LIVING WITH A THUNDERSTORM IN YOUR HEAD: A MULTI-LAYERED QUALITATIVE IN-DEPTH EXPLORATION OF MEN'S EXPERIENCES OF MIGRAINE IN THE CONTEXT OF ONLINE COMMUNITIES AND SUPPORT PLATFORMS

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Abstract

Migraine is a common disabling primary headache disorder that affects several aspects of someone's life. From painful episodes known for their severe pain and intense sensorial symptoms, migraines are a subjective experience that affects three times more women than men. However, men also experience migraines. This thesis has its epistemological grounds in phenomenology and adopts a lifeworld-led approach to inform online support structures for men with migraines. This programme of work includes a Meta-synthesis, an Interpretative Phenomenological Analysis (IPA) of men's experiences of migraines, a Discourse Analysis (DA) study looking at online platforms for people with migraines, and a Thematic Analysis (TA) of men's experiences of navigating online platforms for their migraines. The meta-synthesis highlights the lack of qualitative studies looking at men's experiences of migraines and reports the significant role of the individual when it comes to living with migraines and seeking support. Findings from the IPA study emphasise the variety of physical and emotional symptoms of migraines and how elements of support are linked to the specific ways in which men live with this condition. Additionally, they highlight how masculinity and the fact that migraines are often perceived as a women's condition can act as a barrier to men seeking support. Lastly, findings captured the importance of online platforms for support with migraines. Further findings from the DA and the TA study reinforce the potential of online platforms for support with migraines, in spite of alarmingly strengthening the argument that men are an under-represented and under acknowledged migraine population. Online platforms are often places of expertise by experience and can offer the ideal setting for people to come together and share their experiences and information. These are known for grounding themselves on a sense of community and togetherness which benefit people living with migraines. This thesis demonstrates the benefits of a mixed-qualitative-method approach to research and makes evident that men should be included in the discussions around migraine. Moreover, it reinforces the argument that online groups and communities should be looked at as potential tools for supporting people with migraines in general, and men in particular.

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List of Abbreviations

BPS	The British Psychological Society
CASP	Critical Appraisal Skills Programme
DA	Discourse Analysis
GIF	Graphics Interchange Format
GP	General Practitioner
HR	Human Resources
IMR	Internet-Mediated Research
IPA	Interpretative Phenomenological Analysis
MoU	Memorandum of Understanding
NMC	National Migraine Centre
PICO	Population, Intervention, Comparison and Outcomes Tool
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
TA	Thematic Analysis
WD	Written Descriptions
WHO	World Health Organisation
YLD	Years Lived with Disability

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Chapter 1 – Introduction

1.1 Introductory statements

This PhD places the focus on human experiences as a means to understand migraines from a men's perspective. I believe the best way to inform how we think about care and support is to put human dimensions at the centre of research on ill-health. This approach was the foundation of every study in this thesis.

This initial chapter aims at offering an introduction to my programme of work. It starts by providing an overview of migraines as a health condition and touches upon the complexity of the treatment options for people with migraine. By highlighting this, I attempt to draw some insights into how Health Psychology can have an important role in understanding this condition and in contributing to the body of work around it. Through doing this, I draw upon elements regarding the important role that qualitative research and phenomenology play in understanding different ill-health experiences and approaches to coping with them. Additionally, this chapter also provides a descriptive overview of each of the studies that constitute this PhD.

The initial motivation behind this project arose from a personal interest in men's health, as well as from identifying that men are an underacknowledged population when it comes to the study of migraines. In particular, I wanted to offer an in-depth exploration of men's experiences of migraines (which are commonly represented as a 'women's condition') and set the foundations for designing online support systems that accommodate this specific migraine population.

Lastly, it was my objective that this thesis represented more than a collection of individual studies around migraines. My goal was to show how valuable different approaches to qualitative research can be in Health Psychology, and in contributing to our understanding of ill-health.

1.2 Conceptual framework and reflexive approach

The epistemological approach underpinning this thesis is rooted in phenomenology (Langdridge, 2007). Additionally, it is placed within the wider framework of a lifeworld-led approach to care and support (Galvin & Todres, 2013; Todres et al., 2007; Dahlberg et al., 2009). Overall, this thesis represents an experientially focused programme of work which prioritises men's experiences. That is, rather than looking at participants as an end product that is purely conditioned by their illness, this thesis is a product of research which looks at participants as human beings who are on a journey that can transcend their circumstances. In other words, the focus of this work is placed on the experiential perspective and on a wider understanding of what it means to be a man with migraines in terms of human experience, limitations, and possibilities (Dahlberg et al., 2009).

Through a lifeworld-led approach to research, this programme of work attempts to provide experiential context for considering what we know about migraines as an illness and the support available for people who live it (Galvin & Todres, 2013). Ultimately, the epistemological framework of this thesis places the focus on 'the person' with migraines and what matters to them, and acknowledges this as a starting point to better understanding migraines and what can be done to support those who suffer from them. (Smith et al., 2009; Galvin & Todres, 2013). One of the greater challenges in healthcare is how people are cared for and supported based on their diagnosis, rather than from a human perspective. Often, in healthcare, the human dimensions of patients get lost underneath their diagnoses and labels, and the assumptions that come with them. As we will see throughout this thesis, this is particularly clear when it comes to men and migraines. For that reason, through a lifeworld approach, I focus on placing people's everyday lived experiences at the centre of the research process. I would argue this is the first step to designing care and support that is led from the point of view of the people who engage with it (Galvin & Todres, 2013). At its core, this thesis is an illustration of research-based knowledge to inform lifeworld-led support for men with migraines (Galvin & Todres, 2013)

Additionally, there is extensive reflexive work behind each chapter where I recognise myself as an active player in the research activity. Thinking about my own views and perceptions of migraine before and during data collection and analysis was a constant activity throughout my work. From thinking about ethical aspects of my research to reflecting upon finer details of experience making, I attempted to make reflexivity noticeable throughout the entirety of this thesis. Throughout the whole project, I have spent a great deal of time thinking about my role as a qualitative researcher and placing it in a wider Health Psychology research perspective; as well as in relation to my participants and the data I collected. This thesis focuses on male experiences of ill-health, and as a man, I often related to many testimonies and experiences shared by my participants. For that reason, I embraced this as an active part of the research process as it had undeniable influence in the way I made sense of my data.

1.3 What is a migraine?

Migraine is a common disabling primary headache disorder characterised by two major types. Firstly, migraine without aura, manifesting as severe headaches. These are normally of unilateral location (on one side of the head) and pulsating quality. Moreover, these can be associated with nausea and/or vomiting, photophobia and phonophobia, that is, extra sensitivity to light and sounds (International Headache Society, 2018, pp18-19). Secondly, migraine with aura which is described by the Headache Classification Committee of the International Headache Society as "fully reversible visual, sensory or other central nervous system symptoms that usually develop gradually and are usually followed by headache and associated migraine symptoms'' (International Headache Society, 2018; pp20-21). Some examples of these reversible symptoms are sudden difficulty in walking or keeping balance standing up, and changes in rhythm and speed of speech.

The duration of a migraine episode varies and its symptoms are extremely unpredictable. It is common for people to experience severe symptoms during a migraine episode, severe pain being one of the most common ones. However, type, occurrence, and intensity of symptoms vary from person to person. Moreover, migraines are also regarded as having an initial premonitory phase, where some people feel initial sensory and cognitive symptoms, and a postdrome phase (the period after the headache) where most people experience lethargy or fatigue (International Headache Society, 2018; pp18-21). A migraine episode can last minutes, hours, days or even weeks (Ong & Felice, 2017). Contrary to many other health conditions, the experience and consequences of a migraine episode go beyond the episode itself, because in this case, there is often pre and post migraine symptoms that heavily affect one's life (International Headache Society, 2018).

One of the first known descriptions of migraines and their periodic symptoms refers back to 3,000 B.C. and investigations of their complexity date back to the early stages of medicine. These were from Hippocrates, who provided detailed descriptions of intense pain in the head and visual disturbances (Hippocrates, 1859). One of the pioneers in research into the anatomy of the brain and nervous system, Thomas Willis, also produced extensive work around the causes and symptoms of migraines. His work was particularly relevant to highlight the complexity of migraines in terms of causes and symptoms, and how these could be related to different triggers (Willis, 1981). Willis was responsible for setting relevant foundations for future studies to explore the association between migraines and external triggers.

Migraines are an invisible condition and their causes are still unknown. Over the years there has been great advances in how science and medicine have thought about and explained what causes a migraine (Lowell, 2013; Tfelt-Hansen & Koehler, 2011). Explanations have ranged from vascular causes to neuronal theories involving the central or peripheral nervous systems (Lowell, 2013; Tfelt-Hansen & Koehler, 2011). Causes for migraines have also been associated with different aspects of brain structures (Puledda et al., 2017). Currently, migraines are viewed as a complex brain disorder resulting from a combination of genetic aspects and involving different brain regions (which results in the different range of sensorial symptoms) (Goadsby et al., 2017). That is, ultimately migraines are the result of atypical neural functioning and activity (Goadsby et al., 2017). Because of their symptoms being so subjective, and because of the lack of clear physiological or anatomical explanation for them to occur, migraines are a great mystery to modern medicine and neurology. Not only does this impact our overall understanding of migraines, it also makes it particularly difficult to find ways of treating and preventing them. This is what makes migraines particularly relevant to the field of Health Psychology.

Although the focus of this work is not on pharmacological approaches to coping with migraine, these are undeniably a very important element of the migraine experience. Treatment options available for migraines are often of clinical and/or pharmacological nature, especially for acute situations. The ultimate goal of acute treatments for migraine is to restore an individual's ability to function by reducing the severity and duration of a migraine episode (Ong & Felice, 2017). An interesting aspect of migraine treatment is that when it comes to drugs, migraine non-specific drugs (medication that was created to treat another health condition) also work to reduce the effects of a migraine (Ong & Felice, 2017). For that reason, people with migraines have a multitude of pharmacological options and decisions to make. This makes migraine treatment relatively more complicated given that there is not one single answer to what works and what does not. This opens another potential point of interest for the field of Health Psychology to investigate the complexities and experiences of medication management in people with migraines.

In their extensive review and assessment of the available evidence relating to the efficacy of migraine medication, Marmura et al. (2015) outlined the complexity of prescribing migraine medication. Due to the lack of one specifically effective drug for migraines, they advise clinicians prescribing migraine medication to consider the length of the efficacy of the medication being prescribed as well as its potential side effects and medication-related adverse events. A particularly good example is how they identified the greater effectiveness of opioids for acute migraine treatments in comparison to other drugs, but still recommended these not to be used on a regular basis. Migraine treatments are as complex as migraine itself.

From a psychological point of view, migraines are the representation of how a condition can affect different elements of someone's life and have a true biopsychosocial element to its core. Migraines are an illness condition known for their physical symptoms, but they also have disruptive consequences to one's social and professional structures. They impact the individual, as well as their families and friends. It is of interest to psychological research to approach this phenomenon by exploring the true extent of how the condition affects different elements of someone's life and how these individuals can be supported in their journeys. A key element of the migraine experience lies within whom experiences it. Psychological research such as that presented in this thesis can be particularly relevant in contributing to placing the focus of migraine research beyond its pathology and broaden their spectrum to explore lived experience. The work in this thesis goes in line with this argument and focuses on lived experiences through shifting the focus away from 'the migraine' to 'the person' experiencing them.

1.4 Mixed-qualitative-methods approach and the role of qualitative research in ill-health

The ultimate goal of qualitative research is to develop concepts and notions to better understand a certain phenomenon by including individual, social and cultural dimensions to gain an in-depth understanding of the nature of humankind and how we live. This is done through placing the focus on individual participants and their lives. Through focusing on meaning-making and the importance people place on certain events in their lives, qualitative methodologies offer an ideal way to look at ill-health from the perspective of those who are more affected by it (Miles & Huberman, 1994). This is at the heart of my work.

When thinking about and choosing the most appropriate methodological approach to understanding the experiences of migraines in men, the principal issue was to reflect upon which methodology would be best suited for answering the overarching research questions and objectives this project was targeting. That is, which data collection and analytic methods would be best placed to give voice to men with migraines and to best represent their journeys and lives. According to previous research, this should be the determining factor behind the choice of methodology (Mays & Pope, 1995; Creswell, 2007). My view is that there is not one singular method that is best placed for this. Therefore, in this thesis, each chapter utilises different data collection and analytic methods that represent my understanding of what best suits the different research questions guiding each chapter.

The overall emphasis of my research was not put on one specific methodology in order to explore human experience of migraines, but rather on what a mixed-qualitative-methods approach can achieve in this field. Frost et al. (2010) offered us the concept of ‘pluralism’ in qualitative research as a means to reflect upon how we can combine different methods of analysis on the same dataset to enrich the process. However, this thesis goes beyond that argument and adopts an approach that focuses on using mixed-qualitative-methods to explore different angles towards different subjective experiences. That is, it attempts to understand the male perspective towards the migraine experience by using different research questions, a range of different data sources and participants, and different data collection and analysis techniques. In particular when it came to eliciting the subjective migraine experience from individual participants, the use of visual and written methods in addition to standard interviews proved to be of great importance. This rich process, based on mixed-qualitative-methods, allowed this programme of work to touch upon and unveil the finer details of people’s lived-experiences of migraines.

Within this methodological approach, each chapter plays a distinct role and was informed by results and findings of the chapter that came before. In other words, I adopted an openly progressive methodological approach that was shaped and informed by information and data from chapter to chapter. This can be linked to Guba and Lincoln’s (1994) concept of ‘emergent design’ in a way that each methodological design employed for each study of this thesis emerged from previous work as the overall study progressed in response to my observations and analysis (Guba & Lincoln, 1994; Al-Busaidi, 2008). My programme of work can be seen as a stairway to better understanding the migraine experience where each chapter is a step towards this ultimate goal. Moreover, the different steps adopted different methodological approaches and resulted in and from different analytical insights.

The different analytic methods used throughout this work, Interpretative Phenomenological Analysis (Smith et al., 2009), Discourse Analysis (Foucault, 1980), Thematic Analysis (Braun & Clarke, 2006), reflect the flexibility that qualitative methodologies can have when employed in Health Psychology research.

As seen above, migraine is a subjective condition which affects individuals in several areas of their lives. We can argue that in order to truly explore how a condition with these characteristics affects different life structures of a person, we need to look at migraines from different perspectives and take into account different nuances of the experience. This facilitates a more detailed understanding of what it is like to live with migraines. Through deploying different methodological approaches (i.e. IPA, DA and TA) we will get one step closer to understanding migraines, their relation to gender and how people navigate different types of support.

IPA seeks to situate individual experiences within a social, cultural, and theoretical context (Larkin *et al.*, 2006). In IPA, we look at a certain phenomenon from the perspective of those who experience it. As a method of research, IPA facilitates the understanding of the different nuances of a phenomenon and lays the foundations to learn about finer details of lived experience (Smith *et al.*, 2009). In this programme of work I use that lens to look at the migraine experience, the role of masculinity and people's structure of support from the perspective of human experience.

It is important to look at migraines, not only from the lived experience of those who suffer from it, but also focus on the narratives around migraines as a condition, migraine as a condition affecting men, and the way people navigate different structures of support for migraines. These narratives and discursive constructions can guide action and shape lived experience. In many cases, key stakeholders in the field of migraines (organisations working in the field of migraines, charities that support people with migraines, healthcare professionals with a role in migraines, researchers etc.) are the ones driving the field in terms of how migraines are portrayed, talked about, and supported. This represents an important element of shaping the narrative around migraines as well as the behaviour of those who lived with it. Using Discourse Analysis and by examining the different discourses deployed within the context of migraines, gender, and support, I will be contributing to a richer understanding of the wider narrative of migraines and support for people who live with it (Willig, 2008).

Lastly, Thematic Analysis is a flexible technique that allows for an understanding of the different contexts surrounding a certain phenomenon (Nowell *et al.*, 2017). Through adopting this approach to attempt to understand these contexts, I am not focused on finding a singular, objective, practical truth about migraines, gender and support (Hurley *et al.*, 2021). Instead, the idea is to contribute to the understanding of migraine, gender and social support from the perspective of those with first-hand knowledge and look at it within the context of online platforms. Ultimately, I want to explore the social world of migraines and place emphasis on perceptions, real meanings, and experience of our participants, whilst contributing for a wider understanding of migraines as a phenomenon.

I believe one of the best ways to understand an illness condition is through the eyes and experiences of those who live with it. Only then we can start thinking of producing and adapting different support and healthcare systems that are aligned with people's lifeworld-led needs (Galvin & Todres, 2013). Furthermore, not only does qualitative research give researchers the possibility of engaging in in-depth explorations of ill-health, but they also set the foundations for future approaches and perspectives to improve practice and coping strategies. That is, as a result of a more detailed and in-depth view of lived-experiences elicited by qualitative research, healthcare professionals and researchers will have an overall more informed and better understanding of certain real-world details associated with living with a condition and the barriers that come with it. This consequently places them in a better position to improve healthcare practice and policy (Al-Busaidi, 2008).

To better understand illness and the impact it has on people experiencing it, research should go beyond placing its focus on understanding the condition itself. The lived-experience of a human being can teach us as much about the condition as the condition itself. Additionally, through understanding the personal barriers people experience, as well as the different experiences and routes for seeking and obtaining support, we can be one step closer to the humanisation of support systems and healthcare (Galvin & Todres, 2013). Humanising support systems and approaches to care, means creating systems that based on real-world lived experiences of those who use them. Through conducting research focused on understanding these lifeworld-led experiences, one can provide a vital contribution to improving the overall support that is available to this population. Mixed-qualitative-methods approaches are particularly well positioned to enable the elicitation of in-depth lived experiences as means to better inform lifeworld approaches to care and support.

To sum up, several methods of data collection and analysis were used in this work, and therefore it can be claimed that this thesis adopts a mixed-qualitative-methods approach to exploring migraine experiences in men. My approach to data collection and analysis was guided by placing the experiences of my participants at the centre of the method.

1.5 Overview of each chapter of this thesis

Each chapter in this thesis portrays different perspectives and focal points of the journey for men living with migraines.

My programme of work starts with a meta-synthesis of qualitative research exploring experiences of migraines. With this, I attempt to look at the quality and depth of the available qualitative migraine literature and provide an interpretative synthesis to help our understanding of the state of migraine research looking at people's experiences.

Conclusions drawn from this meta-synthesis were key to informing the first empirical study of this thesis. That is, picking up on these findings and the lack of focus on male experiences of migraines, in chapter 3, I engage in an in-depth exploration of the experiences of a group of men with migraines, using IPA (Smith et al., 2009). To date, the work presented in chapter 3, is the first study employing IPA to explore the lived experiences of men with migraines. This is particularly important as it allowed us to have an in-depth understanding of finer nuances of lived experiences of migraines and explore how an understudied and underacknowledged population experiences such a debilitating and subjective (Minen et al., 2018; MacGregor et al., 2011; Breslau et al., 2001). In line with the structural narrative of this thesis, through adopting a phenomenological approach, the aim was to investigate real-world lived experiences of my participants as means of informing care and support structures, as well as to reflect upon wider concepts of men's access to healthcare services. Moreover, by employing creative approaches to data collection, in chapter 3 I attempt to enrich discussions within the wider field of qualitative Health Psychology in how these methods can be an asset to connecting with and reaching understudied, underacknowledged populations.

Additionally, the work in chapter 3 has allowed me to highlight how online resources can play a significant role in terms of informational and emotional support for people with migraines in general, and men in particular. This crucial finding underpinned the work reflected in chapter 4, the second empirical study of this thesis. In chapter 4, I propose a novel approach for synthesising data from online platforms. Additionally, I offer a discursive analysis of various online resources as a way to explore the experience of migraines through the discourses constructed within these platforms (Foucault, 1980). Moreover, in this chapter I present a thorough reflection of the current guidance for internet mediated research and how they directed this study.

Finally, the last empirical study in this thesis, presented in chapter 5, once again gives men the platform to share their experiences. In particular, men were invited to speak about the role of online communities and resources in supporting them in their migraine journey. Drawing on findings and conclusions from previous chapters, in chapter 5 the focus was placed on using Thematic Analysis to understand the benefits and effectiveness of online communities in supporting men with migraines (Braun & Clarke, 2006).

In each chapter of this thesis I invite the reader to reflect upon the strengths of qualitative research. It is also my intention to offer a lifeworld-led approach to understanding migraines from a male perspective and how those findings can be used to inform support systems for men with migraines. By reading this thesis I want people to adopt an approach focused on active listening/reading, and to try to walk in the shoes of a man with migraines.

Chapter 2 – Meta-synthesis of Qualitative Research Looking at Experiences of Migraines

2.1 Introduction

In order to start delving into the phenomenon of migraine in men through a multi-layered qualitative approach, it is important to place this work within the wider context of migraine research and understand the role and place of qualitative research in what we know about migraines. Qualitative research has been widely used to help shape our understanding of illnesses and support systems through exploring people's experiences (Pope et al., 2002, Galvin & Todres, 2013). In line with that, understanding migraines as an illness through the eyes of those who experience it, is key in my work. It is significant therefore to begin to showcase the empirical work in this thesis with a systematic and thorough exploration of qualitative studies that have focused on exploring the human dimensions of migraines.

Studying and understanding migraines is particularly relevant for this day and age. Migraines are a common disabling primary headache disorder and have been described by the European Headache Federation and World Headache Alliance as the ''forgotten epidemic'' (Diener et al., 2006). The World Health Organisation (WHO) has classified migraines as a major public-health problem and has expressed concerns about the fact that countries throughout the world have revealed inadequate responses to treatment and care for people with migraines (WHO, 2011). According to WHO (2011), globally, migraine has been one of the leading causes of Years Lived with Disability (YLDs) – which is a measure that accounts for severity of an illness and reflects its impact on quality of life. To state the effect that migraines have on quality of life, in their meta-synthesis of migraine management studies, Minen et al. (2018), highlighted that living with migraines can have a severe negative impact on people's social interactions and professional careers. Furthermore, their findings emphasise how subjective and personal the migraine experience can be, and how important personal knowledge of the condition is when it comes to coping with it.

The epidemiological and quantitative literature focusing on migraine is vast. However, large-scale studies mainly focus on pain levels, physical symptoms, and/or on testing the effectiveness of certain treatments and medical approaches to 'cure migraines'. Even though subjectivity of feelings and symptoms has been identified as a trait in migraines, literature focusing on sense-making and offering an in-depth perspective into what it is like to live with this illness is scarce.

Literature rooted in phenomenology tells us that the way people make sense of living with a long-term condition is intrinsically related to the way they make sense of themselves and their surroundings (Osborn & Smith, 2015; Shaw et al., 2018; Larkin et al., 2011). In line with this narrative, at the core of this thesis is the argument that by placing the focus on human experience and by exploring migraines through the eyes of patients, we are one step closer to understanding this illness and consequently informing healthcare practices, and creating and improving support systems that are tailored to people's real needs. Due to the subjectivity of the symptoms and the fact that it affects all areas of someone's life, migraine is a subject that is linked to core structures of 'self' and to extremely personal and subjective constructions. Failing to place qualitative experiential evidence at the centre of the debate, might stop us from being able to fully understand patient experiences and establish support services that are tailor made for the real needs of people with migraines.

Literature clearly states that migraines are an under-recognised and under-treated condition and that personal subjectivity plays a significant role in how people live and cope with it (Buse et al., 2009). However, it still fails to acknowledge the importance of placings the focus on people's lived experiences.

To represent the argument that is intrinsically placed at the heart of this PhD, for the purposes of this meta-synthesis we distinguished two meanings of qualitative research, 'big Q' and 'little q' (Kidder & Fine, 1997; Willig, 2008). According to Kidder and Fine (1997), 'big Q' refers to research methodologies that are used with the objective of exploring meanings. That is, 'big Q' reflects the type of qualitative research that aims to understand and explore participants' constructions of a certain phenomenon or how they attribute meanings to it. The argument of this thesis defends that these are better placed to provide lifeworld-led input to healthcare and support systems, and consequently enable the development of tailored services that correspond to real life experiences and needs (Toombs, 2002, Todres et al., 2009; Todres et al., 2014). On the other hand, 'Little q' methods do not focus on gaining new insights into how participants perceive the world, or a certain phenomenon. They are limited to purely reporting what participants stated when answering open ended questions. 'Little q' methods are often used to validate or 'check' data that has been pre-defined – by either literature or quantitative methodologies – rather than portraying interpretations of authors based on participants experiences and in-depth constructions of the world (Kidder & Fine, 1997; Willig, 2008). In line with this, this review aims to identify and synthesise the available qualitative literature focusing on people's experiences of migraine and answer the question, 'How do people make sense of their experience of migraine?'; additionally, I will aim to understand how this is explored through the perspective of men and answer the question 'What do we know about men's experiences of migraine?

2.2 Methods

2.2.1 Search Strategy

A systematic electronic search for literature was conducted using Web of Science and PubMed in 2018. This search was re-run in October 2021. The SPIDER tool (Cooke & Smith, 2012) was used to develop the search strategy. The SPIDER tool is an adaptation of the traditional PICO method used in systematic reviews. Cooke and Smith (2012) developed the SPIDER tool in order to be used as a search strategy for reviews which focus mainly on qualitative research. Its terminology and search terms are suitable to pick up articles that explicitly contain reference to the data being qualitative or mixed methods (Cooke & Smith, 2012).

The search terms for this review were:

- **Sample** - M?N AND WOM?N OR ADULT.
- **Phenomenon of Interest** - MIGRAIN* OR MIGRAINE DISORDER OR CHRONIC HEADACHE OR HEALTHCARE OR HELP-SEEK*.
- **Design -** FOCUS GROUP* OR PARTICIPANT OBSERVATION OR INTERVIE* OR DESCRIPTION.
- **Evaluation -** EXPERIENCE* OR VIEW* OR OPINION*.
- **Research Type -** QUALITATIVE

Inclusion criteria

- Published qualitative or mixed methods studies.
- Studies about men's or men's and women's personal experiences of living with any type of migraine and/or their healthcare seeking behaviours.
- Studies with adults (18 years or older).
- Studies using a 'big Q' approach

Exclusion criteria

- Systematic reviews or meta-analyses or studies with people under the age of 18, people in care homes, or studies not published in English.

- Studies where migraine is not the main focus and is explored alongside other types of headache (tension type headache, chronic daily headache) or major health conditions (epilepsy/mental disorders).
- Studies where the main emphasis is not on qualitative data
- Studies where the main emphasis is not on personal experiences of migraines or do not include at least one male participant.
- Studies focusing on experiences of receiving a certain treatment, intervention or therapy for migraine, rather than how people with migraine access healthcare (healthcare seeking behaviours).
- Studies using a 'little q' approach

2.2.2 Data screening

All papers generated from the initial search were subjected to screening. After removing duplicates, I screened all papers in relation to the inclusion and exclusion criteria and the purposes of this synthesis. Papers were excluded based on an initial phase involving screening of titles and abstracts. Following this stage, full papers were screened for eligibility. Additionally, my supervisors screened a small subset of the papers to ensure the results generated met the inclusion criteria. Papers that followed the inclusion and exclusion criteria for this review were obtained in full text. A diagram illustrating the data screening process is available in the results section (*Figure 2-2 PRISMA flow chart*).

2.2.3 Critical appraisal tool: CASP

I used the Critical Appraisal Skills Programme: qualitative checklist (CASP, 2018) on each paper included in this review. *CASP* is the most commonly used quality appraisal tool in health-related qualitative evidence synthesis (Long et al., 2020). *CASP* enabled a systematic assessment of the methodological strengths and limitations of the papers, as well as an evaluation of the quality of the results (CASP, 2018).

2.2.4 Data extraction and synthesis of qualitative evidence

After the screening and appraisal phase, and the final subset of papers were selected, I proceeded with data extraction. Data extraction was divided in several stages. Initially, I familiarised myself with the papers, and re-read them several times. I then gathered all the themes and participants' quotes present in the papers using a *Pro Forma*, and organised them in a table. Moreover, I gathered additional interpretative comments made from the authors on each of the themes and participants' quotes. These were then comparatively synthesised.

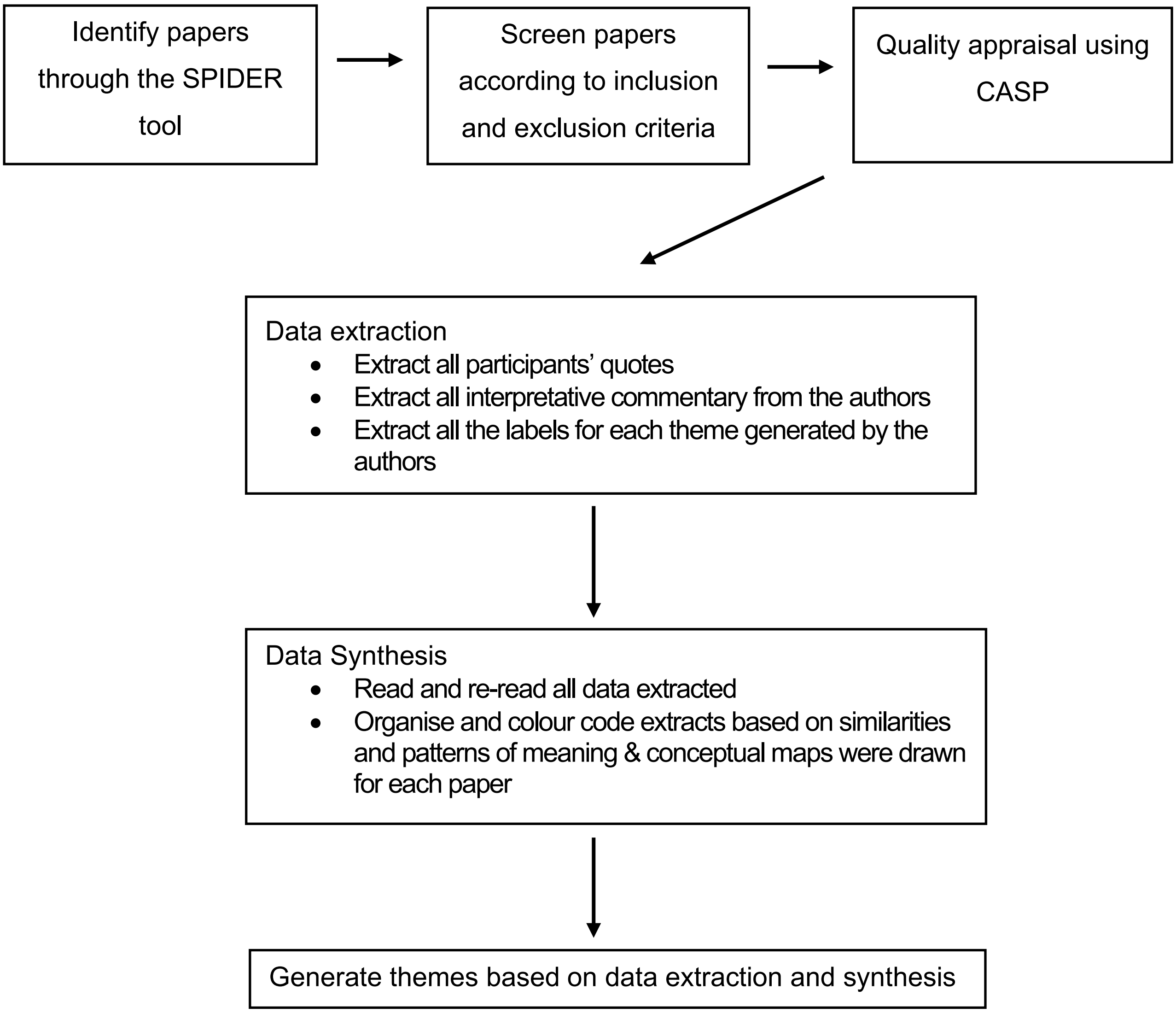
At its core, a meta-synthesis is ‘research of research’ (Paterson et al., 2001, p5). In order to synthesise the data from each study and generate a final set of themes that represented an overview of the data, I performed an interpretative comparison of each subset of data extracted. Additionally, as suggested by Shaw (2012), this comparison involved an interpretative reading of meaning, but not further conceptual development. This stage was influenced by Noblit and Hare’s (1988) meta-ethnographical approach. This has been seen as one of the most influential and conventional approaches used to synthesise qualitative research data (Shaw, 2012) and can be described as the ‘translation of several studies into one another’ (Noblit & Hare, 1988; p25), provided the studies are comparable in terms of topic and method. Which was verified in this case.

Synthesising the data allowed me to translate several qualitative studies into one another, giving us an insight into how these are related to each other and enabling us to understand what different qualitative researchers (and their participants) have to say about the phenomenon of living with migraines. In order to generate themes for this meta-synthesis, I used colour codes and attributed similar colours to data (participants’ quotes, themes, and authors’ comments/interpretations) that I identified as having similar meaning. In other words, themes were generated based on my interpretation of the data available in each paper. Data identified as representing and translating similar experiences or descriptions of phenomena were grouped under the same theme. Additionally conceptual maps were drawn for each theme.

A table with the colour codes of the themes of the seven papers is available in the appendices. Additionally, as the focus was on people’s experiences of migraines, only colour coded quotes from participants who were said to experience migraines, or places where authors provided interpretative commentary towards lived experiences of migraine, were used for the purposes of this review – in instances where papers had quotes from family members or healthcare professionals, these were not coded.

Based on this cross–study comparison and synthesis, I generated a set of themes that represented my interpretation of: 1. How participants from this group of papers made sense of their migraine experience and 2. The authors’ interpretative commentary towards the data presented in their publications. In other words, by investigating different and separate studies (‘the parts’) I generated a set of themes that represent my interpretation of ‘what the migraine experience is like’ based on data from the papers included in this review (‘the whole’). This final set of themes is available in the results section and aims at creating a fuller and clearer picture of the phenomenon of lived experiences of migraines by highlighting metaphors, meanings and concepts from the studies included (Shaw, 2012; p18).

Figure 2-1 Diagram with the processes of the meta-synthesis



Data extraction

- Extract all participants' quotes
- Extract all interpretative commentary from the authors
- Extract all the labels for each theme generated by the authors

Data Synthesis

- Read and re-read all data extracted
- Organise and colour code extracts based on similarities and patterns of meaning & conceptual maps were drawn for each paper

Generate themes based on data extraction and synthesis

2.3 Results

A total of 2442 articles were identified, 733 papers were identified through Web of Science, and 1709 papers were identified through PubMed. Following screening, seven papers were included (see Table 2-1). The CASP appraisal results are presented in Table 2-2.

Figure 2-2 PRISMA flow chart

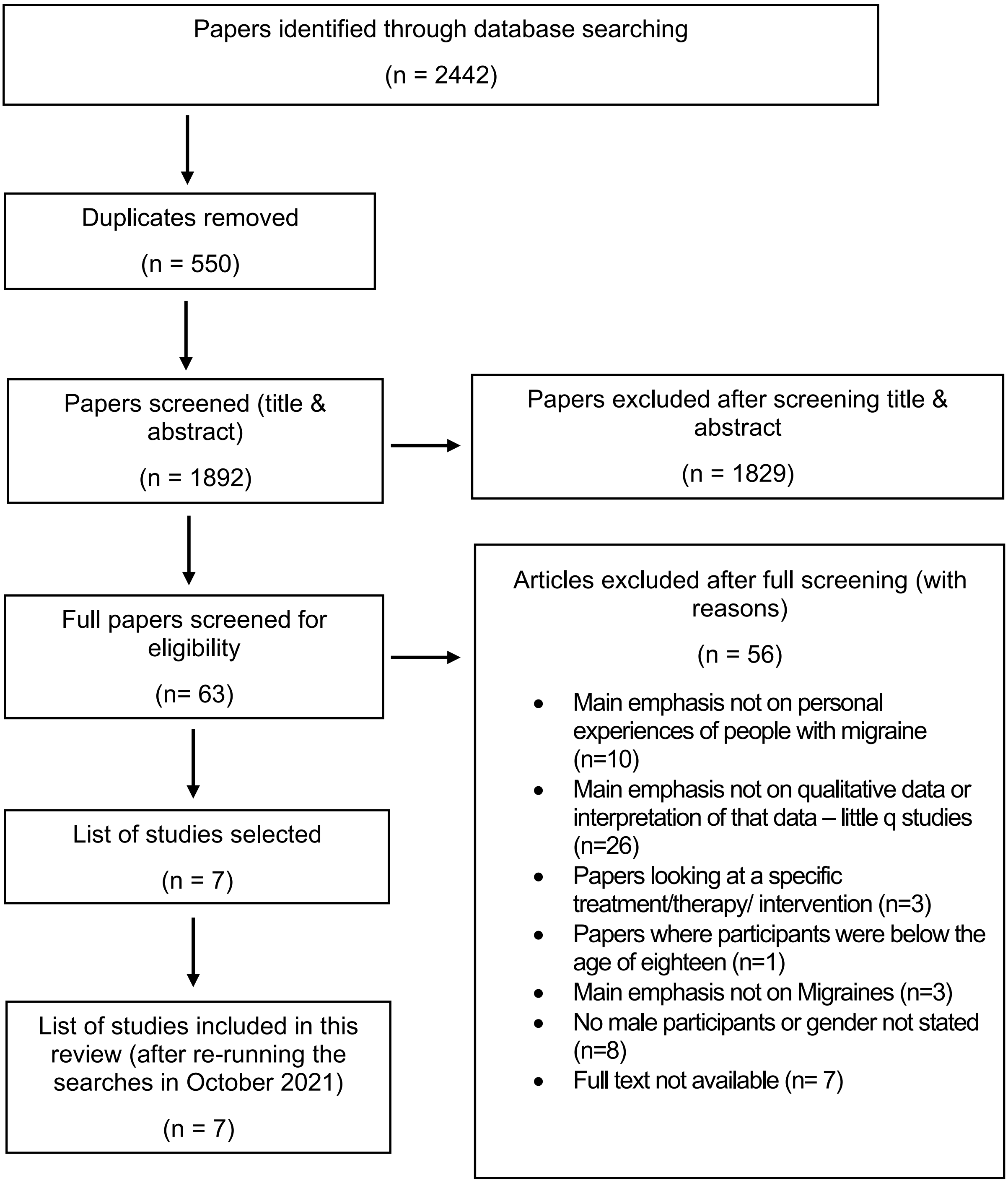


Table 2-1 Characteristics of included studies

Author and date	Phenomena of interest and objectives	Location	Participants	Data Collection methods	Data analysis and/or Theoretical Framework
Belam et al. (2005), UK	Explore what it is to suffer with migraine from patients' perspectives in order to inform health service delivery. Authors also mention that is their aim to ''develop a research partnership between migraine sufferers and healthcare professionals to synthesise tacit and explicit knowledge in the area. ''	United Kingdom	8 participants (two men + six women– aged 30 -61). All participants had received a medical diagnosis of migraine	Informal conversational style interview – authors stated that they '' held a further series of meetings that included mutual learning, role-plays and pilot interviews, to work out how best to conduct interviews that would enable participants to be open with what they told us. This suggested that patient researchers and participants preferred an informal conversational style interview, which led to the development of a broad topic guide''	Grounded theory and participatory research Authors stated that ''we call our methodology consensual qualitative research: all aspects of our research — deciding the research topic and question, planning the design and methodology, gathering and analysing the data, were decided upon through mutual discussion and consensus in a series of meetings of a research team that comprised a mixed group of patients and professionals Analysis was done through ''consensual qualitative approach''
Peters et al. (2003) *	Patients' perspective and factors influencing migraine and chronic daily headache management & factors involved in the patients' decision-making.	United Kingdom	The methods section in the paper states that 15 participants took part. All participants had history of experiencing migraines. Authors also mention that ''patients with coexisting headaches or patients who had developed chronic daily	Semi-structure interviews	Grounded Theory

			headache were not excluded ‘’ However, in the results section, there is a section ‘Participants’ characteristics’ stating that 13 participants took part – four men and nine women. Three participants suffered from tension type headache as well as migraine		
Peters et al. (2004) *	Patients’ perceptions of migraine and chronic daily headache (CDH) management	United Kingdom	13 participants (four men and nine women) –3 three participants suffered from tension type headache as well as migraine	Semi-structure interviews	Authors state that ‘’a guide was devised to standardize the coding procedure for triangulation - a sentence by sentence code was performed to give an initial coding scheme. Codes were grouped into a hierarchical taxonomy to form concepts and theories. These concepts and theories were based on theoretical memos and discussions between the authors. ‘’
Peters et al. (2005) *	Management of migraine and chronic daily headache (CDH) from the patients’ perspective.	United Kingdom	13 participants (four men and nine women) –3 participants suffered from tension type headache as well as migraine	Semi-structure interviews	Authors state that ‘’a coding guide, devised by [authors}, was used to standardise coding. To begin analysis, the first 5 interviews were summarised (by 3 of the authors and an independent researcher). Secondly, the interviews were coded sentence by sentence to give an initial coding scheme - The third stage of analysis involved comparing similar and different codes to group the

					codes into a hierarchical taxonomy to form concepts and theories. These concepts and theories were based on theoretical memos and discussions between the authors.’’
Rutberg et al. (2013)-	Managing life to feel better (while living with migraine)	Sweden	19 participants – 17 women and two men – ranged from 20 to 69 (md:48 years)	In-depth interviews with a narrative approach	Hermeneutic phenomenological approach inspired by Van Manen 1997
Varkey et al. (2013)	Patients’ views/reasoning regarding migraine prevention.	Sweden	21 participants - The participants comprised 15 (71%) women and six men. Of these, 15 had migraine with aura, one had migraine without aura and five had both. They had an estimated migraine attack frequency of four (median), ranging between 2 and 12 attacks/month	Standard Interview	Qualitative content analysis
Velasco et al. (2003)	Quality of life and migraine	Spain	Abstract states 33 migraine patients under physician-directed treatment, 5 self-medicated patients, 5 relatives of migraine patients and 7 healthcare professionals. However, the results state that 2 individuals from the groups treated at hospital and 4 from those self-medicated, refused to participate, the first due to inability to attend the meetings due to their timing interfering with their jobs,	Qualitative methods. 6 focus groups and 9 personal interviews	Authors state that the ‘’analysis of the data was carried out following the method described by Krueger (1996)’’ – Krueger, R.A. (1996). Group Dynamics and focus groups. In Spilker B., editor: Quality of life and pharmacoeconomics in clinical trials (2nd ed) Philadelphia: Lippincott-Raven Publishers (397-402)

			whereas the latter gave no explanation. People with migraine (29) – 27 women, two men Family members of migraine patients - five – four men and one woman Healthcare professionals (7) - two women, five men - Two family doctors, one neurology nurse, one pharmacist, two neurologists, one psychologist		

* Authors have stated that the data described in this article were part of a larger qualitative study, which focused on the patients' perspective of migraine and chronic daily headache and the management of these headaches. Although not entirely clear, all of the three studies seem to have resulted from data from the same 13 participants.

Table 2-2 **CASP checklist results**

Paper:	**Question:**								
	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately addressed?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?
Belam et al. (2005)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	No	Yes
Peters et al. (2003)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	No	Yes
Peters et al. (2004)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	No	Yes
Peters et al. (2005)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	No	Yes
Rutberg et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

Varkey et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Can’t tell	Yes	Yes
Velasco et al. (2003)	Can’t tell	Yes	Yes	Can’t tell	Yes	No	No	No	Yes

2.3.1 Quality appraisal

Each individual paper in this synthesis was reviewed using *CASP* (see Table 2-2). After reviewing the existing literature and paying special attention to the seven papers included (see Table 2-1 for details), it is important to note that within the field of migraine research, qualitative methodologies are sometimes being used to 'report' and 'describe' perspectives (little q) rather than to explore, interpret, and understand them (big Q). In several occasions, when scanning the literature (especially from reading methods sections of several qualitative papers looking at patients' experiences), I found a lack of clarity about the extent and depth in which the phenomenon of 'participant's experiences' was being explored. Often, papers mentioned using qualitative methodologies in the abstract or introduction or methods, but failed to provide interpretative commentary in their results sections. That is, often authors simply provide quotes from interviews without accompanying them with an interpretation. During the screening process, I was often faced with a mismatch between the description of the method and the reality of data interpretation.

Additionally, it was common to see the use of certain theoretical frameworks to understand perceptions and lived experiences of migraine, when in practical terms all that was being reported were vague descriptions of interview data. This is reflected on the overall negative score on item 8 of the *CASP* tool (''Was the data analysis sufficiently rigorous?''). In this group of papers, all authors stated that it was part of their overall objective to explore and understand human experience, however, with the exception of Rutberg et al. (2013) and Varkey et al. (2013), they did not do that to its full extent. That is, there was a lack of interpretation, clarity and 'depth' in the analysis reported.

Another relevant aspect of this quality appraisal is linked to the very basis of qualitative research and the active role of the researcher. By definition, through their analysis, the qualitative researcher is interpreting the data shared by the participant in a double hermeneutic process (Smith et al., 2009). It is known that qualitative research recognises and embraces the active and subjective role of the person who conducts the research, and argues that this should be included in the final published work. The fact that these are interlinked is why we, researchers who conduct interpretative synthesis of empirical qualitative research, extract participants' quotes published by authors, as well as their interpretations of these data (Shaw, 2012). Therefore, a qualitative researcher must be aware of their assumptions and their personal stance towards their methodologies, research process, and participants; and this should be addressed in their published work. Similarly to how reviewers who synthesise qualitative evidence need to also engage in reflexive work, as argued by Lincoln and Guba (1985). This was not verified in any of the papers included, which resulted in an overall negative score on item 6 of *CASP* (‘Has the relationship between researcher and participants been adequately addressed?’). Authors from the seven papers included in this review have not stated or highlighted any reflexive work done upon how their relationship with participants and with the topic in study might have influenced their analysis and the way they presented their results. Especially in cases where the creation of the interview schedule and data collection methods were part of a joint process of collaboration between participants and researchers, this should have been made more transparent (Belam et al., 2005).

The study conducted by Belam et al. (2005) which was based on ‘’a set of conversations’’ between five patients and three professionals, is a good representation of how the current literature on the topic is lacking an aspect of reflexivity. Belam et al. (2005), conducted a study aiming at understanding what it is like to ‘’suffer from migraine from patients’ perspectives’’ based on a research partnership between people living with migraines and healthcare professionals. Even though authors claimed their research was based on a ‘’consensual interpretative approach’’, it lacks transparency and detail. Additionally, their approach to Grounded Theory and to a ‘’research partnership between people living with migraines and healthcare professionals’’ would benefit from further clarification. The lack of detail in explaining how they used this approach reflected the negative score on item 8 of *CASP* (‘Was the data analysis sufficiently rigorous?’). It seems reasonable to suggest that trying to understand such a subjective condition by involving different stakeholders and adopting a patient-centred approach is the way forward to developing relevant and meaningful strategies to coping and living with migraines. However, it is also beneficial to adopt a transparent approach to data collection and analysis, and provide a rich illustration of how the involvement of ‘patient researchers’ in research have influenced the process of data collection and analysis.

Beyond the methodological issues relating to the studies included, one of the bigger issues with the current literature is how authors fail to distinguish migraines from other types of headache. There is a lack of consistency in how literature defines migraines in comparison to other types of headaches. As seen in *Table 2-1* above, some studies have included participants with different types of headache conditions such as tension type headache, chronic daily headache, cluster headache, migraine etc. and conducted their analysis and interpretation of people’s experiences without distinguishing how different conditions might affect people differently. Not only does this make reviewing and synthesising migraine literature more difficult, it might also give rise to inaccurate depictions of migraine symptoms and experiences (as they might be mistaken with other types of headaches).

For example, to look at someone's experiences of cluster headache with the same lens that has been used to look at someone else's experience of migraine, means leaving out condition-specific (and individual) particularities of these two types of headaches (Peters et al., 2003; Peters et al., 2004; Peters et al., 2005). Although it is important to explore the extent to which different types of headache affect people's lives and decision making, it is also important to note that each type of condition might affect people differently, require different coping mechanisms, and therefore should be explored separately in its own right. In addition to not differentiating for different headache conditions, studies adopted this same approach when it came to representing the experiences of men and women. In spite of all papers having included at least one male participant, no study made a clear distinction between the experiences of men and women. In fact, not only did authors not discriminate for men's experiences, some studies did not even specify whether quotations in their paper were from men or women.

To explore people's understanding and experiences of a certain condition is to validate one's experiences of that specific condition in its own right and in its full extent. Therefore, further qualitative studies looking at experiences of headache illnesses would benefit not only from taking into account that people might experience different types of headache differently, but also by noting that men might experience them differently to women. We get closer to understanding individual experiences of a certain type of headache, and consequently develop better care and support services, by acknowledging the uniqueness of symptoms and singularities of its impact on an individual person who experiences it.

It is important to recognise that even though these studies are not flawless, they still provide a valuable contribution to the current field of migraine research. They all highlight the uniqueness of this condition, subjectivity of symptoms, and the impact it can have on someone's life. Overall, they provide a good picture of how qualitative methodologies can be employed differently to explore different perspectives over the same phenomenon.

2.3.2 Themes

Through the synthesis of the data I generated three themes. The themes generated were related to symptoms and perceptions of migraines, the impact of migraines on people, and how people manage this condition. The themes were labelled: 1) *'What do migraines feel like?'*; 2) "*My migraine has ruined my life": the impact of living with migraines;* and 3) *Migraine management and 'being in control' of their illness.*

Theme 1. ‘What do migraines feel like?’

This theme touches upon some of the different symptoms that accompany migraine episodes and how singular and subjective they can be. Participants’ quotes available in the papers, as well as authors’ interpretation of these data, depict migraines as a condition that goes beyond headaches. When it comes to participant data, people tended to focus on how disabling the migraine experience can be as a whole. *Belam et al., (2003),* stated how the way their participants described their migraines *‘conveyed a sense of a powerful, menacing creature ever-lurking and ready to strike’;* portraying how unexpected the migraine episode can be.

Not only did participants describe migraines as being more than just a simple headache with the symptoms being felt all over the body, they also highlighted how severe and disabling the pain can be.

> *‘’It’s the pain, it frightens me sometimes, you think you might die.’’ (Belam et al., 2003).*

The intensity of pain was seen as a central aspect of their experience and is one of the symptoms that was most talked about. The experience of *‘feeling intense pain’* is clearly embedded in the experience of living with migraine. This is highlighted by several authors and supported by quotes from their participants.

An interesting aspect to note from the quotes of the participants included in these papers, is how they reported different degrees of pain and sensations. Nonetheless, the sharpness of the pain was a common trait across the experiences of different people. In order to describe what experiencing this sharp pain and living with this condition feels like, several participants across different papers used metaphors and visual expressions such as ‘’*a shadow‘’; ‘’the beast’’; ‘the pain is excruciating, unbearable’’*

> *“…the first thing that I am aware of, it’s like somebody’s put a knife through my head. The pain is so intense that for several seconds I don’t ever open my eyes, in the hope that I’m just dreaming about it…” (Peters et al. 2005)*

Another aspect which was pointed out by several participants was how experiencing a migraine sometimes meant experiencing a vast variety of symptoms. Even though there was a clear emphasis on pain, people also highlighted how the migraine experience goes beyond that. In fact, Peters et al. (2005) claimed that from the analysis of the data from their interviews, ‘*symptoms, other than pain, were also perceived as distressing and sometimes as more upsetting than the headache pain’*. Several papers showed quotes with descriptions of a range of symptoms

''I feel awful tired (…) I can't cough or bend down to pick something up" (Velasco et al., 2003);

''The worst bit is being sick as it just takes over" (Belam et al., 2003).

From the accounts of several participants and interpretations from the authors, this combination of symptoms often caused great discomfort, which sometimes led to some people feeling frustrated because their bodies '*are flawed'* - this was sometimes linked to feelings of failure towards themselves: '*'I feel a sense of failure when I have a headache." (Belam et al., 2003).*

This theme was generated based on how different authors and participants talk about what it is like to experience a migraine. It portrays how subjective and painful the migraine experience can be. Although pain seems to be a central aspect to migraines, papers highlight how the symptoms of a migraine episode often go beyond that; concluding that migraine as an illness is much more disruptive and disorientating than just a painful headache.

Theme 2. "*My migraine has ruined my life*'': the impact of living with migraines

With this theme, we have identified the far-reaching impact of migraines upon the people who experience them (on an individual level) as well as their family and professional career. From the participants' accounts, living with migraines means experiencing a condition that has the potential to dictate all aspects of their life. One participant of Velasco and colleagues' (2003) study clearly stressed the overall impact migraines can have ''*In every aspect, it has changed every aspect. My state of mind, I don't feel like doing anything, I am desperate. My migraine has ruined my life."*

In this particular study, people often talked about the fact that living with migraine also affected their interpersonal relationships and family structure. Velasco et al. (2003) reiterated that although family members understand the situation, people living with migraine still feel that migraine affects their relationship with their partners and even with their children. They support their interpretation with several quotes from different participants.

"What I am having to put up with affects them (the children) at an emotional level, at a level of their emotional development." (Velasco et al., 2003)

''Relationships with the family: you are always in a bad mood and besides, you see that the way they look at you is being affected and that you are also affected by what they are having to undergo." (Velasco et al., 2003).

Outside the family sphere, migraine was also identified as an ever-present problem. According to some participants in Belam et al. 2003, the constant fear and anxiety of having a migraine episode seemed to determine people's capacity to engage in social activities with friends.

''Migraine has prevented me from going out and enjoying myself and having a drink.''
((Belam et al., 2003).

Belam and colleagues were clear in stating the extensive impact of migraines – having to cancel plans with family and friends, experiencing difficulty to sleep, and a transcendent sense of failure – to the extent that some of their participants have admitted to have experienced thoughts of suicide. For Belam et al. (2005), migraines impact people on a physical, psychological and social level. These feelings and the incapacitating nature of migraines ends up affecting people's overall wellbeing.

In line with these interpretations, Peters et al. (2004) provided some descriptions that clearly illustrate how migraine can have an effect on core wellbeing and general approach towards life and self. Some of their participants spoke about their fear of getting a migraine and not being able to '*fulfil duties'*; these '*duties'* were both related to work and to family. Participants described how much of a '*disaster*' it is that migraine incapacitates them to the point that they are not able to do anything apart from '*lying in bed'*.

In fact, even when migraines are not being experienced, the anticipation of a migraine episode, has in itself a negative impact on the person. Especially when it comes to work performance or overall quality of their work. In the subject of work in particular, data suggest that work life and professional career are heavily impacted by migraine *"It affected my career choice." (Belam et al., 2003);*

''In the workplace: you can't fulfil your real potential. Sometimes you can't even go to work because you can't get out of bed.'' (Velasco et al., 2003).

Even when people do manage to engage in a normal professional activity, the fear of having a migraine episode during working hours seems to still be present. Quotes from participants from Belam et al's (2003) study point in the direction that the 'fear of having a migraine episode' is often extended to fear of being judged or misunderstood *''How you can say you have got a headache and can't come to work — it sounds pathetic.'' (*Belam et al., 2003*)*; Belam et al., (2003*)* relate this to the fact that 'the impact of migraine is not understood by non-sufferers'.

Such interpretation of data was also made Velasco et al., (2003) and supported by quotes from their participants

> *‘’The others don’t understand because it is a sharp pain and if you haven’t experienced it you can’t imagine what it’s like.” (Velasco et al., 2003).*

Data from participants as well as the interpretation of the authors shows that there is lack of understanding from those who have never experienced a migraine towards people with migraines. Not feeling that people understand the true extent of their condition has a very significant impact on one’s life. In fact, the fear of not being believed might lead people to try to carry on working normally, even if they are experiencing an intense migraine, which ultimately exacerbates the impact and consequences of migraines

> *‘’And it is no use either being at work and telling your workmate not to bother you, because your head hurts. You can do that at home, but at work, with your boss, attending to the public, etc., you have to pretend that you are okay, and that is hard to do.” (Velasco et al., 2003).*

This theme sheds light into the real impact that living with migraine can have on different aspects and spheres of someone’s life. Not only does this relate to the impact of a migraine episode itself, but also to fears of having one. Such fears are related to the uncertainty of not knowing when a migraine episode will happen. From individual experience of symptoms, to relationships with family and co-workers, people with migraine seem to experience different levels of uncertainty. There is an aspect of daily uncertainty of how and when a migraine episode will disrupt their plans, as well as the uncertainty and fear of not being believed by those around them. This all stacks together in a deterioration of social and family relationships resulting from the constant impairment of living with migraines.

Theme 3. Migraine management and ‘being in control’ of their illness

Following previous themes touching upon aspects related to the migraine experience and its impact on people’s lives, this theme focuses on management and prevention of migraine episodes. It underlines aspects of self-knowledge in people with migraines as well as how this relates to people’s ability to manage the condition. Moreover, it highlights the importance of feeling supported and having positive interactions with healthcare professionals.

Throughout different papers it was common to come across participant statements on the importance of managing and preventing migraine episodes from happening. Worrying about avoiding triggers seemed embedded in their day-to-day activities *“I have tried to be so careful, no alcohol, no coffee, lots of water, try to sleep properly.” (Belam et al., 2005).* Triggers were seen to be at the core of the migraine experience. Across the seven papers different participants shared strategies they use to identify and minimise migraine triggers.

> *''…yes, you become a bit like that [attentive], like the sun, because when it is really bright, then you need to use sunglasses, yes, you do not need to provoke fate ... all the time you think preventively ...'' (Rutberg et al., 2013)*

Varkey et al. (2013) linked such strategies to *'being in control'* of the migraines. Furthermore, Rutberg et al. (2013) explored the importance of past experiences on one's abilities to recognise migraine triggers. They talk about how people's lives become limited to avoiding triggers and activities that they know are linked to their migraine attacks. Rutberg et al. (2013) concludes that being able to alleviate the symptoms of a migraine enhanced people's sense of being in control of their own lives. In other words, controlling their lives was ascertained through controlling their migraines. Keeping migraines under control is portrayed as the main objective of their day.

Delving into aspects of '*being in control'* of their migraines, one participant in Belam et al's. (2005) study offered a suggestion for people to better manage their migraines: '*self-knowledge'*. From this person's account, the ability to manage and prevent migraine episodes (and ultimately 'being in control') is mainly linked to self-awareness, self-knowledge and the ability to listen to one's body. Here, self-knowledge of their own subjective experience of migraine is seen as a way to reduce '*exposure to triggers'* and consequently the risk of having a migraine episode. Furthermore, listening to one's body and what it tells them about migraines also has the potential of helping the effectiveness of medical treatment.

> *''Self-knowledge of the condition really helps. If you go into the doctors' [surgery] without any idea, it is a real hit or miss situation.'' (Belam et al., 2003)*

From this person's accounts, it is implied that the more a person knows about their condition, the triggers, its effects and causes, the easier it is for doctors to understand it and offer medical help. This links to previous statements around the subjectivity of the migraine experience, and extends it to the fact that this in itself might play a role in seeking support for their migraines and the quality of interactions with healthcare professionals; which opens up the argument around the role of medical professionals in supporting and caring for people with migraines and personal agency of ill-health.

For being the first port of call and the primary person responsible for providing care, people talked about GPs and the importance of their role in several papers. The relationship between migraine patients and healthcare professionals was indeed a reoccurring issue across the majority of the studies. Some participants spoke about the aspects that they see as crucial for care and support – amongst the most relevant was the importance and even the need to feel understood by doctors (which sometimes does not happen) *"I would like doctors to take migraines more seriously and understand how it affects people." (Belam et al., 2003)*; *"I have been upset by the lack of sympathy from doctors." (Belam et al., 2003)*;

> *"…nothing has ever indicated to me that anybody is interested and that there is any medical help…" (Peters et al., 2004)*

Another aspect relating to migraine support and management was medication. In particular, data pointed towards the complex thought process behind deciding whether to take medication. According to different studies, this process could almost be seen as a sort of 'inner self-negotiation' within each individual *"...although migraines are bad, I don't know if I'd want to take medication every day..."* (Peters et al., 2003); as there is always the risk that taking medication might not help and might even escalate their symptoms even further (due to the side effects). This is particularly important and intrinsically linked to the need for self-awareness in order to self-manage and self-treat. Intrinsically, there is a running thread across these papers: one's established responsibility of caring for oneself and self-agency in seeking treatment and support.

Even when it comes to taking medication, patients are in charge of their decisions. Not only do people need to understand their bodies and the way migraines affect them, but they also need to know how they react to different medications and their effectiveness towards migraines. Following this, they then decide what to take. In a way, due to the subjectivity of migraines and the support available, it is almost as if people with migraines are 'forced' to be responsible for managing their condition and take control of the way they seek and navigate care. In these papers, a lot of migraine management was linked to self-management and to deciding what works and what does not work for each individual person, even if sometimes that did not go in line with what their doctors have recommended.

> *". . . you work out what you think it's going to turn into and therefore taking the drugs that you will think will best suit it . . ." (Peters et al., 2003).*

Data available across the seven papers included in this review assert that managing and coping with migraine is a complicated process. Additionally, it highlights the nature of a migraine episode and how it can be triggered by different factors and minimised through the use of different individual strategies. When it comes to treating and coping with migraines, papers focused on the participants' perspectives towards medical care, migraine medication and the relationship between migraine patients and healthcare professional. However, a central aspect of treating and coping with migraines is the role of the individual towards caring for their condition. That is, responsibilities around migraine management, and decisions of how to navigate and seek support for migraines seems to be attributed to the patient. Having migraines requires active management by patients; patients are experts in their own conditions. In fact, the root of the way in which people manage their migraines and seek support is the knowledge they have about themselves, their bodies, and the migraine itself.

2.4 Discussion

This chapter is based on a meta-synthesis of qualitative papers exploring people's experiences of migraines. A systematic search of literature identified seven papers in the migraine literature that focus on the topic of migraines from the viewpoint of the participants and add to the body of knowledge about this condition.

This meta-synthesis is the first of its kind and facilitated drawing a clearer picture on the overall state of the qualitative research looking at migraines. The use of CASP to review all of the papers included allowed me to shed light into the quality of the studies in terms of their methodologies and approaches to the research process (CASP, 2018). In addition, this work synthesises the qualitative data published by groups of different authors, as well as their interpretations of that data. The combination of these two factors resulted in a detailed overview of what the qualitative literature exploring experiences of migraines looks like in terms of its quality and methodological approaches and experiential data. These findings can be particularly relevant for qualitative researchers; to inform how they present their work in publications, as well as to guide their work in terms of their approach to the overall research process, reflexive action, and transparency in the description of data collection and analysis. Moreover, through synthesising results from different qualitative papers exploring the migraine experience, conclusions from this chapter can be used to inform future research and practice in the field of migraines.

In terms of the data from the papers included in this chapter, through my synthesis I generated three themes that represent patterns of meaning and experiences across the seven papers. The themes generated were labelled: 1) *'What do migraines feel like?'*; 2) *"My migraine has ruined my life": the impact of living with migraines;* and 3) *Migraine management and 'being in control' of their illness;* and were related to symptoms and perceptions of migraines, the impact of migraines on people, and how people manage this condition, respectively.

The findings of this synthesis indicate deep social implications associated with living with migraines. These findings corroborate Minen et al.'s (2018), as the participants from the studies included in their meta-synthesis (that contrary to this one, focused on migraine management) also highlighted similar consequences that living with migraines has on people's social interactions and professional careers.

Additionally, data in this synthesis highlight the importance of self-management in migraine patients. Even though healthcare professionals play an important role in supporting and caring for people with migraines, there is a clear sense of migraine patients being the experts in their own illness. They are the decision makers and seekers of their own treatment and support options. This has been seen in other migraine literature beyond the scope of this review. In their study Foley et al., (2005), point towards the importance of individual decision making and patient agency in migraine management. They found that when experiencing the first symptoms, migraine patients often delay their treatment before deciding how to act. That is, the majority of the people in their study stated that they wait to see if their symptoms are in fact a sign of a migraine episode before taking medication. According to their study, many patients did not take medication when the pain and first symptoms were mild - which in combination with the findings of this review, advocates for an opportunity for interventions focusing on educating patients on 'self-knowledge of their migraines' (patterns, types of triggers, body reactions etc.) and on how to better identify that a migraine episode is coming in order to tackle it early and minimise its effects. Rothrock's et al., (2006) results also support the argument that interventions focusing on patient education and self-knowledge have the potential to help people better manage their migraines.

In addition, Wells et al., (2014) found that their intervention focusing on meditation for people with migraines showed positive effects on headache duration, disability, and self-efficacy. Another study conducted by Chaibi et al., (2011) also suggests that interventions like massage therapy, physiotherapy, and relaxation amongst other manual therapies for migraine can be as effective as certain medication. Medication is undeniably the most common strategy used to manage migraines (Chaibi et al., 2011). However, it has been seen that further non-pharmacological migraine management approaches that emphasise self-knowledge should be explored. There is a growing body of research looking at the effectiveness of non-pharmacological treatments to managing pain associated with migraine. However, future studies should look beyond bodily symptoms and pay special attention to the wholesome variety of effects migraines can have on people's lives. This argument sustains the need for future research that follows the approach of this PhD research. That is, placing the focus on an in-depth understanding of ill-health from the perspective of the patient in order to develop lifeworld-led care and support structures. In the particular field of migraines, interventions with foundations on aspects of individual experiences and the far-reaching impact of migraines on different aspects of people’s lives are needed.

Moreover, one argument that stands out in the literature and is supported by data from this chapter is the importance of a positive ‘doctor-patient’ relationship, and how participants valued ‘feeling understood’. Even though identifying papers exploring the ‘doctor-patient’ phenomenon was not the objective of this review, it is a fact that these interactions are part of the lived experiences of people with migraines and therefore need to be touched upon. As stated in the results section, as part of their lived experiences, some people highlighted ‘empathy’ and ‘feeling understood’ as important aspects of the ‘doctor-patient’ relationship when it comes to receiving support for their migraines. These interactions and processes of decision-making have been studied extensively in Health Psychology. One particular study by Xuereb et al. (2016) offers an interesting input into this phenomenon. In their phenomenology rooted study, they explored patients’ and physicians’ experiences of atrial fibrillation consultations and anticoagulation decision making. Here, participants defended that the interactions between them and their doctors should be an opportunity to make informed decisions, and it is the doctors’ role to provide patients with the tools to do that within the context of their lived experiences (Xuereb et al., 2016). Similarly, to the argument made in this chapter, treatment, and support for people with migraines should be based around empathy and aim to be a collaboration between the knowledge and information possessed by the doctor, and the lived experiences and life context of the patient. When it comes to healthcare support, the key message in Xuereb et al.’s (2016) work is aligned with the thread running through this PhD and argues in favour of the benefits of placing lived experiences and context in ill-health in a central role. Not only as a way to understand illnesses, but also to guide interactions between doctors and patients and design and implement healthcare and support interventions.

Finally, one of the key outcomes of this meta-synthesis is that it identified how under-represented men’s experiences of migraines are in the literature. Even though all of the seven studies included at least one male participant, none of them discriminated for men’s experiences, and explored how different these can be from women’s. In some cases, studies did not even specify whether the accounts (i.e., quotations) in their publications were from men or women, implying a degree of gender irrelevancy in the matter (Belam et al., 2005; Rutberg et al., 2013; Velasco et al., 2003). However, one of the quotes from a participant who took part in Belam et al. (2003) suggests the necessity to explore migraine experiences from a male perspective - *'I was told by the psychiatrist that only women get migraines — I must be mentally ill.'* (Belam et al 2003). By dissecting the meaning behind this, it is legitimate to consider the existence of an eventual stigma associated with migraines and men. Not only from society in general, but also from healthcare professionals. From this quote, it is also valid to consider the possibility that many men experiencing migraines have this same perception of 'I must be mentally ill' because 'only women get migraines'

In terms of its prevalence, migraines affect three times more women than men (MacGregor et al., 2011, Breslau et al., 2001). A study found that 84.8% of women reported a moderate or greater reduction in their ability to do housework or participate in recreational activities (compared to 83% in men) and claimed that their migraines cause them to be less involved with their children and their partner (Lipton et al., 2003). So although migraines clearly affect more women than men, data suggest these are likely to affect men to the same extent they do women. However, the way both men and women live with, cope and seek treatment and support for this condition is likely to be different. For instance, in a large study conducted by Buse et al. (2013), they found that women were more likely to have visited an emergency department or urgent care clinic for problems related to severe headache, than men. It is imperative therefore to explore these different details in experience making and how these relate to the way both men and women navigate healthcare. Overall, perhaps due to the characteristics of the migraine prevalence rates (i.e. much higher in women) the majority of the studies that focus on human experience of migraines do it so from the perspective of women, either by not including or by including very few men in their sample of participants. In fact, migraine has been labelled as a ''female complaint'' (Rossi & Nappi, 2014), and the representation of this illness has become so endemic that it has shaped the state of research leaving a gap in the evidence of men's experience of migraines.

There are limitations to this work. It is not my intention to convey that this is a review and synthesis of *all* qualitative papers looking at the lived-experiences of people with migraines. The objective of this chapter is to provide a critical overview and synthesis of the available qualitative migraine literature that is in line with our inclusion and exclusion criteria and objectives of the overall PhD.

Even though our search strategy was thoroughly planned, I am conscious that the way the search terms were designed and organised might have resulted in the exclusion of some relevant papers. Although recognising its value, adopting the SPIDER tool instead of the more traditional PICO tool to search for relevant papers might have decreased the number of hit results for relevant articles. Future work would benefit from a more in-depth look at different search strategies and tools for qualitative meta-synthesis and systematic reviews of qualitative work. Moreover, the identified lack of transparency in the description of data analysis, methods, and theoretical foundations of some of publications, might have hindered my personal interpretation of 'big Q' and 'little Q' of certain papers excluded. That is, I often came across papers lacking a thorough description of their methodologies or stating in their abstracts that they conducted qualitative analysis only to fail to elaborate (or even show proof) of this in the body of their text. This might have influenced my perception of the purpose and approach to their 'big Q' research.

There are some relevant aspects that are worth reflecting upon in terms of the methodologies and general quality of research within the papers included in this review. Specifically, it is important to reiterate the problem that the lack of clarity and detail around the data analysis process presents. It was often the case that authors failed to offer an in-depth interpretation of the participants' data. Even in cases where they stated they thought of and designed their research process and method as a way to explore human experience. Future qualitative literature would benefit from a more thorough description of the data analysis process, as well as a more in-depth look and interpretation towards participant experiences.

Additionally, although this might be partially explained by journal restrictions in terms of word count, it was also noted that reflexive action is not a common practice in published qualitative literature exploring experiences of migraines. That is, none of the papers included in this synthesis explicitly mentioned any reflexivity work undergone during their research process, or even acknowledge the role and importance of the researcher within qualitative research. This would be particularly relevant in cases where data collection methods were part of a joint collaboration between participants and researchers, like it was seen in Belam, et al. (2005). Adopting a reflexive attitude is central in qualitative research in general, and even more in the cases where qualitative research is used to explore lived-experiences of ill-health.

Published qualitative research would benefit from a clear statement around reflexive accounts and a clearer disclosure around the context within which authors situate themselves, as well as the implication of that 'situatedness' for their research. As argued by Shaw (2010), this is a subjective aspect that we (researchers) can never fully escape, and therefore should be included in our research. In other words, the quality of research exploring human dimensions and lived-experiences would benefit from making clear the particular perspective through which authors experience and interpret the phenomenon being studied and/or their participants (Shaw, 2004; Finley & Gough 2003). I would argue that through clearly stating the way in which our perspectives, motivations and involvement towards the phenomenon and participants impact the wider research process, we are closer to producing research that is transparent, reliable, and empirically trustworthy.

Statistically, figures are clear in showing that the prevalence in migraine is significantly higher in women, however, little is known about men’s subjective experience of migraine. The fact that there might be a stigma and a polarised approach in relation to migraine, might prevent men from seeking information and even support. Studies providing an in-depth exploration of men’s experiences of migraines are needed, as qualitative in-depth literature on men’s experiences of migraine has proven to be scarce. Conducting lifeworld-led research on such a matter is important not only to understand the full extent of men’s experiences in their own rights, but also to highlight any specific support needs and add to the pool of knowledge about this understudied condition. The next chapter attempts to narrow this gap in research by placing men at the centre of the migraine debate. Following this overview and synthesis of the migraine literature I aim to explore through an in-depth phenomenological approach, what it is like for men to live with migraines. The objective is to place the focus on a male perspective of migraines and create the stage for future research and interventional work that is sensitive to men’s needs and experiences to be developed.

Chapter 3 - Interpretative Phenomenological Analysis of Men's Experiences of Migraines

3.1 Introduction

Men's health, including the way they cope and seek treatment for health conditions, has been recognised as an area of concern for healthcare professionals, researchers, and policy makers. In fact, according to Galdas et al. (2005), this is a topic which is in urgent need of attention. Literature attempting to explain men's ill-health experiences and behaviours and the role of masculinity in this phenomenon is mixed and needs further and deeper understanding. Although failing to explain why, literature is clear in stating that when exploring ill-health phenomena in men, it is important not to forget the role that men's perceptions of their masculinity have in their approach towards their health and healthcare seeking behaviours (White & Banks, 2004).

Representations of masculinities and their links to men's health have been a focus of academic research for a long time. In academic literature and research, different constructions and perceptions of masculinity have been used to explain poor health, as well as to justify why men might not be as active and engaged in behaviours to protect their health and prevent further health complications (Gough, 2006). In fact, relevant research in the field of health and masculinity, highlights how men are more susceptible to major health problems, such as most cancers, obesity, mental health problems that lead to suicide, and even physical injuries (Courtenay, 2000; White, 2002). Further literature emphasises that when compared to women, men have an overall higher rate of mortality and morbidity (McVittie & Willock, 2006).

Additionally, it is known that men tend to use health services less often than women and delay seeking help when they are ill (Holroyd, 1997; Seymour-Smith *et al*., 2002). In fact, in a study using discursive approaches to understand healthcare professionals' accounts of men's health in a GP context, authors identified narratives of men's positioning as childlike and women as their health supervisors (Seymour-Smith *et al*., 2002). Findings and conclusions such as these add to the narrative that masculinity and health need to be explored further, not only due to its complexity but also to understand potential underlying connections, stereotypes, and societal constructions (Emslie & Hunt, 2009).

As populations have increased life-spans with increased health service needs, it is of vital importance to have a complete understanding of eventual population subgroups who 'under-consult' or 'over-consult' and ensure the effective resources are in place to address these issues and offer appropriate healthcare and support (Wang et al., 2013). More studies with male participants are needed in order to try to understand the way men experience certain chronic conditions, how they navigate healthcare services and ultimately, what is the role that masculinity plays in how men perceive and act upon their ill-health experiences.

Studies normally offer a broad perspective on the differences between men and women rather than providing an in-depth explanation of men's ill-health behaviours and the way in which they experience certain healthcare conditions such as migraines (Galdas *et al*., 2005; Dobransky & Hargittai, 2012). Conducting studies based on differences between men and women to try to explain men's behaviours and experiences might be the reason why the literature appears to be full of disparities. As we have seen in the previous chapter, migraine literature prioritising conclusions sustained by investigations that solely focus on men, and the specificities of their perceptions and constructions, is scarce. Therefore, it is crucial to focus on listening to men's experiences when exploring issues related to men's health.

Rather than trying to understand men's ill-health behaviours by conducting research solely focused on men, many studies opt for conducting studies exploring this phenomenon by looking at men and women in comparison (Wang et al., 2013; Galdas, et al., 2005). Migraines are a subjective experience that might be intrinsically related to the masculine persona and to extremely personal and subjective constructions of self. Therefore, it is not beneficial for the experiences of men to be explored by comparing them to women's, or by applying women's experiences to men (Galdas et al., 2005). There is a clear need to study men's meaning-making processes of their illness experience in their own right, rather than in comparison to what they are not (e.g. women's experiences).

In the previous chapter, I identified a gap in the literature around in-depth studies about men's experiences of a condition that is often labelled as a ''female complaint'' (Rossi & Nappi, 2014). Regardless of the prevalence of migraine being much more common in women, healthcare professionals and health researchers cannot, and should not undermine the fact that many men experience it too. Building on findings from the meta-synthesis, it is adequate to reflect upon and explore the causes that might underpin men's experiences of this condition and the way those experiences and perceptions might influence their ill-health behaviours.

In the meta-synthesis presented in Chapter 2, I identified a lack of studies using qualitative methodologies to explore men's experiences of migraines. Following those conclusions, and the lack of studies specifically looking at men and migraines, I conducted an empirical study based on a phenomenological approach to understand men's experiences of living with migraine. By conducting this study, I am aiming at contributing to narrowing the gap in the literature and to offering a better understanding of what it is like for men to live with migraines. Additionally, not only will we be contributing to the current knowledge around this condition and how it affects men, but this study will also allow us to set the foundations to start exploring and understanding the available migraine support and whether this is aligned with the needs of this population.

3.2 Research question & objectives

This chapter focuses on men's experiences of migraine through an interpretative phenomenological analysis (Smith *et al.*, 2009). The key question driving this particular investigation was 'What is it like to be a man living with migraine, and what is behind their meaning-making processes of their illness experiences?'

As the research question suggests, the aim was to investigate men's sense making of migraines and how they construct and perceive their migraine experience. In order to achieve that, this study employed different data collection methods. Data was collected through semi-structured interviews, written descriptions, and images chosen by participants to visually represent their migraines.

3.3 Methods

3.3.1 Approach

A key aspect to this specific study was the way in which data was collected. For this research, I opted for a novel approach to data collection by incorporating different methods to acquire a better and richer perspective into the different layers of the human experience of my participants. In other words, in order to elicit the subjective experience of living with migraines identified in previous chapters, and give participants the platform to express their experiences through different means, I opted for employing a multimodal approach and used different data collection methods – verbal, written, and visual.

A particular aspect guiding and influencing my approach to this study was the concept of reflexivity and its role within the research process (Shaw, 2010). Shaw (2010) tells the reader about the importance to look within themselves throughout the entirety of the research process, especially during data collection and analysis. For me, this became an essential aspect of my research. In this particular study, reflexivity was a tool I commonly used to explore my perspectives towards the accounts of each participant, the way we established rapport, and ultimately, the role I played in each interview. This is reflected in the way I interpreted and presented my data. In line with IPA, I thoroughly believe the researcher should have an active role in the research process and should not attempt to make his views objective. Even more, I believe researchers should never try to detach themselves from their participants or the data, and therefore, I proceeded to reflect upon that attachment. For these reasons, the reflexive actions I undertook throughout this project are projected in the way I collected, analysed and presented my data.

3.3.2 Design

After the initial contact, participants were requested to write about a migraine episode as they remember it happening and describe the feelings and thoughts they were having at the time. Prior to the interview, participants were told to reflect upon and write about what it was like to experience a migraine episode, what they thought, felt, smelled, and saw. In other words, I asked participants to think about their experience (including sensorial aspects) and write about them. The objective was to allow participants to put their thoughts onto paper in order to make explicit their lived experiences and to externalise what in most cases is something extremely personal and subjective (Van Manen, 1990). By asking participants to write about their subjective and sensorial experience, I hoped to give them a platform to reflect deeply into what it is like to experience a migraine episode, and ultimately share it. For this task, participants were given a set of instructions as guidance. This set of instructions aimed at clarifying the task and supporting the participants in their writing whilst giving them the freedom to express their experience, feelings, and thoughts. These written descriptions were used as data. However, they were also used to inform the creation of an individually tailored interview schedule; this initial task was key for creating a rapport after initial contact and pre-interview.

Alongside writing about a migraine episode (and also prior to the interview) participants were asked to choose an image (or take a picture) that they thought represented their migraine or their migraine experience. In other words, after asking participants to think about a migraine episode and put it onto paper, I asked them to think about their migraines visually and send us an image that represented that. Again, participants were given the freedom to choose whatever picture they thought would represent their migraines the best. With this task I wanted to capture the world through the eyes of the participants, by acknowledging them as the experts of their own lives and as creators of meaning of their experiences. Literature shows us that visual methods have been used as a complementary method to more standard research methods (i.e. interviews), as well as an individual research method on its own

(Balmer *et al.*, 2015). Although visual methods are still relatively novel in health research, by employing such methods I hope to show how helpful these can be to get us one step closer to achieving a better understanding of the human experience of ill-health. By using images, my primary objective was to enhance the richness and depth of data and allow me to access additional layers of meaning and going beyond the kind of data that is gathered from verbal and written methods (Glaw *et al.*, 2017; Barbour, 2014).

Moreover, not only was this task valuable to generate visual data, images were also useful as prompts for the interviews and facilitated the communication with the participant, even before the interview took place. In fact, in one of the most relevant reviews looking at the use of visual methods in research, Pain (2012) found that these may be particularly relevant in improving the relationship between researcher and participant, and the quality and richness of the data collected. It seems reasonable to suggest that one of the strongest aspects of the use of visual methods is that these have a strong impact in facilitating the communication between researcher and participant (if used alongside an interview), and in building rapport. I observed this from the first contact I had with my participants.

Overall, through having the participants write about their experiences and represent them visually, we wanted them to express the density of their experiences and their thoughts in their fullness and entirety.

Following the two initial tasks (written description of a migraine episode and selection of an image that represented their migraine experience) individual semi-structured interviews took place. These in-depth semi structured interviews were guided by the data from the written descriptions and the images. The focus of the semi-structure interview was to understand men's experiences of migraine and constructions of self – what is it like to be a man experiencing migraines. Individual semi-structured interviews were the chosen method because they are particularly useful for exploring people's knowledge and experiences, and even more importantly, to examine how people think, why they think that way and what is behind their sense making (Hugh-Jones, 2010, Sullivan et al., 2012).

Through having participants express themselves and their experiences through different means (visually, in writing and verbally) I was able to capture key in-depth nuances of the subjective experience that is living with migraines.

3.3.3 Ethical approvals

An application to conduct this study was submitted to the Life and Health Sciences Research Ethics Committee (Aston University, Project #1288) and given a favourable opinion. An amendment to add an additional point to the consent form in regards to keeping and using the pictures and images taken by participants was also submitted and given a favourable opinion.

This ethics application was particularly important because it allowed space to reflect upon possible risks that could be present throughout the project. Although no major risk or hazards were anticipated throughout the development of the protocol, the consciousness that some distress or discomfort could arise from the fact that participants would be sharing personal experiences about their condition was present. Questions that would be asked to participants as well as all potential materials to be used during the interview were planned thoroughly in order to minimise this potential issue. Particularly when it came to planning data collection and interactions with participants, this was reviewed several times by both supervisors to ensure all aspects that could provoke discomfort or distress were eliminated.

Individual written consent to take part in the study was obtained from all the participants before data collection. Additionally, participants were informed of their right to withdraw at any time during the interview and they were assured of the confidential nature of the interview. Confidentiality was assured by storing all the data (i.e. recordings, transcripts, written descriptions and images) on a computer with a strong password during the process of analysis. These data will be kept for up to six years to facilitate publication. Moreover, no personal details of the participants were shared or made public at any point.

Each participant was given a pseudonym that was used throughout the entire study and in all verbatim quotes in order not to be recognised. Moreover, any element, name or word used in the interview that could identify the participant was coded or omitted. These codes were used throughout the whole study.

3.3.4 Recruitment Process & Sample

This study had a total of eight participants. The number of participants was decided based on purposive sampling and the objective was to find a defined group for whom the research question was significant.

All participants were men, aged 25 to 55 (according to Lipton and Bigal (2005) prevalence of migraine peaks in both sexes during the most productive years of adulthood, aged 25 to 55 years), who live with migraines or have experienced at least one migraine episode (details of each participant are available in '*Table 3-1 Participant details*).

I recruited participants via several different approaches. Initially, the focus was on private clinics and non-profit institutions, support groups and other agencies that were in contact with people living with migraines. With the permission of the manager or group administrator, leaflets advertising the study were distributed in these places asking for male volunteers. Moreover, recruitment adverts were posted on social media (Twitter). Additionally, I was approached by the *National Migraine Centre (NMC)* with interest in becoming a partner in the research to help support the recruitment of participants throughout this PhD. A plan for recruitment, where the NMC would become the primary recruitment site for our research was established and a memorandum of understanding (MoU) between Aston University and the NMC was signed and put into place from November 2018. The signed MoU is available in Appendix 2 Memorandum of understanding between Aston University and the National Migraine Centre in the appendices section.

All participants were recruited from the adverts we posted online as well as through the NMC.

Table 3-1 **Participant details**

Jacob	At the time of the interview, Jacob was 43 and worked in academia. He identified as someone living with migraine and received an 'official' migraine diagnosis when he was 8.
Charles	At the time of the interview, Charles was 48 and retired. Charles had been experiencing migraines since he was a child and has a migraine diagnosis.
Jack	Jack did not disclose his exact age, but said to fall under the 25-55 criteria. At the time of the interview he worked in academia. Even though he only experienced migraines of the silent type (with aura) he received an 'official' diagnosis for those episodes (silent migraines with aura).
Ryan	At the time of the interview, Ryan was 43 and worked as a manager at a recruitment agency. He identified as someone living with migraines, even though he did not have a formal migraine diagnosis. He had been experiencing migraines since he was a teenager.
Nick	At the time of the interview Nick was 53 and was self-employed. He had a diagnosis of chronic migraine and had been experiencing migraines since his early twenties.
Henry	At the time of the interview, Henry was 29 and worked in a family business. Even though he identified as someone with migraines, he did not have an 'official' migraine diagnosis. Henry had been experiencing migraines since he was a teenager.

Matthew	At the time of the interview Matthew was 29 and worked as a researcher. He had an 'official' migraine diagnosis and had been experiencing migraine for a few years.
Anthony	At the time of the interview, Anthony was 30 and worked as a media freelancer. Even though he did not have an 'official' migraine diagnosis, he identified as someone living with migraines. Anthony had been experiencing migraines since he was a teenager.

3.3.5 Data Analysis Procedure

Data from the written descriptions and interviews were analysed through Interpretative Phenomenological Analysis (IPA) using a double hermeneutic approach. In IPA, the objective is to have a small sample of participants who 'represent' a perspective rather than a population (Smith et al., 2009). IPA is based on a case level idiographic approach aiming at reflecting individual voices and experiences within its analysis. Therefore, this is best achieved with relatively small samples.

My goal was to have each individual participant providing a detailed reflective account of their own experience of migraine. IPA studies use small sample sizes (e.g. 6-8) because the priority is the quality rather than the quantity of the data - this allows the researcher to conduct a more insightful analysis (Larkin & Thompson, 2012). Appropriate numbers of participants vary depending on the aims and context of the research. For this study, we were looking for depth and range rather than numbers (Smith et al., 2009; Larkin & Thompson, 2012).

Ultimately, the aim of IPA is to explore in detail how participants make sense of their personal and social world, and the key points of this approach are related to the study of individual meanings of particular experiences and events – rather than testing a pre-determined approach or making general claims for a larger population, this kind of approach focuses on trying to find out how individuals are perceiving the particular situations they are facing, and what it is like for them to be experiencing what they are experiencing (Smith et al., 2009; Larkin & Thompson, 2012). At its core, that is the objective of this study.

I performed the analysis of the data in three separate phases due to the different data collection methods used in this study. Firstly, I conducted the analysis of the images prior to the interviews took place. Here, the focus was on the elements present in each image sent by each participant (for instance if there was any text, any outstanding imagery, whether participants gave them a title or commented on the overall image etc.). The interpretation of the pictures was then included in the interview script and shared with the respective participant during the interview as a prompt.

Table 3-2 **Details of the images sent by each participant**

Jacob	Jacob sent a picture of a room with closed curtains. The room was pitch black, and according to Jacob, that is what he always associates with his migraines. For him, this image portrayed his view when he is in bed experiencing a migraine episode
Charles	Charles did not send an image because of how difficult it was to capture what he wanted to portray. Even though no image was sent, he offered a description of the ideal visual representation of his migraines. For him, an image of a lightning storm and deep fog is what he visually associated with his migraines.
Jack	Jack sent a picture to illustrate the visual disturbance he experienced. The picture was a boomerang shaped neon light. According to his description, that is what he saw when he experienced his silent migraines.
Ryan	Ryan chose a picture of a box of migraine medication he normally looked for when he struggles with migraines. He particularly remembers looking for and trying to find these when he was younger. Interestingly, during the interview when looking at the picture, Ryan noticed the words ''*can cause addiction''* on the box. His response was that he had never noticed those and that even though he has realised that he had been taking ''*too much probably too regularly*'' he has ''*never really worried about that''.* During the interview he mentioned that another picture he could have chosen would be a capture of him ''*lying in bed in a blacked room with the blinds opening now and then with a rush of wind coming in (…) it is basically an image of me as a kid in that room*''.
Nick	Nick sent two images. The first one is an image of a man (visually in pain) in bed holding his head. For Nick, this is a visual representation of what he looks like when he is experiencing a migraine episode. The second image is a picture of an animated character, driving a car with a pickaxe in his head with the caption ''*just keep going, everything's fine''*. He stated that this represented how he felt at the time. He added that '' *this picture sums up how I feel at the time… I have a pickaxe causing excruciating pain in my head, but I try to stay positive, however, I know I'm going to crash very soon''*
Henry	Henry did not send any picture. However, during the interview he stated that a picture that would represent is migraines would be one of a castle. To portray the importance he attributes to 'home' and to being at home when experiencing a migraine episode.
Matthew	Matthew sent a picture of the painting ''Portrait of George Dyer in a Mirror'' by Francis Bacon, to visually represent his migraines. Even though he admitted that painting does not seem to be intended to represent a migraine, he stated that he often shows this image to people who ask him what experiencing a migraine feels like.
Anthony	Anthony did not send any picture and mentioned that he could not think of anything that he would visually associate with his migraines.

After, I focused on the written descriptions, by reading and re-reading each of them individually for better familiarisation with the data. After becoming familiar with the written descriptions, I then broke the data into several small sections. Aligned with IPA guidance (Smith et al., 2009), summaries were added in the margin of each section and codes were attributed to each section. These codes were in a form of a word, expression or small sentences that represented that section of the data. These summaries and codes translated my personal interpretation of the participants' accounts and were directly related to the data. After exploring the pictures and the written description from each participant was coded, the next step was to produce an individual specific interview schedule.

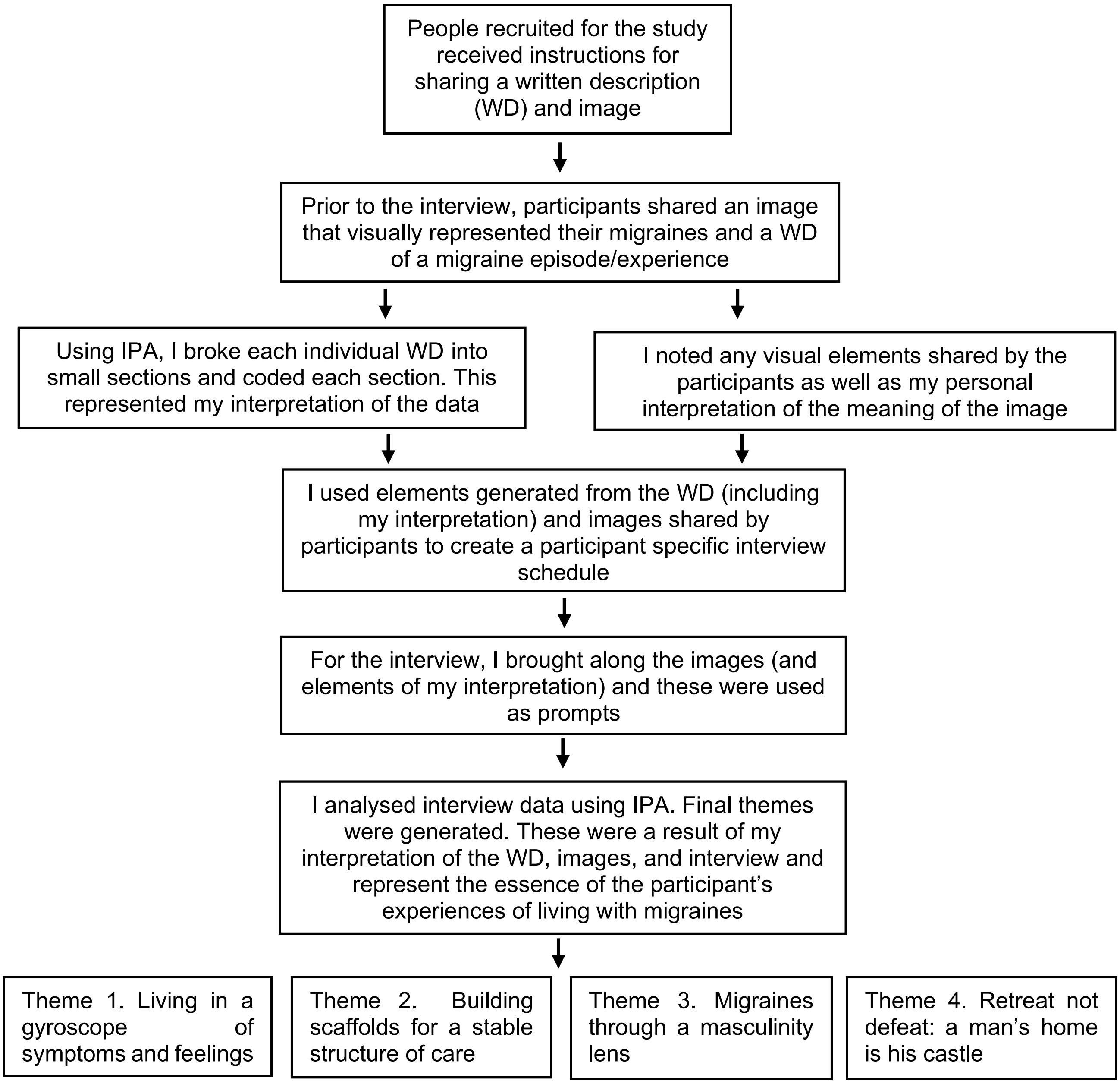
After the interview took place, I analysed each section of the interview. That is, in line with IPA (Smith et al., 2009), I coded each section of the interview using the same procedure described above for the written descriptions. Additionally, I explored in deeper detail and tentatively organised codes from the written descriptions and each individual interview in conjunction. Consequently, several themes were generated. These themes represented a group of codes, and consequently my analysis of an idea, perspective, or concept shared by the participant. Additionally, each theme was carefully revised and its relation to the other themes was investigated. I adopted an idiosyncratic approach, focusing on each individual interview in separate, by generating themes that represented each individual experience in particular.

After themes for each individual were generated, themes were then analysed and combined across transcripts of the eight interviews to categorise and generate superordinate themes that demonstrate the essence of the participants' perceptions and how they make sense of their experiences. In this study I focused on collecting and analysing data to elicit subjective experiences and sensations that are extremely personal to these participants.

The combination of those concepts and the way they are lived and perceived are what makes these participants and their experiences unique. Regardless of having something in common, they are very different. I personally believe this difference is what needs to be celebrated and touched upon as a researcher. The fact that we are looking at the topic of migraines from the perspective of eight different men, makes us closer to having a better grasp of the migraine experience altogether – only after building these foundations can we centre our attentions on trying to improve the way these people are supported and more importantly, listened to. This is my lifeworld-led approach to people's experiences of migraines (Galvin & Todres, 2013).

A visual representation of the data analysis procedure is available below (*Figure 3-1 Visual map representing the data collection and analysis process)*.

Figure 3-1 Visual map representing the data collection and analysis process



3.4 Results.

I generated four superordinate themes that represent what it is like to live with migraines from the perspectives of the participants in this study. These themes are: 1. *Living in a gyroscope of symptoms and feelings*, 2. *Building scaffolds for a stable structure of care*, 3. *Migraines through a masculinity lens,* 4. *Retreat not defeat: a man’s home is his castle.*

Theme 1. Living in a gyroscope of symptoms and feelings

A common thread to all of the individual experiences was the meaningfulness of the symptoms, feelings, and sensations attached to a 'migraine episode'. This superordinate theme explores and describes what is like to experience a migraine episode from the perspective of these participants, in terms of its symptoms, feelings and sensations.

According to the majority of participants, experiencing a migraine episode means going through an extreme variety of physical symptoms and emotional sensations. One of the key elements associated with experiencing a migraine episode, was the idea that once the first physical symptoms appear, a migraine episode can be anticipated. When it came to experiencing initial symptoms of migraines, participants often highlighted that those enable them to 'feel' a migraine coming. This was particularly clear in Ryan's case. Although Ryan *''can often anticipate it [migraine episode] coming'',* in his experience, there is nothing he can do once the first symptoms appear.

> *''I can feel it coming on. I know that I have a period of time where I have to get my head down, try to sleep or take some tablets, but normally there's nothing I can do'' (Ryan)*

From the way Ryan verbalised his perspective, it can be understood that he has a set of strategies and coping mechanisms to try to minimise the impact of a migraine episode and the extent to which it happens. However, it clearly transpired that these strategies are often in vain, because there is nothing he can do to stop the migraine from developing after the first symptoms appear.

From the way Ryan dwelled into his experience, it seems like there is an almost 'fate-like' concept attached to his migraines. Once the first symptoms are displayed, it is impossible to stop their development. Through developing his argument and by exploring this idea in further detail, Ryan brought up the expression *''point of no return''* to characterise the exact point where his migraine stops becoming manageable and starts becoming impossible to cope with, regardless of what he does and the actions he takes.

> *''there is a point of no return, when I know it is only going to get worse and worse and worse'' (Ryan)*

By describing it as a *''point of no return''* Ryan attributes a 'pre-determined' and 'pre-established' nature to how his experience of a migraine episode develops once he notices the first symptoms. Attaching a 'pre-established fate' dimension to a migraine episode enables

Ryan to present coping with a migraine as an impossible task. Complementarily, through exploring Matthew's experience of a migraine episode, one can perceive the 'point of no return' from a different perspective.

> *"You have a threshold after which the ball starts rolling down the hill (…) and there are multiple things that contribute to this" (Matthew)*

In Matthew's experience, the point of no return talked about during the interview was when one's threshold is reached and *"the ball starts rolling down the hill"*. Similar to the idea shared by Ryan, according to Matthew, there was a pre-established threshold after which the symptoms cannot be reversed. One the one hand, this interesting analogy represents the impact the symptoms can have, and on the other hand, it shows how irreversible they can be. The same way the ball cannot be stopped from rolling down the hill, a migraine episode cannot be stopped once the 'point of no return is reached'.

Passed the point of no return, participants highlighted how extreme and debilitating the symptoms can be. For Ryan, *"A migraine episode is one of the most distressing situations I find myself in. It feels like it will never end and the pain is so severe that any slight movement is agonizing".* Additionally, Nick also talked about how severe the symptoms can be in a middle of a migraine episode. Nick used the analogy of a 'pickaxe' to represent how extreme his symptoms can be.

> *"The most recent attack I had which was severe, and sent me to bed, was what I call a 'pickaxe' migraine. This is a quite a regular occurrence for me and is when it feels like someone is standing above me swinging a pickaxe into my temple and eye. It is the most excruciating pain I've ever had and comes with the added complication that it is very hard to go to sleep when the pickaxe is 'attacking' you!"(Nick)*

Often participants used very evocative imagery and analogies to express how relentless a migraine episode can be. Charles compared experiencing a migraine to having his head "*feeling as though it is made of clay, being squished and squashed and pulled in different directions' (…) Feels as though I am inside a gyroscope".* He elaborated on the sensations of experiencing a migraine and compared them to a war-like scenario where the body is overwhelmed by stimuli and an array of transcending sensations.

> *"It feels almost as though the entire Persian army is approaching the pass at Thermopylae, with the ground shaking and an impending sense of doom and outweighed odds stacking rapidly against me"(Charles)*

From the participants’ accounts, although a migraine episode seems to have a progressive nature where people feel different symptoms and sensations, there is a point where the pain reaches its peak. Ryan described this point as the ‘heart of the migraine’.

“yeah obviously there’s a point of no return, but full swing is where it is…you’re right in the centre of it, I mean the heart of the migraine”(Ryan)

Looking at Ryan’s and Charles’ representations of a migraine episode, for Ryan, being at the “*heart of the migraine*” represents what Charles portrayed as being at the “*pass at Thermopylae”.*

From the different interviews, it can be perceived that the symptoms and sensations one experiences during a migraine episode can have different layers, and range from severe pain to what was described as an emotional ‘gyroscope’. Jacob explored the feelings and thoughts that go through his head once he is in the middle of a migraine episode. The pain combined with all the other symptoms often overwhelms him and leaves him feeling like there is no solution in sight.

‘’ I wouldn’t say suicidal ideology but you can wish an end to your life […] the pain can be so bad that you just want it to stop […] you kinda almost reach insanity ‘(Jacob)

For Anthony, these sensations and feelings happen in a loop. He described this feeling of pain and anxiety as ‘loop paranoia’ where he goes through an episode and through trying to cope with pain by fixating his thoughts on something as well as on the pain itself.

‘’I tend to end in something that I would describe as ‘loop paranoia’ which is basically thinking about the same things in loop and having really uncomfortable feeling due to the pain’’(Anthony)

Through a close look at the way participants expressed their subjective experiences of a migraine episode, one can easily understand the burdening nature these sensations and feelings can have on those experiencing them. Nick elaborated on the idea of migraine episodes weighing down on him and being caught in his own thoughts whilst experiencing a different array of symptoms and excruciating pain. Similarly to Jacob, Nick admitted that he often thinks that the only solution that he can contemplate is to end his life. Interestingly, the way Nick put forward this argument and explained his feelings seemed to be an ‘in the moment’ observation rather than a thoroughly elaborated plan; where the idea of committing suicide was portrayed as a swift action that would end his suffering in that time and moment.

‘’when I am having a really bad migraine and I am in bed and I got this in my head, in my eye and everything is weighing down on me and 'I don't see my friends anymore and I can't work

and what has my life come to and I am gonna get dementia' I might as well go to Dignitas and just finish it all. I do think that, I don't mind admit it, I do think that ''(Nick)

From these accounts, pain seems to be a central aspect to how participants perceive and experience a migraine episode. By looking at different perspectives and experiences, it is clear that although there are individual and extremely personal aspects attached to a migraine episode, the intensity of pain seemed to be central to the majority of the participants. However, one of the participants, Jack, experienced what he described as *''silent-painless migraines''*. There is a remarkable contrast between Jack's experiences and everyone else's. According to Jack, his migraines were a pleasant experience.

''Overall I would say that my migraine was a positive and very interesting experience. I am really glad I had one of the silent variety, because no doubt the typical migraine would have been very unpleasant. ''(Jack)

Looking at the experiences of all the other participants, the idea of a silent, painless migraine seemed extremely alien. Jack's experience seemed to represent a reality that most participants were not aware of. In their experiences, migraines are associated with pain and discomfort, which was not seen in Jack's case.

This theme portrays the ways in which different participants spoke about the different feelings and stages of their migraines; here participants portrayed two different concepts: the 'point of no return' where the migraine episode reaches a stage where it cannot be managed anymore and the 'heart of the migraine' where people experience the most pain and all symptoms peak. Even though these participants provided an individual perspective into what it feels like to experience a migraine episode, there were some commonalities. These were mainly linked to the severity of the symptoms and the fact that they all (but Jack) referred to a migraine episode as something that is extremely negative and painful. Symptoms accompanying migraine episodes were often described as profoundly subjective, disorientating and above all, debilitating.

Theme 2. Building scaffolds for a stable structure of care

Living with migraines is living with an unseen chronic condition that is difficult to manage due to the subjectivity of symptoms. This superordinate theme focuses on the several nuances of caring and coping with migraines shared by these eight participants. These nuances seem to be intrinsically related to how migraines are perceived and individually lived, and to how people navigate through different routes in order to find information or new treatment options. Overall, this superordinate theme attempts to shine light onto how people living with migraines find and establish ways of coping and caring for their condition.

It was common for participants to highlight the fact that migraines cannot be seen, which consequently makes it difficult for other people to understand how restrictive migraines can be. Nick explored this idea with a very interesting analogy.

“because I look at me and everything looks fine, but they don't really know what's going on under the bonnet, they don't know I am struggling, really struggling” (Nick)

Through this perspective, and expanding on this particular viewpoint, Nick related his situation to that of a car. The fact that a car might look fine on the outside, does not mean that the engine is running at its highest performance. Only through a detailed look under the bonnet, can one understand the true condition of the car. With this argument Nick raised the point that ‘looking fine’ and ‘being fine’ might be two different concepts when it comes to someone living with migraines. From his perspective, this attributes even more complexity to migraines as one can ‘look fine’ but might not ‘be fine’.

This idea was touched upon by other participants, in particular by Henry. By exploring the ‘unseen’ aspect of a migraine, Henry shared an example of an employer facing an employee who called in sick because of a migraine. Through this example, Henry attempted to look at migraines from the standpoint of someone who is not informed about this condition and is asked to be sympathetic and understanding to the consequences of a migraine. For him, the fact that migraines do not have any ‘showable’ symptoms, makes it difficult for people to believe and understand what one is.

‘’... if I was a boss I just wouldn't, half of the time I wouldn't believe you. I can't really… there isn't a way of me telling whether you've got one or not. And I can totally understand that, you know, it's just me and my old man [at work] but if I was to say to him 'oh I’ve got one' he doesn't, he's got no way of knowing. Unless my Mrs is gonna send him hourly update pictures of me in bed with the lights off, there's no way... and I understand that” (Henry)

Ultimately, this has repercussions on how people with migraines are perceived and potentially cared for. This is particularly true not only due to the fact that it is an extremely subjective condition that might be difficult to explain and portray, but also because of what less informed peers, work colleagues, and managers might think of it. Jacob added to this perspective by expressing a sense of guilt that is attached to the practical consequences of having regular migraines and not being understood.

‘’It makes me feel genuinely guilty! It makes me feel as if and I have no evidence to suggest this, but it makes me feel as if people, that could be my colleagues, but certainly my line manager think "He'll just milking it to go on a long weekend"(Jacob)

From Jacob's angle, there is an attribution of responsibility to his own migraines and the impact they have resulting from not being fully understood. By expressing guilt, Jacob places personal responsibility on his migraines. Asked to express his views on attributing responsibility to his migraines and their impact, Jacob demonstrated that this concept might go beyond 'responsibility' and turn into 'blame'.

> *''I have to accept responsibility and that the blame for that […] there is no one to blame for my migraines but I assign myself that blame'' (Jacob)*

Even though from a rational viewpoint Jacob admitted that *''there is no one to blame for my migraines''* he still assigned that blame to himself. This interesting contradiction sustains the complexity of the issue. By deconstructing Jacob's perspective, blame might be more linked to the resulting consequences of having a migraine and people not understanding those, rather than the actual migraine itself. Jacob clearly stated that *''there is no one to blame for my migraines''* however, he still takes accountability for the consequences, especially those that have direct impact on other people (in this case at work). For this reason, as well as because of the unseen, 'un-showable' aspect of migraines, several participants reiterated the importance of being understood and feeling that their migraines are recognised and validated.

Feeling supported is essential for people with migraines and their structure of care. According to the majority of the participants, when it comes to providing support to someone with migraine, the ability to understand and show empathy is key. For Jacob, having experienced a migraine is a requirement for being able to truly understand what living with migraines means.

> *''People that don't suffer from them will just call them a headache, or say "oh I've heard they're bad" and if you say "yeah, lasts for two or three days" they'll probably to your face say " oh that must be terrible" but then privately I imagine must not be able to genuinely empathise and understand what it's like to be in so much pain and to feel so ill that for 3 days you can't leave your bedroom and therefore you're completely disregarding all of you responsibilities at work, because your unable to look at a screen or pick up a phone to ring to anybody (yeah, to function) to function... '' (Jacob)*

From an overall perspective, it was common for participants to attribute expertise of migraines and ability to sympathise to those who have experienced a migraine episode.

> *''my line manager used to have migraines (…) he understands what's going on'' (Matthew)*

For instance, from Matthew's accounts, 'being able to understand' becomes a concept that can more easily be attainable by those who have experienced similar symptoms. This element of the migraine experience can also be seen in Henry's accounts *''When I got my first one [migraine] she [mother who also experiences migraines] knew what it was''*

From these different perspectives, the 'ability to understand' migraines is attributed to having experience rather than possessing information. This 'ability to understand' migraines then leads to being able to empathise with those experiencing them, and consequently, to being able to support people with migraines. Here is where the concept of feeling supported seems to play an extremely important role. Feeling understood and supported is a key component of the experiences of those with migraines and this is directly related to how they establish a stable and effective structure of care. For some of these participants, being cared for and feeling supported, means being understood.

Living with migraine means actively establishing different approaches to caring and defining personal strategies to accommodate life and daily routines to what is seen as a very subjective experience. Unsurprisingly, some participants talked about healthcare professionals and the role they play in their structure of care. However, Ryan shared a curious view on how he sees himself as the specialist for his own care.

''I feel I can know how to deal with myself, perhaps I don't but there are certain medications I can take which will eventually bring me out of it''(Ryan)

Interestingly, even though he admitted that doctors play an important role, he sees GPs as 'a means to an end' (to the acquire medication that he finds appropriate and effective) rather than a solution to help him cope with his migraines. The main reason for this, according to Ryan, is that *''[GPs] lack resources, lack of understanding, lack of experience''* and ultimately, he implied that he is in charge of his own treatment and that doctors are solely a means to an end.

"I never thought of that [GPs] being a solution to it" (Ryan)

Aligned with this perspective, Nick also positioned himself as being the primary responsible figure for his own care and the one who is in charge of establishing his own structures of care. From the way Nick presented his argument, it was clear that he takes ownership of his own care and treatment.

''yeah I mean going back to what you said a minute ago, you know 'did you have to go outside your GP to get treatment?' I think the answer is yes. Definitely I did! I wouldn't have just been able to go on what they said, I had to go to the neurologist then that didn't work so... (…) done all of that myself, and then when that didn't work I had to go to the migraine clinics and places like that (…) I am doing all of this myself, getting back to your original

> *question, I am doing all of this myself [knock of the table] no one is managing this for me, I am doing it all myself" (Nick)*

Nick passionately and proudly defined himself as the one managing is own care. For him, living with migraines means adopting a strategy of 'doing it all myself'. However, taking into account Ryan's perspective on the lack of resources, understanding, and experience from GPs, this decision might not have come from personal choice, but rather for not having any other alternative.

Additionally, in Ryan's case, regardless of the different strategies he might employ for coping with migraines, his structure of care seems to be based on 'sticking to what works', especially when it comes to medication.

> *''I come across and I see. (…) [I was] coming out of a really bad one and my dad gave me paracetamol and codeine which I had never heard of and I caught it. I caught the migraine for the first time ever. It stopped. I couldn't believe it, I was probably 16 at that point and since then that's what I have been taking. I dropped everything else because that seemed to work" (Ryan)*

Migraine medication seemed to be a central component of what participants considered to be their different coping mechanisms. However, some participants discussed the effectiveness of migraine medication and how negative the side effects can be

> *''I haven't really found anything that stops it, I haven't found a preventive that reduces the frequency to any meaningful degree without horrible side effects (…) this medicine actually completely stopped the pain of the migraine, I was still getting the blindness so I couldn't work because I couldn't see, I could still talk to people, I would talk to people but I wouldn't be able to see properly and I'd get a terrible dryness and nausea in place of the migraine (…) it was actually making me less comfortable, so it was not useful, and my primary objective is to make it so that the frequency of the migraines" (Matthew)*

Although most participants stated that they take medication for their migraines, stories and experiences about its negative side effects were common. Almost all participants referred to the 'nasty' side effects associated with some migraine medication. Charles summed it up by stating that '*'Taking meds is just like rolling the dice almost"* whilst Anthony shared his views on taking medication as a form of coping and how he avoids it.

> *''I don't like to take medicine, I try to avoid taking them because I know they are bad (…) I try to take them if I really need (…) if I am working or whatever I am not even thinking about that [bad side effects or impacts of taking strong medication], because I need to be operative, to do stuff so I just take them (…) I can't do stuff without meds so I don't think too much" (Anthony)*

In addition to this perspective, Charles offered a more detailed account into the decision-making process of taking migraine medications. The way Charles described taking medication reiterates how unpredictable this coping mechanism can be.

> *''my kind of default setting was "if anything felt weird pop a couple of paracetamols and hope for the best" [laughs] and then when paracetamol don't start cutting the mustard you sort of start ramping up through cocodamol and then tramadol and a more... oxycodone etc etc and then of course your run into all the issues with cognitive side effects of those sort of drugs which makes it even harder to know what is going on''(Charles)*

Charles reflected upon the vicious circle that taking medications can become. He admitted that he mainly takes medication to stop the symptoms of migraines, however, that does not help him completely as he gets different sensory symptoms from the medication. It feels as though it is not a simple 'if-then' scenario when it comes to taking migraine tablets. As shown in Nick's account, the process seems to be much more intricate than that and requires detailed thought processes to reach a decision.

> *''When I feel a migraine coming on it would be nice to just be able to take a Sumatriptan and not worry about the effects of that action, but I cannot do that. Every time I am thinking – how bad is it? Will it be a bad one? Shall I take a Sumatriptan? Or shall I wait? how long shall I wait? what if I wait and then it doesn't work? how many Sumatriptans have I already taken this month? one more won't hurt? or will it? what shall I do?... I am sure that this thought process is no good for my impending migraine and may actually make it worse.'' (Nick)*

Here, the rationale underpinning these decisions appears to be related to the information people have about treatment and coping mechanisms. Once again, the individual agency associated to care and treatment is present. According to some testimonies, having detailed information about migraines and treatment options is crucial when it comes to decision-making. However, it is up to the individual to seek information, and then make decisions by combining that information with personal experience. Often, people talked about online platforms as one of their first ports of call for acquiring information about migraines. For Jack, who experienced two silent migraines, the first instinct was to go online and look for his symptoms

> *''If I would have been concerned about it, I would have googled it (…) If I hadn't diagnosed myself with Google, I would go to a doctor'' (Jack)*

Even though some participants admitted going online to acquire information about their symptoms, the use of online resources seems to go beyond looking for symptoms. Charles' was particularly vocal about this and his accounts clearly showed the value of online resources. Especially in terms of understanding different perspectives to experiencing migraines, and consequently understanding his own.

‘’[about gaining more information about migraines] Largely from what I could find online about, from various sort of groups, or research papers or pretty much any information I could get hold of (…) all this sort of thing has just added to the picture and understanding of what a migraine can actually be like and I think because of that, because of that feature of it not always necessarily having to be a headache it can make it very very difficult a) to know if you are actually experiencing an attack at any set point in time b) whether it's just like an aura or pro-drome or c) whether it is just your mind [laughs] because you do start questioning your own sanity sometimes’’ (Charles)

Some other participants gave examples about going online for information or speaking to other people with lived experiences to validate new ways (and tools) of coping with migraines. For instance, Henry recalled a story about a treatment device for his migraine suggested by someone who also experiences migraines. The openness to trying new strategies and trying to find something that works, aligned with valuable information he acquired online, resulted in him trying a new treatment device.

‘’I was recommended to do this [Henry referred to a daith piercing that was located in the inner fold of cartilage above the ear canal] and then when I started reading it online I was like 'fuck it, I am gonna try it' and it really hurt... (…) [a friend suggested it and] I had never heard of it before, just looked it up and (…) he just told me about it, I looked it up online I was like 'oh this has got to be worth a try' and yeah, you just get it done at a piercing place’’ (Henry)

People admitted to having different strategies and structures in place in order to control (and minimise) the impact that migraines have in their lives. From these different perspectives around ways of coping with migraines, several key aspects were identified. Firstly, the importance given to feeling understood. Feeling understood seemed to be the first step to feeling cared for. However, participants highlighted how difficult it is for people who have never experienced a migraine to truly understand what migraines feel like. Secondly, it was clear that different people use different strategies to cope with migraines and minimise their impact. These strategies range from seeking medical advice and treatment, attempting to stop migraines through the use of medication, trying different treatment options etc. However, regardless of the different strategies employed to cope with migraines, it is clear that there is individual agency and personal ownership attributed to treatment and decision making.

Based on their testimonies, people feel it is up to them to build and establish their own structures of care. Ultimately, going online and navigating different platforms to seek information and support for their migraines is a manifestation of this individual agency. In a system where GPs do not often have expertise or resources to become experts in migraines, and due to the lack of any other source of informational support, online platforms were the place participants went to acquire information and individual support for their migraines. Additionally, the information found online is being used to explore different perspectives towards the migraine experience and support decision making over treatment options and coping strategies.

Theme 3. Migraines through a masculinity lens

The topic of masculinity and how it underpins perceptions of migraines and the way men cope with this condition flowed throughout the majority of the interviews. Often, participants looked at and reflected upon their own experiences by referring to the idea and meaning of being a man. This superordinate theme focuses on masculinity and the role it plays in migraines. Based on the premise brought up by some participants that migraines are associated more readily with women, men talked about how this can pose problems. Some participants elaborated on this and brought up the idea that this association might prevent them from thinking they have migraines or from seeking help and for some – or for society – threaten their masculinity. In particular with Nick, he expressed how he perceived migraines as a condition associated with menstrual cycles before he was diagnosed.

> *‘’I think this is a key point as I didn’t know much about migraines and the little that I did know, or thought I knew, was that it was something that women got and was linked to their menstrual cycle. So perhaps there is a general knowledge gap regarding men and migraines.’’(Nick)*

In this extract, Nick clearly admitted that before being diagnosed with migraines he also thought that migraines were a condition that only happened to women. When elaborating his argument further, Nick raised the point that there is a knowledge gap in society when it comes to men and migraines. Following the argument raised above, not only did Nick mention about migraines being perceived as a condition that is predominantly linked to women, he also highlighted the fact that being a man makes it even harder to openly talk about migraine and consequently seek help and support.

> *“if I went down to the pub I would not be able to have a conversation about my migraines, a few people might say to me 'how are you doing?' and I probably say 'yeah I am alright' and that's it that would be it, we would not be able to sit down as a group [him and his male friends] and talk about my migraines, just wouldn't happen, wouldn't happen” (Nick)*

The distinction between how men and women talk about the impacts of their migraines is very clear in Nick’s accounts. In this extract, Nick drew a clear line between men and women in terms of how much they open up about their problems. Furthermore, Nick extended this distinction to how much sympathy men with migraines get, compared to women.

> *''[talking about not feeling sympathy from people] think, let's say percentages wise, I'd say 50% of it is probably because people don't understand [migraines], but the other 50% is because I am a man, and man should just get on with it (…) That's why I say I think women would get more sympathy (hm) whereas with men we're supposed to be all macho and just get on with it and it's as simple as that'' (Nick)*

Nick suggested that *''men are supposed to be all macho''* to justify the differences between the way men and women with migraines are looked at. To some extent, based on his perception, men are clearly being undervalued when it comes to migraines. This overarching idea was also seen in other interviews. Ryan also touched upon the fact that inherently, men tend to *"just get on with it"* regardless of the consequences, and therefore might get less sympathy or comprehension towards their ill-health. This goes in line with the idea of a 'macho persona' brought forward by Nick

> *"I think as blokes there's a tradition of "just get on with it" I think, I am an example, I suffer from these and I don't go and see a doctor" (Ryan)*

Furthermore, Charles was very vocal when it came to talking about the pressure some men might feel to display a 'macho attitude' and not express their feelings and struggles. When elaborating on what it is like to be affected by migraines as a man, Charles linked the 'worth' of a man to 'being able to earn the bread'. Charles used this view to express the 'pressure' that some men might experience when their migraines are at their peak. Experiencing this pressure to 'earn the bread', on top of the negative impacts of migraines (i.e. stopping people from being able to go to work and live a normal life), can give rise to a very complex situation and even to an internal conflict.

> *''whether or not there's an element related to the whole hunter-gather and provider kind of role model that a male tends to see for themselves and therefore that leading to 'I have to carry on regardless, because I am the big man, I have to provide" even though in this day age (…) I am now retired whilst my wife works. and it's it's...it is hard to deal with that, there's no two ways about it, you know, you do feel as a man that "I should be out there earning the bread, bringing home the bacon and all those others {laughs}" (Charles)*

Charles and Nick's views were aligned when it came to gender bias and how society in general perceives the struggles of men compared to women. According to them, this is a dangerous combination that can have a devastating impact on wellbeing.

> *''it adds to whole vicious cycle of depression, because you end up feeling useless if you are not able to work. And I think you know, especially in men then that's because as you say the whole historic gender bias''. (Charles)*

One particular interview contrasted to these accounts and shed a very interesting and complex light into how migraines can define someone, regardless of being a man or a woman. Jacob clearly ascertained his identity as a ‘migraine sufferer’ rather than a ‘man with migraines’. For Jacob, migraines are part of his personality and a core part of himself.

’’Although other people might define that's something that's found in higher frequencies in females and it might be seen as a female disease, I've always associated it with me, so I've always seen it as being something I have, you know. It's not something that is new to me so it's not something that I don't understand, in that respect so I've just always seen it as being part of me. I've always defined myself as being a migraine sufferer, I suppose because I had them as a child particularly I had them before the age of 10. When you grow up with something (you kinda take ownership...) yes! Absolutely! It’s a core part of my identity. (…) And I've never really defined it as being a male or female thing, I've always just seen it as being a core part of my identity.’’ (Jacob)

This view extends the argument of masculinity and migraines and brings it to a different level. Although some participants clearly made a distinction between how men and women experience, are seen by society, and overall live with migraines, Jacob linked migraines to a core part of his individual identity that goes beyond gender differences. Furthermore, in terms of talking about migraines and seeking help, he clearly positioned himself apart from what he believes is the norm for men.

’’I've never been that stereotypical man that is slightly unwilling to take up appointments or to go and see doctors, I think it's too important and I am...if I believe there's something that I can't deal with and it needs a doctor or a physiotherapist then I will immediately make an appointment.’’ (Jacob)

Similarly, Henry also related the act of talking about ill-health and seeking help to his individual nature and personal experiences rather than to being a man or a woman. Through exploring his own perspectives of the issue, Henry linked seeking help for migraines to one’s identity.

“I have been through a lot of that [mental health issues] when I was younger so I feel like I am at a point where if I am having issues I don’t really mind seeking help and talk about it” (Henry)

Through a more detailed view, for Henry, opening up and talking about the struggles caused by migraines (or for instance, mental health issues) should be a priority regardless of gender. Although his views about the stigma of opening up align with Charles’ and Nick’s, *’’there’s stigma in our society about therapy and you know, talking about problems’’ (Henry)* he does not follow that himself, and ultimately believes that that is not the right approach.

’’you need to talk about this rubbish because otherwise it will ruin you! (…) ‘for me whether they’ve got a knob or not is not really relevant’’ (Henry)

There seems to be a clear disparity when it comes to how these participants perceive and position themselves within the topic of masculinity and migraines. Some participants stressed that the strong association between migraines and women might prevent men from thinking they have migraines, and consequently seek treatment and support. Regardless of whether they identified clear differences in how migraines are experienced, lived, and perceived as a man, they were aligned in expressing the pressure that some men feel for having to display a 'macho persona' that often clashes with the negative impacts of a condition such us migraines.

Theme 4. Retreat not defeat: a man's home is his castle

One of the most common behaviours described by participants to respond to a migraine episode was trying to find a quiet, dark, cool space as soon as the first symptoms start appearing. Almost all participants referred to this sort of behaviour, or to at least having a designated space as the 'ideal' place to experience a migraine. This superordinate theme focuses on the element of feeling and being at home in its literal and metonymical sense, and how it is perceived by this group of participants.

The concept of 'home' in its literal and/or metaphorical sense was present in the majority of the interviews. Often participants referred that the first thought they have after experiencing the initial migraine symptoms is to make arrangements to go home.

> *''[when I feel a migraine coming] I immediately make arrangements to go home (…) I try to keep calm until I go home'' (Matthew)*

Through his choice of words, Matthew attributed an emotional component to not being at home when he feels a migraine coming. In his experience, being in a social or professional scenario and not having the safety of being at home enhances his anxiety. Similarly, Henry also admitted experiencing similar feelings of anxiety when starting to experience a migraine outside.

> *"if I'm at home it's not necessarily a big deal but if I'm out and about, if I'm out for a drink or you know...I used to get them a lot at like parties and social gatherings and that kind of stuff (yeah) and you just sort of feel anxious that you don't really want it to be...you're like "maybe it's not, maybe it's not!" and then it gets to a point when you're like "yeah...no." so that can make me feel very anxious" (Henry)*

For Henry and Matthew (as well as for the majority of the participants), experiencing a migraine whilst outside their home, makes the migraine experience even harder to cope with. Some participants projected the idea of perceiving home as the safer space to have a migraine. Matthew and Henry talked about how being at home increases the feeling of control, which they related to being able to rearrange their surroundings and having a certain set of tools at their disposal to better cope with migraines. However, one of the most vocal participants about this topic was Jacob.

Jacob brought forward the idea of the inherited aspect of 'rearranging the physical surroundings' linked to feeling home and seeing home as a safe space. Contrary to experiencing a migraine outside, being at home means the surroundings can be arranged to better accommodate a very painful migraine experience.

> *''If the pain starts to come on, becomes unbearable, there's a lot of things you can do to try and control the symptoms [if you are at home], cold strips are very good at least at giving you a different sensation, on your forehead (yeah) but it really is a case of being in a dark room, burying my head in the pillow, not having any noise in the house, no lights, nobody disturbs and just waiting...'' (Jacob)*

Even though Jacob admitted that the only possible outcome is to 'just wait' for the migraine to go, being at home makes things 'more bearable'. The ultimate outcome seems to be the same (i.e. an inevitable painful migraine experience) however, the physical space where that happens might have a direct relation to how impactful this outcome is. Ryan shared some details about the ideal physical space to be in, when experiencing a migraine. From his accounts, it can be seen that being at home allows him to optimise his surroundings to their fullness.

> *''it has to be pitch black where I am, the slightest bit of light can be really bad. I also need fresh air as well, so a cool breeze is very important (…) my sheets have to be cool, everything has got to be cool dark and no noise at all (…) the only way to get out of it, is to fall asleep'' (Ryan)*

Additionally, Jacob also highlighted the positive aspects of being able to rearrange his surroundings when experiencing a migraine. The idea of being able to fully withdraw from the world is attached to the meaning he attributes to being and feeling at home.

> *''Spend the whole day in bed, in a dark room, hm... Withdrawn from the world for that day, and then for that day you know it's OK'' (Jacob)*

Through an in-depth exploration of Jacob's accounts, one can conjecture that Jacob portrays 'the world' as an active contributor to how negative his migraine episodes can be; and therefore, withdrawing from it is a positive and achievable strategy. He provided a perspective that being away from the world, through being at home in a comfortable environment, minimises how bad a migraine can be. Placing 'the world' as an external source that can escalate the negative impact of his migraine. This idea that one can make home a safe place in order to withdraw himself from the world seemed to be extremely relevant to Jacob as well as to other participants. Interestingly, some participants offered an additional perspective into this concept; that is, the significance behind what makes home, home.

Beyond the fact that physical spaces can be rearranged, Henry was particularly vocal in trying to explain what makes home a safe port for experiencing a migraine.

> *‘’you feel as though you just need to do whatever is right, and if that is you need to take your jumper off or you need to have a shower or you need to just sit in a room with the window open, whatever you feel like needs to be done I am gonna do that’ (Henry)*

The way Henry described home was full of meaning. According to him, ‘’*home is where you can do whatever is right”*. Rearranging the physical space seems to be undoubtedly important, however, from these accounts, there seems to be another layer of meaning and significance being attributed to ‘being at home’. Regardless of how comfortable one feels at any given space, for Henry, one’s home has a different side to it. Often, participants talked about how they might be entirely comfortable being in one space that can easily be rearranged to accommodate their migraine episode (i.e. at their parents or friends house), but still not feeling completely at home. In particular, Henry shared an example that illustrated this idea.

> *‘’ [about staying at a friend’s house whilst having a migraine] as much as they're like 'oh it's fine you can stay here', "you don't get it” (…) I don't want feel like 'well now I'm half naked, sitting in my mate's bathroom I am not gonna walk back through his lounge and I need some water and you know..." [giggles] it's just not…So yeah I definitely feel like being able to be at home is quite crucial” (Henry)*

Additionally, besides ‘doing what is right’ another important aspect of feeling at home is to have the necessary tools to address the impacts of a migraine episode. Matthew talked through what it meant for him to experience a migraine in a safe space where he has everything he needs to cope with his migraine (i.e. his home).

> *‘’I mean I have got all the kit here, I've got a bath, I have a bed, and I have that facial... I don't know if I mentioned the facial (you did yeah) and just because I have all my kit around and there's usually some rice in the fridge if I need to eat (yeah) so it's to do with the convenience (…) I mean emotionally I suppose you could consider it a safe place, I mean I guess that's what theory would say, because you... I mean home is where you spend most of you time because of sleeping, resting yada yada yada so I suppose yeah, that makes sense’ (Matthew)*

Following the narrative of other participants, Matthew linked being at home to being in a safe place. In an attempt to describe the meaning that the concept of home has in his migraine experience, Henry explained it by linking it to a castle.

> *‘’A man’s home is his castle, I just feel a lot safer there” (Henry)*

Once again, this illustration was full of meaning and clearly exemplifies the importance that Henry placed in being at home, which translates the views of some of the other participants. Focusing on this concept, one can describe the migraine experience through the metaphor of a castle being under attack. In this case, the castle (one’s home) is where one can withdraw from the impending attack of external stimuli that exist in the world. Withdrawing from the world inside the castle means rearranging their surroundings to accommodate to light, noise, smells etc.

Clearly, for these participants feeling at home is part of the experience of living with migraines. According to some accounts, home is where people ‘can do what is right’ and rearrange their surroundings in order to minimise the impact of their migraines. For some people, being at home means withdrawing from a world which is often perceived as an external source that exacerbates the negative symptoms of a migraine. ‘Feeling at home’ becomes crucial as it gives participant a sense of control through being able to rearrange their surroundings, access their tools to cope with migraines and ultimately ‘do what is right’ to minimise the impact of a migraine episode.

3.5 Discussion

This study was an in-depth exploration of the migraine experiences of eight men using different data collection techniques. The focus was on exploring and interpreting what living with migraine means for these eight participants.

Throughout this chapter, several key aspects of participants’ experiences were highlighted. Initially, we have seen how a migraine episode can bring a different array of physical and emotional feelings and sensations to people experiencing them. Overall, we have seen that migraines affect people in a great variety of ways. Starting with symptoms, participants shared the different physical, sensorial, and emotional impacts migraine episodes have on them. However, from the accounts of several participants, there seems to be a progressive aspect associated with how a migraine episode develops that is common to different individual experiences. Also, some participants seem to be able to clearly identify a point (referred to as ‘the point of no return’) from when the symptoms only get worse. Up to this point, there is room from preventive measures to be put in place to ‘catch’ the migraine (i.e. make arrangements to go home or take medication). Participants also identified ‘the heart of the migraine’ as the point when all symptoms (including pain) are at their peak.

One of the key aspects of this study was to explore the migraine experience through a male perspective and address the lack of studies in the field focusing on this perspective. In this study, participants explored the role that being a man has in their lived experiences of migraines. Aspects relating to how migraine is often associated with women were mentioned and some participants talked about the pressure that some men feel when it comes to talking about their challenges. The way migraines are sometimes perceived (i.e. a women’s condition) might be having an impact on the way men seek support and care for this condition. Undoubtedly, these participants care about their health, but some of them showed that they are unable to verbalise and make these struggles ‘visible’ to the wider society.

Perhaps it is helpful to reflect upon the fact that male migraine sufferers may not only share other men’s general worries about their health (Banks, 2001), but may also find it difficult to express these worries in some contexts. Banks has argued that this can a barrier to accessing healthcare. In this study, the men with migraines showed clear concerns about their health, however, they highlighted difficulties in talking about their condition; which as a result might affect the way they seek support and medical care. When looking at conditions such as migraines that are predominantly experienced by one specific group (in this case women) it is imperative to also focus on the sub-groups of individuals who are experiencing them. For not fitting into what is perceived as being the ‘norm’, these sub-groups might be put at greater risks of experiencing more severe consequences of the condition.

One of the most prominent aspects throughout this study was the fact that several participants attributed great meaning to feeling at home and to home as being the safest place to cope with a migraine episode. For some participants, home represented a shelter from the world, which becomes a menace once migraine symptoms are being experienced. Dekkers (2011) looked at the experience and significance associated with ‘being at home’ as a fundamental aspect of human existence, particularly for people with dementia. Through an example associated with palliative care, Dekker explored four interpretations of ‘’home’’. These were related to home as a physical place where one lives and dies, home as one’s bodily and psychological wellbeing and ‘coming home’ as the process of dying. It is possible to find some alignment between this perspective and some of the accounts about the concept of home shared by some of participants in this study. The argument of attributing emotional meanings to ‘home’ brought up by Levinas (1971) and further supported by Dekkers (2011) has been extended in this study and to men with migraines. To some men with migraines, home plays a role beyond its physical form. The way people talked about and elaborated on the meaning of ‘home’ and ‘going home’ clearly elicits the idea that for these participants, ‘home’ surpasses its physical state in the world and is perceived as a concept full of psychological and emotional meanings.

In this chapter, ‘home’ was seen as playing two different roles in the migraine experience of some participants. One the one hand, home provides shelter. Home is the physical space placed away from the stimuli of the world that enhance the negative aspects of a migraine episode. This physical space can be rearranged to accommodate the consequences of experiencing a migraine episode. Home is also the place where people store certain objects to better cope with migraines. One the other hand, there is a whole emotional and meaningful side attached to one’s home. For some of these participants, home is seen as the safe place and referred to as ‘’a man’s castle’’. The concept of ‘being-at-home’ proposed by Heidegger (1971), where ‘being-at-home’ becomes more than being within the physical space of the house, is here represented by having the knowledge and control over the situation. In the context of this study, Heidegger’s concept of ‘being-at-home’ becomes ‘being-in-control’. Being-in-control in one place is represented by the fact that at home these men have practical knowledge on how to act within their surroundings and can arrange them if necessary.

This idea is further touched upon by narratives of phenomenology of place attachment (Seamon, 2013), which argue that home represents much more than just an ‘instrument’ that people have at their disposal. The concept of home represents a synergy in which different dimensions of our humanity and our environment come together to complete and sustain each other (Seamon, 2012). Seamon (2012) also suggested that it is possible to phenomenologically interpret places in terms of ‘place identity’. In fact, the concept of place identity (in which people attribute identity to a certain place and perceive it as a significant part of their world) was easily identified in some of the testimonies of the participants of this study.

Clearly, migraines seem to be more than a condition that causes physical and emotional pain. For their complexity and because of the way they affect every aspect of an individual’s life, conditions like migraines need to be thought of, and address, by focusing on different human dimensions. Rather than solely focusing of bodily symptoms and biological factors, migraines should also be looked at by placing the focus on the people who experience and are affected by them. When studying conditions such as migraines, it is imperative to go beyond purely looking at the label of a diagnosis and explore further concepts that might go underneath that, such as the complexity of the human dimensions underpinning people’s lived experiences.

Following this narrative of placing a greater focus on the human dimensions of living with long terms conditions, Todres et al. (2007) introduced the idea of the lifeworld. With the introduction of this concept, the authors explored the idea of a more humanly intimate quality to experience associated with the world we live in. In other words, the lifeworld is represented as the world of meaning; the meaning that we as human beings attribute to our experience and to being and experiencing the world. The work of Todres et al. (2007) becomes particularly relevant when looking at healthcare. Exploring healthcare through the lens of the lifeworld allows us to adopt a more humane approach to care and to ill-health experiences. Through focusing on the lifeworld in relation to healthcare, one goes beyond what is superficial and potentially dehumanising of the human experience in ill-health (Todres et al., 2007). Todres et al. (2007) present the lifeworld through five different dimensions: *Temporality*, *Spatiality*, *Intersubjectivity*, *Embodiment*, *Mood or emotional attunement*.

According to the lifeworld, *Spatiality* refers to the world around us, the places and things around us, what they represent, and the meaning we attribute to them. We exist in terms of spatial distance and closeness (Todres et al., 2007). Similar to the importance given to *spatiality* as a lifeworld dimension, these eight participants highlighted the importance of their surrounding spaces in relation to their experiences. In particular, participants highlighted the meaning of home and feeling at home. Through attributing so much meaning to the concept of home, and focusing on the dimension of spatiality, when experiencing the range of symptoms associated with migraines, home becomes their own, closed, safe world. A world that represents the entirety of their existence and space at that given time, and a world that can be physically shaped and repositioned to accommodate their physical experience. The world outside is involved in loud sounds, bright lights, and intense smells that affect the bodily experience of someone with migraines. When focusing on this dimension of space, one oversees everything outside their room or home when experiencing a migraine, because only that matters at that given time.

Additionally, the dimension of *intersubjectivity* seems to be present in the experiences of some of these participants. *Intersubjectivity* represents our place in the world in relation to others, and how we are understood in relation to how our lives take place in a social world. This is particularly clear when looking at the meaning some participants attributed to 'feeling understood' and how people construct the idea of 'living with migraines' through the eyes of others. The meaning of living with migraines is created by those experiencing it in relation to their personal experience as well as in relation to others. In this case, this is relevant in terms of care and when it comes to support and to feeling understood. Feeling understood and having their condition 'validated' through receiving empathy was seen as a central factor for care. In order to improve care for people with migraines, in particular for men, one needs to focus on what migraines mean (individually and in society) and the way they are lived, as well as on the way they are constructed interpersonally and culturally.

Asking participants to tell me their experiences through verbal, written, and visual means, enabled me to have a better understanding of their journeys and consequently establish a bond with them that aided the research process. This also allowed me to collect different types of data which facilitated my understanding of migraines and the journeys of my participants. In specific, the written descriptions were a great asset to generating insightful and in-depth data for this study. One particular case that stood out was Charles'. In his written description, he started by disclosing that ''As it is, I'm currently sat at my computer, having done a bit of exercise, for 15 mins, on a spin bike and having got off feeling rather nauseous. Yesterday, I experienced similar, but it developed into full blown nausea. However, I shall write something now, kind of amidst an episode, as it will give a real first-hand insight.''. From the perspective of a qualitative researcher working on a phenomenological exploration of migraines, I consider this to be the pinnacle of 'first-hand insight'. This example translates the benefits that thinking about and deploying creative ways of collecting data can bring to our research, and to our understanding of different concepts in ill-health. With this study, I hope to show the benefits of using these specific data collection methods in qualitative research. Moreover, this chapter sustains the argument for researchers to think about their research creatively. That is, to reflect upon 'non-standard' ways of collecting data, and how those can be put at the service of their participants to enable them to better tell their stories. Especially in cases where the phenomenon under study is something as subjective as migraines. Through having this approach embedded in a thorough reflexive and reflective process, we will be working towards advancing qualitative research in the field of Health Psychology in particular, and Psychology in general.

As a researcher, but mostly importantly as a man, I often thought about the impact that I would have on how much these men would disclose about their experiences. I also found resemblances between my behaviours in ill-health and those of my participants. However, rather than all these factors ending up acting as a hindrance to the data collection process, as I had initially thought, those acted as a catalyst for rapport. Part of these commonalities allowed me to achieve a greater level of empathy and understanding towards my participants. The fact that we shared similar hobbies and ways of looking at the world (perhaps embedded in concepts of masculinity), combined with the fact that all of my participants were grateful for the fact that I was giving them a voice, resulted in a bond that helped the research process beyond predicted.

However, the aspect I spent the most time thinking about was the fact that I have never experienced a migraine myself. How could I ever attempt to grasp the entirety of the migraine experience, and showing that 'I understand' if I never experienced one myself? This was particularly accentuated by the fact that some participants often said ‘only those who have experienced a migraine will truly know what it feels like’. Listening to these statements automatically forced me away from the realm of ‘being able to truly understand’. Which contrasted with the key principle of this project, which is to get one step closer to understanding the experiences of men with migraines. The ultimate conclusion is that even though the ability to truly understand might not ever be achieved by those who have never experienced a migraine, I believe that more importantly, one should place their focus on the ability to sympathise with the struggles of another human being. Therefore, the ability to recognise this, places me closer to understanding what living with migraines is like. I believe that only after having a better understanding of ‘’what is it like to live with migraines?’’, one can start thinking about ‘’how can we support and care for those living with migraines?’’.

Part of this construction is based on exploring, sharing, and acquiring information about migraines, symptoms, impacts, and meanings. It was common for people to refer to themselves as being ‘responsible for their own care’ and take ownership over their treatment paths and support structures. People admitted going beyond standardised paths to explore different ways of coping and learning about their migraines. This resulted in having to navigate different platforms and systems to obtain detailed information or specialised healthcare advice on different treatment options and alternatives. Commonly, participants in this study referred to using online platforms and resources to obtain information about their migraines and treatment options. Therefore, it is legitimate to question the potential that these platforms might have when it comes to the lives of people with migraines.

In an ever-evolving world, technology is becoming more prominent in dictating the way we interact with other human beings and evolve as a society. The way we position and perceive ourselves, our surroundings, and the world in relation to others, is undoubtedly affected by technology and the online world. As times progress, the lifeworld dimension of *intersubjectivity* is becoming heavily affected by having easy access to the entirety of content and information available online. In healthcare in particular, literature tells us that online platforms such as support groups and online forums are an efficient way for people with certain health conditions to connect, support each other in their journey, and explore further and deeper dimensions of the individual ill-health experience (Tanis, 2008; Colineau & Paris, 2010). However, not much research is available when it comes to migraines. Although the advantages of online platforms are recognised, the usefulness of online support groups and forums for people with migraines is relatively unknown, especially for men. Online services and resources, particularly related to healthcare advice and support for men should be explored and made better use of (Banks, 2001).

Therefore, it is worth exploring this route and the role it plays when it comes to people with migraines, particularly in men, given their healthcare and support seeking behaviours are undoubtedly complex and multi-layered. One of the central aspects to these participants’ experiences was the way they built their structures of care and support. Feeling supported and having certain tools (in a form of medication, health advice or general information) to being able to respond to the challenges of living with migraines, represented the foundations of their migraine experience. Here, it was seen that a core aspect to feeling cared for, and feeling supported, is the idea of ‘feeling understood’. Being able to recognise that other people sympathise with their pain and struggles is key to these participants.

After highlighting the experiences of men with migraines and given rise to valuable points (such as the importance of feeling understood, ‘being-in-control’ by being at home, the helpfulness and easy access of online resources) it is important to explore the tools that these people have at their disposal in their migraine journey. Living in a world when online resources are an intrinsic part of our day to day, in light of the findings from this study, exploring these in relation to supporting men with migraine can be a way of identifying new ways to improving their migraine experience.

Building on the findings highlighted in this study in the next chapter I will provide an overview of the existing online platforms available for people with migraines. Through a discursive approach, I aim at reviewing the accessibility, content, and design of these platforms, as well as the way the narratives around them are constructed and perceived by men with migraines.

Chapter 4 – Discourse Analysis of Online Platforms as a Means of Support for Migraines

4.1 Introduction

This chapter will extend the discussion around the available support for people with migraines. We have seen how subjective and personal the migraine experience can be in terms of symptoms and coping mechanisms and that different people will build their structures of care and support differently. From the literature provided in previous chapters, and from the results of an in-depth look through an IPA lens at the experiences of eight men with migraines, one can see that for some people, the migraine experience often prompts people to seek alternative sources of support. In fact, one of the aspects highlighted in the previous chapter was the importance of 'feeling understood' and validated, and the role this plays in one's perception of support. When talking about managing their condition, some participants highlighted aspects of self-management and admitted going online to seek support and information.

Literature around managing chronic diseases, such as migraines, emphasise the importance of self-management (Bodenheimer et al., 2002; Lorig et al., 1993; Chodosh et al., 2010). It is clear in the previous chapter, that elements of self-care are central to the migraine experience, and that many times, those with migraines take full accountability and responsibility for their treatment. Determining which medication to take (effectiveness versus negative side-effects), finding different treatment alternatives, looking for information online about migraine, as well as trying out new ways of coping, are some of the aspects that were perceived as being part of the responsibility of the patient and part of a patient's self-management approach.

Seeking support is one of the central aspects of self-management of migraines. For people with migraine, seeking support might mean an opportunity to receive further information regarding medical services or benefits of a certain behaviour or coping strategy. Especially by interacting and sharing their experiences with other people living with migraines, individuals might be able to find alternative methods of care and improve the way they cope and live with their migraines. The phenomenon of social support has received significant attention in the field of health and social psychology over the years. The link between social support and mental and physical health is strong - through its influence on emotions, cognitions, and behaviours (Cohen, 1988). Sharing experiences and receiving information from people experiencing the same condition play a key part in adapting and coping with illness, and the WHO described having a social support network as a ''determinant of health'' (WHO, 2017).

Supporting that argument, literature has shown that migraines and other headache related conditions have been linked to poor social functioning and that prevalence of headache increases in people with fewer intimate social relationships (Cohen & Henry, 2011; Raggi et al., 2012). By simply having a network of friends, family and peers, or even an online community of people who understand what a person is going through in their life, can be enough to enable individuals to talk about their problems and struggles, obtain more information, and consequently diminish intrusive thoughts that can result in maladaptive responses to stressful events (Lepore et al., 1996).

Today, the internet is widely seen as having the potential to host platforms that incorporate functions that are essential in healthcare. Firstly, it allows people to connect with others experiencing similar health conditions, and secondly, even though its reliability might be questionable, the amount of healthcare information available to be explored is vast. In fact, more than ever patients go online to seek extra information about their medical conditions, or to find solutions to any concerns that are not being answered by their general practitioners or specialist doctors. Especially in cases of patients living with chronic conditions, Colineau and Paris (2010) argue that people who once used to only talk about their health in a one-to-one, face-to-face visit to their GPs, are turning to online communities and platforms for information and to share their views and experiences in order to find support in other patients experiencing similar health issues.

Literature offers different perspectives to why people make use of health-related online forums and webpages. More commonly, online resources such as webpages, forums and online support groups are used as a source of information. However, there is also evidence that some individuals use online communities to feel part of a larger group of people who experience similar symptoms and struggles, and ultimately feel that what they are experiencing is not unique (Tanis, 2008). Visiting specific webpages and interacting with online communities of individuals who share similar experiences can be a way of finding new opportunities of social support and information for various health and emotion related issues. Furthermore, there is a clear potential for positive health outcomes in people coming together to talk about what it is like for them to experience a certain condition, and in sharing and listening to day-to-day experiences of how they cope with living with a specific illness.

The use of online resources and online groups in healthcare have become increasingly popular over the past few years; particularly with online support groups and forums, they have their roots in the idea that social relationships, social support, and social interactions are linked with positive outcomes in terms of wellbeing and general health. This argument has been corroborated by several research studies (Christakis & Fowler, 2017; Cohen, 2004). In fact, one study looking at weight management interventions conducted by Verheijden et al. (2005), stated that social support provided by healthcare professionals has limited effect when compared to support provided by one's natural support networks. One can argue that in today's technological era – especially considering the global and social context we are currently living in due to the COVID-19 pandemic - online communities and webpages can be inserted in an individual's natural support networks.

Despite the links between online platforms and social support, and social support and positive health outcomes, the truth is that the real impact of online resources and online peer to peer support for health outcomes is still somehow unclear (Colineau & Paris, 2010).

Research suggests that health-related online resources might have potential benefits in terms of obtaining emotional support as well as in gaining illness specific information and alternative coping strategies from ''experiential experts'' (Tanis, 2008). In other words, accessing online communities enables individuals to gain further and potentially more diverse information that would be difficult to access 'offline' (Rice & Katz, 2001). By being in contact with other people who experience similar illness conditions from all around the globe and without leaving the comfort of their home, these platforms and communities can function as a supplement to the support provided by family and friends, or even healthcare professionals. Online platforms can be a significantly positive addition to one's network of social support systems, as one of the most relevant aspects of online support groups and forums is the feeling of communality and belonging (Wright & Bell, 2003).

Finally, it is a fact that existing literature points towards a positive influence of social relationships on health (mental and physical). Additionally, it suggests the use of online platforms as a viable and more convenient way of establishing social relationships between groups of individuals with similar ill-health experiences. However, literature looking at the nature of these platforms and resources for people with migraine is scarce. In this chapter, using Discourse Analysis (DA) I will be exploring the content of several online resources from a narrative and discursive perspective – studying their meaning, how they are constructed, perceived, and maintained (Foucault, 1980).

Through DA, one can engage in an examination of elements that are present within a certain narrative and set within a certain context as a means to understand and analyse their role in creating knowledge and shaping behaviour. This is aligned with Foucault's work and its contribution to understanding the links between discourse, context, and how language can shape definitions and perceptions of power and behaviour (Foucault, 1980). A key element to this specific approach of DA is the concept of ''power''. In Foucault's work, power is something that is manifested rather than purely owned. It places the emphasis on recognising the legitimacy of different forms and instruments of knowledge and discourse, with the purpose of exploring the different sources and relations that contribute to this power. In this study, I will be looking at specific discourses of migraine, masculinity, and support in the context of several online platforms to understand their role in shaping the narrative around migraine support. To understand their ''power''. I will be focusing on the nuances of discourses, and the differences and commonalities across them, rather than on universal truths and contexts (Kaufmann, 2011).

I use this stance to understand the different discourses present in online platforms for support with migraines, and their role in creating and establishing discursive elements within the field of migraines (Denzin & Lincoln, 2008). That is, the role these platforms might be playing in how migraine support is framed and perceived and how that is shaping social norms and even behaviour. The ultimate objective of this chapter is to add to the growing body of research looking at the use of online resources in healthcare in general, and migraines in particular. I propose to provide an analysis of different online resources for migraine, and ultimately explore the migraine experience through the discourses constructed within these platforms. This will be done in relation to the wider context of the migraine experience, as well as in the more particular context of migraine experiences in men, who constitute the main focus of this thesis. In other words, the focus will be on how these discourses are constructed in these platforms and what they might represent for men with migraines.

4.2 Ethical considerations on data collection

This study used data that are publicly available on the internet. That is, data that is available in migraine websites, and data relating to people's posts in online communities (forums and groups within these websites). Due to the ethical complexities associated with the use of these types of data, I paid special attention to the official guidance for online research in the field of (Health) Psychology; as well as to the concept of 'research participant', 'informed consent', 'anonymity and confidentiality' and how it applies to the particularities of this study. Not only does this study offer a thorough analysis of some of the webpages available for support with migraines, but it also attempts to elicit discussions around conducting research using publicly available online data. The sections below translate the reflexive action and considerations I undertook throughout this study.

In case of this study, the process of data collection did not follow the standard participant/researcher dynamic. In other words, contrary to more traditional research, the data collected and presented in this chapter were not 'purposely produced' for research by consenting and informed participants. The data were freely available online, and for the purpose of this research, collected in order to answer and inform the research question.

4.2.1 Conducting research on publicly available data: official guidance available

Since this study used publicly available data, no research application was submitted to the Aston University Research Ethics committee. According to the Aston University Research Ethics Committee, and their 'Terms of reference and constitution of the University Research Ethics Committee' (which describe the University policy on ethical principles and procedures for research) only research involving data that are not in the public domain and/or do not involve the use of human participants in questionnaires, interventions or interviews, human tissue or animals, require an ethical review by the committee (Aston University Research Ethics Committee, 2019). Whereas it is the objective of this study to use publicly available data in order to analyse websites as sources of information as well as people's posts and interactions with that information or within the website.

Even though the University guidance seems relatively clear, one could (and should) still reflect upon issues relating to using data that are readily available online. At the centre of the debate is the fact that these data have been provided by, either people or organisations running a website, or individuals who are members of the public participating in a debate. In both these cases, they may or may not realise that the content they produced and shared online (treated as data for this study) is publicly available.

Research into online platforms, online discussion forums and groups (using publicly available data) has been under the scrutiny of different associations and regulatory bodies – including the British Psychological Society (BPS) - (BPS, 2021a). In general, their guidance focuses on the idea of 'avoiding harm' when planning and conducting research that takes place online or uses data available online. Particularly for the BPS, in their Ethics Guidelines for internet-mediated research (IMR) document, which is the key guidance for people in the field of Psychology conducting IMR, they extensively address and highlight several principles and key aspects that should guide this type of research. These relate to aspects of respect for the autonomy, privacy, and dignity of individuals and communities, scientific integrity, social responsibility and maximising benefits and minimising harm (BPS, 2021a)

Although those conducting Psychology research using online platforms or data available online have official guidelines from the BPS, there is still a risk that these might fall short. To start with, these are guidance for Internet Mediated Research. The name of the guidance itself implies that the internet is seen as the vehicle used to link the researcher and the participant. That is, the BPS IMR guidance suggests that the internet is used as a means to mediate the research process (and data collection in particular) and assumes an interaction between the participant and the researcher. However, this is not the case for this study. In this study, the internet in itself (as a means of support for people with migraines) is the phenomenon being studied.

It is imperative that clearer and more practical guidelines are specifically designed for online research such as this, to avoid researchers wishing to explore the richness of the online world are left unguided in their research, policies, and practices. Looking at the BPS's (2021a) Ethics Guidelines for IMR, they are at their heart the application of the traditional ethical principles outlined in their Code of Human Research Ethics (BPS, 2021), to online research. Even though there are benefits to this, conducting research on online platforms poses new and different ethical challenges when compared to those of more 'standard research'. Therefore, one can question the effectiveness (or even appropriateness) of simply applying any traditional ethical principle to online research without considering all its nuances. In other words, ethical principles need to be carefully considered for different types of (online) research and (online) data collection in their own right, and not simply adapted from other types of ('offline') research. By failing to think about ethical principles in online research in their own right, the applicability of traditional terms such as 'consent', 'ability to withdraw', 'deception', and 'disruption of personal and social structures' might become difficult to reflect upon. However, as these are the only guidelines for psychological research carried using the internet, this study is thoroughly aligned with the BPS's Ethics guidelines for IMR (BPS, 2021a).

Despite the issues highlighted above, it is still worth emphasising the forward thinking approach from the BPS in flagging, exploring, and producing an official document highlighting aspects related to online research. It is commendable that bodies such as the BPS attempt to elicit ethical considerations and thoughtfulness in researchers who work with online platforms and use online data. As the world progresses towards a more established technological era (and is currently influenced by the social context in which the COVID-19 pandemic is inserted) other scientific areas should follow this approach and reflect upon the possibilities of online research (and all that entails) within their fields.

Lastly, one of the key issues with the Ethics Guidelines for IMR (BPS, 2021a) is that it struggles to accommodate projects like this one, where data are collected from open sources online and used to explore the content of such sources from a narrative and discursive perspective. At its core, this study focused on 'non-interactive' data – these data were used to analyse websites as sources of information as well as people's posts in forums and online communities within these websites. Contrary to this approach, BPS's guidelines seem to be slightly more adequate for studies involving participatory research where a researcher accesses and engages with a webpage (forums, blogs or online support groups in particular) to explore first-hand the experiences of specific users of that platform, or where the researcher interacts directly with the users of specific online platforms. Ultimately, the guidance seems more applicable (as the name stands) for internet mediated research. That is, for studies using the internet to collect data from research subjects, rather than the internet as a research subject itself.

4.2.2 Observational studies and informed consent in research into online platforms

One of the most common questions in this type of research is around the concept of 'publicly available information' and the extent to which there is perception and/or expectation of privacy by those who 'create' and post this information online. This issue is directly related to the concept of 'informed consent'.

In practical terms, this study is observational research in an online setting. The Code of Human Research Ethics is clear when talking about studies based on observation in natural settings – "*unless consent to being observed, observational research is only acceptable in public situations where those observed would expect to be observed by strangers"* (BPS, 2021). Although this guidance might be clear at first, considering this study in particular, and online research in general, reflecting upon this has proven to be particularly difficult. Not only because of 'what' is being observed, but also because of the scope of the phrase '*where those observed would expect to be observed by strangers'*.

The principle underpinning this guidance lies upon the concept of 'public sphere'; and that within their public sphere, people should be asked for consent if they are being observed by strangers. In standard observational research, the researcher places themselves directly or indirectly within the public sphere, observes and captures the behaviour of the research subject. They key aspect being that it is up to the researcher to record and ultimately 'capture' this behaviour, and therefore they should have consent from the person being observed. The issue stands when we turn the 'public sphere' into an online setting, and we go from recording behaviour that otherwise would not be recorded, to interactions and communicative behaviour that is forever imprinted online from the moment it is posted/published.

For this particular discussion, the key question becomes 'to what extent are discussions happening in online platforms considered 'public situations?' and 'to what extent is observing, collecting and analysing data from these open forum discussions considered observational research?' Additionally, what are the limits of in the condition, ''*would expect to be observed''*? From the standpoint of a researcher conducting research and navigating these online platforms, I believe in order to be aligned with these, one should engage in reflexive action in relation to the nature of the forum (open vs private), the topic (sensitive, private), the kinds of posts (private and linked to a personal account, on social media vs easily accessible and public), the way discussions develop, how available are they, what kind of site it is (social media/private, personal platform vs open and easy to access). More generally, think about the extent in which we are we 'using' these posts ('data'). Ultimately, it is vital to establish that the researcher is, like I am in this case, using these publicly available inputs responsibly for research or educational purposes and not for any commercial gain.

I would argue that it is the moral duty of those conducting similar research to this, to reflect, thoroughly think, and clarify their approach to data collection and their ethical practice. In fact, reflexive statements towards 'expectation of privacy' should be included in all qualitative research using (or based on) online methods/platforms. Following up on this argument, a key point in the BPS IMR guidance that is applicable to this study is *'It is important to note that analysis of online discussions or other activities is not precluded, but it should be carefully considered in light of the ethics concerns highlighted here.(…) Where it is reasonable to argue that there is likely no perception and/or expectation of privacy (or where scientific/social value and/ or research validity considerations are deemed to justify undisclosed observation nevertheless), use of research data without gaining valid consent may be justifiable"* (BPS, 2021a). This becomes particularly important for studies using social media and/or platforms where users have to create accounts (and sometimes add their personal information in order to proceed and use the platform). Especially considering backward searchability as a possibility, acquiring informed consent becomes even more important in studies that focus on individual participants or interacting/observing personal social media accounts.

However, in this study, the focus is on what the discourse on the websites can tell us about how migraine is framed for migraine sufferers. The objective is not to focus on individual stories. It is not the intention of my approach to use data that are publicly available online to analyse individual narratives or focus on an individual's experiential insight. The goal, and ultimate epistemological focus of this chapter, is to understand how the phenomenon of migraine is talked about online, by organisations and institutions that provide support to people with migraines, and by people experiencing this condition.

4.2.3 Personal stance and approach to ethical principles of online research

It was key to this study to reflect upon the several aspects related to research into online platforms highlighted above. Firstly, it enabled me to take a stance (informed by official BPS guidance and other literature) and ensure this study respects the autonomy and dignity of all websites (and their users) included in this chapter. Secondly, it allowed me to be guided by a sense of scientific integrity and moral responsibility to those producing data that contributed to this project.

For this chapter, I gave particular attention to the concept of transparency in data collection and reporting. For that reason, the process that led to the selection of the websites included in this chapter is thoroughly explained; and all data retrieved from these websites have been presented in a form of dated screenshots. By adopting this measure, the essence, meaning, and main message presented in all extracts used in this chapter are transparent and true to their original form. Furthermore, the inclusion and exclusion criteria for websites was carefully elaborated in order to answer possible concerns related to issues of anonymity and to the extent to which data used in this chapter was publicly available. That is, this study only included online platforms that are easily and openly accessible through a Google search, and where users do not need to register (or provide any personal information) in order to access or contribute to the webpage (or even read other people's contributions to it).

Lastly, I believe transparency is a concept that should always be at the centre of all scientific research, therefore, all the methodologies and tools used in this study are thoroughly described in the next section. Moreover, for being the central body in Psychology research and within the remit of this PhD, I addressed individually all the principles available in the BPS's guidelines for IMR that are applicable to this study (BPS, 2021a). In other words, the BPS principles were looked at through the lens of this study, and each parameter that was applicable to this research was considered and addressed in the table below (*Table 4-1*). This resulted in an adaptation of the guidelines in order to fit the specificities of this study. Concepts within the principle of '*Respect for the autonomy, privacy and dignity of individuals and communities*' relating to '*valid consent*', '*deception*' '*withdrawal*' and are not directly applicable to this project and therefore not included.

It is also important to note that the last principle ‘*Maximising benefits and minimising harm*’ was removed, and two extra principles were added. These are ‘*Transparency in reporting and referencing’* and ‘*Personal stance and reflexivity’*. These were added because I believe they better reflect the nature of this type of research. It is crucial that researchers show transparency in reporting and referencing the sources of their publicly available data, as well as undergo a thorough and detailed reflection upon the way their research fits within the wider area of online based research.

Table 4-1 List of the main ethical principles to consider when conducting internet mediated research according to the British Psychological Society

Key principles	Key considerations related to the principle according to (BPS, 2021) and how they were addressed
Respect for the autonomy, privacy and dignity of individuals and communities	**Public/private distinction** – All the webpages and platforms included in this chapter were openly available. That is, regardless of its type (blog, forum, web chat etc.) no webpage required a login with personal details for access, or to see any of the content used in this chapter. No data were collected from social media **Confidentiality –** All data collected from online platforms was publicly available and easily accessed through a simple Google search. Furthermore, no webpage required a login with personal details for access, or to see and interact with any of the content used in this chapter. In cases where screenshots from websites were added to sections of this chapter, any pictures shown and associated to people's individual profiles were removed or covered. Even though we are aware that 'backward searchability' is a possibility, in order to add an extra layer of confidentiality, all names shown in screenshots from websites presented in this chapter were redacted/covered with black marker. To further address confidentiality aspects related to 'backward searchability' no data were collected from social media. **Anonymity -** All data collected from online platforms was publicly available and easily accessed through a simple Google search. In cases where screenshots from websites were added to sections of this chapter, any pictures shown and associated to people's individual profiles were removed or covered. To answer concerns related to expectations of privacy, no webpage required a login with personal details for access, or to see and interact with any of the content used in this chapter. Even though we are aware that 'backward searchability' is a possibility, in order to add an extra layer of anonymity, all names shown in screenshots from websites presented in this chapter were redacted/covered with black marker. To further address anonymity aspects related to 'backward searchability' no data were collected from social media. **Copyright –** All data used in this chapter was publicly available. No images or resources were taken from closed forums or platforms that required registration or payment to being accessed. All screenshots of quotes, icons and images used in this chapter are appropriately referenced.
Scientific integrity	**Levels of control –**The list of websites included in the analysis of this chapter was obtained through systematic online searches (described in the section below). The analysis of the data collected was performed with scientific rigour and following guidance available in the literature.
Social responsibility	**Disruption of social structures –** No active or direct interactions with the websites took place at any time (i.e. we did not post anything, contacted the users or the moderators of the webpages or contributed to any of the entries and threads). No data were collected from social media
Transparency in reporting and referencing	**Source of the publicly available data -** All data used for the analysis included in this chapter was true to its original (being written or imagery) and was made available through referenced and dated screenshots of their source webpages. A brief overview of each of the webpages included in this study, including URLs to their home page, is also available. In cases where screenshots from websites were added to sections of this chapter, any pictures shown and associated to people's individual profiles, as well as profile names were redacted/covered with black marker.

Personal stance and reflexivity	**Personal considerations and approach to online research –** My personal stance towards this type of research; as well as detailed and thorough considerations regarding ethical aspects and questions of the current BPS guidance for IMR and how they apply to this project are available throughout this chapter. Moreover, clear inclusion and exclusion criteria for data searchers are included in the methods section.

4.3 Methods

This study was developed in two stages. The first stage aimed at systematically generating relevant data (a number of websites and online platforms that are aimed at people with migraines) for analysis. Following this step, I performed a Discourse Analysis (DA) on the data generated in the first stage (Foucault, 1980), in order to explore how these online resources present themselves as platforms of support for people with migraines. This involved exploring the different discourses around migraines and migraine support on these platforms, and examining how the different platforms position themselves in the social world of people with migraines.

I used this approach to DA to facilitate the understanding of the discursive elements and tools of those who are often in a position to create, disseminate, and legitimatise language and knowledge (Cheek & Porter, 1997; Mills, 1997; Mills 2003). That is, to understand how these forums and online platforms for people with migraines are shaping the way migraines are talked about and how discourses of support are established and legitimatised.

For the analysis, I placed the focus on the different elements of experience and behaviour found in websites and platforms that are aimed at people with migraines. By adopting this stance, the aim was to engage in an in-depth analysis of discursive constructions that point us to the 'whys' and 'hows' of human perception and behaviour (Springer & Clinton, 2015) and the role these platforms have in shaping them. In this case, 'how' these platforms position themselves as support, and 'why' people might be navigating this 'social' world to learn about migraines and obtain support.

Ultimately, the goal of this chapter was to conduct a systematic search to generate online data in order to perform DA (Foucault, 1980) to answer the following research question: 'How is the migraine experience constructed and talked about within the context of online resources to support people with migraines?' This was followed by further questions such as 'What are the different discourses around migraines and migraine support within the context of online resources for people with migraines?' and 'What are the different discourses around men's experiences of migraines within the context of online support?'

With this, the aim was to provide a detailed analysis of the resources available online for people with migraines to obtain support. Following the evidence from previous chapters, I propose to explore in further detail the narratives surrounding these platforms and understand the extent to which these are constructed as support for people with migraines in general and for men in particular. For these purposes, the analysis used both visual and textual data from the platforms Search Strategy. In order to start the search process, I generated a group of key terms that were relevant to the topic being studied and the objectives of this chapter. These were based around words that related to the use of migraine platforms for support. I conducted a total of 12 Google searches with the following key terms:

- Migraine Forum
- Migraine support groups
- Online support groups for migraine
- Male migraines groups
- Migraines online groups
- Migraine online support
- Groups for Help with migraines
- Migraines online forums
- Peer support community migraine
- Online community migraine
- Migraine online experience sharing
- Migraine experience online groups

Inclusion criteria:

- Webpages where the user is required to create an account to interact with the threads, posts and publications, but does not need an account or log-in to access their content and read through threads, posts, or publications
- Any non-social media online platform or website about migraines
- Webpages where the primary focus is not migraines specifically, but there is at least one section or sub-section available for people with migraines

Exclusion criteria:

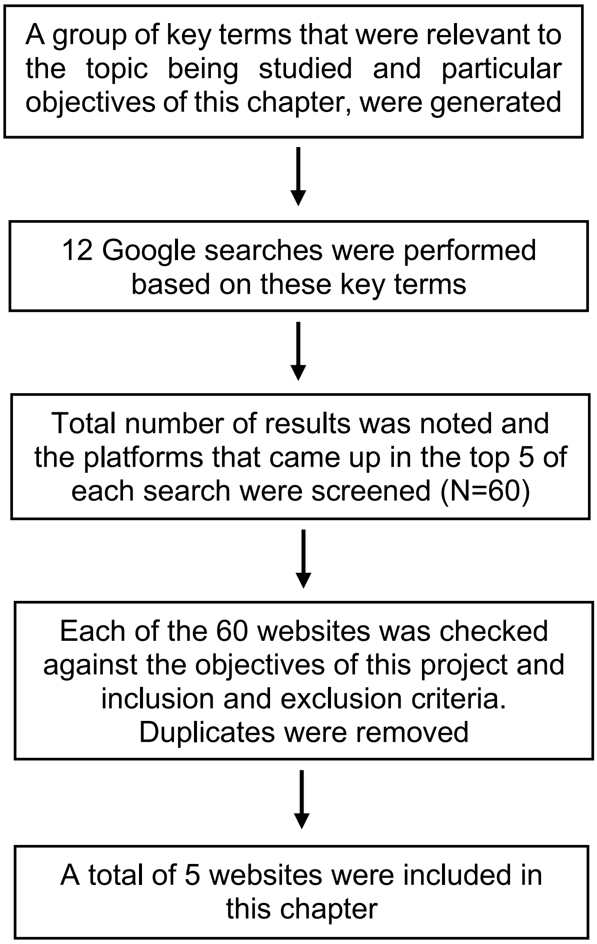
- Webpages in which users have to create an individual profile in order to read or access content of the page
- Webpages where users have to pay in order to access the content
- Social media pages and groups where the user needs permission from the moderator to access the content of the page
- Social media pages or groups
- Websites that only appear once across the total number of searchers (n=60)

The total combined results of the 12 searches was of around 121,700,000 webpages. Due to the vast number of results generated, only platforms that fell within the top 5 results of each search were considered for inclusion. In other words, even though the total number of results was noted, only the top five results of each search were screened.

4.3.1 Data screening

A total of 60 webpages were subjected to screening. Each individual result was checked for relevance in relation to the research question, and duplicates were removed. Here, the objective was to ensure that all of these results were online resources within the area of migraines or had a section relating to migraines, regardless of the nature of their host page (i.e., charities, private blogs or websites, trusts, national health bodies etc.); no social media websites were included. After all the searches were conducted and screened in terms of relevance using the inclusion and exclusion criteria, a total number of 5 websites were included in this study. A mind-map detailing this process is available below (*Figure 4.1. Mind-map detailing the search strategy and data screening)*

Figure 4-1 Mind-map detailing the search strategy and data screening



4.3.2.1 the migraine trust

URL: https://www.migrainetrust.org/

This webpage came up a total of 10 times in the top five pages of the 12 searches. *the migraine trust* is a charity for people affected by migraines in the UK. Their website has a wide range of resources for people with migraines. From news articles with relevant and up-to-date research in the field, to blog entries where different healthcare professionals and people experiencing migraines talk about their personal and professional experiences of migraine. Additionally, their website provides specific information for people who have regular contact with someone with migraines (i.e., their colleagues, managers, HR department, teacher, parents etc.), in order to raise awareness about this condition - *the migraine trust* also has a presence on social media dedicated to migraines and people with migraines.

Figure 4-2 *the migraine trust* website

We are the largest research and support charity for people affected by migraine in the UK

We fund and promote research, provide evidence-based information and support, and campaign for change

What exactly is migraine?

Migraine is a complex and disabling brain disease

Support is available

Find out how our free Information and Advocacy Services can help you

How you can help

There are 190,000 migraine attacks every day in the UK. It doesn't have to be this way

Our latest research

Research we are funding

Screenshot taken from *the migraine trust* on the 30th April 2021

4.3.2.2 Healthline

URL: https://www.healthline.com/health/migraine

This webpage came up a total of 9 times in the top five pages of the 12 searches. The spectrum of *Healthline* goes beyond the subject of migraine. Their main focus is not on migraine itself, but in providing information about a vast range of long term physical and mental health conditions, as well as more general wellbeing tips. In their migraine section, they have information about different types of migraines, as well as resources and links directing people to closed support group options and how to connect with others experiencing similar conditions. *Healthline* also has a presence on social media dedicated to migraines and people with migraines.

Figure 4-3 *Healthline* website

Low Cost Knee Replacement
Experts In Healthcare, Providing Specialist Knee Surgery Services In Barlborou
Group

Everything You Want to Know About Migraine

What is migraine?

Screenshots taken from *Healthline* website on 30th April 2021

4.3.2.3 Miles for Migraine

URL: https://www.milesformigraine.org/

This webpage came up a total of 8 times in the top five pages of the 12 searches. *Miles for Migraine* is a United States based non-profit organisation that focuses on raising awareness and improving the lives of people with migraines. Their website provides detailed content about migraines. It ranges from specific information on how to cope with general migraine symptoms to fundraising events to support research and other initiatives around migraines. They also run face to face support group meetings (which have now been moved to online meetings because of COVID-19), these are private and need registration. They have a sub-section with a blog showing experiences of people with migraines, as well as perspectives and written pieces from people who work within the migraine research and healthcare area; they also have a presence on social media with pages dedicated to migraines and people with migraines, as well as fundraising events.

Figure 4-4 *Miles for Migraine* website

Miles for Migraine

Movement Matters: Mind, Body & Advocacy

The Race for a Migraine Cure Begins with You

Our Programs

Run/Walk/Relax

Find an event online or near you and challenge yourself!

Education Events

Learn more about living with migraine and what you can do.

Youth Events

Online and physical events for teens and their parents.

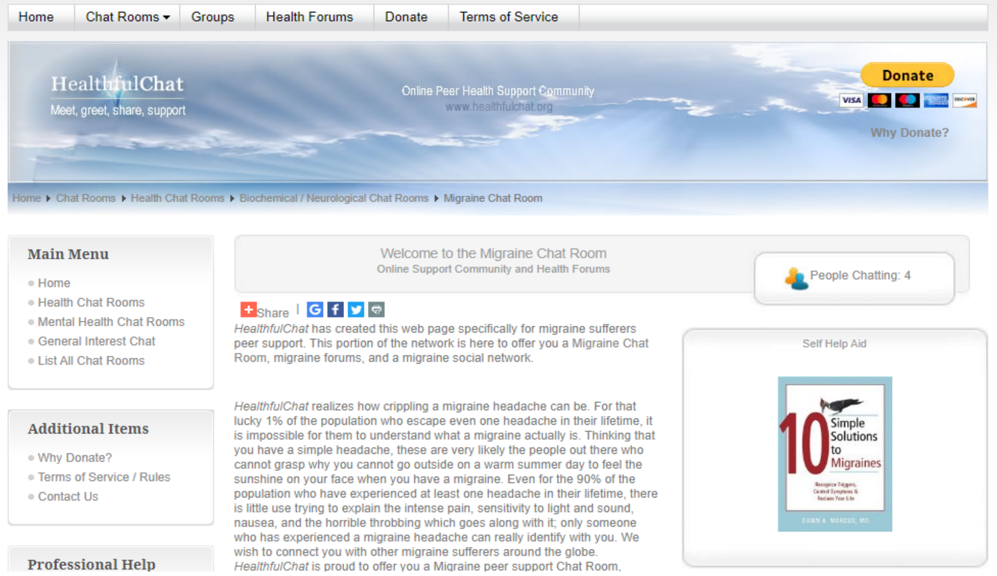
Screenshot taken from *Miles for Migraine* website on 30th April 2021

4.3.2.4 Healthful chat

URL: https://www.healthfulchat.org/migraine-chat-room.html

This webpage came up a total of 5 times in the top five pages of the 12 searches. Contrary to the previous pages, *Healthful chat* has a different format. This is not a traditional webpage, but a chat room. *Healthful chat* is a platform that hosts chat rooms for different health conditions (including rooms on mental health), where users join in to talk about their experiences of living with a certain condition; at the time of writing, they had a chat room for people with migraines.

Figure 4-5 *Healthful chat*



HealthfulChat has created this web page specifically for migraine sufferers peer support. This portion of the network is here to offer you a Migraine Chat Room, migraine forums, and a migraine social network.

HealthfulChat realizes how crippling a migraine headache can be. For that lucky 1% of the population who escape even one headache in their lifetime, it is impossible for them to understand what a migraine actually is. Thinking that you have a simple headache, these are very likely the people out there who cannot grasp why you cannot go outside on a warm summer day to feel the sunshine on your face when you have a migraine. Even for the 90% of the population who have experienced at least one headache in their lifetime, there is little use trying to explain the intense pain, sensitivity to light and sound, nausea, and the horrible throbbing which goes along with it; only someone who has experienced a migraine headache can really identify with you. We wish to connect you with other migraine sufferers around the globe. *HealthfulChat* is proud to offer you a Migraine peer support Chat Room.

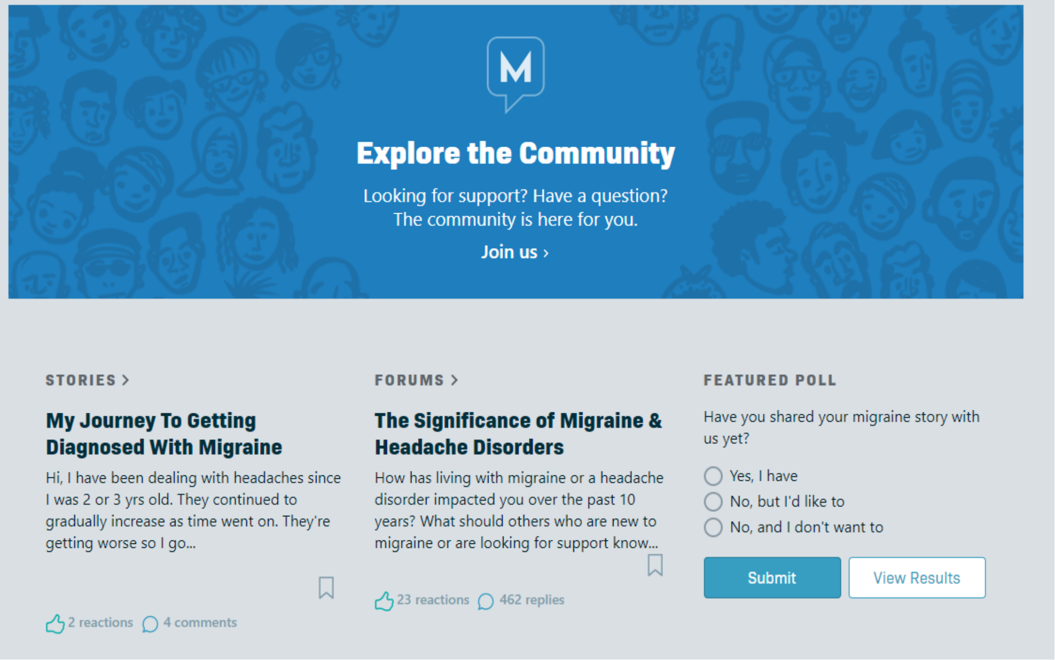
Screenshot taken from *Healthful chat* website on 30th April 2021

4.3.2.5 Migraine.com

URL: https://migraine.com/

This webpage came up a total of 3 times in the top five pages of the 12 searches. *Migraine.com* focuses on providing information to people with migraines with the ultimate goal of improving their overall migraine experience. Similar to other platforms, this webpage has a great range of migraine resources. It ranges from articles discussing treatments and symptoms, to updates on current research in the field of migraines. Users can also create accounts to comment and interact with their publications. Additionally, they have a migraine forum where people join in to discuss different issues related to migraines and to interact with other users for peer-support and sharing their experiences. They also have a presence on social media with pages dedicated to migraines and people with migraines.

Figure 4-6 ***Migraine.com***



Explore the Community

Looking for support? Have a question?
The community is here for you.

My Journey To Getting Diagnosed With Migraine

Hi, I have been dealing with headaches since I was 2 or 3 yrs old. They continued to gradually increase as time went on. They're getting worse so I go...

The Significance of Migraine & Headache Disorders

How has living with migraine or a headache disorder impacted you over the past 10 years? What should others who are new to migraine or are looking for support know...

Have you shared your migraine story with us yet?

○ Yes, I have
○ No, but I'd like to
○ No, and I don't want to

Screenshot taken from *Migraine.com* website on 30th April 2021

4.3.2 Data extraction

After the screening process, and the final subset of websites was selected, I proceeded with data extraction. Data extraction was divided in several stages. Initially, I familiarised myself with the home pages of each website. This was done because, traditionally, home pages are the 'welcome card' for users and the section where they make clear what their main messages and objectives are

Aligned with the primary objectives of this study, I proceeded to identify the different ways each website constructed and portrayed their narrative of support and their use of discursive objects relating to their messages of support (through words, expressions, quotes or images). Using a *Pro Forma* I gathered all the discursive objects identified within each home page. This step was not a simple exercise of looking for key words such as 'support' or 'help', but rather a meticulous exercise of highlighting all the instances where each website presented (directly or indirectly) their narratives of support through different linguistic symbolisms. This exercise was not restricted to written text; this was done towards the layout, the images, GIFs (Graphics Interchange Format), the symbols and logos of each home page.

This was followed up by exploring different sections and sub-sections of each website. Here, the focus was on sections that were directly aimed at the users. That is, 'forum-like' sections showing different comments and interactions from users and moderators of the platform –

such Q&A sub-sections and group chats and forums. After identifying these sections, the same process used to extract data from the home pages was employed.

4.3.3 Data analysis

After identifying all the discursive objects and the occasions in which they were employed, the focus moved to reflecting upon the differences and similarities between these constructions. That is, to reflect upon instances where the same discursive message was used, how it was used, and how differently or similarly it was used in relation to other occasions where it was used.

One of the key objectives with this chapter is to look at different nuances of discourse in online platforms for people with migraines. This was done using Discourse Analysis (DA) (Foucault, 1980). One of the particularities of DA is that it can be carried out on any symbolic system, regardless of whether that system is formed by words (Willig, 2008). That is, through DA, one can explore the discursive and narrative constructions and meanings of different elements. In fact, elements such as images and videos as well as written or spoken words are particularly suitable for this type of analysis (Parker, 1992; Willig, 2008). Consequently, this makes DA a relevant approach to explore the content available in websites, as it is common that key messages are disseminated online through the use of images as well as words. In fact, DA has been used to explore social media and content available in online platforms elsewhere (Sam, 2019; McKenna et al., 2017).

The initial step of this analysis was to get familiar with the data sources. This was in line with the procedure guidelines for conducting DA (Willig, 2008), I started by looking at and getting familiar with the data extracted from each website.

The data was looked at in terms of context and subjective positioning. In other words, I engaged in an attempt to identify and analyse the different contexts in which the discursive objects were deployed, and how they might function as representations of the subjective positioning of each website in relation to ‘providing a platform of support’ for people with migraines. The question guiding this stage was: ‘In what context is this discursive object being deployed, and what does it say about the subjective position of this website?’ Additionally, I focused on how these nuances were directly and indirectly linked to the ultimate goals of the websites, and their relation to practice. In other words, how their subjective position was contributing to a discourse of support.

Through a DA I was able to look at and reflect upon the constructions and perceptions of language and discourses as social practices in the online world of migraine support. A key aspect was to explore the collective meanings of migraine and migraine support rather than focusing on a more individual stance (Garrity, 2010; Diaz-Bone et al., 2008). However, individual narratives were also considered for the purposes of this study. By adopting a DA approach, I explored collective meanings, as well as individual narratives, and the roles they play in contributing to those constructions of social and collective meaning (Sam, 2019). By doing this, I was able to explore the discourse of the individual in relation to the collective.

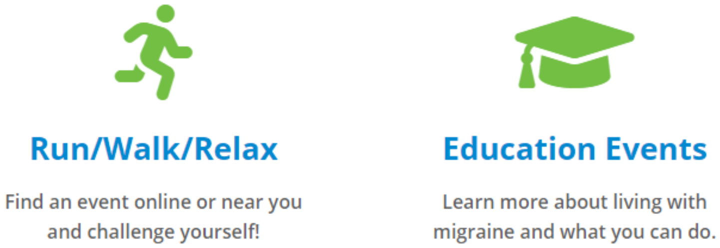
4.4 Results

Discourse 1: A peek inside the front window of the online migraine world

The websites included in this study presented different elements which translate their approach to establishing these platforms as providers of support for people with migraines. Some of these elements are distinct and relate to their policies and approach as an organisation, charity, trust or institution that supports migraine. However, there are commonalities across them. The focus of this section is to provide an overview of the way these websites position themselves in terms of their contribution towards individuals experiencing migraines, through sharing what is perceived as helpful information. I will touch upon how these platforms position their discourse of being 'educators' in the migraine experience and delve into narratives of finding a cure for migraines.

From visiting their website, it is clearly noticeable that these platforms provide helpful information about migraines. Through several sections and sub-sections, these pages offer a great range of informative topics; from basic explanations around symptoms and triggers, to more intricate presentations of the type of medication available and how it is funded. However, one can easily identify one common thread in their overall discourse. Often, the discursive objects used in these websites render their intellectual positioning as educators about migraines or the migraine experience. That is, the language used to introduce, organise or present the amount of information and resources they have, acts as a bridge to position these websites as educators of the migraine experiences (i.e. to explain and support the 'whys and how's' of migraines). Due to the fact that some websites do not offer the option for people to interact with their comments or articles, this results in an interesting dynamic between these websites and potential users, where the websites act as active and dynamic educators and the users play the role of passive learners. This was a different case in *Healthful chat* where the webpage did not provide detailed information on migraines, but instead simply acted as a platform for people with migraine to connect with each other.

In the case of *Miles for Migraines,* the language they used to describe the information hosted, clearly places them as educators, whereas users are, discursively speaking, passive learners. That is, the discourse is framed around a linear relationship - the website hosts valuable information, the user learns from that and decides whether to act on it. This information ranges from general migraine information to promoting events to raise money and awareness for migraines, support groups, and volunteering opportunities. One particular example is the way the discursive elements of 'education events' is constructed. From the way these are phrased, it is perceived that people accessing this content will be able to get something from it, and ultimately apply that to the way they live with migraines; and this is shared through different narratives demonstrating their educational positioning towards the users. The process for obtaining information starts with them (they host it in their website) and ends with the user (they learn from it and act upon it).



Run/Walk/Relax

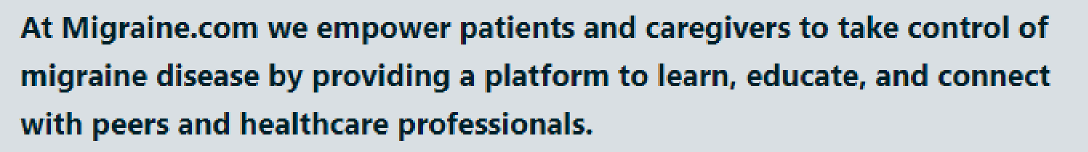
Find an event online or near you and challenge yourself!

Education Events

Learn more about living with migraine and what you can do.

Screenshot taken from *Miles for Migraine* website on 30th April 2021

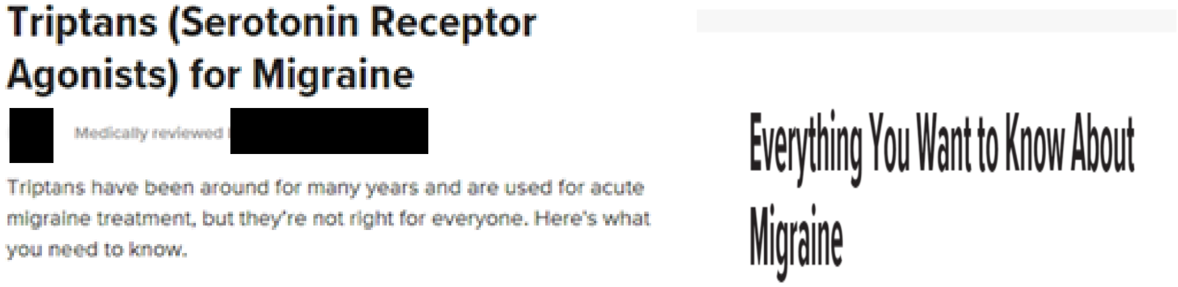
Some of these platforms clearly position themselves as instructors or educators through their discursive performance. Through the language used, they make it clear that people who access these platforms can and will learn from them. There is a clear and direct relationship between accessing these resources and gaining something from them, whether that is being intellectual knowledge or more practical tips for coping with migraines. The discourse fluctuating across different platforms is one of empowerment and resilience, focusing on the role these platforms can play in helping people channelling that towards better coping with their illness.



At Migraine.com we empower patients and caregivers to take control of migraine disease by providing a platform to learn, educate, and connect with peers and healthcare professionals.

Screenshot taken from *Migraine.com* website on 30th April 2021

In some cases, these platforms transparently place themselves as enablers and educators, through the resources they provide. Not only do they offer information that will act as a facilitator of empowerment for ill-health, but they are at the same time enabling that same empowerment as a consequence. This is extremely clear in the particular case of *Healthline*, and their discursive objects pointing to what 'you need' and 'you want'. Here, the website actively links the information they are providing to the users' needs. By employing these subject-focused discursive objects, they are reiterating and highlighting the value that they place in the quality of the information they are sharing. Moreover, by using these discursive objects, they are telling the user that they know what people need and want; echoing their stance as educators for issues relating to migraines. The information they hold (and share) is pitched as instrumental and as something that those with migraines 'need' and 'want'.



Triptans (Serotonin Receptor Agonists) for Migraine

[redacted] Medically reviewed [redacted]

Triptans have been around for many years and are used for acute migraine treatment, but they're not right for everyone. Here's what you need to know.

Everything You Want to Know About Migraine

Screenshots taken from *Healthline* website on 30th April 2021

Another relevant aspect, particularly identified in two platforms, *Miles for Migraines* and *the migraine trust*, was the discursive object of a 'cure'. Interestingly, although still only subtly present on these pages, this emphasis on 'cure' was not as clear or visible in other websites as it is in these two. One the one hand, *the migraine trust* has an option for people to obtain more information about a cure, by having a direct 'finding a cure' sub-section available to access at the top of their main page. In this sub-section they have resources available for people to know more about how *the migraine trust* fund and promote new research into migraines to 'discover new treatments and to find a cure'.

Screenshot taken from *the migraine trust* on the 30th April 2021

On the other hand, the way *Miles for Migraines* construct their discourse around the object of a 'cure' is very particular and worth noticing. Centralising their message on 'finding a cure' seems to be key to their discursive approach, which is seen in their opening message in their main page.

Screenshot taken from *Miles for Migraine* website on 30th April 2021

Known for being a non-profit organisation focused on raising public awareness through walking and running events to raise money, the 'Miles for Migraines' website makes use of their mission to portray their views towards the migraine experience. Through exploring their primary statement '*'the race for a migraine cure begins with you*'' one can easily identify the importance that is attributed to the discourse of finding a cure. Several elements are worth dissecting in this discourse.

Finding a cure for migraines is undeniably the ultimate goal for everyone involved in the field of migraines (patients, researchers, healthcare professionals etc.), however, the *Miles for Migraines* discourse around 'obtaining a cure' acts both as a clear representation of their objective as an institution, as well as a description of how they intend to reach this objective. From their initial statement, they inform the user, in a very clear and transparent way that their objective is to have a role in finding a cure for migraines. However, through the discursive elements employed '[finding a cure] begins with you' they inform the user that they also have a role to play and the process starts with them. Their approach focuses on supporting the race (to find a cure) through being educators and organisers of migraine events, but the first steps need to be taken by those who are going to race (i.e., people with migraines); discursively positioning themselves almost as a map that is key to providing information and guiding people to their destination. Through their discourse, *Miles for Migraines* identify the user of their websites (i.e. person with migraines) as having a primary role in finding a cure. In fact, they place people with migraines at the centre of ‘the race for a cure’ as they state that the race starts with them, which displays an interesting contrast to the discursive constructions of passivity around being educated. In their discourse, the process for obtaining a cure starts with the user (people with migraines), whereas the process for obtaining information starts with them (the hosts of that information).

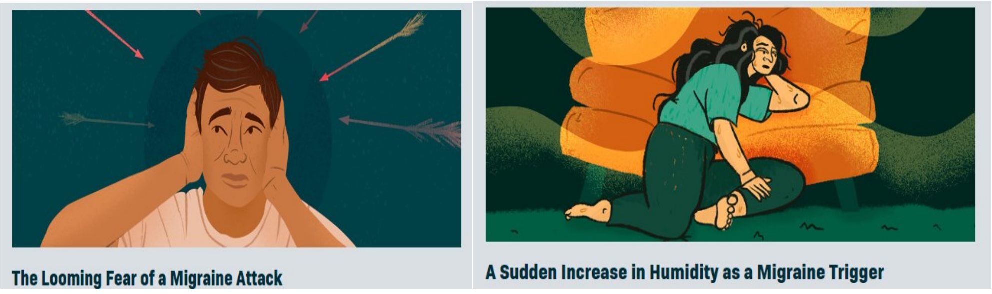
Through exploring the narratives of these webpages, one cannot help but reflect upon their ultimate goal and their path to that goal. The websites included in this review offer a great range of useful options for people with migraines. Some of these are in a form of instant message services to help people connect (for instance *Healthful Chat*), others are built around an approach to raise funds and awareness through different activities (such as *Miles for Migraines*), whereas others offer an incredible range of information and tools to improve the lives of people with migraines. In order to convey their message, they establish themselves as educators in the field of migraines through the types of discourses they employ and the way they describe themselves as platforms that enable people to be empowered and improve the way they cope and live with migraines. It is common to see websites sharing narratives around a cure for migraines. Some websites do this by discursively placing their users on the receiving end of the dynamic (i.e., websites have useful information that the reader ‘needs and wants’) whereas others transparently place the user in a more active role. That is, they highlight their role, but place their mission to find a cure as a joint task where the users are responsible for taking the first step.

Discourse 2. A click beyond words: the imagery on online platforms for support with migraines

Images are an intrinsic part of any online platform and websites for support with migraines are no different. These range from more abstract pictures with meaning attached to them, such as images of green fields and blue skies, to more descriptive pictures, such as images of people experiencing the symptoms of migraines. In this section, I will explore the discourses within the imagery present in the websites and reflect upon their meanings in relation to how these websites portray their platform as a support tool for people with migraines.

Some websites use imagery much more than others. There are websites that attach a picture to the majority of their entries and articles (*Migraine.com* is a good example of this), whereas others barely have any image or picture in display (like the *Healthful Chat* or the migraine sections of *Healthline*). Nonetheless, navigating through the websites included in this study meant navigating through a sea of meaningful and descriptive images that often represented the website's approach to the migraine experience and support offered.

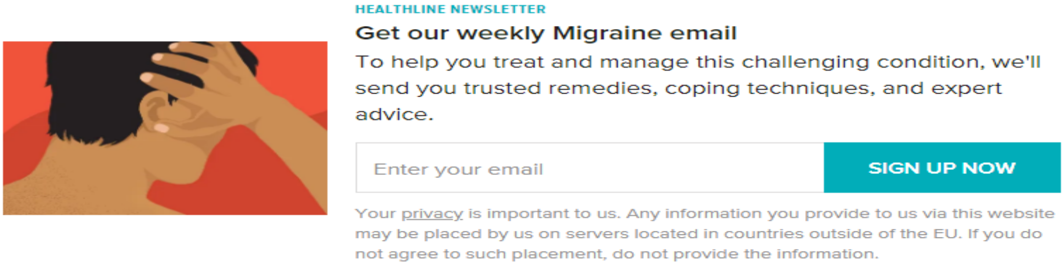
One of the first aspects that was seen across different platforms was the similarities in the images depicting people with migraines and people in the exact moment they are experiencing migraines.



The Looming Fear of a Migraine Attack

A Sudden Increase in Humidity as a Migraine Trigger

Screenshots taken from *Migraine.com* website on 30th April 2021



HEALTHLINE NEWSLETTER

Get our weekly Migraine email

To help you treat and manage this challenging condition, we'll send you trusted remedies, coping techniques, and expert advice.

Your privacy is important to us. Any information you provide to us via this website may be placed by us on servers located in countries outside of the EU. If you do not agree to such placement, do not provide the information.

Screenshot taken from *Healthline* website on 30th April 2021

Often, in spite of the source, the nature of the pictures representing someone experiencing migraines did not vary much. Firstly, there was an inherent gloom to the majority of these, either through the saturation and colours used or through the elements present in them. In other words, images showing people with migraines frequently show these people in positions which have come to symbolise pain. Recurrently, the role of the imagery is to reflect the negative impact of a migraine. Discursive objects such as pain, struggle, discomfort and malaise are often translated and portrayed through images of people holding their heads or by elements such as arrows and thunderstorms going through someone's head. Moreover, some of the images make use of extremely saturated colours to enhance one's perception of these meanings and subliminal messages visually present in the pictures.

It is also important to note that, although there are pictures of men, the majority of the photos and images available in these websites were of women. Through navigating these websites and coming across different images and pictures of people experiencing migraines, one gets a sense that the traditional representation of a person experiencing a migraine, is discursively portrayed using images of women.

The ultimate role of these types of pictures as a discourse is to show that a migraine experience is not pleasant. Pictures are normally used as an addition or supplement to a story or a testimony of a website user or collaborator about their own migraine experience or journey.

Screenshot taken from *Healthline* website on 30th April 2021

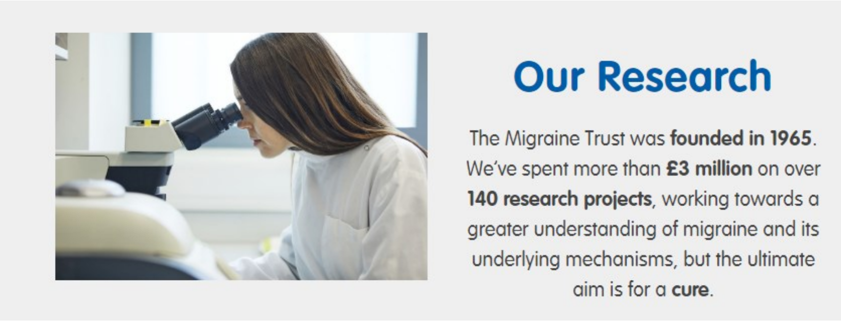
It was not common to come across pictures translating feelings of contentment, which is ultimately understandable given the nature of migraines as an illness. There were occasions however, especially in images of people coming together as a 'migraine community', where the discourses of pain and discomfort were replaced by representations of enjoyment and gratification. For instance, this was particularly clear in the fund raising and events sections of *Miles for Migraines*. In this website one can easily come across pictures of their fundraising events (walks and runs), showing people smiling and enjoying their activities.

Additionally, there were cases where certain images were employed to portray a discourse of 'hope' and the search for better and brighter days. One particular case was the main image shown in *Healthful chat* which is full of meaning.

Screenshot taken from *Healthful chat* website on 30th April 2021

Here, the website makes use of a picture of a blue sky with the sun being covered by clouds. This could be interpreted as a way to exalt and elevate feelings of hope. By displaying an image of the sun temporarily hiding behind the clouds, they establish the focus of their discourse on the object of hope. Ultimately characterising one's happiness and wellbeing as being covered behind the migraine cloud. The link between the discourse present in this image, and their goal as a website, is to use social support and experience sharing as a way for people to find hope (the sun) in spite of their difficult migraine experience (the clouds).

In addition to imagery used to portray the migraine experience, some websites also offer sections for users to know more about their involvement with research. Not surprisingly, due to the focus on cure the images used are very focused on medicalised environments, such as showing researchers in labs or doctors wearing lab coats. In fact, the imagery in these sections often points towards a discourse of 'medicalisation of research', which infers the search for a cure, or development of new medications to help with migraine symptoms.



Our Research

The Migraine Trust was **founded in 1965**. We've spent more than **£3 million** on over **140 research projects**, working towards a greater understanding of migraine and its underlying mechanisms, but the ultimate aim is for a **cure**.

Screenshot taken from *the migraine trust* website on 30th April 2021

How can I get care for migraine or headache disorder?

Maybe you get a lot of headaches, or your headaches stop you from doing your normal activities. Maybe you've already been diagnosed with migraine. In every case, it's important to know that there are healthcare providers who can help you.

For many people, the diagnosis is made by the primary care physician (PCP). He or she can often provide the necessary care. In fact, some PCPs have additional training in migraine disease and other headache disorders. If your PCP is unable to manage your migraine, he or she may refer you to a neurologist or a headache specialist. Neurologists are doctors who specialize in treating the nervous system, which includes the brain. They all have additional training in treating headache disorders.

Screenshot taken from *Miles for Migraine* website on 30th April 2021

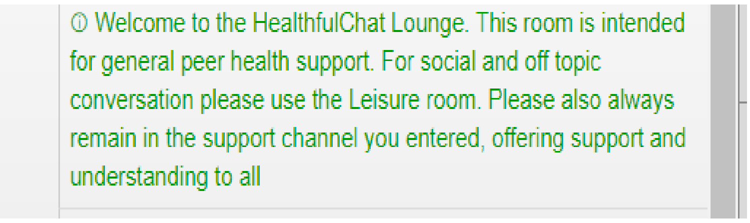
Once again, it is understandable that the main focus of migraine organisations is to find, or fund, a cure for migraines. However, within the wider discourse of support, it was rare to see images related to more social aspects of support – with the exemption of *Miles for Migraines* which have a relatively big 'sub-section' showing pictures of their events and races.

Images are a very effective tool to visually represent different discourses and narratives within the whole of the migraine experience. Overall, images present in the websites included in this study were greatly used to visually represent the negative impact of migraine symptoms; and commonly portrayed the ‘standard migraine sufferer’ as being a woman. They were not commonly used alone, but rather as an addition or supplement to a piece of written information, such a news article or a story shared by someone experiencing migraines. Additionally, some of these websites use images of healthcare professionals and researchers to visually represent the constant search for a medical cure for migraines or the development of pharmacological drugs to treat the impact of a migraine. It was also noticeable the effort of some webpages to relate the discourse of ‘migraine support’ to a medicalised approach (towards a cure and treatment), leaving out all forms of support (for instance social or emotional).

Discourse 3. ‘’You’re not alone in this!’’: navigating the discourses present in forum threads of online migraine communities.

Despite having and showing different approaches to how they construct their narratives of support and the avenues they prioritise to achieve that, some of the websites included in this chapter also had sub-sections for people with migraine to come together and interact with each other. That is, on top of the information they have available, some pages also provide a platform for users to share their personal experiences and interact between themselves or with threads and articles posted in different subsections of the website. For being a place where people with migraines share their experiences and views towards their journey and the way they seek and obtain support, I explored this particular aspect of the websites in this section. More specifically, this theme focuses on the sub-sections of these websites that allow users to come together in a discussion forum or interactive chat to share their experiences and connect with each other (as well as with the people running the website).

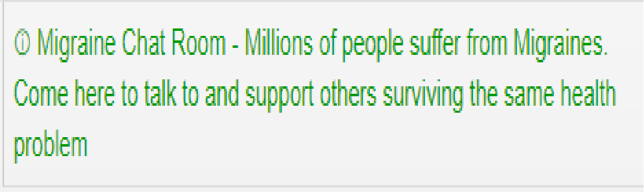
Different websites seem to value experience sharing in different ways. Some of them place experience sharing between people with migraines at the centre of what they do, whereas others just seem to mention its importance without actively building up on it. For instance, *Healthful chat* is an example of a webpage that focuses on experience sharing. This webpage is at its heart, a platform for ‘peer health support’ and for people to come together and share their experiences by means of an instant messaging group chat. Here, people sign up to the chat and are free to ask or post any questions they might have. Upon joining the website, one is directed to a general ‘room’ and from there users can select and get redirected to ‘rooms’ for different illness conditions.



ⓘ Welcome to the HealthfulChat Lounge. This room is intended for general peer health support. For social and off topic conversation please use the Leisure room. Please also always remain in the support channel you entered, offering support and understanding to all

Screenshot taken from *Healthful chat* website on 10th May 2021

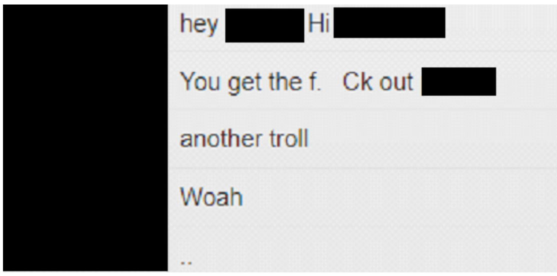
At the time of writing up, this particular platform did not seem to be very active. Even though at different times of the day, the main ‘room’ was particularly full with different people (i.e., users with different usernames) joining the chat. However, the migraine ‘room’ did not have much activity regardless of the time of the day (and across different days).



ⓘ Migraine Chat Room - Millions of people suffer from Migraines. Come here to talk to and support others surviving the same health problem

Screenshot taken from *Healthful chat* website on 10th May 2021

In the main ‘room’ however, conversations seemed to revolve around different healthcare topics rather than migraines. At different occasions, conversations seem to derail from the main purpose of the website (peer support). Despite references to ‘moderators’ being available, there was no clear and visible moderation taking place.



[redacted]

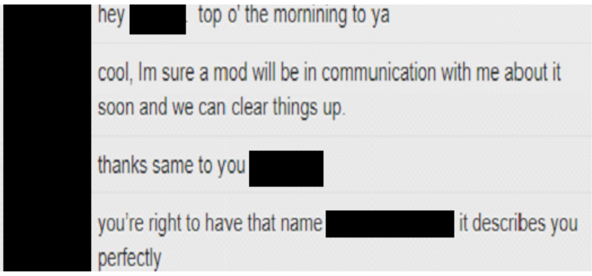
hey [redacted] Hi [redacted]

You get the f. Ck out [redacted]

another troll

Woah

..



[redacted]

hey [redacted] top o' the morning to ya

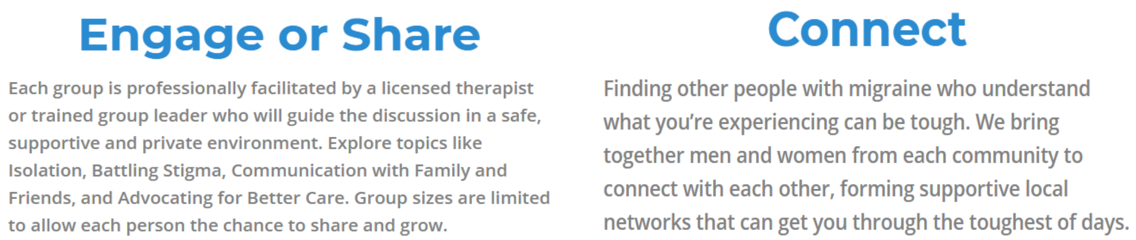
cool, Im sure a mod will be in communication with me about it soon and we can clear things up.

thanks same to you [redacted]

you're right to have that name [redacted] it describes you perfectly

Screenshots taken from *Healthful chat* website on 10th May 2021

On the same line of peer support, *Miles for Migraine* also offer the opportunity for people to come together and share their stories through what they describe as 'Support groups'. These are scheduled meetings organised by *Miles for Migraine*, facilitated by 'licensed therapists' or 'trained group leaders' where people come together to 'Connect', 'Discover', 'Engage or Share' stories about migraines. In order to join these, people have to register and due to the current COVID-19 circumstances, these appeared to have moved from being face to face meetings, to online.



Engage or Share

Each group is professionally facilitated by a licensed therapist or trained group leader who will guide the discussion in a safe, supportive and private environment. Explore topics like Isolation, Battling Stigma, Communication with Family and Friends, and Advocating for Better Care. Group sizes are limited to allow each person the chance to share and grow.

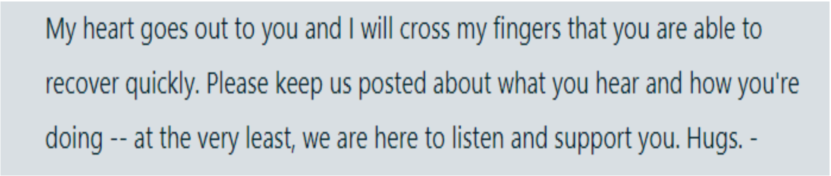
Connect

Finding other people with migraine who understand what you're experiencing can be tough. We bring together men and women from each community to connect with each other, forming supportive local networks that can get you through the toughest of days.

Screenshot taken from *Miles for Migraines* website on 7th May 2021

'*Migraine.com'* offers a more traditional approach to online forums. That is, the platform enables people to post a thread where others can comment, interact, and add more information. Discourses surrounding 'active listening' are very present in these types of subsections within different websites. Regardless of the migraine topic being discussed between users, discourses surrounding the importance of experience sharing is directly placed on people's need to feel listened and understood.

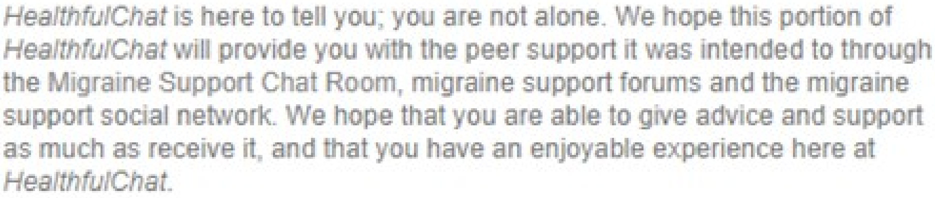
It is easily perceived from accessing online forums and interactive sections within these platforms, that there is a narrative of constant and wholesome reassurance across them. It was common to see interactions and conversations between users and moderators where it is made clear that people are there to 'listen' to each other.



My heart goes out to you and I will cross my fingers that you are able to recover quickly. Please keep us posted about what you hear and how you're doing -- at the very least, we are here to listen and support you. Hugs. -

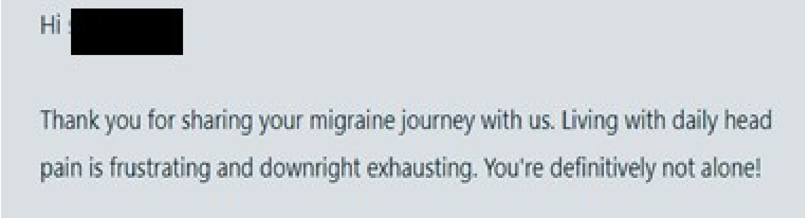
Screenshot taken from *Migraine.com* website on 30th April 2021

The discourse of coming together as a community, is salient in these subsections. This is done through sharing feelings of 'togetherness' and by the use (and even repetition) of discursive objects such as 'you're not alone'.



HealthfulChat is here to tell you; you are not alone. We hope this portion of *HealthfulChat* will provide you with the peer support it was intended to through the Migraine Support Chat Room, migraine support forums and the migraine support social network. We hope that you are able to give advice and support as much as receive it, and that you have an enjoyable experience here at *HealthfulChat*.

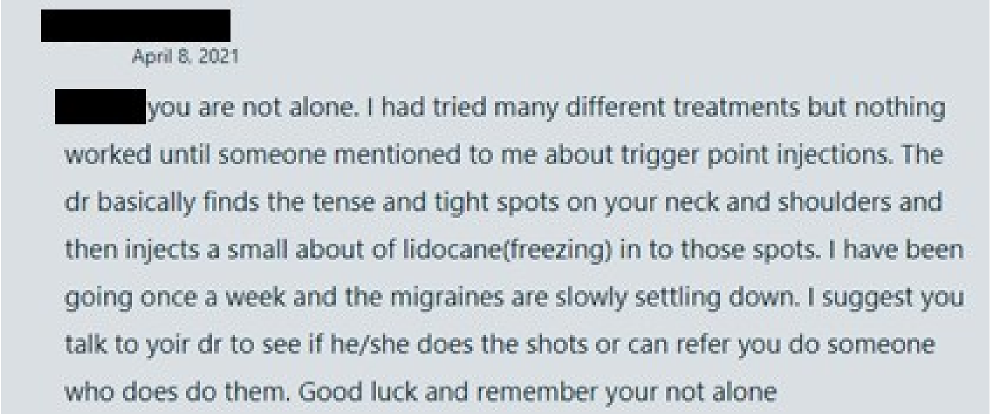
Screenshot taken from *Healthful chat* website on 30th April 2021



Hi [redacted]

Thank you for sharing your migraine journey with us. Living with daily head pain is frustrating and downright exhausting. You're definitively not alone!

Screenshot taken from *Migraine.com* website on 30th April 2021



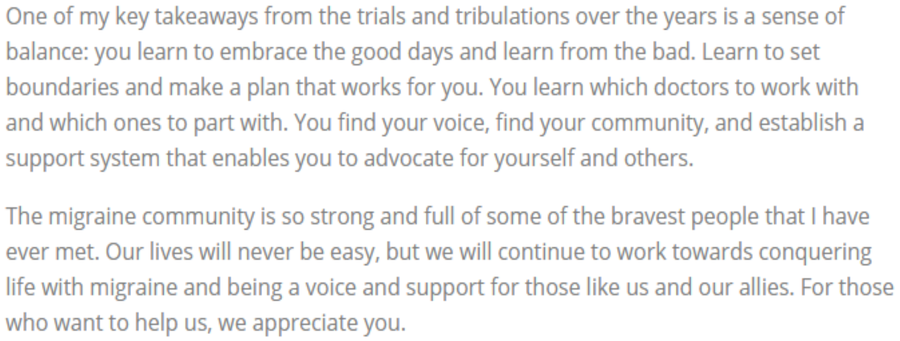
[redacted]

April 8, 2021

[redacted] you are not alone. I had tried many different treatments but nothing worked until someone mentioned to me about trigger point injections. The dr basically finds the tense and tight spots on your neck and shoulders and then injects a small about of lidocane(freezing) in to those spots. I have been going once a week and the migraines are slowly settling down. I suggest you talk to yoir dr to see if he/she does the shots or can refer you do someone who does do them. Good luck and remember your not alone

Screenshot taken from *Migraine.com* website on 30th April 2021

Through constructing these platforms as a place for the migraine community to come together, discourses of empowerment and inner strength are often employed as a way to define, share, and strengthen the values and 'power' of the community. Forum users often used analogies and metaphors relating to bravery and war like scenarios to establish the strength of the community, and the benefits of people who share the same experience coming together. Discursive objects of 'undeniable unity' were often seen.



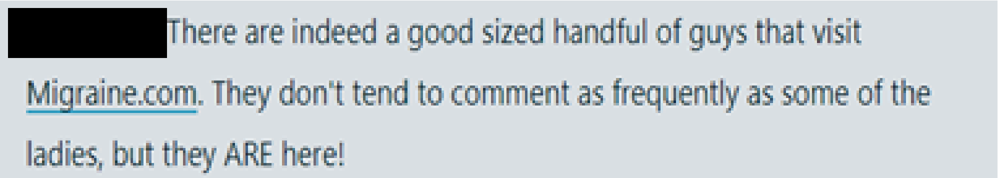
One of my key takeaways from the trials and tribulations over the years is a sense of balance: you learn to embrace the good days and learn from the bad. Learn to set boundaries and make a plan that works for you. You learn which doctors to work with and which ones to part with. You find your voice, find your community, and establish a support system that enables you to advocate for yourself and others.

The migraine community is so strong and full of some of the bravest people that I have ever met. Our lives will never be easy, but we will continue to work towards conquering life with migraine and being a voice and support for those like us and our allies. For those who want to help us, we appreciate you.

Screenshot taken from *Miles for migraine* website on 30th April 2021

It is important to note that these discourses of 'coming together' and 'togetherness' often come from profiles and usernames that seem to be women (based on their username or pronouns used). Often, unless a clear male name (or picture) is provided, or sex is included in their profile, there is an assumption that the user is a woman. However, even though male profiles contribute to these discussions and are sometimes present, they are very rare.

A closer look at this particular issue, revealed a more complex problem. The contribution and presence of men in migraine forums is a matter worth exploring. In one particular case, *Migraine.com*, there are several threads with discussions around how men interact with these platforms and come forward for help and support. Once again, these particular threads had the majority of comments and interactions made by women, or female moderators. This is clearly a subject that is relevant to the community as some users highlighted in several threads. On different occasions, users discussed the issues of men not accessing these platforms as much as women. The idea is that there are men accessing these resources, but they do not interact with them as much (i.e., do not actively post any comments).

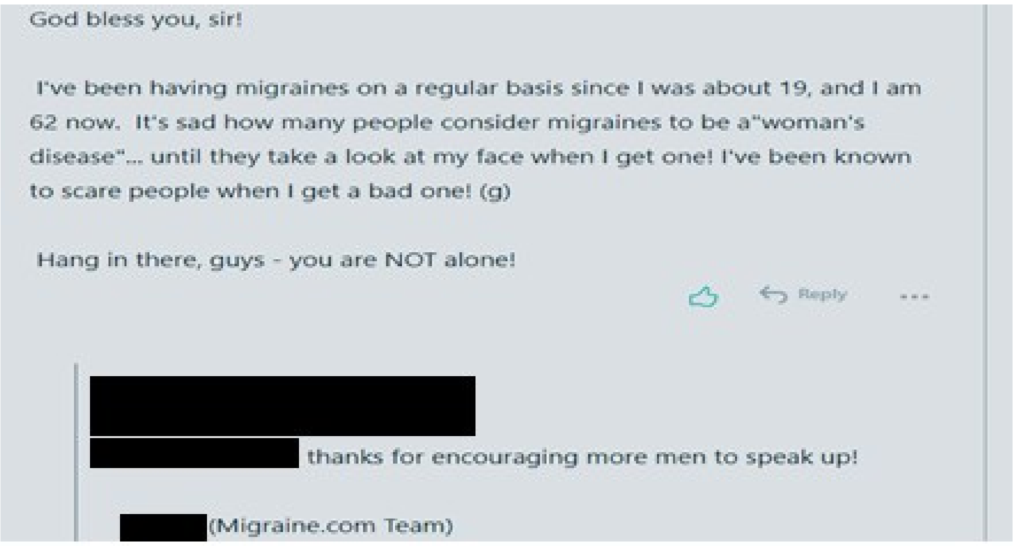


[redacted] There are indeed a good sized handful of guys that visit Migraine.com. They don't tend to comment as frequently as some of the ladies, but they ARE here!

Screenshot taken from *Migraine.com* website on 30th April 2021

In this particular context, the use of capital letters 'ARE' is full of meaning. Through the use of capital letters, this discourse gives emphasis and reinforces the fact that even though men might not interact with the website as much, they do access it. The use of capital letters to signify the presence of men in migraine forums ends up implicitly highlighting a potential focal point. That is, the fact that men might use these platforms in a very particular way and differently to women. It can be argued that this might be a result of how they construct their identity as a person living with migraines and their subjective positioning towards what they perceived as support for migraines

Migraine.com has different threads where users explore how men use these platforms. The nature of migraines, and the fact that they are often considered a 'women's condition' is repeatedly touched upon in some of these threads.



God bless you, sir!

I've been having migraines on a regular basis since I was about 19, and I am 62 now. It's sad how many people consider migraines to be a"woman's disease"... until they take a look at my face when I get one! I've been known to scare people when I get a bad one! (g)

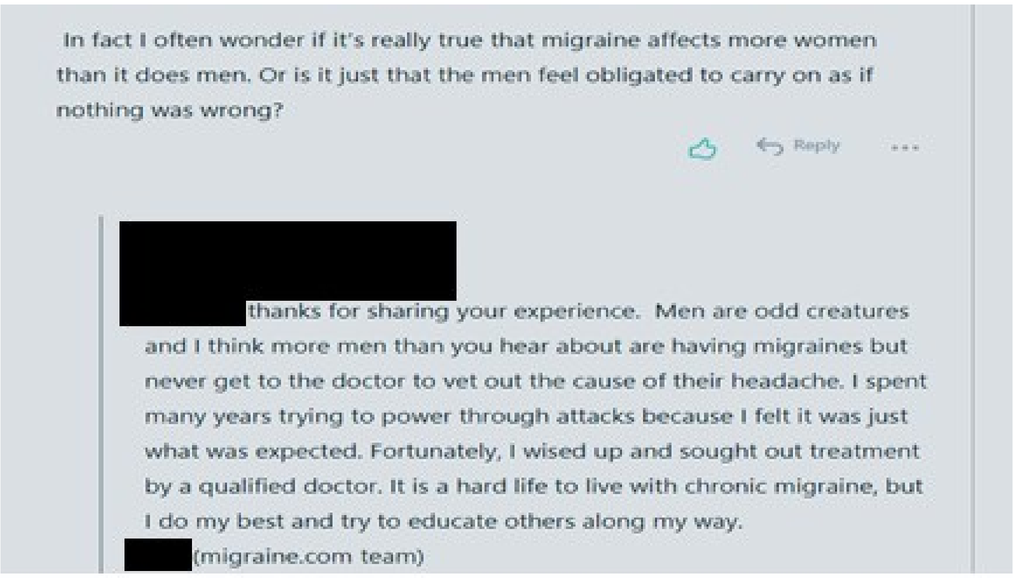
Hang in there, guys - you are NOT alone!

[redacted]

[redacted] thanks for encouraging more men to speak up!

[redacted](Migraine.com Team)

Screenshot taken from *Migraine.com* website on 30th April 2021



In fact I often wonder if it's really true that migraine affects more women than it does men. Or is it just that the men feel obligated to carry on as if nothing was wrong?

[redacted] thanks for sharing your experience. Men are odd creatures and I think more men than you hear about are having migraines but never get to the doctor to vet out the cause of their headache. I spent many years trying to power through attacks because I felt it was just what was expected. Fortunately, I wised up and sought out treatment by a qualified doctor. It is a hard life to live with chronic migraine, but I do my best and try to educate others along my way.

[redacted](migraine.com team)

Screenshot taken from *Migraine.com* website on 30th April 2021

In one particular thread, users of this website explored the reasons why they think it is not common to see men actively participating in conversations within these particular platforms. Reasons linked to 'feeling obliged to carry on as if nothing was wrong' and 'men are odd creatures' are used to justify men's approaches to migraines. Ultimately, there are complex issues when it comes to men and migraines and that has been conveyed in the discourses on these forums.

Additionally, the way internet webpages construct their discourses and share their messages might have an impact in the way men access and interact with these platforms. The fact that most of the users and content creators of these websites are women might prove to be a barrier for men. Even more, where a great number of these articles focus on female specific aspects of migraines.

[redacted]

Thanks for sharing. I have been suffering with migraines as a man for 27 years. I agree - many of the articles are written by women, and somewhat focused on female aspects of the disease. I know there are a lot of men out there that have migraines. We need to step up and take part in helping each other.

[redacted]

Thanks so much for reaching out on this topic. It does seem that men aren't represented enough when it comes to talking about migraine. It may have to take more men being brave enough to speak up! I wish you well on your migraine journey.

[redacted]Migraine.com Team)

Screenshot taken from 'Migraine.com' website on 30th April 2021

The issue then becomes even more complex. It is a fact that migraines affect more women than men, consequently, more women will talk about migraines and create platforms and tools for support with migraines. However, in spite of being under-represented, men still access these platforms. Therefore, presenting a discourse that assumes (and addresses) a default subject who is female, will affect those who are not represented. This under-representation and absence of male-specific articles, threads, and information might act as a barrier to how men access online support and consequently cope with their migraines. Nonetheless, these platforms seem to be an extremely effective and efficient way to obtain and share information and to act as supportive tools. Some offer a combination of relevant migraine information and peer support (sometimes mediated by healthcare professionals) and give users the option of coming together as a community to help each other in their migraine experiences. However, these platforms still seem to be failing to reach men, which is undeniably an under-represented migraine population, even online.

4.5 Discussion

In the previous chapter, following an in-depth look at the experiences of eight men with migraines, I highlighted how useful online resources can be for acquiring information and understanding different perspectives towards the migraine experience. Ultimately, online platforms were perceived to be effective tools for obtaining support. Building upon that argument, the focus of this chapter was to explore existing online platforms, how they position themselves as sources of support for people with migraine and the discourses they draw upon.

The main objective of this study was to add to the findings from the previous chapter and continue to elaborate on the sources and mechanisms of support available for people with migraines. More specifically, I wanted to dissect the narratives surrounding some of these platforms and understand how they establish themselves as sources of support through their discourses. In line with the running thread of this thesis, this study also focused on masculinity and how these resources might be perceived or utilised by men with migraines.

The content of this chapter offers a thorough overview of some online platforms aimed at people with migraines. By means of a systematic search I identified several webpages that present themselves as sources of support for people with migraines. Throughout this chapter I elicited some key aspects of these webpages based on an in-depth exploration of some of the discourses present. This was done by means of Discourse Analysis, which was used in both textual data and imagery (Foucault, 1980). It is important to note that all these websites varied in design, content, and approach. That is, *Miles for Migraines* is a website with resources that are clearly built around their programmes and fundraising initiatives, *the migraine trust* focus on information sharing, with a great number of tools ranging from general information about symptoms to detailed documents for head teachers, co-workers, HR and other people who contact with people with migraines to know more about this conduction. Similarly, *Migraine.com* also has a variety of information available, with the particularity that their website is slightly more interactive by allowing users to comment and create interactive threads. Lastly, *Healthline.com* is a broader website for different healthcare issues and migraine represents only a minor subsection of their page, and *Healthfulchat* is an instant messaging platform with 'virtual rooms' for migraine users to interact with each other. It is also important to note that several of these websites also host social media pages and closed groups (on Facebook and Instagram) as an addition to their websites and in order to increase their range of support. However, for reasons elicited before, no social media pages were included in this review.

Overall, regardless of their content and design, these websites are constructed as readily available 24/7 sources of information and support. Some of these constructions are built by discursively positioning themselves as educators and providers of helpful information, as well by sharing a great range of aids to a journey to find a cure for migraines. Often, these platforms assume the role of educators through sharing resources that 'you need' or tips for living with migraines that 'you will want to know' and having subsections for people to 'learn more' about living with migraines or any specific symptom. They establish themselves as platforms that know what people want to learn about migraines and share a discourse of empowerment. The narratives of some websites portray the reader as a passive learner (who goes to the website to obtain information and may or may not act upon it), whereas others attribute a more active role to the reader, by stating that they are an active part of finding a cure and developing coping strategies (often medical) for migraines.

This discourse can be perceived as being rooted in a position of educational authority which can be explored further through Foulcaudian theories around power (Foucault, 1980). Considering Foucauldian theory, power is not something that is owned, it is rather something that is manifested in a certain way. In the case of migraine websites, this power is manifested by discursively positioning and manifesting themselves as educational authority. Power is therefore a manifestation and not a possession per se (Foucault, 1980). Foucault's approach to discursive positionings of power can help explain potential implications for the type of information that is disseminated by websites established to provide support for migraines. Through this positioning and by often constructing migraines as purely medical/biological, some websites might be limiting the range of migraine discussions that happen in an online context. Aligned with Foucauldian work, definitions and interpretations of power are defined not as something that implies oppression, but rather as something that can guide or even cause new behaviours to emerge (Foucault, 1980). In this case, these educational discourses instituted in medicalised approaches are dictating the narrative around migraines support and consequently the type of support people can seek and get.

It was common to see articles and information pieces about advances in migraine knowledge and interventions illustrated by showing professionals wearing lab coats or in laboratories. Most of these websites provide a medicalised view of knowledge about migraines. In fact, it was clear that the narrative around developments of migraine research is intrinsically rooted in a medicalised discourse. This approach is aligned with the biomedical model of ill-health, which argues that illness conditions can be fully explained by deviations from the norm of measurable biological (somatic) aspects (Engel, 1977). It is important therefore to draw out some potential consequences of this and the impact this might have on how users of these websites might respond to this positioning. That is, similarly to the discursive positionings highlighted above, the fact that migraine research is commonly represented by imagery and language associated with medical advances and medicalised approaches, might hinder the development of other alternatives to supporting people in the whole extent of their migraine experience. Aligning the migraine discourse with the biopsychosocial model, which takes the stance that purely medical/biological approaches and explanations to ill-health are insufficient, might help the development of different alternatives of support, and help validate people's experience (Engel, 1977). Through a biopsychosocial informed discourse, and by integrating psychological (the ''psycho''), environmental (the ''social'') and medical (''the bio'') aspects into their narratives, these websites can capture the full extent of the impact of migraines and define different ways of addressing and showcasing the different range of migraine experiences and people who suffer from them.

From images showing people experiencing a migraine, to aspects related to fundraising or migraine activities, imagery plays a relevant role in the discourse of these websites. In spite of the multitude of images, there are some commonalities across websites. For instance, when showing pictures or images of people with migraines, the focus is to show the exact moment a person is experiencing a migraine or a certain symptom. In other words, many of the pictures in these websites focus on what was described in Chapter 3 as ‘the heart of the migraine’ (the moment when migraine symptoms are at their peak). Moreover, these images clearly elicit how painful migraines are – in previous chapters, pain was highlighted as being a key element in the migraine experience – and tend to use saturated colours to depict gloom and negative emotions.

Even though it is understandable, in online platforms, migraine is very commonly represented by focusing on their (often negative) symptoms. Which can lead to speculation around whether that can have potentially negative triggering effects on those who come across these images. This argument is supported by different studies in other areas which have explored how coming across certain images online might impact one’s wellbeing and behaviour. Although results are not homogenous, there is research stating negative associations between photo exposure, through photo-based social media engagement and body image (Cohen et al., 2017; Meier & Gray, 2014). Other studies also found links between accessing social networking sites (arguably characterised by their use of images and photos) and disordered eating in men and women (Holland & Tiggemann, 2016). The links between coming across ‘negative’ migraine images and wellbeing has not yet been explored. However, due to the evidence in other areas, and how common these images are in migraines website, future research should focus on attempting to shed light into these issues. Moreover, such research would prove helpful to direct and inform the approach migraine websites have to the imagery used in their platforms.

We have seen how subjective and impairing the migraine experience can be. So far in this thesis, we have also seen detailed first-hand testimonies of people with migraines and how much it affects all aspects of their lives. Therefore, centring the development of migraine research on a purely medicalised approach might be translate a reductionist view of the problem (as well as the solution). In order to understand migraines and develop different treatments and support strategies, research needs to consider the human dimension of this condition. In line with the central epistemological argument of this PhD, the field of migraines can only benefit from adopting a more lifeworld-led approach (Todres et al., 2009; Todres et al., 2014). Moreover, research around support for people with migraines, and the development of treatment and new coping strategies for this particular condition, would benefit from bringing different disciplines together to understand migraines from a human perspective. Disciplines such as Psychology, Sociology, Philosophy and others, should not be forgotten and should be looked upon as relevant fields that can offer input and solutions for improving the support available for people with migraines.

Lastly, some of these websites have sub-sections with options for users to interact with their articles and even amongst themselves. These subsections offer a platform for peer-support through means of interactive forums where people post and comment on threads or instant messaging chats for people to use. Literature exploring the use of online forums and online peer support platforms points towards these having clear benefits for health and wellbeing is vast (Hanna & Gough, 2016; Pendry & Salvatore, 2015; Smith-Merry et al., 2019), however, once again, not much is done in terms of their role for people with migraines.

One particular aspect that was noted in this study, is that, not many threads and comments in these pages are from men. Additionally, not many threads and or pieces of information consider how different the migraine experience might be perceived and lived specifically by men and women. Moreover, men are under-represented in terms of the imagery available in most of these websites. Looking at these websites through the lens of masculinity and migraines in men, which underlies this thesis, these are concepts that are only momentarily and briefly touched upon in the webpages included in this study. There are cases where pieces of information or forum entries acknowledge that migraines are not exclusive to women, however, tailored resources, threads or informative articles for men are almost non-existent. In fact, websites do not seem to provide much space for understanding gendered aspects of migraines. It is the core of this PhD to explore migraines through the eyes of men, who are an understudied population. However, there is space for research to be developed around other aspects of the embodied identify of migraines and how it is (not) represented in online platforms. That is, not much seems to be known (and shown) about migraines outside working ages, and in different cultures and ethnicities.

Owing to the nature of this type of research (i.e., based on publicly available data online), several ethical issues relating to data selection, collection, and reporting were explored throughout the development of this study. Due to the increasing number of people going online for healthcare related issues and utilising online support, Internet Mediated Research

(IMR) has the potential to be a growing force when it comes to exploring different aspects of ill-health. Particularly in areas relating to accessing healthcare information and seeking and providing social support for ill-health. However, having gone through the available guidance and reflecting on the nature of the data I was working with, I concluded that some reflexive action was required. In the particular case of Psychology, the BPS offers specific ethical guidance for IMR (BPS, 2021a). Although helpful to guide those conducting this type of research, the guidelines do not to seem to reflect the whole extent, variety, and complexity of what encompasses IMR. For that reason, even though this study is aligned to the BPS guidelines, I propose an adaptation of the principles shared by the BPS when designing, implementing or assessing an IMR study (BPS, 2021a). That is, the addition of two extra principles to the guidelines to better reflect the specificities of this particular type of research and broaden the spectrum of the type of IMR covered in the BPS's guidelines.

The first principle added was 'Transparency in reporting and referencing'. Transparency in reporting and referencing is important in any research. However, this takes different proportions in IMR. The internet is ever-changing, and therefore, information evolves, changes, and is spread within a matter of minutes and 'clicks'. Information and content accessed in a website today, might be completely restructured and changed the next day. Therefore, there should be clear guidance that every project using publicly available online data adopts a particularly strong and transparent approach to reporting and referencing in order to avoid failing to maintain its scientific integrity and value. Making clear where, when, and how the data was retrieved from a certain website or online platform ensures transparency and scientific rigour. In this study, and in line with this principle, I dated and referenced screenshots of the data used to report the findings and analysis, as well as provided a detailed overview of the websites used for data collection.

The second principle added was 'Personal stance and Reflexivity'. I believe that establishing and clarifying the author's personal stance in relation to their research enriches all qualitative research projects in the field of Health Psychology. However, in the case of research using publicly available data online, this concept becomes even more relevant. It is the duty of every researcher conducting research with people, and exploring human behaviours and perceptions, to reflect upon the implications of how the data is collected, handled, and ultimately used. Even more when it comes to publicly available online data. In this case, the websites used to retrieve information focus on supporting people with migraines. They are often run, mediated, and supported by volunteers who put their time and passion to helping others. Moreover, their platforms are used by individuals who seek information, support, and help for a serious condition that affects every area of their lives. I would argue that every researcher exploring ill-health and using online data should engage in an active and thoughtful exercise of reflexivity throughout the whole process and clearly state how and why they are using that data. It of vital importance that the whole process of collecting and gathering data is reflected upon and made clear and transparent.

Researchers conducting research using online data (regardless of its nuances and variety of approaches) should strive to contribute to improving and advancing the quality of the guidance available, as well as the terminology and concepts used to describe and address certain elements of their research. That is, as a collective group of professionals, we should all work together to reinforce the benefits of online based research, through establishing coherent, efficient, transparent and appropriate guidance for future research in this field.

Finally, even though there were occasions in online forums for migraines where men (and women) talked about the lack of male-specific resources, their experiences are still being overlooked. Online webpages and forums are undeniably very important sources of information and peer-support support. However, based on the types of resources they provide, and the way they establish their discourse, these do not seem to accommodate the fact that migraines are a condition that also affect men. It is of vital importance therefore, to give the voice to men who use these platforms in order to gather their experiences and views and understand how these platforms can be improved; and effectively respond to the needs of men who experience migraines. Only then, the migraine community can truly and fully be inclusive and able to respond to the different challenges that migraines impose to men. Throughout this thesis it has been highlighted how men might perceive, cope, and live with migraines in its own right, and not in relation to the experiences of women; this is translated through a representation of different studies adopting a lifeworld-led approach to understanding an illness condition (Todres et al., 2009; Todres et al., 2014). In the next chapter I will explore the perceptions of men who use these platforms and how they position themselves as male users of online resources (including forums and support groups) for people with migraines. I will give particular importance to understanding the ‘why’s’ and ‘how’s’ when it comes to male-users of online platforms for migraines.

Chapter 5 – Thematic Analysis of Men’s Use of Online Platforms and Communities for Support with Migraines

5.1 Introduction

As shown in the previous chapter, there is a great number of different sources of migraine information online, as well as different platforms through which people with migraines can communicate and seek support. Results from the previous chapter raised the issue that men do use these platforms, but might not actively engage with online communities as much as women. Moreover, it was clear that men are an underrepresented and often unacknowledged population when it comes to migraine websites. That is, the majority of these websites do not have male specific information for migraines and the number of female users in migraine forums and online support groups is much higher. Ultimately, in spite of the relevancy and detail on the information they deliver, and the effectiveness of support they offer, they do not provide much space for understanding migraines from a male perspective. Informative pieces and threads focusing on migraines from the perspective of men are almost inexistent.

In this chapter, I build upon those findings and attempt to explore a male perspective towards online communities for migraines. With this, I propose to give voice to men in order to better understand how they utilise these services, the details of the way they access these services for support, and their general opinion around whether these resources are providing adequate support for this specific migraine population. Following the overall narrative of this PhD, this chapters aims at understanding the migraine experience from a male perspective and within the context of online platforms for support. In other words, the key purpose of this chapter is to better understand how men with migraines navigate and use online communities (in the form of online support groups or fora) for people with migraines.

There are a great number of studies exploring the use and benefits of joining online communities for support with health-related issues (Coulson, 2005; Tyler & Williams, 2014). Particularly for men, who traditionally seek help less promptly and less often than women, online settings might work in favour of facilitating help seeking behaviours for more personal and sensitive issues in comparison to an in person environment (Collin et al., 2011; Mo et al., 2009; Galdas et al., 2005). The online world has the potential to be used as a platform to bring people together to share and learn about the experiences of other individuals facing similar challenges. In fact, one can argue that online platforms can be a cost-effective way of improving one’s ability to cope with an illness by providing channels for disclosure, empathic connection with other people, and information, as well as psychological adjustment to life challenges. These communities can be a very valuable way of providing emotional and social support, helping change health behaviours or minimising the risk of disease occurrence and progression. It has even been suggested that these communities can act as support groups. Here, people establish a shared social identity which makes these groups a unique and very characteristic setting for personal growth, self-reflection and mutual support (Rappaport, 1993). This particular perspective has been highlighted in recent studies focusing on online settings, where men-only forums appeared to give men confidence to seek support and advice, ultimately creating a community-like environment with collective knowledge (Hanna & Gough, 2016)

Support groups are commonly available for people experiencing general health related issues such as substance abuse like alcohol or drugs, or for more specific chronic conditions, like tinnitus (Pryce et al., 2019). Even though people join support groups for a vast variety of reasons, initial studies in this area claimed that the primary reason for people to seek and be part of any support group was the experience of a physical illness (Liberman & Snowden, 1993). Even though the research is not particularly extensive for headache related conditions, since their inception, support groups have been found to be an effective form of treatment (Gould & Clum, 1993) and are often considered as a supplement to other medicalised forms of care.

Currently, with more people using the internet in their professional and personal lives, online communities and groups are becoming increasingly popular. Especially under the current social context of the COVID-19 pandemic, things that have once been established solely in an in person setting (i.e., standard support groups), are now taking place at home. The COVID-19 pandemic brought an overwhelming increase of online platforms for social communications. In line with the previous argument, one can maintain that the use of online resources can be a very convenient and cost-effective way to allow people to engage in their own processes of care, from the comfort of their homes (Barrelo et al., 2016). In particular, to come together in groups or communities where they can share their ill-health experiences and see their questions and worries addressed by people who are experiencing similar issues, without needing to leave their homes or fit it around other commitments such as work and family (Chung, 2014).

As pointed out in previous chapters, male social and behavioural norms might play a role in how men seek health and social support for their migraines. Traditional behavioural norms such as emotional control and self-reliance might act as a barrier to seeking medical and emotional support when men experience any form of physical or mental illness. However, it can be argued that online communities and platforms might encourage men to seek support and disclose information that they may otherwise not feel comfortable sharing. Especially because due to the format of these online groups, people can express themselves anonymously and talk freely about health issues that they might perceive as sensitive or even embarrassing (Cooper, 2004). According to some research, this aspect of anonymity has the potential to encourage people to come forward and share their experiences in ill-health, and to remove fears of embarrassment or stigmatisation that could arise in a face-to-face setting (Turner et al., 2001; Chung, 2014).

Current literature on the use of online support groups has helped understanding the potential benefits of these settings and communities on how they can facilitate men's help-seeking behaviours. It has been found that in some cases, men rely on online groups to share their concerns and ask for help because of the anonymity provided by these platforms (White & Dorman, 2000). Phoenix et al. (2009) conducted a systematic review to explore whether the unique features of online support groups played a role in removing gender differences that might exist in face-to-face health related communication and support seeking. Even though their results were inconclusive, they highlighted the fact that in some instances there were clear differences in how gender specific and mixed gender groups work. For example, the way the communication flows in a men's group was different to women's and mixed-sex groups. Men only groups were found to focus largely on practical tasks and information. Phoenix et al.'s (2009) systematic review seems to suggest that men and women have particular styles and approaches to communication in health-related online support groups and communities (similar to what happens in a face-to-face setting). However, further research into the specificities of support and how it is perceived in the context of online platforms is needed.

In the particular case of migraines, there is a significant gap in research when it comes to understanding what online communities might give to people with migraines. Especially if we focus on the male population, as highlighted in the previous chapter. Therefore, this study attempts to contribute to filling that gap by once again, placing men with migraine at the centre of the debate. Understanding how men navigate these platforms and communities for support could shed light into designing more efficient online interventions to meet the needs and communication styles of male patients. Moreover, this would allow us to have a better understanding of migraines as an illness. We have seen how useful and beneficial online platforms can be as elements and/or providers of support, however it is still unknown how this applies to men with migraines. In this chapter, I will add to the knowledge base by examining how men with migraine use online platforms as communities for support.

5.2 Research questions & objectives

The key objective of this study is to build upon findings from previous chapters and further explore the role of online resources for people with migraines. In previous chapters, data analysis highlighted some aspects relating to how men navigate these platforms in a distinct way. Ultimately, the analysis of the data gathered in the previous chapter pointed towards the need to dig deeper into how men in particular make use of online settings for support with their experience of migraines.

In this chapter, I gathered the experiences of male users of online communities and explored what being part of online communities for migraines means for men. Additionally, I focused on how men navigate through the online world of migraine support and what makes online groups effective. Therefore, the research question at the heart of this study is ''what role do online communities for migraines play in how men experience and cope with their condition?''.

In addition, building on findings from the studies reported in previous chapters, the following questions were also touched upon ''how are online migraine platforms, online support groups and forums in particular, being used by men with migraines?''; ''what is the role that online platforms for migraines play in the overarching structure of support in men with migraines?''; ''what are men gaining from their involvement and participation in online support groups and forums for people with migraines?''

5.3 Methods

5.3.1 Approach

A key factor of my approach to this specific study was the use of technology as a means to collect data. This study was developed during the COVID-19 pandemic where social contact and in person interactions were restricted. For that particular reason, I had to adapt the ways in which I collected data in order to fit and comply with these restrictions. This is a qualitative study using semi-structured interviews, for that reason, this was internet mediated research using online methods to collect data.

For this study, participants were given the choice to share their experiences by Skype, real-time text-based methods or asynchronous email exchanges. It is important to reflect upon this and how it could have acted as a barrier and facilitator to participation. That is, it is legitimate to argue that in order to take part in this study and share their experiences, participants would have had to have some basic understanding of technology. Some might argue this could have excluded those who felt uncomfortable with online technology, but since the study was set within the context of online communities, this was not considered a problem or barrier. Therefore, I aimed to study and understand a subset of a specific population who are expected to have a basic understanding of technology; in other words, men who navigate the internet to obtain support with their illness. By offering different platforms through which participants could take part, I believe it has enabled me to recruit a larger number of men and reach people who otherwise would have not been reached. Not only because of how accessible it was to take part in the study (people could do it from the comfort of their homes) but also because of the fact that (if participants wanted) the interview could take place without me ever seeing their face (for instance, if the interview took place through an email exchange, or on an instant messaging platform). I believe this was a particularly important and effective vehicle to reach this specific population.

5.3.2 Design

Semi-structured interviews were conducted via different platforms and through different means. Participants were given the option to be interviewed via Skype, as well as real-time text-based methods (such as Facebook Messenger, using an account created for the purpose of this study) or asynchronous email exchanges (using an email address created for the purpose of this PhD).

An interview schedule was prepared to understand how participants navigate online platforms for support with their migraines and how effective these are as providers of support. Key questions were asked about their participation in online support groups and/or online communities for their migraines. Moreover, participants were asked about their first impressions and requested to draw parallels in terms of support they seek and receive in person and online, as well as different layers of support they might seek and experience. The objective was to understand what online communities and online resources are giving to these participants that different types of support are failing to provide. Lastly, participants were asked to reflect upon the role of masculinity and how it relates to the use of online platforms for their migraines. They were asked to position themselves in relation to specific elements of online communities and resources.

5.3.3 Ethical approvals

Before the start of the study, an application to conduct this research was submitted to the Life and Health Sciences Research Ethics Committee (Aston University) and given a favourable opinion. An amendment to broaden the range of places where we posted and shared our advert poster was submitted and also given a favourable opinion.

Individual written consent to take part in the study was obtained from all the participants before data collection. Due to the nature of the study (adapted because of the COVID-19 pandemic and restrictions in face to face meetings) participants were given the option of signing their consent forms electronically. Additionally, during the interview, participants were informed of their right to withdraw at any time, and they were assured of the confidential nature of the interview. For this purpose, I stored all the data (i.e., recordings and transcripts) on a computer with a strong password during the whole process. Moreover, these data will be kept for up to six years to facilitate publication. No personal details of the participants were shared or made public at any point.

Each individual participant taking part in this study was given a pseudonym which was used in all stages of this study and attached to all verbatim quotes. Any element, name or word used in the interview that could be used to identify a participant was coded or omitted. These codes were used throughout the whole study.

5.3.4 Recruitment process & sample

This study is based on a Thematic Analysis (Braun & Clarke, 2006) of semi-structured interviews with 13 participants. For this study, I looked to recruit men, aged 25 to 55, who live with migraines or have experienced at least one migraine episode in the past. In addition to this criteria, I looked to recruit men who were currently using online resources (online support groups, forums or online communities) for migraines or have used them in the past. A purposive sample of 13 for whom the research question was significant, was recruited.

This study employed a wide and heterogeneous set of recruitment strategies. The initial step in recruitment was to contact administrators and moderators of migraine specific online support groups, websites and forums for men with migraines and ask them to post and disseminate our study advert in the group. Additionally, I opted for sharing and posting the recruitment poster on our personal social media accounts (Twitter and Facebook), and a study specific Facebook account was created to advertise the study.

Throughout the recruitment process, I kept in close contact with the National Migraine Centre – which played a key role as our primary recruitment site for the study in Chapter 3. Additionally, *Healint* (the owners and developers of *MigraineBuddy* -

https://migrainebuddy.com/ - which is a migraine and headache tracking app with more than 3 million downloads in Apple and Google store worldwide*)* contacted me in order to develop a collaboration agreement based on a Memorandum of Understanding (MoU), for them to support our study and recruitment process. Terms were negotiated between *Aston University*, myself and *Healint.* Here, it was established that I would provide a high-level anonymised summary of the participant responses and respective analysis to *Healint*, as well as acknowledge the organisation on publications and presentations that include data from this study. Establishing this MoU was particularly important as it represented an engagement between this research, its findings, and the community being studied. The signed MoU is available in *Appendix 3.* Recruitment was not restricted to people who contacted us through *Healint* and was open to those using other sites, apps and platforms. Nonetheless, as per our MoU, the results from this chapter will be shared with them and utilised to inform their approach to male-specific content on their app, website, and online group chat for men with migraines.

All participants who took part in this study contacted us voluntarily and fit the inclusion criteria stated above. All participants identified as men, have used online resources (including online support groups) for their migraines and were aged 25 to 55. One of the participants (pseudonym Nick) took part in the study in chapter 3, but also wished to take part in this study. Another participant (pseudonym Samuel) not only is an active member of different online support groups for migraines, but is also an administrator for various groups. Including a men-only group for migraines. Lastly, of the 13 participants included, 10 were white British, one Eastern European (pseudonym Patrick), one white American (pseudonym Daniel) and one was Asian British (pseudonym Andrew). Moreover, seven interviews were done over email, one over the phone, three over Skype and two over Facebook Messenger.

5.3.5 Data analysis procedure

All data were analysed by means of Thematic Analysis (TA) described by Braun & Clarke (2006). This method of analysis has successfully been used in similar studies (e.g., Bennett & Gough, 2013; Gough, 2016). This method of analysis was chosen because TA allows us to explore and identify patterns in people's behaviours and perspectives towards a certain phenomenon. In this case, patterns in relation to the use of online communities by men with migraines. In line with our research question, as an analytic method, TA enabled me to determine the factors, perspectives, and lines of thought that might underpin the use of online resources and groups by men with migraines.

In the wider context of this thesis, my approach to TA is deployed with the purpose of understanding and reporting experiences, meanings, and the reality of the lives of my participants (Braun & Clarke, 2006). Therefore, in this programme of work, TA is used to explore a subset of the lived experience of migraines. That is, to explore a branch (the experience of navigating online platforms and communities for support with their migraines) of the wider tree (the experience of living with migraines as a man).

In the context of TA, and considering the overall work of this PhD, the collection of 'themes' present in this chapter reflect a level of 'patterned meaning' generated from the data set (Braun & Clarke, 2006). It is important to note that, these themes are more than a mere label of a pattern reflecting data items with high prevalence across different interviews; or a gathering of data items that have shown to be repeated the most across several interviews The themes generated are a representation of my analysis of different elements of the data. These elements constitute key aspects of the experience of my participants and how they use online platforms and communities for support.

My approach to TA is aligned with a semantic positioning, where the key is to provide a more detailed and nuanced account of a group of themes (Braun & Clarke, 2006). These reflect an aspect of lived experience within the life context of my participants, that was captured and is relevant to the research questions and ultimate purpose of the programme of work of this PhD (Braun & Clarke, 2006). Additionally, I position my approach to TA within an abductive stance (Thompson, 2022). That is, it attempts to find the middle ground between inductive and abductive stances (Braun & Clarke, 2006). In other words, this focus takes up a position which attempts to understand findings by considering how they might best align with existing theoretical accounts, rather than by either formal testing of existing theory using deduction or developing new theory using induction (Mantere & Ketokivi, 2013). Thus, this chapter offers an understanding of lived experience and situates it as one important component contributing to our collective knowledge about men's migraines.

In order to do this, I followed the guidance available in Braun and Clarke (2006) in a form of a six-phase model.

Immersing myself in the data collected was the first step of the analysis. In other words, interviews were transcribed, read, and re-read in order to become familiar with the data. Due to the fact that some interviews took place via email or an instant messaging service, these interviews were already transcribed. Initial thoughts and observations were recorded alongside this process. With the research question and research objectives in mind, I registered and labelled all relevant elements or relevant sequences of elements in the data set – this was done for each individual interview.

After the initial practical process of coding each interview, I started identifying patterns and common traits across different interviews. In cases where codes were similar, or translated similar concepts, perspectives or behaviours, these were synthesised. This was done for all the codes which had similar 'features'; similar codes were clustered together, and codes which were not relevant to the research objectives were not included. On the other hand, codes that were relevant to the research question but illustrated different nuances or stark differences to the overall clusters, were highlighted and included in the analysis.

After generating the initial set of clustered codes, I went back to the interviews to review whether my interpretation of the data was appropriate in relation to the participants' perspectives and whether my analysis of the data was coherent and relevant to the research question. Finally, the clusters which were aligned to the research question were defined into themes.

Definitions for each theme were written down and once again reviewed in relation to the interviews and my initial thoughts and observations.

5.4 Results

Through my analysis of the 13 interviews, three themes were generated in order to translate my interpretation of the views of my participants. These themes are*: 'E-support: feeling supported through a screen', 'One size does not fit all: the jigsaw pieces and the filter for informational support'* and '*Establishing the terms & conditions: the rationale for creating a men-friendly group*. These themes touch upon different aspects and nuances of how men navigate through online platforms to seek support, and how they perceived that same support.

Theme 1. E-support: feelings supported through a screen

In this theme we will navigate through different perceptions and meanings of support and how these relate to online settings. Here, we will see two nuances of support. On the one hand, emotional support, provided by those with similar experiences, eliciting a warming sense of community and togetherness. On the other hand, informational support, related to receiving and sharing practical information about migraines and overall coping mechanisms with those who have similar experiences.

As seen in the previous chapter, online settings are useful and accessible as means to obtaining information about migraines. However, especially in platforms where users can interact between themselves (online support groups and forums), these can also be a great way of offering and receiving emotional support. As one participant stated, at its core, the true meaning of providing support to someone experiencing migraines *''goes beyond just writing a prescription" (Steve).* Which clearly hints to the existence of different layers of support, as well as the limits of the doctor-patient relationship and reveals the complexity of what it truly means to feel supported.

Often, participants elicited the importance of the sense of belonging and community-like interactions within online communities, and how that goes in line with 'feeling supported'. Living with migraines, as seen throughout this thesis, might result in feelings of isolation and make people feel like they are not being understood. Coming together in an online community has been seen to help minimise such feelings.

> *''It feels like we are all in this together I don't feel like an anomaly in the groups as I'm already one in real life" (Stanley)*

Here, Stanley makes a very interesting distinction. The way he described his feelings towards online groups in comparison to 'real life' is full of meaning. He revealed a sense of belonging and normalcy associated with online groups for migraines, in contrast to real life. In real life, his migraine makes him feel like an 'outsider'.

From the accounts of several participants, being part of an online community of people experiencing a similar condition, where individuals come together as one to help and support each other, transmits a feeling of togetherness; of sharing purpose. Finding people who are in similar situations in life, was one of the most common reasons mentioned for these participants to join online communities '*'I joined because I was looking for others who deal with similar health issues." (Mark).*

Not feeling alone and coming in contact with other people with similar experiences is key to what some participants perceived as support. Online communities offer the stage for people to find other individuals that are going through similar experiences and struggles, and support each other.

> *'I could finally actually discuss the illness on a level playing field with people that truly understood what I'm going through, I could talk to people on my level without dismissal but also without getting 'oh poor you that's awful', it gave me empathy rather than sympathy which I greatly appreciate" (Stanley)*

It is worth notice how Stanley emphasises his perception of migraines. In this extract, the fact that he highlighted aspects of 'discussing the illness' in relation to his migraines and online communities was particularly relevant. For Stanley, these communities provide a sense of belonging and legitimate his migraines, to a point that he feels that people are truly and deeply on his level and can clearly relate to his experiences. This enables and empowers him to use the language of illness; a language that is understood, accepted, and validated by all within the community.

Online groups for people with migraines offer the setting for people to connect to each other on a different and deeper level. One participant elaborated on this 'ability' to being able to connect with people who are going through similar health issues.

> *''it's a shared connection isn't it? If somebody else understands, you know (…) it's a shared suffering isn't it so sometimes it just helps when you're feeling pretty fed up and I think also because migraine, when you're at the level of me and other people who've got a migraine you know it impact your life so severely that it's very hard to see a way forward and sometimes getting a little bit of encouragement or feeling useful (yeah) in some way is just really, very very helpful'' (James)*

There is a message underlying James' statement and the way he sees online communities. Biologically speaking, migraines are not life-threatening, however, they threaten one's quality of life, wellbeing and mental health. Migraines affect all aspects of one's life and James conveyed this by emphasising how shared experience facilitates connections between people with migraines in online communities.

Ultimately, this phenomenon of belonging to an online community with shared experiences, understanding, and even values, is what matters. Here, people have shared purposes, which ultimately results in a community-like atmosphere where individuals come together as one. Consequently, this helps normalising living with migraines, and normalising those who live with them. *''It helps to normalise having chronic migraines and realising I'm not alone with it.'' (Steve)*.

> *''I think the biggest role it has is in making it a less isolating experience. It serves to validate that the challenges are real (…) When someone with migraine is there to listen, or to share their own experience, it helps us see that our pain is valid and it's real. (Mark)*

Participants often talked about validation, and how these online communities allow them to feel validated in their illness. That is, finding and interacting with people who experience similar symptoms allows people to feel less isolated and less '*different'*. Ultimately, it allows them to feel normal.

Participants also explored the wider value of these communities, beyond the specific aspects of emotional support depicted above. Steve in particular, talked about how these groups act as a catalyst for him to talk about his migraines at work. Hearing about other people experiencing the same problem, and how they managed to overcome it, was enough to empower him to start some important conversations at work.

> *''I would also add that migraines has a stigma attached to it. It can be exploited to 'bunk' off work which can also make it difficult to share problems with migraine. Online groups would help with opening up outside of groups you have to work with or interact daily with which would also help*
> *I was very reluctant to mention how bad it was for me at work (especially with a very challenging manager!) And online support opens up avenues to support with something that has just as many mental impacts as it does physical'' (Steve)*

Not only are these groups helpful for the personal migraine experience, but they also help on a more social and professional level. That is, through experience sharing, some participants admitted feeling empowered to address certain issues related to migraines at work or with their family and friends. These online communities offer people the confidence to communicate the real impact of migraines to others. Once again, this highlights the potential of these groups, but also how complex and multi-layered this phenomenon is. For example, Daniel talked about how receiving support from online communities differs from the type of support he receives from his family and loved ones.

> *'' [regarding receiving support from family and friends] What I mean is, that those people support me in many ways emotionally, psychologically, financially, etc. But there are some areas where they can only sympathize as a love one. Maybe it's related to the distinction between empathy and sympathy. (…) There is comfort/validation in knowing that at least someone else feels this, and deals with this. Otherwise, we wonder if we are going crazy. We feel alone. (Daniel) ''*

From Daniel's account, one can see how online groups might be offering a particular aspect of emotional support that one cannot obtain from anywhere else, not even from family and friends. Additionally, they illustrate the need to talk with people with lived experience. Being amongst and talking to people who also experience migraines seems to give these participants a different level of support. One participant linked experience sharing to '*creating a different kind of bond/friendship'.* A type of bond that according to some participants is naturally achieved in these online communities for people with migraines.

> *''I find that I've slowly become more aware of other people with migraines. Sometimes it comes from unexpected people, but it creates a different kind of bond/friendship.'' (Conor)*

This *'different kind of bond'* seems to be at the heart of what participants value in terms of emotional support. However, not only did participants talk about feeling supported through experience sharing, feeling validated and sharing a sense of community, but they also shed a different light into what it means to feel supported. Often, people highlighted how important online groups are for seeking and receiving practical information to coping and living with migraines, and that in itself, means support.

> *''[Through online communities you] may end up discovering something new. Many of us have been told numerous times (by numerous people, including the medical professions) that we don't have migraines, but we have something else, or that they can't help us, or that we ate something wrong, etc, etc. (…) And, chances are, there is something we haven't tried that may help'' (Mark)*

All participants in one way or the other mentioned the importance of online resources as a vehicle to obtaining information about migraines. For instance, Nick stated '*'if I need specific information I'll initially go online. Also, if I want to know the latest news on migraine related topics I'll look online.''.* One of the clearest commonalities across different interviews was the sort of information these participants value when going online for migraine related issues. Here, receiving practical information for their migraines was key.

> *''I suppose what really makes the threads helpful is when there is something that I act on immediately, such as a product, vitamin, supplement, food, etc. Even some new research would be useful. Even taking part in research such as your research. It all contributes to the bigger picture for all those that suffer in silence … and hopefully it will help at least one other person.'' (Conor)*

Overall, Samuel captured the views of the majority of the participants: *''the online community, plus google searching are a wealth of information (…) doctors cannot be completely up to date on migraine treatments etc. ''* Interestingly, not only did Samuel highlight the wealth of information available online, he also measured this in comparison to the informational support general practitioners, which are normally the first port of call, can provide. Other participants also compared the value of the information they get online to the information they receive from their GPs. As helpful as GPs and other healthcare professionals can be, participants talked about how these online communities and platforms go far beyond the sort of informational support they would get from their doctors.

> *''there is a difference between what a medical profession can give as much as they'd want to but they just can't and I think you do need a place where you can explore a little bit more*

where you have got the time to be able to understand yourself and others and come to your conclusions that way and I think you can do that (…) I think it's really important that you do have that medical side of things, which you need, but you also, and I'm not saying you don't get this from GPs but you do need an empathetic approach in a way you can explore your own feelings a little bit. I think that is really really important, and in a very small way I think that's what you can get from some online communities'' (James)

Here, James offered a very valuable perspective to understanding the true extent of what people can get from these communities. Ultimately, when it comes to information, online communities (and general informational platforms) are a place for people to understand themselves in relation to their migraines. These communities are often a place of expertise. That is, platforms for people to share and ultimately have contact with expertise by experience. This is a key difference to what a healthcare setting can provide. In addition, some participants highlighted another relevant aspect of these communities. Not only does the information gathered online have value in itself, it can also be an extension to the information that is gathered from their GP's and headache specialists.

''my online community supplements structured medical advice.'' (Mark)

For Nick, the information he gathers online, although valuable, needs to be validated with medical professionals. He highlighted how he recognises the value of expertise by experience but believes sometimes this is not enough.

''online support to me is high level, helicopter view (…) it is not a substitute for proper medical diagnosis and treatment.'' (Nick)

Ultimately, this link between going online for informational support and seeking migraine information from a GP or specialised physician was very much present in every interview. For Daniel for example, looking for information online and seeing a doctor for his migraines should not be seen as 'one or the other' type of scenario. Daniel explicitly pointed out how living with migraines might require people to go to different places in order to seek out support for different needs.

''They aren't mutually exclusive. You need help from both. Sometimes I've found more help and support from healthcare professionals, but other times more help from non-professionals. Example of the former: 0-A doctor who recommends a combination of drugs that helps with migraines; Example of the latter: 0-Members of the church I attend, offering emotional/psychological support. 1-A friend or stranger who mentions a migraine treatment they had tried or heard about. (Daniel)

However, one of the biggest advantages of forums and support groups is that, for being online, these communities are 'places' that are accessible and available at any time of the day. As one participant explained ''*it's a place where people can air concerns in the middle of the night if they need to.''(Mark)*. This is particularly important due to the unpredictability of migraine symptoms and feelings associated with them. Moreover, these settings and the way they are built and established, do not fit into the usual five day a week, 9 to 5 opening hours of a normal primary care surgery. Which combined with the unpredictability of migraines and the responsibilities of adult life makes online communities incredibly convenient.

In this theme we have seen that going online to share and hear about other people's experience might give people a sense of feeling understood and belonging to a community. The feeling of togetherness and 'everyone in the same boat' is extremely important to these participants and that is a key aspect of feeling supported. Shared experience means having a 'different kind of bond' with other people. Moreover, online groups are a vehicle to pursue and obtain information about migraines as well as different ways of coping and living with this condition. These communities are places where people can share and get expertise by experience, which is a key different to medicalised support. People also highlighted that this information can be a valuable addition to the information they receive from their GPs.

Ultimately, feeling supported through online platforms seems to be a combination of feelings of belonging, as well as receiving useful information that might improve their migraine experience. These feelings of support and the type of information they can obtain is not easily accessible anywhere else.

Theme 2 – One size does not fit all: the jigsaw pieces and the filter for informational support

As seen in the previous theme, the online world of migraine communities can act as a prime setting for obtaining information about migraines. This theme builds upon the argument developed above and focuses on the participants' views towards the usefulness and relevance of the migraine information they come across online. For being such a subjective and personal condition, often, the information found online is not relevant for all those experiencing migraines. It is not a case of 'one size fits all'. This makes receiving informational support quite an intricate phenomenon. Therefore, in this theme I touch upon how these participants view the quality of the migraine information available online as well as how they navigate and make use of the wealth of information they find in these groups and forums.

A particular characteristic of the migraine experience is that it is common for different individuals to experience different symptoms. As we have seen in previous chapters, migraine symptoms vary from person to person and therefore, not all treatments and coping mechanisms are effective for everyone. This seemed to be a key aspect to how these participants navigated and made use of the information and informational support they sought online. Accessing migraine communities for migraine information means finding different types and layers of information, some more relevant than others.

Conor talked about how he often has to sail across different types of migraine content online in order to find what is relevant to his particular experience. He shared the analogy that going online for migraine information is like having to find different pieces in different places to complete a jigsaw. This image illustrates Conor's experience of looking online for information about his migraines.

> *''In general, I find the threads don't specifically relate exactly to my conditions/symptoms so I find myself picking fragments of useful information from here and there. Then I have to try fitting them together like a jigsaw. There always seems to be pieces missing or the pieces fit another jigsaw. What I have to remember is that there seem to be multiple types of migraines, each can have different symptoms, and each respond differently to treatments." (Conor)*

The metaphor brought up by Conor during the interview was full of meaning and showed how complex living with migraines and seeking support for it can be. According to Connor, it is as if everyone who goes online for support with their migraines are navigating different platforms to find pieces for their jigsaw. Sometimes they find relevant pieces, other times they do not. However, pieces that might not be relevant to someone's jigsaw, might be crucial and life changing for someone else's. This is the complexity of migraine support.

This feeling was common to other participants. There was a unanimous understanding that there is a great number of resources available online and each individual has to actively look and search for what is relevant to them. Their jigsaw pieces. During his interview Patrick reiterated how '*'There is so much information on the internet, that it is impossible to find relevant information".* Mike also captured this element by stating that *''it is going to be up to each consumer to decipher relevance/truth/etc."*

Mark's view is particularly pertinent. Not only did he sum up the general feeling of these participants, but he also extended the argument by attributing agency to 'the consumer'. That is, the information is there, it is then up to those who want to access it to find what is relevant for their particular case. From this perspective, one can picture the online world as a supermarket with endless aisles of information and it is up to each customer to look for what they need and acquire that ‘product’.

Nick also touched on this idea and offered an even more elaborate perspective. For him, the more a person navigates and gets involved in online migraine communities, the more they develop strategies to look for and find what is relevant and reliable.

For Nick, in order to refine one’s ability to find relevant migraine information online one has to develop a filter. *‘’I think the more you read the more you know/understand and therefore you generate your own filter.”* According to Nick, this comes with time and experience.

> *‘’ when I started I was reading everything to increase my awareness (and the negative I deemed as useful) but then as my knowledge increased and I started to work out what was true and what was not. (Nick)”*

This is analogous to becoming an expert. That is, the more someone looks online for information that is relevant to them, the more they will find. Consequently, this enables them to develop resources and knowledge for their day-to-day experience and migraine scenarios. In a way, reinforced by the knowledge they gain from their day to day lived experiences of migraines, this reflects the process of becoming an ‘expert by experience’. Not only in relation to migraines as an illness, but also in relation to online sources of information for this condition.

Based on this perspective, there seems to be a learning process associated with it. In fact, this was common to other participants. Andrew also talked about this detail and how with time and experience people create their own personal filter.

> *‘’ It's just trying to find a way to sort of knowing about it really and knowing and finding sort of 'okay this website is reliable'” (Andrew)*

In exploring this aspect a bit further, I identified some differences across interviews in relation to why participants seem to have to filter out information. Firstly, because of the subjectivity of the migraine experience, and secondly, and maybe more predominantly, this is due to the fact that the majority of the migraine content available online is shared by and for women. On the latter, Nash talked about his personal experience,

> *‘’most of the articles you do get tend to be from a female's perspective, because...there was one this month with the Migraine Trust and there was a female lady there and she has the problem with the visual sort of thing, and it was quite reassuring actually you know, to read about her case study and that there are some similarities but it does...I tend to think that it is more sort of biased towards a female perspective” (Nash)*

This point was elaborated further by other participants. The fact that the majority of content online is for and from women might make it relatively difficult for men to find usefulness in it. That is, the information being from and for women makes it resonate less with men and therefore threaten its utility for them. As a man, joining online communities or accessing these online platforms in order to find useful information, often means coming across information and tips that are from a female perspective and therefore not applicable.

> *‘’they are at times heavily influenced by female causes of migraine. (Steve)’’*

Andrew also talked about how navigating these platforms as a man might make it difficult to find relevant information. Since the majority of the migraine information online is not ‘male-relevant’, being a man can ultimately act as a barrier to obtaining informational support for migraines.

> *‘’ it sounds horrible but it seemed like a lot of people were women (…) Women yeah, and the symptoms wouldn't match because it used to be like 'when I have my periods and this and that' and 'it stopped when I had my children' hahaha (…) yeah... all of this is sort of irrelevant really (Andrew)*

Moreover, through exploring finer details of people’s experiences of having to filter out information, another relevant aspect was highlighted. Some participants brought up the fact that some information found online might be relevant to people living in one country compared to another. That is, the lack of online resources built for and from people from specific areas or countries can often make finding relevant information more complicated. This is particularly relevant when this information is about specific treatments, medications or how to navigate healthcare systems.

> *“all of this is sort of irrelevant really, especially if you're an American they have different machines and stuff like that” (Andrew)*

The fact that the common approach is to have general discussion forums and groups rather than local online communities might make finding relevant information harder.

> *‘’the problem that I have with all of the fora is that living in Ireland a lot of the drugs that are being recommended aren’t available here (okay…that makes sense) half of them are being licensed but no one is actually manufacturing them here (George)’’*

In order to address this issue, one participant suggested creating local online platforms and communities where people from the same region who use the same healthcare facilities and have access to the same treatments can come together and share information. Establishing a local network of sex-specific online communities for people with migraines would mean creating a platform for people to share information that is relevant to everyone in the community.

> *''if there was like a local support group (…) either face to face or a local support group, either WhatsApp or online with people locally who basically also use the services that you also use. Because there's no point in talking about "oh I can't get this I can't get that" but you're based somewhere else whereas if you're based in where I am […] then people can sort of share their...and then whatever was going on in the forum could also get fed back, or if somebody was from the hospital from neurology was also involved and one of the specialist nurses then whatever scenes were going on could be fed back (Andrew)''*

This theme highlighted different aspects that my participants experience when they go online for obtaining informational support for migraines. We have seen how coming across different types of information online can be perceived as looking for a missing piece of a jigsaw and might require users to develop a filter. This filter comes with time and experience and enables people to easily understand what is relevant for them, and which platforms are more prone to have this relevant information.

As a man with migraines, it is inevitable to develop a filter not only due to the subjective nature of migraines, but also because of the information available online being heavily created from and for women and not always relevant to men. Moreover, the fact that the majority of online support groups are not country/region specific, makes the task of getting tailored and local support much more complicated. People with migraines, men in particular, have multiple and differentiated needs. As seen here, these require multiple sources of support. Ultimately, this adds to the argument about where this support should come from. Especially if local GP services are failing to provide adequate and tailored support to these patients.

In the next theme I follow up on the discussions around usefulness of online resources for men with migraines and explore the accounts of my participants in relation to the key aspects that make an online community or group helpful and supportive for men with migraines.

Theme 3 – Establishing the terms & conditions: the rationale for creating a men-friendly group

This theme was generated as a result of several accounts about what men value in terms of online communities for support with their migraines. All participants touched upon this subject and shared their personal perspectives around the lack of men-friendly, informative, and supportive online groups and forums. In this section, I explore and dissect key elements that men believe contribute to making online communities more accessible, welcoming, and informative for them.

One of the most appreciated aspects of online platforms is how accessible they are. Several participants mentioned how easy it is to express thoughts and share emotional aspects of their lives in an online setting compared to in person. Samuel touched upon this argument and shared is personal experience.

> *'' For me, I find it easier online to express myself online then I do in person. It gives me a chance to formulate thoughts and feelings before making any statements etc. I think men in general would find it easier online. Men are wired differently when it comes to feelings etc I think.'' (Samuel)*

Here, Samuel expressed the fact that he finds it easier to express himself online. Not only did he talk about his personal experience, but he also shared is opinion on the fact that other men might relate to finding it easier to open up in an online setting. Additionally, according to Samuel's account, there is a level of convenience associated with online communities that face-to-face groups might not have. Establishing an online migraine group, means offering men a safe place where they can express themselves at their preferred time in a safer and more comfortable way.

> *'' For some people, online is the ONLY acceptable solution. They may be house-bound, or without transportation, or can only allocate time late at night or after the kids are in bed. For some people, online might be preferred for other reasons like they feel safer or just more comfortable. And recently with the global pandemic going on, think of how much MORE valuable an online group would be. Definitely online groups are viable and useful even if face-to-face groups are available.'' (Daniel)*

Especially during the worldwide lockdowns and social restrictions due to the COVID-19 pandemic, which affected the way people interact and communicate with each other, online groups seem to be particularly valuable. With restrictions to the way people seek and assess support for ill-health, Samuel pointed towards online group as a way to fill this gap.

When elaborating on his accounts, Daniel inevitably made comparisons between face to face and online support groups. The nuances and different levels of effectiveness of both settings were also touched upon by other participants.

> *''I'm not sure if face to face groups would work to be honest as we suffer from a lot of paranoia regarding being able to show up for events and then the guilt hits us when we can't if we are in too much pain to make it (Stanley)''*

Stanley's point goes in line with what we have seen above - online support groups have the potential to be effective and convenient tools of support for men with migraines. According to Stanley, the fact that people can access the group when they want and interact with it the way they want is an extremely positive aspect. James also shared this opinion. For James, who admitted being an ''*anxious person*", he does not ''*always like to comment just in case I get something a little wrong or upset somebody.''* And therefore, being able to feel supported without having to interact directly with the conversations is an aspect he values.

When developing the argument about what makes an online group effective in supporting men with migraines, participants talked about anonymity and privacy at length. As we have seen in the previous chapter, there are different types of online groups and forums. That is, private groups where people need to add their personal details to interact with it (or do it via their social media accounts); or public groups, where any user can see and interact with threads without creating an account.

Two participants in particular, Stanley and Nick, shared two different views on this subject. On the one hand, in Stanley's opinion, engaging with a public group, and clearly making his identity public, allows friends and family to realise that other people also struggle with migraines. He believes that allowing people to identify him and read his comments and interactions in an online group (in this case on Facebook) validates his condition to a certain extent.

> *''Oh a major plus side is Migraine.com on Facebook is public so friends that would normally dismiss my illness can see others having the same issues if I just like the post never mind comment, I not unique or complaining real people out there struggle with it'' (Stanley)*

On the other side of the argument, Nick talked about his preference for private groups. Engaging in a public forum and revealing his identity might mean friends and family are able to identify him and read his posts and get frustrated by seeing him '*complaining and moaning all the time'*

> *''I think I mentioned it in one of my answers that if a Facebook group is public it means my posts will come up in my friends and family's feeds. My friends and family know my issues and I don't want to be seen to be continually moaning, even though internally I might be. So if I keeping 'moaning' in a public forum my friends and family will soon get frustrated with me. '' (Nick)*

In his opinion, the way he engages with a group depends on whether it is private and whether close family and friends will see his interactions. In a way, a private group makes him feel free to express his true struggles without the worry of being judged.

> *‘’ A private group will only have migraine sufferers that have subscribed and therefore are happy to see people posting/moaning about their migraines. And friends and family are excluded. So I’m happy to post on these groups.” (Nick)*

Similarly, Mark highlighted how anonymity is relevant to avoid that people talk about specific cases they know *‘’Another important rule, in my opinion, is anonymity, ie: no gossip.(Mark)”.* This makes assessing the benefits of open versus closed groups a pivotal point in the discussion about online communities for migraines. In spite of some participants (like Stanley) preferring public forums, when it comes to online support, closed communities that ensure people can remain anonymous seemed to be preferred by the majority of the participants. As we have seen from the perspective of Stanley, there might be benefits associated with both approaches. However, the key aspect is having an environment that is perceived as a safe space to share their struggles and personal experiences. A safe space where there is no judgement and people come together to support each other, was for the majority of participants easier to achieve when remaining anonymous.

Through sharing his opinion about this issue, Steve added a different layer to ‘feeling safe and judged’ when seeking emotional support online as a man with migraines. For him, a key barrier to actively participating in an online group is the fear of facing judgement. He linked his worrisome feelings to being a man experiencing a condition that is more common to women.

> *“I think being a male and experiencing chronic migraines is a double edged sword. I think because it is more common in women then when they suffer it may be easily dismissed as hormonal or the like whereas with men as it isn't so common it may be taken more seriously at first. However a male (speaking for myself before I generalise the population) it's harder to admit/acknowledge my pain and seek help for it. In regards to participating online I'm more likely to just read rather than actively participate as I'm worried about potentially facing judgement for the causes or treatments taken (Steve)”*

It is particularly important to dissect some elements of Steve’s view. One the one hand, he inferred how the standard approach towards someone with migraines is to dismiss their symptoms. Especially when these are medically unexplainable. From his perspective, ‘hormones’ are an element that can easily be used as a ‘scapegoat cause’ to explain migraine symptoms in women, when there is no other clear and identifiable cause (which is often the case). However, for Steve, this is relatively more complicated for men. That is, not only did Steve infer that medically unexplained causes for migraines are generally dismissed by ‘scapegoat causes’, he also highlighted how some of these ‘scapegoat causes’ are not applicable to men, which makes the root of migraines even more difficult to make sense of by men.

On the other hand, Steve shared that he found it difficult to disclose his pain and seek help due to fears of being judged; an experience that might be shared by other men, and that might help explain why men do not actively participate in online communities for support with migraines – as seen in the previous chapter. Following this point, participants elaborated on some particular points they value in online communities. Here, practical tips and suggestions people can act on seemed to be what participants valued the most. Conor highlighted how important it is for him to get something that *''would be of benefit to the migraine sufferer''.*

''I am not sure what specific elements attracted me to specific websites and forums but perhaps they went further than just talking about the condition and had additional resources, materials, etc that would be of benefit to the migraine sufferer (Conor)''

For Conor, an effective group is one which goes beyond simply providing a platform for people to share their experiences. That is, he values a community that also shares practical resources to help people live with migraines and cope with the condition on a day-to-day basis. This relates to James' accounts and how important it is for him as a man to belong to a group that is informative and compassionate.

"I find it's informative so that's the first thing, the comment piece writers there's certain people that write every week or every couple of weeks, I find that they're quite informed and quite, mostly quite compassionate which I think it's a really important aspect for it/ And yes, and then I find that some of the people writing the comments it's just really interesting to see their story really, that's the main idea (James)''

The idea of an informative group that stays on track with migraine issues and supports its members through their migraine journeys was particularly valued. Furthermore, Mark highlighted the importance of this latter point by sharing how much he values his online community for being respectful when engaging in online discussions. *''The first (and most important) rule is to be kind and respectful. '' (Mark).* Through developing his argument, Mark talked about the importance of establishing certain rules in an online group.

'I think "rules" are probably very important concepts in any group, but I don't think they should be enforced in a negative way that would make the group possibly intimidating for people. (Mark)

In his opinion, every online group should have clear rules about its structure and ways of functioning. These would act as group identity and guidance for participants and their interactions. Here, group moderators assume a pivotal role and the majority of participants were vocal about this.

In the particular case of Samuel, who has been a moderator for an online migraine support group in the past, he talked about his experience and how important he felt his role was in terms of keeping the group 'on track'. He talked about some practical examples when participants acted against the rules of the group and how that was addressed.

> *''I personally use a gentle approach to start and ask to keep it nice, try to remind people that first, we are all in this together, and second, we need to respect others' opinions. If they still don't play nice, the post gets locked down or removed, and/or the offending member(s) get removed or on a timeout. I then message them privately to try to diffuse any situations and keep things amicable. (Samuel) ''*

As highlighted by Samuel's account, the role of moderators is particularly important in handling situations where the interactions between members affect the wider 'wellbeing' of the group. Having a group that is well moderated is very important and this was clearly valued across different interviews. One participant, Mark, added his perspective to the argument by sharing his opinion about the importance of moderators.

> *''I think they need to monitor the requests to join and monitor activity that goes on in the group. IF something gets out of hand, which it often can, they need to be proactive about this. And if the group gets off track, a moderator needs to bring the group back to a common focus.'' (Mark)*

The importance that Mark attributes to group moderators can almost be linked to the role of a captain of a ship. Similar to a captain, a moderator decides who joins the group and is responsible to stir it in the right direction, whilst guaranteeing the 'wellbeing' of the community.

One aspect that might influence the 'wellbeing' of the group is negative stories. Alex shared his experience of joining a group where the majority of the interactions were 'negative' and the impact those had on him.

> *''It was just lost, scared people all looking for the same thing; help. Once you read a few of those posts, they can weigh you down and make you feel hopeless and depressed. Because of this I mainly stayed away from them, only checking in every now and then to have a look. (Alex)''*

There were several testimonies of people who have been part or joined groups that were not well moderated and where participants felt the group was having a negative impact on members. Not only are moderators expected to keep the group on track and focused on discussions related to migraines, but people also anticipate them to ensure that positive and hopeful stories are shared in the group.

In sharing their perspectives towards the effectiveness of online groups, participants inevitably talked about issues related to being a man and what it was like to seek online support for their migraines. People mentioned the lack of male-only groups for migraines and how the population that normally engages with online support groups '*'seems to be predominantly female''*. For Daniel, the fact that there are more women going online for help means that men with migraines and their needs are being under looked.

> *''But as I said, this [men not talking about their migraines as much as women] is all the more reason to try and help men with migraines.'' (Daniel)*

In line with this argument, creating a male only online support group for migraines was seen positively. For Alex, there is a benefit to having more men coming together to discuss migraine specific issues.

> *''It would be nice to hear from fellow male sufferers, I know men tend to not be so open about health matters but I rarely see men comment. I'd feel better by seeing a male perspective but only in regards to more male-skewed aspects, as an overall experience I don't mind seeing posts from female accounts.'' (Alex)*

Alex was clear in stating that even though he ''*does not mind seeing posts from female accounts''* he admitted he would '*'feel better by seeing a male perspective''.* From Alex's accounts, one can infer that men can still seek and receive informational and emotional support from online groups where the majority of users are women. However, as Alex suggested, the support would perhaps be more effective and efficient if men saw other men's perspective towards similar issues they experience.

In Daniel's case, there is an issue at the heart of the migraine experience that can help explain why men do not feel comfortable in seeking emotional support online. For him, there is a clear difference between how men and women with migraines are treated by society, and this difference helps to explain the benefits of establishing male only online support groups. Daniel was a clear advocate for the creation of online support groups exclusively for men with migraines.

> *''I found that people treated women migrainers with much sympathy. But men with migraines, socially, people treat with very little sympathy, or even attempt to be understanding about not being able to work. None of this, however, means that a support group for men is not "worth" pursuing. In fact, just the opposite. Although there may be fewer men, they are likely some of the most desperate and in-need of the support''. (Daniel)*

Not only does Daniel believe an online group for men with migraines would be beneficial because men (for being fewer) might be most desperate for not having as much emotional support available to them, he also believes a men-only group would make the type of informational support received much more tailored.

> *''I think keeping men and women in separate groups avoids all kinds of complications and allows you to better serve each group. Just one simple example might me that a mixed group spends the entire session discussing the effects of oestrogen as a trigger for migraines. Men would likely not even be interested in the topic. Women might feel uncomfortable talking about related issues "in front of men".(Daniel)*

There was a general agreement that male exclusive online groups for migraines would have a great number of benefits. Samuel added to this idea, and talked about how these particular support groups would make it easier for men to discuss more sensitive issues that might be particularly difficult to discuss and talk about with women.

> *'' [In case of a male-only group] It's easier to discuss topics of a sensitive nature (intimacy issues, etc). (Samuel)''*

In line with other accounts shared by different participants, Daniel, whom in the past tried to establish a male online support group for men, summed up the topic of male only groups very clearly.

> *''I am a man. Male migraines can be caused by different things than female. I wanted to connect with men who might have found treatments that were partially successful. Also, men experience very different social problems (related to Migraines and not having a job) than women. (Daniel)''*

For him, there are clear differences around the social implications for migraine in men when compared to women. This is an element that Daniel believes is worth sharing and discussing with other men in similar situations. Migraines are biologically complex and do not have clear causes. However, their implications are vast and across different elements of one's lives. The fact that sometimes the biological symptoms are particular to an individual, does not mean that the practical and social implications of it are similar to other men. Support groups and communities specifically created for men with migraines can offer the ideal platform to facilitate and empower connections around these specific elements.

This theme touched upon some key ingredients for a functioning and helpful online support group, and the benefits this would have for men with migraines. One of the key aspects highlighted was the importance of ensuring anonymity and privacy in an online group where men open up and talk about the struggles of living with migraines. Participants discussed the benefits of private groups in comparison to public support groups and online groups in comparison to in person settings. Here, online support groups were seen as more convenient and easier to access. Participants also seemed to value well established and clear group rules and getting practical advice. According to participants, group moderators have a key role in ensuring that group discussions stay on track and go in line with the objectives of the group: support people with migraines.

Finally, this theme highlighted the opinions of the participants about male specific online support groups. These were seen as beneficial and most importantly, as needed. Different participants agreed that online support groups and forums for migraines are predominantly used by women and that there is a lack of online groups for men with migraines to come together and support each other. This is a population which has been falling under the radar, and from the accounts of these participants, bringing it together in an online community would benefit the way they live and cope with their condition.

5.5 Discussion

This study gathered the perspectives of 13 men who are or have been part of online communities (in a form of online groups and/or forums) for support with their migraines. The aim of this research was to understand and attempt to draw patterns of meaning across different interviews in order to shed light into the world of online communities for men with migraines. I wanted to explore how these groups act as support, the type of support they provide, and the meaning men place in accessing them. Ultimately, with this research, not only do I want to give voice to a population that has been largely unacknowledged but I also aim to expand the understanding of the true potential that online communities can have in supporting men with migraines.

One of the principal findings of this study was the different aspects of support men seek and obtain from these communities. One the one hand, emotional support linked to shared experience, a sense of community and togetherness. This was also related to aspects of validation of migraines and empowerment to talk about migraines in real life with friends, family and work colleagues. On the other hand, informational support. Practical information they can act upon and improves their coping mechanisms towards migraines. Ultimately, these communities are centres of expertise by experience where people go to share their lived experiences and learn about migraines. There was great value placed on lived experience and the empowerment and validation that comes with being surrounded by other people who experience the same illness and the difficulties that come with it

Some literature has explored the benefits of online communities and the dynamics of receiving social and informative support online. However, most of the studies focus on conditions such as diabetes, depression and other mental health issues (Breuer & Barker, 2015; Ravert et al., 2004; Prescott et al., 2020) and no studies to date have explored these dynamics in migraine communities. Nonetheless, similar to other studies looking at online communities and discussion forums (Coulson, 2005; Ravert et al., 2004), giving and receiving emotional and informational support were amongst the most common reasons shared for why people visit or join these communities. Nonetheless, the majority of empirical work in terms of group dynamics in the field of Health Psychology has been done in regards to standard (face-to-face) support groups. Despite the relative lack of in-depth research exploring group dynamics in online settings, it is a fact that online communities (which include online support groups and forums) have their roots linked to standard face to face support groups. It is legitimate therefore to explore findings, conclusions, and insights from this type of research and ultimately look at them from the perspective of, and applicability to, an online setting.

Festinger's (1954) work and their social comparison theory is often used to understand overall dynamics in group settings. In their theory, Festinger (1954) highlighted that it is part of the human nature to seek and maintain a sense of normalcy and accuracy about our world, and that experiencing a certain illness condition might 'disrupt' one's sense of normalcy. As a consequence, one is drawn towards seeking other perspectives towards their personal experiences i.e., how they are feeling and how they approach and cope with a certain phenomenon. Festinger's theory, and its emphasis on the need to seek and maintain a sense normalcy, goes in line with findings from this study.

Men in this study spoke about a sense of belonging and validation that comes from being part of an online community for people with migraines. This is particularly relevant given migraines are a medically unexplained and invisible condition. In previous chapters, we have pointed out different aspects of validation of migraines and how that relates to one's social sphere. In this case, online communities offer a legitimation and validation and a quasi-social status that is difficult to achieve in real life. Similar aspects of membership and social status were identified in different support group settings (Pryce et al., 2019). Although their study focused on in person settings of tinnitus support groups, similar to this research, they also identified aspects of empowerment and resilience associated with belonging to a group of people with similar lived experiences. It is legitimate therefore to argue that some dynamics of online communities can be seen and identified in an 'offline setting'. Even though we can argue that at their core, this sense of belonging and empowerment is attached to these groups despite their setting, further studies should look into exploring similarities and differences between different online settings.

On the other hand, participants also highlighted the importance of receiving practical and informational support. Some people talked about how they value going online to read informative pieces about migraines and stay up to date with what other people have been trying, as well as to find out new research in the field. Similar findings were present in other studies looking into online forums and message boards (Coulson, 2005; Ravert et al., 2004). Men in this study portrayed these communities as places of expertise by experience. Additionally, participants looked at going online for informational support in comparison to speaking to their GPs. It was often commented how the information they gather online goes beyond what they get from their physicians. In other words, participants highlighted that these communities offer a place for people to spend time to understand themselves, their migraines, and themselves in relation to their migraines; and this aspect is a key difference to what a healthcare professional can provide.

From these findings, which are supported by further conclusions made in previous chapters, we can easily see that in the case of migraines, different people will have different subjective experiences and consequently different needs for support. Some people might value informational support, whereas others might be more drawn towards emotional support (or even both). In spite of the level of subjectivity, we can reflect upon the overall field of provision of support for people with migraines; particularly in terms of patient agency and the responsibilities that different migraine stakeholders have in providing these different levels of support. It is not established, or even clear, who provides all the elements men identified as being support needs; especially those that go beyond the remit of GPs (for instance, lived experience, sense of belonging etc.). It is therefore important to highlight that the data in this chapter explicitly point out that, when it comes to the migraine experience, it is necessary to go to different places and settings to seek out support for different needs. There is a clear need to introduce a transparent pathway of support for men to follow according to their specific needs. That is, clear guidance on where to go in order to have different needs met. Not only would this facilitate meeting the support needs of migraine patients, but it would also prompt the involvement of migraine stakeholders (charities for example) and healthcare professionals to work collaboratively to support this population. In the case of online platforms, these are readily available 24/7 and their potential should be explored further.

Not only are these platforms readily available 24/7, participants also pointed out the wealth of information that is available. An additional finding from this study was related to the need participants expressed to filter out the information they come across online. From the interviews, participants highlighted the complexity of this phenomenon and the barriers that men experience when seeking informational support online. Different information will have different levels of importance for different people. One participant employed a useful metaphor of a jigsaw to explain how they navigate these platforms for information; the majority of the participants did relate to this. Going online to seek and acquire information for migraines is similar to looking for pieces for a jigsaw. It is up to each person to look for and find the pieces that are valuable and relevant to them. This reflects some elements of patient agency identified in previous chapters.

Participants talked about the learning process that is associated with going online for informational support and finding pieces that fit their own, individual, jigsaw. By talking through their lived-experiences, participants explored the process of becoming an expert by experience. Their knowledge comes from their sensorial lived experience, as well as additional information they acquire from various other sources. That is, from interactions with healthcare professionals and from going online to read about and interact with different migraine experiences. The combination of the information they acquire adds to their personal knowledge about the different nuances of the migraine experience

Culturally, we find it more socially acceptable for women to speak about, open up and take action to illness when compared to men (Adamsen *et al*., 2001). In fact, societal and cultural assumptions that men do not seek help might help explain men's underutilisation of health services and how men might delay seeking support for ill-health (Courtenay, 2000). It can be argued that, considering research around masculinity, health and support, men have to break through social and cultural norms and go beyond what in society is perceived as standard masculine behaviour, to actively seek support or attempt to take action and engage in preventative behaviours (Courtenay, 2000). This is in fact seen in this research. Men interviewed for this study have expressed the need to go beyond standard healthcare practices and cross gendered boundaries to obtain effective support for their health problems.

When it comes to support, literature around masculinity and health points out that men often prefer action-oriented approaches (Adamsen *et al*., 2001; Seymour-Smith, 2008) Literature highlights how men and women have different coping styles when it comes to ill-health (mental and or physical) as men are tendentially more prone to seeking and engaging in problem solving/action oriented interventions that place focus on regaining control over a phenomenon

(Klemm *et al.*, 1999, Seymour-Smith, 2008). This study expands on these findings and emphasise that emotional support is also important for men when it comes to receiving support.

Additionally, my participants shared the idea that being a man makes the whole process of acquiring relevant information much more difficult. In other words, being a man is a barrier to obtaining informational support online for migraines. The online community is mostly populated by women because they are the population with higher prevalence of migraines Women's issues, particularly related to their reproductive cycle are often part of the conversation, therefore, some strategies to cope with migraine, as well as information about causes are only applicable to women.

There are several studies touching upon the issue of information quality and credibility of messages in online discussion forums (Savolainen, 2011; Crystal & Greenberg, 2006). In line with the findings from this study, I can assert that the field of migraines would benefit from further exploration of this topic. Understanding the relevance and quality of the migraine information available online would be a step forward towards improving support systems for people with migraines in general, and men in particular. Furthermore, involving different local migraine stakeholders in exploring and creating a network of local online communities where people from the same area or region could come together to support each other and share information about local migraine services could be an answer to some of these issues. The lack of country/region specific migraine information was also seen as a problem by participants in this study.

When discussing the pros and cons of being part of online groups and communities, participants brought up perspectives in support for creating a male-specific online group for supporting men with migraines. In fact, participants clearly emphasised the lack of male-only support groups and communities for migraines. In addition, they reiterated elements of what was found in previous chapters. That is, most of the migraine information online is from and for women. Participants talked about establishing a community for men with migraines and how this would facilitate men coming together to talk about their migraines and share relevant issues that could be perceived as sensitive to share in a mixed group. They highlighted the need to guarantee anonymity and establish the foundations of such a community on respect, clear rules and practical information. In other words, participants in this study defined quality of information, a safe environment, clear rules and structure, as key elements for an effective and functioning online group for men. In addition, group moderators were perceived as being particularly relevant to ensure this and shielding the general wellbeing of the group.

According to these participants, online groups should have moderators trained to protect and shield the wellbeing of the people in the group, as well as to ensure the flow of relevant information. Participants talked about how some groups can become 'too negative' and how moderators have a role in minimising the effect this has on other people. The topic of group moderators has been widely studied in the field of support groups (Pryce et al., 2019; Coulson & Shaw, 2013). Nonetheless, an in-depth exploration of the role and extent to which group moderators can impact and guide group dynamics is needed, especially in the field of migraines. In order to advance the knowledge of support groups for migraines, further research needs to be conducted involving group moderators and the key role they have, especially when it comes to moderating sex-specific support groups. Although people mentioned that all the groups they are involved with have moderators, the analysis of these interviews highlighted that greater moderation might be needed. Similar conclusions were made in a study exploring online support groups for women breastfeeding (Regan & Brown, 2019). Moreover, the involvement of migraine organisations in the growing trend of online support groups might be needed in order to regulate the information that is being shared in these discussion forums. Regulated and well moderated online support groups can act as an effective tool of migraines support.

Ultimately, people stated how important it is to create a safe space for men to come together and discuss their sex-specific migraine issues, and how sometimes, mixed groups might hinder men's willingness to open up and seek emotional support. The benefits of online male groups for peer support have been explored in other areas. For instance, in a review looking at benefits of online prostate cancer communities, Pyle et al. (2020) concluded that it is not completely clear whether men are meeting their support needs by being part of these communities, despite male participants having reported more positive outcomes than negative. Furthermore, in a study looking at online forums for infertility issues, Hanna and Gough (2016), found benefits associated with male only forums. These were related to giving men confidence to seek support and advice, which was also seen by men with migraines in this study.

The present study contributes to understanding what men gain from being part of health-related online communities and support groups for migraines, and attempts to shed light into designing more efficient online interventions to meet the needs and communication styles of male patients. Although studies exploring the foundations and importance of online support are becoming more prominent, there is still little information available on the topic (White & Dorman, 2001; Phoenix et al. 2009). In Fact, Gough (2016) argued that by conducting research that focuses on online spaces and explores men's interactions with their male counterparts, we will open the door to more meaningful insights into men's help seeking behaviours and to a better understanding of how men validate their ill-health experiences and identity. Which will consequently help move forward how efficient and effective these systems can be in supporting men. This study adds to that pool of knowledge and extends the argument to the field of migraines, and how men utilise these settings in their experiences of coping with such condition.

Lastly, following the narrative of previous chapters, this study reinstates how the topic of migraines in men is underacknowledged by health psychology research. Especially when it comes to the way men seek help for their condition and navigate the various support systems available. The creation of a well moderated online group for men with migraines could not only help them with how they receive support for their condition, but also provide the ideal platform for future research in the field. Men are also affected by migraines and all migraine stakeholders need to be aware that this particular population might not seek, help or cope with their migraines in the same way as women. Therefore, not only does this study offer a thorough understanding of men's experiences of using online groups and forums for migraine support, it also sets the scientific foundations for different migraine institutions and stakeholders to establish a network of effective online support groups for people with migraines in general, and men with migraines in particular.

It is important to conclude this chapter by highlighting how these online platforms and groups are particularly important considering the COVID-19 pandemic. In particular, how they can be used to close the gap in migraine service provision and informational awareness. Moreover, they should be inspected as potential new ways of providing emotional and informational support to those living with migraine, even more under the current social restrictions of the pandemic. The pandemic affected the way things are done and how we see the world. As a collective, now that we have experienced a new way of delivering services and conducting research, people with chronic invisible conditions such as migraines cannot be forgotten. Across different fields of expertise, society moved forward in designing and implementing new remote interventions and ways of delivering healthcare services. It is expected that in the near future more research will be able to provide a clearer picture into the benefits of remote working and how we are using technology and the internet to reach further populations for support. However, for now, we need to continue to explore different ways to understand illnesses by placing the focus on the patients and people affected by them. Only then we can have a real-world understanding of an illness and ultimately design lifeworld-led interventions. Regardless of being online or in person, it is imperative that these interventions place their focus on the individual living with the condition.

Chapter 6 – Discussion

6.1 Introductory statements

The objective of this chapter is to provide a reflexive overview of the programme of work portrayed in this thesis. This chapter offers a summary of the main findings of this programme of work as well as further insights into its implications for the field of migraines and the wider field of health psychology research.

This PhD, and my programme of work, are positioned on a clear epistemological premise. That is, looking at ill-health through a phenomenological lens and by placing people's experiences at the centre of research, takes us one step closer to having a better understanding of illness. Consequently, this places us in a better position to design tailored lifeworld-led support strategies and improve healthcare systems for populations (Smith et al., 2009, Galvin & Todres, 2013; Todres et al., 2007; Dahlberg et al., 2009). This is at the heart of my approach to research and to health psychology. Moreover, this premise accompanied every step of this PhD, and there was a conscious effort on my behalf to focus on the human dimensions of ill-health and lived experiences of my participants. This guided my programme of work throughout the different studies in this thesis.

This thesis reflects a detailed and thorough exploration of the experiences of men with migraines, as well as some of the online services (and their narratives) available to support migraine patients. Through using qualitative research to elicit individual experiences of migraines one can access in-depth perspectives, points of view, and perceptions that would otherwise be impossible to acquire. The ultimate goal of this thesis was to showcase migraines in men from their perspective. Men also experience migraines, and research in this field is not placing enough emphasis on how their experiences and needs might be different from women, who are in the majority of people who experience migraines.

6.2 Summary of background and aims

This PhD had a clear set of objectives. Firstly, one of the key purposes of this programme of work was to understand the state of qualitative research looking at migraines. Not only in terms of the quantity of papers available, but more importantly in terms of their quality. Migraines are a disabling headache disorder that has been classified as a major public health problem (WHO, 2011). Living with migraines often means living with a condition that impacts all elements of life, including people's professional careers and interactions with friends and family (Minen et al., 2018). Migraines are much more than just a headache. For that reason, it was important to provide an in-depth overview of qualitative research looking at the finer nuances of lived experiences of migraines. There was a dual aim here – to assess the state of the evidence base and also to examine how that evidence is positioned in terms of how it treats and makes sense of migraines. This was achieved with the research conducted and presented in chapter 2.

Secondly, one of the most important objectives of this PhD was to place men, an understudied migraine population, and their experiences of migraines at the centre of the debate. As we have seen, even though the prevalence of migraines is higher in women, men do experience this condition too. In terms of its prevalence, one in four people affected by migraines is a man (MacGregor et al., 2011; Breslau et al., 2001). Nonetheless, it is crucial to include men in the discussions around migraines and acknowledge them as a population who also experience this condition. This was the premise for the research conducted in chapter 3. Research within the field of migraines needs to make a conscious effort to continuing to contribute to the pool of knowledge about migraines, and migraines in men specifically. Research looking at experiences of men and women in ill-health often focuses on a broader perspective, rather than providing in-depth explanations (Galdas et al., 2005; Dobransky & Hargittai, 2012; Wang et al., 2013). The research conducted and presented in chapter 3, which solely focuses of male experiences of migraines, is the first of its kind and a novel piece of work in the field of migraines.

Thirdly, it was an objective of this PhD to explore online platforms as a means of obtaining support for people with migraines in general, and men in particular. Findings from chapter 3 highlighted how online platforms can have a crucial role in the way men seek and perceive migraine information and support. Not only did chapter 3 reiterate findings of previous research on how self-management is key in conditions such as migraines (Bodenheimer et al., 2002; Chodosh et al., 2010), it also touched on the fact that health related online websites might have potential benefits for obtaining general support with migraines. Additionally, the way they present their narratives and establish their discourses around migraine support has a significant role in framing how migraine is talked about in the wider context of online platforms. Further understanding the role these platforms play in the way people seek and perceive migraine information and support, might unlock potential new ways of thinking about and designing support for this population. As we have seen in previous chapters of this thesis, online platforms host a vast amount of information and options that people can access in order to share their experiences and gain illness specific information from 'experiential experts' (Tanis, 2008). Understanding the discursive positioning of these platforms in relation to migraines and support, allows us to understand how the online world can be used as a precursor of support for people with migraines. This was achieved with the research presented in chapter 4.

The research conducted and presented in chapter 5 achieves another objective proposed for this PhD. That is, to give voice to men and understand how they navigate online platforms for support with their migraines. As seen throughout this PhD, men are an understudied and under acknowledged migraine population. Our knowledge around possible ways to improve support and care for these patients needs to be expanded as findings from this PhD state that being a man can often act as a barrier for accessing support for migraines. Therefore, it was a purpose of this programme of work to not only understand the potential that online platforms have in supporting people with migraines, but also gain insights into how men access them and whether they are designed to accommodate this specific migraine population. Chapter 5 aimed to initiate discussions around the potential of online platforms for men with migraines and provides key information for migraine stakeholders to start looking at these settings to support men living with migraines.

Lastly, it was also an objective of this PhD to explore how different qualitative methods can contribute to understanding ill-health and advancing knowledge in Health Psychology. This programme of work was built upon a mixed-qualitative-methods approach by bringing together different qualitative methodologies to collecting and analysing data. In practical terms, through offering my participants the choice to express their experiences in their preferred way, that is, in writing, visually, or verbally, I managed to facilitate an elicitation of the human dimensions of their experiences on a deeper level. In the wider context of health psychology, when exploring the subjective underpinnings of ill-health, research can only benefit from looking at phenomena from different perspectives and by giving freedom to the person experiencing them to choose the best way to express their experiences and tell their story. Aligned with the objective of investigating human dimensions in health and advancing knowledge of migraines from that premise, collecting data through different methods, and looking at them through different lenses allowed me to get richer, deeper insights into what it really means to be a man with migraines. This PhD has shown that different instruments of analysis such as TA, DA, and IPA are adequate and effective as individual methods to look at specific aspects of ill-health (Smith et al., 2009; Foucault, 1980; Braun & Clarke, 2006). However, and most importantly, it showed that these can be used in combination to provide different perspectives and a fuller picture of the same phenomenon. This is one of the greatest benefits of using a mixed-qualitative-method approach.

My proposed approach was to explore different nuances of migraines by looking at an understudied population who experience it. By employing a mixed-qualitative-methods approach, I acquired rich insights from those with real lived experiences of it. The true richness of these insights was only possible to gather, and make sense of, using different qualitative approaches. Utilising different qualitative approaches to explore the same phenomenon from different fronts, enabled me to present a fuller picture of what it means to be a man with migraines and what it is like to navigate online platforms for support.

6.3 Overview of the principal findings

6.3.1 The state of the current qualitative literature looking at migraines

By conducting a thorough systematic search and meta-synthesis of the qualitative research exploring the experiences of people with migraines, I identified that the lack of studies solely focusing on men was stark. Out of the 1892 articles screened, no study touched on elements of migraines from a male perspective using qualitative methods. In the meta-synthesis from chapter 2, seven papers looked at people's experiences of migraines (and included at least one male participant) using qualitative methods, however, no paper acknowledged that men's experiences might be different from women's. No published qualitative papers were found looking at the experiences of migraines from a male perspective. In fact, none of these papers distinguished their male participants' experience from their female counterparts.

The overall state of the body of research focusing on migraine is worrying. Most of the articles screened had both men and women as participants and did not differentiate for different nuances in experiences, symptoms, and needs. The way the current literature looks at migraine in relation to men and women is through a 'one size fits all' approach. Moreover, the standard and quality of some of the articles also deserves a commentary. The majority of the studies included in the meta-synthesis in chapter 2, did not score highly in the Critical Appraisal Skills Programme: qualitative checklist (CASP, 2018). The most prominent issues were related to the lack of in-depth analysis and interpretation of the data, and the lack of transparency in the research process (Rutberg et al., 2013; Varkey et al., 2013; Belam et al., 2005). Additionally, it was common practice not to differentiate for different headache conditions. Studies often included people's experiences of different types of headaches in the same research piece (i.e., people with migraines, cluster headache, etc.) (Peters et al., 2003; Peters et al., 2004; Peters et al., 2005).

Living with migraines is a subjective experience. As we have seen in chapter 2 (and throughout this thesis), migraine episodes are a combination of symptoms that vary from person to person. Moreover, living with migraines has an everlasting effect on different elements of someone's life (family, friends, work, hobbies etc.), as the experience goes beyond the commonly stated physical symptoms of the episodes (Goadsby et al. 2017; Peters, et al., 2005). Aligned with this, the limited qualitative research in the field is unanimous in arguing that self-knowledge and self-management are key when it comes to living with migraines.

6.3.2 Under-representation of men's experiences in the field of migraines

The work in this thesis highlighted that when it comes to migraines, men are an under-represented and often under-acknowledged population. Results from chapter 2 confirmed this issue, and further studies from this PhD corroborated these findings. Men also experience migraines, and the fact that women are often perceived as being 'the standard migraine patient' might affect the way men make sense of their condition. In chapter 3, I gave voice to men who experience migraines in order to understand more about their experiences and journeys.

From here, I proceeded to address this issue and conducted an in-depth exploration of the experiences of eight men with migraine. I found and identified different aspects of the migraine experiences of these individuals. In line with findings from chapter 2, people talked about how migraines are a subjective experience and a combination of physical, emotional and sensorial symptoms; pain being one of the most common. These symptoms are not exclusive to men and have also been reported in women with migraines (Peters, et al., 2005; Belam et al., 2003). Additionally, aligned with other literature around men's health, this study clarified the argument that men do care about their health (Banks, 2001). Participants in the study presented in chapter 3 talked at length about their health and how they navigate different support systems. However, they often highlighted the difficulty in verbalising the struggles they go through with their migraines and mentioned how difficult it is to make these 'visible and noticeable' to the wider society. Especially when it comes to 'the male persona' and how it is seen by society and the resources available, being a man often acts as a barrier for migraine support. This aspect of the migraine experience was pointed out as being a noticeable difference between how men and women live with migraines. In fact, participants talked about how challenging it is to find appropriate spaces to open up and talk about their ill-health. Even within their close circles of friends and family – once again, some participants made comparisons to women's experiences of migraines and how they think it is harder for a man to open up and talk about their issues. The key element in their narrative was that feeling supported means feeling comfortable to talk about their issues whilst feeling understood, which does not happen often. Moreover, they perceive themselves as primary agents in seeking support and treatment for their migraines. Here, online platforms were seen as playing a key role, as they allow people to come in contact with different understandings of the migraine experience and validate different ways of living and coping with migraines. However, participants highlighted how challenging it is to find information online that is relevant for men.

These men clearly took the role of being responsible for their own care, regardless of the support they seek and get from healthcare professionals. Consequently, they often shared stories of needing to go beyond the standardised migraine support from their GPs in order to learn more about their condition and minimise its impacts. I identified different strategies which participants use to overcome certain barriers to treatment and lack of information. The use of online platforms was one of the most common ways of obtaining informational and emotional support for their migraines.

6.3.3 Migraines in men within the context of online platforms for support

Literature tells us that online platforms are extremely relevant for sharing and obtaining support for ill-health, and this PhD extends that knowledge to the field of migraines (Christakis & Fowler, 2017; Cohen, 2004). Chapter 4 provides an in-depth review around this issue by looking at the discourses present in online platforms for people with migraines. These platforms offer an immense number of resources for people with migraines and often host discussion forums and groups for people to share their experiences. They are based on narratives of empowerment and a sense of togetherness and shared purpose. Their discourses are surrounded by active listening and the importance of understanding others. However, most of these platforms are created for men and women but are dominated by women's accounts and women's issues. It is very rare to see male specific articles or pieces of information online. Moreover, the imagery of these platforms is often based around women experiencing a migraine episode.

Even though men are present in these platforms and forums, they are not being given the same 'air space' as women. Even when users and moderators mention men with migraines, they are not being part of the debate as most of the resources are created by and for women. The overall message transpiring from that chapter highlights how much potential these platforms have as a means of support for migraines. However, it also highlights how little they do to provide a safe space where men can gather relevant information about their migraines. By not normalising migraines in men and not creating safe spaces for them to come together to talk and learn about their migraines, websites are taking one step back and unintentionally excluding men from discussions around migraine support. Through not having migraine information and resources specifically formulated and created for men, these platforms might be contributing to making men feel rejected or devalued because their experience of migraine is not acknowledged.

6.3.4 The rationale for more men-friendly online platforms for migraines

Chapter 5 sheds light into how men navigate the online world for support with their migraines. Findings highlight how these platforms are not inclusive and often exclude men. Additionally, these findings can be translated into indicators to start conversations around what would make an effective online community for men with migraines. From the data gathered and through interpreting individual experience, one can collate several prerequisites for an online community that is inclusive to men. This does not necessarily mean thinking and designing a completely new approach to online communities, but rather adapting to a new context and approaches that were seen to be effective (Moore et al., 2021)

Firstly, for an online community for men to work, there needs to be a strong element of informational support with a level of detail and depth that goes beyond what men with migraines are getting from healthcare professionals. This information can come from articles or news pieces translating current migraine research but should also come from (and be validated by) individual experience of other men. That is, the information shared in the community needs to be practical, relevant, up to date, and informative to men; but there also needs to be an element of experience sharing. Reading testimonies from other men with migraines seemed to be valued by different participants. Additionally, an online community for men with migraines needs to be positioned around elements of social support as a way of eliciting feelings of belonging and connectedness. The importance of this connectedness has been seen in previous chapters and in the literature (Wright & Bell, 2003). These elements can be elaborated even further and thought of from a clinically interventive perspective. That is, even though this is still a relatively novel area of research, systematic reviews have shown that online peer support interventions have a strong potential for clinical effectiveness (Fortuna et al., 2020; Lewkowicz et al., 2021). To sum up, ensuring that an online community is available 24/7 and has been built on expertise by experience whilst still sharing practical and relevant information for men with migraines should be the starting point.

Secondly, an effective online community is one that shares relevant information to their users. Following this argument, some participants highlighted how some online groups share information that is country specific and therefore make it difficult to come across information people can act upon. For that reason, when designing an online community for men with migraines, it is also important to think about alternatives to ensure the information being shared is relevant to the users. Especially if it is a closed community. One way of ensuring this, is involving local migraine stakeholders in coordinating these region-specific online communities so users from certain areas of the country can interact, share information and lived experience.

Thirdly, more emphasis needs to be put on the type and context of imagery used to represent migraine experiences in online platforms and communities for migraines. Within the context of designing an online community for men with migraines, the images used need to be representative of the male experience of migraine. Online websites and communities need to make a conscious effort to depict migraines from a male perspective. That is, these platforms need to start including pictures and images showing men experiencing migraines. This would be a particularly important step in working towards establishing the narrative that migraines are not a women-exclusive condition.

Lasty, the role of group moderators is key for an online community to work for men with migraines. In fact, in the wider context of online platforms for migraines, the role of group moderators needs more emphasis. Based on findings from this PhD, for men in particular, it is important not only to relate to the person moderating the group, but to also recognise their role in keeping the group on track. When establishing a community for men to come together and obtain support for their migraines, group moderators need to be a source of support whilst being well informed of the particularities and specificities of this migraine population. Only then they can safeguard the wellbeing of the group, by shielding men from negative or irrelevant information, and ensure the constant flow of relevant, practical information men can act upon.

6.4 Methodological reflections and limitations

One of the biggest strengths of this PhD is that it is based on a mixed-qualitative-methods approach and on different methodological and theoretical approaches to make sense of the lived experiences of migraine in men. Promoting the flexibility and value of qualitative research is inherent to this body of research.

This programme of work emphasises the flexibility and true potential that lies within a mixed-qualitative-methods approach to understanding ill-health. Throughout this PhD, I used different data collection and analysis techniques to elicit human experience and obtain information from the literature and online platforms. A particular example of this is portrayed in chapter 3, where I offered my participants the chance to express their experiences verbally, in writing or through images. This was key in enhancing their ability to offer a truly rich in-depth insight about their experiences. Here, written descriptions of the migraine experience worked particularly well. By asking my participants to take the time to organise their thoughts and translate them into written words, I was given access to a level of depth in their data that would be difficult to achieve through more standard techniques.

Not only did these methodologies allow me to collect rich data to answer my research questions, but they also enabled me to connect with my participants on a different level. That is, I shifted the power focus that normally takes place in a one-on-one interview and gave them the freedom to tell me their stories as they wanted them to be told. This was particularly noticeable when conducting interviews via email where participants were not expected to give their answers straight after I asked them. By conducting email interviews, I gave space and time for my participants to read the questions, think about their answers and share them with me at their convenience. They were in control of when and how the interview took place. A downside to this approach was the length of the data collection process. People were given complete freedom and no timeframe to get back to me with their answers, and this meant that the process was relatively lengthier.

Furthermore, in different chapters I used different analytical approaches to make sense of my data and answer my research questions. The different analytic methods used throughout this work were Interpretative Phenomenological Analysis (Smith et al., 2009), Discourse Analysis (Foucault, 1980), and Thematic Analysis (Braun & Clarke, 2006). This can be framed as a process of triangulation of analytic methods, which has been described as a pre-requisite for an enriched research process and ensure a more thorough development of comprehensive understandings of phenomena (Patton, 1999; Carter et al., 2014). Going beyond one analytic method and adapting the way we look at data based on the specific purposes of each individual research piece is an advantage of qualitative research.

Through a mixed-qualitative-method approach I highlighted the benefits of looking at the migraine experience from different methodological stances. By conducting an Interpretative Phenomenological Analysis on different types of data, I managed acquire an in-depth understanding of individual experience that would have been difficult to achieve otherwise. With IPA, I placed the focus on the individual with migraines, rather than on the migraines as a condition, as a way to develop further our understand of this phenomenon. As seen in chapter 3, this was critical to highlight finer nuances of lived experiences and meaning making of migraines and shine light towards the wider lifeworld of those who experience this condition (Galvin & Todres, 2013). Additionally, DA was used to enhance the understanding of the discursive positionings of online platforms and explore how they relate to knowledge and behaviour in the field of migraines. This was key to inform reflections upon how these platforms and resources are ultimately shaping understandings, narrative, and behaviours of migraines in men and how they navigate support networks. Additionally, TA was used to deepen our understanding of how men navigate online platforms for support with their migraines. Through a TA lens, the emphasis was placed on understanding online support (a branch of the wider lived experience of migraines) by analysing perceptions and meanings created by those who navigate this world and use these resources in their migraine journeys.

Finally, as an addition to its empirical findings, this PhD also offers a reflexive critique towards the available guidance for internet mediated research (BPS, 2021a). As the world and science move towards a more frequent use of technology and online settings for day-to-day tasks and research, ethical guidance needs to be thoroughly explored in order to ensure good practice. In terms of health psychology and available guidance for internet mediated research (BPS, 2021a), their current format struggles to accommodate studies where data is collected from open online sources. As a matter of fact, this guidance is more applicable to interactive studies where the researcher engages with the participants through online platforms; and does not make room for studies where online platforms themselves are the phenomenon being studied. Future work utilising online methodologies or data that are publicly available online need to be sensitive to the guidance but also offer insights into how to improve it.

This PhD and its programme of work is not flawless, and so, some study specific limitations have been highlighted in the different chapters of this thesis. However, some further limitations are worth addressing with the objective of improving future approaches to migraine research. The empirical studies of this PhD focused on men aged 25-55 as it is the age when migraine peaks in men and women (Lipton & Bigal, 2005). Nonetheless, this does not mean that people outside those age brackets do not experience migraines or that their experiences are not as valid. In fact, there is a lot to be learned from different generations of people experiencing migraines and the nuances of their experience. Not only in terms of the individual experience of migraine in itself, but also how different age groups access online communities for support with their migraines.

Additionally, further studies following up on some of the findings highlighted in this PhD would benefit from further, and perhaps more generalisable, datasets to allow different perspectives into the feasibility of their implementation for practice. Especially in terms of online support for men with migraines, future research should involve medical professionals, group moderators, and include discussions with people who design and run some of these platforms. Having a wider perspective into broader nuances of these communities could be beneficial to establish stronger, more effective guidance to be put into practice. Online interventions facilitated and endorsed by primary care nurses have proven to be successful in other areas (Yardley et al., 2014).

6.5 Implications for research

At the heart of this PhD is the argument that health (psychology) research can benefit from looking at ill-health from the perspective of lived experience and through a lifeworld-led focus (Galvin & Todres, 2013). When exploring a topic like migraines, focusing on personal experience and the human dimensions of those who experience them can be the starting point to designing effective interventions based on real needs. It is important for professionals working in the field of healthcare (including researchers and Health Psychologists) to recognise the importance of lifeworld-led research (Galvin & Todres, 2013).

As highlighted throughout this work, one of the biggest strengths of this research is the data that was generated through employing a mixed-qualitative-methods approach. The experience of migraines is embedded in subjective and very personal symptoms, and this factor alone might make collecting empirical data on the subject particularly challenging. Therefore, it is important to give people the freedom to express themselves and tell their stories in the way they want it to be told. In this case, going beyond more standardised research methods and stepping into the realm of written and visual approaches proved to be extremely beneficial to the quality and richness of the data and consequently to the whole programme of work. In qualitative research, the roles of the researcher and the participant are very much established from the beginning. The participant is 'responsible' for contributing to the project by sharing their personal experiences and perspectives; and the researcher is 'responsible' for collating these experiences and through different methodological or theoretical lenses, make sense of them. As a consequence of this type of interaction, the participant ends up in a linear passive position throughout their participation in research in general and in the data collection processes in particular. However, by employing different data collection methods (written, visual, verbal) and means (face to face interview, instant messaging, email) this was shifted.

Even though the ultimate result is arguably the same, i.e., a participant sharing their introspective reflections to be used as data, the ways in which this was done meant they could share their views in whichever way they wanted and through whichever means they preferred. As a result, participants talked about the therapeutic benefits of these tasks. Particularly the written descriptions, people clearly identified benefits of engaging in reflexive writing about their lived experience. Not only did some participants highlight how writing about their migraines allowed them to ‘get to know’ their condition on a deeper level, it also enabled them to identify certain patterns and characteristics of their ill-health they were not aware of. There is evidence in favour of writing tasks, and how important it can be for people to put things into written words as a means to make sense of them (Shaw, 2004). This PhD argues the value of these techniques in the field of migraine research.

This research focuses on the migraine phenomenon, but these results elicit further thinking into how a mixed-qualitative-methods approach can be applicable (and beneficial) to further qualitative studies in other fields of work. The benefits – for the depth of the data and for the participant – of conducting research where participants are given a power position and the option to lead the data elicitation process should be explored in further detail; these approaches are built around the concepts of action and participatory research and have been shown to be beneficial for participants, especially in areas where personal knowledge can make a difference to identifying certain patterns and elements of the human experience (Heron & Reason, 1997). Moreover, for under-acknowledged and understudied populations (in this case, men with migraines), establishing a flexible data collection approach and offering different means for people to express themselves can help reduce certain barriers. That is, it might help people talk about certain topics or open up about certain life experiences that would otherwise be difficult to express in a standard one-to-one setting with a researcher.

As seen above, exploring the effectiveness and narratives around online resources was an important objective of this PhD and initial studies of this thesis translated the importance that these have on patient experience. That is, more commonly than not, people admitted going online for answers and support with their migraines. Therefore, providing an in-depth view of online resources for people with migraines was crucial to the narrative of my work. However, the lack of guidance on how to systematically collect data that are publicly available on organisational websites proved to be particularly challenging. For the study in chapter 4, I based my approach on the BPS’s guideline for conducting internet mediated research (BPS, 2021a). However, due to the particularities and objectives of that specific piece of research, the guidance was not applicable in its full extent. Which resulted in the necessity of redefining and adapting the guidance to make it relevant to my work. The adaptations and reflections towards the BPS’s guidelines for conducting internet mediated research presented in this thesis can open the door for future discussions around the topic (BPS, 2021a). In other words, the reflexive exercise of critically looking at the guidance and producing directives that are applicable to my work, offer a relevant contribution to the wider discussion of utilising readily available online data for research. In fact, this review will be taken to the British Psychological Society research board for considerations and further reflections towards their guidance. This research provides the rationale for the need to explore online platforms as effective tools in healthcare. Online platforms should be looked at as tools to provide information and support to patients, but also as ways for researchers to disseminate their research.

Finally, I believe this PhD offered a key contribution to the field of migraine research, especially through highlighting the need to focus on men. We have established that men with migraines are being forgotten when it comes to individual migraine experiences and when creating support systems. Men are a minority and there is an alarming lack of men-relevant resources and research. Being a man is a barrier to living with and seeking support for migraines. This is a topic that needs to be given further attention and future migraine research should take this into consideration. We have seen that even though some symptoms and characteristics of the migraine experience might be similar to women’s, there are a lot of particularities associated with the male experience of migraines. Especially when it comes to coping mechanisms and support seeking behaviours.

6.6 Implications for practice

Some of the findings of this PhD point towards the benefits of using online platforms, including online communities, for informational and emotional support for migraines. Ultimately, these are readily available sources of information established around expertise-by-experience whilst also offering a place for people to come together and share their experiences. These platforms seem to be filling a gap and giving people something that normal healthcare pathways are failing to provide. That is, in-depth updated information about migraines and the option to learn about this condition from people with lived experiences. Charities and migraines stakeholders should look at these platforms and settings as an opportunity to improve and maximise the way they reach out to people with migraines. Maximising the potential and quality of the information on their websites and community forums, can be a step forward towards offering a different route (and perhaps more effective) for supporting people with migraines.

In particular when it comes to GPs, there is a clear rationale for practices to incorporate or signpost patients to online communities that have been established as a way of supporting people with migraines. Online migraine communities need to work closely with local practices and establish themselves as supplement to standard migraine healthcare. In the case of men with migraines, as it has been explored in previous chapters, this specific target group rarely seeks support from their GPs. Additionally, the impact migraines have on people in general, and men in particular, should be looked at beyond their physical symptoms, and so these communities can play a vital role in making people feel understood and validated. In this thesis one can see the vast array of symptoms and effects that migraines have on people, and how they can disrupt their day to day lives, hobbies, family interactions, career and mental health. Professionals and stakeholders who work towards improving the lives of people with migraines should not overlook these aspects of the migraine experience and emphasise the health and wellbeing benefits of experience sharing and social support from peer interactions (Pryce, 2019; Litt et al., 2003; Simpson et al., 2001). This research highlights that working towards improving support systems for migraines means going beyond pharmaceutical approaches and including the way people feel supported emotionally.

Lastly, the benefits of employing creative and mixed-qualitative-methods approaches in research should be emphasised and should be disseminated more widely to encourage clinical researchers and clinicians to think creatively. Particularly for clinical research, incorporating the narratives achieved in qualitative research will facilitate a better understanding of patients and their needs in clinical settings. Ultimately, this resonates with the efforts and objectives that this area of research has in pursuing a better understanding of ill-health and its wider impact on individual patients. For that reason, it is important to establish the value of qualitative research in clinical fields, and for that, more training and awareness of its value is needed. (Shaw et al., 2019). In addition, universities and established researchers in the field of Health Psychology have a key role in guiding and advancing the state and quality of Health Psychology as a discipline and in practice. This includes academic settings offering more training and showcasing more qualitative studies that use alternative and creative approaches. Promoting critical thinking and exploring different ways and techniques to look at illness experience is how we as a field can work towards enhancing the knowledge we produce and the support we can offer to patients and healthcare professionals.

6.7 Final considerations and reflections

This thesis enriches the current body of literature available on migraines and its impacts on people's lives. This work also highlights the potential that online platforms have as elements of informational and emotional support for people with migraines in general, and men in particular.

The findings from this work highlight the importance of acknowledging men as a population that also experiences and suffers from migraines. It is fundamental to include men's experiences in the migraine debate and place their lived experiences at the centre of discussions surrounding the effectiveness and applicability of different support systems. Currently, by not providing the support that is most likely to help them, we are failing men with migraines. It is key that future steps are taken towards understanding the role of masculinity in migraines. Especially, using methodologies that place their focus on lived experience and elicit insights from real-world experiences as the starting point to designing support systems and healthcare interventions.

By giving men the platform to speak about their experiences and their journeys, this PhD represented a personal walk in my participants' shoes. In fact, I saw myself in a lot of their stories, decisions, and thoughts. By understanding and relating to their day to day lives and the way these people navigate their conditions and the services available to them, I identified patterns and aspects that can be used to improve how migraine support systems meet the needs of men.

Finally, one will easily identify different reflexive actions throughout the different chapters that constitute this thesis. However, it is important to end this work with one last reflexive exercise to translate my growth as a researcher in my knowledge about migraines, men's health, and online communities. Firstly, this journey was crucial in eliciting my ability to work independently and going beyond following the guidelines to re-mastering them. This PhD was also key to broadening my understanding of migraine experiences. As a matter of fact, at the beginning of this journey, I did not know much about migraines in men, and I saw parts of myself in what my participants said in relation to people not knowing men also suffer from migraines. Changing the way I look at migraines and the people who suffer from them, is the most significant aspect of my academic growth I can identify from my lived experience of conducting research to understand an illness I have never experienced. I place the focal point of my lived experience of this PhD in having had the privilege to hear the stories of my participants and analyse them as part of my work and how that contributed to my personal and professional growth.

In the wider context, when it comes to seeking healthcare and support, men are still an understudied population. Despite what could be thought from the wider society, not accessing, or seeking healthcare in the conventional ways does not mean being uninterested in personal health and wellbeing. It just means that the current standards and systems that are in place to support certain populations might not be adequate for their real needs. This is the case for men with migraines, and the reason why people are going online for information and support rather than seeking medical care. As a scientific field, we need to do more to give voice to different sub-sets of the population by including them in research and by putting them at the centre of decisions to inform health and wellbeing practice.

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Appendices

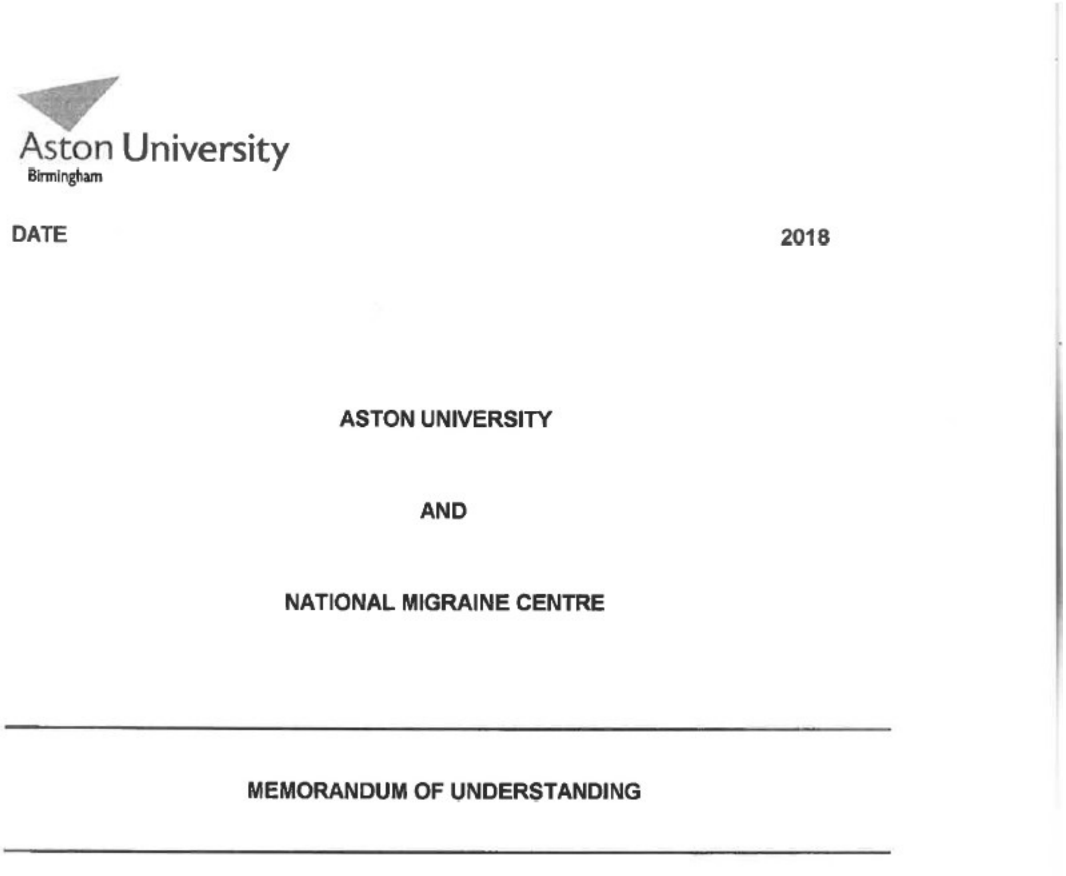
Appendix 1. Table with all the themes from each study included in chapter 2

Source	Theme/Category	Theme/Category	Theme/Category	Theme/Category	Theme/Category
Belam et al (2005)	Impact On life • Physical & Psychological	Making sense of the problem (hard to understand/meaning making)	Putting up with it	Doing something about it (self-help, advice to other People with Migraine & doctors)	
Peters et al (2003)	Headache Severity	Evaluation	Decision	Behaviour	
Peter et al (2004)	Healthcare use	Medication Use	Alternative Therapies	Social Support	Lifestyle and Self-help
Peters et al (2005)	Headaches • Pain and symptoms • Differentiating between their headaches • Perceptions of headaches as barriers and facilitators to management	Headache Impact	Headache as a health issues		
Rutberg et al (2013)	Building a Foundation of safeness • Using experiences of triggers as a guide • Striving for power to be in control	Amplifying the good in life • Acting thoughtfully to increase one's energy • Being in a process of accepting migraine as a part of life			

Varkey et al (2013)	Avoiding Migraine triggers	Introducing migraine inhibiting strategies	Preventing Migraine is a balance between letting it influence life completely and not letting it influence life at all (overarching theme)		
Velasco et al (2003)	Symptomatic aspects	Social aspects - Work and studies - Family Relationships - Social Relationships	Emotional aspects		

Colour code: Red - Different symptoms of migraines and their subjectivity; Green - Impact of migraines in different elements of one's life, Blue - Migraine management and prevention.

Appendix 2. Memorandum of Understanding Between Aston University and the National Migraine Centre.



Aston University
Birmingham

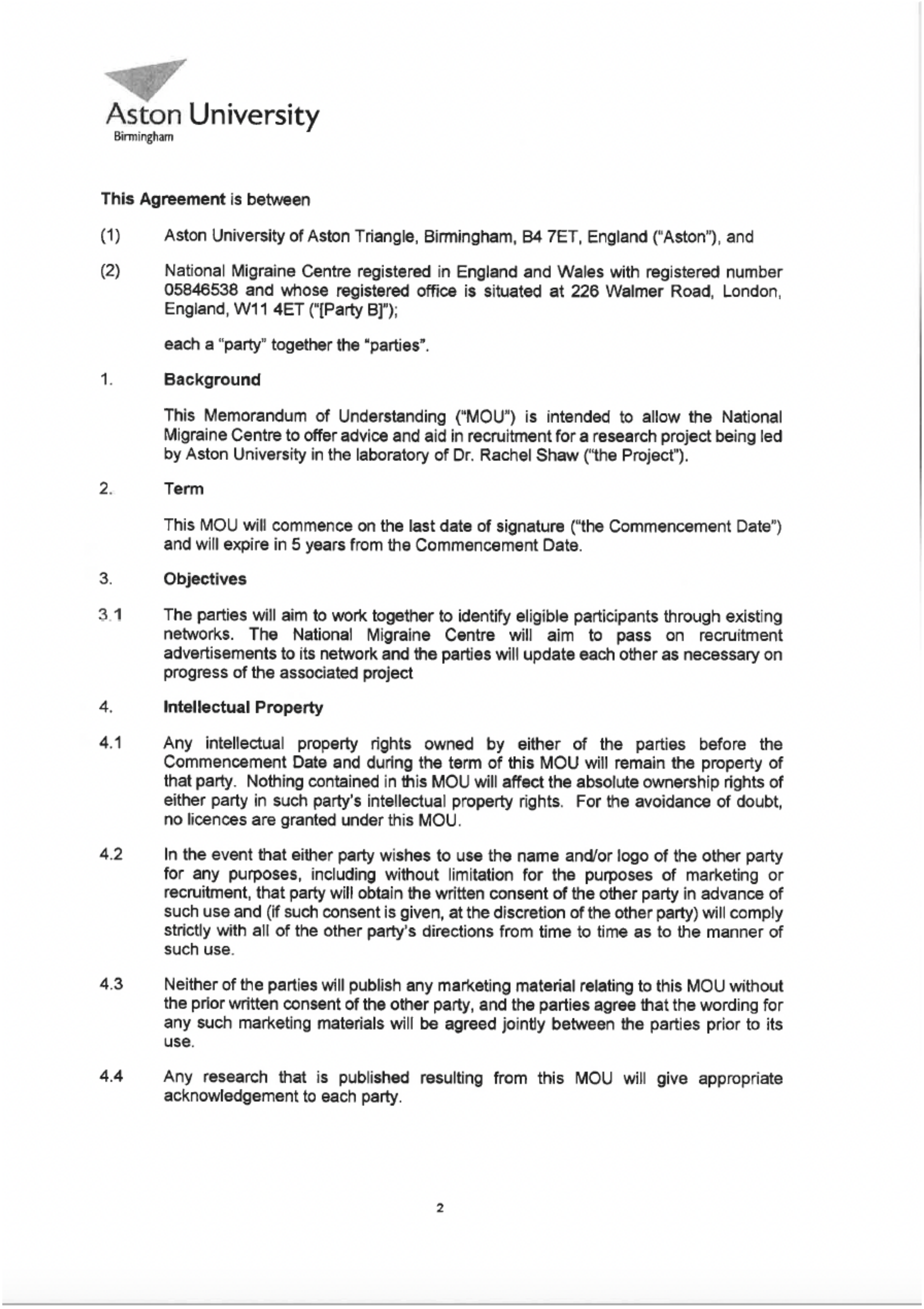
DATE 2018

ASTON UNIVERSITY

AND

NATIONAL MIGRAINE CENTRE

MEMORANDUM OF UNDERSTANDING



Aston University
Birmingham

This Agreement is between

(1) Aston University of Aston Triangle, Birmingham, B4 7ET, England ("Aston"), and

(2) National Migraine Centre registered in England and Wales with registered number 05846538 and whose registered office is situated at 226 Walmer Road, London, England, W11 4ET ("[Party B]");

each a "party" together the "parties".

1. **Background**

This Memorandum of Understanding ("MOU") is intended to allow the National Migraine Centre to offer advice and aid in recruitment for a research project being led by Aston University in the laboratory of Dr. Rachel Shaw ("the Project").

2. **Term**

This MOU will commence on the last date of signature ("the Commencement Date") and will expire in 5 years from the Commencement Date.

3. **Objectives**

3.1 The parties will aim to work together to identify eligible participants through existing networks. The National Migraine Centre will aim to pass on recruitment advertisements to its network and the parties will update each other as necessary on progress of the associated project

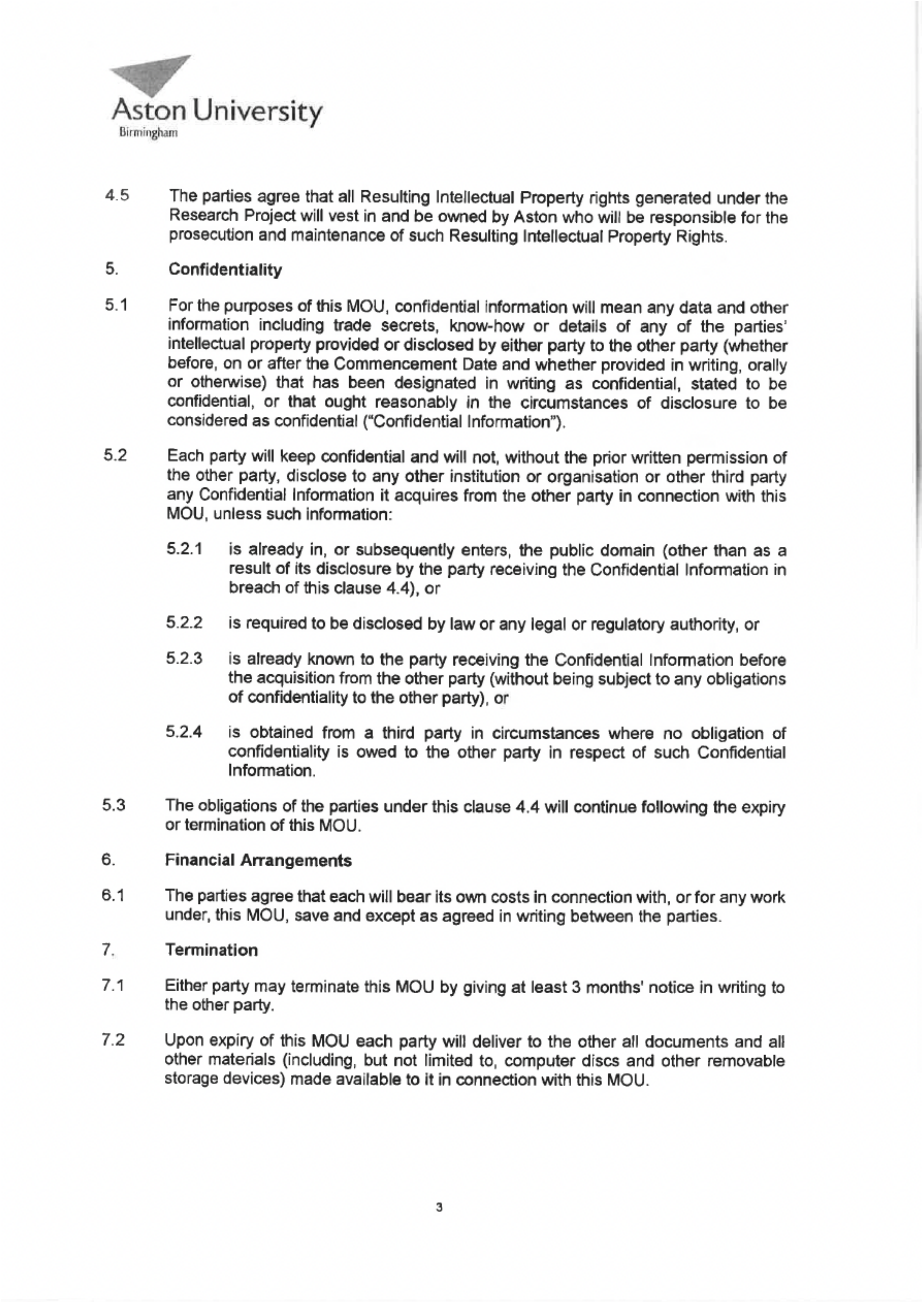
4. **Intellectual Property**

4.1 Any intellectual property rights owned by either of the parties before the Commencement Date and during the term of this MOU will remain the property of that party. Nothing contained in this MOU will affect the absolute ownership rights of either party in such party's intellectual property rights. For the avoidance of doubt, no licences are granted under this MOU.

4.2 In the event that either party wishes to use the name and/or logo of the other party for any purposes, including without limitation for the purposes of marketing or recruitment, that party will obtain the written consent of the other party in advance of such use and (if such consent is given, at the discretion of the other party) will comply strictly with all of the other party's directions from time to time as to the manner of such use.

4.3 Neither of the parties will publish any marketing material relating to this MOU without the prior written consent of the other party, and the parties agree that the wording for any such marketing materials will be agreed jointly between the parties prior to its use.

4.4 Any research that is published resulting from this MOU will give appropriate acknowledgement to each party.



Aston University
Birmingham

4.5 The parties agree that all Resulting Intellectual Property rights generated under the Research Project will vest in and be owned by Aston who will be responsible for the prosecution and maintenance of such Resulting Intellectual Property Rights.

5. **Confidentiality**

5.1 For the purposes of this MOU, confidential information will mean any data and other information including trade secrets, know-how or details of any of the parties' intellectual property provided or disclosed by either party to the other party (whether before, on or after the Commencement Date and whether provided in writing, orally or otherwise) that has been designated in writing as confidential, stated to be confidential, or that ought reasonably in the circumstances of disclosure to be considered as confidential ("Confidential Information").

5.2 Each party will keep confidential and will not, without the prior written permission of the other party, disclose to any other institution or organisation or other third party any Confidential Information it acquires from the other party in connection with this MOU, unless such information:

5.2.1 is already in, or subsequently enters, the public domain (other than as a result of its disclosure by the party receiving the Confidential Information in breach of this clause 4.4), or

5.2.2 is required to be disclosed by law or any legal or regulatory authority, or

5.2.3 is already known to the party receiving the Confidential Information before the acquisition from the other party (without being subject to any obligations of confidentiality to the other party), or

5.2.4 is obtained from a third party in circumstances where no obligation of confidentiality is owed to the other party in respect of such Confidential Information.

5.3 The obligations of the parties under this clause 4.4 will continue following the expiry or termination of this MOU.

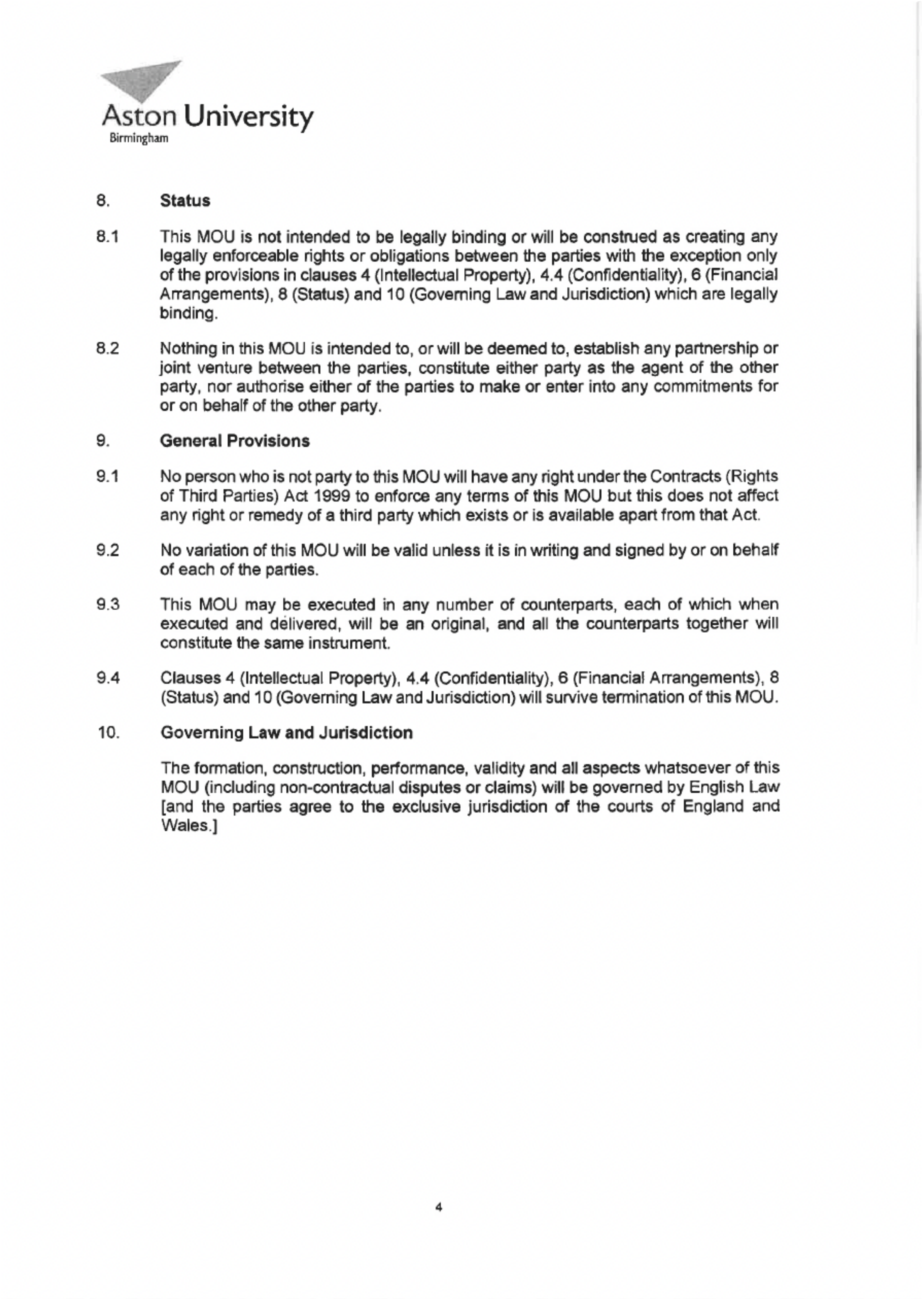
6. **Financial Arrangements**

6.1 The parties agree that each will bear its own costs in connection with, or for any work under, this MOU, save and except as agreed in writing between the parties.

7. **Termination**

7.1 Either party may terminate this MOU by giving at least 3 months' notice in writing to the other party.

7.2 Upon expiry of this MOU each party will deliver to the other all documents and all other materials (including, but not limited to, computer discs and other removable storage devices) made available to it in connection with this MOU.



Aston University
Birmingham

8. **Status**

8.1 This MOU is not intended to be legally binding or will be construed as creating any legally enforceable rights or obligations between the parties with the exception only of the provisions in clauses 4 (Intellectual Property), 4.4 (Confidentiality), 6 (Financial Arrangements), 8 (Status) and 10 (Governing Law and Jurisdiction) which are legally binding.

8.2 Nothing in this MOU is intended to, or will be deemed to, establish any partnership or joint venture between the parties, constitute either party as the agent of the other party, nor authorise either of the parties to make or enter into any commitments for or on behalf of the other party.

9. **General Provisions**

9.1 No person who is not party to this MOU will have any right under the Contracts (Rights of Third Parties) Act 1999 to enforce any terms of this MOU but this does not affect any right or remedy of a third party which exists or is available apart from that Act.

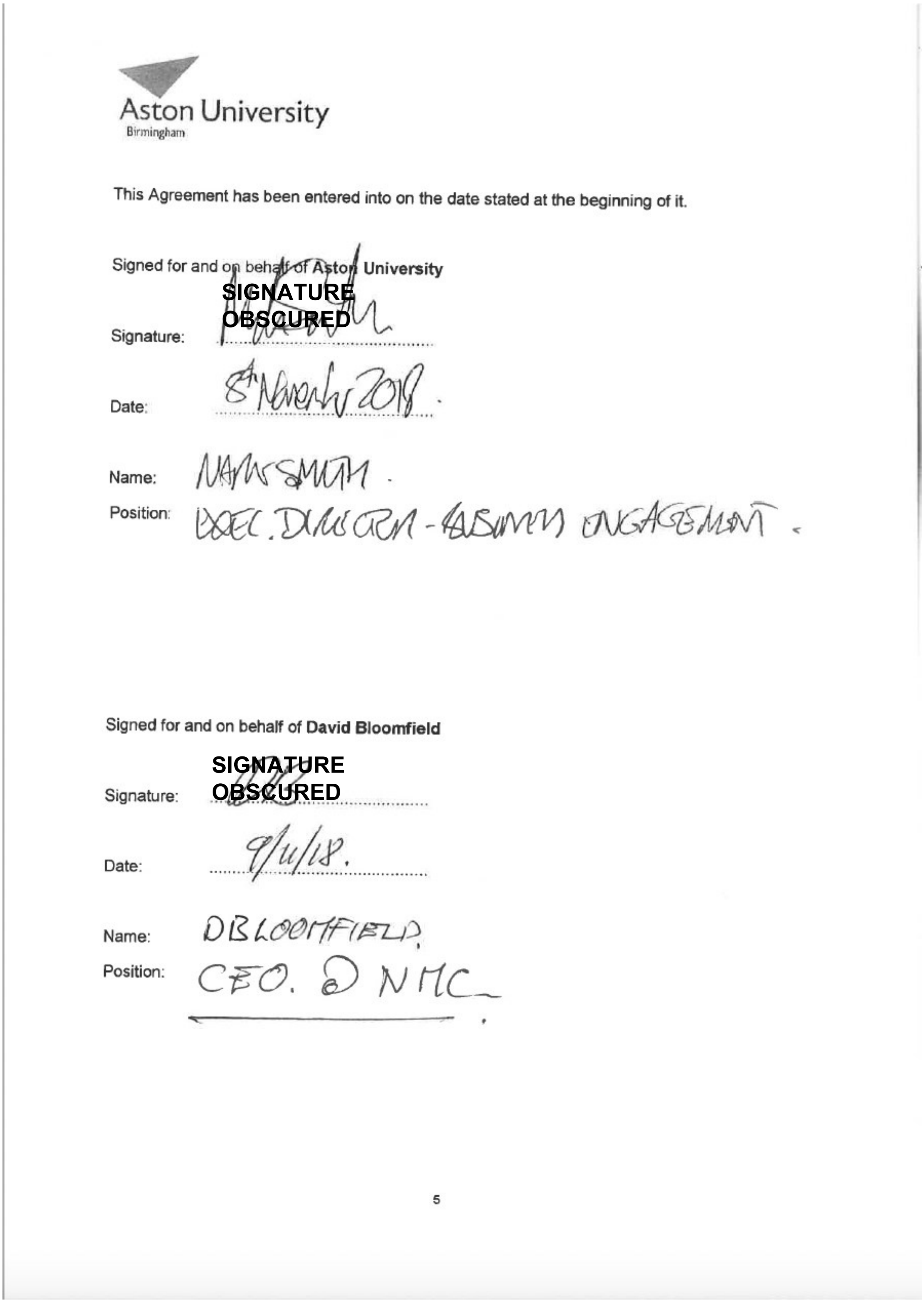
9.2 No variation of this MOU will be valid unless it is in writing and signed by or on behalf of each of the parties.

9.3 This MOU may be executed in any number of counterparts, each of which when executed and delivered, will be an original, and all the counterparts together will constitute the same instrument.

9.4 Clauses 4 (Intellectual Property), 4.4 (Confidentiality), 6 (Financial Arrangements), 8 (Status) and 10 (Governing Law and Jurisdiction) will survive termination of this MOU.

10. **Governing Law and Jurisdiction**

The formation, construction, performance, validity and all aspects whatsoever of this MOU (including non-contractual disputes or claims) will be governed by English Law [and the parties agree to the exclusive jurisdiction of the courts of England and Wales.]



Aston University
Birmingham

This Agreement has been entered into on the date stated at the beginning of it.

Signed for and on behalf of **Aston University**

Signature: SIGNATURE OBSCURED

Date: 8th November 2018.

Name: NAMS SMITH.

Position: EXEC. DIRECTOR - BUSINESS ENGAGEMENT.

Signed for and on behalf of **David Bloomfield**

Signature: SIGNATURE OBSCURED

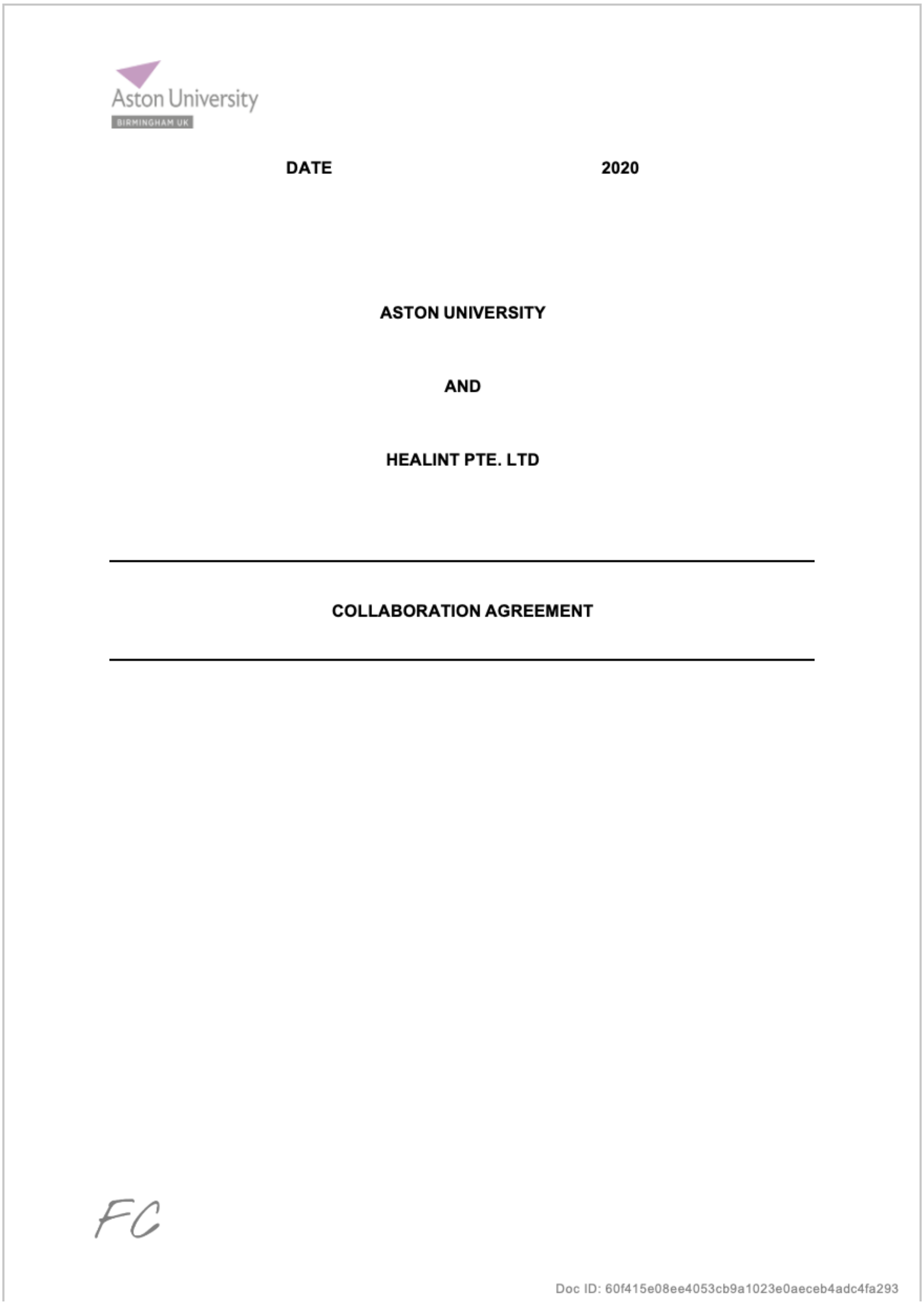
Date: 9/11/18.

Name: D BLOOMFIELD.

Position: CEO. @ NMC

5

Appendix 3. Memorandum of Understanding Between Aston University and Healint PTE Ltd.



Aston University
BIRMINGHAM UK

DATE 2020

ASTON UNIVERSITY

AND

HEALINT PTE. LTD

COLLABORATION AGREEMENT

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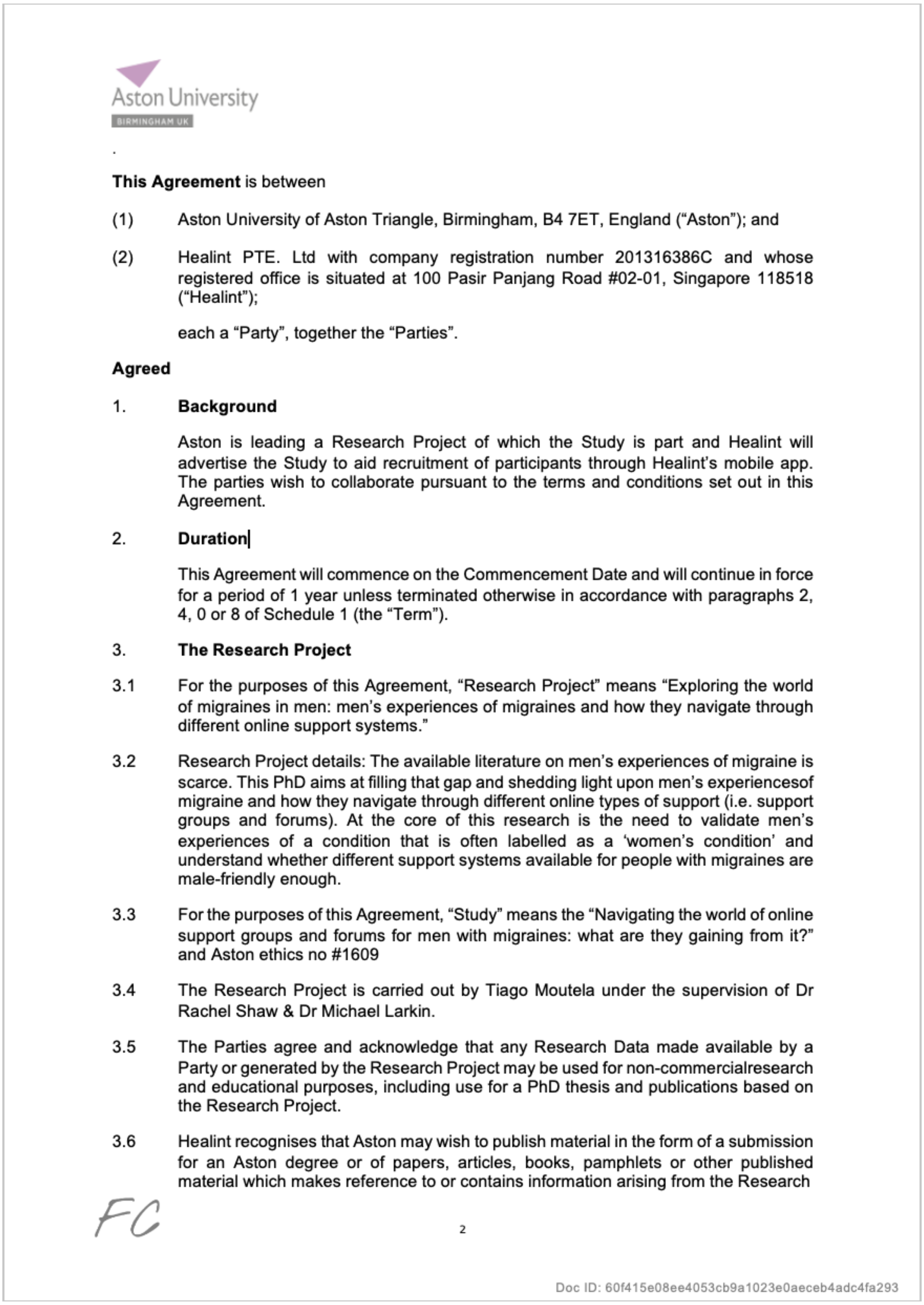

Aston University
BIRMINGHAM UK

.

This Agreement is between

(1) Aston University of Aston Triangle, Birmingham, B4 7ET, England ("Aston"); and

(2) Healint PTE. Ltd with company registration number 201316386C and whose registered office is situated at 100 Pasir Panjang Road #02-01, Singapore 118518 ("Healint");

each a "Party", together the "Parties".

Agreed

1. **Background**

Aston is leading a Research Project of which the Study is part and Healint will advertise the Study to aid recruitment of participants through Healint's mobile app. The parties wish to collaborate pursuant to the terms and conditions set out in this Agreement.

2. **Duration**

This Agreement will commence on the Commencement Date and will continue in force for a period of 1 year unless terminated otherwise in accordance with paragraphs 2, 4, 0 or 8 of Schedule 1 (the "Term").

3. **The Research Project**

3.1 For the purposes of this Agreement, "Research Project" means "Exploring the world of migraines in men: men's experiences of migraines and how they navigate through different online support systems."

3.2 Research Project details: The available literature on men's experiences of migraine is scarce. This PhD aims at filling that gap and shedding light upon men's experiencesof migraine and how they navigate through different online types of support (i.e. support groups and forums). At the core of this research is the need to validate men's experiences of a condition that is often labelled as a 'women's condition' and understand whether different support systems available for people with migraines are male-friendly enough.

3.3 For the purposes of this Agreement, "Study" means the "Navigating the world of online support groups and forums for men with migraines: what are they gaining from it?" and Aston ethics no #1609

3.4 The Research Project is carried out by Tiago Moutela under the supervision of Dr Rachel Shaw & Dr Michael Larkin.

3.5 The Parties agree and acknowledge that any Research Data made available by a Party or generated by the Research Project may be used for non-commercialresearch and educational purposes, including use for a PhD thesis and publications based on the Research Project.

3.6 Healint recognises that Aston may wish to publish material in the form of a submission for an Aston degree or of papers, articles, books, pamphlets or other published material which makes reference to or contains information arising from the Research

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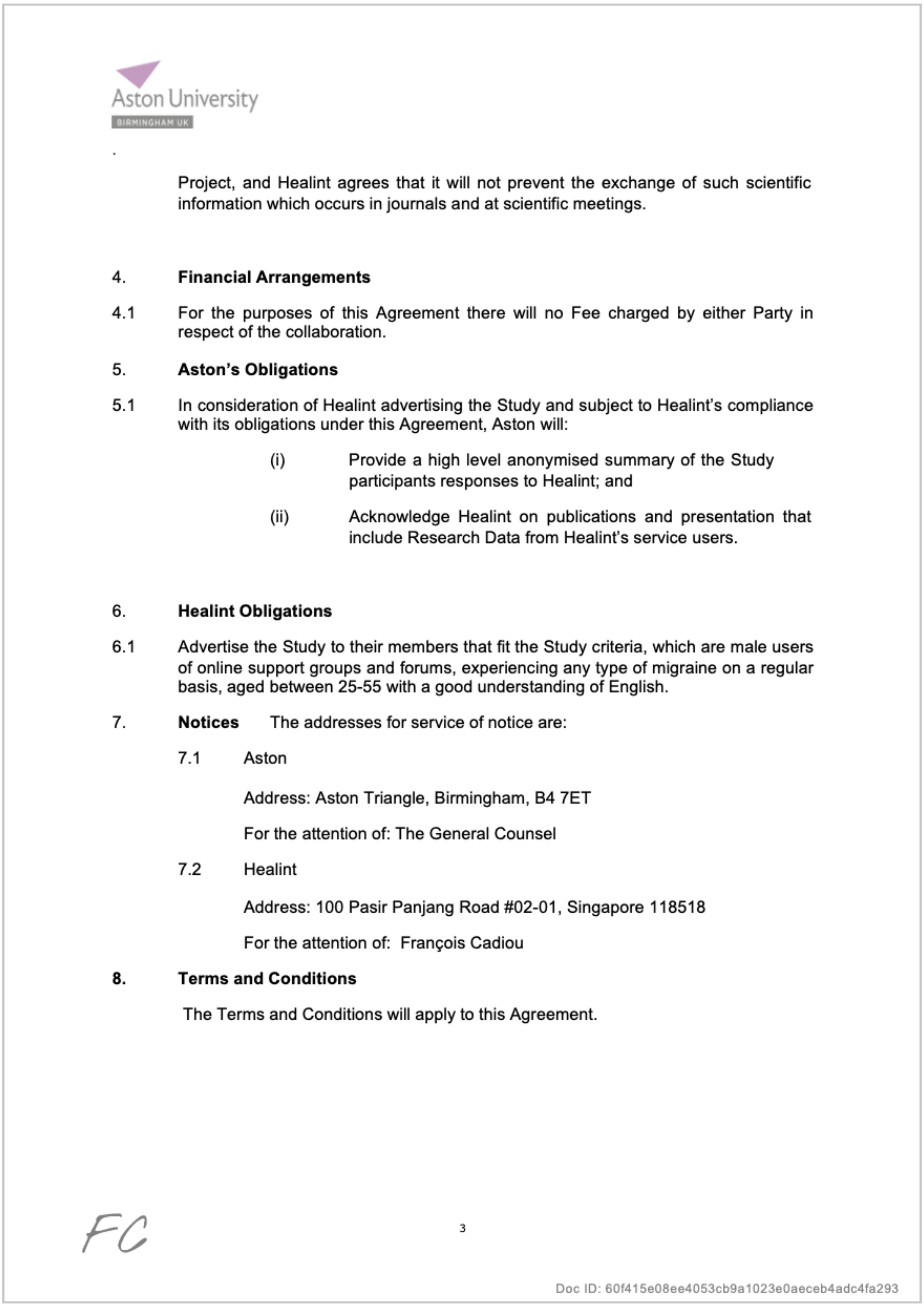

Aston University
BIRMINGHAM UK

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Project, and Healint agrees that it will not prevent the exchange of such scientific information which occurs in journals and at scientific meetings.

4. **Financial Arrangements**

4.1 For the purposes of this Agreement there will no Fee charged by either Party in respect of the collaboration.

5. **Aston's Obligations**

5.1 In consideration of Healint advertising the Study and subject to Healint's compliance with its obligations under this Agreement, Aston will:

(i) Provide a high level anonymised summary of the Study participants responses to Healint; and

(ii) Acknowledge Healint on publications and presentation that include Research Data from Healint's service users.

6. **Healint Obligations**

6.1 Advertise the Study to their members that fit the Study criteria, which are male users of online support groups and forums, experiencing any type of migraine on a regular basis, aged between 25-55 with a good understanding of English.

7. **Notices** The addresses for service of notice are:

7.1 Aston

Address: Aston Triangle, Birmingham, B4 7ET

For the attention of: The General Counsel

7.2 Healint

Address: 100 Pasir Panjang Road #02-01, Singapore 118518

For the attention of: François Cadiou

8. **Terms and Conditions**

The Terms and Conditions will apply to this Agreement.

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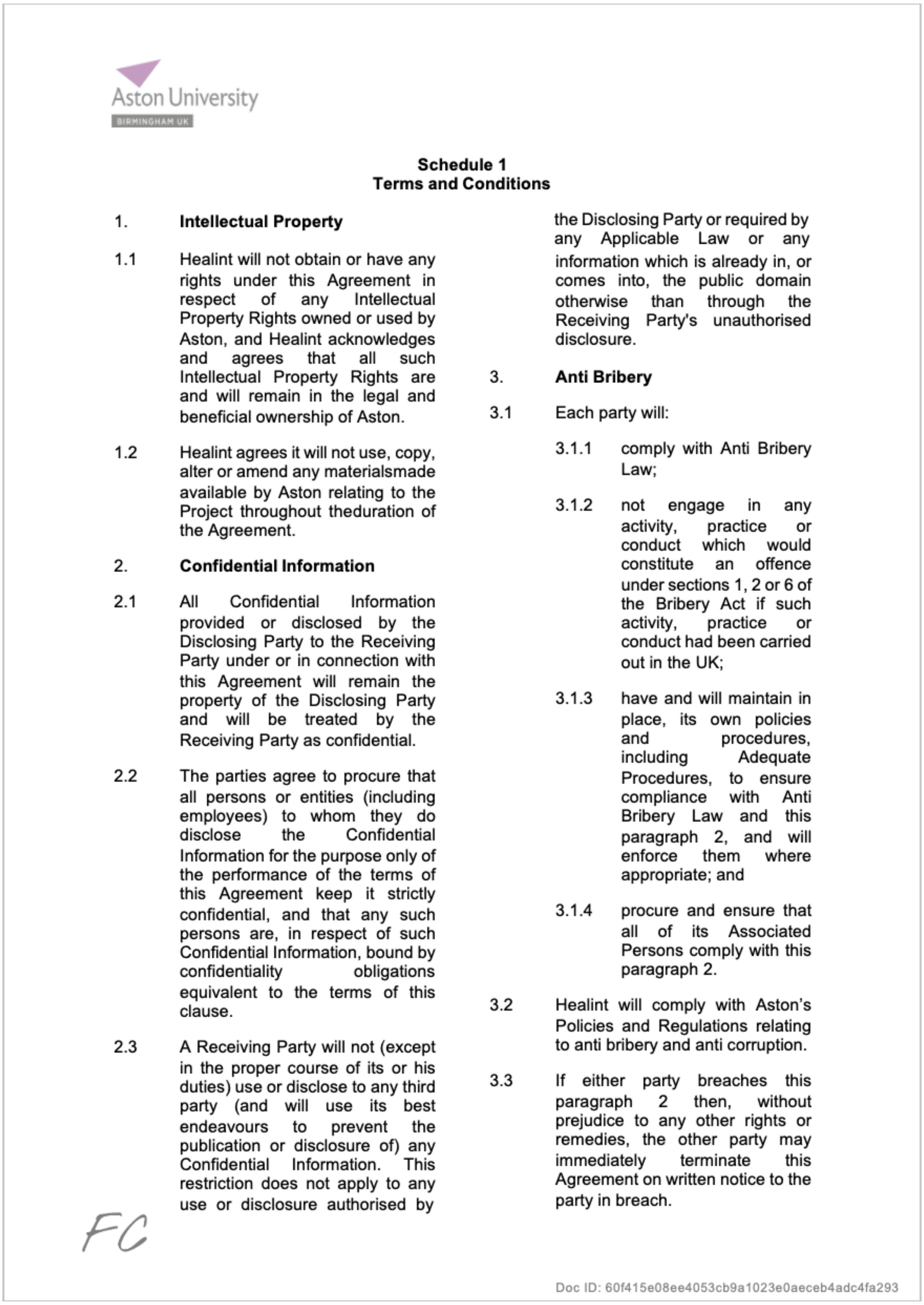

Aston University
BIRMINGHAM UK

Schedule 1
Terms and Conditions

1. **Intellectual Property**

1.1 Healint will not obtain or have any rights under this Agreement in respect of any Intellectual Property Rights owned or used by Aston, and Healint acknowledges and agrees that all such Intellectual Property Rights are and will remain in the legal and beneficial ownership of Aston.

1.2 Healint agrees it will not use, copy, alter or amend any materialsmade available by Aston relating to the Project throughout theduration of the Agreement.

2. **Confidential Information**

2.1 All Confidential Information provided or disclosed by the Disclosing Party to the Receiving Party under or in connection with this Agreement will remain the property of the Disclosing Party and will be treated by the Receiving Party as confidential.

2.2 The parties agree to procure that all persons or entities (including employees) to whom they do disclose the Confidential Information for the purpose only of the performance of the terms of this Agreement keep it strictly confidential, and that any such persons are, in respect of such Confidential Information, bound by confidentiality obligations equivalent to the terms of this clause.

2.3 A Receiving Party will not (except in the proper course of its or his duties) use or disclose to any third party (and will use its best endeavours to prevent the publication or disclosure of) any Confidential Information. This restriction does not apply to any use or disclosure authorised by the Disclosing Party or required by any Applicable Law or any information which is already in, or comes into, the public domain otherwise than through the Receiving Party's unauthorised disclosure.

3. **Anti Bribery**

3.1 Each party will:

3.1.1 comply with Anti Bribery Law;

3.1.2 not engage in any activity, practice or conduct which would constitute an offence under sections 1, 2 or 6 of the Bribery Act if such activity, practice or conduct had been carried out in the UK;

3.1.3 have and will maintain in place, its own policies and procedures, including Adequate Procedures, to ensure compliance with Anti Bribery Law and this paragraph 2, and will enforce them where appropriate; and

3.1.4 procure and ensure that all of its Associated Persons comply with this paragraph 2.

3.2 Healint will comply with Aston's Policies and Regulations relating to anti bribery and anti corruption.

3.3 If either party breaches this paragraph 2 then, without prejudice to any other rights or remedies, the other party may immediately terminate this Agreement on written notice to the party in breach.

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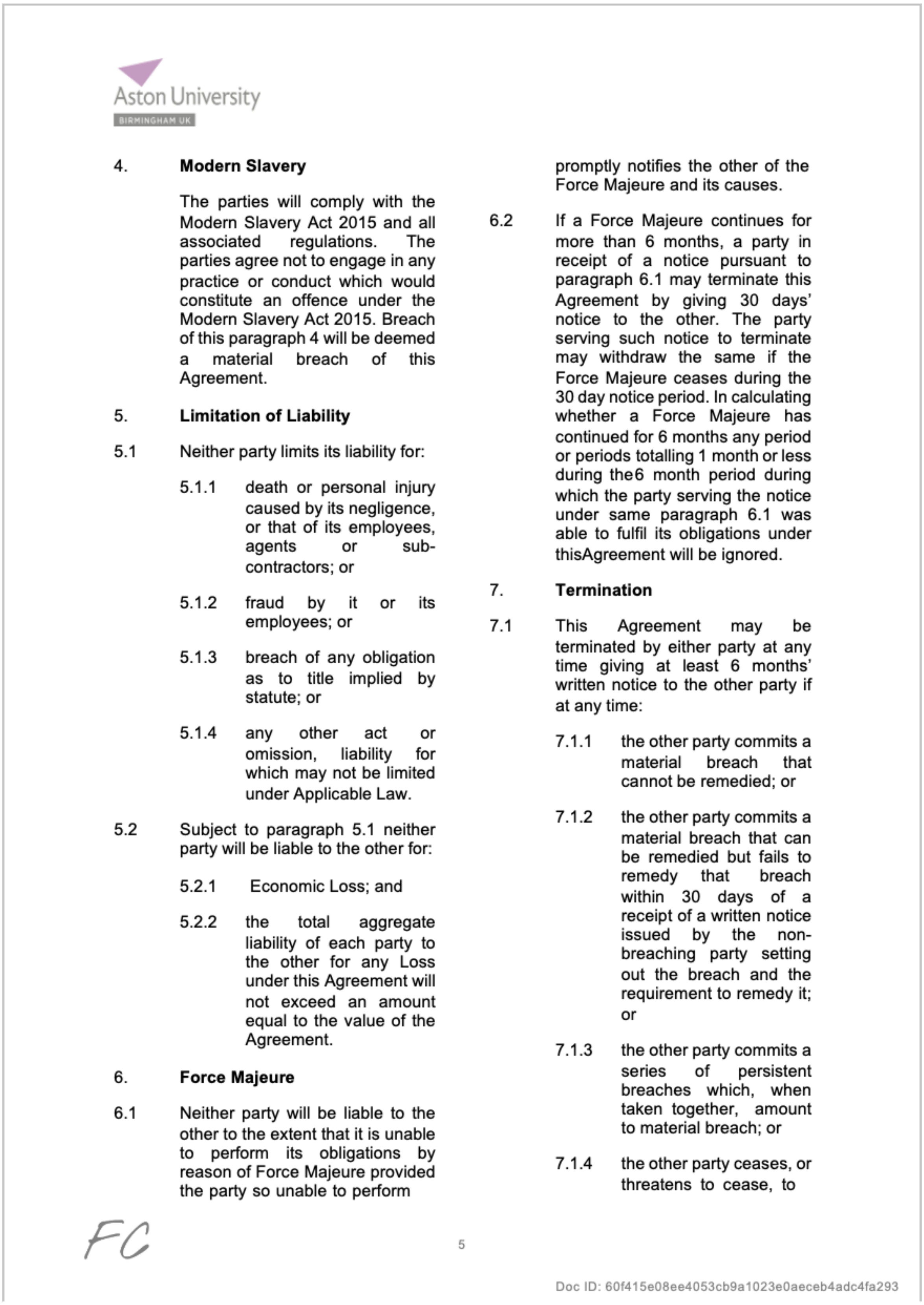

Aston University
BIRMINGHAM UK

4. **Modern Slavery**

The parties will comply with the Modern Slavery Act 2015 and all associated regulations. The parties agree not to engage in any practice or conduct which would constitute an offence under the Modern Slavery Act 2015. Breach of this paragraph 4 will be deemed a material breach of this Agreement.

5. **Limitation of Liability**

5.1 Neither party limits its liability for:

5.1.1 death or personal injury caused by its negligence, or that of its employees, agents or sub-contractors; or

5.1.2 fraud by it or its employees; or

5.1.3 breach of any obligation as to title implied by statute; or

5.1.4 any other act or omission, liability for which may not be limited under Applicable Law.

5.2 Subject to paragraph 5.1 neither party will be liable to the other for:

5.2.1 Economic Loss; and

5.2.2 the total aggregate liability of each party to the other for any Loss under this Agreement will not exceed an amount equal to the value of the Agreement.

6. **Force Majeure**

6.1 Neither party will be liable to the other to the extent that it is unable to perform its obligations by reason of Force Majeure provided the party so unable to perform promptly notifies the other of the Force Majeure and its causes.

6.2 If a Force Majeure continues for more than 6 months, a party in receipt of a notice pursuant to paragraph 6.1 may terminate this Agreement by giving 30 days' notice to the other. The party serving such notice to terminate may withdraw the same if the Force Majeure ceases during the 30 day notice period. In calculating whether a Force Majeure has continued for 6 months any period or periods totalling 1 month or less during the6 month period during which the party serving the notice under same paragraph 6.1 was able to fulfil its obligations under thisAgreement will be ignored.

7. **Termination**

7.1 This Agreement may be terminated by either party at any time giving at least 6 months' written notice to the other party if at any time:

7.1.1 the other party commits a material breach that cannot be remedied; or

7.1.2 the other party commits a material breach that can be remedied but fails to remedy that breach within 30 days of a receipt of a written notice issued by the non-breaching party setting out the breach and the requirement to remedy it; or

7.1.3 the other party commits a series of persistent breaches which, when taken together, amount to material breach; or

7.1.4 the other party ceases, or threatens to cease, to

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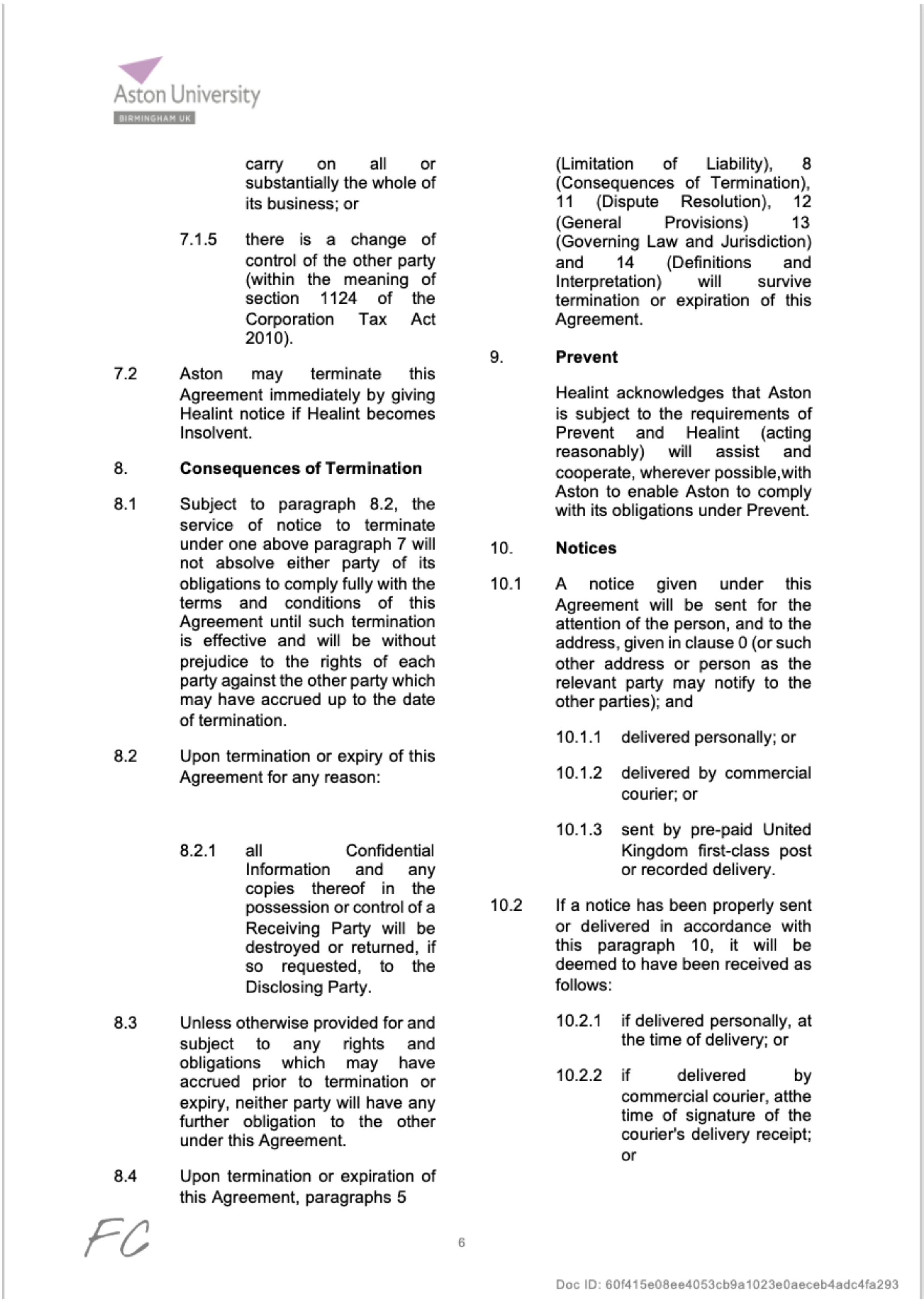

carry on all or substantially the whole of its business; or

7.1.5 there is a change of control of the other party (within the meaning of section 1124 of the Corporation Tax Act 2010).

7.2 Aston may terminate this Agreement immediately by giving Healint notice if Healint becomes Insolvent.

8. **Consequences of Termination**

8.1 Subject to paragraph 8.2, the service of notice to terminate under one above paragraph 7 will not absolve either party of its obligations to comply fully with the terms and conditions of this Agreement until such termination is effective and will be without prejudice to the rights of each party against the other party which may have accrued up to the date of termination.

8.2 Upon termination or expiry of this Agreement for any reason:

8.2.1 all Confidential Information and any copies thereof in the possession or control of a Receiving Party will be destroyed or returned, if so requested, to the Disclosing Party.

8.3 Unless otherwise provided for and subject to any rights and obligations which may have accrued prior to termination or expiry, neither party will have any further obligation to the other under this Agreement.

8.4 Upon termination or expiration of this Agreement, paragraphs 5 (Limitation of Liability), 8 (Consequences of Termination), 11 (Dispute Resolution), 12 (General Provisions) 13 (Governing Law and Jurisdiction) and 14 (Definitions and Interpretation) will survive termination or expiration of this Agreement.

9. **Prevent**

Healint acknowledges that Aston is subject to the requirements of Prevent and Healint (acting reasonably) will assist and cooperate, wherever possible,with Aston to enable Aston to comply with its obligations under Prevent.

10. **Notices**

10.1 A notice given under this Agreement will be sent for the attention of the person, and to the address, given in clause 0 (or such other address or person as the relevant party may notify to the other parties); and

10.1.1 delivered personally; or

10.1.2 delivered by commercial courier; or

10.1.3 sent by pre-paid United Kingdom first-class post or recorded delivery.

10.2 If a notice has been properly sent or delivered in accordance with this paragraph 10, it will be deemed to have been received as follows:

10.2.1 if delivered personally, at the time of delivery; or

10.2.2 if delivered by commercial courier, atthe time of signature of the courier's delivery receipt; or

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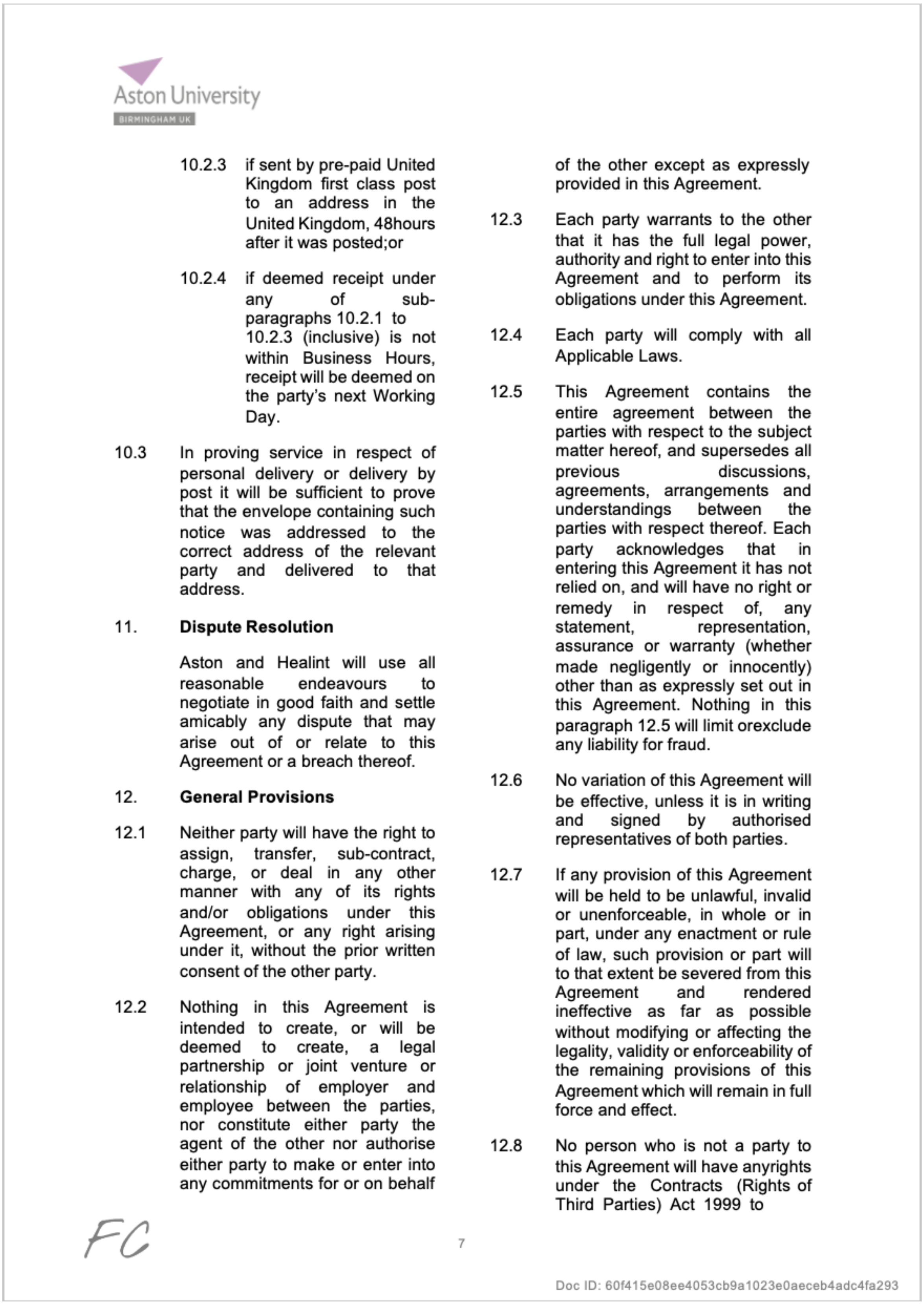

10.2.3 if sent by pre-paid United Kingdom first class post to an address in the United Kingdom, 48hours after it was posted;or

10.2.4 if deemed receipt under any of sub-paragraphs 10.2.1 to 10.2.3 (inclusive) is not within Business Hours, receipt will be deemed on the party's next Working Day.

10.3 In proving service in respect of personal delivery or delivery by post it will be sufficient to prove that the envelope containing such notice was addressed to the correct address of the relevant party and delivered to that address.

11. Dispute Resolution

Aston and Healint will use all reasonable endeavours to negotiate in good faith and settle amicably any dispute that may arise out of or relate to this Agreement or a breach thereof.

12. General Provisions

12.1 Neither party will have the right to assign, transfer, sub-contract, charge, or deal in any other manner with any of its rights and/or obligations under this Agreement, or any right arising under it, without the prior written consent of the other party.

12.2 Nothing in this Agreement is intended to create, or will be deemed to create, a legal partnership or joint venture or relationship of employer and employee between the parties, nor constitute either party the agent of the other nor authorise either party to make or enter into any commitments for or on behalf of the other except as expressly provided in this Agreement.

12.3 Each party warrants to the other that it has the full legal power, authority and right to enter into this Agreement and to perform its obligations under this Agreement.

12.4 Each party will comply with all Applicable Laws.

12.5 This Agreement contains the entire agreement between the parties with respect to the subject matter hereof, and supersedes all previous discussions, agreements, arrangements and understandings between the parties with respect thereof. Each party acknowledges that in entering this Agreement it has not relied on, and will have no right or remedy in respect of, any statement, representation, assurance or warranty (whether made negligently or innocently) other than as expressly set out in this Agreement. Nothing in this paragraph 12.5 will limit orexclude any liability for fraud.

12.6 No variation of this Agreement will be effective, unless it is in writing and signed by authorised representatives of both parties.

12.7 If any provision of this Agreement will be held to be unlawful, invalid or unenforceable, in whole or in part, under any enactment or rule of law, such provision or part will to that extent be severed from this Agreement and rendered ineffective as far as possible without modifying or affecting the legality, validity or enforceability of the remaining provisions of this Agreement which will remain in full force and effect.

12.8 No person who is not a party to this Agreement will have anyrights under the Contracts (Rights of Third Parties) Act 1999 to

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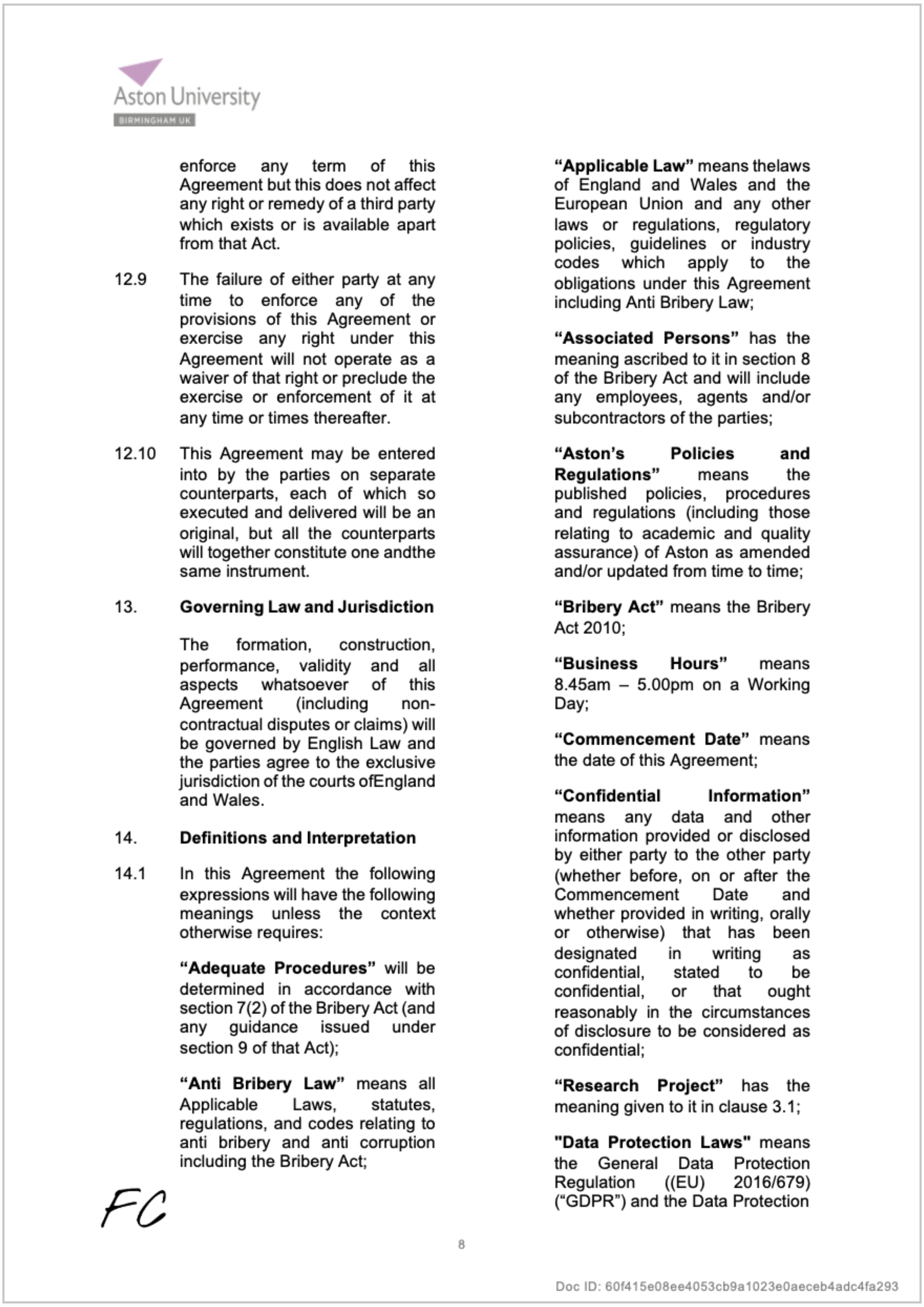

enforce any term of this Agreement but this does not affect any right or remedy of a third party which exists or is available apart from that Act.

12.9 The failure of either party at any time to enforce any of the provisions of this Agreement or exercise any right under this Agreement will not operate as a waiver of that right or preclude the exercise or enforcement of it at any time or times thereafter.

12.10 This Agreement may be entered into by the parties on separate counterparts, each of which so executed and delivered will be an original, but all the counterparts will together constitute one andthe same instrument.

13. Governing Law and Jurisdiction

The formation, construction, performance, validity and all aspects whatsoever of this Agreement (including non-contractual disputes or claims) will be governed by English Law and the parties agree to the exclusive jurisdiction of the courts ofEngland and Wales.

14. Definitions and Interpretation

14.1 In this Agreement the following expressions will have the following meanings unless the context otherwise requires:

“Adequate Procedures” will be determined in accordance with section 7(2) of the Bribery Act (and any guidance issued under section 9 of that Act);

“Anti Bribery Law” means all Applicable Laws, statutes, regulations, and codes relating to anti bribery and anti corruption including the Bribery Act;

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“Applicable Law” means thelaws of England and Wales and the European Union and any other laws or regulations, regulatory policies, guidelines or industry codes which apply to the obligations under this Agreement including Anti Bribery Law;

“Associated Persons” has the meaning ascribed to it in section 8 of the Bribery Act and will include any employees, agents and/or subcontractors of the parties;

“Aston’s Policies and Regulations” means the published policies, procedures and regulations (including those relating to academic and quality assurance) of Aston as amended and/or updated from time to time;

“Bribery Act” means the Bribery Act 2010;

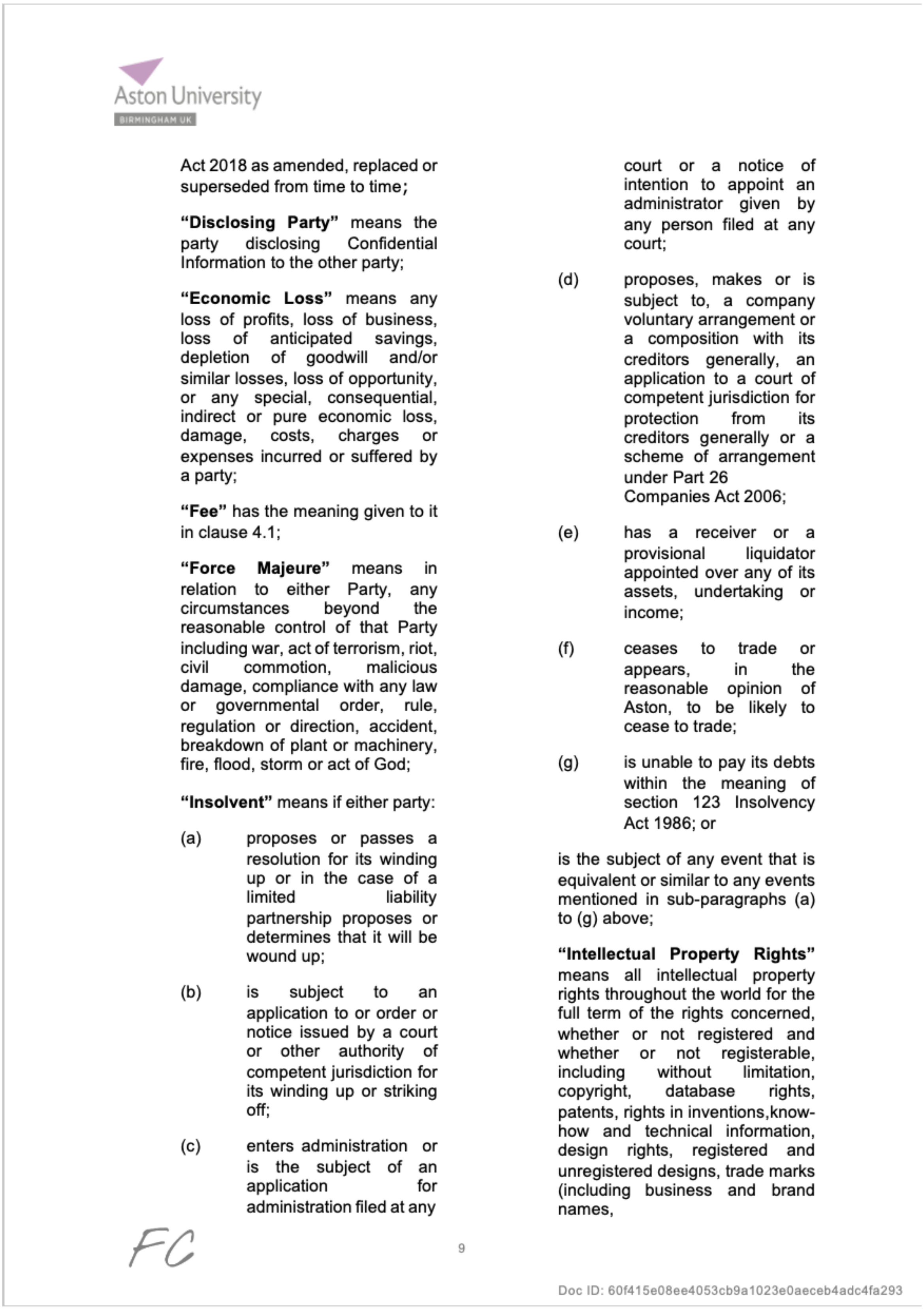
“Business Hours” means 8.45am – 5.00pm on a Working Day;

“Commencement Date” means the date of this Agreement;

“Confidential Information” means any data and other information provided or disclosed by either party to the other party (whether before, on or after the Commencement Date and whether provided in writing, orally or otherwise) that has been designated in writing as confidential, stated to be confidential, or that ought reasonably in the circumstances of disclosure to be considered as confidential;

“Research Project” has the meaning given to it in clause 3.1;

"Data Protection Laws" means the General Data Protection Regulation ((EU) 2016/679) (“GDPR”) and the Data Protection



Act 2018 as amended, replaced or superseded from time to time;

“Disclosing Party” means the party disclosing Confidential Information to the other party;

“Economic Loss” means any loss of profits, loss of business, loss of anticipated savings, depletion of goodwill and/or similar losses, loss of opportunity, or any special, consequential, indirect or pure economic loss, damage, costs, charges or expenses incurred or suffered by a party;

“Fee” has the meaning given to it in clause 4.1;

“Force Majeure” means in relation to either Party, any circumstances beyond the reasonable control of that Party including war, act of terrorism, riot, civil commotion, malicious damage, compliance with any law or governmental order, rule, regulation or direction, accident, breakdown of plant or machinery, fire, flood, storm or act of God;

“Insolvent” means if either party:

(a) proposes or passes a resolution for its winding up or in the case of a limited liability partnership proposes or determines that it will be wound up;

(b) is subject to an application to or order or notice issued by a court or other authority of competent jurisdiction for its winding up or striking off;

(c) enters administration or is the subject of an application for administration filed at any court or a notice of intention to appoint an administrator given by any person filed at any court;

(d) proposes, makes or is subject to, a company voluntary arrangement or a composition with its creditors generally, an application to a court of competent jurisdiction for protection from its creditors generally or a scheme of arrangement under Part 26 Companies Act 2006;

(e) has a receiver or a provisional liquidator appointed over any of its assets, undertaking or income;

(f) ceases to trade or appears, in the reasonable opinion of Aston, to be likely to cease to trade;

(g) is unable to pay its debts within the meaning of section 123 Insolvency Act 1986; or

is the subject of any event that is equivalent or similar to any events mentioned in sub-paragraphs (a) to (g) above;

“Intellectual Property Rights” means all intellectual property rights throughout the world for the full term of the rights concerned, whether or not registered and whether or not registerable, including without limitation, copyright, database rights, patents, rights in inventions,know-how and technical information, design rights, registered and unregistered designs, trade marks (including business and brand names,

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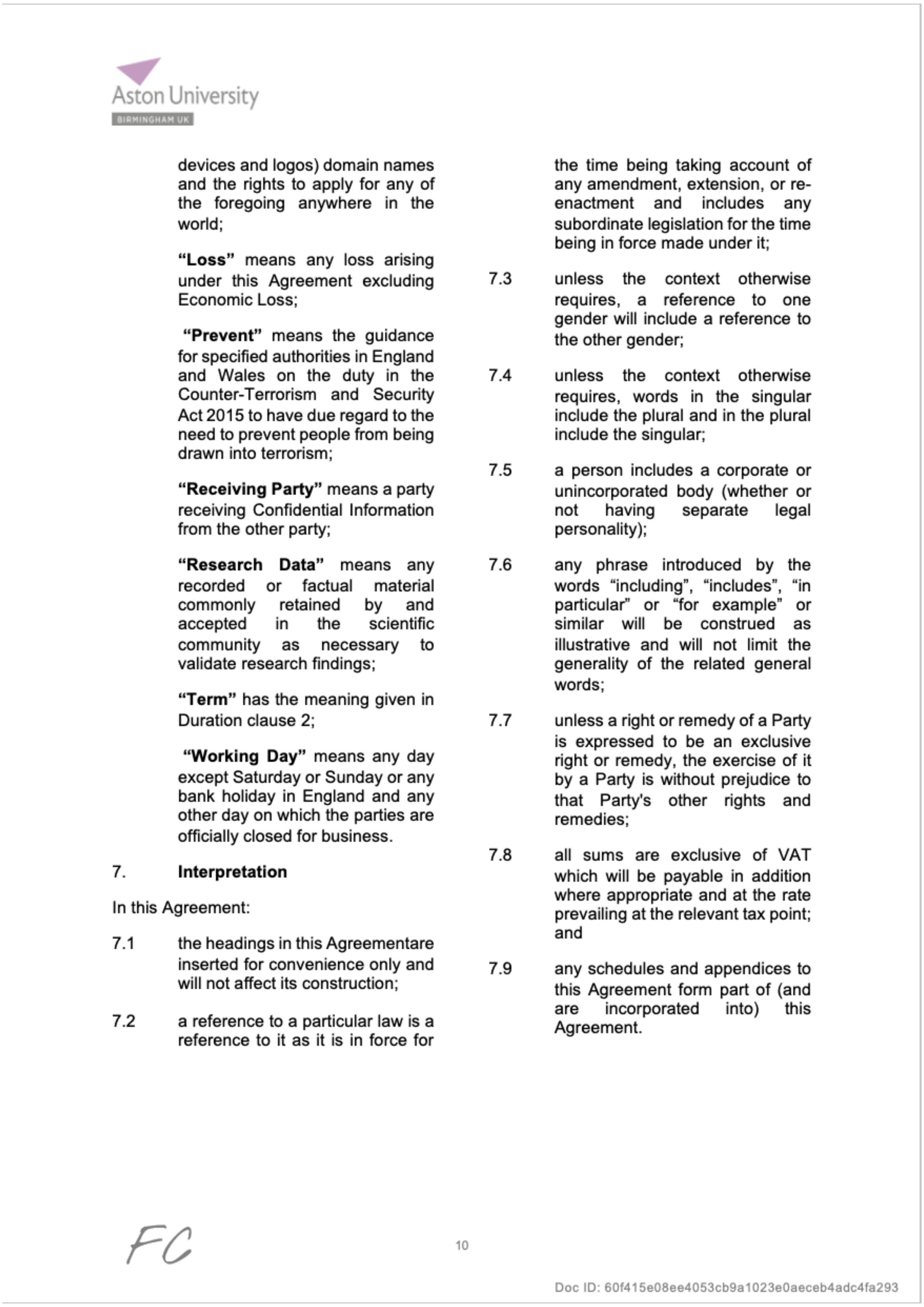

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devices and logos) domain names and the rights to apply for any of the foregoing anywhere in the world;

“Loss” means any loss arising under this Agreement excluding Economic Loss;

“Prevent” means the guidance for specified authorities in England and Wales on the duty in the Counter-Terrorism and Security Act 2015 to have due regard to the need to prevent people from being drawn into terrorism;

“Receiving Party” means a party receiving Confidential Information from the other party;

“Research Data” means any recorded or factual material commonly retained by and accepted in the scientific community as necessary to validate research findings;

“Term” has the meaning given in Duration clause 2;

“Working Day” means any day except Saturday or Sunday or any bank holiday in England and any other day on which the parties are officially closed for business.

7. Interpretation

In this Agreement:

7.1 the headings in this Agreementare inserted for convenience only and will not affect its construction;

7.2 a reference to a particular law is a reference to it as it is in force for the time being taking account of any amendment, extension, or re-enactment and includes any subordinate legislation for the time being in force made under it;

7.3 unless the context otherwise requires, a reference to one gender will include a reference to the other gender;

7.4 unless the context otherwise requires, words in the singular include the plural and in the plural include the singular;

7.5 a person includes a corporate or unincorporated body (whether or not having separate legal personality);

7.6 any phrase introduced by the words “including”, “includes”, “in particular” or “for example” or similar will be construed as illustrative and will not limit the generality of the related general words;

7.7 unless a right or remedy of a Party is expressed to be an exclusive right or remedy, the exercise of it by a Party is without prejudice to that Party's other rights and remedies;

7.8 all sums are exclusive of VAT which will be payable in addition where appropriate and at the rate prevailing at the relevant tax point; and

7.9 any schedules and appendices to this Agreement form part of (and are incorporated into) this Agreement.

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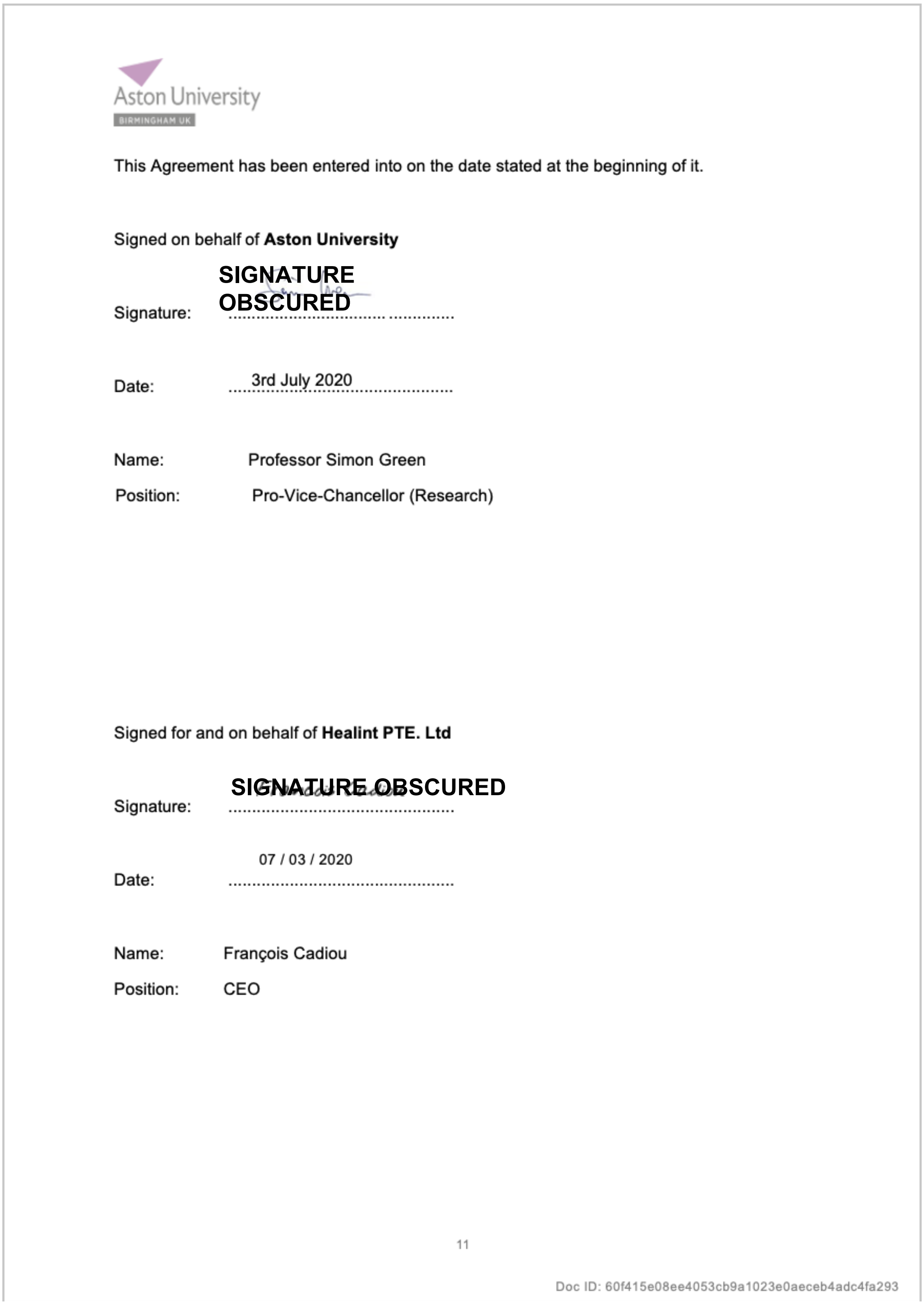

This Agreement has been entered into on the date stated at the beginning of it.

Signed on behalf of **Aston University**

Signature: SIGNATURE OBSCURED

Date: 3rd July 2020

Name: Professor Simon Green

Position: Pro-Vice-Chancellor (Research)

Signed for and on behalf of **Healint PTE. Ltd**

Signature: SIGNATURE OBSCURED

Date: 07 / 03 / 2020

Name: François Cadiou

Position: CEO