

Online Information-Seeking Behaviours of Men Experiencing Fertility Difficulties

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A PhD Thesis in Digital Health & Human-Computer Interaction

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Declaration

I, Dilisha Patel, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Dedication

~For My Son, Veer~
If I can, you can; you just have to keep swimming.

~For Nirav~
Without you, there is nothing.

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Firstly I would like to thank the wonderful men who chose to contribute to this research and share their stories with me. I appreciate every minute of their time, as their words have enabled me to present contributions to knowledge. In essence, this thesis belongs to them. I am very grateful for the support of the Fertility Network UK and to the Fertility Clinic for supporting the recruitment for this research.

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Now for my Family, for never quite understanding what I do, but being proud anyway.

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Abstract

This thesis aims to understand the online information-seeking behaviours of men and how they make sense of and find meaning during their fertility journeys. This research contributes to understanding how online digital tools can support men to fulfil their sense-making and meaning-making needs when they experience fertility difficulties.

Research that explores support for pregnancy planning and fertility has predominantly focused on women, and men's views and experiences are often excluded. A review of existing literature revealed that men were likely to seek digital sources of health-related information for ease and privacy. However, it is yet to be understood how digital tools can best support this population or the opportunities where digital tools would be preferred and used by men. Therefore, this thesis used a qualitative approach to investigate men's needs when they experienced fertility difficulties and how these needs could be fulfilled using digital tools.

Men were found to mainly want information and both practical and emotional support during this time, which led to an instantiation of the 'finding a new normal' model based on the analysis of online forum data. Further analysis revealed that this model is also relevant for men outside online forums. Findings from the interview study led to the development of a novel presentation of the fertility journey represented by 9 stages from trying to conceive to conception, through interactions with health services as experienced by men. I highlight how men's information needs evolve along their fertility journey and how they make sense of and find meaning in information to support the acceptance of a new normal. Participants identified their preference for information to be presented and made available through digital means; therefore, men's needs were translated into requirements for a digital tool. An evaluation study found that existing digital tools do not completely fulfil men's evolving requirements for information and support and there is an opportunity for digital tools to be better designed to support men to make sense of, and find meaning in, online information when they experience fertility difficulties.

Impact Statement

This thesis provides an understanding of men's experiences and informational needs when they experience fertility difficulties and has an impact within and outside academia.

Within the academic HCI field, my work impacts the emerging focus on fertility and people's needs for digital tools during this time. This work is the first within the HCI domain to explore men's needs with regard to their online information-seeking behaviours when they experience fertility problems.

This work responds to the call for research to be more inclusive within the health domain. The inclusion of men in research on reproductive health and fertility has been reported in the literature to be a requirement for some time; however, the focus on men's experiences with healthcare professionals and services is still relatively novel. This thesis contributes an understanding of men's interactions with health services through their fertility journey. By highlighting these interactions, together with findings on the barriers to information access and the gaps in the provision of information and care, this journey presents opportunities for further interventions and services to be appropriately designed and directed.

I also illustrate and contribute to the literature that men are engaged and motivated to participate in research on reproductive health. Previously, it was assumed that they were uninterested in participating. Finally, I demonstrate methodological processes to support the inclusion of men in this research domain that others can build upon.

This thesis also presents a novel instantiation of the 'finding a new normal' model relevant to the fertility population, which has already been adopted and adapted by others with its use in the context of people's working habits.

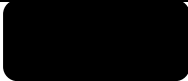

I have received a prize for best presentation based on presenting work from this thesis at an international academic conference, which led to interest from other academics to build upon my findings. MSc students have also built upon my focus on exploring the needs of men in subjects of reproductive health that are traditionally focused on women.

Work in this thesis has been presented at many international conferences, contributed to working group discussions, and was the basis of a large collaborative CSCW workshop

proposal. This brought together academics in the field of information seeking to form a collaborative understanding of the different methods used to explore online information-seeking journeys and how the internet helps people make sense and give meaning to their health experiences.

Outside academia, my work has contributed to a wider understanding of men's needs when they experience fertility problems. For example, since my collaboration with the Fertility Network charity, they now campaign for more support for men and work to men-only events for information and support. The campaign 'HIMFertility' is another example of more information and support now available for men, which is led by men who have experienced infertility and aims to support and guide others. This campaign achieved recognition through its broadcasted documentary and is now an online campaign promoted through websites and social media.

UCL Research Paper Declaration Form

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List of Publications

Work in this thesis has been published at a high-ranking HCI Conference.

Patel, D., Blandford, A., Warner, M., Shawe, J., & Stephenson, J. (2019, October). “I feel like only half a man” Online Forums as a Resource for Finding a” New Normal” for Men Experiencing Fertility Issues. Proceedings of the ACM on Human-Computer Interaction 3. (CSCW)

The following are peer-reviewed workshop position and doctoral consortium papers based on work from this thesis

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Chapter 1 Introduction

Infertility is medically defined as the inability to conceive after at least 12 months of unprotected intercourse. Infertility affects up to 15% of couples worldwide. Male-factor infertility, which describes physiological conditions that directly affect men's ability to conceive ([WHO, 2020](#)), is solely responsible for almost 30% of all infertility cases but contributes to approximately 50% of infertility cases globally, affecting nearly 10 million couples ([Agarwal et al., 2015](#)). Even though infertility impacts both women and men, support is frequently targeted at women, and men are commonly excluded ([Frey et al., 2012](#), [Warner and Frey, 2013](#), [Arya and Dibb, 2016](#)).

When people try to conceive, their choices of information and support range from actively seeking advice from a qualified healthcare professional, searching online or asking friends and family ([Stephenson et al., 2014](#)). However, pregnancy planning and trying to conceive is generally considered a private and personal affair. It is not often publicly shared, and confidential digital sources of information and support are favoured by couples ([Patel et al., 2015](#)). As a result, when couples encounter fertility difficulties and infertility, they often report feeling isolated and alone ([Hinton et al., 2010](#)).

Literature examining men's experiences and feelings towards conception and fertility is becoming more prevalent. It is recognised that the burden of responsibility toward fertility should no longer disproportionately fall on women ([Green, 2008](#)). Equally, the experience of procreating or facing difficulties in conception is felt and experienced by prospective fathers and mothers ([Arya and Dibb, 2016](#)). Despite this, little research has focused on

men's needs or collected data directly from men themselves. This absence of knowledge and support for men motivated this research to focus on men's experiences of fertility difficulties.

The literature indicates that when seeking information for healthcare, men are more likely to engage with digital sources of information (discussed in [2.3.5](#)). In addition, there is an absence of research that specifically explores how men may use digital tools to find information to support themselves and their partners during their fertility journey. Thus, another motivation for this work is the need to understand how we could better design digital tools to support men when they experience fertility difficulties.

This thesis presents an understanding of men's information-seeking behaviours to identify opportunities for digital health tools to support men who experience fertility difficulties.

1.1 Research Questions and Study Outlines

This thesis aims to answer the following research questions to address the gaps in the provision of support for men in fertility care and to understand how men feel and navigate online information-seeking when they experience fertility difficulties. Therefore, the first research question was:

1. What are men's requirements for support when they experience fertility difficulties? (RQ 1)

To answer RQ 1 a qualitative analysis of online forum comments in which men who experience fertility difficulties share and discuss with one another on anonymous online

platforms was undertaken. How men communicate in online spaces was explored, including their motivations behind sharing with others and how online forums are utilised to support one another, to identify men's requirements for support (RQ 1).

In order to support men who experience fertility difficulties, it is crucial to understand their needs that centre around information. Therefore, the second research question was:

2. What are men's informational needs when they experience fertility difficulties? (RQ 2)

The findings from the first study informed the second study, which detailed men's first-hand accounts of their fertility experiences. This study was an in-depth interview study with men who had recently or were currently facing fertility problems. Men's emotional needs are included as part of men's information needs during this time. These findings contributed to developing requirements for a digital tool to support men when they experience fertility difficulties. This led to the final research question.

3. How can the identified needs be fulfilled through the use of digital tools? (RQ 3)

To answer RQ 3 a third study was conducted, which explored and evaluated existing digital tools in accordance with the outlined requirements

1.2 Structure of Thesis

This thesis is structured as follows:

Chapter 2 provides an overview of relevant literature that has informed and directed this thesis. First, the definition of fertility is introduced along with fertility-associated conditions, fertility treatments and what is known about how men are currently supported. Then how learnings from the information-seeking, sense-making, and meaning-making literature have informed the data analysis and how a review of these works motivated the research questions are detailed. Next, what is currently known about how men seek support online is explored, which is followed by a critique of existing work within the human-computer interaction domain focused on digital tools for fertility care.

Chapter 3 outlines the methodological approach used in this research and discusses the ethical considerations pertinent to this thesis.

Chapter 4 presents Study 1, a review of online forum comments which aimed to understand how men communicate in online forums dedicated to fertility and identify men's requirements for support when they experience fertility difficulties.

Chapters 5-9 describe Study 2, an in-depth interview study. The aims, methods and participant overview are presented in Chapter 5, whilst Chapter 6-9 present the specific analysis methods used and results of the interview study. I discuss men's fertility journeys, their information-seeking journey, their emotional journey and finally opportunities for digital tools to support these journeys.

Chapter 10 presents the methods and findings from Study 3, the evaluation of existing digital tools and an evaluation of whether these tools fulfil men's identified needs.

Chapter 11 discusses the implications of the findings from the three studies and how they relate to existing work, whilst providing reflections on conclusions. The limitations to findings are also detailed along with implications for further research in this area.

Finally, concluding with Chapter 12, which detailed how the work undertaken has answered the presented research questions. I describe how these findings have led to contributions to knowledge. Overall, this thesis presents an understanding of men's requirements when they experience fertility difficulties and opportunities for digital tools to support men's evolving information needs through their fertility journey.

Chapter 2 Related Work

2.1 Introduction

This thesis aims to understand the online information-seeking behaviours of men and how they make sense of and find meaning in their fertility difficulties. I then explore how digital tools can support this population; therefore, it is essential to understand the context of fertility, what is known about men's experiences, what they need and how men feel during this time. I present an overview of relevant literature on the basic science of fertility conditions, the demographics of infertility in the UK and the possible causes and treatments available for fertility difficulties, as these will be referred to in this thesis.

I then present a brief overview of what is understood about how to support couples when they experience fertility difficulties. This body of work indicates that men feel ignored regarding fertility-based research, which can lead to a paucity of support and care designed and explicitly delivered for men who experience fertility difficulties.

I explored existing literature regarding men's current health information-seeking behaviours to better understand men's existing practices when they experience fertility difficulties. This leads to an overview of information-seeking literature regarding health-related information.

Men have been a focus of HCI research to understand how they talk to one another through social media platforms, particularly to understand and navigate information concerning

fatherhood, which can facilitate the understanding of the opportunities to support men using digital tools ([Ammari et al., 2018](#)). However, there is a clear gap in the literature on understanding how digital tools may support men when they experience infertility. Therefore, I detail the work undertaken to understand how digital tools can be used to support men with their health and health-related information and what is explicitly known about online support for fertility care.

This chapter presents key findings from the literature and describes how their methods and conclusions have motivated my work on how to support men with their fertility.

2.2 Foundations of (in)fertility

I will now provide an overview of the basic science of fertility and fertility care. It is relevant to understand this as, throughout this thesis, the data discusses specific fertility-related conditions and treatments. First, I define infertility in [2.2.1](#), followed by the demographics of the fertility and fertility-related conditions in [2.2.2](#). Next, potential causes and diagnoses options for couples who experience fertility problems are discussed in [2.2.3](#), section [2.2.4](#) discusses the possible treatment options for fertility problems; these are referred to by my participants in Chapters 5 to 7. Finally, [2.2.5](#) describes how fertility care support is received and the impact fertility difficulties can have on men.

Through this thesis, I use various terms when describing the fertility conditions of my participants. I use the terms fertility, fertility difficulties and fertility concerns and issues interchangeably. I am conscious of the sensitivities around the description of fertility care. Some people do not like to be thought of as having or suffering from '*infertility*' when

they are having trouble conceiving ([Loftus, 2009](#)), therefore refrain from using this term to describe my participants.

Fertility is a multifaceted condition and experience. Infertility is a medical condition that can have psychological as well as medical consequences ([Loftus, 2009](#)). For some, having fertility problems is a strong negative social construct, especially when conception is strongly desired ([Greil et al., 2010](#)). Fertility can then be shaped by social context; therefore, it is vital to understand the psychological impacts of experiencing fertility as well as the medical ([Greil, 1997](#)).

This thesis is concerned with the practical and emotional aspects of experiencing fertility difficulties; therefore, I only provide a brief overview of the physiological characteristics and impact to situate my research but do not go into significant clinical detail, as that is not relevant to this thesis.

2.2.1 Definitions in Fertility Care

Fertility is defined as the ability to produce offspring through reproduction. The World Health Organisation defines infertility as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” from the International Classification of Diseases (ICD-11)¹. The Fertility Network describes infertility as the “failure to conceive after regular unprotected

¹ <https://www.who.int/news/item/04-02-2020-multiple-definitions-of-infertility#:~:text=This%20Glossary%20included%20the%20clinical,female%20infertility%20in%20the%20International> – updated February 2020. Last accessed July 2022.

intercourse.”² The absence of a time limit in their definition indicates the Network's supportive nature, providing support to anyone who experiences fertility difficulties.

The term subfertility, sometimes used interchangeably with infertility ([Vander Borgh and Wyns, 2018](#)), refers to couples who have successfully conceived or had children previously but then experience fertility problems for subsequent pregnancies, sometimes referred to as secondary infertility. Subfertility is reportedly more commonly seen in regions with higher rates of unsafe abortion and poor maternal health care ([Vander Borgh and Wyns, 2018](#)).

Whilst several potential contributing physiological factors can affect fertility, they commonly occur in the male and or female reproductive systems ([WHO, 2020](#)). Female-related fertility concerns refer to health diagnoses related to the female reproductive anatomy or physiology that affects a couple's ability to conceive. Male-related fertility relates to men's physiological conditions that affect fertility ([WHO, 2020](#)).

As stated, this thesis focuses on men specifically, due to the differences in their biological roles and, ultimately, their fertility journey experience is different from that of a female and their experiences are less well documented. However, the female fertility journey must also be acknowledged, as couples usually encounter this experience together; therefore, men are directly impacted by their female partner's experiences. Consequently, the female fertility experience is included in this chapter.

² <https://fertilitynetworkuk.org/trying-to-conceive/treatment-overview/fertility-glossary/fertility-glossary-i-n/> - accessed June 2022.

2.2.2 Demographics of Fertility

Fertility difficulties affect approximately 15% of couples globally; the rates are reportedly similar in the UK, where 1 in 7 heterosexual couples experience fertility problems ([NICE and Excellence, 2014](#)) and 1 in 4 in the developing world ([Vander Borgh and Wyns, 2018](#)). Fertility diagnoses are usually characterised into the following categories: female-related, male-related, a combination of both or unexplained infertility, which is often described as unknown. Unexplained infertility is where no clinical or medical cause can be ascertained to explain the lack of healthy conception carried to term, occurring in approximately 15% of couples who experience fertility problems ([Brugo-Olmedo et al., 2001](#)).

Female-related fertility in the UK can be broken down into ovulatory disorders, which are responsible for approximately 25% of infertility cases, 20% are tubal damage, and 10% are uterine disorders. In addition, 30% of infertility cases are solely due to male-related factors. Still, male factors are involved in almost half of all cases, which will be discussed further below, suggesting that nearly 10 million couples worldwide are affected by male-related infertility.

2.2.3 Causes and Diagnoses of Fertility

Many factors can affect fertility; these include but are not limited to the prospective mother's age, disease or ill-health in the couple, consanguinity, semen quality, and use of drugs and medications that can affect fertility ([Vander Borgh and Wyns, 2018](#)).

Several factors can affect female-related infertility; some are modifiable, such as health, weight, hormone levels, and lifestyle ([Brugo-Olmedo et al., 2001](#)). Other influences can be modified through medical procedures, such as ovulation disorders and problems associated with fallopian tubes, the uterus or the cervix ([Patient.Info. and EMIS, 2021](#)). However, unmodifiable factors such as increasing maternal age are also strongly related to fertility difficulties. Several investigations can be undertaken to explore the cause of female-related infertility. These include blood tests that can identify hormone levels to assess ovarian function and invasive procedures to explore tubal health and ovarian reserve.

As mentioned, male-related infertility is responsible for approximately a third of known infertility cases and contributes to almost half of all infertility cases. The most common factor affecting male-related fertility is concerned with sperm quality ([NICE, 2013](#)). There are several disorders of the sperm of varying severity. Aspermia refers to the absence of semen. Azoospermia means there are no sperm present in semen, whereas if levels are low, it is defined as oligospermia. Sperm in semen can have abnormal morphology i.e., shape, which can also affect conception. These characteristics can be due to unknown factors or pre-existing conditions, such as Klinefelter's syndrome, which is a genetic condition affecting the production of sperm (spermatogenesis). Spermatogenesis can also be affected by the presence of varicocele, which is the dilation of testicular veins, that can affect testicular function ([Brugo-Olmedo et al., 2001](#), [Vander Borgh and Wyns, 2018](#)). General health and well-being factors can also affect sperm quality. The impact of smoking on sperm quality has been particularly well documented ([Santos et al., 2011](#)), as

have the effects of obesity ([Hinz et al., 2010](#)). Many potential factors can affect ejaculatory function ([Brugo-Olmedo et al., 2001](#)), where the treatment options range from medication to psychological interventions. Another concern for the population is the reports of decreasing sperm counts in the general population ([Carlsen et al., 1992](#)), which could affect conception rates.

Physical examinations of the testes and laboratory investigations of semen quality can be undertaken to help identify fertility concerns ([Patient.Info. and EMIS, 2021](#)). Semen analyses explore the quantity, motility, and morphology of sperm, and blood tests can determine optimal hormone levels ([NICE, 2013](#)).

2.2.4 Treatments for Infertility

Several treatments and procedures are available to assist couples with their fertility depending on the cause of the fertility concern ([NICE, 2013](#)). Clinical guidance regarding fertility treatment in the UK is led by the National Institute for Health and Care Excellence (NICE), where the following descriptions have been obtained.

Regarding female-related fertility issues, some medications can stimulate ovulation, or procedures can remove blockages or adhesions within the female reproductive tract. In addition, examinations can identify egg reserve and reproductive tract health to predict fertility health.

Depending on the specific diagnosis of a male-related fertility condition, treatments are available to alleviate the condition, or fertility treatments may progress to assisted reproductive health techniques, such as i.e., in-vitro fertilisation procedures. If the

affected condition results in low numbers of healthy sperm in the semen, assisted conception treatments may be warranted ([NICE, 2013](#)). These include, but are not limited to, intrauterine insemination (IUI), in vitro fertilisation (IVF) with embryo transfer and intracytoplasmic sperm injection (ICSI).

IUI is the process where healthy sperm is extracted from semen and introduced into the uterine cavity at the optimal time during the menstrual cycle. IVF is the procedure where eggs are extracted and fertilised outside the female body and introduced back into the womb. In this case, multiple sperm are mixed with the extracted egg, and sperm will be given the opportunity to fertilise the egg spontaneously. ICSI is a variation of IVF where a single sperm is injected directly into the egg and then transferred into the womb once fertilised. In the cases where the egg and sperm from the couple are not sufficiently healthy to achieve conception with assisted methods, donor sperm and eggs can be used ([NICE, 2013](#)).

2.2.5 Impacts of and Support for Infertility

Significant research has explored the emotional consequences of infertility, which has overwhelmingly focused on women over men ([Hinton and Miller, 2013](#)), resulting in an increasingly widening gap in the literature on support for men who experience similar things. The normative assumptions that family planning, pregnancy and child-rearing are seen as women's responsibilities have been repeatedly discussed ([Culley et al., 2013](#)). There is also an assumption that men do not want to discuss their infertility-related feelings and experiences ([Arya and Dibb, 2016](#)). However, research has shown that men

share similar desires with women in these matters ([Culley et al., 2013](#), [Fisher and Hammarberg, 2012](#)). Participants' motivations for participating in such research can vary, which can impact their engagement and potentially the responses that are given. The underrepresentation of men in this field of research can lead to bias in findings and inaccurate assumptions based on proxy data ([Yaremych and Persky, 2022](#)). There have also been assumptions made about men's interest in research due to logistical, practical and knowledge barriers regarding parenthood ([Davison et al., 2017](#), [Davison et al., 2016](#)). Whilst social and cultural norms have changed over time with women's increased participation in the workplace and changing division of home and parenting duties within couples, the assumptions still exist in research that men may not be interested nor have the time or knowledge to participate in research concerning these topics ([Davison et al., 2016](#)).

Men's knowledge of their fertility has also been explored, and it was found that they could only identify approximately half of the known risk factors ([Daumler et al., 2016](#)). Yet, most men reported that they wanted to obtain fertility-related information, citing online sources and medical professionals as their preferred sources of information ([Daumler et al., 2016](#)). Others have also reported this ([Sylvest et al., 2016](#), [Hviid Malling et al., 2020](#)), exposing the need to inform and support men just as much as women in fertility care.

Since men's experiences or feelings towards their fertility journey are reported not to be openly communicated, there is a potential that these feelings and conversations are perceived internally as sensitive and stigmatising ([Dooley et al., 2011](#)). This can be seen

particularly when dealing with fertility concerns and male-related infertility ([Gannon et al., 2004](#), [Dooley et al., 2014](#)). It has been discussed that men are more likely to feel hesitation to seek help for themselves when required due to emotional vulnerability ([De Choudhury et al., 2017](#)); and whilst this was discussed in the context of mental health, we can see the parallels in my target population as a topic of infertility can also give rise to feelings of vulnerability ([Hanna and Gough, 2016b](#), [Dooley et al., 2014](#)).

It is reported that fatherhood is seen as a proof of masculinity; therefore, anything that threatens that can bring about shame and vulnerability ([Fisher et al., 2010](#)). It is also stated that many men feel stigmatised by their fertility problems and the inability to exhibit their virility ([Gannon et al., 2004](#), [Hanna and Gough, 2016a](#)). Infertility can be conflated with impotence ([Gannon et al., 2004](#)), which further increases the perceptions of stigma, shame and vulnerabilities. Stigma can be defined as “being a mark on someone of questionable moral status” ([Goffman, 2009](#)). Its definition has developed to include personal characteristics such as sexual orientation, health status, income, or nationality. Male-factor infertility can cause internalised stigma ([Gannon et al., 2004](#)), especially as trying to conceive is not often openly disclosed. It is commonly connected to negative responses such as the fear of judgement or prejudice ([Goffman, 2009](#)).

Sharing or reaching out for support can be difficult when a condition is stigmatised. The perceived stigma and sensitivities surrounding infertility can limit the avenues of support men seek ([Wischmann and Thorn, 2013](#)). This is also influenced by the cultural and societal pressures men feel to reproduce and become fathers ([Arya and Dibb, 2016](#),

[Jordan, 1990](#)), which can exacerbate the sense of shame and humiliation some men express feeling. It can be difficult to break these societal and cultural norms constraining the discussions to remain hidden and creating marginalised populations.

At the same time, men have directly reported feeling unacknowledged by healthcare professionals and family members. Even regarding male-related infertility, men report that the focus of care and attention is on their female partners ([Hinton and Miller, 2013](#)). They would like to share and be involved in the process as an equal partner and not feel irrelevant ([Hinton and Miller, 2013](#)). Men report feeling a lack of opportunity to participate in their fertility journey. These feelings are reported to directly impact their perceptions of their deep-rooted and traditional ideals of masculinity, the need to feel strong, not be weak, and provide for others.

Existing research in this domain indicates that men are currently excluded and disregarded but would like the opportunity and ability to participate and share their experiences and feelings regarding their fertility difficulty. Unfortunately, this disregard could contribute to the paucity of research that focuses explicitly on men when they experience fertility difficulties. Therefore, this research aims to understand men's experiences and especially their informational needs to understand how to support them during this time.

In order to do that, I now provide a review of the existing literature on information-seeking and how this relates to men when they experience fertility difficulties.

2.3 Information-Seeking

How men look for and use information through their fertility journey is key to how they manage the process, both practically and emotionally. To understand the implications of how information is found, used, or desired during this process, it is first essential to understand what is already known regarding information-seeking and how people may make sense of information sought through sense-making and meaning-making processes.

Firstly, I will briefly outline the literature on the information-seeking journey ([2.3.1](#)), then how sense-making ([2.3.2](#)) is interleaved in this process and how this process can progress to meaning-making ([2.3.3](#)). I will then detail the theory of ‘finding a new normal’ ([2.3.4](#)), which I found to be significant for people who experience fertility concerns. Finally, I outline men’s health information-seeking behaviours ([2.3.5](#)) and what sources of information are preferred by this population.

2.3.1 Information-Seeking Journey

Information-seeking has been defined as practices individuals undertake to seek, search and retrieve information ([Paul and Reddy, 2010](#)). Information behaviour research has been dominated by the inquiry into information needs, information-seeking and information retrieval over the actual use of information ([Mishra et al., 2015](#)). Numerous information science scholars have presented models to understand information-seeking behaviours, for example; ([Allam et al., 2019](#), [Blandford and Attfield., 2010](#), [Pirolli and Card, 2005](#)). These models have focused on a user’s motivations and practises and then how information is used. Understanding information-seeking behaviours have evolved

from only considering the user, user needs and environment to exploring the psychology and decision-making involved around information needs and contexts ([Allam et al., 2019](#)). This leads to sense-making which is discussed in [2.3.2](#): how information is understood, how it can be used and the information behaviours following from these cognitive activities.

In this thesis, I focus on the information journey model as described by ([Blandford and Attfield., 2010](#)) due to its suitability as a lens to understand men's fertility journey and their information-seeking behaviours.

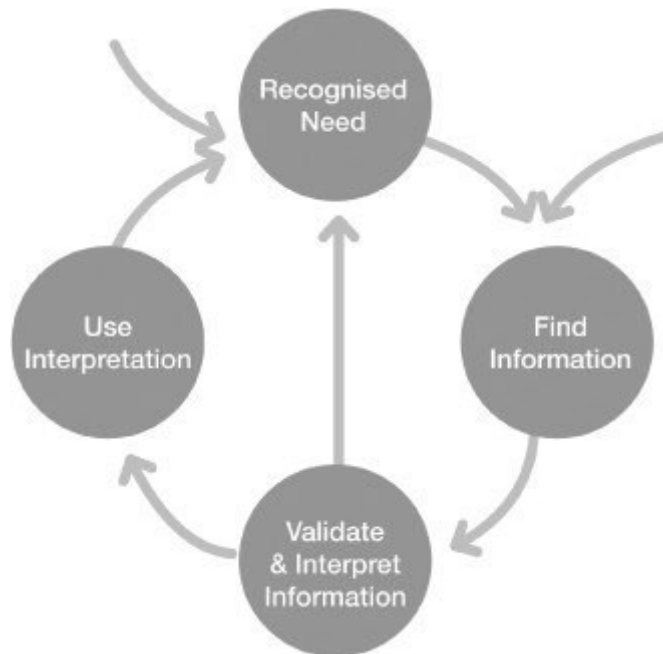


Figure 1 Information Journey Model. ([Blandford and Attfield., 2010](#))

Seeking information is not a single discrete step but encompasses a series of cognitive activities, as illustrated in Figure 1. The initial step is to recognise the need for information. In this stage, people often understand the need to interact with information

related to the specific problem area. This understanding leads to the next stage, which is finding information. The act of finding information can continue throughout the journey and is not usually isolated ([Pirolli and Card, 2005](#)). Information can be personally sought through trial and error or provided by more knowledgeable or experienced others ([Savolainen, 2018](#)). These sources of information can be in-person or through online electronic resources; the choice of source can depend on a multitude of factors such as time, availability, or personal preference.

Once the information has been gathered, there is a need to validate and interpret what has been found. Validating information refers to assessing its reliability and suitability ([Blandford and Attfield., 2010](#)). In this stage, we see the dynamics of the theory of sense-making at play, which can lead to the theory of meaning-making, which enables the user to interpret and form personal understanding and meaning from the acquired information ([Ruthven, 2019](#)). This can also be reflected in using interpreted information where knowledge is interpreted into action. Through the process of interpretation, the user may identify the need for further information and clarifications ([Pirolli and Card, 2005](#), [Blandford and Attfield., 2010](#)). As shown in Figure 1, the process can be cyclical depending on the user's needs.

Inquiry into information-seeking is often undertaken by groups of people experiencing similar health conditions ([Mishra et al., 2015](#)). There may be norms present in these communities on how and where to get information, which can be relevant to other population groups, as there are likely to be preferred and trusted sources of information

for different communities ([Loudon et al., 2016](#)). Sharing and acquiring information from trusted sources is important to reduce the barriers to validation. Information can be found serendipitously or intentionally ([Loudon et al., 2016](#)).

2.3.2 Sense-making

The sense-making literature is often motivated by the desire to understand why information is sought ([Ruthven, 2019](#)). Reasons include the need to solve problems, navigate unfamiliar experiences or obtain new knowledge. Sense-making has been described to occur when there is a gap of knowledge, where there is a clear and defined unknown ([Dervin.B, 1998](#)). Dervin goes on to state that the process of sense-making is more likely to work for individuals if they connect it to personal stories or histories, which can also be referred to as giving the information meaning. Others reflect that sense-making is the process of finding meaning from information and explain how those engaged in sense-making are likely to find structures and links to existing knowledge or previous experiences that enable them to make sense of newly acquired information ([Faisal et al., 2013](#)). Finally, sense-making is also described as the information work undertaken to understand knowledge, a concept or a problem ([Zhang and Soergel, 2014](#)), which is presented as a simple two-step process. The first is the process of *sensing*, which describes acquiring information and sorting what is found, followed by *making-sense*, which is the process of iteratively understanding the knowledge gained, in some cases combining with existing knowledge and experiences. Overall sense-making is recognised as a complex activity.

Barriers to sense-making are outlined through four key challenges: (1) the quantity and unfamiliarity of the information can overwhelm users, (2) the misinterpretation of poor quality information, (3) the reliability or trustworthiness of information can cause uncertainty and (4) if multiple sources do not align in an individual's information seeking, this can lead to poor sense-making ([Jones and Kelly, 2016](#)). Therefore, it is important to consider these four challenges when understanding the information journey of men who experience fertility difficulties.

As stated, understanding what information means can be seen as just one step in the information journey; the next and critical step is understanding what the information means for the user and how they can apply the newly acquired knowledge to their lives, which requires meaning-making.

2.3.3 Meaning-making

Meaning-making is interpreting information obtained into the user's context, usually validating or implementing the information received ([Burgess et al., 2019](#)). Meaning-making can be defined as the action of giving meaning or purpose to oneself, or it can be used to understand oneself and interpret information, events or changes ([Ruthven, 2019](#)). Ruthven goes on to describe the difference between sense-making and meaning-making as being the reason behind understanding. Sense-making is when the user "seeks comprehensibility", and meaning-making is to "understand significance" ([Castelli Dransart, 2013](#)). The meaning-making process can occur as a reaction to an event, or it can be a gradual change as awareness increases. When undergoing meaning-making,

people tend to seek others more knowledgeable for support, such as healthcare professionals or someone who has undergone similar experiences to share their learnings ([Burgess et al., 2019](#)).

Much literature has focused on sense-making and meaning-making when a perceived negative life event occurs, such as bereavement or unexpected health diagnosis ([Massimi et al., 2014](#)); however some have focused on positive sense-making and meaning-making, for example understanding the role of meaning-making when looking for ones ancestors and trying to build and understand their own stories ([Alexander et al., 2017](#)).

Park proposes where there is a schema in life; this brings expectations and assumptions of a natural pathway or journey to follow ([Park, 2010](#)). Where there are deviations from this plan, this can give rise to distress and the process of information seeking and sense-making lead to the need for meaning-making to bring order back to the assumed plan. This is directly related to men's experiences of fertility difficulty. In many cases, fertility is assumed, and it is when the intended fertility journey does not follow the assumed pathway, a process of sense-making leading to meaning-making is required.

2.3.4 'Finding a New Normal'

I have presented how the need for information can lead to sense-making and meaning-making. One aspect of meaning-making is the need to understand how the new information can be validated and implemented into one's life. This implementation can lead to a new normal, which is understanding a new reality. In the context of fertility, it can be hypothesised that progressing through the assisted fertility pathway, or even having

to accept that fertility difficulties are a part of your life, can lead to the need to accept a new unexpected normal in one's life.

This concept has been studied in several different research domains and health conditions in parallel, making its origins unclear - for example, in cancer ([Rubin et al., 2013](#), [Henry et al., 2014](#)), chronic conditions ([Burgess et al., 2019](#)), bereavement ([Massimi et al., 2012](#)) and mental health conditions ([Genuis and Bronstein, 2017](#)).

Massimi and colleagues depict the need for a new normal to be a consequence of a breakdown of routine, which they explore through the use of three case studies of bereavement, domestic violence, and homelessness ([Massimi et al., 2012](#)). Each of these different experiences produces a substantial life disruption; Massimi illustrates how people may use technology to navigate and facilitate the creation of a new normal in each of these scenarios. They also present how technology can be utilised to connect like-minded people, which can help individuals navigate their life disruption and support the creation of a new normal. I find that this is reflected in my findings in [Chapter 4](#).

It has also been argued that the information-seeking patients with chronic conditions undertake contributes to finding a sense of new normal ([Burgess et al., 2019](#)). The authors present the concept of meaning-making as a crucial part of the patient journey to enable patients to prospectively plan what they want their future normal to be and act accordingly in the present. The occurrence of an unexpected life disruption leads people to undertake the act of meaning-making to infer what the disruption means to them personally and help

them to form their new normal. In the context of this thesis, the life disruption discussed is experiencing fertility problems.

The experience of coming to terms with an unexpected diagnosis is described by ([Genuis and Bronstein, 2017](#)), who note that normality is most commonly used to describe a situation in which there is an absence of disease or ill-health. Therefore, making sense of a health condition that disrupts routine is important, especially if it has come on suddenly or unexpectedly. This can lead to the requirement to make sense of a new normal post-diagnosis. These feelings are clearly mirrored in the fertility population, as it is often described as an unexpected life disruption.

The literature describes a process in which people often look to similar others for advice and comparison to explore what is acceptable in their new circumstances when trying to understand their new normal following a life disruption ([O’Kane et al., 2016](#)). This supports Genuis and Bronstein’s postulation that it is important to find information and validate the knowledge with similar others, which can be seen to be an essential step in the information journey ([Genuis and Bronstein, 2017](#)).

However, it is unknown how the fertility journey, which can be dynamic as well as lonely and isolating ([Hinton et al., 2010](#)), can be mapped on the information journey.

2.3.5 Men’s Health Information-Seeking Behaviours

The literature on men’s health information-seeking behaviours and how men may engage with and perceive barriers to accessing healthcare and health-related information indicates

that men may prefer using online information and digital support methods ([Dickerson et al., 2011](#), [Best et al., 2016](#)).

A wealth of literature focuses on men seeking information for particular conditions, such as cancer ([Oberoi et al., 2016](#), [Medina-Perucha et al., 2017](#)) or mental health ([Seidler et al., 2016](#), [Susukida et al., 2015](#)). There is also an emphasis in the literature exploring health-seeking behaviours comparing men to women ([Susukida et al., 2015](#), [Galdas et al., 2010](#), [Tenenbaum et al., 2017](#)), which generally found that women engaged with their healthcare and sought healthcare professionals' support more often than men.

I expand in the following sections on how this literature describes the barriers men face to accessing health-related information and men's preferred sources of health-related information.

Barriers to Health Information-Seeking

Numerous qualitative studies revealed the rationale men shared to explain why they do not spend time visiting healthcare professionals. Primarily, they did not want to look weak and affect their perception of masculinity ([Ellis et al., 2013](#), [Galdas et al., 2007](#)). In addition, seeking healthcare for themselves, especially support for male-related health conditions such as prostate examinations or exploring testicular cancers, made them fearful that their manhood may be lost ([Cheatham et al., 2008](#)). Loss of masculinity was also reported with regards to mental health conditions ([Levant et al., 2013](#), [Seidler et al., 2016](#), [Yousaf et al., 2015](#)).

Barriers to seeking health information are also related to the pressure of responsibility ([Love et al., 2014](#)). Men felt they needed to work and support their families. There was a fear that taking time away from work to seek healthcare professionals' care could lead to a loss of earnings or increased costs of tests and treatments ([Galdas et al., 2007](#)). Along with this came the fear and anxiety of the impacts of a negative diagnosis and its impact on their ability to provide for their families and dependents ([Hawkins et al., 2017](#), [Love et al., 2014](#)).

The literature highlighted several recommendations for health care professionals and health promotion methods when trying to engage men with their healthcare. These included being aware of the needs and constraints of their target group and the awareness of the impact that men's perceptions of social norms have on their masculinity.

Although one paper recommends against gendered-specific health-related messages ([Galdas et al., 2010](#)), the popular conclusions were that gender-specific language might be required to attract attention and engage men. In situations where both men and women could be the potential patients, but the language used was mainly focused on one gender, it was considered detrimental, ultimately arguing for gender-neutral language. This was seen primarily in eating disorders ([Raisanen and Hunt, 2014](#)). We can see how this can be extended to the reproductive health field. Subjects such as fertility are often biased towards women even though men are part of the journey.

The manifestation of expected masculinity can potentially explain the repetitive accounts men express of their masculinity and gendered norms as a barrier to seeking health-related

information and support for themselves ([O'Brien et al., 2005](#)). Furthermore, this feeling of dominance and responsibility could rationalise their feelings of fear, anxiety, and endangerment to their masculinity, which could threaten their ability to access healthcare ([Noone and Stephens, 2008](#)). Others have also found this (e.g. [[Anstiss and Lyons, 2014](#)], ([O'Brien et al., 2005](#))).

However, ([Douglas et al., 2013](#)) state that relying on expected masculine behaviours as the sole barrier to accessing health-relating information is not likely to solve the problem. They report that as much as biological gender can impact whether healthcare information is sought, it will not wholly account for the reluctance men may feel to access care. For example, the rationale of men's responsibility to be well and not take time away from providing for others was a critical barrier to healthcare access.

The lack of awareness of the need to seek support as well as where support can be accessed was also reported as a barrier by men ([Cheatham et al., 2008](#)) and healthcare professionals ([Raisanen and Hunt, 2014](#), [Yousaf et al., 2015](#)). However, through sharing with one another, peers, colleagues, friends or significant others could often motivate men to seek healthcare ([Ross et al., 2007](#), [Saab et al., 2017](#)).

Seeking Healthcare Information Online

Men are often cited as a hard-to-reach population group regarding health promotion, and online methods of communication are recommended to alleviate this issue ([Lohan et al., 2015](#), [Sternberg and Hubley, 2004](#)). Accessing health information online is reportedly preferred due to its ease of access and privacy ([Tyler and Williams, 2014](#)). A mixed-

methods study indicated that whilst 40% of men reported they were likely to use websites as a source of health-related information, over 54% stated they had previously looked online for advice and support ([Ellis et al., 2013](#)). Users are most likely to look for information using search engines ([Best et al., 2016](#)) and use websites and forums where their anonymity is preserved for their health ([Dickerson et al., 2011](#)). The drawbacks of using online sources for information include the inability to assess the validity and reliability of content ([Best et al., 2016](#)). Existing literature indicates that men are likely to use the internet to seek health-related information and advice ([Dickerson et al., 2011](#)); however, there is a lack of high-quality online resources on fertility care aimed at men, with the focus being on women ([Robins et al., 2016](#)).

As men are less likely than women to present to health care facilities and therefore miss out on preventative healthcare ([Thompson et al., 2012](#), [Schlichthorst et al., 2016](#)), the recommendation to target men through online and digital methods is discussed. Online forms of information were favoured due to their privacy and ease of access. Using online sources as a method to seek health-related information provides an opportunity for men to seek support without having to present themselves to a healthcare professional, which limits the self-perceived threat to their masculinity ([Ellis et al., 2013](#)). There is a growing male preference for online healthcare support services ([Best et al., 2016](#)). The affordance of confidentiality provides the ability to discuss sensitive and sometimes stigmatising conditions, which enables this source to be popular amongst men.

A potential limitation to these findings is that much of the literature that has reported online and digital sources as preferred choices for health-related information have recruited their participants from online mediums such as social media and forum groups; therefore there is likely to be bias in these findings ([Ellis et al., 2012](#), [Tyler and Williams, 2014](#)).

Little research has discussed how best to engage men with their healthcare, with the majority focussing on barriers. The research focused on motivating, and engaging men found converse results to the literature that provided information on barriers. For example, the finding that the language used in health information must be gender-neutral when the conditions can affect men and women was found to be unlikely to encourage more men to engage with their health ([Douglas et al., 2013](#)). They posit that age and circumstance are more influential factors than perceived masculinity ([Robinson and Robertson, 2014](#)).

The barriers men face in accessing healthcare and seeking health-related information range from privacy, responsibility, gendered identities, and masculinity. Men are becoming increasingly likely and could be encouraged to use online sources of information for the ease of access and confidentiality it provides them. As reported, online sources of information can provide confidential and private information to the users and are preferred by men looking for information on personal and sensitive topics.

2.4 Digital Tools for Fertility Care

Now that I have outlined what is known about how men are likely to look for and make sense of health-related information, this section details the evidence on how online health

information is provided and used by men ([2.4.1](#)). This leads to a review of digital tools for fertility care and literature from the HCI domain ([2.4.2](#)), which details a gap in the current literature that this thesis aims to fill.

2.4.1 Online Forums as sources of Information and Support for Men

As mentioned, little research has been undertaken to understand how to design health information support for men online compared to women; however, it has been explored how interactive information and communication technologies can support health promotion for men ([Robinson and Robertson, 2010](#)). They report that online communities can be vital to encouraging men's health participation.

A small body of work has also focused on supporting men online during their fatherhood experiences ([Ammari and Schoenebeck, 2015](#), [Ammari and Schoenebeck, 2016](#), [Ammari et al., 2017](#), [Ammari et al., 2018](#)). In their work Ammari et al. outline opportunities for social media to support fathers through collating interview data and analysing their needs, experiences and motivations for using social media relating to fatherhood ([Ammari and Schoenebeck, 2015](#)). Through qualitative and quantitative methods, they found that men used online sources of information to find accounts from similar others and learn from their experiences and mistakes ([Ammari et al., 2017](#)). They were more likely to use anonymous user accounts on discussion platforms to discuss private and potentially stigmatising topics associated with parenting. These studies also found that men reported feeling fearful to share their intimate feelings online, leading to isolation ([Ammari and](#)

[Schoenebeck, 2015](#)). I build upon these findings to explore how men currently use and could potentially use digital tools to support their fertility journey.

Whilst others have explored men's feelings before becoming fathers ([Teague and Shatte, 2018](#)), they tend to focus on the point of transition by exploring forums dedicated to men who are fathers or who will become fathers in the near future and used machine learning techniques to investigate what men are discussing in these spaces. They report that men discuss the challenges associated with fatherhood and share milestones, practises, and preparation advice. Their work highlights the viability of using online data to explore men's experiences, especially as much of the data currently used to narrate men's feelings and experiences are provided by women on men's behalf. This thesis builds upon this feasibility and descriptive work by undertaking an in-depth content analysis of men's data online and providing recommendations on how we may support men's needs based on what they are experiencing and sharing online.

Previous research has explored online forums to investigate several topics, such as how people use forums to navigate experiences or manage specific health conditions, for example, HIV ([Bussone et al., 2017](#)) or cancer ([Ziebland et al., 2004](#)).

People use online forums to look for subjective information to inform and educate themselves and objective information, which could be short factual answers to specific questions ([Biyani et al., 2012](#)). In addition, online forums can be used to develop shared meanings through discussions, negotiations and debates in the online spaces ([Gui et al., 2017b](#)). In addition, forums have also been investigated to understand how like-minded

individuals share experiences or advice ([Toscos et al., 2010](#)). However, Toscos et al found that insights that were found from analysing online forums were not always reported in the literature when using other data collection methods, which reinforces the value of using this method to understand the needs of a specific population.

It has been reported that information regarding health-related experiences from online forums is valuable and can be used in conjunction with advice from their healthcare professionals to navigate their care ([MacLean et al., 2015](#)). This is explicitly seen in the case of chronic health conditions, where patients often become the expert and lead their care through their extensive knowledge and lived experiences ([Gui et al., 2017b](#)). Healthcare professionals are highly trusted; however, patients may prefer to use multiple sources of information when managing their health and healthcare, and online forums are often a valued information source ([Gui et al., 2017b](#)).

However, the disadvantages of using online forums to exchange social support in sensitive topics are that there is a lack of social cues for users to engage with, which can lead to misunderstandings and misinformation ([Massimi et al., 2014](#)). With face-to-face interactions a person intention and tone are more easily deciphered, with the inability to ascertain someone's intention or uncertainty whether their comments are well meant, responses and interactions can be slow ([Wright, 2002](#)).

Users are likely to use online forums to exchange information due to their privacy features such as anonymity, especially regarding reproductive health conditions, which can be considered private and sensitive. The privacy features in online forums can reduce the

stigma and embarrassment experienced by users. Online forums become a space where people who have had similar experiences can share with one another. The availability of and ability to quickly gain insights and share knowledge in these online spaces make online forums a preferable data source for users ([Massimi et al., 2014](#)).

It has been reported that men are more likely to open up and share their feelings and experiences in online spaces ([Larkin, 2001](#)). They have a sense of freedom to overcome the embarrassment and share with unknown peers online, whilst seeking help and support in person can affect some men's sense of masculinity ([Gough, 2016](#)). Some men may feel judgment from others when seeking help; however, the sense of community within the forums can also help men when looking for emotional support and factual and clinical information ([Welbourne et al., 2009](#)). Men are also more likely to turn to online sources of information, as traditional healthcare can favour women and prospective mums, specifically in the context of reproductive healthcare and fertility ([Salzmann-Erikson and Eriksson, 2013](#)). Moreover, men are more likely to use forums over getting support from their partners, as some men feel they have to be the source of support for their partners, which can lead to feelings of isolation and prevent them from getting help themselves ([Richard et al., 2017](#)).

2.4.2 Digital Tools for Fertility Tracking

Research focusing on fertility has recently emerged in the HCI field; however, this is mainly focused on women and how they use their personal informatics data to navigate their fertility journey ([Costa Figueiredo et al., 2018](#), [Costa Figueiredo et al., 2017](#)). Costa-

Figueiredo explored how data is used in the context of fertility and found women undertake intensive emotional work when tracking their data during fertility care. There is value in sharing this data with healthcare professionals to support making sense of the data within their provision of fertility care. This can also lead to personalised solutions within their generic fertility healthcare. They also report that technology solutions to support people's goals and needs during fertility care are inadequate ([Costa Figueiredo, 2020](#)). These findings are based on data from women and healthcare professionals. There is a need to explore whether this is the case for men who experience fertility difficulties.

Therefore, I build upon this work by Costa-Figueiredo and colleagues in that I explore men's experiences and feeling when they experience fertility difficulties to provide a voice for men during fertility care and explore whether current digital tools support men's information-seeking goals.

2.5 Summary

This chapter describes the existing literature that has informed and motivated the work presented in this thesis. Understanding the foundations of fertility makes it clear that this is a prevalent health concern affecting men and women alike. Yet, the provision of online and in-person support is disproportionately focused on women. This impact is that men feel isolated and find it difficult to look for openly and access resources for support due to the surrounding sensitivities.

It has been indicated that men prefer to access information online due to its ubiquitous nature and affordances of privacy and anonymity. Therefore, this thesis investigates men's online information needs when they experience fertility difficulties.

Existing work has shown that men look for information online to find accounts they can relate to. These works have indicated that analysing online data to investigate how men share with one another is a feasible research method for this population. Therefore, these methods had directly influenced my chosen methodologies.

Finally, recognising that existing work in the HCI field that has focused on the needs of people in fertility care has only explored women's needs, it is evident and essential, to explore and understand what men's needs are and how digital tools can support them when they experience fertility difficulties.

Chapter 3 Methodology

In previous chapters, I have introduced my research topic and identified how my research questions are motivated from existing literature. This Chapter describes the methodological approach undertaken to address these research questions and the ethical considerations that were undertaken. Details on the data collection and analysis methods are detailed in their respective study chapters.

3.1 Interdisciplinary Approach

The topic and context of this research are related to digital health and human-computer interaction as well as to health and social sciences, therefore, this research was undertaken in an interdisciplinary manner. As a result, these disciplines have several differences in approach and research practices ([Blandford et al., 2018](#)). Therefore, I focused on combining my knowledge, skills, and expertise from both disciplines to improve rigour and strengthen my contributions to both domains.

I followed a human-centred approach whereby my research questions focused on the end-user's needs and their experiences primarily. My work explores formative evaluation, in contrast to the health domain, which tends to focus on summative evaluation and healthcare professionals as the expert user or content providers. Therefore, my research questions focus on 'men's requirements' and not on how fertility care can be better provided.

3.2 Methodological Approach

Most research methods can be divided into quantitative or qualitative data approaches. I followed a qualitative methodology as my research questions required data that could probe my population's needs and lived experiences. I did not aim to quantify men's fertility concerns but to understand their first-hand accounts of how their needs could be fulfilled through the use of digital tools, as to answer the outlined research questions a rich understanding of men's experiences was required.

My work used both inductive and deductive thematic analysis methods. In the initial inductive phase I explored insights from the data using a bottom-up approach instead of analysing the data with pre-defined notions that would follow a top-down deductive approach. I focused on the phenomena in the data to understand what was relevant and important for my participants and how they found meaning in their experiences. I following thematic analysis processes to understand patterns in the data and generate new in-depth insights ([Braun and Clarke, 2013](#)). This enabled me to identify and report themes to investigate new perspectives without any preconceived notions. Once themes were identified, I then used a deductive, more commonly described as top-down, to confirm and verify the identified themes that arose from the thematic coding.

3.3 Online Data

For my first study, I explored online forums to investigate how men seek information and support, as people are more likely to openly share their true feelings in online spaces where they do not need to reveal their identities ([Berger et al., 2005](#)). Online data is also

a less intrusive method of gathering insights on users' experiences ([De Choudhury et al., 2017](#)). There is an assumed absence of researcher bias with online forum data, as they are not monitored, controlled or subject to specific agendas by any organisation or body. Comments are presumed to be left to be read by members unknown to the users. Analysing online forum data is beneficial as it limits the effect of experimenter bias, whereby the presence of a researcher can influence the responses provided by study participants ([Steuber and Haunani Solomon, 2008](#)). Similar justifications have been reported in works that have explored online data to uncover perceived sensitive topics such as men's depression ([Gough, 2016](#)).

3.3.1 Ethical Considerations of using Online Data

I was granted ethical approval to carry out this study (UCLIC/1718/007/MSc Blandford/Patel). The use of online data for research is a topic of interest and debate within the HCI research community ([Proferes et al., 2021](#)). Therefore, I considered the ethics of carefully undertaking a study using public data before commencing. My main priority was to not cause distress or harm to any community or individual through my work. Content within the forums can be defined as sensitive; in many cases, the users discuss their healthcare and personal and intimate feelings. Some users shared moments of emotional vulnerability, and I, as a researcher, had a responsibility not to exploit or take advantage of this. Therefore, ensuring users' confidentiality and anonymity was paramount.

I explored what processes and practises similar studies had followed. I found that studies either reported not requiring formal ethical approval ([Ayobi et al., 2018](#)) or did not discuss the concept of ethics or gaining ethical approval to carry out a study using publicly available data ([Mamykina et al., 2015a](#), [Jahani et al., 2018](#)). However, just because the data is available online does not mean there is an open and unrestricted right to use it ([Zimmer, 2010](#)). For example, the user or creator of that content may not have posted their comments online, expecting them to be analysed and used by researchers ([Townsend and Wallace, 2016](#)). In fact, in some cases, on popular forums such as Reddit, users will include in their posts that they do not wish for their comments to be used in any research or media outlets. I ensured the forums chosen for analysis did not have any explicit rules against research and were open to public access, i.e., did not require registration and joining or contributing to the community to view the content. Most forums have rules and guidelines that clarify how the forum content may or may not be used.

I considered the users' vulnerabilities and how the use of their data could negatively impact them or potentially cause harm. This included a number of steps I took to ensure their identities remained anonymous. For example, I removed references to locations and names once I extracted the data. I then assigned a unique six-digit code to each thread, not the users; these unique codes are used to identify thread posts in the results below. These steps further ensured the anonymity of the users as I did not analyse the data at the user level; the conversations were the focus of this study, not investigating the patterns of each user.

As I could not speak to each user to probe and ask them about their objectives, implications or outcomes based on their posts, I was careful not to over-interpret users' intentions regarding their posts within the forums.

I was also cautious not to report any broad community findings that could be misinterpreted or cause harm or upset to any members of this community. As mentioned, I was unable to ratify my findings through probing the users; therefore, I report what can be seen within the forum comments and do not extrapolate what users who do not use online forums may feel, or how forum comments relate to users' actions outside the online forum.

As it was not possible to contact each user for their explicit consent, I followed the following steps to ensure that the users' content was respected. First, I drew on the British Psychological Society Code of Ethics ([Society, 2013](#)) and the ACM Code of Ethics and Professional Conduct ([Gotterbarn et al., 2018](#)). The British Psychological Society Code of Ethics outline four main principles when undertaking internet-mediated research. These are (1) Respect for the autonomy, privacy and dignity of individuals and communities; (2) Scientific integrity; (3) Social responsibility; and (4) Maximising benefits and minimising harm. The ACM Code of Ethics covers similar principles such as avoiding harm, being honest and trustworthy and respecting privacy.

I adhered to the specific principles on privacy, dignity, social responsibility and avoiding harm by not naming any of the forums used to prevent identifying the posts analysed, as well as where quotations are used in any report, publication, or dissemination, they are

paraphrased and are not verbatim to prevent deanonymisation. Finally, extracted data were stored on encrypted devices only and not shared outside the research team. Data analysis was also discussed with my supervisory team to ensure scientific integrity.

3.4 Interview Data

Interviews were chosen as a suitable data collection method to explore participants' lived experiences and collate user perspectives, experiences and needs. An in-depth one-to-one interview facilitated the creation of a safe and trusted space where the participant could openly and confidently share their views and experiences ([Ritchie et al., 2013](#)). This setting also helped build rapport and trust between the researcher and participant, which is beneficial when discussing and sharing intimate feelings and experiences about a sensitive and personal topic such as infertility. Furthermore, this method enables researchers to understand how participants construct their lives and probe responses. Similar studies (e.g. ([Arya and Dibb, 2016](#)) & ([Hinton and Miller, 2013](#))) have successfully used similar methods when exploring this topic with men.

Whilst other methods, such as surveys, can highlight users' perspectives and needs, speaking to participants directly enables the collection of reliable data from users in their own words and gives them the ability to narrate their own experiences and requirements. Furthermore, interviewing participants generates first-hand account insights into their lives and lived experiences ([Ritchie et al., 2013](#)). Therefore, to answer the proposed research questions, interviews were deemed the most appropriate research method.

3.4.1 Ethical Considerations for Interview Studies

I sought to ensure carrying out in-depth interviews through my qualitative approach with men who had or were currently experiencing fertility difficulties was an appropriate data collection method to answer the research questions. I also aimed to ensure that no potential participant would be faced with any undue pressures or any unnecessary questions or probing not required or appropriate for the topic of research.

The recruitment methods (Appendix A-C) and topic guide (Appendix D) were reviewed and approved by the ethics committee, UCL Ethics Project ID: 13595/002. As fertility can be an emotional subject to discuss procedures were in place to ensure the safety of the researcher and the research participants. These included ensuring resources for support, such as names and contact details of charitable and support organisations were available for participants if required or requested. Listening to people's stories of anguish, difficulty, and many times, loss was emotional for me too. After interviews, I would take time to decompress and reflect. Resources for support were also available for me if required.

As stated, participants were made aware before consenting that they could change their minds and withdraw from the study anytime. They were also made aware that they could decline to answer any question or not share any detail that they did not feel comfortable with without giving any reason or justification. No participants chose to withdraw or refrain from answering any questions.

All interview audio recordings were held securely as per General Data Protection Regulation and Data Protection Act requirements. All participants were verbally asked if they consented to the interview being recorded before the interview began; no participant declined to have their interview recorded. All transcripts were anonymised to ensure the confidentiality of the participant.

3.5 Evaluation of Digital Tools

I evaluated digital apps to understand whether existing tools fulfilled men identified informational needs. The method of undertaking an app review was appropriate due to the ubiquitous nature of smartphones and that mobile apps are a common tool to be used when looking for information and ongoing support. This final study was designed based on the findings from the previous two studies. Men clearly articulated a preference for mobile apps over other digital information sources; therefore, this was deemed a necessary and appropriate final study to understand whether existing tools fulfilled men's needs or whether there were opportunities for further digital design.

3.6 Summary

This chapter outlines the methodological considerations that were taken in this thesis. I describe the methods used to answer my research questions and outline ethical considerations that were reflected upon when collecting and interpreting the data.

Chapter 4 Study 1: Review of Online Forum

Comments

Parts of the following Chapter have been published in the following papers.

- Patel, D., Blandford, A., Warner, M., Shawe, J., & Stephenson, J. (2019, October). “I feel like only half a man” Online Forums as a Resource for Finding a “New Normal” for Men Experiencing Fertility Issues. Proceedings of the ACM on Human-Computer Interaction 3. (CSCW)³
- Patel, D., Blandford, A., Stephenson, J., & Shawe, J. (2019, October). Understanding The Use Of Social Technologies During A Life Transition: Men’s Experience with Fertility Problems. Association for Computing Machinery (ACM). The 22nd ACM Conference on Computer Supported Cooperative Work and Social Computing. Workshop: Life Transitions and Social Technologies: Research and Design for Times of Life Change⁴
- Patel, D. (2021, October). Online Health Communities as a resource for collective sense-making for men who experience fertility difficulty. The 24th ACM Conference on Computer Supported Cooperative Work and Social Computing. Workshop: The Future of Research on Online Health Communities: Discussing Membership, Structure, and Support⁵

Contributions from this Chapter:

- This Chapter presents a novel instantiation of the ‘finding a new normal’ model relevant to the fertility population, depicting how men use sense-making and meaning-making processes to navigate their fertility journey.
- I also contribute an understanding of how men use online forums to understand their fertility journeys through sharing with one another.

³ This CSCW journal paper presents the main findings of this study. I was the first author and my findings were discussed and refined with my co-authors.

⁴ This workshop position paper reports on selected findings from this study which relate to how men discuss fertility as a life transition in online forums. I was the first-author on this paper and carried out the analysis for this paper. My findings were discussed with the co-authors and they provided comments on the final submission.

⁵ This workshop position paper describes how men undertake collective sense-making in online forums and how they used forums to help find a new normal. I was the sole author of this paper.

- The data from this study also adds to the existing literature on an understudied population and how they use online sources of data for information and to share with one another.

Chapter Summary:

Online forums have long been used for people to exchange health-related information; therefore, in this chapter, I reviewed online forum comments from men who experienced fertility difficulties identifying their needs and understanding how they utilised online forums. I found that men use online forums for three main reasons. The first was to seek clinical and health-related advice. The second was to share negative emotions of internalised stigma, and finally, forums were used as a safe space to share. I then critique how these findings relate to the model of finding a “new normal” and how this model can be used to understand men’s behaviours in online forums. I also describe how men exchange trusted clinical advice with one another and how online forums enable men to seek emotional support and validation for their emotions. Finally, this chapter provides a foundation for my subsequent interview study, which further probed men’s experiences and information needs.

4.1 Introduction

As one of the objectives of my thesis was to identify the needs of men who experience fertility difficulties (RQ 1), Study 1 was a review of online forum comments to explore what topics of conversations were raised and discussed in an online community dedicated to men who experience fertility problems.

Men are often cited as a hard-to-reach population group for health promotion, and online methods of communication are recommended ([Lohan et al., 2015](#)). Accessing health information online can be preferred due to its ease of access and privacy ([Tyler and Williams, 2014](#)). A mixed-methods study indicated that 40% of men reported they were likely to use websites as a source of health-related information, and over 54% stated they had previously looked online for advice and support ([Ellis et al., 2013](#)). Users are most likely to look for information using search engines ([Best et al., 2016](#)) and use online websites and forums where their anonymity is preserved for their health information ([Dickerson et al., 2011](#)).

It has been reported that men find it difficult to speak openly to share their thoughts or concerns with their peers and family due to the assumed stigma surrounding fertility problems and the perceived masculinity associated with fertility and virility ([Hanna and Gough, 2016b](#)). However, posting in online forum groups can provide support to couples dealing with fertility issues ([Malik and Coulson, 2010](#)).

Online forums are internet-based discussion boards where users create and dictate the content; posts are threaded together as discussions ([Wanas et al., 2008](#)). Forums are often organised by topics to support the congregation of like-minded users to discuss similar issues. Most forums require registration to participate; however, viewing the forums online is possible without registration. Users can use their names or pseudonyms to protect their privacy in online spaces ([Tufekci, 2008](#)).

4.2 Study Aims

Whilst there has been research exploring the use of online forums in fertility care as discussed in [2.4.1](#), it is not fully understood how online forums dedicated explicitly to men are used when men experience fertility difficulties or how these spaces can benefit men through sharing with others online.

This study aimed to understand how men communicate in anonymous online communities to help identify the needs of men struggling to conceive. As well as understand how online forums are utilised to support men who experience fertility difficulties.

4.3 Methods

This study explored and analysed online forums dedicated to fertility and preparing for conception, specifically focusing on forums aimed at men only.

4.3.1 Data Collection

To identify relevant online forums, the following search terms were used on an online search engine: “forums for men ttc” (trying to conceive), “forums for fathers/dads discussing pregnancy planning”, “forums for preparing for conception/pregnancy”, “forums for fertility”, “forums for men/prospective fathers”, “forums men planning pregnancy”, “forums for low sperm count and/or poor sperm quality” and “forums for men/fertility”. These terms revealed several online forums; those that had devoted spaces for men to talk to one another were chosen to explore. Forums that did not require registration to view were accessed; the reasons for this are explained in [3.3.1](#). However, users had to register to comment and share content.

An online web scraping application was developed using Scrapy ([Scrapy, 2016](#)), the open-source web crawling framework in Python, to extract comments and threads from the chosen online forums. All comments were extracted from the first ten pages, which was the entirety of the forum in many cases. This process ensured a good cross-section of conversations, including the most recent insights from within the communities. The data were extracted in July 2018 and included comments from January 2005 to July 2018.

Inclusion Criteria: Threads that focused on fertility, preparing for conception, men's health or feelings towards fertility and were initiated by men were included in the analysis.

Exclusion Criteria: Any threads that were not about fertility or were not initiated by men were not included in the analysis.

4.3.2 Data Analysis

The data was first explored by reading each thread title and initial post. Then the entire data corpus was cleaned by ensuring any identifiable data were anonymised; this included any details regarding names or locations. Next, any threads not relevant to the inclusion criteria were removed. These included posts not discussing men's health, experience, or feelings towards fertility, such as posts advertising products, medications or facilities, and advertisements for research. All threads that were not initiated by men were excluded. This was quickly identified as the majority of the posts would begin with an introduction of the user. The fertility context is such that when describing experiences and feelings, clarifying whether the user was male or female was relevant to the narrative. This is explained further in [4.4](#).

I extracted the data into a Comma Separated Values (.CSV) Excel file. All posts were then formatted to ensure the entire thread was attached to the initial post. These were then imported into NVivo 12⁶, a qualitative analysis software.

I familiarised myself with the data by rereading the entire corpus and making notes of my impressions. I then used the NVivo software to code the first post of each thread into broad codes based on the intention or need of the user. These broad themes were further expanded using manual coding techniques, such as post-it notes and descriptive coding labels. Then I categorised the codes into overarching themes, created affinity maps, and tagged and imported them into NVivo. Next, I coded the entirety of the threads, which included replies and ongoing conversations between users, to the developed coding scheme. I primarily conducted an inductive thematic analysis to explore how and why men used online forums when they experienced fertility difficulties and communicated with others. I then investigated their informational needs and, where possible, their intentions behind posting in online spaces.

After some time, I analysed the data again to ensure no key insights were missed. These processes enabled the generation of the final main themes discussed below. Using the software and manual coding collectively aided my immersion into the data and helped to explore the data fully.

⁶ QSR International Pty Ltd. (2020) NVivo 12 (released in February 2018), <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>

4.4 Findings

Initially, 903 threads were extracted from three unique forums, totalling 8336 posts. Of these, 101 threads were initiated by men, totalling 603 posts included in this analysis. The number of posts per thread varied from 1 post to a maximum of 61.

The remaining 802 threads from the initial 903 were initiated by women, identified by the thread's first post, and were excluded from the analysis. It was evident whether a self-identified man or woman wrote a post, as most users would introduce themselves before their query. For example, posts would often begin with "*Please see **my Semen Analysis below***", clearly identifying that the user wanted advice on their male fertility examination results, or "*I'm a 32-year-old guy from [City]*", introducing and identifying themselves.

Overall I found that men used online forums for 12 specific reasons, shown as sub-themes in Table 1. They wanted advice on fertility treatments, medications to take and potential costs for fertility treatment. Men also asked questions about coping emotionally with fertility problems, supporting their partners, and managing their daily lives whilst going through these difficulties.

I grouped these specific needs into three main themes (Table 1) to describe how men used these online spaces.

(1) as a source of community-led advice to seek and provide clinical and health-related information

(2) to share negative emotions of internalised stigma associated with fertility difficulty

(3) as a safe space for men to share anonymously with one another.

Main Themes	Sub-themes
1. Community-led advice to seek and provide clinical and health-related information	
	General advice on trying to conceive
	How often to have sexual intercourse to conceive
	Advice on Medications and Supplements
	Causes of infertility
	Advice on specific fertility-related diagnoses and conditions that could affect fertility
	Information on Fertility treatments
	Advice on Investigation Results
	Costs of Fertility Treatment
2. Share Negative Emotions of Internalised Stigma	
	How to deal with fertility emotionally
	Sharing to get advice on how to manage their partner's feelings
3. Safe Space for men to Share	
	To give advice to others
	To talk to other men

Table 1 Overview of themes and sub-themes

The three main themes are detailed below. All quotations from the online forums are identified by a unique six-digit code. The data was categorised and analysed at the thread level not by each individual user.

4.4.1 Community-led Advice to Seek and Provide Clinical and Health-related Information

Men used online forums to ask questions about their health and for clinical information. These included general advice on trying to conceive, which included how often to have intercourse and on recommended medications and supplements to take. The medical and lifestyle causes of fertility problems and diagnoses, fertility treatment choices and alternatives and interpretations of clinical examinations and test results were also explored

in the forums. Questions about practical steps such as fertility treatment costs and how to improve their chances of conceiving independently of fertility treatment were also frequently shared. All of these subthemes are discussed below in parallel as they focus on a theme of questioning that follows, “Why is this happening?”, “What does this mean?”, “What can I do?” and “Is this normal?”.

Whilst trying to gain knowledge and advice from a community of peers, men tried to make sense of their situations. They used the forums to help understand why they were experiencing difficulties. As explained in [2.2.2](#), unexplained fertility problems occur in up to 15% of all couples; therefore, the uncertainty this diagnosis brings can lead men to turn to online forums to help make sense of the experience.

“I am fine, but [WIFE] has been diagnosed with unexplained infertility, and it has been very frustrating and expensive for both of us. I am trying to hang on to my marriage, but it is hard to accept that I will never have children with her. I don’t know how to cope.” (579641)

Using online forums as a source of information and support indicates some men’s trust in the community. In other cases, men were looking for validation that previous actions and decisions were not to blame for their current predicament.

“I read previous research about side effects of Propecia. I’m afraid my short-term use about 10 years ago might affect my semen quality now. Is there any real reason to be concerned?” (726580)

In response to such concerns, others shared support and encouraging advice.

“I don’t see how this could be the cause, a test with your doctor can give you the answer.” (726580)

Other common questions asked were about clinical tests or examination results, most commonly semen analysis. Men would share their test results in detail and then ask for help interpreting them or advice on improving their semen quality.

“When I first did a semen analysis, I had around 9 million and then it went up to 20 million but the doctor say it was low. They said it isn’t enough, has anyone else had similar experiences?” (291291)

“The doctor said I had 12 million/ml and the total was 75 million. I was told that concentration should be over 20 million/ml but that the total is good. I don’t understand whether or not this is normal.” (712533)

Sharing their specific results also reflects trust within the community. Men felt comfortable sharing their medical data and believed those reading the posts would provide information and advice to improve their condition.

Whilst it was evident from the published forum rules users were advised not to use the online forums as an alternative to their medical healthcare professionals, users validated information and advice that they were given from their healthcare professionals with other online forum users, specifically about treatment and procedure options.

“I want your advice. What can I expect from this treatment? We can’t afford IVF and the specialist said there wouldn’t be any side effects of this, which I find hard to believe.” (726656)

“With my results, can we definitely not conceive naturally? Do we have to have an IUI?” (713087)

Online forums included users who had been struggling with fertility for a long time. They would share their experiences to benefit users beginning their fertility journey. These

newer users would ask questions on what to suggest to their healthcare professional and validate the clinical advice they had received, affording them to have more control and empowerment in their situation. Users also asked for and shared advice on tried and tested behaviour changes to help improve their fertility prognoses.

“I know there are so many people sharing tips on what supplements and vitamins that can help improve sperm count etc., but I’m trying to compile one big list. Does anyone know of a tip that helped their sperm improve?” (69000)

“My Doctor blamed my smoking. I quit smoking, caffeine, and alcohol. I now take vitamins, and now my count has gone up. Whatever you can do to be more fertile, do it. I think it is a percentage thing, so I did what I could do to increase my chances.” (307188)

Along with lifestyle factors, men would ask specific personal questions about how often to have intercourse, to compare themselves to others’ experiences and highlighting their lack of knowledge.

“We are doing it 3-4 times around the time I receive my orders, is that enough? She seems to think that's sufficient but I don't know anything...” (725383)

Forum users’ experiences were highly valued; they helped advise other men on their fertility pathways. Fertility treatments can be ongoing for a very long time and can be expensive for those acquiring treatment privately; therefore, ensuring couples were on the optimal treatment pathways was important to users.

“Also, what are the costs usually associated with the diagnosis? Tests, Biopsy, etc? If anyone can share some numbers so I can have an idea, it would be appreciated.” (722618)

“I am quite scared that our only option will be to undergo IVF. This will impact us massively both emotionally and financially.” (723370)

“If you don’t mind my advice - you really need to put your energy into getting in front of the best doctors in your area and nailing down your diagnosis. You don’t want to waste your time and money with repeat IUIs and IVF when there’s something that might be treatable. It’s surprising in this process the extent to which you really have to educate yourself and manage the process aggressively.” (301338)

Ensuring that treatment options and costs were normalised within the community was also important to users. This relates to another finding that was seen across all themes, the understanding and acceptance that what men were experiencing was normal. Normalcy was assessed in comparison to other people’s journeys. Men wanted to understand whether their cases were the norm for this community or whether they were a special case.

“The Doctor didn’t give us much information or suggest much else. I came to this forum to check whether these actions and steps seem normal?” (722731)

Using the online forum of experienced others helped users place themselves within a ‘normal’? category and community. Their experiences were not out of the norm compared to the fertility journeys of others. Most of the queries and requests for information were met with sympathetic and knowledgeable answers from other forum users. I postulate that knowledgeable and experienced users remained engaged with the forum to pass on and share their advice.

4.4.2 Negative Emotions of Internalised Stigma

Along with the general information-seeking detailed in [4.4.1](#), men also used online spaces to share intimate and private feelings. From these posts, we can see that men felt a sense of internalised stigma and found it challenging to share vulnerabilities experienced when undergoing fertility difficulties with people outside the forum. Therefore, these men used

the online forums as a space to communicate and find support, understanding and reassurance.

“Who [else] do we turn to for support? We carry the burdens of a family. We do so gracefully, but not without internalising the pain of failure.” (713715)

These feelings related to their assumed role in their relationship; men felt that it was their job to impregnate their partners, and failure threatened their masculinity.

“It’s hard to tell the world that I feel like only half a man... I don’t understand why my wife hasn’t left me when all she wants is a child.” (725618)

“I feel like I am less of a man because I cannot give my wife a family or get her pregnant. It hurts so much and breaks my heart when I see other [people] holding their children. I want to hear “Daddy, I love you” and have those tiny arms wrapped around my neck.” (301338)

From this quote, we can see the anguish this user felt at the failure of not being able to conceive as expected. However, others in the forum replied with support and alternative perspectives to such disclosures.

“You may in fact be more of a man for going the extra mile to achieve your goals of becoming a family.” (301338)

Men also shared how the impacts of their fertility problems affected their perception of masculinity. This was especially seen when donor sperm was required for conception.

“It hurts so much that my wife will conceive with another man’s sperm. It just HURTS me so much. She will have to go through the invasive procedures and endure having a stranger’s sperm injected all because I have a defect. I am heartbroken. I don’t know what I need or what will help. I am just hoping that sharing here helps, as I can’t share this anywhere else.” (720227)

In some cases, it is not possible to ascertain the intention behind sharing; however, sharing seems to be cathartic and helpful in voicing their feelings. In addition, this sharing enables men to gain advice on managing the stigma felt when they could not conceive easily.

Men shared that they could not share their feelings openly with their partners. This is because there was fear regarding their masculinities, as shared above, and the thought that they could not show or share weakness, as they had to be strong to support their partners.

“I can’t let her down by being weak. I give my wife everything she desires, but I have already let her down by not being able to give her the one thing she desperately wants: a baby.” (301338)

Men were very aware of how their feelings could affect their partners. Yet, men felt they had to burden themselves with the pressure to ensure their partners felt secure.

In other cases, men state that they could not share with their partners because they felt guilty as the fertility problem lies with them; men express that they thought they were the cause of pain.

“She tells me that it isn’t just my problem, it is our problem, but I don’t feel like that. She doesn’t need any more stress from me, so I keep my feelings to myself. I know I need to be there for her, but what is my role? Do I keep my mouth shut or do I try to make her understand my view?”(435034)

“I’m also dealing with the guilt of being the person in our marriage with infertility problems: she’s normal. The guilt surrounds her being the one taking all the drugs, the shots, etc., and I’m the one with issues.... Are there other men out there who could relate? And because she’s dealing with all her emotional stuff, she let me know last night that she’s dealing with so much that she doesn’t have any capacity for supporting me in the way I need. Hence, here I am writing all of you. I welcome any and all support.” (484619)

When men share these feelings of blame and guilt, they look for others to share similar experiences to validate their feelings. In response, forum users shared empathy, understanding, and positivity to support one another.

“Just sounds like you are VERY supportive and that makes up a large portion of the battle. You can get through anything together if you’re on the same page and are holding each other up.”(301338)

The fertility journey is compared to a *war, battle* or *fight* to win. It is described as the worst thing that they could ever envision happening to them. Many couples plan their journey, and when there is a disruption to the expectation, they find it difficult to cope.

“We had a plan. We had decided when we were going to get pregnant. We had planned the baby would be due when [partner] was off for the summer. What a shock and rude awakening” (3019597)

The forum was also used to share emotions they felt they could not communicate outside of the forum for fear of judgement or social norms prevented them from being honest. An example of this was when couples had to deal with pregnancy announcements from other people.

“We found out her brother [and partner] are expecting in October. They were only trying for ONE month and they got it! If our IVF had worked the babies would have had the same due date. My wife couldn’t take it and just broke down. We are happy for her brother but it feels horrible too. Such imaginable unintentional pain.” (724865)

Men asked for advice from within the forum as this is where there were people who understood and may have experienced similar scenarios. Users had diverse advice

regarding leaning on friends and family, where one response advises a user to share with those around him.

“Do not try to do it alone. Speak to family and friends etc, just too much to keep everything in...”

Whereas others on the same thread advised against this based on their experiences.

“I’m not that sold on telling friends and family. We tried for ten years after our loss and there was so much pressure on us to announce another pregnancy. Some people are okay but others will constantly ask and think you’re not trying hard enough... Stay away from family and friends...you DON’T need the added stress!”(725383).

Sharing and venting was a popular reason men used online forums. Many users supported one another through the intense feelings of internalised stigma and shame.

“I want to share what I wish was available for me when I began my journey. This place to encourage men with their infertility is amazing. Men, let’s all support one another in this FIGHT, without each other’s support, we are just individual leaves falling from a tree, blowing away and alone.” (713715)

4.4.3 A Safe Space for Men to Share Anonymously with one another

Through the comments already shared it can be seen that men utilised online forums as a safe space to share and to alleviate the possibility of negative social consequences from sharing outside of the online space.

*“This has been some of the hardest times in my life, and I wouldn’t wish it on my enemy. I don’t know what I would do without this space to be able to share. I am looking for people who are in the same boat, or who have been able to make it off the boat and give me hope!”
(722737)*

“My desire to leave the house has completely gone. I don’t do anything anymore but cry. I have an appointment today but I am ready to give up. I don’t know what I can do... I have such dark thoughts now; I know they are wrong and I’m being irrational but I love my wife and I’m so scared to disappoint her.” (725618)

Users share their intimate dark thoughts freely in the online space. There is value in the affordances of anonymity that the online forums enable. Men can share without fear or judgement from others. This online community, as mentioned, was very empathetic and supportive. Men clearly stated they shared on the online forums as they had no one else to confide in.

“I just don’t know any other men I can talk to so I am so glad I found this forum today. It is a blessing. It is exactly what I need!” (435034)

I can’t seem to find anyone that can relate to me. I hope there is someone here that can help me make sense of this and how we can get through it all.” (726737)

Having the safe space to openly discuss their experiences with men was another explicit characteristic of anonymous online forums that benefitted these users. However, men repeatedly stated they felt isolated outside the online forum.

“I joined this group to make sure I’m not alone and isolated in this situation.” (725865)

“Thank you letting me rant, and for reading my story. You have given me more than most other people I have spoken to outside of the forum, including therapists! I appreciate anyone who has responded. I felt so horribly alone in this, I didn’t know what to do.” (726737)

“Any other older guys out there feel the same in the same situation? I feel terribly alone in this journey. How do you cope if you are out there?” (725847)

As with other topics shared, users would often respond with sought-after support in the virtual environment.

“I had the same feelings. I know it is OUR problem and it is BOTH of our journeys. It helped me to feel less alone.”(435034).

Men would purposely seek emotional support by sharing their intimate, unexpected fertility journeys. Hearing what others had gone through would help calm others as they would no longer feel like the anomaly.

Online forums often have users categorised as “lurkers”; these are users who consume the forum but do not actively participate. This type of user is challenging to analyse as they do not contribute to the forum. However, some users shared how they changed their status from lurker to contributor, finding value in sharing.

“I am new to this forum, but I have been reading quite a bit using my wife’s ID. I decided to sign up so that I could talk to the husbands out there, to relate with them and also trade experiences.” (579641)

Finally, the safe space the online forum provided was essential for men to hear from other men directly.

“Please! All of your significant others, all of you men, share, talk, shout, cry your feelings if you need to. Share your hopes and desires with us all,” (515685)

“I apologise but ladies, this forum is called [names the forum which is male specified in the title]. I really want to see more husbands/partners/men posting replies. Please encourage your men. No offence but hearing and sharing together can really help us!” (579641)

Overall, men who experienced fertility problems and used online forums did so for advice, information, emotional support, and to freely share due to the affordances of anonymity in online forums.

Men wanted to gain clinical advice and improve their chances of conception through learning from others' experiences. In addition, men wanted to understand how common their experiences were or whether what they were experiencing was normal. Therefore, men shared with one another as they found an anonymous community of like-minded and empathic peers who understood their fertility journeys. This helped them manage their sense of internalised stigma and the threats to their masculinities.

4.5 Study 1 Discussion

The analysis of the online forum comments indicated that men used online spaces to find and communicate with men who are going through similar circumstances, i.e., a like-minded community of others who can empathise and share expertise from first-hand experience. Online forums were also used as a community of peers to share their experiences and feelings of internalised stigma that they were unable to share with others outside the forum. Men often reported that they did not have another outlet to share or obtain advice and therefore turned to online forums. Men who used online forums when experiencing fertility difficulties were in need of emotional support and validation (4.5.3) and sought trusted clinical advice and health information (4.5.2) to be able to undertake collective sense-making to find and accept a 'new normal'(4.5.1). These three main findings are further discussed.

4.5.1 Finding and Accepting a ‘New Normal’

As many comments show, users were exploring whether what they were experiencing was normal compared to others. This relates to the theory of finding a ‘new normal’ as presented by ([Genuis and Bronstein, 2017](#)). Their model indicates that once gaps in understanding occur, there is a breakdown of assumed normal; gathering information and sense-making activities forms a socially constructed new normal. These behaviours can be seen within the online forum community.

Once users experience a breakdown of their assumed normal, which in this scenario is when conception does not easily occur, they turn to seek information and advice from the online forum. Through interaction with other forum users, men gain and share information and experiences to help make sense of one another’s fertility journeys. The supportive and shared sense-making can be indicative of collaborative sense-making behaviours. Several scholars remarked upon this process, including ([Mamykina et al., 2015b](#), [Paul and Reddy, 2010](#), [Shah and González-Ibáñez, 2011](#)). Collective sense-making describes the processes where people congregate to share their own experiences and knowledge to support one another ([Mamykina et al., 2015b](#)), or where information-seeking behaviours are divided between people ([Reddy and Jansen, 2008](#)), which is directly relevant to users’ behaviours in online forums.

Users also undergo meaning-making processes by sharing and understanding the information gathered, whereby they interpret the knowledge gained in their specific context ([Burgess et al., 2019](#), [Ruthven, 2019](#)). Then users can begin to create a socially

constructed new normal within the forum. Here users' experiences are the norm. A novel instantiation based on the 'finding a new normal' model by ([Genuis and Bronstein, 2017](#)) relevant to the fertility experience in online forums is presented in Figure 2.

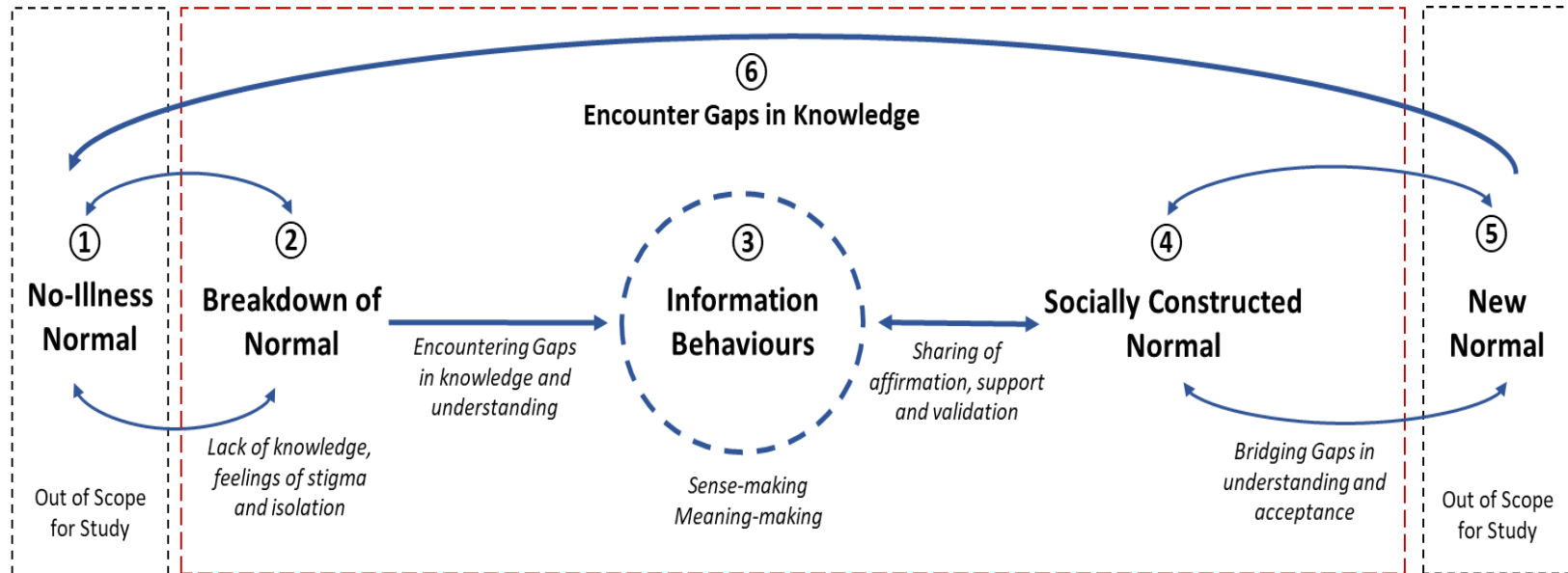


Figure 2 Novel Instantiation of the Finding a New Normal Model relevant to the Fertility Experience in Online Forums

Items 1 and 5 in Figure 2 are experienced outside the online forum and, therefore, out of scope for this analysis.

At point 2, there is a breakdown of their existing normal, as previously explained; this is when fertility problems have been identified. Men experience a lack of knowledge in this phase and exhibit feelings of isolation and internalised stigma at accepting their fertility diagnosis. This leads to gaps in knowledge and understanding, leading to the recognition of the need for information leading to engagement with the online forums. The information behaviour processes of sense-making and meaning-making can be seen to occur within the online forums (point 3). Users raise questions, ask for advice, often clinical information, and support to manage the emotional impacts of fertility difficulties. The information gained is interpreted in their context through discussions with one another ([Ruthven, 2019](#)). Accepting newly acquired knowledge, support, and positive affirmations received within the forum can lead users to accept a sense of socially constructed new normal within the forums, (point 4). Here all users are peers; they are going through similar experiences. In contrast to their external non-virtual world, men do not feel abnormal. Other forum users validate their feelings and experiences.

Through the continued engagement and the progression of users' fertility journeys, more gaps in knowledge can occur, as indicated in point 6 in Figure 2. Hence, the model is cyclical as the information-seeking behaviours may not be linear.

4.5.2 Receiving Trusted Clinical Advice and Health Information

Once men actively engaged with the forums, they openly shared their medical data with an assumed non-clinical community. There was trust within the forums that their information would

not be shared and that the advice received was trustworthy. Though motivations behind this intimate sharing cannot be identified, one such reason could be distrusting their healthcare professionals. This was also reported by ([Bhattacharya and Porter, 2007](#)), who found that couples often sought additional information and support from online sources of information. To find meaning in their clinical information, men could also be aspiring to gain advice from more knowledgeable others, which has similarly been reported in other health contexts ([Burgess et al., 2019](#)). Users could also seek information and advice to seek comprehensibility in their clinical, which was discussed by ([Ruthven, 2019](#)) considering sense-making practises.

([Huh, 2015](#)) also reports that forum users provide constructive and helpful medically related information and often advise other users to see their healthcare professional. This was reflected in our findings. In addition, other forum users provided information and advice for users to take back to their healthcare professionals to make the most out of their consultations and validate the advice their healthcare professional was providing.

Similar findings have been reported that online forum users looked for information and support. However, this data identified that men specifically looked for factual information and support to validate their experiences and clinical data to understand whether their experiences are normal compared to others.

4.5.3 Seeking Emotional Support and Validation in an Online Safe Space

As previously stated, users openly shared their personal and intimate feelings about their complex fertility journeys in online forums. Therefore, we can postulate that the affordance of anonymity

encourages intimate sharing. Others, e.g. ([Larkin, 2001](#)), also found this: they note that men tend to open up in anonymous online spaces.

Anonymity can also help men share their vulnerabilities related to their perceived role to maintain their masculinities. For example, men often stated they felt like a failure as they could not conceive and that it was their job to conceive. This relates to feelings of expected masculinity, referring to the dominant characteristics men feel they are expected to exhibit ([Dooley et al., 2011](#)). These feelings can increase the sense of stigmatisation, isolation and feelings of distress and self-esteem due to fertility problems, making it increasingly difficult to seek support ([Hanna and Gough, 2015](#), [Dooley et al., 2014](#)).

Along with the anonymity, the characteristic of online forums acting as '*a safe space for users to share*' encourages men to engage with one another openly. It can be seen that once some users share their intimate and sensitive stories, it encourages others to respond with their sensitive stories too ([Rains, 2014](#)). This was also reported by ([Ammari et al., 2017](#), [Ammari et al., 2018](#)), who examined this phenomenon when discussing how men share online regarding fatherhood. They postulate that men can fear judgment if they openly share online; therefore, men are more likely to share sensitive topics if spaces are deemed safe.

Repeatedly, I found in most discussions men were trying to find and position themselves within a community of similar peers. When sharing their stories of anguish and difficulty, they find solace and acceptance in the responses of other men sharing similar stories.

4.6 Summary of Findings

Through my analysis of online forum comments by men who experience fertility problems, it was found that men utilised online forums to share their vulnerabilities openly and anonymously with a community of similar others. It was also reported that men explored their fertility needs in online forums by communicating with similar others to make sense of their fertility problems, explore what they could do about it, and understand whether their experiences were normal. Through sharing and exploring other people's experiences, men could find meaning in their own experiences to accept their new normal.

By relating the 'finding a new normal' model to the context of infertility, provides a better understanding of the different stages of information-seeking men dealing with fertility difficulties experience.

As stated, it was not possible to probe the users of the forums to understand why they chose to use online forums or to explore what other needs they may have whilst trying to conceive. This led to the subsequent study introduced in [Chapter 5](#), which was an in-depth interview study that recruited men to understand their needs further whilst trying to conceive and explore men's feelings towards digital tools for support when they experience fertility difficulties.

Chapter 5 Study 2: In-depth Interview Study: Method and Overview

Parts of the following chapter have been published in the following papers.

• Patel, D., Blandford, A., Stephenson, J., & Shawe, J. (2019, October). Understanding The Use Of Social Technologies During A Life Transition: Men’s Experience with Fertility Problems. Association for Computing Machinery (ACM). The 22nd ACM Conference on Computer Supported Cooperative Work and Social Computing. Workshop: Life Transitions and Social Technologies: Research and Design for Times of Life Change⁷

Data from this study has been presented at the following conferences

1. Institute for Women’s Health Annual Scientific Conference, UCL 2019.⁸

Chapter Summary:

This chapter introduces Study 2 of my thesis, an in-depth interview study. I discuss the existing literature that motivated this study. The methodological decisions relating to this study are detailed in [Chapter 3](#); however, the specific methods used in data collection and analysis are described in this chapter. Next, I provide an overview of the general participant demographics and men’s motivations for participation in research relating to their reproductive health. Finally, I detail how the findings from this study are discussed in the following chapters.

5.1 Introduction

This study’s objectives form part of the larger aim to establish men’s requirements for support when they experience fertility difficulties. In addition, this study aimed to understand user

⁷ This workshop position paper reports on various findings from this interview study which relate to how men describe their fertility journey as a significant life transition. I was the first-author on this paper and carried out the analysis for this paper. My findings were discussed with the co-authors and they provided comments on the final submission.

⁸ Preliminary data analysis was presented in a poster presentation at this conference. These included the data presented in 5.6.3.

requirements for a digital tool from men themselves. Therefore, men who had or were currently experiencing fertility difficulties were recruited for in-depth one-to-one interviews. In this chapter, I present an outline of the relevant related work and how this motivated my study aims, followed by a description of the methods used, with an overview of participant demographics and summary findings .

5.2 Study Aims

Much of the research that has explored men and infertility has collected data using online methods, allowing for a level of anonymity. In addition, these studies Have investigated how men feel and speak to one another when experiencing infertility. Significant findings include that the language used was key when supporting one another and gaining insights from those who have experience in the matter ([Hanna and Gough, 2016a](#), [Hanna and Gough, 2016b](#), [Hanna and Gough, 2015](#)). However, these works did not explicitly explore men’s information-seeking behaviours.

Whilst it has been reported that men want more information and support when experiencing fertility problems ([Sylvest et al., 2016](#)), precisely what that information needs to be, or what they require support for, still needs to be understood. This study aimed to provide empirical data on these points.

The main aim of this interview study corresponds to the overall research questions:

What are men’s requirements for support when they experience fertility difficulties? (*RQ*

1)

Further to this, to specifically understand men's informational needs, which includes their emotional needs (*RQ 2*).

Using digital interventions as a means for support was explored with this population as my previous literature review found this was likely to be the desired method of acquiring health-related information ([Chapter 2](#)). Therefore, this study also aimed to answer the final research question.

How can these identified needs be fulfilled through the use of digital tools? (*RQ 3*).

This chapter outlines the methods of the interview study, provides a description of the participant demographics and an overview of their motivations to participate in this study. The findings from this interview study are presented in subsequent chapters.

5.3 Methods

The overall aim of this study was to understand the experiences and identify the needs of men who experience fertility problems when trying to conceive. Therefore, men who were currently experiencing or had recently experienced fertility problems were recruited for in-depth one-to-one semi-structured interviews. The ethical considerations and rationale for using this method are discussed in [3.4](#).

5.3.1 Population and Recruitment

Participants were primarily recruited from two sources; in person from a private fertility clinic and online by collaborating with a national fertility charity, The Fertility Network U.K, which supports people who experience fertility problems. Snowball sampling was also used where recruited participants shared our call for participation with others who met the eligibility criteria.

The fertility clinic displayed information leaflets ([Appendix A](#)) with details on the research aims and the study plan in their communal waiting areas and introduced to patients during consultations. In addition, interested participants were asked to contact the research team if they wanted to participate, ensuring no undue pressure on men in the clinic. The study information described the population of interest to be men as men's experiences were the primary focus. Men not in heterosexual relationships, or men who may have been embarking on the parenting journey alone were not excluded, but no one in these groups responded to the call for participation. A future study should focus on such groups. In addition, it would be valuable to explore the needs and requirements of non-male partners of people who are trying to conceive. The scope of this thesis is limited to men, as discussed further in [11.9](#).

The Fertility Network U.K. also periodically shared the call for participation on their social media channels, including Facebook, Twitter, and Instagram.

The aim was to recruit a diverse range of participants covering different fertility-related characteristics. This included men who had male-related, female-related, or unexplained fertility concerns, whether they already had children, had previous unsuccessful pregnancies, or were nulliparous.

The inclusion criteria for participation were males trying to conceive with a partner and experiencing difficulties, or their partner had recently conceived after experiencing fertility difficulties. A time limit of 12 months was used concerning past conceptions to limit recall bias. Participants were excluded if they were not currently trying to conceive or hadn't conceived within the previous 12 months, were not facing fertility difficulties, or were not based in the U.K. A

geographical limitation was included as the health and fertility systems and resources vary vastly between countries, thus avoiding any inappropriate comparison of the needs and requirements of men from different settings with access to other resources.

All interested participants were sent a copy of the participant information sheet ([Appendix B](#)) over email to ensure they had time to consider the information about the study, its aims and specifically what would happen to any data they provided. Once they had adequate time to consider the material and ask questions, a convenient time and place was arranged to undertake the research interview. All participants provided written, signed consent before the interview took place ([Appendix C](#)).

All participants were offered a £20 voucher as an incentive as well as to show appreciation for their time and participation in the study.

5.3.2 Participant Demographics

Twenty-eight interviews were undertaken from November 2018 to May 2019. Eight men were recruited from the fertility clinic, and 20 men were recruited through online methods with the support of the Fertility Network U.K. A further six men were interested in participating but did not respond when invited to be interviewed, resulting in an 82% response rate for recruitment. The age range of the participants was from 22-46 years old. 39.3% (n=11) of the sample were from London; 14.3% (n=4) were from North England (Yorkshire, Lancashire, or Northumberland); 7.1% (n=2) were from South England (Sussex, Hampshire); 14.3% (n=4) from the Midlands, (West Midlands, East Midlands, Bedfordshire, or Buckinghamshire); and the remaining 25% (n=7) were from Home Counties, (Hertfordshire, Berkshire, and Suffolk).

Figure 3 shows how the men described their fertility diagnoses. Most men shared that they never received a definitive diagnosis and were proclaimed to have unknown or unidentified infertility (n=10, 36%). Eight men (29%) disclosed their partner had been diagnosed with female-related fertility concerns; six men (21%) had male-related infertility factor; and four men (14%) said they received diagnoses that were related to both themselves and their female partner.

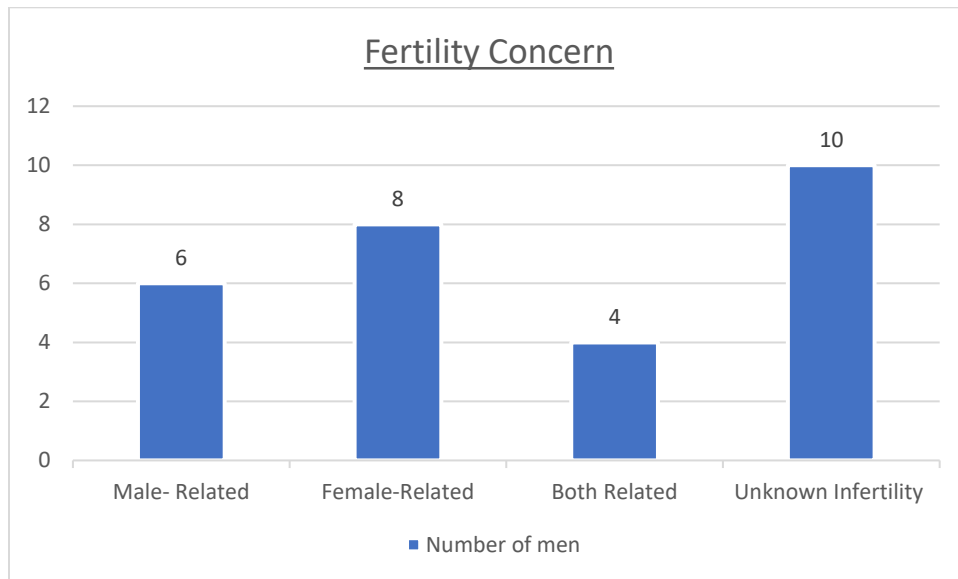


Figure 3 Chart showing a sample of men and stated fertility concern

82% (n=23) of the sample did not have children and discussed trying to conceive their first child, whilst five men were already parents and shared their experiences in trying to conceive a subsequent child. The mode of interview varied based on the participants' convenience. Where possible, preference was given to meeting face to face (53%, n=15), then using video conferencing software (11%, n=3) and finally, phone interviews or using audio with video conferencing software (36%, n=10). Online audio interviews were categorised as phone interviews, as the experience was similar. An overview of participant information is displayed in Table 2.

Participant Number	Age	Source of Recruitment	Fertility Related Diagnosis	Previous Children	Mode of Interview	Fertility Circumstance
#1	32	Online	Male Factor	No	Face to face	Partner currently pregnant through fertility treatment.
#2	40	Clinic	Male Factor	Yes	Phone	Had one child via fertility treatment now trying for subsequent child with fertility treatment.
#3	38	Online	Female Factor	Yes	Video Call	Partner currently pregnant through fertility treatment.
#4	36	Clinic	Female Factor	No	Face to face	Partner currently pregnant through fertility treatment.
#5	32	Online	Unexplained	No	Face to face	Waiting to begin fertility treatment.
#6	34	Online	Female Factor	No	Face to face	Began fertility treatment but partner conceived naturally.
#7	35	Online	Female Factor	No	Face to face	Partner currently pregnant through fertility treatment.
#8	27	Online	Unexplained	Yes	Phone	Has a child and trying to conceive a subsequent child. Under investigations for fertility concern.
#9	38	Online	Both	No	Video Call	Currently on their third round of fertility treatment.
#10	35	Clinic	Both	Yes	Face to face	Has 2 children via fertility treatment and currently trying for their third with fertility treatment.
#11	34	Online	Unexplained	No	Face to face	Does not have any children, is in the early stages of investigation with their General Practitioner.
#12	30	Online	Male Factor	No	Face to face	Does not have any children, had some treatment to understand their fertility options but yet to begin fertility treatment.

#13	46	Clinic	Male Factor	No	Face to face	Have begun fertility treatment for their first child.
#14	37	Online	Unexplained	No	Phone	Had multiple investigations but have found no cause, currently on the waitlist to begin IVF.
#15	34	Online	Female Factor	No	Face to face	Had fertility treatment, which was unsuccessful and conceived naturally before could start next round of treatment.
#16	32	Clinic	Unexplained	No	Phone	Was undergoing IVF, which failed and conceived naturally,
#17	22	Online	Female Factor	No	Phone	Trying to conceive for over 2 years and had multiple fertility investigations.
#18	31	Online	Unexplained	No	Phone	Trying to conceive for over 3 years, have 2 round of unsuccessful IVF. Partner pregnant on 3 rd cycle after changing clinics.
#19	38	Clinic	Female Factor	No	Phone	Was diagnosed with unexplained infertility, undergone numerous investigations. Currently extracted eggs for IVF procedures.
#20	36	Online	Female Factor	Yes	Face to face	Has one child through the use of medication to support ovulation. Is now trying for a subsequent child but yet to begin fertility treatment.
#21	30	Online	Unexplained	No	Phone	Tried to conceive through ovulation induction, resulted in miscarriage and then unsuccessful after 6 rounds. Referred for IVF

						treatment, which was successful on the first round, partner is currently pregnant.
#22	32	Online	Unexplained	No	Phone	Went through multiple rounds of fertility treatment, which was ultimately successful, couple have one child.
#23	31	Online	Both	No	Phone	Investigations found that ICSI was the preferred option of treatment, partner is currently pregnant.
#24	33	Clinic	Unexplained	No	Face to face	Experiencing fertility treatment for a number of years. Male side was not explored till recently, now in treatment, had an embryo transfer at time of interview.
#25	33	Clinic	Male Factor	No	Face to face	Trying to conceive for over 2 years. Had multiple rounds of unsuccessful IVF and now waiting to begin another cycle.
#26	36	Online	Both	No	Face to face	Had multiple rounds of fertility treatment, which was ultimately successful, couple have one child.
#27	41	Online	Male Factor	No	Face to face	Had multiple investigations and have been told ICSI is the only option for them to conceive. About to start their first cycle.
#28	42	Online	Unexplained	No	Video Call	Has no children and has been going through fertility treatment for a number of years.

Table 2 Details of participants recruited. Participants are referred to by their number through this thesis

5.3.3 Data Collection

I undertook the interviews in a semi-structured manner using a topic guide ([Appendix D](#)). The questions were tested in a qualitative discussion group to ensure the questions were appropriate and were interpreted as intended.

All face-to-face interviews were conducted in UCL offices. Remote interviews were over the phone or using video conferencing software in spaces where privacy and confidentiality were assured. I began by verbally confirming the participant was aware of the study's aims and ensuring they provided informed consent for the research and the audio recording of the interview. I reiterated that the participant could stop the interview at any point or not answer any question without having to provide explanations.

Participants were then asked to share information about themselves, such as their job and family structure, to help them relax and feel comfortable sharing details about themselves.

Next, men were asked to share information about their fertility journey, which led to sharing their feelings at each stage of their journey. If not spontaneously mentioned, they were prompted to share where and how they may have accessed information and support during the process. Care was taken to differentiate between information and support sought before the couple started trying to conceive and then once they experienced difficulties and were under the care of a fertility specialist.

Next, the conversation progressed to sources of support and information the participant desired and how this could have helped them during their fertility journey. Digital tools were often mentioned, which led to probing into what kinds of tools they would have liked to use or had

available. The interview also examined how participants thought digital tools would have helped and why. Towards the end of each interview, the design of a desirable digital tool and user aspects were discussed in detail.

Participants shared insights into their emotional journey through their fertility experiences. Participants often spontaneously raised this; however, if they didn't, I specifically asked them to share how they felt through their fertility journey.

Each interview ended with the opportunity to reflect and an open section where participants could ask questions. Many participants took advantage of this and most commonly asked about the next steps of the research and how their data would contribute.

As an additional aid to the audio recordings, I also made written notes during the interview on a printed copy of the topic guide. These would relate to any insights I had whilst participants were sharing.

5.3.4 Data Analysis

I analysed the data thematically, using both iterative deductive and inductive methods ([Braun and Clarke, 2006](#)). Audio recordings were transcribed verbatim and anonymised before analysis. In addition to transcribing the interviews to aid familiarisation, I listened to audio recordings of the interviews to check the accuracy of transcription and support my immersion into the data. During this process, I composed notes whilst listening to the interviews. I used these, along with the notes made during the interview and the analysis process, to recall key insights. Finally, I imported the transcripts into the qualitative analysis software tool NVivo 12, which aided my analysis by organising and managing the data through multiple iterations of analysis.

Following an iterative inductive approach, four broad codes were defined to organise the data. These codes were developed from the topic guide. These were “What do men want (when trying to conceive)”, “Fertility Treatment”, “Specifications (for a digital tool)”, and “Current resources used”. Subsequently, I carried out an inductive approach, developing codes from the data. I also held a data workshop with my supervisory team where I discussed themes generated with data extracts. The themes were refined and defined through this activity.

I then continued to descriptively code each transcript. When new codes were developed, previously analysed transcripts were rechecked to check if that topic was mentioned. This aided further immersion into the data. Miro⁹, an online whiteboard platform, was also used to organise the data and create affinity diagrams from the inductive analysis. Multiple rounds of coding were undertaken to explore further insights from the data.

It was clear through these rounds of analysis that men had different information needs depending on where they were on their fertility journey, therefore, to explore this there was a need to outline men’s fertility journeys. I did this through thematic analyses. I deductively explored the data to understand whether these experiences were common among the men interviewed. The specific methods of how the journey was generated from the data are described in [Chapter 6](#).

As understanding men’s requirements for support was an aim of this study, I analysed the data to explore men’s needs. This formed a broad code of “what men want”. This code contained many references to men wanting information. Therefore, I explored the data specifically to understand men’s information needs, answering my second research question, **What are men’s information**

⁹ Miro RealtimeBoard Inc. (2011), <https://miro.com/>

needs when they experience fertility difficulties? These findings are discussed and presented in [Chapter 7 and Chapter 8, where](#) men shared their emotions; how they felt through their fertility journey. Therefore [Chapter 8](#) discusses men's emotional experiences during their fertility journey.

These findings were then fed into analysing the opportunities for digital tools to support men when they experience fertility difficulties ([Chapter 9](#)). To answer my final research question, **How can these identified needs be fulfilled through the use of digital tools?** First, I coded the interview transcripts deductively to extract references to content and design features desired. In addition, I coded references to what would encourage or discourage their digital tool usage and their experiences with what they thought were good and bad examples of digital tools. Next, I analysed these references to understand how common similar features were amongst the participants interviewed. I then undertook an analysis to infer how the identified feature needs could be translated into requirements.

5.3.5 Motivations to Participate

To understand men's participation in fertility-related research, participants were asked directly about their motivations for participating in this study. Their responses varied from wanting to help others, wanting the opportunity to share their experiences, and taking the opportunity to contribute and support other men, especially as they felt there were currently limited resources and information for men.

"I saw that it was about getting male perspective not being looked at, then thought, how can I turn down the opportunity once it finally came?" (P22)

"Because I find the whole process frustrating and the lack of information and you're hitting on something I really care about." (P24)

"It's nice to see someone looking at what a male goes through during all of this and to help them, so I wish there was more out there to support males than what there is, so it's nice to see what you're doing. That's why I jumped on it straight away." (P14)

Some men shared that they had not been able to share their stories with anyone before being interviewed. Therefore, this was an opportunity for men to voice their experiences and explore their feelings through sharing.

"I was like, oh, it's just an opportunity to, to talk about what I've been going through." (P20)

"Erm probably because I haven't spoken to anyone about it. [...]and seeing if anything useful would come out of it that I would learn from it. (P11)

"...it's actually been quite nice just to talk and get it off my chest and say stuff that I've not really had a chance to say to anyone else, so that's been actually quite good." (P14)

In addition to providing help and support to other men, participants were motivated to share to understand their own experiences. Men felt isolated through their experience and

being presented with the opportunity to share with an interested party benefited men. Men's experiences of feeling isolated is further discussed in Chapter 8.

Men shared their frustrations at not being able to find support for themselves and therefore were motivated to contribute to research that could lead to more awareness and support for men in the future.

“...it's not going to affect me personally, because I've been and gone. Trains already left the station. I'm not one in 7 billion, I will be one of lots of people who feel like this. So if I can help change an outcome for those that follow me, that'd be great.” (P25)

Wanting to help others was a strong motivation for participation. Once men had experienced difficulties, they didn't want others to struggle as they had. Men also shared that people often assumed that the affected person in fertility difficulties were predominantly women, and men are typically ignored.

“It's like the only area like as a kind of white male, you know, relatively privileged person [...] but in terms of fertility, men don't talk about it enough. There's way too little understanding of the fact about that male fertility exists, and I think that's really bad in terms of the perspective of women in society. Because I think every time you hear IVF, almost everybody assumes it's to do with the woman and to do with female problems, and I probably did before we started on this journey.” (P10)

This participant clearly articulated the need to focus on men, where it is assumed, that men are generally privileged in this one domain; they are disregarded. For some participants, this disregard is challenging to accept, and they are motivated to change the conversation to focus on men more dominantly.

Once men's motivations to participate were understood, it became easier to understand their needs and what was important to them during their fertility journey.

5.4 Summary

Participants recruited for this study covered a range of fertility-related diagnoses. Their motivations for participation included wanting to help others and wanting to share their fertility-related experiences. The men were at different points of their fertility journey at the point of interview and shared their experiences and perceived needs. Much of men's needs centred around wanting more information or explanations; this is explored in greater detail in subsequent chapters.

Chapter 6 Analysis of Men's Fertility Journeys

Contributions from this Chapter:

- This chapter presents the fertility journey experienced by men based on their interactions with health services.

Chapter Summary:

This chapter presents the analysis processes involved in composing a 9 stage fertility journey as shared by men and the multiple data visualisations that aided the understanding of the fertility journey. I then discuss how men's fertility journeys differed from one another and the potential factors involved in these divergences. Finally, I end this chapter with an illustration of the final fertility journey used as a framework in subsequent analyses.

6.1 Introduction

As men were explicitly asked to share their fertility journey, many did so by describing their journey as categorised by their interactions with health services. Men mainly described following their partner's lead or their healthcare professional's guidance and advice. They were unaware of any official pathway to follow. Therefore, I present the typical fertility journey experienced by men; I also explore how the journey differed between participants.

6.2 Analysis of men's fertility journeys

Each transcript was deductively thematically analysed to outline each fertility journey in multiple forms. In the first iteration an overall timeline was created, but as some participants did not disclose specific durations when recounting their experiences, it was

not feasible to compare all participants. Next, a summary paragraph was composed for each participant, detailing their journey, and outlining each step described during their fertility journey. From this summary, it was clear that several participants encountered similar experiences and steps through their journey towards conception. Therefore, these stages were named descriptively to label each stage.

The overall journey followed eight clear stages and ultimately and hopefully ended with the ninth stage of conception to lead to a healthy birth.

1. Stage One: Trying to conceive
2. Stage Two: Identifying a Problem
3. Stage Three: Refer to General Practitioner (GP)
4. Stage Four: GP led tests and investigations
5. Stage Five: Refer to Hospital
6. Stage Six: Hospital led tests and investigations
7. Stage Seven: Refer to Specialist Fertility Clinic
8. Stage Eight: Fertility Treatment begins
9. Stage Nine: Conception.

Next, the data was converted into several different data visualisations. One version used PowerPoint's SmartArt, which had a process graphic that was easy to manipulate. Each key stage was outlined, and the text was colour coded within the boxes. Each colour defined a stage as described by the participants, enabling the understanding of the commonalities and differences between the participants more easily. Figure 4 shows the overview of the journey and the colour codes.

- Event 1 = Trying to conceive
- Event 2 = Identifying a problem
- Event 3 = Refer to GP
- Event 4 = GP led Tests and investigations
- Event 5 = Refer to Hospital
- Event 6 = Hospital led tests and investigations
- Event 7 = Diagnosis of Fertility Factor (D)
- Event 8 = Fertility Treatment Begins (tx_(1,2,3,4,5 etc))
- Event 9 = Conception, Pregnancy, Birth



Figure 4 Key of Data Visualisation



Figure 5 Example of Data Visualisation of Participant Fertility Journeys

Figure 5 shows an extract of the participants' journeys. Again, these common encounters can be seen easily, but many participants' journeys end at different points, which this graphic cannot easily identify.

The data was then categorised according to whether participants had been recruited online or from the fertility clinic. However, as the participant journeys did not perceptibly differ based on their recruitment source, this was not further explored.

On further reflection, another version of data visualisation was composed by increasing abstraction. As stated, some of the journey's end at different points, which was not easily seen on the graphic in Figure 5. Therefore, the data was transferred into a table.

A timeline from the SmartArt was developed, laying the basis for a table in Microsoft Excel. This was a simpler version of the first visualisation, using ticks (then coded green) and crosses to indicate whether and when each event occurred for each participant, as shown in Figure 6. This helped to see the participants' commonalities and enabled further data validation to ensure pathways and cross-check occurrences when reviewing the data.

ID	Other Event	Event 1 - tc	Other Event	Event 2 - Identify a Problem	Other Event	Event 3 - Refer to GP	Other Event	Event 4 - Tests & Investigation	Other Event	Event 5 - Refer to Hospital	Other Event	Event 6 - Hospital Tests	Other Event	Event 7 - Refer to Fertility Clinic	Other Event	Diagnosis	Other Event	Fertility Treatment	Other Event	Conception, Pregnancy or Birth	Other Event
P1	x	✓	x	✓	x	✓	x	✓	Diagnosis of male factor	✓	x	✓	x	x	x	x-earlier	x	✓	x	✓	Conception
P2		✓	Diagnosis of PCOS	✓	x	✓	x	x	x	✓	x	✓	Diagnosis of male factor	✓	x	x-earlier	x	✓	Miscarriage > tx	✓	Birth
P3	x	✓	x	✓	x	✓	x	✓	Diagnosis of female factor	x	x	x	x	✓	x	x-earlier	x	✓	Birth-died	✓	Donor Egg-Conception
P4	x	✓	multiple miscarriage	✓	x	x	x	x	x	✓	x	✓	bad exp- went private	✓	x	✓	unknown	✓	x	✓	Conception
P5	x	✓	x	✓		✓		✓	took a long time focusing on wife before	✓		✓	Diagnosis of male factor	✓	waiting for fertility appt to begin IVF	x-earlier	x	x	x	x	x
P6	Event 3- self referral to GP	✓	miscarriage	✓	x	✓	x	✓	x	✓	Natural conception before tests	x	x	x	x	x	x	x	x	✓	Natural Conception - Birth
P7	x	✓	x	✓	x	✓	x	✓	Diagnosis of PCOS	✓	x	✓	Diagnosis of female factor	✓	x	x-earlier	x	✓	3 cycles	✓	Conception
P8	x	✓	miscarriage	✓	x	✓	x	✓	diagnosis	x	x	x	x	x	x	x-earlier	Not Eligible for NHS tx	x	x	x	
P9	x	✓		✓		✓		✓		✓		✓	Diagnosis male factor	✓	miscarriage	x-earlier		✓	continued treatment		
P10	x	✓	x	✓	x	✓	x	✓	diagnosis PCOS & male factor	✓	x	x	x	x	x	x-earlier	x	✓	x	✓	back to fertility for third child
P11	x	✓	miscarriage	✓	x	✓	x	✓	x	x	x	x	x	x	x	x	x	x	x	x	x
P12	x	✓	x	✓	x	✓		✓	diagnosis of male factor	✓	x	✓	x	✓	x	x-earlier		✓	in process of tx	x	x
P13	x	✓	x	✓		✓		✓	diagnosis male factor	x	x	x	x	x	x	x-earlier	male factor	✓	x	x	x
P14	x	✓	x	✓	x	✓	x	✓	diagnosis-unexplained	✓	x	✓	diagnosis	x	x	x-earlier	waiting for tx	x	x	x	x
P15	x	✓	Diagnosis of PCOS	x	x	x	x	x	x	✓	x	x	x	x	x	x-earlier	x	✓	miscarriage > tx > miscarriage	✓	conception
P16	x	✓	x	✓	x	✓	x	x	x	✓	x	x	x	x	x	x	x	✓	x	✓	Birth
P17	Event B- miscarriage	✓	x	✓	x	✓	x	✓	diagnosis- female	x	x	x	x	x	x	x-earlier	female factor	x	referred for tx- waiting	x	x
P18	x	✓	x	✓	x	✓	x	✓	x	✓	x	✓	diagnosis	x	x	x-earlier	unexplained	✓	x	✓	conception
P19	x	✓	x	✓	refer to private	x	x	x	x	x	x	x	x	✓	x	✓	unexplained	✓	still in treatment	x	x
P20	Diagnosis of PCOS	✓	x	✓	x	✓	x	✓	medications = birth	x	x	x	x	x	x	x-earlier	x	x	x	✓	birth
P21	x	✓	x	✓	x	✓	not tests- but tried different drugs via GP	x	x	✓	fertility treatment	x	miscarriage	x	x	x	x	✓	x	✓	Conception
P22	x	✓	x	✓	x	✓	x	✓	x	✓	x	✓	diagnosis unexplained	x	x	x-earlier	x	✓	miscarriage > tx	✓	Conception
P23	x	✓	x	✓	x	✓	x	✓	diagnosis both	x	x	x	x	✓	x	x-earlier	x	✓	x	✓	Conception
P24	x	✓	x	✓	x	✓	x	x	x	✓	x	✓	diagnosis unexplained	x	x	x-earlier	unexplained	✓	x	x	x
P25	x	✓	x	✓	x	✓	x	✓	diagnosis male factor	x	x	x	x	✓	x	x-earlier	x	✓	in tx	x	x
P26	x	✓	miscarriage	x	x	x	x	x	x	x	x	x	direct referral to private fertility	✓	clinic tests	✓	male factor	✓	x	✓	Birth
P27	x	✓	x	✓	x	✓	x	✓	x	✓	x	✓	diagnosis	x	x	x-earlier	male factor	✓	in tx	x	x
P28	x	✓	x	✓	x	✓	x	✓	diagnosis both factor	x	x	x	x	✓	x	x-earlier	x	✓	failed	x	x

Figure 6 Example of Excel version of Participant Journey Visualisation

The next level of analysis intended to understand the most common pathway for the participants and then explore how much other participants deviated and whether the deviations were common. This was composed using the programme Lucid Chart¹⁰, as shown in Figure 7, which shows the flow of participants and how their fertility journeys deviated at each stage more clearly than Figure 5 and Figure 6. This Figure clearly shows the beginning of the fertility journey is fairly common but how men proceed is different.

¹⁰ © 2022 Lucid Software Inc. <https://lucid.co/>

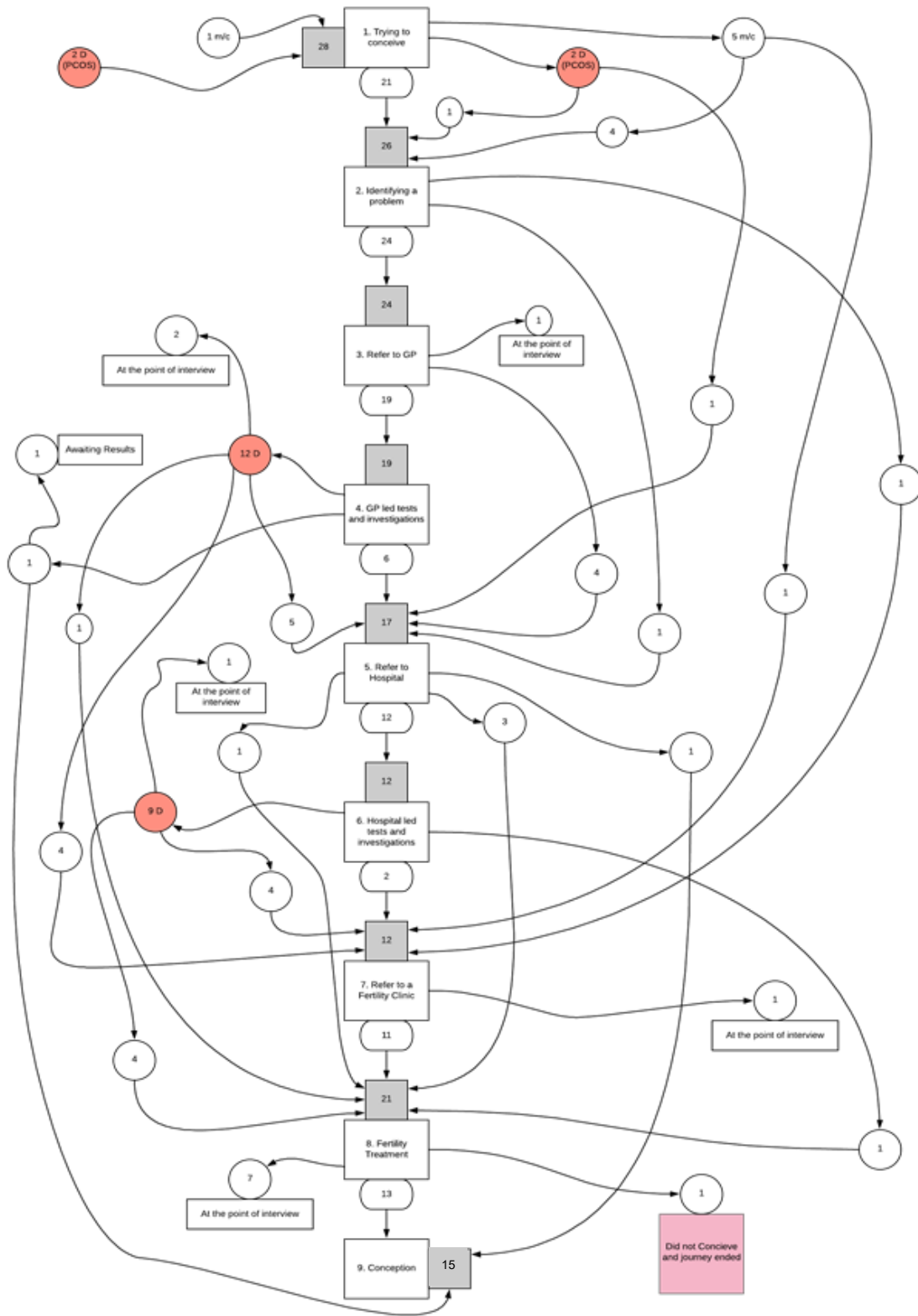


Figure 7 Amalgamated Participant Journey (m/c = miscarriage) (D=Fertility Diagnosis received)

Each participant articulated a journey that enabled the creation of the pathway. Arrows were used to indicate where the participants expressed deviations from the pathway. The numbers indicate participants who experienced each stage of the pathway in Figure 7. It can be seen that participants' fertility journeys are complicated, involving different processes for each couple. The red circle denotes the point and the number of participants who declare having received a fertility-related diagnosis (D) from their healthcare professional. (D) PCOS, describes that the diagnosis received at this point was polycystic ovary syndrome (PCOS), a condition related to the female reproductive system that can affect fertility. The box with the number above the stage name signifies how many participants entered this stage. The number of participants that continued to the subsequent stage is shown in the oval box below the stage.

Participants received their fertility-related diagnoses at varied points through the journey; many men received a fertility-related diagnosis at Stage Four, where they first underwent medical investigations. In total, twenty-four participants received a fertility diagnosis. Of the four men who did not receive a diagnosis, one conceived naturally during the process, and one was undergoing tests and investigations at the point of interview. In addition, two men reported never receiving an actual fertility-related diagnosis.

Of the 28 men interviewed, deviations from the common pathway were generally experienced by only one participant when progressing from Stage One (starting to try to conceive) to Stage Four (being referred for investigations by the GP), but by numerous participants when progressing from Stages Five to Seven.

Some men were referred from their local hospital to specialist fertility clinics, whereas others underwent all of their fertility-related investigations and treatment within the

hospital department. In addition, two men self-referred to private clinics early on due to concerns regarding timing and how long it may take to go through the NHS system.

As mentioned, the ideal endpoint for a couple's fertility journey is conception followed by a healthy birth. Some men mentioned but did not discuss losses during pregnancy in detail. Once a couple conceives, their needs drastically change in comparison to when trying to conceive, therefore, Stage 9 is not discussed or expanded upon in this thesis. At the point of interview, 15 men had conceived with their partners, 12 men were still navigating their fertility journey. One man stated whilst they were not undergoing any treatment, they had not given up hope of conceiving naturally.

6.3 Summary of Findings

Through analysing the interview data, men described their fertility-related experiences by using their interactions with healthcare professionals as structured anchoring points. Therefore, various visualisations were composed to aid the understanding of participants' journeys through data depictions. These visualisations led to a clear common 9 stage fertility journey on which further analysis was based. Understanding the typical pathway and ways in which couples' journeys differ could provide opportunities for healthcare professionals and designers alike to explore how they may support couples through the difficult fertility journey. As can be seen from the various data visualisations, most of the interviewed participants tended to follow this common fertility journey. Therefore, as extracted from raw interview data, the presentation of the fertility journey can be utilised to understand points of intervention and support for men who experience fertility problems. Men's information-seeking behaviours based upon this identified fertility journey is presented in [Chapter 7](#).

Chapter 7 Understanding Men's Information-Seeking Journey through their Fertility Journey

Contributions from this Chapter:

- This chapter presents an understanding of how men who experience fertility difficulties follow the Information Journey model to acquire, make sense of, find meaning, and use information.

Chapter Summary:

This chapter provides a brief overview of the literature on information-seeking and how I used an adapted version of the information journey model to frame my data. Next, I outline how men recognised the need for information, what sources of information they used, what information they found and how they used this information at each stage of their fertility journey. I then summarise this data in Table 3. Finally, I discuss barriers to men's information-seeking behaviours and whether fertility-related diagnoses affects information-seeking.

7.1 Introduction

During the inductive analysis, I identified that men wanted and looked for information for support during their fertility journeys. Therefore, to answer my second research question, *“What are the informational needs of men who experience fertility difficulties?”*, I carried out an in-depth deductive thematic analysis to understand what information was needed, what sources of information were used, what information was found and how this information was used at each stage of the fertility journey presented in [Chapter 6](#). This is based on the basic information journey model as presented by ([Blandford and Attfield., 2010](#)) but is adapted to specifically reflect the information behaviours of men who

experienced fertility difficulties. The act of information-seeking is not limited to wanting information and then acquiring it. Cognitive work needs to be undertaken to find the appropriate information and make sense of it. This framework was applied to my data set after the data had been collected; therefore, the adaptations to the model account for differences observed in this dataset, which are appropriately described. As the fertility journey was also developed once data collection was complete, participants were not explicitly asked to share what information was sought and used at each stage of their fertility journey. Therefore, not all men share their information-seeking needs at each specific stage of the fertility journey.

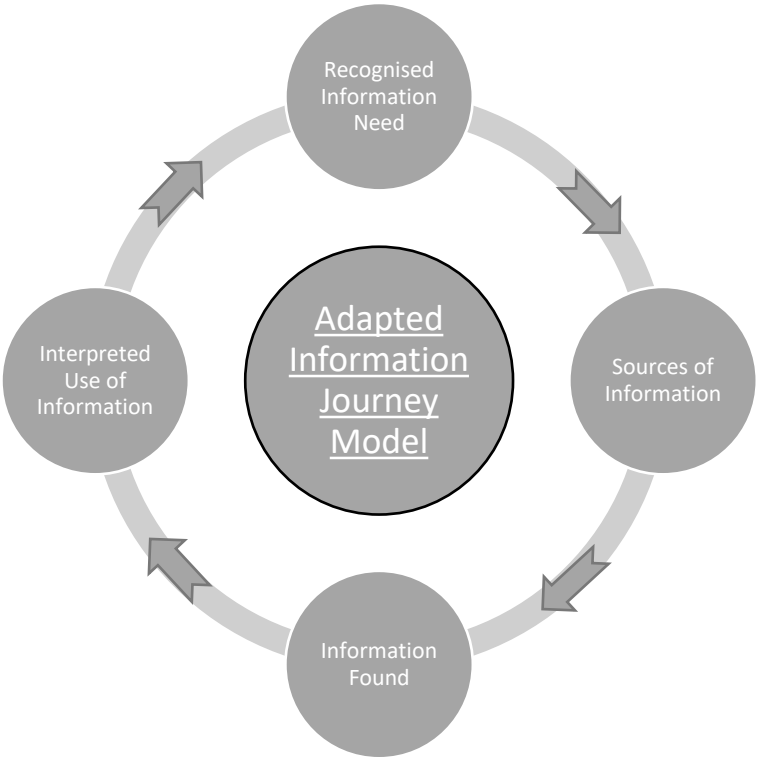


Figure 8 An Adapted Information Journey from Blandford & Attfield (2010), as Experienced by Men who have Fertility Difficulties

To understand men's information-seeking behaviours, it is helpful to understand the motivations behind the need for information, which I articulate under the "recognised information need" stage from the adapted information journey model.

The process of finding information can be further divided into understanding what sources of data men chose to explore and what information was found. Therefore, I divide this step into two stages, *sources of information* and *information found*, as shown in Figure 8. This can also help us comprehend men's current practices and allow us to see what mediums of information delivery would be best suited for this population, as well as understand the content of information that is currently available.

Validating information can be understood as assessing the reliability of information sought ([Blandford and Attfield., 2010](#)) related to sense-making in that evaluating reliability also helps to understand and make sense of information gathered. However, men were not asked how they validated specific information found. Instead, participants were asked broadly how they assessed the validity and reliability of information found, but again not specific to each fertility stage. These broad descriptions of the barriers to information seeking are discussed in [7.3](#), including descriptions of how sources of information were chosen and how men evaluated their reliability. Therefore, in [7.2](#), I do not discuss validating information at each stage of the fertility journey.

Interpreting information can be understood as meaning-making following sensing ([Faisal et al., 2013](#), [Ruthven, 2019](#)), as finding meaning in information and then implementing the interpretation of information to your context can be considered an act of validation ([Burgess et al., 2019](#)). If participants had chosen to use the information found, that in itself can be understood to be giving the information meaning ([Zhang and Soergel, 2014](#))., In

this analysis, I examine men's information behaviours of how *interpreted information was used* to discuss how men made sense of information found and gave that information meaning when interpreting it into their context through use.

Stage 9 'Conception' from the composed fertility journey in [Chapter 6](#) is omitted from this analysis. This was discussed as an optimal end-point in men's fertility journey and not a stage where further fertility-related information and support was required; therefore is out of scope for this thesis.

7.2 Men's Information-Seeking Behaviours along their Fertility Journey

The analysis was conducted where each mention of information was coded to the relevant stage of their fertility journey from Stages 1-8. I then explored each stage in detail to further code the data into four subcategories; (1) Recognised Information Need, (2) Sources of Information, (3) Information Found and (4) Use of Information.

This analysis made it possible to identify what men's key requirements were through their fertility journey, what sources of information were most used, what was missing to understand what information men wanted through their fertility journey and how best to deliver this. A summary of these findings is shown in Table 3, after the results ([7.2.9](#)).

7.2.1 Stage One, Trying to Conceive.

Right at the beginning of the process of trying to conceive, little formal information is sought. However, of the 28 participants interviewed, 11 men shared that once some time had passed after they began to try and conceive with their partner, they visited their General Practitioner (GP) for advice, information, and support. Twelve months was the

most common time frame as couples seemed to know they would not receive specialist support from their GP unless they had been trying for one year.

“I mean I've read a few things, and they were saying like don't even go to the Dr until you've been trying at least 12 months.” (P28)

Some men shared particular information needs at this early stage of trying to conceive before seeing their GP.

Recognised Information Need

Commonly men initially stated that once they and their partner had decided to try to conceive, they stopped using their chosen method of contraception and then simply waited to see what happened.

Of the ten men that specifically stated why they looked for the information before a difficulty in conception was identified, three said their partner had a known diagnosis of polycystic ovary syndrome (PCOS). In addition, one shared that their partner had another condition that affected their hormones and ability to conceive, leading them to seek medical advice.

“And then we started [looking for information] because her hormones were having issues, well she was having issues with her hormones, she's having issues with her periods, she got PCOS.” (P15)

“My wife has chronic fatigue syndrome, and for a long time she was on various hormone treatments that basically meant that she didn't have periods, she couldn't get pregnant, we couldn't get pregnant.” (P4)

Two men shared that their partner had irregular periods for known or unknown reasons and therefore looked into tracking and timing their partner's menstrual cycle to identify

ovulation and when to have sexual intercourse. Three men said they or their partner looked for information or support on tracking the menstrual cycle without known menstruation concerns.

“The first few months we just sort of, just didn't do anything we just tried to conceive. And then I suppose after the third month around that time that was when, my wife started looking at this app to identify when she was ovulating.” (P18)

Another participant who shared they looked for information before they were aware of a fertility concern said they did so to understand how often he and his partner should have intercourse and general health and diet information that could support successful conception.

“It was just all the standard things like how regularly you should be trying what you should be doing health-wise.” (P24)

The remaining participants did not clearly articulate a need for information at this stage. This could be due to not being explicitly asked during the interview or not identifying a requirement for information.

Sources of Information

Next, I explored which sources of information were used. 16 men expressly stated where they looked for or found information; the most common source was the internet. Online sources varied between search engines, where Google was most commonly used, social media sites or online forums.

“I think we were looking at a bunch of places, but Facebook, Mumsnet. She even found some stuff on Instagram.” (P7)

“The usual Google searches for information. which I can’t remember specific things from that, but there have been odds and ends from that.” (P11)

The next most common source of information was asking and sharing with friends and family. If participants were not already parents, family members or friends who had children or had had difficulty having children were chosen to share with, thus trying to learn from their experiences.

*“One thing I did do though is I did talk to two of my friends who have been through it.”
(P13)*

Smart phone applications and tracking technologies, such as fertility monitors, were also used in these early stages to understand the menstrual cycle and find the optimal time to try and successfully conceive.

Two participants stated books as a source of information and thought to be credible reference points. Finally, two participants also mentioned visiting their GP. One shared they went with their partner, and the other said their wife went to get information for both of them.

Information Found

At this early stage, few men clearly articulated what information was found; at this stage, they didn’t think there was any cause for concern. The main topics revolved around timing and frequency of intercourse, health, diet and lifestyle and general tips and advice on how to conceive successfully.

“It was just all the standard things like how regularly you should be trying, what you should be doing health-wise and eating and what vitamins you should be taking” (P24)

“And also, just any sort of literature around top 10 ways to get pregnant” (P19)

Interpreted Use of Information

There was some discussion about the changes in lifestyle behaviours that can support healthy conception, such as reducing stress in their daily lives and stopping smoking.

“So, you know, think, started thinking about jobs. What stresses have we got in our jobs? What do we want more of in our lives? As a couple, as individuals, you know, we set ourselves individual goals as well as goals that we want to achieve together.” (P15)

Some couples began taking additional supplements after getting advice that it could contribute to healthier conceptions.

“I was taking the Wellman as well. The ‘his and hers’ conception and whatever it is, so I was doing that as well. So, anything to help.” (P20)

These actions can be interpreted as making sense and finding meaning in information, as it has been interpreted and given significance by being implemented into their lives.

7.2.2 Stage Two, Identifying a Problem.

Stage Two of the fertility journey, defined as identifying a problem with conception, was not well described by the participants. However, it was a necessary step that led couples to seek information and support from many sources, but this was primarily within or after Stage Three of their fertility journey.

Recognised Information Need

Most participants stated their information need at this point was motivated by the fact that they had been trying to conceive for some time and *“nothing seemed to be happening”*. Only one participant specifically mentioned needing information about their partner’s pre-existing health condition during Stage two.

“My wife went to see her GP because she was having issues such as quite heavy periods and prolonged periods” (P5)

Sources of Information

At this stage, three primary sources of information were referred to, seeing their GP (Stage Three), using internet search engines or online forums and social media, and lastly, using technology in the form of phone applications (apps), fertility monitors or home testing kits.

“There's mainly like online forms and stuff. From other people who are trying for children and from other women who are trying for children. I think there is an ovulation app? [...] That's got lots of information on.” (P17)

Information Found

Once they realised conception was proving difficult, participants sought sources of information to help improve conception rates. For example, one participant shared how they used phone apps to identify optimal windows to improve conception chances. Another stated they looked for health and lifestyle advice that could help improve their fertility chances. Whilst this motivation is evident throughout all stages of the fertility journey, it was a particular motivation in this Stage.

“...[We] got an app for tracking her cycles, when would be the optimum time to be trying, when would her windows of ovulation be...” (P14)

“I was looking at the diet side of things as well to see if there's anything you know, in our lifestyle, we could easily change.” (P18)

Information was also found to help participants understand why conception may not be occurring.

“...the wife had bought this kit that you buy to analyse your sperm sample.” (P12)

Interpreted Use of Information

Once couples made sense of the possible explanations for why conception may not be occurring, they followed the advice from the information they found. This included targeting points in the menstrual cycle and carrying out home-based fertility tests.

“Then we started to target sort of windows of the month basically based on that [app data]. That went on for a good year or so and nothing really happened.” (P7)

“So, the first test I actually did was a home [sperm] test kit. When that came up with a negative result, we thought, oh okay maybe it is worth going through a professional”
(P12)

Some men interpreted the advice found online about health and lifestyle changes that could improve fertility, including the use of vitamins and supplements in their behaviours; for others, the next step was to see a health care professional to pursue clinical investigations.

7.2.3 Stage Three, Refer to GP

Twenty-three participants discussed Stage Three, seeing their General Practitioner (GP), which was most commonly the first port of call when seeking health advice from a healthcare professional. GPs were the gateway to further health care when navigating the UK national health service (NHS) system. Here men discuss receiving or, in some cases, not receiving information to understand their fertility-related health.

Recognised Information Need

The most common reason for visiting the GP was that couples had been trying to conceive for a while without success and therefore sought advice to understand why.

“And then probably after two years, we went to the GP to, to express the fact that it wasn't happening, naturally.” (P25)

“...it got to a point where it's like, it's taking a long time and we're not getting the result that we would like. We went through our GP.” (P27)

Other reasons included medical conditions that may affect conception, such as PCOS or irregular menstrual cycles.

“[...]she [wife] already knew it may be a struggle she started the conversation then anyway... So, the first time I went to the doctor myself and I said that my wife is having this done and I'd like to get tested and the doctor just wrote me a referral” (P20)

One participant mentioned that they went to their GP before identifying difficulties in conception. They shared their need for preconception care and advice to increase the chances of a healthy conception.

“I think the first thing we did was go to the GP and said we were thinking of trying is there anything we need to do?” (P6)

Men shared that they wanted information and advice on things they could do themselves without medical intervention to improve their fertility.

“I mean I've looked online to see if there's anything that like guys specifically can do to help themselves if it is to do with the guy.” (P8)

Sources of Information

The primary sources of information shared by participants were GP led tests and investigations, which are discussed in Stage Four. Other sources of information used at this point were online resources, such as search engines, social media, and online forums for peer support.

“Well, I looked at Facebook and forums.” (P17)

Information Found

Several participants reported receiving generic lifestyle and dietary advice; others stated that they did not get much information or advice from the GP.

“Whenever you go to the GP, they say lose a bit of weight, do a bit more exercise, eat less salt, the usual advice.” (P22)

“If there's anything to discuss, then we'll call you in. And they didn't... but no, no advice, no, nothing like that.” (P20)

[when asked: Did your GP give you any information or advice?]

“Not really.” (P21)

“Not in any great detail, no I don't think they did. I think it was pretty much sign the form, shake my hand, and said good luck and handed us straight over to the unit.” (P22)

Due to this lack of information, many looked online for information and support. In addition, participants shared that they sought information from peers who may have experienced similar things and had tried and tested advice.

“I found a couple of groups online, just random forums things like where guys were saying like, the things that they've been eating and the exercises that they've been doing and stuff like that. To try and help their lifestyle and boost it so then they get higher fertility.” (P8)

Interpreted Use of Information

Some men spoke about changing their lifestyle behaviours at this stage, such as adapting to a healthier diet or taking recommended vitamins and supplements; however, it did not seem this behaviour change resulted from information or advice from the GP.

“We had by that time already started making some lifestyle changes in terms of drinking less and, I was going to the gym a bit more and just generally trying to look after ourselves.” (P7)

“It's like increase zinc in your diet, pine nuts are a good source of source of zinc and stuff like that. That's what I learned through the research.” (P20)

Others spoke about the services or procedures they were referred for from the GP, these included semen analyses or investigations for their partner.

7.2.4 Stage Four, GP led tests and Investigations

Here men discuss undergoing tests and investigations referred by the GP to understand their fertility-related health.

Recognised Information Need

As mentioned, participants often visited their GP once difficulties in conception were recognised. Men expected the GP to arrange tests and investigations to understand their reproductive health and fertility problems.

“They did some tests on me, on my sperm, as I think, a by-product to sort of rule that out.” (P10)

Sources of Information

The primary source of information in this stage was through tests and investigations. Most participants were asked to undergo semen analysis investigations and, in rare cases, blood tests. Their female partners were referred for more invasive tests and examinations.

“I had to do a semen analysis. I had to do those three times. My wife had blood tests and also a couple of scans.” (P27)

“...So initially all the focus was on my wife... Then probably a year and a half later, then they kinda said, ‘let’s get me tested’.” (P5)

Participants shared that it took some time before their GP focused on them as the priority seemed to be investigating their female partner's health factors first.

Information Found

Many participants shared that their first semen analysis investigation was through their GP, and therefore the results of this test dictated the next step in their fertility journey.

“When we received the information back about that, there was flags in my semen sample, so because of that, we got fast tracked to IVF” (P25)

“And the fact that I had sort of a low sperm count and the concentration wasn't great, so I had a bit of, you know, both elements were rubbish, basically, the way they sort of put it and they made it out, like the only way we could conceive was through IVF.” (P9)

Participants were often referred to specialist services, and GPs were seen as gatekeepers to further care.

Interpreted Use of Information

As mentioned above, as most of the information sought from the GP was through tests, investigations, and referrals to specialist care, participants found meaning in the results and followed this guidance. Others spoke about the services they were referred to for further investigations or to begin assisted fertility procedures.

“It was more what the test showed and then we went to the hospital to the gynaecological department.” (P23)

“Different tests that they did, different samples, they all came back okay. They decided that they couldn't see anything wrong with us, and as it had been over 18 months of trying, they'd refer us to [the] hospital for further investigation.” (P14)

Some participants shared that their GP did not help interpret the findings from tests and investigations, so they had to use other sources of information to make sense of their results.

“no one explained anything to me as to what the results of the analysis were, so I searched online myself. Going through all the categories, searching, trying to understand.” (P27)

7.2.5 Stage Five, Refer to Hospital

Stage Five denotes the process of being referred from the GP to fertility or gynaecology services at a hospital. Less than half of the participants (11 in total) mentioned their information journey at this stage.

Recognised Information Need

At this stage, men describe the reasoning behind being referred to other care, which explains their need for information.

The most common reason for further referral was the absence of conception even after seeing their GP, leading to more specialist care.

“We didn't have any success so got referred to hospitals, etc.” (P21)

One participant described their need for a second opinion besides their GP. They felt they were not getting the information or attention they expected and therefore arranged for further referrals to specialist care.

“I wanted a second opinion because I felt when I went to my urologist, it just ended. Like, in five minutes, I just felt like there was no support or no comfort or you can try this or try that and so forth” (P5)

Sources of Information

Three different sources of information were described at this stage. The first was the referring physician; usually, the GP would tell participants what to expect from being referred to the hospital. This could be a basic description of fertility treatment or the timelines to expect appointments.

“He [GP] said it will probably be in January time after Christmas so he said it would just be a local hospital, they will take a sample from me and then they will do a count, to see if I’m healthy and stuff like that...” (P8)

The second source mentioned was using the internet and online forums to find out what to expect.

“...when I found out about my situation, I went on Mumsnet there just to see if anyone else [was] in a similar situation.” (P5)

Lastly, one participant shared that the hospital they were referred to had arranged a patient information evening, which they found helpful.

“They had a patient information evening, where they had a previous patient who went through everything that had happened in almost lecture level of detail” (P22)

Information Found

As mentioned above, some men found out what to expect during fertility treatment. In addition, one participant said they were given health and lifestyle advice from healthcare professionals.

Others said they received no information or advice from healthcare professionals once they were referred to the specialist services.

Interpreted Use of Information

In this stage, the only mention of implementing validated information was following health and lifestyle advice. Men said they trusted the advice given as expert healthcare professionals provided it. One participant who attended the information evening said they took what they were told on board.

“I took it [the information given] and went with it and it worked out in the end, so that’s the only comment I can make.” (P22)

7.2.6 Stage Six, Hospital led Tests and Investigations

18 men described the tests and investigations they and their partners underwent once they were referred to the hospital.

Recognised Information Need

At this stage, the need for information is scarcely discussed. However, of those that did, four reasons were shared. The first was to know what they could do to improve their fertility prognosis. The second was the need to understand what was causing their fertility problems.

“I kept asking the question, so why is my sperm count low? What's causing it? Have I done something in the past? Have I got an underlying medical problem that is causing it?” (P2)

Thirdly, to understand the results of tests and investigations, mainly semen analyses, and finally, the need to understand the fertility treatment they were likely to begin. Men discussed not knowing what would happen or the sequence of appointments or investigations.

“...because it was the first time, I've had to do anything like this. So, I had no idea what the whole process was going to entail” (P8)

Sources of Information

To obtain information, men mostly referred to tests and investigations as sources of information. These enabled couples to understand their fertility prognoses and what further steps would be available to conceive.

Some men shared that healthcare professionals provided them with support and information by explaining procedures. However, four others specifically detailed how their healthcare professional did not provide them with any information.

[When asked if healthcare professionals had provided any information]

“Not really.” (P21)

“No. That’s one of the things that was quite bad in the process and still is, to be honest.” (P2)

Online sources, such as search engines and NHS health websites, were again used to understand this stage of their fertility journey, as they were seen as reliable and trustworthy.

“I was looking on the NHS website. I remember googling that, it was just stuff on there.” (P14)

Finally, one participant shared that their partner was their primary source of information besides their online searching.

“Most of what I’ve learnt has either been through my wife or through doing some research online.” (P27)

Information Found

Following on from above, the fundamental need and sources of information were in the form of tests and investigations; the main types of information found were the results and diagnoses based on these investigations.

“We were told the fact that it was a male as well as a female factor... We were told what the factors were, but there was not necessarily information out there for us. or even advice out there for us on what we could actually do to help the situation.” (P6)

Some information was provided regarding basic health and lifestyle regarding supplements or diets. However, the main complaint shared by multiple participants at this point was that men were not told how they could help their fertility diagnosis.

“...so obviously going through the process then it was upsetting because you're just left in the lurch there's no other help...” (P1)

“And there wasn't even any discussion about, ‘well, I could do this, or my wife could do that.’ It was like, okay, both of these things mean this, so the best thing that you can do is IVF.” (P28)

This lack of information was seen as a lack of support, and couples felt that their choices were limited.

Interpreted Use of Information

The obtained information was utilised in two ways. First, men interpreted these recommendations into their health and lifestyle behaviours or used the results as a basis for further referral. Most commonly, couples were referred to fertility treatment at this point in their journey.

“The report that we got was literally six words, and so we were sent home, at which point we started investigating IVF.” (P7)

“...like it was straight to IVF. So, no other options were given, and so we put in an application for IVF basically.” (P5)

“...we were advised to do IVF.” (P4)

“So, we then got referred to IVF.” (P21)

7.2.7 Stage Seven, Refer to a Specialist Fertility Clinic

Men spoke about how they chose which specialist fertility clinic to be referred to and what information and support they were or, in some cases, were not given once they were at the clinic before the commencement of fertility treatment.

Recognised Information Need

At this point, several men expressed not receiving information or support from the clinic staff. Some attribute it to there not being anything they can do at this point in their fertility journey. If they had been referred to begin assisted reproductive fertility treatment, they felt there was nothing left for them to do individually. It was now in the hands of the clinical fertility healthcare professionals.

“For unexplained infertility, there wasn't anything that said, ‘this is what you need to do’, because no one knows what to do. Just do IVF.” (P18)

One participant stated their information need at the point of referral was to understand the clinic’s success rates with fertility treatment. This helped their decision-making process over what clinic they would choose to undertake their treatment.

The crucial expressed need for information was support regarding the fertility treatment they were about to begin. Men often mentioned that when couples were on the cusp of starting fertility treatment, they felt overwhelmed and looked for information and support from healthcare professionals and within their existing networks.

“...our parents are all very tactful... I suppose we wanted to sort of head that off a bit, but also just get support from them as well because we knew it was going to be a really rough journey and a difficult road.” (P10)

“Obviously, they [Fertility Clinicians] explain things to you, but sometimes kind of when you go for appointments, it can be quite overwhelming. I don't necessarily take everything in that they say. So, you can look into things, like into what they're actually doing.” (P21)

Men also mentioned a need for information and education about fertility awareness and sexual education. They felt women were more informed and men were not. One participant gave the example of “fertility cliffs”, which is a description attributed to the reproductive ability of an individual, often believed to dramatically decrease at a particular age, as knowledge women are more likely to have over men.

“For instance, one example would be the fertility cliffs. I kind of knew there was some, I couldn't have told you when those dates were or those years were, and I couldn't have told you the percentages. I think a lot of that stuff is very missing from a man's perspective; you just don't know it; you don't come across it.” (P26)

Sources of Information

As with many other stages, looking online was a popular source of information. Men discussed using the HFEA (Human Fertilisation and Embryology Authority), independent fertility treatment and research regulator, and NHS websites for accurate, reliable data. Online forums were also used to gain information regarding others' experiences and thoughts on fertility treatment.

“I was looking at different IVF clinics and things, just on their websites. It's on the HFEA.” (P7)

Books and podcasts were also mentioned as sources of information to understand and learn from the experiences of others

“I mean there are books out there that you can read about how to boost your chances of falling pregnant [during fertility treatment]. My wife read one and said, basically said, ‘read this’, so I did.” (P4)

Men discussed the use of further exploratory tests and investigations to provide information, and some healthcare professionals as they provided detailed accounts of what to expect.

“So, I trust what the [health] professionals are telling me basically. The information they gave us at the start of the process, I think they gave us some booklets and some leaflets and stuff like that.” (P2)

Finally, for emotional support and understanding, men said they spoke to friends and family and utilised clinic-based counselling services, which helped them find meaning in their fertility journey.

“We had to have 4-5 sessions [of counselling] before they even put you through to IUI and IVF. I found that really helpful...” (P12)

Information Found

The most common information found was regarding health, diet, and lifestyle advice to optimise the success of the upcoming fertility treatment.

“It was probably going to be things like health, things that I could eat, to make sure that my sperm was, you know, working at the highest level. Exercise that I could do...” (P15)

“...Like here you go. here's all the food that you should be eating here is the dietary requirements, what you should be doing.” (P9)

Information was also gleaned from the tests and investigations undertaken before fertility treatment. The results of which often affected what course of treatment was most appropriate.

Some men said they were told about the fertility treatment process in detail by healthcare professionals, whilst others felt quite unprepared and uninformed at this stage.

“They sent us straight to the IVF clinic to start the process really and yeah to be honest there's not really any support for me, there's nothing for men.” (P23)

“I think I would have liked to have had a better understanding of what was going on at each stage.” (P7)

Interpreted Use of Information

Men then made sense of the information provided by seeking multiple sources for validation and then implemented mainly through altering lifestyle behaviours, such as taking supplements and changing their diet.

“I was given advice on how to improve and given some medication as well. Proxseed [supplement brand name].” (P19)

“I mean I found that there was rubbish food I was eating whilst we were trying. So, [I] cut that out.” (P17)

“And that talks about lifestyle, and diet, and exercise, and smoking, and drinking. And it was, yes, it was helpful. And I started taking vitamin supplements, and reducing the amount of alcohol I drank, and trying to be healthy.” (P4)

7.2.8 Stage Eight, Fertility Treatment

At this stage of men's fertility journey, not many participants spoke about the information they found and implemented but focused on how they felt going through the assisted fertility treatment.

There was a lot of emphasis on what information and support they wished they had and what they believed would have been helpful. Men who had or were currently going through fertility treatment shared how difficult a process it was to follow. There were complexities regarding medication administration and specific timing of procedures that had to be precise for success. Managing the fertility regime was particularly difficult for some men.

Recognised Information Need

As mentioned,, the need for information and support was quite strong at this Stage, which centred around two main topics.

The first was wanting information and support regarding fertility treatment. This referred to understanding the details of the fertility protocol they would follow and the details and implications of the many medications they would be taking. Protocols varied greatly between participants and were extremely sensitive to external factors. For success, medications had to be prepared and administered at specific times and over days and weeks. It was a highly stressful and pressured time for couples. Men shared that they were surprised that fertility clinics did not have digital tools to support this process, specifically mobile applications.

“...and also the effects of the medication, because frankly... she [wife] takes 24 tablets a day, and I don't know what the vast majority of them do, and what the side-effects might be.” (P4)

“I realise that the doses need to be managed on an almost real-time basis, but that can be done through so many different types of technology. Also, it would be great if I could monitor that and be up to speed with what was going on.” (P7)

Participants also wished they had information and support for their emotional well-being at this stage. This could be either through formal support from counselling services or peers to help them navigate the emotionally heavy process.

“...over time we’ve talked, and now that we’re going through IVF, we’ve basically told all our friends that we’re doing it and didn’t keep it a secret because we wanted their support really, because at the time it was very difficult.” (P4)

Men also wanted more information on how to better understand their partner’s perspective of having to endure fertility treatment and being able to support them emotionally.

“...think my wife would agree in saying there are some things you cannot say to each other during it. I suppose some people can, but we didn’t want to say it to each other, so there might have been some searches around that, but I don’t think I found [anything helpful]...” (P26)

Sources of Information

While acquiring information was not discussed in great detail, the sources used were online search engines, forums, and peers for information and support.

“I was looking at forums and things like that” (P7)

“So, we were collecting a lot of information from people on forums, from friends, from scientific literature, sort of systematic reviews and things, about anything that was kind of evidence-based or looked like there might be some evidence behind it.” (P10)

Some men said they got information from fertility clinic staff and clinic-based counsellors.

Information Found

From the sources of information mentioned, men discussed obtaining information about health and lifestyle from healthcare professionals during fertility treatment. They also

received rudimentary information about the protocol and the medications they would be taking.

“They kind of keep the science and what’s going on as a bit of a voodoo art that they don’t want you to really know too much about it and there isn’t really any information.”

(P7)

“Yeah, their advice was what I mentioned earlier about no drugs, limit your caffeine, you can limit your alcohol, eat a balanced diet, try and be healthy... It wasn't tailored or structured or specific. It was just this is the general advice we give.” (P18)

However, most commonly, men discussed how inaccessible or unhelpful information was. For example, men said they were given medication and treatment in a format that was hard to make sense of.

“At one point, we counted, and she was on 19 different medications, combinations, tablets, pessaries, and they were all to be taken on a different rhythm, so one was three times a day, one was before meals, one was after meals. All of this was just provided on a bunch of pieces of paper and actually [...] When I went into the clinics and saw the doctors or the nurses, I said you said that, but this piece of paper says that and that piece of paper that you gave me two weeks ago says this and they conflict and they’re like just look at the latest piece of paper. It’s all done in a very paper-based way, it’s all done very old school. There is a lot that could be improved to give better real-time tracking and real-time communication around doses.” (P7)

Multiple men also spoke about the unhelpfulness of information that they found online. For example, it was not helpful to hear others complaining or being told their feelings were invalid.

“Some of it was ranting men on blogs, not particularly useful. Although because it’s not constructive, it’s sort of nice to know someone else has been thinking the same thing. But then you read it and think I’m not sure if I like them. There’s a lot of things that say

'toughen up, your wife is getting it much worse however bad you think it is'. That's not useful, that actually makes you resent those posts.' (P26)

Interpreted Use of Information

As mentioned, men spoke very little about useful information they obtained at this Stage. Therefore, the main sense-making activities undertaken at this stage were limited to understanding the fertility treatment protocol. We can see how men implemented meaning-making to make changes in their lifestyle behaviours to help the success of the treatment.

"Yes, so my wife stopped all alcohol and caffeine... I didn't make a huge amount. Not that I drink very much at all anyway, but I did stop drinking for the IVF cycles as it were." (P26)

"...we didn't drink for three months. We don't drink tea or coffee anyway, so that was fine. And we started on super foods, like food in your diet that help eggs and sperm and the lining of the womb." (P18)

As one participant mentioned, they would try anything at this point if it would help them conceive.

"Because when you're trying to get pregnant, people are trying anything." (P18)

7.2.9 Summary of the Findings of Information-Seeking Behaviours

The in-depth analysis of men's information-seeking behaviours through their fertility journey is complex. Participants described wanting clinical and health-based advice during their fertility journey, which was expected as men were relaying their needs about their encounters with healthcare professionals. Men described how they made sense of the information provided and used supplementary sources of information, mainly online resources, to help make sense of the advice their healthcare professionals gave. Men then

interpreted this information and found meaning in the information by using this information to adapt their behaviours. For ease of comparison and review, Table 3 summarises the findings from this chapter.

Table 3 shows men's information needs, what sources of information were used, and how men made sense of and how meaning was made from this information at each stage. Online sources of information seemed to be the most common source of information used throughout the fertility journey, irrespective of information need.

Fertility Journey Stage	Information Need	Sources of Information	Sense-making	Meaning-making
One: Trying to Conceive	<ul style="list-style-type: none"> • Female partner had existing medical conditions that affected conception • Female partner had irregular menstrual cycles • Wanted to track menstrual cycles to increase chances of conception • Participant wanted fertility awareness information 	<ul style="list-style-type: none"> • Online Sources; search engines, social media sites and online forums • Friends and Family • Books 	<ul style="list-style-type: none"> • Understanding the timing and frequency of intercourse for conception • Health, diet, and lifestyle tips to help conception • General tips and advice on how to successfully conceive 	<ul style="list-style-type: none"> • Changed health behaviours such as taking supplements and reducing smoking • Changed lifestyle behaviours to reduce stress
Two: Identifying a Problem	<ul style="list-style-type: none"> • Couples were yet to conceive after trying for what they considered to be a long time, therefore, wanted to understand why 	<ul style="list-style-type: none"> • Online Sources; search engines, social media, and online forums • Phone applications • Fertility monitors 	<ul style="list-style-type: none"> • Health advice from forums to identify why conception was not occurring • Used apps to identify optimal time to conceive each month 	<ul style="list-style-type: none"> • Followed advice from experienced others to target times of the month to conceive • Changed health behaviours, such as changing diet and taking vitamins and supplements to improve chances of conception
Three: Seeing a General Practitioner	<ul style="list-style-type: none"> • To understand why they weren't conceiving • Support for existing medical conditions • Preconception and fertility advice • Non-medical advice on how to improve fertility 	<ul style="list-style-type: none"> • General Practitioner 	<ul style="list-style-type: none"> • Making sense of generic health and lifestyle advice to improve chances of conception 	<ul style="list-style-type: none"> • Changed their diet and lifestyle based on advice from GP and from experienced others.
Four: GP led Tests and Investigations	<ul style="list-style-type: none"> • To understand why conception was not happening 	<ul style="list-style-type: none"> • Exploratory tests and investigations 	<ul style="list-style-type: none"> • Given results of tests and investigations and left to interpret them • Understanding what further referrals were needed to specialist fertility care 	<ul style="list-style-type: none"> • Understood what their test results meant by using online information and forums

<p>Five: Being Referred to a Hospital</p>	<ul style="list-style-type: none"> • To understand why conception was not happening • For a second opinion after their General Practitioner 	<ul style="list-style-type: none"> • Online Sources; online forums • Information Evenings hosted by healthcare professionals 	<ul style="list-style-type: none"> • Health and lifestyle advice 	<ul style="list-style-type: none"> • Changed diet and lifestyle behaviours
<p>Six: Hospital led Tests and Investigations</p>	<ul style="list-style-type: none"> • Understand how to improve their fertility prognosis • Understand what was causing their subfertility • Understand the results of exploratory tests • Understand the components of fertility treatment 	<ul style="list-style-type: none"> • Exploratory tests and investigations • Clinical healthcare professionals 	<ul style="list-style-type: none"> • Results of tests and investigations, mainly fertility diagnoses from healthcare professionals and online sources • Diet, health, and lifestyle advice 	<ul style="list-style-type: none"> • Changed diet and lifestyle behaviours • Acceptance that they needed to begin assisted fertility treatment to conceive due to results of investigations
<p>Seven: Being referred to a Specialist Fertility Clinic</p>	<ul style="list-style-type: none"> • Understand fertility clinic's success rates • Wanting information about fertility treatment • Learn about fertility awareness 	<ul style="list-style-type: none"> • Online Sources; websites, online forums, podcasts • Books • Friends and family • Further tests and investigations 	<ul style="list-style-type: none"> • Health, diet, and lifestyle advice • Results of tests and investigations • Information about upcoming fertility treatment options 	<ul style="list-style-type: none"> • Changed dietary behaviours to help improve the chances of fertility treatment succeeding
<p>Eight: Fertility Treatment</p>	<ul style="list-style-type: none"> • Understand the details and implications of fertility treatment procedures • Understand the effects of fertility medications • More support to manage the treatment appointments and protocols • Emotional support to manage the procedures and to be able to support their partner 	<ul style="list-style-type: none"> • Online Sources; search engines, online forums • Friends and family • Health care professionals 	<ul style="list-style-type: none"> • Basic information about fertility protocols and how to manage emotions when undergoing fertility treatment 	<ul style="list-style-type: none"> • Changed dietary behaviours to help improve the chances of fertility treatment succeeding

Table 3 A Review of Men's Information Journey

Using the information journey as a lens to analyse my data, I present an adapted information journey of men's information-seeking behaviours. I detail how men make sense of and find meaning by interpreting and using information. I illustrate that men's needs change and evolve through the stages of their fertility journey. Men begin by focusing on the causes and trying to make sense of why conception is not happening for them, then move on to try and make sense and find meaning in navigating fertility treatment. For some, making sense of information and finding meaning helped them to understand what was expected at each stage, or what was normal.

From these findings, we can see how the instantiation model of 'finding a new normal' presented in 4.5.1, applies to the population of men interviewed. The model is shown in Figure 9 for illustrative purposes; (for the full image, please see [4.5.1](#)). The journey of understanding and accepting what is normal also evolves through the fertility journey. First, Stage 1, Trying to Conceive, directly corresponds with the (1) No-illness Normal, and Stage 2 of Identifying a Problem, is unexpected and breaks down their anticipated normal journey to parenthood. that is correlated with (2) Breakdown of Normal.

"Because everyone just expects to get married and then have kids. That's it." (P11)

"...we kind of didn't really think we'd have any issues with it[conception] kind of thing.

We kind of went with it, like most people kind of normally do." (P21)

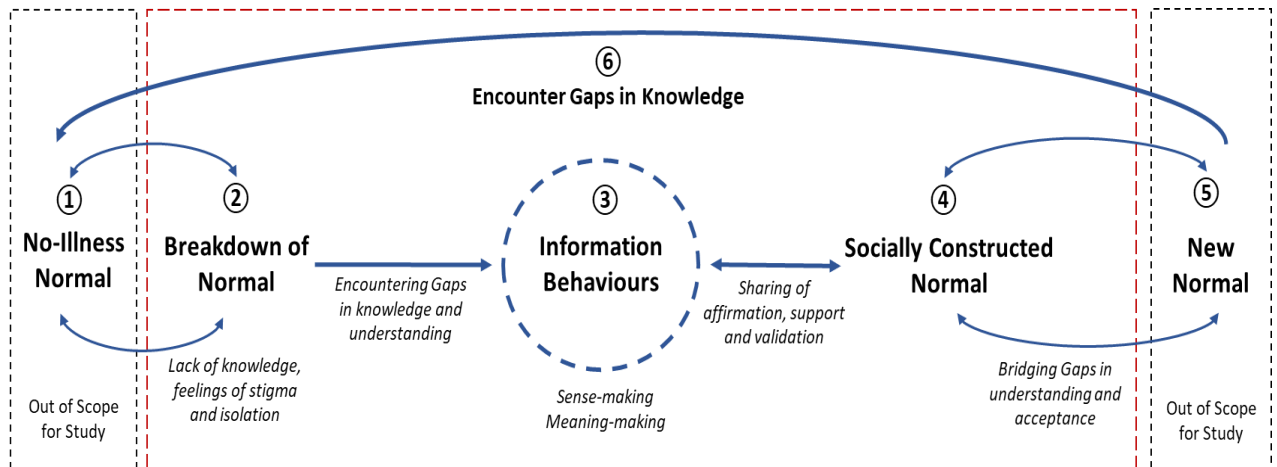


Figure 9 Reproduced from Figure 2, presented for reference. A Novel Instantiation of the 'Finding a New Normal' Model

This breakdown of anticipated normal is triggered by “*nothing happening*”, as described in 7.2.2, which leads to (3) Information Behaviours in the subsequent stages of their fertility journey. To help make sense of their experiences, men consistently undertake sense-making, meaning-making, encountering, and trying to fill gaps in knowledge. We see how this is predominantly done through obtaining reliable information from healthcare professionals (discussed in 7.3.4) or from peers and experienced others to undertake collaborative sense-making. Acquiring information from experienced others supported men to make sense, but more so to find meaning and in being able to interpret the information into their lives. Learning from others and hearing similar experiences also aided this process of making meaning and accepting a (4) Socially Constructed Normal their fertility journey.

“I suppose some of it was looking to just understand other people’s experiences, some of it was a sort of sense of solidarity, to know that there’s other people going through the same thing and to feel like you’re not quite so alone. Some of it was definitely to get tips about how to improve our chances, so we tried a lot of kind of lifestyle factors to improve our chances of the IVF working once we were going down that road.” (P10)

“I think the real help is that you understand that everyone goes into it with a limited understanding of how the journey is going to pan out and what’s going to happen, so I think everyone is equally scared is the main takeaway I got from those conversations.”

(P7)

Sharing with experienced others contributed to an understanding that they were not alone and their experiences are normal, which helps men to accept a (5) New Normal.

7.3 Barriers to Information-seeking

After articulating the information-seeking journey that men report experiencing through their fertility journey, I found that further elaboration is needed around the context of these information behaviours to understand men’s needs fully. Therefore, I present a critique of my interview data to understand how men recognised a need for information, how sources of information were chosen and why required information may not have been found. It is important to understand the information gaps and barriers to identify opportunities for support. Finally, men discussed the concept of mistrust with healthcare professionals when considering information and support. Therefore, I explore men’s experiences on this construct and present their views.

7.3.1 Recognising a Need

The first aspect of the information-seeking journey reported was recognising a need for information; therefore, I explored whether the men interviewed actually recognised a need for information themselves or whether their responses were led from my specific questions regarding information needs.

Some men were very vocal and forthcoming about their needs, while others were more ambivalent. In the ambivalent cases, men would have welcomed support and information

through the journey but did not go out of their way to look for it. They did, however, speak about specific points in their fertility journey that may motivate them to look for information. For example:

“I think at the start you're looking for information and I think when you're going through the cycles and you hit a roadblock, or you hit a problem then you start looking for information so there are trigger points. There's a trigger point for searching for information [when] you find out there is a problem or start going through the process and then once you're in the process and you start having problems then you start looking into that as well... Yeah if everything is seemingly going fine, you're not going to look for information.” (P2)

Incidences or events are described as trigger points, which are given as motivations or indicators towards recognising needing information.

In other cases, the need for information and support was vocally shared without being prompted during the interview. In these cases, it seemed that since men felt they were not supported or given information and therefore unable to control the situation, this led to them recognising and wanting information. These participants were eager to list the resources and services that they felt should have been available or would have significantly helped them through the fertility journey.

7.3.2 How were Sources of Information Chosen?

As mentioned in [7.1](#), how men validated information found was discussed broadly. Men shared why particular sources were chosen and used and how they assessed their reliability.

Sources used ranged from online resources such as online forums, social media websites, NHS websites, podcasts, and videos on YouTube. These were used due to ease of access,

having their phones at their fingertips and being able to search for information quickly and conveniently. They were also used as they enabled the participant to explore in their own time and space to ensure privacy.

Conversely, several participants referred to online forums and Google as untrustworthy and providing anecdotal information without expertise. Many participants mentioned the term “*Dr Google*”, referring to using the internet to seek medical advice and guidance, interpreted as unreliable.

“I guess the issue with this, as I say there is the information out there, but Dr Google is a problem. Because you can so quickly kind of go down, get onto websites that aren't necessarily scientifically supported, it's all just kind of hearsay, and anecdotal evidence about what happens, what doesn't happen, what works, what doesn't work.” (P4)

Some sources were chosen as they were seen as more credible. The need for evidence-based information was discussed many times by participants. One participant said they judged this by the number of citations a scientific paper had, or another stated if they saw the same information or advice in multiple places, they would be more likely to trust it.

“Some of it is, on the one hand, I'm just using my own judgement to decide whether it's something relevant, but then also I'm cross-referencing, so looking at more than one source and seeing which one's match. And then take it from there... If you want more detailed, scientific, there's Google Scholar, and look for the articles that have been cited most.” (P27)

“I'd read a couple of articles, so if say two articles said the same sort of food, to me there has to be some substance in that.” (P12)

In-person resources such as healthcare professionals, friends, and family members were also mentioned. These resources were used as credible and trustworthy sources of

information. For example, they were seen as credible if their friends and family members had experienced similar fertility journeys.

“I suppose we also trusted a lot in the information we got from our friends, particularly, I’m thinking of the couple that we shared most with, who were going through things at a similar time to us.” (P10)

Men also shared that they sometimes found it difficult to share with their friends and family. Healthcare professionals and NHS-related websites were also used and are discussed in [7.3.4](#).

As seen, many men preferred using online sources of information for ease of access but only if the content is reliable and credible. Therefore, focusing on this medium of information delivery for men who experience fertility problems would be ideal.

7.3.3 Why was Information not found?

Men often articulated, with and without prompting, what they wished they had or what would have helped and supported them through their fertility journey. Therefore, I explored the data to understand why men did not look for or did not find what they described wanting.

Most of the interviewed participants shared that they sought resources or services that they thought would help them through their fertility journey but did not find them. This could be due to the uncertainty of where and what to look for. In some cases, what men found was not fit for purpose, other reasons for why appropriate information was not found are described below.

Many participants left seeking information, support, and resources to their partner, which was one reason for not looking for what they described as lacking. In many cases, men reported their partner was more active or enthusiastic in seeking information.

“I don’t know if that is normal with this, but she has very much taken the lead with it, and she has, sort of, kept me informed on it.” (P13)

This participant says their partner was more motivated to look for information as fertility treatment would directly impact her.

“[wife] has always been leading it. You know? I guess she needs to because it’s her... It’s a bigger infringement on her body than it is perhaps mine. But, of course, it is for both of us... So, I sort of see my role more of a prom-, not promoting her, but more of a being with her, standing by her, looking after her.” (P13)

Some men said that when they looked for resources for men, they would only find resources for women or that were dominated by women and therefore did not find them helpful.

“I couldn’t find anything yes, I looked, and I just couldn’t find anything out there that was as popular or was as busy and had a lot of users on there like Mumsnet did. There was no male equivalent of something out there, so it was just random websites of a question and maybe one person who hadn’t commented for nine months , and it just wasn’t anything as supportive as what my wife could find.” (P14)

Others described what they thought would have been helpful but did not articulate looking for such resources. For example, participants talked about how an app could provide information for men for every stage of trying to conceive and the fertility journey. Still, they said they did not specifically look for this and did not know why they didn’t think to look.

Finally, a lack of motivation was reported as a reason for not looking for resources to help men through the fertility journey. These participants either did not receive a male-related fertility diagnosis or were waiting on the results of investigations to see whether there was anything they could do to improve their fertility circumstances. In addition, men shared that if they had explicitly been told there was a concern with themselves, they would have been more likely to look for information and support.

“I’m not sure how active I was during the whole thing maybe because it still feels fairly early on, and say let’s say when the tests come back when there’s something more then maybe I’ll look to research it and see, what can I do next?” (P11)

However, this was not prevalent for all men who did not receive a male-related fertility diagnosis. Some men shared that their partner had received a female-related fertility diagnosis and was still motivated to seek information and support.

7.3.4 Trustworthiness of Healthcare Professionals and the NHS

In many cases, men would refer to healthcare professionals and health-related resources such as NHS websites which were seen as trustworthy and, in some cases, the preferred choice. This is because participants shared an explicit assumption that information and guidance provided by healthcare professionals was to be trusted. In addition, this was because healthcare professionals were seen as fertility specialists and highly knowledgeable.

“He was supposed to be one of the leading urologists in the country... There was a GP who specialises in male fertility local to me. I paid for an appointment with her. Just to get that second opinion to see.” (P5)

Another reason shared was that they trusted the UK health services systems as they are not for profit. This was in contrast to companies and some private fertility clinics, which

provided advice on the basis that couples would purchase products they advertised as helpful for the fertility journey.

“So, I really rely on I think, the doctor’s opinion to know what is right and what isn’t right to take[supplements] there so many different pages on the internet about what you should and shouldn’t do, and you don’t really know how thorough it is, how well researched it is, if they’re trying to sell or promote something, or if they really have your own interests at heart.” (P19)

Men trusted online resources reinforced or endorsed by healthcare professionals, namely NHS websites.

“NHS direct and NHS is good, isn’t it? Like most people trust that and although it’s a bit clunky, most people use that site. So, if this stuff was on there, I’d be happy...” (P16)

Others did not give a reason why they wanted information from healthcare professionals; there was more of an expectation that they were the experts and other sources could corroborate any advice they provided.

As GPs were the first port of call when starting their fertility journey, there was an assumption that GPs would be knowledgeable or direct them towards reliable sources of information.

“I’d say for us, we went to our GP first, so if the GP could recommend this straight away that I think that would ultimately help the most.” (P6)

While men seemed to need information intrinsically, some events led them to look for it. The lack of information from healthcare professionals also led men to comprehend that they would like information. Trust in sources of information found was essential to ascertain before validating and using the found information. This was judged in different ways by different participants. It could have been from the level of scientific evidence

presented along with the information or whether the same advice was found in multiple sources, indicating validity. Finally, men shared that they often did not find what they were looking for or that information and support relating to fertility was directly aimed and targeted at women and, therefore, irrelevant to men.

7.4 Information-Seeking based on Fertility Diagnosis

Exploring whether men's information needs or seeking behaviours differed by their diagnosed fertility condition was challenging to complete; whilst some men declared receiving a formal fertility diagnosis, others did not. In some cases where participants did not receive an accurate or defined diagnosis or were told they had 'unexplained or unknown' fertility problems, and in some cases, the diagnosis was absent entirely. This prevented some men from seeking appropriate and relevant support to help make sense of their fertility difficulties.

In some of the 'unexplained' cases, men discussed the results of their investigations which indicated semen quality concerns or concerns regarding their partner. Yet, they were still formally given an 'unexplained' diagnosis. This was the case for P24.

“They did an additional test, which is comet or something where it does DNA fragmentation test, which showed up really bad for me [...] Unexplained infertility, as far as they're concerned...” (P24)

This would indicate a contribution of male-factor fertility concern, yet his personal acceptance and description were that their fertility problems were unexplained.

There were also cases where men would discuss a specific diagnosis, such as male-factor infertility, but then share their experiences with difficulties in their partner's fertility. For example, P26 shared that he had evident anomalies in his semen quality, which was the

reason for their fertility problems. However, he also mentioned numerous tests and investigations his wife underwent, with discrepancies in the results. Therefore, whilst he was under the impression the fertility difficulty was down to him, there is a likelihood that there could have been an influence of female-factor fertility too.

“We both had that [tests] done, and I had two tests, my wife had something like 16 or something. Came back with a few minor things my wife’s side... Anyway, it turns out I’ve got a chromosome translocation... Effectively half of what would normally work, won’t work in my case, because where the division is, it’s not compatible with life.”

(P26)

This indicates that fertility diagnoses were not clearly defined and not always understood or accepted. Therefore, analysing this construct could lead to unfounded conclusions.

As information-seeking was a theme that was inductively generated, the interviews did not explicitly explore whether information-seeking practices differed by fertility diagnosis. Through further examination, I have found no patterns in information behaviours related to fertility diagnosis. However, further work could be undertaken to validate these findings to explore whether fertility diagnosis affects men’s sense-making and meaning-making behaviours.

7.5 Summary of Findings

This analysis used Blandford and Attfield’s information-journey model as a lens to identify men’s key requirements for information through their fertility journey and what sources of information were most used. This led to recognising what was missing and understanding what information men wanted through their fertility journey. How men made sense of the information they sought through their fertility journey and how men

found meaning in this information through interpretation and use is presented. Men also discussed how information was sought to understand a sense of normality through their journey.

During the fertility journey, men expressed a need for information at the beginning to improve their chances of conception and understanding of their fertility diagnoses. Next, men said a need for support during assisted fertility treatments. Fertility treatment protocols are currently managed manually through written and verbal instructions. The protocol regime was pivotal for conception success, so men expressed a need for information guidance and support. Men wanted to understand the fertility process and the implications for themselves and their partners. Finally, men wanted information and support from others who had experienced similar fertility journeys. Therefore, a description of how men's information needs evolve throughout their fertility journey is presented.

Through further analysis there was no apparent differences in information-seeking behaviours in men in accordance with their formal fertility diagnosis. This indicates that information provision could be beneficial to men experiencing fertility difficulties, regardless of their specific diagnosis. These fundamental information needs are further explored in Chapter 9 when interpreting men's needs into opportunities for digital support.

Next men's emotional needs are explored in more detail in Chapter 8, as this was repeatedly raised when discussing information and support needs during men's fertility journey.

Chapter 8 Men's Emotional Experiences during their Fertility Journey

Data from this study was presented at the following conference

1. 4th European Conference on Preconception Health and Care, 2019. (Best Presentation Award)¹¹

Contributions from this Chapter:

- This chapter illustrates how men's emotional experiences affect their feelings of competence and control during their fertility journey.
- I present information and solutions that could positively affect men's ability to navigate their fertility journey.

Chapter Summary:

This chapter presents an analysis of my interview study based on men's emotional feelings and experiences through their fertility journey. I build upon my previous chapters by reporting what support men would have liked at each stage of their fertility journey. I then summarise the emotional journey men experienced and detail how information could better support men during this time, therefore contributing to answering RQ 2.

8.1 Introduction

Whilst identifying men's information-seeking behaviours through their fertility journey, it was also explored how men felt and what their experiences were throughout their fertility journey to further understand men's needs. As with the findings discussed in [Chapter 7](#), participants were not explicitly asked to share their feelings and experiences at

¹¹ Data relating to men's experiences and feelings towards healthcare professionals was presented at this conference. I undertook the analysis, prepared, and delivered the presentation.

each individual stage of their fertility journey. Therefore, the descriptions of men's feelings at some stages are brief.

Experiencing fertility problems can result in stress and pressure and affect an individual's and a couple's emotional well-being ([Pasch and Sullivan, 2017](#)). As fertility invades the most personal, sometimes private and sensitive aspects of one's life, i.e. discussing one's sexual intercourse habits and signs and symptoms related to reproductive health, people can feel sadness, shame and a loss of control ([Cousineau and Domar, 2007](#)). There has been a particular focus on the need for healthcare services to support accessibility, information, and partner involvement ([Dancet et al., 2010](#)). However, other research has shown how interactions with healthcare professionals can create a sense of shame, guilt, and isolation ([Arya and Dibb, 2016](#)). Therefore, I aimed to understand the emotional impact of fertility difficulties on participants to indicate their needs and gaps in support and further consolidate men's information needs.

This chapter frames men's emotional experiences and interactions upon the fertility journey presented in [Chapter 6](#). It is then presented how men described their overall emotional state and well-being not specific to any stage of the illustrated fertility journey ([Section 8.3](#)).

8.2 The Emotional Experience along their Fertility Journey

How men described their feelings during their fertility journey is presented and end with a summary of these emotional interactions and recommendations on how information and support could help alleviate the negative feelings reported by men who experienced fertility difficulties.

8.2.1 Stage One – Trying to Conceive

The information journey for Stage One indicates that the most common information source used was technology: apps to track ovulation and optimal conception windows to target sexual intercourse. These had adverse effects of increasing stress and pressure to perform.

“We always just thought, let’s just enjoy it... then it turned to almost become more of a plan. You’re almost taking some of the fun out of it because then they [information source] said, every two to three days. Sometimes it might feel like you’re happy, enjoying it. The next day, no, can’t today because it’s not [...] Your sperm quality won’t be so good, so you’ve got to wait until the next day. The next day, I may not be in the mood, or you may not be” (P27)

At the beginning of their fertility journey, participants articulated why and how they decided to begin trying to conceive. Their reasons for deciding to conceive ranged from their increasing age being a factor, knowing that it may be harder to conceive due to pre-existing conditions or their relationship or financial status. How couples decided to begin to try and conceive centred around *‘just trying and see what happens’*, with little emotional investment.

“And then we sort of came to a conclusion that we should think about giving it a go. And then what really happened, what sort of pushed it along in our minds much quicker was that [wife] is 39.” (P13)

When sharing their experiences in Stage One, men often state that *“nothing happened”*, indicating their assumption that conception would quickly happen once they started to try to conceive, which led to feelings of disappointment and surprise. In addition, some mentioned receiving a disproportionate amount of education and information on

preventing pregnancy but less on how to successfully conceive, which indicates how these assumptions may have developed.

“I think I was very naïve about things then, and I just thought it was going to happen, it was going to work. We had no reason to suspect that we were going to have any challenges.” (P10)

8.2.2 Stage Two- Identifying a Problem

As previously mentioned, when men identified difficulties in conception, it was met with surprise. One participant stated that sharing with others helped them manage their emotions.

“It took about a year for me to tell my parents exactly what we were struggling with, and I'll never forget it. It was a huge relief for me to be able to share that.” (P3)

Stage two commonly ended with the realisation that further intervention was needed.

8.2.3 Stage Three- Refer to GP

Emotions and feelings expressed at this third stage were primarily negative. Men described feeling frustrated at GPs for the long waiting times for appointments or how they felt they were treated. One participant expressed annoyance at being made to feel blamed for their fertility difficulties.

“It didn't feel like they wanted to help. They basically blamed me for everything... And that was all my doing, well not my doing they didn't point the finger at me or anything, but it was all down to myself and the fact that my sperm was rubbish.” (P9)

Another shared how he was made to feel that they were ineligible to access support.

“We went to the doctors and the doctors weren't very helpful they were just kind of like well, you should kind of be happy with the one [child] that you got now and that's kind of it.” (P8)

Other frustrations expressed were feeling left out and not included in the conversations or with the investigations to progress their fertility desires.

“When you walk in, they tend to focus mainly on the woman, but I would always make a point of saying, look, what can I do here? And I always tried to insert that question in, and generally the advice was, be sympathetic, be helpful, be as involved or as uninvolved as your wife wants you to be.” (P7)

Men wanted to be included, involved, and have some control in the fertility process but were often relegated to having less control and influence through their journey.

8.2.4 Stage Four- GP led Tests and Investigations

Stage four comprised of initial tests and investigations to understand a couple’s fertility prognosis. Here couples often assumed there would not be any issues or anything found that could be easily rectified. However, when the converse was discovered, men expressed feelings of shock and surprise.

“...for me they said it would be like a miracle, so that was a real shock, because we hadn’t expected that at all.” (P10)

Managing this shock and unexpected information was difficult for some men. In addition, the process of the tests and investigations men had to supply a semen sample for analysis, which was challenging for some men.

“I had to go into the lovely, sitting in a cupboard of shame.” (P9)

Men shared that whilst they understood their role in providing a sample was a small task compared to what their female partner had to experience, they still found it a little challenging to accept less involvement.

“It’s much easier to diagnose a man with fertility problems. We spend 20 mins in a clinic doing our business and then it gets sent off... for a woman it’s a far more complicated apparatus to look at... Aside from a little bit of male pride...” (P3)

8.2.5 Stage Five- Refer to Hospital

When couples were referred to hospitals, men still felt like they were being ignored and disregarded when they attended appointments with their partners. In addition, participants spoke about feeling overlooked when tests and investigations were discussed in the initial consultation appointments.

“...when we have had problems, they've just focused on my partner and nothing else which is what they kind of did this time until I was like ‘No! There must be something out there that can check me as well while she's having her checks!’” (P8).

“Firstly, the NHS does not care about fathers at all... And I sort of understand why, because there could, there could be situations where there isn't a father, and so a mother going through it on her own... But for all those cases where it’s a couple having a baby together, the father gets no attention at all.” (P4)

In the referral stages, men mainly spoke about the interactions with the healthcare professionals, which were strained and led to men feeling isolated and hopeless. Men state that they were not given any attention and were not informed about how they could help their partner. Men expected and were eager to contribute to improving their fertility prognosis; however, they were met with reduced influencing ability.

8.2.6 Stage Six- Hospital led Tests and Investigations

As in other stages, men shared their frustrations with healthcare professionals for not providing adequate information or disregarding them in the process and only focusing on their partner.

“And there is almost zero interest in the male. I'm sure you've heard this before. And every single person we spoke to, we asked if there's anything I should be doing what could I be doing? Because there's two people that make this happen, and there's no way everything falls on the woman.” (P24)

“And all the conversations with the medical professionals it was like 80-90% of the attention was on my wife with a little bit of me.” (P28)

Men also shared their feelings of self-blame and pressure to conceive or be the one preventing the couple from being able to conceive without intervention.

“My wife said to me that she banged on at me since we got married, ‘you should have a better diet! See, if you had a better diet, maybe we wouldn't be where we are now.’ Things could be different.” (P27)

“I can remember walking away from there, [hospital] when we found out, and almost being shocked and a bit sort of like down about it. because it's like... I don't know, but in the process of having babies and giving birth, men have got a pretty easy job and it's not particularly difficult. and if you can't do it then you feel a bit less like a man I guess” (P2)

Once getting to the hospital-led investigations stage there seems to be a realisation that the fertility problems are likely to be serious, as they have not been able to rectify them through routine examinations from their GP. This realisation appeared to lead to further blame within the couple or self-blame.

8.2.7 Stage Seven - Refer to a Specialist Fertility Clinic

At the stage when fertility treatment had not yet begun, there was a period of uncertainty and confusion. Men described going to multiple appointments to try and understand their prognosis but were often ignored. They expected to receive explanations and suggestions from healthcare professionals but felt abandoned.

“I might as well have not been in the room for a lot of it. I’m sure you heard that before. It was not all of them, a lot of them. I might as well have been a coat hanger. It was very much my wife, no making eye contact. So, that was frustrating.” (P26)

“But I often get the impression from doctors that they just sort of look through me when I ask a question.” (P19)

“So just, honestly, it just felt like you[‘ve] gone to your driving test, you failed, and the instructor just said, ‘Sorry, I can’t tell you why you failed.’.” (P18)

The feeling of not being able to understand the cause of their fertility prognosis, and not being able to control or have the autonomy to change the outcome was hard to comprehend and accept. Similarly, and as previously discussed, much of the attention and information were female-centric.

“All the literature and all the speaking with medical professionals is all geared towards it must be the woman.” (P25)

Having to prepare oneself for the prospect of undergoing fertility treatment brought up feelings of uselessness and guilt. In addition, men stated they had no outlet for support to manage these feelings, with literature and information being aimed at their female partners.

“I struggled to deal with that situation myself, it has really affected my mental, you know in my head, like mental health wise.” (P23)

“So, it’s been quite, quite tough. Because you have to be in a bind for weeks and months on end, sitting there thinking that you’re, yeah, personally like a piece of shit to be honest.” (P9)

8.2.8 Stage Eight- Fertility Treatment

During fertility treatment, men reported feeling inadequate, that they did not have a fundamental role to play and did not feel as involved as they would have liked. This again led to feelings of sadness and blame.

“Again, I think with IVF, the man’s role is very limited, and you don’t even have to be there. You know, you’re there to deposit your sample at the time, and that’s it.” (P4)

“It’s like you feel like a passenger as a man in this whole process.” (P7)

Going through the assisted fertility treatment felt like a constant reminder that they could not conceive as they had expected. This repetitive realisation's impact on their feelings and mental health is explicitly shared.

“The sort of mental side of it really because you know, I can’t dress this up, it’s definitely affected me. Hugely affected me, in fact, and I have not dealt with it very well, I’m very good at sort of putting it in a box and shoving it to the back of my mind. And every so often, [it] will manifest in a different way, and I won’t realise it... I think the people at work must think I’m some sort of moody bastard. And I’m really not, I’m just a sad man, who doesn’t know how to deal with his emotions... I just want a family, you know... So, you know, it’s difficult to deal with and think that, shit I might not actually get that...” (P9)

This man was very open with his feelings and shared that he found it challenging to share with others. Others echoed that there was a balance to be had; men wanted to share with others to accept their support but wanted to maintain their privacy and did not want to be pitied.

“...it’s a difficult balance to find between wanting to get support from your loved ones, but then wanting it to be, to some extent, a private journey, where you’re not getting texted every day during the week, whether things are getting fertilised.” (P10)

One participant said it would have been helpful to know how much more he could have been involved in the process, specifically regarding managing the communication channels with the fertility clinic. He felt that as all communication was directly channelled to his partner, he did not feel he could contact them to verify information and procedures during the assisted fertility protocol. Being aware that he could also communicate with the clinic directly could have alleviated some of the pressure on his partner and for him to feel like he had a role and some control.

“I would have liked to have had a better understanding of what was going on at each stage. One of the problems was it was never really made clear to me when my wife was feeling sick or she was busy whether I could actually call the clinic and ask information on her behalf.” (P7)

Another participant expressed similar feelings, that they were unaware they could have been present with their partner while undergoing treatments and procedures in the fertility clinic. One participant found out after that he could have been present during egg collection and implantation but was not, he felt that knowing this could have contributed to him feeling more a part of the process and not being there contributed to feeling isolated and disregarded.

Men also shared how the treatment affected their relationship with their partners. But, again, there was a lot of strain and pressure on the treatment to succeed.

“When it came to doing IVF, and IVF is horrendous, and it placed a really big strain on our relationship. The clinic had counsellors available which we, which they said, you can have a free session, for each cycle of IVF, which was, I think they could have done more to promote that, because you can't force people to get counselling. But I think you can strongly encourage it. And that was joint counselling for the two of us, which we both found very helpful.” (P4)

Fertility difficulties impact relationships because the couple is very involved in the process and sometimes, they do not share with anyone outside their relationship. Men also felt a lot of guilt, especially if their fertility diagnosis was male-related. Going through fertility treatment was a demanding process for couples. It was physically and emotionally challenging and draining. Men shared the most anguish at Stage 8.

8.2.9 Summary of Men's Emotional Experience along their Fertility Journey

Men shared how they felt throughout their fertility journey. In many cases, men felt ignored, disregarded, and uninformed of what was happening. Men reported that they felt a lack of control and competence to improve their fertility prognosis, which was affected by their inclusion during the interactions with healthcare professionals and the provision of information. In these cases, we can assume that increased information and support could have directly helped and enabled men to feel more supported. Each stage of the fertility journey produced negative emotions, and men shared that they had difficulty openly expressing and sharing these. I summarise emotional reactions in Table 4. This table presents potential information and support solutions as articulated by my participants.

Stage of Fertility Journey	Men's Emotional Experience and Needs	Information and Support Solutions
One: Trying to Conceive	Undertaking informed decisions regarding trying to conceive and how to go about it.	Whilst tracking is useful it also added pressure. It would have been helpful if some of the tracking apps had content for men to consume. Men also wanted to have the knowledge that conception may not always easily happen.
Two: Identifying a Problem	Stress and pressure in trying to conceive and not being successful and shock at conception not naturally and quickly occurring.	Men wanted to be able to share their difficulties with others and be informed of the potential outcomes.
Three: Seeing a General Practitioner	Annoyance at GPs for lack of information and proactive action, with the focus being on their female partner	Men wanted GPs to be more proactive in quickly providing information and undertaking medical tests to understand their fertility concerns.
Four: General Practitioner led Tests and Investigations	Embarrassment and shame at having to go through initial fertility testing	Being more prepared for medical investigations and possible outcomes.
Five: Being Referred to a Hospital	Annoyance and anger at being ignored by healthcare professionals	Men wanted to be included in the conversation, in provisions of information and support and for healthcare professionals to not only direct their consultation to their female partner. Feeling included could also help alleviate feelings of guilt and enable the ability to share personal and stigmatising feelings.
Six: Hospital led Tests and Investigations	Annoyance and anger at being ignored by healthcare professionals, as well as feelings of guilt	
Seven: Being referred to a Specialist Fertility Clinic	Annoyance and anger at being ignored by healthcare professionals and feelings of self-blame	
Eight: Fertility Treatment	Intense pressure of treatment, whilst having no role during the fertility protocol. Feeling sad and unable to share with anyone	As in previous stages, men wanted to feel like they had a role and some control. They wanted to be able to share with others to help manage their emotions.

Table 4 show men's emotional experiences and needs and the potential information and support solutions

8.3 Needing Emotional Support

As much of the interviews were semi-structured, men were explicitly asked about the need for information. However, further probing teased out men's needs that were not centred on information. The most common need expressed was the need for understanding and

emotional support. This could have been provided or obtained in several ways. For example, one could have been from healthcare services providing counselling services or independent of health services and through online or in-person support groups.

“I found that [counselling] really helpful, really helped us. With a stranger sitting there and she’s asking you certain questions, I can speak openly with her, even with the wife sitting there because we know we’re in a counselling session, she’s supposed to help us get through whatever we are getting though and you have to be open and honest with her.” (P12)

Dedicated external support for couples was preferred as there was trust that the professional was equipped to help the couples through difficult times. Such support could also encourage making sense of their fertility difficulties and emotions.

“For me in my experience I would describe the process for a man as juggling plates. Because you are the emotional punch bag, you are sort of a third party a lot of the time. It’s far more important, that I think for mental health, for a man to be in a very very strong position emotionally because they are [the] third party and therefore they are the person who is going to have to do a lot of the heavy lifting a lot of being together, a lot of being patient...” (P3)

There was also a need articulated that centred around wanting to be understood by others or being competent to understand and be prepared for what assisted fertility procedures may emotionally and physically subject them to. Being prepared for fertility treatment can also be seen as a component of meaning-making, as understanding the fertility process, and accepting what that could mean for themselves is an outcome of meaning-making.

“I think if there was someone I could meet and talk to, just to share, because none of my friends have gone through that, gone through IVF, none of them. Same with family, we’re the first... much like with women, just to see men sharing... I think men need to be more open.” (P27)

The need to hear from other men or couples to help understand what others had experienced can also contribute to sense-making and the need to feel normal through a sense of solidarity. What they were feeling and experiencing was normal as others had felt it.

“Like I say, I think half of it’s down to us, that we need to, our mentality needs to change... put it out there more to, to normalise it so it’s not something to be shy about.”

(P27)

“I think for myself the fact that I’m not the only one going through this because I think you’re very much stuck in your own bubble at the moment in time. I think the fact that when I talked to people, they say that you just have to relax, the pressure is always going to be there... ” (P6)

Men said had they known that others felt the same or experienced similar things, it would have relieved some of the pressure they felt at navigating their fertility journey alone and what they felt was a female-dominated journey.

“So, I could do with some network support you know... there has been very little support. So, it’s been pretty tough. On the emotional side of things, just be me and my wife... it’s making me think I feel like I want to go off and start a support unit for men to just sit around each other and have a coffee and talk about how crap they feel, because that would help them feel better, you know, because that’s it you know, a problem shared is a problem halved.” (P9)

Wanting to hear from other men was shared throughout most of the interviews. This helped men to understand what to expect. Finding out what is normal in this process would help men manage their feelings and realign their expectations.

8.4 Summary of Findings

I have presented men's emotional interactions along the fertility journey and how men report wanting to be better supported. Men mainly reported feeling a lack of control during Stages 4 to 7 as they felt that healthcare professionals ignored them. Throughout the fertility journey, men reveal their vulnerabilities of having no one they feel they could share with independent of their partner.

Many men focused on needing emotional support whilst they experienced fertility difficulties. These could include support groups or counselling tools to manage their emotions and support their partner, as well as the ability to share with others. Sharing with others could help men make sense of their experiences and hearing about other men's experiences could help support the meaning-making of their fertility journey.

Participants interviewed focussed mainly on their information and emotional needs during their fertility journey. In many cases, the participants described in detail how they would like these to be met in the form of a digital tool, which is further described in [Chapter 9](#).

Chapter 9 Requirements for a Digital Tool

Contributions from this Chapter:

- This chapter identifies the three key opportunities for a digital tool to support men through their fertility journey. These include for preconception health, for support during fertility treatment and for emotional support.
- This chapter details men's content and design requirements for a digital tool, which particularly describes a need for information to support sense-making and meaning-making processes.

Chapter Summary:

This chapter presents the findings from the interview study related to men's needs and desires for a digital tool. First, I discuss three concept ideas that could support men at different stages of their fertility journey. Next, I describe men's preferred design features related to digital tools and finally, I present factors that would affect the use of a digital tool related to their features. Finally, I end this chapter with a list of requirements for a digital tool that could support men when they experience fertility difficulties.

9.1 Introduction

During the in-depth interviews, most men spontaneously discussed what they wished they had to help them make sense of their fertility journey and navigate the process. In many cases, this referred to a digital tool. However, in cases where men did not raise it on their own, they were explicitly asked about their thoughts on how a digital intervention could help support them through their fertility journey.

This chapter aims to answer the third and final research question, which seeks to understand how men's identified needs can be fulfilled through digital tools. These findings are also related to the data presented in [Chapters 7](#) and [8](#) on men's informational

and emotional needs to ensure all opportunities for support are encompassed in the presented digital tool concepts below.

Beginning with content features, I discuss what participants thought would be most helpful during their fertility journey. Then I outline specific design feature preferences followed by what would encourage or discourage men from using a digital tool. Finally, I summarise the outlined specifications of content and design requirements for men who experience fertility problems.

9.2 Specifications for the Content of a Digital tool

From the copious data shared by men on their needs for support when they experience fertility difficulties, their diverse requirements could be categorised into three broad concepts. These were (1) a preconception health tool to support couples before they enter assisted fertility care and finally, (2) a tool to support fertility treatment practically (3) an emotional support tool, to enable men to share with others in an online space. These are presented in chronological order in accordance with the fertility journey outlined in Chapter 6.

9.2.1 Preconception Health & Care Tool

Participants' second most common idea for a digital tool would focus on the time before fertility treatment began. From the early periods of trying to conceive (Stage 1), men said they would like a digital tool to provide information on the preconception period. This would include information on fertility awareness, such as menstrual cycle information and ideal time windows for conception. They would also welcome information and support on health and lifestyle advice to help improve their chances of conception (Stage

2). With this, men wanted to make sense of how and why a specific dosage of vitamins and supplements could improve a couple's chances of spontaneous conception. In addition, men wanted to understand the research behind this guidance, which directly relates to the process of meaning-making by understanding the significance of information attained.

“What I would have liked to see is, for example, a supplement section. You go into supplements and then it will show you, okay, what are the best supplements to take and their dosage that should be good...” (P5)

Moving on from the preconception stage, when couples start investigating their fertility, but before treatment begins (Stages 3-6), men also shared that they would like more support on understanding fertility diagnoses and results of tests and investigations during Stages 4 and 6. Participants shared that they were given the results of tests but did not understand the implications of the results. Therefore, having a tool that could share the ideal or normal parameters and how to improve these would be beneficial.

“And so that would be a really good thing for an app, would be to give you a breakdown of what these things [test results] mean and, I suppose, what the normal parameters are.” (P10)

9.2.2 The Fertility Treatment Tool

The most common idea shared was using an app to support fertility treatment, particularly for Stages 7 and 8. The idea for this tool stemmed from several motivations, including confusion over the complicated fertility procedures and medication protocol regimes. In addition, there was a strong desire for a digital tool to support men to make sense of their fertility journey. Finally, participants suggested that the concept of the tool could follow the basis of traditional pregnancy apps as that is something they are already familiar with.

"This tells me that I'm on week ten and that's on those dates, I should be thinking about a dating scan, a first scan, a test for antibodies... They give you an idea of what is happening next, what's happened, where you're at and where are you right now... This is really good for pregnancy but there nothing that does anything like this for trying to conceive phase or the IVF phase." (P7)

Like pregnancy tools, men wanted this tool to give daily updates of what was happening during their fertility treatment, which could be shared between partners.

The digital tool, as described by participants, could have many features. These included a calendar feature that qualified healthcare professionals can program to alert users to all upcoming appointments, procedures, and medication schedules. This would be complemented with options to look into the individual appointments, procedures, and medications to understand their purpose, method of action, and potential side effects of medications prescribed. Several participants reiterated that understanding the mode of action of medicines was crucial.

Participants shared that information regarding the fertility protocol was currently provided in handwritten forms and making sense of the guidelines in this format was challenging. The days of the fertility protocol are labelled as Day 1, Day 2 etc., so it was up to the couple to understand how it would fit into their lives and schedules.

"So, for instance, like an app where you could have a daily alert saying, you know, at the beginning of the day your alarm goes off, it pops up and it say, okay, this is the plan for today: your wife's taking this injection at 7:30, this injection at 6pm, these tablets... So like just a daily crib-sheet of exactly what's happening that day, so you don't need to think about all the bits of paper or anything else; it's just there" (P10)

The tool could also provide a glossary of terms so users can understand medical jargon used in consultations.

"...kind of like jargon busters because there are the words that get thrown at you, you never would have heard before... if you have ovulation induction, a lot of people aren't going to know what the hell you are talking, when staff talk to you, they talk to you in medical language you don't necessarily always know what that means." (P21)

Some men wanted to know the potential causes of their fertility diagnoses and what options of assisted fertility treatments were available based on their test results and diagnoses. This would help them find meaning in the advice and suggestions their healthcare professionals provided. In these cases, men felt they were not given enough information or options, and clinical staff decided what fertility treatment was best for them.

"Things like common reasons or potential reasons why a male will have low sperm count." (P5)

"Yeah, just sort of like a diagram to show you, this is the start, and these are the different options you've got. So, you can go down this route or that route. And if it doesn't work, you can do this. And just having all your options in one place, like an unbiased perspective, rather than a clinic, putting it on there saying, 'Oh, you should do this'" (P18)

Men also suggested that generic animated videos would be the best option to understand what was happening during the fertility treatment process. The tool would need a female and male partner interface to tailor the content to the user, and the information could be shared. Another benefit of this feature was that information from the clinics was often given over the phone or just to their female partner. The couple could be equally informed if it was programmed onto a digital tool.

9.2.3 A Digital Tool for Emotional Support

Participants also shared that a digital tool would greatly help them emotionally and mentally manage fertility difficulties by enabling them to share with others. Such a tool would be beneficial throughout their fertility journey and not specific to any one stage. This was specific to the feeling of not knowing how to share their emotions or how to get support for their feelings. Men also wanted information and practical advice on how to support their partner whilst going through fertility treatment. There was an understanding and acceptance that once fertility protocols began and their partner took several medications, the side effects and impact often strain their partner's emotions and their relationship.

“Providing tools to a man so he can actually support and understand what stage you are currently in, what to expect next, not just from a medication point of view but also what it's going to do to your relationship and things like that because of mood changes and things like that, to just prepare the person so this is not a surprise and so you are better able to handle it and support your partner through it I think would be very helpful.” (P7)

A tool that has the affordances of being able to support men in this way is indicative of online forums. The idea of online forums to share with others and have the option to talk to other men specifically was frequently raised, as well as having case studies or stories from other men and couples who had experienced similar situations to help men empathise and understand what to expect during their fertility journey. For this type of tool, men valued safety and privacy. They would most likely talk on an online forum if their privacy could be maintained and if it was for men only and women were not in the conversation.

“It’s got to be a safe environment; it’s got to be protected... we still have women trying to join the group that says men only. I mean, come on, it says it in the name, but women are still trying to join...” (P28)

“To me personally, I would probably prefer to go anonymous. But not everyone is as concerned about that. So, I guess it’s just you got to have the option so you can give yourself a pseudonym on there and you can reveal your name, you know, you’ve got the option to do both.” (P20)

One participant requested the tool to provide information on men’s rights during fertility treatment concerning their work contracts and time off to attend appointments.

9.2.4 Summary of Content Features

In summary, from the interview study findings, three types of digital tools that could support men throughout their fertility journey were identified.

Understanding men’s needs for information and supporting their emotional journey has contributed to identifying the opportunities for digital tools to support men when they experience fertility difficulties. These are a tool to support health and well-being before conception and before fertility problems are identified, a tool to support fertility treatment practically and logistically, and finally a tool to support men's emotional well-being. A digital tool containing these content features, particularly information and explanations, would support sense-making, as it can help men identify and fill gaps in their knowledge and understanding. The ability to gain insights from others who had experienced similar things would also support men’s meaning-making by understanding the implications of their own lived context. Participants repeatedly shared that they had many information gaps and a lack of support. Digital tools have the potential to fill these requirements.

Next is a description of specific design features participants shared they would like in digital tools they might use.

9.3 Design Features

Some men were very specific about the type of tool that would be helpful and how it should look. Descriptions such as “clean”, “intuitive” and “simple” were commonly used. These broad descriptions are further explained below.

Basing the design ideas on popular existing tools, such as social media, was suggested by multiple participants to enable ease of use. For example, a constantly updated newsfeed that could drip-feed information relevant to the user was seen as a preferred design choice, as it was simple and would engage the user to keep returning to the tool.

“Because most people use Facebook and Instagram, so not ripping those apps off but something similar to that, I guess. If it’s something we use every day, then you become familiar so everyone will start to like it because you like something you are familiar with.” (P17)

Other preferences included tailoring and personalisation. This could relate to the design, colours used or the type and size of the font used. A preference was for a clean and clear design and not multiple colours or different fonts. Men wanted the option of inputting their specific requirements of what type of fertility journey they were following, so appropriate content was displayed, for example, the fertility diagnosis they had or the type of treatment regime they were following. In addition, men wanted the option to choose whether to have tracking features enabled and to decide what behaviours they wanted to track. Customising alerts and notifications were also crucial to the participants interviewed.

“I think you should tailor it based upon yourself and what is important to yourself.”

(P6)

“...it’s tailored to my dates because the thing I think with fertility and whether it’s IVF, whether it’s trying to conceive, whether it’s pregnancy, everything is very driven by very specific dates. Everything is hyper tailored to the [menstrual] cycle basically.” (P7)

Some participants wanted to skim the content and to have the problem, the cause, and the solution easily visible. Others spoke about the value of other media outputs, such as short videos, animations or audio content that could be consumed whilst travelling. Having mixed media options also enable other accessibility features, just as having audio descriptions.

“I wouldn’t really want to read through loads of literature and I’m busy so in a 10-minute lunchtime a YouTube video quick input of information... (or) audio, I listen to audio at work so even that could work for me too.” (P23)

Another option for the design of the digital tool could be a chronological layout that could be tailored to the participant’s journey. This was thought to be intuitive and, therefore, easy to use. Having screens with less information but with simple navigable options was a preferred option; however, some participants said they would dislike having a tool that required multiple screens to get to the page of information or data they sought. Another vital feature mentioned by three participants was the need for a good search function. They specified this feature was crucial and needed to be intelligent; otherwise, users would likely be discouraged from using the tool.

“Because more often than not, you have a search box and all it does is look for the word in everything you’ve got, and it just brings back random articles that just have that word mentioned. [...] Phrase based searching rather than just keyword searching. Search function is really important.” (P20)

Most participants said they did not care about the choice of colours or fonts but that if it looked unprofessional using large fonts and multiple colours, they would likely be put off using the tool. A few participants said they would advise against using bright colours or pink as this would signal the tool was for women. The preference for the tool to be “clean” was also used concerning the colours.

“I like them [apps] to have darker backgrounds and then the light. [...] And even sometimes on the desktop, I prefer, rather than bright white with black writing.” (P27)

“...whenever you hear the words IVF you automatically think the nice sort of pink and with pink and it’s all very gentle and usually quite female, that’s the only reason I mention that. So, I think that if you approach the IVF in more of a neutral packaging it might take away some of the female bias is what I mean.” (P3)

Men shared that when they looked for mobile apps for support, they did not find any for themselves. Instead, they described how the apps they looked at seemed to be aimed at women.

“Yeah, to be honest there’s not really any support for me, there’s nothing for men. there are loads of videos online of other couples going through the processes [...] it was more aimed at the female side to be honest” (P23)

Therefore, where apps or tools that contain content aimed at men, they need to be clearly evident to the user, otherwise, they are likely to become disengaged.

Other design features shared by a minority of participants were options to gamify the learning experience, the ability to favourite or bookmark pages of interest and the need to log in once to use the tool.

Participants were somewhat divided when asked whether the tool would be preferred as a website or a mobile app, with eight saying an app, four saying a website and six saying it

could be both. The remaining participants did not declare a preference. However, at least four participants shared that if it was a website, it had to be mobile-friendly and not use fancy features such as Flash Player, which can be incompatible on some devices. It is worth noting that Flash Player is no longer supported since December 2020; however, the concern of features that may not be compatible with all devices is relevant and important. Ultimately, men wanted to use the digital tool on their smartphones.

9.4 Encouraging and Discouraging Use of Digital Tools

Participants were asked what would encourage or discourage them from using a digital tool to support them through their fertility journey. Factors that would encourage them included features discussed, such as the ability to personalise and tailor the content, being easy to use and clear that the content was reliable and from reputable sources. In addition, trust in the information was essential to many participants.

Other factors that would encourage use included whether health care professionals recommended the tool directly to them, which increased its reliability.

Factors that could discourage such a tool were if there were too many alerts and notifications that could not be disabled or too many adverts that disrupted the usability. If the tool was slow or had bugs that affected use, it could discourage repeated use. Men said they would be less likely to use the tool if the content was unreliable through not being evidence-based, patronising, or having numerous hidden premium features.

9.5 Requirements for a Digital Tool

Through the in-depth interviews, men shared explicitly how they thought digital tools could support them through fertility difficulties. Much of this centred around providing

information and support, which is discussed in [Chapters 7](#) and [8](#). How men described wanting to receive this information through digital tools is listed in Table 5, along with the identification of the relevant Fertility Journey Stage.

Firstly, the requirements for the three design concepts are listed, followed by the general design features and why they were important to participants in Table 6.

<u>Content Features</u>	<u>Relevant Stages of the Fertility Journey</u>
(1) Preconception Advice	
Information on fertility awareness	Stages 1 and 2
Data on the menstrual cycle	Stages 1-3
Health and lifestyle advice	All Stages
Justifications and information behind advice	All Stages
Guidance on vitamins and supplements	All Stages
Information on dosage of vitamins and supplements and their method of action	All Stages
Information about fertility diagnosis	Stages 4 and 7
Implications of fertility based investigations	Stages 6-8
(2) The Fertility Tool	
Glossary of medical terms	Stages 7 and 8
Potential causes of fertility diagnoses	Stages 7 and 8
Fertility treatment options	Stages 7 and 8
Information about medical investigations	Stages 7 and 8
Investigation and test results and implications	Stages 4 and 6

Integrated appointment schedules	Stage 8
Fertility treatment schedule	Stage 8
Fertility medication guidance	Stage 8
Integration into a personal calendar	Stage 8
Associated female and male partner profiles	Stage 8
(3) Emotional Supportive Tool	
How to get support for self and to manage the emotional impacts of fertility difficulties	All Stages
Information on how to support partner	All Stages
Online Forum features to share	All Stages
Case studies and stories from other men	All Stages
Privacy and anonymity options	All Stages
Space for men to speak to other men only	All Stages
Information on employment rights for fertility care	Stage 8

Table 5 Summary of Content Requirements for a Digital Tool

<u>Design Features</u>	<u>Why is this important for users?</u>
A relevant and updating newsfeed	For ease of consumption of information
Ability to choose what to track	To be able to decide what content to see for continued engagement
Simple layout, that is clean and clear	For ease and intuitive use
Navigation that is easy to use	For intuitive and simple use, users disliked having to go through multiple screens for information
Ability to tailor & personalise content	To only see and consume relevant information
Options to be able to change the theme colours and font style	Personal preferences and to encourage continued use if engaging to the user
Have mixed media options: text, video, audio, and animation	To be able to pick a media option appropriate to where and when a user is engaging with the tool.

Table 6 Summary of Design features for a Digital Tool

9.6 Summary of Findings

By understanding men’s information-seeking behaviours along their fertility journey, I extrapolated how a digital tool could fulfil many of the information gaps highlighted during this time.

The opportunities for a digital tool included the need for information before and during fertility treatment and a tool to support their mental well-being and physical health.

Firstly, men discussed a digital tool to support preconception health and well-being was essential to men because they wanted to improve their chance of achieving spontaneous conception.

Next, a concept of a digital fertility tool to support men practically and logistically through their fertility treatment was discussed. Again, men expressed astonishment that such a tool would not exist or be shared with them directly from their fertility clinic.

Many participants discussed the concept of online forums for men to share. This requirement was essential for men who experience fertility difficulty, as seen through the analysis presented in [Chapter 8](#). Although my analysis of online forums comments presented in [Chapter 4](#) clearly shows that there are online spaces for men to talk to one another, I infer men are unaware that these tools exist. Therefore, there is an information gap indicating that men need to be made aware of existing resources or how to find resources that can significantly improve their fertility journey experience.

Overall, the requirements outlined indicate a need for information which could directly support men with their sense-making and meaning-making processes. An understanding of how to improve their chances of conception and why it may not occur would support men in making sense of their fertility journey. Acquiring information on their fertility treatment and managing the process logistically and practically would help men find meaning in their fertility journey. Finally, sharing with others, comparing their fertility journeys, and making sense of their emotions could help men understand and find a new normal during their fertility journey.

Following identifying these three types of digital tools that could support men with their fertility journey, [Chapter 10](#) explores and analyses existing digital tools against the requirements specified in Tables 5 and 6.

Chapter 10 Study 3: Evaluation of Existing Digital Tools

Contributions from this Chapter:

- This chapter presents an evaluation of existing digital tools, indicating that of the 21 eligible apps reviewed, no apps fulfilled all the outlined requirements for men who experience fertility difficulties.
- Only two apps fulfilled all the criteria of a tool to provide preconception care advice; no apps fulfilled all of the requirements of a tool to support fertility treatment, and most apps did not have any functionality to support men's emotional well-being when they experience fertility difficulties.

Chapter Summary:

Building on the findings detailed in Chapter 9 of men's requirements for a digital tool to support their fertility journey, I reviewed existing digital tools to assess whether existing tools fulfilled men's needs when they experience fertility difficulties. This review explicitly focused on mobile applications and how they fulfilled the outlined features for a tool to support men's fertility journey, preconception advice, and emotional support. From this review, I found that existing digital tools do not fulfil men's information-seeking needs when they experience fertility difficulties.

10.1 Introduction

With the emergence of ubiquitous tools to support health and well-being, many researchers have undertaken mobile application (app) reviews that have explored existing

tools that support sexual and reproductive health. For example, reviews seemingly focused on fertility have only focused on tracking one's menstrual cycle to identify fertile days optimal for conception and are not related to identified fertility difficulties or to manage assistive fertility procedures.

For example, existing reviews have mainly focused on understanding fertility tracking apps for women ([Costa Figueiredo et al., 2021](#), [Ali et al., 2021](#)), privacy, data usage and data sharing in fertility apps ([Mehrnezhad and Almeida, 2021](#), [Lupton, 2015](#), [Hamper, 2021](#)), menstrual tracking or menstruation-related behaviours ([Epstein et al., 2017](#), [Eschler et al., 2019](#), [Pichon et al., 2022](#), [Tuli et al., 2022](#), [Rai et al., 2022](#)) or how to support healthy conception ([Patel et al., 2018](#), [van Dijk et al., 2017](#), [French et al., 2022](#)). Other works that have focused on apps to aid conception explicitly excluded apps that were for men ([Hutcherson et al., 2020](#)).

A comprehensive review of existing technology that can support fertility journeys has generally been absent from the literature to date once difficulties have been identified, specifically tools that can support men. Works focusing on fertility support for both men and women are slowly emerging. I will describe these works in [10.2](#). I then describe the methods used in this analysis in [10.3](#), followed by the results in [10.4](#). Finally, I present the results directly related to the outlined requirements in Table 5 and Table 6 ([Chapter 9](#)).

This study aimed to comprehensively review existing apps that support men with fertility difficulties and investigate whether existing tools fulfil these requirements.

10.2 Related Work

In this section, I outline the existing literature that has focused on reviewing digital tools for fertility support. This builds on the literature presented in [2.4.2](#). These works have been developed and published more recently since the original review was undertaken in Chapter 2.

The literature indicates that the majority of the reviews in this space has focused on trying to conceive and menstrual cycle tracking behaviours to achieve conception. These reviews have exclusively focused on women as the primary user. I will briefly describe the methods used by others to review apps, as well as the literature that has reviewed fertility apps and infertility support.

Motivations behind existing relevant app reviews have varied from understanding the app's content and function to the intended and actual use of the technology by users ([Zwingerman et al., 2020](#)). Others have also explored users' motivations behind the use of the app and whether existing apps can fulfil user needs. Analysing app review comments has been a popular method to investigate whether existing apps fulfil users' needs ([Robertson et al., 2022](#)).

Researchers have undertaken app reviews to understand how developers and individuals think about health conditions ([Hasinoff and Bivens, 2021](#)). This work explored apps as a group to classify what features they contain to understand the constructs and relationships between the aspects of health they focused on and the design. They propose that if a group of apps have focused on the same health conditions and present features on similar symptoms or tracking abilities, this must be what is essential and valuable for users.

However, this disregards whether designers have developed these apps from user experience principles or from their perspectives of what must be necessary for users. We see that there are multiple apps for almost anything you can think of, yet it is unclear whether these apps are building upon one another or whether the users are centred on their design and usability.

A recent study that reviewed fertility apps but only focused on apps for female fertility ([Costa Figueiredo et al., 2021](#)) reports that existing apps support multiple fertility goals and tend to be able to track multiple indicators. Their analysis of user reviews found that users wanted the option to be able to track many things but would only engage with the indicators that are relevant for them at the time for their specific goal.

Again, the study by ([Ali et al., 2021](#)) focused on how only women used fertility tracking apps, and reported that the unregulated nature of fertility tracking could contribute to uncertainty and provide inaccurate information for women trying to conceive and those trying to avoid conception.

A recent study explored digital support for fertility patients but did not specify the gender of the user they were evaluating ([Robertson et al., 2022](#)). In the narrative review, they describe the content of the apps but refer to the target population as what country the app is designed for. In addition, they analyse the user reviews to understand users' opinions towards the tools. However, this review did not explicitly disclose or explore whether existing tools were applicable to men.

A focus on men and women for fertility support is starting to emerge in the literature. In the development of an online tool to support both psychoeducational and psychosocial

needs in fertility care, an extensive review of online supportive tools for infertility support for both women and men was undertaken ([Kruglova et al., 2021](#)). This project evaluated existing online information tools to support patients undergoing fertility treatment. These included app reviews, websites, online blogs, and forums. They reported that only two apps are aimed at supporting men with fertility care and those focused on analysing sperm samples outside fertility health settings. The online information review found that online peer support was freely available to consumers but required registration with options of anonymisation to contribute information ([Kruglova et al., 2021](#)).

A further review of technologies to support the psychological effects of infertility found that mobile apps could be a feasible tool to support couples experiencing fertility problems ([Meyers and Domar, 2021](#)). This review focused on digital tools that had efficacy studies between 2008-2020. They found eight mobile apps that address the psychological and emotional effects of infertility and were targeted at females, only one that was aimed at men only, but this was specifically for men with erectile dysfunction and seven apps aimed at couples. They conclude that very few apps support the psychological burden of infertility for couples.

Another web-based tool, myFertiCare was recently developed to support couples specifically going through intracytoplasmic sperm injection (ICSI) ([Sparidaens et al., 2021](#)). This tool has been developed and evaluated to investigate whether the information on the tool was useful for couples going through this specific fertility treatment; however, it is currently only available in Dutch. The qualitative study presents promising results on acceptability and usability from potential users, but the authors reportedly require further quantitative evaluation.

When exploring technologies specifically to support men with fertility care, home semen testing kits are often what is marketed. However, in a review of current options of home testing kits, it was reported that men tend to be uncomfortable with having their semen analysed in clinic settings, and the availability of home-testing kits could be preferred ([Kobori, 2019](#)). This study reviewed seven systems and found that these technologies can be quite complicated to use and require additional specialist equipment.

Although we are seeing an emergence of reviews focusing on tools that can support fertility difficulties and are beginning to focus on men's needs, a gap in the literature remains. There is a need to explore further whether existing apps support men with their information needs when fertility difficulties arise.

10.3 Study Aims

During the interview study, men stated that they would likely use an app for support during their fertility difficulties; I aimed to understand whether existing apps fulfilled men's needs when they experience fertility difficulties

10.4 Methods

I explored and analysed apps aimed at supporting fertility difficulties from the Apple and Google Play online stores.

10.4.1 Data Collection

I began with the general search term "Fertility". However, in both android and apple app stores, this gave rise to period trackers and ovulation calculators. Therefore I refined my search terms to the following to be more specific, "Fertility treatment/ for men" and "Fertility support/ for men", which also resulted in similar apps. I also used search terms

such as “infertility” and “IVF”, as this term is often used synonymously with fertility treatment.

Whilst previous studies have suggested that users rarely look beyond the first top ten ranked apps when searching for an app to use, and most apps downloaded were from the top 5 ranked apps in their category ([Balaskas et al., 2021](#)) or had more than a 3-star rating based on user reviews, ([Caldeira et al., 2017](#), [Costa Figueiredo et al., 2021](#)), for completeness I explored all apps that resulted from the search terms. This was because even with specific search terms, I found that apps ‘for men’ were never in the top ten results. I followed this methodology to ensure I didn’t unintentionally miss relevant apps, even though it is likely any user looking for these apps would not find them so low down in the list of results. It was also relevant to explore what apps existed and which were more likely to be used.

I extracted the titles of all the apps which resulted from each search term.

10.4.2 Inclusion and Exclusion Criteria

I reviewed apps that provided information and support for couples who experience fertility difficulties and explored whether they contained content specifically for men, including whether there was information aimed at couples. I only reviewed apps that were in English. I excluded all apps that only included information to track fertility cycles to conceive and only had content for women.

10.4.3 Data Analysis

I combined the lists of app titles that had resulted from the different search terms and removed all duplications. Next, I reviewed the app's title and description in the app store

to assess its eligibility. It has been reported that when users choose an app to download, they are most likely to make that judgement from the app pages displayed in the store ([Costa Figueiredo et al., 2021](#)). Therefore in this review, I also explored the app pages displayed in the store to assess whether the apps were eligible for inclusion. I then downloaded and reviewed the remaining apps that fulfilled my inclusion criteria.

I carried out a content analysis of the relevant apps in accordance with whether they fulfilled the requirements outlined by men experiencing fertility difficulties in [Chapter 9](#).

10.5 Results

Table 7 shows the number of apps that were found in the Google Play Store and the Apple App Store for specific search terms. The Apple App store provides different results depending on the device you are searching for compatibility. The results below are based on searches undertaken on an iPhone.

Search Term Used	Number of Apps in Google Play Store	Number of Apps in the Apple App Store
Fertility	248	203
Fertility Men	250	179
Fertility Treatment	248	15
Fertility Treatment for men	249	1
Fertility Support	249	186
Fertility Support for men	150	1
Infertility Support for men	250	0
IVF Support for men	247	0

Table 7 Table to show the number of apps found in the Google Play Store and Apple App Store relating to specific fertility-based search terms

These search terms primarily resulted in duplicated menstrual trackers and apps that supported tracking behaviours to achieve conception. However, it wasn't clear that these trackers support those who experienced fertility problems from their name, description, or app store pages, but these were excluded from the analysis.

1891 apps were returned from the searches in the Google Play store, and a total of 585 apps were returned from the same search terms used in the Apple App Store. Of these, many were the same apps in both stores; as there were no content or functionality differences between the same apps across the two stores, the results were combined. From a review of titles, 2305 apps were excluded. The majority of these were period and ovulation trackers to support conception. This resulted in 92 apps for further review. I then read the app descriptions to understand the purpose of the app. From this analysis, I found that eight were clearly and explicitly for women; 16 were apps to be used by patients registered at specific fertility clinics and could not be used without registration details provided by the clinics. Ten apps were not in English, and six were aimed at healthcare professionals. Finally, 20 apps were excluded as whilst their titles were related to fertility, the content of the apps was not for fertility support. 11 apps could not be analysed as the content of these apps could not be accessed, of these five apps could not be downloaded onto a device, five apps would not open or load any content once downloaded, and one app could only be used if you were covered by private health insurance. Finally, 21 apps were analysed in detail.

Figure 10 combines the search results in the Google Play and Apple App store and shows the number of apps that were excluded and included in the analysis.

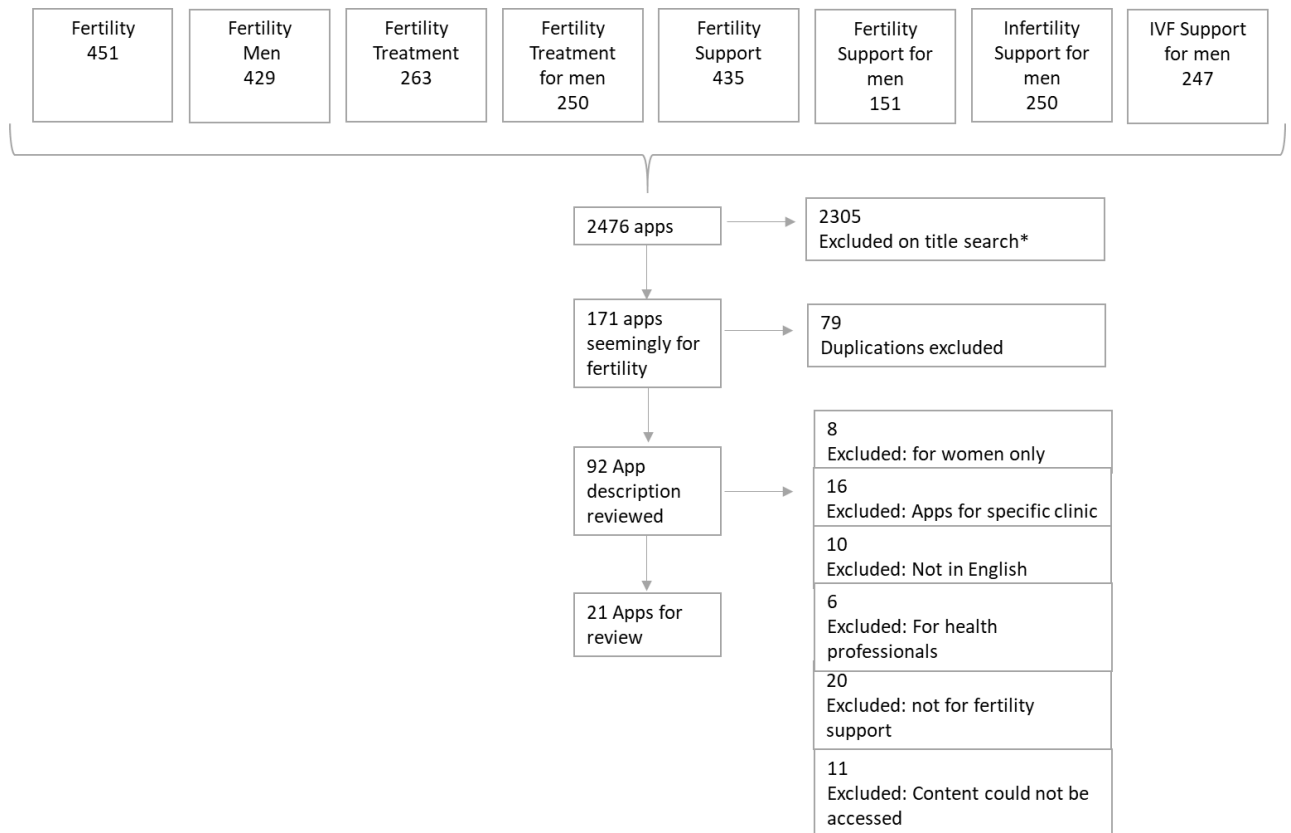


Figure 10 Search results from search terms used, followed by the inclusion and exclusion reasons. *= many of these excluded apps were the same app that resulted from the different search terms

As mentioned, the analysis of the apps was based on the requirements outlined by users. Tables 8-11 illustrate how the 21 apps fulfilled or did not fulfil these requirements. Tables 8-10 are divided by the content features of the three types of tools described in [Chapter 9](#), and finally, design features are analysed and displayed in Table 11. The apps are listed in alphabetical order.

Most of the apps analysed did not clearly identify whether the content was aimed at men or women only; only one app, Fertility Answers, had a feature to be able to set up the profile as a male/partner. They also had other inclusionary features, such as profiles for transgender patients and those in same-sex relationships. The content available was

slightly tailored to these profiles. Only two other apps had categories of information and guidance divided by gender.

Preconception Advice								
App Name	Information on fertility awareness	Data on the menstrual cycle	Health and lifestyle advice	Justifications and information behind advice	Guidance on vitamins and supplements	Information on dosage of vitamins and supplements and their method of action	Information about fertility diagnosis	Implications of fertility based investigations
Artificial insemination	no	no	no	no	no	no	yes	yes
Bonzun IVF	yes- if paid	yes- if paid	yes- if paid	yes- if paid	yes- if paid	yes- if paid	yes- if paid	yes- if paid
Enhanced Fertility	yes	yes	yes	yes	yes	yes	yes	yes
Feronia IVF Tracker & Support	yes	no	yes	yes	yes	yes	yes	yes
Fertility Answers	yes	yes	yes	no	yes	no	yes	yes
Fertility Circle Support Hub	yes	yes	yes	yes	yes	no	yes	no
Fertility Treatments	no	no	no	no	no	no	yes	yes
Fertility View	no	no	no	no	no	no	no	no
Infertility and its Management	yes	yes	yes	yes	no	no	yes	yes
Infertility -(Nature Healthy Care)	yes	yes	yes	yes	no	no	yes	yes
infertility- (Pineapple)	no	no	yes	no	no	no	yes	yes
Infertility Solutions	yes	no	yes	no	no	no	yes	yes
IVF Positivity	no	no	no	no	no	no	no	no
IVF Relax	no	no	no	no	no	no	no	no
IVF Treatment-In vitro fertilization treatment	no	no	no	no	no	no	no	yes
Leeaf: The Fertility treatment guide & planner	yes	yes	yes	no	no	no	yes	no
Mindful IVF	no	no	no	no	no	no	no	no
My fertility diary IVF Rx	no	yes	no	no	no	no	no	no
MY FIV-IVF	yes	yes	no	no	no	no	no	no
Sperm Count Advice	no	no	yes	yes	yes	yes	no	no
YO sperm test	yes	yes	yes	yes	yes	yes	yes	yes

Table 8 Table showing how apps fulfil the content criteria of providing 'Preconception Advice'

Table 8 reveals that 17 of the 21 apps analysed contained some information on preconception advice. Three apps fulfilled all the outlined criteria (*Bonzun IVF, Enhanced Fertility and Yo Sperm test*); however, to access the content on Bonzun IVF, the user was required to pay for premium features. Four apps did not provide preconception care or fertility diary IVF Rx information at all. Only eight apps provided justification and explanations behind the information provided.

Fertility Tool										
App Name	Glossary of medical terms	Potential causes of fertility diagnoses	Fertility treatment options	Information about medical investigations	Investigation and test results and implications	Integrated appointment schedules	Fertility treatment schedule	Fertility medication guidance	Integration into a personal calendar	Associated female and male partner profiles
Artificial insemination	no	yes	yes	yes	no	no	no	no	no	no
Bonzun IVF	no	no	yes	yes	no	yes	yes	yes	no	no
Enhanced Fertility	no	yes	yes	yes	yes	no	no	no	no	no
Feronia IVF Tracker & Support	no	no	no	yes	yes	yes	yes	yes	no	no
Fertility Answers	no	yes	yes	yes	yes	no	no	no	no	yes
Fertility Circle Support Hub	no	yes	yes	yes	yes	no	no	yes	no	no
Fertility Treatments	no	no	yes	yes	no	no	no	no	no	no
Fertility View	no	no	no	no	no	yes	yes	no	no	no
Infertility and its Management	yes	yes	yes	yes	no	no	no	no	no	no
Infertility -(Nature Healthy Care)	no	yes	yes	yes	yes	no	no	yes	no	no
infertility- (Pineapple)	no	yes	yes	yes	no	no	no	no	no	no
Infertility Solutions	no	yes	yes	yes	yes	no	no	no	no	no
IVF Positivity	no	no	no	no	no	no	no	no	no	no
IVF Relax	no	no	no	no	no	no	no	no	no	no
IVF Treatment-In vitro fertilization treatment	no	no	yes	yes	no	no	no	no	no	no
Leeaf: The Fertility treatment guide & planner	yes	yes	no	yes	no	yes	yes	no	no	yes
Mindful IVF	no	no	no	no	no	no	no	no	no	no
My fertility diary IVF Rx	yes	no	no	no	no	yes	yes	no	no	no
MY FIV-IVF	no	no	no	no	no	yes	yes	no	no	no
Sperm Count Advice	no	no	no	no	no	no	no	no	no	no
YO sperm test	no	no	yes	yes	yes	no	no	no	no	yes

Table 9 Table showing how apps fulfil the content criteria of being a 'Fertility Tool'

Regarding features related to providing a fertility tool to manage fertility treatment, most apps did not clearly fulfil the criteria, as seen in Table 9. Of the ten features outlined, only one app fulfilled six of these points (*Leeaf*), and many others satisfied fewer than half of the outlined requirements. For example, whilst six apps had a feature to log and schedule reminders for appointments and medications, no apps enabled the integration of the in-app calendar with an existing personal calendar.

Only three apps had a glossary of medical terms. However, most apps had information about fertility procedures, treatment options, and causes of fertility-related guidance.

Emotional Supportive Tool							
App Name	How to get support for self and to manage the emotional impacts of fertility difficulties	Information on how to support partner	Online Forum features to share	Case studies and stories from other men	Privacy and anonymity options	Space for men to speak to other men only	Information on employment rights for fertility care
Artificial insemination	no	no	no	no	no	no	no
Bonzun IVF	yes	no	yes	no	no	no	no
Enhanced Fertility	yes	yes	yes	no	no	no	no
Feronia IVF Tracker & Support	yes	yes	yes	no	no	no	no
Fertility Answers	yes	yes	yes	no	no	no	yes
Fertility Circle Support Hub	yes	yes	no	no	no	no	yes
Fertility Treatments	no	no	no	no	no	no	no
Fertility View	no	no	no	no	no	no	no
Infertility and its Management	no	no	no	no	no	no	no
Infertility -(Nature Healthy Care)	no	no	no	no	no	no	no
infertility- (Pineapple)	no	no	no	no	no	no	no
Infertility Solutions	no	no	no	no	no	no	no
IVF Positivity	no	no	no	no	no	no	no
IVF Relax	no	no	no	no	no	no	no
IVF Treatment-In vitro fertilization treatment	no	no	no	no	no	no	no
Leeaf: The Fertility treatment guide & planner	yes	yes	yes	yes	no	no	no
Mindful IVF	no	no	no	no	no	no	no
My fertility diary IVF Rx	no	no	no	no	no	no	no
MY FIV-IVF	no	no	no	no	no	no	no
Sperm Count Advice	no	no	no	no	no	no	no
YO sperm test	yes	yes	yes	no	no	no	no

Table 10 Table showing how apps fulfil the content criteria of providing 'Emotional Support'

Table 10 shows that seven of 21 apps analysed gave information on providing emotional support or taking care of mental health. Of the six apps with forum features or links to forums, none had features where it was clear that men could speak to other men. Only one app (Leeaf) provided information on case studies and stories from other men. None of these apps provided privacy and anonymity options.

Design Features							
App Name	Newsfeed	Ability to choose what to track	Simple Layout	Easy Navigation	Ability to tailor & personalise content	Ability to change the theme colours and font style	Have mixed media options: text, video, audio, and animation
Artificial insemination	no	no	yes	no	no	no	only text
Bonzun IVF	yes	no	yes	yes	yes	no	only text
Enhanced Fertility	no	no	yes	yes	no	no	yes
Feronia IVF Tracker & Support	yes	no	yes	yes	yes	no	mostly text
Fertility Answers	yes	no	yes	yes	yes	no	only text
Fertility Circle Support Hub	no	no	yes	yes	no	no	yes
Fertility Treatments	no	no	no	no	no	no	only text
Fertility View	no	no	yes	no	no	no	only text
Infertility and its Management	no	no	yes	yes	no	no	only text
Infertility -(Nature Healthy Care)	no	no	yes	yes	no	no	text and videos
infertility- (Pineapple)	no	no	yes	yes	no	no	text and voice reader
Infertility Solutions	no	no	yes	yes	no	no	only text
IVF Positivity	no	no	no	no	no	no	only text
IVF Relax	no	no	no	no	no	no	only audio
IVF Treatment-In vitro fertilization treatment	no	no	yes	yes	no	no	only text
Leeaf: The Fertility treatment guide & planner	yes	no	yes	yes	no	no	only text
Mindful IVF	no	no	yes	yes	no	no	yes
My fertility diary IVF Rx	no	no	yes	yes	yes	no	text and images
MY FIV-IVF	no	no	yes	yes	yes	no	only text
Sperm Count Advice	no	no	yes	yes	no	no	only text
YO sperm test	no	no	yes	yes	no	no	yes

Table 11 Table showing how apps fulfil design features

Table 11 indicates whether apps fulfilled any of the optimal design requirements outlined. None of the apps found had the ability for the user to choose what behaviour they would like to track. Most of the apps analysed had a simple layout and were easily navigable. Only four apps had a running newsfeed, and only five apps exhibited tailoring and personalisation features depending on the user's input. None of the apps had the functionality to edit the theme colours or font styles, and most of the apps were text-based. One app had an inbuilt voice reader, and one app was simply audio. This was a

motivational app (IVF Relax) and did not fulfil any other requirements outlined. With the exception of two apps, “Sperm Count Advice” and “Yo sperm test”, none of the remaining apps that were for fertility care were obviously designed for or aimed at men.

10.6 Summary of Results

Of the existing apps available, no one app fulfilled all the requirements as outlined by men interviewed who experience fertility difficulties.

About half of the apps found provided preconception and fertility-related advice. The most common feature under these requirements was information on fertility diagnosis and health and lifestyle advice. Yet only a third of apps provided justification and information behind their advice. For example, whilst six apps provided advice on vitamins and supplements, only four apps contained information on the suggested dosage to take.

With regards to a Fertility Tool to support their assisted fertility journey, no apps had the ability to integrate medical appointments or medication schedules into an existing calendar outside the app. Additionally, only three apps had the feature to identify the gender of the user. Finally, the most common feature of these apps was that they contained information about medical investigations. Yet only a third of these apps provided information on investigation results and the implications of the results.

Generally, existing apps for fertility support do not seem to provide emotional support within their tool. A few apps (seven) advised on how to get support or manage the emotional impacts of fertility difficulties, and only six advised on how to support your partner. In addition, none of the apps found had a clear and defined space for men to share and talk with one another.

Most of the apps analysed had a simple-to-use layout and easy-to-use navigation; however, these are subjective features and would need to be evaluated by users to be validated. In addition, none of the apps could change the colours or font style of the display nor had the ability to precisely choose what behaviours the user may want to track.

Overall, many requirements specific to the three types of tools men referred to information. As previously mentioned, these information needs related to men's ability to make sense of and find meaning in their fertility journey. Therefore, I extrapolate from this evaluation of existing tools, that as existing digital tools do not fulfil men's requirements for information and support, they do not support men to make sense of, find meaning or understand and accept a new normal in their fertility journeys. Therefore, there is a space for digital tools to be better designed to support this population with their information needs.

Chapter 11 General Discussion

Chapter Summary:

In this chapter, I discuss the main findings from my three studies and their implications in relation to existing literature. Next, I examine the influence my data gathering methods may have had on my findings and explore the limitations of my interpretations. Finally, I suggest how future work could build on and further develop my contributions to science.

11.1 Introduction

This thesis aimed to understand men's requirements for support when they experience fertility difficulties. I explored online forums, gathered in-depth interview data, and evaluated existing digital tools to fulfil my objective. Overall, I demonstrate that men want information to support sense-making and meaning-making processes and to be included in the fertility journey as equals, not bystanders. With information, men feel they have a sense of control over an experience that is primarily uncontrollable. Accessing and making sense of information contributes to men being able to find meaning and compare their fertility journey with others. This understanding can help men place themselves into a category of normalcy compared to others. Understanding that their experiences of fertility difficulties are 'normal' helps men make sense of their fertility care. Having support for their and their partner's emotional well-being also provides a role for men in a journey that is generally female-centred.

In this chapter, I discuss the interpretations and implications of my findings. As men's needs evolve and depend heavily on the stage of their fertility journey, I first discuss the importance of outlining men's fertility journey ([11.2](#)). Next, I consider the implications

of men's information needs ([11.3](#)) and debate the use of online forums as a source for information-seeking ([11.4](#)). Next, how men's emotional experience significantly affects their well-being and ability to make sense of their fertility experience is discussed in [11.5](#). Then, I reflect on why it was appropriate to explore digital tools to support men's needs when they experience fertility difficulties ([11.6](#)).

I discuss the impact of including men in research regarding fertility ([11.7](#)) and, finally, end this chapter with clarifications regarding limitations considered with respect to my findings ([11.8](#)) and how future work could build upon my contributions ([11.9](#)).

11.2 Outlining the Fertility Journey

As outlined, men stated that they wanted more information and emotional support during their fertility care, and as mentioned, these varied in accordance with their fertility journey. Therefore, to comprehend how men's needs can be understood through their fertility experience, I detailed a fertility journey in Chapter 6. This was developed from men's first-hand accounts and centred on their interactions with healthcare services. It was essential to recognise the journey, as it is upon this that I build my subsequent findings. I also found that whilst the fertility journey through healthcare services is experienced by many and tends to follow a similar pathway, it has not been clearly outlined in the literature before. Healthcare services in the UK are governed and follow guidance from the National Institute for Health and Care Excellence (NICE). This body publishes guidance, last updated in 2017, which outlines advice and information for healthcare professionals and the public, covering diagnosing and treating fertility problems by detailing how fertility should be managed and investigated ([O'Flynn, 2014](#)). However, this guidance does not indicate a pathway through which couples who

experience fertility problems should access care. They do, however, suggest that information should be provided in written format to couples struggling to conceive, which many of my participants report not receiving.

Through extensive searching, I found that only one Clinical Commissioning Group (CCG), which are governing bodies who are responsible for allocating services within local areas, had an overview of the fertility assessment and treatment pathway a couple could follow ([CCG, 2014](#)). This CCG was based in Mansfield and Ashfield in Nottinghamshire. This pathway outlines Primary care, Secondary care, and a Treatment phase with information on what procedures can and should be offered and the guidance around this provision. There is a need for all CCGs to have this information and guidance available so that men who experience fertility difficulties can make sense of what their journey may look like.

Identifying and describing the fertility journey enabled my subsequent findings to be built upon this pathway. The value in this journey also relates to the ability to be able to target men's specific information needs in relation to where they are on their fertility journey, and as discussed in Chapter 9, specific digital tools can support men depending on where they are on their fertility journey.

11.3 Implications of Men's Information-Seeking Behaviours

As mentioned, at different stages of the fertility journey, men outlined specific information needs which evolved over their journey. How participants looked for and acquired this information is detailed in Chapter 7. Men then undertook information behaviours, such as sense-making and meaning-making in accordance with what

information was found and their needs at that time. How men made sense of the information they found, affected their need for further information and helped them understand whether their information needs were fulfilled. Such sense-making activities included sharing their personal stories with others, this enabled them to relate others' experiences to their own ([Faisal et al., 2013](#)). Whilst I have focused on the individual, it is clear that men undertook collaborative sense-making in different circumstances. When looking online for information, they would make sense of the information in collaboration with others online; in other cases, they would share and discuss their findings with their partner or friends and family members. Men also discussed situations where their partner was the lead in gathering information, and their partner would share the acquired information with them to help make sense and find meaning. Paul and Reddy discuss that collaborative sense-making can occur in situations where gathering the information can be intensive, and therefore sense-making tasks can be distributed ([Paul and Reddy, 2010](#)). Collaborative information-seeking behaviours can affect how information sources, specifically online platforms, are utilised and how information is retrieved; this is discussed further in [11.4](#). Others discuss how many create a division of tasks when seeking information to help share the load and then share their findings with one another ([Reddy and Jansen, 2008](#)) or to validate copious amounts of information to efficiently support sense-making ([Greyson, 2018](#)). In the fertility population, we can see that collaborative sense-making is utilised to combat the overwhelming nature of the information found, which can be emotionally draining. There are also benefits of validating and interpreting information with similar others, even if their information goals were different.

After sense-making occurs, meaning-making usually follows to interpret and use information found. This is where men comprehended the meaning of the information found and implemented the advice into their fertility journey or found meaning in their fertility journey. For example, when men looked for information regarding a procedure, they or their partner were due to undergo, they looked for information online about the procedure. Hearing others' experiences would help men make sense of the information and interpret how others' experiences during the same procedure related to themselves. This meaning would then support and enable them to prepare for the procedure and understand its implications for their fertility journey. This cognitive work to find meaning in an upcoming procedure relates to the process of sense-making of making sense of information to support a decision already made ([Zhang and Soergel, 2014](#)). Others have also reported how information-seeking for decision-making is often done to justify and make sense of decisions already made ([Mishra et al., 2015](#)).

I used the information journey model as a lens through which to understand men's information-seeking behaviours. Through this model, I could understand and articulate how men recognised the need for information, what sources of information they used, what information was found and how this information was interpreted and used. This also enabled me to identify gaps in information needs and provision. In addition, the information journey model helped to understand men's motivations for information-seeking, and how they made sense of information found and found meaning through interpreting and using information.

Motivations for information-seeking included the need to understand a health condition, cause of fertility difficulty or implication of actions they could take to improve their

fertility prognosis. Thus the underlying motivation was to achieve Stage 9 of the Fertility Journey, Conception. Therefore, the information sought was more likely to be interpretations and advice that could lead to this desired end point. It could be likely that information or advice from others where fertility journeys did not end positively were disregarded, consequently building a narrative of positive over realistic interpretations of the information.

Other motivations for information included wanting details about fertility clinics and information on fertility treatments. Men wanted to understand their difficulties and make sense of why it was happening to them. The perceived lack of information affects men's ability to control the situation. Men tended to want to control the situation as they felt fertility was a process with little control. This relates to the feelings of expected masculinity, where men wanted the feeling of control and the expectation of dominance or influence ([Dooley et al., 2011](#)). Being able to be open and control a situation can also reduce feelings of the stigma associated with fertility ([Wischmann and Thorn, 2013](#)). It has also been demonstrated that men can delay information-seeking due to their feelings of internal failure to live up to these expected qualities, which can prevent men from openly accepting their fertility difficulties ([Dolan et al., 2017](#)).

While men used healthcare professionals as a source of information, they mostly used online sources due to their ubiquitous nature and ease of access. It has been found that people are more likely to look online for information than to rely on their healthcare professionals. One reason could be the limited capacity and time that healthcare professionals can spend with patients ([Smith, 2011](#)). This study reported that older adults were more likely to trust their healthcare professionals first and foremost, and younger

adults were more likely to use and trust the internet for health information ([Smith, 2011](#)). Sources were chosen based on their reliability, and the access people had to the resources. The satisfaction with health-related information found online can directly influence people's trust in healthcare professionals ([Liu et al., 2018](#)). Information can be used in conjunction with or to question or verify healthcare professionals' advice. Trust was a key factor with men, as they felt that their fertility care was sensitive to change and could have significant impacts. Therefore the information found had to be reliable as it could affect their fertility directly.

Information was also found from similar or more experienced others. This was also seen as highly trustworthy. People who had gone through similar experiences were perceived as highly reliable. Also, what others had experienced was key to accepting whether what men were going through themselves was normal or not. Thus, normalcy was assessed through comparison. This relates to my previous finding of how collaborative sense-making helped men find meaning in information found; it also helped men accept a new normal. Many have discussed the significance of 'finding a new normal' in the context of Covid-19 and effects of the global pandemic lockdown, for example with regards to the changes of the provision of medical care ([Lee, 2020](#)) or how working practises have changed ([Newbold et al., 2022](#)). People had to find a new way of life, mostly by relating to what others were doing and finding new ways to interact. Fertility can be directly compared to the unexpected and disruptive nature of the pandemic. Most couples did not anticipate experiencing fertility problems; therefore, once it was established that the couple had difficulties, there is a need to understand and accept a new normal of how they may conceive.

Combining the findings from Study 1, online forum review and Study 2, in-depth interview study, I can present that the instantiation of the ‘finding a new normal’ model applies to men within and outside online forums who experience fertility difficulties. Men interviewed also described experiencing an unexpected disruption which breaks down their anticipated normal. This led to a lack of control fuelled by a lack of information and support. Most of the information needs outlined were related to the need to understand a disruption or transition. Similar information behaviours have been reported ([Ruthven, 2022](#)), where it was stated that when people experience a transition, they tend to follow a pattern of understanding, negotiating and then resolving. In the case of fertility, transition occurs multiple times throughout the fertility journey. Understanding is related to sense-making behaviours, and negotiating is loosely associated with meaning-making, as there can be some negotiating when an individual is trying to find meaning and interpret and use information. Whilst resolving clearly refers to the act of ‘finding a new normal’.

Once men realised an information gap, they were motivated to seek information. However, men still mostly preferred using online sources of information due to their ubiquity and ease of access. Then men undertook sense-making and meaning-making activities in collaboration with others to validate the information found. The acts of collaborative sense-making were undertaken in both online and offline domains, including with their partners and in collaboration with healthcare professionals or experienced others. Once information regarding their fertility journey was interpreted and used, men were more likely to feel empowered.

Men also detailed looking for and finding useful information as well as not meeting their information needs. Some men described not looking for the information they wanted due

to their lack of knowledge to comprehend what to look for or where to look. Others did not recognise the need for information at the time but, on reflection, realised that having more information could have been helpful. ([Jones and Kelly, 2016](#)) describe four challenges to sense-making, which were: (1) the quantity and unfamiliarity of the information can overwhelm users, (2) the misinterpretation of poor quality information, (3) the reliability or trustworthiness of information can cause uncertainty and (4) if multiple sources do not align in an individual's information seeking, this can lead to poor sense-making.

The first challenge of unfamiliarity was seen as described above, where participants described being unsure what to look for and where. Men also shared their vulnerabilities and feelings of lack of competence at not having the information and knowledge to navigate their fertility journey (Chapters 7 and 8). Findings from Chapter 4 specifically indicate how men used online forums to make sense of and validate the information given by healthcare professionals, which relates to challenges (2) and (3). Men also shared that if multiple sources did not align (4), they found it difficult to make sense of the information or accept what they had found as reliable, resulting in men being unable to validate and use the information found.

In order to appropriately support men with their information needs, we need to be aware of their needs and understand their information-seeking behaviours to be able to provide information in a format via a source they are likely to use and, most importantly, trust. This was also found in a study that explored information needs of couples underdoing ICSI ([Sparidaens et al., 2021](#)), reflecting its importance in fertility care. Similarly to my work, others have also explored information behaviours to understand how to best design

interactions to support information-seeking ([Allam et al., 2019](#)). They report that how people interact with information is ever-changing; therefore, we need to be aware of the requirements of our target users.

11.4 Online Information-seeking

As this thesis focuses on men's online information-seeking behaviours, I explored what men discussed in online forums and how they were utilised. Forums are often a place where people find and exchange information on specific topics. Therefore, dedicated forums for men who experienced fertility problems were ideal for understanding their broad needs. Many others have used this method to explore topics that are seen as private and sensitive ([Ammari et al., 2018](#), [Blackwell et al., 2016](#), [Ziebland et al., 2004](#)). These studies have found that men are more likely to share with one another if there are assurances of privacy and anonymity on the platform. However, there are also risks associated with enabling levels of anonymity in online spaces. These can include the ability for users to hide behind pseudonyms to bully or spread misinformation with no reprisal ([White et al., 2018](#)). Whilst I did not find examples of misinformation in my data corpus, this is still a concern some users may have. As discussed, information reliability was paramount to men.

I found that men looked online for community-led advice on clinical and health-related information and shared the negative emotions associated with internalised stigma. Men utilised online forums as a safe space to share things with one another they felt they could not share outside the forum space.

Forums being used as an alternative or in addition to in-person clinical support has been noted by others ([Bussone et al., 2017](#), [Bhattacharya and Porter, 2007](#), [Himmel et al., 2005](#)). They also report that users would utilise online forums to find normalcy in others' experiences and verify or supplement information or advice from their healthcare professionals ([Bussone et al., 2017](#)). However, we should consider the impact of sharing medical and diagnostic advice on non-moderated platforms. In some cases, forum users providing advice may not have all the relevant or clinical information regarding their medical history and advice ([Huh et al., 2012](#)); this can lead to the provision of inappropriate, inaccurate, and potentially misleading information ([Ellis and Roberts, 2020](#)). There are also concerns that online health information seeking can lead to detrimental offline consequences: a recent study found that users may cease using online sources of information out of fear if they encounter misinformation ([Chi et al., 2020](#)). I found that men used these online spaces as a dedicated space for motivated individuals to share with one another and exchange information, and concerns about misinformation were largely not discussed in my online forum data. However, in my interview study, men were concerned about misinformation online and referred to such sources as "Dr Google", indicating its unreliability. This has been reported by others, where the concern is that misinformation online can impact users' online information-seeking. Still, it can be helped by healthcare professionals directing users to quality online information ([Lee et al., 2014](#)).

In addition, others have reported that people are likely to use the internet to find information about infertility and explore fertility treatment options. They also report that online sources are used to find diagnostic information and treatment options and seek connections with others to understand their experiences ([Brochu et al., 2019](#)). Whilst these

findings report that searchers are more likely to be women in comparison to men, we can see parallels in their needs. It has been reported that men want additional information from that offered by healthcare professionals and tend to use online sources to supplement information given by their healthcare professionals ([White et al., 2018](#)). Online platforms are also reported to provide detailed advice that healthcare professionals do not; therefore, users value the opinions and experiences of others ([Gui et al., 2017a](#)). Online platforms can also engage and empower users with their health care and support the provision of tailored advice ([Van der Eijk et al., 2013](#)).

It is also important to note that the population of men that engaged with the online forums explored were those who were still on their fertility journey, and not those that had ended their fertility journey without conceiving. There are other dedicated online forums for those who face involuntary childlessness, so conversations where fertility journeys ended negatively were largely not discussed in spaces for fertility support. It is also important to note that this may be a potential explanation why these specific online spaces were positive and encouraging for users. This characteristic of the forums could be what attracted users and possibly what kept them engaged with the safe, and supportive environment. Therefore, it is not surprising that most of the online conversations were positive in nature and users that were engaging in the forums were optimistic about their fertility journeys.

11.5 Impact of Men's Emotional Journey

Men shared the emotional implications of their fertility journey in great detail. In some cases, it was the first time the participant had the opportunity to or felt able to open up and share their vulnerabilities. Men's emotional needs could be satisfied with information,

which is related to information needs as shared by ([Ruthven et al., 2018](#)), who identify two categories of needs: informational and situational. Informational needs refer to the clear need for answers, as discussed previously, whereas situational needs refer to narrative descriptions of the situation. Men shared how they feel extremely isolated and underserved through their fertility journey due to their perceived lack of information and resources that were available or specifically intended for them. They also felt ignored by healthcare professionals.

Men wanted to be directly included in the process and felt disempowered by not being able to take control and contribute to improving or changing their fertility prognosis. This lack of empowerment also disabled them from being able to support themselves or their partner. It has long been recognised that fertility problems have psychological impacts ([Edelmann and Connolly, 1986](#)). It is also accepted that emotions are a complex set of interactions among subjective and objective factors ([Kleinginna and Kleinginna, 1981](#)). Men described their fertility journey with subjective influences that affected their emotional well-being and objective factors such as clinical medical diagnoses that they felt they could not impact. This affected their emotional state substantially.

Men equated knowledge and information to power and control, yet many shared that having more information could add more pressure and stress to their fertility journey. For example, the need to understand how to conceive and using digital tracking to help identify times in the menstrual cycle conducive to conception led to more pressure to perform and increased anxieties.

Men also described their annoyance at healthcare professionals, specifically at feeling ignored, disregarded and in some cases not being present during consultations and fertility

treatment. This is in direct contradiction to the NICE guidance that states explicitly that if couples are having difficulty in conceiving, they should be seen together and decisions about their treatment should be joint ([NICE, 2017](#)). Many men report this was not the case and felt ignored with all the focus and attention on their female partner. Whilst this is not a justified explanation, more focus may be given to women in the first instance as according to the demographics, 55% of fertility problems are caused by female-related issues ([Brugo-Olmedo et al., 2001](#)) and they are the ones who are physically subjected to fertility treatments in comparison to men.

Studies have found great benefits in integrating mental healthcare professionals into the fertility care team ([Sax and Lawson, 2022](#)). This was also reflected in my findings, where men who saw counsellors or had mental health support during their fertility care spoke about the advantages and how this contributed to helping men find meaning in during fertility care.

Having mental health support also helped men make sense of the feelings of shame and self-blame that they reported feeling. Many men described feeling like less of a man and how fertility has impacted their sense of masculinity by not being able to easily conceive. This affected their relationships with their partners. In addition, the feelings of shamefulness and blame contributed to the stigma that prevented some men from openly sharing with others information and support. Therefore, sharing with others to support meaning-making and accepting a new normal could reduce men's feelings of shame, isolation, and stigma ([Wischmann and Thorn, 2013](#)).

The implications for men were that they felt more alone and isolated in their journey. If men felt more included and empowered to be able to support themselves and their partners

through their fertility journey, it could help alleviate feelings of guilt and reduce the stigmatised feelings. In addition, supporting their partner with the physical aspects of fertility treatment would enable men to feel they had a role and were a part of the process; this would help men manage their emotions more positively. These findings of men's feelings can be related to needing autonomy and control in a situation and the need to want to help and support others ([Deci and Ryan, 2012](#)). This can be seen to be related to self-determination theory, where individuals are inherently eager to succeed, which is associated with the need to have autonomy, the ability to have choice, and competence, having proficiency and feeling able to affect outcomes ([Michie.S et al., 2014](#)). Through their fertility journey men definitely expressed a need and desire to succeed but were impacted by the perceived lack of choice and control to affect the outcome of conception. These findings are similar to those reported by ([Hanna and Gough, 2020](#)), who describe how men feel their fertility diagnosis is a failure of masculinity, which in turn silences them with shame and increases the stigmatisation felt. Through this isolation, men feel that they cannot share their experiences, resulting in fertility being more focused on and being seen as a "women's issue". However, this exacerbates men's concern, as it has been reported that men desire to be involved in and knowledgeable about fertility ([Genesoni and Tallandini, 2009](#), [Cameron et al., 2021](#)). Including men in the conversation, in the medical consultation and importantly, in research, are critical steps for equality in fertility care support.

11.6 Implications of the use of Digital Tools

Men clearly stated that they would be likely to use digital tools for information support during their fertility treatment. They also shared they expected these tools to exist and to

be signposted towards them by their healthcare professionals. Men shared three types of tools they expected to be available to support their sense-making.

Firstly, men wanted tools to help make sense of their fertility treatment, to be able to manage the medication and procedure protocols and understand how it could fit into their schedule outside of fertility care. Very few tools had the functionality built into input the fertility regime for the tool to alert you to the upcoming appointments or times at which medications need to be administered. Many existing tools serve as medication reminders ([Stawarz et al., 2014](#)), yet men wanted a tool that could be tailored based on their fertility regime specifically.

Men also shared that they wanted a tool to provide information, specifically explanations on the causes of the fertility diagnoses and prognosis. This was a critical content feature for men, as this would help them make sense of the information and guidance provided. Men also reported that understanding the causes of their fertility difficulties was key in making sense of their fertility journey. A review of digital tools found that some satisfy selected requirements but not all. Some tools were designed for specific fertility clinics and could only be used by their registered patients. These tools may have had more integrated and desirable features; however, I was unable to access them to analyse their content and functionality.

New apps are now being developed and tested to support a couple's fertility journey. For example, 'Infotility' is an mHealth app to support fertility patients, but it is not yet on the market. However, their development and usability studies have shown favourable outcomes ([Kruglova et al., 2021](#)). The work undertaken to develop this tool shares similar findings to the requirements I outlined in [Chapter 9](#). They, too, found that people wanted

a glossary of medical terms and information on reproductive health. They also interviewed healthcare professionals to understand their perspectives on the needs of people with fertility problems. However, this tool only provides information, guidance and how to support themselves psychosocially ([Miner et al., 2022](#)); it does not seem to have interactive tools that can provide the types of support men also report wanting to support their fertility treatment.

A new tool is being designed for couples undergoing specific fertility treatment, such as ICSI, MyFertiCare. This aims to provide personalised and interactive functionalities ([Sparidaens et al., 2021](#)); this tool is currently unavailable in English and only accessible to those in the Netherlands. It seems that this tool may contain many features men reported wanting, but it was developed to support one type of fertility treatment.

The second tool men wanted was to support sense-making regarding their preconception health and care to optimise their fertility. When looking for such tools, search results are overwhelmingly for menstrual cycle trackers to support conception success. These are almost exclusively aimed at women, as they are likely to be the primary tracker. Many of these apps may contain information and support for health and lifestyle preparation for pregnancy, yet men were deterred from exploring them due to their targeting to be primarily a tracking app. This is also reflected in research. Many studies that have explored fertility apps have looked solely at the act of menstrual tracking ([Mehrnezhad and Almeida, 2021](#), [Zwingerman et al., 2020](#)). Others have examined the implication and impact of involving men in fertility tracking ([Hamper, 2021](#)). They studied why more fertility preparation work is not shared with men and why normative and cultural assumptions affect and limit the potential for apps to support men's involvement. There

are benefits to sharing tracking information with a couple, including encouraging togetherness and sharing the emotional work of planning and preparing for conception. However, men are often left out of the conversation and decision-making due to assumptions of lack of concern on their part. This is often reported in the literature, where women will share that their male partner was not inclined to be involved in preparing for conception and reduced their role to performing ejaculatory functions ([Hamper, 2021](#)). I report that this is not accurate with respect to the men who participated in my study, as they were clearly interested and want to be involved in the process.

This is not helped by reports in the media that have also largely focused on fertility and reproduction being a conversation for and about women only. For example, a study analysed how the media frames preconception health and optimising fertility ([Budds, 2021](#)). They found that men were hardly mentioned, with articles directed at women, labelling the reader as “you” and then referring to men as “he”, assuming they are not reading and ultimately that they are less important or interested in fertility care.

The third type of tool men wanted was to support their emotional well-being to support meaning-making in fertility care. As mentioned, having fertility problems can be highly stressful and lead to anxiety and emotional stress ([Hanna and Gough, 2015](#), [Arya and Dibb, 2016](#)). Many men shared that they wanted a digital tool to support their emotional and mental health. They wanted the ability to talk and share with others and receive advice on how to manage their and their partner's feelings through fertility care. Many online forums exist to support men who experience fertility problems, yet most men interviewed seemed to be unaware of these platforms. There is a disparity in the needs of men and the provision of services. Some clinics reportedly provide online forums specifically for their

patients; however, their success depends on engagement, interaction and the usefulness of the content provided ([Aarts et al., 2013](#)). Potential explanations for this disparity could also be that men report wanting resources that are aimed at men specifically. Yet, many fertility-related resources were clearly aimed at women and finding those for men was more difficult. This is consistent with my own experience, as when I was undertaking the evaluation of existing digital tools, I did not find any fertility tools aimed at men only, except those that focused on testing semen. I looked beyond the top recommendations, and it is unlikely that the average user will look this hard, as evidenced by others who have undertaken app reviews ([Balaskas et al., 2021](#), [Costa Figueiredo et al., 2021](#)).

11.7 Inclusion of Men in Fertility Research

There is an assumption that men are not engaged in reproductive health, fertility care or hands on parenting ([Yaremych and Persky, 2022](#)). It has been reported many times over that it is difficult to engage men in research topics about health ([Robertson and Williamson, 2005](#)), and they are a hard to reach group, particularly for reproductive health. This returns to the previous argument that these are centred on and important to women, and men are bystanders. I have found that this is not the case, at least among the men willing to participate in my research. Many men have similar fertility desires; they want to be educated and informed ([Daumler et al., 2016](#)), and I report that men want to participate and be made to feel equal in their fertility journey. It is inappropriate to class men in a homogenous group, refer to them as one group, and assume their engagement levels and desires are equal across all health conditions. I have found that some men care very deeply about their fertility health, and infirmity in this area affects them on a physical, emotional, and mental health level, as indicated by the sample of men I was able

to recruit and participate in my study. However, I acknowledge a self-selecting bias in the men who chose to participate in my study; I will further discuss these implications in [11.8](#).

Men had varied motivations for participating in my research, including their overall need for information to enable control and be able to support themselves and their partners. Still, it also included the awareness that there are few resources specifically for men and little opportunity to be able to contribute to change this. In the case of fertility care, men are an underserved population, which is difficult for them to acknowledge and accept. They wanted to help other men so that they would not have to experience this dearth of information and support if they faced fertility problems.

11.8 Limitations

I acknowledge and describe a number of limitations to the research undertaken for this thesis.

Through the review of online forums, I acknowledge some limitations to consider regarding the conclusions derived from this data. Firstly, the conclusions are limited to the population of men who actively participate in online forums. I cannot extrapolate my findings outside the forum nor to consumers of online forums who may not post, i.e., lurkers, discussed below. I am limited to defining my conclusions to the self-selected population of men who use online forums. I also need to consider that people who have access to the internet may be distinctly different to those who do not ([Himmel et al., 2005](#)).

People's needs can be greatly affected by their personal, social, and cultural contexts, and therefore I acknowledge the limitation of interpreting men's needs from anonymous online forums. I was unable to explore the users' demographic information to understand

whether an individual's cultural or demographic background affected their needs and the utility of online forums.

There are also a population of online forum users that I could not account for; these were lurkers. Others have also found a 90-9-1 principle in online forums ([White et al., 2018](#)), 90% of users are lurkers and do not participate or contribute to the forums, 9% contribute a little, while 1% of the forum users contribute to the most content. If this is accurate for the forums I explored, my findings are only generalisable to 1-9% of users.

I was also unable to probe users to explore their intentions and understand their fertility journey; I was limited to the content each user had chosen to share in the online forum. Each user may have hidden nuances not evident in their online content.

On the other hand, the influence of the presence of a researcher is diminished when using online forum data, as it is not monitored, controlled or subject to specific agendas by any organisation or body. The comments are presumed to be left with the intention that they are read by members of the public that are unknown to the users. This can be seen as a benefit as it limits the effect of experimenter bias, whereby the presence of a researcher can influence the responses provided by study participants.

I explored the potential influence of the researcher in my interview study. When collecting qualitative interview data, the role of the researcher can impact the quality of data collected. Researchers should undergo teaching and training to learn how to limit as well as reflect on the impact the researcher may have on the data collected. I have undertaken a number of courses to learn and to refine my interview skills. and have been reflecting and refining my approach. Questions were piloted to test whether they were interpreted

and answered as intended and to ensure the interview followed a semi-structured form where the participant was able to share what was important to them and not only be led by the interview questions. The initial interviews were transcribed and listened to immediately to reflect on these mentioned points.

Men spoke about their preferences and feelings towards sharing with a researcher one-to-one or whether they would have appreciated a group setting to hear and share with others. Most of the men interviewed preferred to speak and share one-on-one, to feel comfortable to be able to open up and share freely and not worry about getting their opinions across or having the nervousness of worrying about what others would think or say. The benefits of a group discussion were also discussed: it could encourage others to share and see that they are not alone and but overall, a one-to-one setting was preferred.

In addition, men also shared their opinions on being interviewed by a female researcher. All participants said they did not mind that I was a female researcher discussing their fertility; some disclosed that they found it easier to openly share due to my gender. Others have explored the impact of women researchers interviewing men or exploring male-focused topics ([Arendell, 1997](#)) and reported on their experiences of being challenged and questioned on their impartiality. Conversely others have reported that men are seldom questioned about their positionality in research ([Lefkowich, 2019](#)). Through the data collection I was conscious that my being female may influence how men shared with me. I was sure to have open body language and was always led by their responses. In some case I was asked to define my role, qualifications, and my fertility knowledge. I believe this enabled me to gain “inside status”, which is discussed by ([Stahl, 2016](#)) when referring to the researcher-participant relationship building. Their study was specifically aiming to

understand the impact of gender, nationality, and class on the construction of masculinities. This work presents how the researcher harnessed their knowledge of norms within this community to gain insider status and build rapport. Whilst I understand that I similarly used my knowledge and open nature to put the participant at ease, there is a potential that my gender and other characteristics, such as race could have impacted data collection. I aimed to reduce any resulting bias by sharing and discussing my data collection and analysis methods with others. I also validated my resulting findings through discussion with others and disseminating my results through peer-reviewed publications. The action of peer-review further validates methods and findings.

However, those who would have preferred talking in group settings or to a male researcher may not have chosen to participate in my studies; therefore, there is potential for selection bias within my sample. I acknowledge that the men who chose to participate may have different views and experiences from those who decided not to participate. There is a possibility that men who saw my call for participation but felt unable or unmotivated to contribute may have had different experiences or information needs to those who self-selected to participate in my study. There is also a population of men who may not have been engaged with the fertility clinic and the Fertility Network and may not have seen my call for participation.

Whilst the men who participated in my interview study shared a preference for using online information and online forums to share with others, most of the men interviewed were under the impression that online spaces for men did not exist. During the interviews, I did not correct them as my aim was to understand men's lived experiences and understanding. I did not want to influence any responses men may have provided. After

the interview was concluded, I shared information about resources that were available verbally. Whilst the participants clearly expressed a preference for engaging with online forums, as I did not probe in detail their actual use in my interview study, it is unknown in what format or capacity these participants would interact with online forums.

With regards to my evaluation of existing digital tools, there were a number of apps that I could not access. There is a possibility that apps that are limited for use by patients of fertility clinics may comprise and fulfil more of the requirements I had outlined. Some of the outlined requirements were subjective to the user, such as the need for the tool to be intuitive and easy to use. These requirements would need to be tested with users to produce a more human-centred evaluation of existing digital tools.

This work is based on men who self-identified as cis- men who were in heterosexual relationships with cis-women. Whilst not a specific inclusion criterion for my work, all those that chose to participate in my research were in heterosexual relationships and spoke about their female partner. I acknowledge that the needs of men who may not have been assigned male at birth or are in non-heterosexual relationships may have different needs through their fertility journey, especially as their fertility journey may be quite different to what has been described in Chapter 6. There is a need for future research to explore the information needs of diverse couples and relationships to enable inclusive resources to be designed to support their fertility journey.

Finally, during this research, we experienced a global pandemic. This affected how almost every individual went about their daily lives, and it affected people's access to health care and health-related resources. It is possible that the pandemic may have impacted and changed men's needs during their fertility journey. However, my data collection was

completed before the Covid-19 pandemic began, so this thesis does not cover the effects this could have on men's needs. However, recent research is starting to explore this impact and has found that men still desire information and that online forum platforms are still being used as an important source of information for prospective fathers ([Cameron et al., 2021](#)). They report that online spaces are a good source to support men with their information and can support men with their mental health needs associated with parenting.

11.9 Future Work

Building on the work I present in this thesis, there are avenues for future work to further extend and develop my contributions, both in understanding men's experiences and needs and in developing tools to support this population.

Firstly, there is a need to understand healthcare professionals' views on providing fertility care and supporting men. Much of the research in this area is focused on the patient's perspective, and the healthcare provider's perspective is generally missing. Research that has sought to explore healthcare professional's knowledge and behaviours have done so concerning the LGBTQ ([Kirubarajan et al., 2021](#)) or transgender community ([Chen et al., 2019](#)), or is based in settings other than the UK, i.e., China ([Cai et al., 2014](#)) or USA ([Costa Figueiredo and Chen, 2021](#)). In my work, men shared a great deal about their interactions with healthcare professionals and how they felt, which was generally negative. Therefore, including healthcare professional voices could strengthen this research and provide a broader perspective on how to support men who experience fertility difficulties.

Future work could also extend these findings to explore the needs and requirement of non-traditional couples trying to conceive. This would include but is not limited to people in LGBTQ+ communities, single parent families and people in same-sex relationships including those with non-male partners.

As mentioned, I did not find any differences in the information-seeking needs of men depending on their fertility diagnosis; however, there is a possibility that my sample size was not large enough to power this analysis. This construct could be explored in future research by undertaking purposive sampling and increasing the sample size.

Finally, now that I have clearly identified men's requirements for digital tools in fertility care and have observed that no existing tools fulfil all of these requirements, there is a need to validate this analysis with users. Undertaking user studies where requirements were validated and existing apps were tested in-the-wild by users could add valuable data to this field of study.

Chapter 12 Conclusions

This thesis aimed to answer three main research questions through the investigation of online forums, in-depth interview data and an evaluation of existing digital tools.

RQ 1. What are men's requirements for support when they experience fertility difficulties?

RQ 2. What are men's informational needs when they experience fertility difficulties?

RQ 3. How can the identified needs be fulfilled through the use of digital tools?

To answer RQ 1, I found that men's needs revolve around the need for support and information and the need to understand whether their experiences are normal in comparison to others.

To answer RQ 2 I found that men seek information online to support sense-making and meaning-making in order to support themselves and their partners through their fertility journey. Men's specific information needs evolved along their fertility journey. My work shows there are clear gaps in information awareness and provision for this population. Men's needs for information are centred on clinical and health-related advice, including advice about fertility awareness, procedures, and implications of fertility-related diagnoses and treatments. However, men report wanting more information and support to manage the emotional impacts of experiencing fertility problems to reduce their feelings of isolation and increase their sense of competency and control.

To answer RQ 3, identified information needs could be addressed through three types of digital tools: a tool for preconception care, a tool to practically support their fertility journey, and a tool to support emotional experiences and ability to share with others.

However, I found that existing tools do not completely fulfil the identified information-seeking needs. This includes men's sense-making and meaning-making needs. Therefore, the main contributions from this thesis are:

1. The novel instantiation of the 'finding a new normal' model relevant to men's fertility experience, which outlines how men undertake information-seeking behaviours both online and offline to understand and compare their fertility journeys with others.
2. A clear and comprehensive outline of the 9 stage fertility journey as experienced by men based on their interactions with health services.
3. A presentation of how the information journey model can be used as a lens through which to understand men's evolving information-seeking, sense-making, and meaning-making behaviours as they go through their fertility journey.
4. Opportunities for digital tools to support men who experience fertility difficulties by outlining men's user requirements to support information-seeking.

Overall, I contribute an understanding of how men's information needs evolve when they experience fertility difficulties as they progress through their journey. Men expressed a need to find, interpret and use information to support sense-making and meaning-making processes to find and accept a new normal, which in turn can help reduce their feelings of stigma and isolation. I found that existing digital tools do not fully fulfil these information behaviours requirements. Therefore, digital tools need to be better designed to support men with their specific online informational, sense-making and meaning-making needs as they navigate their fertility journey.

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Appendices

Appendix A – Call for participation

Appendix B- Information Sheet

Appendix C- Consent form

Appendix D- Topic Guide

Appendix A - Call for Participation

UCLiC

Project ID: 13595/002

Fertility and fatherhood: Would you like to share your views on fertility, fatherhood, and apps you might find useful prior to conception?

We are looking for men who are planning or preparing for a baby to take part in an interview and in return we will offer you a £20 voucher.

The aim of this study is to explore how to support men who are attending fertility clinics whilst they are preparing for conception and how we can design digital interventions to fulfil these needs.

In order to identify men's needs, requirements and views whilst they are preparing for conception, we would like to undertake interviews with men who are either thinking about or currently planning to have a baby. These can be arranged to be in person to be undertaken at UCL or over the phone, whichever is most convenient.

Are you:

- Male
- Interested in your fertility or currently attending a fertility clinic?
- Planning or preparing to have a baby?
- Interested in taking part in an interview, which should last no longer than 1 hour?

Then please contact Dilisha Patel on dilisha_patel@ucl.ac.uk




Researcher: Dilisha Patel
dilisha_patel@ucl.ac.uk
0203-108-7353

Principal Investigator: Prof. Ann Blandford
a.blandford@ucl.ac.uk
0203-108-7049

This study has been approved by UCL Research Ethics Committee (Study ID: 13595/002)

Appendix B – Information Sheet



Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data: data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice. The legal basis used to process your personal data will be your consent, and for your special category data will be for scientific and historical research or statistical purposes.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance; data-protection@ucl.ac.uk. If you remain unsatisfied you can contact the Information Commissioner's Office (ICO).

Contact details, and details of data subject rights, are available: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>.

If you would like to talk to someone confidentially about the topics raised in the interview you can contact:

Fertility Network: <http://fertilitynetworkuk.org/> 01424 732361

Or get information on Fertility from:
 NHS Choices
<https://www.nhs.uk/Livewell/Fertility/Pages/Fertilityhome.aspx>

<p>Researcher: Dilisha Patel UCL Interaction Centre 66-72 Gower Street WC1E 6EA Tel: 0203 108 7353 dilisha.patel@ucl.ac.uk</p>	<p>Chief Investigator: Professor Ann Blandford UCL Interaction Centre 66-72 Gower Street WC1E 6EA Tel: 0207 108 7049 a.blandford@ucl.ac.uk</p>
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Fertility and fatherhood: Would you like to share your views on fertility, fatherhood, and apps you might find useful prior to conception?

We are looking for men who are planning or preparing for a baby to take part in an interview and in return we will offer you a £20 voucher.



Participant Information leaflet

Are you:

- Male
- Interested in your fertility or currently attending a fertility clinic?
- Planning or preparing to have a baby?
- Interested in taking part in an interview, which should last no longer than 1 hour?

Then please contact Dilisha Patel: dilisha.patel@ucl.ac.uk

We would like to invite you to take part in a research interview for men who are planning or preparing for conception.

This study has been approved by UCL Research Ethics Committee (Study ID: 13595/002)
Version 1

You are being invited to take part in this research interview to share your experiences and views on planning and preparing for conception and fatherhood. Before you decide to participate it is important for you to understand why the research is being done and what participation will involve. Please take your time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information.

What is the project's purpose? The aim of this study is to explore how to support men whilst they are preparing for conception. I am exploring how to design digital interventions to fulfil these needs. I plan to interview men who are engaged with their fertility or attending a fertility clinic, to explore their views, experiences and requirements whilst they are preparing for conception.

Why have I been chosen? Men who are currently planning a pregnancy or have recently been preparing for conception are eligible to take part in this study.

Do I have to take part? It is up to you to decide whether you would like to take part in this study. If you agree to take part, you will be given an information sheet to read and will have the opportunity to ask any questions about the study. We would like to audio record the interview if you agree to this. You will be asked to sign a consent form. You can withdraw at any time without giving a reason. If you decide to withdraw you will be asked what you wish to happen to the data, you have provided up that point.

What will happen to me if I take part? If you agree to take part, we will arrange a suitable time and place to undertake the interview with a trained researcher. The interview should take no more than 45mins-1hour. You will also be asked if you would like to be involved in optional future research activities. You will be offered a £20 voucher for your time. This will be offered even if you decide to withdraw during the study.

Will I be recorded and how will the recorded media be used? If you consent for the interview to be audio recorded, it will be used to transcribe (write up) the interview. During this process we will remove any identifiable information, such as names and locations disclosed. Once transcribed the audio recordings will be deleted within 6 months of the interview. No one outside the research team will have access to the original recordings. We will analyse all the transcripts to explore how to support men whilst they are preparing for conception through the use of digital interventions.

What are the possible disadvantages and risks of taking part? We do not expect you to be disadvantaged by taking part in this study. However, should you encounter any discomfort through the interview, please alert the researcher or find contact details in Part 8 to take your comments further.

What are the possible benefits of taking part? Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will contribute directly to the design and development of digital interventions to support men whilst preparing for pregnancy in the future.

What if something goes wrong? If you feel that something has gone wrong during the interview or you would like to raise a complaint you can contact the Principal Investigator. If you feel your complaint has not been handled to your satisfaction you can also contact the Chair of the UCL ethics committee that has approved this research on ethics@ucl.ac.uk. If you feel the interview has raised topics that you would like to discuss with a professional further, we provide details overleaf.

Will my taking part in this project be kept confidential? All the information that we collect during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. If you decide to participate in this study, your name and contact information provided on the consent form will be kept securely in a confidential locked location. You will only be contacted in the future if you have clearly indicated on the consent form that you would like to be.

Limits to confidentiality Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to the results of the research project? The results of this research project will be analysed and written up for publication in scientific journals, conferences and for a PhD thesis. As mentioned all transcripts will be anonymised so no identifiable information will ever be shared or disseminated in any report or publication. If you would like to receive a copy of reports that result from this study, please let the researcher know.

This research is a part of a PhD study, which is funded by EPSRC and hosted at UCL.

Appendix C – Consent Form

Consent Form for men who are planning or preparing for conception

Please complete this form after you have read the Information Sheet and listened to an explanation about the research.

Interview Study with men planning or preparing for conception

UCL Interaction Centre, Institute of Digital Health

Name and Contact Details of the Researcher: Dilisha Patel; dilisha.patel@ucl.ac.uk
0203-1087353

Name and Contact Details of the Principal Investigator: Prof. Ann Blandford;
a.blandford@ucl.ac.uk

Name and Contact Details of the UCL Data Protection Officer: Louse Gaynor;
l.gaynor@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee. Project ID:
13595/002

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction <i>and I would like to take part in an individual interview.</i>	
2.	I understand that I will be able to withdraw my data up to 4 weeks after interview, without giving a reason	
3.	I consent to the processing of my personal information, such as my name and contact details, for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation and that the legal basis used to	

	process your special category personal data will be for scientific and historical research or statistical purposes.	
4.	<p>Use of the information for this project only</p> <p>I understand that all personal information will remain confidential, subject to legal constraints and professional guidelines.</p> <p>I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.</p>	
5.	I understand that my information may be subject to review by responsible individuals from the University, such as members of the research group for audit purposes.	
6.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.	
9.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future, but I will be compensated for the portion of time spent in the study.	
10.	I agree that my anonymised research data may be used by others for future research. [No one will be able to identify you when this data is shared.]	
11.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
12.	I consent to my interview being audio recorded and understand that the recordings will be stored anonymously, using password-protected software, and will be used for specific research purposes. If you do not want your participation recorded you can still take part in the study.	
13.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	

14.	I am aware of who I should contact if I wish to lodge a complaint.	
15.	I voluntarily agree to take part in this study.	

Privacy Statement

Your personal data will be processed for the purposes outlined in this notice. The legal basis used to process your special category personal data will be for scientific and historical research or statistical purposes.

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

	Yes, I would be happy to be contacted in this way	
	No, I would not like to be contacted	

Name of participant Date Signature

Researcher Date Signature

Appendix D – Topic Guide

Topic Guide for Interview Study

The interview aims to answer the following questions:

1. What support is currently available to men attending fertility clinics?
2. What methods of support do men attending fertility clinics want?
3. Are men aware of changes that can be made to their health or health related behaviours to improve their sperm quality to prepare for conception?
4. What are the needs and requirements of men who are preparing for conception?
 - a. How can a digital intervention fulfil these user needs?

Topics and suggested questions:

Ensure anonymity and confidentiality. Explain if they wish to not answer any of the questions that is fine and we can move on.

Background of participant

Including: age, education and employment history, family structure, general health information, hobbies, and interests.

Establish where they are on their fertility journey (if applicable)

- are you currently planning a pregnancy / currently had/ not planning?
- can you tell me about when and how you decided you would like to have children?
- can you tell me about that journey/ process?

Did you talk about your plans to have children with anyone? /who? What did you share/ why that person/people?

- what did you discuss?
- advice/feedback from peer?
- what made you decide to go to a fertility clinic? (if want to share)
- share process/journey through fertility clinic

Before you started trying to conceive did you or your partner look for any information?

- what did you look for?
- where from? – why that source? Repeat for others
- useful/not useful
- what was it about?
- what did you learn or did you already know these things?
- what did you want info/support for?
- what was missing?

- if not mentioned, probe about sperm health
- any changes made for sperm health?
- what info did fertility clinic give
- was it useful
- what would you like to know about your sperm health? (if not mentioned)

If not mentioned, explore digital sources of information

-websites –names if possible

-what did you like about it, dislike about it? Features? Design? Information layout? Content? Use site repeatedly or once?

-apps- names if possible

-what did you like about it, dislike about it? Features? Design? Information layout? Content? Use site repeatedly or once?

If not mentioned: Would you use a digital intervention?

what would encourage you to use an app

what would discourage you to use an app

features /design /info presentation / content / name/ images/ video /interaction type

Did you use any websites /forum/ social media to share/ look for information /support?

what /where/ why- helpful/unhelpful- what was good/bad- what could be improved.

What information/guidance did the fertility clinic give for you? Your partner?

-name of clinic if they wanted to share?

-What information would you have liked to get from the clinic?

Theoretical domains framework style questions.

Do you think your health before you conceive can impact the health of your baby? –what/why/where knowledge from?

What do you know about things you can do before conception to improve the health of your baby? /improve your sperm health

Where did you get this information from?

Did you make any changes prior to trying to conceive? –if yes what, why and where did you get the info from

How do you remember to make/continue (specific behaviour) changes?

Do you use any devices/cues to remember to do (behaviour)?

How easy or difficult is it for you to (specific behaviour)?

What do you think will happen if you (do behaviour)?

Digital intervention

Have you ever used a digital intervention to change a behaviour (what/why)

Would you use a digital intervention to change a behaviour (what kind / what behaviour?)

What would you like to be on it?

How could a digital intervention/app help you change/improve behaviours?

What would improve the likelihood / dissuade you to use an app?

What information would you like to have on it?

Future research interests:

-would you like to be involved in the next stages of this project, which may include testing the use of existing apps and programs as well as influence and contribute to designing digital interventions? Co-design activities –online focus groups