Providing Better Information and Support for the Treatment and Diagnosis of Patients Living with Age-Related Macular Degeneration (AMD)

By

Tawanda Fidelis Pendeke

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Abstract

Age related Macular Degeneration (AMD) is a condition that causes loss of central vision in people aged 65 years and above and has a significant impact on their lives. Literature exploring the lived experiences and potential treatment of this condition has highlighted deficiencies in information provision for this group. As such, the purpose of this programme of work, is to understand and contribute towards the provision of better information and support for the diagnosis and treatment of patients living with this condition, using qualitative methods. This programme of work includes: a qualitative meta-synthesis, focus groups, observation, and analysis of in-depth interviewing using thematic analysis and critical narrative analysis, to get a better understanding of patients' experiences of aspects relating to information provision across multiple dimensions of journey living with AMD. I present four separate studies each designed to answer specific research questions. The first is the meta-synthesis which sort to examine the presentation of information when consenting patients to treatment. The second study evaluated information materials currently available to AMD patients with the view to identify barriers and facilitators to their accessibility. The third study explored patients and clinician' perceptions and experiences of information provision at diagnosis, particularly aspects that determine decision making to consent to treatment, methods to gain consent, including their preferences and priorities. The third study explored the views and experiences of first time attenders to AMD support groups. Through rigorous analysis, I identify a range of themes which highlight the shared and divergent experiences of participants in this programme of work regards information provision processes. I relate the findings of the four studies to the wider psychological literature on information provision & chronic illness and make recommendations for health care professionals and services to develop methods of information provision that are responsive to the needs, preferences and values of AMD patients.

Keywords: Age related macular degeneration, information materials, diagnostic consultations, consent, support groups, qualitative methods, working group, and critical narrative analysis

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Table of Contents

CHAPTER ONE: Giving Context to the Study

1 Introduction

This programme of work presents a series of research studies designed to explore fundamental characteristics concerned with providing better information and support for the diagnosis and treatment of patients living with age related macular degeneration (AMD) in the United Kingdom (UK).

Ageing is a natural and continuous process that brings about numerous physiological changes in a human organism's body throughout their lifespan. However, while this process may be considered natural and a necessary part of life, it causes the degeneration of various body organs that will cease to function optimally in older adults and often leads to the manifestation of various complications and age-related ailments. Amongst these age-related ailments is AMD, a condition that is considered the most common cause of sight impairment and blindness in people aged 65 and above (Owen et al., 2012). It has an impact on older adults' ability to function optimally in all spheres of their lives, albeit occupationally (e.g. reading, writing, driving, and recognising faces amongst other things), and also has a significant impact on their psychological well-being, precipitated by the uncertainty of losing a sensory component that allowed them to visually access the majority of their environmental, social and occupational information (Arking & Arking, 2006). However, while there have been significant strides made within healthcare, in relation to treatments and service provision for this group, fundamentally there are significant discrepancies in information provision, communicated, written or otherwise (Burton, 2012), which impacts understanding of diagnosis, decision making to consent to treatment, adherence and the subsequent management of the AMD over time (Williams et al., 1998). The lack of information to access practical and emotional support further compounds the challenges faced by this group (Singh, 2005). Drawing on Habermas (1984)'s theory of communicative action, it is evident that clinicians need to create an environment that encourages reciprocal actions with regards to information provision and information acquisition. More importantly, they need to recognise that they are proximal determinants of the type and quality of information patients receive in sense making events, such as, diagnostic consultations (French, Green, O'Connor, et al., 2012). This theory offers a solid outline for the process on how to construct a conversation that observes the rules and norms of communicative rationality when disseminating information to patients' during consultations (Walseth and Schei, 2011). Its emphasis lies within three dimensions of the lifeworld (e.g. the objective, the social and subjective world) in seeking to understand the patient, guided of cause by questions that underpin the three dimensions stated above (e.g. what is practically feasible for the patient to do? what is right for the patient to do? And what is good for the patient to do?). These questions are useful in as far as helping clinicians providing relevant (e.g. lifeworld-led) information that helps patients understand AMD better, its treatment and how to manage it.

1.1 Age-Related Macular Degeneration (AMD)

AMD is a progressive chronic medical disorder that may lead to irreversible loss of central vision (Mitchell & Bradley, 2006), amongst older adults. In the UK and other industrialized countries, AMD is the leading cause of registerable sight impairment (Bunce & Wormald, 2006; Owen et al., 2012; Seddon & Chen, 2004; World Health Organisation [WHO], 2004), and in most instances, AMD is bilateral, although both eyes may be affected differently (Klein, 1999), and can occur in two forms; dry form (geographic atrophy) and the wet form (neovascular). At present the aetiology of this complex disorder is poorly understood, although it has been associated with multiple factors playing a role in its pathogenesis, including age, genetic variants and environmental factors (Nowak, 2006; NICE, 2018). Since this condition affects the macular, an important part of the retina that is utilized for valuable activities such as, facial recognition, reading and writing amongst other things (Mitchell & Bradley, 2006), its deterioration has an adverse impact on an individual's ability to optimally access information visually, which directly and significantly impacts on their overall quality of life (Mitchel, Bradley, Anderson et al., 2002). In some cases, following diagnosis AMD patients report substantial health related problems that include amongst others, the Charles Bonnet Syndrome (CBS) (Jackson and Ferencz, 2009), where they experience visual hallucinations, usually unrelated to the underlying pathology (Burton et al., 2012; Menon, 2005). CBS in some instances, may not be recognized in practice and many patients do not disclose experiencing hallucination for fear of being labelled mentally unwell (Vojnokovic, Radeljak, Dessardo et al., 2010). This could be attributed to some clinicians' lacking awareness into CBS, and therefore may be dismissive of the symptoms as either psychosis or a decline in cognitive function, rather than a comorbidity of AMD (Menon, 2005). To this extent there is a need for clinicians to broaden their knowledge base around co-morbidities associated with AMD and their symptomatic presentations in order to address such situations appropriately and provide adequate information during consultations that helps patients understand and equips them to manage it and lessen its psychosocial impact.

It is evident AMD has a profound psychosocial impact on individuals' lives. In most cases they report health resource utilisation issues that includes; increased risks of falling (Brennan et al., 2011; Cruess, Zlateva, Xu et al., 2008; Rovner & Casten, 2008; Tuttle & Tuttle, 2004), increased depression and psychological disturbances (Brody et al., 2001; Rovner, Casten, Hegel, Hauck & Tasman, 2007), social isolation (Cahill, Stinnett, Banks, Freedman & Toth, 2005), disablement in those whose sight has severely deteriorated (Thetford, Bennett, Hodge, Knox and Robinson, 2015), higher needs for treatments relating to anxiety and depression (Brody et al., 2001), assistance with daily living activities, as well as an increased need to have access to vision enhancing equipment and accessible information materials (Cruess et al., 2008). Bury (1982)'s biographical disruption theory embodies these experiences. For instance, loss of vision is disabling and disrupts the 'normal' flow of everyday life occupationally, thus introducing a sense of uncertainty, particularly where information and support are lacking, regardless of the form one is diagnosed with.

1.1.1 Forms of AMD

Of the two forms of AMD, the dry form is the more prevalent of the two and is characterized by accumulation of drusen between the retinal pigment epithelium and Bruch's Membrane (Chong, 2003) and it is associated with profound vision loss and has no approved medical treatments available currently. National Institute for Health and Care guidelines (NICE, 2018), recommended that as part of best practice, clinicians should sign post people diagnosed with this form of AMD to the low visual services and assist with certification for sight impairment. The wet form on the other hand is the least prevalent compared to the dry form and it is characterized by growth of new blood vessels in the retina that subsequently disrupt the photoreceptors. It is more serious and accounts for most cases of severe visual impairment associated with AMD (Loh & Ogle, 2004), though it is treatable if detected early (Bourla & Young, 2006; McConnell & Silvestri, 2005; Querques, Avellis, Querques, Bandello, & Souied, 2011). It also important to note that both principal forms of AMD can impact an individual's eyes, either unilaterally or bilaterally and cause rapid loss of central vision (Cunnsamy, Ufret-Vincenty and Wang, 2013). As such, NICE (2018) guidelines recommend that treatment should commence at least two weeks following diagnosis of the wet form and practical support and information is provided on how to manage the dry form.

1.1.2 AMD Prevalence

In 2010, it was estimated that around 608,213 people were living with AMD in the UK, and this figure was expected to rise to around 755,867 by 2020 (Minassian, Reidy, Lightstone, & Desai, 2011). The prevalence of AMD is of great concern from a public health view point. An AMD diagnosis extends to other related co-morbidities, including depression and the Charles Bonnet Syndrome as highlighted above (Cruess et al., 2008).

According to Klein, Klein and Linton (1992) when it comes to the prevalence of AMD, the dry form accounts for between 80 to 90% of confirmed cases, and the wet form accounts for between 10 to 20% (Bourla & young, 2006). However, AMD cases tend to increase dramatically with age (Bonstre, Le Pen, Anderson et al., 2002; Gibson, Rosenthal & Lavey, 1985). A notion Owen, Jarrar & Wormald et al. (2011) concurred with through finding from their prevalence study of AMD, that showed that the most disabling form of AMD (late stage) was present at least 4.8 % of patients over the age of 65 years and affected 12.2 % of patients over 80 years old. Other prevalence studies (Cook, Patel, & Tufail, 2008) have shown that AMD prevalence varies according to race, with AMD being significantly higher in Caucasians than any other group, and Black people are least likely to have sight threatening AMD compared to their White counterparts (Friedman, O'Colmain, Tomany et al. 2004). A notion which was endorsed in other studies (e.g. Bressler, Munoz, & Solomon, 2008), that focused on various mechanism that included genetics. Understanding the issue of prevalence is important in healthcare as it helps clinicians understand key elements about populations and their behaviours as informed by their cultural habits, which may be a precipitant for disease manifestation and frequency. Hence, understanding these dynamics is important to the optics of information provision in the grand scheme of things.

1.1.3 Treatment

The treatments for wet macular can include the use of anti-vascular endothelial growth factor (anti-VEGF) drugs and laser photocoagulation. However, while these treatments may stabilise a patient's vision, they do not reverse visual impairment (Hooper et al., 2008). It is important however, for individuals to be diagnosed early and to start treatment immediately after, to delay rapid or further deterioration of the sight. Studies (e.g. Arias, Armada, Donate et al. 2009) showed that delay in accessing treatment for wet macular can reduce an individual's visual acuity significantly. Hence, NICE (2018), recommended that for those diagnosed with active wet macular, treatment should commence within two weeks of diagnosis for the treatment to be effective. The most commonly used method of treatment for wet macular is Anti - vascular endothelial growth factor therapy (anti-VERGF), an injection of drugs such as; Lucentis (Ranibizumab), Avastin (Bevacizumab) and Eylea (Aflibercept) (Informed Health Online, 2015), which are administered directly into the affected eye. These drugs have been approved by NICE for the use of treating wet AMD and are funded for use in the National Health Service (NHS) Hospitals. These drugs have helped transmute the visual outlook of patients with wet AMD who are receiving them as treatment. Brown, Michels, Kaiser et al. (2009)'s study on the efficacy of these treatments showed that at least 40% of patients in receipt of treatment for wet macular gained some visual improvement, while some 90% maintained their current visual levels. The findings of Thetford et al., (2015)'s study focusing on the experiences of AMD patients regards treatment also corroborate with those presented in the study above. However, they also brought to light information deficiencies across the diagnosis and treatment spectrum. A notion also demonstrated in other studies looking at the lived experiences of AMD patients (Burton, 2012; Wormald et al., 2014; Wong, 2012).

The lack of treatment for patients diagnosed with dry AMD however, means there is little to no hope of their eyesight ever improving, unless new treatment modalities are developed soon. Evidence from various studies (e.g. Burton et al, 2013) has demonstrated that patients diagnosed with dry AMD tend to struggle with the uncertainty the condition brings and the inevitability of their eye sight deteriorating and leaving them blind. However, associated feelings of hopelessness and the distress that the diagnosis brings can be somewhat reduced, through provision of adequate information about the condition and ensuring patients are aware of the impact, visual changes pose on their well-being and quality of life. NICE (2018) recommended that clinicians should sign post patients diagnosed with dry AMD to the Low Visual services and group-based rehabilitation programmes where they can access more resources and information about the importance of lighting and other visual optics such as magnifying glasses, and listening devices such as talking books (Lamoureux, Pallant, Pesudovs et al. 2007), that improve their quality of life following diagnosis. Clinicians can also point patients in the direction of an Eye Clinic Liaison Officer (ECLO) usually located within the clinic, to provide advice and information on accessing emotional and practical support, referral to social services and assisting with registration and certification (e.g. severity of eye impairment) (Subramanian, Conway, & Gillespie-Gallery, 2011). Receiving holistic information and support at diagnosis can help AMD patients,' psychologically adjust to and cope with the altered self and subsequently manage their condition over time. Conversely, when there are information deficiencies at diagnosis including treatment options and procedure, the implications to the patients' well-being are more pronounced. For instance, this can impact their decision making to consent to treatment, and for patients with the dry form of AMD, where treatments are unavailable, the lack of adequate information and support, the prospect of being sight impaired or going blind places a huge burden of uncertainty that impacts their mental health. However, it can be argued that huge strides have been made within health care, where patients are now uniquely placed to consider how health care services fit into their lives. Meaning that they have the power to determine their care by drawing out relevant information and support from clinicians, agencies of the state, private and third sector organisations, including friends and relatives that helps them to understand their diagnosis, make informed decisions about treatment and manage the condition over time (Dearden, Wright, Bowen, Rahman, Cobb and Wolstenholme, 2010). As active participants, patients can demand for adequate information materials (both verbal and written) that meet their status and needs in order to understand the complexities of their condition and its management. A generic systematic review conducted by Johnson, Sandford and Tyndall (2003) examining the effectiveness of provision of verbal and written information versus verbal information only in an Acute hospital setting, showed that when patients are provided with both verbal and written information about their condition, understanding and knowledge increased significantly and there was an improvement in management of their condition. It can be argued here that when knowledge increases individuals can make better decisions about, and to consent to treatment and can manage their condition better over time.

1.1.4 Consent and Decision Making

The consenting process is a vital and significantly important concept in the provision of health care and has legal, ethical and practical dimensions associated with it (Consumer Health Forum, 2013). From an ethical perspective, it forms an essential component of the moral right of patients to autonomy over their own bodies and is largely based on the principle of agency. In this instance, agency refers to the individuals' sense of feeling in control of their actions and the ensuing consequences with regards to the decision made to consent to treatment (Moore, 2016). From a legal stand point the consenting process can be viewed as an agreement or process by which the rights of patients to agree or refuse treatment are upheld. In practical terms the consenting process refers to how clinicians communicate and provide information to patients about their treatment options-procedure, and associated risks and benefits, and supports them to evaluate this information to make an informed decision about their care (Consumer Health Forum, 2013). More importantly, clinicians need to ensure an atmosphere of freedom prevails where information provision and information acquisition is a reciprocal process and the patients' values and choices are duly respected throughout the dialogue (Eekelaar, 2006; Skivenes, 2002). A notion that is supported by Habermas communicative theory (1984), which argues that clinicians should observe the rules and norms of communicative rationality when disseminating information to patients' during consultations (Walseth and Schei, 2011).As previously highlighted earlier this theory's emphasis lies within three dimensions of the lifeworld (e.g. the objective, the social and subjective world) in seeking to understand the patient and what is going on with them, and then provide information that helps them understand the condition and the treatment options, including benefits and side effects in order for them to make an informed decision to consent to treatment.

Carey (2006) argued that information provision during consultations relating to diagnosis and treatment should be person specific, in other words clinicians need to use their emotional intelligence to evaluate the capacity of the patient in understanding what is being communicated to them. Capacity refers to the determination made by clinicians, that a patient has the ability to make a specific decision at a specific time following disclosure of information. NICE guidelines (2018) support the notion of capacity raised by Carey and stipulate that clinicians should be checking whether the individuals they are offering treatment to, have (a) capacity, (b) are voluntarily consenting and (c) have been provided sufficient information prior to consenting. Carey (2006) further advanced his argument based on the decision-making model, which reflects the notion that, when making decisions that involve a degree of uncertainty and apprehension about the treatment procedure, patients require not only information about the range of choice available to them, but also the likely outcomes of each one – good or bad. Since the ageing process carries profound implications for the health and well-being of older adults. It is safe to infer that they are typically more challenging to provide information to than the younger patients, mainly because of the heterogeneity of this group and the greater number and complexity of comorbid conditions that accumulate with age (Saleh, 2004). These challenges may include deterioration of other sensory functions outside vision such as, hearing. Thus, clinicians need to be aware of the differing information needs of each patient. This is a key issue amongst this group as providing too little or too much information in whatever format can compromise their comprehension during the consenting process. Varano, Eter, Winyard, Wittrup-Jensen, Navarro & Heraghty (2015) argued that deficiencies in information provision including the use of complex medical language, lack of understanding, and the frequency of treatments were notable barriers to older patients consenting to treatment. There is also a high probability that older adults may consent to treatment because they are afraid of losing their sight completely rather than understanding of the information provided (Consumer Health Forum, 2013). It can be argued here, that being exposed to information (e.g. medical terminology), related to treatment and or procedure, does not necessarily equate to being informed. It therefore raises issues around the presentation of information, the condition in which it is given and how clinicians assess patients' understanding of that information (Renya and Hamilton, 2006). Furthermore, it raises issues around priorities and preferences in the patients and clinician dyad in as far as information provision and the decision making and consent process is concerned, and this present program of work is uniquely placed to explore this element.

There are specific groups of patients amongst those living with AMD, for whom a standard consenting process may not be appropriate, because of deterioration in sensory functions (e.g. hearing) and the possibility of other comorbidities that come with ageing. Such instances, require an individualized approach by the clinician when communicating and providing information. In a generic study conducted by Bottrell et al., (2000) exploring the consent process pre-procedure in a hospital setting, they reported that patients were confused about the consent process, felt intimidated, and stressed during the consultation and felt under-pressure to decide without having had the time to deliberate or reflect on the information provided (Dixon-Woods et al.,2006). It can be argued here that while the sample for this study had no visual impairment, the findings are transferable to patients with wet AMD, more so because NICE (2018) guidelines recommend that treatment should commence as soon as possible following diagnosis, giving a lead time frame of at least two weeks, if the treatments is to be effective. Thus, AMD patients may feel under-pressure to make decisions about treatment, because of their fear of losing their sight. It can be argued therefore, that issues that impact the consenting process are multi-faceted, but the clinicians have a duty of care to provide information in a sensitive and accessible manner. That is, information provided should be driven by a patient's life contexts (i.e. level of understanding, including health and or disability status and so on).

1.1.5 Importance of Information Provision within Health Care

In the UK, when it comes to health, providing better information and support to patients that helps them understand their diagnosis, treatment and to manage their condition over time is a significantly important matter that is duly enshrined in policy:

"Better information, better choices, better health: putting information at the centre of health" (Department of Health, 2007).

Provision of '*adequate*' accessible information is key to patients' understanding their diagnosis and treatment and informs their ability to make informed decisions to consent to treatment, and to adjust and manage living with a life altering condition such as AMD (Beverly, Bath & Booth, 2004). Bergman and Johnson (1995) argued that providing 'adequate' and 'accessible' information was a means of removing barriers that prevented patients with visual impairments from actively participating in substantial aspects of their lives including understanding their diagnosis and treatments. This argument illuminates the fundamental importance of providing adequate and accessible information to AMD patients, for them to function as competent social beings. Lack of it thereof, can lead to social exclusion (Brody et al., 2001; Owsley et al., 2006), which means that without access to adequate information people cannot play their roles as patients, citizens or consumers, they cannot make informed decisions or rational choices concerning their lives. Consequently, they are unable to benefit from services they should otherwise be benefiting from (e.g. information regarding treatment options and procedures, visual rehabilitation aids, benefit entitlements, and support groups) (Moore, 2000). It is important to recognise that people with vision impairment have the same information needs just as much as people with *'normal'* eyesight.

Information is a powerful tool, an ingredient for creating knowledge and an element for empowerment. As such, it can be argued that information is a vehicle that informs individuals of their rights and entitlements within society (Hasler, 1993), that allows them to function effectively within the context of their multiple identities, as patients, disabled persons, consumers and citizens in an ever-changing environment. While information provision is important, Schmidt, Bauer, and Pen-McAlpine (2003) argued that information acquisition was equally important for persons diagnosed with a chronic illness such as AMD. Their argument is based on the notion of self-determination as a driver and how this has a positive impact on individuals' sense of self, well-being and the subsequent influence it has on adjusting to interactions with the environment and managing AMD over time (Schmidt et al., 2003).

According to Bury (1982) following a life altering diagnosis such as AMD, an individual will go through multiple phases, including emotional experiences of loss. However, to move on, individuals' will re-evaluate their biography and self-concept. In doing so they will seek to access resources (e.g. information, written, online or verbal) that enables them to understand their condition better and create an awareness of the different support systems available to them. Going through this information acquisition phase is fundamental to these individuals', adjusting to their altered self and is instrumental to them subsequently managing their condition over time. Thus, it can be argued here that information provision for this group needs to be tailored to meet their status, and more importantly meet their individual needs.

In practical terms the process of information provision should begin with clinicians creating an environment that enhances participation at diagnosis for information exchange to prevail in a manner that benefits the patient's understanding of the diagnosis, treatment options, available support and what the diagnosis means for their well-being and quality of life thereafter. A notion that Habermas' theory of communicative action strongly supports. While this process maybe the beginning of a journey to understanding their AMD diagnosis, stakeholders involved in creating information resources that support the information communicated by clinicians at diagnosis need to produce resources, print or otherwise that are accessible with content that is both readable and easy to understand for this group.

1.1.6 Print and Electronic Materials

Inaccessible print or electronic materials can impact negatively on an AMD individual's ability to acquire useful information pertinent to their life. An element that can further impact their self-esteem and self-worth in society and overtly validates their disability (Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005). The World Health Organisation [WHO] (2016) argued that disability is an umbrella term that refers to challenges an individual may face due to factors such as; impairment, participation restriction and activity limitations. They define impairment as a problem in body structure or function; participation restriction as problems an individual experience when engaging in life situations, while activity limitations relates to problems experienced by an individual when performing a task or action (WHO, 2016). As such, disability is not just a health problem, but a complex phenomenon, that reflects the relationship between characteristics of an individual's body and characteristics of the society in which they live in. While the above statement from WHO is inclusive, the medical model however, holds that disability is for the person affected and no one else. The classic example often used to illuminate this notion is of a person in a wheelchair who cannot get in to a building because of the stairs. In this instance, the medical model would argue, it is the wheelchair stopping the individual getting into the building rather than the steps. Furthermore, statements such as he/she cannot read the consent form or information materials because they are visually impaired are influenced by the medical model which views the person as the problem rather than the design of the consent form or the information materials (Public and Commercial Services Union [PCSU], 2016). On the other hand, the social model of disability is more inclusive in approach and in the same scenario would argue that the steps are the barrier to the individual accessing the building, and similarly the same would hold true of the information materials (e.g. design or font size being the barrier). It draws on the premise that society is the one that disables people, by making everything to suit the needs of the majority of individuals who are not disabled. This is evident (e.g. lack of accessible information) in findings from most studies that have focused on people living with visual impairments. The social model focuses on things that can be done to remove barriers to inclusion, and also acknowledges that attitudes towards disability can create unnecessary barriers to inclusion. Thus, it requires people to take a more pro-active role to remove these barriers. In this instance information producers and stakeholder involved in the information chain adapting an iterative process (develop –test-revise- repeat to ensure the information materials are user centred (Nilsen, et al., 2006).

The Royal National Institute of Blind People's (RNIB) (2008) clear print guidelines, set out the parameters for producing written information materials that are accessible to the widest audience possible. These guidelines are based on previous experiences in the field over the years, advice from experts and research. They mainly address design elements that include; font, type size, contrast, background colour and paper quality (RNIB, 2008). According to these guidelines font size 12 to 14 are generally accessible to most individuals, however other factors need to be considered that include the contrast and design. It is a legislative principle (e.g. The Disability Discriminatory Act) for clinicians and other stakeholders who provide services to people with a disability such as those who are sight impaired, including those diagnosed and living with AMD to provide information in accessible formats (Hardisty, 2008).

Coulter, Ellins, Swain et al. (2006) argued that providing accessible information relating to health was fundamentally important for patients, particularly in understanding their diagnosis, treatments and available support. They argued that providing information that was current, easy to understand and reliable was key to promoting health literacy amongst patients, thus leading to better choices, shared decision making, self-care, treatment adherence and better management of their condition (Coulter et al., 2006). The importance and benefits of providing accessible written information materials to patients alongside adequate verbal information is clearly articulated in Johnson et al.'s (2003) systematic review. The findings of which showed that providing these significantly increased patient's knowledge and satisfaction. This suggests that written information reinforced verbal information provided by clinicians and allowed patients to understand their condition better, make informed decisions about their health and treatments and could manage it better over time. A notion Gibbs, Water and George (1989) concurred with suggesting that written materials had a beneficial effect on treatment adherence, and management (Raynor, Blenkinsopp, Knapp, et al., 2007).

However, much of the information materials produced for patients, consumers or citizens is not of the desired standard or quality and in some instances is not accessible (Bruce & Baker, 2001; Tyson & Turner, 1999; Simon et al., 2003; Aslani, Hamrosi, Feletto et al., 2010; Beverly, Bath & Booth, 2007; Coulter, Entsile and Gilbert, 1999; Coudeyre, Turbach, Rannou, et al., 2007; Hamrosi, Aslani, Raynor, 2014; Koo, Krass, & Aslani, 2006; Little, Rumsby, Kelly et al., 2005; Sustersic, Jeannet, Corzon-Rein et al., 2013). Abraham, Krahe, Dominic and Fritsche (2002)'s study argued that in some instances the information materials provided to patients were not theory or research driven. The lack of accessible print materials led patients to look elsewhere (e.g. internet) for information. Burton et al. (2013)'s study pointed that most AMD patients struggled with the font size of information materials, including reading prescription medication instructions. Another significant issue identified in this study was the inaccessibility of appointment letters. Particularly, the lack of clear information on what the appointment was for. Clinicians involved in the care of sight impaired individuals agreed that the letters sent out to this group were inaccessible for many (Goyder, Carlisle, Lawton, & Peters, 2009). One could argue that perhaps hospitals should consider using telephone helplines as a means of providing accessible information for this disenfranchised group.

Research published (Coulter et al., 1999) involving an in-depth examination of patient needs and evaluation of the quality of audio visual and written information materials by clinicians and patients showed that; quality of information materials produced were poor, and some contained inaccurate information. Topics of relevance to patients were often omitted and coverage of treatment options was often incomplete. Furthermore, technical terms were not always clear and information regarding treatment effectiveness was often missing or unreliable, while a few materials actively promoted shared decision making (Coulter et al., 2006). Raynor, Blenkinsopp, Knapp et al., (2007) conducted a systematic review that included both quantitative and qualitative studies, to examine the role and effectiveness of written information materials available to patients in terms of improving their knowledge and understanding of diagnosis, treatments and health outcomes. Findings from this review showed that most patients do not value written materials they receive, because they were concerned about issues such as poor visual presentation of the materials and use of complex language.

Conversely, this review also showed that patients valued information that was tailored to their circumstances and illness and had a balance in harm and benefit information (Raynor, Blenkinsopp, Knapp et al., (2007). It was also reported in this review that patients did not want written information to be a substitute for spoken information from healthcare professionals. Clinicians in this review and other studies (e.g. Ford, Schofield & Hope, 2002) agreed that written materials should be brief and made simple for patients to understand their diagnosis and treatment better. Whilst Coulter's study was conducted almost fifteen years ago, Raynor et al.,'s study in 2007, and more recent studies by (Burton et al., 2013; Thetford et al., 2015), which explored the lived experiences of people with AMD, corroborated their findings. There are common strands interlinking these studies; deficiency in information that aids understanding of disease, and deficiency in providing information that promotes healthy living with the condition. Kinnell and Creaser (2001) argued that these strands were valid by suggesting that there was an imbalance in provision of information for people with visual impairment. They argued that reading was equally important for the visually challenged as was for those with good vision. The dissatisfaction that visually impaired people expressed in these studies related to both accessibility of information and relevance. It can be argued from a health psychology perspective that interventions to effect attitude change in organisations that produce information for visually impaired individuals are needed in order for them to produce materials that are research driven. Furthermore, clinicians and other stakeholders involved in the care and service provision to AMD patients should encourage them to access information from electronic sources such as the radio, electronic newspapers, audio books, and the internet.

1.1.7 Use of Technology to Access Information

"Getting connected"
Photo source credit: Myageingparent.com (2015)

Modern technologies fuel both hope and discussion (Peek, 2017). Hope in the sense that they offer so much potential in relation to providing platforms to access information (health and social), and connectivity (Skype, Microsoft teams, email, mobile phones e.g. WhatsApp) with loved ones or health institutions. And discussion, because of various concerns that exist relating to design, application, accessibility and usability. Despite these discussions being pertinent, particularly to the group of focus in this programme of work, some of the technologies have the potential to help older adults living with AMD maintain their independence across aspects of their occupational life, this includes home appliances for activities of daily living, and information and communication technologies to support social contact (Brien, Olson, Charness et al., 2004; Fausset, Kelly, Rodgers and Fisk, 2011; Peek, 2017). Studies (e.g. Peek, 2017), focusing on older adults use of technology, shows that they acknowledge the potential of technology. However, acquiring it and using it can also be stressful and challenging for this group. An interesting aspect of technology is that perceived benefits do not necessarily translate into acceptance. This can perhaps be understood using the technology acceptance model (TAM), which is underpinned by two key variables (a) perceived usefulness and (b) perceived ease of use. Research has indicated that these two variables highlighted an individual's intention to use technology in a variety of contexts including accessing health information (Legris, Ingham, Collerette, 2003; Holden & Karsh, 2010), and that intention to use may (Turner, Kitchenham, Brereton, Charters & Budgen, 2010) or may not (Wu & Du, 2012) predict actual use of technology (Peek, 2017).

Most people of all ages, backgrounds, abilities and disabilities are accessing information about their health and social activities from the internet. The Royal Institute for the Blind (RNIB, 1998) commented that:

> *"the internet is one of the most significant developments since the innovation of Braille [because] for the first time ever, many blind and partially sighted people have access to the same wealth of information as sighted people and on the same terms"* (cited in Berry, 1999. p1).

Berners-Lee, the inventor of the World Wide Web, concurred with this statement by arguing that the power of his search engine was in its universality, meaning that it could be accessed by all regardless of visual impairment. However, some studies have highlighted that there are numerous barriers that hinder people from accessing information from the internet. These include; age, fear of using the computer (Muller, Wharton, McIver & Laux, 1997), lack of skills (Penney & Associates, 1996) and challenges of getting trained (Sinks and King, 1998). Williamson, Wright, Schauder and Bow (2006) conducted a qualitative study exploring the role of the internet as an information source for the blind and visually impaired. They used a sample of fifteen visually impaired participants and sixteen professionals who worked with these individuals and they found that participants who had recently developed visual impairment were more reluctant to engage with technology, particularly if they were advanced in age. Though some of their participants were 60 years old living with a visual impairment, they welcomed the use of the internet as an information source, citing that it gave them some sort of independence to look at things in their own time. It can be argued here that AMD patients like everyone else require good quality and reliable information that is accessible to inform their choices and help them understand their condition to manage it better over time. Furthermore, the web particularly has become a ubiquitous aspect of the global society's lives, with most people able to access and use it to search for health information. Similarly, government institutions aligned to health and other third sector organisations use the web to make health and support information available to target audiences, while clinicians provide more information and encourage participation during clinical encounters (Marton and Choo, 2011).

1.1.8 Importance of Information in Managing AMD

Managing AMD is an important aspect of an individual's well-being and has a bearing on their overall quality of life. Barlow, Wright, Shearsby, Turner, Hainsworth, (2002) defined the concept of managing AMD as; ***"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition"*** **(**cited in Embuldeniya et al., 2013.p 3**).** However, regardless of the form (wet or dry), one is diagnosed with, the key lies in the quality of information provided throughout the stages of diagnosis, treatment and the subsequent journey living with it (AMD). That is, communication of adequate information, spoken or unspoken (e.g. use of accessible print materials), the environment created, that is the clinician-patient dyad and dynamics and the support offered, have a huge impact on information acquisition. Studies (Burton et al., 2013) have shown that there are information deficiencies across the board for people living with AMD, either at diagnosis or treatment, or both. This also includes the lack of sign posting patients to relevant support groups and the Low Visual Clinics for rehabilitation following diagnosis. In the above study most, patients reported finding out information on their own, to learn more about and how to manage it.

This supports Bury's notion of re-evaluation, were individuals become self-aware and begin to make sense of what has happened and start seeking for relevant information that helps them adjust to living with their 'altered self'. Information is what makes the world go around, it is after all the premise of *how we know what we know*, and more importantly it is essential that those involved in the care of people diagnosed with a visual impairment, a sensory element that allows us to have spatial awareness and an ability to soak in the world in a visual sense are supportive by providing accessible resources of information. Binns, Bunce & Dickson et al., (2012) argued that in providing information to this group, clinicians and other stakeholders should include self-management strategies and educational programmes that will help improve this groups' quality of life, that is managing their condition from an occupational viewpoint daily.

In a random controlled trial (RCT) study conducted by Brody, Roch-Levecq, Gamst et al., (2002) of an AMD self-management intervention, the findings showed that incorporating skills training, behaviour modelling and provision of information regards available aids and biological processes in the transition of *'former self'* to *'altered self'* was significantly important in improving mood and functionality. The same study indicated that participants that were depressed at baseline had significantly improved following this self-management intervention compared to their counterparts who were not depressed at baseline. Other scholars (Birk, Hickl, Wahl et al., 2004) have also argued that education-based programmes and self-management interventions are an integral part of AMD patients managing their condition over time. Their study conducted in Germany utilised a six module approach with the view to improving psychosocial elements that included behavioural and emotional outcomes covering the following topic areas; exchange of AMD related experiences, progressive muscle relaxation, understanding the connections between thought, emotion and behaviour, the description of and deliberate emphasis on use of resources available, improving problem solving skills and the exchange of information relating to treatment and rehabilitation options. Findings from this study showed significant improvements in 5 out of the 6 measures. These included perceived increase in autonomy, improvement in activities of daily living (ADL), decreased negative effect and depression, and an increased active problem orientation. In this study the positive effect measure was the only measure that did not show any improvement. The improvement noted in the negative effect measure, demonstrated the effectiveness of the intervention, the positive effect on the other hand remained stable. These findings are similar to the one discussed earlier, were patients with depression benefited significantly from the interventions involving self-management (Brody et al., 2002).

In another study Dahlin-Ivanoff, Klepp & Sjostrand (1998) implemented and evaluated an education-based health programme for AMD patients using the Health Belief Model (HBM), which works on the premise that an individual's decision to take any health-related action is determined by his/her perception of the following elements; severity of disease, susceptibility to disease, benefits of health action and barriers to performing the required action (Burton, 2012; Dahlin et al. 1998). The HBM in this study was however, modified to include self-efficacy and instead of perceived susceptibility, acceptance was used instead since patients had already been diagnosed. The study was conducted for eight weeks with a sample of 45 older adults participating in two three hourly meetings of the intervention, which covered information and skills training in self-care, communication, shopping, food preparation and meals, cleaning, mobility and orientation, and financial management. To evaluate this intervention, this study used focus groups and they findings were variant showing improved or maintained security in daily occupation for the sample used (Dahlin et al. 1998). While there may have been reported improvement in this study, it can be argued that participants did not fully comprehend all the information provided and they (participants) indicated the need to consider variation in visual acuity within the groups participating in the programmes. Furthermore, participants in this study highlighted some positive elements that could help them manage the condition over time and these included, social support, regaining hope and the opportunity to meet and share with others living with the same condition. This could suggest that these elements were seen by participants as more helpful than the intervention itself. For instance, the concept of regaining hope illuminates a pronounced need for research that transcends the prescriptive tenets within models such as HBM and focus more on life contexts of the patients. Dahlin et al's study elucidates a fundamental factor that patients' experiences are important in understanding how they make sense of a diagnosis, adjust to living with it and manage it over time. The studies reviewed here speak to the essence and effectiveness of group-based intervention, suggesting that support groups have a place in the management of AMD for older adults. This may include supportive friends, carers, relatives or local AMD focused support groups. A key element to this suggestion is the evidence from the studies that demonstrate that skills and information shared in these groups enabled participants to meet new challenges in the face of their eye sight deteriorating (Binn et al. 2012).

1.1.9 Importance of Support Groups in Managing AMD

Since vision offers the most dominant method for recognising and processing information to meet the needs of individuals on a day to day basis, loss of it can significantly impact all spheres of an individual's life (Loh & Ogle, 2004), particularly for those without a stable support network in place (e.g. family, friends, and peers). These functional limitations experienced by people living with a visual impairment such as AMD may lead to issues relating to social isolation and loneliness (Brennan et al., 2011; Crews & Campbell, 2001), depression (Banerjee, Kumar, Kulhara, & Gupta, 2008), concerns around illness disclosure and difficulties interacting with healthcare professionals (Bennion, Shaw & Gibson, 2012). Furthermore, the inability to recognise faces or indeed facial cues can impact negatively on their primary means of social interaction, as it limits their ability to use visual feedback in relation to their life world, thereby placing them at an increased risk of cognitive decline (Zunzunegui, Alvarado, Del Ser, & Otero, 2003), and disability (Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005). As such, Singh (2005) argued that because of the numerous challenges AMD presented on individuals', it required a multi-layered approach involving the patient, clinicians, other third-party sectors and the broader society were support and information provision is concerned. Thus, suggesting clinicians and all individuals involved in the care and support of individuals living with AMD are part of this social network (Hooper, Jutai, Strong and Russel-Minda, 2008). Orth-Gomér and Undén (1987) defined social networks and social contacts as the structural elements of social support, and available support as the functional element of social support. An aspect O'Reilly (1988) concurred with, by suggesting that social networks are by nature an analytic concept that depicts linkages between individuals or groups of individuals, where as social support is one of the network's functions, which is offered through behaviours' and actions of the members of the network and communicated through the network's structure.

House, Landis and Umberson (1998 cited in Patel, Peterson & Kimmel, 2005 p.98), defined social support as the "perception that one is a member of a complex network in which one can give and receive affection, aid, information and obligation". A notion that Papakonstantinou & Papadopoulos, (2010) concurred with by postulating that the fulcrum and the pith of social support relates to the type of help that an individual receives or expects to receive from those who he/she comes into contact with, in relation to their needs. As such, it can be argued here that being part of a group, organisation or community that care, value, love and understand how you perceive your condition can have tremendous positive appraisal benefits for the ‘altered self’ which can subsequently lead to better coping and management of the condition over time.

Brough & Pears, (2004), suggested that within the context of social support, received and perceived support as highlighted by Papakonstantinou and Papadopoulos can be subdivided further into two elements; practical and emotional support. Practical support in this instance relates to provision of or sharing of information that helps one understand their diagnosis, treatment, coping and management strategies. It also includes provision of and access to services such as the Low Vision Clinic, Eye Clinic Liaison Officer, support groups and materials (e.g. Aids, print and alternative resources). Emotional support in this instance relates to expressions of concern (Brough & Pears, 2004; Chang & Schaller, 2000), affective support (Kahn & Antonucci, 1980), and feelings of belongingness, respected, and acknowledgement of one’s emotions (Chang & Schaller, 2000).

Studies (e.g. Reinhardt, 2001b) have shown that when practical support and emotional support are offered and provided to older adults particularly in support groups settings, it resulted in greater life satisfaction and less psychological disturbances (Kozora, Ellison and Waxmonsky, 2005). A notion that Mazzoni and Cicognani (2005) concurred with and argued that support groups not only had a predictive role of improving these individuals’ psychological well-being, but also their physical well-being, by managing their condition better over time. Accessing support groups has value in the sense that individuals’ access practical support - information about specific elements relating to their condition, become adequately informed about how the condition impacts their health and lives and learn to co-exist with it. Dennis (2003) concurred with this notion by arguing that support groups provided emotional, appraisal and informational assistance for peers and were usually facilitated by individuals with a wealth of experiential knowledge of the condition, the stressors, and associated characteristics of living with the AMD. He also argued that support groups had the potential to build an individual’s social identity, infuse a sense of belonging, hope and drive to co-exist with the altered self. Studies (e.g. Reinhardt, 1996; Reinhardt, Boerner & Benn, 2003) showed that the needs of visually impaired older adults and those who were not, are similar in terms of support and information that helps them feel as part of the community, alleviate feelings of social isolation and manage living a fulfilling life within their respective environments. Van Zandt, Pearl, Van Zandt et al., (1994) concurred and argued that support groups were a vital source of information for older adults with visual impairments, in terms of shared experiences and were meaningful friendships developed (Reinhardt, 1996; Reinhardt, Boerner & Benn, 2003).

Other generic studies (e.g. Mazzoni & Cicognani, 2011; Patel et al, 2005; Zhang, Zhang, Aleong & Thomson, 2011) have also demonstrated the significance of attending support groups, in coping, adjusting, complying with treatments and self-management for people diagnosed and living with a chronic condition. In psychology this concept of using others' experiences as a coping strategy is known as, social comparison (Birk et al., 2004; Dahlin-Ivanoff et al., 1998). Draucker (1991) argued that in most instances people diagnosed with a chronic illness often made down ward comparisons when in a support group as a way of coping, adjusting and to subsequently manage their illness. In other words, downward comparison for these individuals embodies a way of coping with the illness activity and its social consequences (Repping-Wuts et al., 2008). As such, it can be argued here that accessing support and support groups is a significantly important phase in the lives of people diagnosed and living with AMD, particularly where understanding of treatments and lack thereof, coping and managing the condition is concerned.

However, while the benefits of accessing social support and support groups are vast as highlighted above, various studies have (e.g. Sarason et al., 1987; Ruehlman & Karoly, 1991; Chang & Schaller, 2000; Cimarolli & Boerner, 2005) highlighted elements relating to negative aspects or barriers of social support and support groups that include; negative forms of behaviours, such as criticism, hostility, and insensitivity. Goll (2014) in her study exploring the barriers to social participation in support groups for lonely older adults found that older adults refrained from joining support and social groups because they believed the opportunities therein did not support preferred aspects of their identities. These preferred identities related to roles and interests they had developed within social and occupational arenas over time (Goll, 2014). For example, some individuals may not see the benefits of joining a group that does not share their previously acquired interests, such as going for walks, regardless of ailments. Some participants reported not needing support groups on the basis that it validated their status (e.g. disabled) (Goll, 2014). Because of old age and visual impairment, studies (e.g. Ivers, Cumming, Mitchel & Attebo, 1998) argued that fear (e.g. perceived restriction) and experiences of falling impacted negatively on older adults' willingness to engage in physical and social groups or activities (e.g. going for walks, driving), thus adversely impacting on their chances of acquiring useful information, quality of life, and independence (Scott, Smiddy, Schiffman, Feuer, & Pappas, 1999). Perhaps it can be argued from a social selective viewpoint (Carstensen, 2006) that some older adults, including those with AMD, value and invest more in close relationships (e.g. family, friends) rather than support groups because of the limited future time in older old age they have.

1.2 Chronic Illnesses and Health psychology

Health psychology has played a crucial role within the context of research into chronic conditions. It is concerned with understanding how psychological, behavioural and cultural factors contribute to physical health and illness. For instance, health psychologists have explored the lived experiences of people diagnosed with a range of chronic illnesses, including AMD (Burton, 2012), experiences of treatment procedures (Thetford et al., 2015), psychosocial impact (Brody et al., 2001), adjustment to illness and compliance with medication (Wellard, 1998), behaviour change in managing chronic illness (Williamson 2014; Shaw et al., 2013), information needs or information seeking behaviours (Burton, 2012; Beverly, Bath and Booth, 2012). However, medical sociology has conducted most in-depth qualitative studies focusing on individuals' experiences of chronic illnesses (Nettleton, 1995). Bury (1982)'s theory of biographical disruption highlighted how disabling and disruptive chronic illnesses can impact an individual's life. Bury (1997) argued that the symptomatic representation of a chronic illness can significantly disrupt an individual's day to day functioning and increase the sense of uncertainty. This theory is underpinned by three elements; "the disruption of taken for granted assumptions and behaviours", "the fundamental rethinking of the person's biography and self-concept", and "the responses to the disruption involving the mobilisation of resources, in facing an altered situation" (Bury, 1982, p.169-170). Charmaz (1983) advanced a similar argument, suggesting that when an individual is diagnosed with a chronic illness, their experiences often clash with the taken for granted notions, that is; their physical body, sense of normality and valued aspects of the 'self" and their social relationships. However, most important and pertinent to this program of work is the assertion by Bury that when an individual is diagnosed with a chronic illness, they go through numerous phases including loss, but they come to a point they re-evaluate and seek to acquire information that helps them understand their condition and means to co-exist with it. As such, clinicians have a duty to ensure they create an environment that encourages patients to participate during sense making events such as consultations, after all it is a tenant of best practice.

1.2.1 Best Practice in Working with AMD Patients

In the last two decades, guidelines have become an integral part of clinical practice. Field and Lohr (1990) defined guidelines as "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific circumstances" (cited in Woolf, Grol and Grimshaw, 1999. p 527). It can be argued from this description that guidelines offer concise instructions of operation within healthcare and provide consistency with reference to clinical practice, regardless of whether it is the National Health Service (NHS) or a private healthcare institution providing the services for the benefit of patients in improving health outcomes.

Prior to guidelines being instituted, evidence suggested that AMD patients did not always receive best practice-oriented service from clinicians. For example, a study conducted 2002 by Mitchell, Bradley, Anderson et al., exploring AMD patients' perceptions of healthcare services using a postal survey, highlighted several issues, including dissatisfaction with clinicians' attitudes, and deficiencies in information provision at diagnosis. Other studies (e.g. Burton et al, 2012; Caban-Martinez, Davila, Lam et al., 2011; Hochestetler, Scott, Kunselman, et al., 2010), had similar findings and have since put forward recommendations that clinicians need to follow set guidelines and do better with regards to providing information to AMD patients at diagnosis. These recommendations are in line with those instituted in the NICE guidelines 2018 [NG82] and the Royal College of Ophthalmologist (2013). They provide scope for the type and quality of information that should be given to AMD patients at diagnosis, treatment, its management and support available.

1.2.2 Table 1 – Nice Guidance

NICE guidance recommendation for provision of information and support to AMD patients adapted from: *Age related Macular Degeneration (2018) [NG82]. Information and Support.*

Information and Support
Provide AMD patients, their family and carer with information on an ongoing basis, relevant to the stage of the condition, tailored to meet patients' needs, and should be delivered in a caring and sensitive manner.
Clinicians should provide patients with the opportunity to discuss all aspects relating to their conditions including; what is AMD and how common it is, types and causes, possible deterioration and complications, possibility of experiencing any visual hallucinations- Charles Bonnet Syndrome (CBS), treatment options, including benefits and risks, who to contact for practical and emotional support, where appointments will take place and which clinicians will be looking after their care, expected waiting times for consultations, investigations and treatments, when and were to seek help should their vision change, discuss the benefits and entitlements available through certification and registration when sight impaired, and lastly sign posting AMD patients to other sources of information and support.
Clinicians should provide information materials in accessible formats for AMD patients at diagnosis and these should include; information about AMD, treatment pathways and likely timelines, advice about what to do and were to go should their eyesight deteriorate, available support including links to local and national support groups.
Clinicians should create an environment that allows patients to discuss their concerns, diagnosis, treatments, management and prospects of their vision. They should also consider patients' priorities when making management decisions.
Clinicians should promote peer support, particularly for AMD patients beginning intravitreal injections- they may benefit from discussion with someone that has gone through this experience.

NICE guidelines emphasize the need for clinicians to be aware that it is their obligation to provide information in an accessible manner and in line with the NHS Accessible Information Standard. This Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, carers and parents with a disability, impairment or sensory loss (NHS, [DCB1605 Accessible Information], 2018). Clinicians can also get further guidance on information provision and aspects of discussing AMD patients' preferences from NICE guidelines on patient experiences in adult NHS services (2012). Recommendations include; knowing the patient as an individual, establishing essential requirements of care, tailoring services based on patient' s lifeworld and providing a platform for patients to actively participate in their care, including communication, information and shared decision making (NICE, 2018 [CG138]).

The Royal College of Ophthalmologists (2013) designed guidelines of practice for ophthalmologists across the country to encourage best practice within the NHS and the private sector. The guidelines compliment recommendations in the NICE guidelines and provide steps for information provision during diagnosis, treatment and for managing AMD patients, including how clinicians should break the news to the patients at diagnosis (see, Table 1a). The guidelines recommend that clinicians should provide both verbal and written information in large print about the condition, treatments, rehabilitation, support groups and its management, as it had been noted in past that patients often left the consultation room without adequate information after receiving the bad news. Below is a table that shows some of the observations made by RCOphth and recommended actions to be taken in the eye clinic.

1.2.3 Table 1a. Observations by RCOphth

Observations by RCOphth and recommended action to be taken in the clinic adapted from: The Royal College of Ophthalmologists (2013). *Age Related Macular Degeneration guidelines for management*. London: Royal College of Ophthalmologists.

	Observations made by RCOphth	**Actions to be taken in clinic**
Breaking bad news	After receiving news of their diagnosis particularly the dry AMD which is not treatable, no further information is provided	Clinicians should at all times provide written information at the end of each consultation and provide useful contact details and sign post patients to the low visual clinics for support with rehabilitation
Avoid diagnosing and immediately discharging	AMD patients with lesions that are not treatable are often seen once and discharged from the clinic. Usually they are unaware of what to expect in the future living with this condition and where to obtain further information on how to find services that may be useful to them in managing the condition	Receiving bad news has a negative impact on individuals' understanding information provided on the day. However, it is beneficial to have a follow up appointment after receiving bad news. This gives patients the opportunity to receive further information and ask questions that allow them to understand the condition better. Furthermore, they can be provided with useful contact details

		(e.g. Eye Clinic Liaison Officer), who they can talk to.
The clinic experience at time of diagnosis	AMD patients often reported that diagnosis was provided in uncaring manner.	The initial experience in the clinic if good, it will help patients' future outlook, expectations and achievements. A satisfactory patient experience can be achieved by providing good training to all clinicians
Importance of signposting	Receiving a diagnosis without the follow up information required with regards support, can leave patients' feeling lost and isolated and not knowing where to find help.	Clinicians need to provide information about services such as; Visual rehabilitation officers, social services, local help/support groups- Macular Society or RNIB.
Provide literature in the clinic	Patients want to be given information materials regards their condition that are accessible which they can read in the comfort of their homes.	It is the responsibility of clinicians to make information materials available to patients and ensure they given before they leave the clinic.
Staff training	Clinicians should handle new diagnosis empathetically	Continuous training for clinicians is needed and all staff should be aware of the impact of a diagnosis on patients'

1.2.4 Table 1b: Provision of information for AMD patients at diagnosis

Provision of information for AMD patients at diagnosis adapted from: The Royal College of Ophthalmologists (2013). *Age related Macular Degeneration Guidelines for Management*. London: Royal College of Ophthalmologists.

Recommendations by RCOphth for type and quality of information to be provided during diagnosis:
a. A clear diagnosis. Patients should know the name of the condition causing their sight loss, including the type of AMD they have (wet or dry), or a combination of these, provide information both verbally and in writing (large print). Providing such information means that patients have vital knowledge which they can use to seek further information and advice about the condition when they are ready. Giving a vague description such as "you have an eye condition to do with ageing" is not enough.
b. Vision prognosis. Clinicians should always aim to provide information about the outlook of the patient's vision clearly. For instance, is it likely to develop in the second eye, is it dry and could it become wet? Clinicians must educate patients by providing information regards signs of deterioration and when and where to seek help (e.g. urgent appointment for review) should distortion or blurring in the second eye occur.

c. Treatment options. • Clinicians need to be aware that even if there are no appropriate treatments for patients with sight loss, these individuals can still be helped using various non-medical interventions. • Eye departments across the country need to be aware of what is currently available to treat AMD, in the context of the NHS and current NICE guidelines, and if unable to offer one of the current treatments they must make patients aware of the full range of treatments available both on the NHS and privately. • Clinicians should refrain from using phrases like “nothing more can be done” in a medical sense, as this terminology can be devastating and unhelpful to the patient. • Instead, they should be providing information about condition, prognosis, emotional support, low vision assessments and practical input such as rehabilitation covering daily living skills, mobility and resources that aid accessibility so they can manage their condition better over time. • Clinicians and patients need to be aware of the need to treat exudative AMD urgently. Patients should be made aware that they need to contact the clinic if they have not received an appointment for treatment or further assessment within 2 weeks
d. Hallucinations-Charles Bonnet Syndrome (CBS). Clinicians should inform patients about the possibility of CBS and its symptomatic presentation, which typically improves by 18 months, but can last many years. Patients should be informed that this comorbidity of AMD can be distressing-as they may think they are suffering from a mental health illness.
e. Risk and improvement factors. Patients have no control over their age, however clinicians can discuss other risk factors including smoking- a recognised risk factor for both wet and dry AMD and advise them to stop smoking for harm minimisation. Clinicians should also provide information on diet and nutrition that helps slow down the degeneration process- eating a diet rich in fruit and vegetables and nutritional supplements. Information on the impact of bright sunlight for AMD patients should be given and the appropriate intervention to deal with it given -good quality anti-glare lenses are essential
f. Continuing ocular exams. Patients should be advised of the importance of regular eye examinations, especially if they are going to be discharged from the hospital system. They can be attended to by their opticians at least every two years or more frequently if necessary.
g. Date of next appointment. Clinicians should provide information concerning the patients’ next appointment, or whether they have been discharged.
h. Change of vision. Clinicians need to educate patients on what to do should they experience a sudden in vision and similarly clinicians should be aware of AMD patients need to be seen urgently should their sight deteriorate rapidly.

1.2.5 Evidence Based Practice (EBP)

The National Institute of Clinical Excellence (NICE), the Cochrane Collaboration and professional bodies such as Royal College of Ophthalmologists disseminate recommendations for practice in the UK through reviews they conduct. This means all guidelines and recommendations they institute are informed by Evidence Based Practice (EBP). EBP is the “conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett, Rosenburg, Grey et al., 1996 p.71). As described in the definition EBP advocates using the best available evidence integrated with clinical experience. However, while clinical expertise is useful in making decisions about patient care, incorporating experiential knowledge captured via in depth, transparent and systematic qualitative research will make EBP a more robust and holistic approach to making decisions about the management and treatment of AMD, including improving the quality and type of information to patients at diagnosis as recommended by the guidelines.

EBP was developed on the positivist medical model which holds that research can be a value free process where objective knowledge is gained via empirical methods. This premise or epistemological stance has traditionally recognised certain types of evidence over others. For instance, Meta-analysis of RCTs and Individual RCTs appear at the top of NICE hierarchy of evidence, while qualitative studies are ranked last. This over reliance on RCTs is problematic in the sense that, the epistemological, ontological, and methodological assumptions that may be deemed “appropriate for clinical medicine could be inappropriate for non-biomedical health and social care” (Marks 2002, p.7). Therefore, missing out on crucial lifeworld data that may help improve interventions or practice. However, in recent years researchers across the academic spectrum (e.g.Sackett & Wennberg, 1997; Shaw, 2012) acknowledge that randomised controlled trials cannot answer many of the questions that improve practice, and it has become acceptable that other approaches to gaining evidence can contribute significantly to this knowledge base (Shaw, 2012). No approach should be viewed as greater than the other when it comes to knowledge generation. Instead what we seek to understand should be the driver of how we gain understanding, including determining the means with which to generate data that gives us that understanding. While it might be impossible to achieve true objectivity, engaging an interpretivist approach to inform policy and practice may be needed. Interpretivism provides a philosophical basis for research that states there are no correct or incorrect theories (Walsham, 1993). Instead it argues that knowledge and meaning are acts of interpretation, hence there is no objective knowledge that is independent of thinking, reasoning humans (Gephart, 1999: [online]). Unlike the positivist approach that is underpinned by observations and measurement, the interpretivist paradigm is underpinned by observation and interpretation, thus to observe is to collect information about events, and to interpret is to make meaning of that information by drawing inferences between the information and some abstract pattern (Aikenhead, 1997: [online]). In other words, this approach attempts to understand phenomenon through the meanings individuals assign to them (Deetz, 1996). Hence, the most significant aspect of this approach is that it places the individual as the starting point for human science, thus ensuring that policy and practice are underpinned by an empathic understanding of people’s experiences. In other words, interpretations would be grounded in the lifeworld of what individuals’ actually go through (Todres et al., 2007). In addition to evidence generated by RCTs, incorporating experiential research into EBP guidelines is of fundamental importance, as this would help broaden clinicians’ experiential knowledge beyond their own. This will help improve their practice in providing better information in a sensitive manner at diagnosis and beyond that is also driven by the patient's lifeworld in as far as the decision-making process is concerned. As such, this program of work will be using a qualitative approach underpinned by an interpretive paradigm.

1.3 Purpose and Significance of the Study

The objective of this programme of work was to qualitatively explore fundamental elements concerned with providing better information and support for the diagnosis and treatment of people living with age related macular degeneration (AMD), to help them manage it over time. To this end this programme of work aims to:

1.3.1 Research Aims

- To evaluate existing information made available to patients with AMD to determine preferred content and format;
- To examine methods of gaining consent to treatment during a clinical consultation to ascertain patients' priorities and preferences regarding treatment and visits to the clinic;
- To explore patients' perceptions of support groups in-depth in order to better communicate their value to non-attenders;
- To develop ways of incorporating better information provision and raising awareness of support groups in local NHS settings.

And intends to provide answers to address these fundamental questions:

1.3.2 Research Questions

- What information about age-related macular degeneration (AMD) is useful to patients on diagnosis and helps them manage the condition over time?
- How is consent to treatment negotiated and obtained during the consultation?
- What are patients' views on engaging with organised support groups?
- How can we boost attendance at organised support groups?

A total of three studies using qualitative methods underpinned by an interpretivist approach were conducted to answer the research questions presented above. The findings of which will be discussed in more detail in the in the ensuing chapters, with the view of providing a narrative that best represents this group’s perceptions and experiences with information provision and support at each stage of their journey living with AMD.

1.3.3 Rationale

There is a paucity of qualitative research studies, particularly those focusing on elements relating to information provision and support for sight impaired individuals more specifically people diagnosed and living with AMD (Beverly, Bath & Booth, 2003; Coulter et al., 1999; 2006; Raynor, Blenkinsopp, Knapp et al., 2007). Most of the research conducted in recent times has tended to focus on the lived experiences of this group (e.g. Burton, Shaw & Gibson, 2012; Brody et al., 2002; Wong et al., 2013), treatment experiences (Thetford et al., 2013; 2015). However, what is evident from all these studies is the fact that there are common strands interlinking them that is, the issues around; deficiency in information and support that aids understanding of disease, treatment, decision making and consent process and deficiency in information and support that promotes living optimally with the condition. Kinnell and Creaser (2001) argued that these strands were significant drivers in patients managing their condition and as such an area that required to be explored in depth. A notion the UK Vision (2015) concurred with. It is this major gap in literature that this programme of work addresses in bringing about a better understanding of this marginalised groups’ perceptions of and experiences with information provision and support across multiple dimensions of the lives.

From a policy point of view, while information provision is a key initiative within Healthcare, more needs to be done in sensitising clinicians of the importance of best practice to ensure patients are knowledgeable about and aware of the key stages within their AMD journey to access relevant support (i.e. treatment, visual aids, support groups and benefit entitlements related to their disability status). To this end, this programme of work aims to also contribute to strengthening the policy framework and or influencing reform and practice, particularly where sight impaired patients are concerned.

From a practice point of view, there is an apparent need to increase knowledge and awareness amongst stakeholders (e.g. Clinicians and Providers of information resources), who work with this group about their information needs, and the impact it poses on their psychological well-being when the information and support needs are not met, particularly around the time of diagnosis and treatment. It is anticipated that this programme of work to this end will help stakeholders acknowledge and understand AMD patients’ perceptions of and experiences with provision of information and support across multiple dimensions of their journey living with the condition. The significance of this programme of work lies in giving a voice to an underrepresented group to share their experiences and recommendations that would potentially improve their experiences with information and support at diagnosis and treatment. It is anticipated that the data generated from these experiences has the potential to inform pragmatic outcomes, such as providing information resources that are life context led for AMD patients, alongside interventions (e.g. teach back) that will improve understanding of condition and its management over time. Having a holistic outlook to how information is provided at diagnosis, treatment and support will benefit both provider (e.g. re-shaping their practice) and the recipients' (e.g. better understanding- coping/adjustment; better management- psychological well-being) immensely.

The overall design of this programme of work uses qualitative methods with the view of developing a better understanding of AMD patients' perceptions and experiences of information provision across multiple dimensions of their lives. This included the use of a stakeholder approach (will be discussed explicitly in the methodology chapter), which brings something unique to the table, where stakeholders collaboratively work with the researcher and assist in developing the interview questions focusing on areas pertinent to improving patient experiences regards information provision within Healthcare. Not many studies have gone down this route, in particular addressing the issue at hand. As such it is hoped this novel way of conducting research helps information providers with the framework to tailor information resources to AMD patients' life contexts.

The methods used were deemed more appropriate for responding to the aims, objectives and the research questions pertinent to this programme of work.

Since completion of the fieldwork conducted for this programme of work a new treatment has become available for managing dry AMD. Up until recently, there had been no clinically proven treatment available. Interventions were mainly centred on improving diet, taking macular supplements and smoking cessation programmes. However, a new treatment – photo-bio-modulation has become available. This will be delivered using a device called the Valeda Light Delivery System. This treatment is available in the UK, although not widely reported as research in this area is on going. The availability of such treatments will go a long way in mitigating some of the psychological challenges patients diagnosed with dry AMD experience after being given a life altering diagnosis that has a significant impact on their occupational life and being told there are no treatments for it.

It is worth mentioning here that this researcher conducted a systematic literature search with the intention of conducting a meta-synthesis to get a deeper understanding of the consent to treatment process for wet AMD patients within a healthcare setting. However, the search produced no suitable papers. The literature found was largely randomized controlled studies focusing on efficacy of treatments, with some focused on information only. None of the studies reviewed included details specific to the consent process for AMD and/or visually impaired patients within a clinic or outpatients setting. (See appendix I for search strategy and Prisma flow chart). In summary there was no substantive literature looking at patients' *experience* of the informing, consenting and deciding processes in this field, so the best we can do is contextualize the findings of this programme of work with regard to analogous literature from other fields.

1.4 Organisation and Overview of Chapters

Chapter one; provides the context of this programme of work by outlining the background, the purpose, the significance, research questions and objectives of the studies contained therein.

Chapter two; discusses the methodology and paradigm used in this programme of work. It outlines the key issues relating to sampling, data collection, analysis and ethics.

Chapter three; focuses on exploring AMD patients' perceptions and experiences with information materials, this includes evaluating information materials currently available to them to determine their preferred content and format.

Chapter four; focuses on the patient-clinician dyad, particularly the consenting process and how information is communicated at diagnosis including information that helps patients make an informed decision to consent to treatment. Their experiences within the clinic, including priorities and preferences.

Chapter five; focus on the first-time attenders to support groups with the view of illuminating the importance of support groups as an information source and potentially increase traffic to these groups for AMD patients.

Chapter six; provides general discussions and a synthesis of the studies highlighted above and includes the main findings, strengths, limitations, and recommendations and implications for research and practice are presented.

1.5 Summary

This chapter outlines the introduction/background and rationale for the study as well as the issue of focus and purpose of this programme of work. It also provides a preview of the contents of subsequent chapters.

CHAPTER TWO: Research Methodology

2 Introduction

This chapter aims to provide a detailed account of the philosophical and theoretical underpinnings as well as the practical methods employed in this programme of work. As such, it will begin by outlining the aims and objectives of this thesis. This will be followed by a discussion on the researcher's interpretivist stance towards the research, and consequent choice of a qualitative approach and rationale. Specific details about the characteristics of the researcher and approaches implemented to enhance methodological quality will also be provided. Finally, details regarding ethical and research governance approval and the identification of study sites will be given.

2.1 Research Aims and Objectives

There are three studies that will be conducted within this programme of work.

The main aims of these studies are:

Study 1

i. To evaluate existing information made available to patients with AMD to determine preferred content and format.

Study 2

ii. To examine methods of gaining consent to treatment during a clinical consultation to ascertain patients' priorities and preferences regarding treatment and visits to the clinic.

Study 3

iii. To explore patients' perceptions of support groups in depth in order to better communicate their value to non- attenders.

iv. To develop ways of incorporating better information provision and raising awareness of support groups in local NHS settings.

The overall objective of the study is to provide better information and support for AMD patients, by first exploring and understanding their perceptions, experiences and visions with regard to accessing information from print materials, clinicians and support groups.

Table 2, below, provides an outline of different aspects of this body of work in relation to the aims and objectives described above.

2.1.1 Table 2: Aspects of this study in relation to its aims and objectives

Study 1	Study 2	Study 3
Semi-structured interviews – AMD patients/carer/family. Experiences with information materials.	*Observation* – patient/clinician consultations at diagnosis.	*Observation* – AMD patients in a support group setting.
Focus groups – AMD patients present information materials for evaluation. Determine preferences of content/design/format. *Analysis* – Thematic analysis.	*Semi-structured interviews* – clinicians: perceptions/experiences of information provision. Decision-making and methods of gaining consent. Including priorities and preferences. *Semi-structured interviews* – AMD patients: perceptions/experiences of information provision at diagnosis, decision-making and methods of gaining consent to treatment. Including priorities and preferences. *Analysis* – Critical narrative analysis	*Semi-structured interviews* – AMD patients' thoughts/experiences of support groups. *Analysis* – Critical narrative analysis.

Table 2 is a summary of the data collection methods used for each of the studies in this research. The methods will be discussed in greater detail later in this programme of work.

2.2 Paradigm

Terre Blanche and Durrheim (1999) posited that a research paradigm is an all-encompassing system of interrelated practice and thinking that defines the nature of enquiry along three dimensions: ontology, epistemology and methodology. Ontology refers to the philosophy of reality (Krauss, 2005), that is, what we believe constitutes social reality; for example, the way we describe things and the relationships that exist between them – claims and assumptions about what exists, what it looks like, what units make it up and how these units interact with each other (Blaikie, 2000, p.8). Epistemology can be described as a way or ways in which we gain knowledge of social reality and how we understand it (Blaikie, 2000), while methodology is concerned with how researchers employ different practical methods to find out whatever they believe can be known about a particular phenomenon. It can be argued here that differences in the approach or methods used to research exist due to the underlying nature of the beliefs that researchers bring to the matter (Lyons, 1999).

Kuhn (1970) described this set of beliefs as a paradigm. Guba and Lincoln (1994) put forward that the notion that paradigms represent a view of the world as we perceive it, how we interact with it, and where we 'fit' in that context. Paradigms are said to '[establish] the parameters and [set] the boundaries for scientific research and, in the ordinary course of events, scientific enquiry is carried out strictly in line with it' (Crotty, 1998, p.35). Historically, research has been influenced by two major paradigms, positivism and interpretivism, which in turn influence the methods by which data is collected.

2.2.1 Positivism - A Quantitative Approach

Objectivism is reality-orientated and theorises that everything exists independent of consciousness. These assumptions underpin the positivist perspective, which is often regarded as a 'scientific method' involving knowledge being gathered in ways that are not subjective but are direct experiences (Crotty, 1998) and that are replicable, involving logically deduced hypotheses and confirmed evidence (Charmaz, 2006). Reality is said to depend upon cause and effect principles and it can be measured. Positivists test causal explanations through the testing of theories and hypotheses, using variables quantified through methods that yield numbers such as questionnaires or surveys and subjecting them to statistical analysis. Data collected in this manner is efficient in testing pre-determined hypotheses, and the importance of the researcher remaining objectively separated from the subject under scrutiny is stressed. It has been argued that such an approach fails to capture the complexity of human behaviour and social interaction (Jensen, 1989). Hence, the positivist emphasis on experimental and quantitative methods has been superseded in this programme of work by an interest in expending qualitative methods to collect broad information, outside of readily measured variables (Gephart, 1999).

2.2.2 Interpretivism

Interpretivists believe that reality exists and can be experienced in different ways while recognising that interpretation of information cannot be wholly objective; rather, there is a need to control or limit the biases present when collecting data (Hanson, 1958). Interpretivism thus proposes that there can be multiple realities of phenomena, and that these realities can differ across time and place. This allows the researcher the scope to adopt an inter-subjective epistemology and the ontological belief that reality is socially constructed. Interpretivism aims firstly to understand the context and then to make an interpretation that is shaped by experience. Qualitative methods are frequently used when we know little about a phenomenon or subject (Morse & Field, 1995), and where the investigator seeks to collect ‘information rich’ cases (Patton, 2002). Qualitative research, broadly defined, means ‘any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification’ (Strauss & Corbin, 1990, p.17). Data are collected by qualitative means through interviews, focus groups and observations, including naturalistic data, and analysis involves examining the words that are recorded during these interactions. Studies involving qualitative approaches are regarded as being subjective, where the researcher’s interpretation of the events recorded is paramount to address ‘research questions that require explanation or understanding of social phenomena and their contexts’ (Snape & Spencer, 2003, p.5).

Gephart (1999) argued that interpretivists assume that knowledge and meaning are acts of interpretation; hence, there is no objective knowledge that is independent of thinking, reasoning humans. Myers (2009) argued that the premise of interpretivism is through social constructions such as language, consciousness and shared meanings. An interpretive paradigm is underpinned by observation and interpretation; thus, to observe is to collect information about events, while to interpret is to make meaning of that information by drawing inferences or by judging the match between the information and some abstract pattern (Aikenhead, 1997). It attempts to understand phenomena through the meanings that people assign to them (Deetz, 1996).

Reeves and Hedberg (2003, p.32) note that the ‘interpretivist’ paradigm stresses the need to put analysis in context. The interpretive paradigm is concerned with understanding the world as it is from subjective experiences of individuals. They use meaning (versus measurement) oriented methodologies, such as interviewing or participant observation, that rely on a subjective relationship between the researcher and subjects. Interpretive research does not predefine dependent and independent variables but focuses on the full complexity of human sense-making as the situation emerges (Kaplan & Maxwell, 1994). This is the interpretive approach, which aims to explain the subjective reasons and meanings that lie behind social action.

The interest of interpretivists is not in the generation of a new theory, but in judging or evaluating and in refining interpretive theories. Walsham (1995b) presents three different uses of theory in interpretive research studies: theory guiding the design and collection of data; theory as an iterative process of data collection and analysis; and theory as an outcome of a research study. The use of theory as an iterative process between data collection and analysis has been applied in this research study.

According to Burrell and Morgan (1979), interpretivism is not a single paradigm; rather, it is a large family of diverse paradigms. The philosophical base of interpretive research is hermeneutics and phenomenology (Boland, 1985). Hermeneutics is a major branch of interpretive philosophy, which emerged in the late nineteenth century (Kaboob, 2001), with Gadamer and Ricoeur being arguably its best-known exponents (Klein & Myers, 1999). Hermeneutics can be treated as both an underlying philosophy and a specific mode of analysis (Bleicher, 1980). However, the chosen mode of analysis for this programme of work, critical narrative analysis (CNA) (Langdridge, 2007), fits nicely into this philosophical base and will be discussed in depth in the analysis section. As a philosophical approach to human understanding, hermeneutics provides the basis of understanding the meaning or trying to make sense of textual data that may, in one way or another, be unclear.

The most fundamental principle of hermeneutics is that all human understanding is achieved by iterating between considering the inter-dependent meaning of parts and the whole that they form. Modern hermeneutics encompasses not only issues involving the written text, but everything in the interpretative process that includes verbal and non-verbal forms of communication as well as prior aspects that affect communication, such as pre-suppositions and pre-understandings (Smith, 2009).

The movement of understanding 'is constantly from the whole to the part and back to the whole' (Gadamer, 1976b, p.117). According to Gadamer, it is a circular relationship. It attempts to understand human beings in a social context. This principle is foundational to all interpretive work that is hermeneutic in nature.

Although the study is not primarily phenomenological, some of its aspects are underpinned by the principles of phenomenology, which focuses on discovering and expressing essential characteristics of a certain phenomenon as they really are. Literally, phenomenology is the study of 'phenomena' – appearances of things, or things as they appear in our experience, or the ways in which we experience things; thus, the meanings things have in our experience (Moran, 2000). It is the study of structures of consciousness as experienced from the first-person point of view. In its most basic form, phenomenology attempts to create conditions for the transcendent study of topics usually regarded as subjective: consciousness and the content of conscious experiences such as judgments, perceptions and emotions (Smith, 2009).

Creswell (1998, p.51) contends that a phenomenological study describes the meaning of the lived experiences for several individuals about a concept or a phenomenon. In the human sphere, this normally translates into gathering 'deep' information and perceptions through inductive qualitative research methods such as interviews and observation, representing this information and these perceptions from the perspective of the research participants (Lester, 1999). Observation and interviews are the key data collection methods within phenomenology (Aspers, 2004). Phenomenological strategies are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore challenging structural or normative assumptions (Lester, 1999).

This programme of work is situated in the interpretivist paradigm. As such, it is considered that there are multiple realities that make measurement difficult, and we can only seek to understand real-world phenomena by studying them in detail within the context in which they occur. In numerous ways, this interpretivist position is based on the belief that a qualitative approach to the research aims highlighted at the beginning of this chapter will provide the best insight into the phenomena of interest.

In achieving this aim, consideration of methodologies and the methods that could be used took place. Morgan argued that while the theoretical underpinnings of a methodology and the methods themselves should be considered of equal importance, ‘we need to use our study of methodology to connect issues in epistemology with issues in research design rather than separating our thoughts about the nature of knowledge and from our efforts to produce it’ (Morgan, 2007, p.68).

The programme aimed to gather knowledge and gain an understanding of AMD patients’ perceptions and experiences with the provision of information at diagnosis, information materials and support groups.

Table 2a, below, displays the characteristics of interpretivism, as used in this study, categorised into the purpose of the research, the nature of reality (ontology), nature of knowledge and the relationship between the inquirer and the inquired-into (epistemology) and the methodology used (Cantrell, 2001).

2.2.3 Table 2a: A summary of possible epistemological and ontological positions

	Epistemology	
Objectivism (positivism): There exist measurable facts, independent of self.	**Interpretivism**: The world is independent of human minds, but knowledge of the world is always a human and social construction (Crotty, 1998).	**Subjectivism:** **(Structuralism):** all knowledge comes from within a person's mind.
	Ontology	
Objectivism: Reality is independent of our beliefs and thoughts.	**Relativism:** No real, objective truth exists.	**Subjectivism:** Whatever is experienced by one's self is real. Many social realities exist due to varying human experiences, including people's knowledge, perceptions, interpretations and experiences. Reality can be explored, and constructed through human interactions, and meaningful actions.
	Methodology	
	Processes of data collected by interviews, focus groups and observations. Research is a product of the values of the researcher.	
Purpose of this programme of work: Highlighted at the beginning of this chapter.		

Note: *The ontological and epistemological stances of this research study are highlighted above*

Overall, the study is a piece of applied qualitative health services-oriented research in the interpretivist tradition using a stakeholder approach. The key words pertaining to this methodology are participation, collaboration and engagement (Henning, van Rensburg, & Smit, 2004). In the interpretive approach, the researcher does not stand above or outside, but is a participant observer (Carr & Kemmis, 1986, p.88) who engages in the activities and discerns the meanings of actions as they are expressed within specific social contexts.

This study draws upon this conceptualisation of social reality to explore the competing and conflicting ways in which AMD patients perceive and experience information provision at diagnosis, information materials currently available to them and attending support groups for the first time. Different viewpoints are therefore recognised and accepted, although it is acknowledged that not all available perspectives are revealed. While accepting that individuals interpret and perceive the world differently, the study aims to group viewpoints together, to enable us to get a clearer conceptualisation of the competing positions. Henwood and Pidgeon (1992) contend that researchers seek to construct a '*negotiated reality*' with participants, a version of the '*truth*' that all can identify with, even though they may have a different emphasis or apply different examples. In this research, the examination of different viewpoints will produce a number of 'negotiated realities', through consultation with the supervisory team and the stakeholders' working group, which will be discussed in detail below and interpreted by the researcher.

2.3 Strategy

Different realities exist within health care, and experiences are perceived with varying degrees from provider to receiver of service (Normann, 2001). Thus, a different orientation based on engaging and collaborating with patients, clinicians and relevant stakeholders is needed in order to gain multiple perspectives and to find common ground for improving information provision for AMD patients (Bate & Robert, 2006). Interpretivists are anti-foundationalists who are flexible in their approach to gaining knowledge within research, citing the notion that there is no 'right or wrong way of gaining knowledge' (Willis, 1995). As such, for this programme of work, in order to optimise knowledge generation, research quality, and improve patient experiences of information provision, the researcher adopted an approach that involves stakeholders as a framework to inform each stage of this programme of work. Consequently, Hiles (1999) argued that using a strategy afforded the researcher options and choices and provided links between the research paradigm and methods of data collection and analysis.

The strategy adopted in this programme of work involving stakeholders will be defined as an element that places patients and those involved in their care at various levels as collaborative partners in identifying ways to improve their experiences with information provision, either communicated or written. The process involves sharing human experiences and sense-making emotions connected to information provision at diagnosis and in support groups (Bushe & Marshak, 2009). In other words, this approach empowers patients to participate as equal partners in addressing issues relating to information provision in health care. Through sharing narratives, patients and clinicians can try to understand how the other makes sense of their experiences (Weick, 2000) and, as a result, come to a common understanding about areas that require improvement.

The adopted approach involved setting up a working group of experts to help shape this programme of work at each stage. These experts were identified through networking at conferences, local trusts and support groups. Their role included helping in developing the interview questions, identifying materials to be assessed, and analysis of the data, making recommendations and shaping the programme of work as required. All members of the working group were formally invited via a letter (see Appendix F), with their roles outlined. The list working group membership comprised:

- Supervisory team
- R&D rep:
- ECLO: at BMEC
- Ophthalmic nurse
- Reps from Birmingham Focus
- Macular Society rep:
- Expert researcher: Amy Burton
- Expert by AMD experience
- Patient rep

The use of such a strategy fits in with the paradigm chosen for this programme of work, including its aims and objectives. Research has shown that if patients, clinicians and stakeholders are included in research as collaborators and viewed as co-creators of value in health care, it increases their capacity to influence and improve service, quality, health outcomes and their overall experiences within health care (Kim et al., 2014; McColl-Kennedy et al., 2012).

Involving patients as collaborators in health care empowers them; it allows them to gain greater control over the actions and decisions that affect their health (WHO, 2006). The phrase 'nothing about me without me' has become widespread within health care (Delbanco et al., 2001). Tritter and McCallum (2006, p.157), arguing that this phrase was deliberate in order to empower the patient to be more involved in their care, described it as:

'*a complex phenomenon through which individuals formulate meanings and actions that reflect their desired degree of participation in individual and societal decision-making processes.'*

This programme of work involving patients as collaborators not only included empowering them but also provided them with opportunities to participate in research activities (e.g. focus groups and support groups) to improve their experiences with information provision, that is, understanding their AMD diagnosis better and managing it better over time. Involving the patient within the context of the stakeholder approach is an interactive, collaborative, and dialogical process based on knowledge and experience between patients (sometimes relatives and or carers) and health care professionals about actions that affect patients' understanding of their diagnosis, decision-making and managing their condition better over time.

The aim of this approach was to capture and understand experiences of AMD patients within the clinic regarding the provision of information that pertains to their condition. Specifically, the aim was to capture: their experiences with information materials currently available to them; their experiences of information provision at diagnosis decision-making and methods of gaining consent to treatment; and their views on and experiences of support groups. This information would be gathered with a view to improving patients' overall experiences with access to information. This fits in with the purpose and objectives of this programme of work.

2.4 The Researcher's Role

The interpretivist position taken within this programme of work requires open acknowledgement of the role the researcher has played in the production of knowledge. Throughout the research process, the researcher has a great deal of power: to formulate and direct the questions asked; to interpret the findings; and to decide what will be presented in the final report (Rapley, 2001). For example, the process of coding an interview transcript is a subjective activity, as the researcher decides what aspects of data to code, what levels of generality to go into and what aspects to exclude from the study (Coffey & Atkinson, 1996). This reveals the unequal power relations that exist between researcher and participant. Participants are encouraged to express their thoughts and ideas explicitly, but the direction of the study and control over the exchange remains firmly in the researcher's control. As Oakley (2000, p.66), paraphrasing Bloor (1997), says:

> '*everything participants share with researchers is ultimately grist for the researchers*.'

The difference in power between researcher and participant cannot be overcome, but it can be acknowledged, and steps taken to minimise it. In this programme of work, the researcher sought to address this issue using the stakeholder approach cited above, which sees participants as collaborators, thereby empowering them and giving them an opportunity to share their experiences with information provision and suggest areas for improvement. To establish trustworthiness in the data, the researcher took data back to the participants for checking. However, because of their AMD status, the researcher had to read some of the transcripts for them, to give them an opportunity to amend or retract any statements made. Thus, participants were actively involved in decisions about what should and should not count as research data. Oakley (2000) warns that conflicts can arise from this practice if participants then retract what is considered important and interesting data. However, given the high level of control the researcher has over the research process, and the lack of control that participants have over the interpretation of their statements, the opportunity to retract statements appears to be a reasonable concession. It also helped to establish a relaxed environment during the interviews, with participants encouraged to express themselves explicitly, expansively and as honestly as possible in the knowledge that they could amend or retract statements later if they wished.

To summarise, this research is based on an interpretivist position, which views **‘**social reality’ as ‘constructed and impermanent’ and knowledge as ‘subjective and personal ‘. This underlying position is reflected in the acceptance of different viewpoints. Contrasting and even conflicting accounts of participants’ perceptions, and experiences of accessibility of information written or verbal where understanding their diagnosis or treatment options is concerned, none of which are to be considered along the lines of ‘right’ or ‘wrong’, based on the assumptions discussed above. In saying this, the philosophical basis of this programme of work also demands acknowledgement of my role as a researcher in the production of knowledge and this fits in with the core aims of the strategy adopted for programme of work.

While attempts were made to reduce the effect, the researcher maintained a great deal of control by leading and directing the study; for example, conducting the interviews, focus groups and interpreting, presenting and disseminating the findings. The overall objective of this programme of work is to provide better information and support for AMD patients, by first exploring and understanding AMD patients’ experiences with and perceptions of information provision, specifically accessing information from print materials, clinicians and support groups. It aims to not only shed some light on this under-researched area, but also to develop ways of raising more awareness of the information needs of AMD patients in clinics – regarding diagnosis, treatment and support – and for information providers, to produce more accessible materials that are driven by AMD patients’ needs.

2.5 Method Adopted Within this Programme of Work

Addressing the differences in the approaches revealed that to meet the main aims of this programme of work, an interpretive approach was deemed to be the most appropriate choice, as it permits for multiple methods of data collection and analysis. Those main aims were: Study 1) to explore AMD patients’ experiences with information materials, as well as engaging them to assess, identify and determine their preferences of these materials in as far as the format and content is concerned; Study 2) to explore clinicians’ and patients’ perceptions and experiences with regard to information provision within a diagnostic consultation, decision-making and methods of consenting to treatment; and Study 3) to explore AMD patients’ views on and experiences of support groups in as far as accessing information is concerned.

2.5.1 Qualitative Interviews

Interviews are integral to interpretivist research, and interviewing was considered to be the most appropriate method for exploring patients' experiences with information materials. Dingwall (1992) argued that interviews are now widely used in health services research to help to capture the dynamic aspects of service provision and to understand what patients and clinicians do, believe and think about a particular phenomenon (Britten, 1995). Interviews and focus groups can be described as forms of conversation or dialogue that are 'initiated by the interviewer for the specific purpose of obtaining research-relevant information and focused on content specified research objectives of systematic description, prediction or explanation' (Cohen & Manion, 1989, p.307). They provide the opportunity to explore ideas or concepts that cannot be directly observed (Patton, 1980) from the participants' point of view, not how they are perceived by the researcher (Marshall & Rossman, 1989). Interviews can take a variety of formats, including unstructured or semi-structured; however, it is argued that the flexibility of semi-structured interviews allows for the generation of 'rich and illuminating data' (Robson, 1993, p.229), which is particularly suited to studies investigating new ideas.

Open ended questions are used in a semi structured interviewing process. The interviewer, based on their own perceptions, has the opportunity to modify the order in which questions are asked, change the way that they are worded, probe or include additional questions should further exploration of a concept or idea be required or indeed leave out a question if it is regarded as inappropriate, in order to enhance the context of the conversation. Robson (1993) argued that the benefits of such interviews can be strengthened even further by conducting them in a face-to-face manner where the interviewer has the ability to respond to the participants' non-visual cues or other responses by modifying their questions appropriately. This also fits into the aims of the strategy adopted in this programme of work involving stakeholders, which seeks to empower the participants.

In conducting interviews, Britten (1995) emphasised the importance of not deferring from the participants' own views and meanings and stated: 'In a qualitative interview the aim is to discover the interviewee's own framework of meanings and the research task is to avoid imposing the researcher's structures and assumptions as far as possible. The researcher needs to remain very open to the possibility that the concepts and variables that emerge may be very different from those that might have been predicted at the outset' (p.251). Interviews, particularly those standardised in nature, have additionally been criticised for not acknowledging participants' views appropriately, taking into consideration the context in which they were generated (Mishler, 1979; Murphy et al., 1998).

Adopting a semi-structured approach can help to overcome some of these issues but it is also important that researchers use a good interviewing technique. Building a rapport with participants, listening and responding appropriately, asking questions in a straightforward, non-threatening, non-guiding and non-judgemental way are all techniques that can help to ensure that data generated is as true a reflection of participants' views and opinions as possible. Loftland et al. (2006) argued that interviews should be recorded to allow for an in-depth analysis of the data. Recording the interview, in addition, allows the researcher to be more responsive during the process, which is important when sensitive issues are discussed. Field notes are an important addition to enable the researcher to reflect upon any issues that may have impacted upon the way the interview was conducted. Following advice from the working group and being mindful of the participant group (older adults), the researcher spoke slowly and as audibly as possible to ensure that participants understood what was being asked of them.

2.5.2 Focus Groups

Focus groups are a valuable tool in evaluation studies and across the health and social care field. They have the capacity to capture specific social and psychological processes and phenomena that prevail in group settings, e.g. group interaction and group dynamics. Interactions in the focus groups can reveal insights into specific expressions of philosophy (such as beliefs, value systems, language and specifically issues around information provision), as groups construct and re-construct their perceptions and experiences during these shared narratives (Bergin et al., 2003; Heath, Brooks, Cleaver, & Ireland, 2009; Hyde et al., 2005; Warr, 2005).

Focus groups have the ability to generate rich data from several individuals at once in a short time (Robinson, 1999). They promote self-disclosure, mutual social and psychological support. For example, the interactive nature of focus groups triggers ideas between group members, in a sense developing a shared collective social identity (Hyde et al., 2005; Roberts et al., 2005; Van Teijlingen et al., 2007; Warr, 2005). Therefore, a group setting has the potential to generate data that would not be accessible using other methods (Gough et al., 2009; Robinson, 1999). Conversely, using focus groups can present other issues including power dynamics, potential for inappropriate disclosure by individuals as they psychologically identify with other in-group members. Thus, in preparing for focus groups, consideration of these factors needs to be taken into account by the researcher to mitigate dilemmas that might impact the psychological safety for the group (Owen, 2001). However, it is also important for the researcher to ensure the environment is guided by respect, allowing individuals to express themselves explicitly regarding the phenomenon of interest. As such, in preparing for the focus groups this researcher explored the need to create an affirming, collaborative, and non-judgmental space in which AMD participants would be able to co-construct narratives relating to their perceptions and experiences of information materials under evaluation. In order to achieve this, the stakeholder group and researcher designed a focus group schedule (questions) to use a reminder for the researcher of the general areas to be covered, rather than as a prescriptive tool, which has the markings of inflexibility and creates an atmosphere of due process, power and structure. The focus group schedule produced in collaboration with the stakeholder group was considered useful in providing a framework to ensure similar questions were asked across the three focus groups.

In choosing focus groups for generating data for study 1, three characteristics were of particular importance. Firstly, creating a natural setting (quiet room within eye clinic), in which AMD participants would feel comfortable, safe and more likely to engage. Secondly, data generated from focus groups has the potential to provide more than the sum of separate individual interviews. This is because they provide a focus on the broader collective rather than just the individual. This allows the researcher to not only move beyond the individual, but also allows the participant to co-construct their narratives beyond the self in collaboration with other group members (Field, 2000; Madriz, 2000). Using focus groups for study 1, provided a great opportunity to consider AMD patients' shared views of information materials currently available to them (e.g. perceptions, preferences, and so on). Lastly, the use of focus groups can allow participants' voices to become dominant in the research process (Bergin et al., 2003; Kitzinger, 1994; Mosavel & Oakar, 2009). For example, in study 1 we approached AMD patients to learn from them about their experiences with and perceptions of information materials, thereby creating settings in which the common psychological power differential between the researcher and researched lessened as the participants became the experts teaching the researcher about their experiences (Mosavel & Oakar, 2009), and empowering participants to find their voices (Robinson, 1999).

2.5.3 Observations

Observation methods are important for understanding people's actions, roles and behaviour more so within healthcare (Walshe, Ewing & Griffiths, 2011). Specific to our study, observations are necessary because of their focus on the natural setting which provides the researcher with a real time understanding of the diagnostic consultation. In particular, observations can facilitate understanding of what people do and how these can alter in response to situations and perhaps over time. In a sense observations are useful as they help to identify and guide relationships with participants', to learn how people in the setting interact and how things are organized and prioritised in that setting, to learn what is important to the people in the setting under study, to become known to the participants, and to learn what constitutes appropriate questions, how to ask them, and which questions may best help the researcher answer the research questions (Schensul, Schensul & LeCompte, 1999). Researcher positioning when using observations in research is very important were validity is concerned. The quality of data collected and relationship with participants observed are affected how the researcher positions himself within the context of the research setting (Kawulich, 2012). In this study, the researcher's preferred way of observing was overt observation, where participants where aware they were being observed and knew the purpose of this method. This positioning was in line with tenets advanced by Gold (1958) around observations as a data collection method.

This programme of work used focus groups, individual interviews and observations as data collection tools. Semi-structured interviewing was adopted to elicit experiences and preferences of information materials from individual interviews and focus groups.

2.5.4 Transcription

Bazeley (2007) stated that transcription of interview or focus group data is one of the most common ways to prepare it for analysis. The researcher undertook the task of transcribing the interview and focus group data himself. This process was the second step in immersing himself in the data and developing initial ideas about it. Aitkin's (1990) standardised rules of transcription were employed to ensure that participants' pauses, use of slang, notations of emotional content, such as whispering, were conserved, ensuring that the transcript reflected as accurately as possible the views of the participants and that any possibility of misrepresentation was minimised. Standardised rules also ensured that transcripts followed the same presentational format. Schegloff (1997) described this as allowing the participants to speak for themselves. Reading the transcripts again after they had been typed afforded the researcher the opportunity to re-familiarise himself with the data and this was a great help for the data analysis process. All participants, clinicians and identified clinical areas were anonymised at the point of transcription to maintain confidentiality.

2.6 Analysis

Since there are three studies within this body of work, this section will duly discuss the different analytical approaches employed for each study in order to provide the best answer to the questions posed. As such, the statement 'the pond you fish in determines the fish you catch' (Suzuki, Ahluwalia, Arora, & Mattis, 2007, p.295), meaning if the tools are right for the job the outcomes will be evident. In other words the chosen methods of analysis will shape the different types of knowledge generated from this body of work.

2.6.1 *Study 1*

The data obtained for this study (focus group discussions and individual interviews) were analysed using thematic analysis (TA) (Braun & Clarke, 2006). Boyatzis (1998) argued that using TA permits for data to be encoded through a systematic process and allows an entire data set to be analysed through themes that are emerging (Braun & Clarke, 2006).

This analytic approach was chosen for a number of reasons: firstly, for its flexibility, which fits within the paradigm chosen and aligns with the worldview adopted for this programme of work; secondly, for its capability of providing ‘a rich and detailed, yet complex account of data’ (Braun & Clarke, 2006, p.78); thirdly, because its flexibility enables the researcher to explore themes across the data set, and also permits representations and considerations of salient idiographic issues to be made (Braun & Clarke, 2006).

While it is a widely used approach in analysing qualitative research, it is a poorly acknowledged method when compared to more prevalent methods such as grounded theory. It can be argued, however, that what distinguishes thematic analysis from approaches such as grounded theory or discourse analysis is the fact that it does not rely on pre-existing theoretical frameworks and that it is therefore a more accessible approach (Braun & Clarke, 2006), with the ability to be used with a wide variety of frameworks, such as the one adopted for this programme of work. Thematic analysis lends itself to providing a rich thematic description of the whole data set and it is for this reason that it is a useful approach when exploring new or under-researched areas. It is particularly relevant to this body of work focusing on issues related to the provision of better information and support for AMD patients, an otherwise marginalised group. A well-conducted analysis involves some level of interpretation of the data. Using thematic analysis assists with this by providing clear links between themes and the aims of the study in order to guide the development of analytical claims.

In summary, the rationale to use TA was largely influenced by: (a) the research questions; (b) data extraction methods used (e.g. focus groups and interviews); and (c) its alignment with the adopted worldview within this programme of work. AMD patients’ perceptions, experiences and the contextual influences on their accounts were taken into consideration, in line with a ‘contextualised’ thematic analysis, as defined by Braun and Clarke (2006).

2.6.2 Studies 2 and 3

Langdridge’s (2007) critical narrative analysis (CNA) was chosen as the method of analysis for these studies, and a rationale for choosing this method of analysis over others will be provided. In doing so, the basic assumptions and philosophical underpinnings will be duly discussed, as they have a huge impact on the knowledge generated. Finally, a synopsis of how the analysis was conducted will be provided.

CNA is based on contextual constructionist epistemology; therefore, it rests on assumptions that people's language reflects, in a relatively straightforward way, their experiences and the meanings they attach to them. This approach is particularly useful in analysing the language used when dialogue or communication between clinicians and patients takes place during a diagnostic or treatment consultation. It is also based on a phenomenological approach, which asserts that, by focusing on detailed descriptions of individuals and experiences, it is possible to extract an essence or specific truths about the experience (Ling, 2013). CNA is particularly useful in analysing individual interviews with patients and clinicians to further explore their experiences of the consultation and the adequacy of information communicated or exchanged. Perhaps more importantly, this approach recognises the role of the researcher in opening up and interpreting individuals' meanings and experiences. My role in observing the consultations fits into this approach's assumption that by being present, the researcher can access cultural meanings that may be attached to participants' narratives and can utilise them to good effect when analysing data, while also giving an account of my background and context.

2.7 Rationale *for Critical Narrative Analysis (CNA)* over Interpretative Phenomenological Analysis (IPA) & Discourse Analysis (DA).

Murray (2003, p.113) defined narrative as an:

'*organized interpretation of a sequence of events [which] involves attributing agency to the characters in the narrative and inferring causal links between the events*.'

A narrative approach can involve asking different questions of the account provided by the participant. The questions could concern content, themes, story structure and both social and psychological functions of the narrative (Ling, 2013). This is where a narrative approach differs from other qualitative methods such as interpretative phenomenological analysis (IPA) and discourse analysis (DA). An IPA approach, in most cases, involves excavating for overarching themes between accounts of the participants, whereas CNA looks not only at themes (as in IPA) but also examines the narrative structure and its connection to societal context. The difference between discourse analysis and narrative analysis is embedded in the way DA disputes attributing personhood and inner experience to participants, while CNA has a humanistic image of the participant as agentic and self-aware, and involved in striving for fulfilment and control (Ling, 2013; Strawbridge & Woolfe, 2010). This view of CNA is in alignment with the core aims of this body of work and its methodological underpinnings.

Using CNA is appropriate, particularly where there is nominal extant research on an area. As such, I felt that this approach would not impose assumptions on volunteering participants' data;

instead, it would allow for more focus on their experiences, perceptions, visions and feelings and would facilitate an emphasis on each individual's meaning-making (Ling, 2013). This fits in neatly with the purpose of this body of work to uncover AMD patients' perceptions of, experiences with and visions of accessibility and information provision that allows them to understand their diagnosis and manage their condition better over time.

Following in-depth, wide reading and an exploration of various narrative approaches (Gee, 1991; Hiles & Cermak, 2008; Labov, 1997; Riessman, 2008), I chose critical narrative analysis as developed by Langdridge (2007), whose work was based on Ricoeur's concepts. My decision rested upon selecting the best approach that would enable me to extract appropriate material from the data that aligned with the research questions and aims of the study. That is, gaining an in-depth understanding of AMD patients' perceptions, and experiences of information provision in relation to diagnosis, treatment and support, with a view to extending this understanding to relevant stakeholders via the working group. It is my belief that provision of information in whatever context is very much a product of culture, time and place. These are elements ingrained within social constructionism. As such, one of the distinguishing features of Langdridge's approach is the attempt 'made to interrogate the text using aspects of social theory as a hermeneutic of suspicion' (2007a, p.130). Hermeneutics can be defined as a practice of interpretation or theory, while hermeneutic (singular) relates to a specific method of interpretation. Thus, Langdridge's approach examines material using a strand or theory that relates to the subject matter as a tool to critically examine or understand the data/material relating to information provision.

Langdridge's critical narrative analysis method involves six stages: Stage 1) a criticism of the illusions of the subject; Stage 2) identifying narratives, narrative tone and rhetorical function; Stage 3) identities and identity work; Stage 4) thematic priorities and relationships; Stage 5) destabilising the narrative; Stage 6) a critical synthesis. A fuller account of these stages will be provided in the method section in chapter five and six respectively. I will also provide a brief description of how the adopted elements of each stage have been applied within this programme of work. However, for a full breakdown of this approach refer to Langdridge (2007).

2.8 Issues of Quality in Qualitative Research

Quality in qualitative research remains a 'complex and emerging area' (Creswell, 1998, p193) and it has been argued that such research lacks scientific rigour. There is considerable debate as to whether the principles of validity, reliability and generalisability, which many consider to be deeply rooted within positivist research, can be applied effectively to studies adopting a qualitative interpretative approach (Healy & Perry, 2000; Stenbacka, 2001). Researchers have argued that alternative criteria are more applicable in qualitative research and new terms such as credibility, transferability and confirmability have been argued to better reflect the interpretivist outlook (Lincoln & Guba, 1985; Seale, 1999).

2.8.1 Transferability

Lincoln and Guba (1985), stated that transferability refers to the extent to which findings can be generalised to other settings. Morse (1999, p.5) stated that 'if qualitative research is considered not generalizable then it is of little use, insignificant and hardly worth doing'. While qualitative studies are not, and do not consider themselves to be, generalizable in the traditional sense, there are qualities of the research that have inherent value. As Ritchie and Lewis (2003) highlighted, there are a number of potential ways that the concept of generalisation can be applied. One of these was inferentially by generalising from one particular study context to another. To enable this to occur, it is imperative that in reporting the research a 'thick description' (Geertz, 1978) of the original research process and setting is provided. The importance of representational generalisation is also highlighted, where there is clear demonstration that the sample is a true reflection of the population studied and that the conclusions drawn are an accurate reflection of the data provided by the participants (Lewis & Ritchie, 2003; Murphy et al., 1998). Within the context of this study, the data collected were used appropriately and fully to strengthen the interpretation provided; this involved ensuring that the diversity of the data set was encompassed within all reporting. The use of thematic analysis further facilitated the levels of interpretation at all stages of the analytic hierarchy. Furthermore, scrutiny was placed upon the way in which the research was conducted and designed to further explore any features of the research, such as sampling, that may limit the way in which inferences can be drawn.

2.8.2 Credibility

Lincoln and Guba argued that for interpretive research to be considered as credible readers have to find its inferences believable. To achieve this the researcher has to provide evidence of his extended engagement in the field, by demonstrating data triangulation across subjects or data collection techniques, maintaining data management and analytical procedures such as verbatim transcription of interviews, notes and methodological decisions e.g. being aware of aspects of the research that may influence the way in which data is collected such as participant characteristics (Mays and Pope, 2000).

2.8.3 Triangulation

Triangulation is extremely important where a combination of different methods and study populations are involved. Within Study 1, different methods of data collection (individual interviews and focus groups) were required in order to produce a meaningful understanding of patients' preferences in terms of information materials. While triangulation itself does not ensure validity, it is regarded as ‘a way of ensuring comprehensiveness and encouraging a more reflexive analysis of the data’ (Mays & Pope, 2000, p.51). Using triangulation in this study was a means to explore similarities between data collected through different methods but also to identify whether any contradictions arose. In triangulating the findings, an overall interpretation of the findings will be developed.

2.8.4 Dependability

Joppe (2000 p.1) defined dependability as ‘the extent to which results are consistent over time and an accurate representation of the total population under study’. He went on to say that ‘if the results of a study can be reproduced under a similar methodology, then the research instrument is considered to be reliable’ (ibid.). Determining dependability within qualitative studies can be challenging as the data collected is often based on face-to-face situations where participants are providing information on real-life experiences. Such methods are prone to elements of misinterpretation or personal biases. Therefore, in demonstrating and enhancing reliability in qualitative research, it is important to carefully describe each of the processes involved in the study (Lincoln & Guba, 1985; Miles & Habermas, 1994). Several methods have been identified to assist with demonstrating the reliability of qualitative research, such as conducting and reporting the research in a systematic way, ensuring that any interpretations/themes provided are supported by the data/extracts (Lewis & Ritchie, 2003) and seeking clarification when uncertainty is present (Shank, 2006). Throughout the research process, the concept of reliability was addressed to minimise any possible misinterpretation or bias. This involved conducting fieldwork by using a consistent approach that allowed participants to readily portray their experiences, with the researcher clarifying any ambiguities with participants during the interview, confirming interpretations of interview data by multiple assessments with colleagues, the supervisory team and the stakeholder working group, and reporting the findings in a systematic manner with comparison to existing literature. In order to ensure that quality was maintained throughout the research process, various applications of these principles have been applied in context and demonstrated throughout this programme of work.

2.8.5 The Researcher

Before embarking on this PhD journey, I had very little understanding of AMD, apart from knowing that my uncle had it. Despite this, I had never taken time to really understand it. To me, it represented ‘blindness full stop’. However, I was familiar with aspects relating to researching chronic illnesses in participants of varying age groups. I prepared myself for this study by reading and gaining knowledge relating to the condition, policy and guidelines for treating AMD in order to create a contextual platform for the study. To this effect, I also attended the Vision UK conference to network and gather information from a programme designed to address some of the issues my study would be pursuing. My study would be looking at providing better information and support for the diagnosis and treatment of AMD patients. Because aspects relating to information provision are broad, the research was split into three studies to make it manageable and maximise on outcomes of the elements being explored. The methodological approach (stakeholder) chosen for this study permitted the researcher to put together a working group of experts to help develop the study at various stages, which was useful in shaping the outcomes.

As the chief investigator, I completed all elements of the research study including: recruitment of participants (*AMD patients and Clinicians*), gathering consent from participants, data collection, and conducting all analysis with the help of the stakeholder working group. In Study 1, the data collection process involved using interviews and focus groups for AMD patients; in Study 2, it involved using interviews for both clinicians/patients; and in Study 3, it was a case of observing and using interviews for AMD patients. Having a background in health psychology, but not being a registered ophthalmologist working within the Birmingham Eye Clinic, I was concerned that I would be considered an ‘outsider’ to the target populations. Hockey (1993) stated that being in such a position could influence the way in which the research study is approached, analysed and potentially evaluated. Conversely, being an outsider can be advantageous, as the researcher can retain an objective outlook that is impartial to conflicting evidence (Schutz, 1976), which to a greater extent may be regarded as more valuable (Robson, 1993). On the other hand, an ‘insider’ has the opportunity to access the complex social worlds of those involved in the research more readily and there is the potential that this may enhance the ‘rapport’ between themselves and the participants.

Consequently, in qualitative research, the researcher is regarded as the primary data collection tool and direct, personal contact with participants is a vital part of the process. Hammersley and Atkinson (2007, p.16) acknowledged that within this encounter, as researchers, there is ‘no way in which we can escape the world in order to study it’; as such, it is assumed that the researcher has the potential to introduce bias and subjectivity to the data collected. Although the influence that a researcher’s pre-conceptions, beliefs and experience can have upon the interpretation of data is accepted, it is regarded as necessary that such influences are critically evaluated and recognised (Altheide & Johnson, 1994). In analysing data collected, the researcher, informed by their theoretical position, interprets what participants have said rather than simply reproducing their meanings. In order to ensure that the data collected and explored is a true reflection of the participants’ views or opinions, researchers should make every effort to set aside their own pre-conceptions or assumptions by reflecting upon how such factors may influence the process.

2.8.6 Interview Observations/ Field Notes

It has been ascertained that making notes during interviews can lead to 'distraction or distrust' (Hammersley & Atkinson, 2007, p.142), and thus interfere with the interview process. Observational field notes were made following all interviews in Study 1, 2 and 3. These notes touched on issues such as the significance of previous profession in accessing technological gadgets, influence of differential access, age in seeking opportunities to reclaim independence and functionality, relationships with clinicians, treatment process and lack of reassurance, signposting, waiting to be seen, service resource, perception of treatment outcomes, and the role of carer/spouse and their contribution to the experiences of how AMD patients perceived information materials currently available to them. The participants seemed more concerned with issues of service resource/lack of information regarding treatment process/lack of accessible information materials/sign-posting issues and waiting times. Use of focus groups and the number of people involved per group, the researcher-participant rapport, and other points were raised by the AMD patients' post-interview. In study 2, there was an element of power dynamics evident in the patient-clinician dyad. Most of the decision making was largely influenced by fear of losing sight rather than understanding. There was obvious reluctance by some clinicians to share in depth or discuss treatment options, benefits or side effects. Lack of follow-up information post verbal communication of diagnosis- left some patients anxious about the procedure. Not having an expert patient in the clinic to reassure them about the procedure was highlighted as a source of anxiety. Lack of optimal participation in the consultation by patients was largely drawn from the notion *"the doctor knows best and you do as you are told approach".* In study 3. Most of the patients stated that they didn't know about AMD support groups and happened to find out during their participation in focus groups in study 1. Those that attended these groups for the first time spoke highly of them and one had remarked that there are "*a fountain of information and you can learn a lot about the illness and what it may look like at a certain age".* The participant who made this comment, was significantly younger than his peers at the time of attending and was overjoyed by having an opportunity to ask questions from those you had been living with AMD or longer and how they are managing currently.

The field notes generated were important in shaping the researcher's critical thinking about the data collected: (a) they allow the researcher to reflect on both context and content generated in the interview; (b) they give the researcher an opportunity to identify aspects of what worked well and what did not, to inform ways in which subsequent interviews will be conducted; (c) they were useful in identifying key themes/concepts of this study. The researcher developed a standardised sheet to record personal reflections. However, while collecting field notes, the researcher continued to engage with relevant literature throughout data collection. This is a practice that Tuckett (2005) argues is significantly important and it immensely enhanced the data collection process. The supervisory team was also helpful to this effect, providing me with useful materials, links, and advice throughout the course of the research. This was something I personally appreciated, as it was more beneficial than detrimental to my personal development and to the building of a knowledge base of the phenomenon I was exploring.

2.9 Ethics and Governance Approval

The principles of the National Institute for Health Research (2014), Department of Health's Research Governance Framework for Health and Social Care (Department of Health, 2005c), Aston University Research Governance, and the Safety Policy for Lone Workers instituted by Aston University underpinned the planning and delivery of this body of work. The study protocol was approved by York & Humber Research Ethics Committee for Study 1 in March 2016 and for Studies 2 and 3 in February 2017 (REC reference number: ref: 16/YH/0099; IRAS project ID: 186422). HRA for the study was approved for the chosen study site- Birmingham City Hospital Eye Clinic. The ethical approval process took longer than expected due to various issues transpiring, including a change in the application process. However, these will not be discussed in detail here; apart from the frustration experienced, the researcher has learned a great deal from it. See approval documents in appendix section.

2.10 Ethical Considerations

This being a qualitative study, the researcher has to interact deeply with the participant group of older adults, thus entering their personal domains of values, AMD diagnosis, and experiences with information materials and provision and acquisition of information within a consultation room and at support groups, to collect data. Silverman (2000, p.201) reminds researchers that they should always remember that while they are doing their research, they are entering the private spaces of their participants.

Understandably, this raises several ethical issues that should be addressed during the research process and after it has been conducted. Creswell (2003) states that the researcher has an obligation to respect the rights, needs, values and desires of the informants. Miles and Huberman (1994) list several issues that researchers should consider when analysing data. They caution researchers to be aware of these and other issues before, during, and after the conducting of the research. Some of the issues involve the following:

– Informed consent (do participants have full knowledge of what is involved?)
– Harm and risk (can the study hurt participants?)
– Honesty and trust (is the researcher being truthful in presenting data?)

– Privacy, confidentiality and anonymity (will the study intrude too much into group behaviours?)
– Intervention and advocacy (what should researchers do if participants display harmful or illegal behaviour?)

One of the normally unexpected concerns relating to ethical issues is the cultural sensitivity. Silverman (2000) argues that the relationship between the researcher and the subject during an interview needs to be considered in terms of the values of the researcher and cultural aspects.

Therefore, appropriate steps should be taken to adhere to strict ethical guidelines in order to uphold participants' privacy, confidentiality, dignity, rights and anonymity. In view of the foregoing discussions, the following section describes how ethical issues in the conduct of the research have been addressed:

2.10.1 Informed Consent

The researcher informed the participants of the purpose, nature, data collection methods, and extent of the research prior to commencement. Further, the researcher explained to them their typical roles. In line with this, the researcher obtained their informed consent in writing, in the format given in Appendix E.

2.10.2 Harm and Risk

In this programme of work, the researcher guaranteed that no participants were put in a situation where they might be harmed, physically or psychologically, as a result of their participation, as stated by Trochim (2000a).

2.10.3 Honesty and Trust

Adhering strictly to all the ethical guidelines serves as a standard of the honesty and trustworthiness of all the data collected and the accompanying data analysis.

2.10.4 Privacy, Anonymity and Confidentiality

Total anonymity was provided through assigning pseudonyms for all participants. The researcher ensured that the confidentiality and anonymity of the participants would be maintained through the removal of any identifying characteristics before widespread dissemination of information. The researcher made it clear that the participants' names would not be used for any other purposes, nor would information be shared that reveals their identity in any way.

2.10.5 Voluntary Participation

Despite all of the aforementioned precautions, it was made clear to the participants that the research was only for academic purposes and their participation in it was absolutely voluntary. No one was forced to participate.

2.10.6 Identifying and Accessing Study Site

The site for this study was identified at the planning stage of this research following the conclusion of a previous PhD student’s study. The site was the main clinic within the West Midlands that supported AMD patients from a diagnosis, treatment and accessing support from the Low Visual Clinic and providing information on support groups in the greater communities of West-Midlands perspective.

The next chapter will focus on evaluating information materials currently available to AMD patients and determine their preferences, as well as exploring in-depth their perceptions of and experiences with these materials.

CHAPTER THREE: STUDY 1 - Evaluation of 'take away' information materials currently available to AMD patients. A qualitative study.

3 Introduction

Over the last few decades, numerous scholars (Aslani, Hamrosi, Feletto et al., 2010; Beverly, Bath & Booth, 2007; Coulter, Entsile and Gilbert, 1999; Coudeyre, Turbach, Rannou, et al., 2007; Hamrosi, Aslani, Raynor, 2014; Koo, Krass, & Aslani, 2006; Little, Rumsby, Kelly et al., 2005; Sustersic, Jeannet, Corzon-Rein et al., 2013) have investigated the readability and usability of information materials in accessible formats by various patient groups, including those with a sight impairment. Findings from these studies suggested that when information materials are provided in preferred and accessible formats for the various patient groups there were positive outcomes. These included improved recall of the information exchanged during the diagnostic consultations (Sustersic et al., 2013), better understanding of condition and treatment options (Gibbs, Waters & George, 1989), which led to patients making informed decisions to consent to treatment, satisfaction with treatment choices (Brody et al., 2001; Owsley et al., 2006), and better management of the condition over time (Raynor, Blenkinsopp, Knapp et al., 2007). Some of these findings have been influential in shaping guidelines for improving accessibility of information materials for sight impaired individuals that include AMD patients.

However, despite the clear print guidelines as set by RNIB in 2008, there are still various challenges that impact accessibility of information materials for this marginalized group (Burton et al., 2013; Coulter et al., 2006; Thertford et al., 2013; Thurston and Thurston, 2015). Burton et al.'s (2013) study pointed out that most AMD patients struggled with the font size of information materials provided following diagnosis. Another significant issue identified in Burton and colleagues' study was the inaccessibility of appointment letters, particularly, the lack of clear information on the reason for the appointment. Clinicians involved in the care of sight impaired individuals agreed that the letters sent out to this group were inaccessible for many (Goyder, Carlisle, Lawton, & Peters, 2009). There are persisting issues with inaccurate information (Coulter et al., 1999), use of complex language (Coulter et al., 2006) and poor visual presentation (Raynor, Blenkinsopp, Knapp et al., 2007). These findings corroborate those highlighted by Burton et al.'s and Thetford et al.'s studies both carried out in 2013. It can be argued here that despite the RNIB guidelines being in place not much has changed, particularly where meeting the status of AMD patients or sight impaired individuals is concerned. Hence, in some instances patients have resorted to using alternative mediums to access information about the self with illness, its management, and to maintain social connections.

This supported Abraham et al.'s (2002) findings that poor quality and the lack of accessible print information materials often led patients to look elsewhere (e.g. internet) for information. They posited that despite the challenges, some older adults with visual impairments had generally embraced the use of technology as it provided a platform for them to access information that allowed them to understand aspects of their diagnosis or treatment as well as keep abreast with activities of daily living (e.g. reading, writing and staying socially connected). A notion concurrent with Berners-Lee's (the inventor of the World Wide Web) statement of universality supported (Berners-Lee, Cailliau, Groff & Pollerman, 1992).

Technological advancement in the United Kingdom has been rapid. Figures published by the Office of National Statistics (ONS, 2020) showed that more than 96% of UK households in 2020 had internet access compared to only 55% in 2006. Since 2006, the number of internet users has significantly increased and, due to technology, people (including those living with AMD) can now access information relating to multiple aspects of their life (including health conditions). They can do so via a variety of media, including websites, email, television, mobile phones, computers, audiobooks and tablets, as well as other assistive devices, such as closed-circuit TV, also referred to by its acronym – CCTV, which used as a reading machine.

These modern technologies fuel both hope and discussion where older adults are concerned (Peek, 2017). Hope in the sense that they offer so much potential in relation to providing platforms to access information (health and social), and connectivity (Skype, Microsoft teams, email, mobile phones e.g. WhatsApp) with loved ones or health institutions for this aging group living with AMD. And discussion, because of various concerns that exist relating to design, application, accessibility and usability of technologies. Despite these discussions being pertinent, particularly to the participant group in this study, some of the technologies have the potential to help older adults living with AMD maintain their independence across multiple aspects of their occupational life, this includes home appliances for activities of daily living, and information and communication technologies to support social contact (Brien, Olson, Charness et al., 2004; Fausset, Kelly, Rodgers and Fisk, 2011; Peek, 2017). Studies (e.g. Peek, 2017) focusing on older adults' use of technology, shows that they acknowledge the potential of technology. However, acquiring it and using it can also be stressful and challenging for this group. An interesting aspect of technology is that perceived benefits do not necessarily translate into acceptance. This can perhaps be understood using the technology acceptance model (TAM), which is underpinned by two key variables: (a) perceived usefulness and (b) perceived ease of use. Research has indicated that these two variables highlighted an individual's intention to use technology in a variety of contexts including accessing health information (Legris, Ingham, Collerette, 2003; Holden & Karsh, 2010), and that intention to use may (Turner, Kitchenham, Brereton, Charters & Budgen, 2010) or may not (Wu & Du, 2012) predict actual use of technology (Peek, 2017).

The RNIB validated the use of technology particularly the "internet as one of the most significant developments since the innovation of Braille [because] for the first time ever, many blind and partially sighted people have access to the same wealth of information as sighted people and on the same terms" (cited in Berry, 1999. p1). Indeed, Berners-Lee (the inventor of the World Wide Web) argued that through the power of technology, especially his search engine, it was possible to create universality, meaning that information could be accessed by all regardless of (visual) impairment. However, studies have highlighted that there are numerous barriers that hinder people from accessing information from the internet. These include: age, fear of using the computer (Muller, Wharton, McIver & Laux, 1997), lack of skills (Penney & Associates, 1996) and challenges of getting trained (Sinks and King, 1998). In a study by Williamson et al. (2006), despite these challenges older adults living with a visual impairment welcomed the use of the internet as an information source, citing that it gave them some sort of independence to look at things in their own time. It can be argued here that AMD patients like everyone else require good quality and reliable information that is accessible to inform their choices and help them understand their condition and to manage it better over time. The use of technology provides choice of alternative sources of information, helps them to maintain their independence across aspects of their occupational life, this includes home appliances for activities of daily living, and information and communication technologies to support social contact (Brien, Olson, Charness et al., 2004; Fausset, Kelly, Rodgers and Fisk, 2011; Peek, 2017).

Inaccessible print or electronic materials can impact negatively on an AMD individual's ability to acquire useful information to help understand their condition and manage their life. An element that can further impact their self-esteem and self-worth in society and overtly validates their disability (Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005). The World Health Organisation [WHO] (2016) argued that disability is an umbrella term that refers to challenges an individual may face due to factors such as: impairment, participation restriction and activity limitations. They define impairment as a problem in body structure or function; participation restriction as problems an individual experiences when engaging in life situations; while activity limitations relates to problems experienced by an individual when performing a task or action (WHO, 2016). As such, disability is not just a health problem, but a complex phenomenon, that reflects the relationship between characteristics of an individual's body and characteristics of the society in which they live in. While the above statement from WHO is inclusive, the medical model however, holds that disability is for the person affected and no one else. The classic example often used to illuminate this notion is of a person in a wheelchair who cannot get into a building because of the stairs. In this instance, the medical model would argue, it is the wheelchair stopping the individual getting into the building rather than the steps. Furthermore, statements such as he/she cannot read the consent form or information materials because they are visually impaired are influenced by the medical model which views the person as the problem rather than the design of the consent form or the information materials (Payne, 2006; Woodhams and Corby, 2003; Public and Commercial Services Union [PCSU], 2016). On the other hand, the social model of disability is more inclusive in approach and in the same scenario would argue that the steps are the barrier to the individual accessing the building, and similarly the same would hold true of the information materials (e.g. design or font size being the barrier) (Anastasiou and Kauffman, 2013). It draws on the premise that society is the one that disables people, by making everything to suit the needs of the majority of individuals who are not disabled. This is evident (e.g. lack of accessible information) in findings from most studies that have focused on people living with visual impairments. The social model focuses on things that can be done to remove barriers to inclusion, and also acknowledges that attitudes towards disability can create unnecessary barriers to inclusion (Bailey et al., 2015). Thus, it requires people to take a more pro-active role to remove these barriers. In this instance, it requires information producers to adapt to an iterative process (develop-test-revise-repeat) to ensure information materials are user centred (Nilsen et al., 2006).

3.1 Rationale for study

The key challenge is in producing good-quality information materials for older patients diagnosed and living with AMD by adapting to their needs as they perceive them; not what the information producers or researchers think their needs ought to be. As Kuhn aptly put it, “What a man sees depends both upon what he looks at and also upon what his previous visual–conceptual experience has taught him to see” (1970, p. 113). Hence, understanding AMD patients’ perspectives on and experiences of information materials and knowing their preferences is of significant importance as it provides valuable information to guide the quality improvement of the information materials for this heterogeneous group and provides perspective on what aspects in the information chain help them understand their diagnosis better.

To the best of our knowledge, no previous study has specifically focused on this group of patients in terms of exploring their perceptions of, and experiences with, information materials currently available to them. For this study, the idea was to gain an in-depth understanding from the perspective of people living with AMD in respect of barriers and facilitators – both perceived and actual – to their accessing information materials and to determine their preferences and, perhaps, obtain a sense of how inaccessibility of information pertinent to their well being impacts their quality of life. It is hoped that the findings will enhance the understanding of AMD patients' experiences of information materials, as well as highlight their preferences and willingness or ability to use devices to aid access to information. It is also anticipated that the findings may provide useful information for reducing the gap between current policy, guidelines and the production of information materials for AMD patients and ensure production of information materials in the future that reflect their preferences and actual needs.

Below is a reminder of this study's research questions:
What information materials about the diagnosis of AMD are useful to patients?
What information materials help patients to manage AMD over time?

3.2 Methods

3.2.1 Context

There are established Charities and services (e.g. RNIB, Macular Society and NHS), that produce for and provide information materials to AMD patients. However, it is unclear if the information materials provided, are uniform in quality elements that make them accessible to this group. Most patients access information materials from clinicians or from the Eye Clinic Liaison Officer at the Macular Clinic following diagnosis. Some access information materials through their support networks.

This study was part of a programme of work focused on providing better information and support for the diagnosis and treatment of patients living with AMD. However, the present study was specifically focused on evaluating information materials currently available to AMD patients and determine their preferences, as well as exploring in-depth their perceptions of and experiences with these materials. As such, a two-step approach was used to address the aims of this study. The first step involved conducting three focus groups with AMD patients to get their views of and determine their preferences of the take away information materials presented for evaluation (for example, to identify the best features of the materials or those features that need improving to enhance accessibility). The second step involved conducting semi-structured individual interviews with a view to gaining a broader understanding of AMD patients' perceptions of and experiences with the information materials currently available to them. These two methods of data collection were deployed in this study because it was felt they would efficiently enable both productive discussions (Morgan, 1997) and an elicitation of a multiplicity of views (Bowling, 2002) from the volunteering participants regarding the phenomenon of focus.

3.2.2 Study Design

Based on a qualitative design, the researcher used an interpretivist perspective as an appropriate theoretical position (Crotty, 1998), to understand this heterogeneous group's perceptions of and experiences with information materials currently available to them and to determine their preferences. The goal was to rely on their perspectives to obtain a broader understanding of this phenomenon of interest. The study was carried out between January 2016 and March 2017.

3.2.3 Setting and Sampling Strategy

The study was undertaken in the UK, and a purposive sampling strategy (Creswell and Poth, 2018), was used. Participants aged 65 and above were recruited from a local West Midlands Eye Clinic and this extended to AMD support services around the West Midlands. The inclusion criteria were that participants had an AMD diagnosis, aged 65 years or above, able to communicate in English, with no severe cognitive or hearing impairment and could participate in both the individual interviews and focus groups without requiring assistance. Participants who were unable to give informed consent were not included in the study.

Health professionals at the eye clinic and Coordinators at the AMD support services identified participants who fulfilled the inclusion criteria, and if they assented, their details were passed on to the researcher, TP. The researcher approached the identified patients, informed them of the study, asked if they were willing to take part and, if they assented, consent was then sought after they had read (format adjusted to suite visual needs of each individual) and understood the participant information sheet. A total of nineteen participants aged 66 to 95 years old were recruited and volunteered to participate in this study, participating in either one of three focus groups (n= 12) or in a semi-structured individual interview (n=7). The average age across the focus group was 77 years and the average age in the semi-structured interviews was 83 years. Two individuals were co-opted into the study in their capacity as carers, one participated in the focus groups and the other in the interviews.

In general when using qualitative methods, there is no specific sample size recommended. However, the rule of thumb to achieve a 'gold standard' of data is data saturation (Tashakkori and Teddlie, 2010). Data saturation relates to the point at which extra data does not provide any new information. The phenomenon of data saturation usually occurs within 12 interviews, provided that a homogenous sample is selected (Tashakkori and Teddlie, 2010).

3.3 Statement of Ethics

The conduct of this study conformed to the research methods and actions approved by Aston University Ethics Committee and the NHS York and Humberside Ethics Committee in application number Y1009. The study was carried out between June 2016 and March 2017. All the participants gave written consent for their inclusion and were made aware that participation was voluntary and informed of their right to withdraw from the study at any stage. They were assured that this would not affect their current or future access to services relating to their AMD diagnosis. The researcher gave an assurance of the confidentiality and anonymity of the study to all volunteering participants. Moral principles of beneficence, justice, informed consent and human dignity (Polit and Beck, 2012; McCloud and Lake, 2015), were addressed and upheld throughout the conduct of this study.

3.4 Data Collection

Data collection took place between 2016 and 2017. A guide with open ended questions for the focus groups and the individual interviews was co-designed by the researcher and the working group (e.g. experts by experience, Eye Clinic Liaison Officer, Birmingham Focus Coordinator, Macular Society Coordinator and academics) (see table 2 below). These were refined following a pilot focus group and an individual interview being conducted.

Focus groups and the semi-structured individual interviews were chosen as the most relevant data collection methods for this study. Focus groups are a valuable tool in evaluation studies and across the health and social care field: they have the capacity to capture group dynamics, interactions and specific psychological processes and phenomena that transpire in a group setting, including the development of a shared collective social identity (e.g. older adults with AMD), which takes place when individuals in the group interrelate and engage positively in the phenomenon of interest (Roberts et al., 2005; Van Teijlingen et al., 2007). The interactions in focus groups can reveal insights into specific expressions of philosophy (such as beliefs, value systems, language, ways of dealing with issues and evaluating information materials) as groups construct and re-construct their perceptions and experiences during these shared narratives (Bergin et al., 2003; Heath, Brooks, Cleaver, & Ireland, 2009).

3.4.1 Table 3: Practical steps taken to organise the focus groups

- Negotiating the date and time of the focus group;
- Choosing a neutral venue and ensuring that it was easily accessible for participants;
- Ensuring the recording device was charged and working;
- Ensuring all materials were in order and the appropriate number of participants were present;
- Ensuring participants were aware of the potential length of the focus group;
- Being clear about the researcher's role as moderator (to ask questions and facilitate interaction within the group); and
- Informing participants that the researcher could not assure full confidentiality and anonymity, as information is shared within the group/s.

Semi-structured interviews were chosen as the data collection method for the second phase of this study because this method allows the researcher and participant to engage using a format that facilitates direct responses one on one. The use of this method also gives the participant an opportunity to elaborate and the researcher recourse to clarify, which is not possible with questionnaires or structured interviews. This method, however, can be time-consuming; not only in terms of the length of the interviews themselves but also in terms of post-interview analysis time. All semi-structured interviews for this study were conducted face-to-face, allowing the researcher to respond to social cues and ensuring a closer rapport was developed.

3.4.2 Table 3a: Practical steps taken to organise individual interviews

- Negotiating interview time and date; offering options to hold interviews in the comfort of the patients' home or in a quiet space at a local eye clinic;
- Rapport building; briefing participants on the interview process and encouraging open and honest dialogue about the phenomenon of interest;
- Liaising with the working group regarding the final version of the interview schedule (open-ended questions);
- Ensuring the recording device was fully charged and in good working order; and
- Reassuring participants that anonymity will be upheld.

The focus group and interview schedules developed for this study were not prescriptive but purposefully flexible, set in order to allow the researcher to explore AMD patients' existing, and emerging perceptions and experiences regarding the materials currently available to them. Prompts were also employed in order to ensure that participants elaborated on elements pertinent to the phenomenon of interest.

3.5 Research Instrument

3.5.1 Table 3b: Summary example of the interview schedule used for focus groups

Summary example of the interview schedule used for focus groups: AMD participants' perceptions/experience with/preferences of Information materials.

Interview stage	Purpose	Questions
Opening	Purpose of focus group: Brief introductions of participants. Rapport building.	Age, name, how long they have lived with AMD, type of AMD, treatment.
Initial questions to start focus group discussions	Participants' perceptions of presented information materials.	Can you tell me what your initial thoughts are on the information materials that you have just looked at?
Transitional questions	Barriers/enablers to accessing information materials currently available to them.	Can you tell me what you liked or disliked about them?
Key questions	Determining preferences.	Can you tell me what could have been done better to improve these materials and make them more accessible to you? Can you tell me what are your preferences regarding formatting (font size, print, quality, use of pictures and colours?)
Closing questions		Can you tell me; do you use any other methods to enhance your ability to access information materials? What are your thoughts on using technology to access information? Is there anything you think the researchers ought to have discussed but did not?

3.5.2 Table 3c: Summary example of semi-structured interview questions

Summary example of semi-structured interview questions to gain an in-depth understanding of AMD participants' perceptions of and experiences with information materials.

Interview stage	Purpose	Questions
Opening	Introductory. Rapport building.	Can you tell me a bit about yourself (age, background, diagnosis of AMD, treatment status and for how long you have been living with AMD)?
Key questions	Gain an in-depth understanding of participant perceptions of and experiences of information materials.	Following your diagnosis, can you tell me if you were given any information materials to help you better understand your diagnosis and treatment? If yes: did you get a chance to read them? Did you find them easy to read? Can you share your experiences of these materials?
		Do you think you were given adequate information to understand your diagnosis at the time, including treatment options to help you consent to the treatment of choice?

		Can you share with me your thoughts about communicated information and information materials? What are your preferences?
		Can you tell me how are you accessing information materials to manage your day-to-day living access? What methods are you using to access your favourite sources of information?
	Barriers/facilitators in determining your preferences.	Can you share with me the challenges your face when accessing information materials? What would you like to see change? What are your preferences regarding information materials? Can you tell me what your thoughts are on using technology to access information?
Closing questions		Is there anything you think the researchers ought to have discussed relating to this study but did not? If yes: Can you share your thoughts?

Focus group sessions were organised based on participant availability and took place at a local eye clinic in the West Midlands. The sessions lasted for at least 60 minutes, with each session supervised by TP (researcher also acting as the moderator). At the beginning of each session, TP introduced himself to the group and highlighted the purpose of the focus group. This was followed by asking the participants to introduce themselves to the group, briefly state their AMD diagnosis and how long they had lived with it for. TP then distributed information materials (for example, booklets from the NHS, RNIB, the Macular Society and Birmingham Focus), which had been pre-selected by the working group, for the participants to evaluate. Among other elements, the evaluation process involved examining issues around content, formatting, design, relevance and quality of information contained therein. Following a careful examination of each of the information materials participants were provided with, the researcher used the guide above to ask open ended questions to elicit participants' thoughts of and experiences with the materials, as well as to determine their preferences. The researcher, TP took some field notes during the discussions and observed that participants in all sessions were respectful of each other's opinions, which created an environment of open dialogue in which each participant freely expressed themselves. Each session was audio-recorded to enable transcription. Transcriptions were made anonymous and all data were used only for the current study. At the end of each session, participants were debriefed and reminded that, should they wish, they could also participate in the individual interviews.

Individual interviews were also organised based on participant availability and took place in a safe and quiet place – mostly in participants' own homes, with only one taking place in a pre-booked office at a local eye clinic in the West Midlands. The sessions lasted between 40 and 60 minutes each and were conducted by TP. At the start of each interview, TP briefly reminded the participants about the study, checked that they understood and were happy to continue. Open-ended questions were used to explore the participants' experiences with and perceptions of information materials in depth. An example question here is: can you tell me about your experiences with information materials? Prompts were employed throughout the interviews to help amplify some of the details shared by the participants. All interviews were audio-recorded and transcriptions were made anonymous. All participants who took part in this study were either identified through the eye clinic by the clinical team or AMD support service within West Midlands. They were asked if they would be willing to participate in our study. Those who had expressed willingness to participate and consented were contacted by the researcher TP, who went through the participant information sheet with them. After this, participants were given a further 48 hours to consider participation or withdraw.

3.6 Data analysis

Verbatim transcripts of the focus group sessions and individual semi-structured interviews were analysed using thematic analysis (Braun and Clarke, 2006; Holloway and Todres, 2003), a method for identifying, analysing and reporting patterns in qualitative data (Lilleheie, Debesay, Bye and Bergland, 2020). Instead of starting with a theory, the researcher inductively developed patterns of meaning (Creswell and Creswell, 2018). In order to ensure consistency in data analysis, the researcher adopted the six phase approach to thematic analysis as described by Braun and Clarke (2006). The six phase approach includes: (1) familiarisation with the data, (2) creating initial codes, (3) searching for themes across the data, (4) reviewing the themes, (5) defining and naming the themes and, finally, (6) writing the report. This approach has been widely used and accepted as robust across a wide range of disciplines, including health research (Braun and Clarke, 2014).

In establishing and optimising trustworthiness and limiting threats to validity, the criterion for 'trustworthiness' outlined by Lincoln and Guba (1985), was employed. The criterion of credibility was satisfied through open-ended questioning, prolonged engagement with the data and by providing a detailed description of the methods (Lilleheie, Debesay, Bye and Bergland, 2020). The criterion of transferability was fulfilled by presenting detailed and in-depth descriptive data and by quoting the participants. To satisfy the criterion of dependability, reiterative reading of the transcripts by (TP and RS) was performed to transform the ideas generated into a set of codes to identify the interesting features of the data. These initial codes were then categorized into potential themes. The themes were discussed and reviewed by TP, RS and the working group to reflect on their relevance to the research questions. The analysis was performed by an individual educated within the field of health psychology and the research supervisor RS has extensive experience working with older adults. The working group, who contributed to the theme reviewing process, are individuals with extensive experience working with AMD patients in various capacities as support providers, information providers and some with lived experiences of AMD. The themes generated in this study were then refined to ensure that each was meaningful and clear (Patton, 2015).

3.6.1 Table 3d: Coding Strategy

Quotation	Initial code	Subtheme	Theme
I prefer the macular society materials. The paper is a better quality, for a start, and it's not shiny. *The leaflets adequately explained what the eye condition was and about the treatments if it's wet. The way it's written is easy for me to follow* *the information materials are current [year produced] and they address issues relevant to AMD patients*	Accessibility-characteristics of preferred written sources Thoughts on content in the written sources Usefulness of materials	Use preferences: Improving accessibility Content and design of information materials Relevance of the information materials and impact on experiences	AMD journey with information materials
I think I was more disappointed with how details of the diagnosis were communicated, he just said you have dry AMD and there is nothing that can be done about it. That's very frustrating; especially if you have no information about what's really going on with you.	Experiences of information provided in the eye clinic	---------------------	Clinicians as a source of information- an interpersonal dimension
We are beings that thrive when relevant information at key moments in our personal journeys with the condition is provided	Accessing supportive information to adjust and live well with AMD	-----------------------	Supportive information giving for a degenerative condition
I find it useful using the internet. Shopping online saved me a lot because going in the supermarket was becoming challenging as my eyesight deteriorated.	Thoughts on technology as a driver for accessing information	------------------------	Proactive use of technology

3.7 Results

3.7.1 Demographics and Details

Twelve male and seven female participants aged between 66 and 95 years old were recruited to this study (see Tables 4.6 and 4.7). Twelve participants took part in the focus group discussions (one was a spouse/carer for a participant) and seven participants took part in the individual interviews (one was a son/carer for a participant). All participants in this study, with the exception of the carers, had a diagnosis of AMD in at least one eye and were either undergoing an 'as-required' treatment management strategy or had been advised that no further treatment was required due to the nature of the diagnosis (for example, dry AMD). Participants' duration of AMD since diagnosis ranged from six months to multiple years.

3.7.2 Table 3e: Demographics: Focus group participants

Focus groups	Pseudonym	Age	Gender	Ethnicity	Family status	Work status	Diagnosis AMD type	Treatable?
Focus group 1 (FG1)	Danny	83	Male	White	Has Partner	Retired	Wet	Yes
	Jones	91	Male	White	Widowed	Retired	Wet	Yes
	Susan	84	Female	White	Widowed	Retired	Wet	Yes
	David	72	Male	White	Divorced	Retired	Dry	No
Focus group 2 (FG2)	Gideon	72	Male	White	Married	Retired	Dry	No
	Martha carer	66	Female	White	Married	Part-time	---	--
	Brian	67	Male		Widowed	Retired	Dry	No
Focus group 3 (FG3)	Stan	72	Male	White	Married	Part time	Dry	No
	Grace	87	Female	White	Widowed	Retired	Dry	No
	Naomi	75	Female	White	Widowed	Retired	Dry	No
	Jim	69	Male	White	Married	Retired	Wet	Yes
	Jill	88	Female	White	Widowed	Retired	Dry	No

3.7.3 Table 3f: Demographics: For participants in individual interviews

Pseudonym	Age	Gender	Ethnicity	Family status	Work status	Diagnosis	Treatable?
Danny	83	Male	White	Has partner	Retired	Wet type	Yes
Jones	91	Male	White	Widowed	Retired	Wet type	Yes
Primrose	84	Female	White	Widowed	Retired	Wet type	Yes
Grahame	95	Male	White	Married	Retired	Dry	No
James	95	Male	White	Widowed	Retired	Dry	No
Donna	66	Female	White	Divorced	Part-time	Dry	No
Henry (carer)	66	Male	White	Married	Semi-retired	---	--

To add context to the findings generated in this study, the word "information" was used in a broad or general sense to include information as a physical entity (for example, in leaflets, computer, audiobooks, TV, Kindles, iPads and so on) and also as facts – advice given by, for example, clinicians or Eye Clinic Liaison Officers – and other, less formal, opinions (for example, friends, family or carers). Accessibility was viewed in the context of its relation to factors such as: content, design, format, and how and to whom information is given. These factors can be a barrier or facilitator that enables individuals living with AMD to access information materials that meets their status requirements. As such, accessible information can be understood as information provided in formats that allow AMD patients to access content on an equal basis as those regarded as having 'normal sight' or 20/20 vision. Ideally, 'accessible information' is information that allows AMD patients to orientate themselves with content that they can effectively perceive and understand through their limited 'perceptual channel' (Information accessibility in learning [ICT4IAL], 2017). Definition of these concepts important as they are used in this study as a method to illuminate how information and accessibility were operationalised within the context of this study, thus adding clarity to the findings of this study.

Themes presented in this study will include extracts from focus group discussions and individual interview transcripts to enable the researchers to better understand participants' perceptions of and experiences with information materials, allowing for the determination of their preferences. Furthermore, using extracts from these transcripts will help to clarify links between data, researcher interpretation and conclusions drawn from the data (Long & Godfrey, 2004).

Wherever possible in this study, concepts have been exemplified using the participants' own words: a phenomenon that serves to enhance readability, improve result transparency, enables and illuminates the participants' voices and, perhaps, deepens the reader's understanding of the findings (Corden & Sainsbury, 2006). In addition to the purely descriptive findings that will be presented, the researcher will also analyse the results in light of what is currently known in order to demonstrate its relevance regarding contribution to the evidence base in this field.

The themes presented in this study are presented separately. However, they are interconnected and do not occur as separate features in the participants' post-diagnosis lives. In both the focus groups and individual interviews, their accounts reflect the importance of information accessibility as an element by which to gain a better understanding of their diagnosis and treatment, reclaiming functionality and independence and better managing the condition over time.

3.8 Focus Groups

3.8.1 Overview

The focus group discussions were a collaborative exercise as they prioritised the participants' viewpoints on take away information materials.

Picture credit: The National Council for Older Adults, 2019.

Above are some of the information materials that were pre-selected in collaboration with the working group and are among those shown to participants and on which their reactions were sought.

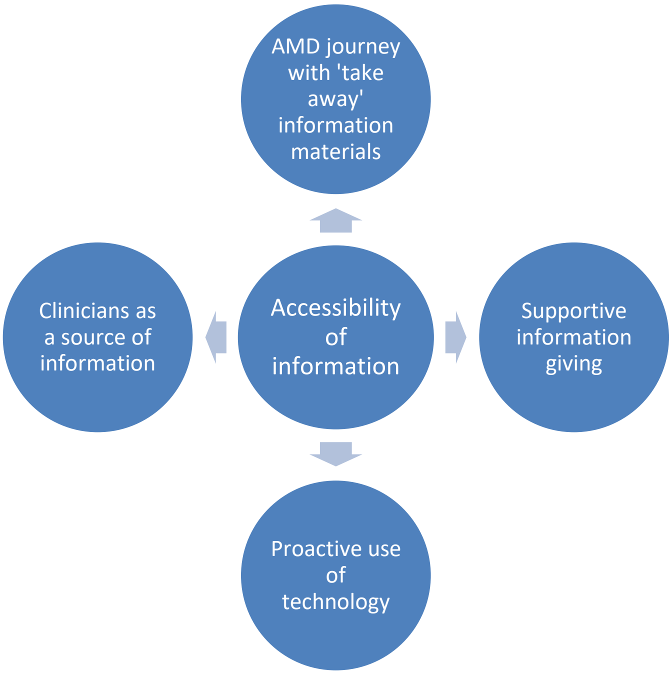
AMD patients' perceptions of and experiences with accessing information in this study generated four superordinate themes:

a) AMD journey with take away information materials. This theme had three subthemes: (1) content and design of information materials, (2) Relevance of the information materials and impact on experiences, (3) User preferences: improving accessibility;
b) Clinicians as a source of information: an interpersonal dimension;

c) Supportive information giving for a degenerative condition;

d) Proactive use of technology. We make the argument that these themes are interconnected as observed in participants' accounts around the concept of accessibility. They do not occur separately but are elements AMD patients perceive and experience across multiple dimensions of their lives living with the condition and are largely influenced by the amount of sight one has. More so, in trying to access information that makes them understand their condition and manage it better over time.

3.8.2 Figure 3.1: Representation of themes



3.8.3 AMD Journey with 'Take Away' Information Materials

The availability of information materials does not necessarily translate to or guarantee the accessibility to the information contained therein. For information materials to be useful, they must contain evidence based and reliable information presented in a form that is acceptable and useful to the targeted group. This theme and the subsequent subthemes encapsulate participants' perceptions of and experiences with information materials and highlights the barriers and facilitators, including expressed preferences that may improve accessibility of information materials. Participants were presented with several sets of information materials from different sources relating to their diagnosis, treatment and support, for them to analyse and discuss.

3.8.4 Overview of why AMD patients need accessible information: - Impact list

▪ To gain a better understanding of diagnosis and treatment options
▪ Understand benefits and or side effects of treatment and procedures

▪ Understand how to identify further signs of deterioration
▪ Gain understanding of self-care and management of AMD /dietary changes
▪ Get information about support and support groups
▪ Help others understand condition

The subthemes below provide evidence of participants' realities of accessing take away information materials, highlighting what is good, not so good and their preferences.

3.8.5 Content and Design of Information Materials

"The information [content] was fairly easy to understand, it was in English and not much wrong with the design per se, but I would have thought there would be a variation in the size and type of font to make it an easier read for someone suffering with AMD, like me. The size of the print made it challenging and tedious. Particularly the RNIB booklet because the paper is shiny." (Grace, 103-106).

Content and design including language used was generally not seen as a problem by most participants in understanding their AMD diagnosis. However, formatting was a notable barrier in their ability to access these information materials that help them understand and manage their diagnosis better over time. This was observed as some participants were reliant on aids (e.g. magnifying glass) to assess some of the materials presented in this study.

The carer shared similar views regards the content, its comprehensibility and accessibility:

"I mean the booklets, the leaflets adequately explained what the eye condition was and about the treatments if it's wet. The way it's written is easy for me to follow and explain it to my father. The language and design are ok for me and they do provide contact details for users to seek further information, which is good. But I think they are problematic for people like my dad who have AMD and struggle with the font sizes, colours used and sometimes quality of the paper like this one [RNIB]. See I have had to read this one for him" (134-139, Henry – Carer).

The carer's account highlights how accessibility of the information materials presented was not an issue for people that are fully sighted and noted that content was comprehensible to understand the AMD diagnosis and treatment. However, his account also illuminates an evident parallel regarding how disempowering it can be to a patient if information materials are not designed to meet their status requirements, particularly if someone else has to read for them. This takes away their independence and to some extent impacts their privacy were confidential matters are concerned. An element Hasler (2003) agreed with and argued that AMD patients have the same rights and entitlements as fully sighted people including the right to accessible information to allow them to adequately function within the context of their multiple identities, as patients, disabled persons, consumers and citizens in an ever changing environment.

"You see, if you were reading a page with writing (pointing to Macular Society booklet), you don't focus on the pictures, because it's not easy trying to make out what the pictures are all about with our condition." (108–111, Stan).

While the writing was appreciated, pictures were viewed as unnecessary due to the challenges AMD imposed on them. However, the inclusion of the Amsler grid in the booklets was well-received:

"I think the grid (Amsler) at the back of the booklet (Macular Society) is important and useful for us to check if our sight has deteriorated further." (88–89, Susan)

This participant had an expressed appreciation of the tool included in the 'take away' information materials. They were aware of its relevance in terms of monitoring their sight for any further signs of deterioration.

3.8.6 Relevance of the Information Materials and Impact on Experiences

This sub-theme related to how current and relevant the information materials being analysed were in their journey living with AMD. The majority of information materials (all except one photocopied leaflet) assessed and discussed by participants in the focus groups had a publication date, so it was possible to ascertain whether they contained information that was current and relevant to the targeted patient group:

"Umm the information materials are current [year produced] and they address issues relevant to AMD patients. However, quite a few things are challenging. The print can be very small and inaccessible…. the colours used can also be a barrier. And you can't pick up things like that very easily, you know. I can't, anyway. I suppose the other thing is the damned paper they use – you know that shiny paper is no good to us. You can't see clearly." (99-103, Gideon)

Participants did not have any issues with the relevance of the information materials in articulating their diagnosis. However, several other issues were highlighted as barriers to their accessibility. In some materials, presentation was noted as an issue that impinged on their ability to access information materials e.g. photocopied leaflets. In some participants this evoked feelings of frustration where some had to depend on technology, other assistive devices to access or get other people to read for them as pointed out in the carer's extract in the sub theme above:

"Well, without using the magnifiers or my CCTV, I can't read any of them – print is too small for me to see anything…" (53-54, Jim).

For some participants, the use of assistive devices such as a CCTV (also known as a closed-circuit TV), a reading machine or magnifiers was an important element to enhancing their reading experience and/or navigating their way through print materials. This participant's active use of a CCTV to access information from take away information materials lends evidence to the theme: proactive use of technology, which will be explored further below.

During the focus group discussions, some participants struggled to access information materials without any assistive devices (e.g. magnifying glass) and expressed feelings of disappointment:

"This information is relevant to us understanding our diagnosis better, but I think it would have been useful if I had been signposted to the Low Vision Clinic to access some of the gadgets that some of my colleagues here have had the opportunity to use in reading these information leaflets. See, following my diagnosis I was just given leaflets but I couldn't really read them, just like these [information being evaluated]; the print is a bit small for me and the paper quality on this one is not good – it's too shiny for me. Maybe they didn't help me probably because my sight is too low. But, then again, I think all the more reason they should have supported me..." (147-154, David)

This participant's account illuminates a disconnect within the system in terms of providing adequate information including sign posting individuals to other services to access further support that allows them to function fully as equal members of society regardless of their disability. It can be argued here that this extract also lends evidence to the theme 'supportive information giving' as this participant highlights a missed opportunity for him to access to services that could have supported him to live well with the condition through use of assistive devices or access to other alternative formats (e.g. audio) of information. The Eye Clinic Liaison Officer (ECLO) who was part of this study's working group concurred with participant's account arguing that:

"More must be done regarding consultants signposting patients to me and other services. I believe some patients don't even realise I am here to assist them. It is important there is a strong link between myself and the clinicians to ensure every patient they see is also aware of what assistance they can get or expect from me." (80-86, Ramon, ECLO (eye clinic liaison officer).

There is a strong need for relations to improve within the system to ensure patients get the full benefits of information and support following diagnosis within the clinic. The ECLO plays a huge role in providing supportive information to patients ensuring that they are assessed correctly following their diagnosis and are aware of their benefit entitlements and support available in and around the areas they live in.

3.8.7 User Preferences: Improving Accessibility

Participants in this study were fully aware of their visual status and the limitations it imposed on them. In this sub-theme they identified what was good (e.g. quality of paper for Macular Society materials) and what was not good about the materials (e.g. quality of paper of RNIB materials, Font size) presented to them. They expressed their preferences explicitly and suggested the changes needed to make information materials more accessible to them:

"I prefer the macular society materials. The paper is a better quality, for a start, and it's not shiny." (45-46, Brian).

This preference was a commonly shared view amongst participants and the issue of the quality of the paper was aptly captured in the extract below:

"If it's a glossy surface, [like the RNIB booklet] it's no good for me because you get the glare back. I think having the matte finish is better like this one [Macular Society leaflet] and increasing the font size to large will go a long way to making it readable for us you know" (46-49, Grace).

Matt finish was the more preferred choice for the majority of the participants in this study. They argued the gloss finish had a glare back effect when read under light and this was not good for people living with their diagnosis. They also suggested that for take away information materials to be accessible the font size needed to be larger. Some suggested that font type was also an important factor in improving accessibility:

"I couldn't agree with you more, Grace, about the font [Arial or Calibri], I find, these are easy enough font styles to read and I also think increasing the font size would go a long way." (49-51, Stan).

This was the general consensus across the focus groups:

"Oh yes, I agree with these guys. I think increasing the font size to at least 18 or above will make these leaflets more accessible. I wouldn't change the design; I think it's presented well but the quality of paper also needs improving. Look at this one [photocopied leaflet black-on-yellow background] – this is poor; no one can read this. Like Stan said earlier; for me, lighting is equally important in accessing information from print materials." (59 -64, Jill).

Participants put forward their preferences and made several suggestions that might improve access to print materials. Standard use of large print was viewed as beneficial for the wider group of people with AMD. The Royal National Institute for Blind People (RNIB, 2016) recommends font size 14 for people with a sight impairment. However, this size, as demonstrated in the assessed materials, does not meet the status requirements of AMD participants in this study. This development highlights the need for information producers to involve researchers and end-user. Nilsen et al.'s (2006) study examining information materials for non-sight impaired individuals had similar findings and recommended that information producers should adapt an iterative process (develop test-revise-repeat) to ensure the take away information materials are user centred.

Quality of the paper in the assessed materials was identified as an issue – particularly, the gloss paper used on some of the information leaflets:

> *"I think the paper can be challenge because of the glare, but I must say the letters in this one [RNIB] look a little bolder than in this one [Macular Society]; I feel on an appropriate paper and background, I would be able to read it." (92–95, Jones).*

The visual status of each patient was a determinant in how they were able to access information from the 'take away' information materials. While this participant points out similar issues with the quality of the paper as others, he also mentioned his preference for the font to be bolder as it would make it easier to read the materials. Again, this reaffirms the need for information producers as argued by Nilsen et al (2006) adapt an iterative process to ensure the materials are user centred. The use of black on yellow background on a matte paper quality was discussed extensively and the majority of participants agreed this made easier to access the materials:

> *"The other one [Macular Society] has matte finish, normal font and yellow background in some, which makes it easy to read for sight impaired people like myself." (99- 101, Naomi).*

Design was not seen as an issue; however, another participant was philosophical about his ability to access print materials and was grateful for the treatment and sight they had:

> *"I am listening to all these exchanges here and I feel I am very, very fortunate and thankful because my eyesight has not deteriorated as badly yet, thanks to the injections. I am still able to read a vast majority of written materials like these. I can read and fully understand about my condition with ease, though I tend to struggle a bit reading information boards at the train station. I still do most things myself, despite my age. I do think, though, for the benefit of those with eyesight poorer than mine, a lot can be done to improve these materials, like producing them in large print and having a matte finish makes it easily accessible compared to the ones with the gloss finish" (119–126, Danny).*

However, while they perceived their eyesight to be better that their peers, they made recommendations for information materials to be improved in recognition they too may reach a stage where they would struggle. Some participants made suggestions for alternative formats to print that they deemed effective when accessing information:

"I think for someone who can't see enough to read, using an audio device might be useful. I don't know whether they are available because I didn't need them. But, that would be a good solution. Perhaps the people that make the information materials should increase the size of the font – make them a bit bigger. Just like I said earlier on, using black ink on yellow background is helpful. Some of my friends who are also living with AMD say they struggle reading anything on gloss paper, so maybe they should produce materials on a different paper other than gloss paper." (115-123, Jill).

Some participants highlighted their preferences for alternative formats to print that they deemed effective when accessing information:

"I feel that improving the provision of information for us AMD patients is the beginning of a better understanding and acceptance, once we get over the initial shock, to cope and manage the condition. Imagine at our age we have gone through a lot with regards to illness and, frankly speaking, I would rather information is communicated to me than be given a leaflet that I will struggle to read anyway." (312-318, Jim).

This participant's account amplifies concerns on the accessibility of print materials, which reinforced their preferences for alternative formats regarding accessing information relating to their diagnosis and treatment. Alternative format resources, such as audio or communicated information with written accessible information, had better outcomes as these could improve health knowledge, health behaviours, self-efficacy and user satisfaction (NHS, 2003). This corroborates findings from Berkman *et al.* (2004), in which the authors argued that information provided in the patient's preferred format could improve knowledge of the condition and information recall and thus help to manage it better over time.

Participants had numerous ideas that could improve accessibility to the take away information materials they analysed. This included standard use of larger print, use of colour, quality of paper e.g. matte finish and receiving information in an alternative format e.g. audio. Participants in the present study generally preferred take away information materials from Macular Society than RNIB based on quality of paper or other pieces presented (e.g. photocopied) based on quality of print. Some of the determinants that led participants to actively choose these are highlighted below, although the font size is a suggestion across all, that they thought would help improve accessibility for take away information materials. This finding corroborates Thurston and Thurston (2015)'s study findings. The preferences also include alternative formats:

3.8.8 Table 3g: Summary of preferences

Preferences	Rationale
Large font (e.g. 18)	More accessible
Matte paper (easy to read from)	More accessible - gloss made it difficult to read (glare under light)
Black on white or yellow background	Easy to access
No pictures	Not necessary and usually difficult to access
Alternative format (Audio)	Choice and helps reinforces what has been communicated.
Concisely written to cover symptoms, causes, progression, treatment options, benefits and side effects.	Excess length of sentences can inhibit complete reading of information and impact understanding and managing of AMD better over time.
Avoid technical jargon	Can be confusing and intimidating
Information on available support options	To allow them to access information on how to live well with AMD and manage it better over time.
Amsler grid	Useful tool to test eyes and see if there is any further deterioration.
Leaflets/booklets on diet/support	Slows down degeneration/ living well with condition

The summary of preferences above highlights elements that participants perceived would improve accessibility of take away materials and help them to understand their diagnosis, treatment options and manage it better over time.

The findings here suggest the need to improve the accessibility of print materials for AMD patients to optimise their understanding of their condition and its subsequent management over time. From this evaluation exercise, it could be argued that participants in this study did not have any major concerns regarding the information contained in the information materials being comprehensible. They stated that the information in the take away materials was adequate for them to understand their diagnosis and manage over time. However, formatting issues were identified as a significant barrier to accessing them or reading these materials. This corroborates study findings from Thurston and Thurston (2015), in which they evaluated RNIB produced information materials for sight impaired people. Other studies (e.g. Burton et al., 2013; Coulter et al., 2006; Kenny, Wilson and Purves, 1998; Thetford et al., 2015), that reviewed or explored lived experiences of patients with and without sight impairment found similar challenges regards design, formatting and language being a significant barrier to patients accessing information. These and findings from our study highlight a noteworthy element in that provision of information, particularly in print form, is a fundamental pre-requisite for patient education and participation within healthcare (Currie *et al.*, 2001). As such, there is a need for information producers to bridge the gap between patient preferences, guidelines and policy to ensure materials are accessible to the target group. Similarly, clinicians must ensure that the take away information materials they are handing over to patients following a consultation, corroborates communicated information (Paul and Redman, 1997; Berkman et al., 2004), and equally they must be able to provide information in alternative formats to optimise patients understanding of their diagnosis, treatment options and support.

3.8.9 Clinicians as a Source of Information: An Interpersonal Dimension

This theme was generated largely from the in-depth interviews the researcher conducted exploring participants' perception of and experiences with information materials in a broader sense. Their accounts were rich with tentative views of their experiences with clinicians; there was a sense that clinicians lacked sensitivity or empathy that goes with breaking news about a diagnosis. Participants felt that clinicians could do better around the time of diagnosis by providing better information:

"I think I was more disappointed with how details of the diagnosis were communicated, he just said you have dry AMD and there is nothing that can be done about it. That's very frustrating; especially if you have no information about what's really going on with you. I mean, I would have accepted it if I didn't have a diagnosis and just took it as part of my ageing..." (110- 114, James).

James's account evokes images of a man who had hoped something could be done regarding his diagnosis, only to be disappointed with the prognosis. Frustrations were compounded by communication around diagnosis and a paucity of information provided. This finding is consistent with the findings from Peel, Parry, Douglas and Lawton (2004); a study in which the authors focused on information provision to patients diagnosed with diabetes. Other studies (e.g. Evans, 1995; Makoul, Arntson & Schofield, 2005) have shown that a lack of information, explanation and support was the greatest source of psychological disturbances for patients, following diagnosis. A generic survey conducted in the UK, which included 227 patients and relatives taking legal action against hospitals, highlighted the importance of communication when providing information – particularly at the diagnosis and treatment stages. The majority of complaints centred on a lack of clear, sympathetic explanations concerning diagnosis, support, treatment benefits and side effects (Vincent, Young & Phillips, 1994). It could be argued here that clinicians' poor communication and attitude constrained some of these AMD patients' access to information:

> *"With the current diagnosis, she [consultant] may have [provided information re: treatment], but her attitude is what probably distracted me from actively listening… the lady, I must say, seemed rushed and wanting to send me on my way." (186-188,194-196, Primrose).*

Some – particularly those with dry AMD – reported that, even when they asked what they could do to manage their condition following diagnosis, the clinicians did not explain or provide practical answers. Dahlberg, Todres, & Galvin's (2009) study highlighted the importance of adequate information provision in the clinician-patient dyad as it allowed patients to understand their diagnosis and manage the condition better over time. They argued clinicians needed to make the environment conducive for information to be exchanged in a productive manner. However, as demonstrated in the extract below some clinicians preferred to respond in the way that lacked empathy:

> *"She [consultant] just said, "Well, you just have to get on with it" – that's all." (120-121, Donna)*

Donna's account highlights an observed lack of empathy, compassion and support at diagnosis, at which she was told that she just had to get on with it because the type of AMD she had was not treatable. In their study examining the patient-clinician encounter relating to untreatable diseases, Budych and Schultz (2012) argued that clinicians needed to be sensitive and sensible when providing supportive information that would help the patient to live well with the condition. They highlighted the psychological implications of receiving a diagnosis that has no cure or cannot be treated and argued that clinicians need to be aware of their role in the information symmetry. They advocated for better use of language that shows empathy and compassion. For those receiving treatment, there were concerns around a lack of information about procedure, reassurance and support:

> *"I mean, the brochure – the leaflet – explained what the eye problem was and about the treatment. But the treatments to an old person sound all very, very frightening. There was nothing really to reassure anyone about the fact that it's not actually as bad in reality as its perceived. They [clinicians] need to do more – to provide better information about the procedure and reassurance. I wouldn't fancy it. I think my father would, you know, but most people would be quite weary about having an injection in the eye." (115-122, Henry- carer).*

The carer's account highlights the need for there to be a balance between communicated information and take away information to ensure patients understand treatment options and in particular the procedure as it can be an anxiety provoking thought. Studies (e.g. Bentley et al. 2012; Thetford et al 2015) have shown when minimal information about a procedure is given, particularly one deemed to be invasive [e.g. injection into the eye], patients experience an array of psychological emotions that include anxiety and fear of the unknown. These findings have also been corroborated across numerous studies looking at the lived experiences AMD patients (Burton et al 2012; 2013; Cloud and Lake, 2015). One participant expressed an element of frustration with the route to diagnosis and subsequent treatment:

"In a way, I think the opticians didn't know what this condition was and just assumed the glasses will sort this problem out. Sometimes you wonder if these people even know what they are doing. It's frustrating at best because, here I am a few years down the line with the wet macular, and I now have to endure having the injections to avoid further deterioration." (45-48, Grahame).

This participant's account demonstrates an expectation of people who are considered eye specialists [e.g. opticians] to know and be aware of any issues related to that part of the anatomy and provide adequate information about it. However, their lack of knowledge and the delay in receiving the correct diagnosis became a source of frustration. Similarly, some participants did not seem to think clinicians do enough with regards to information provision at diagnosis:

"I think the folks at the eye clinic did try explaining a bit. It's amazing how things like explaining something of this sort, that is life-changing, can be trivialised by clinicians. They just don't do enough giving you information, that's just my own opinion... perhaps some [patients] have had a better experience." (52-56, Grahame).

There is an acknowledgement that clinicians try to explain the diagnosis and associated treatment and procedure. However, the perception from this account was that not enough information is provided and there is a feeling this important process of communicating a life altering diagnosis is not being taken seriously. Most participants in this study alluded to the information provided by clinicians at diagnosis as not being adequate. This finding reinforces the need for better information provision throughout the diagnosis treatment, care and support phases to ensure patients have made informed decisions and are equipped to manage their condition better over time. However, some participants in this study expressed a degree of satisfaction with information provided and the clinician's approach at diagnosis:

"Yes, he did a fine job explaining that I had the wet macular and it is sort of age-related and it has to be treated. Though, to some extent, I was a bit ahead because of some people I knew who had it and the very good letter from the optician; he somehow knew what was coming up but was not going to jump the gun. He was pleasantly warm

and professional, which is always good when talking to someone about these things." (417-425, Danny).

Danny's account (above) conjures an image of an individual who was psychologically capable of absorbing information about his diagnosis. His psychological and mental preparedness can be attributed to pre-exposure from people in his social network who shared their lived experiences of AMD. It can also be argued that the clinician's relational skills created a supportive environment.

"I am happy with the doctors here and the job they have done including the information given. But I should say my satisfaction with the information provided does not extend to other patients. I still think there is room for improvement, in regards to how information is given – the care and sensitivity. The information materials should support what they tell us and also they need to do something about improving the font, size-wise, to meet our status. I think providing information in an easy-to-understand manner on what causes AMD, how to minimise risk of further deterioration, support available and the treatment can help you better manage the condition over time." (162-173, Stan).

It is evident that information is an important resource; it is a commodity, rather, that gains value if accessed in a format or provided in a manner that meets AMD patients' visual status and helps them to understand it and manage it better over time. Stan expressed satisfaction with how information was provided, but his account also illuminates an implied need for the provision of information that is person-centred – it "*does not extend to other patients*" experiences. Stan's account also highlights an element he feels would help for individuals understand their diagnosis, "*providing information in an easy to understand manner, on causes and how to minimise risk of deterioration*". For some participants the information provided went beyond just the diagnosis, but extended to elements of how to manage it over time:

"Although I was not given any information material on this, I was told during the consultation about eating plenty of green veg in my diet. All questions I had were addressed – and it was suggested it might be a good idea to get eye caps. So, right, ok; I started taking eye caps. So, I do eat a lot of Chinese food because of my background. And they have a wide variety of nice green vegetables. So, that is not a problem eating green vegetables, I like green vegetables… hmmm, but I also took from that point on buying the eye caps. I take one eye cap every day, to slow the deterioration." (207-217, Danny).

Information materials should be used to corroborate communicated information. However, from Danny's account it is evident information materials pertinent to managing his condition were not provided. This is not to imply he did not understand the information communicated. Instead from his account it can be argued that information given in a balanced relational environment can lead to changes in a patient's state of knowledge, recall, behaviour and beliefs and, potentially, be a driver for better management of the condition over time. This corroborates Sustersic et al.'s (2013) findings which explored the impact of information leaflets on the behaviour of patients with gastroenteritis. The element of a balanced relational environment is supported in the account below:

> *"The consultants I saw – fortunately, Consultant X and Consultant Y would answer any questions and give you straight answers… there was no pussy-footing. They are excellent communicators, both of them. They also provided me with some useful take away information to read at my own pace. I have met others who are not that aware at all." (143-147, James).*

This account brings to the fore the importance of creating an environment in which the patient is an equal participant in the diagnostic process as an expert of their body and the clinician using their clinical knowledge to communicate an appropriate diagnosis based information shared and a thorough examination. Mirivel (2010) concurs with this finding and asserts that an assertive but frank approach in clinicians' communicative conduct was important in order to gain the patient trust of their competence and credibility.

The findings presented here suggest that there is an expressed need for clinicians to improve their interpersonal skills. This could have a positive impact on communicated information at the time of diagnosis and beyond. Participants' accounts were mixed but mostly highlighted the need for good communication based on professional awareness of patients' experiences and understanding of AMD. The importance of sensitivity, individualising provision of information to meet patients' information needs, is necessary to avoid increasing unnecessary anxiety on their parts. Also highlighted was the omission by clinicians to provide 'take away' information materials to patients at the time of diagnosis in some instances. Take away information materials are important as they corroborate communicated information and have been shown in several studies (e.g. Gibbs, Waters & George, 1989; Brody et al., 2001; Coulter et al., 2006; Owsley et al., 2006; Raynor, Blenkinsopp, Knapp et al., 2007) to better patients' understanding of their condition, treatment options and making informed decisions about the treatment and care, and managing better over time, particularly when they are provided in accessible formats, current and easy to understand language.

Inherent in participants' descriptions of information-provision was the importance of supportive information, which feeds into the next theme.

3.8.10 Supportive Information Giving for a Degenerative Condition

There is something significant about the degeneration element of the condition, which feeds into a sense of inevitability for participants. Access to information relating to AMD were important to participants; however, this theme captures a deeper need for information in a supportive sense to help them accept and live well with the condition. To some extent it highlights expectations unmet at critical moments following diagnosis e.g. validation, reassurance and supportive information on how to live well with a degenerative condition.

"I didn't know where to turn, who to talk to. I spoke to my dad, who was still alive at that stage, and my dad just said "you got to get on with it". You know… It was alright for him because he was my dad. The clinician had said something similar because I had the dry type and there were no treatments. My dad was one of nine children and they all had different eye conditions; glaucoma and quite bit of macular going on, a bit of wet and the dry. So when he just said "Well, get on with it", I wanted to understand and do just that but I was just lost. I don't think I was ready for it. I spent some time in self-pity. My mother, bless her soul, was worried about my well being, then… She would call to check I was safe… I wasn't going crazy – I was distraught. I didn't know who to talk to about it" (Donna, 34-48).

Donna's account indicates a 'double whammy': an unsupportive clinician and an unsupportive father with lived experience of AMD. Following her diagnosis, there was a failure to equip Donna with relevant supportive information:

"There were no resources. No information given. I am going back quite a while back, you know. I was distraught. I eventually…. I had a nervous breakdown." (Donna, 48-52).

Donna's account highlighted the negative emotions brought on by a lack of 'take away' information materials for this degenerative condition she had been diagnosed with. This finding corroborates Smith and Duman's (2009) assertion that when there is a mismatch between high levels of trust placed in the clinician, family or carer and the desired information needs are not met, patients are more likely to experience some psychological disturbance, which can impact their well being. In Donna's case she expressed having a nervous breakdown absent of the much needed supportive information that would have grounded her had it been availed. This corroborates findings from other studies (e.g. Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005), that argued that lack of supportive information exacerbated the psychological impact on an individual following diagnosis. Other participants argued that more can be done to be supportive and to mitigate some challenges patients experience following diagnosis:

"I suppose more could always be done… like, when you go for these injections for the first time, it's frightening – so, a bit reassurance and information on the procedure from possibly someone who has been through it would go a long way. I'm lucky I have gone to all my appointments with my wife and she was gold in reassuring and seeing me through the process and asking questions on my behalf and sharing useful information with me. Now, imagine someone without that support and how they feel" (207-213, Grahame).

Grahame’s account highlights the importance of informational and emotional support from his wife who is always asking questions on his behalf and sharing with him. This level of support typifies the whole concept of supportive information giving. The sum benefit of that is an informed husband about his condition and can lead to better management of his condition over time. Every appointment should be viewed as an opportunity to gain more information pertinent to the condition.

“It’s all about supporting each other through life’s challenges, whether dealing with a diagnosis, bereavement or social issues, isn’t it? We are beings that thrive when relevant information at key moments in our personal journeys with the condition is provided.” (622-627, Danny).

Danny’s account exudes optimism and belief that adequate supportive information can help individuals overcome psychological challenges of the diagnosis.

“I must say I was never given what I would deem adequate information or take away information following diagnosis. Most of what I know I learned from a family member who has the same condition as me” (119-126, Jones).

This participant’s account highlights expectations unmet from a clinical sense and an expressed gratitude of having received supportive information of how to live well with the condition from a family member.

The participant below expressed receiving supportive information about slowing the degeneration from a clinical sense and through dietary advice from take away information materials:

“I learnt that lutein was important in slowing the degeneration process and I also know, when I am thinking of food, I go by the theory that dark is best. [Laughs] So, I eat spinach and broccoli. I had two books from the macular society - cookery books - and one of them dealt with vegetables and the other one dealt with fruit, you know. And they were written by… I believe he is an eye specialist in macular degeneration. And they are good, actually; everything is in very big print and very easy to see and understand.” (400-405, 415-418, Susan).

This supportive information received about lutein and dietary advice was hugely appreciated by this participant. It can be argued here that this has helped them manage the condition better over time and live well with it. This corroborates findings from Dwarswaard, Bakker, van Staa and Boeije’s (2015)’s thematic synthesis of qualitative studies which explored patients’ perspectives of living with chronic illnesses. They argued that receiving supportive information was crucial to the effective self management of their condition over time and living well with it.

"We are old, our memory is not as sharp, our sight not the best, so support in the form of information for me is more important because little things that you could do before, you can't do now because of AMD. It irritates you. If you have to ask people and people help you, it's good but it makes you dependent, doesn't it? I guess we are all dependent at some point in our lives; it's a cycle and support is good. My children depended on me at some point; now they have their own, I am dependent on them and their children now depend on them" (Primrose, 390-400).

Primrose's account highlights the need for clinicians to be aware and take into account the impact of aging on her body and function when providing supportive information. Her account also demonstrates acceptance that aging is a degenerative process that has a significant impact on her day-to-day activities and is likely to change her sense of self; that is, the way she sees herself and her role within the family shifting to being dependent on her children. In dealing with some of these challenges some saw opportunity in building a network of support to understand and manage their condition better:

"I had to make a lot of connections." (Donna, 61)

This is a powerful expression by Donna which demonstrates a drive necessitated by unsupportive information experiences, in which information about AMD, rather than about how to live with it, was offered. Thus, she sought to make connections that had the sum benefit of information beyond the diagnosis; that is, to understand it and to live with it well.

This theme is a very important finding in understanding that while information provision is important and helps patients understand their diagnosis it is equally important to provide *supportive* information of how to live well with this degenerative condition. This theme to some extent supports Bury's (1982) notion of re-evaluation, where individuals become self-aware and begin to make sense of what has happened and start seeking for relevant information that helps them adjust to living with their 'altered self'. Information is what makes the world go around, it is after all the premise of how we know what we know. More importantly, it is essential that those involved in the care of people diagnosed with this condition, a sensory element that allows us to have spatial awareness and an ability to soak in the world in a visual sense are supportive by providing accessible resources of information (Binns et al., 2012). Some participants identified making connections as an important element to gaining supportive information and knowledge that would allow them to live well with the condition. Some expressed a sense that supportive information giving can help individuals overcome psychological challenges following diagnosis, which supports findings from previous studies (e.g. Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005). A similarly study (Dwsrswaard et al., 2015), highlighted the importance of supportive information giving for patients as crucial to their ability to manage their condition over time. Some highlighted that supportive information was not unique to clinicians, but an element that goes beyond the clinical realm. For instance, the role a spouse or carer in providing supportive information by asking those in the know (e.g. clinicians) or using technology to research and share with people living with AMD was empowering. Technology has provided people from all works of life an opportunity to empower themselves with a wealth of information about all aspects of life, including staying connected. The next theme will look at how this group perceives this phenomenon in the context of their lifeworld living with AMD.

3.8.11 Proactive Use of Technology

In this study, many participants felt that the use of technology was both a way to keep in touch and up-to-date and a way of improving their daily lives in terms of living with and managing AMD. They felt that the ability to use technology enhanced their sense of belonging within society by circumventing some of the challenges that sight loss had imposed on their undertaking of certain activities. They also expressed a degree of contentedness with the devices and/or software at their disposal regarding accessing information and staying connected. The benefits that technology and software can bring to their individual lives – that is, the inter-subjective connection to the world or sense of maintaining privacy and reclaiming independence lost due to the condition – were evident in their accounts:

> *"I have come to terms with having this eye condition. I can empathise with others that have it, including my colleagues. If there is information I need or something I am unsure of regards my condition I always try and find a solution and I research for things that may help. I use my phone. I have learned new things from "OK Google". I don't like Siri much because it doesn't recognise my voice most of the time. I am learning all the time. I think that's the best way to say it" (Dana, 320-328).*

Dana's account evokes images of acceptance and illuminates a deliberate process to locate and access information about her condition using technology, a process that was underpinned by fortitude and persistence. *"I research and research and research things that may help."* This statement from Dana radiates salience and belief. Salient in her account is the sense of persistence and eagerness to learn more about AMD so that she can manage it to the best of her ability. There is an expressed sense of belief in her ability to live well with AMD. Self-efficacy and confidence are demonstrated in her proactive approach to seek information to help her understand and manage and living well with AMD. Johnson and Meischke (1993) argued that components such as salience and belief were important drivers that motivated individuals to engage in information-seeking behaviours following a diagnosis. For some participants, the use of technology was not just an information-seeking tool but a way of circumventing loss of activity, independence and purpose:

> *"I am a writer; I have managed to keep my passion for writing going on because I can go up to font size 26 on my Macintosh computer. I also use it to do my audit trail. So, using it is a "must" at the minute... it keeps me going" (131-134, Naomi).*

For Naomi, losing the ability to write would have had a huge impact on her life. To her, the ability to write was an identity and an activity that she felt gave her purpose in life. The expression *"it keeps me going"*, encapsulates this and conjures up a sense of gratitude for the role technology has played in allowing her to continue writing. Jones also valued the use of technology to access information:

> *"It's called CCTV – a very helpful piece of equipment. Anything that comes on the screen, I can magnify it. So, when I get a letter in the post or need to sign any documents, I use this machine to be able to read. At least using this, I know I still have my independence and privacy – I don't have to get someone to read my letters for me" (308-313, Jones).*

For Jones, the use of technology meant that he could maintain his independence and privacy. One aspect that seemed important to him regarding maintaining his levels of *normality* following his diagnosis. Some studies have suggested that relinquishing valued activities was associated with an increased risk of depression and cognitive decline in older adults with vision impairment (Casten & Rovner, 2006; Rovner *et al.*, 2009). Donna, Jones and Naomi's narratives (above) demonstrated how they used technology to access information about how to manage their condition, compensate for their sight impairment and deal with difficulties such as reading. These findings suggest that, despite the limitations AMD presented in their lives, participants were able to use technology to find ways of navigating through some of the challenges. For instance, some participants reported that accessing the internet for travel information and using emails provided them with an opportunity to better manage their social engagements. This is illustrated in David's account:

> *"Well, I do use a computer; I've used it since the 1990s, shortly when it became available with Windows XP because I like to keep all my records on a computer – it's easy. Although, I do most of my stuff on my phone, like accessing information about travel, sending and reading emails, and making calls to friends and colleagues from the walking group." (484-487, 492-495- David).*

Generally, the benefits of using technology to access information materials are multifaceted, as illustrated in David's account. For Donna, active use of technology to access information provided an opportunity to empower herself and reclaim independence from a practical view-point; that is, being able to do for herself:

> *"...Remember earlier on, I was saying I used to get people to read my emails? Well, guess what? Not anymore! That's how much this software has empowered me and I am loving it. There is also now another thing called Sara and Sara is a reader only where it takes a picture of the article and then reads back out. So, it's not visual – more just about hearing. I have …one of those as well. Fantastic pieces of software, they are coming up with" (177-183, Donna).*

While technology benefited David, Donna, Jones and Naomi in terms of accessing desired information, for some AMD patients (particularly those who lived alone), use of technology was both an instrument of accessing information and an element that helped supplement their offline inter-personal interactions and reduced feelings of social isolation and loneliness:

> *"To be honest, I do find I would be lost without the television; I have nothing else because I am now living alone. As well as being a useful device where I can access information from, it's companionable. I often turn the volume up while I'm cooking so I can hear the voices; it takes the loneliness away" (178-183, Susan).*

Using the internet facilitated some participants with increased and easier access to information about a variety of issues, which enabled them to better understand their condition and to retain a sense of independence and functionality. Anderson *et al.* (2003) argued that accessing information from the internet had numerous benefits for all, including sight impaired individuals with AMD because cross-linkages between the various webpages supported flexible information search processes. This notion was endorsed by some of the participants:

> *"I find it useful accessing information from the internet. Information at the click of a button, I have just been on the xxx website and I have gradually built up a list of preferred authors, which I must now put in an email and send to the library. The list is for the audiobooks I want to hear next – they are useful, very useful and keeps me occupied" (162-165, Jill).*

The account from Jill mirrors that of other participants in demonstrating the role technology plays filling a void for AMD participants who lived alone. Due to limited mobility and the challenges presented by AMD, one participant said that she found it difficult to go shopping and had to seek information from other people and depend on them to show her where items where. She felt that depending on other people diminished her sense of independence and, thus, expressed some gratitude in her account (below) at being able to access the internet and shop online – a feat she felt subverted some of the challenges presented by AMD:

"I find it useful using the internet. Shopping online saved me a lot because going in the supermarket was becoming challenging as my eyesight deteriorated. The labelling in the store wasn't the greatest and they are constantly moving things around and it's just an inconvenience having to ask were stuff is. Besides, because I am prone to falls, it's difficult to recognise people's faces you know with this condition, online shopping is a godsend" (235-245, Susan).

The above findings corroborate findings from a previous study on internet use in older adults, the authors of which argued that, despite the challenges, access to email and other internet platforms was fundamental to combatting these "four plagues among the elderly; boredom, loneliness, helplessness and decline of mental skills" (Cacioppo & Cacciopo, 2014; The Associated Press, 1999, p. 2A). However, some participants expressed concerns.

"I think some sites are poorly designed and make it difficult to access information. Some of them, you cannot even adjust the font size. Sites where I do my grocery shopping, I am ok with - but some of the other sites, it's a struggle to access information from" (235-245, Susan).

Susan was comfortable using the internet to shop for her groceries but expressed a degree of frustration when it came to accessing information from other sites that she deemed less user-friendly. These findings corroborate those of Cline and Haynes (2001), who argued that, while the internet offers widespread access to a range of information and the advantages of interactivity, access for AMD and other sight impaired individuals is inequitable and use is usually hindered by navigational challenges due to numerous design features (for example, interface or layout, disorganisation, technical language and lack of permanence). Despite the guidelines stipulated by the World Wide Web Consortium (W3C, 1994) on how to make websites more accessible for sight impaired individuals, there continues to be interface challenges. Jones's account (below) captures some of the challenges that impact accessibility:

"What I find difficult is navigating websites. It's just the websites; they are difficult to get round - they can be so complicated. Pages upon pages and pages displaying different things in different text sizes. As hard as I may try to use the software package I got from blind Veterans, it still is difficult." (274-280, Jones).

Similarly, some participants criticised some websites for using fonts not designed to support usability by people who are visually impaired:

"I am having a little problem at the minute with Google. It is not very accessible with Gmail. I cannot enlarge the font on that. I have tried. I have even got my other colleagues to look into it. That is a challenge because the team now are using Gmail to email each other.

So I am having to rely on my support worker to read the mail? You just don't have your privacy." (243-249, Donna).

As evidenced in Donna's account, not being able to adjust the font was a constraint that was frustrating. This constraint impinged on her privacy as she had to rely on her support worker to assist her with accessing her emails. One of the participants intimated that some interface designs did not meet the visual status of AMD patients, labelling them as not being "inclusive" in design because they made information accessibility difficult:

"I think some of the websites on the internet are not inclusive at all. I don't think they consider people, like my dad, who have AMD. Some of the designs are shocking – even I struggle with the usability element." (164-167, Henry carer).

The same participant believed that, since his father did not grow up in a technological era, it was more difficult for him to learn how to use technology for accessing information materials while simultaneously dealing with the constraints of living with AMD and other ailments:

"I think my dad, as much as he was a college teacher, he is of the generation where computers passed him by technology-wise. He is 94 and he is content watching telly and DVDs for company, so really to access information about his condition and other things, he prefers written material – though it's now a challenge." (158-162, Henry - carer).

Technology in the form of television was accessed as an element for companionship, structure and routine to their daily life. There was also an expressed preference for accessing information from written materials despite living with AMD. Similarly, some participants' who were not competent using technology, but appreciated its benefits relied on their partners to use it to meet their information needs and social goals. They expressed an element of contentedness:

"Yes; if I need to find out any information relating to either my condition or what time a programme is showing, I just ask my wife to check online using that tablet thing. I have no clue how to work it – besides, the TV has all the information I need right now and it keeps me entertained, too. I am an old man, now, and I think it's too late to learn new tricks" (242-247, Grahame).

Grahame's account encapsulated the saying "*You can't teach an old dog new tricks*"*.* His attitude and reluctance to learn how to use technological gadgets such as tablets and computers can, perhaps, be understood using the technological acceptance model as advanced by Bagozzi, Davis and Warshaw (1992). They argued that two elements (those of 'perceived usefulness', which relates to a measure of the individual's subjectively defined benefits of technology use, and 'perceived ease of use', which relates to a measure of an individual's degree of satisfaction with accessibility) were strong determinants to older people’s rational intention to use technology (Ryu, Kim, & Lee, 2009). In the account from Henry’s and Grahame carer, perceived usefulness is evident. However, perceived ease of use and previous occupational status seems to be a barrier more so in Grahame case, as elaborated upon by his wife:

> *“We got a computer, internet, as well as an iPad, but he does not use it. You see, my husband used to work in a warehouse and doing menial jobs and all this technology stuff flew past him. He didn’t really use any of these gadgets, except the telly, so he asks me to find information. He doesn’t want to learn to use the iPad, which his daughter got him as a Christmas present – he thinks it’s difficult because of his AMD and advancing age – so, I tend to use the gadgets and give him the information he needs as a way to support him.” (237-244, Martha –Grahame’s wife).*

In a previous study (e.g. Simpson 2009) related to technology use, it was argued that the speedy rate of advancement in technology and software may have rendered some knowledge and skills accumulated by older people redundant and thus contributing to their disinterest in learning to use new gadgets. To an extent, this notion resonates with Grahame assertions that it’s ‘too late to learn new tricks’. However, Jones, who grew up in the same era, understands the limitations AMD has imposed on his life and has embraced technology by taking classes to learn how to use various gadgets and software as a means to access information, stay connected and keep abreast with the twenty-first century. This is illustrated in his account:

> *“I don’t think much else will change about my condition, but I have been on a course [IT skills run by a local Army veterans Charity] – learning to access information from the internet. They have given me the best opportunity to access information through these different gadgets and software packages... I am grateful for that. So, I do the best I can with my limited ability not to get left behind with all that’s happening” (322-328, Jones).*

In summary this theme lends evidence of the experiences of AMD participants about the relevance and benefits of using technology as a vehicle to access information relating to their condition. Including maintaining a level of connectedness socially as well as combatting these four plagues; boredom, loneliness, helplessness and decline of mental skills. Proactive use of technology in the face of a life altering condition allowed some participants to maintain a level of functionality, privacy and independence. These findings advance on previous studies (Comyn, Olsson, & Guenzier, 2006; Simpson, 2009), the authors of which focused on older adults with disabilities not specific to AMD and suggested that the use of technology to access information could, among other things, help this heterogeneous group to live autonomously and to cope and manage the challenges of daily living.

3.9 Discussion

Results generated from this study provide an insight into AMD participants' perceptions of and experiences with 'take away' information materials (e.g. leaflets and or booklets), and how they prefer such information to be designed and presented in a more accessible manner in order to meet their visual status requirements. Though not overtly expressed, it was recognised that the implicit aim of information materials evaluated in this study was primarily to educate or inform AMD patients about their diagnosis, treatment options and available support. Participants' accounts in both focus groups and the individual interviews interwove demonstrating the interconnectedness of their views and experiences across multiple dimensions of their journey with take away information materials following diagnosis as operationalised in these emergent themes; (a) AMD journey with take away information materials. This theme had three subthemes (1) content and design of information materials, (2) Relevance of the information materials and impact on experiences, (3) User preferences: improving accessibility. This theme captured participants' views of take away materials currently available to them, particularly barriers and facilitators for accessibility and elements that helped them understand their diagnosis and manage their condition better over time; (b) Clinicians as a source of information: an interpersonal dimension. This highlighted participants' experiences of clinicians as information providers at diagnosis; (c) Supportive information giving for a degenerative condition. This highlighted participants' experiences following diagnosis and their need to rediscover self and live well with a degenerative condition; (d) Proactive use of technology highlighted how most participants despite their limitations valued using technology as a vehicle to access information relating to their condition. Including maintaining a level of connectedness socially as well as combatting these four plagues; boredom, loneliness, helplessness and decline of mental skills.

The participants in this study had some differences in the degree of sight loss, age, competency with aids and technology. Similarly, the take away information materials evaluated had variable quality (e.g. paper used, background colour etc.). However, participants' unanimously agreed that the content and language contained in the take away information materials (e.g. Macular Society, RNIB, or Birmingham Focus) was appropriate for them to comprehend and understand their AMD diagnosis and included elements (e.g. Amsler grid, diet and support information) that could help them manage it better over time. They stated that the content was appropriate as it covered symptoms, causes, progression, treatment options, benefits, and to some degree side effects, diet and support available. This resonates with tenets of McGuire's (1969) information processing theory. It argues that information materials with easy to understand content and language and make use of meaningful diagrams or pictures, enhanced comprehension and information recall for patients (Kenny, Wilson and Purves (1998), thus reducing anxieties (Tutty and O'Connor, 1999), empowered them (Nilsen et al., 2006), and positively impacted on their ability to manage their condition better over time (Currie et al., 2001). It can be argued here that failure to provide information materials in easy to read language and content can be a significant barrier for AMD patients that has an impact on their ability to live well with the condition. A point that has been highlighted in previous studies (e.g. Coulter, 2006; Taylor and Bramley, 2012; Thurston and Thurston, 2015) that have evaluated information materials for a wide variety of patient groups, including those exploring lived experiences of sight impaired individuals (e.g. Burton et al., 2013), was the use of complex language or technical jargon which was shown to be a barrier that impacted accessibility, readability and comprehension of information pertinent to AMD patients' understanding their condition.

Several barriers impacting the accessibility of take away information materials analysed for AMD patients were identified in this study. These included font size, font style, background colours, and the use of pictures, paper quality and quality of photocopied materials. Some participants had to rely on aids (e.g. magnifying glass) for this process, thereby reaffirming their struggles accessing information from the leaflets and booklets currently available to them and to an extent validated their disability (Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005). This corroborates findings from previous studies (e.g. Allensworth & Luther, 1986; Kitching, 1990; Baker, 1991; Estey, 1991; Walsh, 1991; Beverly, Bath, & Booth, 2004; Thurston & Thurston, 2014) that highlighted similar challenges for various patient groups including those with sight impairments whose information materials they have evaluated. The present finding highlights AMD patients' lived realities and the gap that currently exists between their preferences (e.g. larger font, matte paper finish black on yellow background), guidelines (e.g. RNIB, 2016; AbilityNet and UK Association for Accessible Formats [NHSE], 2014), policy (e.g. DoH, 2012; National Quality Board, 2012) and what is produced for them.

The ECLO, part of the working group in this study acknowledged and concurred with our findings. He argued that some organisations involved in the process of producing information materials in some instances advanced a 'professional look', rather than producing information materials that met the visual status requirements and needs of AMD patients. Advancing a 'professional look' over patient preferences goes against recommendations of the Guidelines International Network (2012), which argued information should be produced in formats that meets the needs of the target group. It can be argued here that by not following guidelines, policy and patient preferences and needs, information producers where perpetuating health inequalities for this group. An element that would significantly impact on their ability to make informed decisions regarding treatment and care (Chinn, 2019). Furthermore, information not being made available in accessible formats amplifies patients' disability (Mendes de Leon et al., 2003). To this extent there is a need for information producers to desist from being guided by surface visibility markers (e.g. "it looks professional") and instead adapt an iterative process (e.g. develop – test – revise – repeat) premised on collaboration and co-production to ensure take away information materials are user centred (Nilsen et al., 2006).

Despite the variable quality of the take away information materials evaluated in terms of elements of accessibility, participants were able to discriminate between the materials and identify their preferences. Of the various leaflets and booklets evaluated, a very large portion preferred take away information materials from the Macular Society. They praised and appreciated the layout, quality of the paper and colours used, particularly the black on yellow print which they cited as useful in making information more accessible. They also stated that these materials were concisely written and appreciated the inclusion of the Amsler grid, a useful tool that allowed them to check for further deteriorating of their eyesight. The small portion that preferred the RNIB materials argued that the degree of impairment to their eyesight, the boldness of the font played a major role in their ability to access the materials. However, they admitted like everyone else in the study that paper quality was an issue because of the glare back effect. This finding is in contrast to Thurston and Thurston (2015) whose study also evaluated information materials for sight impaired individuals and showed a strong preference of RNIB materials by their participants. Although, it can be argued here that in the absence of balance, choice or comparative materials their findings could be viewed as biased as they evaluated RNIB produced materials only. Furthermore, in contrast to Thurston and Thurston's study, our study highlighted participants' preferences of colour in enhancing accessibility e.g. black on yellow.

Participants' appreciated materials for being concise, with reasonably short blocks of text and structured with clear headings for important sections. They agreed the content on diagnosis, treatment options and support in all the take away information materials was relevant, current and facilitated understanding of their condition, but made suggestions for improving accessibility e.g. changing font size, quality of paper and no photocopied materials. Working group members e.g. the ECLO concurred and argued that knowledge impact was greater when AMD patients were given verbal information, reinforced by take away information materials that met their visual needs. The study from Johnson, Sandford and Tyndall (2003), in which they examined the importance of information materials, corroborates the ECLO's assertions and findings of this study.

RNIB guidelines stipulated that font size 14 was adequate for sight impaired individuals to access take away information materials. However, participants in the present study had a different view of this and stated they preferred a slightly larger font. Some stated 18 was a reasonable font size in either Arial or Calibri. They argued that this would make the information materials more accessible and potentially minimise the use of aids or depending on others to read for them. The font size element had an implication on participants' independence and privacy as captured in the carer's account stating that he had to read some of the materials for his dad because they were simply inaccessible. Treadgold and Grant's (2014) evidence review examining what good health information looks like, highlighted several elements from content, design, quality of information, to the importance of guidelines, policy and user voice. They identified content, design and quality of information as major barriers to users accessing information around their diagnosis. However, in contrast to Treadgold's review, findings from our study demonstrate that service users did not have an issue with the content or quality of information per se, but rather identified persisting issues with font size, colours and quality of materials used impacting on accessibility of the information materials. It can be argued here that findings from our study also illuminated the misalignment in guidelines, policy and patient preferences. Hence, we make the argument that to ensure equality of access, it is imperative that information producers frame production of materials on the voice of the user to ensure they are not disenfranchised (Kuhn, 1970). This process needs to be collaborative in nature involving all stakeholders.

While the focus groups highlighted participants' preferences for information materials, the individual interviews provided us with an in-depth understanding of participants' views and experiences with information materials. As such, several elements came to the fore and these included experiences with clinicians as information providers at diagnosis, the need for supportive information to deal with a degenerative condition and the proactive use of technology to access information, stay connected and reclaim their independence and privacy. Participants' accounts on clinicians were mixed but mostly highlighted a strong need for clinicians to improve their interpersonal skills and exercise sensitivity and individualise provision of information to avoid increasing unnecessary anxiety for patients. This finding corroborates Burton's (2012; Williams et al., 1998) study which highlighted a deficiency in information provision from clinicians including not receiving accessible take away information materials which often led to dissatisfaction and lack of understanding of their diagnosis. In the present study some participants highlighted that clinicians had not provided them with take away information materials following diagnosis. Hasler (2003) argued that clinicians needed to create an environment that allowed patients to participate as equal partners in the clinician-patient dyad and provide information that meets individual needs. He argued further that clinicians needed to ensure the information materials they provided were in accessible formats for patients, as understanding their condition would allow them to adequately function within the context of their multiple identities, as patients, disabled persons, consumers and citizens in an ever changing environment (Hasler, 2003).

Findings from our study support the work from a number of different studies (e.g. Gibbs, Waters & George, 1989; Brody et al., 2001; Coulter et al., 2006; Owsley et al., 2006; Raynor, Blenkinsopp, Knapp et al., 2007). In particular, the failure to provide adequate communicated information, and failure to provide accessible take away information materials. It can be argued here that omissions to provide this by clinicians hinders patients from making informed decisions about their treatment and care. Clinicians need to be aware they are proximal determinants of the type and quality of information patients receive in any sense-making events (e.g. during diagnosis giving) (French, Green, O'Connor, et al., 2012). Despite dissatisfaction expressed by some participants about clinicians as a source of information, some praised clinicians' ability to provide the information they required to understand their condition. Similarly, some stated they preferred information to be provided by a clinician rather than struggle to access it from a booklet. Doak, Doak and Root, (1985) argued that some patients would feel this way because some clinician just handed out information materials with little explanation. They argued rather than just handing these out at the end of a consultation, clinicians should make an effort to go through it with the patient highlighting pertinent points and conclude with an authoritative recommendation to read it. However, it can be argued here that while take away information materials are important providing information in the patients' preferred format yielded better outcomes in relation to knowledge of condition and its management (Treadgold and Grant, 2014). National Voices (2014), in their review of 85 systematic reviews focusing on improving and understanding information, argued that promoting choice where information provision is concerned. They argued that providing information to a patient in a format they preferred and tailored to meet needs, significantly improved knowledge and understanding of their condition including their ability to manage it better over time.

Findings highlighted the significance of supportive information giving, in terms of rediscovery of self and living well with this degenerative condition. Participants praised clinicians who shared dietary and the use alternative medication such as lutein to help slow down the degenerative process. This corroborates findings from Dwarswaard, Bakker, van Staa and Boeije's (2015) study, a thematic synthesis of qualitative studies exploring patient's perspective living with chronic illnesses. They argued that receiving supportive information was crucial to the effective self management of their condition over time and living well with it. Some participants identified making connections as an important element to rediscovering self. An element that Bury's (1982) biographical disruption theory labelled as re-evaluation, were individuals become self-aware and begin to make sense of what has happened and start seeking for relevant information that helps them adjust to living with their 'altered self'.

Lack of supportive giving can significantly impact an individual’s psychological well-being as captured in some of the accounts. This corroborates with findings from other studies (e.g. Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005), that argued that lack of supportive information giving exacerbated the psychological impact on an individual following diagnosis. A notion Smith and Duman (2009) concurred with and argued that when there is a mismatch between high levels of trust placed in the clinician, family or carer and the desired information needs are not met, patients were more likely to experience some psychological disturbance, which can impact their well being. Participants in this study agreed that supportive information was not unique to clinicians, but a phenomenon that transcended the clinical realm. For instance the role a spouse or carer in providing supportive information by asking those in the know or using technology to research and share with people living with AMD was seen as empowering.

Use of technology has provided people from all works of life an opportunity to empower themselves with a wealth of information about all aspects of life, including staying connected. Most participants in the present study valued using technology as a vehicle to access information relating to their condition. It also helped them maintain a level of connectedness socially as well as combatting these four plagues; boredom, loneliness, helplessness and decline of mental skills (Cacciopo & Cacciopo, 2014). Thus, it can be argued here that in the face of a life altering condition, proactive use of technology allowed them to maintain a level of functionality, privacy and independence. These findings advance on previous studies (Comyn, Olsson, & Guenzier, 2006; Simpson, 2009), the authors of which focused on older adults with disabilities not specific to AMD and suggested that the use of technology to access information could, among other things, help this group live autonomously, cope and manage the challenges of daily living.

However, a minority of the participants could not use technology despite encouragement from their partners and felt it was too late for them to learn. For instance, “You can’t teach an old dog new tricks”. This reluctance to embrace technology can be understood using the technological acceptance model as advanced by Bagozzi, Davis and Warshaw (1992). They argued that two elements (those of ‘perceived usefulness’, which relates to a measure of the individual’s subjectively defined benefits of technology use, and ‘perceived ease of use’, which relates to a measure of an individual’s degree of satisfaction with accessibility) were strong determinants to older people’s rational intention to use technology (Ryu, Kim, & Lee, 2009).

3.10 Strengths and Limitations

This study had a number of strengths and limitations. A significant strength of this study is the research strategy which allowed collaboration between the researcher and the working group as discussed in chapter three. They helped shape the study, identify information materials for evaluation and development of the interview questions. The design and content of the identified information materials were largely consistent across all of them with the exception of the photocopied material. These were analysed across the three focus groups (n=12) that included contributions from two carers – a son to one of the participants and a spouse to another of the participants that supported them to hospital appointments. Their contributions brought balance to the discussions about take away information materials. It was recognised that the implicit aim of information materials evaluated in the focus groups was primarily to educate or inform AMD patients about their diagnosis, treatment options and available support. Individual interviews (n=7) in this study provided a broader understanding of AMD patients' views and experiences with information materials across multiple dimensions of their lives. Data saturation was considered as this is the gold standard of data in qualitative research although there is no specific sample size recommended. The key findings in our study is the misalignment in guidelines, policy and patient preferences and what is produced. The implication of which is inaccessibility of take away information materials for AMD patients.

Several limitations were identified in this study and need to be taken into consideration when interpreting the results. The participant group was homogeneous with respect to their ethnicity. All were white, from West Midlands and most came from a medium to high socio-economic class. This means that the broadest spectrum of views was not elicited in this study and it is not possible to extend or generalise the findings of this study to a wider population of AMD patients' views and experiences of information materials, particularly those from ethnic minorities groups. Hence, future studies need to focus and encourage participation of ethnic minorities as perceptions, interpretations and meanings they attach to experiences with information materials could differ along cultural lines.

Perhaps future studies in this area can use both qualitative and objective measures such as DISCERN (a quality index tool used to evaluate quality of information materials), and accessibility formulas like Flesch (that help to evaluate readability for information materials), to examine these materials to get a balanced picture of patient preferences of specific elements of information materials. Given that there have been numerous studies focussing on information materials across multiple disciplines in the last twenty years or so and still similar issues persist with minor improvements here and there. Perhaps there is a need for an independent reviewing body to give some kind of 'kite mark' or standards for rating accessibility, usability, content and design to ensure materials meet the needs of the target group.

3.10.1 Table 3h: Summary Impact Statement:

What was known before

- Use of technical jargon/Language were a known barrier in studies evaluating information materials for various patient groups.
- Content and design were also noted as a barrier in previous studies evaluating information materials
- Information deficient of pertinent information around diagnosis, treatment and support.

What this study adds

- This study sheds light on elements that impact accessibility of information materials for AMD patients currently.
- It highlights the gap between guidelines, patient preferences, policy and practice
- Provide relevant services (e.g. Producers of information), with insight into the needs of AMD patients regards information materials and make positive adjustments to their practice (e.g. working collaboratively with all stakeholders to co-produce and ensure they meet the needs of end users).
- Information currently contained in the take away information materials is sufficient for AMD patients to understand their diagnosis and treatment options, check for signs of deterioration and elements (e.g. diet) to slow down and manage the condition.
- Help clinicians anticipate and understanding patient views and experiences of take away information materials and their preferences to (e.g. alternative format- audio).
- Understanding aspects of multiple dimensions of their lives were accessing information is concerned (e.g. use of technology, the importance of colour - black on yellow background).

3.11 Implications for Practice

It is perhaps useful for clinicians to adapt as routine practice sign posting AMD patients to the low vision clinic following their diagnosis for further assessment and to access tailored visual aids that support and enhance their ability to access information materials, as acquisition of knowledge is after all a key strand to understanding and managing their condition and aspects of their daily living with AMD.

3.12 Conclusion

This study has succeeded in evaluating information materials currently available to AMD patients. They highlighted barriers that impacted and facilitators that would make materials more accessible to them. There was general consensus from participants that despite accessibility issues information contained in the materials presented to them was adequate for them to help understand their condition, treatment and care, and managing it over time. It is evident from participants' shared views and experiences with information materials across multiple dimensions of their AMD altered lives, and from their expressed preferences and suggestions, that there still exists a gap between policy, guidelines, user preferences and practice. Thus, to bridge the gap there is a need to align services and relevant stakeholder to take a collaborative approach to co-produce materials that are user centred. There is a need for clinicians to improve aspects of their information provision strategies (e.g. interpersonal skills) to ensure patients get the full benefits to understand their condition, treatment and care beyond the consultation room.

In addition to findings from the meta-synthesis, this study provides further context and a desire to explore aspects of the clinician-patient dyad, particularly at diagnosis to get an in-depth understanding of the information provision processes from both a clinician and patient's perspective. The next chapter will examine this dimension including related elements that influence the treatment decision making process and methods of consent for AMD patients.

CHAPTER FOUR: Living with Wet Age-related Macular Degeneration: a Qualitative Study of Consultations at Diagnosis

4 Introduction

Diagnostic consultations for AMD are a sense making event for both clinicians and patients to explore a variety of issues that include; symptoms, causes, prognosis, treatment options, procedure, and extend to its management and the support available (French et al., 2012; Wallberg, Michelson, Nystedt, et al., 2000). However, it must be equally recognised that this is also an emotional event for patients and clinicians need to be sensitive and aware of each patient's information needs. As such, clinicians need to create an environment that encourages reciprocal actions with regards to information provision and acquisition which are underpinned by a shared understanding of the patients' priorities and preferences of information regards the diagnosis and treatment options (Habermas, 1984). Studies (e.g. Butow et al., 1997; Leydon, Boulton, Moynihan et al., 2000) focusing on cancer patients explored patients' priorities and preferences for information provision and participation during diagnostic consultations and demonstrated that, amongst other things, patients require specific information about their condition (Jenkins, Fallowfield & Saul, 2001; Murtagh, Furber & Thomas, 2013). However, it can be argued that patients' information needs are not static and will vary significantly from person to person in terms of their preferences for timing, content, format and detail of information required for them to understand the condition, treatment options, and participate in collaboratively making a decision to consent to the treatment of choice. The contingencies briefly discussed above, indicate a real need to understand more about the clinician-patient dyad regards information provision at diagnosis for AMD and explore what their experiences, priorities and preferences are in this encounter, particularly the process for decision making to consent to treatment for those diagnosed with wet AMD.

Receiving news of a diagnosis, particularly that of a chronic illness is an emotional event for any patient (Buckman 1992; Sharp, Strauss & Lorch, 1992). Regarding AMD, Burton et al. (2013; Brody et al., 2001; Desrosies et al., 2009; Owseley et al., 2006; Thetford et al., 2015), reported that their patient participants; 'when told they had AMD, expressed feelings of varying degrees, that included, shock, despair and anxiety. The majority of Varano et al.'s (2016) 910 questionnaire respondents diagnosed with wet AMD reported experiencing strong emotional reactions during the diagnostic consultation, including anxiety, shock and frustration. These psychological reactions feature prominently in literature related to chronic illnesses, including AMD (Heisler & Friedman, 1981; Burton et al., 2013; Tolman et al., 2005; Thetford et al., 2015). The same studies also highlight issues of information deficiencies at diagnosis particularly for AMD patients (Burton et al., 2013). However, research (e.g. Jedlicka-Köhler et al. 1996) indicated that experiencing strong emotions during the diagnostic consultation impacted on an individual's ability to optimally process communicated information. A notion supported by Histock, Legard and Snape's (2001) qualitative study on patients diagnosed with type 2 diabetes which showed that following news about their diagnosis, patients could not absorb or process any information adequately thereafter. They reported that patients needed time to deal with the emotions the diagnosis evoked before taking in more information. Loftus and Burns (1982) reported that experiencing strong negative emotions can significantly disrupt one's memory, and it is generally assumed that patients will struggle retaining information provided under the stress of a diagnostic consultation (Scott, 1983; van der Molen, 1999). It can therefore be argued here that the implicit and/or explicit orthodoxy regards information provision at the time of diagnosis for any chronic illness should be kept as simple (e.g. minimal use of medical jargon) and as brief as possible to avoid overwhelming the patient with information, as patient education at this point maybe ineffective, demonstrated in research focusing on information provision of a cancer diagnosis (e.g. Carlsson & Strang, 1998; Rodriguez-Man, Lopez-Roig & Pastor, 1996). While receiving the diagnosis evokes emotional responses that may impact absorption and retention of information provided, the attitude the clinicians display towards patients can have a significant impact on their understanding of the information provided at diagnosis and the subsequent management of the condition over time. Deitrich (1996) concurs with this assertion through findings from his study exploring the experiences of patients with diabetes patients of the diagnostic process and attitudes of clinicians. Emotional reactions, attitudes of health care professionals and provision of clear information are significant factors in patients understanding their diagnosis and being able to make decisions to consent to treatments. However, these factors can negatively impact understanding and the treatment decision making process.

May, Allison, Chapple et al. (2004) conceptualized the diagnostic encounter as a negotiation of two kinds of expertise; the authoritative general expertise of the clinicians often conceptualized as professional, expert or medical knowledge, and the specific experience of the patient, often conceptualized as lay beliefs (May et al., 2004). However, it is important for there to be a balance where patients share information about their symptoms and experiences and clinicians respond using their medical expertise to diagnose. Key to this is attending to patients' information needs to help them gain knowledge about their condition, develop a strong patient - clinician relationship, reduce uncertainty and assist with decision-making. The Department of Health (1998) concurred and argued that without adequate and current information at diagnosis, about potential treatment options, side effects and prognosis, it is not possible for patients to be part of the shared decision-making process or give informed consent (Cegala and Street, 2007; Safran, Taira, Rogers et al., 1998). Murtagh et al.

(2013) argued that in some instances, it was not the lack of information but rather the clinicians' communicative style (e.g. dominating the clinical narrative, a didactic, paternalistic approach of sorts), that impacted negatively on patients' information seeking behaviours in consultation rooms reducing their chance to actively participate. This suggests there is a need for clinicians to be engaged in training to improve their interpersonal skills, to ensure they are more relatable and take a lifeworld led approach where they view patients as sentient, autonomous beings capable of making informed decisions when adequate information is provided in a format they understand (Wirtz, Crib & Barber, 2006; Borg Xuereb et al., 2015). This requires clinicians to create an environment that promotes open dialogue, as advanced by Habermas' concept of communicative rationality.

Numerous studies focusing on generic chronic conditions, have shown that when patients are actively involved in the diagnostic process, including the critical element of decision making and consenting to treatment, they reported higher levels of satisfaction (Fiscella, Meldrum, Fanks et al., 2004; Williams, Weinman & Dale, 1998), compliance with treatment (Safran, Taira, Rogers et al', 1998), improved information exchange (Cegala and Street, 2007; Street, 1991), better psychological adjustment where specific information is provided (Street, 1991), and improved self - management and health outcomes (Rao, Weinberger & Kroenke, 2000). However, Butow, Mclean & Dunn, (1997) argued that while creating a conducive environment was crucial during the clinician-patient diagnostic encounters, one of the main problems that contributed to information deficiencies was the clinicians' inability to gauge accurately patients' information needs. Sharp, Strauss & Lorch (1992) took a different view to the above argument by positing that, since diagnostic consultations were an emotional event for patients, it was highly likely this impacted on their ability to fully process the information provided, let alone evaluate it to make an informed decision to consent to treatment. Most studies (e.g. Burton et al., 2013; Tolman et al., 2005; Thetford et al., 2015) exploring the lived experiences of AMD patients corroborate both arguments, when highlighting the existing information deficiencies at diagnosis for this group. Suffice to say, as already alluded to, patients' information needs are not static and vary across individuals, suggesting their priorities and preferences regards information and experiences at diagnosis differ as well. Studies (Gattellari, Butow & Tattersall, 2001; Cox, Jenkins, Catt et al., 2006) exploring cancer patients' priorities and preferences relating to information provision during diagnostic consultations, demonstrated amongst other things, that patients required specific information regards their condition, including prognosis, treatment and management for them to be able to make an informed decision to consent to treatment or care, while some were only interested in information relating to treatment and support (Jenkins, Fallowfield & Saul, 2001). It can be argued here that variations between patients regards priorities and preferences for content, timing and detail of information at diagnosis are significant to how they understand their condition, make an informed decision to consent to treatment, adjust and manage living with the condition over time (Butow et al. 1997).

4.1 Rationale

As demonstrated above, diagnostic consultations are a sense making event for both clinicians and patients to explore a variety of issues that include; symptoms, causes, prognosis, treatment options, decision making and consent to procedure, and extend to its management and the support available. Walseth and Schei (2011), concurred with this assertion and advanced that the patient is at the centre of consultations as aptly captured in the description below:

"Decisions should spring from a respectful dialogue concerning patients' commitments, feelings and practical circumstances, sharing reflections concerning what is right, what is good and what is practically feasible for the patient; conversations where the world of everyday life is given language and reflected upon"(p.81).

The statement above highlights the need to draw from patients' life contexts in consultation rooms in order for the dialogue to meaningful and meet their needs and values preferences. Given the significance of this event and the implications it has on the patient's well being there are currently no studies to our knowledge that have specifically focused on the AMD patient-clinician dyad. Particularly, regards gaining multi-perspective insights into patients' and clinicians' experiences and views on treatment decision making, as well as ascertain the method (s) used to gain consent to treatment and determine clinicians and patients' priorities and preferences regards information provision, and visits to the clinic. It is hoped that the findings will enhance understanding of the patient-clinician dyad at diagnosis. In particular, the quality of information provided and how it influences decision making to consent to treatment. It is also hoped that highlighted priorities and preferences can be used to inform practice to ensure better approaches and interventions to transfer knowledge are used and optimise understanding.

Below is a reminder of the research question:

How is consent to treatment negotiated and obtained during the consultation?

4.2 Methods

4.2.1 Context

Diagnostic consultations provide an opportunity for patients to gain insight and understanding of symptoms impacting their health and well being. Clinicians use their expertise to determine what the symptoms mean in terms of a diagnosis and should discuss treatment options to allow patients to make an informed decision and consent to treatment of their choice. The decision-making process to consent to treatment in older adults with AMD is a complex phenomenon in health care which has however, not been fully explored as highlighted in the meta-synthesis and in study one. Recommendations from these studies suggest that aspects of the clinician-patient dyad need to be explored, particularly at diagnosis to get an in-depth understanding of the information provision processes from both a clinician and patient's perspective were treatment options, decision making, and consent to treatment, priorities and preferences are concerned.

There are a lot of interview studies with patients, a few with healthcare professionals, but very little research that has directly observed consultations as they happened (Pryce, Hall, Marks, Culhane, Swift, Straus & Shaw, 2018). This study was specifically focused on the diagnostic consultation. In particular, gaining multi-perspective insights into patients' and clinicians' experiences and views on treatment decision making, as well as ascertain the method (s) used to gain consent to treatment and determine clinicians and patients' priorities and preferences regards information provision, treatment and visits to the clinic. As such, a two-step approach was used to address the aims of this study. The first step involved the researcher observing the interaction between the patient and clinician during the diagnostic consultation to get an understanding of the dialogue, depth and quality of information provided. The second step involved conducting semi-structured individual interviews with a view to gaining a broader understanding of AMD patients and clinicians ' perceptions and experiences of information provision at diagnosis, including discussions around treatment options, methods of consent, determining their priorities and preferences and overall experiences in the clinics. These two methods of data collection were deployed in this study because it was felt they would efficiently enable the researcher to have productive discussions with participants (Morgan, 1997) aimed at eliciting multiple views (Bowling, 2002) regarding the phenomenon of focus.

4.3 Design

Based on a qualitative design we used an interpretative perspective to explore and describe patients' and clinicians' views and subjective experiences of the AMD diagnostic consultation. The goal was to rely on their perspectives to obtain a broader understanding of this phenomenon of interest. The study was carried out between June 2017 and January 2018.

4.3.1 Setting and Sampling Strategy

The study was undertaken in the UK, and a purposive sampling strategy (Creswell and Poth, 2018), was used. Participants aged 65 and above were recruited from a local West Midlands Eye Clinic. The inclusion criteria were that patient participants had been referred to the AMD fast track clinic with emerging or suspected AMD symptoms, able to communicate in English, with no severe cognitive or hearing impairment and would be willing to be observed during the diagnostic consultation and participate in the individual interviews without requiring assistance. Participants who were less than

65 years old, unable to speak English, had advanced incapacity and could not give informed consent were not included in the study. For clinician participants, to be eligible, they had to be working within the AMD fast track clinic and be either a nurse or consultant ophthalmologist.

The participating patient sample consisted of (n=6) older adults aged 70 years and above who were newly diagnosed with wet AMD at a local eye clinic in the Midlands. The clinician sample included two consultants (n=1 female) and (n=1 male), responsible for the Macular fast track clinic and 2 female nurses whose ages ranged from 25 to 55. One individual was co-opted into this study, in their capacity as a carer in the individual interviews.

4.4 Clinician and Patient Recruitment

Participants were recruited after obtaining approval from the relevant ethics board. All participants were recruited from an approved site at a local city hospital in West Midlands that provided specialist eye services. Potential participants with suspected AMD were tracked through the referral system for the Macular fast track clinic. Recruitment letters were sent attached to the appointment letters (n=36). However, only 2.16% (n=6) agreed to take part in the study. Clinicians in this study were recruited through email and by direct approach. A total of (n=4) clinicians, that is (n=2 consultants) and (n=2 nurses) agreed to take part in this study (100% recruitment rate). All volunteering participants gave informed consent, and none withdrew from the study before data collection was completed.

4.5 Data Collection

Data collection took place between 2017 and 2018. A guide with open ended questions for the individual interviews was co-designed by the researcher and the working group (e.g. experts by experience, Eye Clinic Liaison Officer, Birmingham Focus Coordinator, Macular Society Coordinator and academics) (see table 2 below). These were refined following a pilot focus group and an individual interview being conducted.

Participant observations and the semi-structured individual interviews were chosen as the most relevant data collection methods for this study. Observation methods are important for understanding people's actions, roles and behaviours (Walshe, Ewing & Griffiths, 2011). Specific to our study, observations are necessary because of their focus on the natural setting which provides the researcher with a real time understanding of the diagnostic consultation. In particular, observations can facilitate understanding of what people do and how these can alter in response to situations and perhaps over time. In a sense, observations are useful as they help to identify and guide relationships with participants. They also help us learn how people in the setting interact and how things are organized and prioritised in that setting. Highlights what is important to the people in the setting under study, and helps us understand what constitutes appropriate questions, how to ask them, and which questions may best help the researcher answer the research questions (Schensul, Schensul & LeCompte, 1999). Researcher positioning in research observations is very important where validity is concerned. The quality of data collected and the relationship with participants observed affect how the researcher positions himself within the context of the research setting (Kawulich & Garner, 2006). In this study, the researcher's preferred way of observing was overt observation, where participants were aware they were being observed and knew the purpose of this method. This positioning was in line with tenets advanced by Gold (1958) around observations as a data collection method.

4.5.1 Practical Steps Taken for Observation of Diagnostic Consultations

- Checking and confirming with the hospital every Monday and Thursday morning, the AMD fast track clinics were going ahead in the afternoon and being present;
- Checking with consenting participants they were still attending their scheduled appointments;
- Liaising with Clinicians before consultations started to briefly discuss sitting arrangement and being clear about the researcher's role as an observer;
- Ensuring all study materials were in order and consenting participants were present;
- Ensuring the recording device was charged and working;
- Reassuring participants that anonymity would be upheld throughout the study.

Semi-structured interviews were chosen as the data collection method for the second phase of this study because this method allows the researcher and participant to engage using a format that facilitates direct responses one on one. The use of this method also gives the participant an opportunity to elaborate and the researcher recourse to clarify, which is not possible with questionnaires or structured interviews. This method, however, can be time-consuming; not only in terms of the length of the interviews themselves but also in terms of post-interview analysis time. All semi-structured interviews for this study were conducted face-to-face, allowing the researcher to respond to social cues and ensuring a closer rapport was developed.

4.5.2 Practical Steps Taken to Organise Individual Interviews

- Negotiating interview time and date; offering options to hold interviews in the comfort of the patients' home or in a quiet space at a local eye clinic;
- Rapport building; briefing participants on the interview process and encouraging open and honest dialogue about the phenomenon of interest;
- Liaising with the working group regarding the final version of the interview schedule (open-ended questions);
- Ensuring the recording device was fully charged and in good working order; and
- Reassuring participants that anonymity would be upheld.

The interview schedule developed for this study were not prescriptive but purposefully flexible, set in order to allow the researcher to explore clinicians' and AMD patients' existing, and emerging perceptions and experiences regarding information provision during an AMD diagnostic consultation. Prompts were also employed in order to ensure that participants elaborated on elements pertinent to the phenomenon of interest.

4.5.3 Research Instrument

4.5.4 Table 4a: Summary example of the interview schedule used following diagnostic consultations:

Interview stage	Purpose	Questions
Opening	Purpose of focus group: Brief introductions of participants. Rapport building.	Can you tell me about yourself e.g. Age, name, etc.?
Initial questions to get interview going	Participants' perceptions and experiences of presented information at diagnosis.	Can we talk about your AMD diagnosis? What were your initial thoughts? How did you process that the information provided? How did you feel? Did you feel you were given adequate information and time to process it?
Transitional questions	Barriers/enablers to understanding information provided.	Can you tell me what your initial thoughts are of the information provided? Do you feel information provided allowed you to make an informed decision about treatment? If yes what aspects of the information provided were the drivers to consent to the treatment? Can you tell me what methods were/did you use to gain consent? Do you feel the consultants did a good job as informants? If not what did they miss and what would you have wanted done differently?
Key questions	Determining priorities and preferences.	Can you tell me what your priorities and preferences where in the diagnostic consultation? Do you feel information provided or the diagnosis shaped your priorities? Can you tell me what are your preferences regarding information provision at diagnosis? Can you tell me where you given any take away information materials following diagnosis? If yes, did you have a chance to read these? Did they help with understanding information given at diagnosis? If not, is there a reason why you haven't read these? What are the challenges to accessing them?
Closing question		Is there anything you think the researcher ought to have asked and would like to discuss?

4.6 Procedure

Before the consultation, participating patients and clinicians were informed of the study's aims and requirements and permission was sought to audio record the AMD diagnostic consultations and follow - up interviews. The researcher took some field notes during the discussions and observed that participants in all sessions were respectful of each other's opinions. See table below highlights the diagnostic process and the researcher's positioning as an observer in this context. Since the consultation rooms at the clinic are not uniform in terms of size and set up the researcher did a sketch of the lay out and highlighted were patient and clinician sat during the consultation and observed how this may impact communication. See proforma in the appendices section.

4.6.1 Table 4b. Representation of what happened at diagnosis – the clinical interaction

1. Salutation: • Ophthalmologist goes to corridor and calls out patient name and directs them to consultation room, greetings to patient at door. • Introducing his/herself in pleasant voice • Gesturing and telling patient and attendant [if escorted by carer/family member or friend] where to sit • Introduces the researcher and informs them consultation will be recorded – confirms they consent to recording [all patients consented]
2. Brief History taking: - medical Facing patient, asking required medical questions, and taking notes. Intermittently making eye contact. Speaking to the patient in a language they understand or in some cases for Asian patients speaking in their language if they knew how to. [Language was a noted barrier in circumstances were patients expected the consultant to speak the same language as them because of their ethnicity/race] • Making social conversation in between to make the patient comfortable; to pique the patient's attention and interest, or to manage the digressions of a 'malingering' patient [this was mostly observed during the examination and the ensuing discussion relating to the diagnosis though not used all the time] • Answering questions patient's ask carefully, providing information they need to make an informed decision [though it was observed, this did not happen in all the consultations the researcher sat in] for instance, a family member/carer escorting her friend was left frustrated after asking questions of patient having some visual hallucinations and wanted to know if it was the Charles bonnet syndrome.
3. Eye examination: • Patients wearing spectacles were asked to remove them • Following this, table was adjusted to suit height of where patients were sat. They were then requested to lean forward in the chair, put their feet on either side of the table to ensure they were comfortable. • Patient was then instructed to position his or her head and chin at the slit lamp. All the while the consultant was communicating and informing the patient what he was doing and how long it would take, what to expect and how highly unlikely they would experience any pain. • Patient was instructed to look in a particular direction when performing the eye examination at slit lamp, one eye after the other [e.g. look up/down/left/right/straight ahead]

- In case patient was teary from light exposure from slit lamp, a cotton swab to wipe his or her eyes was provided [instructions of were to dispose it given]
- Instructions were patiently repeated [for patients who struggled with hearing, voice was raised a bit to ensure they heard]
- If additional tests were required, patients were duly informed [dye]
- Telling patient to sit back in the chair and announcing the end of examination before gently moving the slit lamp away [Not jerking it away without announcement]

4. Diagnosis and treatment:

- Opening computer and bringing up pictures of patient’s eye (s) and informing them what the picture means in terms of diagnosis.
- Utilizing all the communication opportunities when showing the pictures [minimising medical jargon]
- Briefly explaining what condition is and discussing treatment [While this was observed for patients with wet macular, there was little information provided regards dry macular management]
- Diagnosis and advice provided in reassuring tone. Inviting queries [although not evident in all consultations]
- Consultants politely answered queries of the patients [though some patients felt let down]
- Patients patiently listened to the consultant and vice versa [though it was also observed that patients tended to just listen and not ask questions, perhaps due to the overwhelming news]
- Consent form:- Treatment summarized- statistical figures given re: risks [Minimal discussion of benefits, side effects, procedure, alternative treatment and support available]
- Summarize things to look out for should the eyes deteriorate any further [this did not happen consistently in the consultation rooms]
- Information leaflets given [although this was not done consistently. None of the patients observed were sign posted to ECLO, nor referred to low visual clinic]
- Patient informed a minimum of 3 injections would be administered and assessment will be an ongoing process. [again the procedure for the injections was not fully explained]
- Reminded they would receive letter in the post for their appointments
- Patients were asked if they had any question [mostly at the end]. Those who attended with relatives, spouse or a carer in most instances did ask questions from time to time.
- The diagnostic consultations on average lasted 8-10mins

End of consultation

Following findings/recommendations from chapters 3, I needed to delve more deeply into the procedural aspects of consultations to get access to any systematic or recurrent issues. More specifically, this study focused on establishing how communication styles and communicated information shaped patients’ responses, or participation in the process of decision making to consent to treatment. The researcher contacted participants after a week to arrange for individual interviews. This was mainly to allow time for patient participants to process information provided by the clinicians at diagnosis and gather their thoughts and experiences of the event. The interviews were organised based on participants’ availability.

Semi-structured interviews were conducted with patient participants in the comfort of their homes. While interviews with clinicians took place in a private and secure area, such as their office or pre - booked conference rooms at the Hospital site. These interviews lasted between 30 and 60 minutes each and were conducted by TP. At the start of each interview, TP briefly reminded the participants about the study, checked that they understood and were happy to continue.

All patient participants were recruited via the AMD fast track referral system at a local hospital in West Midlands. The researcher worked in collaboration with the hospital admin team identifying suitable participant and using their hospital number to send out study details with clinic appointment letters. Those who expressed willingness to participate and consented, the researcher TP, went through the participant information sheet with them to ensure they fully understood the requirements of the study. After this, participants were given a further 48 hours to consider participation or withdraw. Clinician participants were recruited directly from the AMD fast track clinics and were provided with the participant information sheet which the researcher explained ad they understood and consented to participate in the study.

Consistent with the strategic tenets of this programme of work as described in Chapter three and also highlighted in Chapter four all interview materials used in this study were developed in collaboration with the working group.

Volunteering patient participants were asked about their experiences in the consultation and more specifically about the information provided at diagnosis, including establishing whether the benefits and risks of treatment options were discussed and understood. They were encouraged to share their experiences and perspectives of the treatment decision making and method(s) of gaining consent, as well as share their priorities and preferences in the diagnostic process and visits to the clinic. Clinician participants were asked to talk about their experiences as informants at diagnosis and their role in the treatment decision making process, as well as establishing the method(s) they used to gain consent from AMD patients in relation to treatment. Furthermore, they were also asked to talk about their priorities and preferences during the diagnostic consultations.

All interviews in this study were audio-recorded and transcribed verbatim. All identifying data, including names or proper nouns were excluded at the point of transcription. All transcripts were checked against the original audio recording by the researcher, and any adjustments made were discussed and approved by the volunteering participants.

4.7 Data Analysis

Verbatim transcripts of the individual semi-structured interviews were analysed using Langdridge’s (2007) critical narrative analysis, a method that neither imposes assumptions on the participants' data nor forces them to focus on specific details. Instead, it focuses on participants' experiences and feelings while also promoting individual meaning-making. In order to ensure consistency in data analysis, the researcher adopted the six stage approach as described by Langdridge. These include; (1) critiquing the illusions of the given subject, (2) Identification of narratives, the narrative tone, and the rhetorical function, (3) identifying the work and its identities, (4) Thematic relationship and priorities, (5) Destabilizing the narrative, (6) A critical synthesis. The process involving the six stages is briefly described below.

4.7.1 Stage 1: Critiquing the illusions of the given subject

Participant personal identifiers were removed to enhance confidentiality, and transcripts were produced from the interview audio recordings. These unedited transcripts were read through many times to better understand participants' narratives. Langdridge encourages researchers to critically assess hermeneutics that best suits the study's focus. For instance, he highlighted several examples of suspicion-oriented hermeneutics, including gender, social class, racism, and sexual analysis. In our case the focus is health related for older adults in particular the clinician –patient dyad. The role of this stage is to expose assumptions made by researchers. The researcher wrote a reflexive account in chapter three outlining their position and how that may influence his comprehension of the interviews across this programme of work. This element offers a more personal component in the research process, and encourages more attentive self-awareness about the dynamic relationship between them and the individuals they are studying.

4.7.2 Stage 2: Identification of narratives, the narrative tone, and the rhetorical function

In the identification of rhetorical function and narrative style, the most reliable tactics employed in most narratives were used e.g. stage 1 reading and immersing oneself in the data. An interview can be seen as a single narrative but also functions as a setting for other narratives. The researcher had to look for varied storylines in the text during this stage. The stories a person tells indicate how they link their accounts to other stories that have already been told. A critical examination of the stories symbolizes the more significant social stories on how people live or should live. For instance, how the people should live with AMD or behave during an AMD diagnostic consultation. The narrative tone was found to characterize the interview content. For instance, one might have an optimistic or a pessimistic attitude during the diagnostic process. After identifying the text's rhetorical purpose, the next step was analysing it. The analysis part aimed at focusing on the meaning of the narrative and its relevance.

4.7.3 Stage 3: Identifying the work and its identities

This stage is based on stage two above. An examination of respondents' rhetorical work or responsibilities in their stories was also examined to explore their position in the patient clinician -

dyad, which could have influenced their decision making process or lack thereof to consent to treatment.

4.7.4 Stage 4: Thematic relationship and priorities

Identifying the critical ideas in each narrative with a close focus on the narrative coherence was covered in this stage. The goal was to analyse the main themes directly from the text without examining the individual words and their constituent parts. The researcher read books, searching for new ideas and the possible way to structure sentences. The researcher was careful to remember his thoughts from Stage 1 and to ensure that the participants' different viewpoints were captured in the ideas that emerged from the writing. The developing concepts were recorded individually with line numbers to examine if thoughts might be organized into clusters of meaning. To distinguish if the themes could be further categorized, they were analysed to determine if they were dependent on each other or could exist independently, as argued by (Langdridge, 2007a). This approach was very interactive, beginning with a thorough examination of the original transcripts, leading to better categorization. Finally, at heart, it is about the themes and interactions among categories.

4.7.5 Stage 5: Destabilizing the narrative

The penultimate stage denotes a critical distinction between other narrative analysis techniques. They include discourse network analysis. To understand each participant's narrative, it is essential to use an appropriate hermeneutic (interpretative lens). This stage is considered political since it involves researchers working with social theories critical of the dominant power structure, as shown by identifying six possible hermeneutics of suspicion, including gender analysis as argued by Langdridge (2007). Critical Narrative Analysis uses hermeneutics to throw "imaginative scepticism" on the interviews concerning their presumed ultimate purpose. This is to say, the story needs to reveal new story possibilities rather than focusing on trying to find hidden meaning, and the researcher decided to use a hermeneutic derived from the clinician-patient dyad in the context of the AMD diagnostic process.

4.7.6 Stage 6: A critical synthesis

To provide details on how the findings are presented, Langdridge recommends that important narratives be given alongside the themes that place participants at the forefront. The critical synthesis stage is underpinned by processes in the stages highlighted above and brings forth findings that can be gleaned from a framework of suspicion as described in stage 1 (Langdridge, 2007a). The results section will provide full findings of the study, while a synthesis, or summary, of themes will be found near the beginning of the findings being presented.

In establishing and optimising trustworthiness and limiting threats to validity, the criterion for 'trustworthiness' outlined by Lincoln and Guba (1985) was employed. The criterion of credibility was satisfied through open-ended questioning, prolonged engagement with the data and by providing a detailed description of the methods (Lilleheie, Debesay, Bye and Bergland, 2020). The criterion of transferability was fulfilled by presenting detailed and in-depth descriptive data and by quoting the participants' narratives. To satisfy the criterion of dependability, reiterative reading of the transcripts by (TP and RS) was performed to transform the ideas generated into a set of codes to identify the interesting features of the data. These initial codes were then categorized into themes. The themes were discussed and reviewed by TP, RS and the working group to reflect on their relevance to the research questions. The analysis was performed by an individual educated within the field of health psychology and the research supervisor RS has extensive experience working with older adults. The working group who were part of the theme reviewing process are individuals with extensive experience working with AMD patients in various capacities as support providers, information providers and some with lived experiences of AMD.

Agreement between the researcher (TP), the supervisory team (RS) and the working group was reached after careful deliberations using the consensual validation process on the categorization scheme, their characterizations and narratives. The researchers (TP, RS and HB) worked collaboratively by discussing and reviewing initial and emerging categories. However, TP and RS discussed and agreed on the final themes and associated definitions. Table 5c, below, provides an overview of the initial themes before they were synthesized into superordinate themes that will be discussed in the result section.

4.7.7 Table 4c: Coding strategy - themes generated from patient's interview data

Initial themes	Characterizations	Exemplar narratives
Trust in Clinicians	While patients expressed an element of trust in clinicians as part of their decision making process to consent to treatment.	*I didn't know what I was having [treatment wise] they said most of the outcomes were positive. At the time I couldn't have cared less. So you could say I put my faith in them [clinicians] and I was just happy that I was getting something done basically because we couldn't really afford to wait while my eyesight deteriorated*

	This characterization to a greater extent includes implied trust were patients were going along with the clinicians' decisions or recommendations even if they didn't understand the treatment options discussed.	*"You know you are in the hands of people who know far more than you do. So, you don't start effing your button you do as you are told."*
Shock at diagnosis	Some patients expressed shock, a feeling that overwhelmed them and perhaps impeded their ability to process information communicated by the clinician during the diagnosis and full participation in the treatment decision making process.	*I don't think much of what was said about the diagnosis sank in, I was in shock, I didn't want to go blind and not be able to see my grand children's faces.*
Decisions/consent to treatment driven by fear of losing sight	Fear of losing sight was enmeshed in Some of the patients treatment decision making, Past health experiences, outside AMD influenced treatment decision making	*I suppose you could say my decision to consent and go along with the injection was partly because I didn't want to lose my sight. I trusted the doctor's recommendation and I didn't know whether they were any other options. You could also say my previous experiences with illness and treatment also played a part*
Consenting to treatment: the decision making process	Some patients characterized their experiences in the treatment decision making process as negative. They sighted lack of information/discussion of the treatment options by clinicians and the lack of opportunity to ask questions to get a better understanding of the diagnosis and treatments. Some participants delegated the treatment decisions to the clinician because they viewed them as more knowledgeable.	*No, I don't think he went into much details about treatment options. He just said you will be having injections, that's all he told me.*
Participants' views of clinicians as informants in the diagnostic and treatment process	Some patients stated that the attitudes of the clinicians impacted understanding of diagnosis/treatment and not achieving the desired level of participation in the process. These attitudes also did little to alleviate feelings of apprehension relating to the treatment procedure. Some patients described negative experiences at diagnosis, such as the lack of meaningful discussion about treatment options, prognosis, side effects and having questions not fully answered.	*You would think they [clinicians] would be good at communicating and be compassionate and be reasonable when dealing with patients but, she wasn't particularly the easiest to talk to* *I just felt she rushed and was somewhat dismissive of my concerns*

Use of language in the diagnostic and treatment process	Patients described and seemed to agree that nurses did a better job at communicating information regards treatment issues using language they understood easily than the consultants.	*I would want to say yes she did, but there are some words that I don't understand, like this macular what exactly is it? Then she [consultant] started saying you have AMD are they different from this macular thing. That's confused me a bit*
Patient priorities and preferences at diagnosis and decision making to consent to treatment.	They described wanting to stop deterioration as their number one priority, more than anything else at the time. Life context were also an influence attached to this priority –fear of losing sight	*It was more to do with getting the treatment early to avoid eyesight deteriorating any further*
Consent methods	Participants recalled consenting to treatment by signing a piece of paper they did not even read. Some described the font of the consent as inaccessible, thus could not read its content further and instead put their trust in the clinician. Some suggested that instead of the written consent, considering their status, consent in an alternative format such as audio would be more suitable.	*We are all different audio consent could be useful. Personally I prefer written but in a more accessible format*

4.7.8 Table 4d: Coding strategy - themes generated from Clinicians interview data

Initial themes	characterizations	Example quote
Clinicians' perspectives on decision making consent/patient participation	Consultants outlined their role of providing information about diagnosis and treatment to empower them to make decisions. The described giving patients' statistical figures relating to the treatment procedures when asking them to consent. They perceived AMD patients as passive participants within the consultations whose priority was preserving their quality of life, as informed by their life contexts. Nurses described that when most patients came in for the injection, they had little understanding of what was about to happen. They attributed this to inadequate information being	*A consultation is a dialogue between ourselves and the patients, an exchange of information if you will, and the ultimate decision to go ahead with treatment lies with the patient, with myself providing relevant information for them to be able to make those decisions. That's empowering the patient, though sometimes you get patients that will leave you to make decisions for them because as you said earlier they believe we know better.* *Well to be honest I wish consultants would try and be as caring as nurses and just explain things in a simpler manner. If we can do it, it*

	communicated in the consultation.	*means it's possible for them to do that for this group.*
Methods of gaining consent	Clinicians unanimously stated that currently only one method is utilised to gain consent from patients. However, they a preference and a need for alternative methods e.g. audio	*At the minute we are using the forms you mentioned to gain written consent.* *I think for this group we could use audio consent. The audio format would circumvent issues of writing on a line they may not see*
Navigating through systemic barriers	Clinicians acknowledged that there were systemic constraints that impacted the diagnostic potentially process and these were varied.	*There are only a few structural issues here and there. For instance, space can be tricky for wheel chair bound patients and the fact that we don't high ceiling means if they were other people using the rooms next door they could hear what is discussed in here.*
Awareness of emotional responses: a barrier to information acquisition	Clinicians acknowledged that emotions could impact on patients' ability to fully grasp or understand information provided and suggested ways to adapt in this situation	*I suppose the shock for some, of being given a diagnosis can impact understanding or retention of the information we give them regards the diagnosis or treatments, which is why we provide take away information materials for them to read in their own time*

The initial themes in the tables above were organised further into seven synthesised superordinate themes and one sub-theme to represent patients' and clinicians' perceptions and experiences of information provision at diagnosis, decision making and consent process. The synthesised analysis will be presented in the results section.

4.8 Statement of Ethics

The conduct of this study conformed to the research methods and actions approved by Aston University Ethics Committee and the NHS York and Humberside Ethics Committee in application number ref: 16/YH/0099; IRAS project ID: 186422. The study was carried out between June 2017 and January 2018. All the participants gave written consent for their inclusion and were made aware that participation was voluntary and informed of their right to withdraw from the study at any stage. They were assured that this would not affect their current or future access to services relating to their AMD diagnosis. The researcher gave an assurance of the confidentiality and anonymity of the study to all volunteering participants. Moral principles of beneficence, justice, informed consent and human dignity (Polit and Beck, 2012; McCloud and Lake, 2015), were addressed and upheld throughout the conduct of this study.

4.9 Results

4.9.1 Demographics and Details

A total of 36 potential patient participants who were due to attend a local Eye Clinic in the Midlands were sent recruitment letters through the referral system prior to their diagnostic appointment from June 2017 through January 2018. Of these 36 potential patient participants, 12 responded (4.32 % response rate). However, six of these were excluded based on their inability to speak English. As such only 6 patient participants were recruited for this study (2.16 % recruitment rate), while 4 clinicians responded and volunteered to participate in this study (100% response /recruitment rate). All clinicians were directly involved in the diagnostic and the treatment process of the volunteering patients in one way or another.

The volunteering patients' sample mean age in this study was 76.86 years (SD=7.26), all white; men (n=2) and women (n=4). The sample of 4 clinician participants was comprised of mainly women (n=3) aged between 25 and 49 years and one male aged 55 years, both from an ethnic minority group (n=3 Asian) and (n=1 African), title (n=2 Ophthalmologists) and (n=2 nurses). One carer co-opted into the study.

The tables below provide all demographic information collected for the volunteering patient and clinician participants.

4.9.2 Table 4e: Patient demographics.

Pseudonym	Age	Gender	Ethnicity	Family status	Work status	Diagnosis	Treatable?
Primrose	70	female	White- British	Married	Retired	Wet AMD	Yes
Margo	73	female	White-British	Widowed	Retired	Wet AMD	Yes
Roselyn	74	female	White-British	Widowed	Retired	Wet AMD	Yes
Johnson	76	male	White-British	Widowed	Retired	Wet AMD	Yes
Maria	84	female	White-British	Widowed	Retired	Wet AMD	Yes
Chris	91	Male	White-British	Married	Retired	Wet AMD	Yes
Carer/Maria	70	female	White British	Widowed	Retired	Wet AMD	Yes

4.9.3 Table 4f: Clinician participants' demographics

Clinician ID	Age	Gender	Ethnicity	Title/Position
C 1	55	male	Asian	Ophthalmologist
C 2	49	female	Asian	Ophthalmologist
N 1	40	female	Asian	Nurse
N 2	25	female	African	Nurse

Themes presented in this study will include extracts from the interview transcripts to enable the reader to understand participants' perceptions of and their experiences in the diagnostic consultation in relation to information provision (Corden & Sainsbury, 2006). Particularly, aspects that help patients make decisions to consent to treatment, methods of gaining consent and determining clinicians and patients' priorities and preferences around this phenomenon. Furthermore, using extracts from these transcripts will help to clarify links between data, researcher interpretation and conclusions drawn from the data (Long & Godfrey, 2004).

In addition, the researcher will also discuss the results in light of what is currently known in order to demonstrate its relevance regarding contribution to the evidence base in this field. The themes are presented separately for patients and clinicians to facilitate sense-making from the two groups in relation to their views and experiences of the diagnostic consultation, decision making, consent to treatment process and their preferences and priorities in this context.

For the patients – four superordinate themes were generated: (a) Impact of emotions on processing information at diagnosis; (b) Diagnostic engagement: the unmet needs; (c) the decision maker – 'navigating' towards consenting to treatment; (d) Language as a barrier to understanding diagnosis.

For the clinicians – three superordinate themes were generated: (a) Clinician perceived- Patient-centeredness information giving, with sub theme (i) Emotional awareness and adaptability; (b) steering patients towards the 'right' decision; and (c) Working through systemic barriers.

4.10 Patients' Perspectives

4.10.1 Impact of Emotions on Processing Information at Diagnosis.

Receiving an AMD diagnosis can evoke emotional responses in some patients, particularly if they least expect it or have never heard of it. The latter suggesting they may be a deficiency of public discourse, considering AMD is one the leading causes of sight loss in the United Kingdom amongst individuals aged 65 years and above. Conversely, the prospect of losing sight in itself can be daunting and presents many challenges for this group, which have been well articulated in studies focusing on their lived experiences (e.g. Burton et al., 2013). Essentially, this theme describes patients' perceptions and experiences receiving an AMD diagnosis for the first time. They described experiencing strong emotions which may have impacted understanding of communicated information at diagnosis:

"I don't think much of what was said about the diagnosis sank in, I was in shock. I didn't want to go blind and not be able to see my grand children's faces." (Primrose-174-177)

Primrose's narrative exudes a strong emotional response intertwined with her fear for losing sight, particularly the idea of missing out on seeing her grand children's faces. She describes not being able to take in any information relating to her diagnosis because of the shock. For another patient they thought their referral to the fast track clinic related to an existing problem, only to be given a new diagnosis:

> *"I went to the clinic thinking they were going to talk about cataracts initially. That's what I thought any way. So perhaps you can see why the information relating to the diagnosis for this other condition [AMD] didn't register much, because I was in shock" (Roselyn, 348-352).*

Prior to her AMD diagnosis Roselyn had cataracts which seemed to be the main impetus for seeking medical attention. Roselyn's narrative however, evokes images of an "ambush "scenario, were she described going to the clinic to have what she thought was an existing condition attended to, only to be given an unexpected AMD diagnosis. There is a subtle sense Roselyn could not reconcile her former self with cataracts to the current self with the AMD diagnosis, given that both conditions cause a significant negative impact on eyesight. As such, for Roselyn shock was the immediate reaction, which also impeded maximum understanding of information communicated at the time of diagnosis. For some, while the experience of having twice gone through a cancer diagnostic process and treatment regiment, the shock of receiving the AMD diagnosis was somewhat temporary:

> *"Um, it's a bit of a shock really getting this diagnosis, it's one of those things I guess… you just wonder what's going on. Can't seem to catch a break, I don't know if you know I've had throat cancer twice and I have just got over that, I was discharged last year" (Johnson, 149-153)*

This narrative evokes emotions interwoven perhaps in him transitioning from a life limiting condition to a life altering condition which are aptly captured with him stating "*can't seem to catch a break"*.

On the whole participating patients inherently knew referrals were made to the clinic because they had experienced some difficulties with their eyesight. While the diagnosis validated the experienced symptoms prior to attending the diagnostic appointments at the clinic, participants expressed feelings of shock, mainly precipitated by fear of going blind as endorsed in Primrose's excerpt. For some it was the idea of being given a different label to the one they already possessed as endorsed by Roselyn. It was also evident from participants' narratives that 'shock' to a large extent precluded understanding of communicated information at diagnosis. Studies suggest that strong negative emotions, such as shock can disrupt memory (Loftus and Burns, 1982), and impact one's ability to retain information provided during the diagnostic (van der Molen, 1999) or treatment (Scott,

1983) consultations. Evidently, for these participating patients what they knew pre-diagnosis and what they came to know post diagnosis influenced the emotional responses and experiences they shared with the researcher and the meanings they are attached to, and connected to their changing physical state.

Conversely, outside the shock, some patients felt that clinicians' relational skills during the consultations had further impacted understanding of their diagnosis and treatment.

4.10.2 Diagnostic Engagement: The Unmet Needs

This theme highlights the extent to which patients' expectations from the diagnostic consultation were left unmet, largely due to the perceived interactive disposition of clinicians. In particular, their lack of warmth in how they related to patients, and perceived failure to provide adequate information on treatment options. Experiences of their engagement during the diagnostic consultation shaped patients' perceptions and views of clinicians. For instance, some of the patients described negative experiences at diagnosis, such as the lack of meaningful discussion about the condition, treatment options, side effects, prognosis and having questions not answered satisfactorily. Some patients stated that the attitudes of the clinicians impacted understanding of diagnosis and treatment:

"The consultant did a lot of the talking and I don't think I even got a chance to ask any meaningful questions, I just didn't want to lose my sight". (Roselyn, 162-165)

Roselyn's narrative invokes images of communication dominance. An imbalance in power dynamics where the clinician is the 'all knowing', and does most the talking, and fails to create an environment that permits the patient to participate fully in the diagnostic process. It can be argued here the clinician stuck to her own agenda in this process and failed to create an egalitarian platform for Roselyn to engage and have her information needs met. In her narrative there is also an element of conceding to this power dynamic and a reprioritisation from engaging to understand - to getting on with it - to get treatment to stop further deterioration of her eyesight. Diagnostic consultations should be a place where information is exchanged between the patient and the clinician to ensure both parties understand what is being communicated. A notion that Habermas' (1984) theory of communicative action advanced by arguing that for a positive, dynamic process to occur, the parties involved must have an open dialogue and seek to understand the other and be willing to change their understanding when new insight is gained. However, the clinician needs to create a conducive environment that affords the patient an opportunity to participate optimally which also helps inform patients' decision making to consent to treatment. However, for some patients who tried to engage further during the diagnostic consultation to understand information being communicated, expressed feeling rushed:

> *"I just felt she rushed and was somewhat dismissive of my concerns" (Roselyn, 415-416).*

This narrative shows that patients attach great importance to how the clinicians provide and communicate information to them. It can be argued here that when older adult patients perceive that the clinician rushed, they are less inclined to provide information about their own and it can have a negative impact on their overall experience within the clinic. As such clinicians need to be aware of how they communicate information and this includes non-verbal cues and their attitudes:

> *"You would think they [clinicians] would be good at communicating and be compassionate and be reasonable when dealing with patients but, she wasn't particularly the easiest to talk to" (Primrose, 275-279).*

Primrose's narrative conjures images of frustration with the clinician's lack of compassion and competence as an informant. This and her perceived attitude and personality created an atmosphere where Primrose didn't feel particularly comfortable to participate:

> *"She wasn't that personable, she wanted to get through it, and I don't know if that's right. I felt she just wanted to get on with the job and get to the next patient" (Primrose, 281-283).*

Primrose's narrative highlights some of the barriers patients endure when interacting with clinicians during consultations and the emotional roller coaster they experience; from experiencing emotions owing to receiving the diagnosis, to frustrations of perceived clinicians' attitudes. The narrative also highlights issues around time constraints being a perceived contributing factor to clinicians' attitude. Diagnostic consultations in this study were observed to be averaging between eight and ten minutes in length. A study (Elmore, Burt, Abel, Maratos, Montague, Campbell & Roland, 2016) examining the relationship between consultation length and patient experience, suggested that longer sessions may be more useful to achieve better understanding for patients, particularly for a life altering condition such as AMD that comes with anxiety provoking treatment procedure.

All the elements highlighted in Primrose's narratives can be deconstructed into unmet needs e.g. information and supportiveness and have an impact on the patients' overall experiences within a healthcare setting. As such, clinicians need to create an atmosphere of freedom based on respect, sincerity and equality to allow patients to participate freely in the diagnostic process and gain a better insight of their diagnosis or treatment. This process starts with a smile, a hand shake and non-verbal cues of empathy. It is evident from Primrose's experience that clinicians need to put emphasis on interpersonal skills during their encounters with this vulnerable group. They have the opportunity to soften the asymmetry by trying to understand the AMD patient's concerns and addressing them accordingly and collaboratively. However, while this is ideal, it's not always the case particularly when it comes to provision of information as observed in this Primrose's narrative:

> *"I think, I would have wanted a bit more explanation about the condition and the symptoms, because I didn't know about the differences between the leaks and bleeds and also I felt a little bit pushed like you ought to go to xxx [another clinic closer to her home] and I didn't want to particularly do that, since I was referred here. I just wanted my eye done that was my main thing". (Primrose, 445-454).*

There is a common strand in Primrose's narratives -that of frustration with the clinician's attitude, and inability to communicate information around her condition's symptoms and the lack of supportiveness, were she felt the clinician wanted her to be treated at another clinic when she had already presented herself to one and had been given a diagnosis. Our findings here corroborate Breemhaar, Visser and Kleijin's (1990) study of elderly patients' perceptions of interactions with clinicians, which demonstrated that perceived negative attitudes by clinicians were a communicative barrier that impacted interactions with patients and the subsequent understanding of information provided to them. Similarly, Irish (1997) indicated that when clinicians are less respectful of, or provide minimal information and support to their older patients, it impacted on their understanding and subsequent self-management of the condition. However, some patients expressed positive experiences, particularly when dealing with nurses at treatment who they regarded as warm and had better communication skills when providing pertinent information about the treatment procedure:

> *"Yes you are right, the nurses seemed to do a better job explaining things" (Carer for Maria, 131-132).*

In summary, our findings highlight issues around clinicians' interpersonal skills and power dynamics during the diagnostic engagement, as noted in Roselyn's narrative where the clinician did most of the talking. This power dynamic suggests a paternalistic model and didactic approach which prevented her from being an active participant in her diagnostic consultation. Foucault's (1973) concept of power/knowledge as inseparable, highlighted that clinicians communicate power by providing a diagnosis and prescribing a treatment plan. A characteristic that was noted across narratives in this study. However, in relation to this finding, perceived attitudes of clinicians impacted on patient participation. Foucault argued that clinicians needed show empathy, provide information in a sensitive and supportive manner that instils confidence for patients to actively participate in the consultation. An element that was more evident in the narratives of patients' interactions with the nurses rather than the consultants.

Furthermore, a perceived inability to communicate pertinent issues around diagnosis in a satisfactory manner by clinicians, for some patients, evoked feelings of frustration and dissatisfaction.

Findings from our study corroborate literature focusing on older adults living with chronic illnesses including AMD (Breemharr et al., 1990; Irish, 1997; Burton et al., 2013; Thetford et al., 2015; Varano, et al., 2015), which have reported similar results. Given these findings, it can be argued here that patients evaluate information provided based on both verbal and non verbal communication style of the clinician providing the diagnostic and treatment information. A notion Svenacus (2000), concurs with and advanced that how clinicians speak (not just what they say) creates an impression, such as those highlighted in this present study. Hence, clinicians have the responsibility to manage not only the information they provide, but also the patient's impressions during the communication process given that pertinent information around diagnosis is being discussed (Svenacus, 2000). Roter et al., (1997; Deveugele, Derese & De Maeseneer, 2002) argued that clinicians can manage these communication expectations by including social talk to make patients feel at ease in the interaction and be active participants. This argument is consistent with findings from our study regards nurses, whom patients could relate to more and observed them to be better communicators and providers of information. It can be argued that discussions with nurses facilitate improved understanding and knowledge for patients around diagnosis and treatment. Deveugele et al. (2002), also argued that clinicians needed to be mindful of the language they used when providing diagnostic and treatment related information as this impacted patient understanding.

4.10.3 Language as a Barrier to Understanding Diagnosis

This theme relates to the linguistic content of the interactions between clinicians and patients in the diagnostic consultations. It reflects how different patients assigned different meanings to the same content or context and how language used can impact the understanding of a diagnosis and treatment discussed:

"I must say when I initially got my diagnosis, I didn't really understand what macular degeneration was or meant. I had to ask them to break it down and explain in a way I could relate to. The lady [consultant] was nice enough to explain that it was age related, so I got that and just thought to myself blimey! I'm old, ok that's why it's happened, then she said the degeneration bit is like the wear and tear to the central vision and if we don't start you on treatment your sight may deteriorate further. Umm when she said about wear and tear, I just thought to myself you are damned if do and damned if don't use it. All my life I have practically relied to my eyesight to get on. [Laughs]Who knew they would come up with a diagnosis like this? I am grateful though for the treatment I'm now receiving". (Maria, 58-69).

Maria portrays herself as a lay person seeking an explanation to a perceived complex diagnosis to meet her level of understanding from a person she considers an expert. Using language loosely about diagnosis has several implications to the patient's understanding. Her reaction to the statement that it is age related affirmed to her that advancing in age was the reason her sight was deteriorating and there was almost a tone of hopelessness in her narrative to suggest she couldn't change her age related predicament, a natural phenomenon. However, when the consultant further explained that deterioration meant wear and tear to the central vision, while some patients may understand this to mean over use or abuse of their vision depending on their life contexts, Maria used an expression to make sense of what was being communicated and rationalised it along the lines of you are *'damned if do and damned if you don't'.* Suggesting either way it was inevitable her sight would deteriorate, a notion she endorsed by stating, *"Who knew they would come up with a diagnosis like that"?*

There was an element of acceptance of her condition based on the age principle. However, the use of loose language, which is open to different interpretations and the use of medical terminology not readily understood by the patients can impact their understanding of the condition and the subsequent management of their condition over time. Clinicians should aim to provide and communicate clear unambiguous information, to meet each patient's needs. A notion Hellstrom (1998) concurred with by positing that some patients were left uncertain of their status when given a diagnosis of *"AMD",* a term they weren't familiar with. For instance, one of the patients was asked by the interviewer: *"Do you feel the Consultant on the day explained your condition in a way that you understood"?*

And her response was:

"Umm... I would want to say yes she did, but there are some words that I don't understand, like this macular what exactly is it? Then she [consultant] started saying you have AMD are they different from this macular thing. That's confused me a bit. I know my eyesight isn't the best but perhaps we could have had more discussions about the things she says I have". (Margo, 66-79)

Margo's narrative evokes abstract images of understanding of her diagnosis where she is aware her sight isn't the best. However, because the consultant used abbreviated language *AMD* to describe her diagnosis and "macular" in general terms as if to imply the patient was already aware of the diagnosis, created confusion in Margo understanding the diagnosis. This confusion led to her assuming perhaps these were two different conditions. This lack of understanding of one's condition can have a negative impact on acceptance, coping and managing the condition over time. As such, it can be argued here that clinicians need to be aware of their patients' level of understanding and come up with strategies of communicating information using clear non-complicated language at diagnosis, to ensure they understand their diagnosis better. For instance, individualising their approach in the context of the patient's circumstances i.e. level of understanding or disabilities (Yardley, Davies and

Sheldon, 2001). Conversely nurses were seen by participants as better information providers or communicators in their treatment journey, as they used relatable easy to understand language.

"Oh yes, the nurses did use language I understood better than the consultants, when I was having the injection they explained the process of what they were going to do" Maria, 103-105).

Maria's narrative suggests nurses had a warmer approach and explained the treatment procedure in a manner they understood without using complex language. The narrative also implies this interaction with the nurse put them at ease during a procedure that is otherwise anxiety provoking. There is a sense from this narrative that Maria's experiences with the nurse as an information provider were more positive than with the consultant. Chapple, Rodgers, MacDonald & Sergison's (2000) study, exploring patients' perceptions of changing professional boundaries in the future of nurse led services, showed that patients in most instances preferred to be seen by a nurse than a consultant because nurses appeared more empathetic and communicative. This argument was validated by some of the participants in this study:

"Yes you are right, the nurses seemed to do a better job explaining things" (Carer for Maria, 131-132).

The carer's narrative paints a positive picture of the nurses' competency in executing their job educating patients about an anxiety provoking treatment procedure. Within the Nursing and Midwifery Council (NMC, 2015) code of conduct, it is argued that while caring is central to practice, communication was however an element nurses needed to embody, to effect positive treatment outcomes. They also needed to integrate within the scope of their practice values, such as human dignity, integrity, autonomy, altruism and social justice, as these demonstrate compassion, competency, commitment and caring. Perhaps these elements were more evident to patients in their interactions with nurses than with consultants. A notion Svenaeus, (2000), advanced by stating that, how clinicians communicate (verbal and non-verbal) information creates an impression on the patient.

The findings demonstrate that language is a very important aspect of the diagnostic consultation as it influences patients' understanding of the diagnosis, treatment options, benefits and associated side effects. As such, clinicians need to be culturally and linguistically competent, and have the skill to evaluate a patient's capacity to understand complex medical terms. For instance, they need to be mindful about how they communicate medical terminologies to avoid confusion as noted in Margo's narrative. A notion Hellstrom (1998), concurred, arguing that it distorts understanding of one's diagnostic status. It can be argued here that words do matter and contribute towards context and meaning one perceives and ascribes to them, as highlighted in Maria's narrative. In using simple language, clinicians need to be aware of how patients perceive it. For instance, using 'wear and tear' to explain a diagnosis could trigger psychological implications associated with self blame and impact management of condition over time. Our findings also showed that patients felt nurses used language they understood. Perhaps this could be related to their interactive disposition as highlighted in the theme above and in Chapelle et al & Svenaeus's (2000) studies. Varano et al.'s (2015) generic study of older patients and the use of complex terminology in a medical encounter, found that the use of complex medical language was a notable barrier to older patients fully understanding of their diagnosis and treatment, which had an implication on informed consent to treatment in some instances.

4.10.4 The Decision Maker – 'Navigating' Towards Consenting to Treatment:

An important goal of providing adequate information during the diagnostic consultation is to transfer knowledge to patients and enable them to make an informed decision to consent to the treatment of their choice. Consenting therefore is not just signing of a paper, but rather a process premised on information provision. This theme captures patients' narratives around decision making and consenting to treatment. To a large extent it captures the patient's positioning in the context of the patient-clinician dyad relating to this phenomenon. It highlights a process (a), in part driven by fear of losing sight rather than understanding of the treatment options and their side effects, (b) trusting the clinician as the medical guru, in a sense submitting to their expertise, regards treatment recommendations, and (c) wanting to retain independence and their quality of life underpinned by their life contexts. Slowing down deterioration was a major priority for participants and an influential factor in the decision making and consenting to treatment process:

"I suppose you could say my decision to consent and go along with the injections was partly because I didn't want to lose my sight. I trusted the doctor's recommendation and I didn't know whether they were any other options" (Johnson, 97-101).

This narrative highlights two key things a fear driven decision to consent to treatment rather than an understanding of the treatment offered and absence of information on options available to manage this condition, and submitting to the expert. It can be argued here based on the omission to provide pertinent information around treatment options this consultation event could be viewed with a paternalistic lens. A characterization that is apparent in the narrative below where the patient voiced their disappointment at the lack of information/discussion of the treatment options by clinicians and the lack of opportunity to ask questions to get a better understanding of the diagnosis and treatments:

"I didn't know what I was having [treatment wise] they said most of the outcomes of what I was offered were positive, that was it. There wasn't much discussion beyond this. When your choices are limited making a decision is influenced by people looking after you. So you could say I put my faith in them [clinicians] and I was just happy

that I was getting something done basically because we couldn't really afford to wait while my eyesight deteriorated" (Chris, 115-121).

In this narrative the paternalistic and didactic approach comes to the fore. It highlights an important factor in the decision making process, choice or options in this case, absent of these, and that means patients will submit to the clinicians' recommendation as a default rather than from a place of understanding. It can be implied from the tone that they were an active participant in the dialogue who simply did not get enough information around options in the consultation. However, there was also an element of expressed gratitude that they had been on a treatment plan to stop their eyesight from deteriorating further.

Some participants delegated the treatment decisions to the clinician because they viewed them as more knowledgeable.

"You know you are in the hands of people who know far more than you do. So, you don't start effing your button you do as you are told." (Chris, 63-65).

This narrative exudes an element of trust and confidence on the premise of expertise as highlighted in the narratives from the patients above. It can be argued given the patient group, older adults that trust and confidence placed on the clinicians was also influenced by their trust in the health system (NHS). Studies (Halter, Drennan, Joly, Gabe, Gage & de Lusignan, 2017) have highlighted that there was an interplay between trust and confidence placed on clinicians by older adults and appreciating the NHS, particularly for those who have lived long enough to understand its importance as a healthcare provider and the strides made over the years.

The narrative below further deconstructs experiences of patients in a diagnostic consultation:

No, I don't think he went into much details about treatment options. He just said you will be having injections, that's all he told me. While my priority was to stop further deterioration, I would have appreciated more information around options or associated side effects and the procedure itself. (Maria, 263-267),

Despite the level of trust expressed in Chris, Johnson and Margo's narratives. Maria's narrative demonstrates this was not a universal occurrence in this study and highlights an unmet need were information that allows her to make an informed decision to consent is concerned. For some patients, consent to treatment was driven by the urgency to stop further deterioration:

"To be fair I don't think the decision to consent was influenced by the pair of us understanding what Mr Xxxx said. It was more to do with getting the treatment early to avoid her eyesight deteriorating any further" (Carer for Maria, 132-139).

Gruman (2013) argued that families and carers play a crucial role in the diagnostic and treatment decision making process in supporting patients make an informed decision. However, in this study the carer's narrative neither suggests a lack of information being provided nor understanding of the information provided. Rather, it suggests stopping further deterioration of the eye as a driver for consenting. While for some decision making and consent to treatment were trust driven. When asked if treatment options, benefits and side effects were discussed, Roselyn responded:

> *Umm… to be honest I'm not sure she did. I don't recall, but again my decision to consent to treatment was purely based on my trusting the doctor, not wanting to lose sight. I live on my own you know and value my independence, so sight is very important to me. So if the doctor said injections are going to save my eyesight then I will do it. I hope I'm not getting her into trouble for saying I didn't hear her talk about options (Roselyn, 171-179).*

In the face of failing to recall if pertinent information about the treatment options, their benefits and side effects, trust of the clinician as an expert was the currency used to make a decision to consent to treatment by Roselyn. It can be argued here, that being exposed to information relating to treatment and or associated procedure, does not necessarily equate to being informed. Thus, it raises issues around the presentation of information, the condition in which it is given and how clinicians assess patients' understanding of that information (Renya and Hamilton, 2006). Furthermore, one then questions the validity of the consent to treatment, if it's (a) driven by fear of losing sight and (b) trust of the clinician rather than understanding of pertinent issues around options, benefits and side effects. After all this process is premised to adequate information provision and understanding it, for individuals to make an informed decision of their preferred treatment.

Some participants expressed their preferences and made suggestions around the consent process advancing that an alternative format such as audio would be more practical and suitable for some instead of the written format:

> *"We are all different therefore, audio consent could also be useful. Personally I prefer written but in a more accessible format. I also feel doctors need to tailor information based on each patient's needs prioritising pertinent information such as the diagnosis, prognosis and communicating the treatment options. We want to be part of the process in making decisions. Now when it comes to information about the treatments I would much rather hear the statistics of how successful it is and percentages of how it is going to improve my eyesight or odds of things going wrong. Just like he gave me the odds of the blister bursting. My priority is to minimise deterioration" (Johnson,202 -206).*

While Johnson's priority was getting treatment to minimise further deterioration of his eyesight. His narrative highlights a preference for written consent, but in a more accessible format. He also states he prefers treatment information around effectiveness and side effects given in percentages as it highlights the odds for him. This preference is underpinned by his previous experiences with a life limiting condition (*I had stage 3 I was told the survival rate wasn't great*), that he has just overcome against the odds. He makes a strong suggestion for clinicians to tailor information to individual needs. A notion Carey (2006) concurs with that information should be packaged to meet the needs of an individual rather than take a one size fits all approach. Maria's carer who also has AMD shares similar sentiments as John:

Doctors' priority should be to provide adequate information for us to understand the condition and treatment options better, that's the process for gaining consent not the signing of the paper. To be honest I found out more from my optician when I was given my diagnosis and I suppose it's because of the relationship we had built up over the years. See I also found out more about side effects from our neighbour who has been having these injections for some time now (Maria's carer 180-189).

This narrative suggests that clinicians were not meeting the patients' information needs at diagnosis. She argues that what she knows about her condition and the treatment side effects she has learnt from other sources, people she has relationships with either professional or social. Literature (Asan, Yu, & Crotty, 2021; Dang, 2017; Turabian, 2019), has shown that when clinicians and patients build good trusting relationships, patients were more likely to be satisfied with information communicated about their diagnosis and treatment, which led to better health outcomes.

Well the same things X1 mentioned to be fair and being given accessible information materials. I am I hoping I could see better with this treatment that's my number one priority (Margo, 193-195).

Margo's narrative below validates the carer's account and highlights her priority to stop further deterioration of their eyesight. A narrative shared by all participants in this study. Outside this priority participants also shared their preferences around the decision making and consent to treatment process and made suggestions:

But the only thing I think could be improved on is the appointment letter. They should state what the appointment is for specifically. Because, I didn't realise I was going for the treatment procedure when I turned up at the hospital after the diagnosis. Besides the font size also needs to be bigger, because not all of us can read that. Or perhaps they could have a telephone service for these kinds of appointments (Maria, 316-324).

Maria's narrative highlights a need for information communicated via letters to be clear about the purpose for the scheduled appointments or procedure. She also makes a suggestion of using alternative communication regards appointments and their aim (e.g. phone system), which would work better for those already struggling to read the letters. As per preferences of participants in study one, Maria also prefers and suggests the font size should be bigger for them to be accessible to AMD patients. The issue highlighted in this study around the quality of the letters sent out to AMD patients corroborates findings from Burton et al.'s (2013) study looking at the lived experience of patients with AMD.

In summary, the decision making to consent to treatment in this study was largely driven by fear of losing their sight and a need to slow down further deterioration of their eyesight as a priority. In a sense a desire to retain a quality of life underpinned by their life contexts. For example, Primrose reported that she didn't want "to go blind and not be able to see my grand children's faces". While some like Roselyn valued their independence. Trust of the clinician, drawing from the concept 'the clinician knows better' and the institution also played a significant part in patients' decision making to consent to treatment. This aggregate dimension of paternalism was a significant finding in our study. More, so in the context of patients putting their trust in clinicians where the decision making to consent process is concerned. A notion corroborated in Halter et al.'s (2017) study that highlighted an interplay between trust and confidence placed on clinicians by older adults and appreciation of the NHS, particularly for those who have lived long enough to understand its importance as a healthcare provider and the strides made over the years. It can be argued here that there were competing priorities exhibited across the patients' narratives. For instance, while the desire was there to understand their condition, learn about other treatment options and associated side effects, the pre-occupation to stop further deterioration of their eyesight became a priority, leading patients to go along with the clinicians' recommendations. This phenomenon goes against the tenets of the decision-making model, which reflects the notion that, when making decisions that involve a degree of uncertainty and apprehension about the treatment procedure, patients require not only information about the range of choice available to them, but also the likely outcomes of each one – good or bad, thus confirming my assertion of competing priorities being at play. Findings from this study, corroborate previous literature (Burton et al., 2013), on AMD patients' lived experiences regards aspects of information provision. Participants preferred for letters to highlight purpose of the appointment, as some had turned up at the clinic only to be informed they would be receiving an injection in the eye, an element that heightened their anxieties. Participants made suggestions to make the font size bigger on the letters, for them to be accessible to AMD patients. This suggestion lends support to findings from study one- Chapter four of this programme of work. Furthermore, participants made suggestions of audio recorded consent as the font size of paper version was difficult for them to access. Use of a telephone system for appointments was also suggested as an alternative for letters, as participants stated this would mitigate against the challenges of having to read an inaccessible letter. Since the ageing process carries profound implications for the health and well-being of older adults. It is safe to infer these preferences and suggestions are necessary in order to meet the information needs of each individual (Saleh, 2004).

4.11 Clinicians' Perspectives

4.11.1 Clinician Perceived- Patient-centeredness information giving:

Providing information in a manner that is responsive to individuals' needs and preferences is key to them understanding their diagnosis, treatment options and prognosis. There was a feeling amongst some of the clinicians that meeting patients' informational needs was also dependent on how involved they are in the diagnostic process. This theme relates to clinicians' perceptions of self and how they position themselves as informants at diagnosis to meet patients' information needs:

"My role as informant is influenced by understanding the needs of each patient at diagnosis and how I interact with them is informed by how well they can understand what I say, either language wise or other factors such as hearing impairments or cognitive challenges" (171-177, Consultant 2).

Drawing from Habermas' communicative rationality, it's imperative for clinicians to fully understand the patient's needs. More so, they need to understand their life contexts and this can only be achieved through an environment that promotes an open dialogue at diagnosis. This consultant's narrative demonstrates an awareness of some of the elements that need to be considered when communicating and providing information at diagnosis to ensure they are meeting the patients' needs. A notion that has also been echoed in the narrative below:

"Each individual is different, so I try to explain to them in detail about the condition in a manner they may understand, using non technical language were possible. It's not always easy, which is why sometimes you have to simplify it and say for instance it's because of wear and tear their eyesight is deteriorating" (30-37, Consultant 1).

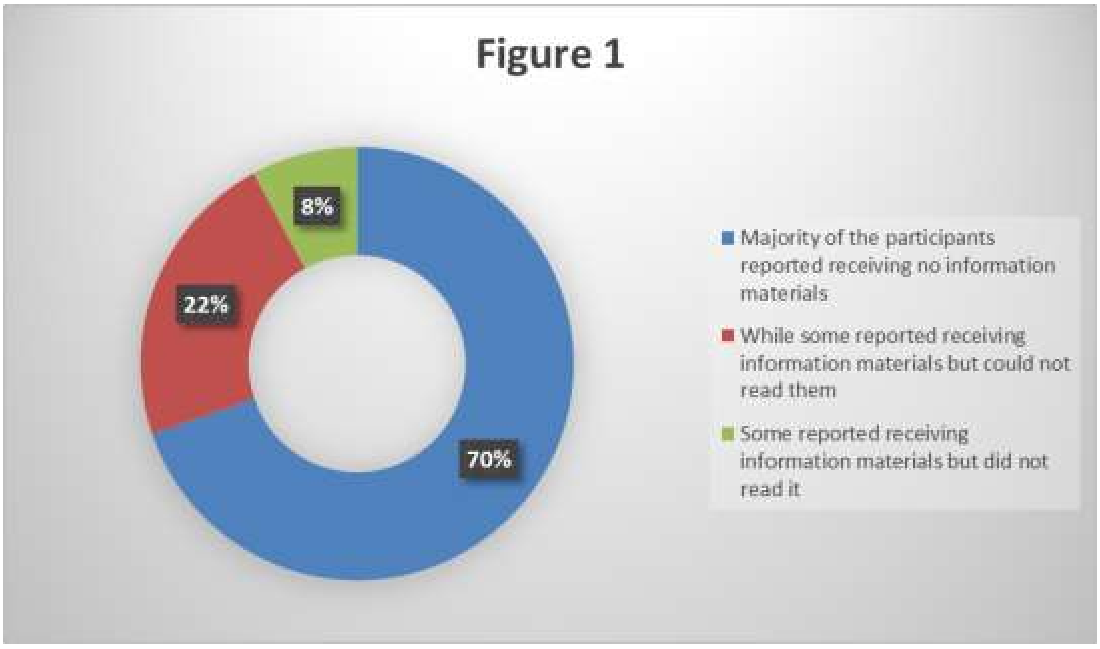
Recognizing diversity in information needs is very important and informs the perceived depth of detail provided. Carey (2006; Renya and Hamilton, 2006) concur and argued that clinicians need to be aware of the differing information needs of each patient, as providing too little or too much information in whatever format can compromise their comprehension during the decision making to consent process. It is important to provide information in multiple formats to optimize understanding:

"Sometimes I tend to give them leaflets about the diagnosis and the treatment options to allow them to read these at their own pace. These are usually the ones from Macular Society. They have given us- books

and leaflets available in the clinic. They help corroborate what we say in the consultation" (30 - 37, Consultant 1).

Take away information materials are used as a tool to corroborate information provided during the diagnostic consultation. Johnson et al. (2003) argued that providing these significantly increased patient's knowledge and satisfaction, as they reinforced verbal information provided by clinicians. A notion Gibbs, Water and George (1989) concurred with suggesting that written materials had a beneficial effect on treatment adherence, and self management (Raynor, et al., 2007). However, while it is important to note clinicians provide these at diagnosis, the narrative tone *"sometimes",* suggests it was not regular practice. This corroborates the descriptive statistics shared in the impact statement below in Figure 1. It can be argued here that more needs to be done to ensure the practice of providing information materials is standard for all patients receiving a diagnosis for the first time.

Figure 1. Impact statement - Following diagnosis, were you given any information materials about the diagnosis, treatment and treatment options?



Having time and opportunity to read and consider information communicated at diagnosis, including treatment options away from the clinic is vital for all patients. Particularly when it comes to making informed decisions and consenting to treatment they may perceive to be most suitable for them. Our findings however, highlighted that at least 70 % of the sample did not receive any information materials at diagnosis:

Oh no, I didn't get any information leaflets, not at all no, …I would have thought that's standard for them [doctors] to provide them and give us an opportunity to perhaps understand a bit more about the condition and type of treatment I am getting (Johnson)

The descriptive statistics provided here in relation to participants in this study, lend evidence to findings from chapter 4, highlighting a gap in the information provision chain and furthermore, brings to the fore issues of accessibility.

Nurses perceived themselves as educators in the matrix of information provision:

"So we give them information, educate, care by being empathetic and compassionate. That means treating each patient as an individual and responding to their needs in a person centered way" (48-52, Nurse 2).

They understand the need to provide information in a sensitive and compassionate manner. This speaks to emotional awareness and adaptability in the context of being empathetic to the individual's confirmed and changed health status.

4.11.2 Sub theme – Emotional awareness and adaptability:

Clinicians were aware that emotional responses may impact on patients being able to fully understand information provided during a diagnostic consultation. As such, this sub theme highlights elements of adaptability which include providing take away information materials, preference for involving family or carers, to a humanistic approach by clinicians - being sensitive and compassionate.

"Another challenge which is understandable is the emotional response experienced of being given a diagnosis, it can impact on them comprehending all the information discussed. You know this group is not young, aging comes with many health problems, from impaired cognitive abilities, hearing problems, mobility issues and so on. So it increases the challenges we have to overcome to ensure we do our job providing information, while being cognizant of these factors" (113-123, Consultant 2).

While emotional responses are highlighted as a potential barrier, clinicians also recognize that the ageing process carries profound implications for the health and well-being of older adults. It is safe to infer that they are typically more challenging to provide information to than younger patients, mainly because of the complexity of comorbid conditions that accumulate with age (Saleh, 2004). As such, there is a constant need for clinicians to adapt to situations as they present drawing from the expertise and emotional intelligence (Carey, 2006). The consultant below concurs and highlights an element of adaptability:

"I suppose the shock for some, of being given a diagnosis can impact understanding or retention of the information we give them regards the diagnosis or treatments, which is why we provide take away information materials for them to read in their own time" (197-202, Consultant 1).

Some clinicians recognize the impact of emotional responses at diagnosis and adapt by providing take away information materials for patients to read and gain a better understanding of information communicated at diagnosis in their own time, away from a clinical environment. They also felt that in some instances it was easier providing information about diagnosis and treatment in the presence of their relatives or carers:

> *"If they have a relative with it makes our life a little bit easier but sometimes it makes it worse that's the difference. Because you might be answering to them and not to the patient, it's all about adapting to the situation and making sure you provide an equitable platform for dialogue that's the difference but having someone else there it's always better in terms of information retention" (219-228, Consultant 1).*

While there is an expressed preference and benefit of having a relative or carer present with regards to information retention it can also be argued here the benefit also extends to emotional support. Literature Boyle (2015), exploring the role of family in patient experiences, concurred with our finding and advanced that family involvement was significantly important where understanding of diagnosis, treatment adherence and management of condition is concerned.

Nurse 1's narrative deconstructs the impact of the patients' disposition regards information retention:

> *"Sometimes the patients are quite nervous and anxious when they're with the consultant and sometimes first time information about diagnosis takes time to sink in so it's more like having to repeat things to them. I explain it in a simpler way and allow them time to process it and offer reassurances were needed. The key thing is showing empathy and being a good listener to their concerns and responding appropriately" (21- 25, 65-73, Nurse 1).*

Nurses adapt a sensitive approach to meet patients' information needs at diagnosis and during the treatment procedure drawing on their communication skills and tenets of their practice domains as advanced by the NMC. Our findings here corroborate findings from a critical review examining evidence of nurses as information providers for cancer patients by Koustopoulou, Papathanassoglou, Katapodi and Patiraki, (2009). They found that nurses were effective as information providers and advanced that they are able to provide information of both high quality and of appropriate quantity and also assisted individuals to interpret information provided by others. More importantly, demonstrating a degree of compassion and care in the process.

The findings presented here, speak to clinicians' awareness of the need to individualize information provision based on patients' life contexts to meet their needs and preferences. They however, recognized for information to be patient centered, they need to create an environment that promotes open dialogue as advanced in Harbermas' views of communicative rationality. Kamimura, Weaver, Armenta, Gull & Ashby's (2019) study on patient centeredness corroborates our findings and advances the need for clinicians to be responsive to patient preferences, needs, values and ensure that all patient values guide clinical decisions. The findings also highlight clinicians' awareness that diagnostic consultations can be emotive for patients impacting on their ability to retain information communicated. Koustopoulou et al.'s (2009) findings highlighted that nurses are effective information providers who have the capability to interpret information provided by others. A notion evident in patients' narratives on their views of nurses in contrast to consultants. As such, it can be argued here that there is a need for consultants and nurses to work collaboratively to ensure patient centeredness is maintained and patients are supported to make an informed decision regards their treatment and care. Evident in this study was also the expressed intermittent provision of information materials by clinicians and perhaps the reluctance by patients given to the materials to read based on either their inaccessibility or just not having time, as highlighted in the impact statement above. There is a need to provide accessible take away information materials as they help patients understand information communicated in the consultation room and aids making informed decision about their treatment and care.

4.11.3 Steering Patients towards the 'Right' Decision:

Providing information that meets patient needs around treatment options, associated side effects and benefits empowers them to make an informed decision to consent to the treatment of choice. Clinicians' priority was premised on providing information around diagnosis, treatment available and ensuring those diagnosed with wet AMD commenced treatment early as per NICE guidelines. This theme captures clinicians' positioning in the decision making process, methods used to gain consent and highlights perceived factors that drove decision making to consent to treatment for patients in this study.

> *"My priority in this role is providing information to ensure patients understand. [] I talk to them about the benefits and the risks because they need to know that. As you know the benefits of these injections are slowing down the degeneration process, and when I tell them about the risks I don't go into too much detail I prefer using statistics or numbers to demonstrate the chances of something going wrong before asking them to give written consent. Usually this works, but of cause some will ask for further information and this depends on their level of understanding" (117-122, 127-136, Consultant 1).*

The clinician's priority in the patient-clinician dyad should rightly be provision of information, transfer of knowledge rather, to ensure patients know what they are consenting to with regards to treatment. There was an expressed preference to use statistics to articulate issues around side effects or potential negative impact on patients being. Conversely, while literature (Climent, 2019; Nusbaum, Douglas, Damus, Orlow, & Estrella-Luna, 2017), suggests this practice is underpinned by an evidence base clinicians should do more to provide information that balances understanding implications from a statistical perspective to experiential. For instance, long term implications for taking treatment.

Incidentally, clinicians also recognize that providing information in its statistical form or otherwise does not necessarily translate to patients understanding as highlighted in the narrative below:

> *"I must admit some patients will consent to treatment not because they have understood what's been communicated to them, but because they are petrified of losing sight. When people get to a certain age in their lives, and their social circle has diminished significantly, add to that the prospect of losing sight, and the potential to buy time or slow down the degeneration with treatment regardless of other potential side effects, most will go with quality of life rather than quantity of life. So from my experience this is a key driver in the treatment decision making process you know. Remember gaining consent is an ethical obligation for us, it's a process that starts with providing information and using all tools like the statistical information on potential risks to information materials. Anything to help them be informed" (59-75, Consultant 1).*

Clinicians acknowledge that most patients' decisions to consent to treatment are driven by fear of losing their eye sight. The element of a shrinking social circle as people age and an evaluation of priorities in the context of their lifeworld, plays a significant part in the grand scheme of decision making. A point so aptly put by this consultant that the focus becomes, "*quality of life rather than quantity of life* ". In this narrative there is an element of demystifying the concept of consent as just a single bureaucratic event, but rather highlighting it as a process that involves providing information about diagnosis, treatment benefits and associated risks and prognosis. It can be argued here that on the whole, take away information materials are an essential element of the consent process (Tam et al., 2015).

In some instances, clinicians take on the advisory role in the decision making to consent process:

> *"We tend to help patients make the decision to start on treatment ASAP. Sometimes patients just go along with what we say without understanding information provided. It's them trusting and putting faith in us as medical experts" (166-170, Consultant 2).*

Clinicians play an important role imparting advice on the need and benefits of starting treatments early, as recommended by the NICE guidelines. However, they acknowledge in this narrative often times patients absorb the advice without necessarily understanding it and the decision to consent is driven trusting the clinician as an expert. Involving family or carers in the process follows the tenets a collaborative encouraged within healthcare:

> *"I feel it's easier to give information about diagnosis and treatment when they bring in their partner, carer or any family member. Even when it comes to the treatment decision and consenting its easier, because they can discuss and seek clarification" (104-110, Consultant 2).*

This narrative speaks to shared decision making by involving people close to the patients in the process. An element highlighted in the theme above as significantly important, as family can support in the decision making and consent process. Providing reassurance and validating concerns where appropriate with the expert's guidance (Boyle, 2015). In the narrative below, the clinician deconstructs the diagnostic consultation as a shared environment where information is exchanged in the context of decision making to consent:

> *"Remember, a consultation is a dialogue between ourselves and the patients, an exchange of information if you will, and the ultimate decision to go ahead with treatment lies with the patient, with myself providing relevant information for them to be able to make those decisions. That's empowering the patient, though sometimes you get patients that will leave you to make decisions for them because as you said earlier they believe we know better. If that happens our decisions are driven by best interest for the patient more than anything else, or in some instances it can be a shared decision based on information exchanged" (253-268, Consultant 1).*

It demonstrates a flexible approach in terms of positioning for clinicians in the decision making matrix, where it is acknowledged that the ultimate decision to consent to treatment rests with the patient. However, there is also room for the advisory role underpinned by best interest to dominate the conversation to negotiate and reach a shared decision with the patient to consent to treatment that slows down degeneration of their eyes. This finding corroborates Alderson (1988) views on the decision making and consenting, clinician and patient positioning. She further argues from a critical theory of consent perspective that the consent process is not a one-way information provision exercise, but an exchange of knowledge in the clinician-help patient dyad, to facilitate shared decision making (Xuereb et al., 2016).

In summary, narratives from clinicians showed that their priority was to provide information to patients relating to their diagnosis and available treatment options. They believed this transfer of knowledge was key to empowering and subsequently helped patients make a decision to consent to treatment. However, they acknowledged that communicating information around treatment options, benefits and side effects does not necessarily translate to patients understanding to consent. Clinicians were fully aware of the factors that influenced decision making to consent to treatment for some patients. These included trust in the expert and the institution they represented, fear of losing the eyesight, maintaining independence and quality of life rather than quantity of life. Some clinicians stated that where patients were reluctant to consent, they found themselves defaulting to their expert advice giving mode and encouraged them in arriving at a shared decision around treatment. Our findings corroborate literature across the research landscape exploring decision making and consent processes (Bloom, 2005; Coulter et al., 2006; Paley, 2002; Princeton, 2015; Xuereb et al., 2016).

Clinicians in this study also highlighted that there is currently only one method of gaining consent from patients in the clinic, which is the written format an issue they recognized a systemic challenge.

4.11.4 Working Through the Systemic Challenges:

Clinicians were aware there was a need to improve their practice and find better ways to provide information about AMD and its treatment to patients. Thus, this theme captures the systemic structural elements perceived as potential barriers to patients' fully comprehending information provided during the diagnostic consultation, impact on decision making and patients overall experiences. Some of these elements include the method used to gain consent using an inaccessible form, time and room set-up:

"Our set up here is quite good from a medical point of view particularly, this fast track macular degeneration clinic. There are only a few structural issues here and there. For instance, space can be tricky for wheelchair bound patients and the fact that we don't high ceiling means if they were other people using the rooms next door they could hear what is discussed in here. But nonetheless I think it's running as well as it should" (278-288, Consultant 1).

This narrative highlights an issue around accessibility for disabled individuals who use wheelchairs and also highlights an issue around maintaining confidentiality due to the structural design of the consultation rooms. The struggle for wheelchair bound patients to negotiate their way into some of the consultation rooms can be anxiety triggering which can subsequently impact information acquisition for patients. It is a legislative principle (e.g. The Equality Act, 2010) for the clinic which provides services to individuals with a disability such as those in a wheelchair who are also sight impaired with accessible rooms and formats of information materials (Hardisty, 2008).

Clinicians did not see any issues with the number of patients seen in the clinic:

"We see about 7 patients each, I can't fault that at all but sometimes Clinics are busy so they might be a delay. [] Sometimes it can feel that way for them, because it's never easy receiving a diagnosis we perhaps need to improve on our interpersonal skills to ensure we fully address patient concerns at diagnosis" (278-280,293-296, Consultant 2).

However, clinicians reluctantly acknowledged that potential delays in the clinic could have a knock on effect to issues around time spent with a patient during the diagnostic consultation. There is also acknowledgement they may need to improve how they relate to patients. It can be argued here that improving issues around time and how they relate to patients can improve participation, experiential satisfaction of the diagnostic consultation (Ranjan, Kumari & Chakrawarty, 2015) and understanding of the information communicated (Kee & Koh, 2018). Presseau, Sniehotta & Campbell (2009) examined multiple goals and time constraints and their perceived impact on clinicians' behaviours and found that time constraints had an interfering influence on their behaviours during consultations. This finding corroborates with our study's finding in particular how patients perceived clinicians behaviours in the context of their interactive disposition. An element that further highlighted by nurse's view of consultants as informants:

"Well to be honest I wish consultants would try and be as caring as nurses and just explain things in a simpler manner. If we can do it, it means it's possible for them to do that for this group. That's what I would prefer for them to keep things simple. My priority is advocating for my patient, creating a safe, caring and welcoming environment for the patient. Offering reassurances pre-treatment and educating the patient on self-care after the procedure to avoid infections into the eye" (77-87, Nurse 1).

This narrative highlights differing perspectives of how information should be provided to patients. It almost portrays consultants as rigid in approach lacking the interpersonal skills and empathy to provide information in a manner that meets the need of the patient. It asks: if we can do it, why can't they? It highlights a contrasting style of practice in which the nurses want consultants to espouse compassion related tenets when communicating with patients. In essence the nurse's preference is for the consultants to become relatable and provide patients with easy to understand information. This narrative provides an insight into nurse's priorities, educating, promoting good self care, care and safety. Our findings here are consistent with literature (Koustopoulou et al., 2009), highlighting nurses' strengths in providing information. Conversely, consultants in this study acknowledged their weaknesses as informants and expressed an openness to receiving pertinent training to improve their interpersonal skills and practice:

Yes, definitely. Training is always welcome, I am sure there are some patients who are not happy with how we conduct ourselves during the consultation (310- 313, Consultant 2).

Ranjan et al.'s (2015) study focusing on how doctors can improve their interpersonal skills showed that regular training was key to developing and maintaining these skills. They argued these skills improved patients understanding, decision making, treatment compliance and overall satisfaction with the dialogue. However, information provided needed to be corroborated with accessible information materials including providing consent forms that meet their visual status (Hardisty, 2008). In our study clinicians unanimously agreed that the current method to gain consent may not be accessible to the majority of patients:

"I think for this group we could use audio consent, but at the minute we are using the forms you mentioned to gain written consent []. The font is not that user friendly for the group. The audio format would circumvent issues of writing on a line they may not see. However, this is out of my hands" (363-364, 368-372, Consultant2).

The narrative suggests that while they maybe other ways of gaining consent, clinicians could not effect the change to facilitate alternative formats. This was recognized as a systemic issue that would require the involvement of relevant stakeholders within the hospital to sanction the changes. The health foundation report dubbed "what's getting in the way?", barriers to improvement in the NHS (2015), argued that due to organizational factors financial or otherwise it was difficult to make immediate changes within the NHS. This is perhaps validated by the consultant's statement, "*this is out of my hands"*, with an implied sense these discussions have been had before.

In summary, clinicians' narratives acknowledged there were systemic constraints that had the potential to impact patients' overall experiences in the clinic. These ranged from delays, time constraints, method used to gain consent and set-up or the rooms. Despite these constraints clinicians adjusted to the environment and continued with their mandate as expert informants, providing diagnostic and treatment related information to patients. This was validated by Consultant 1's statement "*Our set up here is quite good from a medical point of view particularly, this fast track macular degeneration clinic".* However, as observed changes and improvements are needed, particularly accessibility to the rooms for wheelchair bound patients. Legislation (Equality Act), policy initiatives such as; "Better information, better choices, better health: putting information at the centre of health" (Department of Health, 2007) have highlighted the need to adapt environments and aspects of information provision to ensure patients' needs are met.

Impact statement - key areas identified for improvement

Diagnosis- Clinicians need to provide information in a manner that is responsive to each individual's life contexts, preferences and needs and also be culturally and linguistically competent.
Informed decision making – clinicians should find ways of ensuring patients understand information on treatment options, benefits and associated side effects. To check for understanding using tools such as, teach back to ensure they are consenting to treatment of their choice from an informed perspective.
Practical support and information – clinicians should provide patients with information that helps them manage their condition over time following diagnosis e.g. (diet and life style change, understanding signs of further deterioration and where to access visual aid devices if needed). They should also sign post them to support groups for information consolidation from shared experiences.
Structural improvements - there is (a) a need to have spaces that are wheelchair friendly, (b) use rooms where confidentiality is not compromised –as current setup people in rooms next door can hear conversations, (c) improve the written consent forms to meet the visual status of AMD patients or offer alternative formats and give choice to patients making decisions about their treatment and care.

4.11.5 Eye Clinic Experiences

Overall, patients were aware once they consented to treatment they would be seen regularly, initially for the first three months and the treatments would be on going for some time commensurate with assessments in the clinic. The dissatisfaction was mainly around clinicians' interactive disposition at diagnosis and perceived lack of meaningful discussion around treatment options, benefits and associated side effects. Clinicians on the other hand perceived the clinic to be running as smoothly as intended for a fast track clinic. However, they acknowledged certain things could be improved in terms of their practice and were aware patients may have a different view of their conduct and thus were open to the idea of engaging in training to enhance their interpersonal skills. There was a recognition that there was a need for alternative methods of gaining consent as the current method was inaccessible to AMD patients due to the font size used.

4.12 Discussion

This study's design enabled us to gain in depth multi-perspective insights into patients' and clinicians' experiences of and views on information provision during AMD diagnostic consultations. A critical narrative analysis of participants' accounts generated synthesised meaning-led descriptions of parts of the phenomenon as experienced by patients and clinicians at diagnosis (Mishler, 1984), and discussions of treatment options that led to decision making to consent to treatment. The implicit priority for the patients was to get diagnosis of the presenting symptoms confirmed and understand what this meant in their life contexts. There was an explicit focus on trying to understand the diagnosis, treatment available and prognosis. However, there was an expressed frustration across their narratives that these information needs were not adequately met. Thus, consent was not necessarily a negotiated phenomenon premised on knowledge transfer by clinicians, but rather driven by elements such as, fear of losing their sight and independence, quality of life related contexts e.g. seeing grandchildren's faces, rather than quantity of life, trust in the clinicians' suggestions, rather than understanding of the suggestions.

Clinicians' priorities were explicitly premised on providing adequate information to patients about their diagnosis and treatment options and prognosis. They were focused on knowledge transfer. However, they acknowledged barriers such as emotional responses to the diagnosis impacted understanding and retention of information provided. Clinicians' perceived consent as a process rather than an event in which patients use information provided to reach a decision about their treatment and care. They however, acknowledged patients did not always consent because they understood information provided and they corroborated factors stated above as drivers for consent. There was an implied sense that consent was negotiated based on the advisory information provided converging with patients' priorities regards self with AMD. Seven synthesised superordinate themes and one sub-theme emerged that represent patients' (four) and clinicians' (three) perceptions and experiences of information provision at diagnosis, decision making and consent process. For the patients these were; (a) Impact of emotions on processing information at diagnosis; (b) Diagnostic engagement: the unmet needs; (c) the decision maker – 'navigating' towards consenting to treatment; (d) Language as a barrier to understanding diagnosis. For the clinicians these were; (a) Clinician perceived- Patient-centeredness information giving, with a sub theme, emotional awareness and adaptability; (b) steering patients towards the 'right' decision; (c) Working through systemic barriers.

Patients' narratives highlighted that emotional responses at diagnosis had impacted on their ability to fully comprehend information provided. Studies (Sharp, et al., 1992; Aminzadeh, Byszewski, Molnar, & Eisner, 2007), corroborate our findings arguing that emotions had significant implications on patients' ability to fully process the information provided, let alone evaluate it to make an informed decision to consent to treatment. Loftus and Burns (1982) reported that experiencing strong negative emotions can significantly disrupt one's memory, and it is generally assumed that patients will struggle retaining information provided under the stress of a diagnostic consultation (Scott, 1983; van der Molen, 1999). It can therefore be argued here that clinicians adapt methods of communicating that respond to such situations to ensure patients understand key issues about their diagnosis and treatment. For instance, using easy to understand language (e.g. minimal use of medical jargon), providing take away information materials and keep it as brief as possible to avoid overwhelming the patient with information, as patient education at this point maybe ineffective, as demonstrated in research focusing on information provision of a cancer diagnosis (e.g. Carlsson & Strang, 1998; Rodriguez-Man, Lopez-Roig & Pastor, 1996). Clinicians in this study demonstrated an awareness of the impact emotional responses had on patients and adapted some of the elements mentioned above. They expressed a preference for family presence at diagnosis as it eased the burden on the patient and posited that to a large extent information provided could also be retained by family to discuss with the patient in the comfort of their home. This finding is corroborated by Boyle (2015), whose study explored the role of family in patient experiences of healthcare encounters and highlighted that their involvement was significantly important where understanding of diagnosis, treatment adherence and management of condition over time is concerned. Given that emotional responses have an impact on information acquisition and retention, it can be argued here that these patients can benefit from future educational sessions, particularly as they continue to access the clinic for treatment (Lane et al., 2015a).

Clinicians perceived themselves as patient-centred information providers. Their narratives highlighted an awareness to individualize information provided based on patients' life contexts to meet their needs and preferences. They however, recognized for information to be patient centred, they needed to facilitate an environment that promoted open dialogue as advanced in Harbermas' concept of communicative rationality. A notion advanced by clinical guidelines that advocate for the inclusion of patient values and preferences in the diagnosis and decisions relating to treatment (NICE, 2014; Camm et al., 2012). Clinicians in our study acknowledged that patients may have a different perception of the conduct as informants and expressed a keenness to hear the other side in order to improve their practice. Kamimura, Weaver, Armenta, Gull & Ashby's (2019) generic study on patient centeredness lends evidence to our findings and advances the need for clinicians to be responsive to patient preferences, needs, values and ensure that all patient values guide clinical decisions. Coincidentally, as clinicians suspected, patients had a different view and experiences of clinicians as informants and expressed unmet needs during the diagnostic engagement. This was largely due to the perceived interactive disposition of clinicians. In particular, their lack of warmth in how they related to them, and perceived lack of meaningful discussion about the condition, treatment options, side effects, prognosis and having questions not answered satisfactorily.

Findings from our study corroborate literature focusing on older adults living with chronic illnesses including AMD (Breemharr et al., 1990; Irish, 1997; Burton et al., 2013; Thetford et al., 2015; Varano, et al., 2015), which reported similar results where patients and clinicians attached different meanings to their experiences of the diagnostic event. Given these findings, it can be argued here that patients evaluate information provided based on both verbal and non verbal communication style of the clinician providing the diagnostic and treatment information. A notion Svenacus (2000), concurs with and advanced that how clinicians speak (not just what they say) creates an impression, such as those highlighted in this present study. Hence, clinicians have the responsibility to manage not only the information they provide, but also the patient's impressions during the communication process given that pertinent information around diagnosis is being discussed (Svenacus, 2000).

Roter et al. (1997; Deveugele, Derese & De Maeseneer, 2002) argued that clinicians can manage these communication expectations by including social talk to make patients feel at ease in the interaction and be active participants. This argument is consistent with findings from our study regards nurses, whom patients could relate to more and observed them to be better communicators and providers of information. A notion corroborated by Koustopoulou, et al. 's (2009) study focusing on nurses as information providers. They found that nurses were effective as information providers and advanced that they are able to provide information of both high quality and of appropriate quantity and also assisted individuals to interpret information provided by others. More importantly, demonstrating a degree of compassion and care in the process, an element that was evident in both patients' and nurses' narratives.

Patients perceived language to be a barrier at diagnosis. This finding reflects how they assigned different meanings to the same content or context and how language used can impact the understanding of a diagnosis and treatment discussed. It can be argued here that words do matter and contribute towards context and meaning one perceives and ascribes to them, particularly when words like ”wear and tear”, are used loosely in the context of a diagnosis. This could potentially have psychological implications associated with self blame and impact management of condition over time. As such, Deveugele et al. (2002), argued that clinicians needed to be mindful of the language they used when providing diagnostic and treatment related information as this had a bearing on patient understanding. Our findings are consistent with Varano et al. ’s (2015) generic study of older patients and the use of complex terminology in a medical encounter. They found that the use of complex medical language was a notable barrier to older patients fully understanding of their diagnosis and treatment, which had an implication on recall (Safeer & Keenan, 2005; Watson & McKinstry, 2009) and impacted informed consent to treatment (Varano et al., (2015). Patients’ narratives in our study further highlighted that nurses used language that they understood and this helped. This is consistent with Koustopoulou et al.’s (2009) assertions that nurses could interpret information provided by others in a manner that met the individual’s needs.

An important goal of providing adequate information during the diagnostic consultation is to transfer knowledge to patients and enable them to make an informed decision to consent to treatment of their choice. This suggests consenting is not just signing of a paper, but rather a process negotiated and premised on adequate information provision by clinicians and retention and understanding of that information by patients. This was evident in our study findings which highlighted patients’ and clinicians’ positioning and their differing priorities in the decision making to consent process. Clinicians adopted a flexible approach in terms of positioning in the decision making matrix, as advisor and acknowledged that the ultimate decision to consent to treatment rested with the patient. A notion Walseth & Schei (2011: 81), concurred with arguing healthcare consultations should put patients at the centre of everything. For clinicians, an advisory role was influenced by best interest to dominate the conversation and negotiate to reach a shared decision with the patient to consent to the treatment that slowed down degeneration of their eyes given as soon as possible as per recommendation by NICE guidelines. As such, clinicians’ key priority was to exchange and transfer knowledge to enable patients to make a decision to consent to treatment.

This is consistent with Alderson’s (1988) argument from a critical theory of consent perspective that the consent process is not a one-way information provision exercise, but an exchange of knowledge in the clinician-patient dyad, to facilitate shared decision making for the patient to consent to treatment (Xuereb et al., 2016). Clinicians’ narratives also highlighted that patients did not consent to treatment because they understood the information provided but rather did so out of fear of losing sight, need to maintain independence, and quality of life commensurate with their life contexts. Patients narratives across the study acknowledged this notion and expressed that their priority was slowing down the degeneration. In a sense a desire to retain a quality of life underpinned by their life contexts. For example, Primrose reported that she didn't want "to go blind and not be able to see my grand children's faces". While some like Roselyn valued their independence. Trust of the clinician, drawing from the concept 'the clinician knows better' and the institution also played a significant part in patients' decision making to consent to treatment. This aggregate dimension of paternalism was a significant finding in our study. More so in the context of patients putting their trust in clinicians where the decision making to consent process is concerned. Halter et al.'s (2017)'s also reported similar findings and argued that older adults trust in clinicians was also linked to their trust and confidence in health institutions such as the NHS.

It can be argued here that there where competing priorities exhibited across the patients' narratives. For instance, while the desire was there to understand their condition, learn about other treatment options and associated side effects, the pre-occupation to stop further deterioration of their eyesight became a priority, leading patients to go along with the clinicians' recommendations. A phenomenon that this goes against the tenets of the decision-making model, which reflects the notion that, when making decisions that involve a degree of uncertainty and apprehension about the treatment procedure, patients require not only information about the range of choice available to them, but also the likely outcomes of each one – good or bad, thus confirming my assertion of competing priorities being at play.

Our study showed that clinicians were aware there was a need to improve their practice and find better ways to provide information about AMD and its treatment to patients. Key to this practice were systemic constraints that needed to be addressed. For instance, making the consent form more accessible and perhaps using alternative formats e.g. audio to increase the methods used for gaining consent and addressing the structural issues that impact wheelchair bound patients. However, there was an expressed sense of powerlessness to effect some of the changes required, *"this is out of my hands",* implying these discussions may have happened before. This finding is consistent with elements identified in The health foundation report dubbed "what's getting in the way?", barriers to improvement in the NHS (2015), which advanced that due to organizational factors, financial or otherwise it was difficult to make immediate changes within the NHS. Despite these constraints clinicians adjusted to the environment and continued with their mandate as expert informants, providing diagnostic and treatment related information to patients. This was validated by Consultant 1's narrative *"Our set up here is quite good from a medical point of view particularly, this fast track macular degeneration clinic"*. However, changes and improvements are needed, particularly accessibility to the rooms for wheelchair bound patients. Legislation (Equality Act), policy initiatives such as; "Better information, better choices, better health: putting information at the centre of health" (Department of Health, 2007) have highlighted the need to adapt environments to and aspects of information provision to ensure patients' needs and preferences are met. Patients' narratives also highlighted time as a systemic constraint that also impacted on any meaningful dialogue with the clinicians *"I just felt she rushed".* This finding corroborates some of the elements identified in Borg Xuereb et al.'s (2015) study on experiences of atrial fibrillation consultations.

4.13 Strengths and Limitations

This study had a number of strengths and limitations. A significant strength of this study is the research strategy which allowed collaboration between the researcher and the working group. They helped shape the study, and development of the interview questions. As far as we are aware this is the first study to report of the characteristics of the patient-clinician dyad in relation to the AMD diagnostic consultation, decision making and consenting to treatment, including establishing methods utilized to gain consent. This in depth qualitative study draws attention to and deepens our understanding of the processes or factors that can be involved or influence the decision making process to consent to treatment. The use of non-participation observation alongside semi structured interviews enabled us to validate both clinician and patient accounts against what was observed. Taking a critical narrative approach to this research study has enabled in-depth analyses of the meanings patients and clinicians attach to their experiences and has prioritised the narratives of how the phenomenon of the diagnostic consultation, decision making and consenting appears to them. It can be argued in analytical conclusion that a diagnostic a consultation should constitute an open environment that facilitates a two-way dialogue, where issues pertinent to the patients are prioritised. This should involve a collaborative consideration of options, where clinicians take into account patients' life contexts, and patients actively participate and feel genuinely confident to make an informed decision (Habermas, 1984; Walseth & Scheis, 2011). The findings also corroborate those highlighted in our previous study relating to clinicians' interpersonal skills and issues around inconsistent practices of providing takeaway information materials at diagnosis. This study contributes to an under- researched area providing scope for understanding multi-perspective insights of the diagnostic consultation, decision making and consenting process. Patient participants where all Caucasians and all clinician participants where ethnic minorities. However, while there was element of diversity, the findings may not be generalizable to other ethnic groups culturally on either side. Future studies may need to recruit a more diverse group balance on either side and perhaps adopt different positions to the unit of analysis and by exploring this phenomenon using different interpretative set of lenses (Frost, 2011). Furthermore, all participants were recruited from one sight in the West Midlands, which perhaps limits the scope of generalisability. It's recommended that further applied research in this are using recordings of consultation and interviews following them will deepen our understanding of what happens in the consultations, the experiences and the meanings individuals attach to this phenomenon.

4.14 Implications for Practice

Fundamental issues related to the provision of information and clinicians' interactive disposition were identified in this study. As such, there is a need for clinicians to broaden the content within consultations and shifting the focus to patients' life contexts. In a sense, provide information in a manner that is responsive to the patient's preferences, needs values, and ensure these values guide clinical decisions. Emotional responses were highlighted as a barrier for information acquisition, thus clinicians need to adapt multifaceted interventions for information provision, that include teach back- to check what they have understood and involve family or carers where possible to optimise information acquisition. Furthermore, there is a need to create an environment that supports genuine patient involvement, as this aids better understanding of diagnosis, treatment, and fosters participatory decision-making to consent to treatment of their choice and care, in light of the highlighted issues around clinicians' poor interactive disposition. It is therefore, imperative they attend regular training to improve their interpersonal skills.

4.15 Conclusion

This study's design enabled us to gain in depth multi-perspective insights into patients' and clinicians' experiences of and views on information provision during AMD diagnostic consultations. A critical narrative analysis of participants' accounts generated synthesised meaning-led descriptions of parts of the phenomenon as experienced by patients and clinicians at diagnosis, and discussions of treatment options that led to decision making to consent to treatment. Findings highlight the need for clinicians to create an environment that facilitates a two way dialogue that permits patients to actively participate in the decision making to consent to treatment. Drawing on Habermas' communicative theory, inclusion of three dimensions – the objective, social and subjective worlds – within a consultation would ensure discussions include medical evidence but also the life context for patients to ensure consent to treatment decisions are not fear driven, but informed by understanding of the knowledge transferred and right for them. Collaboratively working and using nurses as part of the multifaceted process for information provision, including teach back, and accessible information materials may help improve patient engagement, and understanding of diagnosis, treatment and foster active participation in the decision making to consent process. Furthermore, clinicians may benefit from training programmes designed to improve their relational skills to optimize relationships with patients and improves their understanding of communicated information at diagnosis.

The next chapter will explore the perceptions of first time attenders to and AMD support group in-depth in order to better communicate their value to non-attenders.

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CHAPTER FIVE: Living with Age-related Macular Degeneration: Perceptions and Experiences of First Time Attenders to Support Groups

5 Introduction

Vision offers the most dominant method for recognising and processing information to meet the needs of individuals on a day to day basis. Thus, loss of it can significantly impact all spheres of an individual's life (Loh & Ogle, 2004). Particularly, for those without a stable support network in place (e.g. family, friends, and peers). The functional limitations visual impairments such as AMD impose on individuals may lead to issues relating to social isolation and loneliness (Brennan et al., 2011; Crews & Campbell, 2001), depression (Banerjee, Kumar, Kulhara, & Gupta, 2008), concerns around illness disclosure and difficulties interacting with healthcare professionals (Bennion, Shaw & Gibson, 2012). Furthermore, the inability to recognise faces or indeed facial cues can impact negatively on their primary means of social interaction, as it limits their ability to use visual feedback in relation to their life world, thereby placing them at an increased risk of cognitive decline (Zunzunegui, Alvarado, Del Ser, & Otero, 2003), disability (Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005) and may also impact on their self – esteem, self –efficacy, which resulted in feelings of losing control (Lesko, Ostroff & Smith, 1991), and the need for identity re-evaluation as articulated by Bury (1982). Conversely, accessing support groups for individuals living with a chronic illness has been shown to ameliorate, distress and negative feelings associated with the diagnosis, resulting in better adjustment to, management of condition and psychological well-being (Chang & Schaller, 2000; Hoeck et al. 2017; Newell, Sanson-Fisher & Savolainen, 2002; Pryce, Moutela, Bunker and Shaw, 2019).

The premise of support groups is help individuals adjust, cope and manage living well with chronic health conditions such as AMD. These groups may be led by peers or professionals, organized by charities, health service providers, or lay groups (Pryce et al. 2019). Third sector organizations (e.g. Macular Society or RNIB) provide a range of interventions for AMD, including befriending and support groups (Henry et al. 2009). These support groups provide opportunities for information-giving and mutual sharing of experiences (Dibb & Yardley, 2006; Doherty 2004; Henry et al., 2009), mutual connections (Hoeck et al. 2017; Ussher, Kirsten, Butow & Sandoval, 2006), and using information given or shared to develop own strategies to cope and manage living with the condition (Dibb & Yardley, 2006). The benefits of support groups are vast as highlighted above and these are thought to arise from the opportunity to clarify appraisals of the health threat by making comparisons with other people who share the same condition. Scholars Birk et al., (2004; Dahlin-Ivanoff et al., 1998; Draucker,

1991) argued that making social comparisons for group attendees had the potential to improve coping abilities. Similarly, mutual sharing of experiences and support from peers in the group improved coping and management of condition (Birk et al., 2004; Dibb & Yardley, 2006; Van Zandt, Van Zandt & Wang, 1994). Previous qualitative explorations of older people with visual impairments such as AMD used interviews to gain an understanding of the effects of participation in peer support groups for this group. Their study findings highlighted that those who participated in support groups felt they were successful in coping with their visual loss, were satisfied with their level of activities, and generally had a positive outlook on life (Van Zandt, Van Zandt & Wang, 1994).

Studies (e.g. Reinhardt, 2001b) have shown that when practical support and emotional support are offered and provided to older adults particularly in support groups settings, it resulted in greater life satisfaction and less psychological disturbances (Kozora, Ellison and Waxmonsky, 2005). A notion that Mazzoni and Cicognani (2005) concurred with and argued that support groups not only had a predictive role of improving these individuals' psychological and physical well-being, by managing their condition better over time. Accessing support groups has value in the sense that individuals' access practical support - information about specific elements relating to their condition, become adequately informed about how the condition impacts their health and lives and learn to co-exist with it. Dennis (2003) concurred with this notion by arguing that support groups provided emotional, appraisal and informational assistance for peers and were usually facilitated by individuals with a wealth of experiential knowledge of the condition, the stressors, and associated characteristics of living with the AMD. He also argued that support groups had the potential to build an individual's social identity, infuse a sense of belonging, hope and drive to co-exist with the altered self. Studies (e.g. Reinhardt, 1996; Reinhardt, Boerner & Benn, 2003) showed that the needs of visually impaired older adults and those who were not, are similar in terms of support and information that helps them feel as part of the community, alleviate feelings of social isolation and manage living a fulfilling life within their respective environments. Van Zandt, Pearl, Van Zandt et al., (1994) concurred and argued that support groups were a vital source for information for older adults with visual impairments, in terms of shared experiences and were meaningful friendships developed (Reinhardt, 1996; Reinhardt, Boerner & Benn, 2003).

Other generic studies (e.g. Mazzoni & Cicognani, 2011; Patel et al, 2005; Zhang, Zhang, Aleong & Thomson, 2011) have also demonstrated the significance of attending support groups, in coping, adjusting, complying with treatments and self-management for people diagnosed and living with a chronic condition. In psychology this concept of using others' experiences as a coping strategy is known as, social comparison (Birk et al., 2004; Dahlin-Ivanoff et al., 1998). Draucker (1991) argued that in most instances people diagnosed with a chronic illness often made down ward comparisons when in a support group as a way of coping, adjusting and to subsequently manage their illness. In other words, downward comparison for these individuals embodies a way of coping with the illness activity and its social consequences (Repping-Wuts et al., 2008). As such, it can be argued here that accessing support and support groups is a significantly important phase in the lives of people diagnosed and living with AMD, particularly where understanding of treatments and lack thereof, coping and managing the condition is concerned.

However, while the benefits of accessing and support groups are vast as highlighted above, various studies have (e.g. Sarason et al., 1987; Ruehlman & Karoly, 1991; Chang & Schaller, 2000; Cimarolli & Boerner, 2005) highlighted elements relating to negative aspects or barriers of support groups that include; negative forms of behaviours, such as criticism, hostility, and insensitivity. Goll (2014) in her study exploring the barriers to social participation in support groups for lonely older adults found that older adults refrained from joining support and social groups because they believed the opportunities therein did not support preferred aspects of their identities. These preferred identities related to roles and interests they had developed within social and occupational arenas over time (Goll, 2014). For example, some individuals may not see the benefits of joining a group that does not share their previously acquired interests, such as going for walks, regardless of ailments. Some participants reported not needing support groups on the basis that it validated their status (e.g. disabled) (Goll, 2014). Because of old age and visual impairment, studies (e.g. Ivers, Cumming, Mitchel & Attebo, 1998) argued that fear (e.g. perceived restriction) and experiences of falling impacted negatively on older adults' willingness to engage in physical and social groups or activities (e.g. going for walks, driving), thus adversely impacting on their chances of acquiring useful information, quality of life, and independence (Scott, Smiddy, Schiffman, Feuer, & Pappas, 1999). Perhaps it can be argued from a social selective viewpoint (Carstensen, 2006) that some older adults, including those with AMD, value and invest more in close relationships (e.g. family, friends) rather than support groups because of the limited future time in older old age they have. Other barriers highlighted in literature that impeded access to support groups for older adults with a chronic illness such as AMD was the lack of awareness. Burton et al. (2013)'s study exploring lived experiences of this group highlighted information deficiencies across multiple dimensions of these individuals' lives. They argued these deficiencies impacted on their ability to access needed support and this had a subsequent effect on their quality of life. Brody et al., (2001; Owsley et al., 2006) concurred and argued that this impacted on individuals ability to function competently as social being which usually led to social isolation (Owsley et al., 2006).

5.1 Rationale for Study

Given the information deficiencies highlighted in Burton et al.' s study, our study sought to explore the perceptions and experiences of first time attenders to AMD support groups. To the best of our knowledge, no previous study has specifically focused on this group with regards to this phenomenon. For this study, the idea was to gain an in-depth understanding from the perspective of first attenders of their expectations of and motivations to attend and establish factors that would encourage regular attendance beyond the study. It is hoped that the findings will enhance the understanding of first time attenders' views of support groups. It is also anticipated that the findings may provide useful information for organisers, third sector organisations, and health care professionals around building alliances and collaborating to raise awareness and profile of AMD support groups and help increase traffic to these groups.

What are patients' views on engaging with organised support groups?

How can we boost attendance at the organised support groups?

5.2 Aims

To explore patients perceptions of support groups in depth in order to better communicate their value to non attenders.

To develop ways of incorporating better information provision and raising awareness of support groups in local NHS settings.

5.3 Methods

5.3.1 Context

Support groups can be an important source of practical information and emotional support for individuals living with AMD, as well as a means of establishing new social connections. There a number of support groups across the West Midlands run by various organisations including, Birmingham Focus, RNIB, and Macular Society, that provide accessible peer support for individuals living with AMD. Information and support are vital tools in empowering individuals diagnosed and living with AMD to take steps to access the support they need to manage living with the condition as well as maintaining a good quality of life. However, access to support groups has in some studies been reported as patchy at best and this is largely down to information deficiencies at diagnosis or throughout individuals' journey with AMD (Burton et al., 2013; Thetford et al., 2015).

This study was specifically looking at exploring perceptions of individuals diagnosed and living with AMD of support groups in order to raise awareness and better communicate their value to non attenders. As such, a two step approach was employed to address the aims of this study. The first approach was observing the interactive disposition of first time attenders in a support group setting and the second approach was sitting down with the individuals for a semi structured interview to gain insights of their experiences and their views of the group e.g. value, benefits. Aspers (2004), argued that observation, demographic data and interviews are the key data collection methods within qualitative studies and are particularly effective at bringing to the fore the participant's story from their own perspective, and therefore challenging structural or normative assumptions (Lester, 1999). These 2 data collection methods where duly deployed in this study as they present an opportunity for understanding in depth the views of first time attenders to AMD support groups.

5.4 Study Design

This study used a qualitative case study design, underpinned by an interprevitist perspective (Crotty, 1998) to understand AMD diagnosed first time attenders to support groups' views in order to better communicate their value to non attenders. Justification for using a qualitative approach has been duly discussed in Chapter three. As such, I will use this section to provide justification for using a case study design. It has a number of specific advantages that respond to the aims of this study. For instance, its key characteristic is using multiple sources of evidence (Gillham, 2000), and its flexibility allows for multiple data collection methods as highlighted in the section above. Using directly observed behaviours, demographic data and interviews, can produce robustly evidenced understanding of first time attenders' views of support groups. Focusing on a relatively small number of cases studies can help facilitate the construction of an in-depth understanding of the attendees' perceptions of AMD support groups. In other words they can enable research to focus on the significance of the idiosyncratic (Hodkinson and Hodkinson, 2001). Using a case study approach can facilitate exploration of the unexpected and the unusual, revealing significant issues which were unanticipated when the research commenced, with the complexity and depth of the data generating new theoretical concepts (Smith, 2014). Furthermore, they are grounded in the lived reality of personal experiences whereby complexity and the real-life context can be explored in detail (Hodkinson and Hodkinson (2001). The study was carried out between August 2017 and June 2018.

5.4.1 Setting and Sampling Strategy

The study was undertaken in the UK, and a purposive sampling strategy (Creswell and Poth, 2018), was used. Participants' aged 65 and above were recruited from a local West Midlands Eye Clinic. The inclusion criteria were that participants had a confirmed AMD diagnosis, aged 65 years and over, able to communicate in English, with no severe cognitive or hearing impairment, and never attended an AMD support group before and would be willing to be observed during an AMD support group session in their local area and be able participate in individual interviews without requiring assistance.

Participants who were less than 65 years old, unable to speak English, had advanced incapacity and could not give informed consent were not included in the study.

The participating sample consisted of (n=5) older adults aged 71 years and above who had diagnosis of wet or dry AMD. Of the five participants, one individual was co-opted into this study, in their capacity as a support group facilitator/organiser in the individual interviews. The rationale for including the organiser was to gain an insight of group events and views of how traffic to the groups could be increased.

Early in this programme of work, the researcher TP liaised with members of the working group either face to face or virtually to discuss all pertinent areas about the research project. The rationale for the discussions were to seek relevant guidance and support across all spheres of this programme of work e.g. design of the case study, particularly sampling and identifying of ways to optimise recruitment of participants for the case study e.g. talking to participants from the study 1, and also asking if they had friends or family who had the same diagnosis but had never attended a support group. Another strategy was linking in with the Eye Clinic Liaison Officer, who collaboratively with clinicians at the clinic to identify suitable participants.

5.4.2 Statement of Ethics

The conduct of this study conformed to the research methods and actions approved by Aston University Ethics Committee and the NHS York and Humberside Ethics Committee in application number Y1009. The study was carried out between August 2017 and June 2018. All the participants gave written consent for their inclusion and were made aware that participation was voluntary and informed of their right to withdraw from the study at any stage. They were assured that this would not affect their current or future access to services relating to their AMD diagnosis. The researcher gave an assurance of the confidentiality and anonymity of the study to all volunteering participants. Moral principles of beneficence, justice, informed consent and human dignity (Polit and Beck, 2012; McCloud and Lake, 2015), were addressed and upheld throughout the conduct of this study.

5.4.3 Data Collection

Data collection took place between 2017 and 2018. Participants' interactive disposition were observed in the peer support group settings and field notes were taken to provide depth to scheduled individual interviews. A guide with open ended questions for the interviews was co-designed by the researcher and the working group (e.g. experts by experience, Eye Clinic Liaison Officer, Birmingham Focus Coordinator, Macular Society Coordinator and academics).

Participant observations and the semi-structured individual interviews were chosen as the most relevant data collection methods for this study. Observation methods are important for understanding people's actions, roles and behaviour more so within healthcare (Walshe, Ewing & Griffiths, 2011). Specific to our study, observations are necessary because of their focus on the natural setting which provides the researcher with a real time understanding of the support groups and how they function. In particular, observations can facilitate understanding of what people do and how these can alter in response to situations and perhaps over time. In a sense observations are useful as they help to identify and guide relationships with participants', to learn how people in the setting interact and how things are organized and prioritised in that setting, to learn what is important to the people in the setting under study, to become known to the participants, and to learn what constitutes appropriate questions, how to ask them, and which questions may best help the researcher answer the research questions (Schensul, Schensul & LeCompte, 1999). Researcher positioning when using observations in research is very important were validity is concerned. The quality of data collected and relationship with participants observed are affected how the researcher positions himself within the context of the research setting (Kawulich & Garner, 2006). In this study, the researcher's preferred way of observing was overt observation, where participants where aware they were being observed and knew the purpose of this method. This positioning was in line with tenets advanced by Gold (1958) around observations as a data collection method.

Practical steps taken for observation participants in support group settings

- Checking and confirming with the support group organiser/facilitator date, time and location.
- Checking with consenting participants they were available to attend on the dates, times and location given.
- Checking they had transport means to get to the location.
- Ensuring all study materials were in order and consenting participants were clear about the researcher's role as an observer.

Semi-structured interviews were chosen as the data collection method for the second phase of this study because this method allows the researcher and participant to engage using a format that facilitates direct responses one on one. The use of this method also gives the participant an opportunity to elaborate and the researcher recourse to clarify, which is not possible with questionnaires or structured interviews. This method, however, can be time-consuming; not only in terms of the length of the interviews themselves but also in terms of post-interview analysis time. All semi-structured interviews for this study were conducted face-to-face, allowing the researcher to respond to social cues and ensuring a closer rapport was developed.

Practical steps taken to organise individual interviews following attendance to a support group

- Negotiating interview time and date (offering options to hold interviews in the comfort of the patients' home or in a quiet space at the university).
- Rapport building; briefing participants on the interview process and encouraging open and honest dialogue about the phenomenon of interest;
- Ensuring the recording device was fully charged and in good working order; and
- Reassuring participants that anonymity would be upheld.

The interview schedule developed for this study were not prescriptive but purposefully flexible, set in order to allow the researcher to explore clinicians and AMD patients' existing, and emerging perceptions and experiences regarding information provision during an AMD diagnostic consultation. Prompts were also employed in order to ensure that participants elaborated on elements pertinent to the phenomenon of interest.

5.4.4 Research Instrument

5.4.5 Table 5: Summary example of the interview schedule used following attendance to support groups:

Interview stage	Purpose	Questions
Opening	Purpose of focus group: Brief introductions of participants. Rapport building.	Can you tell me about yourself e.g. Age, name, etc.?
Initial questions to get interview going	Participants' perceptions and experiences of attending support group for the first time.	Can we talk about your perceptions of support groups? What are your initial thoughts about the peer group you attended?
Transitional questions	Barriers/enablers to understanding information provided.	Can you tell me what you found useful and of particular interest to you? Do you feel information shared experiences improved your understanding of AMD? If yes what aspects of the information provided were the most useful? What did you think of the activities or guest speakers who participated in these groups? Do you feel the organiser/facilitator did a good job managing the group and providing guidance? If not link with question below;
Key questions	Determining priorities and preferences.	Can you tell me what do you think should be done to improve the peer group setting and what activities do you think would be of great benefit? Can you tell me what your priorities and preferences where and would be in peer group settings? Do you feel information shared would help you live and manage your AMD better? Can you tell me what your thoughts are on the group mix and if you have any preferences? How do you think we can get more people to attend these peer

	groups? And how important do you think they are? Can you tell me would you attend this group again? If not why? What would make you want to attend the group? Do you feel you made any connections with some of the peers? Would you see this group as a way of building new friendships? Do you know when the group is meeting next?
Closing questions	Is there anything you think the researcher ought to have asked and would like to discuss?

5.5 Procedure

A working group consisting of expert members as described and highlighted in chapter three, acted in an advisory capacity to help design interview questions, strategize recruitment and deliberations on preliminary findings of the research. Five participants who had never attended an AMD support group were invited to take part in this study to explore their perceptions of these groups following attendance. Prior to the group attendance, the researcher met with the participants to explain study and advise that they would be introduced to the group by the group organiser on the day and be observed by the researcher (TP) in the in the group setting and would participate in individual interviews after attending the support group. For assenting participants, written consent was obtained. The researcher interacted with the participants before, during and after the support groups and took some field notes on phenomenon observed immediately after each group session. The purpose of this was to provide a greater understanding of the form and content of the group, and the relationship between participants, in order to assist with interpretation and analysis of interview data.

5.5.1 Contextual Features

Participants were observed in groups that varied in membership size, age, and length of lived experience with AMD, organisation and content emphasis and activity on the day. Seebohm, Chaudhary, Boyce et al. (2013), argued that support groups are diverse in the way they are organised, including the content of their meetings which can be driven by group consensus or organizer of the group. However, the common feature across the groups in which participants were observed was that there was an organizer that facilitated and provided structure to the meetings. In the four groups were participants were observed the organizers reported that membership or rather numbers for regular attenders ranged from 12 to 15 sometimes. The four groups attended by participants for this study were held in event rooms in pubs, church buildings and local community halls to engage and share experiences of living with and managing AMD. These support groups were on going, meeting monthly, and where open to new members joining at any time.

Following the regular support group session, the researcher invited participants to take part in a semi-structured interview at a suitable time for them the next day to examine the experiences of the support group attended. They also had the option of having the interview on the same day. However, the researcher felt this may be a bit much, given the age group and associated comorbidities. Questions asked in the interviews are highlighted and summarised in schedule above. However, it should be noted these were not prescriptive, but a guide that could be adopted based on participants responses and experiences around phenomenon of interest. Support group sessions took place in event rooms in pubs, church spaces or local community halls in participants' local areas. All interviews were conducted in participants' homes. The interviews lasted between 45 minutes to an hour.

5.6 Analytic Strategy

All of the interviews were transcribed in full and these were analysed using Langdridge (2007)'s critical narrative analysis. A method that neither imposes assumptions on the participants' data nor force them to focus on specific details. Instead, it focuses on participants' experiences and feelings while also promoting individual meaning-making. In order to ensure consistency in data analysis, the researcher adopted the six stage approach as advanced and described by Landridge. These include; (1) critiquing the illusions of the given subject, (2) Identification of narratives, the narrative tone, and the rhetorical function, (3) identifying the work and its identities, (4) Thematic relationship and priorities, (5) Destabilizing the narrative, (6) A critical synthesis.

5.6.1 Stage 1: Critiquing the illusions of the given subject

Personal identifiers were removed to enhance confidentiality, and transcripts were produced from the interviews' audio recordings. These unedited transcripts were read through many times to let participants immerse themselves in their surroundings and narrative. Langdridge's phases were followed, followed by reflective work. The expert encourages researchers to critically assess their hermeneutic that best suits the study's focus. Langdridge includes several examples of suspicion-oriented hermeneutics, including gender, social class, racism, and sexual analysis. The role of this stage is to expose assumptions made by researchers. The researcher made paragraphs explaining their position and how that may influence his comprehension of the interviews. The researcher in this programme of work employed reflexivity, which offers a more personal component in the research process, and encourages more attentive self-awareness about the dynamic relationship between them and the individuals they are studying.

5.6.2 Stage 2: Identification of narratives, the narrative tone, and the rhetorical function

In the identification of rhetorical function and narrative style, the most reliable tactics employed in most narratives were used. An interview can be seen as a single narrative but also functions as a setting for other narratives. The researcher had to look for varied storylines in the text during this stage. The stories a person tells indicate how they link their accounts to other stories that have already been told. A critical examination of the stories symbolizes the more significant social stories on how people live or should live. For instance, how the society should live with people affected by AMD. The narrative tone was found to characterize the interview content, and significant changes were made. For instance, one might have an optimistic or a pessimistic attitude when speaking. After identifying the text's rhetorical purpose, the next step was analysing it. The analysis part aimed at focusing on the meaning of the narrative and its relevance.

5.6.3 Stage 3: identifying the work and its identities

This stage is based on stage two above. An examination of respondents' rhetorical work or responsibilities in their stories was also examined to examine their position in society, which could have influenced their social support needs.

5.6.4 Stage 4: Thematic relationship and priorities

Identifying the critical ideas in each narrative with a close focus on the narrative coherence was covered in this stage. The goal was to analyse the main themes directly from the text without examining the individual words and their constituent parts. The researcher read books, searching for new ideas and the possible way to structure sentences. The researcher was careful to remember his thoughts from Stage 1 and to ensure that the participants' different viewpoints were captured in the ideas that emerged from the writing. The developing concepts were recorded individually with line numbers to examine if thoughts might be organized into clusters of meaning. To distinguish if the themes could be further categorized, they were analysed to determine if they were dependent on each other or could exist independently, as argued by (Langdridge, 2007a). This approach was very interactive, beginning with a thorough examination of the original transcripts, leading to better categorization. Finally, at heart, it is about the themes and interactions among categories.

5.6.5 Stage 5: Destabilizing the narrative

The penultimate stage denotes a critical distinction between other narrative analysis techniques. They include discourse network analysis. To understand each participant's narrative, it is essential to use an appropriate hermeneutic (interpretative lens). This stage is considered political since it involves researchers working with social theories critical of the dominant power structure, as shown by identifying six possible hermeneutics of suspicion, including gender analysis as argued by '

(Langdridge, 2007). Critical Narrative Analysis uses hermeneutics to throw "imaginative scepticism" on the interviews concerning their presumed ultimate purpose. This is to say, the story needs to reveal new story possibilities rather than focusing on trying to find hidden meaning, and the researcher decided to use a hermeneutic derived from social support groups linked with age-related macular degeneration.

5.6.6 Stage 6: A critical synthesis.

To provide details on how the findings are presented, Langdridge recommends that important narratives be given alongside the themes that place participants at the forefront. The next portion of the post describes the work of being in one's identity or one's authentic self as per (Langdridge, 2007a). Then a description of the findings gleaned from a framework known as suspicion: this portion of the post provides full results in the results section, whiles the synthesis, or summary, of findings, is found near the beginning of the discussion section.

In establishing and optimising trustworthiness and limiting threats to validity, the criterion for ‘trustworthiness’ outlined by Lincoln and Guba (1985), was employed. The criterion of credibility was satisfied through open-ended questioning, prolonged engagement with the data and by providing a detailed description of the methods (Lilleheie, Debesay, Bye and Bergland, 2020). The criterion of transferability was fulfilled by presenting detailed and in-depth descriptive data and by quoting the participants. To satisfy the criterion of dependability, reiterative reading of the transcripts by (TP and RS) was performed to transform the ideas generated into a set of codes to identify the interesting features of the data. These initial codes were then categorized into themes. The themes were discussed and reviewed by TP, RS and the working group to reflect on their relevance to the research questions. The analysis was performed by an individual educated within the field of health psychology and the research supervisor RS has extensive experience working with older adults. The working group who were part of the theme reviewing process are individuals with extensive experience working with AMD patients in various capacities as support providers, information providers and some with lived experiences of AMD.

5.7 Results

5.7.1 Demographics and Details of Observed Participants

A total of (n=5) participants were recruited for this study. Of these five participants (n=4) were female and (n=1) male. These were recruited through study 1, and through collaboration between the researcher, ECLO and the clinicians. The volunteering patients’ sample mean age in this study was 78 years (SD=5.46), and all self identified as white British. In this section the demographic narrative and some of details have been paraphrased by the researcher to limit the length of the report.

Participant 1 – Chris	male
Age	84years old
Resident	West Midlands, UK
Ethnic Group (self-identified)	White British

Marital status

At the time of the interview, Chris stated he was widowed, wife had passed away a few years ago and was now in a relationship with someone residing in London.

Household composition/Support network

Chris stated that he lived alone and had no children. He described his support network as his sister who also has visual problems and his girlfriend who leave in London. Chris also reported that from time to time he joins a local group organised through the Church to go on walks. Chris stated that his eye sight has not deteriorated badly compared to his sister and is still able to do things on his own without needing visual aids. Clinicians at the eye clinic and GP were seen as part of his support network.

Description of home

Chris lives in a small two bedroom bungalow in a quiet in an area in West Midlands. He owns the property and has lived there for the past 30 years. No special adaptations were fitted.

Proximity of local mainstream services (e.g. Shops, clinic, town, etc.).

Chris does go out alone. He used to drive, but not anymore due to the change in his visual status, so now relies on public transport. The bus ride into the city centre or train station takes him about half an hour.

Diagnosis

Chris has a confirmed wet AMD diagnosis, and first noticed it affecting everyday things in his mid to late sixties following retirement. He reported that he had not registered as visually impaired, because he could still get around without needing assistance and could access information from any format print or otherwise.

Participant 2 – **Ann**	female
Age	71years old
Resident	West Midlands, UK
Ethnic Group (self-identified)	White British

Marital status

At the time of the interview, Anne stated she was married and had two grown up children and grandchildren she adored.

Household composition/Support network

She stated that she lived with her husband, and described her support network as her husband and children who live locally. Anne reported that she is the AMD support group facilitator in her local area and her husband supports with this aspect. GP and clinic clinicians, ECLO, Macular Society were seen as part of her support network.

Description of home

Anne and her husband live in a three bedroomed house in a quiet area in West Midlands. She reported that they own the property. No special adaptations are fitted.

Proximity of local mainstream services (e.g. Shops, clinic, town, etc.).

Ann does go out alone at times, but stated that she does struggle times due to her eyesight. Her husband does support to get round. There are amenities near by that she accesses, but stated a trip to the eye clinic took about forty five minutes.

Diagnosis

Ann reported that had a confirmed wet and dry AMD diagnosis, given eight years ago. She started she first noticed deterioration while shopping at local food supermarket where she struggled reading labels and had booked an appointment with the optician and thereafter referred to the eye clinic and was informed the injections needed to start soon for the right eye which was diagnosed as wet AMD. She reported that she was put in touch with the ECLO following diagnosis and he referred her to a support group in her local area and soon became a facilitator for the group.

Participant 3 – Mariam	female
Age	73 years old
Resident	West Midlands, UK
Ethnic Group (self-identified)	White British

Marital status

At the time of the interview, Mariam stated she was widowed, husband had passed on eight years ago.

Household composition/Support network

Mariam reported that she lived alone and had three children. She described her support network as her children and the local church she attended. GP and clinicians at the eye clinic where seen as part of the support network.

Description of home

Mariam lives in a small two bedroom bungalow in a quiet in an area in West Midlands. She started she had bought the property ten years ago. No special adaptations were fitted.

Proximity of local mainstream services (e.g. Shops, clinic, town, etc.).

Mariam does go out alone. She used to drive, but not anymore due to the change in her visual status, so now relies on public transport. The bus ride into the city centre or train station takes him about forty minutes. She stated she does some of her shopping online and goes to the local shops for basic things.

Diagnosis

Mariam has a confirmed wet AMD diagnosis. "*I went to my Optician because I couldn't focus, I was having trouble focusing, and things appeared blurred. He asked if I had driven over today and I said yes and he said well I can't put the drops in your eye so he said but I'll have a look so when he did he went oh! And I said what's the matter is? And he said you have bleed behind the eye and fluid behind the left eye. You need to go to the BMEC ASAP. So he made the referral to the clinic and I was given a wet macular diagnosis" (Mariam, 15-22).*

Participant 4 – Bridget	female
Age	81years old
Resident	West Midlands, UK
Ethnic Group (self-identified)	White British

Marital status

At the time of the interview, Bridget stated she was widowed, but was in a relationship with a gentleman who lived locally.

Household composition/Support network

Bridget stated that she lived alone and had two children. She described her support network as the gentleman she was in relationship with and did not her children as part of her support network due to on going family issues. She reported that she used to attend a knitting group, but had stopped because she didn't enjoy being there anymore. GP was considered as part of her support network.

Description of home

Bridget lives in a small one bedroomed bungalow in West Midlands. She stated it was a shared ownership with a local housing provider. No special adaptations were fitted. However, she had a clock with audio system to alert of what time it was on the hour.

Proximity of local mainstream services (e.g. Shops, clinic, town, etc.).

Bridget reported that she does go out alone, but in most instances her partner would drive her around for appointments or to go on holidays. She reported the bus ride into the city centre or train station took her about hour.

Diagnosis

Bridget has a confirmed dry AMD diagnosis, given some time in 2016. She stated that she started noticing the lines on her cupboards or the door appearing wavy. She reported that she had not registered as visually impaired, but had been encouraged to do so by her friend who also had received an AMD diagnosis, and had encouraged her to participate in this study.

Participant 5 – June	female
Age	79 years old
Resident	West Midlands, UK
Ethnic Group (self-identified)	White British

Marital status

At the time of the interview, June stated she was widowed, her husband had passed away sometime ago.

Household composition/Support network

June stated that she lived alone and had two children and grand children. She described her support network as her children and local church were she participates in activities from time to time. GP and Clinicians at the eye clinic were also considered as part of the support network.

Description of home

June lives in a small two bedroom bungalow in a quiet in an area in West Midlands. She stated that she owns the property and has lived there for the past 20 years. No special adaptations were fitted.

Proximity of local mainstream services (e.g. Shops, clinic, town, etc.).

June does go out alone. She used to drive, but not anymore due to the change in her visual status, so now relies on public transport. The bus ride into the city centre, clinic or train station takes her approximately half an hour.

Diagnosis

June has a confirmed wet AMD diagnosis, and first noticed it affecting her when she was doing things around the house – "*I thought that my eye felt rather funny. I couldn't put* *it any differently from that I thought I might have a piece of grit in it or something like that and so I arranged an appointment at the Opticians and got my eyes checked out. When I went in to see the Opticians she was quite worried and started shining a very bright light into my eyes and referred straight away that day to the Hospital" (June, 5-13).*

5.7.2 Demographic Context

The majority of participants in this study had wet AMD (n=4), and were still attending the clinic for treatment. One had dry AMD and another had both wet and dry AMD diagnosis. Their support network was mainly family, partners or church oriented and extended to professionals that were involved in their health and care. All participants had been diagnosed and living with AMD for no less than two years.

No stories perceived as negative stories were shared in the groups that participants attended, just expert information and sharing experiences.

Participants stated that they could not recall much of what was discussed at the time they were given their AMD diagnosis and its treatment and the type of support available. They expressed that consent to treatment was mainly due to wanting to slow down the degeneration rather than fully comprehending the information provided, an element highlighted in chapter five. To highlight the lack of meaningful discussions around diagnosis, treatment and support. Participants in this study had been living with AMD for some time and did not know they had AMD support groups they could access in their local areas. "*I was never given information on these AMD support groups at the time I was diagnosed" (Bridget 114-116).* These information deficiencies were highlighted in previous studies exploring lived experiences of individuals diagnosed and living AMD (Burton et al. 2013; Thetford et al. 2015). Furthermore, the demographics captured above highlighted that participants had a small support network. This corroborates literature (e.g. Kemperman, van den Berg & Uijtdewillegen, 2019), on older adults that highlighted that this group in general have smaller social/support networks than their counterparts, attributable to changes in their life cycle stages. For instance, age related losses along with declining health and increased mobility issues and retirement (Kemperman, van den Berg & Uijtdewillegen, 2019). The diminished social/support networks amongst this group directly correlated with feelings of loneliness and social isolation. "*I feel isolated, not many friends you see" (Mariam, 208)*. Our findings corroborate literature exploring social isolation in older adults living with a chronic illness (Tang & Lee, 2011).

5.7.3 Support Group Experience Prior to Attending an AMD Specific Group:

There were no negative experiences expressed about support groups pre-attending the scheduled AMD support groups by participants in this study. Some participants stated that they had attended some group activities unrelated to their AMD status before and had found them useful because of shared interests. For instance, Bridget talked about being involved with a group that shared same interests as her in regards to knitting and she had found it therapeutic. While, Mariam highlighted that her first experience of support groups was when she had accompanied her grandmother and aunt. *"You know I used to take my grandmother and aunt to groups so they wouldn't be stuck all alone" (Mariam, 205-206).* She expressed that in these groups she enjoyed the arts and crafts activities as it got her mind off any stressors. This is consistent with studies (e.g. Kozora, Ellison and Waxmonsky, 2005), that have shown attending support groups and engaging in activities of interest improved an individuals' psychological well-being and gave them a sense of satisfaction. Mariam stopped attending this group after her grandmother and aunt had passed away, and felt since she was not driving anymore it was a bit far out. It can be argued that one of the biggest barriers to attending support groups is distance (Banerjee, Kumar, Kulhara, & Gupta, 2008). Since getting an AMD diagnosis Mariam reported that she had felt very isolated and did not know there were to find AMD support groups in her local area, as no one had shared that information with her. This is consistent with finding from Burton et al. (2013) that highlighted information deficiencies. Chris spoke about attending church organized group walks as the only experience of support groups he had, and reported that he found it enjoyable and a place to make friends and feel a sense of belonging. This is consistent with findings from several studies on support groups (Sarason et al., 1987; Ruehlman & Karoly, 1991; Chang & Schaller, 2000; Cimarolli & Boerner, 2005; Goll, 2014; Pryce et al. 2019). June, like Chris was involved with the church were she participated in activities from time to time, but was not specific about the type of activities she engaged in. Ann had prior experience of support groups as a peer following her AMD diagnosis and had since taken over responsibilities as an organiser/facilitator in her local area.

While participants did not express any negatives about support groups. They had expectations of what AMD support groups should be able to offer. Information and knowledge through shared experiences was one of the elements they were looking forward to amongst other things including connecting with people who had the same condition as them. The section below captures their experiences in AMD support groups as first time attenders and their narratives will provide insights into these groups. Ann's narratives are included in this study to validate group format, activities and share her views on how to increase traffic towards these groups.

Attending a group setting can be anxiety provoking. As such, the researcher liaised with the group organisers to create a welcoming environment for participants – first impressions are often lasting impressions. Veteran members in the group acted as ambassadors and made participants feel comfortable. Organisers were aware participants were under no obligation to share their experiences. The organisers took the lead in introducing participants to the group and gave everyone an opportunity to introduce themselves. Organisers were encouraged to follow up with first time attenders after the group meeting and share information on frequency of meetings and upcoming events. Researcher (TP) prepared participants by checking in with them before the group meeting and talking through how the session was going to be run. To alleviate any anxieties, the researcher encouraged participants to focus on similarities rather differences as this may help for some information or experiences to become clear. Veteran ambassadors showed participants were the toilets were. TP reassured them it was ok, to take a break if they felt overwhelmed.

5.7.4 Experiences of first time attenders' to AMD support groups - findings by theme:

The section provides a rich narrative of participants' views on engaging with organised support groups. As described in the 'methods' section, data generated from the interviews was analysed using Langdridge's critical narrative approach in which data was coded into initial themes before being synthesized into master themes. In all, four master themes were identified including: (a) "Had I known there were AMD groups locally I would have started attending a long time ago": A need for awareness creation; (b) Empowerment through mutual identification and mutual sharing; (c) Information Needs - an opportunity to gain new knowledge and consolidate information.

As with other qualitative research methods, the themes presented in this section will be supported by detailed narratives of participants' views of AMD support groups. These narratives are verbatim, the text is italicised and boxed.

5.7.5 Had I known there were AMD groups locally I would have started attending a long time ago": A Need for Awareness Creation*.*

This theme captures the lack of awareness of AMD support groups available in participants' local areas. It speaks to the lack of information at the time of diagnosis and across multiple dimensions of their illness journey of such important support structures. Participants' expectations and desire to continue attending are also captured in this theme. It also captures their views on raising awareness and increasing attendance to support groups.

> *"Now that I am in a similar age group and living with AMD, I feel isolated, not many friends you see. Had I known there were AMD groups locally I would have started attending a long time ago". (Mariam, 207-210).*

Mariam's narrative tone highlights a life living with AMD absent of needed support and a sense that this support group presented an opportunity circumvent feelings of isolation. This finding corroborates previous studies (Keperman et al., 2019; Tang & Lee, 2011) that found that the absence of supportive networks, whether peer or support groups can lead to social isolation for older adults and feelings of loneliness. The majority of participants in this study did not know they had AMD support groups in their local areas. They only found out after being asked to participate in this study and expressed gratitude:

> *I was never given information on these AMD support groups at the time I was diagnosed. It would have helped me a lot. I am grateful that I managed to attend this group as part of your research and I intend to continue going, I learned so much in one day. (Bridget, 114-119).*

Bridget's narrative tone exudes an element of gratitude for this research study providing an opportunity for her to connect with a group she identifies with. There was an expressed intention to become a regular attender to the group, where she felt she had learned a lot. It can be argued based on conversations prior to attending the group around expectations that for Bridget these had been met, that gaining knowledge and support around managing and living well with AMD. Literature on support groups corroborates our findings that attendance to support groups correlated with expectations being met (Sarason et al., 1987; Ruehlman & Karoly, 1991; Chang & Schaller, 2000; Cimarolli & Boerner, 2005).

June's narrative below deconstructs a lack of awareness of support groups being available in her local area:

> *I wasn't aware they had these groups in my local area and it's sad they never gave us this information to begin with. We are at an age our friends have either died or moved to care homes due to ill health, so it can be an isolative life. Our children have their own families and life to manage so we can't always rely on them. I think when we visit the clinic and get our diagnosis more should be done with regards to provide information on these groups. I think macular society and the other ones can do better too, to raise awareness. (June, 242-253).*

This lack of awareness, in June’s narrative tone was as a result of information not being provided. Our findings here are consistent with Burton et al. (2013)’s study, exploring the lived experiences of AMD patients which highlighted deficiencies in information provision across multiple elements of their journey with the condition. Furthermore, June’s narrative demonstrates that her expectations of the group were linked to making social connections. An element highlighted in other studies exploring the benefits of attending support group (Hoeck et al. 2017; Pryce et al. 2019). There was also an expressed need for organisers and third sector organisations that provide services to individuals living with AMD to do more to raise awareness of support and get more people involved. Stefan, Magnuson & Joe (2020) argued that while stakeholders needed to create and raise awareness of support groups to improve traffic. There was a need for organisers to engage more in recreational based events to make the groups more attractive. In essence striking a balance between condition driven agenda and living a life of co-existence with the condition outside its limitation.

Ann the organiser concurred with the recreational –based approach to make the groups fun:

> *We have loads of different things that we do and some have become popular and regular events. We have a lady that comes and does armchair yoga and everybody loves that, it’s a laugh if nothing else. We do regular once a year trip which this year turned out to be quite a large number, I think we had 35 people, it was good fun and I think it helped get more people in. We also have always once a year, one of the Consultants from the Hospital comes down and has a session telling us about the latest research, which is always a very popular meeting although as I say we do have fun things as well. We had a ukulele group last month, we like to think of things were they can hear it not see it and it’s not easy” (Ann, 76-89)*

Ann’s narrative demonstrates an understanding of AMD participants’ needs and expectations within the context of support groups and appears to have a grasp of how to keep participants interested and attend on a regular basis. These activities enhance a sense of connectedness and keep attenders interested.

> *“The group was well organised and everyone was respectful of each other’s contributions. The organiser has a likeable personality and knows how to moderate and keep things moving and she made it fun. She has already told us there is a guest coming next month to share information on new research and I am excited about it and definitely attending” (June, 253-259).*

June’s narrative tone highlights an appreciation of how the group was run and the organiser’s interpersonal skills in managing the activities. June also intimated that she was attending the next group meeting where new AMD information will be presented. It can be argued here that these activities met June's expectations and this group has potentially gained another regular member. Ann's narrative further deconstructs the issue of increasing traffic to support groups:

> *"Having the signs put up in the clinics in visible areas is important to increasing the traffic to support groups and our good doctors and eye clinic liaison officers need to keep raising awareness that there are support groups if you need it at diagnosis or during follow-up treatments. Macular society and other organisations support sight impaired individuals can also play a huge role in creating awareness that increases traffic to our support groups. There is a need for us to collaborate" (Ann, 191-200).*

There is a recognition that clinicians and the Eye clinic liaison officer can play a significant part in raising awareness of support groups by sharing this information at diagnosis, when patients attend the clinic for assessment and treatment or putting visible signs in strategic areas of the clinic highlighting that support groups are available in their local areas and how they can reach out.

June agrees and feels information about support should have been provided at diagnosis:

> *"I feel, I should have been given information on the groups at diagnosis. This group is a god sent. This is just what I needed, the organisation of the group was great, and I didn't feel out of place, the members were so welcoming. To imagine, I didn't know this group wasn't too far from my house. My friend from church also has AMD and he didn't know about and when I told him about my group experiences he said he wants to come with next time. So I guess if it's anything like my first time attending, he may become a regular member like I intend to" (June, 259 – 268).*

June's narrative tone is that of gratitude she had attended a group that met her expectations of the self with AMD. The positive experiences she had in the group, she shared with a friend who also lacked awareness of AMD support groups in their local area and had volunteered to attend the next group meeting with her. Literature has shown that organisers skills to moderate in a group, the format, information giving, and environment they created, were drivers for retaining members, encouraging regular attendance and attracting new members (Hoeck et al.2017).

> *"I think the support groups are an important part for us aged people with AMD. Imagine living on your own with a sight impairment without any understanding of the condition and no support. It's horrible, I for one am grateful that you introduced me to this group and it's in my local area too" (Mariam, 368-373).*

Mariam expressed gratitude to the researcher for introducing her to her local AMD support group. Her narrative provokes a thought of life lived with the altered self, without an understanding of the condition underpinning the altered self. More so, when the condition relates to a sensory element she have used for the greater part of her life to relate to the environment around her. Her gratitude is embedded in now having a group where she shares a mutual identity.

In summary, a key finding was the lack of awareness of support groups in their local areas by participants. An element rather reflective of the information gaps experienced by individuals living with AMD (Burton et. 2013). There was an expressed sense of time lost not knowing about these groups "*I would have started attending a long time ago*". In essence the study created an awareness about the groups for them and they expressed gratitude. There was a general consensus more needed to be done to create awareness and this needed all stakeholders to play a part from group organisers, Eye clinics and third sector organisations that advocate for people with AMD. While increasing traffic to support groups was important, retention of attenders was dependent of their expectations being met. Some participants wanted to be involved as this platform provided an opportunity to break the cycle of loneliness and isolation. The group organiser's skill and experience was a fundamental element to the general group dynamic and helped create a conducive environment were participants felt relaxed and welcome to share. Our findings here corroborate elements highlighted in Robson (2018)'s study exploring the impact of support groups on cancer patient's experiences. It can be argued here that when it comes to increasing traffic to support groups there needs to be a collaborative approach between support group organisers, third sector organisations (e.g. macular society), and clinicians to create awareness, sharing information at appropriate times in AMD individuals' journey living with the condition.

5.7.6 Empowerment through Mutual Identification and Mutual Sharing:

Participants positioned support groups as a safe and supportive environment where shared commonalities around their illness identity provided an opportunity to build social capitol for individuals' diagnosed and living with AMD. They also expressed a sense of empowerment drawn from the realisation that they were not alone, could access emotional support and felt a sense of belonging even though it was their first time attending.

> *"There is something about being in an environment where people share experiences about the same condition, I felt empowered with the experiences and information shared and I didn't feel out of place. I interacted with others and didn't feel judged, I didn't see strangers, but peers gathered to support each other and encourage each other manage and live well with AMD". (Bridget, 120-126).*

Bridget’s narrative highlights a supportive environment were participants treated each other with respect and didn’t view each other as strangers. She saw these groups as a place where participants helped each other grow in knowledge and manage their condition. This finding corroborates Smith, Flowers and Larkin (2009)’s assertions that attendance to support groups offer participants an opportunity to gain insight into the self with AMD. Other studies (Hoeck et al. 2017; Owen et al. 2007) exploring experiences of cancer patients in support groups, corroborate our study’s findings. They found that support groups were a safe environment where individuals could discuss with peers and share similar experiences without fear of being subjected to judgemental attitudes.

A striking issue that emerged in the participant observation of the support groups was the level of humour and warmth between group members who also accommodated study participants, an issue which many of the participants also positioned as a key factor in attending future meetings. This and the organiser were seen as aspects that potentially helped maintain group cohesion, outside the shared mutual identity:

> *I found the people in group very welcoming and accommodating of a new face. The organiser was fun, respectful and kept things moving seamlessly. I found it easy interacting and sharing with others in the group (Chris, 485-490).*

June also felt the warmth of the group:

> *“I must say sharing experiences is a useful way for others to gain invaluable knowledge to understand and manage this condition and I agree they [support groups] provide a sense of belonging for most who may feel isolated because of the condition or for the lack of family support you know. I certainly feel I can identify with this group and I intend to keep attending, everyone was warm and welcoming” (June, 282-291).*

June narrative tone demonstrates an understanding of what she could gain by attending the support *“invaluable knowledge to understand and manage”* her condition and validated her intention to keep attending this group with *“I can identify with this group”.* An element that speaks to mutual identification. Hoeck et al. (2017)’s study exploring support groups using cancer participants corroborates our findings and argued that support groups created a sense of community based on shared illness identity which fostered an element of togetherness and created an environment where people felt safe and relaxed to share experiences, advice, and interest. Feeling relaxed was evident in Mariam’s narrative:

> *"So being amongst them made me feel more relaxed to an extent. I felt my eyesight was better than most of the folks in attendance. They became my point of reference of how worse things could get and I am glad to have joined the support group so I can hear directly from my peers about their experiences to prepare myself and adjust for when I get to their stage" (Mariam, 215-222).*

The shared identity element made Mariam feel relaxed and comfortable. Her narrative demonstrates a comparative tone of her eyesight to that of her peers, who she felt had poorer eyesight to her based on their shared experiences. It further highlights how she was going to draw from these shared experiences to cope and manage when her eyesight deteriorates to the same stage as some of her peers in the group. In psychology such phenomenon is referred to as social comparison. Birk et al., 2004; Dahlin-Ivanoff et al., 1998). Draucker (1991) argued that in most instances people diagnosed with a chronic illness often made down ward comparisons when in a support group as a way of coping, adjusting and to subsequently manage their illness (Pryce et al. 2019).

> *"I do feel that sharing of experiences is important, it connects us and gives us opportunities to build ways of managing to live well with this poor eyesight. I think for some of the chaps in there this group provides an opportunity to meet friends, jxx said he sometimes gets lonely and this group has been helpful in breaking that circle for him and feels emotionally supported" (Chris, 561-567).*

Chris's narrative highlights the benefits for mutual sharing as an element that connected people and provided an opportunity to build mutual relationships based on a shared identity and for some who had the friendship agenda, it afforded them a chance to break the cycle of loneliness through mutually shared experiences. This finding corroborates literature on loneliness (Kallejian, 2003; Martina & Stevens, 2005), that posited that the best way to break the cycle of loneliness was getting involved and support groups were viewed as conducive environment for older adults. Schriff (2000) argued that support groups by their nature helped to address loneliness and gave participants hope and control. Our findings on building mutual relationships also corroborate literature on support groups (e.g. Ussher, Kirsten, Butow & Sandoval, 2006), that argued that support groups provide a sense of community where friendships developed out of mutual connections. Support groups in their essence offer emotional support, an element highlighted in Chris's narrative as being significantly important to the peer he interacted with in the group and a support group characteristic that brings him back – a need met. This finding is consistent with literature on the benefits of support groups, which suggests that despite shared mutual illness identities, individuals' expectations, needs and motivation to attend groups were diverse (Mendes de Leon, Glass, & Berkman, 2003; Rovner & Casten, 2002; Tolman, Hill, Kleinschmidt, & Gregg, 2005).

One of the key priorities for participants engaging in illness specific support groups was the desire to have their information needs met and an opportunity to share their story:

> *I can share my experiences and I can get information from others on how they cope and manage various aspects of their lives living with AMD you know. I noticed there people of different ages and different forms of AMD which just expands our understanding of the condition and how people deal with it (Mariam, 373-379).*

Like Chris, Mariam was aware that there was diversity in the group with regards to age, range of eyesight and form of AMD. None the less, she saw an opportunity to learn and broaden her understanding of the condition from this diversity. There was also an expressed willingness to share her experiences too. From observation, her willingness to share her experiences were a testament to the organiser's ability to create an open environment that was premised on mutual respect for each other. Ivers, Cumming, Mitchel & Attebo, (1998), argued that environments where a key determinant for older adults attending support groups regularly. If the environment was perceived unhelpful, attenders were unlikely to return. From a social selective viewpoint (Carstensen, 2006), it can be argued that some older adults, including those with AMD, would re-evaluate and invest more in close support networks (e.g. family, friends) rather than support groups because of the limited future time in older age they may have.

Shared struggles:

> *"We shared our struggles of how some can't watch television, could not read or access information from available print material. Some even shared their annoyance of pavements or failing to read signs when they are outside and walking". I found it useful that it wasn't just venting, but also sharing practical advice to manage these situations like use those sticks with the wheel to feel the surfaces when out and about" (June, 203 -211).*

June, like other participants provided the view that they struggled in watching television, reading books, and walking on uneven surfaces and reading signs when in the community walking. There was an appreciation that the group did not share experiences of frustration but offered practical solutions to some the challenges.

In summary findings from this study demonstrate that participants viewed AMD support group as having a positive impact drawn from mutual sharing and mutual identification. There was a sense from their narratives that identity fostered a sense of community which facilitated hope and empowerment. This is consistent with findings from Kessler, Egan and Kubina (2014)'s generic study which highlighted that mutually sharing experiences increased participant's confidence in managing the illness and fostered positive feelings underpinned by a sense of belonging. For some this environment circumvented issues relating to isolation and provided them an opportunity to break the cycle of loneliness. Participants attending these groups felt safe and relaxed and could reflect and share their experiences without fear of being judged. Our findings here corroborate findings from various generic studies (e.g. Hoeck et al. 2017; Kessler, Egan & Kubina, 2014; Owen et al. 2007; Pryce et al. 2019), focussing on participants' experiences of support group that also found that support groups offered emotional, and affirmational support, validation and decreased feelings of being alone. It can thus be argued here that participants narratives in this study demonstrate an increased sense of personal agency, in relation to self, others and AMD. From observing the groups there was a realisation for participants they are not alone, they share the same problems and similar experiences, which to some extent made them feel normal in that setting. It helped them re-conceptualise their health status more positively, and evoked a deep need for interpersonal learning.

5.7.7 Information Needs - An opportunity to gain new knowledge and consolidate information:

This theme captures how participants in this study positioned support groups as an invaluable source of information, providing education about the course of AMD. Particularly about new developments relating to treatments and ways of managing and living well with the condition. There was an appreciation of different experts being brought in to provide informative sessions that promoted living well with the condition. For instance, the altered self with AMD not limiting your interest and attendance to theatre shows, getting practical information that aided reading materials or access to pertinent information on diet and management of the condition:

> *"I must say one of the highlights of my attendance was realising how good these support groups are. There was a professional who visited and shared information on developments regards treatment and talked about areas of improvement in our care or management of the condition. I certainly wasn't expecting that on my first attendance. I'm glad I took your offer to participate. A lot of useful and practical information was shared amongst peers, like using the torch to read. I have since bought myself one" (Chris, 451-461).*

Chris's narrative has a tone of appreciating information shared and its usefulness from a practical perspective. For instance, buying the torch to make reading materials more accessible. Similarly, in her group Bridget had received information about diet and healthy living, including information on complimentary medication that could slow down AMD:

> *"I got some useful information from the support group. One of the guys there said if I look at the macular website there will be information on diet and healthy living. The lady organiser did say something about some tablets you can buy from the pharmacy. So I guess in a short while attending the support group I have gained some invaluable information from my peers than I did with the so called expert. I'm looking forward to the next meeting" (Bridget, 99-107).*

Bridget's narrative tone demonstrates the value of support group as a source of information that could help her manage her condition better. There is an expressed sense that she got better quality information from peers in the group than clinicians. This is consistent with findings from chapter five, were patients expressed unmet needs where information is concerned. Other studies (e.g. Halter et al. 2017), exploring patients experiences with clinicians corroborate our findings were information deficiencies have been linked to dissatisfaction with services, lack of understanding of condition, poor management of the condition and lack of meaningful support. From observation participants appeared to value the information shared and expressed a willingness to continue attending these groups beyond the study.

> *"The organiser and other members of the group shared their experiences with medications and I found this information useful and true to my own experiences. In hindsight attending this support group and seeing others in same predicament, lets me know I wasn't alone in the struggle with the eyesight and the feelings I experienced post diagnosis" (Bridget, 71-78).*

Bridget felt organizers and the group members of the AMD support groups shared information and their experiences in relation to the medication, what they opted for and how they felt after the use of those medications along with any difficulties or side effects they might have faced. This offered encouragement to the participants of the study, that they weren't alone and it also clarified confusions they may have had in their mind about treatment related experiences. The most important fact highlighted by the participants is that they have felt more confident after participating in the support groups and they felt it took away an element of feeling lonely in the context of the condition after being in an environment were people shared mutual identification.

Access to practical supportive information was appreciated:

> *"I liked it very much, learned a thing or two from the theatre guys that came and gave us an informative presentation on how to use our limited eyesight effectively in a theatre environment and still enjoy the things we used to" (Mariam, 211-215).*

In Mariam's group, this presentation from a theatre group provided useful tips on how to enjoy theatre activities while living with AMD. It was evident across all groups there were some useful informational nuggets that participants picked up and valued within their life contexts. This is consistent with findings from other studies (e.g. Kessler et al. 2014; Pryce et al. 2019) that highlighted the importance of support groups as a platform that enhanced personal growth for participants through knowledge gained from the information provided.

The group organiser highlighted that bringing experts in the field was an activity attenders appreciated:

> *"We also have once a year, one of the Consultants from the Hospital that comes down and has a session with the group telling us about the latest research, which is always a very popular meeting although as I say we do have fun things as well" (Ann, 86-91).*

Ann's narrative highlights how she organised her group, inviting clinicians to share knowledge on new developments relating to AMD. Her narrative tone also demonstrated the group was not just about serious stuff, but engaging in fun activities as well. On the day this group was held they had invited someone who played a ukulele and group members and the study participant had joined in. It can be argued that striking a balance between information giving and sharing experiences is very important were support groups are concerned. It keeps participants interested and provides and opportunity for them to gain new information from experts in their field. An element consistent with Pryce et al. (2019)'s findings of their study exploring experiences of participants to tinnitus support groups.

In summary, the information gained was perceived as invaluable by these first time attenders. A key finding was the balance in the availability of expert information and practical information that participants found useful. For instance, buying a florescent torch to use when reading print materials or learning that adaptations had now been made in theatres to accommodate their visual status. Our findings here are consistent with findings from Pryce et al. (2019). The presence of experts inferred a sense of being worthy for participants in their study, an element also appreciated by participants in our study, including the knowledge imparted which fostered confidence and alleviated feeling associated of being alone with the AMD. This aligns with other qualitative study findings (Boltong et al. 2017), that found that experts sharing new information on treatments or management of a condition within a support group setting was empowering for attenders and helped them consolidate new information with what they already know.

5.7.8 *Table 5a. Impact statement: What participants liked or found useful attending AMD support groups*

Location – local area and format (including; discussions engaged in, being able to ask questions, all having chance to speak and having views and opinions respected).
Meeting/learning from others in similar situation, sharing stories, learning how others with similar challenges were managing living with AMD.
Professional advice/answers (including; helpful, well-presented information on diet, research on treatments, accessing theatre for individuals living with AMD). Practical information
Bonding between participants, supporting each other
Organiser welcoming, supportive, patient, empathetic, reassuring

5.8 Discussion

This study examined the question what are patients' views on engaging with organised support groups. Support groups were positioned as providing a unique sense of community where participants felt safe and not judged, information giving and sharing experiences, in contrast to isolation, loneliness and lack of awareness and knowledge experienced outside these groups. A critical narrative analysis of participants' narratives generated synthesised meaning-led descriptions of parts of the phenomenon as experienced by participants in the support groups (Mishler, 1984), and highlighted factors that would influence continued participation in the group beyond the research or increase traffic to these groups. Three synthesised master themes that represent participants positioning of support groups are included for discussion: (1) "Had I known there were AMD groups locally I would have started attending a long time ago": A need for awareness creation; (2) Empowerment through mutual identification and mutual sharing; (3) Information Needs - an opportunity to gain new knowledge and consolidate information.

Motivations for and experiences of attending support groups in previous studies (Pitts, 2015; Robson, 2018) have been shown to involve an intertwining of practical decisions on the one hand, relating to accessibility, availability and format preferences, and philosophical perspectives on the other, concerning the group dynamic and venue (Pitts, 2015). In the present study these elements were underpinned by a psychological framework, in which participants positioned themselves as first time attenders – or will be positioned by external factors, on continuums of participation, should they choose to continue attending after the first session. Participants in this study had prior experiences attending non illness specific groups. Hence, their motivations to attend were specific to their AMD diagnosis, a desire to gain knowledge through mutual sharing of experiences with individuals they mutually identified with. There was a desire to socially connect to break the loneliness cycle and feelings of isolation. This is consistent with findings from other generic studies (Kessler et al. 2014;

Doherty, 2004; McSharry et al. 2018; Robert, Piper, Denny & Cuddleback, 1997; Ussher et al. 2006; Ussher, Butow, Kirsten, 2008; Tise, 2015).

Generally, participants' narratives in this study were positive about their experiences as first time attenders to AMD support groups. In theme one, "Had I known there were AMD groups locally I would have started attending a long time ago": A need for awareness creation. A key finding was the lack of awareness of support groups in their local areas by participants. An element reflective of the information gaps experienced by individuals living with AMD. This corroborates studies (Burton et al. 2013; Thetford et al. 2015) that showed information deficiencies across multi aspects of individuals living with AMD. The argued that these deficiencies impacted on individuals ability to access adequate support and this had a subsequent effect on their quality of life. Hence, it can be argued there is a need to create awareness for AMD support groups and this process should start at diagnosis. Bergman and Johnson (1995) argued that providing 'adequate' and 'accessible' information was a means of removing barriers that prevented individuals with visual impairments such as AMD from actively participating in substantial aspects of their lives including understanding their diagnosis, treatments and accessing support. This argument illuminates the fundamental importance of providing adequate information to AMD patients, for them to function as competent social beings. Lack of it thereof, can lead to social exclusion (Brody et al., 2001; Owsley et al., 2006), which means that without access to adequate information people cannot play their roles as patients, citizens or consumers, they cannot make informed decisions or rational choices concerning their lives. This is consistent with our findings, were there was an expressed sense of time lost not knowing about these groups. Consequently, Moore (2000) argued that were there is a lack of awareness or provision of adequate information, individuals are unable to benefit from services they should otherwise be benefiting from (e.g. support groups) and this potentially impacts the way they adjust, cope and manage their condition over time. In our case, the study did in essence create an awareness about the availability of support groups for participants in their local areas and for that they expressed gratitude. There was a general consensus across their narratives that more needed to be done to create awareness and this needed all stakeholders to play a part from group organisers, attenders, Eye clinics and third sector organisations that advocate for people with AMD. Stefan et al. (2020) corroborated these suggestions and argued that awareness of these groups should start at the point of diagnosis and throughout the treatment journey. Reblin and Uchino (2008)'s study exploring social and emotional support and it implications for health corroborated these assertions and stated that it was in the best interest of health institutions, particularly healthcare professional to provide pertinent information to patients and be part of the awareness campaign for support groups as associated benefits reduced reliance on the healthcare system. It can be argued here there is need for a collaborative approach between organisers, healthcare professionals, Eye clinic liaison officer and third sector organisations to improve traffic. However, while increasing traffic to support groups was important, retention of attenders' was equally important and organisers are key to this. Robson (2018)'s study exploring experiences of cancer patients in a support group corroborated our findings and argued that organisers needed to strike a balance between information giving, sharing experiences and engage in recreational based events to make the groups more attractive and retain current members. It can be argued that organisers in this study ticked this box and participants were satisfied with the format and organisers' qualities as a facilitator. They saw these qualities as a fundamentally important element to the general support group dynamic. This corroborates findings from previous studies (Robson, 2018; Mc Sharry, Dinneen, Humphreys, et al. (2018), that argued that when attenders are satisfied with format, group dynamics and organisers, participants would continue attending future groups and voluntarily become part of the awareness drive by extending invites to people in their circle who may be in a similar situation. However, Ivers, Cumming, Mitchel & Attebo, (1998), argued that environments where also a key determinant for older adults intending to attend support groups regularly. They stated that if the environment was perceived unhelpful or chaotic, attenders were unlikely to return. This is consistent with other studies (e.g. Sarason et al., 1987; Ruehlman & Karoly, 1991; Chang & Schaller, 2000; Cimarolli & Boerner, 2005) that highlighted barriers that include; negative forms of behaviours, such as criticism, hostility, and insensitivity, impacted potential attenders accessing support groups. It can be argued from a social selective viewpoint (Carstensen, 2006), that in such instances some individuals, including those with AMD, would re-evaluate their position and rather invest more in close support networks (e.g. family, friends) than such support groups because of the limited future time in older age they may have. In this study however, participants reported positive experiences were mutual identification and mutual sharing, a point of convergence.

In theme two, empowerment through mutual identification and mutual sharing - while attending a group for the first time can be anxiety provoking, participants perceived the support groups to be a safe, relaxed and non-judgemental environment in which they felt they could share their experiences mutually and felt a sense of belonging. This is consistent with previous reports that highlighted that such positive environments produced a sense of belonging and empathy, even for first time attenders and increased their ability cope (Kessler et al. 2014; Doherty, 2004; McSharry et al. 2018; Robert, Piper, Denny & Cuddleback, 1997; Ussher et al. 2006; Ussher, Butow, Kirsten, 2008; Tise, 2015). In our study, the sense of empowerment was underpinned by participation in these groups for participants. This finding is consistent with Mok and Mattison's findings that argued that participation not only fostered a sense of empowerment, but also inspired hope and confidence, which promoted a greater sense of interconnectedness with others and opportunities to build supportive relationships. Similarly, in a support group study exploring experiences of women with breast cancer by Gray, Fitch, Davis and Phillips (1997a) reported similar findings. However, they reported that participants who experienced support groups positively as highlighted in our findings, improved their ability to relate to healthcare professionals in an empowered manner, and a sense of connectedness to other individuals living with AMD in the group participants, that results from feeling understood by their peers, mutually sharing experiences and having a sense of hope. Adamsen (2002)'s study also corroborated our findings and argued that when first time attenders experience empowerment through mutual identification and mutual sharing, it increased their confidence and changed their psychological framework, that is, their positioning from victim (e.g. lack of support) to agent (e.g. in relation to self, others and AMD). From observing the groups there was a realisation for participants they are not alone, they share the same problems and similar experiences, which to some extent made them feel normal in that setting. It helped them re-conceptualise their health status more positively, and evoked a deep need for interpersonal learning. The diversity within the groups they attended with regards to age, range of eyesight and form of AMD allowed some to make comparisons based the shared experiences around range of eyesight. They reported that drawing from these shared experiences would allow them adjust, cope and manage should their eyesight deteriorate to the same stages as some of their peers in the group. In psychology such phenomenon is referred to as social comparison. Birk et al., 2004; Dahlin-Ivanoff et al., 1998). Draucker (1991) argued that in most instances people diagnosed with a chronic illness often made down ward comparisons when in a support group as a way of coping, adjusting and to subsequently manage their illness (Pryce et al. 2019). Dibb and Yardley (2006)'s study exploring how social comparison within support groups influence adjustment to chronic illness, corroborated our findings and emphasised that positive social comparison allowed participants to self –evaluate against others using information shared to build capacity for coping and managing the condition over time. Another key finding from this study was that participants saw an opportunity to circumvent isolation and break the loneliness cycle through building mutual relationships when attending these groups. Studies (Reinhardt, 1996; Reinhardt, Boerner & Benn, 2003), corroborate our findings and argued that the cycle of loneliness and isolation could be broken through attending support groups and developing meaningful mutual relationships (Van Zandt et al. 1994). It can be argued here that breaking the cycle of loneliness and circumventing social isolation were a motivating factor for attending these groups for some of our participants. This finding is consistent with previous studies (Hoeck et al. 2017), that argued support groups which had a positive environment and allowed attenders to openly share experiences fostered a sense of community which broke feelings of loneliness and isolation for first time attenders and those who attended regularly.

In theme three, information needs– an opportunity to gain new knowledge and consolidate information. Participants' positioned support groups as an invaluable source of information, providing education about the course of AMD. Particularly, about new developments relating to treatments and ways of managing and living well with the condition. There was an appreciation of different experts being brought in to provide informative sessions that promoted living well with the condition. They appreciated the balance between information giving (e.g. experts) and sharing experiences (e.g. gaining practical information), which could help them manage their condition over time. Our findings are consistent with findings from Pryce et al. (2019)'s study exploring experiences of individuals living with tinnitus attending support groups. The presence of experts inferred a sense of being worthy for participants in their study, an element also appreciated by participants in our study, including the knowledge imparted which fostered confidence and alleviated feeling associated of being alone with the AMD. This aligns with other qualitative study findings (Boltong et al. 2017), that found that experts sharing new information on treatments or management of a condition within a support group setting was empowering for attenders and helped them consolidate new information with what they already know. This finding is consistent with previous literature (Moore, 2000). Moore argued that support groups involving older adults with visual impairments needed to provide information that was both practical and informative. By practical information they were referring to information that allowed attenders to function optimally within the context of the limiting eye sight status, and by informative information they were referring to knowledge that would allow them to adjust, cope and manage the condition better. It can be argued here that knowledge acquired from information provided in these groups was empowering for participants with some buying suggested aids to help with accessing information materials and reported a positive effect on accessibility. (Hasler, 1993) corroborates our findings and argued not only does information and knowledge empower, but it also allows individuals to function effectively within the context of their multiple identities, as patients, disabled persons, consumers and citizens in an ever-changing environment (Schmidt et al., 2003). Docherty (2003)'s study examining the experience, functions and benefits of a cancer support group lend support to findings from the present study. They found that information giving in support groups and sharing experiences was associated with better coping with the diagnosis, less distress and greater feelings of control, reduced negative life events and improved self – esteem (Bloom, 1982). It can therefore be argued here that the positioning of support groups as an invaluable source of information by participants was uniquely based on each participant's conceptualisation of how information given and experiences shared enhanced their reality-based knowledge and awareness of self with AMD and how they would manage living well with it. Getting information and sharing experiences was one of the motivations for participants attending support groups and quality of information giving and shared experiences contributed partially to the reason for the continued attendance beyond the research.

Various theories can be drawn on to understand the phenomenon of and in support groups. In the present study the social comparison theory (Festinger, 1954) can be used to understand some of the mechanisms employed by participants in support groups. Comparison allowed participants to self –evaluate against others using information shared to build capacity for coping and managing the condition. In a sense, it helped them validate their feelings of living with AMD, normalise illness, improve self-esteem and encouraged positive health behaviours –through practical information received (Davison et al. 2000). Narrative theory, where AMD support groups were viewed a safe and mutually supportive environment where biographical work is conducted and identity re-evaluated (Yaskowich & Stam, 2003). Biographical work, in the sense that this was an illness specific support group were they mutually shared experiences and mutually identified with each other. It ca be argued here that these theoretical descriptions are not mutually exclusive, as each provides a framework to partially interpret and understand our findings. Majority of participants narratives were positive in their views of AMD support groups, they positioned them as a safe, non judgemental environment that fostered a sense of community, information giving and mutual sharing of experiences. In contrast to feelings of isolation, loneliness and lack of awareness and knowledge experienced outside theses groups. Experiences in the groups gave participants a sense of empowerment and agency in relation to self, AMD and others.

5.9 Strengths and Limitations

This study had a number of strengths and limitations. A significant strength of this study is the research strategy which allowed collaboration between the researcher and the working group. They helped shape the study, development of the interview questions and synthesis of the themes. As far as we are aware this is the first study to explore perceptions and experiences of individuals living with AMD as first time attenders to support groups. This in depth qualitative case study approach draws attention to and deepens our understanding of the AMD participants needs, preferences and expectations of support groups and highlights elements that would make them return and become regular attenders. The use of non-participation observation alongside semi structured interviews enabled us to validate participants' narratives against what was observed. Taking a critical narrative approach to this research study has enabled in-depth analysis of the meanings participants attach to their experiences of attending AMD support groups for the first time. It can be argued in analytical conclusion that the benefits of support groups are obvious and having been highlighted in this and many other studies. However, to increase traffic to these groups there needs to be a collaborative effort by group organisers, third sector organisations e.g. Macular Society and Eye clinic health professionals to raise awareness of these groups. This study contributes to an under- researched area providing scope for understanding AMD participants views and experiences of attending support groups for the first time. A limitation of using a case study approach is that there is typically too much data to analyse (Colley and Diment, 2001). The researcher was conscious of being swamped in data by capturing participants' stories as a whole. Hence, chose not to tell individual stories at all, but rather to analyse issues across the stories (e.g. Hodkinson and Sparkes, 1994). This is undoubtedly a more orthodox approach. For the findings the researcher drew out narratives from the stories participants shared regards their experiences attending AMD support groups for the first time. All participants in this study self described as White British and were all residents in West Midlands. Hence, our findings may not be generalizable to other ethnic groups culturally and also geographically. Future studies may need to recruit more widely, a diverse group and perhaps adopt different positions to the unit of analysis and a different interpretative set of lenses to explore this phenomenon (Frost, 2011).

Table Summary impact statement

What is known about support groups

- They are recognized as an effective forum for providing - Psycho-social support for people with chronic illness/long term conditions such as AMD.
- Other generic studies have shown the value of support groups as a protective factor for both health institutions and families through - community, mutuality and information
- Driving factors to attend support groups
- However, there is little to no evidence of views of first time attenders to AMD specific support groups and how to increase traffic to such groups.

What this study adds

- This study sheds light on participants' expectations of and motivations for attending AMD support groups.
- It highlights the organiser, format and environment as key drivers for attending the groups beyond the research.
- Awareness creation should be a collaborative approach between organisers, group members, health care professionals, and third sector organisations. Healthcare professionals have an opportunity to provide information at diagnosis and throughout the treatment phase. Similarly they can sign post individuals to the Eye clinic liaison officer for further details around supportive elements. Third sector organisations can be part of the awareness campaign by placing accessible posters in strategic areas.
- AMD support groups are a safe, non judgemental space that promotes participation through mutuality, which fosters a sense of belonging.

5.10 Implications for Practice

Fundamentally, this study created an awareness of local AMD support groups that participants who had been diagnosed and living with AMD for some time did not know about. This highlights a significant problem in the information provision chain from the time of diagnosis and throughout their treatment journey. These information deficiencies impact on individuals' ability to access adequate or needed support, thus impacting their quality of life. Hence, it can be argued that there is a need to create awareness for and raise the profile of AMD support groups and this process should start at the point of diagnosis. There should be a collaborative effort between organisers, health care professionals and third sector organisations in raising awareness beyond the diagnostic and treatment phase. Support group organisers also need to strike a balance between information giving, sharing experiences and engaging in recreational based events to make the groups more attractive and retain current members. It's also not lost on the researcher that another key finding of this research was the participants' view of the organisers. Their skills, expertise and contributions added value to the groups and first time attenders identified this as one of the factors that was encouraging and driving them to return and bring along new faces.

5.11 Conclusion

In conclusion, first time attenders to AMD support expressed positive views and experiences of the groups. Their motivations to attend were specific to their AMD diagnosis, a desire to gain knowledge through mutual sharing of experiences with individuals they mutually identified with. The desire to socially connect with others with a similar condition to break the loneliness cycle and feelings of isolation. These expectations were met. The format of the groups was well received, particularly the inclusion of experts. In essence striking a balance between condition driven agenda information and practical information - living a life of co-existence with the condition outside its limitation. In regards to awareness creation, there needs to be a collaborative effort between organisers, health care professionals and third sector organisations (e.g. macular society) to raise the profile for support groups. This starts with health care professionals at diagnosis and throughout the treatment process. Consequently, organisers need to ensure groups provide a supportive environment premised on information giving and sharing experiences, mutuality and breeds a sense of community and belonging.

The next chapter aims to inform and provide the reader with an overview discussion of this programme of work.

CHAPTER SIX: Discussion and Conclusion

6 Introduction

The main research questions for this programme of work were:

- What does the evidence tell us about the consent to treatment process for patients with wet AMD?
- What are the barriers and facilitators for adequate, good quality information provision in the consent to treatment process for this group?
- What information about age-related macular degeneration (AMD) is useful to patients on diagnosis and helps them manage the condition over time?
- How is consent to treatment negotiated and obtained during the consultation?
- What are patients' views on engaging with organised support groups?
- How can we boost attendance at organised support groups?

Throughout the studies presented in chapters 3, 4 & 5, I have aimed to answer these research questions using qualitative methods underpinned by an interpretivist approach. The aim of this chapter is to consider this programme of work as whole and its implications for the development of theory and practice. Firstly, I will summarise the key findings of each of the chapters and then discuss how these finding can contribute to health psychology theory and evidence based practice. I will then discuss some of the practical implications that emerged from this research, possible limitations and I will introduce possible areas for further research. Lastly, I will reflexively cogitate my role within the research process and end with concluding comments.

6.1 Summary of Findings

The meta-synthesis, aimed to explore and gain a deeper understanding of the consent to treatment process; more specifically gain an insight into the type and quality of information that allows patients to make an informed decision to consent to treatment. However, the search conducted for this review and synthesis did not yield any relevant results in this area, making for a strong rationale for empirical work of this phenomenon to be carried out as part of this programme of work and future studies to address the gaps in knowledge e.g. (i) the presentation of the information, (ii) the condition in which it is given, and (iii) how clinicians assess a patient's understanding.

The second study (Chapter 3 - Evaluation of Materials) aimed to address gaps in knowledge as highlighted in the summary for chapter 2, by evaluating information materials currently available to AMD patients and determine their preferences, as well as exploring in-depth their perceptions of and experiences with these materials. A two-step approach was used to address the aims of this study. The first step involved conducting three focus groups with AMD patients to get their views of and determine their preferences of the take away information materials presented for evaluation (for example, to identify the best features of the materials or those features that need improving to enhance accessibility). The second step involved conducting semi-structured individual interviews with a view to gaining a broader understanding of AMD patients' perceptions of and experiences with the information materials currently available to them. The chapter presented master four themes and three sub themes which were evident across participants' accounts; (a) AMD journey with take away information materials. This theme had three subthemes: (1) content and design of information materials, (2) Relevance of the information materials and impact on experiences, (3) User preferences: improving accessibility; (b) Clinicians as a source of information: an interpersonal dimension; (c) Supportive information giving for a degenerative condition; (d) Proactive use of technology. These themes are interconnected as observed in participants' accounts around the concept of accessibility. They do not occur separately but are elements AMD patients perceive and experience across multiple dimensions of their lives living with the condition and are largely influenced by the amount of sight one has. A key findings in this study is the misalignment in guidelines, policy and patient preferences and what is produced for them. The implication of which - is inaccessibility of take away information materials for AMD patients which impacts understanding of the condition and ability to make informed decision relating to their treatment, access to adequate support or manage it better over time.

The third study (Chapter 4- Diagnostic Consultations), explored experiences of information provision during a diagnostic consultation. In particular, gaining multi-perspective insights into patients' and clinicians' experiences and views on treatment decision making, as well as ascertain the method (s) used to gain consent to treatment and determine clinicians and patients' priorities and preferences regards information provision, treatment and visits to the clinic. As such, a two-step approach was used to address the aims of this study. The first step involved the researcher observing the interaction between the patient and clinician during the diagnostic consultation to get an understanding of the dialogue, depth and quality of information provided. The second step involved conducting semi-structured individual interviews with a view to gaining a broader understanding of AMD patients and clinicians ' perceptions and experiences of information provision at diagnosis, including discussions around treatment options, methods of consent, determining their priorities and preferences and overall experiences in the clinics. The chapter presented seven master themes and one sub-theme:

- For the patients – four superordinate themes were generated: (a) Impact of emotions on processing information at diagnosis; (b) Diagnostic engagement: the unmet needs; (c) the decision maker – 'navigating' towards consenting to treatment; (d) Language as a barrier to understanding diagnosis.
- For the clinicians – three superordinate themes were generated: (a) Clinician perceived-Patient-centeredness information giving, with sub theme (i) Emotional awareness and adaptability; (b) steering patients towards the 'right' decision; and (c) Working through systemic barriers.

For patients there was an explicit focus on trying to understand the diagnosis, treatment available and prognosis. However, there was an expressed frustration across their narratives that these information needs were not adequately met. Thus, consent was not necessarily a negotiated phenomenon premised on knowledge transfer by clinicians, but rather driven by elements such as, fear of losing their sight and independence, quality of life related contexts e.g. seeing grand children's faces, rather than quantity of life, trust in the clinicians' suggestions, rather than understanding of the suggestions.

Clinicians' priorities were explicitly premised on providing adequate information to patients about their diagnosis and treatment options and prognosis. Their perceived focus was on knowledge transfer, but acknowledged patients views that consenting was not necessarily a result of understanding information provided but the fear of losing sight or trust in the clinician. They acknowledged barriers such as emotional responses to the diagnosis impacted understanding and retention of information provided. There was only method of gaining consent identified that is the written – a systemic barrier due to its inaccessibility to most people diagnosed with AMD. A key finding was the impact of clinicians' interpersonal skills on patients understanding information provided at diagnosis.

The fourth study (Chapter 5 - Support Groups) aimed at exploring perceptions and experiences of individuals diagnosed and living with AMD of support groups in order to raise awareness and better communicate their value to non attenders. As such, a two step approach was employed to address the aims of this study. The first approach was observing the interactive disposition of first time attenders in a support group setting and the second approach was sitting down with the individuals for a semi structured interview to gain insights of their experiences and their views of the group e.g.

value, benefits and establish factors that would make continue attending beyond the study. The study present three master themes; (a) “Had I known there were AMD groups locally I would have started attending a long time ago”: A need for awareness creation; (b) Empowerment through mutual identification and mutual sharing; (c) Information Needs - an opportunity to gain new knowledge and consolidate information. Participants positioned support groups as providing a unique sense of community where they mutual identified and felt safe and not judged, information giving and mutually shared experiences, in contrast to isolation, loneliness and lack of awareness and knowledge experienced outside these groups. The elements of contrast identified above were precisely their motivation for wanting to attend an AMD specific support group. Lack of awareness of the support groups was attributed to the lack of information at the time of diagnosis and throughout their treatment journey. The group organiser’s skills and experience was seen as a fundamental element to the general group dynamic and helped create a conducive environment were participants felt relaxed and welcome to share their experiences. Participants cited this as one of the key reasons they would be attending the groups beyond the study, become regular members and raise awareness to other people they know who have the same condition but have never attended on account they do not know of the groups’ existence in their local areas. Awareness creation should be a collaborative effort, between healthcare professionals, third sector organisations and organisers and it must be recognised that it starts at the point of diagnosis and throughout the treatment journey for those with wet AMD.

There are common strands interlinking these studies; deficiency in information that aids understanding of condition; deficiency in knowledge transfer that allows individuals to make an informed decision to consent to treatment of their choice; deficiency in information that allows individuals to access adequate support; and inaccessible information materials. Kinnell and Creaser (2001) agrees with the strands identified in this programme of work, and argued that the information needs of visually impaired individuals and those fully sighted are the same and therefore policies, guidelines and practice needed recalibrating to align and meet the information needs of AMD patients and other visually impaired groups as per findings in chapter 4. The majority of participants were dissatisfied with information provision at diagnosis. Makoul, Arntson & Schofield, (2005) argued that clinicians often over-estimate the amount of information they provide to patients, while some struggle to present information to patients without using medical terminology and/or technical language which subsequently compromises understanding, decision making and consent (Bentley et al. 2012; Jenkins et al., 1999). This is consistent with findings in this programme of work which also highlighted poor interpersonal skills as a barrier for understanding communicated information. Across the studies, participants’ dissatisfaction with information materials was mainly related to accessibility premised on format issues rather than the content. Similarly communicated information was perceived as inadequate by participants for them to understand their diagnosis, treatment and access relevant support. It can be argued from a health psychology perspective that interventions to effect behaviour change in terms of relational skills at diagnosis are needed to improve the information provision process. We draw on Habermas' theory of communicative action to recommend broadening the content within consultations and shifting the focus to patients' life contexts. Multifaceted interventions for information provision, including teach back, and accessible information materials may enable the creation of an environment that supports genuine patient involvement, better understanding of diagnosis, treatment, and foster participatory decision-making. Furthermore, there needs to be shift in mind set and attitude for organisations that produce information for visually impaired individuals in order for them to produce materials that are research driven and aligned with policy, guidelines and patient preferences, values and needs.

6.2 Contribution to Health Psychology Theory

In this programme of work, I have drawn attention to the importance of understanding and attending to life contexts, when providing information to people with chronic illnesses such as AMD. Health and illness have typically been understood from a biomedical perspective (Welland, 1989). However, this programme of work has challenged concepts based on this perspective, individualistic and paternalistic frameworks, by elucidating the significance of other facets drawing on life context (lifeworld-led) in understanding patients and be able to provide information that is responsive to their needs, preferences and values.

6.3 Contributions to Knowledge about the Experiences of AMD Patients Regarding Information Provision

The themes discussed across the studies presented in this programme of work illustrate the challenges faced by individuals diagnosed and living with AMD regards information provision across multiple dimensions of their journey with AMD. Findings from this programme of work highlights evidence of underlying shared themes, which can be linked to existing research into the experiences of people living with chronic illness in regard to information provision across the psychological and sociological landscape (e.g. Burton et al. 2013; Thetford et al.2015; Nettleton, 1995). Clinicians' behaviours and comments within a diagnostic consultation can influence patients' views about the condition, and about the clinicians themselves, particularly if the information provided is not fully understood (Troughton, Jarvis & Skinner, 2008). Participants across this programme of work, particularly in chapter 4 and 5, highlighted issues with clinicians' relational skills impacting information acquisition. In chapter 5, however participants deconstructed differences between Consultants and nurses' interpersonal skills and capabilities to provide information in manner they understood. Nurses were perceived to be caring, empathetic and better communicators and consultants as the diagnosticians were seen to be somewhat lacking of these attributes. These perceptions of nurses are consistent with literature (Koustopoulou et al., 2009), highlighting nurses' strengths in the information provision matrix. They argued that nurses had the ability to interpret complex information in a more relatable manner for patients to understand diagnosis given and the treatments due. Emotional responses have also been highlighted as a barrier to information acquisition by both clinicians and patients. This is consistent with findings from other studies (Sharp, et al., 1992; Aminzadeh, et al., 2007), disrupts memory (Loftus & Burns, 1982) and retention of information (Scott, 1983; van der Molen, 1999).

This programme of work has been useful in highlighting attitudinal differences between patients and clinicians, their priorities and preferences at diagnosis. It has also highlighted information producers attitude regards materials currently available to this group. For instance, the ECLO argued that sometimes they go for the professional look rather than what meets the needs of the intended target market.

6.4 Limitation of this Programme of Work

The studies presented in this programme of work comprised of largely a Caucasian patient sample. This is perhaps consistent with the higher prevalence rate of AMD in this ethnic group in comparison to other races (Cook et al. 2008). Older adults from black minority ethic groups diagnosed and living with AMD remain an under researched group regards their perceptions and experiences of information provision at diagnosis, treatment and beyond. Research that includes ethnic minorities in relation to this phenomenon could provide cultural insights that could be invaluable when coming up with new strategies to improve information provision within healthcare settings. The clinician participants involved in chapter four of this programme of work where Asian and black minorities respectively.

Use of a qualitative methodology, while ideal for exploratory questions such as those posed in this programme of work, has inherent limitations. The use of a small sample size means that the research study does not make claims to generalisations about all individuals living with AMD's experiences.

Similarly recommendation made in the discussion sections across this programme of work are suggestions rather than directives.

6.5 Practical Implications

Findings in this programme of work, suggest that patients are not receiving adequate information across multiple dimensions of their journey living with AMD. This clearly has a direct impact on their ability to understand their condition, treatment options, associated risks and benefits, and decision making. The lack of information also impacts on their ability to access adequate support (e.g. support groups specific to their diagnosis), particularly for a condition that restricts opportunities for social engagement in a number of ways (e.g. not recognising faces, limited reading, driving), which has a detrimental effect on their subjective well-being.

Findings from the diagnostic consultations highlighted perspectives from both clinicians and patients regarding information provision. For instance, patients did not feel empowered to ask or clarify information provided by clinicians due to the power dynamics, patients' perceptions of what clinicians would think of them, or the lack of meaningful engagement. For example, in chapter 4, Roselyn felt she was rushed and her concerns were somewhat dismissed. Primrose expressed that communication by the clinician was poor and she found it difficult to talk with the clinician. Our findings here corroborate cancer related literature (e.g. DiMatteo, 1998; Murtagh, Furber and Thomas, 2013; Zanini, Sarzi-Puttini, Atzeni, DiFranco and Rubinelli, 2014), which highlighted that clinicians' communicative behaviours during consultation deterred patients from asserting their need for information and explanations; a scenario that often left patients disempowered. Dalma, Zota, Veloudaki et al.'s (2020) generic study conducted across four European countries exploring physician-patient communication identified similar issues. For instance, patients in that study highlighted four elements as barriers that impacted on clinicians' ability to provide adequate information and these included, attitude, emotional, systemic and educational factors. In our study some of these elements resulted in patients' poor understanding of their condition and treatments, meaning that consent to treatment was largely driven by fear of losing sight, as highlighted. This is consistent with Wood, Martin, Carson-Stevens, Elwyn, Precious and Kinnersely's (2016) study on clinicians' perspectives of informed consent for non-emergency surgical procedures, which highlighted that in the absence of adequate information, fear and anxiety can be a driver for patients consenting. While our study contributes to knowledge gaps around presentation of information both written and verbal and the condition or context in which it is given, beyond this there is a need to explore further issues around the consent process to address the gaps in knowledge. This could include exploring how clinicians assess a patient's understanding of information communicated and examining what it is that drives the decision to consent, taking into account individual challenges.

The clinicians' communicative behaviours could be viewed through the lens of Foucault's (1973) concept of power/knowledge. For instance, Foucault saw power and knowledge as inseparable elements and from observing the diagnostic consultations clinicians' priorities were premised on knowledge transfer to patients regarding the presenting problem. Offering a solution to that problem was top of the agenda for clinicians, rather than creating an environment that incorporated both the clinician agenda and the patient agenda. Stewart and Roter's (1997) consultation model advocates for exactly that: an interactive exchange that fosters consensus in terms of understanding diagnosis, treatment and shared decision making to reach authentically informed consent to treatment (Mehay, Beaumont, Draper, Lamb, Moulton & Kenny 2021). As such, within a consultation the concept of information or knowledge exchange should be broadened to encompass a range of physical, social, psychological, affective and communicative variables relevant to the interaction and individual needs of the patient, in other words, patient-centred consulting (Engel, 1977; Balint, 1968; Pendleton, 1983; Byrne & Long, 1976; Levenstein, McCracken, McWhinney, Stewart & Brown, 1986; Middleton, 1989; Stewart & Roter, 1997).

Clinicians in our study acknowledged that patients may perceive their encounters at diagnosis as unhelpful or unsatisfactory for reasons ranging from poor information provision to perceived clinician attitudes about them. Our findings here are consistent with findings from cancer related literature and beyond (e.g. Korfage, Audrey, Hak, Blazeby, Abel and Campbell, 2013; DiMatteo, 1998; Murtagh, Furber and Thomas, 2013; Zanini, Sarzi-Puttini, Atzeni, DiFranco and Rubinelli, 2014). There is a need for clinicians to adapt communication styles that enable them to provide adequate information that is premised on patients' life contexts - their needs, preferences and values. This will help improve patients' understanding of AMD, treatments options and their ability to access support systems that meet their needs to manage their condition better over time. Our findings combined with this other literature relating to a number of chronic illnesses suggests there is a strong need for clinicians to engage in training that helps them improve their interpersonal skills in order to create positive experiences for patients at diagnosis and beyond. It can be argued here that by accessing relevant training clinicians can improve their communicative abilities to cater for individuals with different capabilities, impairments, levels of knowledge and other socioeconomic factors which might impact their ability to engage with their health management.

This research showed that information materials currently available to AMD patients do not meet their needs in the context of the quality of the paper that some are printed on (e.g. gloss), the font sizes. A clear example of this is seen in Grace's account in chapter 3, were she highlights accessibility challenges with the above issues, but appears satisfied with the content which they deemed adequate to understand their diagnosis. This finding is consistent with literature on information materials in healthcare (Beverley, et al. & Barber, 2011; Coulter et al. 2006). There is a need to provide information in alternative formats. However, the majority of participants were proactively using technology to access information pertinent to their well-being. For instance, they used technology to maintain a level of connectedness socially as well as combatting some of these four plagues; boredom, loneliness, helplessness and decline of mental skills. It can be argued here that use of technology in the face of a life altering condition allowed them to maintain a level of functionality, privacy and independence. Our findings corroborate previous studies (Cacciopo & Cacciopo, 2014; Comyn, Olsson, & Guenzier, 2006; Simpson, 2009), whose authors have focused on older adults with disabilities not specific to AMD and suggested that the use of technology to access information could, among other things, help this group live autonomously, cope and manage the challenges of daily living.

Support groups were positioned as providing a unique sense of community where participants felt safe and not judged, information giving and sharing experiences, in contrast to isolation, loneliness and lack of awareness and knowledge experienced outside these groups. This is consistent with findings from other generic studies (Kessler et al. 2014; Doherty, 2004; McSharry et al. 2018; Robert, Piper, Denny & Cuddleback, 1997; Ussher et al. 2006; Ussher, Butow, Kirsten, 2008; Tise, 2015). There is a need for clinicians to raise awareness about these condition specific groups and it starts by providing them with information about the groups at diagnosis and sign posting the patients to the ECLO to get pertinent information about groups in their respective local areas. Third sector organisations can play a significant role, by placing posters in strategic areas of the eye clinic. Participants in this programme of work, highlighted that they had not received information about support groups at diagnosis nor throughout their treatment journey. This research created an awareness of AMD support groups in local areas where patients living with AMD did not know of their existence. For example, Mariam in chapter five started that had she known about the group in her local area she would started attending a long time ago. There was a huge appreciation of the group format and organisers by participants. The organiser’s skill and experience was a fundamental element to the general group dynamic and helped create a conducive environment were participants felt relaxed and welcome to share. The balance between information giving (e.g. invited experts) and mutual sharing of experiences (struggles, social, advice and practical information), was appreciated by first time attenders, with all expressing they intended continue attending the groups beyond this study and some were going to bring friends who had AMD, but never attended support groups to the next meeting. This corroborates findings from cancer literature (Robson, 2018; Mc Sharry, Dinneen, Humphreys, et al. 2018), that argued that when attenders are satisfied with format, group dynamics and organisers, they naturally would continue attending future groups and voluntarily become part of the awareness drive by extending invites to people in their circle who may be in a similar situation. However, Ivers et al. (1998) argued that environments where also a key determinant for older adults intending to attend support groups regularly. They stated that if the environment was perceived unhelpful or chaotic, attenders were unlikely to return. This is consistent with findings from other studies (e.g. Sarason et al., 1987; Ruehlman & Karoly, 1991; Chang & Schaller, 2000; Cimarolli & Boerner, 2005) that highlighted barriers that include; negative forms of behaviours, such as criticism, hostility, and insensitivity, impacted potential attenders from accessing support groups or continuing to attend. It can be argued from a social selective viewpoint (Carstensen, 2006), that in such instances some individuals, including those with AMD, would re-evaluate their position and invest more in close support networks (e.g. family, friends) than such support groups because of the limited future time in older age they may have. In this study however, participants reported positive experiences were mutual identification and mutual sharing, was a point of convergence.

Various theories can be drawn on to understand the phenomenon of and in support groups. In the present study the social comparison theory (Festinger, 1954) can be used to understand some of the mechanisms employed by participants in support groups. Comparison allowed participants to self –evaluate against others using information shared to build capacity for coping and managing the condition. In a sense, it helped them validate their feelings of living with AMD, normalise illness, improve self-esteem and encouraged positive health behaviours –through practical information received (Davison et al. 2000). Narrative theory, where AMD support groups were viewed a safe and mutually supportive environment where biographical work is conducted and identity re-evaluated (Yaskowich & Stam, 2003). Biographical work, in the sense that this was an illness specific support group were they mutually shared experiences and mutually identified with each other. It ca be argued here that these theoretical descriptions are not mutually exclusive, as each provides a framework to partially interpret and understand our findings. Majority of participants narratives were positive in their views of AMD support groups, they positioned them as a safe, non judgemental environment that fostered a sense of community, information giving and mutual sharing of experiences. In contrast to feelings of isolation, loneliness and lack of awareness and knowledge experienced outside these groups. Experiences in the groups gave participants a sense of empowerment and agency in relation to self, AMD and others.

There is a need for follow up studies to explore the experiences of these first time attenders to support groups over time to gain in depth understanding of the perceived benefits to their subjective well-being attending AMD specific support groups.

The studies in this programme of work contribute to the advancement of current literature around information provision for sight impaired individuals, particularly AMD throughout their illness journey. However, there are areas that would need further exploration in order to address and meet the information needs of this group to this extent I make submissions for future research below.

6.6 Future Research

Future research could add to findings from this programme of work in a number of ways. In this research, it was evident that there is a need for clinicians to re-evaluate the way they provide information to patients and engage in training to improve their interpersonal skills.

There is a need to develop methods to transfer knowledge to AMD patients at diagnosis premised on their life contexts to ensure they adequately understand their diagnosis, treatment, support available and its implications on their lifeworld.

Future studies could explore the role of accompanying carers/families to diagnostic consultations in the information provision matrix and establish their experiences and the part they play in the decision making process.

Future studies also need to explore how clinicians assess a patient’s understanding of information provided at diagnosis or during treatment assessment consultations. This could also extend to establish elements that drive decision making to consent to treatment.

Where information materials are concerned there is a need explore whether the reading capacity of AMD patients improves once certain characteristics of information materials have been improved.

6.7 Reflexivity

As a researcher, interviewer and analyst it is important for me to acknowledge how my role and involvement in this research has shaped the outcomes of this programme of work. As such, after establishing rapport with participants at commencement of the studies, what was striking to me was how they positioned me as a potential source of information for some of the elements they had not fully understood about their condition. In hindsight this may have been precipitated by the fact recruitment was mostly done through the eye clinic. They asked a wide variety of questions mainly about treatments, causes, support and complimentary interventions to slow down deterioration. I believe these aspects were important to participants and came out strongly in the research in terms of highlighting the persisting issues around information provision.

The information shared during interviews by participants made me feel I was part of their experiential journey with AMD, and this is something I appreciated and found value in. After all, the primary aim of the interviews was to gain an in depth understanding of their perceptions and experiences of information provision across multiple dimensions of the lives.

Using critical narrative analysis was largely a positive experience. However, as a novice using this method of analysis for the first, it did feel at times as if the method was too long, complex and protracted to enable a succinct distillation of useful findings. In carrying out the analysis there was a conflict felt between looking across a group to find common themes and yet privileging the subtleties of each individual. In reflection, Langdridge (2007)'s worked example, outlining the use of CNA in a single case study, does end the chapter with recognition that it is a particularly demanding method to use. Given the nature of elements this programme of work explored, I feel that the methods, while ambitious, have offered illumination that may be difficult to replicate using other methods.

Having a working group in place was a great comfort. This group helped shape aspects of this programme of work, from putting together the interview questions to being a great sounding board for ideas and discussing preliminary findings. Each expert brought something unique to the table in terms of guidance and it is a research strategy that I feel adds value to the findings.

It is my hope that this research adds value to a seemingly under researched area and that it can contribute to evidence based practice and improve provision of information in the clinician – patient dyad at diagnosis and beyond. I believe the language I have used throughout this programme of work is accessible to all readers who may be unfamiliar with the epistemological and ontological stances that underpin my chosen research methods and programme of work.

6.8 Concluding Comments

This programme of work is an important step towards understanding the perceptions and experiences of information provision in whatever format for individuals diagnosed and living with AMD. The use of various qualitative methods to research this phenomenon has allowed me to develop an understanding of these individuals’ experiences. In particular, the impact it had on how they understand their own condition and treatment, and how lack of adequate information limited their ability to access needed support with regards to support groups. I have been able to highlight these experiences contextually deriving from participants’ narratives and I argue that clinicians need to broaden the content within consultations and shift the focus to patients’ life contexts, to ensure information provided meets their needs, preferences and values. Multifaceted interventions for information provision, including teach back, and accessible information materials may enable the creation of an environment that supports genuine patient involvement, better understanding of diagnosis, treatment, and fostering participatory decision-making.

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Appendices

Appendix A Patient Participant Information Sheet

Participant Information Sheet (PIS) - Patients only

Living with age-related macular degeneration: a qualitative study of consultations and support groups (Parts 2 & 3 Patients).

Chief Investigator: Mr Tawanda Pendeke
(pendetf9@aston.a.cuk)

Academic Supervisor: Dr Rachel Shaw
(r.l.shaw@aston.ac.uk; 0121 204 4050)

We would like to invite you to take part in our research study being conducted at Birmingham and Midland Eye Centre, part of Sandwell and West Birmingham Hospitals NHS Trust. This study forms part of a PhD degree undertaken at Aston University by Tawanda Pendeke and a team of researchers.

Before you decide whether to participate, please read the study information provided in this leaflet. This explains why you have been asked to participate, why the research is being carried out, and what it will involve for you if you wish to participate. Please feel free to talk to the researcher, Tawanda, who will talk you through the information sheet. Tawanda's contact details along with those of the research team are provided at the end of this leaflet. Please talk to others – family or friends- about the study if you wish.

What is the purpose of the study?

We would like to understand what it is like to live with Age-related Macular Degeneration (AMD). In particular we would like to know about your views, thoughts and experiences of communicating with clinicians, and the information they provide you with – to help you understand your diagnosis and the treatment options that may be available.

The aim of this study is to help improve provision of information by clinicians to empower AMD patients to make informed decisions about their condition (e.g. treatment and support). Better understanding leads to better choices.

Why have I been invited?

You have been invited because you:

1. Have AMD;
2. Have visited the Birmingham Midlands Eye Centre (BMEC) within the Sandwell & West Birmingham NHS Trust; and
3. Are 65 years of age or older.

Do I have to take part?

No. It is up to you to decide whether to take part in the study.

If you agree to take part, we will then ask you to sign a consent form.

For Part 2 of the study you are consenting to:

(i) The researcher observing and recording your consultation.
(ii) Participate in a recorded interview (with the researcher) post-consultation at a date, time and place agreed between yourself and the researcher.

For Part 3 of the study you are consenting to

(i) Observation of attendance at a support group.
(ii) A recorded interview post support group.

You are free to withdraw at any time, without giving a reason. Withdrawing or not taking part in the study will not affect the standard of treatment and care you receive.

What will happen to me if I take part?

Part 2: Recording the Consultation and Follow-Up Interview:

i. Recording the Consultation**:** with your permission, the researcher, Tawanda will observe and record the consultation between you and the clinician. The purpose of recording this consultation is to gain an understanding of the quality of information being communicated to you. This will be followed by an interview with the researcher, Tawanda, at a time and date that is convenient for you. We are particularly interested in learning about AMD patients' views, thoughts and experiences about the information that is communicated to them and how it helps them understand their condition and make informed decisions about treatments and accessing support.

ii. Follow-up Interview: After the consultation and with your permission, the researcher will ask you some questions about your day-to-day activities and specifically about how your vision impairment impacts on your day-to-day life. The research team is particularly interested in what information you have received from the clinicians during the consultations and whether the information that you have been given or have access to which:

   - Helps you understand the diagnosis, treatment and support options available to you (although not all patients are suitable for treatment).
   - Helps you understand how AMD is likely to progress over time.
   - Provides the information that you need to cope with AMD as it progresses.

   - Whether information has been obtained from sources other than the clinic or clinicians.

Part 3: Support group and Follow-Up Interview:

i. Support Group: With your permission we will arrange and observe your attendance at a local support group (Macular Society or Birmingham Focus). The purpose of observing your participation in a support group is to explore the benefits support groups - as an information resource.

ii. Interview: If you agree, after the Support Group, the researcher will contact you by telephone to arrange a date and time to visit you either in your own home or somewhere else you feel comfortable (or in a quiet room at Birmingham Midlands Eye Centre). The purpose of the interview is to gain an understanding of your perceptions and experience(s) of attending a support group and to find out if support groups are useful as an information resource in enabling AMD patients adjust and manage their condition over time. The interview will last approximately 1 hour (depending on how much you have to say). During this time, breaks will be provided as and when required. You may stop taking part in the study whenever you like without giving a reason and this will not affect the standard of treatment and care you receive.

If there are any questions (in the interviews) you would rather not answer, you are free to say so and that is fine.

With your permission, the researcher will audio-record the conversation so that the researcher can listen to it afterwards and not have to take notes at the time of the interview.

What will happen if I don’t want to carry on with the study?

You may withdraw from the study at any time without giving a reason and this will not affect the level of care you receive.

If you do decide to withdraw, we will still use the information you have given us unless you tell us otherwise.

What will happen to the information that I provide?

The researcher will transcribe (type-up) the audio recordings word for word and then anonymise them. This means that your name will be replaced by a false name.

After the transcripts have been anonymised, the researcher will analyse the content of the transcripts. The transcripts may also be shared with the Research Working Group, but because the transcripts will be anonymised, it will not be possible for anyone to identify you from anything that you may have said that is later used in a report.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential; your name will be replaced by a false name which will be used in all documentation. Additionally, your address will be removed from all information that is transferred from the hospital/clinic and.

All recordings from the consultations and interviews will be stored on a password protected computer at the University, only accessible to the researcher and supervisor; copies of audio recordings stored on the recording device will be destroyed after the recordings have been typed up and checked for accuracy.

Paper-based data will be filed in a Site File which will be kept in a locked cabinet in a secure room at xxxxx.

We will keep the anonymised data for up to 6 years after the study has finished.

What will happen to the results of the study?

You will be invited to attend an event at which we will give an overview of the study findings. We will also send a brief report of results to all participants. We intend to circulate our findings to interested parties including Sandwell & West Birmingham NHS Trust, Macular Disease Society, Birmingham Focus, RNIB, local and national Low Vision Clinics, Ophthalmologists’ and GPs. We will also report findings to scientific meetings and submit findings for publication in scientific journals. As mentioned earlier, all information that you provide will be anonymised before it is report, published or shared with colleagues.

Who is organising and funding the research?

The research is funded by a partnership between ARCHA (Aston Research Centre for Healthy Ageing) at Aston University and Sandwell & West Birmingham NHS Trust.

Who has reviewed the study?

The study proposal was reviewed by independent colleagues at Aston University and then assessed formally by the Sandwell & West Birmingham NHS Trust Research & Development department. In addition, all research in the NHS is looked at by an independent group of people who sit on a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by the xxxxxxxxxxxx xxxxxxxx Research Ethics Committee.

What do I do if I have a concern?

If you have any concerns about the way in which the study was conducted, you should in the first instance, contact any of the team listed below. They will do their best to address your concerns but if they are unable to resolve the concerns you raise or you wish to make a complaint, you can contact the Aston University Director of Governance, Mr John Walter on j.g.walter@aston.ac.uk or telephone 0121 204 4869.

If you would like independent advice about participating in research you can contact the NHS Patient Advisory Liaison Service (PALS) at Sandwell and West Birmingham Hospitals NHS Trust. Tel: 0121 507 5836, 10am – 4pm, Monday– Friday.

Further information and contact details

If you would like further information about the study please contact:

Chief Investigator (Researcher)	Tawanda F. Pendeke T: 07838301156 E: pendetf9@aston.ac.uk
Academic Supervisor	Dr Rachel Shaw T: 0121 204 4050 E: r.l.shaw@aston.ac.uk
Clinical Team Contact	Ms Bushra Mushtaq E: bushramushtaq@nhs.net
Clinical Team Contact	Prof Jonathan Gibson T: 07833478682 E: j.m.gibson@aston.ac.uk

Appendix B Clinician participant information sheet

Participant Information Sheet (PIS) - Clinicians only

Living with age-related macular degeneration: a qualitative study of consultations and support groups (Part 2).

Chief Investigator: Mr Tawanda Pendeke

(pendetf9@aston.a.cuk)

Academic Supervisor: Dr Rachel Shaw

(r.l.shaw@aston.ac.uk; 0121 204 4050)

We would like to invite you to take part in our research study being conducted at Birmingham and Midland Eye Centre, part of Sandwell and West Birmingham Hospitals NHS Trust. This study forms part of a PhD degree undertaken at Aston University by Tawanda Pendeke and a team of researchers.

Before you decide whether to participate, please read the study information provided in this leaflet. This explains why you have been asked to participate, why the research is being carried out, and what it will involve for you if you wish to participate. Please feel free to talk to the researcher, Tawanda, who will talk you through the information sheet. Tawanda’s contact details along with those of the research team are provided at the end of this leaflet.

What is the purpose of the study?

We would like to understand what it is like to live with Age-related Macular Degeneration (AMD). In particular we would like to know about patients’ views, thoughts and experiences of communicating with clinicians, and the information they provided you with – to help them understand their diagnosis and the treatment options that may be available.

The aim of this study is to help improve provision of information by clinicians to empower AMD patients to make informed decisions about their condition (e.g. treatment and support). Better understanding leads to better choices.

Why have I been invited?

You have been invited because you:

4. Are a Clinician that deals with patients that have AMD;
5. Currently working at the Birmingham Midlands Eye Centre (BMEC) within the Sandwell & West Birmingham NHS Trust.

Do I have to take part?

No. It is up to you to decide whether to take part in the study. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Withdrawing or not taking part in the study will not affect your rights and practice within the clinic.

What will happen to me if I take part?

Part 2: Recording the Consultation and Follow-Up Interview:

iii. Recording the Consultation**:** with your permission, the researcher, Tawanda will observe and record the consultation between you and the patient. The purpose of recording this consultation is to gain an understanding of the quality of information being communicated to the patient. This will be followed by an interview with the researcher, Tawanda, at a time and date that is convenient for you. We are particularly interested in learning about your views, thoughts and experiences about how well AMD patients receive and understand the information you communicate to them and how it helps them understand their condition and make informed decisions about treatments and accessing support.

iv. Follow-up Interview: After the consultation and with your permission, the researcher will contact you by telephone to arrange a date and time for an interview in a quiet place at Birmingham Midlands Eye Clinic. The purpose of the interview is to gain an understanding of your perceptions and experiences providing information to AMD patients relating to their diagnosis, treatment and support needs. The interview will last approximately 1 to 2 hours. The researcher will ask you some questions about your experiences in the consultations disseminating information to AMD patients. Specifically about time spent with patients in consultation, methods of communication, patients understanding, language and quality of information given. The research team is particularly interested in what information you provide to the patients during the consultations and whether the information that you provide helps them to:

- Understand their diagnosis, treatment and support options available to them (although we understand not all patients are suitable for treatment).
- Understand how AMD is likely to progress over time.
- Understand how they can manage and cope with AMD as it progresses.

- Understand what signs to look out if condition is deteriorating further and what steps they should take.

NB. If there are any questions (in the interviews) you would rather not answer, you are free to say so and that is fine.

With your permission, the researcher will audio-record the conversation so that the researcher can listen to it afterwards and not have to take notes at the time.

What will happen if I don’t want to carry on with the study?

You may withdraw from the study at any time without giving a reason and this will not affect the level of care you receive. If you do decide to withdraw, we will still use the information you have given us unless you tell us otherwise.

What will happen to the information that I provide?

The researcher will transcribe (type-up) the audio recordings word for word and then anonymise them. This means that your name will be replaced by a false name.

After the transcripts have been anonymised, the researcher will analyse the content of the transcripts. The transcripts may also be shared with the Research Working Group, but because the transcripts will be anonymised, it will not be possible for anyone to identify you from anything that you may have said that is later used in a report.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential; your name will be replaced by a false name which will be used in all documentation. Additionally, your address will be removed from all information that is transferred from the hospital/clinic and.

All recordings from the consultations and interviews will be stored on a password protected computer, only accessible to the researcher and supervisor; copies of audio recordings stored on the recording device will be destroyed after the recordings have been typed up and checked for accuracy.

Paper-based data will be filed in a Site File which will be kept in a locked cabinet in a secure room at Aston University

We will keep the anonymised data for up to 6 years after the study has finished.

What will happen to the results of the study?

You will be invited to attend an event at which we will give an overview of the study findings. We will also send a brief report of results to all participants. We intend to circulate our findings to interested parties including Sandwell & West Birmingham NHS Trust, Macular Disease Society, Birmingham Focus, RNIB, local and national Low Vision Clinics, Ophthalmologists’ and GPs. We will also report findings to scientific meetings and submit findings for publication in scientific journals. As mentioned earlier, all information that you provide will be anonymised before it is report, published or shared with colleagues.

Who is organising and funding the research?

The research is funded by a partnership between ARCHA (Aston Research Centre for Healthy Ageing) at Aston University and Sandwell & West Birmingham NHS Trust.

Who has reviewed the study?

The study proposal was reviewed by independent colleagues at Aston University and then assessed formally by the

Sandwell & West Birmingham NHS Trust Research & Development department. In addition, all research in the NHS is looked at by an independent group of people who sit on a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by the Yorkshire & the Humber - Bradford Leeds Research Ethics Committee.

What do I do if I have a concern?

If you have any concerns about the way in which the study was conducted, you should in the first instance, contact any of the team listed below. They will do their best to address your concerns but if they are unable to resolve the concerns you raise or you wish to make a complaint, you can contact the Aston University Director of Governance, Mr John Walter on j.g.walter@aston.ac.uk or telephone 0121 204 4869.

If you would like independent advice about participating in research you can contact the NHS Patient Advisory Liaison Service (PALS) at Sandwell and West Birmingham Hospitals NHS Trust. Tel: 0121 507 5836, 10am – 4pm, Monday– Friday.

NB: Clinicians have a duty of care to promote patient safety through good and ethical practices at all times. If the researcher observes poor or dangerous practice due process of disclosure to the Clinical supervisor will be taken.

Further information and contact details

If you would like further information about the study please contact:

Chief Investigator (Researcher)	Tawanda F. Pendeke T: 07838301156 E: pendetf9@aston.ac.uk
Academic Supervisor	Dr Rachel Shaw T: 0121 204 4050

	E: r.l.shaw@aston.ac.uk
Clinical Team Contact	Ms Bushra Mushtaq E: bushramushtaq@nhs.net
Clinical Team Contact	Prof Jonathan Gibson T: 07833478682 E: j.m.gibson@aston.ac.uk

Appendix C Patient Consent Form

CONSENT FORM- Patients only

Personal Identification Number for this study: _____________

Living with age- related macular degeneration: a qualitative study of consultations and support groups – Part 2 (i) & (ii)

Name of Chief investigator: Mr Tawanda Pendeke

(pendetf9@aston.ac.uk)

Name of Project Supervisor: Dr Rachel Shaw

(r.l.shaw@aston.ac.uk)

Please initial box

1. I confirm that I have read and understood the Participant Information Sheet (version...) dated............ for the above study. I have had the opportunity to consider the information, ask the	

Researcher some questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I agree to the consultation being observed and audio recorded.	
4. Following the consultation, I agree to an audio recorded interview with the Researcher.	
5. I agree that anonymised word for word extracts from my recorded conversations with the Researcher can be used in any reports or presentations about the study findings.	
6. I agree to take part in the above study	

Participant name	**Signature**	**Date**
Person taking consent	**Signature**	**Date**

When completed: 1 copy for research participant; 1 copy for researcher.

Appendix D Clinician Consent form

CONSENT FORM –Clinicians only

Personal Identification Number for this study: ____________

Living with age- related macular degeneration: a qualitative study of consultations and support groups – Part 2 (i) & (ii)

Name of Chief investigator: Mr Tawanda Pendeke

(pendetf9@aston.ac.uk)

Name of Project Supervisor: Dr Rachel Shaw

(r.l.shaw@aston.ac.uk)

Please initial box

1. I confirm that I have read and understood the Participant Information Sheet (version...) dated........... for the above study. I have had the opportunity to consider the information, ask the Researcher some questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	
3. I agree to the consultation being observed and audio recorded.	
4. Following the consultation, I agree to an audio recorded interview with the Researcher.	

5. I agree that anonymised word for word extracts from my recorded conversations with the Researcher can be used in any reports or presentations about the study findings.		
6. I agree to take part in the above study		
Participant name	**Signature**	**Date**
Person taking consent	**Signature**	**Date**

Appendix E Participants Positioning in Consultation Room

Part 2 – Pro-forma consultation room observation

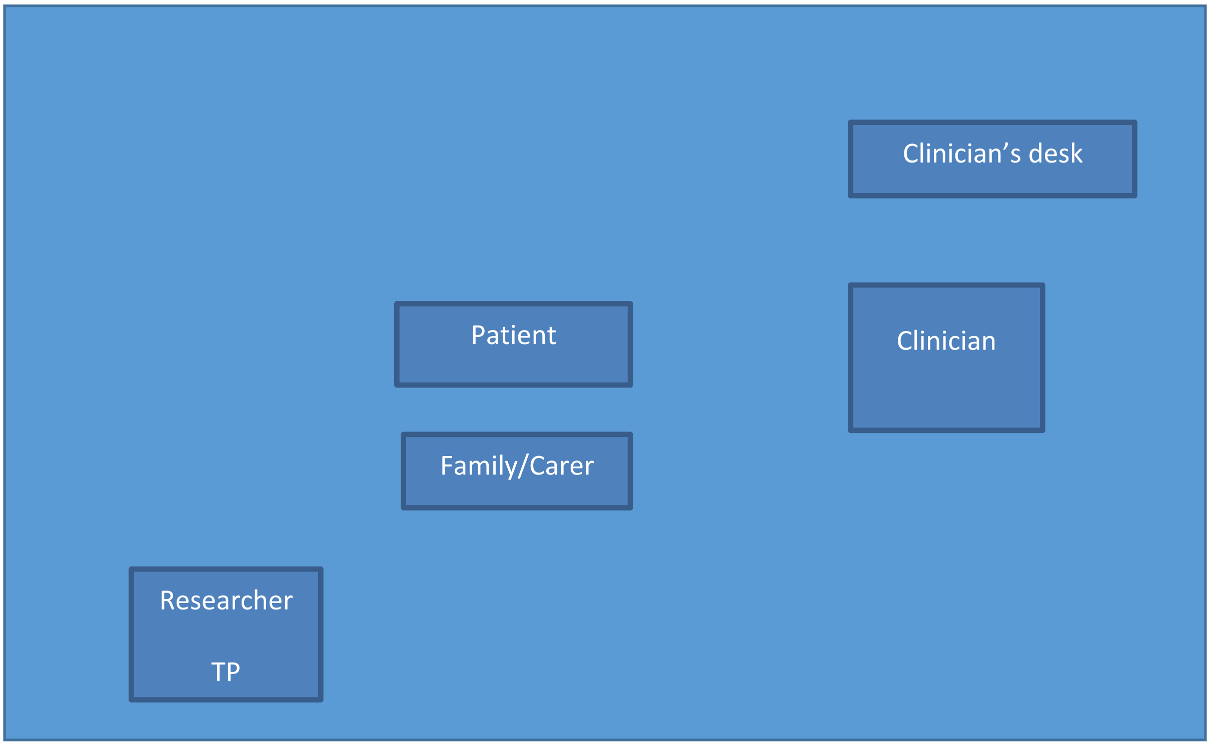


Figure 1

Since the consultation rooms at the clinic are not uniform in terms of size and set up the researcher will do a sketch of the lay out and highlight were patient and clinician will be seated during the consultation and observe how this may impact communication. Above is an example of positioning in the big clinic room.

Appendix F Working group invitation letter

Tawanda F Pendeke
PhD student
Aston University
pendetf9@aston.ac.uk

Project title: Providing better information and support for the diagnosis and treatment of patients living with age-related macula degeneration (AMD).

Dear D M

RE: Invitation to participate in the working group for my research project.

This PhD research project is split into three phases.

Phase 1, will evaluate information materials currently available to AMD patients with the view to identify the best factors of their design and content and to determine whether and how content and formatting could be improved and make them more accessible.

Phase 2, will focus on consent to treatment for AMD. Communication between patients and clinicians during consultation will be recorded. This will be followed by interviewing a sample of both patients and clinicians to get a fuller account of their consultation, its limitations and ideas about how information provision and consent-taking could be improved.

Phase 3, will focus on perceptions of support groups. AMD patients will be invited to attend local support groups organised by Macular Society/Birmingham Focus and will be asked for their thought about it- its venue, other attenders, what happened at the group, information received and so on in order to improve provision for what is a wide age group of patients living with AMD (i.e. those over 65 and the older old, aged over 85).

You are being invited to participate on this group in the studies within the PhD programme of research as an expert. Your expertise maybe required at various stages of the study or may be required throughout. As a member of the working group/management group your knowledge will assist us in developing aspects of the study as we go through.

Please note: As members you are not research participants, but collaborators or co-researchers. This is a virtual group that will aim to meet 2-3 times a year.

Remit of the working group:

- To provide expertise from their own experience to the design/development of different elements of the study
- To provide feedback/comment on materials used in the study, e.g. interview schedules, info materials to be evaluated
- To provide expertise from their own experience on the consultation, diagnosis, and treatment issues for patients, families and clinicians
- To provide expertise from their own experience on the idea of support groups and how to engage people with them
- To help make sense of the data analysis and to link it to implications for practice
- To help develop materials to improve information provision, consultation, info/integration of support group into NHS clinics
- This list not exhaustive, hence other ideas can be discussed to improve information provision for AMD patients.

Working group membership:

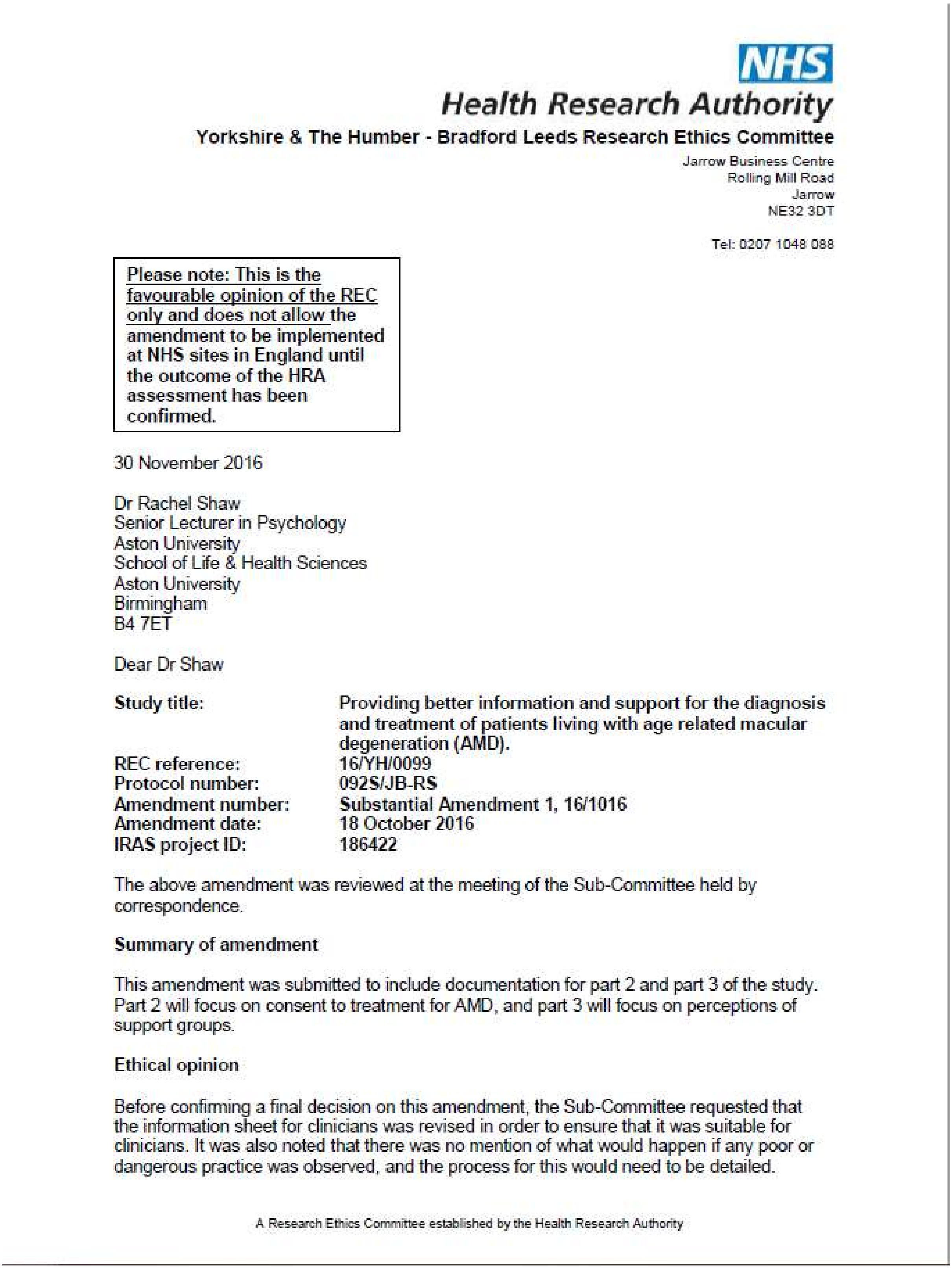
- Supervisory team: Dr Rachel Shaw, Prof Jon Gibson, Bushra Mushtaq
- R&D representative: Dr Jocelyn Bell
- ECLO reps: Steven at BMEC, Lisa Crandon at Sandwell
- Ophthalmic nurse
- Focus reps: Graham Rollison, Sutton Coldfield and/or Andrew, AMD rep
- Macular Society rep:
- Low Vision Clinic rep:
- Expert researcher: Amy Burton (Staffs University)
- Others –
- Patient rep:

I would be grateful if you can join this working group and share your expertise with us in improving aspects of this study.

Many thanks

Tawanda F. Pendeke

Appendix G Ethical Approval



NHS
Health Research Authority
Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Tel: 0207 1048 088

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

30 November 2016

Dr Rachel Shaw
Senior Lecturer in Psychology
Aston University
School of Life & Health Sciences
Aston University
Birmingham
B4 7ET

Dear Dr Shaw

Study title:	**Providing better information and support for the diagnosis and treatment of patients living with age related macular degeneration (AMD).**
REC reference:	**16/YH/0099**
Protocol number:	**092S/JB-RS**
Amendment number:	**Substantial Amendment 1, 16/1016**
Amendment date:	**18 October 2016**
IRAS project ID:	**186422**

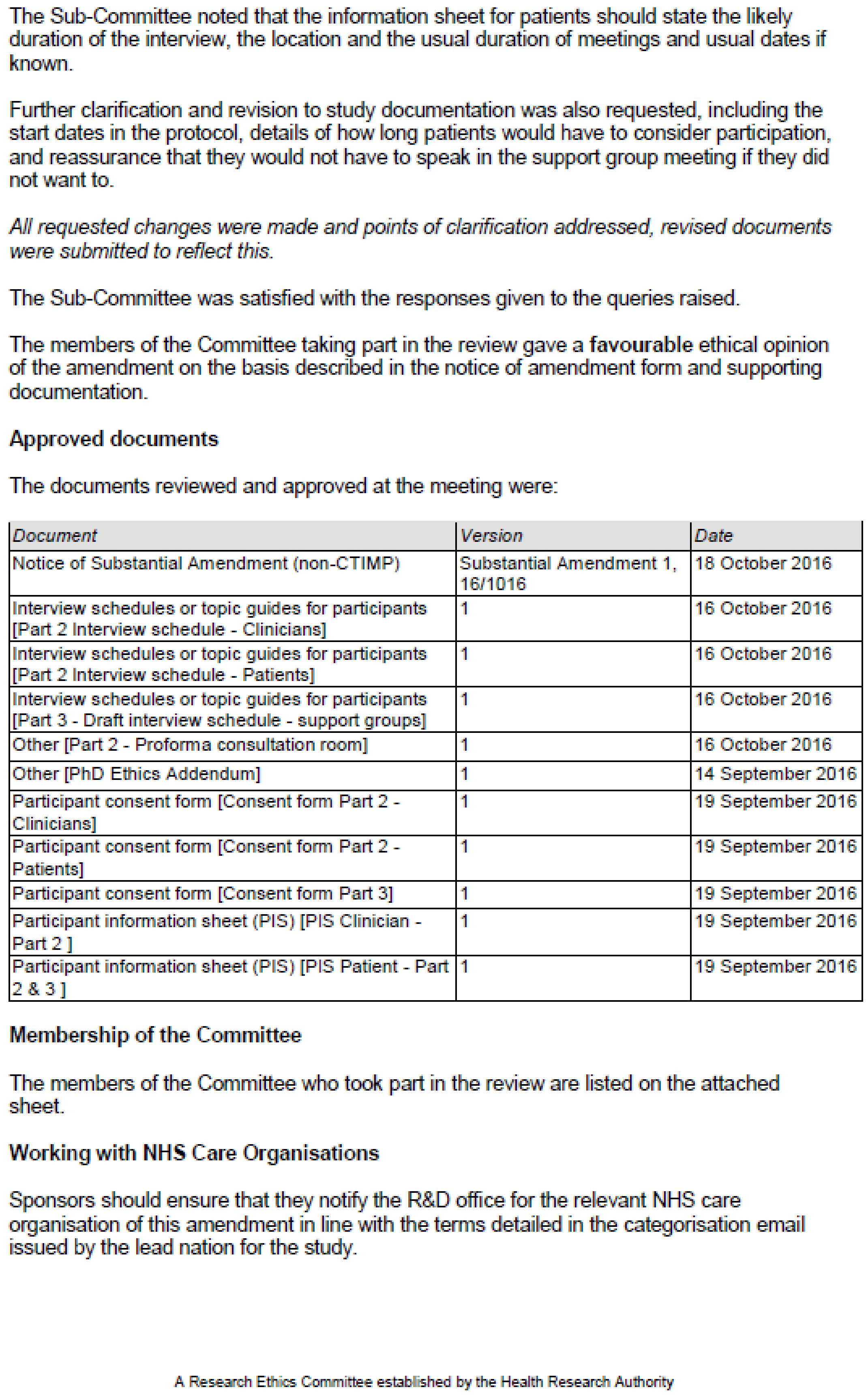
The above amendment was reviewed at the meeting of the Sub-Committee held by correspondence.

Summary of amendment

This amendment was submitted to include documentation for part 2 and part 3 of the study. Part 2 will focus on consent to treatment for AMD, and part 3 will focus on perceptions of support groups.

Ethical opinion

Before confirming a final decision on this amendment, the Sub-Committee requested that the information sheet for clinicians was revised in order to ensure that it was suitable for clinicians. It was also noted that there was no mention of what would happen if any poor or dangerous practice was observed, and the process for this would need to be detailed.



The Sub-Committee noted that the information sheet for patients should state the likely duration of the interview, the location and the usual duration of meetings and usual dates if known.

Further clarification and revision to study documentation was also requested, including the start dates in the protocol, details of how long patients would have to consider participation, and reassurance that they would not have to speak in the support group meeting if they did not want to.

All requested changes were made and points of clarification addressed, revised documents were submitted to reflect this.

The Sub-Committee was satisfied with the responses given to the queries raised.

The members of the Committee taking part in the review gave a **favourable** ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 1, 16/1016	18 October 2016
Interview schedules or topic guides for participants [Part 2 Interview schedule - Clinicians]	1	16 October 2016
Interview schedules or topic guides for participants [Part 2 Interview schedule - Patients]	1	16 October 2016
Interview schedules or topic guides for participants [Part 3 - Draft interview schedule - support groups]	1	16 October 2016
Other [Part 2 - Proforma consultation room]	1	16 October 2016
Other [PhD Ethics Addendum]	1	14 September 2016
Participant consent form [Consent form Part 2 - Clinicians]	1	19 September 2016
Participant consent form [Consent form Part 2 - Patients]	1	19 September 2016
Participant consent form [Consent form Part 3]	1	19 September 2016
Participant information sheet (PIS) [PIS Clinician - Part 2]	1	19 September 2016
Participant information sheet (PIS) [PIS Patient - Part 2 & 3]	1	19 September 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

16/YH/0099:	**Please quote this number on all correspondence**

Yours sincerely
pp

Sarah Prothero

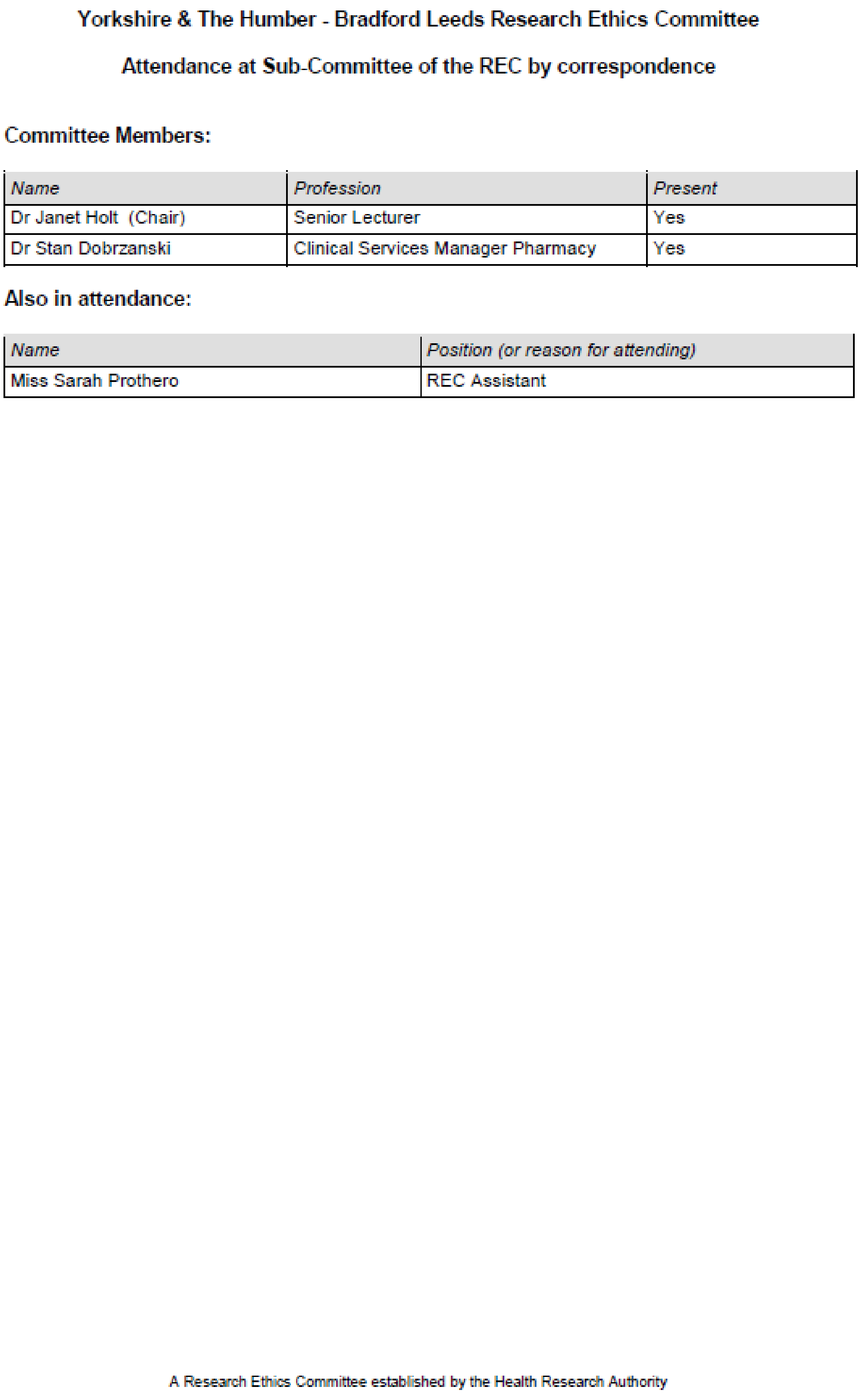
Dr Janet Holt
Chair

E-mail: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Dr Jocelyn Bell, Sandwell & West Birmingham Hospitals NHS Trust*

A Research Ethics Committee established by the Health Research Authority



Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

Attendance at Sub-Committee of the REC by correspondence

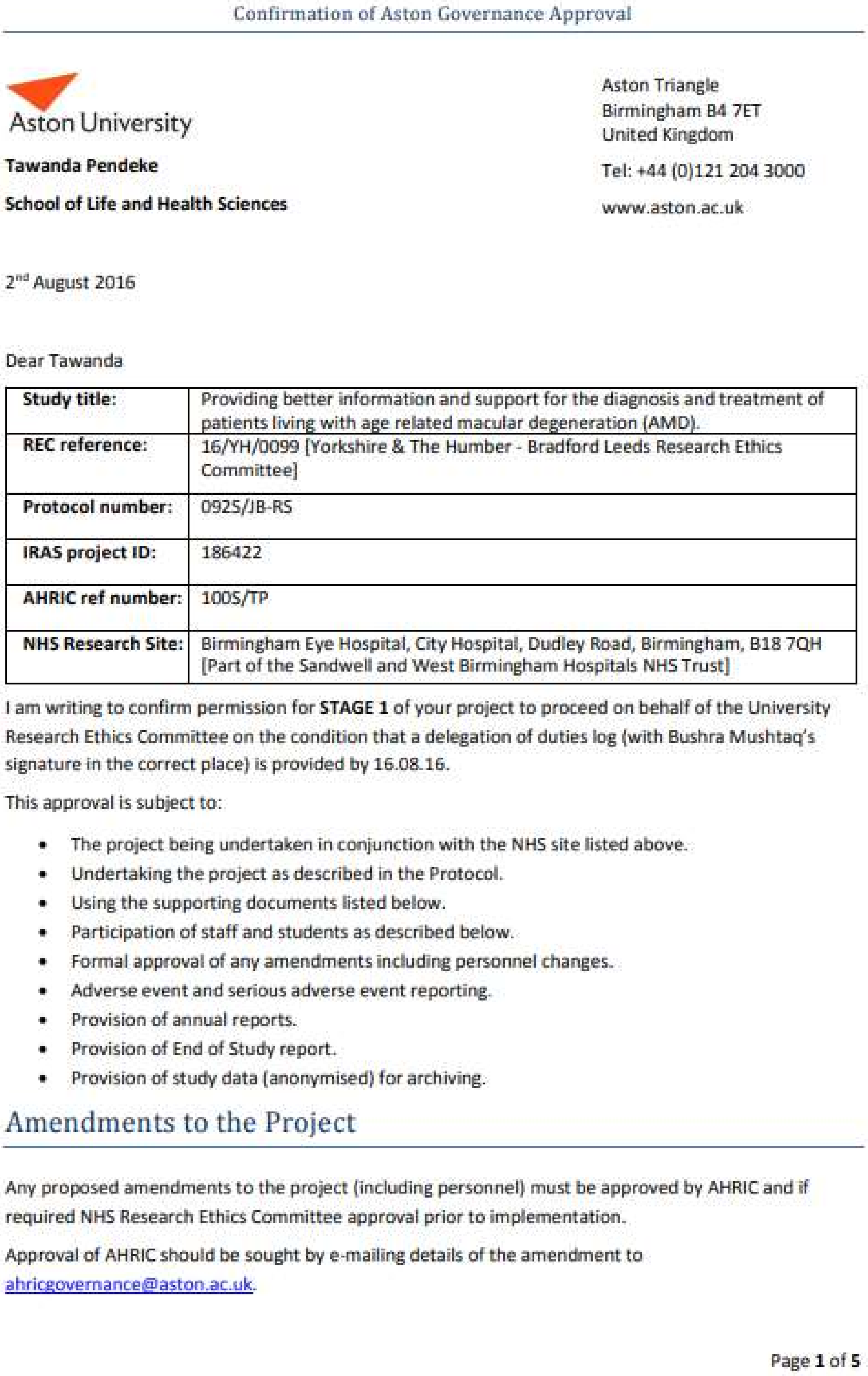
Committee Members:

Name	*Profession*	*Present*
Dr Janet Holt (Chair)	Senior Lecturer	Yes
Dr Stan Dobrzanski	Clinical Services Manager Pharmacy	Yes

Also in attendance:

Name	*Position (or reason for attending)*
Miss Sarah Prothero	REC Assistant

Appendix H Ethical Approval



Confirmation of Aston Governance Approval

Aston University

Aston Triangle
Birmingham B4 7ET
United Kingdom

Tel: +44 (0)121 204 3000

www.aston.ac.uk

Tawanda Pendeke

School of Life and Health Sciences

2nd August 2016

Dear Tawanda

Study title:	Providing better information and support for the diagnosis and treatment of patients living with age related macular degeneration (AMD).
REC reference:	16/YH/0099 [Yorkshire & The Humber - Bradford Leeds Research Ethics Committee]
Protocol number:	0925/JB-RS
IRAS project ID:	186422
AHRIC ref number:	100S/TP
NHS Research Site:	Birmingham Eye Hospital, City Hospital, Dudley Road, Birmingham, B18 7QH [Part of the Sandwell and West Birmingham Hospitals NHS Trust]

I am writing to confirm permission for **STAGE 1** of your project to proceed on behalf of the University Research Ethics Committee on the condition that a delegation of duties log (with Bushra Mushtaq's signature in the correct place) is provided by 16.08.16.

This approval is subject to:

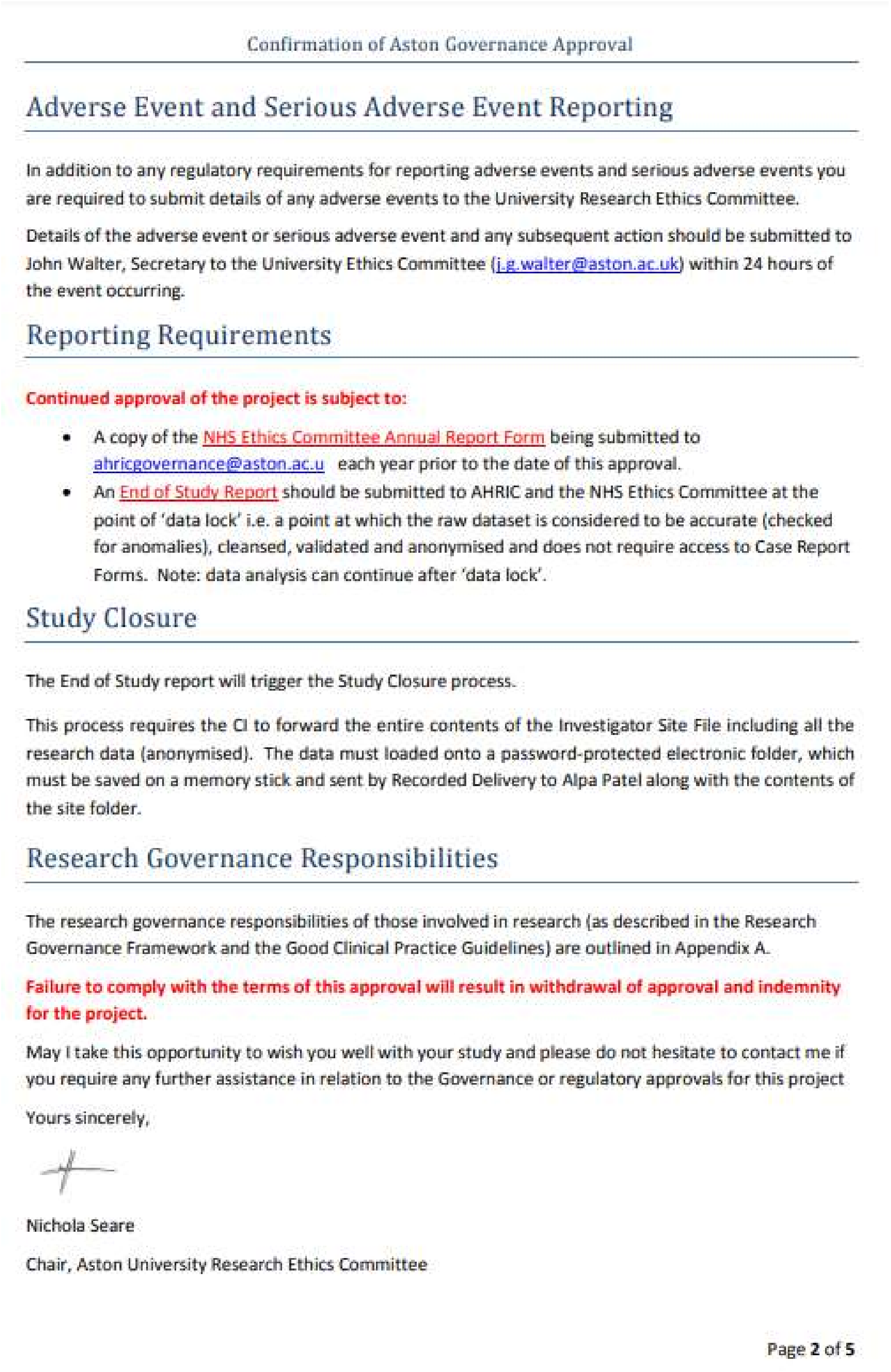
- The project being undertaken in conjunction with the NHS site listed above.
- Undertaking the project as described in the Protocol.
- Using the supporting documents listed below.
- Participation of staff and students as described below.
- Formal approval of any amendments including personnel changes.
- Adverse event and serious adverse event reporting.
- Provision of annual reports.
- Provision of End of Study report.
- Provision of study data (anonymised) for archiving.

Amendments to the Project

Any proposed amendments to the project (including personnel) must be approved by AHRIC and if required NHS Research Ethics Committee approval prior to implementation.

Approval of AHRIC should be sought by e-mailing details of the amendment to ahricgovernance@aston.ac.uk.

Page **1** of **5**



Adverse Event and Serious Adverse Event Reporting

In addition to any regulatory requirements for reporting adverse events and serious adverse events you are required to submit details of any adverse events to the University Research Ethics Committee.

Details of the adverse event or serious adverse event and any subsequent action should be submitted to John Walter, Secretary to the University Ethics Committee (j.g.walter@aston.ac.uk) within 24 hours of the event occurring.

Reporting Requirements

Continued approval of the project is subject to:

- A copy of the NHS Ethics Committee Annual Report Form being submitted to ahricgovernance@aston.ac.u each year prior to the date of this approval.
- An End of Study Report should be submitted to AHRIC and the NHS Ethics Committee at the point of 'data lock' i.e. a point at which the raw dataset is considered to be accurate (checked for anomalies), cleansed, validated and anonymised and does not require access to Case Report Forms. Note: data analysis can continue after 'data lock'.

Study Closure

The End of Study report will trigger the Study Closure process.

This process requires the CI to forward the entire contents of the Investigator Site File including all the research data (anonymised). The data must loaded onto a password-protected electronic folder, which must be saved on a memory stick and sent by Recorded Delivery to Alpa Patel along with the contents of the site folder.

Research Governance Responsibilities

The research governance responsibilities of those involved in research (as described in the Research Governance Framework and the Good Clinical Practice Guidelines) are outlined in Appendix A.

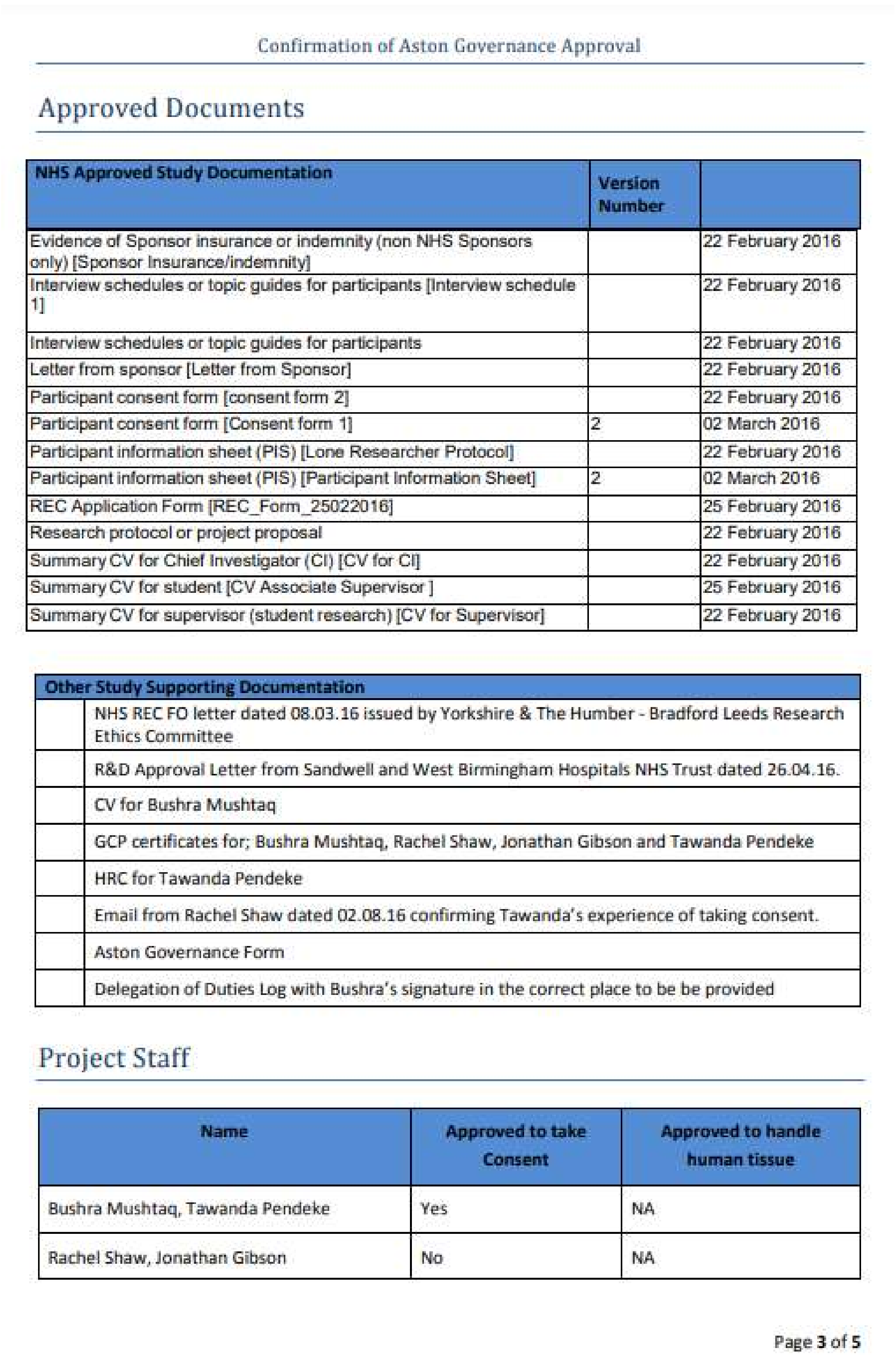
Failure to comply with the terms of this approval will result in withdrawal of approval and indemnity for the project.

May I take this opportunity to wish you well with your study and please do not hesitate to contact me if you require any further assistance in relation to the Governance or regulatory approvals for this project

Yours sincerely,

Nichola Seare

Chair, Aston University Research Ethics Committee



Approved Documents

NHS Approved Study Documentation	Version Number	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance/indemnity]		22 February 2016
Interview schedules or topic guides for participants [Interview schedule 1]		22 February 2016
Interview schedules or topic guides for participants		22 February 2016
Letter from sponsor [Letter from Sponsor]		22 February 2016
Participant consent form [consent form 2]		22 February 2016
Participant consent form [Consent form 1]	2	02 March 2016
Participant information sheet (PIS) [Lone Researcher Protocol]		22 February 2016
Participant information sheet (PIS) [Participant Information Sheet]	2	02 March 2016
REC Application Form [REC_Form_25022016]		25 February 2016
Research protocol or project proposal		22 February 2016
Summary CV for Chief Investigator (CI) [CV for CI]		22 February 2016
Summary CV for student [CV Associate Supervisor]		25 February 2016
Summary CV for supervisor (student research) [CV for Supervisor]		22 February 2016

Other Study Supporting Documentation	
	NHS REC FO letter dated 08.03.16 issued by Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
	R&D Approval Letter from Sandwell and West Birmingham Hospitals NHS Trust dated 26.04.16.
	CV for Bushra Mushtaq
	GCP certificates for; Bushra Mushtaq, Rachel Shaw, Jonathan Gibson and Tawanda Pendeke
	HRC for Tawanda Pendeke
	Email from Rachel Shaw dated 02.08.16 confirming Tawanda's experience of taking consent.
	Aston Governance Form
	Delegation of Duties Log with Bushra's signature in the correct place to be be provided

Project Staff

Name	Approved to take Consent	Approved to handle human tissue
Bushra Mushtaq, Tawanda Pendeke	Yes	NA
Rachel Shaw, Jonathan Gibson	No	NA

Appendix A

RESPONSIBILITIES UNDER THE RESEARCH GOVERNANCE FRAMEWORK

Chief Investigator Responsibilities

- Developing the protocol, including where possible involving potential participants
- Study management procedures
- Compliance with legal, ethical and research governance requirements
- Ensuring the research team is appropriately qualified to undertake the study
- Protocol amendments, their approval and implementation
- Ensuring participant welfare
- Dissemination, including feeding back results to the participants

Principal Investigator Responsibilities

- The Principal takes overall responsibility for a study at a site. This included but is not restricted to the duties listed below. Some duties may be delegated to other members of the research team but the responsibility remains with the PI. Duties that are underlined and in bold cannot be delegated.
- Negotiation and completion of the financial agreement
- Indemnity, compensation and insurance
- **Delegation of study related duties**
- **Ensuring all staff delegated to work on the study are adequately informed as to protocol requirements and trained in specific procedures**
- Participant recruitment strategy
- Medical care and supervision of patients (if applicable)
- Screening participants for eligibility
- Informed consent process
- Randomisation (if applicable)
- **For trials of Investigational Medicinal Products (IMPs):** Familiarity with the Investigator Brochure
- Administration of Investigational Medicinal Product
- Dispensing (if applicable)
- IMP accountability and monitoring of compliance
- Collection of study-related blood samples (if applicable)
- Completion of data collection forms
- Documenting of Adverse Events (AE)
- Timely reporting of Serious Adverse Events (SAE)
- **Deciding causality and expectedness of SAE**
- Ethics committee approval / communication re: amendments
- Availability for audit and inspections
- Archiving

Confirmation of Aston Governance Approval

Researcher Responsibilities

- Ensuring research undertaken follows the current version of the protocol
- Helping care professionals to ensure research patients receive appropriate care whilst involved in research
- Protecting the integrity and confidentiality of clinical and other information generated by the research
- Reporting any adverse events and suspected misconduct

Sponsor Responsibilities

- Assuring scientific quality (peer review)
- Ensuring research ethics committee approval
- Resources and financial management
- Ensuring arrangements for the management and monitoring of research are in place
- Compensation to participants

Employer Responsibilities

- Developing and promoting a high quality research culture – accountability for professional conduct
- Ensuring employees meet obligations set out in law and relevant guidance
- Compliance with employment and health and safety legislation
- Undertaking agreed management and monitoring roles
- Ensuring anyone who is harmed as a result of negligence can be compensated
- Systems to detect and address misconduct and fraud

Care Organisation Responsibilities

- Ensuring that research undertaken in their organisation meets the standards in the Research Governance Framework
- Ensuring ethics committee approval
- Retaining responsibility for research participants' care

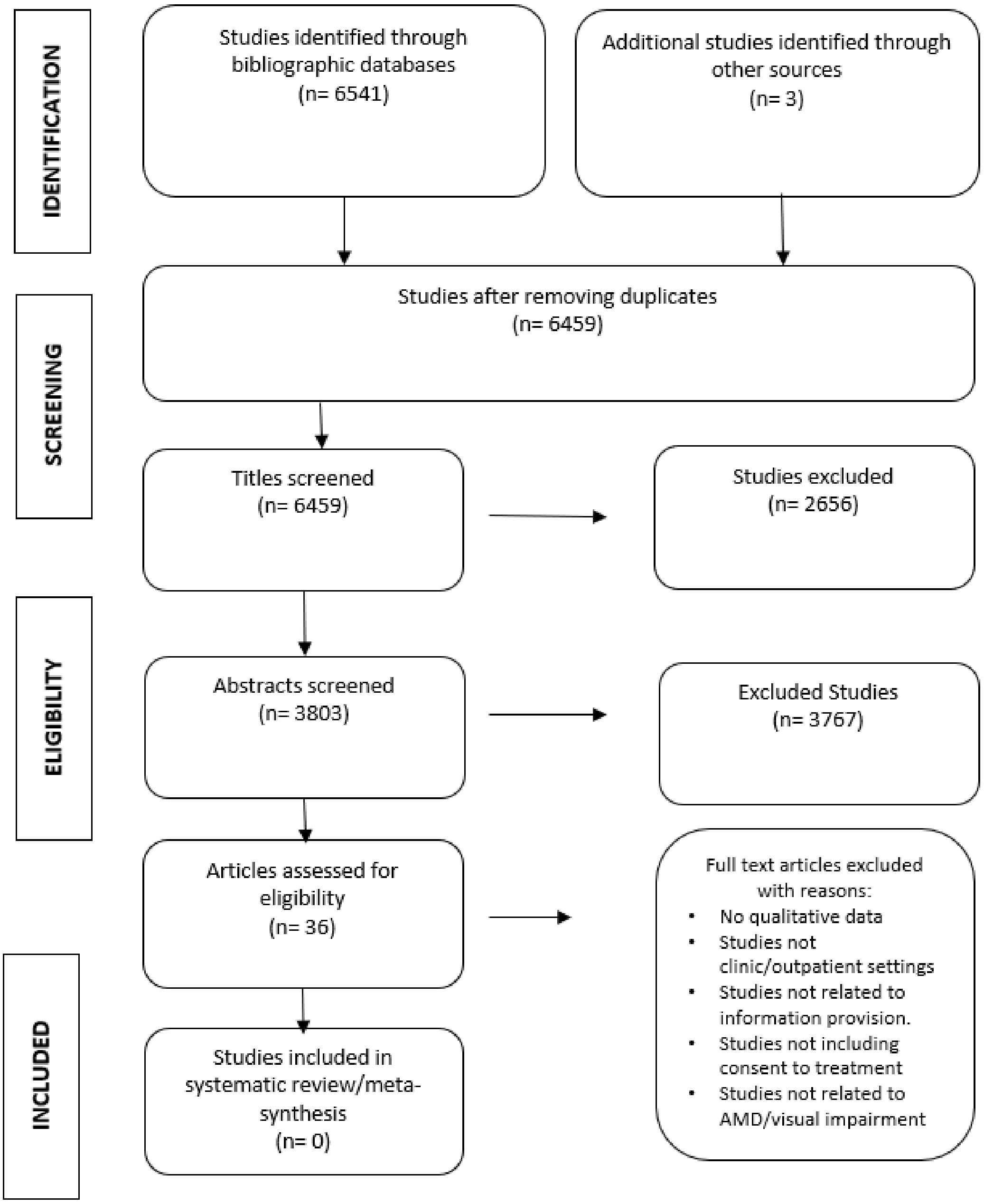
Appendix I Search Strategy and PRISMA Table

CHIP analysis of the consent to treatment process

Context	Consent to treatment process within a healthcare setting.
How	Qualitative methods
Issues	Information provision, pamphlets, treatment options/procedure, benefits and risks
Population	Older adults diagnosed with wet AMD

Following the CHIP analysis, individual search terms were identified to develop the search strategy conducted in this review.

Search terms
(kw: information provision* OR kw: communication kw: pamphlet) and (kw: consent to treatment* OR kw: ranibizumab OR kw: bevacizumab OR kw: aflibercept) and (kw: elderly* OR kw: older adults* OR kw: geriatric OR kw: age* OR kw: old*) and (kw: age related macular degeneration OR kw: AMD OR kw: vision loss OR kw: eye clinic* OR hospital) and (kw: interviews* OR kw: focus groups OR kw: qualitative) and tl= "English".


IDENTIFICATION
SCREENING
ELIGIBILITY
INCLUDED
Studies identified through bibliographic databases (n= 6541)
Additional studies identified through other sources (n= 3)
Studies after removing duplicates (n= 6459)
Titles screened (n= 6459)
Studies excluded (n= 2656)
Abstracts screened (n= 3803)
Excluded Studies (n= 3767)
Articles assessed for eligibility (n= 36)
Full text articles excluded with reasons:
• No qualitative data
• Studies not clinic/outpatient settings
• Studies not related to information provision.
• Studies not including consent to treatment
• Studies not related to AMD/visual impairment
Studies included in systematic review/meta-synthesis (n= 0)