

**Developing patient information for
women and their whānau choosing to
electively end their second-trimester
pregnancy because of foetal
abnormality**

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A practice project submitted to the Auckland University
of Technology in partial fulfillment of the requirements for
the degree Master of Health Practice (MHPrac)

2022

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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.”

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ACKNOWLEDGMENTS

It is with sincere thanks that I acknowledge the input, guidance, support, and mentorship of my supervisor Dr. Catherine Cook. You have a plethora of knowledge in the politically and socially charged arena of the abortion debate and should be considered a true champion for women. I am thankful that our paths have crossed.

Thank you to my colleagues ... both nursing staff, social workers, cultural support staff, and medical staff for your input, and for your focus on improving the patient journey. Your contribution and the difference this makes to the journey of women and their families/whānau doesn't go unnoticed or unappreciated. It is the little things that matter.

Thank you to Waitematā District Health Board for your financial support and encouragement to complete this degree. I appreciate your faith in my skills and experience. Thanks are also extended to Kassie Choo, Ivana Nakarada-Kordic, and Alyssa Tai from Waitematā District Health Boards Institute for Innovation and Improvement (i3) & AUT School of Art and Design for your expertise and skill with the layout and graphics of the patient literature.

Most importantly, I would like to offer my heartfelt thanks and gratitude to my children (Flynn, Mia & Noah) and my husband (Ian) for your continued support, enthusiasm for my achievements, and patience. You are my reason for being, my every breath, and the beating of my heart.

Ehara taku toa, he takitahi, he toa takitini

My success should not be bestowed onto me alone, as it was not individual success but the success of a collective

ABSTRACT

Medical terminations in the first trimester of pregnancy are one of the most commonly performed medical procedures undertaken in New Zealand. It is, however, far less common to electively end a pregnancy in the second trimester on the grounds of foetal abnormality. New Zealand data obtained in 2018 suggests that 238 women chose to electively end their pregnancy because of foetal abnormality.

The diagnosis of a foetal abnormality presents the parents with a difficult and often traumatic decision ... to proceed with the pregnancy and give birth to a child with known disabilities, or to electively end the life of the foetus by terminating the pregnancy. When faced with a diagnosis of severe foetal abnormality, most women choose to electively end the pregnancy.

A review of the current literature suggests that the incidence of medical terminations of pregnancy for foetal abnormality is increasing. This is thought to relate to advancing maternal age, the increased availability of antenatal screening, and advances in diagnostic testing. Medical termination of pregnancy for foetal abnormality was considered a major life event for most women. The psychological consequences of making this decision came with a range of emotional consequences including (but not limited to) grief, sadness, doubt, anger, and regret.

Research showed that written information given to women making this decision was considered inappropriate, did not support their emotional requirements, and failed to prepare them for the ordeal ahead. Providing sensitive and relevant patient literature can improve their psychological well-being, reduce the impact of their decision and improve their journey. Scrutiny of the literature distributed at Waitematā District Health board revealed it to be inadequate, unsuitable, and insensitive. This quality improvement project aimed to develop a sensitive, informative, and supportive pamphlet to support women and their families/whānau through the labour and delivery of their pregnancy.

The psychological consequences of choosing to end a wanted pregnancy because of foetal abnormality require specific regard to the development of a patient-centered resource to support women and their families/ whānau as they navigate this difficult and isolating event in their lives.

AIM OF THE PROJECT

This practice project aimed to develop a sensitive, informative, non-judgmental, and compassionate resource for those women and their whānau/family who have chosen to end their second-trimester pregnancy because of a foetal abnormality. Currently, the Waitematā District Health Board issues literature that is geared towards women who no longer wish to be pregnant (a social abortion). The current resource is not fit for purpose. It does not acknowledge or address the challenges and difficulties that accompany the decision to end a wanted pregnancy because of foetal abnormality. It does not recognise or address the different emotional needs of women who are electively ending a wanted pregnancy. It fails to prepare the women and their whānau for the challenges and complications they may experience with their baby's birthing nor prepare them for the practical considerations of the procedure.

It is anticipated that this enhanced patient resource will support those women and their whānau by acknowledging the difficult decision they have made and the emotional impact this may have. The content will include practical suggestions on how they can prepare for their procedure and what to expect during the labour and delivery of their baby. It will encompass the difficult decisions they may need to consider, such as seeing and holding the baby, post mortem, and funeral options. The patient resource will also include options for remembering their baby, cultural and spiritual support, contact details for the ward, support groups, and pregnancy loss services. The resource produced is not designed as a substitute for nursing care. It is intended to be used as an adjunct to the development of a therapeutic relationship between the woman, her whānau, and the health professionals delivering her care.

Going forward it is anticipated that this practice project will form the basis of a research project that will engage the women and their families and whānau that have elected to terminate their second-trimester pregnancy because of foetal abnormality.

CHAPTER 1: OVERVIEW OF RELEVANT BACKGROUND AND CONTEXTUAL ISSUES

1:1 History of Abortion in New Zealand

To companion women effectively through a second-trimester abortion it is useful to have an appreciation of the complex history of this often stigmatised though common procedure. New Zealand is no stranger to the abortion debate and has its share of anti-abortion politics, religious influence, and pro-choice history. Abortions were illegal in New Zealand up until the late 1930s unless the woman's life was considered at risk if the pregnancy was to continue (Te Ara, 2018). The social and moral climate of the time disapproved of abortion and women who did not want to be pregnant often resorted to backstreet abortions to end their pregnancies. Women who did receive an abortion were reluctant to admit to it publically given the taboo nature of the topic (Sparrow, 2017; McCulloch, 2013; Te Ara, 2018). There is no accurate data to reflect the number of illegal abortions performed in this period however in the 1930's it was estimated that 10,000 illegal abortions were being performed annually in comparison to a live birth rate of 24000. Statistics from 1934 show that 42 women died in New Zealand from complications arising from an illegal abortion (Te Ara, 2018).

By the end of the 1960's the debate around the morality of abortion vs the rights of a woman to decide her fertility became more intense. Groups on either side of the abortion divide organised protests and became more vocal and organised in their lobbying of the government and influential organisations in this period (McCulloch, 2013).

The Roman Catholic Church remained steadfast in its view of abortion and the roles of women. The Bishop of Auckland (1974-1983) John Mackey wrote that "if a woman did not want to have children she could choose a life of virginity and service ... but a marriage without children is not a marriage." (McCullouch, 2013). The Catholic Church were determined supporters of pro-choice group SPUC (Society for the Prevention of the Unborn Child) whose success in the 1970's has been credited to the influence and support of the Catholic Church.

The feminist movement was not well tolerated by many in New Zealand society in the 1970's (McCulloch, 2013). The connotation of being labeled a feminist drew backlash and unfair criticism and even influential women took umbrage at being labeled a 'women's libber' seeking to distance themselves from the movement (McCulloch, 2013). McCulloch (2013) further suggests that attitudes to women were often blatantly sexist and patriarchal in this period and very few men of power agreed with women deciding their reproductive rights.

By the 1970s pro-life groups including church groups and organisations such as SPUC were well funded and held large memberships. SPUC and its members regularly picketed abortion providers, harassing and bullying the women entering the clinics seeking an abortion (Du Plessis, 2014).

By the mid-1970's independent abortion clinics were operating improving the access to legal abortions in New Zealand (Du Plessis, 2014). Abortion rates were increasing rapidly throughout this period (Te Ara, 2018) and dissension and friction between pro-life and pro-choice campaigners continued.

In 1975-1977 a Royal Commission of Inquiry was set up by the then reigning Labour government to review contraception, sterilisation, and abortion. The resulting Contraception, Sterilisation, and Abortion Act (1977) was a conservative endeavour at diffusing tensions surrounding the availability and legality of abortion. The act complicated the process of obtaining an abortion. It stipulated that the woman had to initially approach her general practitioner, then two certifying medical professionals, who would then make a decision if the continuation of her pregnancy was a risk to her physical or mental health (Te Ara, 2018; McCulloch, 2013).

In 2020, an amendment to the Contraception, Abortion and Sterilisation Act (1977) decriminalised abortion and simplified the process of obtaining an abortion in New Zealand. Under the Act, women can now obtain an unrestricted abortion under 20 weeks gestation. The changes to the Act reflected the view of the majority of the population of New Zealand Ministry of Health [MOH], 2020)

1:2 *Abortion for Māori in New Zealand*

Māori perspectives on pregnancy tend to censure abortion as not being tikanga to Māori. Māori place a strong cultural connection and value to family and the condition of being hapū is revered and celebrated (Le Grice, 2020). There is limited literature about Māori views on abortion. However, the scant literature appears to indicate that Māori sought the deliberate end of their pregnancies as early as pre-colonisation (Le Grice, 2020; Le Grice & Braun, 2017) and that the practice of deliberately ending a pregnancy was not completely condemned.

New Zealand abortion data obtained in 2018, indicate that as a percentage of ethnicity, women who identify as Māori are more likely to obtain an abortion than those women who identify as New Zealand European (Abortion Supervisory Committee [ASC], 2019). This is also supported by Le Grice & Braun (2017) with research that suggests that women who identify as Māori have higher abortion rates than New Zealand European, Pacific, and Asian women. It is important to note that some women identify with more than one cultural group and therefore abortion data might be included more than once. I have been unable to find any published data on the ethnicity of New Zealand women undertaking Medical Termination of Pregnancy for Foetal Abnormality in their second trimester of pregnancy.

There are significant inequities in a woman's ability to access abortion services in Aoteroa. This was reiterated by the 2016 New Zealand Health Strategy paper which acknowledged that geographical and cultural inequality exists for women who chose to electively end their pregnancy (Silva & McNeill, 2008). Termination of Pregnancy providers are not available in all centres precipitating the need for women who choose abortion to travel for the procedure. Access to abortion for Māori women remains a challenge in rural New Zealand, not only from a geographical standpoint but because more isolated communities of Māori are often more resistant to colonial change and practices (Le Grice, 2020).

Quantitative research undertaken in 2008 has shown that 75% of Māori pregnancies were unplanned (Hohmann-Marriott, 2017) which may be one factor in explaining why more Māori women (as a percentage of ethnicity) seek more abortions than other ethnicities (ASC, 2019; Le Grice & Braun, 2017).

1:3 Medical Termination of Pregnancy for Foetal Abnormality

Termination of pregnancy is achieved either by surgical means or by medical management. The decision whether the pregnancy is ended via a medical or surgical termination is usually medically driven and will be based on gestation, crown-rump length of the foetus, risks to the patient, and experience of the surgical team. Those women who have chosen to medically terminate their pregnancy because of foetal abnormality (MTOFPA) are often directed to a medical abortion to ensure that a post mortem of the fetus is possible.

Second-trimester MTOFPA at Wāitemata District Health Board is achieved by the administration of a combination of two medications. Mifepristone and Misoprostol. Mifepristone is administered buccally and/or vaginally and stops the pregnancy hormones from supporting the pregnancy. It also softens and dilates the cervix and prepares it for the labour process. Misoprostol is usually dispensed 48 hours post-Mifepristone administration and will start the uterine contractions that will expel the pregnancy (Wāitemata District Health Board 2018).

The woman's fully informed written consent must be gained by the medical team before administration of Misoprostol because it is not licensed for its intended use in New Zealand (to induce a medical termination of pregnancy) and therefore requires strict consenting pathways (Abortion Services New Zealand, n.d.)

On average, the baby is delivered 6-8 hours post-administration of the first dose of Misoprostol (Abortion Services New Zealand, n.d.).

CHAPTER 2: LITERATURE OVERVIEW

The following literature review was conducted between March 2020 and November 2020 by searching databases including Science Direct, PubMed, Wiley, Scopus, Google Scholar, and DOAJ. Descriptors included “termination for foetal abnormality”, “abortion in New Zealand”, “abortion history New Zealand”, “emotions surrounding abortion”, “abortion access in America”. Publication language was limited to English and publication dates restricted to 2006 to current.

Historically, abortion is a hotly contested, polarising, and complex topic with involvement and discourse from political, social, religious, cultural, moral, and feminist viewpoints. Globally, an estimated 40-56 million women abort their pregnancies each year (Mainey et al., 2019; ASC, 2018; Shellenberg et al., 2011).

Medical termination in the first trimester of pregnancy is one of the most common medical procedures undertaken in New Zealand (Kirk et al., 2018). It is, however, far less common to electively end a pregnancy in the second trimester on the grounds of foetal abnormality (Lysus et al., 2014; Wyldes & Tonks, 2007). New Zealand data obtained in 2018 suggests that 238 women chose to electively end their pregnancy because of foetal abnormality (ASC, 2019). However, a Sullivan & de Faoites scholarly review (2017) proposes that the collection of abortion data may not be an accurate representation and can be dependent on the political, social, and geographical climate of a country providing statistics. Not all countries have requirements for reporting abortion data. For countries where abortion is not legalised, or where there is a strong political, social or religious stigma attached to the procedure, the reporting of abortion data may not be accurate (Moorthie et al., 2018; Moseson et al., 2015;). In the United States of America, for example, the recording of abortion statistics is voluntary and will be dependent on which state reports the data (Moseson et al., 2015). In essence, the statistics remain unclear for the number of pregnancies with a confirmed foetal abnormality that proceeds to medical termination of pregnancy. Comparability and comparison of global incidences should therefore be interpreted with caution (ASC, 2019).

Numerous academic studies have concluded that the global prevalence of MTOPFA is increasing (Bourguignon et al., 1999; Deas, 2017; Hunt et al., 2009; Korenromp et al., 2005; Mainey et al., 2019; Wyldes & Tonks, 2007). This is also reflected in a review of New

Zealand data (2008-2018) which demonstrates an increase in the number of MTOPFA performed (ASC, 2019). There is, however, a paucity of published New Zealand data giving the reasons for MTOPFA. Many studies have suggested advancing maternal age (and the resulting likelihood this brings of foetal anomalies), the advances of diagnostic testing, and the availability of antenatal screening to be the contributing factor in the global rise of MTOPFA (Bourguignon et al, 1999; Deas, 2017; Geylani et al., 2020; Hunt et al., 2009; Korenromp et al., 2005; Nazaré et al., 2014; Ramdaney et al., 2015).

Antenatal screening is now considered routine in pregnancy and no longer reserved for high-risk pregnancies (Forbes, 2008). The timing of antenatal screening may be a contributing factor in the emotional turmoil experienced by parents requesting a second-trimester termination of pregnancy for foetal abnormality. In New Zealand, nuchal translucency scans are offered between 11 and 14 weeks gestation to screen for Trisomy 21 (Down Syndrome) and an anatomy scan is offered between 18-20 weeks gestation where developmental issues will be identified (MOH, 2019). The results of these scans are therefore not available until late into the second trimester of pregnancy when women have already formed a connection with their baby. They have felt the baby kicking and moving in their womb, they have seen the baby on an ultrasound, informed family and friends, developed aspirations for their baby and its future, and formed an emotional attachment (Blakeley et al. 2019; Bourguignon et al., 1999; de Souza Patrício et al., 2017; Forbes 2008). Women are attending the anatomy scan to find out the gender of their baby, and to gain their first glimpse of their baby on the ultrasound, and they are therefore shocked and unprepared to hear of an abnormality (McCoyd, 2009). McCoyd (2009) calls this the 'mythic expectation' of pregnancy where receiving the devastating and unexpected news of an abnormality is in direct contrast to their expectations of delivering a healthy baby.

The diagnosis of a foetal abnormality presents the parents with a difficult and often traumatic decision. To proceed with the pregnancy and give birth to a child with known disabilities, or to choose to electively end the life of the fetus by terminating the pregnancy. Parents choosing to continue with a pregnancy with known abnormalities gamble on the possible consequences and significant emotional, physical, and fiscal implications that the birth may bring.

Women who decide to undertake an abortion (either because this is an unwanted pregnancy or for foetal abnormality) put themselves in a position where their decision becomes open for impassioned public debate and scrutiny (Cockrill & Nack, 2013; Goldblatt Hyatt, 2019;

Shellenberg et al., 2011). The deliberate end of a pregnancy, regardless of whether MTOPFA or a social abortion, is generally a difficult decision in a woman's life (Hannah et., 2019). Numerous studies have shown the psychological implications of having to make such a definitive and defining decision (Blakeley et al., 2019; Coleman, 2018; Freeman et al., 2016; Goldblatt Hyatt, 2019; Hunt et al., 2009; Korenromp et al., 2005; Nazaré et al., 2014).

Despite the moral and legal acceptance of medical termination for foetal abnormality in many countries, those women that choose to electively end the pregnancy face a significant challenge to the usual grief process and face long term psychological consequences (Korenromp et al., 2005; Deas, 2017; Hunt et al, 2009). The fact that a MTOPFA is a voluntary process is thought to interfere and augment the grief process (Korenromp et al., 2005; Nazaré et al., 2014; Fisher, 2008). Nazaré et al. (2014) also suggest in their qualitative study that in addition to having to make the harrowing decision to terminate their pregnancy the grief is also magnified by the change in life order of a parent having to bury a child. This contravenes the natural order of life adding to their sense of confusion. Despite this, when faced with the news that the woman is carrying a child with severe foetal abnormality most women will choose to electively end the pregnancy (Athanasiadis et al., 2008; Fisher, 2008; Korenromp et al., 2005; Lyrus et al., 2014; Ramdaney et al., 2015; Sullivan et al., 2017; Wyldes et al., 2007).

Women's rights to unrestricted abortion continue to be challenged internationally. Abortion remains a divisive and controversial procedure in the culture, politics, and society of the United States of America. Former American President Donald Trump made his anti-abortion stance clear during his candidacy when he introduced strategic changes to policy that further restricted access and equatability to abortions in the United States of America (Wilson, 2020). The right to abortion access, even though endorsed by the World Health Organisation as essential to sexual and reproductive health, remains a precarious right that is readily overturned.

Regardless of the laws determining the ease or difficulting of obtaining an abortion, it remains a contentious and polarising procedure in many parts of the world (Shellenberg et al., 2011). A qualitative study by Shellenberg et al. (2011) suggests that the social stigma attached to abortion is not as conspicuous in countries with more liberal approaches to abortion, and yet many women choose to keep their procedure a private affair because of

perceived or actual stigma attached to their abortion. Shellenberg et al. (2011) also suggest that women who acknowledge they have had an abortion may suffer social consequences such as persecution by family and community members, social isolation, intimate partner violence, divorce, and the dissolution of relationships.

These social consequences also prevent women from sharing their feelings about their abortion which augments their feeling of grief and social isolation (Shellenberg et al., 2011). The research by Shellenberg et al. (2011) faced some challenges and limitations. The qualitative study consisted of ninety-six in-depth semi-structured interviews and fifteen focus group discussions. It was undertaken in five participating strongly religious countries where abortion is highly stigmatised; Nigeria, Mexico, Pakistan, Peru, and the United States of America, and this, in itself, limits the data and results collected. Further research in other countries where abortion is more socially and morally acceptable is required to ensure that data obtained is more representative and reflective (Cockrill & Nack, 2013; Le Grice & Braun, 2017). Whilst society tends to consider an abortion for foetal abnormality more acceptable than a social abortion of an unwanted pregnancy, stigma remains. This societal stigma adds to the burden of women having to decide to end their pregnancy because of foetal abnormality (Cockrill & Nack, 2013; Goldblatt Hyatt, 2019; Shellenberg et al., 2011).

In a qualitative study by Forbes (2008), they suggest that a second-trimester abortion for a foetal abnormality is equally as difficult physiologically as a social abortion, and often more public, given the pregnancy is often visibly obvious at this gestation. Regardless, an MTOPFA is very often a difficult and stressful episode (Goldblatt Hyatt, 2019; Korenromp et al., 2005; Nazare et al., 2013) and is considered a major life event for most women (Korenromp et al., 2005; Lyrus et al., 2014).

There are indications that grief may be more intense with late trimester abortions. A cross-sectional study of 254 women by Korenromp et al. (2005) proposes that medical termination of pregnancy for foetal abnormalities occurring after 14 weeks gestation increases the severity of grief to the mother than those performed under 14 weeks. It showed that perceived partner support was a significant factor in adjusting to the loss of a baby post MTOPFA. The study authors acknowledge that perceived partner support could be influenced by the current emotional well-being of the mother and her current relationship with the father and should be interpreted with caution.

A review of the literature highlights a generous number of studies discussing the psychological impact on women and their families/whanau who choose to terminate their pregnancy because of foetal abnormality. Nearly all the studies identified a range of negative responses including depression, grief, sadness, doubt, regret, anger, guilt, denial, disappointment, and post-traumatic stress syndrome (Atienza-Carrasco et al., 2019; Blakeley et al., 2019; Cockerill et al., 2013; Coleman 2018; Geylani et al., 2020; Goldblatt Hyatt, 2019; Korenromp et al., 2005; Nazaré et al., 2013; Nazaré et al., 2014; Robson, 2002; Ramdaney et al., 2015; Sullivan et al., 2017). There is however divergence in the range of emotions experienced with some studies highlighting positive emotions experienced, such as reduced anxiety, relief, and solace experienced by patients following a MTOPFA (Blakeley et al., 2019; Fergusson et al., 2006; Rocca et al., 2015; Rocca et al., 2020).

Guilt, whilst not uncommon from both parents of MTOPFA, is more likely to be experienced by women. It can have a profound effect and have long-term consequences (Nazaré et al., 2014). A qualitative study by Nazaré et al. (2014) found that guilt following MTOPFA influenced grief outcomes in both men and women. The study gives credence to the voice of the men and fathers involved in MTOPFA and is important because the man's voice is rarely heard in what is, traditionally, a study centered around the women's voice. The study is not without its detractors, namely the small sample size which may influence variables. Some women declined to participate because of the feelings of grief they continued to face following MTOPFA and felt discussing the event was too painful and distressing for them. This may lead to a distortion of the results and an underrepresentation of those women and their partners who struggled to move forward from MTOPFA.

The relevance of the literature provided was considered important to parents as the information provided was often considered irrelevant and inappropriate. This is supported by numerous studies that suggest literature provided is often geared towards social abortion of unwanted pregnancy and not the termination of a much-wanted pregnancy due to a foetal abnormality (Asplin et al., 2014; Deas, 2017; Fisher & Larfarge, 2015; McCoyd, 2009). A study by de Souza Patrício et al. (2017) found the wording used in literature was important in reducing patient anxiety and that the term '*termination of pregnancy*' should be evaluated for its suitability for MTOPFA. Fisher (2008) also supports this when she suggests that 'abortion' insinuates an unwanted pregnancy. Fisher (2008) also suggests that the rights and rituals offered to other kinds of pregnancy losses are not always reciprocated for those women choosing to end their pregnancy because of fetal abnormality. This often unintentional bias adds to the confusion and burden of grief for these women.

The labour and delivery of a second-trimester abortion are more akin to the delivery of a stillborn infant, and if managed medically will involve contractions and the pain associated with the opening of the cervix and the passage of the baby through the birth canal (Forbes, 2008; Georgsson & Carlsson, 2019). Women are often not prepared for the physical pain associated with delivering a second-trimester abortion, and this intense pain adds to their fear and their distress (Georgsson & Carlsson, 2019). Georgsson and Carlsson (2019) studied the recollections of the pain experienced during medical termination of pregnancy. They highlighted the importance of preparing women for the process of delivering their second-trimester pregnancy and recommended women be offered information about the emotional and physical pain that is likely to eventuate during their procedure. They concluded that inadequate preparatory information and poor pain management through the procedure carried long-term psychological consequences after the termination including anxiety surrounding deliveries in subsequent pregnancies.

A qualitative study by Deas (2017) indicated that when providing post-decision information to women who have chosen to electively end their pregnancy because of foetal abnormality it was important to acknowledge the woman as an individual. Some women prefer advanced notification of decisions they will have to make post-delivery while other women found it too overwhelming and were unable to cope with the information pre-termination procedure. Hunt et al. (2009) conducted a study with 38 mothers who had ended their pregnancy because of foetal abnormality and concluded that they often had received no preparatory information about the choices they would have to make leaving them feeling unprepared for these decisions. Information that was considered helpful pre-procedure was the expected length of labour, coping strategies (especially for the first time mother), pain experience, options for mementos, the option of holding the baby after delivery, and the option to be able to implement a birth plan (Asplin et al., 2014; Hunt, 2009). Live birth following a MTOPFA in the second trimester of pregnancy is uncommon, however, women and their partners should be informed of the possibility to reduce further shock and distress following delivery (Royal College of Gynaecologists, 2011). Written information in this context is beneficial allowing the mother to choose the time to accept and process the information offered. Compounding the decision-making process is the urgency of the decisions being made.

The psychological consequences of choosing to end a wanted pregnancy because of foetal abnormality require specific regard to the development of a therapeutic relationship between the health professional and the patient (Deas, 2017). Certainly, research shows that a

positive and supportive relationship from the health professional reduces patient anxiety, improves self-efficacy, and can reduce the long-term emotional burden related to MTOPFA (Freeman et al., 2016). This has been supported by several studies that suggest that communication from health professionals can have far-reaching consequences on women and their families (Altshuler et al., 2017; Atienza-Carrasco et al., 2018; Atienza-Carrasco et al., 2020; Ramdaney et al., 2015). The absence of empathy and quality emotional support from health professionals can hinder the women's ability to process the diagnosis, their decision to electively end their pregnancy, and their ability to move forward (Altshuler et al., 2017; Atienza-Carrasco., 2019; Coleman, 2018; Geylani et al., 2020; Ramdaney et al., 2015). Studies also suggested that providing literature was useful to parents because they often felt unable to grasp information or instructions that were presented to them verbally and required time to process the information (Bourguignon et al., 1999; Deas, 2017;). Supporting this is a scholarly paper by Asplin et al (2014) that suggests that the provision of care is essential to the bereavement process and encompasses both emotional support and the provision of appropriate written literature and should incorporate the antenatal, intrapartum, and postnatal period of MTOPFA. Atienza-Carrasco et al. (2018) discuss this when they reiterate the essential role that health care professionals play in the provision of care for women who chose MTOPFA.

Nurses form the largest group of health professionals in the New Zealand health service (New Zealand Nurses Organisation, 2018). Given the large numbers of abortions performed in New Zealand (both abortions for unwanted pregnancies and abortions due to foetal abnormality), nurses working in this field must be aware of the innate difficulties faced by MTOPFA women and ensure that a therapeutic relationship is formed to enhance the patient journey. It is therefore important to ensure that staff that are supporting women through a second-trimester MTOPFA are experienced and competent communicators that can take their cues from the woman (Hunt et al., 2009).

In summary, the bulk of the literature suggests that parents undertaking a second-trimester termination of pregnancy for foetal abnormality experience a range of emotions including grief, loss, anxiety, post-traumatic stress disorder, and also contrasting emotions such as relief, and reduced anxiety. Providing sensitive and relevant post-decision literature for these women and their whanau can improve their psychological well-being, reduce the impact of their decision (Deas, 2017) and support them on their journey of choosing to electively end their pregnancy because of foetal abnormality. It is therefore fundamental to

women undertaking a second-trimester medical termination of pregnancy for a fetal abnormality that we give due consideration to the language used in both oral and written communication and that we provide sensitive, supportive language that prepares them for the physical and emotional consequences ahead.

CHAPTER 3: PROJECT DESIGN

This quality improvement practice project aims at developing a sensitive, supportive resource to improve the patient experience when women embark on the personal decision to terminate their second-trimester pregnancy due to foetal abnormality.

For the purpose of this project I have utilised the Plan, Do, Study, Act (PDSA) change model. The PDSA model provides a framework for developing, testing, and implementing change and is grounded in scientific methods (National Health Service [NHS], 2018; Health Navigator New Zealand, 2020; Little & Busick, 2019). The model is discussed in more detail below.

Currently, the Waitematā District Health Board [WDHB] policy and literature utilises the phrase '*termination of pregnancy*' and is geared towards a social termination of an unwanted pregnancy (WDHB, 2016). It does not recognise the specific emotional needs of those parents that have chosen to end their pregnancy due to foetal abnormality and fails to prepare the women and their family/whānau for the physical and emotional reality of a MTOPFA procedure. The proposed development of an improved patient-centered resource has been endorsed and supported by the Associate Director of Nursing (Surgical & Ambulatory Division) and the Associate Gynaecological Clinical Director of Waitematā District Health Board.

Delivering quality improvements is a key objective of the Waitematā District Health Board and can be evaluated across three key dimensions: the effect on the patient experience; safety; and clinical effectiveness. This quality improvement project meets all three criteria.

There are four stages to this quality improvement project that are iterative. Included in the first stage is the review of the literature surrounding MTOPFA and in particular, the difficulties experienced for families that have chosen this option for their pregnancy. In summary, the literature overview reiterated the importance of appropriate patient focussed literature that prepared the woman and her family/whānau for the MTOPFA procedure ahead.

The second stage was the collation of data obtained from interviews and self-administered questionnaires, and the analysis of any themes emerging. This entailed the gathering of data from some of the key stakeholders involved in the delivery of care to MTOPFA women and their families/whānau. This quality improvement project did not require ethics approval as only key stakeholders who were expert informants in MTOPFA as part of their everyday work role participated. The gathering of data was achieved by way of face-to-face interviews with key social workers, nursing staff specialising in MTOPFA, doctors who have specific and regular participation with MTOPFA, and staff from Asian Patient Support Services, Pacific Health, and He Kāmaka Waiora (Māori Health Services). Self-administered questionnaires and/or face-to-face interviews were offered as an option for all stakeholders.

Self-administered questionnaires are a measurement tool and allow researchers to discover a recipient's thoughts and behaviours (Sue & Ritter, 2012). Sue & Ritter (2012) suggest that the best questions are those that are short, self-explanatory, and meaningful. Health professionals and supporting staff completing self-administered questionnaires were given the opportunity of anonymous completion (returning completed questionnaires via the internal mail system) or if anonymity was not of concern, the questionnaires could be returned by email. Confidentiality was promised.

The third stage of the project was the thematic analysis of the themes that emerged. The meta-theme that emerged was that women need better preparation heading into their MTOPFA procedure.

The fourth stage of the project was the successful development of an evidence-based, peer-reviewed resource and the implementation of this resource to the health professionals at Wāitemata District Health Board involved in the delivery of care to 2nd-trimester MTOPFA. Further iteration, which is beyond the current scope of this project, will be planning the rollout of the improved patient literature, implementing the rollout, getting feedback from staff and family about its effectiveness, and evolving the literature to meet current patient needs and evidence.

This Quality Improvement Project has been limited in its scope by the restrictions and implications of the global pandemic, Covid-19. Further research involving the input of women and their family/whānau who have chosen MTOPFA would provide additional benefits, however given the above restrictions this was outside this quality improvements

project's scope and remains a research project for the future. It is anticipated that with further consultation this resource could be offered to other groups working in MTOPFA nationally and has the potential for improving outcomes beyond the current scope.

This Quality Improvement Project aligns with the six domains of healthcare quality suggested by the Institute of Medicine [IOM] in their watershed report, *To Err is Human: Building a Safer Health System* (Kohn et al, 2000)

- Safe
- Effective
- Patient-centered
- Timely
- Efficient
- Equitable

3.1 Change Model

The change model I have applied to this quality improvement project is Plan, Do, Study, Act model (PDSA). The PDSA model is a continuous improvement model meaning reflection of progress is required to effect change and continual growth (NHS, 2018).

Phase	Actions
Plan: What do we want to achieve?	<i>To improve the patient resource for those women and their whānau who have chosen to end their pregnancy because of foetal abnormality</i>
Do: Develop a plan of action?	<i>1: Identify key stakeholders involved in the provision of care offered to women and their families/whānau who have chosen MTOPFA. Key stakeholders for this quality improvement project are; social workers that work directly with MTOPFA; registered nurses who agree to care for women and their whānau who MTOPFA; medical staff involved in the MTOPFA process; and cultural support staff.</i>

	<i>2: Interview key stakeholders and seek their views on the current patient literature and MTOPFA process and what we could do better.</i>
Study: Analyse the information gained from the interviews and electronic surveys completed by key stakeholders. Summarise what was learned.	<i>Analyse the results of the interviews and questionnaires and summarise the meta-theme that emerges.</i>
Act: Based on what we learned to determine the best plan:	<i>Based on the expert opinion of key stakeholders and the identified theme from the literature review, determine what information should be included in the patient literature for women and their families/whānau who MTOPFA</i>

Plan: What do we want to achieve? *We want to improve the patient journey for those women and their whānau who have chosen to end their pregnancy because of foetal abnormality*

Do: Develop a plan of action? *1: Identify key stakeholders involved in the provision of care offered to women and their families/whānau who have chosen MTOPFA. Key stakeholders for this quality improvement project are; social workers that work directly with MTOPFA; Registered Nurses who agree to care for women and their whānau who MTOPFA; Medical staff involved in the MTOPFA process; and Cultural Support Staff. 2: Interview key stakeholders and seek their views on the current process and what we could do better.*

Study: Analyse the information gained from the interviews and electronic surveys completed by key stakeholders. Summarise what was learned. *The key points from the meetings and electronic questionnaires from key stakeholders were:*

- *that staff provide caring and empathetic delivery of MTOPFA*
- *a 7 day per week service should be offered*

- *Cultural support should be offered prior, during, and post MTOPFA procedure*
- *Patient literature should be improved to reflect the difficult decision that parents who MTOPFA have made and this should include more information about the process of delivering their baby*

Act: *Based on what we learned to determine the best plan:*

- *Adopt the changes and test*
- *Adjust the plan and test again*
- *Abandon the plan*

At this stage of the Quality Improvement Project, we are in the phase of adopting the changes and testing. The premise of the PDSA change model is the implementation of small changes before revisiting the process to ascertain what has worked, what needs further input, and what needs to be abandoned (McNamara et al., 2016).

Given the global implications of the Covid-19 pandemic and the sensitive nature of the quality improvement project, it was beyond the scope of this practice project to engage women directly affected by MTOPFA. It is however anticipated that this planned quality improvement project will form the basis of a research project with those women and their whānau that have been directly affected by MTOPFA.

This quality improvement project will be underpinned by Collaborative Learning Theory.

3.2 Collaborative Learning Theory

Collaborative learning theory is a pedagogical approach of using groups of novice and experienced people to enhance their learning by working collaboratively (Myron, et al, 2018). These groups may comprise a group of two or more stakeholders to share knowledge and skills, facilitating interprofessional collaboration. A collaborative learning approach encourages the sharing of problems to be examined with collaborative input into the discussion of solutions. In this quality improvement project, collaborative learning will involve groups of different stakeholders with a commonality of their involvement with women and their family/whānau who have chosen MTOPFA. Key stakeholders for this project are as follows; registered nurses with a background in second-trimester medical termination of pregnancy; women's health social workers directly involved in pre-decision, procedure, and

post-procedure support; gynecological doctors involved in post-procedure review; and cultural support services attached to the women's health ward that have been requested to support MTOPFA women and their whānau. Effective collaborative learning entails active listening to different viewpoints, the sharing of ideas, the participation of all members, and the recognition and value of shared contributions (Roberts, 2004).

Given the inherent difficulty in coordinating health professionals that work fully rostered shifts, the offer of participating in structured interviews or completion of an online questionnaire was offered. Both interviews and questionnaires were tailored specifically to MTOPFA to gauge the effectiveness of the current process, how women and their families/whanau responded to the current literature and what was important to consider when considering any possible changes to the current literature. Stakeholders were also asked what we (as a team) currently do well and where we could make improvements.

Three, face-to-face interprofessional structured interviews were held that were facilitated by the Charge Nurse Manager of the Women's Health Ward (myself). Acting as a facilitator, I asked a series of questions to the different cohorts and invited their shared responses. Given the diverse professions and scope of practice of the key stakeholders, different questions were asked for different cohorts.

A key feature of structured interviews is the methodical approach to questions asked. Structured interviews can be undertaken in various formats including; phone interviews, electronic meetings, face-to-face, and electronic surveys, and questionnaires. For the purpose of this project, I completed both face-to-face interviews and electronic questionnaires depending on the availability and preference of the stakeholders.

As expected, the option of completing an online questionnaire was a popular option for staff working rostered shifts. A questionnaire is a tool that allows the researcher to discover a respondent's opinion or their knowledge or behaviour on a particular subject. Sue and Ritter (2012) suggest that well-constructed questions are essential to the integrity of the survey. They add that survey questions should be brief, self-explanatory, understandable, unambiguous, and have meaning to the respondent.

Service-specific social workers are key stakeholders in the MTOPFA process and were offered face-to-face interviews or asked if they would prefer to complete an online

questionnaire. Questions asked in both formats were identical. Two social workers elected to attend one 60 minute collective inter-professional meeting. No social workers elected to complete the questionnaire.

The current WDHB literature we give women and their whānau post decision making for MTOPFA use the term medical termination of pregnancy. How do you feel about this term for women who have chosen MTOPFA?
How do women and their family/whānau react to this literature?
Are women offered any cultural support at this first meeting?
If yes, when is the cultural support requested by the women and their whānau (ie) pre-decision, during the procedure, or post-procedure?
Can you give me specific examples of what type of cultural support women and their whānau request?
Staff who work with women and their whānau who MTOPFA can find the process very distressing. How do you cope with the emotions surrounding MTOPFA?
Staff can find the morality of working with women and their whānau who choose MTOPFA challenging. How do you cope with the morality of MTOPFA?
Do you feel well supported with the emotional and moral aspects of MTOPFA by management?
If not, what would make you feel supported?
Do you ask women what they would like their pregnancy referred to? (ie) baby, fetus, or a name they have already selected for their baby?
Do you discuss if they would like to incorporate a birth plan into their procedure?
If not, do you think women would respond well to being offered the opportunity to incorporate aspects of their planned birth plan into their termination procedure?
There are some difficult decisions that women and their family/whānau have to make such as; to see or hold the baby, do they want baby mementos, do they want the baby blessed,

do they want to take their baby home or would they prefer the hospital arrange the cremation. When do you think women and their partners are ready to hear about these options and make these decisions?

Do you inform women and their partners that some babies are born alive and that if the baby is born alive (regardless of gestation) then a formal birth and death certificate is a legal requirement?

Do you think the current literature we provide is adequate for those women and their families choosing to terminate their pregnancy because of a foetal abnormality?

If not, what would you like to see changed?

Currently, MTOPFA procedures are performed Monday to Friday because of reduced medical support. What do you think about the availability of MTOPFA?

In terms of MTOPFA on Hine Ora ward, what do you think we do well?

In terms of MTOPFA on Hine Ora ward, what do you think we could do better?

Is there anything else you would like to add?

Given the difficulty in organising meetings with registered nurses who undertake fully rostered shifts, and the reality of them being unable to participate in an interview during their shift, the option of completing a questionnaire or attending a face-to-face interview was offered. A total of sixteen nurses that manage MTOPFA responded to my request. Fourteen elected to complete the questionnaire. Their experience in MTOPFA ranged from competent to advanced practitioner. Given that I am their direct line manager the nurses all declined the opportunity of anonymity. Two senior nurses elected to attend a group structured interview that lasted sixty minutes. Because the MTOPFA procedure is predominantly nurse-led they were asked additional questions to those asked of the social workers. The additional questions were:

When you meet the woman and her partner for the first time do you feel they are well

prepared for the procedure to follow?
If not, what are they unprepared for?
How could we prepare these women better and at what stage should they receive this information?
Do you ask them if there are any specific cultural requirements we should be aware of?

Again, given the challenges faced with rostered staff, the doctors were given the option of attending an interview or completing an electronic questionnaire. All four doctors that responded elected to complete an online questionnaire. The option of anonymity was offered but not accepted. The majority of doctors on Hine Ora ward have less direct involvement with the women and their families that have elected to MTOPFA and were therefore only asked the following questions.

The current WDHB literature offered to women who MTOPFA refers to their termination of pregnancy. Do you think the current literature we provide is adequate for those women and their families choosing to terminate their pregnancy because of a foetal abnormality?
If not, what would you like changed
Some health professionals feel that women and their family / whānau are not well prepared for the emotional and physical aspects of their MTOPFA? If you agree with this statement, what changes can we make to ensure their preparedness?
Currently, MTOPFA is offered Monday to Friday because of reduced medical staffing on the weekends. What are your thoughts on this?
In terms of MTOPFA on Hine Ora ward, what do you think we do well?
In terms of MTOPFA on Hine Ora ward, what do you think we could do better?
Is there anything else you would like to add?



The implications of the global pandemic and the resulting two Covid lockdowns in Auckland have impeded my ability to formalise a hui with all members of He Kāmaka Waiora despite best endeavours to meet. I have however had the chance to meet and kōrero with the Director of Māori Nursing at Wāitemata District Health Board. She has acknowledged that pregnancy is a revered condition for Māori and further consultation with He Kāmaka Waiora will be necessary to ensure tikanga and will be imperative to the success of the project. To date, no women have requested the support of He Kāmaka Waiora staff in any MTOPFA procedures on Hine Ora ward. Ongoing discussions with He Kāmaka Waiora staff have focused on facilitating the sourcing of whenua pots for the return of pregnancy tissue to women and their whānau. At the date of submission, I am waiting for a whakatauki to be gifted from the Kaumāta of He Kāmaka Waiora.

Given the high numbers of women of Asian ethnicities seeking MTOPFA (as a percentage of ethnicity) staff at Asian Patient Support Services were also asked if they would like to participate in a face-to-face interview or complete an electronic questionnaire. The team leader chose to respond in a 60-minute face-to-face interview on behalf of her team. Despite the proportionally high numbers of MTOPFA, staff at Asian Patient Support Services have, to date, had no involvement in Hine Ora ward for Asian women who MTOPFA. Given their lack of exposure to MTOPFA on Hine Ora they were asked a different set of questions.

Are you aware of the difference between MTOP and MTOPFA?
If yes, are you aware of the different challenges that women who MTOPFA face?
The current WDHB literature we give women and their whānau who have chosen to MTOPFA discusses their medical termination of pregnancy. How would Asian women who have chosen MTOPFA feel about this term?
Does culture play an important part for Asian women who chose MTOPFA?
If culture plays such an important part, what should we consider from a cultural

perspective?

Do you think cultural support would be more beneficial pre-procedure, during the procedure, or post-procedure? Why is this?

Do you feel supported by your direct line manager with MTOPFA women and families?

CHAPTER 4: ANALYSIS OF QUALITATIVE INTERVIEW/SURVEY DATA

For this quality improvement project, I have analysed the data collected from key stakeholders in face-to-face interviews and questionnaire answers by using thematic analysis. Thematic analysis is a common method of capturing, analysing, and recording qualitative data to identify themes (Braun & Clarke, 2006).

According to Braun and Clarke (2006), there are six phases involved in thematic analysis:

1. Become familiar with the data from your interviews or survey and note down your initial thoughts. Braun and Clarke (2006) suggest looking for themes emerging by 'actively' reading the transcripts
2. The generation of initial codes. Codes identify features of interest to the researcher and look for repeated patterns.
3. Examine the codes for themes that are arising and group them together.
4. Review and analyse the themes. Generate a thematic map.
5. Define and refine the themes
6. Relate the analysis to the original research questions or aim.
Produce the report

4.1 Findings

The themes that emerged from the data supported the project design of providing improved patient literature for women and their families/whānau that have chosen MTOPFA.

In the initial coding of the interviews and survey questions with key stakeholders, the collective features that became apparent revealed the following themes:

4.2 *The importance of emotional support*

Key stakeholders felt the process of MTOPFA on Hine Ora ward was generally a supportive process for staff and that anecdotal feedback from women who MTOPFA are often extremely thankful for the emotional care they receive from the staff.

4.3 *The importance of appropriate literature*

All nurses and women's health social workers agreed that the current format of literature was not appropriate for MTOPFA women.

All medical staff felt the current literature was not inappropriate in its current format. This was an unexpected result and may demonstrate their 'medical model' approach and be illustrative of their lack of involvement in MTOPFA which is predominantly nurse-led on Hine Ora ward. At the time this survey was conducted there was no alternative literature available for comparison however since the completion of this survey the Doctors have reviewed the new format draft literature and all agreed it is a compassionate and thoughtful piece of work that will greatly support women and their family/whānau who MTOPFA.

4.4 *Preparing women for the physiological process*

Nursing and women's health social workers felt that women were generally not well prepared for the physical aspect of labour, particularly those mothers who had not delivered vaginally before. Medical staff were not asked this question given their limited involvement in the labour process unless complications arise. "I'm not sure some women have comprehended that they will be labouring to deliver this baby and with that often comes significant physiological pain"

4.5 *Preparing women for possible complications*

Nursing and medical staff felt that women are not well prepared for complications that may occur. For second-trimester deliveries, this is likely to be a retained placenta and post-partum haemorrhage. This is often a very fraught and frantic time with heavy blood loss, invasive and sensitive examinations conducted in emergency situations, and multiple staff involved in preparing the woman for manual removal of her placenta and/or prepping her for emergency theatre. "I feel the women and their partners are not prepared for an emergency. They are shell-shocked ... it's all very chaotic with the woman actively bleeding, we are all in the room attending to her, trying to offer them both reassurance but knowing this is an emergency. I think this would be more manageable and reassuring if they knew this was something that may happen."

Nursing staff felt that women were not adequately warned that they may give birth to a live baby and the emotional distress this may cause to the women and their whānau. "It's

dreadful when the baby is born alive. I know they are told it could happen but the reality is it happens regularly.”

From these themes, the meta-theme that has emerged was that women and their family/whānau who MTOPFA require better preparation for their procedure.

CHAPTER 5: DISCUSSION

The initial goal of this quality improvement project was to enhance the patient literature the Wāitemata District Health Board provides women who have chosen to medically end their pregnancy because of a diagnosed foetal abnormality.

The improved health literature “Supporting you through a difficult time: Interrupting a pregnancy for medical reasons” has been reviewed by the Waitematā District Health Board’s Consumer Review group to ensure that the wording and format can be understood by our community. They acknowledged that this was a sensitive piece of literature and felt that very little change was necessary to support health literacy. All changes recommended by the Consumer Review group have been implemented.

The new format of patient literature will be peer-reviewed and is evidence-based. At the time of submitting this project, the improved patient literature is scheduled to be formally reviewed by key stakeholders in August 2021 and is currently awaiting further graphic design input and consultation with Māori tikanga advisors. Going forward the paper-based patient literature will also be made available in electronic format and different languages (as recommended by the Consumer Review group, He Kāmaka Waiora, and Asian Patient Support Services). The use of an electronic format will allow patients to have a direct link to support group websites, and of course, allows for information to be readily updated to reflect current evidence and practice standards. He Kāmaka Waiora, Asian and Pacific Support services have been contacted to provide feedback on the literature and to seek their support in translation.

Three main themes were identified in the literature review. The significance of patient information that was relevant to women who choose MTOPFA, the provision of empathetic care, and the emotional impact on woman and their families/whānau who have chosen MTOPFA. The review highlighted the complex and varied emotions experienced by women. These emotions can have a significant and lasting effect. Women felt supported by their health care provider when staff connected with the patient and offered kindness and empathy. It is therefore important that staff providing care for these women have strong communication skills and can deliver care based on the woman’s specific needs.

The provision of suitable written literature was identified as being essential. The literature was too often geared towards a social abortion of unwanted pregnancy and failed to address the specific needs for women who experience MTOPFA. Women felt they were unprepared for the procedure, particularly the pain they would experience and the decisions they would need to make post-delivery. The new format literature is sensitive, informative, and acknowledges the difficult decision they have made. Informal peer review of the new literature has been overwhelmingly positive and for some staff reviewing the literature has been an emotional experience.

The timing of the quality improvement project has not been without its unexpected complications. The consequences of the global pandemic Covid-19 placed unprecedented stressors and strains on those working in the health sector who were involved in pandemic planning and delivery of care. There were unexpected constraints on our ability to access stakeholder participation and restrictions on the ability to seek consent for research. The uncertainty surrounding the duration that Covid-19 would impinge on the quality improvement project restricted my ability to plan. The current health crisis, and ongoing bed and staffing shortages in District Health Boards have reached critical levels obstructing my ability to maintain momentum with this project and impeding the ability of key stakeholders to provide feedback and to engage effectively.

There are two major limitations of this quality improvement project that could be addressed in subsequent research. The Covid 19 global pandemic prevented me from including women and their families/whānau who have decided to MTOPFA. The women's voice will be a critical component for future discussions on this important and emotive subject. The second limitation was my lack of experience in interviewing key stakeholders and my direct relationship with them. My hierarchical influence as the direct line manager for the nurses interviewed may have had a direct influence on the answers they have provided. Going forward, I would gain more experience in this aspect of research and use impartial staff to participate as the facilitator.

The journey through this Master's project has given the author a chance to critically reflect on the service we deliver to women and their families/whānau, not just from a MTOPFA perspective, but to all women and their family/whānau who have or are experiencing pregnancy loss.

It has created opportunities to enhance collaborative relationships and has broadened my knowledge of the Wāitemata District Health Board and the available support and interdisciplinary networks. This quality improvement project connects with the Wāitemata District Health Board's values of "connected", "everyone matters", "with compassion" and "better, best, brilliant" and their priorities of "improving patient experience" and "better outcomes".

It was always envisioned that this quality improvement project would form the basis of further research into this polarising and emotive topic and there is a need for further patient-focused research in this arena to enhance the care we deliver. Whilst this project is nearing its completion, I envisage that this is just the beginning of something more significant than I had originally anticipated. Knowledge discovered during this project has already been implemented at ward level, and discussed at the Gynaecological Quality Governance forum and the Wāitemata District Health Board "Changes to Abortion Law Working group". I am very excited to bring this patient literature to fruition and look forward to improving the very difficult journey that women who choose MTOPFA.

A perusal of other district health boards' literature reveals that the emotional distinction between a social abortion of unwanted pregnancy and the abortion of a much-wanted pregnancy because of foetal abnormality is not always well recognised or acknowledged. There is therefore potential for this quality improvement project to improve outcomes beyond the Wāitemata District Health Board.

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