enduring

As participants progress along the process of *readying* the initial flurry of physical preparation and gathering family support, there is the continual interaction with multiple hospital staff and participants describe this as *enduring*. There is a type of acceptance, a patient persistence of going through all the stages they are required to do, by the hospital and doing all that they need to do on a personal level. Underlying

this process of *enduring* there is a real sense of diminished control. Participants expressed their position as one of non-involvement, of not having a voice in their own decision-making and maintained this experience was where everyone else is telling them what to do. This diminished control influences *readying*, by eroding self confidence in the participants' ability to manage themselves and guide their close family members, and caused slight but persistent annoyance, discomfort, or anxiety.

> … and yeah I guess you're you're (sic) working around them as opposed to them working around you so if you get sent an appointment time you have to go really to that appointment time otherwise you're gotta reschedule for three weeks later or something like that … umm and that does make it kind of you do feel a little bit out of control of the situation and when it's something happening to you physically you kind of wanna have a feeling of control just a little bit … (compared with) I'm going to have my baby today because I'm in labour umm so they have to work around you so you do feel more empowered when your having a baby you call the shots, you do feel more empowered, you definitely feel a lot more unless it's an elective C-section or whatever but then again there's that whole elective word again that you're electing to have it done so you would sort of think that if you're electing to have something done that you'll be in the driver's seat but it kind of comes turns around the other way … (Anna 179-182, 465-468, 838-847).

The continual interaction with multiple hospital staff for some participants widens the gap between what is communicated to them and what is understood by them, further drawing attention to their forbearance with *enduring* the process of *readying*. Anna spoke of attending some of the clinic appointments and being unable to take anything in that was verbally presented to her, and she also described too many points of contact: surgeon (male) that she met in clinic, surgeon (male) that telephoned, another surgeon (female) texted her. Conversely, Sonny felt the doctors had adequately explained things to him, but he described a different experience of having to act as the go between for two health professionals:

> … I thought the doctors more or less did a good job in communicating to me what was going to happen next, although I did not enjoy the lack of communication between orthopaedics and plastic surgery… so they both had different objectives and they didn't talk to each other… they wanted me to talk to each other… um … I didn't understand why they were telling me their part, when I felt they needed to talk to each other … um to achieve their ends um so I

> didn't I just couldn't understand why they just couldn't talk to each other … (Sonny 9-12, 18-20).

*Enduring* overlaps with *making space*. There are aspects in both of participants doing what they are told, by the hospital, connected with the sense of non-involvement and the feeling of being led. Someone else is driving the process along and it is not the participant. If they are on a carousel, someone tells them when to get on, someone tells them where to sit and when to stand up. Someone starts and speeds up and stops the carousel, not them. They are along for the ride. There is a real sense from the participants of going around and around while *readying*, not knowing what will happen next, where they will end up and what it will take to get there.

## Waiting

Table 5: Waiting

| Category | Subcategory |
|---|---|
| **Waiting** | Struggling with hesitating<br>Wondering<br>Accepting distress |

Something begins to happen within the hospital, there is a hesitation, a pause and participants cannot see a reason for this pause. They begin a process of *waiting*, some participants were *waiting* in hospital, while others were *waiting* at home. In both places they were *waiting* for news, because of something someone said to them or an alteration to what was anticipated as part of the process, a time of stalling. It is uncomfortable to feel that you have stopped, and you are not making any progress. Because participants did not receive information in a timely manner there was this intense questioning that occurred. Who made this happen? Why did it happen? What happens to me now? How can I get moving again? When can I get moving again? Some of the questions were verbalised, others were kept internally.

### Struggling with Hesitating

For those participants in hospital there appeared to be a shift in what was normal and expected, which gave an indication that something was not right. There was an internal struggle with the possibility that this change in process would influence the participant's expectation of outcome. This was a time when there was a gap between

what was happening around them and what information they were made aware of, a sense of being left in the dark.

> … I had it booked I went into hospital I umm then was you know was got ready nurses came I was gowned up gel on my arms for the needles... and I'm still sitting on my bed and all these other people are coming in as surgeons starting to turn up and it's getting busier… when the anaesthetist came in and then halfway walked away then went away midway through I was like ooh that's a bit strange and then you saw that there the nurses just chatting there and I was like ooh that's a bit strange … (Katie 19-20, 100-101, 128-130).

Teresa, also in hospital, woke up early in the morning to hear more people talking louder. Activities started happening around her that indicated a change from the normal routine.

> ...I had been admitted the night before it was due umm and interestingly enough I and I'd fasted and I'd woken up and there was a buzz around the ward I heard people talking about how busy the surgery had been last night and I thought oh that might affect me … and no one came to say anything and I was I was actually told go and get dressed and do all that and by that time the buzz was getting louder and I thought it's not going to happen … (Teresa 4-6, 7-9).

Participants did not enjoy this part. The hesitation they could sense and feel, knowing they had no influence making it worse. *Struggling with hesitating* happens because they do not understand, there is a change in routine, a procedure was started then stopped, other people coming and going and no-one coming to them.

## Wondering

Some participants were told to wait and wait again and wait some more. Katie described a man saying he would get back to her in the next hour. She waited, uncomfortable with hesitating and then began *wondering*. *Wondering* what was happening and because this was so uncomfortable, she then did not want to wait for more information she just wanted to go home. Other participants were telephoned while at home. Anna described being at home in the shower the morning of her surgery day, getting ready to come to hospital, her husband was with her and he took the call. The message was she might not be having surgery later that morning, the reason being the first patient was still in surgery. With no number to call back she sat

down to wait, not knowing if she could eat, not knowing if she should take medications that were now due.

> … umm the person before me that they anticipated was only going to take a short period of time took a lot longer than they thought … umm which also didn't do much for my nerves because they've been in for quite a while as it was umm the person and they were having the same surgery … there's definitely a couple of hours because my husband and I were basically sitting here umm just waiting it was a couple of hours, basically sitting, just waiting wondering what was going on … (Anna 42-46, 79-80).

Anna was left *wondering* what was really happening, thinking to herself it is not going to happen. This lack of information contributed to her panic of being left in the dark, because the first person was taking longer than expected and she was having the same procedure. She was *wondering* if another person's experience will impact her.

Anna was the only participant that spoke about being unable to eat as part of the *readying* for surgery. She texted one of the surgeons to ask if she could eat, but that person did not know she was potentially cancelled, they were on leave. She struggled with the lack of information surrounding this and the longer it went on the more frustrated she became.

> …. because I didn't want to eat just in case they rang me and said no no (sic) we've changed our mind but then I got to the point when just before they rung for the last time and said it was cancelled I said to my husband I don't want them operating on me now anyway … (Anna 65-68).

*Wondering* is closely tied to *struggling with hesitating,* there was a lack of information and what was rapidly happening to them was not being explained by anyone. Participants are given limited information and were left to make up the rest.

## Accepting Distress

As the participants move through the process of *waiting*, they appear to reach a position of acceptance. The acceptance that the possibility exists of something going wrong and surgery being cancelled. Included in their acceptance is, for most, a measure of distress and certainly bewilderment. It was a time when intellectual understanding was overwhelmed by emotional turmoil and distress.

> … but again like for me because I I (sic) mean this was my 14th surgery I'm very familiar I'm very kind of accepting of my end of things that they do so I'm not overly concerned about you know they run behind you know things happen' I'm just like I was quite relaxed about that, however when they told me initially I was relaxed because for me it meant that all those things … the initial things that I was worried about I didn't have to then deal with it wasn't till I got home that it was like doh fucks sake excuse my language [laughing] … (Katie 137-138, 141-146).

> … umm bloody awful to be honest [chuckle] … umm and then I got told that it wasn't going to happen umm so yeah it was kind of that whole I don't know I can't I can't even explain it I cried let's put it that way umm because my kids were geared up for it as well my husband was geared up for it and then bang it's finished there's nothing happening … but umm it was just that whole then it just stops you don't you don't hear anything else … they spoke to my husband because I was getting myself organised to go umm and I it was kind of it almost it sounds ridiculous, but it almost feels like somebody's passed away getting that phone call because you've been so geared up for something and then it just yeah peters out … (Anna 9, 23-26, 34, 83-86).

> … I'm still quite emotional about that [long pause] so I got dressed and went home saw my sister burst into tears and she didn't have a clue what that that (sic) stage what had happened [sniffle] and my family who'd taken me in and being with me were there and [long pause] it was like at sea I was utterly at sea … I felt bereft that first day …(Teresa 15-19, 41).

While the emotional distress is centre stage at this point, acceptance is occurring underneath because as each participant has indicated previously, they are not in control. They are experiencing even less control over what happens for themselves than was previously thought. The emotional shock of surgery cancellation is due to this event being completely unanticipated. All the focus of preparation had been around getting ready for the surgery, with minimal or no thought given to the possibility of cancellation, therefore no preparation was entered into for this to happen. *Accepting distress* appears to be the way to move forward.

For one participant there was no experience of distress, more an expression of an inconvenience. Des was notified that his surgery was cancelled two days before via a telephone call to his home.

> … and we're cancelling the operations I didn't umm I didn't particularly worry about it … well when my surgery was cancelled I just had to wait until they decided that they could fit me in this was a little disconcerting because I had done all the preliminary stuff up till my surgery was cancelled and I had followed their instructions… but I did think that they might have contacted me and seen whether I'd used any of the medications and they didn't …(Des 5-11, 32).

To provide more depth to the category of *waiting* Sonny was asked if he had experienced any periods of hesitating or *wondering* as previous participants had expressed. He was also in hospital when his surgery was cancelled.

> … no I didn't have that feeling at all. I thought I was going to go through for my surgery and it came as a complete surprise that I was getting cancelled … (Sonny 58-59).

While not expressing the same emotional distress, which could be due to different personal coping mechanisms, there was that element of surprise at being cancelled, which indicates that Sonny had also not anticipated that this event could happen. Throughout the process of *waiting* is the ineffective communication, by the hospital, to the participants about what was happening or not happening. They were very much left to figure things out for themselves and manage their own discomfort and unhappiness. The intellectual understanding happened first, followed by the emotional response. For some participants this response was delayed until they reached home, a place of safety. The emotion was held in until it could be completely let out and examined in private or with loved ones. It appeared some participants recovered faster than others and some participants were not affected at all. During *waiting* not one of the participants questioned themselves – had they done something wrong to cause this? Because they all knew that they had done everything necessary therefore it cannot have been them that caused this. They did what they were told to do.

## Being Let Down

Table 6: Being Let Down

| Category | Subcategory |
|---|---|
| **Being Let Down** | Suffering delay |
| | Feeling excluded |
| | Resigning |

Once participants were booked for a surgical procedure, their expectation was that this booking would be realised, and they would proceed to surgery. This event was prepared for, longed for and waited for and then was taken away, surgery was cancelled. Participants were *being let down*, by the hospital. They did everything they were asked to do. They turned up to all the appointments, did all the preparation with extra medications and skin preparations. They were where they were supposed to be, doing what they were supposed to be doing. The hospital failed to deliver what they said they would. Tied up with this was the way participants were told surgery was cancelled. Vague promises were given about calling back and this not happening. The people that were delivering the news were just doing that and did not know anything else.

For some participants their reaction to the news that their surgery was cancelled was very calm and measured, for others it was a total surprise and bought with it some feelings of annoyance. The news of surgery cancellation was delivered very quickly, almost abruptly, with very little notification. It was surprising and devastating all at the same time, some spoke of suffering abandonment and loss. For some it felt like their world had stalled and they struggled to make sense of the experience to enable to continue.

> … I'm feeling now as I go back to a quite a lot of distress … I had put away all the crutches and things that I had been using thinking I won't need them all the paraphernalia and I had to bring it all back … I I (sic) think I just sit around all day thinking I don't know what to do what's g… what's going to happen now how how (sic) is this going to play out in terms of the timeframe for my sister the the (sic) timeframe for my son the operation itself and what it had offered to me … (Teresa 33-34, 36-39).

> … yeah it kicked in yeah when as soon pretty much as soon as I got home that same day it kind of oh crap and then probably over the next week just became a little bit lost like actually I actually don't quite know what to do … (Katie 532-538).

The amount of effort the participants put into *readying* directly influences *being let down*, such as, some had different medications to take, some had skin preparation regimes, and all this *readying* had to be put on hold, increasing their burden of *being let down*.

## Suffering Delay

Participants' expectations were not reached and through no fault of their own. Surgery was cancelled and there was no information given about when the surgery would be rebooked. Participants, when describing this period of delay, spoke of it as not being easy, they were not in a relaxed state. On the contrary, they spoke of experiencing distress and hardship, likening it to entering a process of suffering. There appears to be very little the participants or their family members can do to alleviate this suffering, except to encourage the participants to keep going, as they are again navigating through a loss of power in this process.

*Recruiting family*, influences the *suffering delay.* For some participants, the distress they felt was increased, after seeing the extent to which family members were involved in their preparation and seeing what these others had done to assist and support them.

> … and I was back to where I've been really thinking I would be a different person I wasn't the same person but the other thing [long pause] was the thinking do I really want to do this anyway do I really want this because it did involve so much … (Teresa 52-55).

> … and a lot of people sort of said you're not bad enough to get it removed it like didn't doing it urgently and stuff … it's like well no it's not not (sic) that at all it's just that's umm there was someone in more need than me at the time… (Anna 317-321).

> … it so it was yeah it was me and my husband really that it affected the most … because it's just the two of us … (Katie 523-524).

> … the next day one of my sons went in with me and we met with the specialists and they told me they couldn't tell me when my surgery would be because the person that makes the bookings was off sick and in all I think that was the one thing that I couldn't understand ... we can't tell you anything wait two weeks… what about my family what about my sis… the travel and the cost to my sister [sniffle] the cost of my family my friends they were upset…... so I left that day not knowing … I think the worst part of it was that no man's land we had to know, and we had to go back to being in a state you were in … (Teresa 44-47, 49-51, 80-81).

Participants were having to navigate through their own reaction to cancellation and the delay that followed. Amongst this, they were having to go through the process of

telling everyone what had happened. Their family members, close friends and work colleagues all had opinions on what could have happened, and participants were forced to cope with their reactions, advice and comfort. It appeared to be too soon for participants to be comforted and encouraged, as they were trying to make sense of it.

## Feeling Excluded

Receiving the details about why participants were cancelled seemed important. For some participants this was an easy information gathering exercise. For example, where the reason for cancellation was that the surgeon was sick, this was accepted as a real reason and made sense. This indicated there was nothing further for the participant to be concerned about and appeared to help mitigate the feeling of being excluded. One participant did not feel excluded from the decision making. What was more important to him was a timeline of the process which he was not given, and no one explained. For others this was a very murky situation and the lack of information was intensely frustrating. One participant explained that she knew she was cancelled for a reason, but that this did not stop her feeling distressed.

> … I don't remember any of the nurses coming up to me and talking to me about it or anything [long pause] umm I remember knowing that it would not have been cancelled unless it had to be cancelled I knew that and that that didn't stop my distress it didn't stop it … (Teresa 25-28).

When one participant was asked if the reason for the cancellation had been withheld or missed and how would he have felt, he replied:

> … Um … I would not … I would have felt even more unsettled … I would have been more upset … because then I would have to make up and rationalise reasons in my own mind as to why I got bumped off … um … bumped off the surgery schedule … (Sonny 103-105).

The geographical location of the participant when they heard that their surgery was cancelled also impacted. Anna describes, that due to her geographical location of 1.5 hours' drive away from the hospital location, she feels she would have felt much worse if she had already travelled the distance to hospital and then been cancelled when she got there. Even though it appeared Anna had less information than the participants who were cancelled in hospital, the fact that she received the news in a safe place,

with her closest relative, was very important to her navigating through the cancelled surgery experience.

The subcategory of *feeling excluded* contains threads from the previous subcategory *struggling with hesitating*, due to the continual limited information and not knowing about the timeframes of when things should or would happen. Particularly around medication regimes, Anna suffered a lot of unnecessary stress as she was unable to contact anyone for advice. Participants remain left in the dark about when their surgery would be rebooked and this *feeling excluded*, that participants voiced, did not appear to be very important or a consideration in the decision making.

> … you know like there's all sorts of things do we does she do I need to carry on with the iodine that I'm taking? and do I need to all that sort of stuff … that actually had to wait until the following day because I couldn't get hold of them for the rest afternoon … (Anna 668 -673).

> … yes, let down and um… being uncertain. I did not like the uncertainty of when they were going to reschedule my surgery. So, it was the next day that they told me. That it was going to be in another two days, and I went "Oh ok". So, once they had told me that … um … I was a bit more settled. But not knowing … um … I didn't know how long it would be before they were going to do the surgery, cause they said that I needed to do it … (Sonny 76-80).

> … because they didn't quite follow up as quickly as they said they would so I was bringing going umm excuse me so you know please someone told me that would ring me the day of my surgery (cancellation) with an approximate date it's now been a week like I I (sic) give them the again or I give benefit of doubt so you've probably got 500 people you know so many people ringing so you just rung and then they got back to me and gave me a couple of dates and then I relaxed once I had a new approximate date that's when I felt I fully relaxed … (Katie 621-628).

They each voiced concern over limited information, no one contact person, having to be fitted around the hospital plan and processes. They all talked about not knowing about the timeframes and how it appeared that what was happening to them was not really important or a consideration in the decision making, that occurred on their behalf.

## Resigning

The subcategory of *resigning* speaks, in part, to the previous subcategory of *suffering delay*. The participants are starting to understand that surgery cancellation can occur, they have completed informing family, friends and work colleagues and with each moment of telling the story they move towards greater acceptance. Participants are navigating through the no-man's land of *suffering delay*, they are accepting of the inevitable, a resignation, a *resigning* to the process that they have no control over and what little power they perceived to have continues dwindling.

The development of strategies to help participants cope through the *resigning* process are an important focus of successfully navigating, such as, meditating, talking with friends who have had similar experiences, going for walks, gardening and cooking.

> … I was just like just you know it's just settle it'll be okay and I am a distracter I distract myself [chuckle] … I have like a few techniques just like breathing and just calming down and changing the thought pattern as opposed to stressing about this … what would happen if I started to think about ohh no it would just spiral it would just spiral and I just sit you know you know how you just get those like glum days and it's like nothings working and aww it's so hard that and I would have the odd one of those and okay no go and walk your dogs and off I go you know I'm just change the setting and bring the mood up and then I kind of stopped thinking about it cause at that point of time I said there was actually nothing I could do … (Katie 574-575, 584-585, 606-610).

> … my sister and I because we hadn't been together so there was time for catch-up in that week umm I was off work we didn't go out much I actually really wasn't all that able to do that I cooked I clean… so my main strategies were really reflecting and deciding I guess umm I tend to I tend to journal must days I meditate I do those things and I did a of that a lot of bringing bringing (sic) myself together because I was so scattered … (Teresa 159-161, 168-170).

Other participants appeared to manage this experience better, smoothly transitioning back to normal everyday activities, as much as their incapacity allowed. The strategies they employed were of a longer duration, due to their illness and understandably were already embedded as part of their everyday routine.

Participants suffered varying loss of income as a direct result of having surgery cancelled. Some took sick leave from fulltime work which turned into annual leave as

the time taken off extended. One participant was retired, and his voluntary work had to be managed by others as his incapacity extended. Another participant lost potential income through having to cancel clients from her private business enterprise and another participant took so much annual and sick leave that she felt forced to quit her job.

> … it just was like ooh this is so frustrating was the worst thing that happened at the time umm because I had to leave a job because of my physical disability I was starting up a new business but I couldn't do it until I knew when the date was and then they gave me a date that was ages away so I started the business because I saw that they gave me the time and I got a date that was way sooner so I had to cancel clients … and then when it was postponed I was like I now have to go another three months with no income like I have to I can't continue my business from when it was cancelled over Christmas to then have to go in for the surgery again so just put us in a real bugger of a financial situation for me and my husband … (Katie 183-186, 193-196).

> … I ended up having I ended up all annoyed quite a few I ended up resigning from the position actually because it was just too hard with all the umm the after stuff umm but yeah I ended having to take quite a bit of time off which wasn't really planned … (Anna 102-105).

The participants describe a positive step towards the end of *being let down* is when they receive a new date for surgery, either via a letter in the mail or from a telephone conversation. For some participants the timeframes were not what they had expected, and most appeared relieved to be moving forward again.

> … cause at that point of time I said there was actually nothing I could do like no matter how I'm asking myself like how no matter how much I stress about it it's not gonna change anything and the only thing for me that was gonna change was for them to get me an estimate date quickly … (Katie 616-619).

> … so umm then it was actually rescheduled for the following week which was even harder because I perceived it to be maybe the next day or a couple of days later… umm it was just that whole then it just stops you don't you don't hear anything else sort of thing that's it then you get a letter and then you're back into it again … (Anna 27-29, 34-35).

… it was I think probably the next day that I was booked for the following week so it was a week delay in the long run which we could live with we could manage… (Teresa 60-61).

… and they said 'can you would you cope with the 22nd of December' which I said yes it didn't worry me I'm don't have little kids at home or anything like that that I have to worry about so I accepted that date but it turned out to be a little inconvenient to say the least… but when they offered me the 22nd of December I took it because I knew if I didn't it would probably be the end of January before the operation came up again… so if I couldn't drive for six weeks that meant that the sooner that I got the operation over the sooner I could be back driving and the sooner I could do things without causing problems for other people (Des 21-23, 33-34, 226-227).

Participants begin preparing again. One participant found, after being cancelled twice for the same procedure, that he did not feel the same way after having surgery cancelled the second time. He had developed a form of cancellation awareness and through this new knowledge was able to move through the uncertainty of *being let down*.

… So, I didn't have the same angst, the second time the uncertainty. I was still slacked off though… Ah if I look back on it I think I didn't feel I was excluded from the decision making, but if they had just let me know the timeline of the process … yeah … because I have confidence that they know how to do their job and it's just that I didn't know what the timelines were and nobody explained that, ah … even after my second one they didn't explain it. It's just that I thought … yeah … it's gonna be they'll tell me the next day … once they had sorted out their schedules… (Sonny 85, 90-94).

## Rebuilding Fragile Trust

Table 7: Rebuilding fragile trust

| Category | Subcategory |
|---|---|
| **Rebuilding Fragile Trust** | Repeating and adjusting |
| | Understanding cancellation |
| | Expecting acknowledgement |

All participants made a conscious decision to continue with their elective surgical procedure. Most participants had experienced a very intense response to *being let down* and consequently it was a difficult task to begin *rebuilding fragile trust*. There was a conscious decision made to move forward and rebuild, perhaps because of the

belief that the surgical procedure would bring physical relief of pain and suffering. Because participants bring with them the experience of surgery cancellation, they have a different grasp of preparing and this awareness brings through the doubts and fears of abandonment and loss. There is a different apprehension. This is a time of nervousness, full of doubts, as participants were so confident the first time that surgery would go ahead.

## Repeating and Adjusting

Participants spoke of going through the same preparation as before. All the physical preparation is known to them, it is familiar and appears easily repeatable. Most participants described a marked difference in that the mental preparation was much bigger than the physical preparation, requiring increased concentration and focus to make the necessary adjustments. Hence, while there was duplication for the physical aspects of preparing and this felt familiar and safe, there was the challenge of adjusting to the new knowledge of surgery cancellation and for some participants part of adjusting was becoming more confident. Within themselves and when interacting with the hospital, there was expressed a new sense of empowerment to ask questions and advocate for others.

> … the first time I went for surgery I thought "Oh yeah, this should just go ahead" and then after it was cancelled, and I went for my second one I doubted that … I had a had a healthy scepticism as to whether the surgery would go ahead or not… and so I had to prepare myself more mentally than physically… (Sonny 118-121).

> … and then I had to then go through all the same traumas of having blood tests again you know had to go through the same traumas you like build up for that process … and I'm so bad with that and you know go through the whole process of getting prepared mentally for the couple of things I'm really bad with and you know it's cancelled and that instant release was great but then I was like oh no I have to do it again [sigh] (Katie 212-213, 220-223).

> … umm so and I think that the the (sic) mental preparation for it is a lot bigger than what my physical prep was for it even though it impacted on me it was the mental mental (sic) prep for it umm and even on the day that I was going in for it with that thought in the back of my mind that we might drive all the way over [chuckle] there and have to come back again… (Anna 146-149).

… umm the experience as a whole has changed me as umm far as me standing up a little bit more… umm and I I (sic) think that's probably made me a little bit more vocal about where I'm at or what I need… (Anna 555, 560).

… I think I've learned to manage the system better and to stand up for myself probably a bit more assertively rather than aggressively… (Teresa 200-201).

## Understanding Cancellation

The newfound awareness of surgery cancellation causes participants to have hope of something different and fears of something too. There is a definite change from full confidence in the hospital to deliver a booked elective procedure, replaced by an uncertainty and doubt that it will happen, because what is booked can be cancelled. This doubt affected the participants and their families, as they could not state with certainty that surgery would occur.

> … and then the second time around when it was rescheduled I wasn't sure whether they were gonna do it again … even my kids that morning like they were like are you going to be going in today? and I'm like well yeah I think so but you couldn't you couldn't sort of guarantee it… umm but yeah it it (sic) does put you on sort of on tenterhooks because you're not just not too sure that it's going to happen or not … so it was that whole umm doubt sort of thing yeah but umm yeah it affected quite a few people in the long run… (Anna 89, 124-125, 130, 283).

> … I turned up not expecting [laughter] maybe it could happen again maybe not … (Teresa 62).

> … ah, lower my expectations that this is a 100% we're gonna have my surgery … ah … I just went hopefully it will go through … um … yeah so … um … yeah … so the second time it still slacked me off… I think I was more realistic, sceptical and realistic because the first time I thought the um … the probability of having cancelled surgery … um that it was a rare thing … and um sometimes it's not (Sonny 125-126, 148-150).

Participants described feeling a loss of faith in the hospital's ability to carry through with what was agreed to. They accepted that other things impacted on this schedule and it was more complicated than was first thought. There were grey areas in the hospital schedules that were unknown by participants, who had to navigate around

them. Participants described accommodating the hospital plans and processes, as opposed to the hospital working around the participants' commitments.

> … you're not always guaranteed things it's a grey area umm and yeah I guess you're you're (sic) working around them as opposed to them working around you so if you get sent an appointment time you have to go really to that appointment time otherwise you're gotta reschedule for three weeks later or something like that and ahh same with the surgery like obviously you don't get a choice as to [chuckle] when that surgery is going to happen… (Anna 179-182).

Even when booked for surgery there were many moving parts to be coordinated and therefore surgery could not be guaranteed. Each participant varies over the time taken to process the new *understanding cancellation* and a part of this is the slow *rebuilding fragile trust*. Some participants describe difficulty in rebuilding trust due to the large number of hospital people involved and an inability to form connection.

> … I started with the Endocrinologist… I had to meet the anaesthetist then I had to meet the surgeon then I had to go back in again and they had to check things out and then I had to go in again for a pre-op check-up it's one two I think it was three three preop checks and then I went for the surgery and then the anaesthetist I met wasn't even my anaesthetist anyway so that was kind of a waste of a meeting waste of time meeting the anaesthetist umm and the surgeon that I talked to wasn't the surgeon [chuckle] that did the operation so (at the time of surgery) it kind of basically ended up being random people that I didn't really know umm so yeah there was a lot of prep for it… (Anna 519-526).

> … I would ask better questions. So, I would ask them what the chances are of having cancelled surgery… um … yeah … having numbers or predications would help me cope … yes. Whereas before I didn't really … yeah, I was very ignorant that there could be cancellations of surgeries because I had an unrealistic expectation that there are always enough personnel and that you can always rely on them to be there because it just is. Whereas now I realise that … um … you know ahh … other more important surgeries come up, Drs get sick, might not be enough anaesthetists any one of a number of reasons… (Sonny 191-198).

Participants spoke of still having confidence in the hospital, as a system. Some participants revealed progress in their understanding of elective surgery, that it was not to be taken for granted and could not be guaranteed, therefore the process became something more complex and variable. Once participants rationalised this to

themselves, they appeared to settle back into trust, albeit a fragile trust. Realisation grew that the people working within the hospital system were trustworthy, and for the most part, trying to do their best, within a system that was variable and open to internal change.

## Expecting acknowledgement

For some participants it appeared part of *rebuilding fragile trust* included some form of acknowledgement, that surgery had been previously cancelled. The expectation was that this would be forthcoming on entering the hospital for the rebooked surgery. This appeared to be an acknowledgement of not only the cancelled surgery, but also what the participant had endured though this event. Some participants expressed a longing for understanding and connection, with hospital staff, that appeared to remain unfulfilled. Alongside this was, for some participants the desire for some form of an apology, either spoken or written is unclear, perhaps a regretful acknowledgement of a service not provided.

> … I think I was looking for umm acknowledgement umm some sort of like you know things get really tough around here we're so sorry … but people don't have to go on saying sorry but yeah that was a particularly bad night and we didn't expect to have to do that [long pause] that's that whole thing isn't that only takes a minute takes so little from us to be present to another person… (Teresa 360-364).

> … one of the things that I kind of felt would have been nice as a follow-up is that when I actually went in for my second surgery I know surgeons can't remember everyone and they he probably had no idea who was the person that was cancelled on him when he was sick but what would have been nice if someone had written a note and said this was your patient that was cancelled so just some form of acknowledgement kinda of says 'sorry I know I was unwell last time I'm so glad we can get you in now' just like yeah like just like I wouldn't expect him to remember that… (Katie 361-372).

When told that other participants had sought acknowledgement of their cancellation and spoke of not receiving an apology from the hospital, Sonny was asked 'would this be his feeling too?' He felt that acknowledgement of surgery cancellation was unimportant.

> … I did not feel that they owed me an apology for cancelling my surgery due to a more urgent case turning up, I don't see why they

needed to apologise to me for that. I mean they did at the time, they said, 'I'm really sorry but we have to cancel your surgery because of a more urgent case' and there's not really anything I can say um… that would change that. It wasn't their fault it was what it was… (Sonny 229-233).

And when he presented for surgery after the first cancellation:

… umm no they didn't [acknowledge that you had surgery cancelled], because it was different staff. But I did make a joke saying. "Oh, you know umm… I was cancelled the last time and I might get cancelled this time". And they all laughed and then it happened. So that was sad… (Sonny 237-239).

Through the *rebuilding fragile trust* and preparing for the rebooked surgery, some participants described a new ability to take responsibility for themselves and thus feel stronger from the experience. Participants described new knowledge around what to look for when attending appointments, what questions to ask when conversing with hospital staff, equipping them to navigate a way so they could cope better in the future. Participants acknowledge feeling controlled by the hospital, and that this is part of the engagement process.

## Summary

This chapter has presented the constructivist grounded theory process of *Navigating Abandonment*. Described within are the findings of this study, in relation to each stage of the process the participants experienced. This chapter demonstrated the cyclical nature of the process of elective surgery cancellation and how each participant moved through this process, individually and collectively. *Navigating Abandonment* is the core category depicted through Figure 1. Navigating is the process that occurs throughout the experience of elective surgery cancellation and each participant had to do this in their own way. Navigating occurs within each of the four categories, from *readying*, *waiting*, *being let down* and *rebuilding fragile trust*. Depending on the participant and what they needed, the length of time spent within each category varies, as does the experience. Abandonment clearly enters navigating at the first hint of surgery cancellation and was chosen because of its strength. Participants *Navigating Abandonment* described intense negative feelings as a result of having surgery cancelled and this is reflected in the choice of the core category.

The following chapter is a discussion about the developing substantive theory of *Navigating Abandonment.* Comparisons are made between the findings of this study and existing knowledge, and what can be added to current research on elective surgery cancellation.

# Chapter 5  Discussion

## Introduction

This chapter discusses in detail, the findings, presented in chapter four and situates them within the existing body of knowledge on elective surgery cancellation. A summary of the substantive theory of *Navigating Abandonment* is presented, with a brief overview on how each of the categories contribute. Literature relevant to the theory of abandonment and each of the categories will enlighten this discussion and inform the clinician about how best to assist the patient as they are *Navigating Abandonment* of elective surgery cancellation. New insights arising from this study and the implications for clinicians will be discussed. Strengths and limitations are evaluated and recommendations for future research are suggested, as the significance of this study is concluded.

## The Theory of Navigating Abandonment

*Navigating abandonment* captures the common experiences of the participants as they moved through the process of elective surgery cancellation. A diagram of interlocking cog wheels was deliberately chosen, to reflect this process of a cyclical participant experience, underpinned by the machinations of a large governmental organisation. The cyclical nature of the cogs also allows for the varying time frames of the participant experience within each of the subcategories and resultant category. Throughout the process of *Navigating Abandonment* is the preparation that occurs through *readying.* Participants prepare by *making space, recruiting family* and when they have completed preparing, they start *enduring* the hospital engagements, becoming more aware of how little control they have over this process. It is evident participants continue preparing when entering the period of *waiting.* They are left in the dark while *struggling with hesitating, wondering* what is happening and then *accepting distress* because they have limited options. Preparing ceases when participants are *being let down.* They experience a complete loss of power and as they are *suffering delay,* with limited information and minimal communication, they are *feeling excluded*. An acceptance of the inevitable follows with participants *resigning* to the whim of the hospital. Preparing returns as participants begin *rebuilding fragile trust*. This has to happen for them to make progress and re-enter the surgical pathway.

This time of *repeating and adjusting* has some familiarity and has a settling effect. With this familiarity brings new *understanding of cancellation* and participants confess to feeling controlled by the hospital demands. Some participants attempt to bring closure to *Navigating Abandonment* through *expecting acknowledgement* and seek some form of apology for what occurred.

As previously mentioned in Chapter 4, the word abandonment is used in this study, because of the strength of the experience described by participants. The participant was the one that was abandoned, for a time and a place, on the part of the organisation and it is the surgical procedure that is re-established by another part of the organisation, thus allowing the participant's abandonment to end. The sense of abandonment may be because a relationship based on mutual expectations was established with the surgery acceptance and preparation and the sudden cancellation fractures this mutuality.

The fracturing of mutuality aligns with published literature on abandonment in health care settings. According to Mapukata (2019), much of the international literature on patient abandonment focuses on the legal implications as the outcome of the premature termination of a health service, without the consent of the patient. Parallels can be drawn as the abandonment of patients is discussed. The Department of Health of Rhode Island, undertook a review of patient abandonment by the physician, considering the duties and obligations inherent in the physician-patient relationship (Crausman & Baruch, 2004). Patient abandonment has been defined as the withdrawal by the physician from a patient's care without first formally transferring that care to another qualified physician who is acceptable to the patient. The physician-patient relationship is based on trust and ultimately patients expect and are entitled to know that physicians place the interests of their patients ahead of their own. The healthcare professional and the patient relationship is the heart of the clinical practice of medicine. Abandonment and the fear of abandonment, harms the patients, the healthcare profession and society at large (Crausman & Baruch, 2004). These sentiments are confirmed by Schleiter (2009), a senior research associate for the Council on Ethical and Judicial Affairs for the American Medical Association in Chicago, reinforcing that the patient-physician relationship is the cornerstone of the medical profession. Encounters between patients and their physicians are based on trust and

successful care requires ongoing collaboration between the two groups. Despite the evident power imbalance, effective communication and timely information delivery are key to this success (Schleiter, 2009).

It appears from the above discussion on abandonment within healthcare that the patient-physician relationship is accepted as vital and highly valued. Therefore, the abandonment that happens with elective surgery cancellation can be made better, by focusing, in particular, on effective communication and the establishment, at the beginning of the surgical pathway, of an honest and open relationship between the hospital and the patient and family. Realistically, this could be via specially trained nurses, who case-manage the patient and family through the surgical process from the beginning to the end.

## The Components of Readying

This *Navigating Abandonment* study has shown through *readying* just how much is involved when the offer of surgery is accepted. Each participant must make allowances for surgery to enter their lives. They must make room for it to come into their day to day activities and some things have to be put to one side or given up altogether. This appears to be a source of stress all on its own. People are busy and do not have much room in their lives for something this unknown to enter into it. Griffin (2013), conducted a phenomenological study to describe the lived experiences of patients undergoing major outpatient surgery. The study data came from audiotaped interviews, with four themes identified, one being 'appraisals of uncertainty'. Uncertainty is natural during surgery preparation and appraisal leads to a view of uncertainty as either a danger or an opportunity (Griffin, 2013). This is similar to the component of *readying* and the subcategory of *making space*.

### Making Space – Recruiting Family – Enduring

The participant has a huge task of organising themselves through *making space* in their lives for this event and all the preparations of clinic visits and tests that are included. Griffin (2013) ascribed the uncertainty patients experienced, to learning they are not in control. This aligns with the diminished control the participants discussed feeling as they were *readying* for surgery.

*Recruiting family* to provide emotional support and to take over tasks and responsibilities that cannot be postponed, is the second component of *readying*. Thirdly is the *enduring* that occurs for both participants and close family members: attendance at clinics, making sure the right medications are available, receiving body washes and skin preparations and learning how to apply these things and when to do it. Chan et al. (2012), conducted a systematic review of eleven studies on patients' experiences before surgery. This review identified four themes relating to patients' experience of preoperative communication with health professionals: need for information, involving relatives, the need for control and professionalism (Chan et al., 2012) . The theme of 'involving relatives' is applicable to two subcategories of *recruiting family* and *enduring*. Chan et al (2012) described family being important during the preoperative communication to help patients prepare better for surgery, by helping to reduce worry and induce calmness, providing some encouragement and reinforcing what patients had been told. These findings are very similar to the *Navigating Abandonment* study subcategory *recruiting family* and *enduring,* as participants relied heavily on family members for emotional and practical support throughout the process of *readying*.

## New Insights and Implications

The process of *readying* is vital to the preparation for elective surgery. How participants received surgery cancellation, alerts us to the possibility of measuring the magnitude of the cancellation reaction, being dependant on how much *readying* was required. For example, Sonny was an inpatient and expressed that he only had himself to worry about as his family were all at home getting on with things, as opposed to Anna, who was at home when surgery was cancelled and therefore had a husband, small children and elderly parents to deal with, as well as her own reactions.

Components of *readying* highlight the need for participants to have information and for control. This is not new information as Chan et al (2012) found that "patients wanted independence to confirm their own findings and opportunities to make decisions for themselves" (p. 18), and Griffin (2013) found that "taking a few minutes to allow patients to share part of their stories, their hopes for particular outcomes, and their health goals would help alleviate the loss of identity and fear that many patients experience before surgery" (p. 250).

Recognising that patients have a contribution to make to the healthcare they receive will ultimately benefit the service. Accordingly, returning a sense of control to the patients, within the decision-making process, should be part of any change as much as possible, as mentioned by participants of this *Navigating Abandonment* study (pp. 43-44).

## The Components of Waiting

Further along the surgical pathway, the time of *readying* is over, and the day of surgery is very close or has arrived. For some of the participants, the time between thinking that something has changed in the elective surgery process (the hesitation), and the start of the *wondering* if they are going to be cancelled, this is the period of *waiting*. The period of *waiting* varies amongst the participants and is described as a time of intense feelings and reactions happening in a relatively short time frame, for example, hours. During the *Navigating Abandonment* study, the more participants that were interviewed, the more this period of *waiting* emerged. *Waiting* appears to mean different things, depending on many factors and the myriad of emotions expressed, such as, fear and anxiety, anger that others were being attended to and not themselves, frustration at delay with no clear decision making. These findings are confirmed by Ivarsson et al (2004), who conducted a descriptive study of seventy-four patients who experienced cancelled cardiac surgery. A questionnaire was sent home, for participants to complete and return. Interviews were not able to be done due to participant numbers and wide geographical distribution. Findings included that patients found the waiting time filled with anxiety, and the strain further increased when the waiting time was increased (Ivarsson et al., 2004). Freeman and Denham (2008), explored the problems patients might have with surgical wait times, showing that waiting in a surgical setting can induce additional stress for those already nervous about surgery. This confirms the anxiety already apparent prior to a surgical procedure expressed by participants of the *Navigating Abandonment* study and how the levels of anxiety increased as they struggled with the sensed hesitation in the process.

## Struggling with Hesitating – Wondering – Accepting Distress

Participants expressed the struggle that was happening, between their emotional response to the perceived delay and the not knowing what was coming next. Because they did not know what was coming next the *wondering* began and different scenarios

of outcomes were considered. What was rapidly happening to them was not being explained by anyone. They were given limited information and were left to make up the rest. As time continued with no plan forward, the degree of emotion increased. Chan et al (2012) as mentioned, discussed four themes, one being the need for information. Guessing that their surgery was cancelled generated a feeling of worry and fear in patients. Especially if they could not get clear information about an area of concern (Chan et al., 2012).

Ideas about time perception must be acknowledged here. The *Navigating Abandonment* study clearly shows, within the category of *waiting,* the unmet time perception the participants endured as they waited, (pp. 45-46). Participants expected a process to start that would take them through the surgical experience in a reliable, effective and timely manner. Freeman and Denham (2008), explain patients have different expectations about what will happen when they enter hospital setting for surgery. They may be ill-informed about what to expect, have little knowledge about the surgical process and may concentrate on their fears about the procedure (Freeman & Denham, 2008).

 When the final decision was made and surgery was cancelled, for the participants of the *Navigating Abandonment* study this caused a huge emotional upheaval. There was an intellectual understanding of being cancelled, quickly followed by increased levels of distress. Davenport (1991), interviewed eighteen patients to investigate the effects of sudden cancellation of cardiac surgery. The interview was completed two hours after the patient received the news of cancellation. Information was recorded by writing down the responses afterwards in another room away from the patient. This was done to limit stress to the vulnerable patient. Findings showed the most stressful time following cancellation was when the realisation dawned on them, which was several hours later or the next day when back home (Davenport, 1991). These results are similar to those reported by participants of the *Navigating Abandonment* study, with some waiting until they had reached the safety of their homes before acknowledging the cancellation through crying. This distress had to be acknowledged and worked through to acceptance by the participant, allowing them to reengage with the elective surgery process.

## New Insights and Implications

Preoperative fear and anxiety are normal and what participants from the *Navigating Abandonment* study found most reassuring was information. Similarly, Freeman and Denham (2008) discuss that being attentive, giving verbal reassurances, explaining aspects of care and providing updates on waiting times are often viewed by patients as caring behaviours demonstrated by healthcare providers. Collaborating and including family in updates during the waiting time is reassuring for patients and empowers them to be involved and clarify reasons for delays (Freeman & Denham, 2008). This is comparable to the *Navigating Abandonment* study; family members can play a key role in helping to decrease participant anxiety. Encounters that aim to provide good communication and develop a therapeutic relationship can establish a bond that enables the healthcare provider to identify patients' needs and provide a more positive experience for the patient and their families.

Chan et al (2012) discussed healthcare professionalism as one of the themes of their study. This showed that patients were sensitive to the attitudes of healthcare professionals and whether a caring and positive attitude was shown (Chan et al., 2012). Compared to the *Navigating Abandonment* study this was something that was hinted at by the participants and, on reflection, there are initial codes that relate to healthcare professionalism, but due to time constraints were not fully integrated into the study.

## The Components of Being Let Down

The category of *being let down* appeared to have the most significant impact over time for the participants and their families. The participants did all the things they were supposed to do to get ready and make things work, but the surgical team were unable to deliver. The consequences of this break in trust affected a lot of people, not only the participants, also their family and friends, work bosses and colleagues. Dadas and Eti-aslan (2004), conducted a study to identify the causes for cancellations of surgery and to define patients and their families' reactions to the situation. A questionnaire was developed and was answered after the notification of the patients' cancellation (Dadaş & Eti-aslan, 2004). Understandably, the findings of this study (noted in more detail on pp. 12-13) show intense emotional reactions by both patients and families, perhaps due to their responses being recorded in a short timeframe from cancellation

notification. The findings of this study are similar to the *Navigating Abandonment* study, even though the approach is different for the timing of the data collection, which was after the cancelled surgery was completed. Even though time had passed, for some, the memory of the emotional reaction to the event remained strong for the participants of the *Navigating Abandonment* study.

## Suffering Delay – Feeling Excluded – Resigning

Within the *Navigating Abandonment* study, the participant expectation was not reached, and they are forced to enter a time of suffering, through the delay of having their surgery cancelled. This occurred through no fault of their own. They had never entertained the thought that their surgery could be cancelled, it was all booked in and they were ready.  For most of the participants this was not an easy time of relaxing, confidently accepting that this delay was not permanent. This was emphasised by all the participants as a time of continuing pain, hardship and distress, caused in part from *feeling excluded* from the process. Ivarsson et al (2002), aimed to study patients' reactions to cancelled or postponed heart operations. Findings revealed the longer the time interval from the cancellation to the expected operation, the more negative the patients' reaction to staff. If information about a new operation date can be given at the same time as the cancellation, patients' were more satisfied (Ivarsson et al., 2002).

As the period of time lengthens, it appears emotions begin to settle and acceptance comes, causing participants to enter a time of resignation to the inevitable. It was said to be a no-man's land experience, where participants start to understand that surgery was cancelled and begin telling family and friends. Previous studies of elective surgery cancellation have not dealt with the ongoing emotions that patients experience as a result of this event, nor discuss the length of time taken for acceptance to be reached.

Included in this, participants are grappling with the loss of income this process has engineered. Participants in the *Navigating Abandonment* study expressed a lot of frustration and stress around this. Herrod et al (2019), demonstrated in their study of winter cancellations of elective surgical procedures in the UK, that a large proportion of patients suffered a negative economic impact from both the additional work days lost and the additional non-refundable travel and childcare costs. Some of the

participants in the *Navigating Abandonment* study had to give up employment due to the cancellation experience.

## New Insights and Implications

Throughout the initial engagement with health professionals, while a diagnosis is being formulated, it is understandable that the possibility of surgery cancellation is not high on the agenda of information to impart to the patient. Within the *Navigating Abandonment* study, at no time can any of the participants remember any discussion or comment about the possibility of their elective surgery being cancelled. Whether it had been mentioned, possibly at the end of a clinic consultation and just was not heard is debateable. There appeared to be no written information regarding the possibility of surgery cancellation and the intense emotional response to cancellation supports this.

There is an argument that people become overloaded with information. Klerings et al (2015), explored the issues of information overload for patients, healthcare practitioners and systemic reviewers, in preparation for the 2015 Cochrane Colloquium in Vienna. They found both patients and clinicians', appear to resort to the easily accessible and quicker web search, while knowing this is not the best way to identify high quality evidence. They analysed this through the concept of filter failure, stating the main problem is not that there is too much information, but that the traditional means of managing and evaluating information are ill suited to the digital age. Klerings et al (2015) propose that a possible solution would be new or adapted filtering systems, familiarising literature review to the specific needs of healthcare practitioners or patients, thereby improving health literacy. An implication for the category of *being let down*, is if the participant had been given the information of possible cancellation prior to surgery, their experience may have been different. As mentioned in Chapter 2, the use of a patient booklet containing pertinent information, including possible surgery cancellation relating to the elective surgical procedure they have been offered, could mitigate this. A practical tangible resource with information, contact numbers and 'what happens if…' scenarios are recommended.

## The Components of Rebuilding Fragile Trust

The process of *being let down* changes when the participant receives a new surgery date. They are rebooked and consequently return to *readying*, but it is a different kind of *readying* because of the cancellation. Because of being cancelled and let down there is a break in trust, between the participant and the hospital, and this break must be repaired and rebuilt. This rebuilding takes time due to the large numbers of people that the participants had to interact with. Because of these large numbers participants found it difficult to connect and rebuild trust. After all, they were seeking treatment for disability or pain and for some participants they were longing for some connection, to see the human side of all this. Banjerjee and Sanyal (2012), interviewed one hundred and ninety-eight patients as part of a cross sectional study on three dimensions of the doctor-patient relationship; doctor patient concordance (agreement), trust in the doctor and patient enablement. An important finding in this study was that better doctor-patient agreement has a strong and highly significant association with trust in the doctor, which in turn had a strong and highly significant relationship with patient enablement or empowerment (Banerjee & Sanyal, 2012). This interpretation is similar to the adjustments the participants of the *Navigating Abandonment* study had to make. As acceptance grew from the new knowledge that surgery was not guaranteed, even though booked, participants went into preparing for surgery with a more realistic attitude of results. Some spoke of learning to ask better questions, others felt stronger and more empowered through the experience of surgery cancellation.

## Repeating and Adjusting – Understanding Cancellation – Expecting Acknowledgement

Through *repeating and adjusting* the physical preparation is known to participants and is easily repeatable.  It is the mental preparation that is bigger and requires more focus. Family support is pivotal for participants to keep on going, as some participants had to overcome the disruption to work and income and experienced termination of employment. Coupled with adjusting to repeating a process is the new understanding of cancellation. The prior feeling of full confidence in the surgical process is replaced by doubts and uncertainty. Having been cancelled once, the participants all expressed the idea that it was entirely possible this could happen again. Being unable to

guarantee something leaves a lingering sense of reservation and participants described feeling a loss of faith in the surgical teams' ability to keep to their side of the bargain. Kraetschmer et al (2004), conducted a survey of six hundred and six patients, asking 'does trust in doctors aid or hinder patient autonomy?' Findings showed that most respondents in the study trusted their doctor and most also wished to participate in making decisions about their care, adopting a shared approach. Shared decision making often accompanied a trusting patient-doctor relationship (Kraetschmer et al., 2004). The implication for the participants of the *Navigating Abandonment* study is they did not experience a shared approach to the decision making around the care they received and found they were kept in the dark. The key components of caring and communication were unavailable. Hovlid el al (2013), interviewed eight patients who had experienced a redesigned pathway designed to reduce surgery cancellations. Three common themes concerning how patients experienced the interventions were identified: the importance of being involved in scheduling time for surgery, individualised preparation prior to surgery and the importance of establishing relationships with a minimal number of clinicians. Patients appreciated the changes because they contributed to making the care more patient-centred (Hovlid et al., 2013). The experience of participants of the *Navigating Abandonment* study are significantly different from this study in several key respects: the non-involvement in the planning and scheduling of surgery, no individualised pre surgery preparation and the struggle to connect with any hospital staff due to the increased number. Because of this, most participants looked to the surgical teams for some recognition of their experience in the form of a statement of acknowledgement and for some this included an apology from the surgeon.

## New Insights and Implications

The expectation of acknowledgment and apology was a surprise finding to the researcher. My understanding was that whoever had informed the participant that surgery was cancelled would have apologised at the time. Did this in fact happen and because of the nature of the news that followed, did the participant not hear the apology? Immediately following the news or surgery cancellation, the participant will have been very upset and perhaps not yet ready to forgive. Bismark (2009), states in a viewpoint article based on Humanity of Healthcare, apologising can be a formidable

challenge for many health practitioners, and they should be adequately trained in open disclosure and apology. Broadly speaking an authentic apology is likely to include the following five elements: recognition of the event, an expression of regret and sympathy, an acknowledgement of responsibility and where appropriate the facts, effective reparation and one or more opportunities to meet again after reflection (Bismark, 2009). Lazare (2007), presents a behavioural analysis of the apology process and its application to medical practice. Apologies can be organised into three parts: acknowledging the offence, expressing remorse and offering reparation where appropriate, stating most people can assess whether an apology succeeds or fails from their gut reaction. With successful apologies we feel healed, the emotional distress is improved. With failed apologies, people often feel they are being 'conned', further humiliated or more distressed than before (Lazare, 2007). Proper acknowledgement of the offence is important for the participants of *Navigating Abandonment* study because part of this is an explanation on why the cancellation happened. This is what the participants needed to know. Heartfelt expressions of sympathy and sincere apologies can have profound healing effects for all parties. They can bring comfort to the patient, forgiveness to the health practitioner and restore trust to the relationship (Lazare, 2007).

White et al (2017) conducted in-person training sessions in eight Washington hospitals. While this training was primarily concerned with error disclosure to patients, parallels can be made to the disclosure of elective surgery cancellations. Overall, participants rated the training highly and the element that was felt to be most helpful was the skill of disclosure coaching role play. Approximately two thirds of participants reported that their clinical areas routinely disclosed minor to serious events and felt few doctors and nurses were adequately trained to do this (White et al., 2017). There are implications here for healthcare institutions to include training for disclosure of events and apology.

## Strengths and Limitations

This *Navigating Abandonment* study has a clear and concise research question, meaning there is no ambiguity about what is being researched. With further development, the substantive theory may have relevance for multiple disciplines of the healthcare organisation from elective surgery, booking and scheduling,

outpatients, anaesthesia and theatre. The methodology of constructivist grounded theory suits the research question. Due to my professional role within the anaesthetic department and my knowledge of elective surgical cancellation, this adds dimension and contributes effectively to the co-construction of this grounded theory study. The method of data gathering, and analysis provide creditable answers to the research question of 'what is going on when elective surgery is cancelled, from the patient perspective'.

Due to the limitation of the timeframes of a master's degree, the number of participant interviews was severely reduced, from what was originally planned. A cross section of the different cultures that currently reside within the WDHB catchment area was unable to be represented amongst the participants. One Pacific Island participant was recruited for the theoretical sampling interview, unfortunately no Māori participants were recruited. Dr Helen Wihongi, Māori Research Advisor WDHB, suggested using texting rather than mailout. This was unable to be achieved due to timeframes and financial limitations.

## Future Research

Due to the limitations already mentioned this research topic would be suitable for a bigger cohort of participants. Firstly, from different cultural backgrounds and secondly, by investigating the experiences of booking staff, theatre administration staff and clinical staff. This broader view could investigate the experience of engagement with the patient, who has experienced elective surgical cancellation and it possibly would provide further depth and reflexivity to the existing *Navigating Abandonment* theory.

## Conclusion

A significant proportion of surgical procedures in New Zealand are elective and cancellation of these procedures is recognised as a major cause of emotional distress to the patient and their family/whānau. To date, the focus of research into elective surgery cancellation has been from the hospital and administration perspective. Little is known about these cancellations from the patient perspective.

The aim of this *Navigating Abandonment* study was to answer the question 'what happens when elective surgery is cancelled from the patient perspective?' The focus

was directly on the cancelled patient and investigated how they construct reality of what is happening to them.

After exploring a number of research methodologies, grounded theory seemed to be the most appropriate choice. There are a number of grounded theory approaches, however constructivist grounded theory argues that we exist in a world that is acted upon and interpreted by the research participants and the researchers, as well as being affected by other people and circumstances. The researcher, due to experience and existing knowledge, was placed within the study as co-constructor of the *Navigating Abandonment* theory.

This study has generated answers based on the understanding of people who have experienced cancellation of elective surgery, who have had surgery rebooked and completed, who are adults fluent in conversational English and agreed to be interviewed. The participants experience can be interpreted diagrammatically, through four interlocking cog wheels, depicting four interlocking cyclical processes of: *readying*, *waiting*, *being let down* and *rebuilding fragile trust*.

This study highlights the importance of understanding this topic from the patient's perspective because it had such a profound negative effect upon not only themselves, but their families, close friends, work bosses and colleagues. *Readying* spoke of how much patients and families contributed to preparing for surgery. There is a real sense from the participants of going around and around while *readying*, not knowing what will happen next, where they will end up and what it will take to get there. *Waiting* was the intense period of not knowing if surgery would be cancelled. Throughout the experience of *waiting* is the ineffective communication, by the hospital, to the participants, about what was happening or not happening. They were very much left to figure things out for themselves and manage their own discomfort and unhappiness. Participants were *being let down*, by the hospital. They did everything they were asked to do. They turned up to all the appointments, did all the preparation with extra medications and skin preparations. They were where they were supposed to be, doing what they were supposed to be doing. The hospital did not hold up their side of the bargain and failed to deliver what they said they would. In the aftermath of getting cancelled, the emotional response and physical impact and *rebuilding fragile trust* is

the pathway back to the beginning of preparing for elective surgery again. Participants spoke of still having confidence in the hospital, as a system. Some participants revealed progress in their understanding of elective surgery, that it was not to be taken for granted and could not be guaranteed, therefore the process became something more complex and variable. Once participants rationalised this to themselves, they appeared to settle back into trust, albeit a fragile trust.

This study will make a significant contribution to understanding what is happening for the elective surgical patient when their surgery is cancelled, either on the day of the planned surgery or sometime beforehand. This contribution will inform practice, so that changes can be initiated to improve the patient experience. This understanding will enable future elective surgical patients and their families to have the knowledge about what happens when elective surgery is cancelled and to provide solutions to the problems identified by the participants in this *Navigating Abandonment* study.

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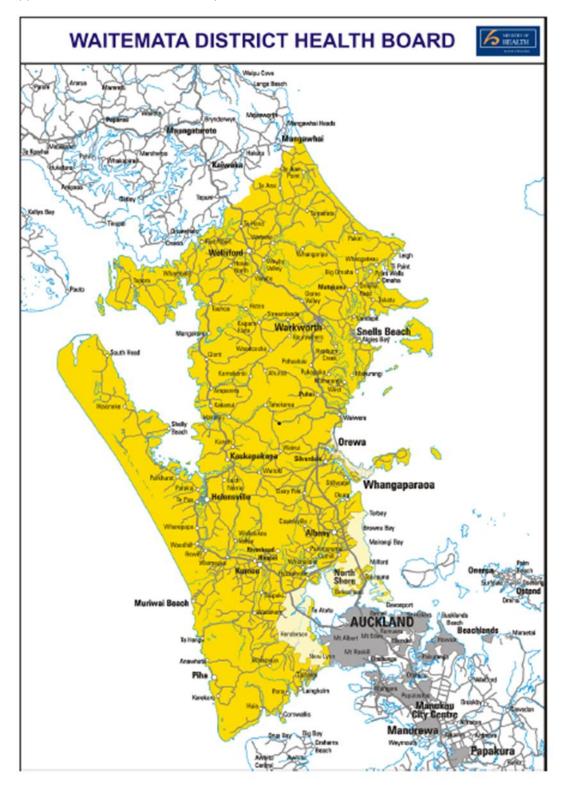
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# Appendices

Appendix A: The location boundary of the Waitemata District Health Board

Appendix B: Invitation Leaflet

Appendix C: Participant information sheet



# Participant Information Sheet

**Date Information Sheet Produced:**

October 2017

**Project Title**

Elective surgery cancellation.

**Definition:** Cancellation refers to surgery that has been postponed once or multiple times, for whatever reason, then rebooked and completed later.

**An Invitation**

My name is Joanne Inivale. I am currently employed by Waitemata District Health Board (WDHB) as a Perioperative Specialty Nurse working within the Anaesthetic Department. I would like to invite you to participate in this study as someone who has experienced surgery cancellation. This study is part of my Masters programme through Auckland University of Technology. Whether you choose to participate or not will neither advantage nor disadvantage you.

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

The purpose of this research is to gain insight into what has happened from the patient (yours) perspective. It is hoped this new understanding will inform practice and enable the nurses and doctors to provide better care and to assist with meeting the needs of you as the patient, your family/whanau, friends, support people, employers and members of the community directly or indirectly involved with you. The results of this study will be published in the appropriate journals and WDHB publications.

**How was I identified and why am I being invited to participate in this research?**

Contact details are part of your electronic record obtained when you first attended clinic. The Anaesthetic Service has sent to those adults 16yrs or older, who are fluent in conversational English and have had surgery cancelled a pamphlet advertising the research and inviting you to participate. You can only participate in this research if you have had your surgery rebooked and completed.

**How do I agree to participate in this research?**

You agree by completing a consent form which I will provide. Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

**What will happen in this research?**

This research involves an interview between myself and you, to be completed in your home or at a place of your choosing. You can have a support person present at your interview. I will ask you what happened when surgery was cancelled and possibly one or two other questions as prompters. You can stop and or pause the interview at any time you choose. I will be recording the interview and may jot down some notes as we go along. The data will be analysed by myself, with help from my supervisor and if there are gaps in my recordings or notes I may need to return to you for clarification. There is a possibility that a follow up interview maybe required. The data obtained from this interview may possibly be used for other research in the future.

**What are the discomforts and risks?**

There is a possibility that you may feel uncomfortable talking about your experiences during the interview. Be reassured this is entirely reasonable and is expected.

**How will these discomforts and risks be alleviated?**

You can choose not to talk about subjects that you find uncomfortable. We can pause and return to the interview at any time. There is always the option to withdraw from the interview and/or the study at any time. In addition, if you would like it, referral can be made to a counsellor to discuss any concerns following the interview. Confidentiality of the data and your anonymity will be maintained at all times.

**What are the benefits?**

There are no immediate benefits for you taking part in this study. The information you provide will be used to inform practice for the nurses and doctors caring for patients who present for surgery, so the benefits are for others and while removed from you these benefits can be long lasting. This study as mentioned is part of my Masters qualification and the results of the research will probably be submitted to the appropriate journal for publication. Presentation will also be made to relevant WDHB employees. There is a possibility for further study and some participants may be contacted for a follow-up interview later, subject to their approval.

**How will my privacy be protected?**

All participants who are interviewed will be given a pseudonym (a fictitious name). The researcher will not know who the participant is. The data from the interview will be stored securely on AUT premises in a location separate from the consent forms. Electronic data will be downloaded to an external storage device (e.g. an external hard drive, a memory stick etc.) and securely stored. Confidentiality and privacy will be maintained always.

**What are the costs of participating in this research?**

The cost is your time and availability. I anticipate the interview will take approximately 40 minutes but I will allow an hour to complete.

**What opportunity do I have to consider this invitation?**

You are asked to indicate if you would like to take part in the research within two weeks of receiving this information sheet.

**Will I receive feedback on the results of this research?**

You can choose to receive a summary of the findings of this research. Once these are available, you can choose to have them sent to you at an address you provide. You will get details of these options once the study has been completed, approximately 12 months after your interview.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, My Supervisors contact details are: Dr Shelaine Zambas, shelaine.zambas@aut.ac.nz 09 921 9999 ext 7865

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz 921 9999 ext 6038.

**Whom do I contact for further information about this research?**

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

***Researcher Contact Details:***

ResearchAutJo@gmail.com 02102312850

***Project Supervisor Contact Details:***

shelaine.zambas@aut.ac.nz 09 921 9999 ext 7865

## *Cultural Support:*

If you require Māori cultural support talk to your whānau in the first instance.

Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning

09 486 8324 ext. 42324

Appendix D: Consent form



# Consent Form

*Project title: Elective surgery cancellation.*

*Project Supervisor: Dr Shelaine Zambas*

*Researcher: Joanne Inivale*

○ I have read and understood the information provided about this research project in the Information Sheet dated October 2017.

○ I have had an opportunity to ask questions and to have them answered.

○ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

○ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

○ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

○ I agree to take part in this research and that I am aged 16yrs or older.

○ I wish to receive a summary of the research findings (please tick one): Yes○    No○

○ I have completed my surgery (please tick one): Yes○    No○

○ I give permission to be contacted for a follow up interview if required (please tick one): Yes○    No○

○ I give permission for my data to be used for other research in the future (please tick one): Yes○    No○

If you require Māori cultural support talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 42324

Participant's signature: ………………………………………………………………………………………………………

Participant's name: ………………………………………………………………………………………………………

Participant's Contact Details (if appropriate):

…………………………………………………………………………………………..

…………………………………………………………………………………………..

…………………………………………………………………………………………..

…………………………………………………………………………………………..

Date:

## Appendix E: Ethics approval – AUT

11 December 2017

Shelaine Zambas
Faculty of Health and Environmental Sciences

Dear Shelaine

Re Ethics Application:    **17/416 Elective surgery cancellation**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 11 December 2020.

Once locality authorisation has been received, please forward to AUTEC.

**Standard Conditions of Approval**

1.  A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2.  A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3.  Any amendments to the project must be approved by AUTEC prior to being implemented.  Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4.  Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5.  Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only.  If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
**Auckland University of Technology Ethics Committee**

Cc:        researchautjo@gmail.com; gael.mearns@aut.ac.nz

## Appendix F: Ethics approval – Waitemata DHB

| | |
|---|---|
| From: | Research & Knowledge Centre <research@waitematadhb.govt.nz> |
| To: | Joanne Inivale (WDHB) |
| Cc: | |
| Subject: | RM13827 Locality Authorisation |

Sent: Wed 28/02/2018

Dear Joanne

The Research & Knowledge Centre has now received the relevant approvals for the following study:

Title: To discover what happened to patients when surgery was cancelled

Registration #: RM13827

This study now has Waitemata DHB Locality Authorisation. Please continue to forward to us copies of all correspondence regarding ongoing ethics approval for this study (if any). All amendments to your study must be submitted to the Research & Knowledge Centre for review.

Note that all research, audit and related activity must meet ethical standards in relation to the safe storage, retention and destruction of research data.

At the conclusion of this study a copy of any outputs, reports or publications should be forwarded to research@waitematadhb.govt.nz

Good luck with your study.

Regards
Research & Knowledge Centre
Level 1, Kahui Manaaki (Building 5)
North Shore Hospital Campus
Waitemata DHB

# School of Clinical Sciences
## Mātauranga Māori Committee

### Verification of Māori Consultation

This document provides verification that the research project named below was discussed with the School of Clinical Sciences Mātauranga Māori Committee, Auckland University of Technology. Specific comments and recommendations are indicated below.

| Research Title: Elective surgery cancellation | | |
|---|---|---|
| **Researcher(s):** Joanne Inivale | | **Date:** 12/2/18 |
| **Discussion Areas** | **Discussed** | **Comments/ Recommendations** (see next page) |
| **Whakapapa: Relationships** | | |
| Researcher experience in field | X | 1 |
| Consultation with local stakeholders | X | 4, 6 |
| Consenting process | X | 7 |
| Clarity of data usage | X | 2 |
| Dissemination of findings | | |
| Benefits to participants | | |
| **Tika: Validity of the research** | | |
| Clear purpose of project | X | 1 |
| Relevance to Māori | X | 3 |
| Likely outcome for participants, communities, other stakeholders | | |
| Participant recruitment methods | X | 8 |
| Māori involvement in project (participants, researchers, etc.) | X | 3, 3, 5, 6, 7 |
| **Manaakitanga: Responsibility and respect** | | |
| Participants' access to appropriate advice | | |
| Participants treated with dignity and respect | X | 4, 7 |
| Privacy and confidentiality | | |
| Whānau support | X | 7 |
| Transparency of research process | | |
| **Mana tangata: Power & Authority** | | |
| Reciprocity (acknowledgements, compensation, gifts) | | |
| Risks of participation identified | | |
| Ownership of outcomes | | |
| Informed consent process | x | 7 |

**Comments and Recommendations**

1.  Joanne Inivale is employed by the Waitematā DHB, and works at North Shore Hospital as a Specialist Nurse in the Anaesthetic Department. In her role she is required to look at day-of-surgery cancellations for elective surgery patients. Her study will look at both cancellations made by the hospital and cancellations made by the patient.

2.  The applicant will be using grounded theory methodology and she has already completed a literature review. She is not aware of any studies where patient interviews have been used in a grounded theory research on this topic. To date, she has not considered ethnicity in her work on elective surgery cancellation and she is anxious to avoid any preconceptions affecting her research.

3.  The Committee pointed out that general research usually involves very low numbers of Māori. Some targeting of Māori is usually necessary to get Māori participation up to a point where the numbers surveyed are representative of the population. It will also ensure that Māori views are captured within the grounded theory she is developing, enriching the research overall.

4.  In order to maintain participant anonymity within the research project, another nurse will send out the information to the patients. The Committee confirmed that this needs to be managed carefully. It was also suggested that sending information by mail may not be the best way to engage with Māori participants. Face to face contact (perhaps at a Māori health service) may work better, as it is important to establish credibility within Māori communities. If the applicant has existing connections, or is able to build connections during the research process, it would improve the chances of recruiting more Māori.

5.  Some potential participants may feel whakamā about the cancellation – especially if they have done the cancelling. Even if the hospital has cancelled the elective surgery appointment, Māori participants may feel as though they have done something wrong that brought about the cancellation. *Te Ara Tika Guidelines for Māori Research Ethics* may be helpful here.

6.  The involvement of Helen Wihongi (Waitematā DHB) will be at the beginning stages of the project. Dr Wihongi has looked over the Māori review process for this study, and the applicant expects to meet again with her once she has received this Committee's summary of the meeting's discussions.

7.  Data collection, and involvement of whānau in the process: The applicant initially had included whānau presence during the interview process but AUT Ethics had instructed her to remove whānau from the process, and advised that consent would be needed if they were present. The Committee confirmed that consent would be needed if whānau or other support people were interviewed during the process. It was noted that it would be important for Māori participants to have their whānau or support persons with them, and the presence of support persons would be preferable if the participant wished them to contribute during the interview process. An Ethics amendment may need to be sought to do this, however. If an Ethics amendment is not sought, and whānau become unexpectedly involved in the conversation between the researcher and the participant, the researcher would need to work out, from a

methodological standpoint, how she will deal with the data that whānau have contributed.

8.  Location of the data collection:  The applicant will go to the participants, wherever they are located. It was suggested that the researcher take a support person with her to assist with matters of protocol, and she was advised that there are students at AUT North Campus who would be willing to fulfil that role. For this assistance, an offer of koha would be appropriate.

9.  Confidentiality: The application is confidential at the applicant's request. She wishes to protect her work until it has been completed.

Please contact the Committee's Administrator Eleanor Fearn at eleanor.fearn@aut.ac.nz if you have any questions about this feedback.

You may be contacted in 12 months' time for feedback about the process and the usefulness of these comments and recommendations to your project.

Signature:                                         Date:    12 February 2018

Grant Mawston
**Mātauranga Māori Consultation Committee**

28 February 2018

Joanne Inivale
Perioperative Speciality Nurse
Waitematā District Health Board
Auckland

**Re: To discover what happened to patients when surgery was cancelled**

Thank you for providing the following documents the:

- Māori review form
- Study protocol
- PIS/CF
- Approvals
- HDEC application
- Matauranga Māori  Committee comments

The study is seeking to investigate people's thoughts and feelings about having their surgery cancelled. The investigator will be recruiting 20 to 30 participants.  At this point the investigator does not know how many of these will be Māori but will endeavour to include Māori in the study. Participants will be recruited through a mail out.

Comments:

- Approvals have been received from the service and the departments
- Ethical approval has been received from AUT
- The DHBs are tasked with addressing equity issues and the Waitemata DHB is committed to this. In the research domain this means gathering ethnicity data. Please review the Ministry of Health Ethnicity Data Protocols.
- You may find if you record the difference between Māori experience of cancellation and non-Māori experience there will be a difference based on socio-economic determinants and this will help inform the DHBs funding and planning teams.
- Recruiting by post alone may not recruit enough Māori. Texting might improve these numbers.
- I note the comments made by the AUT Matauranga Māori Committee and support their comments.
- Please add the Māori cultural contact details to the participant information and consent form (see below).

If you require Māori cultural support talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324

Please send a summary of the study results to the research advisor Māori to disseminate to the DHB Memorandum of Understanding partners (Ngati Whatua and Waipereira Whanau Trust).

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee the study has been approved.

Heoi ano

*H.A Wihongi*

**Dr Helen Wihongi**

**Research Advisor – Māori/Senior Research Fellow**
**He Kamaka Waiora/Waitematā and Auckland DHB**
Level 1, Kahui Manaaki – Building 5
North Shore Hosptial/ Auckland 0740, New Zealand
p: +64 9 486 8920 ext. 43204, m: + 64 21 0203 1167
email helen.wihongi@waitematadhb.govt.nz

Appendix H: Confidentiality agreement



# Confidentiality Agreement

*Project title: Elective surgery cancellation.*

*Project Supervisor: Dr Shelaine Zambas*

*Researcher: Joanne Inivale*

○  I understand that all the material I will be asked to transcribe is confidential.

○  I understand that the contents of the tapes or recordings can only be discussed with the researchers.

○  I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:    ...........................................…………………………………………………………

Transcriber's name:    ...........................................…………………………………………………………

Transcriber's Contact Details (if appropriate):

……………………………………………………………………………………………..

……………………………………………………………………………………………..

……………………………………………………………………………………………..

……………………………………………………………………………………………..

Date:

Project Supervisor's Contact Details (if appropriate):

Dr Shelaine Zambas

email: shelaine.zambas@aut.ac.nz

telephone:  09 921 9999 ext: 7864

………………………………………………………………………………………..

**Approved by the Auckland University of Technology Ethics Committee on 11 December 2017, AUTEC Reference number 17/416.**

Appendix I: Indicative questions for interviews

## Indicative Questions for Interviews

### *Initial Open-ended questions:*

Tell me about what happened when your elective surgery was cancelled?

What was it like? What did you think then?

Who, if anyone, influenced your actions? Could you tell me about how he/she or they influenced you?

If you recall, could you describe what was going on in your life then?

How would you describe how you viewed having surgery before it was cancelled?

How, if at all, has your view of having surgery changed?

How would you describe the person you were then?

### *Intermediate Questions:*

Could you tell me about your thoughts and feelings when you learned that your surgery was cancelled?

Who, if anyone, was involved? In which ways were they involved?

How, if at all, have your thoughts and feelings about having surgery changed since you experienced cancellation?

Tell me about how you learned to handle cancelled surgery.

Would you tell me how you would describe the person you are now? What do you think most contributed to this change?

### *Ending Questions:*

Could you describe the most important lessons you learned about yourself and others through experiencing surgery cancellation?

Tell me about how your views [and/or actions depending on topic and preceding responses] may have changed since you have experienced surgery cancellation.

How have you grown as a person since surgery cancellation?

Tell me about your strengths that you discovered or developed through this experience.

What do you most value about yourself now? What do others most value in you?

After reflecting on your experiences with cancelled surgery is there something else you would like to add?

Is there anything you would like to ask me?

Appendix J: Researcher safety protocol

Researcher Safety Protocol

For semi structured interview if occurring in patients' private residence:
- ensuring that a colleague has a schedule of one's visits for a morning or afternoon
- text/call to a colleague when entering and leaving a participant's home. If text/call not received by the agreed timeframe researcher will be contacted to ensure safety. If researcher unable to be reached colleague will travel to the participants address and call emergency services if required.
- when visiting participants in their homes act in culturally and socially sensitive ways.
- remembering that I am a guest and that it is the participants who are doing the favour by agreeing to participate in the research and to share their homes.
- GPS location on researcher's cell phone will be linked to colleague
- ICE number readily accessible on researcher's phone prior to entering participants home
- Ensure researcher is seated close to the door with ready exit if required
- If the researcher feels uncomfortable at any stage will make an excuse and leave
- No interviews after 4pm, all interviews to be completed by this time