

DOCTOR OF PHILOSOPHY

Patients' and physicians' experiences of
atrial fibrillation and anticoagulation
therapy

a qualitative journey

Christian Borg Xuereb

2014

Aston University

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March 2013

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Thesis Summary

Background: Oral anticoagulation (OAC) reduces stroke risk in patients with atrial fibrillation (AF) however it is often underutilized and sometimes refused by patients. This programme of work included a meta-synthesis and two inter-linking studies aiming to explore patients' and physicians' experiences of AF and OAC.

Methods: A meta-synthesis of qualitative evidence was conducted which informed the empirical work. Semi-structured individual interviews were utilised. Study 1: Three AF patient sub-groups were interviewed; accepted (n=4), refused (n=4), or discontinued (n=3) warfarin. Study 2: Four physician sub-groups (n=4 each group) prescribing OAC to AF patients were interviewed: consultant cardiologists, consultant general physicians, general practitioners and cardiology registrars. Data was analysed using interpretative phenomenological analysis.

Results: Study 1: Three over-arching themes comprised patients' experiences: (1) the initial consultation, (2) life after the consultation, and (3) patients' reflections. Patients commented on the relief and reassurance experienced during the consultation but they perceived the decision making process mostly led by the physician. Lack of education and take-home materials distributed during the initial consultation was highlighted. Patients who had experienced stroke themselves or were caregivers, were more receptive to education aimed towards stroke risk reduction rather than bleeding risk. Warfarin monitoring was challenging for patients, however some patients perceived it as beneficial as it served to enhance patient-physician relationship.

Study 2: Two over-arching themes emerged from physicians' experiences: (1) communicating information and (2) challenges with OAC prescription for AF. Physicians' approach to the consultation style shifted through a continuum of compliance-adherence-concordance during the consultation. They aimed for concordance, however challenges such as time and the perceived patient trust in them as the expert, led to physicians adopting a paternalistic approach. Physicians also pointed out challenges associated with guideline adherence and the need to adopt a multi-disciplinary approach, where other health professionals could provide on-going education.

Conclusion: This programme of work has illustrated the benefit of taking an in depth phenomenological approach to understanding the lived experience of the physician-patient consultation. Together with the meta-synthesis, this work has strengthened the evidence base and demonstrated that there is a need to target patients' and physicians' ability to communicate with each other in a comprehensible way.

Keywords: Patients' and physicians' experiences, interpretative phenomenological analysis, meta-synthesis, atrial fibrillation, oral-anticoagulation therapy

Dedication

This work is dedicated to my parents, Joseph and Rita Borg Xuereb.
Thank you for everything.

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Publications

Chapter 2 of this thesis, 'Patients' and health professionals' views and experiences of atrial fibrillation and oral-anticoagulant therapy: a qualitative meta-synthesis', has been published in a peer-reviewed journal:

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List of Abbreviations

AF	Atrial fibrillation
ARISTOTLE	Apixaban for Reducation In STroke and Other Thromboembolic Events in atrial fibrillation
BAFTA	Birmingham Atrial Fibrillation Treatment of the Aged
BDI	Beck Depression Inventory
BPM	Beats per minute
CABG	Coronary artery bypass graft
CAD	Coronary artery disease
CI	Confidence intervals
ECG	Electrocardiogram
HF	Heart failure
ICH	Intra-cranial haemorrhage
INR	International normalised ratio
IPA	Interpretative phenomenological analysis
MI	Myocardial infarction
NHS	National health service
NICE	National institute for health and clinical excellence
NOACs	Novel oral anticoagulants
NVAF	Non-valvular atrial fibrillation
OAC	Oral anticoagulation therapy
OR	Odds ratio
PAF	Paroxysmal atrial fibrillation
PCI	Percutaneous coronary intervention
PTOT	Probability trade-off technique
QoL	Quality of life
RCT	Randomised control trial
RE-LY	Randomised Evaluation of Long-term anticoagulant therapY
ROCKET-AF	Rivaroxaban Once daily oral direct factor Xa inhibition Compared with vitamin K for the prevention of stroke and Embolism Trial in Atrial Fibrillation

SD	Standard deviation
SPAF	Stroke prevention in atrial fibrillation
STAI	State-Trait Anxiety Inventory
TIA	Transient ischemic attack
TTO	Time-Trade Off
UK	United Kingdom
US	United States of America
WHO	World Health Organisation

Glossary

Ablation	Procedure to treat AF that uses the blood vessels to access or reach the heart. A small, flexible catheter is passed into the heart through a tiny opening in the vein or artery in the groin that will deliver radio frequency waves to ablate or “burn” the area causing AF.
Angina	Chest pain or discomfort that happens when your heart doesn't get as much blood and oxygen as it needs.
Antiarrhythmic drug	A medication aimed at treating abnormal heart rhythms such as atrial fibrillation and maintaining normal sinus rhythm, if possible.
Anticoagulant	A medicine that thins the blood and helps prevent blood from clotting, sometimes referred to as a "blood thinner".
Anticoagulation	The process of thinning the blood to help prevent it from clotting.
Aorta	The largest artery in the body. It carries oxygen-rich blood away from the heart to the rest of the body.
Arrhythmia	Any change in the normal rhythm of the heart.
Asymptomatic	AF episodes that the patient does not feel or for which there were no symptoms.
Atria (singular atrium)	The two smaller, upper chambers of the heart. The right atrium receives blood from the body. The left atrium receives blood from the lungs.
Atrial fibrillation	The most common type of arrhythmia. When you have AF, the atria of the heart quiver rapidly and unevenly - changing the rhythm of the heart. The heart beats in an irregular manner.
Bradycardia	Slowness of the heartbeat, usually defined as a rate under 60 beats per minute.
Cardiovascular	Involving the heart and blood vessels.

Cardioversion	An approach to convert (change) the heart rhythm from atrial fibrillation into normal sinus rhythm. May be accomplished by an electrical shock (electric cardioversion) or by special medication (pharmacologic cardioversion).
Clot	Also known as <i>thrombus</i> , is a clump of blood cells that can form when the flow of blood is slowed down.
Congestive heart failure	A condition in which the heart can't pump enough blood to the body's other organs. The heart keeps working, but not as efficiently as it should. People with congestive heart failure have difficulty exerting themselves because they become short of breath and tired.
Diabetes	A disease where the body doesn't make enough insulin, or can't use its own insulin as it should.
Echocardiogram	A technique used to make images of the heart's tissues by recording the reflections of ultrasonic waves (waves too high for humans to hear). Sometimes used to diagnose illnesses.
Electrocardiogram	A printed recording of the heart rhythm which shows how the heart beats.
Embolus	A thrombus that travels from the blood vessel or heart to another location in the body.
Fibrin	A white insoluble fibrous protein which forms part of the blood clot.
Heart attack	Also known as a <i>myocardial infarction</i> . Damage or death of a portion of the heart muscle (myocardium) caused by a blocked blood supply to that area.
Heart disease	Any condition that doesn't allow the heart to function normally.

High blood pressure	High arterial blood pressure, also known as <i>hypertension</i> , is generally defined as being above 140 mm Hg systolic and 90 mm Hg diastolic. Normal blood pressure is considered to be less than 120 mm Hg systolic and 80 mm Hg diastolic (120/80).
International Normalised ratio	A system established by the World Health Organization (WHO) and the International Committee on Thrombosis and Haemostasis for reporting the results of blood coagulation (clotting) tests. Abbreviated INR. Under the INR system, all results are standardized.
Intra-atrial blood stasis	Stoppage of the normal flow of a blood in the atria (the top chambers of the heart).
Lone AF	Atrial fibrillation that occurs in an otherwise structurally normal heart, in a patient without other medical conditions.
Normal sinus rhythm	The 'normal', regular rhythm the heart.
Pacemaker	An electrical device (a small metal case containing a tiny battery and computer chip) that creates an electrical impulse to stimulate the heart muscle to beat in a more normal rate.
Palpitations	A term often used to describe an irregular heartbeat, or the sensation of skipped or extra heartbeats.
Percutaneous coronary intervention	Non-surgical invasive procedure used to treat narrowing of the coronary arteries of the heart
Paroxysmal AF	The heart beats in and out of normal sinus rhythm, going from atrial fibrillation to normal sinus rhythm on its own. Episodes last no longer than 1 week.
Persistent AF	Episodes of atrial fibrillation lasting longer than 1 week which do not go away on their own. Medical treatment is necessary to restore normal sinus rhythm.
Permanent AF	A person's normal heartbeat is atrial fibrillation and cannot be returned to normal rhythm.

Plaque	A build-up of substances from a fluid, such as cholesterol, in the blood vessels.
Platelet	A type of blood cell that helps prevent bleeding by causing blood clots to form.
Prophylaxis	Prevention
Rate	The speed of the heartbeat.
Rhythm	The pattern of the heart-beat.
Stroke	An interruption of blood supply to the brain. A stroke happens when blood flow to a part of the brain is interrupted because a blood vessel in the brain is blocked or bursts open. If blood flow is stopped for longer than a few seconds, that part of the brain cannot get blood and oxygen. Brain cells can die, causing permanent damage.
Systolic dysfunction	A loss in the efficiency of the function of the cardiac muscle, leading to an increased blood volume and decreased contractility of the heart muscle.
Tachycardia	Increased speed of the beating of the heart, usually with a heart rate above 100 beats per minute.
Thrombosis	The formation and development of a thrombus or blood clot in the blood vessel.
Thromboprophylaxis	The prevention of a clot (thrombus) forming.
Time in therapeutic range	For patients taking warfarin the term therapeutic range signifies the range at which the blood thinning is maximised to reduce the risk of stroke and minimise bleeding risks. For patients with atrial fibrillation taking warfarin the therapeutic range should be 2.0-3.0.

Transient ischemic
attack

Often called a "mini-stroke", they are considered to be warning strokes as a blood clot temporarily blocks an artery. TIAs usually last no more than five minutes, and may only last for seconds. Those who have had a TIA are much more likely to have a stroke. One-third of those who have had a TIA will have a stroke, often within a year.

Ventricle

The two lower chambers of the heart. The left ventricle pumps blood to the body. The right ventricle pumps blood to the lungs.

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Chapter 1: Introduction

1.1 Introduction

Atrial Fibrillation (AF), is the most common heart rhythm condition and is associated with increased morbidity and mortality (Camm, Kirchhof, Lip, Schotten, Savelieva, Ernst et al., 2010; Fuster, Ryden, Cannom, Crijns, Curtis, Ellenbogen et al., 2006; Rudolf, Lip, Bakhshi, Camm, Davis, Deacon et al., 2006). AF is an independent risk factor for stroke, with AF patients having a risk five times higher than normal to get a stroke (Wolf, Abbott & Kannel, 1991). Hence, stroke risk reduction with oral anticoagulation therapy (OAC) is a crucial component of AF management (Camm et al, 2010; Lane & Lip, 2008a). However, although warfarin is the recommended OAC treatment for AF patients at moderate to high-risk of stroke (Camm et al, 2010; Camm, Lip, De Caterina, Savelieva, Atar, Hohnloser et al., 2012) it is still underutilized (Ogilvie, Newton, Welner, Cowell, & Lip. 2010). There is a paucity of literature that qualitatively explores the experiences that influence physicians' decisions to prescribe or withhold warfarin in eligible AF patients and the experiences that influence AF patients' to accept, refuse or discontinue warfarin. Thus the objective of this thesis was to understand the physicians' and patients' experiences of AF and OAC therapy and how these experiences influenced their choices with regards OAC therapy prescription and acceptance, refusal or discontinuation.

Therefore, this chapter will aim to provide an overview of the bio-psychosocial perspective of AF and OAC with warfarin. AF and OAC will be introduced. In addition discussion of, the epidemiology and prognosis of AF, the use OAC therapy for stroke prevention in AF and current clinical guideline recommendations for OAC will be outlined. Also discussed in this chapter are the barriers to OAC therapy. These include patient barriers, such as patient beliefs and illness perceptions, and the psychological influence on the perceptions of symptoms. Physician barriers, including the difference between physicians' and patients' perception of stroke risk reduction, fear of litigation and knowledge of guidelines are also explored. In addition, health-care system

barriers, which include consultation time constraints and system influences on OAC monitoring are also discussed. These discussions will provide a background for the rationale of the study outlined in the final section of this chapter.

1.2 What is Atrial Fibrillation (AF)?

1.2.1 Definition

AF is defined as a supraventricular tachyarrhythmia which is characterised by a predominantly uncoordinated atrial activation with consequent deterioration of atrial mechanical function (Camm et al., 2010, 2012; Fuster, et al., 2006; Rudolf et al., 2006). Put more simply, AF is a condition of the heart that causes an irregular pulse. The electrical impulses that usually coordinate the heartbeat become disorganised and the heart starts beating irregularly and too fast (Camm et al, 2010; National Institute for Health and Clinical Excellence [NICE], 2006). Patients may experience AF symptoms that include palpitations, chest pain, dizziness, shortness of breath and fainting, however, in the majority of cases AF is asymptomatic (Camm et al., 2010; Fuster et al., 2006; NICE, 2006; Rudolf et al., 2006).

1.2.2 Classification of Atrial Fibrillation

Atrial fibrillation is categorised into four clinical sub-types, based on the temporal pattern of the arrhythmia (Camm et al, 2010): paroxysmal, persistent, long-standing and permanent AF. Paroxysmal AF occurs when episodes of the arrhythmia terminate spontaneously, usually within 48 hours but may continue for up to seven days. Persistent AF is when the episode of arrhythmia continues requiring electrical or pharmacological cardioversion for termination and lasts for more than seven days. AF patients are categorised as 'long-standing persistent' when the AF has lasted for more than one year but a decision is adopted to try to return the patient to sinus rhythm utilising a rhythm control strategy (anti-arrhythmic drugs and/or cardioversion/AF ablation). Atrial fibrillation is classified as permanent when the arrhythmia has been present for

one year or more and this is accepted by the patient (and physician) as the patient's 'normal' heart rhythm.

1.2.3 Epidemiology

1.2.3.1 Incidence and Prevalence

Data from the Framingham Heart Study (Lloyd-Jones, Wang, Leip, Larson, Levy, Vasan, et al, 2004) suggests that the lifetime risk for the development of AF for men and women aged 40 years and older is approximately 1 in 4. This lifetime risk is similar to that reported in the Rotterdam study (Heeringa, van der Kuip, Hofman, Kors, Van Herpen, Stricker, et al, 2006), which found that the risk associated with developing AF in people over 55 years of age was 24% for men and 22% for women. The age- and sex-adjusted incidence of AF per 1000 person-years among the 4618 US patients of Olmsted County, Minnesota, who had ECG (Electrocardiogram) confirmed first AF in the period 1980 to 2000, was 3.04 (95% CI 2.78 – 3.31) in 1980 and 3.68 (95% CI 3.42 – 3.95) in 2000, with a relative increase of 12.6% (2.1% - 23.1%) in total (Miyasaka, Barnes, Gersh Cha, Bailey, Abhayaratna et al., 2006). They estimated that by the year 2050, the projected number of persons with AF in the United States alone could reach 15.9 million, if the age-adjusted incidence continues to increase at the same rate (Miyasaka, et al., 2006).

The prevalence of AF continues to rise with advancing age and appears to be similar to the UK, in Europe and the United States, at around 2-3% (Heeringa, et al., 2006; Lloyd-Jones, et al., 2004; Nieuwlaat, Capucci, Camm, Olsson, Andresen, Davies, et al., 2005; Rietbrock, Heeley, Plumb & van Staa, 2008; Stewart, Murphy, Walker, McGuire & McMurray, 2004; Wilhelmsen, Rosengren, & Lappas, 2001). In the United States, the number of people who are diagnosed with AF is above 2.2 million (Fowler & Ruh, 2006; Go, et al., 2001; Miyasaka et al., 2006; You, Singer, Howard, Lane, Eckman, Fang et al., 2012). In the UK, the Renfrew-Paisley study (Stewart, Hart, Hole, & McMurray, 2001), analysing ECG data of 15,406 patients (45.8% male) aged 45-64 years, the population prevalence of AF was 6.5 cases per 1000 patients. Locally, in the West Birmingham AF project (Lip, et al., 1997), the prevalence of AF was 2.4%

in two general practices and a further extension of this project showed that the prevalence of AF among Indo-Asians aged over 50 years in primary care was 0.6% (Lip, et al., 1998). The Newcastle survey screened 4,843 people aged 65 years or more in general practices and found a prevalence of AF of 4.7% (Sudlow, Thomson, Thwaites, Rodgers, & Kenny, 1998). Among UK hospital admissions, AF is present in 3-6% of the acute medical admissions (Lip, Tean, & Dunn, 1994; Zarafis, Beevers & Lip, 1997).

1.2.3.2 Risk factors for the development of atrial fibrillation

There are many well-established risk factors associated with the development of AF, namely age, male sex, hypertension, diabetes mellitus and metabolic syndrome. As indicated in the previous section, increasing age is associated with a greater prevalence and incidence of AF (Heeringa et al, 2006; Kirchhof, Lip, Van Gelder, Bax, Hylek, Kaab et al., 2012; Lloyd-Jones et al, 2004; Miyasaka, et al., 2006; Rietbrock et al, 2008; Stewart et al., 2001; Wilhelmsen, Rosengren, & Lappas, 2001). Male sex has also long been associated with incident AF (Benjamin, Levy, Vaziri, D'Agostino, Belanger & Wolf, 1994; Gami, Hodge, Herges, Olson, Nykodym, Kara et al., 2007; Gammage, Parle, Holder, Roberts, Hobbs, Wilson et al., 2007; Kirchhof et al., 2012; Marcus, Alonso, Peralta, Lettre, Vittinghoff, Lubitz et al., 2010; Schnabel, Sullivan, Levy, Pencina, Massaro, D'Agostino et al., 2009; Smith, Newton-Cheh, Almgren, Struck, Morgenthaler, Bergmann et al., 2010). Interestingly, this is in contrast with the observation that female gender is a risk factor for stroke in patients with established AF (Lane & Lip, 2009; Stroke Risk in Atrial Fibrillation Working Group, 2007). In the Framingham study (Benjamin, et al., 1994) the development of AF was associated with increasing age (odds ratio (OR) 2.1 for men and 2.2 for women, $p < 0.0001$), diabetes (OR 1.4 for men and 1.6 for women), hypertension (OR 1.5 for men and 1.4 for women), and valve disease (OR 1.8 for men and 3.4 for women).

Similarly, lifestyle and dietary factors are also associated with development of AF. Such factors include excessive alcohol consumption over a short period of time, excessive caffeine consumption and emotional or physical stress and

obesity (Camm, et al., 2010; Fuster, et al., 2006; Kirchhof et al., 2012; NICE, 2006). Interestingly, recent studies have also documented a relationship between long-term vigorous endurance sport practice or rigorous occupational physical activity in athletes and AF (Heidbuchel, Anne, Willems, Adriaenssens, Van de & Ector, 2006; Kirchhof et al., 2012; Molina, Mont, Marrugat, Berruezo, Brugada, Bruguera, et al., 2008; Mont, 2010; Mont, Tamborero, Elosua, Molina, Coll-Vincent, Sitges, et al., 2008; Taggar & Lip, 2008)

1.2.4 Prognosis

1.2.4.1 Morbidity and mortality

Several factors associated with AF, including intra-atrial blood stasis, structural heart disease or blood vessel abnormalities and abnormal platelets and haemostasis, lead to a prothrombotic state. This in turn leads to a predisposition to thrombus (clot) formation, known as thrombogenesis (Lip, 1995). Further, this prothrombotic state can lead to stroke and thromboembolism in AF patients, with an approximately five-fold greater risk ($p < 0.001$) than that of people without AF (Wolf et al., 1991). This can be compared to the risk of stroke in patients with hypertension or coronary heart disease, who have a three- and four-fold increased risk of stroke, respectively, than patients without either of these conditions (Wolf et al., 1991). Results from the Framingham study identified AF as an independent risk factor for stroke (Wolf et al., 1991). In addition, AF accounts for approximately 10-15% of all ischaemic strokes (Wolf et al., 1991). The incidence of strokes attributable to AF increases from 1.5% at age 50–59 years to 23.5% at age 80–89 years (Wolf, Mitchell, Baker, Kannel, & D'Agostino, 1998). Furthermore, the risk of stroke is similar in all AF clinical sub-types; paroxysmal, persistent, long-standing or permanent (Flaker, Belew, Beckman, Vidaillet, Kron, Safford, et al., 2005). Strokes that occur in the presence of AF are often more severe resulting in greater likelihood of death or disability, and need for residential care than strokes that occur in patients without AF (Steger, Pratter, Martinek-Bregel, Avanzini, Valentin et al., 2004).

1.2.4.2 Quality of Life

In the late 1940s, the World Health Organisation (WHO) extended the definition of health to encompass the presence of physical, mental, and social well-being, giving rise to the concept of quality of life (QoL) (WHO, 1947). The WHO's Division of Mental Health officially defined the term QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO, 1993: 153). Reviews conducted to evaluate the QoL in patients with AF and the impact of rate- and rhythm-control strategies on QoL, found that most studies demonstrated that patients with AF report poorer QoL compared to the general population (Thrall, Lane, Carroll & Lip, 2006; Lane & Lip, 2008b). Among highly-symptomatic AF patients, QoL is improved following either rhythm- or rate-control treatment strategies, with such improvements in QoL most probably attributable to the relief of symptoms (Thrall et al., 2006; Lane & Lip, 2008b).

QoL related to AF patients starting warfarin therapy was likewise studied. In a study with utility-based approaches using time trade-off (reflecting a person's preference for a shorter but healthier life) and standard gamble methods (measuring what chance of death someone would be willing to take to be healthier), patients felt that warfarin therapy would slightly decrease QoL (Gage, Cardinalli, & Owens, 1996). Lancaster and colleagues recruited 333 AF patients into a randomised controlled trial to determine the effect of long-term warfarin therapy versus placebo, on patient's QoL (Lancaster, Singer, Sheehan, Oertel, Maraventano, Hughes, et al, 1991). They found that there were no significant differences in validated measures of functional status, well-being and health perceptions between warfarin-treated and control patients. Unless a bleeding episode occurred, patients did not associate warfarin therapy with a decrease in health-related QoL.

Das, Wilcoxson & Corrado (2005) argue that strokes are more likely to cause neurological impairment than death and therefore stroke prophylaxis should improve QoL more than longevity. In the early stages of treatment, OAC may

affect QoL from bleeding complications and in the longer term QoL may be affected by the inconvenience of clinic visits, blood tests and restricted lifestyle (e.g. diet and alcohol) (Das et al., 2005). Therefore understanding the impact of stroke and OAC therapy on QoL could play a major role during clinical decisions, as patients may value the same level of functional status differently (Das, et al. 2005).

Based on this premise, Das, Wilcoxson, Corrado and West (2007) conducted a cross-sectional study comparing patients who had been taking warfarin for less than one year with those who were on warfarin for more than one year, to assess the perceived change in QoL with the duration of anticoagulation. Concurrently they also compared QoL in patients taking warfarin with people from the general population (Das et al., 2007), using an abbreviated version of the SF-36, which provided composite mental and physical QoL scores. There were no differences in mental or physical QoL in older patients with AF treated with long-term warfarin compared with the general population and no difference in QoL with duration of anticoagulation (Das et al., 2007). However they found that increasing age had an effect on the mental QoL and that physical QoL was affected by the patient's stroke risk (assessed by the CHADS₂ score (the CHADS₂ score is a risk score commonly used to assess the risk of stroke in a patient suffering from AF and will be further discussed in section 1.3.3.1) (Das et al, 2007). A limitation of the study was that older patients who had previous complications arising from warfarin treatment were excluded. Thus one cannot say if warfarin related complications would have an effect on patient's QoL.

Health-related QoL can be defined as a subjective measure of how physical impediments, as well as psychological and emotional discomfort, impact a person's day-to-day life. A medication's net impact on a patient's QoL can be thought of as a balance between the potential side effects of a medication, the burden of complying with an appropriate dose of the medication, and the medication's ability to prevent the targeted adverse health outcomes (Das, Billet, Cohen & Arnsten, 2005). Research demonstrates that generally AF patients value the potential of warfarin to prevent stroke over the risk of adverse drug effects or inconvenience of the drug regimen (Devereaux,

Anderson, Gardner, Putnam, & Flowerdew, 2001; Kneeland & Fang, 2010). Physicians may tend to over-emphasize the impact of long-term warfarin on QoL. Differences between physician and patient perceptions of the risks, benefits, and lifestyle burden of long-term warfarin may have important implications in under-prescribing and medication compliance patterns (Das et al., 2005; Kneeland & Fang, 2010; Kutner, Nixon, & Silverstone, 1991; Protheroe, Fahey, Montgomery & Peters, 2000).

The few qualitative studies, included in the meta-synthesis presented in Chapter 2, have identified several domains that relate to the impact of long-term warfarin therapy on patient's health-related QoL. These are the inconvenience of taking the medication and frequency of blood monitoring, dietary and alcohol restrictions, perceived efficacy and safety of the medication, drug-drug interactions, anxiety related to potential and actual side effects of the medication, patient autonomy, quality of information given to patients by physicians, shared decision-making before initiating the medication, symptom alleviation (or prevention), and impact of the medication on physical activities (Dantas, Thompson, Manson, Tracy & Upshur, 2004; Prins, Marrel, Carita, Anderson, Bousser, Crijns, et al., 2009; see Chapter 2).

While available data argue against attributing a significant negative QoL impact to long-term warfarin therapy, all of the studies have limitations. First, we do not know whether QoL would have been more negatively impacted in patients who were not selected to start warfarin; similarly, little is known about QoL changes in patients who discontinued warfarin. Second, most studies were of patients who were already taking warfarin, who may be more compliant or agreeable to chronic therapy. Greater variability in QoL may be more likely in unselected patients (Sweeney, Gray, Steele, & Evans, 1995; Protheroe et al., 2000). Third, the majority of studies have evaluated older patients and potentially lack generalizability to younger patients who might experience a more pronounced detriment to their QoL when forced to limit activities, like contact sports or travelling, due to risk of bleeding and frequent blood-tests, respectively (Lancaster et al., 1991). Finally, the impact of experienced side effects (i.e.,

bleeding), even if minor, likely plays a significant role in determining patient's QoL while taking warfarin and needs a more robust assessment in future QoL analyses.

1.2.4.3 Depression and Anxiety in AF

The relationship between AF, depression and anxiety has not been extensively studied. Thrall, Lip, Carroll and Lane (2007) assessed depression and anxiety (using the Beck Depression Inventory (BDI) and State-Trait Anxiety Inventory (STAI), respectively) in 101 AF patients and 97 patients with hypertension in sinus rhythm (as "disease control"), in a cross-sectional study (Thrall, Lip, Carroll, & Lane, 2007). AF patients, displayed significantly higher levels of trait anxiety at baseline compared to 'disease-controls'; there were no significant differences in depression, state anxiety, or QoL between groups at baseline. Symptoms of depression and anxiety persisted in AF at 6 months in 36.8% and 33.3%, respectively. Multivariate analyses revealed that baseline depression scores provided the best independent prediction of 6-month QoL (Thrall et al, 2007).

In a more recent study, Lane, Langman, Lip and Nouwen (2009) explored how health-related QoL, depression, and anxiety change over the first 12 months following diagnosis of lone AF (without any other risk factors for stroke) . Data from 70 lone AF patients (mean age 71.4 [S.D. 9.1]; 64% men) was collected using the BDI, STAI, and SF-36, at baseline, six and 12 months after diagnosis. Consistent to the findings of Thrall et al. (2007), Lane et al. (2009) found that lone AF patients do not appear to experience significant levels of depressive symptoms following diagnosis. The predominant affective response appeared to be anxiety and there were no significant changes in depression and anxiety over the first year (Lane et al., 2009).

1.3 Anti-thrombotic therapy for atrial fibrillation

1.3.1 Antiplatelet therapy vs. control

Eight randomised controlled trials examined the effects of antiplatelet therapy (predominantly aspirin) compared with placebo on the risk of thromboembolism in patients with AF (Hart, Pearce & Aguilar, 2007). In seven trials where aspirin alone was compared with placebo/no treatment, aspirin was associated with a non-significant 19% (95% CI: -1%-35%) reduction in the incidence of stroke. However when data from all comparisons of aspirin and placebo/control were added in the meta-analysis, this showed a significant reduction of 22% (95% CI: 6%-35%) associated with aspirin.

1.3.2 Anticoagulation therapy with warfarin vs. control

For nearly 50 years, vitamin K antagonists, such as warfarin have been the mainstay of oral anticoagulation for stroke prevention in AF. Evidence from six randomised controlled clinical trials, five in primary prevention and one secondary prevention, supports the use of warfarin as anticoagulant treatment for thromboprophylaxis in AF patients (Hart et al., 2007; Lip & Lim, 2007). A meta-analysis of these trials revealed that adjusted-dose warfarin was associated with an overall 64% (95% CI, 49%-74%) reduction in the relative risk of stroke compared to placebo (Hart, et al, 2007). Further, all-cause mortality was also significantly reduced (26%; 95% CI, 3%-43%) with adjusted-dose warfarin compared to placebo or control (Hart et al., 2007). However, warfarin was associated with a relatively small absolute increase in major extra-cranial haemorrhage ($\leq 0.3\%$ per year) (Hart et al, 2007; Lip & Lim, 2007).

1.3.3 Anticoagulation therapy with warfarin vs. antiplatelet therapy

Direct comparison between the effects of warfarin and aspirin therapies was undertaken in 12 trials (Hart et al., 2007), demonstrating 39% (95% CI: 22%-52%) relative risk reduction in stroke with adjusted-dose warfarin therapy compared to antiplatelet therapy (Hart et al., 2007). In addition, the Birmingham Atrial Fibrillation Treatment of the Aged (BAFTA) study found that

warfarin (INR 2.0-3.0) was superior to aspirin 75mg (daily) in reducing the primary endpoint of fatal or disabling stroke (ischaemic or haemorrhagic), intracranial haemorrhage, or clinically significant arterial embolism by 52%, with no difference in the risk of major haemorrhage between warfarin and aspirin (Mant, Hobbs, Fletcher, Roalfe, Fitzmaurice, Lip et al., 2007). However, despite the evidence of the significant benefit of warfarin over aspirin/anti-platelets and no therapy in the reduction of stroke, the inherent difficulties associated with warfarin, such as drug-, diet-, and alcohol-interactions, and lifestyle changes because of regular monitoring and dose adjustments (Bungard, Ghali, Teo, McAlister, & Tsuyuki, 2000), and patients' beliefs about warfarin, have led to the development of novel oral anticoagulants (NOACs) which sought to minimise these difficulties.

1.3.4 Novel oral anticoagulants (NOACs)

1.3.4.1 Dabigatran

The randomised evaluation of long-term anticoagulant therapy (RE-LY) trial (Connolly, Ezekowitz, Yusuf, Eikelboom, Oldgren, Parekh, et al., 2009) compared blinded-dose dabigatran (150mg bid or 110mg bid) to open-label dose-adjusted warfarin in 18,113 AF patients with one or more risk factor for stroke. Dabigatran 150mg bid was superior to warfarin in reducing the risk of stroke and systemic embolism, albeit with similar rate of major bleeding, while dabigatran 110mg bid significantly reduced the risk of major bleeding but had similar efficacy to warfarin in reducing stroke and systemic embolism (Connolly et al, 2009).

High-dose dabigatran was also associated with a significant increased risk of major gastrointestinal haemorrhage (1.51%) compared with dabigatran 110 mg (1.12%) or warfarin (1.02%) (Connolly et al., 2009). In addition, both doses of dabigatran had significantly higher discontinuation rates than warfarin (Connolly et al., 2009). The main influence for the increased discontinuation of dabigatran compared to warfarin was its tendency to cause dyspepsia, demonstrating that warfarin appeared to be better tolerated than dabigatran (Connolly et al., 2009)

1.3.4.2 Rivaroxaban

The oral direct factor Xa inhibitor, rivaroxaban, was compared to warfarin in the Rivaroxaban Once Daily Oral Direct Factor Xa Inhibition Compared with Vitamin K Antagonism for Prevention of Stroke and Embolism Trial in Atrial Fibrillation (ROCKET-AF) study (Patel, Mahaffey, Garg, Pan, Singer, Hacke, et al., 2011). This double-blind, randomised, event-driven non-inferiority trial compared rivaroxaban (20mg once daily or 15 mg once daily in patients with moderate renal impairment) with dose-adjusted warfarin (target INR 2.5) in 14,264 patients (Patel et al., 2011). Rivaroxaban was non-inferior to warfarin for the primary efficacy endpoint of prevention of stroke and systemic embolism, however it was not superior to warfarin (Patel et al., 2011). Major and non-major clinically relevant bleeding was similar with rivaroxaban and warfarin, however the rivaroxaban treatment group demonstrated significantly less fatal bleeding and intracranial haemorrhage (0.5 versus 0.7 per 100 patient years; $p < 0.05$). Nevertheless, significantly more patients receiving rivaroxaban had a haemoglobin decrease and required a blood transfusion (Patel et al., 2011). Premature discontinuation rates on rivaroxaban and warfarin were comparable, at approximately 23% (Patel et al., 2011).

1.3.4.3 Apixaban

The Apixaban for Reduction in Stroke and Other Thromboembolic Events in Atrial Fibrillation (ARISTOTLE) trial was a randomised, double-blind, international trial comparing apixaban 5mg twice daily with warfarin (INR 2.0-3.0) in over 18,000 patients (Granger, Alexander, McMurray, Lopes, Hylek, Hanna, et al., 2011). The rate of stroke or systemic embolism in ARISTOTLE was significantly lower with apixaban compared to warfarin (1.27% vs. 1.60% per year, respectively) primarily driven by a reduction in haemorrhagic stroke (Granger et al., 2011), Apixaban also significantly reduced all-cause mortality compared to warfarin (3.52% vs. 3.94% per year, respectively). Apixaban was also found to be safer than warfarin in, significantly reducing the risk of major bleeding (2.13% vs. 3.09% per year, respectively) (Granger et al., 2011). Drug

discontinuation also occurred significantly less frequently with apixaban compared to warfarin (25.3% vs. 27.5%; $p= 0.001$).

Although the new OACs have been recently approved for use in patients with AF in Europe, they may bring a new set of challenges for physicians, mainly concerning the lack of agent to reverse the anticoagulant effect, long-term safety, and 'real-world' clinical experience. In addition, some AF patients (particularly those with significant renal impairment) are not eligible for the new OACs (Camm, et al., 2012). Although the new OACs generally have a predictable anticoagulant response that allows for convenient, fixed-dose, and unmonitored treatment, regular monitoring of warfarin may also be seen as a benefit as it can help in the assessment of patient adherence to treatment, whereas with the new OACs it is more difficult to ascertain medication adherence. Therefore, warfarin still has a clearly defined place in therapy, as the established gold standard antithrombotic for stroke prevention in atrial fibrillation. The efficacy and safety of warfarin has been established, and it is readily reversed by vitamin K. Furthermore, the challenges posed by blood monitoring are also offset by the benefit they provide in the opportunity to assess patient adherence.

1.3.5 Current recommendations for OAC

1.3.5.1 Stroke Risk Stratification

The traditional risk factors for stroke in AF are previous stroke or transient ischaemic attack (TIA), increasing age (≥ 75 years), hypertension, diabetes mellitus, and congestive heart failure or left ventricular systolic dysfunction and these risk factors comprise the well-known CHADS₂ score (Gage, Waterman & Shannon, 2001). The CHADS₂ stroke risk stratification scheme assigns one point to each risk factor, except for previous stroke which gets two points. Scores range from 0-6, with higher scores denoting greater risk of stroke (see Table 1 and 2). The CHA₂DS₂-VASc (see Table 1 and 2) is a refinement of the CHADS₂ schema, but also incorporates female gender, age 65-74 years, and vascular disease (previous MI, peripheral vascular disease, and aortic plaque),

as additional risk factors (Lip, Nieuwlaat, Pisters, Lane, & Crijns, 2009). The CHA₂DS₂-VASc score assigns one point to: congestive heart failure, hypertension, diabetes mellitus, vascular disease (including MI), age of 65-74 years, sex category and two points to prior stroke and age ≥75years (Lip et al., 2009), with total scores ranging from 0-9. CHA₂DS₂-VASc clearly identifies truly 'low risk' patients (Lip et al., 2009; Coppens, Eikelboom, Hart, Yusuf, Lip, Dorian et al., 2013). Patients with CHA₂DS₂-VASc of 1 or more are eligible for OAC unless the only risk factor is female sex (Camm et al., 2012). At the time of this programme of work, none of the new OACs were available to prescribe for stroke prevention in AF, so warfarin was the only OAC available.

Recent guidelines for antithrombotic therapy in AF recommend that stroke risks should be based on the presence (or absence) of risk factors for stroke and thrombo-embolism, rather than on an artificial division into high, moderate, or low risk categories (Camm et al., 2010; 2012).

Table 1: CHADS2 and CHA2DS2-VASc scoring systems (adapted from Gage et al., 2001 and Camm et al., 2010)

CHADS₂	Score	Condition/Risk Factor	CHA₂DS₂-VASc	Score
C	1	Congestive heart failure	C	1
H	1	Hypertension (including treated hypertension)	H	1
A	1	Age (≥75 years)	A	2
D	1	Diabetes	D	1
S	2	Prior stroke or TIA	S	2
	†	Vascular disease	V	1
	†	Age (65-74)	A	1
	†	Sex category (female sex)	Sc	1
Total score	6			9

† not included in the CHADS2 score

Table 2: CHADS2 and CHA2DS2-VASc score and stroke rate (adapted from Camm et al 2010)

CHADS₂ Score	Patients (n=1733)	Adjusted stroke rate (%/year)	CHA₂DS₂-VASc Score	Patients (n=7329)	Adjusted stroke rate (%/year)
0	120	1.9	0	1	0
1	463	2.8	1	422	1.3
2	523	4	2	1230	2.2
3	337	5.9	3	1730	3.2
4	220	8.5	4	1718	4.0
5	65	12.5	5	1159	6.7
6	5	18.2	6	679	9.8
			7	294	9.8
			8	82	6.7
			9	14	15.2

1.3.5.2 Optimal International Normalized Ratio (INR)

To be effective and to reduce the risk of bleeding, control of warfarin is essential. Anticoagulation control is measured by the International Normalised Ratio (INR), a measure of the clotting time (derived from the ratio between the actual prothrombin time and that of a standardized control serum). For patients with AF, their INR needs to be between 2.0 and 3.0 (Camm et al., 2010; Fuster et al., 2006; NICE, 2006). If INR is lower than 2.0, it means that the blood is 'thicker' and there is a higher risk of stroke. If the INR is more than 3.0, it means that the blood 'too thin' and there is higher risk of bleeding. Warfarin and other vitamin K antagonists are difficult to control because of high inter-individual and intra-individual variations as well as significant drug, food and alcohol interactions (Camm et al., 2010; Fuster et al., 2006; NICE, 2006). On average, trials found that patients need to remain in the therapeutic INR range of 2.0-3.0 for more than 60% of the time to for the reduction of stroke risks to outweigh the risk of bleeding (Connolly, Pogue, Eikelboom, Flaker, Commerford, Franzosi et al., 2008) and preferably >70% of the time (Morgan, McEwan, Tukiendorf, Robinson, Clemens & Plumb, 2009).

1.3.5.3 Bleeding Risks

The main side effect of OAC, particularly with warfarin, is the risk of bleeding. Guidelines advocate that bleeding risks should be assessed before patients are started on OAC therapy. Using a 'real-world' cohort of 3978 European patients with AF from the Euro Heart Survey, HAS-BLED (hypertension, abnormal renal/liver function, stroke, bleeding history or predisposition, labile INR, elderly (>65), drugs/alcohol concomitantly), a new bleeding risk schema was constructed which has demonstrated good consistent predictive accuracy (Pisters, Lane, Nieuwlaat, de Vos, Crijns & Lip, 2010) (See Table 3). Scores range from 0-9. Patients who achieve a score of ≥ 3 are at a higher risk of bleeding and physicians should use OAC therapy with caution and ensure regular review of the patient following initiation of OAC therapy (Pisters et al., 2010).

Table 3: HAS-BLED scoring system (adapted from Camm et al., 2010)

Letter	Clinical characteristic	Score
H	Hypertension	1
A	Abnormal renal and liver function (1 point each)	1 or 2
S	Stroke	1
B	Bleeding	1
L	Liabile INRs	1
E	Elderly (e.g. age >65 years)	1
D	Drugs or alcohol (1 point each)	1 or 2
		Maximum 9 points

1.4 Barriers to oral-anticoagulation therapy

Despite the benefit of OAC for stroke thromboprophylaxis in AF, such treatment is underutilised (Bungard, et al., 2000; Ogilvie, Newton, Welner, Cowell, & Lip, 2010), with only 15% to 44% of patients without contraindications being prescribed warfarin (Bungard, et al., 2000). The reasons for this underutilisation are numerous but the barriers to anticoagulation can be divided into three main categories: patient, physician-, and health-care related barriers (Bungard et al, 2000; Gattellari, Worthington, Zwar, & Middleton, 2008a; Lane & Lip, 2008a; Pugh, Pugh & Mead, 2011; see Chapter 2).

1.4.1 Patient barriers

Bungard et al (2000) reviewed surveys that identified several patient-related barriers, which could influence physicians' decisions in prescribing warfarin to patients. These barriers including age, perceived embolic risk and perceived risk for haemorrhage were consistently identified as influencing the decision in

prescribing anticoagulation in several studies (Bungard et al., 2000; Gattellari et al., 2008a; Pugh, et al., 2011) and will be explored in more detail in this section.

1.4.1.1 Age

The literature suggests that advancing age often influences physicians' decision to not prescribe warfarin in older patients (Partington, Abid, Teo, Oczkowski, & O'Donnell, 2007; Pugh et al., 2011). This could be due to age per se increasing the risk of bleeding (Cosmo & Palareti, 2009). However, the BAFTA trial revealed that warfarin in patients over the age of 75 years, was associated with a significant reduction in fatal strokes, with no significant differences in the risk of major bleeding between the warfarin and aspirin trial cohorts (Mant et al., 2007). Therefore the patients that are most likely to benefit from OAC are not receiving treatment. In addition, the increased likelihood of a greater risk of falls, decline in cognitive ability, and multiple comorbidities in older people, also increase the risk of bleeding, with the latter two also complicating OAC management, and reducing a patient's ability to adhere to the warfarin regimen which requires regular monitoring, dose-adjustment and lifestyle changes.

1.4.1.2 Patient beliefs and perceptions

Patients' beliefs about their healthcare are important factors that influence their decision to accept, decline, or comply with anticoagulant therapy, particularly warfarin (Howitt & Armstrong, 1999; Protheroe, et al., 2000). Some of the patient beliefs and perceptions that act as barriers to warfarin prescription identified in the literature are fear of bleeding risks caused by warfarin, the fact that warfarin was also used as rat poison and the responsibility warfarin brings with it regarding diet, alcohol consumption, and lifestyle change (Dantas et al., 2004; Lipman, Murtagh & Thomson, 2004).

1.4.1.2.1 Illness beliefs and perceptions

Beliefs about illness will determine the action a person chooses to take, which information they give to a physician, the kind of treatment they want, whether they adhere to that treatment, and their emotional, behavioural, and cognitive responses to the illness (Leventhal, Brissette, & Leventhal, 2003; Leventhal, Nerenz, & Steele, 1984). Illness representations are people's organised sets of beliefs about the experience, impact, effect and outcome of an illness and hence are not necessarily accurate or coherent with the evidence-base. They are unique to each individual and will be shaped by many factors, including their personal history, experience of different illnesses, and social and cultural learning. Five main dimensions of illness representations have been established: identity, timeline, cause, control, and consequences (Leventhal et al., 2003; Leventhal et al., 1984).

The concept of illness *identity* refers to the way a person labels the illness and symptoms, such as what AF and OAC are and what they involve (Leventhal et al., 2003; Leventhal et al., 1984). The more various symptoms match a person's model of a particular illness the more likely it is they will diagnose themselves as having that illness (Leventhal et al., 2003; Leventhal et al., 1984). The *timeline* is the length of time that a person believes the illness will last and the pattern it will take, e.g. chronic, acute, remitting, or cyclical. This will affect their adjustment to the illness and adherence to treatment (Leventhal et al., 2003; Leventhal et al., 1984). The *cause* is what a person thinks caused their symptoms or illness (Leventhal et al., 2003; Leventhal et al., 1984). However, they might not be medically accurate. Beliefs about *control* concern whether the person believes their illness can be prevented, controlled or cured (Leventhal et al., 2003; Leventhal et al., 1984). People who think their illness is controllable are more likely to take an active part in their treatment and rehabilitation (Scharloo, Kaptein, Schlosser, Pouwels, Bel, Rabe, et al., 1999). Conversely, thinking an illness is uncontrollable is associated with using passive coping strategies, such as avoidance, and increased hospital admissions (Scharloo et al., 1999). Beliefs about *consequences* are concerned with the effect of the illness (Leventhal et al., 1984; Leventhal et al., 2003).

Perceived consequences are usually closely linked to the severity of someone's symptoms. Therefore asymptomatic illnesses, such as AF, may be often viewed as having no consequences. People can also have beliefs and representations about treatment procedures which, in turn, will affect how likely they are to adhere to particular treatments.

Furthermore, managing an illness or treatment which is abstract (i.e. something that patients cannot perceive or feel, e.g. asymptomatic atrial fibrillation), might be harder than managing an illness or treatment when a person has concrete (i.e. when patients can perceive or feel symptoms, such as palpitations in symptomatic atrial fibrillation) experience of it (Leventhal et al., 1984; Leventhal et al., 2003). Therefore, asymptomatic AF patients might be less likely to adhere to treatment as they perceive no concrete symptoms. This could also be linked to the issue of motivation: if people do not have symptoms, they may be more likely to favour an immediate reward (not taking on the burden of OAC) over the long-term consequences (risk of stroke).

Chronically ill patients have increased levels of anxiety and depression when they believe their illness has a psychological cause, serious consequences (Grace, Krepostman, Brooks, Arthur, Scholey, Susken, et al., 2005; Hirani, Pugsley, & Newman, 2006; Jopson & Moss-Morris, 2003), poor controllability (Grace et al., 2005; Petrie, Weinman, Sharpe, & Buckley, 1996), is chronic (Fabbri, Kapur, Wells, & Creed, 2001; Grace et al., 2005; Petrie et al., 1996), and identified with a higher number of symptoms (Fabbri et al., 2001; Steed, Newman, & Hardman, 1999). Beliefs that an illness has significant consequences and poor controllability are related to increased fatigue (Treharne, Lyons, Hale, Goodchild, Booth, & Kitas, 2008), pain (Hirani et al., 2006), decreased vitality (Jopson & Moss-Morris, 2003) and poorer physical functioning (Scharloo et al., 2007). Modifying illness beliefs through education, cognitive therapies, and emotional regulation interventions will lead to positive clinical outcomes, including improved functional status, symptom management, psychological well-being, and better adherence to treatment recommendations (Cameron, & Jago, 2008; Kaptein, Scharloo, Fischer, Snoel, Cameron, Sont, et al., 2008; McAndrew, Musumeci-Szabo, Mora, Vileikyte, Burns, Halm, et al.,

2008; Petrie, Broadbent, & Meechan, 2003). Thus, identifying the individual patient's experiences and physician's interpretation of patients' beliefs and experiences of the consultation is critical for developing interventions to promote adaptive illness beliefs.

A few investigators described illness beliefs in patients with coronary artery disease (CAD) or heart failure (HF). Patients awaiting elective coronary artery bypass graft (CABG) surgery (Hermele, Olivo, Namerow, & Oz, 2007) and those treated with elective percutaneous coronary intervention (PCI) (Astin, Closs, McLenachan, Hunter, & Priestly, 2009) viewed their illness as less chronic compared to patients with HF (Cherrington, Lawson, & Clark, 2006) and patients attending cardiac rehabilitation (Yohannes, Yalfani, Doherty, & Bundy, 2007). Patients who completed a cardiac rehabilitation programme after myocardial infarctions (MI) (Yohannes et al., 2007) reported lower personal control beliefs compared to patients with heart failure (Cherrington et al., 2006) or those treated with PCI (Astin et al., 2009). Treatment control beliefs were highest in patients undergoing elective PCI (Astin et al., 2009) and awaiting CABG surgery (Hermele et al., 2007). Heart failure patients perceived greater consequences (Cherrington et al., 2006) of their illness compared to patients with CAD (Astin et al., 2009; Grace et al., 2005; Hermele et al., 2007; Safford, Berk, & Jackson, 2009) and endorsed more emotional distress related to their illness compared to patients awaiting CABG surgery (Hermele et al., 2007).

Studies of illness beliefs directly related to AF are sparse. The belief that AF was related to a higher number of symptoms was associated with greater psychological distress (Steed et al., 1999) and sharper declines and slower improvement in physical health scores over 12 months after diagnosis (Lane, et al., 2009). In addition patients perceived psychological factors, age, and heredity caused AF and reported that AF induced worry, anxiety and depression (McCabe, Barnason & Houfek, 2011a).

Research has pointed out that arrival at the doctor's surgery is often the last stage in the construction of sickness. For example, according to Scambler (1991), the majority of patients consult widely with lay (non-medical) contacts

before deciding to visit the doctor. Patients rely upon lay beliefs about the nature of their illness (i.e. a diagnosis function) in conjunction with lay beliefs about the nature of alternative remedies (i.e. a treatment function). During diagnosis, patients attempt to identify the nature of the illness by relating symptoms to the originating illness or disease. During treatment, consumers attempt to select the health remedy most appropriate to the illness identified during diagnosis.

In a study which draws on a large national study of health and lifestyles in the UK, Blaxter (1990) has provided a detailed picture of some of these variations. This study also shows that health is not a single or unitary concept, but one that has a number of dimensions as applied to different areas of life and lifestyles (Blaxter 2003, 2004). Blaxter's (1990) discussion of lay beliefs is drawn from responses to open-ended questions about health put to 9,000 respondents in England, Wales and Scotland. Overall, these responses show that for lay people 'health can be defined negatively, as the absence of illness, functionally as the ability to cope with everyday activities, or positively as fitness and well-being' (p. 14). However, there are two important additions to this general picture. The first is that health has a moral dimension, reflecting not only the adoption or maintenance of a healthy lifestyle, but also how people respond to illness and deal with its aftermath. Illness runs the risk of devaluing a person's identity, either because of its causation (e.g. smoking, sexual contact, failure to 'keep well') or because of inappropriate behaviour in the face of symptoms. Moral dimensions of health have been found in a number of other studies, such as Conrad's (1994) study of students in the USA and Williams' (1984) study of middle-aged and older people with arthritis in England. From this viewpoint illness is not simply a deviation from biological norms, as in the medical model, but a significant departure from social norms.

Second, Blaxter (1990) shows that health, illness and disease are not always mutually exclusive in lay thought. Respondents in her study often reported that they saw themselves as healthy despite having serious conditions such as diabetes. There is clearly a strong motivation towards feeling and being seen to be healthy, if at all possible.

Cohen et al. (2001) emphasises the importance of understanding the ways in which the meaning of medication is culturally constructed in as much as medicine is 'socially embedded' (p. 442) in differing thresholds of normality and abnormality which reflect wider social relations. Acknowledging that while there are specific cultural features characterising this class of drug (in their link to lifestyle and behavioural expectations for example), they believe that 'all classes of prescribed medications' can be understood as being mediated and their use shaped and constructed by cultural repertoires and social relations 'beyond an individual consumer's body' (p. 449). As they say:

Medications themselves are much more than material objects with physiological effects; they are also representations that carry meanings and shape social relations as they evolve in conjunction with individuals and collectivities (p. 442).

The internal and external physiological effects (bleeding and bruising) of warfarin are therefore extremely important for a large number of people both positively as a therapeutic agent but also more negatively as a potential source of serious side effects and risks. It is important to understand how the drug is experienced and how these effects are understood by those taking it, especially for a chronic disorder.

1.4.1.2.2 Psychological influence on symptom perception

Psychological factors can also affect the perception and interpretation of symptoms in a number of ways including the role of *attention* in whether people notice their symptoms, the effect of the *environment* on symptom perception and interpretation, *individual differences in the interpretation* of symptoms, and the *influence of emotions* on symptom perception and interpretation (Sarafino, 2006). The degree of attention we pay to our internal physical state has a strong influence on the perception of symptoms. Broadbent's (1958) theory of attention assumes we have a limited capacity to pay attention to different

stimuli at the same time. Therefore, changes in our internal states have to compete with what is going on around us for attention.

Research evidence confirms the importance of attention in the perception of symptoms (Broadbent & Petrie, 2007). People are more likely to report symptoms if they are unemployed, living alone, or when in boring situations in laboratory research (Pennebaker, 2000; Pennebaker & Epstein, 1983). People will also report more symptoms if they are instructed to attend to their internal physical stimuli rather than external stimuli (Broadbent & Petrie, 2007; Pennebaker & Lightner, 1980). The implications of this for healthcare are that taking a person's attention away from internal stimuli by using strategies such as distraction can lower the perception of symptoms. Distraction might therefore be useful for managing symptoms like the elevated heart rate from AF.

Individuals will also have sets of beliefs, about which illnesses they are vulnerable to, which symptoms indicate potential illness, and which illnesses comprise a threat to their overall health (Broadbent & Petrie, 2007). Schemas people have about their health and illness will therefore be influenced by their past experience of illness and others' attitudes to illness.

Thus qualitative studies that adopt an idiographic focus on the experiences of the patients are critical in understanding these beliefs. Schemas will usually operate unconsciously to influence what symptoms people attend to and how they interpret them. Broadbent and Petrie (2007) argue that this might be due to the fact that patients scan their symptoms for any that fit with the illness they are learning about.

Emotion is also strongly associated with the perception and reporting of symptoms. Strong emotion is accompanied by physiological changes that can be misinterpreted as symptoms. Research into anxiety has established that this results in a narrowing of attentional focus and a bias towards the perception of threat (Bar-Haim, Lamy, Pergamin, Bakerman-Kranenburg, & van Ijzendoorn, 2007). Anxiety will therefore make people hyper-vigilant, in which case they will

scan themselves and the environment for any potential threat (Bar-Haim et al., 2007). Anxiety may influence people's perceptions and result in the reporting of more concurrent, or momentary, physical symptoms, patients with a depressed mood report having experienced more symptoms in the past (Howren & Suls, 2011)

1.4.1.3 Patient knowledge and understanding

Another issue concerning older patients is knowledge surrounding AF and OAC treatment. In Dantas' et al. (2004) study, older patients above 75 years of age demonstrated poor knowledge regarding warfarin treatment with less than half the sample being able to name a warfarin related benefit, risk or lifestyle change. Researchers found that in most cases family members or spouses that accompanied the patients were more knowledgeable and play an important role in warfarin management. Furthermore, this study sample was from a patient population of an academic primary-care practice that was both well-educated and of medium-high socio-economic status, thus a more heterogeneous sample may demonstrate even less treatment related knowledge. The AF Aware group (Aliot, Breithardt, Brugada, Camm, Lip, Vardas et al., 2010) examined the level of understanding, perception, and attitudes of cardiovascular risks associated with AF in 825 patients and demonstrated that one in four patients felt unable to explain AF and 55% considered AF life-threatening.

A prospective study of 122 Chinese AF patients attending an anticoagulation clinic evaluated patient's treatment-related knowledge and its relationship to anticoagulation control (Tang, Lai, Lee, Wong, Cheng & Chan, 2003). Overall knowledge of OAC was poor. Patients generally knew the colour of their warfarin tablets but were deficient in knowledge related to consequences of over- and under-anticoagulation, drugs that interact with warfarin and management of a missed dose (Tang et al., 2003). However, many of the patients were unable to read and thus may not have received any appropriate educational information. This study also found a positive correlation between patients' knowledge of warfarin treatment and the number of INR values within

range ($r = 0.20$; $p = 0.024$) (Tang et al., 2003). Therefore, patient knowledge has an important impact upon INR control; patients were more likely to have INR scores within range if they also scored higher on their educational questionnaire (Tang, et al, 2003).

Lip et al. (2002) studied patient knowledge related to their anticoagulation and their perceptions of AF in 119 chronic AF patients attending a hospital clinic. They found that 37% of the sample population were not aware of their heart condition and almost half were not aware of the reason they were taking OAC. In a pilot study to increase knowledge of AF patients regarding their condition and OAC treatment, Lane and colleagues report similar findings with 51% of patients unable to name their cardiac condition at baseline and only about half the patients perceived AF as a serious condition or were aware that AF predisposes to thromboembolism at baseline (Lane, Ponsford, Shelley, Sirpal & Lip, 2006). After a brief educational intervention there was an 18% increase of participants that were aware that anticoagulants prevented blood clots. In addition, there was minimal change in number of patients who were aware of the benefit of stroke prevention associated with anticoagulants (6% increase). The educational intervention significantly improved patient's knowledge of the target INR range and factors that may affect INR levels ($p = 0.001$ and $p = 0.014$, respectively) for those who completed both questionnaires.

Therefore, in order to optimize AF management and allow patients to participate in maintaining their health, in consultation with health professionals, they need to be appropriately educated about the condition and the treatment options.

1.4.1.4 Decision-making

Dantas et al. (2004) argued that patients tend to have limited input into the decision to initiate warfarin therapy. Moreover, the majority of patients in their study appear to lack a comprehensive understanding of the risks and benefits associated with the treatment. A study was conducted to explore patients' perceptions of their roles during decision making, 12 patients were interviewed

and data analysed using a grounded theory approach (Waterworth & Luker, 1990). From their analysis researchers came up with one major theme, called 'toeing the line' (Waterworth & Luker, 1990). This theme suggests that patients are sometimes more concerned about doing what is right, rather than participating in decisions concerning their own care. Thus, Waterworth & Luker (1990) argued that if health professionals adopt practices which encourage involvement, patients might be influenced to comply so they do not go against their perceptions of the recommendation(s) of the doctor. This is similar to a response bias. In the qualitative study conducted by Dantas et al. (2004), patients reported that they had no involvement in the decision making process and that decisions to initiate warfarin were mostly taken by physicians. These reports were often accompanied by a high level of trust in the medical expertise of the physician (Dantas et al., 2004).

1.4.1.4.1 Models of involvement in decision making

Although several policy documents have advocated patient participation in decisions about their own health care, they have been criticised for failing to adequately delineate what they mean by the term participation (Entwistle, 2000; Rhodes & Nocon, 1998). For example, policies may not differentiate between public participation in health services and patient participation in decisions about their own health care. Furthermore, reference to the academic literature may increase the confusion as several models of participation in treatment decision-making can be identified.

One of the models discussed in the academic literature is a non-participatory model, paternalism, which is sometimes referred to as the traditional medical model (Charles, Gafni, & Whelan, 1999; Coulter 2002; Emanuel & Emanuel 1992). It is important to identify this model because the more 'participatory' models tend to be explained as a contrast to the paternalistic model. In the paternalistic model the physician decides what is wrong with the patient and what treatment will be implemented. The patient's role in decision making is limited to agreeing with what has been recommended by the physician. However, a paternalistic approach is beneficial in certain circumstances where

patients whose action or choice is insufficiently voluntary to be genuinely his or hers. Such circumstances may include older people suffering from severe cognitive impairment and where no family member is available to make the decision for them.

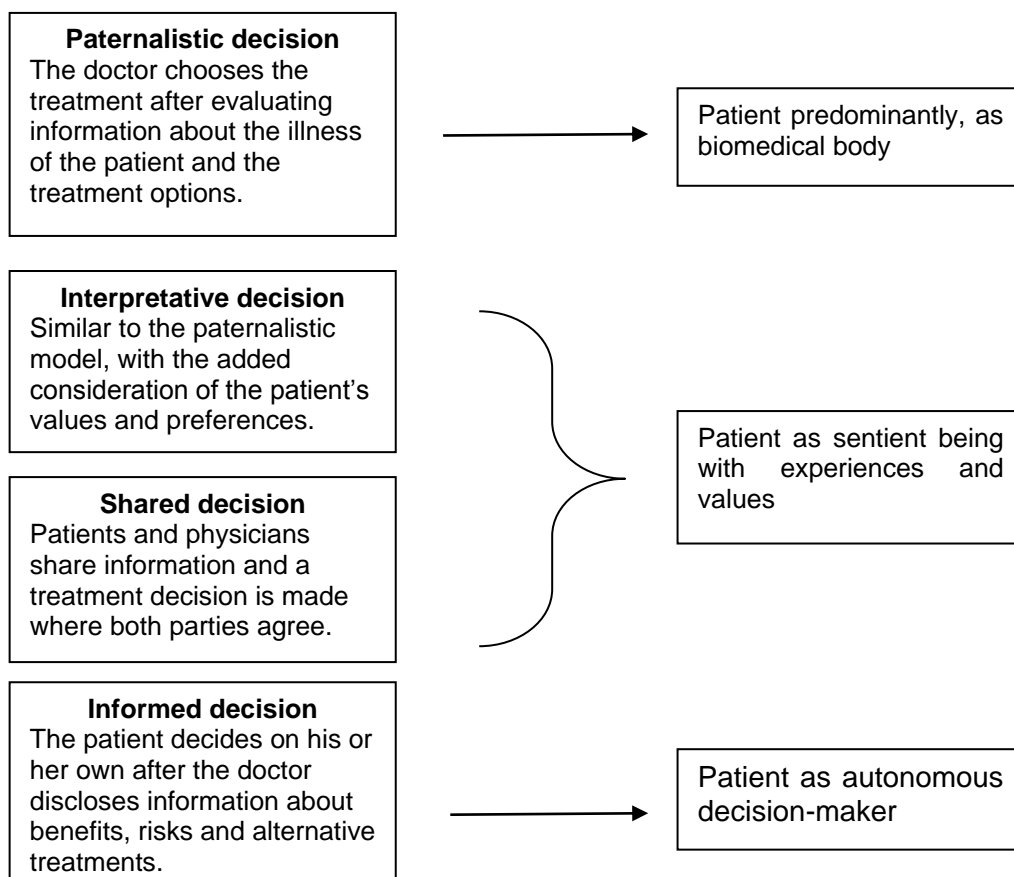
Various decision-making models, which incorporate components of patient's participation in decision-making are described in the literature. Emmanuel and Emmanuel (1992) describe three treatment decision-making models in addition to the paternalistic model: the informative model, the interpretive model, and the deliberative model. In the informative model the physician provides all the relevant information to the patient, for the patient to decide on a treatment option (while considering their own values and preferences). In the interpretive model the physician gives the patients all the information but in addition aims to get the patient to disclose his/her values and then matches an intervention to the patient's values. In the deliberative model, the physician aims to help the patient identify their health related values and an intervention that will yield the best return in terms of these values. In this deliberative model, the physician also persuades the patient as to the best health related values for their situation.

Charles and her colleagues also discuss three models of treatment decision-making in addition to paternalism: the informed model, the physician as agent model and the shared model (Charles et al 1999; Gafni, Charles, & Whelan, 1998; Charles, Gafni, & Whelan, 1997). However, they rejected the physician as agent model (where the patient discloses all information about their values to the physician and the physician considers the options based on these values) due to the difficulties in patients being able to recognise and voice all their values (Gafni et al., 1998). The informed model was described as the physician giving all the information to the patient and the patient being responsible for the decision (this is similar to the informative model described by Emmanuel and Emmanuel, 1992). The shared model was where the patient and health professional share information with one another, debate the pros and cons of the options (with each party giving their views and preferences) and reach a shared decision. A further model that is presented in the literature

is evidence-based patient choice where patients are given research-based information about the risks and benefits of at least two treatment options and have some input into the decision-making process (Entwistle, Sheldon, Sowden, & Watt, 1998; Hope, 1996).

Wirtz, Crib, and Barber (2006) discussed four models of patient-physician decision-making that encompass most of the models discussed before (see Figure 1). In the paternalistic decision model, where the patient is seen predominantly biomedically, i.e. as a body, the physician chooses the treatment after evaluating information about the illness of the patient and the treatment options (Wirtz et al., 2006). The shared decision and interpretative models both perceive the patient as a sentient being with experience and values (Wirtz et al., 2006). However, in the shared decision model, patients and physicians share information and a treatment decision is made where both parties agree, whereas the interpretative model is similar to the paternalistic model, with the added consideration of the patient's values and preferences (Wirtz et al., 2006). In the fourth model, the informed decision, the patient decides on his or her own after the physician discloses information about benefits, risks and alternative treatments (Wirtz et al., 2006).

Figure 1: Models of patient-physician decision making process (adapted from Wirtz et al, 2006)



A participatory process of decision-making that refers specifically to decisions about taking medication is concordance (Horne et al., 2005). Concordance can be defined as an agreement reached after negotiation between a patient and a health professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken (Horne et al., 2005). The concordance decision-making process recognises that patients and health professionals may have different views about taking medication and gives each viewpoint equal importance (Britten, 2003). It is a move away from the more paternalistic notion of compliance to drugs and relies on patients and health professionals sharing information, debating the pros and cons of options and patients' involvement in the treatment decision (Elwyn et al., 2003). In order to achieve a concordant process of decision-making physicians may need to use the same competencies as for a shared decision-making approach (Elwyn et al., 2003).

In view of this, a recent three step model of shared decision making to guide clinical practice was proposed (Elwyn, Frosch, Thomson, Joseph-Williams, Lloyd, Kinnersley et al., 2012). Elwyn and colleagues suggest three key steps of shared decision making for clinical practice (see Table 4), namely *choice talk*, *option talk* and *decision talk*, where the clinician supports deliberation throughout the process (Elwyn et al. 2012). *Choice talk* refers to the step of making sure that patients know that reasonable options are available. *Option talk* refers to providing more detailed information about options and *decision talk* refers to supporting the work of considering preferences and deciding what is best (Elwyn et al. 2012). The model outlines a step-wise process, however Elwyn et al. (2012) note that such a model is not prescriptive as clinical interactions are by necessity fluid.

Table 4: Summary of shared-decision making model proposed by Elwyn et al. (2012): choice talk, option talk, preference talk (adapted from Elwyn et al., 2012)

Choice talk	Option talk	Preference Talk
<ul style="list-style-type: none"> • Step back • Offer choice • Justify choice - preferences matter • Check reaction • Defer closure 	<ul style="list-style-type: none"> • Check knowledge • List options • Describe options – explore preferences • Harms and benefits • Provide patient decision support • Summarize 	<ul style="list-style-type: none"> • Focus on preferences • Elicit preferences • Move to a decision • Offer review

There are many similarities between some of the models presented above (although they are given different labels), but there are also significant differences. To some extent a similarity between the models is that they are a contrast to (and in some cases a rejection of) the non-participatory nature of paternalistic model (Charles et al., 1997; Charles et al., 1999; Emanuel & Emanuel, 1992; Gafni et al., 1998; Hope, 1996). Each model, to varying degrees, aims to involve patients in the treatment decision making process and may represent an attempt to overcome the paternalistic position where the physician is the expert and therefore able to decide what is best for an individual patient.

Several studies (see Table 5) have examined patient preferences for antithrombotic therapy in AF patients (Gage, Cardinalli, Albers, & Owens, 1995; Gage, Cardinalli & Owens, 1998; Gage, Cardinalli & Owens, 1996; Man-Son-Hing, Laupacis, O'Connor, Biggs, Drake, Yetisir et al., 1999; Howitt & Armstrong, 1999; Man-Son-Hing, Laupacis, O'Connor, Wells, Lemelin, Wood et al., 1996; McAlister, Man-Son-Hing, Straus, Ghali, Anderson, Majumdar et al., 2005; Protheroe, et al., 2000; Sudlow et al., 1998; Thomson, Eccles, Steen, Greenaway, Stobbart, Murtagh et al., 2007; Thomson, Parkin, Eccles, Sudlow & Robinson, 2000) and in patients at high risk of developing AF, but without AF

(Devereaux, et al., 2001; Fuller, Dudley & Blacktop, 2004; Man-Son-Hing, O'Connor, Drake, Biggs, Hum & Laupacis, 2002; Holbrook, Labiris, Goldsmith, Ota, Harb & Sebaldt, 2007; Alonso-Coello, Montori, Sola, Schunemann, Devereaux, Charles et al., 2008). Use of decision aids, such as audio booklets (Man-Son-Hing et al., 1999, 2002; McAlister et al., 2005; Holbrook et al., 2007) decision boards (Devereaux et al., 2001; Fuller et al., 2004; Holbrook et al., 2007; Howitt & Armstrong, 1999; Man-Son-Hing et al., 1996, 1999) and interactive videos or computer programs (Gage et al., 1995, 1996, 1998; Holbrook et al., 2007; Thomson et al., 2007) were prominent in these studies. These decision aids were developed to facilitate a shared decision making process and ensure that treatment choices were consistent with patients' personal preferences and values. They contained information on the likelihood of clinically important outcomes, including stroke and major haemorrhage associated with OAC with warfarin, aspirin or no treatment and researchers asked patients to indicate their treatment choice based on the information presented (Lip, Andreotti, Fauchier, Huber, Hylek, Knight, et al., 2011).

Patients in these studies placed greater emphasis on reducing the risk of stroke than the risk of bleeding. This could be due to the lack of knowledge on consequences of major bleeding. However, some studies (Fuller et al., 2004; Protheroe et al., 2000) suggest that there was a decrease in patients choosing to accept OAC when information on intra-cranial haemorrhage risk was also included. Decision aids provided an opportunity to improve patient knowledge of AF and OAC which empowered patients to make a decision (Holbrook et al., 2007; Man-Son-Hing et al., 1996, 1999, 2002; Thomson et al., 2000). However, research also suggested that the use of decision aids resulted in less patients opting for OAC (Fuller et al., 2004; Holbrook et al., 2007; Howitt & Armstrong, 1999; Man-Son-Hing et al., 1999; Protheroe et al., 2000; Thomson et al., 2000) than the current guidelines would recommend (Lip et al., 2011).

However, several issues were raised whilst drawing general conclusions from these studies. The main issue is the heterogeneity of methods amongst the studies (see Table 5) including the different methods to elicit patient preference and how patients in the intervention groups were educated. In addition it is

important to distinguish between studies of patients with and without AF, (see Table 5) as perceptions, values and beliefs that influence preference may differ between patients with AF who need to decide about lifelong therapy and those in a hypothetical situation (Lip et al., 2011). In addition enrolled patients with previous experience of OAC or who were already on OAC during these studies might have chosen their current therapy over other treatment choices to prevent cognitive dissonance (i.e. distress/conflict between preferences and actual treatment choice) (Fuller et al., 2004; Holbrook et al., 2007; Howitt & Armstrong, 1999; Lip et al., 2011; Man-Son-Hing et al., 2002; Protheroe et al., 2000; Thomson et al., 2007).

Table 5: Summary of the studies on the use of patient decision aids in AF patients (Adapted from Lip et al., 2011)

Author, year, country	Sample size, mean (SD) age	Study design	Method of eliciting patient preference	Outcomes
<i>Studies in patients with AF</i>				
Gage et al., 1995, US	n=57; 70	Cross-sectional, Markov decision model	Interviews, computer-based TTO	<ul style="list-style-type: none"> High utility for daily aspirin (0.998) or warfarin (0.988) Disutility associated with severe stroke (0.39) or extra-cranial haemorrhage (0.76)
Gage et al., 1996, US	n=70; 70.1 (7.3)	Cross-sectional, longitudinal	Interviews, computer-based TTO	<ul style="list-style-type: none"> High utility for daily aspirin (1.0) or warfarin (0.997) Disutility associated with moderate-to-severe stroke (0.07 and 0.0, respectively)
Man Son Hing et al., 1996, US	n=64; 68.9 (9.0)	RCT	Interviews, PTOT	<ul style="list-style-type: none"> 52% willing to take warfarin for absolute risk reduction $\leq 1/100$
Gage 1998, US	n=69; 70	Cross-sectional, Markov decision model	Interviews, computer-based TTO	<ul style="list-style-type: none"> Disutility association with stroke
Sudlow et al., 1998, UK	n=176; ≥ 50	Cross-sectional	Questionnaire and interview	<ul style="list-style-type: none"> 89% willing to take warfarin to prevent stroke
Man Son Hing et al., 1999, US	n=287; control 67, intervention 65	RCT	PTOT vs Usual care	<ul style="list-style-type: none"> Proportion choosing warfarin greater in control group PTOT increased ability to make decision choice

Howitt & Armstrong, 1999, UK	n=56	Cross-sectional	Qualitative interview, PTOT	<ul style="list-style-type: none"> 20 choose not to take warfarin despite knowledge of stroke risk
Protheroe et al., 2000, UK	n=97;77 (3.9)	Observational, Markov decision model	Individualised decision analysis	<ul style="list-style-type: none"> 61% preferred warfarin based on individualised stroke risk
Thomson et al., 2000, UK	n=57; 73	Cross-sectional, Markov decision model	Interview, standard gamble	<ul style="list-style-type: none"> High utility for daily warfarin (0.94) Disutility associated with severe stroke (0.19)
McAlister et al., 2005, US	n=43.4; 72	Cluster randomised trial	Self-administered, PTOT	<ul style="list-style-type: none"> PTOT increased patient ability to choose 'appropriate' antithrombotic therapy in short-term only
Thomson et al., 2007, UK	n=109; 73 (6)	RCT	Computerised decision aid vs. guideline evidence	<ul style="list-style-type: none"> Computerised decision aid let to significantly fewer patients choosing warfarin
<i>Studies in patients at high risk of AF but without AF</i>				
Devereaux et al., 2001, Canada	n=61; 40-74	Prospective observational	Interview, PTOT	<ul style="list-style-type: none"> 74% willing to take warfarin if just one stroke in 100 patients were prevented over 2 years 57% willing to accept 22 extra bleeds in 100 patients over a 2-year period on warfarin Most patients willing to take aspirin if it prevented just 1 stroke in 100 patients over 2 years
Fuller et al., 2004, UK	n=81; 81	Cross-sectional	Qualitative interview and questionnaire, PTOT	<ul style="list-style-type: none"> Avoiding of stroke paramount >50% would decline warfarin when presented with stroke risk information plus increasing ICH risk Need for daily tablets, regular blood tests, and restrictions on alcohol, reduced number willing to take warfarin slightly
Man Son Hing et al., 2002, Canada	n=198; 71 (7)	RCT	Qualitative vs. quantitative, PTOT	<ul style="list-style-type: none"> Patients more likely to choose aspirin Patients at moderate-stroke risk more likely to choose warfarin No significant difference in treatment choice between groups
Holbrook et al., 2007, Canada	n = 98; 73.6 (6.1)	RCT	Interview, decision board vs. decision booklet with audiotape vs. interactive	<ul style="list-style-type: none"> When treatment names were blinded, 40% chose warfarin, 42% chose aspirin and 18% no treatment Un-blinding of treatment led to fewer people choosing warfarin

			computer programme	or no treatment
				<ul style="list-style-type: none"> • Most people chose aspirin
Alonso-Coello et al., 2008, Spain	n ≥96; ≥60	Cross-sectional	Interview, PTOT and visual analogue scale	<ul style="list-style-type: none"> • Data not yet published
<p>Legend: AF - atrial fibrillation; SD - standard deviation; UK - United Kingdom; US - United States of America; ICH - intra-cranial haemorrhage; PTOT - probability trade-off technique; RCT - randomised controlled trial; TTO - time-trade off</p>				

1.4.1.5 Patient Adherence to OAC

Data from the Anticoagulation and Risk factors in Atrial Fibrillation (ATRIA) Study suggest that over one in four patients newly started on warfarin therapy for atrial fibrillation discontinue therapy within one year (Fang, Go, Chang, Borowsky, Pomernacki, Udaltsova, et al., 2010). These results are consistent with data from clinical trials showing a 22% discontinuation in the first year and 33% during a mean study period of 2.7 years in patients randomized to warfarin versus alternative agents (de Schryver, van Gijn, Kappelle, Koudstaal, Algra & Dutch TIA and SPIRIT study groups, 2005; Mant et al., 2007), as well as an observational study demonstrating that 26% of patients older than 79 years newly started on warfarin had stopped therapy within the first year (Hylek, Evans-Molina, Shea, Henault, Regan, 2007). However, in another more recent study conducted in the US, non-persistence with treatment on warfarin was reported in 46.5% of the AF patients on warfarin during at least one year (Song, Sander, Varker, & Amin, 2012). Song et al. (2012) found that this was similar to other long-term medications commonly prescribed to the AF population in their study. Although a high frequency of haemorrhagic events partially explained the significant discontinuation rate in one study (Hylek et al., 2007), discontinuation rates were large even in studies without many major bleeding episodes (Mant et al., 2007; Fang et al., 2010). Similarly, in Song et al.'s (2012) study 42.6% of AF patients on warfarin permanently discontinued the OAC treatment within one year. This was also consistent with the discontinuation rate of 32.9%-52.0% of other long-term medications in this study (Song et al., 2012).

Although a higher risk of haemorrhagic complications is associated with old age, studies have found that younger age is a risk factor for poor warfarin adherence (Arnsten, Gelfand, & Singer, 1997; Gallagher, Rietbrock, Plumb, & van Staa, 2008). Patients with fewer risk factors for stroke were also found to have lower adherence rates with warfarin (Arnsten et al., 1997; Gallagher, et al., 2008; Go et al., 1999). Prevalence and risk factors of inconsistent warfarin use was examined in the INR Adherence and Genetics (IN-RANGE) study (Kimmel, Chen, Price, Parker, Metlay, Christie, et al., 2007; Platt, Localio,

Brensinger, Cruess, Christie, Gross et al., 2008) by monitoring patient adherence through the use of electronic pill bottle caps for almost eight months. The study revealed that 92% had at least one missed or extra bottle opening and 36% of the participants missed more than 20% of the prescribed bottle openings. In addition, findings show a link between poor adherence and several risk factors, including education beyond high school and being actively employed, but also to lower mental health functioning and poor cognitive functioning (Platt et al., 2008).

Active employment has also been found to be a risk factor for poor adherence for both anticoagulation as well as other diseases (Ediger, Walker, Graff, Lix, Clara, Rawsthorne, et al., 2007; Palareti, Legnani, Guazzaloca, Lelia, Cosmi, Lunghi, et al., 2005). This might be due to the fact that patients who are employed might have greater competing time interests, than patients who are unemployed or pensioners. On the other hand, while poor adherence was associated with active employment, so was extreme poverty. Data from an underserved urban population in the US showed an association between an annual income greater than \$10,000 and higher self-reported adherence rates (Davis, Billett, Cohen, & Arnsten, 2005).

Investigation into psychosocial determinants specific to warfarin adherence has been limited, but evaluation of medically ill patients in general has identified multiple associated factors including depressive symptoms, perceived lack of social support, poor cognitive function, and poor health related QoL (Nikolaus, Kruse, Bach, Specht-Leible, Oster & Schlierf, 1996; Schauer, Moomaw, Wess, Webb & Eckman, 2005; Schillinger, Wang, Rodriguez, Bindman & Machtinger, 2006; Wang, Bohn, Knight, Glynn, Mogun & Avorn, 2002). In a study of patients on warfarin for non-valvular atrial fibrillation, patients with presumed psychosocial risk factors for non-adherence, in particular substance abuse, had increased risk for adverse medical outcomes, though adherence rates were not directly assessed (Schauer et al., 2005). It was found that only 9.7% of studied patients with new atrial fibrillation filled a prescription for warfarin within 30 days of diagnosis (Johnston, Cluxton, Heaton, Guo, Moomaw & Eckman, 2003). In Johnston et al.'s (2003) cohort study, alcohol and drug abuse, psychiatric

disease, homelessness, and lack of caregiver support were inversely related to warfarin use, though the study could not differentiate between patients who were given a prescription and failed to fill it versus those who never received a prescription. Cognitive functioning has inconsistent associations with adherence, but such studies might be confounded by caregiver involvement (Nikolaus et al., 1996; Schillinger et al., 2006).

In addition to psychosocial determinants of warfarin use, a few studies have investigated attitudinal correlates to warfarin adherence. A study of patients in an academic anticoagulation clinic evaluated self-reported compliance and found that in addition to being homeless, non-married, and having a higher pill-burden, patients' perceptions of barriers to taking warfarin correlated to poor compliance (Orensky, & Holdford, 2005). Interestingly, Orensky and Holdford (2005) elected to use the word 'compliance' throughout their study, denoting the possible adoption of a paternalistic attitude or a lack of awareness about this issue. Barriers measured in this study included the perception of taking too many pills, the perception that taking warfarin increases worry about bad health outcomes, and the perception that taking warfarin increases bruising and bleeding. Qualitative data also hint at the potential impact of high pill burden as a perceived barrier to warfarin adherence (Dantas et al., 2004). In another analysis, trends linking several attitudinal assessment scores with warfarin non-adherence were found (Cruess, Localio, Platt, Brensinger, Christie, Gross, et al., 2009). Of these attitudinal scores, higher 'Information Discomfort,' specifically a measure of 'patient reluctance to hear information about their medical conditions and treatments,' was independently associated with poor adherence (Cruess et al., 2009).

1.4.2 Physician barriers

1.4.2.1 Stroke risk reduction; Physicians' vs. patients' beliefs

Devereaux and colleagues (2001) conducted an observational study, using educational information and clinical scenarios, to compare physicians' (n=63) and patients' (n=61) perceptions on the degree of bleeding on OAC and the

reduction in the risk of stroke, that was acceptable for warfarin to be prescribed or taken as treatment (Devereaux et al., 2001). Researchers found that 74% of patients were willing to accept warfarin if one stroke in 100 patients was prevented, however 62% of physicians refused to prescribe warfarin based on the same risk reduction. Similarly, patients were more willing to accept a higher risk of bleeding (22 additional episodes of bleeding in 100 patients over a period of two years); there was little consistency amongst physicians on the acceptable level of risk of excess bleeding (Devereaux et al., 2001). This study demonstrated that patients were more willing to accept the risk of bleeding associated with OAC in order to prevent a stroke whilst physicians were more concerned with the risk of treatment-associated bleeding (Devereaux et al., 2001).

Similarly, in a recent national survey with Australian family physicians, researchers showed that experience of bleeding events and fear of bleeding in patients appear to influence warfarin prescription (Gattellari, Worthington, Zwar, & Middleton, 2008b). Furthermore, the experience of a major bleed in a patient with AF on warfarin, led physicians to feel responsible for this outcome. However, when patients experienced a stroke from not prescribing warfarin, which was a more common experience, it did not affect their sense of responsibility (Gattellari et al., 2008b).

Omission bias and the closely related status quo bias are well-described and validated cognitive biases that result from a preference for omission or inaction and preservation of the status quo (Aberegg, Arkes & Terry, 2006; Ritov & Baron, 1999). This preference can lead decision makers to choose the risks and benefits of the status quo even when the relative risks and benefits of changing the status quo through action are objectively superior. Similarly, decision makers may inappropriately judge harms due to omission as less severe or blameworthy than harms that result from action (Aberegg, Arkes & Terry, 2006; Ritov & Baron, 1999). These biases stem from heuristics that guide everyday choices but may be barriers to optimal decision making when applied in contexts such as medicine in which they are not relevant. Researchers argued that clinicians could feel more responsible for bleeding

episodes rather than stroke episodes because of harm arising from ‘acts of commission’ as they feel that they ‘caused’ the bleeding episode from a direct consequence of prescribing warfarin (Aberegg et al., 2006; Ritov & Baron, 1999). Tendencies toward this bias may be reinforced by the time-honoured clinical dictum “first do no harm,” which emphasizes risk avoidance and may serve as a justification for “doing nothing” or “holding course.” Thus even when stroke risk reduction outweighs bleeding risks, physicians may abandon potential harmful therapies (Aberegg et al., 2006).

1.4.2.2 Fear of litigation

The difference between physicians and patients in their thresholds for prescribing and accepting warfarin, discussed in the previous section, could also be partly due to physicians’ fear of litigation when prescribing warfarin. In a survey conducted with general practitioners (GPs), it was found that 29% of the participants (126/440) reported fear of litigation as a factor that limited their ability to manage warfarin (Rodgers, Sudlow, Dobson, Kenny, & Thomson, 1997). Clinical uncertainty about patient management in AF could be one of the reasons behind this fear. In a qualitative study conducted to improve understanding of physicians’ decision making in AF and the use of antithrombotics, when physicians were faced with complex scenarios, a small proportion of the participants seemed content to exercise patient-centred decision making to a point where the physician appeared to abdicate responsibility (Anderson, Fuller, & Dudley, 2007). Lipman and colleagues (2004) demonstrated that GPs’ way of making decisions about anticoagulation, whilst including research evidence, is strongly influenced by many other factors, which also influence their perception and interpretation of the research itself (Lipman, et al., 2004). They argue that decisions emerge from a complex social process and these are only partly influenced by a rational or objective evaluation of the risks and benefits of treatment (Lipman et al., 2004). Conversely to the fear of litigation, clinical uncertainty in AF patient management is commonly reported in the literature as a barrier influencing warfarin prescription (Bungard et al., 2000; Lipman et al., 2004; Murray et al., 2011). Clinical uncertainty, including not being aware of the current literature

and guidelines or being aware of the literature but not accepting the results, was an often reported barrier (Bungard et al., 2000; Lipman et al., 2004; Murray et al., 2011). Rodgers et al., (1997) found that the GPs in their survey believed that guidelines on whom to anticoagulate (78%), availability of consultant advice (77%) and further training (48%) would facilitate their willingness in prescribing warfarin.

1.4.2.3 Physicians' knowledge of guidelines

Clinical practice guidelines have become a common tool for promoting best care. Their impact on practice is however, highly variable (Grimshaw, Thomas, MacLennan, Fraser, Ramsay, Vale, et al., 2004; Lomas, Anderson, Domnick-Pierre, Vayda, Enkin & Hannah, 1989;). A meta-synthesis was recently conducted to explore and synthesise qualitative research on GPs' attitudes to and experiences of clinical practice guidelines (Carlsen, Glenton, & Pope, 2007). Researchers included English, Spanish or Scandinavian qualitative studies whose participants were GPs and that focused on experiences and attitudes towards the use of clinical practice guidelines (Carlsen et al., 2007). Using narrative synthesis framework as their method of analysis, synthesis of the studies revealed six broad themes. The first theme, 'Questioning the guidelines' showed that in most studies, GPs indicated that they were sceptical about the evidence base for guidelines, arguing that population-based trials and a narrow inclusion criteria in the studies mentioned in guidelines could weaken the applicability to individual patients (Carlsen et al., 2007). The second theme, 'GPs' experience', revolved around the anxiety GPs experienced when faced with guideline recommendations because their experience is different than what is stated and that patients in clinics were more complicated than what is portrayed. GPs' desires and empathy for patients that are suffering was mentioned as a factor that influenced them against recommendations (Carlsen et al., 2007). Additionally, the third theme, 'Preserving the physician–patient relationship', non-adherence to guidelines was also influenced by the fear of jeopardising the relationship with the patient (Carlsen et al., 2007). As noted above, researchers also found that the emotional burden of missing a diagnosis and fear of litigation was an issue with

GPs. This was the main concept of the fourth theme, 'Professional responsibility' (Carlsen et al., 2007). The final two themes, 'Practical issues' and 'Guideline format', discuss issues that GPs believe influence the use of guidelines, including lack of time to read, assess guidelines and negotiating with patients, lack of skills with new procedures and that guidelines needed to be short and simple and include patient leaflets (Carlsen et al., 2007).

The lack of knowledge on guidelines leads to an overestimation of the associated risks of bleeding and underestimation of the stroke risk during clinical practice, and is identified in the literature as one of the barriers to warfarin prescription for anticoagulation in AF (Boulanger, Kim, Friedman, Hauch, Foster & Menzin, 2006; Lane & Lip, 2008a; Murray et al., 2011; Taggar & Lip, 2008; Tay, Lip, & Lane, 2009). Similarly, in the Euro Heart Survey, researchers found that some of the key risk factors in patients with AF such as prior stroke and age >75, which are associated with a significant increase in the risk of stroke, were not associated with anticoagulant prescription (Nieuwlaat, Capucci, Lip, Bertil Olsson, Prins, Nieman, et al., 2006). Investigators in the Euro Heart Survey argued that stroke risk stratification schemes, to determine which drug is most appropriate were scarcely employed and that future education and guidelines should focus on providing one uniform and easy to use stroke risk stratification scheme (Nieuwlaat, et al., 2006).

In a retrospective study to investigate the determinants of warfarin use in patients with AF (Choudhry, Soumerai, Normand, Ross-Degnan, Laupacis & Anderson, 2006), warfarin was prescribed more often to patients who were male, younger, and had already received a prescription for warfarin in the past. Furthermore patients who were given warfarin were more likely to have stroke risk factors with less bleeding risk factors and were less likely to have been hospitalized for other reasons in the previous year (Choudhry, Anderson, Laupacis, Ross-Degnan, Normand & Soumerai, 2006). Researchers also argued that only 55.6% of the patients who had at least one major stroke risk factor received warfarin. Furthermore, older patients (>90 years) and patients with comorbidities were associated with significantly less likelihood of being prescribed warfarin, possibly because of risks associated with old age

(cognitive function and risk of falls) and risk of bleeding associated with the comorbidities (Choudhry et al., 2006).

Choudhry and colleagues (2006) found that patients in Canada who received care from family physicians with cardiology consultations were more likely to be prescribed warfarin (53.2%) than patients who are treated by family physicians (also defined as general practitioners in the study) alone (42.3%). Interestingly, even patients whose primary provider was a cardiologist were less likely to receive warfarin than patients of family physicians, even in the absence of cardiology consultation (Choudhry et al., 2006). They argue that cardiologists may be more knowledgeable about the care required for AF (Ayanian, Hauptman, Guadagnoli, Antman, Pashos & McNeil, 1994) and thus would only be more willing to prescribe warfarin if patients have another physician who is able to supervise therapy. Another reason given was that the involvement of more physicians, regardless of specialty, may result in higher quality care, and that patients who agree to see a cardiologist may be more likely to accept warfarin (Choudhry et al., 2006; Rutten, Hak, Stalman, Verheij, & Hoes, 2003).

These results suggest that some medical practitioners are either not aware of the current guidelines for thromboprophylaxis for AF or they are actively choosing not to prescribe warfarin to eligible patients. Nevertheless, according to more recent results from the Euro Heart Survey (Nieuwlaat, et al., 2006), only 33% of eligible patients were not prescribed warfarin. Nieuwlaat et al. (2006) argue that the increase in warfarin prescription in this survey could be due to several factors, including the fact that the cohort was not representative of average Europeans and the use of a relatively high proportion of university and specialized centres in the survey. Conversely, an interesting finding of this survey was the fact that 40% - 50% of patients, who fall in the low risk category, were prescribed warfarin. This means that a high proportion of patients were being exposed to a relatively high bleeding risk, when anti-platelet therapy would suffice (Nieuwlaat, et al., 2006).

1.4.3 Health-care system barriers

1.4.3.1 Consultation time constraints

On average, patient visits in the US last about 16 minutes (Fiscella & Epstein, 2008; Mechanic, McAlpine, & Rosenthal, 2001; Tarn, Paterniti, Kravitz, Heritage, Liu, Kim, et al., 2008). The average amount of time spent with patients in the UK is even less than that (Deveugele, Derese, van den Brink-Muinen, Bensing, & De Maeseneer, 2002). Analysis of videotaped consultations of general practitioners in six European countries revealed that the overall mean length of consultation was 10.7 minutes, ranging from 7.6 minutes to 15.6 minutes; in the UK, the mean length of consultations was 9.4 minutes (SD 4.7). The literature suggests that this is not enough time to transmit higher quality information, to establish rapport, to effectively address patient needs and tackle multiple complex problems (Braddock, Edwards, Hasenberg, Laidley & Levinson, 1999; Fiscella & Epstein, 2008; Tarn et al., 2008). By analysing tape recordings, Tarn et al. (2008) found that most of the time available is allocated to justification and purpose of the prescribed medication, directions of use and side effects. Furthermore, this time would need to be increased if physicians also talked about guidelines and if the patient was accompanied by family or friends (Tarn et al., 2008). In addition, more time is needed when consultations are done across different race, ethnicity, language and educational level (Fiscella & Epstein, 2008; Lott, 2002; Saha, Komaromy, Koepsell & Bindman, 1999). Such barriers severely limit patients' ability to understand information together with the physicians' capacity to confirm patients' understanding and ability to take an informed decision (Braddock, Fihn, Levinson, Jonsen, & Pearlman, 1997; Braddock et al., 1999; Fiscella & Epstein, 2008).

1.4.3.2 Health-care system influences on OAC monitoring

In a survey conducted in the UK by Rodgers et al., (1997) several health care system barriers were found that limited the ability of GPs to manage warfarin, including lack of time (57%), delay in receiving laboratory results (40%) and space constraints (22%). Results from the Euro Heart Survey also showed that

the absence of an OAC monitoring outpatient clinic leads to a lower probability of warfarin being prescribed, and also an increased frequency in the prescription of antiplatelet drugs (Nieuwlaat et al., 2006).

A systematic review and meta-regression was conducted to describe and explore the effects of different settings on anticoagulation control (van Walraven, Jennings, Oake, Fergusson, & Forster, 2006) and evaluated 67 studies involving 50,208 patients with 57,155 patient-years of follow-up. The overall percentage of time spent in the therapeutic range was 63.5% (95% CI, 61.6-65.6%). However, anticoagulation control varied extensively among study groups, with study setting, drug type, and self-monitoring being the most important factors influencing anticoagulation control. In their meta-regression, van Walraven et al (2006) found that anticoagulation setting had the greatest effect on anticoagulation control with studies in community practices having significantly lower control than either anticoagulation clinics or clinical trials (-12.2%; 95% CI = -19.5 - -4.8; $p < 0.0001$). Self-management was also associated with a significant improvement of time spent in the therapeutic range (+7.0%; 95% CI = 0.7 - 13.3; $p = 0.03$).

Similarly, another meta-analysis was conducted to evaluate the effect of specialty clinic versus usual care by community physicians on anticoagulation control, measured as the proportion of time spent in therapeutic INR range, for AF patients that received warfarin anticoagulation in the United States (Baker, Cios, Sander, & Coleman, 2009). Authors assessed eight studies involving 22,237 warfarin-treated AF patients with 41,199 years of follow-up. AF patients in the 14 groups spent 55% (95% CI = 51 - 58) of their time within the therapeutic INR range. In the studies found by Baker et al (2009) patients in anticoagulation clinics spent on average 63% (95% CI = 58 - 68) of their time in the therapeutic range versus 51% (95% CI = 47 - 55) for patients in community practice. Therefore when compared patients treated in the community setting spent 11% (95% CI = 2 - 20) less time in therapeutic INR range (Baker et al, 2009).

1.5 Rationale

Several studies have shown that although warfarin is the recommended antithrombotic treatment for AF patients at moderate to high-risk of stroke, it is still underutilized. Reasons why physicians choose not to prescribe warfarin to eligible patients is very limited and there are no qualitative studies that explore the experiences that influence physicians' decisions to prescribe or withhold warfarin in AF patients. Additionally, there is also a paucity of qualitative literature that explores the factors that influence AF patients' acceptance or refusal of warfarin.

The importance of treating the patient and not just the disease is recognised by the NHS (NHS Department of Health, 2010). Each person is a unique mix of thoughts, emotions, personality, behaviour patterns, and their own personal history and experiences. Thus by utilising qualitative methods, studies can focus on an exploratory in-depth approach that allows the idiographic analysis of the participants' experiences in making sense of what is going on in the consultation and AF and OAC with warfarin.

The study will be divided into two related projects. *Study 1* will explore the experiences, beliefs and attitudes of patients diagnosed with AF during their initial consultation and what influenced them to accept, refuse or discontinue warfarin as their bleeding thinning medication. *Study 2* will explore physicians' experiences, beliefs and attitudes during their initial consultation with a patient diagnosed with AF and their reasons for prescribing/withholding such medication.

1.4 Aims

The overall aim of the programme of work is to explore patients' and physicians' experiences of AF and anticoagulant therapy in two related studies.

Study 1

To explore the experiences, beliefs and attitudes of patients diagnosed with AF during their initial consultation and what influences them to accept, refuse or discontinue warfarin as their blood thinning medication.

Research Questions

What are the experiences, beliefs and attitudes of patients diagnosed with AF during their initial consultation?

What are the experiences, beliefs and attitudes that influence patients' decisions to accept, refuse or discontinue warfarin as their blood thinning medication?

Study 2

To explore physicians' experiences, beliefs and attitudes during their initial consultation with a patient diagnosed with AF and their reasons for prescribing/withholding such medication.

Research Questions

What are physicians' experiences, beliefs and attitudes during their initial consultation with a patient diagnosed with AF?

What are the experiences, beliefs and attitudes that influence warfarin prescription by physicians?

Chapter 2: Patients' and health professionals' views and experiences of atrial fibrillation and oral-anticoagulant therapy: a qualitative meta-synthesis

2.1 Introduction

AF is the most common arrhythmia in clinical practice and is associated with increased morbidity and mortality (Camm et al, 2010; NICE, 2006;). AF is an independent risk factor for stroke conferring a risk five times that of matched controls (Wolf et al, 1991). Hence, stroke risk reduction with antithrombotic therapy is a crucial component of AF management (Camm et al, 2010; Lane & Lip, 2008a). Guidelines recommend life-long OAC for patients with one or more risk factors for stroke (Camm et al., 2010). However, such therapy remains underutilised (Ogilvie et al., 2010; Ogilvie, Welner, Cowell, & Lip, 2011).

There are a number of complex factors which make prescription, and adherence, of OAC challenging. Physicians may display uncertainty about balancing the risk of stroke and the risk of bleeding, which may be passed onto patients (Bungard, et al., 2000). Two recent systematic reviews emphasised the impact of physicians' apprehension about feeling responsible for a major bleed which seemed to outweigh their concern about risk of stroke (Choudhry et al., 2006; Pugh, et al., 2011). This may be related to the Hippocratic Oath to 'first do no harm' (Aberegg, Arkes & Terry, 2006): responsibility is attributed to harm perceived by 'acts of commission', i.e. prescribing OAC, which are not felt with 'acts of omission', i.e., increasing the risk of stroke by not prescribing OAC (See section 1.4.2.1).

In addition to factors relating to health professionals, very little is known about patients' understanding of AF and OAC treatment. What we do know is that patients with AF report poorer QoL compared to the general population (Thrall, et al., 2006; Lane & Lip, 2008b), and greater levels of anxiety (Thrall et al., 2007).

This meta-synthesis will address the need to consolidate existing evidence about patients' and physicians' experience of AF and OAC. The complexity inherent in this field make the need for patient-centred care, effective communication skills, and individually-tailored education, as recommended by AF guidelines (NICE, 2006; Camm et al., 2010), particularly significant. The benefit of incorporating qualitative evidence like that presented in this meta-synthesis within the larger hierarchy of evidence is that it can add depth; it can bring the focus back to the individual to ensure that population-based findings retain their applicability to the individual case (Carlsen, et al., 2007). Consequently a meta-synthesis of qualitative evidence examining patients' and health professionals' experiences and beliefs about AF and OAC therapy was conducted to determine what is already known, implications for practice and to indicate where further research should be focused.

2.1.1 Aim

The aim of the meta-synthesis was to explore and review the qualitative literature on patients and healthcare professionals perspectives on the experiences of AF and OAC therapy. This was achieved by synthesising studies that adopted a qualitative approach for data collection (such as interviews and focus groups) and data analysis (including thematic analysis, framework analysis, grounded theory etc), to explore experiences of patients' and/or health professionals' experiences of atrial fibrillation and/or anticoagulation by warfarin.

2.2 Method

Meta-synthesis of qualitative evidence is modelled on traditional systematic review methodology (Shaw, 2011) and follows the methodological techniques described in Taylor, Shaw, Dale & French (2011). A systematic search strategy, screening and quality appraisal were employed.

2.2.1 Systematic search

Search terms were developed from two main bibliographic database categories: 'atrial fibrillation' and 'anticoagulant therapy'; a qualitative methodology filter was used to ensure the retrieval of qualitative studies (Shaw, Booth, Sutton, Miller, Smith, Young, et al., 2004: see Appendix A for the full search strategy). Web of Knowledge, Ingenta connect, ScienceDirect (EBSCO), Swetswise, Sage Journals online, PsycInfo and the Cochrane Library were searched to include publications up to 26th August 2011. The UK electronic theses online service (EThOS) and Google scholar were searched to identify UK dissertations and grey literature.

2.2.2 Screening

Studies retrieved were screened using the following inclusion criteria: studies that explored views or experiences of patients or carers and/or health professionals (e.g. physicians and/or nurses and/or pharmacists) about AF and/or OAC using qualitative methods (defined as using qualitative techniques for recruitment strategies, data collection, and data analysis). Once screened, duplicates were removed and reference checking and citation searches were conducted. Authors were contacted directly if pertinent data or methodological information such as the method of data analysis used were missing.

2.2.3 Critical appraisal

The quality of studies was appraised using the Critical Appraisal Skills Programme (CASP) Tool for qualitative research (Public Health Resource Unit, England [CASP], 2006), independently by each member of the research team (CBX, RS, DAL), who then met to discuss their quality appraisal and agree on the quality of the studies (see Appendix B). Papers were deemed to be of low quality when any or all of the following issues were identified: incomplete description of the methods used, missing qualitative data linking to authors' interpretations and conclusions, and omission of discussion of the trustworthiness of the study. Papers with missing data although deemed to be of low quality were not excluded but their findings were given less "weight"

during the synthesis process (Dixon-Woods, Bonas, Booth, Jones, Miller, Sutton, et al., 2006).

2.2.4 Synthesis of the studies

Synthesis of studies (i.e. the method of analysis) followed the principles outlined by Malpass et al. (2009). Articles were read in-depth and their findings, including the original authors' interpretations and conclusions were recorded in data extraction forms. Key themes and categories were identified (first-order constructs) and grouped through descriptive coding to form second order constructs (See Table 6 for an example). First order constructs are study participants' interpretations of their experience (direct quotes from participants and or authors comments) and they represent sub-themes; second order constructs are the grouped themes of all the studies developed through descriptive coding; second order constructs represent the themes.

Table 6: Examples of first-order constructs and the development of second-order constructs

First-order constructs		<i>Developing second-order constructs</i>
Lipman et al, 2004	Anderson et al, 2007	
“I like to advise... identify what the patient thinks they need, what I think they should have, and then if it's acceptable we come to an agreement and we try to take it forward, its negotiation, try more and more nowadays to do that in a consultation...” (GP1)	“I would almost put the decision or the ball in his court and I would go down the lines of describing to him his absolute and relative risk reductions with aspirin and warfarin... and I'd see what he'd prefer to do” (Physician)	The physician's perspective of the decision making process
Dantas et al, 2004	Bajorek et al, 2006	The patient's perspective of the decision making process
“I can recall that I had no objection. I said, " <i>You are the experts, you are the doctors. If I get any help, I mostly will appreciate it.</i> ".... I don't think I would trust myself that much (to make the right decision).” (P15)	Nurses believed that patients were generally familiar with what type of medication warfarin was (a 'blood thinner'), although they did not always understand why it was prescribed for them.	

The synthesis then involved the interpretative activity of translating studies into each other, i.e. comparing and contrasting second order constructs to identify third-order constructs, which are the researchers interpretations, of the study authors' interpretations of the participant interpretation of their experience. These higher ordinate themes, or third order constructs, represent the collective meanings of findings from individual papers to enable a theoretical interpretation of the phenomenon. This whole process was facilitated by the use of mind maps (See Figure 2) and discussions (led by CBX) with the research team (CBX, RS, DAL) to think through interrelations between first- and second-order constructs within and between papers to ensure the development of third-order constructs remained true to the data throughout the synthesis.

Figure 2: Example of a mind map used in the development of third-order constructs

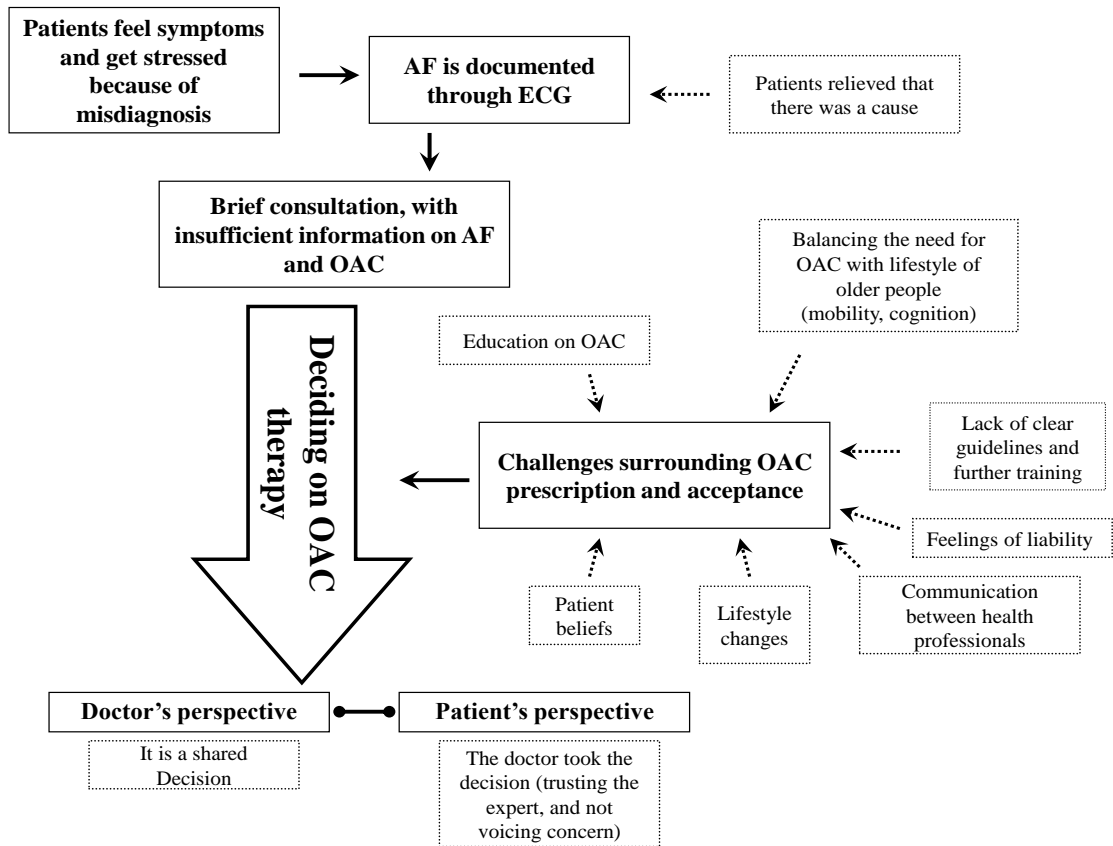


Figure 2 Legend:

- > : Direction of process
- - - - -> : Description of “action” or Influences on “action”
- : Diverging perspectives
- : Action or perspective

2.3 Results

The topic-based search terms yielded over 100,000 references but with the inclusion of the qualitative methodology filter this number was reduced to 12 unique studies (see Figure 3 for the PRISMA flow diagram, which helped in depicting the flow of information through the mapping of the number of records identified, included and excluded, and the reasons for exclusions).

Two studies were excluded: one explored experiences of patients with an implantable atrial defibrillator (Deaton, Dunbar, Moloney, Sears, & Ujhelyi, 2003); another was a method-based paper about using qualitative research to discontinue one arm of a trial (Murtagh, Thomson, May, Rapley, Heaven, Graham, et al., 2007). These two studies were excluded since the aims explored by the relevant authors were not conducive to the aims of the meta-synthesis. Ten studies met the inclusion criteria and were included in this meta-synthesis (see Table 7 for summary of study characteristics).

2.3.1 Critical appraisal

Quality of studies was assessed using the Critical Appraisal Skills Programme (CASP) Tool for qualitative research (Public Health Resource Unit, England [CASP], 2006). The papers reviewed were judged to be of generally good quality. Only Howitt and Armstrong (1999) and Murray et al. (2011) were deemed to be of lower quality. Common weaknesses within both studies included the lack of a clear description of analytic method and insufficient raw data from participants to support interpretations. However, this may have been caused by the journals' restrictions with regards to word limit.

No papers were excluded on the basis of critical appraisal discussions. However, the appraisal exercise was completed to highlight potential limitations with individual papers.

2.3.2 Theoretical frameworks of studies

The studies used various methodological frameworks and methods: thematic analysis (Howitt & Armstrong, 1999; McCabe, Schumacher & Barnason, 2011b; Murray et al., 2011; Wild, Murray & Donatti, 2011), thematic analysis with a phenomenological approach (Bajorek, Krass, Ogle, Duguid, & Shenffield, 2006; Bajorek, Ogle, Duguid, Shenffield & Krass, 2007), content analysis (Dantas et al., 2004; Fuller et al., 2004), framework analysis (Lipman et al., 2004; Murray et al., 2011), grounded theory (Anderson et al., 2007).

It may be argued that the synthesis of research with different epistemological standpoints is not desirable as each individual study is theoretically unique (Sandelowski, Docherty, and Emden 1997). However, researchers commented that combination of findings from different epistemological approaches can enhance the synthesis (Finfgeld, 2003; Yardley & Bishop, 2010; Zimmer, 2006).

2.3.3 Findings

The four third-order constructs identified are presented in series (see Table 8).

Figure 3: PRISMA diagram depicting the selection of relevant studies

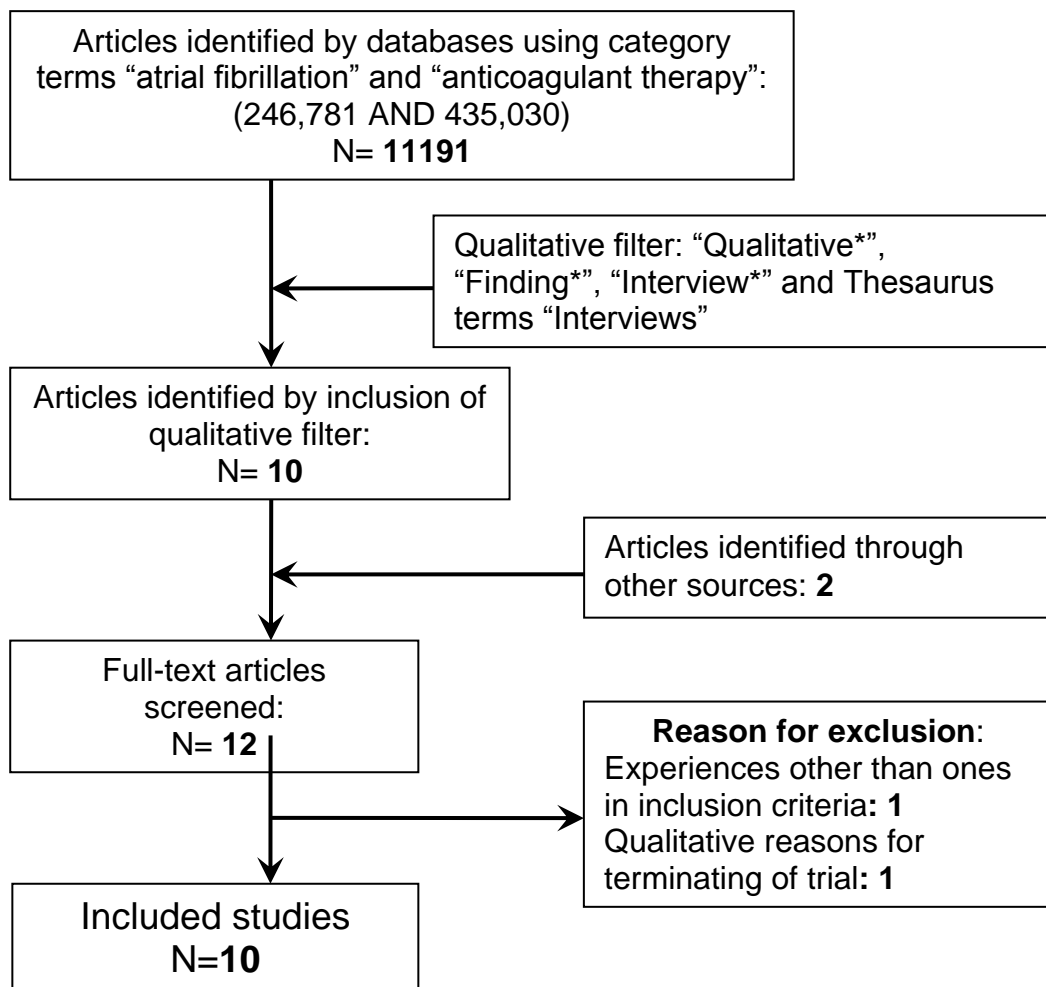


Table 7: Summary of the characteristics of included studies

Author, year, country, journal	Aim	Demographics [mean age (SD),% male]	Methods of data collection and analysis
Howitt & Armstrong (1999) UK. British Medical Journal	To determine the extent to which implementation of an evidence based treatment, anti-thrombotic treatment in AF, is possible in general practice.	• N = 56 patients [†]	<ul style="list-style-type: none"> • Face to face semi-structured interviews • Thematic analysis (information through email)
Dantas et al (2004) , Canada. BMC Family Practice	To examine the experience and perspective of patients on long-term warfarin therapy for AF, and compare to physician-identified barriers reported by Bungard et al 2000.	• N = 21 patients [74yrs(†), 57%]	<ul style="list-style-type: none"> • Face to face semi-structured interviews • Content analysis
Lipman et al (2004) , UK. Family Practice	To explore how GPs with an active interest in research or evidence based medicine make decisions about anticoagulation in patients with AF	• N = 11 GPs [43yrs(†), 82%]	<ul style="list-style-type: none"> • Face to face semi-structured interviews • Framework method
Fuller et al (2004) , UK. Age and Ageing	To examine treatment choices of older patients when given information about the <i>cumulative</i> benefits of warfarin on stroke risks over a 10 year period, and qualitatively examine the themes that surrounded these decisions	• N = 81 patients [81yrs(†), 55%]	<ul style="list-style-type: none"> • Face to face discussions • Content analysis
Bajorek et al (2006) , Australia. Australian Journal of Advanced Nursing	To explore the nurses' experiences surrounding the long-term use of warfarin in elderly patients	• N = 11 nurses [42.5yrs (10.4), 0%]	<ul style="list-style-type: none"> • Focus-group interviews • Thematic analysis with a phenomenological approach

<p>Anderson et al (2007), UK. Quarterly Journal of Medicine</p>	<p>To improve understanding of physicians' behaviour and attitudes in respect to decision making in AF and the use of anti-thrombotics</p>	<ul style="list-style-type: none"> • N = 14 [†] • 5 cardiologists (2 Consultants, 3 SpRs) [†] • 9 physicians in geriatric or general medicine (4 Consultants, 5 SpRs) [†] 	<ul style="list-style-type: none"> • Face to face semi-structured interviews • Grounded theory
<p>Bajorek et al (2007), Australia. Medical Journal of Australia</p>	<p>To explore the attitudes of doctors, other health professionals, patients and carers.</p>	<ul style="list-style-type: none"> • N = 63 participants (8 groups) • Group 1: 6 patients, 1 career [78.9yrs (4.1), 43%] • Group 2: 8 patients, 2 carers [76yrs (9.2), 50%] • Group 3: 5 consultants, 1 registrar [42yrs (10.7), 33%] • Group 4: 3 consultants, 3 registrars [41yrs (13.8), 66%] • Group 5: 8 GPs [51.8yrs (11.1), 75%] • Group 6: 11 nurses [42.5yrs (10.4), 0%] • Group 7: 9 hospital pharmacists [39.6yrs (11.8), 11%] • Group 8: 6 community pharmacists [50.5yrs (16.9), 83%] 	<ul style="list-style-type: none"> • Focus-group interviews • Thematic analysis with a phenomenological approach
<p>Wild et al (2009), UK, USA, Spain. Expert Reviews Pharmacoeconomics Outcomes Research</p>	<p>To explore patients' perspectives of VKA therapy in respondents with atrial fibrillation or venous thromboembolism</p>	<ul style="list-style-type: none"> • N = 60 patients [60yrs (†), 57%] • 20 patients from each country, 47% with AF/53% with VTE 	<ul style="list-style-type: none"> • Face to face semi-structured interviews • Analysed with ATLAS using thematic analysis

<p>McCabe et al (2011b), USA. Journal of Cardiovascular Nursing</p>	<p>To describe the experience of living with recurrent symptomatic AF.</p>	<ul style="list-style-type: none"> • N = 15 patients [59.8yrs (14.5), 53%] • Patients who are undergoing treatment with an anti-arrhythmic drug or scheduled for ablation therapy for AF 	<ul style="list-style-type: none"> • Face to face semi-structured interviews and field notes • Thematic analysis
<p>Murray et al (2011), Canada, Canadian Journal of Cardiology</p>	<p>i) To determine the attitudes and clinical practice gaps in knowledge, skill, and competence among community-based physicians ii) To provide evidence to guide the development of educational interventions to effectively address the clinical practice gaps</p>	<ul style="list-style-type: none"> • Family physicians: 6 (21%) [†] • Cardiologists: 8 (29%) [†] • Internists: 2 (7%) [†] • Emergency physicians: 6 (21%) [†] • Neurologist: 1 (4%) [†] • Patients with AF: 5 (18%) [†] 	<ul style="list-style-type: none"> • Semi-structured telephone interviews • Analysed with N-Vivo7.0 using open coding and later selective coding.

Legend: † - not reported; AF – Atrial fibrillation; SD – Standard deviation; VKA – Vitamin K antagonists

Table 8: Map of second and third-order constructs

Second-order constructs	Third-order constructs
Being diagnosed	Diagnosing AF and the communication of information
The lack of education within the consultation	
The patient's perspective	Deciding on OAC therapy
The physician's perspective	
Patient beliefs	Challenges revolving around patient issues
Accepting lifestyle changes	
The need for on-going patient education and support	
Communication between health professionals	Healthcare challenges
Limited time allocated to patients	
Raising awareness through clear guidelines and the need for further training	

2.3.3.1 Diagnosing AF and the communication of information

Only McCabe, Schumacher & Barnason (2011b) explored patients' pre-diagnosis experiences. They found that some were diagnosed accurately and quickly, whilst for others the process was slow because arrhythmia is difficult to document on an ECG and AF symptoms are not always clear which led to some patients being misdiagnosed with stress. Murray et al (2011) also found a lack of agreement on the severity of AF and physicians expressed a lack in confidence in detecting paroxysmal AF (i.e. self-terminating episodes of AF typically lasting <48 hours but no longer than 7 days) due to its intermittent nature. Nevertheless, once AF was diagnosed, patients reported a sense of relief despite this sometimes being shocking news (McCabe et al, 2011b).

“The doctor came in and said: “The good news is you're not crazy. The bad news is there is something wrong.” I'm like - I told you - you should have believed me in the first place. It was almost a relief - not that something was wrong with my heart, but that at least I know something's wrong. It may be fixed versus going on

feeling yucky and not getting an answer.” (Patient) (McCabe et al, 2011b)

Participants from three studies (Bajorek, Ogle, Duguid, Shenfield & Krass, 2007; Dantas et al, 2004; McCabe et al, 2011b) found that additional information on possible treatments to control AF symptoms and OAC was lacking. According to their participants’ accounts, educational efforts aimed at increasing knowledge about AF and warfarin were minimal and insufficient.

“Nobody really explained to me in full what Coumadin is all about, but I did some reading about it. I know it's a blood thinner, an anti-coagulant... helps with the atrial fibrillation that I have, because apparently blood stays longer than it should in the atrium, and if it thickens it can go to your brain and you can have a stroke.” (Patient 8) (Dantas et al., 2004)

This viewpoint is corroborated by health professionals in Bajorek et al (2007) study who suggest that the educational information provided is often inadequate to the point that existing educational resources, referring to the standard manufacturer-produced warfarin booklet, are not readily employed. Furthermore Lipman et al. (2004) explored with General Practitioners (GPs) what educational information on OAC was discussed during consultations. More than half reported that they gave a limited amount of information about risks of warfarin to the patient.

“... I don't use risk tools, facts and figures it's a... more of a generality of erm... 'It's just going to reduce your risk of stroke and it should prolong your life' and erm... ...you know maybe I shouldn't but I don't have... I don't use NNTs [Number Needed to Treat]” (GP10) (Lipman et al., 2004)

Indeed, GPs were found to have different communication styles with varying rates of success. Some GPs preferred discussing statistics about risks associated with warfarin to help the patient reach a decision about warfarin uptake, while others preferred to discuss the benefits of warfarin without using probabilities or statistics to provide a rationale for their recommendation (Lipman et al., 2004).

Patients commented that information during the consultation is often rushed. The following patient suggested that written information should be given, which could be further explained by the GP.

“The cardiologist . . . says you should cut out certain food, vegetables, or reduce the quantities . . . I found it very difficult to sit on the other side of his desk and try and make notes of what he was saying. Now to him it is a regular thing, it is a routine thing . . . for me it is the first time I hear this. For 50 years I have been eating this or that . . . I don't think it should be left verbally . . . (You) should be given a briefing sheet or something to take away . . . (then) see your GP and he follows this up with verbal advice.”
(Patient) (Bajorek et al., 2007)

A further complication is that diagnosis or treatment advice may be given in secondary care. This is not always the best context for patients to take in the information provided (Bajorek, Krass, Ogle, Duguid & Shenfield, 2006).

“Education in the hospital ward...you are asking a lot when somebody is in a four bedded room...(pharmacist) trying to explain something to you...you can't hear, you can't sleep very well...probably not the best place for you to have all this stuff explained to you...only so much we can do, it's just too hectic.”
(Nurse) (Bajorek et al., 2006)

2.3.3.2 Deciding on OAC therapy

Following information provision at diagnosis is the decision-making process regarding OAC therapy. Again the literature reveals a mix of strategies. Three studies explored OAC therapy decision-making with patients (Dantas et al, 2004; Bajorek et al., 2006; Bajorek et al., 2007), and in each, patients reported that the decision was taken by the physician and that they were happy with this approach.

“I can recall that I had no objection. I said, "You are the experts, you are the doctors. If I get any help, I mostly will appreciate it.".... I don't think I would trust myself that much (to make the right decision).” (Patient 15) (Dantas et al., 2004)

However, other health professionals (nurses, hospital pharmacists) caution against this didactic consultation style, where a patient accepts a drug based on the trust they have in the expert (Bajorek et al., 2006; Bajorek et al, 2007). The argument was postulated that patients should be responsible for their health and voice their concerns, rather than abdicating responsibility for health care decisions to their physician.

“A lot of the older patients – ‘my doctor says it is good for me so I’ll take it...they are an expert’...are pretty bad because they don’t ask questions.” (Nurse) (Bajorek et al., 2006)

Some patients wanted sufficient information to make an informed decision but also required time to reflect on it before discussing it further with their GP.

“I would personally prefer that I read the book first and then come back and say “I am not sure about this or that; could you explain this to me?” (Patient) (Bajorek et al., 2007)

Dantas et al. (2004) found that some patients had commenced OAC while hospitalised because of an emergency or another illness and therefore preventing an active informed decision. Under these circumstances patients often ended up being presented with warfarin as their only therapeutic option which is perceived as a problem by some (Dantas et al, 2004; Bajorek et al., 2006; Bajorek et al., 2007).

“When I went into the (clinic) to see my doctor, they admitted me to the cardiac emergency, and they kept me there all day... I was in for just about a week... and when I was discharged the doctors explained that they were putting me on to certain medications, and Coumadin was one of them.” (Patient 10) (Dantas et al., 2004)

“They just don’t voice a concern about taking it because they don’t see they have any other option...just part of the treatment that’s been prescribed...they have to put up with it.” (Nurse) (Bajorek et al., 2006)

In contrast some physicians perceived this decision-making process as more of a negotiation (Lipman et al., 2004; Anderson et al., 2007). All GPs and senior physicians in these studies argued that patients’ ideas, concerns and expectations about OAC therapy should be central to consultations but the

conclusion was that there was “a range of views as to the extent to which physicians would allow patients to be the ‘final’ decision-maker” (Anderson et al., 2007).

“I like to advise... identify what the patient thinks they need, what I think they should have, and then if it’s acceptable we come to an agreement and we try to take it forward, it’s negotiation, try more and more nowadays to do that in a consultation...” (GP1)(Lipman et al., 2004)

“I would almost put the decision or the ball in his court and I would go down the lines of describing to him his absolute and relative risk reductions with aspirin and warfarin... and I’d see what he’d prefer to do” (Physician) (Anderson et al., 2007)

However GPs feel responsible for the outcome (stroke or bleeding event) when a patient doesn’t take the “right” treatment decision (Lipman et al, 2004). This is more often the case with the ‘family-doctor’ relationship built over time, than hospital physicians (Lipman et al, 2004). These feelings often prevent GPs from prescribing warfarin for fear of causing bleeds.

“Well it’s my fault for putting it in a way that . . . that perhaps didn’t put the benefits and harms quite in context. I’ve made a mistake in how I’ve described the risk for that individual patient because they made a decision which I think is probably the wrong decision . . .” (GP4) (Lipman et al, 2004)

2.3.3.3 Challenges revolving around patient issues

Researchers found that patients’ beliefs were influenced by their ‘experiential’ knowledge (Pinder, 2008) that is knowledge gained through first-hand experience. This knowledge often had a negative influence on warfarin acceptance (Howitt & Armstrong, 1999; Dantas et al., 2004; Fuller et al., 2004; Lipman et al., 2004). A common patient belief mentioned in these six studies was the awareness of warfarin being used as rat poison.

“‘Hang on doctor’ he said ‘That’s the stuff they use to poison rats with isn’t it’, I said ‘That’s . . . well it is and how do you . . .’ and he

said ‘Oh I was a rat catcher for the council, I don’t want that because I’ve seen too many things happen to rats with that.’ (GP1) (Lipman et al., 2004)

Similarly, older participants in Fuller et al’s (2004) study saw friends or family members have haemorrhagic strokes, and associated the increased risk of bleeding from OAC therapy with a possible haemorrhagic stroke. This could easily be misconstrued as the same medication that is lowering the risk of an embolic stroke is increasing the risk of a haemorrhagic stroke.

“Bleeding into the brain – isn’t that fatal? Happened to someone I know” (Patient 72, aged 78) (Fuller et al, 2004)

Howitt & Armstrong (1999) argued that patients who refused to take warfarin did not perceive themselves as vulnerable. Such patients believed that a stroke can only happen to people with an unhealthy lifestyle. This constitutes an avoidant coping mechanism, or denial, lived out in their agreement to take only aspirin.

“People who have strokes are overweight, drink and smoke. I don't think it will happen.” (Patient 16, final treatment aspirin) (Howitt & Armstrong, 1999)

There are other issues related to lifestyle which resulted in refusal of, or a negative perception of, warfarin: the need for regular blood tests to monitor anticoagulation control, the amount of time it takes to do the tests, abstinence of alcohol, and an ever increasing amount of tablets (Dantas et al., 2004; Fuller et al., 2004; Lipman et al., 2004; Bajorek et al., 2006; Wild, Murray & Donatti, 2009; McCabe et al., 2011b)

“I’ve had one patient who has refused to go on warfarin . . . because he doesn’t want to take it, he doesn’t want to have that commitment to taking medication, to being monitored you know to possibly having the side effects that he might have, even though he is aware of the potential benefits, now if that’s . . . if that’s his decision that’s fine by me, it’s not my life, I’m not taking warfarin for the rest of my life you know.” (GP11) (Lipman et al, 2004)

Monitoring was reported as particularly disruptive when planning holidays or working. These patients were more likely to feel inconvenienced than those who were monitored less frequently (Wild et al., 2009). Patients' resistance to follow-ups was also reported as a challenge (Murray et al., 2011).

"I have to miss work to get my blood work done or go visit the doctor to get a prescription and depending on their hours, sometimes I have to leave." (Patient US Group 6) (Wild et al., 2009)

However, some patients viewed the regular blood monitoring positively as it confirmed their warfarin control (Dantas et al, 2004; Wild et al., 2009).

"I like getting it checked. It makes me feel more comfortable, as far as know I'm okay." (Patient US Group 11) (Wild et al., 2009)

2.3.3.4 Healthcare challenges

Communication between primary and secondary care was a key challenge identified in the synthesis (Lipman et al, 2004; Bajorek et al, 2007; Murray et al, 2011). The lack of communication between hospital physicians and GPs meant neither took responsibility for patient education, which in turn has significant consequences for patient adherence (Lipman et al, 2004; Bajorek et al, 2007).

"Decision making for who goes on warfarin is taken often by one person, monitoring of warfarin is taken by another person and in our practice people are monitored in 5 different systems, alright and er . . . ongoing responsibility for patient education is nonexistent . . . the potential risks of warfarin to me are so large in terms of errors basically." (GP2) (Lipman et al, 2004)

"It may create conflict with the patient too . . . especially if the other health professional said something (different)" (GP) (Bajorek et al, 2007)

The common problem of limited personnel and time pressures on consultation time was identified by health professionals, nurses and GPs, as a barrier to investment in patient education (Bajorek et al, 2006; Bajorek et al, 2007).

“The doctors all roll up at 9 o’clock in the morning to do their rounds - ‘yep they can go home...there are five other people down in A&E waiting to come up, let’s ship them down to transit lounge.’ - they get home and open up this little plastic bag with all their drugs...pharmacist hasn’t had a chance to talk to them...we haven’t seen what they’re on...pressure to get them out.” (Nurse) (Bajorek et al., 2006)

The nurse above and GP below suggested that since time is limited, responsibility to educate patients could be shifted to pharmacists, either at the hospital or in the community which may improve compliance. In addition, Bajorek et al. (2007) argued that such a strategy could aid patient surveillance and education.

“If they are in there looking at the patient in-house . . . then that is probably quite useful . . . I usually don’t have the time. . . If the pharmacist is actually sitting down with them and looking at how they are managing their tablets at home. . . [monitoring] compliance [and] suggesting that the dosette is the way to go with this patient . . . It’s a very practical way actually.” (GP) (Bajorek et al, 2007)

2.4 Discussion and Conclusion

2.4.1 Discussion

This meta-synthesis has enabled consolidation of the knowledge about patients’ and physicians’ understanding of AF, risk perception management in relation to OAC therapy and the settings in which AF is diagnosed and treatment discussed. AF guidelines (NICE, 2006; Camm et al., 2010) prioritise patient-led care which requires better rapport between physicians and patients than is currently represented in the literature.

Shared decision-making is imperative for patient-led care. Patients’ experiences during the decision-making process synthesised here suggest a mixture of the paternalistic and interpretative models (Wirtz et al., 2006). While the physicians’ experiences clearly indicate that a shared decision making model is being used. This contradiction warrants further study but could be related to the patients’ trust in the expertise of the physician and may explain

why patients submit to physicians' decisions. Evidence suggests that the concept of trust between patients and physicians is vital for a successful relationship (Kao, Green, Davis, Koplan & Cleary, 1998; Pearson & Raeke, 2000), which in turn is crucial for treatment adherence. Trust, in this case, is manifest in a positive acceptance of the sick role and belief that physicians will care for their interests (Hall, Dugan, Zheng & Mishra, 2001). In critical consultations, where potential risk and negative outcomes are discussed, what is interpreted as trust in the physician could also be due to the need to escape the responsibility of a difficult decision.

Participants, both patients and health professionals commented that lack of time was an issue within the health-care system both with regard to patient education and physician workload. Deveugeule et al. (2002) found that the mean length of consultations in the UK was almost 10 minutes. Similar to the findings of this synthesis, the literature suggests that this is not enough time to establish rapport with the patient, transmit information, and address the patient's needs (Fiscella & Epstein, 2008; Tarn et al., 2008), which could have an effect on patient adherence to treatment. Findings from this study also demonstrate that doctors often refrain from changing the decision taken by other doctors (especially doctors in primary care changing the decision of doctors from secondary care) or prescribing OAC for fear of being held responsible. This was similar to findings from Carlsen's et al (2007) meta-synthesis, where the emotional burden of missing a diagnosis was tied to fear of litigation with GPs.

Similar to the findings of this synthesis, Carlsen et al (2007) meta-synthesis about GPs' attitudes to clinical practice guidelines, found that GPs were sceptical about evidence-based guidelines in general. GPs in this meta-synthesis argued that population-based trials and a narrow inclusion criteria in the studies mentioned in guidelines could weaken the applicability to individual patients (Carlsen, Glenton & Pope, 2007). Healthcare professionals in this synthesis raised similar concerns, mentioning that RCTs do not always reflect the 'common 80 year old' patient. Sackett and colleagues also point out that the practice of evidence-based medicine means integrating individual clinical

expertise with the best available clinical evidence from systematic research (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). This issue strengthens the need to incorporate qualitative studies not only before or after interventions or RCTs, but as an on-going parallel study. Such a combination of studies could provide the breadth covered by quantitative studies with the depth that only a qualitative study can provide (Yardley, 2007), thus adopting the holistic approach desired by guidance agencies including NICE (Kelly et al, 2009).

Developments in health psychology have resulted in several theoretical models for understanding variations in adherence to treatment (Horne & Weinman, 1998). In explaining how beliefs might influence patients' decisions on adherence with prescribed medications, Horne (1997) proposed that although beliefs about medicines in general influence the patients' initial orientation toward medicines, adherence behaviour is likely to be more strongly related to personal views about the specific prescribed medication. In particular, adherence decisions are influenced by a cost–benefit assessment in which personal beliefs about the *necessity* of the medication for maintaining or improving health are balanced against *concerns* about the potential adverse effects of taking it (Horne, 1997). This means that within studies which have examined OAC therapy, patients' *concerns*, such as the knowledge of OAC side effects and the need for lifestyle change, outweigh the *necessity* of the medication in the reduction of thromboembolism. This may be due to the complexity of OAC management where the patient has to balance the current risk of stroke with future risk of bleeding. In addition, unlike other medications such as hypertension or diabetes where the medication can (with the addition of other medications and appropriate self-care) ultimately 'control' the condition, OAC therapy does not guarantee that the patient will not experience a stroke, however, it does reduce the stroke risk considerably.

2.4.2 Conclusion

This meta-synthesis clearly identifies the key challenges facing AF patients and healthcare professionals who manage their treatment, namely the importance of an early and accurate diagnosis, necessity of sufficient education pertaining to AF and available treatment, particularly OAC, and identification of patient barriers to treatment to improve adherence. In addition the synthesis of the qualitative studies emphasises the differing experiences, perceptions and attitudes of health professionals and patients towards AF and OAC commencement. This qualitative meta-synthesis further highlights that central to all these issues is the effective communication of information in a variety of formats by different health professionals, and the need for an individualised approach based on discussions with patients regarding their preferences for decision-making and treatment options rather than a 'one-size fits all' approach.

2.4.3 Practice and Research implications

Adopting a model of mixed evidence, utilising qualitative research with quantitative randomised control trials, enables a holistic approach to evidence-based health care that contextualizes the biomedical data by also making sense of the social determinants of health which are critical when designing interventions for individuals leading complex lives (Kelly, Stewart, Morgan, Killoran, Fischer, Threlfall, et al, 2009).

In contrast to patients' experiences, findings show that physicians indicate that a shared decision model is being adopted, highlighting the need to further explore this dichotomy of experiences from the physicians' and the patients' own perspectives. Qualitative methodologies focusing on the individual lived experience of patients and physicians could help to illuminate the differing of opinions highlighted in this meta-synthesis.

Additionally NHS policy should focus on increasing time allotted to initial patient consultations and improve physician education with regards to teaching adequate communication techniques and skills geared towards adopting a more shared decision making process in the available patient contact time.

Patients should be regarded as active decision makers who will be more motivated to use their medication if imparting of information targets the *necessity* of OAC outweighing their *concerns* about taking it. However further research on patients' and physicians' lived experiences are required to corroborate this. Such research could have an impact on practice, by encouraging health professionals to understand and attend better to the needs and concerns of the patient. The following chapters, aim to expand this further by exploring patients' and physicians' lived experiences of AF and OAC.

Chapter 3: Methodology

3.1 Introduction

As outlined in the review of the literature, several studies have shown that although warfarin is still the recommended antithrombotic treatment for AF patients at moderate to high-risk of stroke, it is still underutilized. The qualitative literature regarding the experiences that influence physicians' decisions in prescribing warfarin to patients with AF is very limited. Additionally, there is a paucity of qualitative literature that explores the experiences that influence patients to accept or refuse warfarin as their blood thinning medication. The systematic literature search conducted as part of the meta-synthesis of qualitative studies portrayed in Chapter 2, highlights this paucity with only 10 studies available. The studies synthesised adopted various method qualitative methods, including: thematic analysis (Howitt & Armstrong, 1999; McCabe, et al., 2011b; Murray et al., 2011; Wild et al., 2011), thematic analysis with a phenomenological approach (Bajorek et al., 2006; Bajorek et al., 2007), content analysis (Dantas et al., 2004; Fuller et al., 2004), framework analysis (Lipman et al., 2004; Murray et al., 2011), grounded theory (Anderson et al., 2007). Although the studies conducted by Bajorek and colleagues (2006; 2007) conducted a thematic analysis with a phenomenological approach, they focused more on descriptive analysis rather than being interpretative. Conversely, this study was conducted using an IPA approach which apart from focusing on the phenomenological aspect, it also gives importance to the hermeneutic philosophical approach while maintaining an idiographic nature. In addition, Bajorek et al. (2006; 2007) conducted focus groups as their data collection method, while this study used individual interviews. There are advantages and disadvantages for both data collection methods. However individual interviews were used because of the sensitive nature of the phenomenon in question. The researchers felt that participants should not feel threatened by speaking openly about what happened in their consultation. Thus an individual interview offered a safer environment to build rapport between the researcher and participant.

This chapter includes the operational definitions, the rationale for the research methodology, the philosophical framework, research design, ethical issues and operationalisation of the interview guide. The project was divided into two interlinked studies. *Study 1* explored the experiences that influence patients' decision to accept or refuse warfarin as their OAC medication. *Study 2* explored the physicians' experiences of warfarin prescription and their reasons for prescribing/withholding such medication.

3.2 Aims and research question

The overall aim of this empirical work is to explore patients' and physicians' experiences of AF and OAC.

Study 1

The aim of this study was to explore the experiences, which motivate patients to accept/decline/discontinue warfarin as their OAC medication.

Research question

What are the experiences which motivate patients to accept/decline/discontinue warfarin as their OAC medication?

Study 2

The aim of this study was to understand and describe the experiences that influence warfarin prescription by physicians.

Research question

What are the experiences that influence warfarin prescription by physicians?

3.3 Objectives

To achieve the study aims, *Study 1* will:

- Explore the experiences and attitudes that have an effect on the patients' decisions to accept, decline, or discontinue warfarin.
- Explore the effect that these decisions have on patients' everyday experiences following diagnosis of AF.

Study 2 will:

- Describe the experiences of cardiologists, general physicians, general practitioners and cardiology registrars in prescribing warfarin.
- Explore case scenarios with cardiologists, general physicians, general practitioners and cardiology registrars to discover what influences their decisions in prescribing warfarin to patients with AF.

3.4 The research approach

To answer the research question, it is imperative to listen to the participants' own experiences as they live their own life story and to determine *their* meaning of this phenomenon. To explore this lived experience, a qualitative stance was chosen for this empirical work.

3.4.1 Rationale for choosing a qualitative approach

Qualitative research is interested in exploring human experiences (Ashworth, 2003). This type of research approach takes into account how the individuals experience events and make sense of the world, rather than imposing pre-conceived ideas and assumptions (Smith, Flowers & Larkin, 2009). Such an 'insider' or 'user' approach which explores the nuances of phenomena is becoming more popular in health psychology (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007; French, Maissi, & Marteau, 2005; John, Hale, Treharne, Carroll & Kitas, 2009; Pothoulaki, MacDonald, & Flowers, 2012)

Qualitative researchers focus on the meanings of the experience that are important to research participants. This is in direct contrast to quantitative research that aims to examine existing theory through testing variables that are pre-defined by the researcher (Willig, 2001). According to Willig (2001) the goal of qualitative research is not to predict, but rather to define and clarify events and experiences.

In contrast to quantitative research, qualitative research, which is typically inductive, allows for new insights from research participants to be discovered. Quantitative researchers aim to test a pre-defined hypothesis on a large cohort (Smith, 2003) in order to generalise results in support of a truth about experience (Parker, 1994; Willig, 2001). In contrast, qualitative researchers do not aim to conduct studies that can be replicated or generalised to all people who have shared a similar experience but instead aim to understand the view of a small number of participants, from their individual reference (Smith, 2003). Thus, instead of attempting to test and measure variables to try to reach a “scientific law”, qualitative researchers believe that rather than the seeing the world in a universal way where people live in their different ways, the world should be seen individually from each person’s existence and perspective (Ashworth, 2003). A qualitative approach is thus more suited to explore the patients’ and physicians’ own individual experiences and perspectives, especially to understand the dichotomy of findings with regards to decision making outlined in the introduction.

Another clear difference between quantitative and qualitative research is the concentration on objectivity and subjectivity. Quantitative research attempts to produce objective findings through controlled experiments and the measurement of confounding variables that could affect the ‘validity’ of the research such as attempting to avoid demand characteristics and experimenter effects and to try to maintain ecological validity (Parker, 1994). In contrast, a qualitative approach embraces subjectivity through reflexive practice (Elliott, Fischer & Rennie, 1999; Parker, 1994). Reflexivity is the practice of being aware about the research process through a continuous cycle of self-

observation and self-evaluation in order to understand actions and the reactions and decision making throughout the research process. This reflective practice helps in maintaining subjectivity as it is impossible to avoid own fore-understandings and prejudgements becoming part of the research (Finlay, 2003a).

Qualitative research can be considered more naturalistic because instead of attempting to conduct research in an entirely controlled environment set up by the researcher it acknowledges and works with the effects that the research will have on the participants, researchers and the overall findings (Parker, 1994). Additionally, qualitative research methods enable health sciences researchers to delve into questions of meaning, examine institutional and social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions (Sokolowski, 2000).

Qualitative research can be loosely split into two main branches: approaches that explore individual experiences and a person's individual lifeworld (a phenomenological position); and approaches that explore how people's language constructs or defines the social world (social constructionist approaches). Phenomenological approaches are interested in the subjective experience within the socio-cultural context in which people live, thus experience is the unit of study in this approach. By comparison, social constructionist approaches are loosely deterministic in that they examine language and communication practices in order to determine how they facilitate or inhibit people's ability to function in the social world. Language therefore rather than experience is the unit of study here. The current research took a phenomenological approach as the focus of the current research programme was to investigate the lived experience of patients and physicians as understood within the constraints of the UK health care services.

3.4.2 Phenomenology

Phenomenology is *"the study of human experience and the way in which things are perceived as they appear to consciousness"* (Langdrige, 2007, pp.10).

Phenomenology, rooted in early 20th-century European philosophy, involves the use of rich descriptions and close analysis of lived experience to understand how meaning is created through embodied perception (Sokolowski, 2000). The aim of phenomenological research “*is to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place.*” (Giorgi & Giorgi, 2003, pp. 28). Central to phenomenology is the individual ‘lived experience’ and a person’s perception of their lifeworld or, expressed another way, as the meanings people place on their experiences (van Manen, 1990). van Manen (1990) defined lifeworld through four interconnected fundamental themes: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality). *Lived space* concerns with the way participants experience spatial dimensions of their day-to-day experience. For example, van Manen (1990) argues that spatiality does not mean the space inside the hospital, but rather the experience of entering the hospital. Another example could include how patients on OAC would have more existential spatial awareness of the potential hazards that could lead to internal bleeding, such as falling. The concept of the potential bleeding could then influence the *lived body* existential. The *lived body* existential includes aspects of habits, feelings, perceptions and experiences of the participants’ own body. The theme of *lived time* revolves around the temporal perspectives of past, present and future, the participants’ experience of subjective time rather than objective time. For example, how patients and physician perceive and experience time during the consultations. The fourth existential, *lived human relation*, is concerned with the lived relation participants have with others in the interpersonal space that they share, for example the experience of the relationship formed between the patient and their health professional.

In order to locate the epistemology of the current research it is important to discuss some of the theoretical underpinnings of phenomenology. Therefore, this section briefly explores the theoretical underpinnings of phenomenological psychology. As will be seen, although the phenomenological movement is rooted in the early philosophy of Husserl, over time variations of

phenomenology have been taken up, embracing the ideas of existentialism and hermeneutics.

Phenomenology proposes that central to any experience is intentionality, which is a key feature of consciousness (Moran & Mooney, 2002). In fact, this theory of intentionality is central to phenomenology. Intentionality here means that all experience has an object-relatedness and thus whenever we are conscious, it is always to be conscious of something. As human experiences are always already related to the world, it is mistaken to overlook this basic fact (Moran & Mooney, 2002). Phenomenology focuses on the inherent social situatedness of human experience (experience is already interpreted when lived). Therefore, it emphasises the investigation of the person-in-context and therefore the need to keep together the person and the world. This is different from other approaches, mainly that of Rene Descartes, whose subject-object division evolved into rationalism and empiricism where the focus is always on one of these aspects at the expense of the other. How can we ever come to understand the world of another person who is just as much trapped in their own subjectivity? Phenomenology therefore may be seen as a movement away from this Cartesian dualism of reality being somewhere 'out there' or completely separate from the individual (Koch, 1996). Phenomenology offers the researcher an explanation of how the experiencing participant and the object experienced are not externally linked but internally unified, Idhe stated that:

“...every experiencing has its reference or direction towards what is experienced, and, contrarily, every experienced phenomenon refers to or reflects a mode of experiencing to which it is present.”
(Idhe, 1986, pp.42-43)

In phenomenological research, the researcher attempts to explore the lived experience as perceived by the participant. This requires a certain level of what Husserl termed epoché, or 'bracketing off' one's own perceptions and preconceived ideas about the phenomenon to be open to discovering the phenomenon as experienced by a participant (Spinelli, 1989). However, it is debateable as to how much a researcher can bracket off their ideas. The

phenomenological movement is essentially split between early phenomenologists who believe that experience is transcendental (e.g. Husserl), and later phenomenologists who believe it is existential (e.g. Heidegger and Merleau-Ponty, Langdrige, 2007; Moran & Mooney 2002;).

Transcendental phenomenology relates to the belief that a person can step outside of their experience and 'view the world from above', and thus believe that epoché is possible (Husserl, 1936). Through the epoché we can identify the essence of a phenomenon and it is that essence which transcends the individual, subjective experience. This notion, however, has been a bone of contention, with the majority of those that followed Husserl rejecting this type of philosophy.

Heidegger gave the phenomenological movement an existential turn when he asserted that the person remained an important part in the relationship between the subjective lived experience and the world in which we live (Moran & Mooney, 2002). Existential phenomenologists believe that experience is embodied and we exist only through 'being-in-the-world'. Existential phenomenologists therefore believe that a person cannot completely achieve epoché. Existential phenomenology also recognises both the temporal and social nature of experience. Our sense of being-in-the-world is understood through our concept of time where *"we all live in time in a verb-like way, as meaning-making machines seeking to realize ourselves"* (Langdrige, 2007, pp.39). Furthermore, we exist in a world with others and therefore all experiences occur in relation to other people (e.g. relationship between patients and physicians); 'being-in-the-world' can thus be thought of as being-in-the-world-with-others. It is also important to remember the idiographic nature of experience. Each person's experience of a phenomenon will be different thus there is no 'correct' interpretation. We cannot know the truth about a phenomenon because one person's truth will not necessarily be the same as another's (Spinelli, 1989).

Similarly, Finlay (2003a, pp.107), drawing on the ideas of Heidegger, notes *"each person will perceive the same phenomenon in a different way, each*

bringing to bear his or her lived experience, specific understandings and historical background.” Moreover, experience is ever-changing, as an example from Spinelli (1989), the first time I see a painting in a gallery that I have been meaning to see for a while will be a different experience when I see it for a second time: *“Our interpretations of the world, therefore, are not only unique, they are also unfixed (‘plastic’) in their meaning”* (Spinelli, 1989, p.9).

Phenomenological psychology also employs the use of hermeneutics (meaning the ‘art of interpretation’ – Smith et al., 2009). Phenomenological research is considered a co-creation between the researcher and the participant and the meanings that both bring to the data through their individual subjectivities (Finlay, 2003b). Thus, phenomenology acknowledges the important role that the researcher and their fore-understandings play in the interpretation of the research (Finlay, 2003b, Smith et al., 2009) yet, at the same time, recognises the need to remain open to the insights obtained through the participants’ experience. The researcher’s fore-understandings may work to block the participants’ meanings from appearing yet also serve to open up the interpretation. Thus, ‘tension’ between reduction and reflexivity occurs in phenomenological research whereby the researcher must ‘bracket’ their fore-understandings yet also utilise them as a ‘source of insight’ (Finlay, 2008).

This complex nature of interpretation may best be understood as a hermeneutic circle, whereby one needs to look at the whole to be able to understand the part and vice versa (Smith et al., 2009). Interpretation is seen as moving back and forth between the part and the whole to reach the interpretation (seeing the participant and the data in a holistic way; understanding the whole account in the transcript, but also paying attention to the smaller details within the account where inconsistencies or other patterns might emerge). Each time one looks at the part, one’s understanding of the whole becomes strengthened and with each strengthening of the whole, new questions and new understandings of the part becomes apparent. Similarly before data is collected, the researcher already has fore-understanding of the phenomenon under investigation, which inevitably becomes modified through hearing the experience of a participant. This new understanding causes new questions and understandings of the

participant's experience to be formed. Thus the research process involves a constant moving back and forth between the researcher's and participant's subjectivity until a plausible interpretation is reached (Finlay, 2003a; Smith, 2007; Smith et al., 2009). Thus researchers should proactively manage their interactions with their participants and the world and to actively explore how these encounters impact on their pre-existing beliefs and knowledge in order to grasp the phenomenon under study (Shaw, 2010)

The complex role of the researcher's understandings in the interpretation of data renders it essential for the phenomenological researcher to be reflexive throughout the research. Finlay (2003) defines reflexivity as the process of frequent reflections on both the phenomena being studied and our own experiences of it, so as to move beyond the bias of our fore-knowledge and our investment in particular research outcomes. Lamb and Huttlinger (1989, p. 766) state that reflexivity is "self-awareness and an awareness of the relationship between the investigator and the research environment". The researcher must constantly reflect on their own experiences and understandings regarding the phenomenon under investigation from the outset and throughout the research process through reflexive notes or a reflexive journal

To summarise, phenomenological psychology acknowledges that lived experience, and the meanings we place on that experience, are the result of 'being-in-the-world-with-others'. Experience is embodied, on-going and a result of our interactions with the world and others. Phenomenological psychology also involves a process of interpretation (hermeneutics) and acknowledges the intersubjectivity between the researcher and participant. In the next section (section 3.4.3), interpretative phenomenological analysis, the particular phenomenological psychology approach chosen for this research will be explored.

3.4.3 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a relatively recent qualitative phenomenological approach developed by Jonathan Smith (1996) for

psychological research. Since its inception, it has become one of the most widely known and well-used qualitative methodologies in health psychology (Brocki & Wearden, 2006; Chapman et al., 2007; French et al., 2005; Smith, 2011).

As with all phenomenological approaches, the focus of IPA is the detailed examination of individual experiences of a particular phenomenon and the meanings participants attribute to these experiences. The aim of IPA is to conduct this examination in a way which as far as possible enables that experience to be expressed in its own terms, rather than according to predefined category systems (Smith et al., 2009).

The current research project aims to understand participants' meanings of AF and OAC (prescription/acceptance/refusal) through their lived experiences of it and therefore a phenomenological approach is suited. Grounded theory, an approach that originated from sociology is appropriate for phenomenological research but its emphasis on generalising findings to whole populations means that any differences in individual accounts may be missed (Charmaz, 2003). As Willig (2001) shows, grounded theory aims to identify and explicate contextualized social processes which account for phenomena. By contrast, IPA is concerned with gaining a better understanding of the quality and texture of individual experiences (i.e. it is interested in the nature or essence of phenomena).

As discussed previously (see section 3.4.2) phenomenological research (including IPA) allows a more individual approach. So rather than aiming for nomothetic, generalised research findings, IPA is concerned with idiographic experiences and understandings and how the individual interprets phenomena, rather than how it is socially constructed. Only when each individual's experience has been interpreted can the researcher move to a shared understanding across the group (Smith, 2004). The idiographic nature of IPA allows the researcher to identify participants' distinct meanings and experiences of a phenomenon but also allows for the identification of the areas where these meanings and experiences are shared by a group of participants

(Shaw, 2001; Reid, Flowers & Larkin, 2005; Smith et al., 2009). Phenomenologists explicitly seek out idiographic meanings in an attempt to understand the individual, which may or may not offer general insights (Ashworth & Ashworth, 2003). However, Halling (2008) accepts both the particular and general by arguing that idiographic research can also be universal in that it may well identify common structures of experience. He suggests that phenomenologists engage in three levels of analysis: looking at the particular within an individual's experiences; looking at what is common about the experience across people; and looking at what in the phenomenon helps us understand human existence in a broader philosophical sense (Halling, 2008). He also suggests that, similar to previous arguments on the relationship between the part and the whole and the researcher-participant subjectivities (see section 3.4.2), researchers need to move back and forth between experience and reflection at these different levels (see section 3.4.2). Nonetheless, it is also important to consider that although IPA focuses explicitly on the individual experience, it also recognises the role of sociocultural and historical influences in the way people experience and understand their lived world (Eatough & Smith, 2008)

Related to this, another difference between IPA and other approaches to data analysis is the focus of IPA on cognitions, which it shares with mainstream cognitive psychology. It is concerned with the process participants go through in order to make meaning. However unlike mainstream cognitive psychology, which uses positivist measures of cognitive functioning to predict cognitive performance, IPA enables the researcher to explore participants' own cognitions through the interpretations of their own meanings and understandings (Smith, 2004). In this way, IPA provides us with "a deeper understanding than traditional psychological methods" (Reid et al., 2005, pp.20). For example, IPA asks how people make sense of what is happening in a particular phenomenon, thus incorporating the person's own cognitions. A focus on cognitions is also another way in which IPA is distinct from discourse analysis. Smith et al. (2009) describes IPA as a middle ground between the opposing stances of social cognition (which draws on positivist approaches to

look at cognitions) and discourse analysis (which uses qualitative data but does not consider cognitions).

By discussing the researcher's own interpretations of the participants' own meaning (a double hermeneutic approach), IPA is explicit about what the researcher brings to the analysis (Smith et al., 2009). Reflexivity is also apparent in grounded theory with the use of memos throughout the analysis but the final presentation of results does not include this focus, instead the research findings are presented as completely data-driven. Discourse analysis also does not present research findings as a meaning-making process between the researcher and the participant but links participants' discourses with institutions and current social explanations and practices (Willig, 2003). An interpretative approach to data analysis, therefore, does not mean that themes can simply 'emerge' or 'be discovered', rather data analysis requires the researcher to 'actively' work with the data (Braun & Clarke, 2006). The use of the term "emerging":

“...can be misinterpreted to mean that themes reside in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them.” (Ely et al., 1997, pp. 205-206 cited in Braun & Clarke, 2006)

IPA goes beyond simply using participants' own words to describe a particular phenomenon it then uses these words to interpret the meanings expressed by the participants. IPA uses a double hermeneutic as the researcher is making sense of the participant making sense of their experiences (Smith et al., 2009).

Smith (2004) outlines three characteristic features of IPA; it needs to be 'idiographic, inductive and interrogative'. IPA's commitment to the individual account has already been discussed. IPA is *inductive* as it allows unanticipated areas of experience to be explored (Smith, 2004). In this sense, it is important to employ a semi-structured approach using open-ended questions, which allow participants to discuss areas of importance for them. Once the results of an IPA study are obtained, they are then discussed with reference to the

existing psychological literature on that topic. In other words, the results of the IPA study are then used to inform, support or problematise findings from previous work and it is in this way that IPA is *interrogative* (Smith, 2004).

Reid et al. (2005) also outlines three characteristic features for a successful IPA study: they believe it must be 'interpretative', 'transparent' and 'plausible'. To be *interpretative* the researcher must subjectively and reflexively work with the data to interpret the meanings the participants hold, these interpretations can be based on theoretical perspectives as long as they are *transparently* linked to the participants' words ("grounded within the data"). Furthermore the analysis needs to be *plausible* to the participant: those working on the data and to those reading the analysis, in other words the interpretations need to resemble what it is actually like to live those experiences.

3.4.4 *The researcher's beliefs*

In interpretative phenomenology, fore-knowledge and beliefs are integral to interpretation and should be acknowledged for their influence on the interpretation of data (Plager, 1994). Thus the following section, the researcher will discuss his fore-knowledge and beliefs with regards to AF and OAC. This section will be written in the first person.

I am a 28 year old Maltese male, who is a Roman Catholic by religion. As a young boy I used to spend a lot of my free time with my grandfather, and from there I learnt to respect and to feel at ease talking with but most importantly listening to older people. Personally I have never experienced AF or OAC, nor have members of my family. However, when my grandfather died, the family took it in turns to go and sleep at our grandma's house, so she would not feel lonely. During one of my stays, she had a minor stroke during the night, and I remember that she woke me up and was asking me questions that did not make sense. After calling my parents, my mum realised it was a possible TIA and we called for the ambulance. That was my first 'real-life' experience with stroke. In addition, my father has a heart condition and when he had his first heart attack and went to emergency care; I was struck by the attitude taken by

the healthcare professionals. The lack of information and empathy shown was disconcerting.

Thus when I started this journey I was motivated to explore such attitudes and to understand whether these attitudes were experienced elsewhere. Furthermore, since AF increased the risk of stroke, I was driven to understand this condition more. During some of the AF clinics I observed, physicians I used to be paired with seemed very helpful and empathic to the patients. Some patients seemed to be concerned about the new heart condition, especially when they felt no symptoms. This reminded me of the abruptness of medical emergencies that had happened to my grandma and my father. In addition I could understand how patients who were not feeling any symptoms might only perceive the burden of taking OAC, rather than the benefits. When I started informing myself on the literature of AF and OAC I felt that physicians might be doing the right thing when they were taking the decision themselves to prescribe warfarin as it was after all for the patient's benefit. Thus I could understand how physicians could easily take a paternalistic role and prescribe the medication. Thus throughout the course of this study, my personal thoughts and reflections have changed as I have become more aware of the patients' own lived experiences. I understood how convincing a patient to abide by your decision would impact on his perception of both the relationship with the physician and the treatment, especially when I was discussing some of these issues with physicians. Returning to my health psychology mind-set I started to think more along the lines that patients have the right to decide what medicines they are taking as they are the ones that are going to live with their choice and warfarin could be a potentially dangerous drug.

3.5 Research Design

This project adopted a qualitative design using IPA, as it was coherent with the theoretical underpinnings of phenomenology as described above. The programme of research was divided into two interlinked studies examining the experiences that influence patients to accept or refuse warfarin and physicians'

experiences of warfarin prescription and their reasons for prescribing/withholding such medication.

3.5.1 Ethical Considerations

Ethics approval was sought and granted by the South Birmingham Research Ethics Committee on the 23rd September 2009. The School of Life and Health Sciences Ethics Committee, Aston University approved the study on 11th December 2009. To conduct a study within the NHS, Research and Development approval was also needed, and this was obtained on the 11th January 2010.

Participants' informed consent is considered very important in research methods (Munhall, 2001; Rubin & Babbie, 2001). After going through the Participant Information Sheet (see Appendix C, D) and any questions participants had about the study were answered by the researcher, and all participants in this study provided written informed consent (see Appendix E, F). Participants were told why they have been chosen to take part in the study. They were also informed about the nature of the interviews, namely that the interviews would be held at times convenient to them, that they would be conducted in a quiet office in City Hospital and that all travelling expenses to and from the hospital for the study would be reimbursed. Addressing participants' privacy and comfort was thus considered a priority.

Since the interviews were going to explore personal and work related matters, participants were also informed about issues of confidentiality. They were told that their name was not going to appear in any part of the study but rather a pseudonym would be used instead. Furthermore, participants were assured that the information gathered would not identify a given response with a given respondent (Rubin & Babbie, 2001). They were also informed about the total duration of each interview and that it would be digitally recorded.

Furthermore participants were advised that their participation was voluntary and that they had a right to accept or refuse to take part or to withdraw from the

study up to two weeks after the interview. Another ethical issue was the sensitive nature of the interview itself. Since the study was dealing mainly with older individuals, feelings of distress and sadness, could ensue from the particular nature of the questions. In the event of the participant becoming distressed several actions could be taken such as taking a break, changing the conversation if the participant wishes it, or stopping it altogether. In addition every participant was debriefed at the end of the interview (see Appendix G, H).

3.5.2 Inclusion criteria and sampling

IPA allows the researcher to obtain detailed accounts of individuals' experiences of living with a particular condition (Shaw, 2001) and therefore participant samples were purposive and participants were recruited for their '*expertise*' on a particular subject, as they can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words (Reid et al., 2005).

Reid et al. (2005) described how to conduct comparison studies by looking at a phenomenon from multiple perspectives; the researcher can thus obtain a more thorough account of it. Smith et al. (2009) commented on the use of such '*bolder designs*'. They argue that such multiple-perspective designs of one phenomenon can help researchers to develop a more detailed and multifaceted account of that phenomenon as well as serving as a form of triangulation of data (Smith et al., 2009).

Conforming to this, the project opted to explore multiple perspectives: *Study 1* – patients with AF who accepted, refused, or discontinued OAC therapy; and *Study 2* – physicians in different specialties (cardiology, general practice, and general medicine) and at different levels (registrar and consultant).

Small sample sizes are normally recommended for phenomenological research as the aim is to provide detailed, in-depth accounts of participants' lived experience (Smith et al., 2009). The sampling method used for this particular study was purposive. This is a non-probability sampling method which is quick

and provides an opportunity to select participants with the characteristics of interest. This method is considered to be appropriate when conducting phenomenological studies (Polit, Beck & Hungler, 2001). Participants were carefully selected; in that they had to be individuals who had all experienced the phenomenon in question (see section 3.5.2.1.2 and section 3.5.2.2.1). Participants needed to give more than just an opinion or view about the topic under study; they had to be willing and able to give detailed descriptions of their own personal experience.

The sample size in this project was determined on the basis of informational needs and for the aim of the study to be achieved (Morse, 1994). Smith and colleagues (2009) stated that there is no right answer to the question of sample size; however, they suggested using between three and six participants (Smith et al., 2009). Thus the aim was recruit four participants in each of the groups listed in Table 9, to make a sample of 32 participants in total.

Table 9: Planned recruitment of patients and physicians

Physicians	Patients
4 Consultant Cardiologists	4 Accepted OAC
4 Consultant General Physicians	4 Refused OAC
4 Cardiology Registrars	4 Discontinued OAC themselves
4 General Practitioners	4 Discontinued OAC by physician

3.5.2.1 Study 1: Patient participants

3.5.2.1.1 Sampling

This study planned to explore patients' experiences in order to understand what led them to their decision to accept, decline or discontinue warfarin as their OAC therapy. Participants were eligible for inclusion if they were aged over 18 years and had been diagnosed with AF. Participants were not excluded on the basis of gender or age. Patients diagnosed with severe cognitive impairment

were excluded from the study as participants had to recall, in detail, events from the past and present; decisions regarding cognitive ability were judged with the help of a physician who went through the potential participant's medical notes. Initially, the study planned to explore the experience of a fourth group of patients (see Table 9); patients whose OAC was discontinued by their physician. However, no living patients were found that were eligible for inclusion into this group. Two cardiology registrars helped the researcher in finding such patients from medical notes. Patients whose physician had stopped OAC were mostly due to terminal cancer. Furthermore, the study aimed to recruit four patients into each of the remaining three groups (accepted, declined or discontinued warfarin), however, only three participants who discontinued OAC were found to be eligible and were willing to participate.

In keeping with the requirements of an IPA study, the group under study should be homogenous (Smith et al., 2009). This has been stressed by several authors (Smith & Osborn, 2003; DeVisser & Smith, 2006) so as to focus the investigation as far as possible upon the phenomenon of interest, without it being confused by other factors. Smith et al. (2009) contends that the extent of 'homogeneity' in a group varies from one study to another. Smith et al. (2009) argue that participants are chosen on the basis that "they can grant us access to a particular perspective on the phenomena under study" (pg 49.). They further reason that since IPA is an idiographic approach, it is concerned with particular phenomena in particular contexts or outcomes (Smith et al., 2009). For example, a study by Kam and Midgeley (2006) explored how mental health professionals chose whether or not to refer a child for individual psychotherapy. They chose five referrers; counsellors, psychiatrist, psychologist, family therapist and social worker. The common phenomena between these participants was their experience with referrals of children to individual psychotherapy.

Similarly, the phenomena in the present study was the experience of AF and OAC within the consultation, in particular: the exploration of what experiences influenced patients in accepting/refusing/discontinuing warfarin and what experiences influenced physicians in prescribing or withholding warfarin

treatment. Therefore, homogeneity across groups in *Study 1* was defined as 'patients who had a consultation where they were diagnosed with AF and accepted, declined or discontinued warfarin treatment.'

3.5.2.1.2 Recruitment process

Patients were recruited from City Hospital. The clinicians working in the AF clinic suggested patients who met the inclusion criteria for the study. Initially, the clinicians talked to the patients about the study during the clinic and if they were interested, the researcher contacted them at a later stage, either by telephone or at their next meeting at the anticoagulation clinic or the AF clinic at City Hospital. The researcher explained the study in detail and also provided the participant information sheet (see Appendix C). The participant had at least two weeks to decide whether to take part in the study or not. After two weeks, the researcher contacted the potential participants. If the participant agreed to take part in the study, s/he was asked to sign a consent form and a meeting was scheduled for the interview (see Table 10 for patient characteristics).

Table 10: Patient Characteristics

Accepted	Age/Gender/Ethnicity	CHA₂DS₂-VASc Score (% annual stroke risk)
Lionel	78/M/White British	5 (6.7)
Jonas	67/M/White British	2 (2.2)
Fiona	70/F/White British	4 (4)
Daniel	83/M/White British	4 (4)
Refused	Age/Gender/Ethnicity	CHA₂DS₂-VASc Score (% annual stroke risk)
Will	69/M/White British	3 (3.2)
Greg	53/M/White British	2 (2.2)
Josephine	58/F/White British	5 (6.7)
Shona	77/F/Black Trinidadian	5 (6.7)
Discontinued	Age/Gender/Ethnicity	CHA₂DS₂-VASc Score (% annual stroke risk)
Katrina	80/F/White British	4 (4)
Raj	72/M/Asian	4 (4)
Robert	71/M/White British	2 (2.2)

3.5.2.2 Study 2: Physician participants

3.5.2.2.1 Sampling

The study aimed to recruit four cardiologists, four general physicians, four general practitioners and four cardiology registrar level physicians that work at West Midlands hospitals and in general practices in primary care. Participants included were qualified medical physicians with experience in conducting consultations with AF patients. Participants were not excluded on the basis of gender or age.

Following the aims outlined previously, homogeneity across *Study 2* was defined as 'physicians who were at a similar specialty level and had experience

of consultations with patients who had AF, and had undertaken decisions whether or not to prescribe warfarin’.

3.5.2.2.2 Recruitment procedure

A member of the supervisory team (GYHL) initiated contact with the physicians by sending e-mail invitations to colleagues to participate in this study. Participants interested in participation were then contacted by the researcher who explained the study in more detail and gave physicians a Participant Information Sheet (see Appendix D) Participants were given two weeks to decide whether to take part in the study or not. After two weeks, the researcher contacted the participants and if they agreed to take part, they were asked to sign the consent form and a meeting was scheduled to conduct the interview at the participants’ convenience (see Table 11 for physician characteristics).

Table 11: Physician Characteristics

Consultant Cardiologist	Spoken Languages	Ethnicity	Age/ Years in Specialty level
Sean	English, Urdu, Punjabi, Hindi	Asian	39/4
John	English	White British	45/20
Melanie	English	White British	50/24
Peter	English	White British	44/10
Cardiology Registrars	Spoken Languages	Ethnicity	Age/ Years in Specialty level
Jeffrey	English	White British	35/5
Dheepak	English, Hindi	Asian	33/4
Ted	English	White British	32/6
Chan	English, Cantonese	Asian	37/6
Consultant General Physicians	Spoken Languages	Ethnicity	Age/ Years in Specialty level
Balu	English, 3 South Asian (not specified)	South Asian	48/7
Nilan	English, Urdu	Asian	46/9
Tom	English	White British	39/4
Manpal	English, Urdu	Asian	42/9
General Practitioners	Spoken Languages		Age/ Years in Specialty level
Matthew	English, Urdu, Punjabi	Asian	40/12
George	English	White British	40/11
Nick	English	White British	60/31
Samir	English, Punjabi, Urdu	Asian	37/9

3.5.3 Data collection

Both studies used semi-structured interviews as the method of data collection. Interviewing is the most widely used method of data collection within qualitative psychology (Brocki & Wearden, 2006; Gough, 2006; Smith, 2011). In phenomenological studies, the main data sources are typically in-depth

conversations, with researchers and informants as co-participants. Researchers help informants to describe lived experiences without leading the discussion (Gerrish & Lacey, 2006).

The research interview is a specific form of human interaction in which knowledge evolves through a dialogue (Kvale, 1996). Semi-structured interviews were used to gather data as these facilitate rapport, allow greater flexibility of coverage, and allow the interview to explore new areas (Smith & Osborn, 2004). Semi-structured interview guides are practical as questions are planned beforehand in a standardised format, yet are flexible enough for participants to talk about their experiences and express their opinions (Rubin & Babbie, 2001). Semi-structured interviews, as the name entails, are in contrast to a structured interview format as the schedule is only designed as a guide, where questions may be adapted to the interview at hand (Kvale, 1996). Kvale (1996) argues that semi-structured interviews are more akin to a guided conversation where the interviewer explores topics when the interviewee introduces them.

3.5.3.1 Operationalisation of the interview guide

Semi-structured interview guides were developed for each individual study. These interview guides aided the researcher in focusing on the participant's experiences of the phenomenon in question. The initial guide drafts for both patient and physician interview guides were developed based on previous findings in qualitative literature outlined in Chapter 2.

3.5.3.1.1 Patient interview guide

Initial interview guide drafts were developed specifically for each individual patient group in Study 1. These initial drafts contained between 22 and 24 questions (see Appendix I). However, this initial list was shortened post-pilot into one main interview guide consisting of nine questions. This was done as most of the original questions were used as prompts rather than actual questions to be asked. Therefore questions were grouped and marked as prompts (using letters) to facilitate the interview (see Table 12).

Table 12: Patients' Interview Schedule

<ol style="list-style-type: none">1. Tell me something about yourself<ol style="list-style-type: none">a. Lifestyleb. Familyc. Workd. Health2. What are your experiences of living with your heart condition?3. What were your experiences of the first consultation with your doctor on your heart condition?<ol style="list-style-type: none">a. Feelingsb. Family reactionc. QOL4. What is your experience of the part of the consultation when you were told about warfarin?<ol style="list-style-type: none">a. Feelingsb. Family reactionc. QOL5. From your experience, how was the decision for warfarin taken?6. What experiences influenced you in ACCEPTING/ DECLINING/ DISCONTINUING warfarin?<ol style="list-style-type: none">a. Previous experience?b. Family/Friends?7. Living with warfarin<ol style="list-style-type: none">a. If warfarin was accepted - What are your experiences of living with warfarinb. If warfarin was accepted & discontinued – What were your experiences of living with warfarin8. From your experiences, did you find support?<ol style="list-style-type: none">a. Familyb. Friendsc. Health care9. Looking back at what we talked about, is there anything you wish to add about your experience? <p>Thank you for your patience</p>
--

These open-ended questions aimed to elicit the patients' lived experience of the first AF consultation with the physician, their feelings, and their family's reactions. Furthermore, their experience of the communication style of the physician and the decision making process during their consultation was also discussed. The questions also explored the patients' experiences after the consultation.

3.5.3.1.2 Physicians interview guide

The initial draft of the interview guide contained 16 questions (see Appendix J). These questions were based on the barriers physicians reported in the literature explored in previous chapters and later condensed post-pilot into eight general questions after the pilot interview, so as not to impinge on the fluidity of the interview (see Table 13). The open-ended questions were used to elicit the physicians' accounts of their initial consultations with patients diagnosed with AF, including: communication style, patient concerns, the decision making process and barriers experienced during the consultation.

Case scenarios (see Appendix K) were also used to foster discussion and to aid physicians to focus on discussing their experiences with regards to decision making about OAC. These case scenarios were extracted from the literature (Gattellari, et al., 2008b; Watson & Lip, 2006), suggested to the researcher by an expert in the field of AF. Although the case scenarios from the literature had a 'correct' answer in relation to the presented cases, the researcher assured the physicians that the aim of their use during the interview was not to test the physicians' knowledge but rather as an aid for discussion and to help them think about their own experiences with patients. During the interviews, the researcher asked the participant to read the cases and asked questions like, What would you do in such a case? Can you relate such a case to a previous experience of yours?

Table 13: Physicians' Interview Schedule

<ol style="list-style-type: none">1. Can you tell me something about yourself?<ol style="list-style-type: none">a. Can you tell me something about your line of work? 2. What is your experience of the first consultations with patients with AF?<ol style="list-style-type: none">a. Questions or concerns?b. What do you think your patients are feeling at that moment?c. How do you explore oral anticoagulation with the patient 3. How do you decide about treatment? 4. How do you deal with a situation where you do not agree with the patient's decision? 5. Could you take me through your thought process when deciding to prescribe warfarin to patients with AF?<ol style="list-style-type: none">a. Could you share some actual case experiences that you had during your career? 6. I have brought with me some case scenarios of AF patients, could you go through them one by one and explain to me your thoughts about their situation?<ol style="list-style-type: none">a. What do you think would be going through the mind of the patient?b. Would you prescribe warfarin?c. Why? 7. From your experiences, what barriers do you think physicians face when prescribing warfarin? 8. Looking back at what we talked about, is there anything you wish to add about your experience? <p>Thank you for your patience</p>
--

3.5.3.1.3 Pilot Interview

Before the actual studies were started, a pilot study was conducted to ensure that the questions were easy to follow and understand and that they were sufficiently appropriate to obtain the required data. The pilot work was also useful in determining the timing of the interview and data transcription (Polit & Hungler, 1995). The first interview of each group served as the pilot study for that particular group. The interview schedules were shortened (see sections

3.5.3.2.1 and 3.5.3.2.2) after these pilot studies so that they would not impinge on the flow of the interview. The revised interview guides appeared to be appropriate and relevant to the research questions being asked and no changes were made thereafter.

3.5.4 The semi-structured interview

All interviews employed an interpretative phenomenological approach, i.e. they were partly biographical, open-ended, and asked participants to describe their experiences, and the researcher aided the participant to keep focus on their experience of the consultation. The latter was critical with physicians as they tended to talk more based on opinions. So the researcher had to use repetition and summarise what the participant was saying, and then prompting about their own experiences.

All of the interviews with the patients were conducted in the researcher's office in Arden House, City Hospital, Birmingham. Some patients requested to have their spouses present during the interview. Reasons participants brought up ranged from having to care for their spouse, or that the spouse would help the participant recall the details of events. In addition one female participant requested her spouse be present as she did not drive. The request for having a spouse present was not denied, as the researcher defends that spouses or family members might also be present during the consultation. Spouses in the interviews were treated as co-informants, sometimes adding to the information the participant was recounting on his experience. However the focus of the interview was always on the experience of the participant. Interviews with hospital general physicians and general practitioners were conducted in the participants' own offices. One cardiologist preferred that the interview was conducted in his office. Another cardiologist preferred that the interview was conducted in an empty room next to the wards because of his busy schedule. The interviews of the other two cardiologists and the cardiology registrar level physicians were conducted in the researcher's office.

The interviews were digitally recorded and transcribed verbatim within a day of the interview by the researcher. Each interview lasted on average about 70-90 minutes, with 15 minutes for briefing about the study and obtaining written informed consent, 40-60 minutes for the recorded interview, and five minutes for debriefing.

In the extracts presented, WORDS IN BLOCK LETTERS mean that the participant spoke louder, putting emphasis in his words. Opposing square brackets “[” indicate that some text has been omitted. Round brackets containing text, i.e., (his father), either indicated text that was added to clarify the meaning of the quote or non-verbals (Sighs) that happened at that particular moment.

3.5.5 Analysis of data

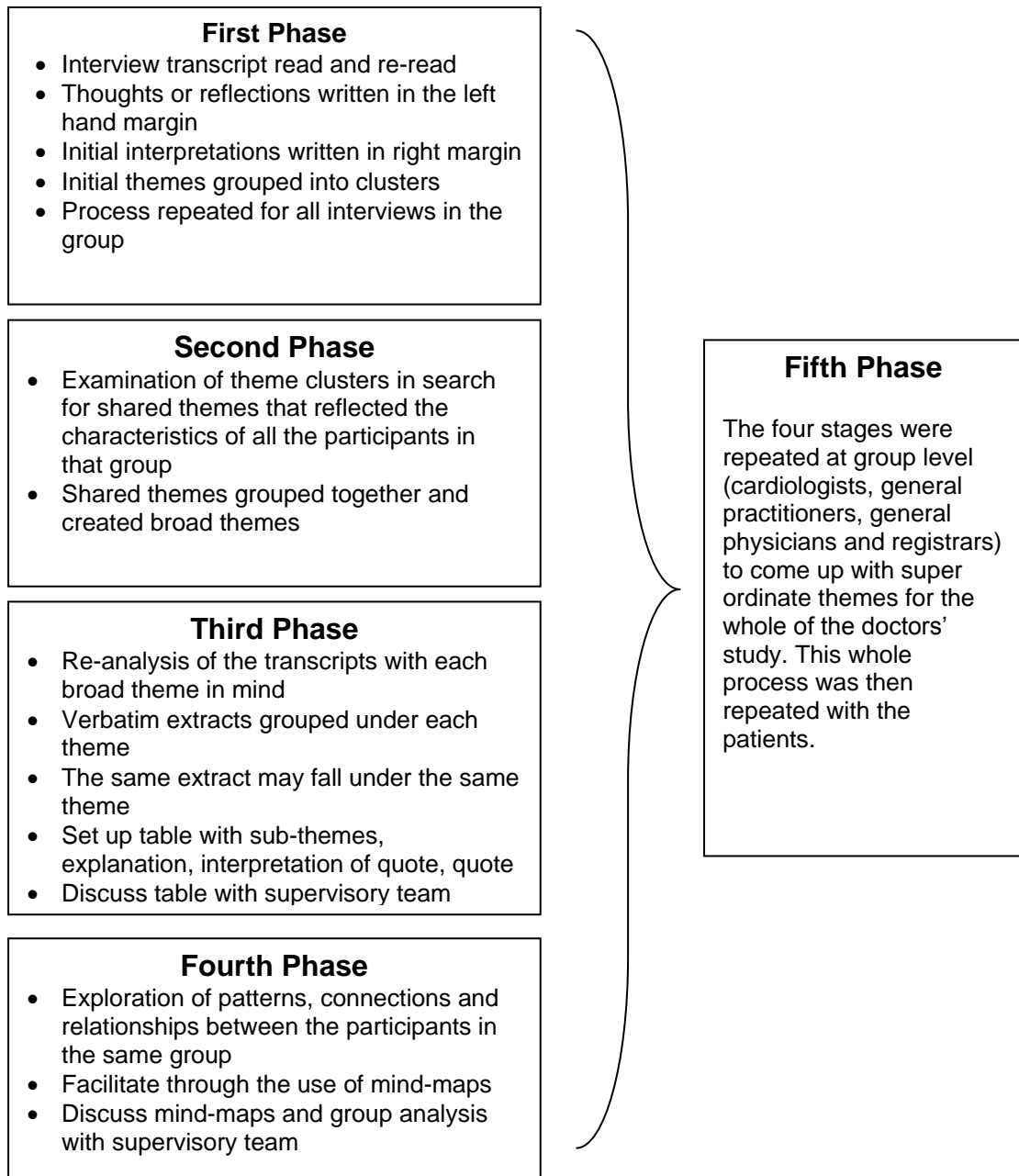
IPA (Smith et al., 2009) was used to analyse the data collected. The initial analysis process described below was undertaken separately for each of the seven cohorts: physicians (cardiology registrars, cardiology consultants, general practitioners, and general physicians); and patients (accepting/declining/self-discontinuation of warfarin) (see Figure 4 for a flow diagram of the analysis process). Each individual transcript was read several times, until the researcher became very familiar with them. All emerging thoughts or reflections while reading the text were written in the left hand margin, these included short phrases on what the participant was saying or the meaning in that particular sentence and also possible descriptive themes. During this the researcher also highlighted metaphors, and linked contradictions within the participant's own arguments. In addition the researcher noted the emphasis the participant placed on the use of certain words or phrases as well as non-verbal cues, for example when participants talked about their past experience of stroke or bleeding, they sometimes demonstrated visible emotion when recounting their experience. In addition, the researcher was also attentive to issues such as how patients made sense of their experiences of OAC, the consultation and the decision making process,

how physicians interpreted their patients' experiences, and what experiences had an influence on physicians' decisions.

Initial interpretative themes were written in the right hand margin as suggested by Smith et al. (2009). These included interpretations of the phrases written on the left hand side. The analysis was designed in this way, so that on re-reading the interview, the researcher could first read the left-hand margin, then the quote, then the initial interpretative themes (see Appendix L for a scanned example from one of the general practitioner transcripts). Initial themes were then grouped together in clusters. Following the analysis of the first interview, the process was repeated for all interviews in the same group. The transcribed interviews resulted in a large amount of printed paper, and this procedure was very time-consuming. The first phase was completed when all the themes or concepts emerging for one participant were grouped in meaningful clusters (i.e. similar themes and contradictions were grouped). This analysis phase was repeated for all participants within a specific group.

Figure 4: Flow diagram of the analysis process

The initial four stages were conducted within each group (e.g. cardiology consultants, general practitioners, patients who accepted warfarin, patients who refused warfarin etc.)



The second phase involved the examination of the clusters of themes to search for the shared themes that reflected the characteristics of all the participants in that group. All the shared themes were further grouped together and created broad themes that were relevant to more than half the participants in the group Smith et al. (2009).

The third phase comprised the re-analysis of the transcripts with each theme in mind. Each transcript was re-examined while focusing on each theme to identify examples that explicate that theme through a more focused lens and included verbatim extracts under each theme. Throughout this procedure, the researcher continuously asked himself what extracts seem particularly essential for the experience being described. Some extracts fell under more than one theme. At the end of the third phase, a table was constructed for each theme with the sub-theme in the first column, a general explanation of that sub-theme in the second column, the interpretation of the verbatim extract in the third column and the participant's extract in the fourth column (see Appendix M for example table used to facilitate grouping of shared themes across participants in a group).

The fourth phase consisted of an exploration of patterns, connections and relationships within and between the participants in the same group. The interrelationships between the broad themes were examined, aiding the researcher to better understand the life-world of the participants, to understand their experiences and to draw out the emergent analytic or super-ordinate themes. The analysis took on a highly reflexive practice on how each super-ordinate theme contributed towards the "whole". As discussed previously (see section 3.4.2 on discussion of part-whole relationship in hermeneutics) the constant interaction between the part and whole was crucial for the analysis process in this study; working on the constituent parts of the individual transcript and the whole interview, similarly at the individual participant and the whole group, and later at the specific group (e.g. patients who accepted OAC) and the whole cohort (e.g. the three patient groups). The researcher and supervisors also met regularly to reflect on how the different themes came

together, led by the researcher. To further facilitate these discussions of how themes came together to represent the groups, mind maps were created, having colour-coded themes and the interlinking relationships between themes, to aid explanation and discussion (see Appendix N for scanned example of mind maps from patient groups). This facilitated the discussion of the analysis of each group with the supervisors. These four phases were repeated for each of the patient (Study 1) and physician (Study 2) groups.

In the fifth and final phase, the same procedure outlined above was conducted at group level. With the help of the mind-maps and tables, connections, relationships, similarities and contrasts among the groups were examined to form overarching themes. New mind maps were drawn to discuss group level analysis (see Appendix O for physicians' group analysis mind map; see Appendix N for patients' group analysis mind map). Devising such a design enabled the researcher to maintain not only an idiographic perspective, as needed in an IPA study (Smith et al., 2009) (as each theme can lead to the individual participant), but also enabled the interpretation of the lived experience at group level. This was an innovative adaptation of IPA, which Smith et al (2009) refers to as a bolder IPA design. Instead of having one homogenous group, several small homogenous groups form a patchwork of experiences from patients and physicians to enable a multi-experiential understanding of the phenomenon.

3.5.6 Quality, trustworthiness, sensitivity and rigour

Trustworthiness is an essential component of qualitative research, as findings should reflect the reality of the experience of participants. Benner (1994) suggested the use of repetition and reflection (for example the use of phrases such as 'is that what you mean,') during the data collection phase, which was an integral part of the interview technique in this study. Furthermore, such a prompt during the interviews served as an on-going process of verification from the participant. Additionally, supervision throughout the whole study and more frequently during the analysis stages was used to discuss and challenge the depth of the researcher's analytic interpretations (Smith et al., 2009).

In addition, Yardley (2000) argued that a qualitative study should be assessed on its ability to accurately interpret and present the experiences and views of those involved in that particular study. So, rather than assessing research based on 'reliability' and 'validity' a qualitative researcher will aim for 'sensitivity' and 'rigour' (Yardley, 2000). Yardley (2000) proposed four broad principles for assessing the quality of qualitative studies, sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

The first principle, sensitivity to context, refers to the ways in which the research is sensitive to the context of the phenomenon being investigated. As Smith and colleagues (2009) point out, sensitivity in this study is demonstrated in its conception. The very choice of IPA as its methodology revolved around the need for sensitivity and the importance of taking an idiographic approach to the phenomenon studied. Furthermore, sensitivity to context was also shown during the interview process. Smith et al. (2009) argue that showing empathy, putting the participant at ease and negotiating the intricate power play between the researcher and the experiential expert are all ways that show sensitivity to context. The researcher took these into consideration during all the interviews conducted. Time was taken to explain the research in detail and to put the participant at ease, e.g. by telling the physicians in Study 2 that their real names and names of places that could lead back to their identity will not appear anywhere in study. In addition, the researcher always spent the first few questions to talk a bit about the participant's life in general.

With the patients, the researcher always made it a point to meet the participants at the entrance of the hospital, thus the walk back to the office served as an introduction and to build some rapport. Another method to demonstrate sensitivity to context in IPA studies is by grounding the interpretations in the data. According to Smith et al. (2009), it is important for findings to be presented in a way that 'resonates' with readers as an accurate account of participants' experiences. Readers must also be presented with enough detail about participants and their circumstances to enable the reader to do this (Elliott et al., 1999). Care has been taken so that analytic and

interpretative claims are always backed up by participant extracts and interpretations were presented as possible readings while general claims were offered cautiously (Smith et al., 2009).

The second broad principle proposed by Yardley (2000) is commitment and rigour. Conducting the research, analysis and write-up in a thorough manner and providing a detailed description of the whole process is one of the ways that this principle is demonstrated (Smith et al., 2009). Additionally the study took a rigorous approach in participant selection to conform to the IPA requirements (Smith et al., 2009). Yardley (2007) proposes that methodological competence is of paramount importance in demonstrating rigour. The researcher was already knowledgeable of IPA methodology at the start of the study, however he still opted to attend advanced workshops to become more versed in the method. In addition, triangulation serves as ways to ensure rigour (Reid et al., 2005). This can include any number of ways that are felt to be relevant to the particular investigation, including investigating a phenomenon from a number of viewpoints (different participant groups), using multiple qualitative methods, or asking another researcher to 'audit' or provide feedback on the study.

Lincoln and Guba (1985) and Colaizzi (1978) advocated the use of member-checking as a final step in validation for qualitative studies. However, there is no directive in interpretive research to prove or generalise, so the idea of validation is illogical (Chapman, Francis & McConnell-Henry 2011). Certainty has little resonance with the interpretative research. Revisiting a participant for clarification is a potential threat to the rigour of interpretive studies (Chapman, Francis & McConnell-Henry 2011). When asked to revisit a concept, a participant may overemphasise it, believing the researcher must think it important or relevant to the study. The desire of participants to say 'the right thing' is known as the 'halo effect'.

By going away, examining and carefully considering the data, then returning to participants for clarification, researchers may then guide the participants in the directions they desire (Chapman, Francis & McConnell-Henry 2011). As the

balance of power is heavily in the researcher's favour, a participant is unlikely to resist the direction in which the researcher is leading them. Equally, returning to participants is antithetical to phenomenology's requirement that a recounting is presented in native, or original, form and that it considers a snapshot in time, not a generalisable right answer (Chapman, Francis & McConnell-Henry 2011).

The preferred quality control procedure for IPA is that of an audit trail or triangulation of data analysis rather than any form of external "member checking" (Smith, 2003) as those checking the interpretations cannot have a full understanding or appreciation of the context in which the research interactions take place. As a result, the audit trail or the triangulation of data is not left to enable others to assess the interpretative decisions made, but to make transparent the procedure and to demonstrate the reasonableness of the analysis (Smith, 2003).

In this study, triangulation was presented through the investigation of different viewpoints, such as physicians at different specialty levels and patients who accepted, or refused or accepted and then declined. Thus, as explained previously, by engaging in an 'intra-study' triangulation (i.e. triangulation by analysing multiple perspectives and experiences in each study) and at the same time, an 'inter-study' triangulation (i.e. triangulation by comparing the perspectives and experiences of physicians with patients), a more thorough understanding of patients' and physicians' experiences of AF and OAC therapy was obtained (Reid et al., 2005). In addition, the researcher had monthly supervision sessions that served as an audit of the research. In these supervision sessions, the researcher led the discussions and two further analysts contributed the discussions about what constituted a theme and how themes might interact with each other, thus providing triangulation in analysis.

Transparency and coherence, the third broad principle proposed by Yardley (2000), refers to how clearly the stages of the research process are described in the write-up of the study (Smith et al., 2009). Transparency in this study can be seen in the detailed write-up of participant selection and recruitment, how the interview guide was developed and how the interview was conducted. In

addition, a detailed account of the data analysis process was outlined in the previous sections. Furthermore the detailed description of the research design and analysis presented show sensibility to the core philosophical assumptions that IPA requires (Smith et al., 2009). That is, the study showed sensibility towards being phenomenological, hermeneutic and idiographic.

The final broad principle proposed by Yardley (2000) is the need for the study to show impact and importance. Yardley (2000) argues that the real validity of a qualitative study is its contribution to current knowledge (Smith et al. 2009). Multiple perspective IPA studies are still in their infancy and there is paucity of IPA research in general and specifically in AF patients. Therefore, a study such as this will provide an innovative methodological contribution. Furthermore the practical recommendations emerging from the participants' own experiences and published meta-synthesis (refer to Chapter 2) have provided important new knowledge for the medical and patient community, policy makers and health workers.

This chapter has established the philosophical perspective of the research and provided a clear rationale for the use of IPA as the methodology for addressing the research questions. Semi-structured interviews were identified as the most appropriate means of collecting data and details of interview preparation and process were discussed. In addition the process of data analysis through the use of IPA was explained. Quality issues in qualitative research of this nature were discussed and consideration was given to the ethics of researching sensitive topics such as this. The following chapter focuses on the results from Study 1, the patients' lived experiences of AF and OAC.

Chapter 4: Patients' experiences of AF and OAC prescription

4.1 Introduction

This chapter includes the analysis of the lived experiences of patients during the consultations with their physicians when they were diagnosed with AF and their experiences with OAC treatment. Data were collected from three sub-groups; patients who accepted warfarin as their OAC, patients who refused OAC during the consultation and patients who at first accepted OAC during the consultation and then decided to discontinue OAC themselves at a later stage. The study attempted to answer the following research question: *What are the experiences, beliefs and attitudes that influence warfarin acceptance, refusal or discontinuation by patients?*

The patients in this study recounted their lived-experiences during the initial consultation with their physicians, their feelings about the diagnosis of AF, and what experiences influenced them to accept or refuse warfarin as their OAC medication. In addition, the patients explored what it meant to live with AF and take OAC life-long. Patients also commented on how the constraints brought about through living with warfarin compelled some to discontinue OAC, despite leaving them at an increased risk of stroke. Patients also discussed how their everyday experiences affected their perceptions of aspirin compared to warfarin. Some recommendations put forward from the participants for health care followed.

Three over-arching themes emerged from the interviews with patients, each with two themes which were divided into two or more sub-themes as shown in Table 14. The following sections discuss in further detail the themes and sub-themes that comprise the over-arching themes. Verbatim extracts and their interpretations are included in the text to highlight particular experiences that patients went through.

Table 14: Main themes emerging from patients' own experiences of atrial fibrillation and oral anticoagulation

Over-arching themes	Themes	Sub-themes
Patients' experiences of the initial consultation – "it's not a consultation"	Understanding the diagnosis	Initial relief through knowledge
		Lack of take home material
	Reaching a Treatment Decision – the interplay of paternalistic and shared decision making	What influences the decision to accept warfarin
		What influenced the decision to refuse warfarin
Life after the consultation	The challenges of living with OAC	Food interactions
		Regular blood tests
		Support
	Experiences that lead to OAC discontinuation	Balancing fear of stroke with negative experiences of OAC on QoL
Being informed about patient rights		
Patients' experiential reflections	Perception of Warfarin vs. Aspirin	Aspirin perceived as 'old' natural wonder-drug
		Warfarin perceived as dangerous/end-of-life drug
	Patients' recommendations	Time & physicians' communication skills in initial consultation
		On-going patient support
		Raising awareness about warfarin through the media

4.2 Patients' experiences of the initial consultation – “it's not a consultation”

The first over-arching theme encapsulates the patients' experiences during their initial consultations about AF and is sub-divided into two themes: (1) the diagnosis of AF and (2) the decision to accept or refuse oral anticoagulation treatment.

4.2.1 Understanding the diagnosis

This theme explored the patients' recollection of their experiences of their initial consultation where they were given the diagnosis of AF by their physician. There were two sub-themes related to the diagnosis: physician's reassurance about the AF diagnosis and (2) the absence/paucity of educational material about AF to take away from the consultation.

4.2.1.1 Initial Relief through knowledge

Symptoms caused by AF were a source of anxiety for most of the symptomatic patients; nonetheless they provide an aid for the physician to focus on in diagnosis. Most symptomatic patients, such as Jonas, clearly remembered the moment they felt their first symptoms, which were a major cause of distress. In his experience, Jonas thought that he was going to have a heart attack, exacerbating his trauma which in turn led to the onset of panic attacks. It is also important to note that the following excerpt shows that Jonas was not sure that his heart condition was called AF.

The first time in my life I had ever thought 'you're ill'. It's hard to explain. I was frightened I was gonna fall out of bed. Erm... Everything was just really weird and I had to go into work that day. It was before I retired. I phoned up my gaffer and his son answered the phone and I said 'I feel really ill and don't know what's the matter? I can't come in today' and he said 'oh come in'. Give it 20 minutes and you'll be alright'. I don't know how I managed to drive to work, because I was having panic attacks. I think I got to work anyways and his father (his employer's father) took one look at me and said to me get my car out, 'There is only one place for him and that is the hospital'. That was how it was

found out. It wasn't a heart attack; it was the fibrillation or what it's called (Jonas, Accepted OAC)

Likewise, Will described his experience as "distressing". He almost relived it when discussing it as he could even remember what he was eating when he first experienced the symptoms. Unfortunately, Will was highly sensitive to his AF and every time he experienced symptoms, it felt like a traumatic event. This caused so much distress to him that he could not lie down for fear of triggering an event, which could possibly lead to sleep deprivation. For him, the fear of having a symptomatic event was even more distressing than being diagnosed with cancer, describing the AF symptoms as 'mental torture'. In addition, because of the constant fear of the recurrent symptoms Will has even contemplated suicide.

W- I was over here, at work. I WAS EATING A BANANA! It was so distinct I can you know... remember it clearly. Then they sent me home] [Then it happened again the next day and they rushed me here. That's how they found out.][They said 'Unfortunately Mr. Will, you're very sensitive to it...'

Researcher - You're very symptomatic

W- yes yes that's the word... I'm very sensitive to it.][I can't lie down... I haven't lied down for 20 odd years. I sleep in the chair, because if I lie down, in 20 minutes, the position of the heart... triggers the heart off.] [the biggest problem is my heart. Mhm. I'm still concerned on that. More than the cancer. I said to the surgeon, I'd rather have the operation 10 times rather than going into fast AF...] [It's terrible... mental torture.] [I'm under a psychiatric team, cause I wanted to kill myself because of it... it's terrible (Will, Refused OAC)

In other symptomatic patients who had few recurrent episodes, such as paroxysmal AF, the length of time needed for a complete diagnosis was a source of stress. Katrina explains how several tests were conducted and although she knew that she "had something wrong" the physicians could not diagnose it.

R - Did you know that you had anything?

K - Oh dear God no... I didn't even know that I've got it. They also did an Echo in 2003, but they found nothing.] [I knew I had something wrong with my heart. I had told the doctor that sometimes my heart misses a beat and it didn't feel right you

know. I couldn't put my finger on it you know. Of course when I came to the (consultation) they managed to diagnose it. (Katrina)

In asymptomatic patients, however, the diagnosis process was less systematic. Asymptomatic AF patients were usually diagnosed with AF during a routine check-up or when diagnosing other conditions, such as the experience of Lionel below. As with the other asymptomatic AF patients, Lionel was diagnosed only after a routine check-up for symptoms of anaemia by a private clinic.

R – Do you remember when you first got to know about your heart condition?

L – It was a long drawn out process. I kept going to the GP cause I didn't feel well. Erm and... I suffered from migraines, almost twice a week and he used to ramble on my brains, but I used to tell him, it's not my brain, I'm just not generally well. So I was in BUPA at the time, so I went to a private check-up you know. Then they discovered that I was anaemic and that I had an irregular heartbeat. That is how the condition was discovered. (Lionel, Accepted OAC)

The initial consultation served as a relief for all patients in the study. During this short consultation, patients including Greg, Raj and Rob, initially were anxious when receiving the news that they suffered from a heart condition and later assured through adequate information given by the physician that AF is a common condition.

I did yeah (get concerned) cause it's your heart and it's a big thing your heart eh? But I felt alright about it once he told me what it was. (Greg, Refused OAC)

The patients describe being concerned during the initial consultation because they thought they were having a heart attack or they did not know what was happening. The added anxiety when the heart was mentioned was probably due to the fact that patients knew that the heart is central for life. Thus news concerning the heart brought about the possible threat of death.

R – Yes that's right... they discovered it when we called the ambulance 999. I felt very giddy and light headed, I thought I was going to pass out. Erm I thought I was having a heart attack. The ambulance came, and told me I have an irregular heartbeat.

Res – so you were told about the irregular heartbeat in the ambulance basically?

R – Yes that's right. They treated me in the bungalow, that when the doctor said that 'You've got an irregular heartbeat'.

Res – and how did you feel at that?

R – In a way relieved, that erm... it wasn't anything serious. (Raj, Discontinued OAC)

The initial assurance provided did not have an influence on whether patients accepted or refused warfarin. However, time spent assuring the patient did impact on patient-physician relationship. Josephine perceived her physician as "an excellent doctor" because he spent the needed time to explain to her about her condition and reassure her.

I've got an excellent doctor and he always explains everything to you. He's told me which ventricle's not working properly. And erm... we think the TIA was due to it not being able to pump the blood well from the heart so it is clotting and then the one clot just came up and gave me this TIA. (Josephine, Refused OAC)

Similarly, Raj had first felt the symptoms of AF when he was abroad. In the following quote, Raj's wife explains that although the hospital structure was not well maintained, the impact of the social interaction with the health professionals was positive.

R – we were on holiday in Goa] [I felt some palpitations and I was taken to hospital. I was told that erm... they put me in intensive care. I was with my wife.]

[Wife - although the place was very badly maintained, the treatment was excellent. Doctors, nurses everybody.

Res – When you came back to the UK, did you go to the hospital again?

R – I recovered (from the bout of AF symptoms) quite well (in India) (Raj, Discontinued OAC)

4.2.1.2 Lack of take home material

Patients in this study commented that during and after the initial consultation there was a lack of take home educational material both on AF and OAC medication. Patients, such as Jonas, pointed out that during the initial consultation they were only informed about the name of the heart condition and the reason for initiating warfarin. Take home educational material could have

reinforced what the physician explained during his consultation and aided in lessening the cognitive burden posed by information overload during the consultation. Jonas only received further information on warfarin from the nurse only when he was going to start the warfarin clinic. He commented that such information would have been important for him immediately after the consultation.

They didn't tell me exactly what has happened apart from they gave it the name of atrial fibrillation. That was as much as I knew and what I know up till now. That it is an irregular heartbeat. [I would've liked to know a bit more at the time. They told me why they were giving me warfarin. Which was to thin the blood, so clots wouldn't form.] [It's only after I came back here, I think it was a week after. I can't remember the nurse's name, but she was very nice. She described what the warfarin did. i.e. thin the blood. Then went through the different pills, the colour and things (Jonas, Accepted OAC)

Shona and Robert had a similar experience during the initial consultation. When prompted on this issue they divulged that the only information they received was on the course of action for treatment following diagnosis.

R – So you told me, that they told you it was fast heartbeat... did they give you any information about it?
S – No... erm... no not really. They only thing they told was what they would do. (Shona, Refused OAC)

However on further exploration of this issue with Robert, although educational material was not given to Robert, he understood and remembered the physician's explanation during the consultation. However, he did not seem sure about what it meant, showing different levels of understanding.

R – You told me before about 'blood going up and down' (the INR reading) do you know what that is?
Rob – Not really, they say 'look it increased so we're going to change the number of tablets'. They experiment to find the exact level.
Res – But did they explain to you what the level is? What it means?
Rob – No, no (Robert, Discontinued OAC)

Katrina was the only patient who commented that although no educational material was provided during the consultation, she took a booklet which was

available from the clinic. Indicating that although educational material might be present in the hospital, patients or physicians themselves might not be aware of them.

Oh I like to read on what I'm taking. I read a lot on the irregular heartbeat on heart magazines in the clinic. I even took a booklet to read at home and read about it from there initially (Katrina, Discontinued OAC)

4.2.2 Reaching a Decision – the interplay of paternalistic and shared decision making

After being diagnosed with AF, patients shared with the researcher what experiences influenced them in accepting or refusing warfarin.

4.2.2.1 What influences the decision to accept warfarin?

The approach to the treatment decision was the main influence on the patients' decision to accept warfarin. Patient experiences can be divided into two distinct approaches; a paternalistic approach or a decision based on a more inclusive discussion regarding antithrombotic medication choice.

4.2.2.1.1 The paternalistic approach

Conversely to the relief experienced from the physician reassurance in the initial diagnosis part of the consultation, some patients commented that their perception of the decision making process was that of a paternalistic approach. Patients commented that the physician either took the decision to initiate warfarin or the patient trusted the physician as the expert and did not voice his/her concerns. In addition some patients, like Lionel, had negative past experiences associated with AF. This had an impact on Lionel's ability to understand and process the information given to him. Thus he was not able to discuss the issue of OAC treatment.

L – It was a bit of a shock. I can't say that it made me very worried. But it was a shock to realise that I had the same complaint as my mother. But I just accepted whatever they said and then got referred to the GP and prescribed medicines and I erm... just accepted it.] [I don't worry about it. I know it's dangerous and

erm... I know that presumably one day it will cause me to maybe, maybe have a stroke. (Lionel, Accepted OAC)

Lionel commented that he felt that he had no alternative in the choice of OAC treatment as he was still coping with the fact that he was afflicted with the same condition that his mother suffered from. However, he later points out that OAC does not worry him, as he acknowledges that AF may cause stroke. In addition he was also put on the same drug (digoxin) his mother was taking before she died. Either the consultant failed to explore this issue with Lionel or Lionel preferred not to voice his past experience.

When the cardiologist saw me, (the cardiologist) told me, 'With the current medicine you're on, you're not doing so well'. Which was a surprise for me because I felt alright. Then (the cardiologist)said 'We'll put you on digoxin'. This was the drug my mother was on before she died. (Cardiologist then said) 'That means that we have to put you on warfarin as well'. And I was 'Oh no... no not warfarin. I had heard tales about warfarin. You have to keep coming to hospital every week for a check-up. Oh no'... I expressed my concern. But (the cardiologist) just explained and that's it. (Lionel, Accepted OAC)

Lionel's experience is an example of how challenging the decision process can be for a patient, i.e. weighing the risks and benefit of a treatment in light of his experiential knowledge from family and friends' experiences. Lionel further explains that he felt he was left without any alternative. Since the consultant was going to change his medication and warfarin had to be initiated with this medication, he felt that he could not refuse. Lionel's experience highlights that receiving bad news during a medical consultation challenges a patient's ability to take a decision and the right to say "no". In addition, Lionel experienced conflicting beliefs, or cognitive dissonance, when thinking about the cardiologist's reason for the change in medications. Since his perceptions of his past medications were that they were "working", he did not see the need for change.

R – So you told (the cardiologist)that you didn't want warfarin?

L – Well I didn't tell (the cardiologist) I didn't want warfarin, I just expressed my dislike of having warfarin. So (the cardiologist) said that it was necessary, (the cardiologist) didn't present me with any other alternatives. I've been quite happy, thinking about, I would've been quite happy to stay on the medicine I was on. But you don't

think of what to say during the consultation, if you've had some bad news. You don't know what to think. So I had to accept the reasons she gave, that the other medications weren't working well... and you're gonna go to warfarin. I wasn't happy, but I didn't realise that I could've said no. Of course I could've said no, I'm not stupid, but it never struck me that I could say no. The change of medication and the switch to warfarin was all too easy as far as the consultant was concerned. That's my opinion now...

R – Looking back

L – Yes... I went back home and realised; I've got to go on warfarin.][I just accepted what the consultant said. Which now I think that one ought to challenge what they tell you. Cause you never know, there might be an alternative, or an alternative they don't particularly favour. (Lionel, Accepted OAC)

In addition, Katrina perceived the choice for taking the OAC medication as a “death or life” choice. Thus apart from provoking anxiety in Katrina, the perception of choice of medication was taken out of her hands. In the following quote, Katrina also emphasised her non-participation in the decision making.

R – So did they tell you what it was when you went to the specialist?

K – NO, I mean they just explained what it was. They put me on the tablets and that's it.] [I said no I'm not going on it (warfarin), I know what warfarin is, I worked in hospital me self.] [I really felt it was a life or death decision, they just kept telling me you should take it. I felt like if I didn't take it, something was going to happen to me tomorrow you know. (Sighs)

R – So you didn't feel free in your decision if I may say?

K – No no, I don't think so. (Katrina, Discontinued OAC)

Another indirect pathway towards a paternal approach to decision making was when patients accepted the medication out of trust in the physician's expertise. Daniel commented on his trust with the physician. Although he presents himself as a passive patient, there is trust in his relationship with the physicians as he emphasised the point that he still asserts his opinion even though he does not want to participate in the decision making process.

D – I was never given a choice, it was just prescribed for me, though I accept that.] [The exact words I do not remember. But I remember what I felt. I didn't feel bothered or worried about it.][I think that in all the years I've been with my GP or [the] clinic, I haven't had reason to complain. There is no one who has upset me by telling me what it is and all this business. I just leave it to

them. I always make it a point to tell them HOW I FEEL. (Daniel, Accepted OAC)

Daniel further discussed the issue of trust later during his interview. According to Daniel's experience although his physician did give the choice of medication, he wishes to be passive and does not want to engage in the decision making process in an interactive way. Jonas also emphasised that he perceived the physician as the expert. He compared the consultation to an analogy of a broken down car to explain his lack of knowledge on the subject matter. However, his analogy also highlights his opinion on shared decision making and the passivity a patient should adopt. On probing further, Jonas concludes that trusting the physician as the expert could also be the patient's way of escaping responsibility for his health.

J - He was the doctor... he was the doctor. To my way of thinking he knew what was best for me. I bloody sure I didn't. I mean you could have an engine breakdown and I could look at this and say whatever. You've got to think to yourself, well he's the mechanic, let him get on with it. Doctor said you're on warfarin, fair enough if that is his opinion... that's the way it goes.][I think it would have been nice to learn a bit more about it.

R – So it would have been better if they gave you some information and then you made up your decision?

J – Yeah make your own decision, and then at the end of the day it's not the doctor's fault. It's your fault. (Jonas, Accepted OAC)

Similar to Jonas' and Daniel's experience, Robert also highlighted his trust in the expert and accepted warfarin as advised.

Res – So to summarise what you told me, and correct me if I'm wrong, you took on warfarin because it was the consultant's advice

Rob – That's right, I took it right away. Well if the doctor tells you it is the best thing you can have, you take his advice. (Robert) (Robert, Discontinued OAC)

However Robert, in the excerpt below, contradicts himself. He explains that the physician did describe why warfarin was better than aspirin in a way that he could compare the two medications through the use of an analogy. This shows that even though during the consultation the physician might have provided education on the medication, nonetheless, the perception of the patient towards the expertise of the physician influenced the acceptance of the medication.

Rob – When the doctor explained it to me, he said, ‘well look, to thin the blood this is a lot better than aspirin’.

Rob Wife – you weren’t very keen on it because it could be unstable

Rob – yeah but once it was stable then you can have 3 or 4 weeks’ time before you need to go back to hospital again.] [The doctor had said ‘this is the best thing for you, it’s like the Rolls Royce of the blood thinners.’ I took it as it was the best thing I could have so I had it, you know what I mean. (Robert, Discontinued OAC)

4.2.2.1.2 A decision based on a more inclusive discussion

Although the paternalistic approach had a more dominant role in the patients’ experiences, an inclusive discussion that led to a decision was the second approach that some patients experienced during the consultation. Patients who perceived that they were included in the discussion for the choice of warfarin were aware about the need for warfarin and/or fearful of the risk of stroke. Fiona had started off on aspirin however when they proposed warfarin as a better alternative, the choice was left with her. Nevertheless, only when the difference between warfarin and aspirin was explained did she accept to initiate OAC.

F – When it was explained to me what it was for, at first erm at the first clinic, they put me on aspirin. That was the starter. Then in clinic they said you can carry on the aspirin, but a better way was with the warfarin. I said ‘EXACTLY... what is it? What is the purpose for it?’ They said, ‘It helps to thin the blood and that will help prevent any clots’.

R – So you were given an option whether to stay on aspirin?

F – Yeah yeah yeah I could decide one way or the other. I said ‘I’ve been on the aspirin’ and they said ‘Well yeah all right’... I said ‘what difference will it make?’ They said it wasn’t making the same amount of difference that the warfarin was going to make. You know in the INR. (Fiona, Accepted OAC)

Raj’s wife, who was a nurse, was present with him in the consultation when he was offered warfarin. Similar to Fiona’s experience, Raj’s wife mentioned that their cardiologist explained in detail why warfarin was needed and how it helps protect against stroke. Although Raj’s wife knew about warfarin, she lacked the knowledge of how a stroke can occur because of AF. The fear that Raj might

contract a stroke could have influenced Raj's wife to suggest him to accept warfarin.

R (wife) - well the cardiologist did say that you had to take warfarin because after the heart stops from the atrial fibrillation, erm, there could be a blood clot that starts off after your pulse becomes regular again. It can break up and you can have a stroke or... which I didn't really know before until he mentioned it. He said that is why you should be taking warfarin. (Raj, Discontinued OAC)

On a similar note, Katrina pointed out the influence the fear of strokes had on her in accepting warfarin. She was aware and knowledgeable on what a stroke was and what it can cause, but was not aware of the consequences of bleeds.

K – Well they said there were a lot of risks if I didn't take it. I may have had a stroke. So I didn't have much of a choice didn't I... I wasn't happy taking it from day 1.

R – So you're more afraid of strokes than you are of bleeding

K – Oh I wouldn't want to have a stroke you know. It comes on suddenly doesn't it? (Katrina, Discontinued OAC)

4.2.2.2 What influenced the decision to refuse warfarin?

Several factors influenced the patients to refuse warfarin as their OAC medication. These include the patients' perception of the lack of education, communication skills and rapport building during the consultation, patient's religious influence on treatment beliefs, and the challenges associated with a change in lifestyle brought about from need of blood monitoring, bruising and the fear of non-adherence to treatment based on past experiences.

4.2.2.2.1 Perception of a lack of education during the consultation

The lack of education as an influence in refusing warfarin was pointed out by several patients, as highlighted by Josephine's excerpt below.

I don't think there was any discussion about it (use of warfarin to minimise the risk of stroke). They just said 'would you like to go on it?' and I said 'no, no I don't think so'. (Josephine, Refused OAC)

On further prompting about the benefits of warfarin with Josephine, she points out that no one explored any educational information with her. In addition,

Josephine's perceptions highlight the need for education for allied health professionals. Due to this Josephine had to obtain information herself from the internet.

J - Nobody has ever mentioned these things that you are bringing up (warfarin better than aspirin in risk reduction of stroke) and I don't have to come to the hospital anymore, so nobody really mentioned it. So erm I've never really thought about it.

R – and also for example did they mention that with diabetes and AF you get a higher risk for stroke? Sorry (worried look on Josephine after researcher pointed out new information) I feel like I'm worrying you even more

J – no no... to be honest, nobody has ever discussed diabetes. I mean I've got a wonderful GP, but I think he is so overworked at the moment that you tend to see the nurse and she is not good. She never really told me anything and what we found out, we did ourselves on the internet. (Josephine, Refused OAC)

4.2.2.2.2 The perception of lack of rapport and a paternalistic attitude

Greg's AF was caused by his heavy drinking and he had refused to take warfarin as, like in Josephine's experience, he felt he was not educated about the need for warfarin. However, in a second consultation, Greg was offered the chance to participate in a trial with NOAC tablets which were not affected by alcohol. However, Greg's perception was that the physician was more concerned in enrolling him in that trial rather than treating him with care and respect. Since they were health professionals, Greg had expected the physicians to discuss with him the issue of binge drinking. In addition the fact that his physician asked another health professional to concur with his advice put Greg on a defensive attitude affecting his perception of the health care system. The perception of lack of empathy and respect during Greg's consultation was a major influence for him to refuse OAC.

G - They came and told me 'since you're a heavy drinker, we've got a new drug that you can try... if you're prepared to try? Where you can drink... still drink' and I still wasn't happy about that. Then he called the other doctor, sort of to back him up and say 'yeah you can sort of drink' 'you can be an alcoholic' that's the impression I got. That you can drink as much as you like but you take this one. The way I've seen it, they wanted me to take it. This

new drug, and not too concerned about... me. That was the impression I got.

R – So correct me if I misunderstood you... the fact that as a doctor they didn't tell you to stop the drinking, but they told you 'look we have another tablet that's coming out that you can still keep drinking'

G – Definitely definitely, that's the impression I've got. That they wanted me to have a go at this sort of... not that... it was a bit confusing, cause I was just told that the monitor, my heart had corrected. Then they're telling me you have to have warfarin. I didn't understand it and they never explained it. (Greg, Refused OAC)

Similar to Greg's perceptions, one of the experiences that influenced Will to refuse warfarin as his OAC medication was the perception that his consultant did not have his best interest in mind. Will believed that physicians are biased in prescribing more medications than what is needed. In addition, Will had been a participant in previous trials and he believed that consultants get remuneration for prescribing different drugs.

W - I flatly refused (warfarin)... because... they told me about aspirin at first... you know 75mg. They said "Well you can have a stroke"... cause he's a good cardiologist (named cardiologist) but I tend to think that the cardiologist (named cardiologist) likes a lot of medication... to take on a lot of medications. That's my opinion anyway. That's my honest opinion. You know, the guy gives you more medication than you need. They do a lot of tests, because they get paid for new drugs anyway. That's why I was on a lot of drugs. (Will, Refused OAC)

The influential paternalistic attitude of the physician was also felt by Josephine. During her consultation she felt that the physician was surprised that she refused the advice given by the expert. However Josephine later opposed her previous assertion by implying that she believed that a physician would be more assertive and paternalistic with vital drugs. This belief negatively influenced her perception on the importance of warfarin.

J - He looked like a bit like 'I'm your doctor, you should do what I tell you'...] [In my mind... if it (warfarin) was that important, he should have put me on it straight away when I was in the hospital.

R – So if I understood you correctly, if a drug tablet is important, the doctor would just prescribe it to you rather than asking you 'would you like to go on warfarin'

J – Yes I think so. (Josephine, Refused OAC)

4.2.2.2.3 The perception of lack of communication skill in physicians

In Greg's second consultation he also misunderstood the physician in thinking that since he did not have AF symptoms at that time, he was in good health and he did not have a risk of stroke anymore. Greg's experience was a clear indicator of the need for good communication skills and the importance of continuous education.

G - And last time I came to the hospital, they told me that it has corrected itself, 'you're ok now', so... that's what the impression I got anyway... 'you're ok now, might happen again in the future'... and that's why I don't understand they were saying I should have warfarin. I still don't understand why I should have had warfarin.
(Greg, Refused OAC)

Josephine also felt that since she did not have any symptoms, she did not understand the importance of warfarin. She perceived the importance of a medication based on how well it manages symptoms. Since warfarin was a medication that prevented symptoms, Josephine did not perceive it as important. On discussing this issue, Josephine also highlighted her cognitive dissonance as later she pointed out that it is difficult for a patient to change the status quo especially when the perception was that aspirin was working. .

When somebody asks you to go on warfarin, you think 'why? I'm better', 'I'm doing fine', 'I don't need anything else'.] [I understand... (laughs) I think it's bit... it's denial that you think 'oh I don't need that, I'm better, I was going along fine with what I've got' (Josephine, Refused OAC)

Similar to Greg, Shona refused warfarin because she believed she was in good health. This could be due to the misinterpretation of the physician's education as she considered blood pressure as a sickness but not AF. Furthermore she was also confused about the benefits and risks of warfarin. Shona did not perceive any benefits from taking warfarin but rather only perceived the risks.

S – But erm... so I look into it and erm... I don't have a sickness I only have blood pressure, so I told them no want it. And that is it...

and they wanted to give me the warfarin for the heart thing and I said I don't want either one or the other.

Friend – because she don't feel ill at the moment, and since she don't feel ill she don't take it.

R – So correct me if I'm wrong, just so I understand you better, since warfarin is not going to HEAL you, it's not going to change things for you like they are right now... erm that's why you didn't want it?

S – mhm (nods) I don't want it. (Shona, Refused OAC)

Shona later emphasised again that she believed that the tablet was not going to provide her with any benefits as she associated warfarin with death because it was a life-long medication and her friends were on warfarin when they passed away. In addition Shona's perception of warfarin was that the bleeding could cause an untimely death, and thus it was going to interfere with God's plans for her. This religious belief may also have influenced her decision in refusing OAC.

R – And if I may ask, what was the reason for not wanting it?

S – Because if I take it I'm going to die, and if I don't take it I am going to die, alright? And I am not ready to die until god is ready for me. So I'd rather not try.][They (her friends) were on warfarin... and they passed away. I don't think they really liked it that much.

R – so kind of, the people you talked with had bad experiences with warfarin and they died while they were on warfarin.

S – Yeah (elongated sigh) (Shona) (Shona, Refused OAC)

4.2.2.2.4 Challenges associated with a change in lifestyle

Some participants who refused warfarin as their OAC medication also commented that the challenges associated with a change in lifestyle had an influence. These challenges include the need for blood monitoring, the bleeding and bruising associated with warfarin and the fear of adherence to warfarin treatment regime. 'A priori' knowledge of blood monitoring could have an influence on the patient's perceptions, as shown in Greg's next quote. Greg pointed out that he got to know about blood monitoring from another patient. However from his friend's experience it seemed that her INR was not stable and thus she divulged with Greg her negative experience. This influenced Greg to the point that he believed that his life would end up revolving around warfarin.

G – It is the monitoring thing that sort of put me off. I was talking to that girl I was on about. She said she has to come regular because they have... sometimes they give you more, sometimes they give you less. It seems to be taking over your life as well. (Greg, Refused OAC)

Similarly Josephine who still worked at the time perceived the monitoring as a challenge to her lifestyle. Josephine was afraid that the responsibility of having to go for monitoring would clash with the responsibilities of her work. Additionally she hides her distress about this issue through jokes.

Then you have to return to clinic every month or whatever, you know... to have your blood taken. I suppose you can... but when you work full time, where can I... I can't have the time off to be doing all that. Erm... It seems to be doing alright, the drugs I'm on... I mean does anybody ever takes your blood and tells you 'oh it's lovely, it's just the right consistency' I don't know (laugh) (Josephine, Refused OAC)

Apart from blood monitoring, the risk of bleeding and bruising also posed a significant threat to the participants' lifestyle. Since Josephine was still working at the time of the consultation and because of her social position at work she was very aware of bruises. She claimed that she was not careful of her surroundings and thus she was more prone to "bump" with the surroundings which she knew 'a priori' that it could increase the number of bruises when on warfarin. Knowledge from this past experience influenced her in becoming more aware of the social impact of visible bruises.

J – I said (to the doctor after refusing warfarin) 'well because, you'll never get anybody more clumsy than me', I'm walking and I bump myself. I thought... this is what you hear about warfarin you see. Covered in bruises and all that...][This having to mind yourself you know... you know with the bruising and that sort of thing because, erm... I am clumsy, I am very very clumsy. And I cut myself with the vegetable knife and it's just the thought of all that. (Josephine, Refused OAC)

Contrasting to Katrina's experience with her fear of stroke and the subsequent influence in accepting OAC, Will discussed how his past experiences had led him to develop a fear towards bleeding to death. Will was so distressed when

emphasising the issue of his blood not clotting that he almost started to panic and stutter.

The other problem is that my blood doesn't clot very good. I bleed a lot. You know and and and (stuttering)... they were so concerned with me heart, because if you into fast AF and you're on the table with your kidney taken out, you'll lose a lot of blood. And if they aren't quick, they may not be able to stem the flow. I only just have to cut myself to bleed you know. (Will, Refused OAC)

In addition to the above experiences, the fear of adherence was another factor that influenced the participants into refusing warfarin. Will expressed his concern towards his own adherence from his past experience with aspirin. However he did not perceive the non-adherence to aspirin as dangerous as if it would have been with warfarin.

W – I don't take the aspirin as well as I should do, I got to be honest. But it's only 75mg. I wouldn't take warfarin though.
R – and why don't you take the aspirin?
W – mhm well I can't really answer that. Maybe it's because I forget them, but I shouldn't... I don't know. I've got to be truthfully honest. I do take them, but not every day. (Will, Refused OAC)

Similarly, apart from Shona's beliefs explored previously, she was aware of her problem with adherence. From her own experience with other medication she surmised that she would end up with similar practices with warfarin.

S – Yeah I don't think I can keep the timing. Sometimes I even forget the blood pressure tablets. So I couldn't keep up the timing either. (Shona, Refused OAC)

4.3 Life after the consultation

The second over-arching theme (see Table 14) focuses on the patients' experiences post diagnosis and the experiences that led some participants to discontinue their OAC treatment will also be explored.

Table 14: Main themes emerging from patients' own experiences of AF and OAC

Over-arching themes	Themes	Sub-themes
Life after the consultation	The challenges of living with OAC	Food interactions
		Regular blood tests
		Support
	Experiences that lead to OAC discontinuation	Balancing fear of stroke with negative experiences of OAC on QoL
		Being informed about patient rights

4.3.1 The challenges of living with OAC

Living with OAC sometimes proved to be challenging for the patients who accepted warfarin. This theme will discuss these challenges and how patients adapted to incorporate warfarin into their lifestyle and how they coped.

4.3.1.1 Food interactions

Since vitamin K found in certain foods can interact with warfarin affecting the patient's INR control, patients had to be aware of the types of food in their diet. All of the patients who accepted warfarin mentioned that they were knowledgeable about the types of food that could interact with warfarin. Although these interactions did not have a negative influence on the patients, there were misunderstandings on the dietary advice and that they could maintain their normal diet. Instead, patients like Fiona, in the quote below, mentioned that they stopped eating broccoli completely. In addition, participants like Fiona used humour, as seen below, as a way to cope with this challenge.

F - There are things that you can't eat, or have to be careful of with eating. Unfortunately that is something that I really love. (laughs) like cranberries (laughs) I used to love cranberry sauce with the turkey AND BROCCOLI... but that you can live without (laughs) (Fiona, Accepted OAC)

A similar misunderstanding on dietary knowledge was raised by Raj's wife. Raj and his wife pointed out that they stopped eating grapefruits. However, grapefruit, is a fruit which is usually recommended to be stopped when patients

are taking statins (drugs used to lower cholesterol), rather than warfarin. Thus although these participants commented that they had to stop eating certain fruits which were normally perceived as 'healthy food', patients had some misunderstandings on the dietary advice.

R (Wife) – he couldn't take cranberry... and he couldn't have grapefruits, which

R – I eat those every day

R (Wife) – yeah he eats them every day. (Raj, Discontinued OAC)

4.3.1.2 Regular blood tests

Regular blood monitoring also proved a challenging experience for the patients. For Lionel, the regular blood tests had an impact on his QoL. He was the type of person who tried to keep his mind active, and for him the time was being wasted in the hospital while he could be doing something more interesting. In addition he discussed financial issues, related to hospital parking charges, that older patients who are on their pensions would find difficult to cope with. This prompts the need for raising awareness about possible GP practices who do blood monitoring that might be nearer to the patients.

L – It's a real inconvenience... getting here, by bus, I live 5 miles from here. I can't get here by bus. In a car it's 15 to 20 min. You can only get here by car or taxi. If you come by car, erm, you've got car parking charges. For what is exactly a 5 minute job. The longer they take to do it, the more money you have to pay them for the privilege of parking] [plus the fact that you have to come in regularly to be monitored. Plus the fact that there are car-parking charges. There's no way that you can get in and out within 20 minutes. So it's going to cost you a couple of quid a time. Just to go in and have you finger pricked. One time it was chaos there, and you could get stuck for even an hour. (Lionel, Accepted OAC)

Moreover the time consuming experience for Lionel was aggravated when warfarin had to be stopped for a few days because of other health procedures and then restarted. When warfarin is initiated, INR tests are done once a week until it is stabilised. Once INR is stabilised patients only need to go for blood tests every three to four weeks, so for Lionel every time he stopped warfarin

this meant that the blood tests had to be done more frequently until the INR was stabilised again.

L – It does have an impact on my quality of life. This inconvenience is time consuming in coming to the hospital and taking part, having your INR checked. You have to be very careful if you've got a cut or a bruise. And erm... particularly at my age, everything you do... there is the dentist, any internal examinations at the hospital, you have to knock off warfarin.][Then you have to start the INR again and it's all over the place. (Lionel, Accepted OAC)

Conversely some patients commented that having their blood tested did not impinge on their daily lives. Jonas had good adherence to his medication. He pointed out that it was part of his character. In addition for patients like Jonas who lived alone, blood monitoring also served as a social activity.

J – It didn't bother me the monitoring. If I had to come here every week, if it had to be done, it had to be done. That is how I am. If you're gonna go on, then you have to do it and I do have a good rapport with the nurse that does it, so it gives me a bit of a giggle when I go there. (Jonas, Accepted OAC)

Similar to Jonas, Daniel complies with the expert's advice, as explored in previous themes. However, Daniel also used his past experience with diabetes medication to justify the change in warfarin dosages.

D - I was never bothered about the medication they used to prescribe. If I'm going to take it, I'll take it. I have a check every so often and if they want to, they change it.][I just accept it, what I am told, I believe. As sometimes happens with the diabetes, when it goes high, they increase the dosage, it sounds like common sense to me. (Daniel, Accepted OAC)

4.3.1.3 Support

Patients talked at length about how the support they experienced from their relatives encouraged them to both to stay on warfarin or to discontinue it and also about the lack of support offered at work. On being prompted about this issue, Fiona jokes about how she broke news of the need of warfarin to prevent a stroke to her family. Interestingly, her children also used humour to cope with

the distressing news. She also pointed out the importance of assuring the family members through educational information.

R – Did you tell your family about warfarin?

F – Yes of course, and the general comment was, we always knew you were a rat... mum. (laugh) I think they joked about it because they didn't know what to say to start with. I said it's just to regulate things, to thin the blood down and prevent clotting and hopefully prevent any strokes and things like that. (Fiona, Accepted OAC)

Fiona commented on how roles in her family got inverted, with her children taking on a protective role. Family support combined with humour was invaluable for Fiona and gave her a sense of pride towards her family.

F – Sometimes they'll tend to become a little bit overprotective shall we say. If they picked that I've got something planned that I shouldn't be doing, that THEY think I shouldn't be doing. They'll mother me and I'll be yes yes mhm mhm and do it (laughs)

R – And how does this make you feel?

F – It makes me realise that... even though they've not always said that they appreciate what I've tried to do to them. They show it to you through their actions. These actions. (Fiona, Accepted OAC)

Lionel also disclosed how his friend provided constant emotional support throughout the years. In Lionel's account he shows how they both find comfort and solace in sharing their concerns and support each other.

R – In the beginning you told me that you lived with someone for 40 years. Did you tell him about the AF?

L – Oh yes yes.

R – And what was his reaction?

L – Well erm... I think it's erm, acceptance of the inevitable really. He knew how I felt before this check-up. We talked about it and obviously he was concerned, erm... but at that time it wasn't... we thought it wasn't serious. It was just the start of something, so he's just developed with it. He's got his own problems... prostate cancer. He worries about me. Worries tremendously. When I got hepatitis back in 1980, I was very near to death's door with hepatitis b and he nursed me back. (Lionel, Accepted OAC)

Lack of knowledge on warfarin and its side effects, also had an influence on the type of support provided. In Katrina's anecdote, she mentioned that her husband was already negative towards warfarin before she accepted it.

However, instead of supporting her during OAC, he encouraged her to stop warfarin because of his fears brought about from the visible side effects of warfarin.

K – My husband was against me going on it, but I had to start it. Then when he saw the effects it was having on me he said you should get off the bloomin stuff. It's not doing any good. I think he was worried when he started seeing me with the patches and the bruises. (Katrina, Discontinued OAC)

On the contrary, since Katrina's daughter was more knowledgeable on warfarin due to her work, she kept trying to educate her mother on the risks and benefits of OAC.

K – My daughter, you know how nurses are, she said you are more at risk of a stroke, you should carry on it you know. (Katrina, Discontinued OAC)

Robert, uncovered the lack of awareness of AF and INR testing in his workplace, leading to a lack of support from work.

Rob – I cannot take time-off from work for monitoring. I can take time-off for other things, but not for this. It doesn't work for them. They just don't like it! (Robert, Discontinued OAC)

Josephine also expressed her frustration from the lack of support shown at her workplace after she had a TIA.

J - At work, no I wasn't supported to be honest. (when she had the TIA) Erm they were like you're back to work, get on with it. Not very supportive. Erm... the hospital's been wonderful. Really really good. You can't fault them. Every appointment has been bang on time. In the new treatment centre. At work no, but hospital yes. (Josephine, Refused OAC)

4.3.2 Experiences that lead to OAC discontinuation

The next theme discusses what experiences influenced patients to discontinue warfarin as their OAC medication. Participants argued about how they had to balance whether to live with the fear of stroke or live with the impact of the negative side-effects of warfarin on their QoL.

4.3.2.1 Balancing fear of stroke with negative experiences of OAC on QoL

For some participants, however, the impact warfarin was having on their QoL was not bearable, especially when they could not perceive any benefit from taking warfarin, as Raj's wife pointed out.

R (wife) – He did take it for a little while, but it wasn't doing anything to his blood and then he decided....Then they increased the dose to 4mg I think but it wasn't changing anything (Raj, Discontinued OAC)

Older patients also complained about the issue of polypharmacy (when patients take a myriad of medication). Raj believed that taking numerous tablets would prove more harmful than beneficial. He had explained how according to his perceptions, influenced by informal discussions with his friends who were physicians, most of the medications are actually placebo and that they were not as important as the health care system portrayed them to be. Raj used this logic to justify himself that warfarin was not an important medication. Interestingly however, he perceives hypertension as an important condition to monitor.

R – Then I discovered I was taking tablets after tablets after tablets, erm for diabetes, high blood pressure tablets, aspirin and then warfarin erm... and I was just erm... any tablets you take do have a side-effect as well. And erm... I decided I'll take the ones that I certainly DO NEED. Like the ones to keep my blood pressure controlled. (Raj, Discontinued)

In addition to polypharmacy, Raj's main reason that influenced his discontinuation of warfarin was the perception of loss of liberty from enjoying his retirement. Raj explained how when his children were younger he devoted his life to provide them with the best education. Since he had retired and his children are settled, he wanted to enjoy his retirement before he became less independent from ageing.

R – I've worked as a financial advisor, I'm retired and I like erm to spend my time going on holidays. Whilst the children were young, we couldn't afford to go away on holiday because of their education. They both went to University (named university) and they're both dentists. Now we getting old and we want to try and make the most of it before it's too late.] [While we have the

opportunity and good health we can do these things which we may not be able to do after, I guess. (Raj)

Raj's wife provided a rationale for what influenced this reasoning. She discussed how during one of their holidays, they had met an English gentleman who was also on warfarin. However he was bleeding from mosquito bites. As mentioned before, for Raj, travelling represented a very important aspect of his QoL. Raj's observations of how warfarin had an impact on this English gentleman's experience, clashed with his beliefs of what travelling represented and since he perceived himself as still in "good health" the risk of stroke was not as imposing as the impact warfarin would have on his QoL.

R (Wife) – I'll take you back to when we were in Goa, there was a gentleman there, an elderly man who was covered in bandages

R – He was on holiday from England

R (Wife) – yeah from England and we said, what's happened to you and he said he's on warfarin and he's being picked by mosquitoes and it wouldn't stop bleeding.

Res – From the mosquito bites?

R (Wife) – yes cause he was on warfarin and he had mosquito bites, and they inject something to stop the blood clotting, cause with his warfarin he started to bleed and the bleeding wouldn't stop and he had to go to hospital because of that.

R – We were all sitting there by the pool and nice and sunny (Smiles) and he was all bandaged from head to toe (laughs)

R (wife) – and that was another thing that put him off continuing warfarin (Raj, Discontinued OAC)

Raj disclosed that he was not against taking warfarin. However for him, being on warfarin influenced him in becoming more mindful of his situation. Thus, severely affecting his ability to enjoy his travels. Raj was aware of the risk of stroke when not on warfarin, thus he mentioned that he would "start it again" when it would not impinge on his travelling.

R – I would go back to warfarin, but at the moment we're trying to go away for holiday as much as we can. WHILST we can, this opportunity won't stay forever. Erm... if I'm on warfarin I have to be very careful where we go. Basically it put me off for the time being. But when the time is right I would start it again. (Raj, Discontinued OAC)

In rare occasions, patients might get an allergic reaction to warfarin, which would have a biopsychosocial impact on QoL. Robert developed such an

allergic reaction to warfarin. He described how the allergy to warfarin caused him great distress and covered most of his body. Robert's wife further explains their long ordeal in trying to identify the cause of this rash (which was warfarin) and the distress this caused Robert until warfarin was discontinued. Apart from the physical itch that the rash gave him, Robert became so aware of it that he was too embarrassed to go out in public. Before warfarin was discontinued Robert ended up in a vicious circle, the more he became aware of the rash, the more he became distressed and isolated, which in turn made him more mindful of what was happening to him.

Rob – The Rash was also on my face sometimes

Rob (wife) – really bad blisters... they were like watery. They were terrible ones, and very itchy.

Res – and that had an effect on your quality of life?

Rob – OH YES OF COURSE!!!

Rob (wife) – OH YES... the doc gave him ointments, tablets, nothing worked.

Res – and how did that affect you when you go out?

Rob – Of course I'd be embarrassed. We're not posh or anything like that, we don't go to fancy restaurants or thing like that, but even walking in the streets you feel embarrassed by people looking at you sideways (Robert, Discontinued OAC)

Conversely for the patients who discontinued warfarin, participants that were on warfarin decided to continue taking warfarin because of the fear of stroke. This fear was worse when the participant had direct experience of the disastrous impact of stroke on QoL. The fear of stroke was a critical factor in Lionel and Jonas' experiences. Both of them had experienced caring for a relative who had a stroke. Although Lionel had accepted warfarin, he was not positive about the medication. However he was so distressed by the thought of having a stroke that he did not discontinue OAC. He preferred to wait for new OAC treatments to be licensed.

L – I really can't wait to get off digoxin, I really can't wait to get off warfarin. I'm hoping that they had this alternative that they are testing, and that it works out. (Lionel, Accepted OAC)

Lionel's mother had experienced a stroke and this had left a traumatic experience on him. Lionel's fear of stroke was not only related to the effects it

would have on his own QoL, but also he was afraid of the impact it would have on his friend's QoL.

L - That is my greatest fear is having a stroke, rather than dying outright, the greatest fear is having a stroke.

R – Why is this?

L – Erm cause it will affect other people. I can't erm (forming tears in his eyes)... I can't bear the thought (deep breaths) of somebody... I don't want to label them or anything, but I can't bear the thought of someone I love having to take care of a cabbage (cries) (Lionel, Accepted OAC)

Similarly Jonas had taken care of his mother for 17 years after she had a stroke. Jonas was put on warfarin without his consent and when he was able to make an informed decision, through knowledge gained about AF and the knowledge gained from his experiences with stroke, he decided not to discontinue OAC.

J – It was explained to me that I would've gotten a blood clot if I hadn't been on warfarin. That is the reason I stayed on it. Obviously if the blood clot goes to the brain or the gets to the heart, you've got a problem. So that was why I stayed on the warfarin.

R – So if I understood you correctly you stayed on warfarin because you were more afraid of the stroke then the bleeds.

J – YEAH. My mother she had a stroke. I was with mum for 17 years after she had a stroke. It's something that I wouldn't wish on anybody. Living it, with it or seeing it. She could do absolutely nothing. She could hardly speak, she got no control over any of her bodily functions. I wouldn't like to end up like that. If that happened to me I would ask somebody to put a gun to my head. (laughs). (Jonas, Accepted OAC)

4.3.2.2 Being informed about patient rights

Similar to Lionel, Katrina had a negative perception towards warfarin. What encouraged Katrina to discontinue warfarin was when a health professional explained to her that it was her right as a patient to discontinue a medication that she did not like taking. Katrina had accepted warfarin because she felt that the physician gave her a "life or death" choice. In the below excerpt Katrina discussed how during one of her visits to the anticoagulation clinic, one of the nurses explained her rights as a patient.

K – The nurse told me ‘They can only offer the medication. (leaned forward) They can’t force you to take it. You shouldn’t take a medication if you’re not happy about it’ (Katrina, Discontinued OAC)

Katrina’s perception of the decision making process was that of a paternalistic persuasion by the physician. Thus, on accepting warfarin, Katrina felt restrained for life with warfarin, and the knowledge gained from a health professional, gave her the ‘permission’ needed to stop warfarin.

K - I was under the impression that you couldn’t come off it once you’d gone on it.

R – So to summarise you were talking with the nurse about this issue and she went to check if you could stop it or not?

K – Yes, she went to see the doctor I think. They tried to tell me again about the in’s and out’s about the risk, which I already knew. But she (the nurse) said ‘You know you got rights, they can’t make you have it against your will, it’s against the law’

R – Did you know about your right to come off it before?

K – I didn’t think you could come off it you see. I thought it was a ‘that’s it, once you’re on it, that’s it for life’. I wasn’t told I could come off it. (Katrina, Discontinued OAC)

4.4 Patient’s experiential reflections

The last over-arching theme revolves around the patient’s reflections on their experiences of OAC. These reflections were most often a result of their insights having thought and talked through their experiences during the interviews. Two themes emerged (see Table 14): (1) patient’s perceptions about warfarin and aspirin and (2) patient’s recommendations towards the changes needed to ameliorate the consultation and OAC experience for other patients and the need to raise awareness about OAC.

Table 14: Main themes emerging from patients’ own experiences of AF and OAC

Over-arching themes	Themes	Sub-themes
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Patients' experiential reflections	Perception of Warfarin vs. Aspirin	Aspirin perceived as 'old' natural wonder-drug
		Warfarin perceived as dangerous/end-of-life drug
	Patients' recommendations	Time & physicians' communication skills in initial consultation
		On-going patient support
		Raising awareness about warfarin through the media

4.4.1 Perception of Warfarin versus Aspirin

Most patients in this study perceived aspirin as a natural 'wonder-drug' while warfarin was perceived as a dangerous drug usually given to people at the end of their life. Interestingly they perceived both drugs as 'old'. However, for aspirin this had a positive association, with 'old' meant tried and tested and familiar, while for warfarin, 'old' meant "has been around for too long".

4.4.1.1 Aspirin perceived as an 'old' natural 'wonder-drug'

Patients commented that aspirin was always perceived as a safe drug that was widely known to be helpful in everyday situations and for many medical conditions. Josephine aptly called it a 'wonder drug' and admitted that her family used to take it as prevention to other ailments.

J - We've always taken aspirin, even before...

Husband – 75mg a day

J – Yeah we've always taken that. Cause it's a wonder drug really.

It's aspirin. So we've always taken it. So when they said do you mind taking aspirin, I said no. I always do anyways (Josephine, Refused OAC)

Josephine and her husband rationalised that they perceived aspirin as being a 'wonder drug' because of the knowledge they gained through the media. They concluded that since it is made from a natural product, aspirin was safe. However, they did not know that even warfarin was derived from a natural product, highlighting the lack of knowledge and awareness about warfarin. Furthermore for Josephine, the perception of aspirin being 'old' meant that as a drug it is efficacious and safe because it had been around for a long time and

used widely by people for a variety of conditions. Conversely, Josephine did not perceive warfarin as an efficacious drug even she called 'old' like aspirin.

R – Before... you called aspirin a wonder drug. How come you called it a wonder drug?

J – Well it's old isn't it? It's so... I mean...

Husband – It's from the bark of the willow.

J – Yeah bark of the willow, sort of natural thing... and it's... I've always known that...I've always taken it... (Josephine, Refused OAC)

Greg commented that aspirin and warfarin had a similar function. He argued that patients perceive the two drugs in different ways. In addition, similar to Josephine, he added that patients do not think about whether they take aspirin or not, since it is perceived as safe. To Greg's perception, aspirin has no negative connotations, unlike warfarin.

R – did they he (his father's friend) ever tell you that aspirin can cause bleeds too?

G – yeah but not like that (warfarin). It does seem to be the same (as warfarin),strange... it's the perception of it... I don't know.

R – so how do you perceive aspirin?

G – I don't perceive it as anything... you just take it. (Greg, Refused OAC)

Moreover, since a patient does not need a prescription to buy aspirin, further intensifies the perception of aspirin as a safe drug.

R – So if I understood you correctly aspirin is not like other medication, it's more of a normal tablet

W – No no, I mean yes yes...the other tablets are more important. I've had aspirin for quite a while, operation and after and all that.

R – So aspirin is not that important of a drug, if I understood you correctly

W – Yes yes that's how I feel.

R – So it's like a normal over the counter thing

W – Yes yes (Will, Refused OAC)

4.4.1.2 Warfarin perceived as dangerous end-of-life drug

Most patients in this study had a negative perception of warfarin. This was also influenced by the fact that it was used as rat poison in the past. Lionel comments that he was distressed the first time he became aware of this.

However he said this did not influence him to not take warfarin. Lionel was surprised by the way the word 'poison' influenced his perception of the drug, later arguing that what kills the rats was an over-dose of warfarin. In addition, the quote below highlights Lionel's medicine perceptions. Lionel perceived all medications as being poisonous, probably from the belief that if a patient over-doses from most medications it can lead to death.

L – It was also used as rat poison

R – And where did you hear that if you don't mind me asking?

L – Well it was YEARS ago that I heard that it was rat poison but also used on human beings, not to kill them but keep them alive. I was unhappy, knowing it was rat poison, but in a sense all medicines are a bit of a poison aren't they.] [well it's not really poison isn't it, as it just makes them bleed, an internal bleeding. (Lionel, Accepted OAC)

Like Lionel, Josephine pointed out the issue of rat poison. However she also labelled warfarin as an old-fashioned drug. Josephine had previously also categorised aspirin as an old drug, however by old-fashioned Josephine meant that she believed it needed to be changed. Josephine's experience emphasised how she believes that people are more conscious of the negative information, probably because she is more risk averse.

J - And it's such an old fashioned drug as well. It's been there for years and of course, when it first came out, everybody was 'oh it's rat poison' cause that is what they used to kill the rats with you see (laugh). And that sticks in a lot of people's mind. That it's rat poison.] [Your dad was on it was he? (to husband) and he used to call it rat poison. (Josephine, Refused OAC)

Interestingly, all patients mentioned that they became knowledgeable about warfarin being used as rat poison through informal communication. Josephine discussed how education from informal sources, such as relatives, only covers the negative perceptions associated with warfarin. In addition, Josephine pointed out that patients associated warfarin with a drug that is given near the end of life, as a last resort.

J - This is what you hear about warfarin you see. Covered in bruises and all that... then you have to return to clinic every month or whatever, you know... to have your blood taken] [I think that

comes into it a bit that... that you 'oh no warfarin... that will end you up dead']

[R – so what you said before, if I understood you correctly, you meant that warfarin is associated with end of life?

J – Yes that's right, I think it is, isn't it? Cause you have to have something major with your heart... erm for them to put you on warfarin. (Josephine, Refused OAC)

This was an interpretation shared by Lionel as well. Since warfarin was similar to a stronger version of aspirin, being on warfarin meant that a harsher treatment was needed for a more severe condition.

L – yeah aspirin it's a fixed dose. Warfarin is different; it's like... erm... It's stronger so in a sense it feels like a warning sign, that things are deteriorating rapidly (Lionel, Accepted OAC)

However not all patients had negative associations to warfarin. Robert uses an analogy that his cardiologist had told him to describe warfarin, comparing OAC to a luxury car.

Rob – They call it like the Rolls Royce of the treatment you know, warfarin... (Robert, Discontinued OAC)

4.4.2 Patients' recommendations

Throughout the interviews patients provided several recommendations, based on their experiences, emphasising the need for better consultations, on-going support, and the importance of raising awareness of AF and the need for warfarin.

4.4.2.1 Time & physician communication skills in the initial consultation

A common argument brought about by patients throughout the study was the need for an increase of available quality time with patients during the initial consultation. Most of the patients talked about the paternalistic attitude taken by the health professionals during the most crucial consultations. Patients should be given time to assess the situation especially after receiving distressing news.

L - But you don't think of what to say during the consultation, if you've had some bad news. You don't know what to think. (Lionel, Accepted OAC)

On a similar note, Greg pointed out that from his experience a longer first consultation is imperative for the patients. The extra time is critical in providing adequate educational information.

R – We mentioned kind of time before and how much time they spent with you... from your experience, what do you think of the length of the consultation?

G – Yeah I think a longer one would be better so... especially to take in all of this, cause it was sort of new to me.

R – So new consultations should be allocated more time

G – Definitely... the first initial one. The nurse in the ward told me a little about it... but when you go and see a surgeon or a doctor... it's more serious... it's the FACTS of what it is. (Greg)

According to the participants, quality time and communication skills were both crucial in improving education to patients. They highlighted that a patient needs to know exactly why the need for a particular medication.

J (Husband) – you need to know what is wrong with you, why you're giving me those tablets... once you know... it's not just a case of taking the tablet. It's a case of taking a tablet knowing why you are taking it.

J – Yeah yeah definitely. You just need to know (Josephine, Refused OAC)

The time spent during the interviews to discuss Josephine's experiences, helped Josephine to change her negative perceptions of warfarin. She had failed to weigh the risk of bleeding with the risk of an eventual stroke and through these discussions, she argued that warfarin would actually benefit her more since she already had a previous TIA.

R - so thinking a bit about the side-effects of warfarin vs stroke, which would you weigh the most important to

J – (laughs) well you would have to go with the fewer side-effects wouldn't you (laughs) Better just a few bumps than that yeah.

R – so you're more worried about the bleeding?

J – oh no no... I am more worried about the stroke

R – oh sorry I misunderstood you.

J – no no, sorry... for a few tablets it's worth it isn't it... but it's the erm... it's just the thought of having to attend a clinic you know. But I suppose it won't be that often. But if it's gotta be done, it's

gotta be done. It will get me out of the office for a bit wouldn't it (laughs). (Josephine, Refused OAC)

Communication skills were also an asset that patients thought was lacking in consultations. Fiona had two differing experiences from different clinics, so she was in a position to comment on what were the ingredients of a good consultation. She highlighted the need for health professionals to be more aware of their communication skills, particularly listening.

R – if you had to point out differences between a good consultation you had and a less good one from the clinics you went through for AF, what would those differences be?

F – I felt when I came out of it that he (the first clinic where she didn't experience a good consultation) treated me as though I was wasting his time. You know.] [LISTENING. You know, I mean... if in the consultations questions are asked... you don't want to feel that (when) you(are) answering somebody is just like (doing them a favour)... you know what I'm saying? It erm... as I told you before, I'm not an attention seeker, but if somebody is asking me questions and wanting to know about myself I do expect them to listen. (Fiona, Accepted warfarin)

Others commented that there was a lack of empathy from the specialists, contrary to the relief some of the patient experienced. From his experience, Lionel concluded that there was a lack of patient-physician bonding. In the following quote he points out how the lack of empathy towards his feelings and the lack of interaction, between the patient and physician, he experienced has altered his perceptions of NHS health professionals.

Consultations aren't consultations. It is the wrong expression for what is happening. You're just told what... this is the medicine and this should be your dose. So I see you in 6 months' time. It's not a consultation; there is no interplay of patient's feelings or thoughts.] [This doesn't do anything to improve my opinion about NHS consultants. (Lionel, Accepted OAC)

A similar account was experienced by Fiona. She commented on the lack of empathy and communication skills shown by the consultant who was visiting her. Furthermore, Fiona mentioned that the consultant was telling her about "this and that". However because of his communication skills, she did not perceive it as adequate education. In addition similar to Lionel, Fiona

commented that she perceived that her feelings were not being taken seriously. Thus she perceived that the consultant took a paternalistic approach.

I was told that they thought I had atrial fibrillation, sent to (hospital) he went through all the jargon, he did the bits and bobs... he said yes it was definitely an irregular heartbeat.][Don't get me wrong... I'm not a hypochondriac and I'm not an attention seeker. But I didn't feel that I was being taken seriously and it proved correct, cause I didn't go back to that other hospital. He (the consultant) didn't seem... he seemed non-plus. He didn't care. He was just there asking questions, just doing erm... so and so and so, and you have to do this and that and the ECG... and I was just sitting there and trying to understand what he was on about. (Fiona, Accepted OAC)

After this experience, Fiona and her husband decided to go to a different hospital. In the quote below, Fiona recounts how a different attitude adopted by the health professionals changed her perception of the consultation.

F - My husband took me to) [another hospital] and compared to the first it was totally different. They said it was irregular heart beat and explained it a bit and said that it needed attention as we were away from home and gave me a letter for my doctor.][then my doctor sent me to [the] clinic in the hospital and erm...
R – and how was the consultation?
F – they were explaining things and what it meant... (Fiona, Accepted OAC)

Daniel, although he was the type of patient that would accept a medication if advised by the expert, also stressed the need to include patients in the discussions, and to use terms that the patient is able to understand.

But when they were consulting with each other while looking at my notes, they were consulting in their own language. I thought well that really is not right. They should be talking in a way that I would understand what they are saying. (Daniel, Accepted warfarin)

Greg also suggested that presenting patients with probabilities could help them understand the risk to benefit ratio.

G - They need to tell you WHY you need it] [give you some odds like 70% this or that, to weigh it up. Give me a reason why... no one ever told me that. (Greg, Refused OAC)

4.4.2.2 On-going patient support

On-going emotional and financial support from the healthcare professional was cited by several patients as a crucial function a good health care system should adopt to ameliorate patient-physician relationships. Emotional support and empathy from health professionals helped lessen the feeling of paternal attitude. Fiona explains how she asked to be transferred back to a clinic where she felt respected as a patient. Having a positive attitude towards her health professionals helped her cope with some of the challenges of warfarin, especially blood monitoring, where she felt she was visiting friends rather than a hospital setting.

F – I was transferred to a different clinic. But I asked to be transferred back to this one. I mean it's true it's a bit further away but come on, this feels like a family. They make you feel at ease. That is what you need. If you have a problem health-wise, I think that if you can be put at ease by the people who are dealing with it and your health and help you get through it. If you can be brought in as a member of a group... build a relationship, it helps. You don't feel as though you're wasting anybody's time. You don't feel as though you're another number on a piece of paper. You're part of things. People ARE taking notice and you feel like you're being cared for. (Fiona, Accepted OAC)

Likewise, Josephine's husband recalled an episode in their life where a consultant they just met once, called them on their mobile to check on her after the TIA. Such empathic gestures helped patients to open themselves to discuss issues with their physicians.

Husband – that weekend (after Josephine came out of the hospital from her TIA, they went straight to their caravan) we received a call and it was the doctor from the hospital here, checking... to make sure that she was ok

J – I thought that was wonderful. I couldn't believe they bothered to do that.

Husband – no no (Josephine, Refused OAC)

Apart from emotional support, patients also commented on the need for financial aid to patients who are pensioners. Robert suggested that parking fees in hospitals would have a significant impact on older patients who were not working and are living on only their pensions. In the beginning INR testing is more frequent until the INR becomes stable and patients may need to go to

hospital once a week. In addition, although INR testing does not take long, patients may still end up waiting in queues for a long time because of multiple appointments.

Rob – It's a little thing but over time the expenses will go up very high. Especially for pensioners or disabled people. Parking should be free, for disabled people it should be free you know. Average price it's almost £3 every time. (Robert, Discontinued OAC)

4.4.2.3 Raising warfarin awareness through the media

Patients commented that knowledge about warfarin was more easily acquired from diverse media sources. Participants emphasised the need to raise public awareness about the need and risks of warfarin for stroke prevention in AF patients. Furthermore Robert added that media could help augment such awareness by providing appropriate education.

Rob - People should know that warfarin is the best there is, but it has its dangers. They should carry a card on them, you know in case of an accident. So the ambulance would know what they're on and also people should be careful about cuts. Maybe an advert on the media showing that you can get a cut and it will take longer to stop but it's not a big bleed that you should risk a stroke. (Robert, Discontinued OAC)

However educational material available publically in the media is not always appropriate and Raj explored this issue in the quote below. Raj pointed out the lack of awareness about warfarin amongst patients. This lack of knowledge would impinge on the patient's ability to follow the discussion during the consultation. In addition Raj commented that patients end up accepting information they deem is coming from reliable sources, such as newspapers.

R – You need to reason things rather than just accepting things for the sake of it. A lot of people who have very little knowledge don't even know what the physician is saying. Not only that, even the gardener says take aspirin as I read in the paper... so he starts taking aspirin.

R (wife) – well on the newspaper there was written that 75mg daily aspirin can prevent bowel cancer.

R – And because of this a lot of people start taking aspirin for no reason. Whether the people need it or not, just because the

newspaper media says so, they start taking the tablet. (Raj, Discontinued OAC)

Other patients like Josephine commented on the negative connotations that are associated with the brand name warfarin and that rebranding might help alter patients' perceptions. She suggested this change because patients associate warfarin with rat poison and although the fact that it was used as rat poison did not appear to bother the participants, the association of warfarin with the word poison did.

Really I think they should just change the name (laughs), 'This is a new drug we've got here' People would have it more easily (Laughs)] [It's warfarin isn't it, it's the name. Change the name. (Josephine, Refused OAC)

4.5 Conclusion

The aim of this study was to explore the experiences which motivate patients to accept/decline/discontinue warfarin as their OAC medication. Patients explored their experiences during their initial consultations about AF. Most of the patients, except Daniel, vividly reminisced about their first experiences with AF and their initial consultation where they got to know that they suffered from AF. Patients' felt that in their consultations, there was a lack of take home material. Since most of them did not cope well with the education that was given to them, educative material that could be taken home could have been of benefit to increase their knowledge.

After being diagnosed with AF, patients recounted what experiences influenced them in accepting or refusing warfarin. These include how the paternalistic approach forced some to accept OAC, while in others a paternalistic attitude demotivated them and ended up refusing OAC. Other patients commented that a shared-decision making process, mainly the imparting of information from the physician played a key role in helping them accept the medication.

Patients also explored their lived experience while on OAC and how these experiences influenced some participants to discontinue their OAC treatment. Being mindful to food interactions, blood monitoring and support where the

emergent sub-themes. Some patients commented that blood monitoring was a challenging issue on their life, especially having to take time off and the financial drawbacks they incur from parking charges in the hospital. However, some patients like Jonas and Daniel did not mind the monitoring as it gave them an opportunity to socialise. This was especially prominent for Jonas since he lived alone. Patients also explored the issue of how support was given from different sources. Some patients mentioned that their family were supportive, while others commented how their family members were fearful for them as the side-effects started to show. Participants also argued how the side-effects of warfarin had a negative impact on their QoL.

The last over-arching theme explored the patients' own introspections on OAC. Patients discussed their different perceptions of warfarin and aspirin and also provided some recommendations that could ameliorate OAC management in AF and the healthcare system. These include an emphasis on the need of raising awareness, better consultations and on-going support.

Chapter 5: Physicians' experiences of AF and OAC prescription

5.1 Introduction

This chapter includes the interpretation of the lived experiences of physicians during their consultations with patients who were diagnosed with AF and their experiences with OAC prescription. Data was collected from four sub-groups of physicians in different specialties (cardiology, general medicine, and general practice) and at different levels (registrar and consultant); consultant cardiologists, consultant general physicians, general practitioners and cardiology registrars. The study attempts to answer the following research question: *What are the experiences, beliefs and attitudes that influence warfarin prescription by physicians?*

The participants spoke of the consultation with the patients, the issues with AF and warfarin and how they approached decision-making. They also talked about how they discussed information relating to AF and OAC with patients, and how they tried to help patients understand what is happening during the time available in the consultation. In addition they discussed how decisions were taken during their consultation. During the interviews, they all indicated that they keep themselves updated with current research in their field and although they have gained a lot of experience on how to tackle patients' concerns during the years, they still discussed some challenges that they face when prescribing warfarin. These challenges could be categorised as their interpretations of patient related concerns, and the challenges that they, as professionals face.

Analysis of the data lead to the development of two over-arching themes (see Table 13): (1) Communicating information – a shifting paradigm and (2) Challenges within OAC prescription for AF. Within each of these overarching sub-themes were two themes and a number of sub-themes, as illustrated in Table 15.

Table 15: Overarching themes, themes and sub-themes elicited from physician's experiences of AF and OAC prescription

Over-arching themes	Themes	Sub-themes
Communicating information – A shifting paradigm	Patient focused information – Aspiring for adherence	Reassuring the patient
		Knowledge of warfarin as 'rat poison'
		Pictorial reference
		Use of analogies
		Use of statistics
		Motivating the patient
	Physician focused decision making – Focusing on compliance	Paternalistic approach & issue of patient trust
		Exploiting the fear of stroke - Highlighting benefits and minimising risks of warfarin
		Passing on the decision about OAC treatment to secondary care
		Hope from new drugs
Challenges with OAC prescription for AF	Challenges that physicians face as health professionals	Lack of Time
		Language and cultural barriers
		Guideline adherence
		Information overload for the patient
	Physicians' interpretation of patient related challenges	Impact of blood test monitoring
		Side-effects and interactions of OAC therapy
		Differences between symptomatic & asymptomatic patients
		Physicians' perceptions of the patient's experiential knowledge

Each of the over-arching themes, their themes and sub-themes are discussed in more detail in the forthcoming sections. Verbatim extracts and their meanings are included in the text to highlight the physicians' experiences.

5.2 Communicating information - a shifting paradigm

Good and effective communication skills were imperative during the participants' medical consultation. This over-arching theme focused on how different physicians in different specialties (cardiology, general practice, general medicine) and at different levels (consultant and registrar) communicated information on AF and OAC to their patients. The medical consultation with regards to AF and OAC took the form of a shifting paradigm, where the model of patient inclusion changes during the consultation. The beginning of the consultation adopted a patient-focused communication style where physicians aspired for patient adherence. When the consultation shifted to the decision making, it adopted a physician focused communication style where physicians took the decisions and focused on maximising compliance. These two opposing communication styles were the main themes that structure this over-arching theme.

5.2.1 Patient focused information – Aspiring for adherence

In this theme, participants explored how they initiated their consultation by focusing on diagnosing and imparting information about AF and OAC to the patient. The initial part of the consultation took a patient focused style, where the emphasis lay in patient education and reassurance. The physicians' focus was to increase patient knowledge about AF and OAC through the use of several communication aids, as a preparation to decision making. These communication aids and how these were used by the various physicians are discussed in following section.

5.2.1.1 Reassuring the patient through a structured consultation and the use of everyday language

All of the physicians discussed how they provided a structure to their consultation. Irrespective of specialty or level, generally all physicians structured their consultation in a similar generic way however, some also commented that they individualised it. They began with the diagnosis of AF, talking about the likely cause of the individual patient's development of AF and

possible recommendations for rate and/or rhythm control as well as OAC therapy. However, consultant cardiologists and registrar-level cardiologists went into more detail regarding possible treatments for AF, such as cardioversion (electrical or drug therapy) and rate or rhythm control (medications to control the heart rate) (rate-control) or to try to return the heart rhythm to 'normal' sinus rhythm (rhythm control), than consultant level physicians and general practitioners. In addition, all physicians discussed the increased risk of stroke associated with AF and how it can be subsequently reduced with OAC therapy, most commonly with warfarin. Thus by providing a structure to the consultation, physicians' perceptions were that patients would be in a better position to follow the ongoing discussion. The following extract from consultant cardiologist Sean, provides an example of the generic structure and the crucial issues that need to be covered by physicians for an AF consultation. The consultation is split into two main issues, how AF leads to a speeding up of the heart rate and how clots formed from the irregular irregularity of AF.

The issues that we need to convey to the patients are two-fold. Firstly they have a heart rhythm disturbance which results in two main problems. Firstly it can cause the heart rate to speed up, the second thing is it causes clots to develop within the heart and both of those are associated with problems.] [The SECOND issue which is probably the more important issue is that of thromboembolic events, meaning the risk of them having a stroke. (Sean, Cardiologist)

On the other hand, Cardiology registrar Jeffrey argued that there cannot be a single simple structure to follow as a consultation should be individualised to the educational background of the patient.

I think you have to... you have to describe it in terms that the individual patient can understand. So obviously people come from different backgrounds, different educational levels. But I just try and start off in a simple way and explain it... some patients almost don't want to know too much. But some people are really interested. You have to pitch it in the right way. (Jeffrey, Registrar)

Furthermore, physicians pointed out the importance of communicating information that is easily understood by the patient as they do not have an understanding of medical terminology. In addition to using everyday language, physicians emphasised the need for reassurance. Consultant cardiologist John highlighted this need in the following extract.

Many people have had relatives with atrial fibrillation who have not done well and partly because it happens in mostly in older people and older people get things... and it is important for us to reassure them... they can live for many years with atrial fibrillation although you and I know that the prognosis is not as good as if they did not have atrial fibrillation... and we can reduce the risks and complications via medications, mostly via anticoagulation... (John, Cardiologist)

Consultant cardiologist Melanie, apart from using every day language to describe an irregular rhythm (shown in the phrase 'the rhythm has gone a bit wonky') she believed she reassured her patients by normalising AF as part of the ageing process.

As I told you before most of my patients are in their 70s and 80s and I describe atrial fibrillation as an ageing process of the heart. Nearly most of the people... it's just of those things that happens. Some people will get it earlier than others and it doesn't necessarily mean that there is something wrong with your heart... it just means that the rhythm has gone a bit wonky (Melanie, Cardiologist)

Similar to cardiologist Melanie, registrar Jeffrey also reassured his patients by normalising AF (i.e. telling patients that it is a common condition). From the following excerpt, Jeffrey was showing that most of his patients were very anxious when they came to medical consultation. Thus reassurance was a critical communication skill.

So I think the first thing to do is that I try to reassure them that it's erm a very common problem and it's something that we can do something about and... they are not going to come to any immediate harm. Just to try to reassure them, because often they think that they have some kind of time-bomb ticking that is going to explode and that something badly wrong is going to happen. (Jeffrey, Registrar)

From his experiences, cardiology registrar Ted showed that patients that were referred to secondary care always expected the worst outcome. Furthermore he emphasised the role reassurance played when explaining that AF is a condition that is more common with age and that normally it is not a result of the patient's lifestyle as shown through the phrase 'probably nothing that they've done'.

I think what they want to know is, is there heart going to stop? Is it a heart attack?... or a sign of heart failure or something they've done wrong in life?... you know could it have been their excess alcohol?... where it could be?... and you have to educate that. Is it the fact that they're a bit overweight... well probably not... so just trying to reassure them that it's probably nothing that they've done... it's a condition that becomes more common as you get older. (Ted, Registrar)

Likewise, general physicians, such as Nilan reassured the patients that AF is a common disturbance. This alleviates the initial anxiety of the patient when receiving medical news on his heart. Furthermore, in his experiences, he informed his patients about both the actual name of the disturbance and a more common name that more easily describes the condition.

I mean generally I say, you have an abnormal heart rhythm. In a normal person, the heart is beating at regular intervals. In you the heart is not beating at regular intervals, so that's why your heart beat has become irregular and it's not an uncommon rhythm disturbance. It's very common as people grow older. Erm there is a medical term for this, what we call as atrial fibrillation or in simple lay terms, irregular heart rhythm. (Nilan, General physician)

Tom also focused his consultation on patient reassurance. At every stage where he gave information which could have caused anxiety to the patient, he balanced it out by normalising the issue of the irregularity of the heartbeat. Furthermore, he assured the patients that both the AF and the clotting of the blood can be controlled.

The heart is beating irregularly, it's not a regular pattern. And that's fine. It could have been doing that for years, but there are

problems with that. Sometimes it goes too fast in that pattern, so we have to slow it down a bit so we may use tablets for that. The other problem is, while it's being irregular, it can slightly increase your chance of getting clots. Not necessarily happen... most people don't but it slightly increases your chance and we think you would need blood thinning (medication) included. That's the simple way I describe it. (Tom, General physician)

On being prompted, he provided further rationale for why reassurance was an integral part of any consultation. He argued that providing only information without reassurance on the safety of treatment, may lead to stress and anxiety on the patient.

R – So kind of... from what you told me before, it's like trying to keep the situation calm, reassuring the patient on the treatment?
T – Yes... I don't want them to go away thinking that they're certain to have a clot and a stroke. Certainly, the warfarin keeps away. You know I say there is a risk, but it's not a definite thing. (Tom, General physician)

On a similar note, general practitioners also focused their communication style to the patient's "level". Through this excerpt, one can note that Matthew reassured the patient by focusing on their concerns. Periodically questioning the patient helped Matthew to recognise the amount of information to be conveyed.

The heart is basically beating irregularly and you are sending them for an ECG. You bring them back and they're a little bit apprehensive in terms of the results. So you need to pitch your consultation based on their level, so I always... particularly if they're elderly and particularly if English isn't their first language. I always tend to take it a little bit slower and explain to them at their level. So the heart isn't beating regularly, what does that mean, trying to get their understanding a bit, what the implications for that is, and part of that consultation is offering them the option to be seen at the specialist clinic at the hospital or being referred to... 'cause obviously we have our own specialist here, being referred to one of our specialists for further consultations based on that. (Matthew, General practitioner)

One major skill difference that was mentioned in the communication style used between the hospital physicians (cardiologist, general physicians, and

cardiology registrars) and general practitioners was probing patients' concerns and understanding of the condition. According to the general practitioners' accounts, probing the patient at certain stages of the consultation helped in exploring the patient concerns and through reassurance, alleviated the stress and anxiety built from inaccurate associations through 'a priori' knowledge. General practitioner George discussed the importance of exploring the patients' concerns through the use of probing questions. Similar to hospital physicians, George also commented that his patients got anxious about the 'worst case scenario'.

When the people have chest pains, their main concern is, are they having a heart attack. That's the worst case scenario as far as they are concerned. So when you start doing heart traces on people, they are thinking straight away... he thinks I'm having a heart attack. So... and actually addressing that is important. You should ask them, what are you worried about today? (George, General practitioner)

General practitioner George adopted this probing style throughout his whole consultation, constantly exploring the patient's existing knowledge about AF and the treatment options to reduce the chance of a stroke and building upon it, as one can see in the next quote.

To treat AF, we got this stuff to control the random electricity around the heart, and we got stuff that lessens the risk of getting a stroke and these are drugs that thin the blood. So the drugs that we use are usually two. One is aspirin and one is warfarin. Erm and there are advantages and disadvantages to both, erm... to me then I would talk about warfarin and not necessarily about aspirin. So I would say, do you know anybody on warfarin? Do you know anybody with a yellow book? And see what their perception of that is. Usually you can pick up something. Most people usually know somebody on warfarin and what that means. You can say that the downside of warfarin is that the dose that I need to give you, I don't what it is exactly. So the only way we can get to know is by doing regular blood tests. So the problem with warfarin is that we have to have regular blood tests. And we do have to change the dose around depending on the results of the monitoring. And then I ask them what you think about that (George, General practitioner)

Furthermore, when he was about to discuss warfarin, rather than explaining warfarin itself, he explored whether the patient was already familiar with the treatment. This probing style made the consultation more interactive, helped to reduce the patients' anxiety by addressing their concerns and also aided in building a rapport between the physician and the patient. In the above excerpt, George first provided some information about possible treatments and then probed the patient on his 'a priori' knowledge. In this way, George gauged the level of knowledge the patient had on AF, whether the information that was provided was understood and addressed the patients concerns directly. In addition, all physicians used humour such as laughter or smiling within their experiential accounts of their consultation, as they believed it lessened the patient's anxiety level, enhance rapport and trust during the consultation. This was portrayed in consultant cardiologist Melanie's next quote. She sometimes introduced humour during the consultation as a way to minimize a stressful or difficult situation. While trying to explain a difficult concept, such as statistics, she laughed with the patients at her own statements, as seen in the latter part of the following quote.

I say that if there are a hundred of you without AF, 1 of you will have a stroke over the year. If you've got this irregular heartbeat, then 4 people will have a stroke. I use the figures so I can make you like everybody else. Rather than you be 4, you'll be 1, and that's it. It doesn't mean of course that 96 people won't have one but I am not clever enough to know whether you are the 1 or 1 of the other 96. That's what I explain to them and we laugh (smiles)
(Melanie, Cardiologist)

Humour was especially used by physicians, particularly by general physicians and some registrars, when discussing the concerns of warfarin being used as rat poison. General physicians and registrars illustrated how they are friendly within their consultation through the use of humour, such as Nilan's or Chan's quotes below by smiling or keeping the discussion light hearted, to assure patients that even though it was used as rat poison, warfarin was a modified version of it, so they are not going to be poisoned.

Well generally I tell them 'look I am going to start this new drug, which is called warfarin, in the past it was used as rat poison. But

we are not going to poison you with that (smiles). (Nilan, General physician)

Well sometimes, just to break the ice... erm... a lot of patient would have heard as well. I tell them, (leans forward) I know that you probably heard from somewhere else that warfarin is used as rat poison. So you start with that and then they start laughing and they go yeah fine whatever. (Chan, Registrar)

5.2.1.2 Knowledge of warfarin as rat poison

There were mixed experiences between physician groups with regards to their perceptions of patients' knowledge on warfarin being used as rat poison. Cardiologists argued that patients were very knowledgeable and anxious about warfarin previously being used as rat poison. In the excerpt below by consultant cardiologist John, he argued that according to his experiences, the knowledge that rat poison works by causing fatal bleeding in rats was well known among patients and therefore he believes that this lead to an increase in bleeding concerns in the patients.

They [patients] worry about warfarin itself... erm everybody knows that initially warfarin was used as rat poison] [and they worry about the bleeding complications as everyone knows how rat poison works. (John, Cardiologist)

Cardiology registrars in this study had similar experiences as those of consultant cardiologists. Their patients were anxious about the fact that warfarin was used as rat poison. In the quote below, registrar Ted argued that it was the meaning that patients attached to the word poison that gives rise to this negative perception of warfarin.

I think especially with the older generation... a lot of them, as soon as you mention warfarin, they will say rat poison. So many patients say that... because it was used as rat poison... I'm not sure if it is still used as the poison. But this is what they automatically say so... erm... That is automatically a negative perception on warfarin. (Ted, Registrar)

Registrar Dheepak and Registrar Jeffrey argued that they preferred bringing up this subject themselves as they believe that patients would not make the

connection between warfarin and rat poison unless raised by themselves. Dheepak pointed out that older people were more aware of this fact, prompting the question that this could be a generational issue. Older patients may remember the time when warfarin was still the main ingredient in rat poison. Dheepak educated the patients by telling them that it was a poison for rats not for humans.

Sometimes I do tell them it was used as rat poison. Some people would remember using it... and would ask me whether they should be taking it or not.] [older people are more aware of these things than younger people. I tell them that it was used as rat poison, but you are not a rat. That tends to avoid any further questions about it. (Dheepak, Registrar)

Likewise, general physicians' and general practitioners' experiences conform to those of cardiologist and cardiology registrars where they agreed that knowledge of warfarin being used as rat poison is wide-spread among patients. However, in contrast to cardiologists, they also commented that rat poison was not a major patient concern in their experience. On being prompted, general practitioner Nick pointed out that his patients are not concerned about the fact that warfarin was used as rat poison. However he did not say that they did not know about it.

R - Do you get patients that ask you about some daily concerns on warfarin... like the issue of rat poison for example?

N – No no they are not concerned about that (Nick, General practitioner)

In addition, general practitioners did not try to change patient perceptions on warfarin being used as 'rat poison'. General practitioner George, rather than trying to change the patient's perception of warfarin, he just stated that even though it is used as rat poison that is not a good reason to decline it.

R – And do you get patients that tell you about rat poison?

G – yeah

R – And for example, how would you react to that?

G – I say it's true, that's what it is, but that doesn't mean that it's not worth taking. (George, General practitioner)

Differing from other specialties, general physicians such as Nilan commented that they take advantage of the patients' experiential knowledge of rat poison to explain what warfarin was and how it worked. Nilan explained that his rationale in linking to the patients' knowledge about rat poison was to lessen their anxiety about starting a new drug.

What I explain to them is that it is a blood thinning tablet, erm... and the way it works is erm... it's like the old rat poison, but of course this is a modified version of it] [If you tell them warfarin or a blood thinner, majority of people don't know, but once you tell them about the rat poison. They all know about it, they [click] (Nilan, General physician)

Similar to the other general physicians, Manpal argued that mentioning rat poison aids in lessening the burden of explaining the mechanism of warfarin. However, he also assured the patients on the safety of warfarin by telling them that it is a "modified version".

R – And erm... can you tell me... how you would explain warfarin to the patient?

M – What I explain to them is that it is a blood thinning tablet, erm... and the way it works is erm... it's like the old rat poison, but of course this is a modified version of it (Manpal, General physician)

5.2.1.3 Pictorial reference

Drawing the heart to explain how the heart beats normally, how AF affects the heart's natural pacemaker causing it to beat faster and irregularly, how the irregular beating of the heart increases the likelihood of a blood clot forming, and the consequences of such a clot, was a technique used by most of the physicians interviewed, with the exception of the consultant general physicians.

Consultant cardiologist Sean shows that pictorial aids during an AF consultation helped him in explaining procedures in non-medical terms and improved time-management. Furthermore, according to the physician's

experiences, the patient needed to have good understanding of the link between AF and stroke (which was the responsibility of the physician to impart) in order to understand the necessity and importance of OAC.

We speak in very basic terminology. Now obviously they don't know what arrhythmias is so we say there is a heart rhythm disturbance within the heart and erm and usually I do it on the basis of drawing pictures (Sean, Cardiologist)

In addition, these pictorial aids would help the patient in understanding the rationale of the physician when advising the appropriate medical treatment, as can be seen in the next quote by consultant cardiologist John.

J - Sure I draw a heart and I draw the normal ECG and then I explain what happens in atrial fibrillation... how the back chambers stretch and how the front chambers are more like a tyre and don't tend to stretch... the back chambers and that's what we think causes in majority of patients and they understand that as it's a simple concept.

R – So you use a visual impact kind of

J – Absolutely

R – And that helps [to]

J – [Yes] cause they understand why it's happening and why for instance... why they will be suitable for either ablation or cardioversion (John, Cardiologist)

Cardiology registrars also used pictorial aids within their consultation. This could be linked with cardiology registrar Dheepak's argument with regards consultation structure. He argued that the way a physician structures his consultation is partly based on experience. Dheepak believed that through medical practice, he realised that patients have poor knowledge of the heart's anatomy and that a picture can aid explanation of AF. Cardiology registrar Ted observed how patients may lack anatomical knowledge of the heart, thus by drawing a picture of the heart he helped the patient identify the origin of the problem, included them in the discussion and focused the discussion on the issue, thus saving time.

A very simple picture of what a heart is. Cause some patients won't know where are the atria in the heart, where the clots are going to be building up. So I just draw a left atrium appendage...

Just to show them that the blood doesn't circulate very well... because of the fibrillation.] [That is how I usually talk to them about stroke... sometimes I show them the ECG... just to show them the irregularity...it's easy to do a quick diagram (Ted, Registrar)

Pictorial aids during the consultation were also used as a way to reassure the patient. General practitioner George used pictures of the heart to emphasise to the patient that if the condition was controlled, the heart would still operate normally.

If I have got to describe it, I would draw a picture of the heart really quickly and show the two top chambers and the bottom chambers. Now electrically the rhythm of the opposite chambers, top and bottom, can go wrong. The heart muscle on the top can decide it wants to fire on its own way and what then happens is you get an incoordination between the two. Now the heart works still, there are no problems with the heart, but provided it stays well controlled. (George, General practitioner)

Contrary to other physicians, all general physicians showed confidence in their ability to impart information to patients and commented that they do not make use of any visual aids within their consultations. On being prompted about this issue, general physicians Balu and Manpal mentioned that they do not use drawings in their consultations. Furthermore Manpal also gave the impression that he dismissed AF as a simple disturbance that according to his interpretation, patients understood easily as he argued that for other conditions he may adopt pictorial reference.

R – Do you kind of use any... any other things to help your explanations? Like do you do drawings or stuff like that?

M – For AF probably not, for other conditions maybe... if they didn't know what it is. But for AF, no (Manpal, General physician)

Conversely, apart from drawings, general practitioners were more prone to use or print off educational material to help them explain AF rather than using their own drawings. Both general practitioners Matthew and Nick described using educational materials printed off from their own computers.

N - that is part of our practice. I haven't mentioned it... but I'll always try and print off some materials
R – so you give information to the patient
N – yeah I try to print off on some occasions from my computer, information about AF (Nick, General practitioner)

Moreover, general practitioner Matthew argues that by providing these educational materials, he felt more at ease than if new patients had to read information from a random website which was not approved by a health professional as shown in some patients' experiences in this study where they mentioned that they printed off material from internet. Such a procedure also helped the consultation to adopt a patient centred approach as it facilitated discussion.

I would say most of my consultations... certainly every NEW patient that I see with a particular diagnosis, I generally will always print something off. And it gives them an opportunity to just read something that erm... is kind of vetted by a medical professional as it were. As opposed to just going on the internet and trying to log on to some random website. And it gives them to opportunity to sort of read that, digest that, or get it read to them if they don't read English... and then come back with questions. I tend to do that rather than draw myself (Matthew, General practitioner)

5.2.1.4 Use of Analogies

Analogies were also something that physicians used in their experiences as a way to explain information in non-medical terms. The following three excerpts illustrate how physicians used analogies to explain what AF is, how OAC medications work and differences between warfarin and one of the new OACs, and how much risk reduction a patient might gain from OAC treatment. General practitioner Nick commented on his use of analogies to explain AF to a patient. He compared AF to wiring in the house, and similar to the wear and tear brought about through time in these wirings, he explained to the patient that AF was an illness most commonly brought about by the ageing process. However, such an analogy is mechanistic and portrays the body as a machine. As seen by the analogies used by patients, such as Jonas, where he describes how you go to the mechanic to fix your car engine, such mechanistic analogies might not

be good definitions. For example in Nick's quote, a patient might see Nick as the 'expert electrician' that has to decide on what needs to be done to ameliorate the 'wiring of the old house'.

I would explain to them that they have an irregular heart and their heart is going irregularly, irregularly and I usually sort of tap it out for them as to what is happening. I tell them that the electrical wiring of the heart is erm still there and fine but like any wiring in an old house. You know the insulation is just got a bit worn. So the currents tend to short-circuit and not connect up. That is a sort of analogy for the patients. And erm... that erm in the short term they are not in any risk but we need to get it sorted out. (Nick, General practitioner)

In the following excerpt, consultant cardiologist John portrayed how such analogies were used in his consultation. He also mentioned a new upcoming OAC drug, dabigatran, to patients and compared the two through the same analogy. Also it was interesting to note the imagery used in these analogies. However, similar to Nick's analogy, it objectifies the human body, taking out of the equation the control and behaviour of the patient.

Well I tend to explain to them that it's a bit like target bombing and we basically stop one of the vitamins, vitamin K, working but that effects a more different bunch of pathways which is why it has all these reactions with alcohol, foods, medicines. Erm... whereas to some extent, the new drugs that are coming, dabigatran in particular because it is coming so soon... is more like cruise missile. It specifically targets, the thing that causes clots in the blood, and they understand that. Most people get the idea of target bombing and cruise missiles (smiles) (John, Cardiologist)

An interesting analogy was also presented by cardiology registrar Jeffrey. Through his experiences he argued that when describing stroke risk reduction, patients might not understand percentages correctly and a 10% stroke risk reduction when on warfarin might not seem as a viable option for them. However he used an analogy to explain what 10% means through a real-life scenario. By using the lottery as a real-life scenario patients can compare experiential knowledge with their 'a priori' knowledge, thus Jeffrey "put things in perspective" for the patient. However Jeffrey did not mention if patients do understand his statistical analogy.

J - If you had a 10% chance of winning the lottery, you'd buy a lottery ticket. You have to kind of put into
R – Perspective
J – Exactly... (Jeffrey, Registrar)

5.2.1.5 Use of statistics

Almost all of the consultant cardiologist and cardiology registrars mentioned that they discussed statistical figures or probabilities, during their consultation. General physicians and general practitioners did not mention the use of specific statistics or probabilities in their consultations to explain risk to the patients. Similar to cardiology registrar Jeffrey, consultant cardiologist Peter brought about the notion of probability and “odds” of playing the lottery to justify the use of statistical figures during his consultation. He argued that since patients know and play the lottery, they could have an understanding of odds in reducing the risk of stroke.

I think giving patients and figures, maybe it's a bit too much, I don't know, but if you do... patients do sort of enter the lottery and presumably have some appreciation of odds and things, and they know how to do betting things... if you say that you are reducing the risk of stroke by 7% in absolute terms per year then that's... that's a really, it sounds quite substantial I think... it's similar to a lottery (Peter, Cardiologist)

In addition, some cardiologists, such as Melanie, did not mention percentages directly, but used numbers of people as figures of speech in an attempt to make probabilities easier to understand. However, she herself noted that she did not know if patients actually understood these statistical odds.

Conversely cardiology registrar Chan used statistical data to reassure the patient on warfarin. The focus in registrar Chan's quote below was not in the percentages, but rather the emphasis lay in the phrases exactly after talking about the percentages (shown in italics). After Chan mentions percentages he mentions if this percentage is actually high or not according to medicine, thus

linking percentages to an everyday concept, making the rationale for recommending warfarin more apparent.

Your risk of getting a stroke based on what we know... is going to be 7-8%. If I put you on aspirin I'll bring you down to 4-5%... *which is still quite high, higher than the average population.* But if you start warfarin, you bring it down to 2-3% *which is only slightly higher than someone at the same age.* (Chan, Registrar)

5.2.1.6 Motivating the patient

Physicians in this study, except for consultant cardiologists who did not mention the issue of motivation, pointed out that since warfarin was a potentially dangerous drug, patients needed to be motivated to adhere to treatment. In this respect, registrars also argued that a consultation should adopt a shared decision making process rather than the physician adopting a paternalistic approach and taking all the responsibility. Although physicians contended that patients should be motivated to be responsible for adhering to their treatment, no one suggested who should take the responsibility to motivate the patient or what needs to be done to motivate the patient. The importance of motivation was clearly seen in registrar Chan's quote below.

So with warfarin it is something that you need to have a shared responsibility. Cause you cannot go chasing the patient... you need your INR checked today. The patient needs to have some motivation. (Chan, Registrar)

Similarly, general practitioner George also emphasised the notion of motivation within his consultation. He argued that during his consultation he pointed out to the patient why decision making should also entail some patient responsibility as ultimately it was the patient that has to maintain optimal blood control.

I can't make the decision for you, I can give you a recommendation, you're the one that has to go to have the blood tests. You're the one that comes here and you're the one that is going to take the medication, not me. So it's still going to have to be their decision. (George, General practitioner)

General physician Nilan emphasised the issue that the patients and not physicians were responsible for their own safety with regards warfarin interactions with alcohol and other medications. Rather than focusing on side-effects, Nilan seemed to shift his communication style to how the patients should be responsible for their own safety.

Again I tell them that there are a few precautions that you need to take, like if you cut yourself, to apply pressure for 5 minutes, secondly don't buy any pain killers from the counter and take them. If you need any pain killers, go to your physician. If you are going out for a party, don't indulge in binge drinking. (Nilan, General physician)

According to Nilan, the patient was responsible for his care and to keep within the therapeutic range of warfarin. He stressed the precautions that the patients needed to keep in mind when on warfarin, especially when alcohol was involved.

That is why there is the need for all these precautions you know... that you don't take any tablets or pills which you get over the counter which can react with it. Again it's very important that you have the blood tests regularly because that is what we use to monitor and again like I said to you, not to indulge in bad binge drinking, because that can make your INR to go all over the place. (Nilan, General physician)

When general physician Balu was informing the patient on the side-effects of warfarin, one can note the use of the word "efficiency". Rather than arguing on the side-effects that can be caused from warfarin, he shifted the responsibility of care to the patient by pointing out that if the patient does not adhere to the treatment, warfarin will lose its efficiency, thus increasing the possibility of having the side-effects.

The two sides of the equation with warfarin; if drugs interact with it, you can lose efficiency or the drug can be over-efficient and cause bleeding. So you need to be aware of certain antibiotics so when you are prescribed by the GP, make sure to let the GP know that I am on warfarin. So that drug interaction is very important. They need to know! Then again you stress to them the importance of keeping the INR between 2 and 2.5 so when they are ill, when

they are on antibiotics they need to take a bit more, there are certain drugs that when they are taking it, they will need to take in a little less. (Bal, General physician)

Likewise general physician Tom argued about the importance of adherence to OAC treatment. He argued that if patients were not responsible with their treatment, safety was not assured. Thus Tom believes that if his patients do not show an interest during the consultation, he might be influenced in not prescribing warfarin as OAC therapy. This is a crucial factor when considering that some patients, like Daniel and Jonas, might prefer a paternalistic consultation where they trust physician as the expert to take the decision for treatment.

If he's not very committed to it, it's not going to work anyways isn't it? They won't be taking it, they won't be going to their appointments. You want to erm... make sure they are on board. (Tom, General physician)

Concurring with Tom, general practitioner Nick highlights that according to normal practice, patients were responsible for adhering to treatment and that motivating patients to be responsible had an impact on their level of adherence. However Nick did not specify who has the responsibility to motivate the patient.

And in this case we are talking about the risk of embolus, it's significant and that they need to take the situation seriously. Well it's standard general practice that patients should take personal responsibility for their condition. They should be motivated to manage it responsibly (Nick, General practitioner)

Similar to Nick, registrar Ted also noted the need for the patient to be motivated towards adherence to OAC, i.e. taking the pills regularly and being aware of the interactions with warfarin. In addition, like Nick, he also does not explore who should shoulder the responsibility to motivate the patient. From the following quote Ted is also pointing out a drawback of a paternalistic approach in decision making. He believes that if a patient is not educated and involved in the discussion about AF and the risks of OAC, the patient would not be knowledgeable of his role in adherence. Furthermore, Ted was assuming that education is enough to motivate patients.

Not enough is done to make the patients think. So motivation is important. (Ted, Registrar)

5.2.2 Physician focused decision making – Focusing on compliance

This theme explored how communication during the decision making process adopted a paternalistic approach rather than a shared decision-making style between the physician and patient. Physicians in different specialties used various methods to influence the patient into complying with their choice for treatment. These included the hope from new forthcoming OAC drugs, highlighting the benefits of, and minimising the risks of, warfarin, and taking decisions in a paternalistic way. In case of general practitioners' experiences, although they comment that in some practices they started warfarin themselves, the decision to initiate warfarin was usually passed onto secondary care.

5.2.2.1 Paternalistic approach

Physicians often talked about how their patients asked their advice on what medication they should take as the patient viewed the physician as the expert. Cardiologist Melanie commented that this was a common practice. She tried to build rapport with the patient by taking a familial approach, stating that she would advise the patient as if they were her relatives. Melanie perceived herself as not being "paternalistic or maternalistic". However, she later argued that her job is to provide the expertise needed by the patients and that it is important that patients pay attention to the expert's advice. This brings to the forefront the issue of an unavoidable paternalistic attitude, as Melanie is trying not to take a paternalistic role, however it is a role that she feels she has to take. In addition, Melanie highlights the problem of using mechanistic analogies which takes away the proactive role that a patient plays during a shared decision making process.

M – well I often say to the patient... if they are not sure, I say look. If you were my mum, I would really like you to go on this medication. Okay? But I can only do that to people that I know obviously. And the other thing is they (the patient) say...erm... well what would you do physician... and I say well if I am this or the other I would do this. Because it's a bit like if somebody asked me about my car. Oh madam should we fix that... if it was your car, would you fix it. It's like... I'm not paternalistic OR maternalistic towards my patients but I hope that they listen to the degree of guidance that we offer as physicians. That is our job. So I sometimes use that car experience to them, cause they... sometimes they throw back at me

R – I see you use it as an analogy

M – They usually say I work in business and I wouldn't expect you to tell me about my... I have come to ask you... and my opinion, this is what it is... and allow me to use the granny test. If you were my grandmother or grandfather, what would you do? (Melanie, Cardiologist)

Conversely cardiologist John, in the quote below, actively tried to persuade the patient to conform to his preference for treatment by telling him 'if I were you'.

So yeah most people say that they want to go with aspirin rather than with warfarin... erm again that's a common thing and you have to persuade them of the pros and cons and you have to tell them the truth which is, if I were you I would be taking warfarin at this stage. (John, Cardiologist)

However not all cardiologists were of a similar opinion. Cardiologist Sean stated that power used to be in the physician's hands. However he emphasised that there was a need to empower patients to be able to make the right decisions because according to him this influenced the patients' level of adherence. His reflection meant that patients should show a degree of responsibility when agreeing to take on warfarin as they have to manage the treatment. He argued that the only way to empower patients is by providing them with appropriate information. At the end of this excerpt, however, he stated that the majority of his patients ultimately left the decision to him. Thus, in Sean's experience the patients preferred to abdicate responsibility of decision regarding OAC treatment to the expert out of trust, a patriarchal solution where the expert's decision was dominant. As mentioned before, such

an experience would place the physician in an unavoidable paternalistic position where the physician has to take the final decision.

R – so you took the initiative to learn, to learn the language?

S – yeah yeah. Because it's something that you do not understand the importance of when you are young. But when you are older, you suddenly realise how important it all is.

R – So you did it (learning other languages), to help you build a better erm

S – I think so, it is important erm... because the olden day relationship, the physician was in a superior position and the patient was in a passive erm... inferior position. This no longer applies and if you empower the patient to make decisions erm and erm... the only way you can empower the patient to make decisions is to provide the information that they require to make that decision. AND if you don't then they make the decision on the basis on inaccurate or inadequate information and they often come to the wrong conclusion. Erm whereas if you provide them with a balanced argument, it erm... essentially you give your best advice to the patient and then it's their decision to make, but it's important for you to provide them with that information. But often time the majority of my patients leave it to me to decide okay. I still give them information so that they understand the decision making that I am erm... erm I'm making but erm the majority just allows me to choose what's best for them. (Sean, Cardiologist)

Registrar Dheepak echoed the sentiments of Sean and also tried to adopt a shared-decision making style during his consultation. However, as with Sean, the patients themselves led him to take a paternalistic approach and asked him to decide for them. In addition, because of the potentially harmful side-effects of warfarin, neither the physician nor the patient may want to take responsibility for the final treatment decision, as illustrated in the next excerpt:

Well I always give them the choice. I will ask them what they would want, because particularly with warfarin... it can have harmful side-effects. So I think the patient should take a role in the decision making. He has to be sure on going on to it. That is the ideal way, however most of the times... the patient may say you're the physician, you tell me. (Dheepak, Registrar)

Registrar Chan drew a similar argument as the one proposed by registrar Dheepak and Sean. He pointed out that since warfarin management was the responsibility of the patient, decision making should also include the patient's

choices. Further, he stated that rather calling it a shared decision, it should be a shared responsibility.

I don't like to take the paternalistic approach where I tell the patient what to do. They need to understand the disease] [I prefer a shared decision, cause if you take... especially with warfarin... there is a lot of responsibility lies with the patients. You need to know when they need to be tested, not to miss them. They need to be sure why they're doing it. As taking a higher dose or lower those would be not only ineffective but it is dangerous. So with warfarin it is something that you need to have a shared responsibility (Chan, Registrar)

The issue of responsibility was further explored by registrar Jeffrey. He suggested that a physician's responsibility and moral duty was to educate the patient on the best treatment available. In the following quote Jeffrey emphasised through repetition the importance of patient education during decision making. In addition Jeffrey believes that patients should not make rash decision based on an emotional response to warfarin being rat poison, but rather make an informed logical decision which is the need to take warfarin to reduce the risk of stroke.

Well I think that you're not really doing your job properly unless you've had really kind of... full front discussion. If one wants to take warfarin, it's straight forward. But if someone doesn't want to... I think you really got to talk to them for quite a long time to try to... erm erm... erm... educate them... put them in the whole picture so they do reach a rational conclusion.] [I think you have to make an effort to go through it with enough time and enough detail for them to reach that rational conclusion. Which is very difficult sometimes when you got kind of 10 minutes to see someone in a busy outpatient. It's very easy to say... ok you don't want to be on warfarin, that is fine. Then you write in your notes, warfarin discussed, patient declined. Job done. (Jeffrey, Registrar)

As showed in previous experiences with regards the unavoidable paternalistic attitude, Jeffrey also points out how difficult and stressful it is for physicians to balance the patients' needs during the consultation which might lead them into taking the easy way out. However, Jeffrey later commented that because of warfarin's mode of action, patients had to trust physicians that it was the best treatment.

Yeah they have to kind of trust you... because you're asking them to take a drug that is not going to make them feel any better. For the majority of the patients it won't do them any good, as the majority of the patient don't have a stroke. So they do have to.... They do have to put some kind of faith in you, to take a drug that isn't going to make them feel any better. (Jeffrey, Registrar)

Conforming to the registrar's point of view, general physician Nilan explained that, through education patients were empowered to take informed decisions. However, immediately after, he contradicted himself and agreed with the cardiologists, that when patients put him on the spot and asked his expert advice directly, he took a paternalistic approach in conveying the message. Using a similar method as that used by cardiologists, 'If I were you I would'.

So YOU are EMPOWERING them rather than you are taking decisions on their behalf. That's what I tend to do. So I say 'let's look at this' and then 'If I were you' I mean generally people ask you, 'what would you do in my place' then I say 'if I were you I would take this' and they 'okay then, it's fine' (Nilan, General physician)

Similar to other the other specialty groups, general practitioner George argued that patient education was imperative in a consultation for a patient to be able to take a decision. However, George further pointed out that a physician should not fall into the unavoidable paternalistic approach and just abide by the patient's trust. George outlined the importance of adapting the consultation to the individual patient within the medical consultation, arguing that patients should be involved, and through discussion empowered with the knowledge of risks and benefits.

You have to give information so that the patient can base his decision on something. When the patient says 'okay, whatever you want doc', that is not a good way how to decide on things. So you have to adapt to the patient, but there is always a certain way. Good medical practice says that there are ways that you should prescribe drugs, and that is involving people and helping them understand the risks and benefits. (George, General practitioner)

General practitioner George also explored the issue of his interpretation of the patient's perception of trust. He argued that since physicians are trusted so much, they should be more responsible. At the end of the following quote he pointed out that patients expected physicians to take decisions 'on behalf of them'. Thus George's experience is that a paternalistic approach was also ingrained within the patient's attitude during the consultation.

There is an absolute evidence that the most trusted bunch of people that we have as far as the population goes, are doctors. And so I think having such a responsibility means that you are trusted, erm... you are trusted to do decisions on behalf of your patients, with your patients, but on behalf of them as well. (George, General practitioner)

He went on to argue that patient's illness perceptions are an important facet in a consultation with a general practitioner. A patient presented the general practitioner with their interpretation of their symptoms, where in turn they trusted the general practitioner to interpret their interpretation.

If you're gonna see a GP, what you're coming with when you see a GP, you're presenting with an illness, but you're also presenting perceptions of an illness as well. (George, General practitioner)

George's accounts highlight the need for physicians to understand the individual patient's illness perceptions and beliefs. He believes that this can lead to a better involvement of the patients during the consultation and decision making process, however as other physicians showed, there are historical and power-related challenges that need to be overcome.

5.2.2.2 Exploiting the fear of stroke - Highlighting benefits and minimising the risks of warfarin

When discussing warfarin during their consultation, physicians often used two opposing strategies in discussing warfarin with patients. The two strategies were highlighting the benefits of warfarin in terms of stroke risk reduction and minimising discussions on the risks involved, predominantly from bleeding, in a bid to obtain medication compliance from patients. Conforming to the first

strategy, consultant cardiologist Peter argued that in his experience, patients were afraid of the disabling effects of stroke. This was corroborated by the experiences put forward by the patients in the previous study. Patients commented about their knowledge of what stroke can cause, especially in patients like Jonas where he took care of his mother for almost two decades after she suffered a stroke. In lieu of this, he emphasised this part of the consultation on the negative aspects of strokes, the risk of losing their independence and having to go into nursing homes. By doing this he believed that patients were more receptive to the OAC treatment proposed.

If you ask patients what you think about having a stroke and becoming disabled, I think that obviously they fear THAT as well and you know if you go into WHY you want to anticoagulate them, strokes can be very disabling and end up in a nursing home and locked in and that sort of thing. ERM... risk of strokes can be reduced by two-thirds by the anticoagulation and then... erm then they might be more receptive (Peter, Cardiologist)

Likewise, general physician Nilan pointed out that patients were apprehensive of the effects of stroke. According to his experience, the fear of the loss of independence from stroke, was one of the reasons patients complied to treatment. In addition, Nilan commented that adherence to treatment was ameliorated by assuring the patients of the safety provided through treatment.

I mean generally, if you tell them it's a stroke, they get worried about it and generally as you know, when people think of stroke. They think 'oh my god, I'll become bed bound, very disabled, I wouldn't be able to do it'. So they start to take it very seriously that AF is not as benign as they expected it. (Nilan, General physician)

Furthermore, general physician Manpal argued that the fear of stroke increased compliance to warfarin prescription, using the word 'promote'. However Manpal said that "If they can understand", eliciting the idea that if patient education was not done appropriately, patients would not understand the benefits of warfarin.

If they can understand the risk of stroke from AF, that will help to promote warfarin as a much better medication (Manpal, General physician)

The second strategy involved minimising the patient's perceptions associated with warfarin causing bleeds. As one can note from consultant cardiologist Melanie's following excerpt, when patients asked about the side effects of warfarin, she transferred the focus from the side-effects to the action of the drug. She then only mentioned the smaller risks involved, like bleeding from "small things like shaving". She also used certain words that would highlight the benefit of warfarin over the risks involved, such as the word "protect".

They also ask about side effects and I say, there aren't very many because it really is just a drug that stops your blood being sticky or thinner. And then I warn them about the small things like shaving or whatever happens to be, about the little bleeds. I don't usually warn them about brain haemorrhage... perhaps I should. But I don't] [I explain what is happening as part of the explanation as I start to tell him about the blood clots. To say although I know you are well, I do want you to think about this treatment because it will protect you against stroke and I use the word protect. (Melanie, Cardiologist)

In justification of this, consultant cardiologist Sean argued that from his experiences, patients' did not perceive a haemorrhagic bleed in the brain as a stroke. In his consultation, Sean focused his discussion on an embolic stroke (from a clot), opting to leave out haemorrhagic stroke (from a bleed). By leaving out such a discussion on possible haemorrhage, Sean might have influenced the patients towards the more beneficial aspects of warfarin. Interestingly it is important to note the disjuncture between physicians' accounts that emphasised the need for education in the previous theme and the strategies employed in this theme where the physicians explored partial truths and actively left out information that might scare patients.

R – Do they associate bleeding in the brain with stroke?

S – erm... no... usually they perceive what they have seen and usually it means bleeding from somewhere that they can see. Like bleeding from the vomit or bleeding from the back passage. Erm... spontaneous cerebral haemorrhage isn't something that they consider and usually stroke... I don't think they conceptualise embolic or haemorrhagic stroke... erm

R – but more the symptoms of the stroke

S – yeah... but when we counsel them the thing that we try to stop is a clot type stroke. Erm and when they conceptualise when I

draw the diagram of the heart and I put little dots meaning these are bits of debris and if they break off they'll go to the brain causing a stroke, then I think they conceptualise that is an embolic episode. Although I don't use the term embolic. (Sean, Cardiologist)

Registrars pointed out that their patients knew that bleeding in the brain was also a type of stroke. Registrar Chan took advantage of this patient knowledge to further strengthen his rationale for recommending warfarin.

They [patients] do [associate bleeding in the brain with strokes]... erm... but then I tell them that if they're not on warfarin, then they also... they are at a MUCH higher risk of having a stroke. Less likely to be haemorrhagic but the effects could just be as devastating. (Chan, Registrar)

Equally, registrar Jeffrey used a different strategy than that of the cardiologists. Like Chan, he explained both the pros and the cons of taking warfarin, and opted to divulge to the patient that bleedings could pose a threat as well.

You say warfarin is good because it would reduce your risk of having a stroke, but it does thin your blood and that can give you bruising and bleeding and most bleeding is just annoying bleeding, like shaving or nose bleeds. But you can get nasty bleedings within the bowels or the brain. (Jeffrey, Registrar)

5.2.2.3 Passing on the decision about OAC treatment to secondary care

Although general practitioners had experience in prescribing warfarin, they commented that usually patients were referred to secondary care so the decision to initially prescribe warfarin was taken by the cardiologist. One of the reasons, as shown in the below excerpt, was that to diagnose AF, patients still had to be referred to secondary care to undertake an echocardiogram as suggested by the NICE guidelines.

N – Well funnily enough I think that I on the whole don't do that. Because usually most of the cases, one refers down to hospital... for an echocardiogram... and the cardiologist having done the basic work-up of AF, excluded the obvious causes. One then refers them to the secondary sector, and only after having the

echocardiogram, they are... the severity of AF is graded and erm... and a decision is taken about warfarin in the secondary sector. (Nick, General practitioner)

General practitioner Nick further provided a rationale for the benefits of referring patients to secondary care. He argued that a patient was often assured by seeing a cardiologist as he believes that patients see a cardiologist as the expert on the heart. This also pointed out that through Nick's experiences, although general practitioners had a strong relationship with their patients (which was also agreed by patients in the previous study), he believes that patients do not perceive them an authoritative figure on AF, as hospital physicians (cardiologists or general physicians).

Unless the GP is known to have a specific expertise in the world of cardiology... which there are some. Erm... I would think the patients are reassured by the fact that they have seen a cardiologist. (Nick, General practitioner)

Likewise general practitioner George argued that it was not the GP's role to make the decision with regards warfarin. He believes that this gives the general practitioner a way out of the responsibility of dealing with this issue as seen in the final part of the quote below.

I think because GPs can still stand back and say... erm... to prescribe warfarin or not in a patient is a specialist decision rather than a GP decision. *So it's easy to say well... if the specialist told me to do, I'll do it, but they haven't.* (George, General practitioner)

5.2.2.4 Hope from new forthcoming OAC drugs

Consultant cardiologists and cardiology registrars in this study were more informed about current research in relation to AF and stroke prevention than physicians in other specialties, and had greater awareness and knowledge of new OAC drugs for stroke prevention in AF patients that were currently under investigation in clinical trials. Cardiologists used this information as a way to reassure patients that they were not going to stay on warfarin for their whole life, but only as a temporary solution until the "better drug" got a license. During the interview, consultant cardiologist John mentioned that he took an evidence-

based approach and illustrated the pros and cons of warfarin by quoting studies. Later, he motivated patients to initiate warfarin by informing them about new OAC which did not need blood monitoring, implying that in the future they could change their therapy from warfarin to the new drug. He likened the race between warfarin and the NOACs to that of horse races. He explained that warfarin is the 'favourite horse' as it is tried and tested and it is known to work, however sometimes 'the outsider', which are the NOACs, are 'win' over the 'favourite horse'.

I tend to be very evidence based. I go through the evidence and I show the studies... and I show them the pros and cons and you tell them that erm... that it is a double edged sword and you tell them that dabigatran is just round the corner and erm... so, but yeah there are no... there are you know... you back the favourite in a horse race you don't back the outsider, but sometimes the outsider wins, so you have to work on probabilities (John, Cardiologist)

Likewise, when Melanie's patients did not want to start warfarin because of the constant monitoring involved, she sometimes used John's same strategy.

I keep telling my patients that we are looking forward for the next drug where they won't have to have their blood tests] [Once we get around that, then we have to make your blood less sticky, or thinner and to do that we need to thin your blood or we may use something called warfarin. They all stop me there, they ALL know about warfarin... I don't wanna be on that, oh my mum was on it or whatever and then you have to... erm you have to explain that yes it is a bit of a nuisance having a blood tests but I tell them it won't be for very long because we have got a new drug that is going to be along very soon. (Melanie, Cardiologist)

However she went on to say that she did not discuss this issue with all the patients, but mostly with younger patients with whom she envisioned a longer lifetime on OAC.

Yes, it depends on the age mostly, for example, if a patient of 65 comes in I tell him that we'll start this drug but it's not going to be lifelong as there are new drugs round the corner... I used to say that for ximegalatran and then it didn't get its licence (laughs) (Melanie, Cardiologist)

In contrast, cardiology registrar Ted argued against such a method as even though it might reassure the patient during the consultation, because it might give false hopes on a longer term, especially if they are not commenced on the new NOACs such as patients with renal problems.

Now you have much more research coming out about these new factor 10a inhibitors, thrombin inhibitors... you know, relegation of warfarin so... patients who see that, they tell you, I don't want warfarin... I want to take this, but you have to tell them... it's not licensed yet... sometimes it gives false hopes. (Ted, Registrar)

5.3 Challenges with OAC prescription for AF

This over-arching theme focuses on the challenges that the physicians in different specialties and levels of clinical experience, face when prescribing OAC for AF. This over-arching theme was split into two different sub-themes (see Table 13 on the next page); The challenges that physicians faced themselves as health professionals and physician's interpretation of patient-related challenges with OAC treatment.

5.3.1 Challenges that physicians face as health professionals

This theme will explore what experiences physicians find challenging when prescribing OAC to AF patients. Within this sub-theme, four themes emerged relating to the time available for each consultation within the various health care settings and how this had a major impact on content, structure and delivery of patient education, the physician-patient relationship and patient satisfaction. Physicians also discussed issues regarding language use. Furthermore, general physicians and general practitioners pointed out the problems they face with regards to adhering to AF clinical guidelines. In addition, information overload for the patients during initial consultation was also a concern that influenced physicians in how much educational information they gave to patients regarding their condition and its treatment.

Table 15: Overarching themes, themes and sub-themes elicited from physician’s experiences of AF and OAC prescription

Over-arching themes	Themes	Sub-themes
Challenges with OAC prescription for AF	Challenges that physicians face as health professionals	Time Language and cultural barriers Guideline adherence Information overload for the patient
	Physicians’ interpretation of patient related challenges	Impact of blood test monitoring Side-effects and interactions of OAC therapy Differences between symptomatic & asymptomatic patients Physicians’ perceptions of the patient’s experiential knowledge

5.3.1.1 Time

Time as a barrier within the health care system was a challenging experience commented on by all the physicians in this study, irrespective of specialty or level. This barrier was even more noticeable when physicians had to conduct the initial consultations with the patient and this was corroborated by the patients in the previous study, who perceived that was a lack of time during their initial consultation (see Section 4.4.2.1). Physicians had to diagnose the patients, convey appropriate educational information and negotiate the treatment with the patient in a short amount of time; thus leading to concern in physicians in trying to allocate appropriate time to each patient.

5.3.1.1.1 Lack of time

Consultant cardiologist Sean balanced his consultations by allocating time according to the patient’s needs (i.e. he spends more time with initial consultations and less time during follow-ups). Furthermore, Sean talked about a dichotomy of patient types, those who accepted a paternalistic consultation

and do not give any input and those with whom the consultation is a shared discussion.

You will always be (constrained with time) because... it's a bit like being a general practitioner. You can't tell what's going to come through the door. And you have designated slots for... for that patient. And sometimes you get very simple patients who you finish in 5 to 10 min and other times you get patients who take much longer because they are more complicated. And also there is less time to answer any questions that they may have and erm... it depends on the intelligence level of the patients. Sometimes people are very amenable to whatever you give them, that's fine. Other times they are more questioning and they want to know all the ins and outs of a particular therapy. But there is always constraints for time. That is the nature of medicine really. (Sean, Cardiologist)

In addition, cardiologist Sean argued that because of this time barrier, cardiologists are tempted or sometimes forced to adopt a paternalistic attitude and Sean advocated against it. He pointed out that warfarin was a potentially dangerous drug and for patients to adhere to treatment they needed to be educated about the risks and benefits involved.

There is a tendency especially in cardiology clinics because of pressure for time... just for somebody to come and you say, you've got atrial fibrillation and you need to go on this pill and this pill, thank you very much and see you in 6 months' time. Nobody is going to take medication on that basis. So it's important to explain things in detail so that they understand that you are giving them drugs which are potentially dangerous and warfarin can be potentially dangerous (Sean, Cardiologist)

Registrar Chan admitted that patient education was limited in his practice mainly because of these time constraints. Physicians were aware of the areas of knowledge they needed to educate the patient on, but lacked guidance on how much education a patient needed.

Patient education is very important, but it is one that we do badly, because there isn't enough time. In general I see about 15 to 16 patients in 3 hours... so there is not enough time to talk about AF, talk about what you're gonna do... and start talking about warfarin and then educate patients as well. (Chan, Registrar)

In contrast, registrar Dheepak perceived that enough time was allocated for the diagnosis, patient education and to reach a decision on treatment. However, at the end of his interview, when he realised that he spent an hour and a half discussing issues on the consultation, he emphasised that perceived time spent with the patient may be actually shorter than the actual time spent.

From doing this interview you realise how much time is actually needed to explore all the educational information with the patient when putting him on warfarin and in 10min you can't really explore all of it. So I guess what we talked about (the whole interview) would probably be the ideal consultation, but we try to make it as close to that as possible (Dheepak, Registrar)

General physicians' experiences agreed with those of cardiologists and registrars. General physician Tom pointed out that in his experience, time available for his consultation with the patient was further limited because of ward rounds. He admitted that decisions were taken in a brief amount of time, so a paternalistic approach was most probably used. The patients in these cases ended up not receiving adequate information.

It's a brief... I'm doing a ward round, late at night or 7 in the morning. Making quick decisions on whether sending them to the right wards or home and that's quite a brief discussion. It's not long enough really (Tom, General physician)

Similar to cardiologist Sean, general practitioner Matthew commented on how time in his practice was usually balanced out between patients that needed a long discussion and those that did not. However he also pointed out that in his general practice it was normal to go beyond working hours, which shows that although the system is flexible, it is not adequate and GPs are required to extend their time with patients.

The way we run it is we have 3 hour surgeries and erm... some patients would take 20min others would take just 5... the course of the 3 hours, overall it balances itself out... usually running maybe 20-30min behind at the end. So some of these patients who are sometimes a bit more difficult, absolutely if you need to spend more time... you spend that time. Cause it's important that patients need to be told at their level of understanding. Most of

them don't and you need to follow them up. (Matthew, General practitioner)

General practitioner George also discussed the issue of time in the excerpt below. He posits an argument where he differentiates between enough time for legal consent (where enough information is given to the patient as required by law) and time for proper patient education. According to George, the current amount of time given to physicians to spend with the patient was enough to comply with the former of the two. However, as a general practitioner, he was in a position to give the patient time to think, by offering multiple follow-up sessions. This helped George to form longer-lasting relationships with the patients.

Time...you don't have as much time with the patient as you would like... I think you can. What's enough time mean? Is it enough to get consent to do it legally? Then yes. Is it as much as patient seem to want most of the time?... Probably if I had more, would I use it? Definitely. Would the patients like it if I had more? Definitely. In general practice at least I could tell them we don't have much time right now, but we can meet again next week and chat about it in more detail, so the follow-up time is much shorter then with hospital. I could see the same patient every day if I wanted to. (George, General practitioner)

5.3.1.1.2 Psychological impact of lack of time on physicians

Consultant cardiologist Melanie comments on the difficulty she faces at the thought of having to do a first consultation with a new patient as it would take her at least 20min, expressing her emotions by saying, 'my heart almost sinks'.

For some reason, as doctors we never got it right, but I have been in medicine 20 years and it still doesn't feel. I think it's partly a time issue, erm... the other thing about warfarin is the discussion is so time consuming and to be fair to a general practitioner he does not have a lot of time to do it] [oh I'm very slow... I give the patient the time they need, which is not long clearly (laughs)... but... so if I see someone that I need to start on warfarin... my heart almost sinks... as its going to take 20 minutes. ATLEAST to get through it all. (Melanie)

Further, Melanie stated that because of the lack of time, patient education would be limited by the amount of information they can absorb. To counteract this, she suggested the use of literature within the clinics or the use of specialist nurses; however she re-iterated that the lack of time was a barrier that every health professional faced. Prompting the notion of whether it was more an issue of lack of staff rather than available time.

Well since it's new news... I don't think they take in half of what I have said. Erm... but then again in the old days, he'll go to the anticoagulation clinic and he'll get the message repeated AGAIN... and that would've helped and then they get the booklet. So there is a lot of backup. Maybe we need to think about having some form of literature in the clinic and we try to persuade our specialist nurses to be more involved with this... but everyone is so busy already... its quite difficult. (Melanie, Cardiologist)

Consultant cardiologist Peter also experienced this issue. Peter added the fact that apart from the burden of workload, even if he managed to find the extra time to spend with a first consultation, he was still concerned by the pressure from the patients waiting outside. This was due to a 'conveyor belt' effect where he believed that the patients perceived that they were just another number waiting in line and thus vented their frustration through complaints to the system, which in turn placed more distress on the physician.

I think that one of the things is the national patient safety agencies are just... it requires extensive education about warfarin... erm... I think that if I actually write to my haematology colleagues... and say 'Can you initiate warfarin?' they would tend to go over the yellow book with the patient and you know... if physicians have to do that, erm... then again it might sort of tip the balance, you know... you need 10 to 15 minutes running over this with the patient, which of course if it's an important thing in the patient's lives... it's not unreasonable in general terms... but the way ward rounds and clinic works in the NHS, it is difficult to find that extra 10 or 15 minutes, when there is a queue of patients outside the door, getting a bit irate (smiles) (Peter, Cardiologist)

5.3.1.1.3 The importance of continuity

Since follow-ups were easier to conduct with general practitioners, they had more time to spend with patients. Furthermore, because they knew patients for a longer time general physicians were in a better position than other hospital physicians when it came to familiarity with the patients. Consultant cardiologist Melanie commented that one of the main challenges she faced was her limited knowledge about the patient's life. Thus, Melanie was influenced, by this lack of knowledge on the patient, not to prescribe warfarin if she was not sure about the patient's background, especially as she did not want to cause more harm by prescribing warfarin to a patient who might end up not adhering to treatment and cause bleeding.

I will always err on the side of not giving warfarin if there are falls. As I see too many people with head injuries and intracranial bleeds] [their GP... I think via the GP... not much helpful is the wrong word, but I am not sure how much, how much they feel they have input in these decisions.] [Yes I think they should do. I think GPs should... they know the patients better than I do, they know whether they take the pills, they know what the family circumstances are. I don't what worries me is also patients who have a habit of taking over the counter medications] [it is a decision that is better made by somebody who knows the patient. That's a barrier to me prescribing it. I would probably not prescribe it and erm... I would always err on the side of not prescribing... maybe other people don't, on the basis of first do no harm. But if I knew the patient, I may well be able to make that step... (Melanie, Cardiologist)

In addition, registrars also commented about the lack of knowledge on their patients, especially because of the lack of continuity. Registrar Jeffrey interlinked the issue of continuity and time pressures in secondary care, forming a vicious circle.

I think maybe this highlights that continuity is important. I think that is one of the problems in the health services especially in the hospital setting. Each time a patient comes to the hospital, they don't see the same person. I think that is the difficulty. Cause it is going back to TIME pressures. (Jeffrey, Registrar)

Registrar Chan's view on the subject agreed with that of Jeffrey. He argued that for hospital physicians it was difficult to build rapport because of the lack of

continuity. This in turn had an effect on the shared discussion that the hospital physicians needed to conduct with the patient.

I think it is important to develop a relation but unfortunately we don't get as much follow ups to build such a relation. With the new system it's being lost more and more. Because most of the patients just go and see the GP. We only see them once or twice.
(Chan, Registrar)

Registrar Ted further discussed how the lack of rapport had an impact on the discussion with the patient. He commented how his patients preferred to consult with a GP 'who's known me for 20 years', showing the difference between the patient physician bond in primary and secondary care. This was similar to what some patients, like Josephine mentioned, where they mentioned that they had a strong rapport with their GP. However, what Ted proposed was against what general practitioners mentioned that patients perceive the hospital physicians as the experts.

Sometimes patients don't want to commit to you, to take warfarin. They say I hear what you are saying... but I'd rather talk this through with my GP who's known me for 20 years. And that's absolutely fine. (Ted, Registrar)

Similar to the other general physicians, Tom also pointed out that other health professionals were an unexploited asset in patient care. He commented how his responsibility towards the patient ended with the consultation as he did not do follow-ups. However since GPs follow the patients more often, he argued that they should be "responsible long term" for their treatment.

R – erm... you think other health professionals could have a role in warfarin management or education?

T – Yes... they probably disagree but GPs or pharmacist, have more time to do things. For example I only have a couple of minutes in the ward round. I'm sure they have more. Plus this is a fluid decision. This could be reviewed every time they see them. One might think it is safe now, in two years' time, they may reach a point where it's not safe. And they [GPs] are the ones who review this and say 'now I think we should get you off the warfarin' or 'now it's time we should start you on warfarin again'. So yes

they should. They should be responsible long term. We may never see them again. (Tom, General physician)

Similar to other General physicians, Manpal pointed out the role GPs could have in influencing warfarin prescription.

GPs should have a huge responsibility about these kind of things as they would know the patient for a number of years, so they would know more. Erm whereas we see them once, twice, maybe three times. That's it, we might not see them again. Or we might see them for another medical condition... so GPs are central to this and they need to help us when deciding whether to put them on warfarin or not. (Manpal, General physician)

5.3.1.1.4 General practitioner's perceptions of their own role

Conforming to the perception put forward by the cardiologist, registrars and general physicians, all of the general practitioners mentioned that they felt they had more concrete knowledge of the patient's background and stronger relationships with their patients than hospital physicians. General practitioner Samir argued that since the patients can see the same practitioner, this ameliorated the rapport between them. According to Samir's experiences a general practitioner would also be knowledgeable about the patient's social history and support systems and how these could influence adherence to medication.

S - In our chronic disease clinics... the people with AF on warfarin will see the same practitioner.

R – yes and would that have an effect on their relationship?

S – yes exactly it's a very good system... helps build a very good relationship] [I know how they live, where they live, their family members, what support system they have got. As well as the medical history I know their social history. (Samir, General practitioner)

Likewise, general practitioner Matthew argued that knowing the patient's background would influence him in deciding against warfarin if social factors demanded so. Matthew pointed out that the knowledge that general practitioners possess about the patient was different than that of hospital

physicians, thus it provided him with a better judgement on the patient's ability to adhere to treatment.

If they've got co-morbidities or a little bit older that might sway you a bit more towards... I'm worried a bit about compliance here, I'm a little bit worried about are they going to get their blues and brown tablets mixed up. So that is probably my... physician-patient knowledge about the particular individual which is probably different to someone at the hospital who doesn't know that background. (Matthew, General practitioner)

In the following excerpt, general practitioner George agreed with the rest of his group when talking about his knowledge of patients. However, George also pointed out that even though general practitioners were more familiar with the patient than hospital physicians, they were not comfortable in conducting a warfarin risk versus benefit assessment.

[I think] GPs are more likely to know the patient's social background or the way that the patient's health seeking behaviour generally and I think GPs are in a better situation, NOT ALL THE TIME, most of the time... GPs are not as used to working the benefit versus risk in patients. (George, General practitioner)

5.3.1.2 Language and cultural barriers

Since Birmingham is a multi-cultural city in the UK, the majority of the physicians mentioned that they faced several language and cultural barriers when it came to communicating information to patients from minority-ethnic groups as often they were not able to communicate directly with the patient but through an interpreter. Furthermore, when interpreters were used, the physicians felt that, the message was lost in translation. This was evident in what cardiologist Melanie stated in the quote below. Melanie seems to be saying that she felt a higher cultural affinity with white people than other ethnicities because of the common ethnicity and language.

In our populations that is a bit tricky. And of course we haven't even started to mention, but I can't communicate in this way with half my patients, so you sometimes need an interpreter, which is, I find it really hard, because you can't get the patient's real feelings

for it] [if I had an elderly Caucasian man in front of me, I would pick up a lot of non-verbal cues as to what why he doesn't want warfarin, what he's thinking and how to get around. Yes... but I wouldn't necessarily know all the cues, or interpret them appropriately (with other ethnicities). (Melanie, Cardiologist)

Later Melanie also talks about her connection with her Asian patients. Melanie points out that she does not have the same language and cultural link with Asian patients as she has with her own ethnicity. She emphasises the obvious language issues which can be overcome with an interpreter. However it is through repeated clinical practice with ethnic patients that she is able to understand some of the cultural nuances.

You really need to be able to switch on who they are and where they are coming from to get them to understand it. And erm... and mostly our population are usually erm... the older patients are generally English Caucasian, so whereas now we are getting a bigger cohort... And I find that families... in the Asian cultures for example... the older members of the family, won't do a thing without the younger members saying that's the right thing to do... (Melanie, Cardiologist)

Cardiologist Sean went on to add that during his medical training years, when he used interpreters or family members to translate what he was trying to say, the message was also being lost. Sean's anecdote also highlights the need for additional time when using an interpreter. In addition, there is an issue of trust between Sean and the interpreter as Sean cannot understand first-hand the patient replies. He has to trust the interpreter to be translating 'properly' which would be impossible to judge if he does not know the language. Sean later stated that after learning some of the Asian dialects aided him both during the diagnosis and in having a compliant patient, thus implying that the consultation could adopt a more negotiated style rather than a paternalistic approach. However in the last sentence of this quote, Sean still used phrases such as 'take the medication that you need them to take' referring to a paternalistic approach to decision making.

S - What I found is that even if you use the relative as for translation or even trained translators, the message is lost. Initially when I first became a physician I used to use translators or relatives. And I found that what they... erm my explaining to the

patient relative then the patient's relative to the patient and then the patient back to the relative and then the relative back to me... there was so much loss of the message that it became pointless. And you can well understand that if you do not understand somebody's language... we have a lot of eastern European patients here as well and I don't understand for example, Polish. And therefore I have the same difficulty in that context. But the majority of patients are either Afro Caribbean, and I grew up in an area where there was lots of Afro-Caribbeans so I understand the dialect. Erm... and most Asian languages I speak as well... so it transforms the consultation, firstly it takes less time. Because you are not going through a...

R – yeah a bridge

S – but also you can explain things in a much more detail and if the patient understands that you understand, then they are more amenable to take the medication that you need them to take.
(Sean, Cardiologist)

Registrars' accounts also highlight the mistrust in interpreters' abilities to convey their message. Dheepak argues that an interpreter may not be as committed as the physician in putting the same emphasis on the important risks involved with AF or the treatment involved.

I think the emphasis you give on certain things, may not be appropriately conveyed to the patient. Particularly in the necessity of stroke prevention. I feel that the interpreter is not putting as much emphasis I would want to try to pass on to the patient.
(Dheepak, Registrar)

However, registrar Chan pointed out that in his experience, using a professional translator was better than using a family member. He emphasised the importance of translating correctly the medical terms, something which a family member might not be knowledgeable of. The mistrust in the interpreter's ability to transmit the discussion to the patient was also shown in general physicians. Some physicians were advantaged when speaking with Asian patients as they knew some of the dialects. Manpal argued that if he knew parts of the language, it was preferable for him to talk to the patient rather than involve an interpreter.

That's where the difficulty comes in (patients with different dialects of Urdu). If that does happen, you either get a family member involved or you get a translator there, to help you.] [Always a risk.

Stuff can get lost with translation, so that's why I prefer to talk myself rather than getting a translator. If I know the language or some parts of it (Manpal, General physician)

The experiences of the physicians show that communication during the consultation was more than just the use of different languages. Physicians are showing that because of the cultural difference, communication during the consultation had to change with the addition of an interpreter as the rules of reciprocity in normal conversations, the direct eye contact, metaphors, and analogies used naturally in conversation between the physician and patient get pushed aside. This has an impact on the relationship with the patients because these restrictions weaken the normal interactions. In the long excerpt portrayed below by general practitioner Matthew, similar language challenges were experienced, emphasising the multi-cultural side of Birmingham. However, on being prompted on the effect of this barrier on the patient-physician relationship, Matthew stressed that an interpreter during the consultation is an issue of concern for him as he feels uncomfortable exploring certain issues which he believes would be distressing for the patient.

M – I am lucky that I know several languages of this area and that stroke is stroke no matter which language it is... but lately we've been getting a lot of Eastern-Europeans and Somalians which I don't know the language. In that case you have to use an interpreter and things get lost during translation and you worry if what you told the interpreter is being told the same way to the patient.

R – And you also mentioned the relationship built between you and the patient several times as well... does the fact that you have to talk through an interpreter affect that relationship?

M – always... forget about AF, put that to one side... generally speaking when you are trying to have a consultation with a third person there, there are disadvantages, the whole conversation gets a bit uncomfortable. It's not the ideal scenario. And sometimes you also avoid asking intimate questions that could be relevant because of another person being there. So a good example of that would be erm... erm... get a lot of patients with blood pressure...and you want to talk about impotence for example... as a side effect and you can't because of the third person. The patient may not feel comfortable talking about these sort of things. (Matthew, General practitioner)

Like cardiologist Sean, general physician Tom argued that language barriers could also influence the physician to take a similar paternalistic approach. Rather than going through the “hassle” of checking if the patient understood him, Tom took a more direct approach in decision making, opting for a paternalistic at the detriment to the patient’s right for education.

T – Oh that would mean the use of an interpreter. This isn’t just to do with AF, this has to do with everything. It’s not as good. It’s not the same conversation. All you could do is say a few statements, they are interpreted, and you don’t get much back. This is not as easy.

R – So meaning gets lost in the translation

T – Yes... definitely. And then in that case, we end up doing the decision. We try to involve the patient but when you are using an interpreter, you end up saying ‘so we are going to do this, do you have any questions’ and that’s it (Tom, General physician)

In addition, this impact on the approach taken by the physician was something experienced by primary care as well. Conforming to the challenges lived by the cardiologists and general physicians, general practitioner Samir also pointed out the inevitable use of a paternalistic approach to decision making with patients who speak other languages.

R – Erm... do you get patients that speak languages that you don’t know?

S – Yeah, Chinese, some of the Arab languages, there we rely on the family members or translators. And it is much more difficult.

R – And what do you feel?

S – I don’t think the message always gets through.

R – So patients with other languages get less information?

S – yesyes inevitably...

R – with regards to decision making

S – it will be very difficult to get what they are thinking, most of the times you end up deciding for them (Samir, General practitioner)

5.3.1.3 Adhering to guidelines

Physicians commented on how they are usually influenced by evidence-based medicine rather than their own opinion or hunches. Most of the cardiologists

mentioned that they either followed the NICE guidelines in deciding whether warfarin therapy is recommended or stroke risk scoring systems such as the CHADS₂ score. Sean's interview was later than the other cardiologists and in that time a new acronym was developed. It was interesting to note that after only two weeks that the acronym was published; Sean had already started implementing it in his consultations. This quick uptake of the new scoring system was probably influenced by the fact that he works closely with one of the authors of this new stroke risk score.

R – [yeah]... and erm... now you mentioned and even before you mentioned it. The CHA₂DS₂-VASc... and that before there was the CHADS and now it's updated... erm how come you started using the CHA₂DS₂-VASc rather than the CHADS

S – erm because as times go on, things get refined. So it was the CHADS₂ score, then it was the CHADS₂ score, then it's been refined even further] [this is why the CHA₂DS₂-VASc score has increasingly put emphasis on people ending up on warfarin which basically... if you have any risk factor, you will end up on warfarin.] [I think you have to (be influenced by evidence) because otherwise, if for example you manage somebody based on your opinion and there is a problem, then people can argue. Because the opinion is yours... it belongs to you. It's your entity. Somebody else's opinion may be different to yours. But if you base your opinion, based on, on the evidence base. Then it's not your opinion any more. It's the opinion of experts or peers in the field. Erm and therefore if somebody argues you can say... look according to such and such and such society guidelines or according to such and such erm research study... we elected to manage you in a particular way but it's based on this evidence. Therefore it's a much more difficult for them to challenge your decision making. (Sean, Cardiologist)

At the end of this excerpt cardiologist Sean rationalised that the diagnosis needs to be evidence-based rather than on opinions because of the need for physicians to demonstrate they're up to date and practising within the guidelines especially when their decision is questioned. In contrast, cardiologist John pointed out that evidence-based medicine was only part of the physician's diagnosis. One also has to take into consideration the patient's lifestyle and how the system works. He argued, for example, that because there was the need of monitoring, warfarin would not be suitable for patients who are housebound and cannot regularly go to have their INR tested. John

emphasised the importance that a medical consultation should be a combination of evidence and experience aimed at the care of the individual.

J – sure... erm at the moment I use the CHADS₂ score that was invented by my esteemed colleague and erm...but I also am significantly influenced by erm... co-pathologies, structural abnormalities within the heart, any mitral stenosis would probably go for warfarin... so yeah it is a balance to be had but the CHADS₂ score is straightforward and allows us to choose. It's going to be a bit more difficult when dabigatran is available because it doesn't quite use the CHADS₂ score and erm... but that's the basic evidence that we use at the moment...] [Clinical practice, clinical experience is a combination of evidence and past experience so for sure yeah ABSOLUTELY... and knowing how the system works and doesn't work, there is no point in putting someone on warfarin if he cannot get out for blood testing for instance.] [well the evidence is one side of things, but you also have to put in the patient scenario, which does not always fit into the CHADS₂ score. Every individual is an individual by definition... (John, Cardiologist)

Unlike cardiologists, general physicians like Nilan, argued that since they have to be knowledgeable on a myriad of conditions and not just heart related, it was more difficult to remember and adhere to specific guidelines. Thus Nilan commented that in his experience it was easier to remember a short acronym like the CHADS₂ score rather than the complex and ambiguous table of the NICE guidelines.

I mean generally, to me, looking at NICE guidelines, I mean I find it very difficult, especially if you do not have it, it is very difficult to remember and then see what it is. What I tend to use is the CHADS₂ score, which is much more simpler (Nilan, General physician)

Similarly, general physician Balu voiced his dissatisfaction with the AF guidelines several times in his interview. However one can note, that initially he showed agreeableness towards the use of guidelines, but went on to emphasise the benefits other health professionals would reap from a simpler version. He argued that guidelines should be specific to the specialty of the physician.

To most people, they are confusing. Because there are so many cut offs, it's not simple. The defined asymptomatic and symptomatic patients, then you've got the paroxysmal, permanent, lone atrial fibrillation, to a lot of health professionals, particularly GPs, a. they don't have the time and b. it's too confusing, because it's not very simple to follow. That's my personal view.

R – So you think that simplifying or shortening the guidelines could be an easier way to put them? Or focusing the guidelines to the type of health professionals

B – That would be very useful. To cardiologists, you can make it as difficult or as complex as it is. But to general physician you can perhaps divide it into risk categories. But to a general practitioner, again it's a bit difficult. (Balu, General physician)

Further on during the interview, Balu reflected on this issue again, where he commented that in guidelines, a single cut-off which in this case is age, is difficult to apply to the individual patient. He pointed out the need to educate health professionals through the use of guidelines that are specific to each specialty.

Well it's by education, by making guidelines simpler and easy to use and by stratifying the guidelines, there should be 1 A4 page for an emergency department medical assessment unit, a different A4 for cardiology clinics, different A4 for general practice, and different one for general physicians. All probably saying the same thing, but the way it is being put across, the simplicity is the important point. (Balu, General physician)

The need for health professionals to be educated on how to adhere to guidelines was also picked upon by general practitioners. GP Matthew specified the need for health professionals' education with regards AF guidelines. In contrast, when general practitioner Samir was prompted on this issue, he argued that education should not be relocated to just general practitioners but also to secondary care. He felt that an important aspect that influenced patients' adherence to treatment is common knowledge between health professionals in different specialties. However at a later stage of the interview he also suggested ways in which this educational system may be broken down, wherein the guidelines would specifically suggest when to refer patients to secondary care.

R – Erm... and what do you think about the current guidelines?

S – I think the most important thing is that we have a responsibility that they agree across both primary and secondary care. So we can't have a disagreement. Otherwise the patient will think, who will I rather believe? So we all need to do the same thing. As long as we are doing the same thing... I don't mind.] [The beginning bit should be the same for both, the last bits should be different. So for example when there is a complicated consultation, for GPs it should say that at that point, refer to the specialist and then in the specialist bit it would include more detail. (Samir, General practitioner)

Cardiologist registrar Ted also commented about the ambiguity in AF guidelines. Ted pointed out that guidelines only took into consideration the biological aspect of treatment, while during diagnosis Ted suggested that other individual factors should be given equal importance, for example the individual's likelihood of falling.

Then the present NICE guidelines as you know are a little bit ambiguous and say that you can either go down the warfarin or the aspirin route. Sometimes you've got to take into account the other side of things. Like if they are very elderly, they are prone to falling... (Ted, Registrar)

Likewise general physician Manpal pointed out the difficulty in adhering to the guidelines and making decisions on an individual setting.

R – And erm... what do you think about the current guidelines of AF?

M – erm... you want my honest opinion (laughs) yeah you would]

[M – (Laughs) yeah yeah... it's just a national thing you know, that's why. I think AF is still a complex disease, still no one knows the perfect way of treating it. There are some guidelines out there. People still do their own thing sometimes. There is no right or wrong. I think and as you mentioned with the cases, every case is different. You have to risk assess them separately. And even within the cardiologists themselves they all disagree with each other as well sometimes. (laughs) so I don't think there is an actual perfect way (Manpal, General physician)

Later on, Manpal reinforced his argument by discussing how guidelines give a general solution which is difficult to apply to the individual, highlighting the issue that during the consultation, the individual patient might be different than the patient whose average characteristics are portrayed in the guidelines.

M – I don't think there is an easy answer, because there have been so many studies, so many different groups of patients have been studied. Do your patients fit into that group or not? That's always the difficult thing. Erm so I don't think there will be a clear cut answer for it. It's just gonna get more and more harder because more and more studies are coming out. Some conflicts, some support what previous ones have found out. (Manpal, General physician)

5.3.1.4 Information overload for the patient

According to physicians, educational information given during the consultation was critical to ensure that the patient was able to participate in a shared decision making process and to enhance adherence to treatment. However, physicians in this study, mainly general physicians and general practitioners, commented on the risk of providing too much information to the patients and how much of this information patients would be able to recollect. Interestingly patients in the previous study commented that they did not receive education on AF and OAC. It could be possible that although some patients were given education, they did not remember it due to information overload as suggested in this sub-theme. Concurring with cardiologist Melanie, where she commented that she is unsure whether patients remember all the information they are given, general physician Manpal, also discussed his awareness of evidence that had shown patients' limited ability to retain knowledge after the consultation, and questioned the usefulness of bombarding the patient with information.

Yeah usually I do make an effort to tell them all these things. The problem is how much they are going to retain. Studies have been done to show that patients probably only remember 20% of whatever you tell them (Manpal, General physician)

Similarly general practitioner Matthew pointed out that according to his experiences, in an initial consultation, the information that a patient would remember most was the name of their condition. He argued that since the patient was receiving important news they might be too distressed to remember what was said with regards risks and benefits to treatment.

I'm sure that if they walk out the door and see someone else and asks them, so what did the physician say, they would say, my heart is beating irregularly, I don't remember anything else. So you again, you telling them some profound news which they may or may not be expecting. (Matthew, General practitioner)

Following the model of concordance, where patients are given the needed time to reflect and discuss with significant others the information provided before taking a decision, general practitioner Matthew, remarked that patients needed time to understand medical information. Thus he used follow-ups as an advantage to give patients time to reflect and then discuss treatment later. However one must note that during the wait for this follow-up patients were still at high risk of developing a stroke if not commenced on warfarin.

Lots of patients need that time to digest it (information). That's why I always do that. Give them a leaflet] [you have to give them the opportunities to digest that information at their own pace and come back to you before you sort of... yes I've decided, you're going on warfarin. It's not like that. (Matthew, General practitioner)

5.3.2 Physicians' interpretation of patient related challenges

The second theme under the over-arching theme of challenges with OAC prescription for AF, explored the physicians' interpretations of their experiences of concerns relating to OAC treatment that were raised by their patients. Physicians reported what they believed were experiences that proved challenging to the patient, including the impact of blood monitoring, concerns about the side-effects and interactions of warfarin, how the patients' experiential knowledge had an influence on the consultation and the concerns raised by symptomatic and asymptomatic patients.

5.3.2.1 Impact of blood monitoring

Some patients in the previous study raised concerns about the regular blood tests required to check their INR as part of OAC treatment. Similarly almost all of the hospital physicians, particularly the cardiologists, commented that they

felt that patients were concerned about having to have regular blood tests, illustrated by the quote from cardiologist Melanie.

M - ... I think it's the blood tests that mostly puts them off

R – Do you think that is a barrier?

M – I think that is a huge barrier for most

R – The fact that they have to come in for the

M – Yeah they have to do the blood tests (Melanie, Cardiologist)

Registrar Ted agreed with cardiologist Melanie when he stated his assumption that one of the downsides of warfarin from the patients' views was the inconvenient frequent blood monitoring in the early stages of the treatment.

It's (blood monitoring) however inconvenient for the patient... having to have it monitored... initially quite frequently eventually, probably and hopefully about 6 to 8 weeks. (Chan, Registrar)

Cardiologist Sean also added that this was not only a hassle to the patients (which some the patients agreed with) but also had a significant financial impact on the health care system, where a specific service had to be employed to cater for the anticoagulation service.

The main downside of warfarin is the hassle of having to have it monitored. Erm... it's a hassle for the patient because they have to come to the anticoagulation clinic and it's erm... it has financial constraints, because you have to employ a service to look after anticoagulation and hence that's the downside to warfarin. (Sean, Cardiologist)

Like Sean, cardiologist Peter also pointed out that he perceived that the health care system was experiencing similar financial stressors. He stated that not all patients are mobile or have transport available to them, and thus ambulances had to be utilised, adding to the financial impact on the health care system.

Even now, patients in a lot of visits, although people say it only costs 300 pounds a year. Some of the patients need ambulances to get to the hospital to have the INR checks. I think domiciliary anticoagulation must be considerably more expensive. (Pete, Cardiologist)

General physicians like Nilan also experienced similar concerns. Patients, according to Nilan, would be more willing to accept warfarin if monitoring is done in their homes as it would remove the financial impact on the patient brought about by the increase in parking fees and public transport fares. The financial impact was also highlighted by patients in the first study, particularly by Lionel, when he commented on the increase of hospital parking fees.

Registrar Chan further added that he had experience with reassuring anxious patients concerned with travelling overseas when on warfarin. This argument was also brought up by one of the patients, Raj, who discontinued warfarin. One of the factors that influenced Raj to discontinue warfarin was that he believed he could not travel while on warfarin (see Section 4.3.2).

I've been asked are whether travelling is still possible. I tell them that INR management is standardised now... so it won't make a difference between a level 2 here and a level 2 in Spain or Portugal... so if anytime you're not sure and you need to check... then someone is going to be able to check it for you. (Chan, Registrar)

Registrar Ted comments that in his experience, patients might be concerned that blood monitoring would have an impact on their QoL by limiting their available free time. This was also commented on by patients in the previous study. Patients like Lionel commented how time was lost waiting in long queues at the clinic (see Section 4.3.1). However, Ted also pointed out that although in his experiences he perceived patients as being inconvenienced by monitoring, other patients found solace in knowing that they are within the therapeutic range of warfarin.

Some of them they tell you that they are going on a holiday and the blood monitoring would disrupt travelling, others would tell you that they are already having a number of blood tests for diabetes or kidneys or whatever... or going every 4 days to the GP because their INR is all over the place. On the other hand... you find some people that like to go to the GP often, because they get reassurance that their warfarin level is ok. So for some monitoring is a pro because of the reassurance they get. (Ted, Registrar)

Registrar Jeffrey also experienced similar time concerns as those pointed out by Ted. Jeffrey emphasised the issue that since most AF patients were older people they probably had other comorbidities that had similar monitoring issues. So when a physician prescribed a medication that needed monitoring, such as warfarin, Jeffrey believed that the patient perceived it as an extra encumbrance. Furthermore, Jeffrey's perception was that the older person found the constant travelling to and fro hospital as a major inconvenience.

I think the older ones... erm are worried about the blood test that they need. Because a lot of them go to different outpatient clinics for different things and they spend half their life going to clinics and to the GPs. Some of them see it just as an extra thing. It is a big deal for them. If you tell them you need to go see the anticoagulation clinic, you know... ultimately maybe only once a month... but it's still a big ordeal for an old person. It's a big ordeal for them to go to the hospital, get the bus, park, wait around... there are always delays... it is a big deal for them. I think a lot of people think that having a lot of blood tests is just too much. (Jeffrey, Registrar)

In contrast to hospital physicians' (cardiologists, cardiology registrars and general physicians) interpretations of their patients' experiences, general practitioners commented that their patients did not appear to them to be concerned by blood monitoring. General practitioner Matthew commented that regular monitoring was a normal routine for older patients.

Many of these patients are used to coming, cause of the comorbidities, they are used to having blood tests and used to being monitored on a regular basis for certain things on a regular basis. So it's not a big thing from that point of view. (Matthew, General practitioner)

In the following quote, General practitioner Nick, added that concerns around routine blood monitoring dissolved once they had an actual experience of the anticoagulation clinic. Thus, pointing towards the notion that general practitioners' patients changed their perceptions and concerns of blood monitoring once they had experienced the clinic first hand.

Most of them, by the time they've seen the cardiologist and been to the anticoagulant clinic... erm I would say most people feel comfortable about it... well it is slightly an unnerving experience starting life on warfarin. But I think they feel reassured by the monitoring (Nick, General practitioner)

General practitioner Samir argued that since monitoring of OAC treatment had started in his general practice, patients did not have negative associations. Samir pointed out that patients associated monitoring in the hospital with long waiting queues (as pointed out by some patients in the previous study as well), which could explain the cardiologists' interpretations. Patients might feel like on a 'conveyor belt' in a hospital environment, while at the general practice Samir explained that the experience was different.

It is interesting now that more and more now, as we offer it locally, more of them are happier to come here than to go to hospital. I think the bad thing they hear is the long waiting queue in hospital and in clinic and they get results on books and have to come back you know. Whereas at the surgery the experience is different. There are set appointments, they come in, give them the results and that's it. (Samir, General practitioner)

5.3.2.2 Side-effects and interactions of OAC therapy

Physicians in this study commented on their interpretations of what they perceived as patients concerns with regards to side-effects and interactions of warfarin. One of the side-effects of warfarin that physicians believe is commonly raised as a concern during the consultation was the risk of bleeding and bruising because of the thinning of the blood. Registrars pointed out they believe that bleeding was one of their patients' main concerns as can be seen in registrar Chan and registrar Jeffrey's quotes below.

They generally worry about the risk of bleeding. Erm... that's the main one. (Chan, Registrar)

People do worry about bleeding. I think that is a significant concern for a lot of people. (Jeffrey, Registrar)

Cardiologist Melanie said that gentlemen in her practice complained of bleeding from cuts when they are shaving, showing the impact warfarin have on these patients even in minor everyday life situations. Furthermore, Melanie added that female patients often complained about age spots and rusty coloration of the legs. This meant that according to her, even minor bleeds and bruises in visible areas could be having an impact on the patients' perceptions of warfarin.

[It's the bleeding]... they also don't like, particularly the gentleman, they don't like I when they are trying to shave... they get... they get cuts. And the women don't like... the age spots get worse. They say... they come and say I got this rash which is getting worse and I also do think that the other red... the sort of rusty coloration of the legs with patient's high venous pressures, I think that does get worse with warfarin. And that makes sense because that is due to capillary rupture and the leaving of haem in the cell. And that would make sense because they are more likely to rupture... well rupture, but ooze. So that makes it worse] [yeah, a lot of patients, they... look for any reason to come off it. They have gone on it reluctantly and you know they are gonna come to you to take them off. (Melanie, Cardiologist)

However, although she found a medical explanation for the possible colouration and hair loss in patients, she often dismissed the patients' concerns as excuses that patients found in an attempt to stop taking warfarin. Similarly, in the quote below from cardiologist Sean, rather than attributing bleeds to warfarin, Sean attributed the causes of bleeds to other external factors which are in the patients' control.

Erm it (warfarin) doesn't cause bleeding by itself but if they were to bleed for another reason, then any bleed that would occur would be heavier. (Sean, Cardiologist)

In contrast general physicians and general practitioners did not explore bleeding as a major concern like the cardiologists and registrars did. Other challenges presented by patients, as perceived by the physicians, that influenced warfarin prescription with regards side-effects of warfarin were the numerous interactions warfarin had with various other substances. These included vitamin K, which was found in green leafy vegetables as well in food supplements, alcohol and other drugs. The interaction of OAC with food and

alcohol was also commented on by some patients in the previous study; however it was only expressed as a minor concern. In the following extract, cardiologist John highlighted a misconception with regards to warfarin and vitamin K consumption. He said that in anticoagulation clinics patients are told that there are certain foods they shouldn't eat, which confused the patients especially since the same foods that are being stopped are the foods the NHS was promoting as "super-foods" in the "five-a-day" campaign.

J –In the warfarin clinic they tell them that there are certain foods that they don't like them having. So they also complain that they can no longer have broccoli and other things that they very much enjoy. And these are of course foods, super foods that we are pushing as health foods

R – yeah and with the five, five

J – five a day yeah exactly... so a lot of them don't like that. (John, Cardiologist)

This was also similar in cardiologists Melanie's experience. She commented that her patients were accustomed to buying several over the counter medications and vitamin supplements. Thus during her consultation she needs to take extra care when discussing warfarin treatment.

So I get some ladies that come in and I say what tablets are you taking, and I say well that's ok... they come with a bag full of tablets and I say... show me and they start emptying them, and I say no no, you can empty the bag on the desk... and I say what are all these, and they say oh yeah, that's my vitamin, and so you have got to be really careful. (Melanie, Cardiologist)

Cardiologist Sean explored the issue of alcohol consumption. He argued that in the current society, excessive consumption of alcohol was fairly common and this could interact with the chemical pathways of warfarin, possibly making the blood thinner and increasing the risk of bleeding. Later, he divulged that with patients who did not agree in lowering their consumption of alcohol, he did not recommend the use of warfarin as it would cause them more harm than benefit.

I had patients who have been drinking excessive amounts of alcohol and you say look. It would be difficult for you... for example I had a gentleman who drank nothing during the week and on a weekend consumed maybe 30 or 40points of alcohol.

Now that fluctuating level of alcohol does cause serious fluctuation in anticoagulation. *So I explained to him that this kind of drinking pattern firstly wasn't good for him anyways and particularly wouldn't be good if he was on warfarin and therefore he elected to not go on warfarin* (Sean, Cardiologist)

The above anecdote brings to the forefront the experiences from one of the patients in the previous study. Greg, whose AF was caused by excessive alcohol (which he later stopped) commented on his perception of the cardiologist's behaviour in his consultation. Greg mentioned that according to him, his cardiologist was less empathic of his feelings and his problem with alcohol, and more interested on starting him on a clinical trial with a NOAC. On the other hand Sean had a similar experience with a different patient. However in Sean's anecdote, as the final italic part of the above quote, firstly addressed the patient's problem with the alcohol and then addressed the influence of alcohol on warfarin.

Registrars also underlined that alcohol, apart from being perceived as a patient related challenge; they also perceived it as a patient concern. Registrar Dheepak commented that his patients were concerned by the fact that alcohol can cause interactions with warfarin. Thus he emphasised the need for appropriate patient education on alcohol interaction during the consultation.

For some reason they are always concerned about the alcohol. Because they are aware that it would cause trouble. (Dheepak, Registrar)

As mentioned previously, unlike the physicians' perceptions, although patients in the previous study expressed only minor concern with regards to food and alcohol, it was not an issue that influenced them in accepting or refusing warfarin.

5.3.2.3 Asymptomatic vs. symptomatic patients

Most of the participants discussed the differences in recommending warfarin to symptomatic and asymptomatic patients. Physicians know that OAC treatment will not have any effect on AF symptoms and it is recommended whether the

patient is symptomatic or asymptomatic because stroke risk is not dependent on the presence or absence of symptoms of AF. However since asymptomatic patients did not feel any symptoms from the AF (such as the irregular beating of the heart, palpitations, breathlessness, fatigue), physicians believe that patients often find it difficult to accept a life-long medication with potentially serious side-effects, for a condition that according to them, they would not see any tangible benefits. Cardiologist John went on to state that prevention was difficult to explain to patients when there was no link. In the below quote, John also pointed out that with asymptomatic patients, education on the risk reduction with warfarin was critical in increasing adherence to treatment.

J – erm most of the patients surprisingly are asymptomatic and erm... yeah you know when you say you are going for a drug for a long time if not forever, and these are the reasons why, it's quite an undertaking to put someone particularly on warfarin erm who... is entirely asymptomatic, who now is gotta have to come to the hospital every 4 to 6 weeks forevermore or at least until dabigatran comes. So for them it's a big undertaking. So they have to realise the reasons why they are doing it, the stroke risk and the reduction of stroke risk with warfarin therapy. It's quite a big undertaking

R – Cause they don't associate kind of the medicine with something they can feel

J – Prevention is much harder to convince patients to erm... than link... once they had the mini stroke or the stroke, erm it's much easier to convince them to take warfarin. But if they do not have any symptoms, it's very hard to convince them. (John, Cardiologist)

Likewise Cardiologist Sean stated that when asymptomatic patients received their medication, they only perceived the disadvantages of the medication rather than the benefits. This was something that physicians were aware of and concerned about when communicating the need of warfarin to patients.

Somebody who is asymptomatic and therefore you give them the medication and the medication gives them side effects, they only perceive a disadvantage to being on medication and therefore compliance might be an issue. (Sean, Cardiologist)

Similarly, general physician Manpal discussed the issue of warfarin acceptance by asymptomatic patients. One can note Manpal's concern and frustration from

discussing appropriate treatment with the patient, when he used the phrase “a bit harder to convince”.

M – Yeah I think, the symptomatic ones are probably more amenable to have treatment, because they have symptoms. Asymptomatic patients ‘why should I have warfarin with the risk of bleeding and all the other complications, and have to have lifestyle changes’ so a bit more harder to convince the asymptomatic group as compared to the symptomatic group.

R – Since they never had experiences of symptoms?

M – Absolutely, since it doesn’t bother you, why should you take medication. It’s all about primary prevention. (Manpal, General physician)

In agreement with general physician Manpal, general practitioner Matthew compared the discussion he conducted with asymptomatic AF patients to other asymptomatic conditions such as hypertension. Matthew was pointing towards the crucial role that education and communication skills play in explaining the benefits of warfarin.

Blood pressure is another example... where patients are asymptomatic. They don’t feel any problems. It’s the same with some of our AF patients. They feel fine. You pick it up on an incidental ECG or what have you or check the pulse. And erm, the concept is slightly different in trying to erm go through the benefits long term benefits. Erm... potentially giving them drugs that will make them feel unwell and require a lot of monitoring in particular and lot of input from us. And what the benefits for them as an individual are. The blood pressure is slightly easier, because you can sort of say, you’re going to have a heart attack, and you know... you’re reducing the risk of that. With AF, it’s a little bit more grey area. Because of the side effects of warfarin and they are much greater, and the risks are much greater. (Matthew, General practitioner)

Cardiology registrars, like Chan in the excerpt below, commented on the difficulty of diagnosing asymptomatic patients and the distress this causes to the older patients because of the repeated tests.

Problem with asymptomatic patients is you can’t tell when AF started.] [Asymptomatic ones are very difficult. Sometimes you end up doing a number of 24hr tapes just to make sure that there isn’t any other paroxysms of AF. (Chan, Registrar)

Similar to registrars, general physician Nilan highlighted the anxiety asymptomatic patients go through during their consultation. Since they did not feel symptoms, discussing risks brought about by AF caused anxiety in the patients because of the unexpected severity of the situation. Furthermore, while other patients were assured that warfarin can lower the stroke risk, asymptomatic patients get more anxious as they perceived only the bleeding risks associated with warfarin.

Some of these patients, you know, you see them in the TIA (transient ischemic attack) clinic or in the clinic, they had it... they just started or its new and they are rate controlled. So they are not symptomatic from it. So that's why when you try to tell them that there is a risk that you can get a stroke. THEN they get worried about it, and then you say yes you can get a stroke. Therefore you should be getting warfarin. THEN they get more worried about it. (Nilan, General physician)

General practitioner Nick further emphasised the importance of reassurance with asymptomatic patients in the initial stages of the consultation. Furthermore, Nick was showing that asymptomatic patients might be more anxious than symptomatic patients in these initial stages of the consultation.

I suspect that its patients who are asymptomatic, and the lone fibrillators and so on, who are gaily going through life and then suddenly something is found, may be a little bit more disconcerted and need a little bit more convincing on the significance of their illness (Nick, General practitioner)

5.3.2.4 Physicians' perceptions of patient's experiential knowledge

Since AF is a heart condition that is most common in older people, and given that warfarin had been around for the past 60 years, most of the physicians' patients had family members or neighbours or friends who were taking or had taken warfarin. Physicians believed that the experience of these family members or friends often influenced the patient's perceptions. This was something that was experienced by most physicians in this study. They talked about the difficulty in prescribing warfarin to such patients who already had 'a

priori' knowledge of the possible course of the treatment. Cardiologist Melanie argued that she found it hard to persuade these patients to take warfarin. So, like the general practitioners, she preferred to give the patients time to think about their treatment decision and discuss the issue again during a follow-up. She argued that patients had all these misconceptions because warfarin is a well-known drug and compared it to digoxin which was usually given alongside warfarin. She believed that her patients did not complain in the same way about digoxin, as it was not a well-known drug like warfarin.

Well some of them say I'm not having it. My friend has it and it was not good for her or whatever. And you cannot persuade them. But then you can say that despite explanation... I usually tell them, have a think about it, and we'll talk about it next time you come and you know, just leave it like that. Erm cause quite a lot of older people don't want to come on it] [lay people do know about it, cause so many of their friends are on it. And therefore the sort of whispers about what happens in medicines... so sometimes they need a long time to think about it. You don't get the same problem with digoxin, which is used alongside it, cause they don't PERCEIVE THAT as a drug with problems because they don't know what it is. (Melanie, Cardiologist)

Similarly the patient Josephine commented that because warfarin was well-known, patients might already have formed their own perceptions about it before the discussion with the physician. Conversely, cardiologist Peter blamed the negativity of patients on the lay press and other health professionals who exaggerated the risks involved with taking warfarin. The patient Raj, from the previous study, took a similar stance. He argued that patients should not believe everything they read but rather question the information they are presented with. Cardiologist Peter also mentioned the possible lack of knowledge that non-specialist physicians have.

Patients will vary in perception. As patients do frequently look at individual experience and you know, if a relative or a friend has had a certain treatment and it went well. They say oh yes of course my neighbour had an angioplasty and if they happen to know about somebody who has had a bad experience for example a patient went to have a bypass graft, had complications and died. The same applies to warfarin. People have heard of friends or relatives on, and some patients are positive about it, but there is

quite a lot of negative vibes about it going on] [I think that doctors and as well as the lay press may again exaggerate the risk of warfarin so some patients are negative] [Another problem is that sometimes it's not even clear to the doctors... people do think that aspirin is a suitable alternative to warfarin... I don't think it is but, there is a wide spread perception, including amongst some non-specialist doctors that it is a suitable alternative... (Peter, Cardiologist)

In addition, registrar Chan commented that when the patient had 'a priori' knowledge of bleeding in relevant others, the patient formed a strong negative association to warfarin.

Sometimes patients tell you my wife or my relative died because she or he was on warfarin and bled to death. I'm not going to have the warfarin at all (Chan, Registrar)

Conversely to the above statements, cardiologists, such as Melanie's excerpt below, also stated that 'a priori' knowledge could even work in favour of the consultation.

Well the positive side is that sometimes you get patients who had a positive experience, oh yes my dad was on that and it was fine, or my husband took that for years before he died. There is a familiarity with it... it can be a good thing, not necessarily a bad thing (Melanie)

Like cardiologist Melanie's experience, registrar Ted also pointed out that perceptions based on 'a priori' knowledge varied according to the experiences of the patients. These perceptions in turn influenced the discussion on warfarin and therefore the readiness for concordance with the physician's suggestion.

I suppose it depends on if they know friends, relatives who have been on it who had a good experience. Then they'll already... be erm more willing to take it.] [you often have patients who say that my grandma was on warfarin, didn't get on with it at all, had lots of side effects, so I'm not taking it... so you definitely do come across patients like that. (Ted, Registrar)

Conforming to Ted's arguments, as shown in the previous patient study, past experiences with stroke or bleeding had an influence on the patient perception of warfarin. Registrar Dheepak also believed that patients' perceptions of

warfarin were not always negative but influenced by other's experiences. Dheepak pointed out that the experiences of new patients with warfarin, influenced the experiences of the possible future generations. Suggesting that raising awareness of warfarin could help in alleviating the negative perceptions. Raising awareness of warfarin was also something suggested for the same reasons by patients in the previous study.

D – I think it's when they have heard about it... sometimes it's bad, sometimes it's good news... it's about 50/50 I think.

R – Cause you get some patients that heard kind of positively about warfarin?

D – Yeah exactly... so erm... people who had bad experiences, have pre-fixed ideas. This in turn influences on people who they talk to. Especially if they are family members or close relatives. (Dheepak, Registrar)

General physician Nilan added that he encouraged relatives to come to his consultation with the older person. He argued that sometimes the relatives accompanying the older person had researched the condition on the internet. Nilan found that according to his experiences this ameliorated the discussion for the choice of treatment, and helped understand the rationale for need warfarin.

Some of the patients are older patients, and they come with relatives. The advantage of that is... you find that the majority of the relatives have been to Google and they know more than what you are expected to know. So in a way it makes your task slightly easier, they go 'oh yes yes'. So when you tell them it's irregular, they say 'yes yes I read it, it's atrial fibrillation' and then you say there is a scoring for it to find out how... CHADS₂ score to find out what your risk of stroke, 'oh yes I looked at that and I scored myself as two' and then I say ok look, there are these drugs that we can give to you and there is the risk so... In some ways it makes an advantage, but certain times, they ask 'yes I have read' or 'I've seen on the internet, you know, that you can give (Nilan, General physician)

5.4 Conclusion

The lived experiences of physicians (consultant cardiologists, consultant general physicians, general practitioners and cardiology registrars) during their consultations with patients who were diagnosed with AF and the physicians' experiences with OAC prescription were explored. The medical consultation model that seemed to transpire from the interviews with the physicians, was similar to a shifting paradigm. The initial section the consultation focuses on a patient-oriented communication style where physicians aspired for patient adherence. Good and effective communication skills were imperative during this part of the medical consultation. Assurance and patient education was also critical; this was enhanced with communication aides such as drawings of the heart and the use of metaphors. However, the use of drawings or the use of statistical figures was an individual preference in physicians, with general physicians opting not to use drawings to explain AF (however they pointed out that they do use pictorial aids for other conditions) and cardiologists and registrars mostly mentioning percentages to patient. General practitioners were especially adept in assuring patients, mostly due to the fact that they might know the patient from before and thus may have a stronger or more familiar patient-physician relationship.

In line with a shifting-paradigm model, the second part of the consultation revolved around decision making. During this part, the consultation, adopted a physician focused communication style where physicians took the decisions, focused on maximising compliance and used a paternal style where patient wouldn't adhere, also to expedite consultation; even though all the physicians commented that they try to have a shared decision making process. Physicians in different specialties used various methods to influence the patient into agreeing with their choice for treatment, such as when some cardiologists used the hope from new drugs. Physicians also highlighted the benefits and minimised the risk of warfarin. Some of them also admitted that they sometimes end up taking the paternal route either because of patient trust or because the physician feels the patient would not adhere to medication. In addition even though general practitioners interviewed commented that in their practices they

offer blood monitoring services, all of the general practitioners mentioned that they refer patients to secondary care rather than taking the decision to commence OAC.

During the interviews, the cardiologists and registrars indicated that they keep themselves updated with current research in their field. General physicians although knowledgeable about risk scores, such as the CHADS₂ score, commented that they also need to be knowledgeable about other non-cardiology related issues which makes it harder for them to be aware of new guides. Similarly general practitioners expressed their lack of knowledge on AF and OAC, highlighting their concern in trying to adhere to AF guidelines.

Although physicians in this study have gained a lot of experience on how to tackle patient concerns during the years, they still discussed some challenges that they face when prescribing warfarin. These challenges could be categorised as their interpretations of patient related concerns, and the challenges that they, as professionals face. All physicians from different specialties commented that the major challenge they experience, especially with a first time patient where they need to be educated on AF and OAC, was time. They commented this was a challenge not only with regards to AF and OAC but also transferable to the healthcare system as a whole. Physicians also discussed language barriers and how the use of a translator impinged on the transfer of knowledge and shared decision making.

Physicians also interpreted the challenges and concerns that from their experience, patients routinely faced. All physicians mentioned that they believe their patients were concerned about the monitoring, the side-effects and the interactions of warfarin. In addition they explained how patients' experiential knowledge (knowledge gained through their own experiences) or 'a priori' knowledge (knowledge gained before from other sources) of strokes and bleeds influenced their decision to accept or refuse warfarin.

Chapter 6: Discussion and Conclusion

6.1 Introduction

This study explored the patients' and physicians' experiences of AF and OAC. To reach these aims, the programme of work was divided into two interlinked studies. One study focusing on the patients' experiences and another study focusing on the physicians' experiences. This chapter intends to draw the findings of the two studies together and compare them to the literature (see Chapter 1) and the findings from the meta-synthesis (see Chapter 2). In addition, the strengths and limitations of the study will be discussed. Reflexivity during data collection and data analysis will also be outlined followed by future research and practical recommendations based on the findings of this programme of work.

6.2 Summary of the key findings from the patients' and physicians' experiences

6.2.1 Communication within the consultation

The experience of the initial consultation was explored with both patients and physicians. Some symptomatic patients expressed concern when they first felt the AF symptoms, as they thought it was a heart attack. However they all experienced relief during their initial consultation where they said that their physicians told them it was not a heart attack. This finding was confirmed through the physicians' experiences as they also pointed out that they believed their patients were initially worried that they were going to have a heart attack. In addition physicians commented that a critical component of the AF consultation was to provide assurance to the patient that it was not a heart attack and that the condition could be managed. The continuous relief resulting from the physician assurance and reassurance during the consultation was similarly confirmed in patients' accounts.

All physicians explored the importance of patient education during the consultation. However, this was an issue that patients still felt was lacking in

the AF consultation, especially the absence of take home educational materials. Another key difference in experience between the patients and physicians was the perception of the approach taken during the decision making process. Most patients commented that they perceived the approach taken by the physician during the AF consultation as a paternalistic approach to decision making, where they believe the physician took all the decisions without involving them, sometimes without giving them any alternative. Their perception of the paternalistic approach was the most influential reason why patients both accepted and refused OAC treatment for AF. Some patients also commented that they preferred the physician to take the decision as he/she was the expert. These patients also pointed out that they made sure to let the physicians know their opinions if they did not agree. Physicians explained how they tried to take a shared approach to decision making, however they admitted that because of external factors, such as available time, language barriers or patient trust in them as the expert, physicians ended up taking a paternalistic approach. Physicians' continuous use of the word compliance during this study, denoted a lack of awareness of the connotation of the word and its association with a paternalistic approach to the consultation.

6.2.2 Emerging challenges from the patients' and physicians' experiences

A crucial challenge that was reported by both patients and physicians was the perception of time within the consultation. Some patients reported that they were dissatisfied with the way their consultation was managed and felt that more time was needed with the physician so that they could be more adequately informed about their condition. In contrast patients who were satisfied with their consultation did not perceive the need for extra time. Some physicians also pointed out that the lack of time available with the patient was a challenge to their practice. They argued that in secondary care there is limited amount of available time that can be spent with a patient. This lack of time also had an impact on the amount of education imparted to the patients and the choice of approach taken to decision making. General practitioners also reported that time constraints were a challenge however in primary care they had an advantage over secondary care as general practitioners said they were

in a better position to have follow-up appointments with patients, albeit at the patient's request. Through these follow-ups, they argued that patients were given more time to reflect on their discussions and come back with concerns. In addition, follow-ups increased continuity which in turn were perceived as critical in increasing the physicians' knowledge of the patient and in ameliorating the relationship with their patient. Some patients also commented that they had a better relationship with their general practitioner and the health professionals in the INR clinics. Physicians in secondary care (cardiologists, registrars and general physicians) commented that this continuity of care was often lacking in their practice. General physicians and general practitioners also pointed out the challenges in following clinical guidelines. They commented that there was a need to educate non-specialist physicians through simpler guidelines that highlight what steps physicians in different specialties should take.

Patients in this programme of work also commented on how OAC influenced their QoL. Similarly, physicians presented their beliefs of what influences patients' QoL. A common influence reported by physicians and confirmed in patients' experiential accounts was the influence of repeated INR testing on QoL. Some patients commented that they perceived INR tests as an inconvenience. Some patients even added that because monitoring was going to affect their overseas travel plans, they decided to discontinue OAC. In addition, patients felt that INR monitoring incurred a financial burden to them through the increase of hospital parking charges. However, other patients, especially patients who lived alone or were satisfied with their treatment, commented that they enjoyed the INR clinic because they perceived it as a social activity. Another aspect of OAC's influence on QoL that both patients and physicians mentioned was the interaction warfarin has with certain foods and drugs. However while physicians believed this was a major issue for patients, patients suggested that they were not concerned by food interactions. The other impact OAC had on patients was bleeding and bruising. Physicians believed that patients were concerned about the increased bruising and bleeding risk incurred from taking warfarin. Some patients pointed out their concerns about bruising and others even mentioned that this could have had an impact on their social life since they were still working. Patients, who had

past experiences with bleeds, either when a significant other had a bleeding episode or during travelling, commented how this negatively influenced their perception on warfarin. Patients' understanding of warfarin and aspirin varied considerably. Warfarin was described by patients as an old (therefore unsafe) drug which is usually prescribed when a person is near the end of life, while aspirin was described as an old (therefore safe because it is tried and tested) natural drug. This clearly demonstrated that other significant factors, like past experience and influence from the media, played a role in patients' beliefs about two similarly old medications.

6.3 Communication within the consultation

6.3.1 Physicians' and patients' experience of reassurance

Both patients and physicians commented about the importance of assurance and reassurance during the AF consultation. Physicians from all groups in this study commented that patients needed to be reassured through appropriate communication to minimise the initial anxiety of the patients. This study further confirmed the findings of McCabe et al. (2011b) where symptomatic patients commented on their relief on being diagnosed with AF. Building rapport with the patient and adopting a patient-centred communication style was a useful method for physicians in this study to alleviate illness concerns and increase reassurance (Kessel, 1979). Physicians believed that this was achieved by ensuring that the patients' thoughts and fears had been adequately addressed, thereby conveying to the patient that they had been heard and understood.

However, even though assurance may appear successful during the medical consultation, once the patient leaves the medical environment they may be influenced by a number of social factors that present obstacles to reassurance (McDonald, Daly, Jelinek, Panetta, & Gutman, 1996). Media stories concerning health threats have become commonplace, especially with regards warfarin and its previous use as rat poison. This can have the effect of undermining individuals' perception of their own health, heightening vigilance for symptoms and increasing the likelihood that symptoms will be interpreted negatively

(Barsky & Borus, 1995). The influence of media on OAC treatment perceptions will be discussed later in this chapter.

6.3.2 Education within the consultation

All physicians in this study reported that they tried to engage patients in an educational approach to help them understand AF and OAC. Confirming previous studies and the findings of the meta-synthesis, the majority of patients in this study wanted more education about AF and OAC than they were typically provided with (Audit commission for local authorities and NHS, 1993; Benbassat, Pilpel, & Tidharet, 1998; see Chapter 2). Furthermore, although knowledge was acquired, it was not necessarily understood. Similarly some physicians in this study showed concern about how much patients actually remembered from the information given to them during the consultation. Likewise, the patients often perceived the consultation as lacking an adequate educational component. This was highlighted in Ley's (1992) work, that patients have gaps in understanding and recall following face-to-face consultations. Knowledge acquisition does not necessarily transpose to understanding. The acquisition of knowledge is multi-layered and may not be attained by one educational session (Ley, 1992), a finding which is supported by the present study. One example is where general practitioners pointed out that they could have an advantage over secondary care. Time could also be a measureable denominator to ascertain whether the knowledge had been acquired (Mazor, Baril, Dugan, Spencer, Burwinkle, & Gurwitz, 2007). The effects of time will be discussed in a separate section.

Doctors in this study, like Melanie, commented on the patient's ability to recall information after the consultation. Doctors in secondary care argued that since they have limited availability for follow-ups, patients receive large amounts of new information and medical advice at a single consultation. In order for patients to adhere to this advice, they must be able to recall it afterwards; however, similar to several studies, doctors in this study have shown that most patients do not fully understand or memorize it. Lack of understanding and recollection reduces patient satisfaction and commitment to treatment (Kessels, 2003; Watson & McKinstry, 2009). Recall is also affected by the use of medical

terminology (which is sometimes difficult to understand), the form of the given information (oral or written), and patients' expectations and level of education (Jansen, Butow, van Weert, van Dulmen, Devine, & Heeren, et al. 2008; Watson & McKinstry, 2009).

Recollection of information also declines with age (Kessels, 2003), with older people being less able to recall information successfully (Watson & McKinstry, 2009). The association between intelligence and recall has not been shown to be significant, but a higher level of medical knowledge was associated with better recollection (Kessels, 2003; Safeer & Keenan, 2005). Memory and anxiety levels are connected to recollection in an inverse U curve: there is significantly better recollection at a moderate level of anxiety than at low or high levels of anxiety (Kessels, 2003; Jansen et al., 2008; Safeer & Keenan, 2005). There also seems to be an association between the amount of information given and how much is recalled; the more information is provided, the more is lost (Safeer & Keenan, 2005).

The effectiveness of different ways of introducing information (i.e. written, oral, pictorial) has also been studied. Some studies have shown that the use of pictorial instructions is beneficial (Jansen et al., 2008; Watson & McKinstry, 2009), although this has not been supported by others (Kessels, 2003; Watson & McKinstry, 2009). The combination of oral and written advice appears to be the most effective (Jansen et al., 2008; Watson & McKinstry, 2009). Written information was more commonly reported to have been used by general practitioners in this study, which could play an important role in knowledge acquisition, to serve as a reminder of what has been discussed or to provide more detailed information. In addition, findings in this study confirm Mazor et al. (2007) that on-going educational support sessions are required, however, according to participants in this study, this does not occur in clinical practice. Research also indicates that patients are more passive in consultations than they intend to be (Harrington, Noble, & Newman, 2004). This was sometimes found to be the case in the experiences of patients in this study. For example although Lionel had concerns about warfarin, he did not voice these concerns, similarly Daniel took on a passive attitude during the consultation as he

believed in the expertise of the physician. Improving patient participation in consultations was shown to improve outcomes (Harrington et al., 2004).

Similar to previous qualitative studies (see Chapter 2), patients highlighted the need for educational material. However provision and production of educational material were not without limitations (Audit commission for local authorities and NHS, 1993; Eysenbach, Powell, Kuss, & Sa, 2002). Patient focus groups have reported a number of problems with written information, such as omission of topics of importance to them, over-optimism, and avoidance of uncertainty and lack of detail (Coulter, Entwistle, & Gilbert, 1999). Feedback from patients is not commonly sought when written materials are being prepared, despite the use of techniques such as lists of 'frequently asked questions'.

The literature on patient leaflets was examined by Dixon-Woods (2001), who identified two discourses: a 'patient education' theme, where patients are perceived as passive recipients of information and healthcare in general; and a 'patient empowerment' theme, which takes into account patients' priorities and promotes active participation in decision-making. Physicians' accounts shown in this study are more congruent with the former discourse, where patients were believed to passively absorb information given to them (Dixon-Woods, 2001). General practitioners however commented on the importance of making sure that patients understood what is being given to them, which conforms more to the latter of the discourses found by Dixon-Woods (2001). Dixon-Woods (2001) argued that the majority of patient leaflets serve a biomedical agenda, by aiming to save time in the consultation, increase staff's motivation towards patient interaction and promote behaviour changes desired by professionals, such as compliance. Other investigators have concluded that written materials may serve professional or commercial agendas, such as encouraging an uncritical approach to treatment (Kenny, Wilson, Purves, Clark, Newton, Newton, et al., 1998). However, Coulter et al. (1999) made a series of recommendations for the preparation of written materials, which included involving patients throughout the process, being honest about uncertainty and risks, and educating clinicians about techniques to promote shared decision-

making, such as using educational leaflets in aiding physicians to elicit questions from patients regarding treatment (Ehrenberger, 2001).

6.3.3 Communicating risk

Cardiologists and registrars in this study commented on the use of numerical information within their consultation. Much discussion of risk communication has centred on how numerical probability information should be presented (Calman & Royston, 1997; Edwards, Elwyn, Mathews & Pill, 2001; Edwards, Elwyn, & Mulley, 2002; Edwards, Unigwe, Elwyn, & Hood, 2003; Paling, 2003). However, there are differences between estimates of actual risks, as calculated from mortality statistics and how patients perceive these statistics (Lichtenstein, Slovic, Fischhoff, Layman, & Combs, 1978). These include a tendency to under-estimate the frequency of large risks and over-estimate small risks, especially when there is a lack of knowledge on the subject, for example the overestimation of the associated risks of bleeding and underestimation of the stroke risk during clinical practice in OAC for AF (Boulanger, et al., 2006; Lane & Lip, 2008a; Pugh et al., 2011; Taggar & Lip, 2008; Tay et al., 2009).

Providing information about the probability of health risks alone only has a small influence on how people think about those risks and on their risk-related behaviour. Rothman and Kiviniemi (1999) argue that that people find difficulty in understanding and interpreting numerical probability statistics. However, some physicians in this study commented that there might be an association between how patients perceive medical risk and how they perceive lottery probabilities. Meta-analyses of studies investigating the effects of fear-rousing communications show that perceptions of vulnerability have on average a small effect on intentions to change behaviour and on concurrent and subsequent behaviour (Floyd, Prentice-Dunn, & Rogers, 2000; Milne, Sheeran, & Orbell, 2000; Witte & Allen, 2000). Reasons for the lack of influence on patients might include difficulty following the logical sequence of probabilities during a consultation and in evaluating risk without supplementary information.

When people receive probabilistic risk information, it can be difficult to evaluate this, if they have nothing against which to compare it (Roth, Morgan, Fischhoff, Lave, & Bostrom, 1990). People need additional information to clarify the implications of absolute risk information. This includes the risk that others similar to them have, or their own risk if they were to adhere to recommended medical advice (Roth et al., 1990). Thus, when asked what information they want in order to understand a health risk, people typically ask for comparative information about the probability of other risks (Roth et al., 1990). Presenting information about relative risks generally has more impact on perceptions of likelihood, emotion and decision-making, than information about absolute risks (Edwards et al., 2001; Nexoe, Gyrd-Hansen, Kragstrup, Kristiansen, & Nielsen, 2002).

Changes both within and outside of healthcare have resulted in an increasing emphasis upon providing services in ways to facilitate patients making informed choices. Core elements of definitions of informed choice are an understanding of the different options and their likelihoods (Bekker, Thornton, Airey, Connelly, Hewison, Robinson et al., 1999; Marteau, Dormandy, & Michie, 2001). Despite understanding being a central outcome to risk communication, there have been few attempts to define what it means to understand a risk (Weinstein, 1999). In addition, although studies have shown that fewer patients opt for OAC when presented with statistical information in decision aids (Fuller et al., 2004; Holbrook et al., 2007; Howitt & Armstrong, 1999; Man-Son-Hing et al., 1999; Protheroe et al., 2000; Thomson et al., 2000) (see Section 1.4.1.4.1), there is no persuasive evidence that patients understand risk in OAC for AF.

A general framework for selecting the appropriate strategy for communicating risk information and supporting decisions has been developed (O'Connor, et al., 2003). According to this framework, the most appropriate risk communication strategies depend upon whether patients are faced with decisions concerning either 'effective' health services, where there is firm evidence of benefits that greatly outweigh limited harms (e.g. in OAC where the reduced risk of stroke outweighs the increased risk of bleeding), or 'preference-sensitive' health services, where benefit is unclear relative to harm (O'Connor

et al., 2003). Where clinicians are discussing 'effective' health services with patients, consultations surrounding risk may be more direct and concern motivations and barriers to change. On the other hand, where clinicians are discussing 'preference-sensitive' health services, counselling is non-directive, including discussions of potential benefits and harms, probabilities and options. This was similar to the approach adopted by physicians in this study in order to influence patients to accept OAC treatment (i.e. highlighting the benefits of warfarin). Health communication aimed at educating AF patients on OAC risks should aim to provide a clear and simple explanation of these risks, and also needs to be accompanied by an explicit plan concerning how OAC treatment works in reducing stroke risk (Sheeran, 2002).

6.3.4 Decision making in OAC for AF

In line with the meta-synthesis (see Chapter 2), the present study found that patients and physicians' experiences of decision making differed. Only one patient, Fiona, commented that she accepted warfarin on the basis of a more shared information process, i.e. through discussing the pros and cons of warfarin. Other patients, both in the accepted and refused group commented on their perception of the paternalistic attitude of the physicians. Patients who accepted OAC felt that either they were not given any alternative to warfarin, or the physician took the decision himself or the patient accepted OAC out of trust in the expert. Similarly, patients refused OAC either because they felt that the physician did not give them enough information or because of the belief that the physician did not have their best interest in mind, for example during Greg's consultation he perceived his physician as pushing him towards participating in a trial where he could keep on his drinking habit rather than telling him to minimise his alcohol consumption. Physicians on the other hand commented that they tried to maintain a shared decision style; however some did mention that they ended up taking decisions themselves because patients put trust in them. Classical sociological research has shown that patients and physicians can have different perspectives of a clinical encounter (Freidson, 1970; Mishler, 1984; Silverman, 1987) and that patients make sense of their clinical

experience in the context of their own views and beliefs (Blaxter, 1983; Eyles & Donovan, 1990; Williams & Calnan, 1996).

Furthermore, similar to findings in the meta-synthesis, this study found that reports of a paternalistic decision-making style were accompanied with a high level of trust in the medical expertise of the physician (see Chapter 2). Relationships with health professionals were an integral part of OAC treatment. Patients judged these relationships from an ability to trust, communicate and connect with the physician. In addition, some patients, such as Josephine, did report their general practitioner's ability to be inclusive of their values and perspectives. Patient participants highlighted that long-term relationships demonstrating trust and respect increased their confidence in their physician. Research has shown trust to be essential to patients and that it is strengthened by regular contact and communication (Pullon, McKinlay, Stubbe, Todd, & Badenhorst, 2011). In light of this, general practitioners working in primary care had an advantage over hospital physicians (cardiologists, general physicians and registrars). General practitioners were in a better position to give more time or several consultations to patients to reflect on their discussions through follow-ups and also to provide continuity of care. In contrast, hospital physicians tended to see patients only once or twice and they only had a limited time in which to build trust and rapport with the patient. Trust in the physician in the case of secondary care was based on the physician being seen as the expert, rather than built through time and rapport like in general practitioners.

This was also seen in the physicians' choice of analogies within the consultation. Similar to previous literature, findings in this study show that doctors are conscious of using metaphorical analogies with patients, and may indeed have one or two well-trying analogies (Olweny, 1997; Skelton, Wearn, & Hobbs, 2002). Metaphors are acknowledged as playing a part in the construction of theory (Harman, 1994) and in the often pictorial and aesthetic imagination at work in, for example, the labelling of things (Banville, 1998). Participants' more literal use might casually be interpreted as a medical attempt to repackage the body as the mechanical. For example the doctors'

representation of the patient's body as a house that needs attention to its wirings. Nevertheless, on the whole, a central difference between doctors and patients appears to be that doctors use a greater frequency of metaphors to do with machines. Similarly, doctors talk of themselves as solvers of problems and controllers of illness, or the mechanics that are there to fix the car, metaphors which hint at knowledge and power (Olweny, 1997; Skelton et al., 2002). Such use of metaphors creates an imbalance of power within the consultation that in turn promotes a paternalistic approach.

6.3.5 Adherence vs. compliance

This study also highlights the need to change the language used to signify the nature and outcome of patient-physician relationships, i.e. whether patients understand their diagnosis, take appropriate medication and have the knowledge to self-manage long-term conditions like AF. Physicians in this programme of work often used the word 'compliance' to describe how patients accept and follow treatment instructions set out by them. Compliance is commonly defined as the extent to which the patient's behaviour matches the physician's recommendations (Haynes, Taylor & Sackett, 1979). Although the term compliance is commonly used in the medical and pharmaceutical literature, it has been criticised because of its negative connotations in terms of the power difference between the health professional and patient within the consultation (Stimson, 1974). Compliance denotes a relationship in which the role of the physician is to decide on the appropriate treatment and issue the relevant instructions, whereas the role of the patient is to passively follow 'the physician's orders'. Although during the first part of the consultation physicians do seem to adopt a patient centred approach, aiming for adherence, the aim during the decision making process, as explored before, was more in line with the definition of compliance. Within this connotation, non-compliance may be interpreted as a patient's incompetence in being unable to follow the instructions, or worse, as deviant behaviour. This was also corroborated in the some of the patients' perceptions of the consultation, where patients felt they did not have any alternative but follow the physicians' decisions. The term

adherence, on the other hand, has been adopted by many, particularly within the psychological and sociological literatures, as an alternative to compliance, in an attempt to emphasise that the patient is free to decide whether to follow the prescriber's recommendations and that failure to do so should not be a reason to blame the patient (Barofsky, 1978; Delamater, 2006; Meichenbaum & Turk, 1987). Adherence develops the definition of compliance by emphasising the need for agreement and may be defined as, the active, voluntary and collaborative involvement of the patient in a mutually acceptable course of behaviour to produce a therapeutic result (Delamater, 2006; Meichenbaum & Turk, 1987)..

In view of the physicians' experiences, although they used the word, compliance, their meaning suggested they aimed for adherence, and indeed concordance. Physicians' accounts show that they worked along a sliding continuum between compliance-adherence-concordance, however their aim was to use concordance, i.e. give patients adequate information and opportunity to empower patients to make their own decision. However, they sometimes resorted to a model of compliance by 'advising' the patient what they thought they should do.

6.4 Challenges that have an influence on OAC for AF

6.4.1 Time within the consultation

This study supports previous literature with regards the perception of the lack of time in the consultation as a health-care system barrier for OAC prescription (see Chapter 2). Quantitative surveys (Airey, & Erens, 1998; Williams & Calnan, 1991) and qualitative research (Pollock & Grime, 2002) indicate that many patients would like more time with their physician. Patients often want longer consultations but are aware of time constraints and are anxious not to waste their physician's time (Pollock & Grime, 2002). Time constraints may lead to patient dissatisfaction and thus to non-adherence. This problem of

patient dissatisfaction has been addressed in two ways. Some researchers have addressed the actual length of the consultation (Freeman, Horder, Howie, Hungin, Hill, Shah, et al., 2002; Howie, Heaney, Maxwell, Walker, Freeman & Rai, 1999; Shah, 1999; Wilson & Childs, 2002). This has led to either a call for longer consultations (Freeman et al., 2002; Howie et al., 1999; Shah, 1999; Wilson & Childs, 2002) or a proposal to change the allocation of time via the introduction of new technologies and more flexible practice management (Freeman et al., 2002; Wilson & Childs, 2002). Patients and physicians in this study confirmed the former, when they recommended that the consultations should be longer to allow more time for discussion.

These solutions have drawn upon the evidence that longer consultations are of higher quality and are associated with a range of better patient outcomes (Howie et al., 1999; Wilson & Childs, 2002) and recognition that each patient's problem requires a different amount of time for appropriate management, which was also pointed out by some physicians in this study.

In contrast, others have focused on how the time is spent. From this perspective, it has been argued that rather than simply extending the length of the consultation, the time available should be managed more effectively. For example, Mechanic (2001, 2002) suggested that a change in the process rather than the length of the consultation could reduce such patient dissatisfaction, stressing the importance of 'meaningful time'. He also indicates that patient dissatisfaction with time remains high in the United States even though actual consultation length is twice that in the United Kingdom. This could also be related to the difficulty for health care access in the US, as it is operated by a privatised system, (i.e. patients usually need to pay some form of health insurance to get "free" health care) while in the UK, the NHS is free at the point of need. The fact that US patients have to 'pay' for their health care could have an influence their satisfaction. Similar to Mechanic (2001, 2002), Cape (2002) concluded that patients' perception of time was a better predictor of satisfaction than actual time, suggesting a role for each patient's perceptions and experience.

Findings in this study support previous studies that patients are dissatisfied with their consultation time (Williams & Calnan, 1991; Airey, & Erens, 1998). They also indicate that physicians show flexible time management and allocate more time where a problem requires it, such as in cardiologist Melanie's experiences. This could indicate that some patients, such as those undergoing initial consultations, require more time so that their emotional needs can be met, which in turn would allow for greater concordance. This approach is in line with research which has addressed patients' desire for more time by changing the actual time patients receive (Howie et al., 1999; Shah, 1999; Freeman et al., 2002).

An alternative explanation considers the desire for more time as a reflection on the content of the consultation. In line with this approach, the results from the present study indicate that if patients have their emotional needs met, feel listened to and understood, such as in Fiona's experience, regardless of the actual time spent with the physician, they are satisfied not only with the process of the consultation but also with the consultation length. Furthermore, they then may feel more likely to adhere to the treatment. Accordingly, the desire for more time highlights the sense of dissatisfaction with how the time has been spent rather than how much time they received. This explanation provides empirical support for the concept of 'meaningful time' spent in the consultation (Mechanic, 2001, 2002). According to this argument, if physicians wish to leave their patients feeling satisfied with the time they have given to them, then maybe rather than giving them increasing amounts of time they need to consider how that time is spent. They can create the sense of more time through the process of listening and understanding rather than the reality of more time which remains dissatisfactory because it is filled with medical facts and information.

6.4.2 Physicians' adherence to guidelines

All physicians in this study were aware of existing NICE guidelines on the management of AF. However not all general practitioners were knowledgeable of the updated European Society of Cardiology clinical guidelines by Camm et

al (2010). Conforming to previous studies, general physicians and general practitioners commented on the difficulty in adhering to guidelines as real-world patients are different from participants recruited in randomised-controlled trials with narrow inclusion criteria (Carlsen et al., 2007; see Chapter 2). Furthermore, all general practitioners in this study preferred to refer patients to secondary care for OAC initiation, supporting the lack of confidence in OAC prescription highlighted in previous studies (Boulanger, et al., 2006; Lane & Lip, 2008a; Taggar & Lip, 2008; Tay et al., 2009; see Chapter 2). This could be a result of the fear of jeopardising the relationship with the patient or the fear of causing harm to the patient from the wrong decision to treatment (Carlsen et al., 2007). Another reason for the referral to secondary care might be the belief that cardiologists are more knowledgeable (Ayanian et al., 1994) or the belief that the involvement of more physicians, regardless of specialty, may result in higher quality care (Choudhry et al., 2006; Rutten et al., 2003). General practitioners and general physicians, conforming to findings in the Carlsen et al. (2007) study, argued that guidelines needed to be short and simple and focused to the particular specialty level of the physician.

6.4.3 Influence of AF and OAC on patients' QoL

Patients on this study explored the impact that AF and OAC had about their quality of life. Some patients, such as Will, commented that symptoms from the fast AF had a major impact on his life, so much so that he could not sleep lying down. Although Will's experience was unique among the patients interviewed in this study, there are undoubtedly other patients that had similar experiences. Such experiences were also reported by patients in McCabe et al.'s (2011b) study, who commented that patients were distressed by the symptoms brought about from AF. The overriding desire to obtain normality and thereby sustain QoL was dominant for Will. In addition to that Will lived in a mental health nursing home under constant supervision, which made him feel depressed. Literature shows that emotions have an influence on symptom perceptions (Sarafino, 2006). Furthermore, the more attention a patient gives to the symptom, the more feelings of anxiety are elicited (Broadbent & Petrie, 2007). In turn, anxiety will influence patients by making them more mindful, in which

case they will scan themselves and the environment for any potential threat, thus becoming trapped in a vicious circle (Bar-Haim et al., 2007). This vicious circle may have had an impact on Will refusing OAC. His main aim was to overcome the symptoms of AF but since OAC treatment was not going to change his 'cure' beliefs (Leventhal et al., 2003) regarding his perception of AF, he refused treatment. This finding was similar to previous literature explored in the meta-synthesis (see Chapter 2). Concurring to Horne (1997), although the patients' beliefs and knowledge of OAC side effects and the need for lifestyle change, outweigh the need for the use of the medication in the reduction of thromboembolism.

Warfarin is a complex medication that requires lifestyle changes that can be perceived as restrictive by some. Patients and physicians in this study confirmed previous findings on the influence of OAC on the patients' lived experiences (Bungard et al., 2000; see Chapter 2). Fiona and Jonas commented that OAC did not have an impact on their QoL, whilst others such as Lionel or Raj commented how they perceived INR monitoring as an inconvenience. Previous studies showed that OAC patient related barriers included the influences from diet restrictions and regular INR monitoring (blood tests). The present study found that with regards to diet physicians' interpretations of patient concerns did not match the patients' actual experiences. Physicians commented that patients found the limitations to diet challenging, which confirms previous research findings (Bungard et al., 2000; see Chapter 2), however, although patients in this study mentioned that OAC had limited their choice of vegetables, they did not feel it had a significant negative influence on their QoL and did not impact their decision as to whether they accepted or refused OAC. However, patients' accounts of their dietary concerns showed that their knowledge of the dietary influences of vitamin K on warfarin was limited, for example Fiona was still unaware of dietary interactions when she mentioned that she cannot eat broccoli and that INR would be tailored to each individual.

Similar to previous studies, another drawback that patients and physicians commented on was the impact of regular OAC monitoring on their QoL (Bungard et al., 2000; see Chapter 2). Patients, like Lionel, commented that for

him time was of utmost importance to his QoL and he felt that because of OAC, it was taken away from him. Raj also commented on the impact of blood monitoring OAC on his and his wife's QoL. Travel, while still undertaken, was regarded as bothersome and unsafe on OAC. Raj commented how his experiences, when he and his wife saw a patient bleeding in India during his travels, influenced his treatment beliefs about the consequences of OAC (Leventhal et al., 1984) and bleeding. Further, the change in his treatment beliefs also had an impact on his QoL, thus influencing him to discontinue OAC treatment. In addition, patients or their carers who were present at the interview, like Raj's wife, expressed their fear in their accounts, when they associated the need for INR monitoring with the lack of safety in warfarin. This was not reported in other studies. Similarly previous studies have not explored the emotional support and the inevitable impact on patient-health professional relationship that some patients experienced from repeated monitoring sessions, like for Jonas. Jonas explained how he lived alone with his dog after taking care of his mother for 17 years when she had a stroke. In his anecdotes Jonas points out his rapport with the nurse at the INR clinic, and how going to the INR clinic is more of a social event rather than an inconvenience. In addition, another aspect of OAC monitoring that was not explored in previous studies is the financial burden. Both physicians and patients reported dissatisfaction with costs incurred from travelling and hospital parking associated with OAC monitoring, especially for pensioners.

This study also highlighted the lack of support by employers who are not well-informed about OAC. For example Josephine commented on the lack of support she received at work after her TIA and Robert commented that he could not take time off from his work. In Josephine's experience, this could have influenced her in refusing OAC on the basis that her employers would not understand the need for blood monitoring. No study has yet explored the issue of support from employers with patients with OAC and how this has impacted on its long-term management. In addition, this study told of the support patients received from family, e.g. Lionel and Fiona. Health psychology research has shown consistently that social support has powerful effects on both

psychological and physical wellbeing (Cohen & McKay, 1983; Cohen & Wills, 1985).

6.4.4. Impact of family members and interpreters on the consultation

Doctors and patients in this study commented on the presence of family members during the medical consultation. Evidence suggests that patients are accompanied by family or companions in between 20% to almost 100% of consultations and this raises issues about how the presence of others influences the process and treatment decision (Audrey, Abel, Blazeby, Falk, & Campbell, 2008; Ellingson, 2002; Street & Gordon, 2008; Wolff & Roter, 2008).

Available research shows that companions are more frequently present in consultation with older, less healthy and less well-educated patients, and suggests that there are some practical benefits associated with companions attending a consultation such as provision of emotional support and information recall (Audrey et al., 2008; Ellingson, 2002; Street & Gordon, 2008; Wolff & Roter, 2008). Companions may also communicate information between the patient and the physician, and ask questions on the patient's behalf, being sometimes described as a patient advocate or watchdog (Adelman, Greene, Ory, 2000; Beisecker, 1989; Ellingson, 2002; Street & Gordon, 2008; Wolff & Roter, 2008). This may lead to physicians giving more attention to concerns and topics raised by patients if consultations include significant others (Shields, Epstein, Fiscella, Franks, McCann, McCormick et al. 2005; Schilling, Scatena, Steiner, Albertson, Lin, Cyran et al., 2002).

Possible drawbacks associated with the presence of companions are uncommon but include examples of companions discussing their own problems, excluding patients from the conversation with the physician or playing a more direct role than anticipated by patients (Greene, Majerovitz, Adelman, & Rizzo, 1994)

Another area where physicians commented that patient-physician communication is interrupted, occurs when interpreters or translators are used

because of the multi-cultural aspect of care Birmingham. While the provision of interpreters potentially addresses the language barrier, studies have revealed problems with medical interpretation, including inaccuracy and inconsistency (Dysart-Gale, 2007; Flores, 2005), and confusion regarding the interpreter's role within the consultation (Kaufert & Koolage, 1984). Ways in which physicians can work more effectively with interpreters to minimise the language barrier, have been identified in several studies (Abbe, Simon, Angiolillo, Ruccione, & Kodish, 2006; Butow, Lobb, Jefford, Goldstein, Eisenbruch, Girgis et al., 2012; Schapira, Vargas, Hidalgo, Brier, Sanchez, Hobrecker et al., 2008) and include keeping to the schedule so that interpreters' time is spent in the consultation, using a trained professional interpreter who is familiar with the terminology or area of discussion, briefing the interpreter on the case beforehand and discussing potential challenges, speaking directly to the patient rather than to the interpreter, checking patient understanding and paraphrasing, providing access to written information in the patient's language, and debriefing with the interpreter after the consultation (Abbe et al., 2006; Butow et al., 2012; Schapira et al., et al., 2008).

6.4.5 Perception of warfarin vs. aspirin

Patients in this study reflected about their perceptions of aspirin and warfarin. They perceived aspirin as a natural old wonder drug, while warfarin was considered an old drug that needed monitoring. The media had an important role in patients' perceptions of these two drugs. This finding is unique to this study as previous studies have not explored how media influences patient perceptions of OAC treatment. Lay individuals have at least two main sources of information regarding risk and, by extension, from which to base their judgments of risk: the media and interpersonal networks (Frewer, Miles, & Marsh, 2002). Interpersonal networks are, by their nature, idiosyncratic and dependent on the lived experience. By contrast, information provided through media sources may well lead to systematic over- or underestimates. For example research has shown in classical studies that individuals' estimates of causes of mortality were not correlated with actual mortality statistics, but

participants' estimates were strongly correlated with the frequency of print media reporting (Coombs & Slovic, 1979; Frost, Frank & Maibach, 1997; Kristiansen, 1983).

Nevertheless, popular media, including newspapers, television and increasingly the Internet, has a role in disseminating information to the public about health concerns. However the way popular media frames warfarin and aspirin, influences patients' perceptions of said medication. Durfee (2006) states that messages are constructed or 'framed' by translating scientific information for popular consumption. According to Entman (1993, pp.52), "to frame is to select some aspects of a perceived reality and make them more salient in a communicating context in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation". In short, how news is presented may influence what patients think about issues, people and events (Durfee, 2006). Therefore framing can have an influence on patients' illness or treatment perceptions (Leventhal et al., 1984, 2003).

There are a number of 'framing' techniques used in media to structure issues such as "using certain words or phrases, making certain contextual references...giving examples as typical, referring to certain sources, and so on" (McQuail, 2005, pp. 378-379). For example similar to the patients in this study, a recent online article in Forbes magazine referred to aspirin as a 'Wonder Drug' (Haiken, 2012). This is consistent in newspapers, where aspirin is constantly positively-framed as reducing the risk for a myriad of conditions, including 'cancer', 'tumour growth' and even Alzheimer's disease (BBC News, 2002, 2003, 2006; Borland, 2012; Smellie, 2012).

In contrast lay articles and newspapers mostly refer to warfarin as 'rat poison' (e.g. Hope, 2011; Laurance 2013; Kobodlt, 2010;) and all the patients interviewed in this study had some knowledge of warfarin being used as rat poison. Some patients, such as Josephine and Lionel argued that it was the word 'poison' that had a negative influence on their perception of warfarin. Likewise, even when the benefits of warfarin are described, these are

neutralised by the very act of calling it 'rat poison' (Hope, 2011; Laurance 2013; Kobodlt, 2010). Thus, as mentioned before, patients may associate the word 'poison' with the identity of warfarin, and from internal cognitive schemas they have of the word 'poison', they might infer dire consequences of them taking warfarin. Scheufele (1999) suggests that people also develop in their minds what he calls 'audience frames' or 'cognitive schemas' about topics and issues. The way people understand the news is a function of the schemas they receive from the mass media. Thus patients may inherently be influenced by the way popular media portrays warfarin, which in turn would influence the outcome of their decision to refuse or discontinue warfarin.

6.5 Strengths and limitations of the study

The main strength of this study is that it is the first study to use IPA to explore patients' and physicians' experiences of the AF consultation and OAC management in the United Kingdom. A phenomenological perspective enabled the collection of detailed data that has provided an insight into the ways that physicians and patients perceive themselves, their relationship towards each other and the condition and its treatment. One-on-one interviews provided patients with the opportunity to talk about their feelings, to reflect on their experience of the consultation and the influence of OAC on their QoL after they accepted the treatment. In addition, the collecting of information through direct, face-to-face contact with the participants had several advantages over data collected from self-report questionnaires. Specifically, questions were more likely to be answered in more depth about their experience rather than choosing options from a predetermined list. Furthermore, participant nuances could be investigated and clarified through further questioning by the researcher. Open-ended questions also allowed for the richness and complexity of human experiences to emerge, where participants were given time to expand on their responses and the supplementary data of respondents' non-verbal behaviour could also be observed. For these reasons, the semi-structured interviews were better in eliciting interaction and offered better advantages in terms of both the overall quality and the quantity of responses (Kvale, 1996).

Another asset of this study lies in its innovative bolder IPA design to analyse multiple perspectives. This was the first IPA study on AF and OAC that conducted individual interviews with physicians in different specialties (cardiology, general physicians and general practitioners) and at different specialty levels (cardiology registrars). Furthermore, this was also the first study that used an IPA method and conducted individual interviews with patients who accepted, refused and discontinued OAC for AF. Working with both data sets alongside each other enabled an in depth reading of both sides of the health professional-patient relationship and the unpacking of the concepts of compliance and adherence as experienced in the consultation. The design was such that small homogeneous groups made up sub samples. This meant the commitment to idiography, central to IPA, was maintained while facilitating the exploration of accounts from a varied sample. In the development of methods, IPA is still relatively young, it is important to entertain creative designs (Smith et al., 2009). Indeed, rather than rigid adherence to a specific research design, Popay, Rogers & Williams (1998, pp.346) argue that, “the hallmark of good qualitative methodology is its variability, rather than its standardisation”. Presenting the experiences of participants from different groups side by side served to illustrate the complexity of the sense-making process, and how it can be influenced by a multitude of personal, social, or historical factors as well as the interactional quality of the consultation itself.

This study is also subject to some limitations, which need to be taken into account. Interviews were conducted with different participants during the same period. The study could have adopted a serial design by first interviewing all patient groups and then using those data during the physician interviews to elicit discussion, instead of case scenarios. However, case scenarios facilitated discussion with physicians about their own past experiences of communicating with patients; whereas using patient interviews as data could have lead the physicians to take a defensive role in trying to reply to the patients' perceptions.

It is important to consider the role of the researcher's interpretations on the analysis. As highlighted at the beginning of the research process, the results are a co-construction between the participant and the analyst (Smith & Obsorn, 2003; Smith et al., 2009), and these findings therefore present just one interpretation of the data, and as emphasised above remain tentative, emergent, open and uncertain (Finlay, 2008). However, frequent discussions with the supervisory team acted as a validity check by reflecting on how the themes and experiences were interpreted.

As discussed in the methodology chapter (see section 3.4.1) the aim of qualitative research is not generalisability as understood in nomothetic research. Nevertheless, theoretical transferability is possible (Smith et al., 2009). In quantitative work generalizability is based on statistical assumptions, i.e. the study sample is matched to the target population at large ensuring comparability of demographic characteristics and, if done correctly, then it is assumed that the findings from the sample are generalizable. In qualitative work, however, participants are selected by means of purposive sampling, i.e. for their ability to provide information about the phenomenon under investigation. Situational, rather than demographic, representativeness is what is sought. It may be said, then, that generalizability in qualitative research refers to the extent to which theory developed within one study may be exported to provide explanatory theory for the experiences of other individuals who are in comparable situations (Smith et al., 2009). This position is supported by the comments of Popay et al. (1998, pp.348) on the subject of generalizability, who emphasize that, '...the aim is to make logical generalizations to a theoretical understanding of a similar class of phenomena rather than probabilistic generalizations to a population'.

6.6 Reflexivity

As with the previous reflexive account, this section will also be written in the first person.

6.6.1 Reflexivity during data collection

6.6.1.1 Patients' data collection

Conducting interviews with patients was something I looked forward to since I had started reading about AF and OAC, I wanted to understand their side of the story, how they felt, what influenced them, their experiences. The first patients I interviewed were those who had accepted warfarin as their OAC medication. What I experienced during these interviews was not something I had expected. Even though the literature I had read showed that because of warfarin's side-effects, patients had some concerns, in my mind I was expecting that these patients would have accepted warfarin through a shared decision making process with their physician. However most of these patients, and later I found that most of the patients in the study, commented that they perceived their consultation as paternalistic, with the physician taking the decisions based on the trust they the patient had placed in them, and for some because they were not given any alternative. In later interviews with patients who refused warfarin, I also found it interesting how even in this group they mentioned that their perception of a paternalistic approach had an influence on them. Patients who refused OAC were also more difficult to invite to participate than patients who accepted OAC. I had to assure some of them about the aims of the study before the interview. Patients who discontinued OAC were the most difficult to recruit.

Some patients had asked me if they could also bring their partner to the interviews. I had reflected about this and thought that during a normal consultation, significant others would sometimes be present, so I did not refuse. In addition having their partners present during the interviews, I felt that they added to the experience. I had explained that the main focus of the interview was about the AF patient and the experience of AF and OAC however, if they had something to add to the experience of the consultation they were free to do so as they would do during the consultation.

Throughout this programme of work, this reflective journal and supervisory discussions were critical in helping me keep in mind that the patients' accounts of their experiences during the consultation with physicians were their

perceptions, it is how they perceived and remembered their experience. Through the interviews I felt I could connect with the patients and I could empathise when they disclosed some of their experiences with their significant others. I clearly remember almost all the interviews with the patients. I think that sometimes their pain transferred on to me and I think it showed at times. I remember how Jonas told me about his mother's experience of stroke and how he took care of her for 17 years and I think he could hear that I could not speak because of the knot I felt in my throat. Similarly, when Lionel burst into tears while talking about his fear that one day his partner might have to take care of a "cabbage" if he had a stroke, and when Fiona talked about her children. However there were also some positive and fun interviews. I really connected with Daniel, even though there was more than a span of 50 years and even though during his and other older patients' interviews they sometimes went off on a tangent and talked about their younger days, I felt at ease. On doing past interviews with older people I found that this was a very good way to build 'rapport' in that short period of time and that in doing so, participants felt more at ease in disclosing their experiences with me. At the end of the interview Daniel told me to "feel free to call him for a chat again". Positive instances like these encouraged me during the study.

6.6.1.2 Physicians' data collection

The first set of interviews conducted with the physicians were a bit daunting. The first interview was conducted with one of the consultant cardiologists and I felt somewhat anxious. This was something that I noticed during all the interviews with the consultant cardiologists. I think that this was due to the fact that I perceived them as the experts on AF and that I felt as if I was a young student in health psychology that could not offer anything more than what they already knew. However, this feeling subsided when I did Peter's and Melanie's interviews, probably because of the interest they showed in the study and also because they smiled a lot.

Consultant general physicians were also happy to help with the study. However, like with some of the consultant cardiologist I felt I was intruding on

their time. One of the participants also kept on asking me how long the interview was going to take, even just 10 minutes into the interview. Interviewing general physicians I had the feeling that they struggled with the available time more than the cardiologists. During the interviews of both cardiologists and general physicians, I sometimes felt that they thought I was testing them on their knowledge which influenced me in explaining to the participants before the start of the interviews that I was not looking for right or wrong answers, but rather experiences, beliefs and perceptions. Another issue I struggled with during the interviews with physicians was to help them focus on their experiences rather than just evidence and facts. Case scenarios helped during this process. I think providing case scenarios helped the physicians remember their own particular cases which they sometimes discussed. However, before I started the case scenarios I always pointed out that I was not searching for a right answer but rather they were there to help them in focusing on their experience.

Amongst all the physician interviewees, I felt most comfortable with registrars and general practitioners. This was probably because of the smaller age gap that there was between registrars and myself. I think registrars were also the most at ease during the interviews than the other physicians. General practitioners were very accommodating and made me feel comfortable. I only interviewed one general practitioner during his office hours, and even though he asked me in the beginning how long the interview was going to take, he did not put the same pressure on me as the general physician I mentioned previously. In addition, before the interviews with the other general practitioners, they showed me around their GP surgery.

During the interviews with the physicians I had already started to notice the continuous use of the word compliance. Furthermore I started to notice a trend towards paternalism. However, I kept in mind a comment which Paul Flowers made during an advanced IPA workshop. He said that we should not start analysing participants' anecdotes during the interviews themselves, so I postponed thinking about this paternalistic attitude until later in the analysis. However, after the first seven interviews, I was sometimes torn between

thinking that a paternalistic attitude was important for the patients' benefit as sometimes patients might not be able to make the best decision for their health. Keeping a reflective journal helped me in thinking through these thoughts and helped me to better understand who I am by engaging and becoming accustomed to reflexive practice. Writing my thoughts and decision making down in the journal helped me understand how and why I took certain decisions. For example when Lionel started crying, through reflection, I understood what counter-transference meant. When Lionel became emotional, I was becoming emotional as well from the feelings that I was getting when remembering my experience with my grandmother's stroke. Furthermore, although I had come to the conclusion that a paternalistic approach was not the answer to better patient adherence, I still remain fascinated by how easy it was to fall for the lure of a paternalistic approach (in thinking that patients might not be able to take the best decisions for their own health).

6.6.2 Reflexivity during analysis

I added reflections from my journal such as thoughts, questions, doubts and trends. Reflexive note-taking continued throughout the rest of the analytical steps. The reflective journal I had kept during the interviews helped to refresh my memory regarding my own evolving beliefs and perceptions during the data collection process, and helped keep track of my interpretations during analysis. Needless to say, the journal, although full of rough notes and sometimes incomprehensible phrases, was a critical feature to cope with the multitude of data throughout each analytical step, especially when synthesising the single groups (patients who accepted, patients who refused, patients who discontinued, cardiologists, registrars, general physicians, general practitioners) and even more crucial when synthesising the analysis across the individual studies (the patients' study, and the physicians' study). Using mind-maps were another critical feature that made analysis easier, clearer and more comprehensible especially during supervisory discussions. The reflexive activity together with the supervisory discussions provided opportunities to think about new emerging connections between themes, or possible alternative interpretations. Furthermore, I felt that these meetings were crucial for me as a

researcher to help control the level of interpretation, in terms of not being over interpretative and make assumptions which were not based on evidence, as well as generalising to all participants too early in analysis process.

6.7 Conclusions

This study examined the experiences of patients and physicians with regards AF and OAC treatment. This examination included experiences during the consultation, such as patient assurance, patient education, and communicating risk, and how physicians' skills in communication had an influence on these experiences. Key challenges faced by AF patients and physicians were also highlighted. These comprised the issue of time within the consultation, physicians' adherence to guidelines, the influence of AF and OAC on the patients' lived experience and the perceptions of warfarin and aspirin. This qualitative study has highlighted the need for implementation of a shared-decision making process where the individual patient's values and past experiences are taken in consideration when deciding upon treatment.

6.7.1 Research recommendations

Future studies need to explore the effects of patient reassurance within an AF consultation on OAC acceptance. Research into health literacy is an area that requires development especially for people from different cultures, non-English speaking people, those with cognitive impairment and low/no literacy levels which demand the development of appropriate non-traditional educational resources. Research is also needed to explore the influence and role the media plays in shaping perceptions of OAC treatment.

Observational studies could further help understand the dichotomy of perceptions (patients vs. physicians) on decision making within AF consultations. Observational methodologies could explore experiences of patients and physicians that were present within the same consultations. In addition these studies could also be used to aid understanding of the models of decision making being used. Researchers could also explore the how skills

learnt from motivational interviewing (MIInt) could impact the consultation in motivating passive patients to participate in decision making. MIInt is a goal-oriented, client-centred counselling style for helping clients to explore and resolve ambivalence about behaviour change which has been incorporated across diverse populations, settings and health topics (Rollnick, Miller & Butler, 2008). The efficacy of MIInt was first demonstrated in the treatment of addictions, such as illegal drugs and alcoholism, however two meta-analyses (Hettema, Steele, & Miller, 2005; Rubak, Sandbaek, Lauritzen, & Christensen, 2005) have consolidated the evidence of this client-centred approach and have shown it to be effective in improving well-being, promoting exercise and smoking cessation, improving dietary lifestyle, encouraging medication adherence and managing chronic conditions such as hypertension, hypercholesterolemia, obesity and diabetes (Hettema et al., 2005; Rubak et al., 2005). Observational studies could also investigate the impact of time within the AF consultation, comparing longer consultations with more 'meaningful' consultations on patient satisfaction.

Having significant others present in some of the patient interviews emphasised the need to explore the perceptions of family on OAC and how their perceptions have an influence on the AF patient. Researching the family's experiences and perceptions of OAC would provide further context and add to this research. In addition, there is the need to study the impact of social support from significant others on AF patients' experience and acceptance of warfarin.

The investigation of continuous educational support was also recommended by patients in this study. There is the need to study the impact of education on AF patients and their ability to recall information on a long term basis. Interviews showed that some patients were still confused on certain issues related to warfarin, for example the dietary limitations. Studies exploring educational interventions are also warranted with physicians, such interventions could explore communication skills as well as incorporating skills from behaviour change techniques such as motivational interviewing. In addition, educational interventions could be devised that focus on increasing knowledge and

ameliorating adherence to guidelines in general physicians and general practitioners.

6.7.2 Practical recommendations

This study has assisted in giving a voice to the AF patients' and physicians' experiences, providing examples of good and bad practice and experience. It has also identified areas for improvement in relation to patient-physician consultations regarding AF and OAC treatment decisions.

This programme of work has shown that health professionals play a crucial role in on-going educational support towards patient education. Patients could be referred to such an educational service immediately after their initial consultation where health psychologists, or health care assistants trained in appropriate behaviour change techniques, could go over educational material with patients and where time is given to patients to voice their concerns. Such theory-led and evidence-based programmes could target patients' confidence in communicating with health care professionals, and their skills in self-management as well as providing accessible information about OAC and AF.

There is also a need to increase physicians' communication skills. In particular the awareness of the diversity of learning styles, an awareness of cultural diversity and the use of differing modalities in educational delivery. Health literacy needs consideration together with the development of tools that are culturally and intellectually sensitive with alternative learning modalities. In addition, physicians need to be aware of individual patient values, beliefs and past experience during the consultation. For example, patients with past experiences of stroke through family or friends may be more influenced by increased knowledge of warfarin's benefits in reducing strokes. Furthermore, clinical guidelines need to be tailored towards specialty level, thus facilitating OAC management and providing clear roles for each specialty level. Physicians also need to be aware of the risks or negative consequences that may result from their behaviour, so that they do not transfer their anxiety on to the patients. Physicians need to be educated on the benefits of treatment using

psycho-social techniques, persuasion techniques, and motivation-enhancement methods. Also, physicians must be educated about their decision biases and the inconsistency of these biases with best practice.

This qualitative research has found that educational efforts can be focused on physician concerns, prescribing barriers, and system specific challenges. Physicians need to know that their concerns are acknowledged and understood and that any solutions proposed will be relevant to their situation. Educational interventions also need to emphasise skills needed by physicians to help enhance patient engagement and adherence concerning diet and regular INR testing. Finally, on-going education, monitoring and feedback systems are not only warranted in patients, but also in physicians, especially in primary care. General practitioners could be encouraged to maintain contact with secondary care to increase confidence in the initiation of OAC prescription.

There is also a need to increase awareness in patients with regards to the possibility of INR testing in GP surgeries. Furthermore, awareness and knowledge of AF and warfarin should be increased in the general population through the media, so as to minimise myths and connotations associated with warfarin. This increase in awareness could also help to improve AF patient support from work colleagues and employers, especially when the patient needs to attend appointments for INR testing. In addition, patients who are still employed should be made aware of the benefit of the new OACs (i.e. that they do not need INR monitoring) however they should also be advised about their risks (i.e. the lack of antidote).

6.7.3 Conclusion

This programme of work has used an innovative bolder IPA design to explore the patients' and physicians' experiences of AF and OAC. It has shown the patients' and physicians' different experiential perceptions of the consultation. While most patients perceived the consultation as taking a paternalistic approach to decision making for OAC, physicians showed that although they tried to take a shared approach to decision making, because of certain

challenges including time, language and trust from the patient, they ended up taking a paternalistic route and taking the decision themselves. Interestingly this paternalistic approach was the main influence for most patients to either accept or refuse warfarin as their OAC medication. This study also showed that patient education is still lacking as can be seen from patients' lived experience while on OAC and physicians' lack of guidance on how to provide appropriate education. There is also a need to shift the physicians' perceptions of the connotations associated with patient compliance towards an approach which highlights concordance.

This study has also showed how the perception of time had an impact on the quality of the consultation. Both physicians and patients believed that time spent in the consultation could be used to better advantage. Difficulty in adhering to guidelines was reported as a challenge to general physicians and general practitioners. Finally, this programme of work has uncovered patients' perceptions of warfarin and aspirin, i.e. the perception that 'old' in relation to aspirin treatment means safe and tested, while in relation to warfarin treatment it inferred outdated and unsafe. Likewise, patients were aware that aspirin was natural, while they were not aware of warfarin being made from natural products. In addition the lack of awareness on warfarin was negatively influencing patients before they attend to a consultation.

This programme of work has illustrated the benefit of taking an in depth phenomenological approach to understanding the lived experience of the physician- patient consultation. Together with the meta-synthesis of qualitative evidence, this work has strengthened the evidence base and demonstrated that there is a need to target patients' and physicians' ability to communicate with each other in a comprehensible way; patients require support to become active in the consultation while physicians need to work on ways of communicating complex material in an accessible manner.

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Appendix A: Meta-synthesis search strategy

1. ATRIAL FIBRILLATION
2. atrial flutter
3. atrial*
4. (atrial next fibrillation)
5. cardiac arrhythmia
6. (cardiac next arrhythmia)
7. heart rhythm disturbance
8. (heart next rhythm next disturbance)
9. irregular heart rhythm
10. heart rhythm *
11. supraventricular arrhythmia
12. arrhythmia*
13. (#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12)
14. ANTICOAGULANT THERAPY
15. oral anticoagulation
16. coagu*
17. anticoagulants*
18. vitamin K antagonist
19. ethyl biscoumacetate
20. blood thinner
21. warfarin
22. clopidogrel
23. plavix
24. enoxaparin
25. lovenox
26. clexane
27. acenocoumarol
28. sintrom
29. sinthrome
30. jantoven
31. marevan

32. waran
33. phenprocoumon
34. marcoumar
35. marcumar
36. falithrom
37. phenindione
38. clorindione
39. tioclomaro
40. bishydroxycoumarinl
41. dicumarol
42. dicoumarol
43. coumadin
44. aspirin
45. acetylsalicylic acid
46. (#14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45)
47. (#13 and #46)
48. Qualitative*
49. Finding*
50. Interview*
51. Thesaurus terms: Interviews
52. (#48 or #49 or #50 or #51)
53. (#47 and #52)

Appendix B: CASP (CASP, 2006) table for quality in papers included in meta-synthesis

	Howitt & Armstrong, 1999	Dantas et al., 2004	Fuller et al., 2004	Lipman et al., 2004
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes
3. Was the research design appropriate?	Yes – no justification given for the choice of research design	Yes – authors mentioned how qualitative methods could be more valuable in this study than quantitative methods	Yes - The idea of using pictograms and later participants encouraged to discuss their decisions about treatment in more detail is appropriate. However, participants were not patients who suffered from AF, so their decisions could have been affected by the fact that they did not go through the same experiences as actual patients. Furthermore the researcher did not justify	Yes – authors gave justification for the design

			this issue.	
4. Was the recruitment strategy appropriate?	Yes - authors gave a detailed account of the recruitment strategy	Yes - authors gave a detailed account of the recruitment strategy.	Yes - authors discussed briefly inclusion and exclusion criteria, however they did not describe the recruitment process	Yes – authors gave a detailed account of the recruitment strategy
5. Was data collection appropriate?	Yes – authors gave no information on the interviews (whether recorded, semi- or structured etc)	Yes – authors gave details and justification for data collection method, setting and saturation of data	Yes - Interviews and a questionnaire were used to collect data. The authors did not mention if they used a topic guide. Only that the participants were encouraged to talk about their decision. Furthermore, there is no description of the actual interview.	Yes - Authors gave detailed account of the settings from where the participants were recruited. Audio recorded semi-structured interviews were used to collect data. Furthermore the authors gave in-depth information on how the interviews were conducted. In addition the authors discussed saturation of themes
6. Has the relationship between researcher and participants been adequately considered?	No - authors did not discuss their role in sample recruitment, choice of location and formulation of research question.	Yes – discussed how the risk of bias during interviews was minimised. Moreover, interviewers were blind to interviewees' INR status.	No - Authors did not discuss the relationship between the researcher and participants. Neither did they discuss their role in sample recruitment and choice of location	Yes - Authors discussed how measures were taken to minimise bias during the interviews. However, authors did not discuss bias during research question formulation, choice of location and participant recruitment.

<p>7. Have the ethical issues been taken into consideration?</p>	<p>Authors only mention the exclusion of participants who could not give consent and that study was approved by the local research ethics committee. Letter was sent explaining study if agreeable to patients.</p>	<p>No ethical issues apart from informed consent and approval by the Research Ethics Board of the host institution were mentioned</p>	<p>Authors mentioned that participants consented to participate, however they did not say if it was informed consent. The REC approved this study. However the authors did not discuss any other ethical issue</p>	<p>Informed consent - GPs contacted by E-mail, given an outline of the proposed research and its background, and invited to contact TL if they were willing to be interviewed.</p> <p>Confidentiality – was only towards (patients' aide memoirs) apart from that authors did not mention if the study was assessed by an ethical body and no other ethical issue was discussed</p>
<p>8. Was the data analysis sufficiently rigorous?</p>	<p>No detail regarding data analysis was mentioned in the study; No mention of rigor or validity or trustworthiness issue in the study</p>	<p>Authors mentioned that content analysis was used to analyse data. Team analysis was conducted + discussion. Furthermore, they gave a detailed account of the coding process.</p>	<p>A very brief description of the analysis method was given (just one sentence). Authors mention triangulation with regards rigour, however they did not mention the process.</p>	<p>Researchers described in detail the analysis process. The authors discussed the issue of bias during analysis. Shared assumptions between interviewer and participant may have led to some issues not being explored. Not much interpretative commentary included, furthermore it's not easy to see constructivist approach.</p>

9. Is there a clear statement of findings?	No – authors have not discussed the credibility of their findings	Yes - The findings in this study are clear. Furthermore the researchers have discussed validity issues that would increase their credibility, such as having more than one analyst and their limitations	Yes – Clear findings. Furthermore authors discussed validity issues (though not the process) and their limitations.	Yes - The findings in this study are explicit. Furthermore the researchers have discussed rigour issues – use of Potter and Wetherell’s criteria for validity in qualitative research.
10. How valuable is the research?	A lot of issues associated with qualitative studies’ methodology were not covered. However authors discussed limitations and importance of the study	Importance in illustrating experience, however study was not exploratory/experiential enough because of the use of pre-coded themes. Imp in illustrating decision making style during consultation	The study highlights the importance of clear explanation of risks through pictorial info (more easily understood) and willingness to trade risks (bleeding/stroke). However patients in study do not have AF, so it is based on a “what if” scenario and authors do not justify their choice of patients.	The figures that show what influences GPs’ choice of treatment (figure 2 and 3) give an idea of the plethora of things that have an effect on decision making. However it looks too complicated. Other studies might simplify this. Importance of GPs interpretation of evidence and the significance of accuracy in INR.

	Bajorek et al., 2006	Anderson et al., 2007	Bajorek et a., 2007	Wild et al., 2009
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes
3. Was the research design appropriate?	Yes - The authors have justified the suitability of the design	Yes - The researcher has justified the research design	Yes - The authors did not justify the suitability of the design. However it was appropriate.	Yes - The authors have justified the suitability of the design
4. Was the recruitment strategy appropriate?	Yes - Researchers gave a detailed account of the recruitment strategy	Yes - The researchers did not explain how the participants were selected. Neither did they mention the sampling method. However, the participants included in this study were appropriate to provide access to the type of knowledge sought.	Yes - Researchers gave a detailed account of the recruitment strategy	Yes - The researchers gave a detailed account of the recruitment strategy

<p>5. Was data collection appropriate?</p>	<p>Yes – authors justified the data collection method. In addition the authors gave detailed information how the focus group was carried out</p>	<p>Yes - Audio recorded semi structured interviews were used for data collection. The author has also justified this method. The authors did not mention the use of a common topic guide in all interviews. Authors also mentioned theoretical saturation.</p>	<p>A series of audio recorded group interviews (focus group) were the method used for data collection. In addition they gave a brief description on how the focus group was carried out. Individual interviews would have been better. Consultants & registrars in the same group which may impact on honesty.</p>	<p>Yes – data collection was appropriate. With detailed information on how interviews were carried out</p>
<p>6. Has the relationship between researcher and participants been adequately considered?</p>	<p>Yes - In their limitations the authors discussed researcher's bias. However, They did not discuss their role in sample recruitment and choice of location.</p>	<p>No - Authors did not discuss the relationship between the researcher and participants. Neither did they discuss their role in sample recruitment and choice of location.</p>	<p>No - The authors did not discuss their role in sample recruitment, choice of location and formulation of research question</p>	<p>No – the authors did not discuss their role in sample recruitment, choice of location and formulation of research questions</p>

<p>7. Have the ethical issues been taken into consideration?</p>	<p>Authors mentioned that participants gave informed consent and that the study was approved by the institutional human research and ethics committee. No other ethical issues apart from informed consent were mentioned.</p>	<p>The authors did not discuss any ethical issues, like informed consent or confidentiality. However they mentioned that, "Ethics committee approval was secured"</p>	<p>Authors mentioned that participants gave informed consent, that participating was voluntarily and that the study was approved by the Northern Sydney Health Ethics Committee. Anonymity not mentioned.</p>	<p>Authors mentioned that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations and also informed consent was obtained from the participants involved.</p>
<p>8. Was the data analysis sufficiently rigorous?</p>	<p>Researchers mentioned that thematic analysis with a phenomenological approach was used to analyse the data. However not much detail is given on the process.</p>	<p>An in-depth description of the analysis process (grounded theory), is given in the paper. Additionally authors gave an account of the rigour issues in both their methods section and at the end of the discussion section.</p>	<p>Phenomenology described briefly without giving a lot of detail (Husserl/ Heidegger). Member validation for accuracy does not fit phenomenology.</p>	<p>Researchers mentioned that thematic analysis was used. Detail is also provided on the process of coding of interviews into ATLAS.ti.</p>

<p>9. Is there a clear statement of findings?</p>	<p>The findings in this study are explicit. Furthermore the researchers have discussed rigour issues that would increase their credibility, such as triangulation of data with the literature, user verification, having more than one analyst</p>	<p>The findings in this study are explicit. Furthermore the researchers have discussed rigour issues that would increase their credibility. Good interpretative commentary.</p>	<p>The findings in this study are explicit. Furthermore the researchers have discussed rigour issues that would increase their credibility, such as triangulation of data with the literature, user verification, having more than one analyst.</p>	<p>The findings in this study are explicit. Furthermore the researchers have discussed rigour issues that would increase their credibility, such as recoding by an independent researcher</p>
<p>10. How valuable is the research?</p>	<p>Study highlights nurses' lack of knowledge and power with regards warfarin prescription. The study shows the importance of nurses to help patients because of their special relationship and that they are an underutilised resource.</p>	<p>Significant findings that focus on physicians in unusual but necessary in this area. Authors discuss these findings with the available literature. The researchers also mentioned that findings are not generalisable. Physicians are not heuristic in their decision making but are uncertain in decisions/lack knowledge</p>	<p>The study demonstrates the importance of communication between health professionals. Guidelines need to be publicised and made relevant for them to be used effectively by several health professionals.</p>	<p>The study highlights patients experience with OAC and hypothetical new drug without OAC drawbacks.</p>

	McCabe et al., 2011b	Murray et al., 2011
1. Was there a clear statement of the aims of the research?	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes
3. Was the research design appropriate?	Yes - The authors have justified the suitability of the design	Yes – The authors have justified the suitability of the design
4. Was the recruitment strategy appropriate?	Yes - Researchers gave a detailed account of the recruitment strategy	Yes - Researchers gave a detailed account of the recruitment strategy
5. Was data collection appropriate?	Yes – authors did not justify the method for data collections, however it was appropriate. In addition the authors gave detailed information how the interviews were carried out	Yes - authors did not justify the use of qualitative data collection method, and the use of telephone interviews instead of face-to-face. In addition the authors gave some detail on how the interview guide was developed and how the interviews were carried out.

<p>6. Has the relationship between researcher and participants been adequately considered?</p>	<p>Yes – Authors mentioned that “prior and throughout the study, the primary investigator sought to identify and record her opinions and perceptions in regard to living with AF to heighten self-awareness and examine their influence on data analysis.” However, they did not discuss their role in sample recruitment and choice of location.</p>	<p>No - Authors did not discuss the relationship between the researcher and participants. Neither did they discuss their role in sample recruitment and choice of location.</p>
<p>7. Have the ethical issues been taken into consideration?</p>	<p>Authors mentioned that participants gave informed consent and that the study was approved by the institutional human research and ethics committee. No other ethical issues apart from informed consent were mentioned.</p>	<p>The authors did not discuss any ethical issues, like informed consent or confidentiality. Authors only mentioned that the study was approved by an independent ethical committee.</p>

8. Was the data analysis sufficiently rigorous?	Researchers gave a detailed description of the analysis process. Though no formal name was given to the method of analysis. Authors also discussed their role in potential bias during analysis and gave sufficient data.	Researchers gave a detailed description of the analysis process. Authors mentioned that open coded based on their own developed conceptual framework was initially used, followed by selective coding. However authors did not present sufficient qualitative data.
9. Is there a clear statement of findings?	The findings in this study are explicit. Furthermore the researchers have discussed trustworthiness issues that would increase their credibility, such as having more than one analyst, auditability of process, and member verification with 6 participants after initial analysis.	Researchers have discussed trustworthiness issues that would increase their credibility, such as having more than one analyst, and triangulation of data.

10. How valuable is the research?	Study is valuable. It is the first qualitative study that describes in depth the experiences of patients with symptomatic AF.	Study is valuable as it highlights physicians' educational gaps and the need for professional development
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Appendix C: Patient Participant Information Sheet

Participant Information Sheet

Part 1

Title of Main Project: Patients' and physicians' experiences of atrial fibrillation and anticoagulant therapy: a qualitative journey

Study 1: Patients' experiences of warfarin

Dear Patient

We would like to invite you to take part in a study. Before you decide it is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. **Part 1** deals with the information about the purpose of this study and what will happen to you if you decide to take part. **Part 2** gives you more detailed information about the conduct of the study. Please Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of this study is to explore the experiences which influence a patient's decision to accept or decline warfarin as their blood thinning medication. We would like to talk to you to explore your experiences and what had an effect on your decision in accepting or declining warfarin as your blood thinning treatment. We will also explore the effect that this decision has had on your everyday experiences following your diagnosis of atrial fibrillation.

Why have I been invited?

You have been asked to take part in this research study because you have atrial fibrillation (an irregular heart rhythm). This means that your heart does not beat in a regular rhythm, some or all of the time. As your physician will have explained to you, having atrial fibrillation can increase your risk of having stroke (a blood clot in your brain). Other conditions, such as having high blood

pressure, diabetes, heart failure, having had a previous stroke or mini stroke (transient ischaemic attack) and being 75 years of age or older, can further increase your risk of having a stroke. Your physician has offered you treatment with a blood-thinning medication called warfarin, to decrease your risk of a blood clot forming and reduce your risk of having a stroke. Your experiences that had an influence on your decision whether to accept or refuse warfarin as your blood thinning medication are important to us. So we would like to know what influenced your decision to accept or decline treatment with warfarin.

Do I have to take part?

It is up to you to decide whether or not to take part in the study. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show that you have agreed to take part. If you decide to take part, you are still free to change your mind at any time during the interview and up to two weeks following it and stop taking part in the study, and you do not have to give a reason. Your decision will have no bearing on your medical treatment.

What will happen to me if I take part?

If you agree to take part in this study you will be asked to attend the ASCOT centre on one occasion. The researcher will ask you to sign a consent form to state that you agree to take part.

After you have signed the consent form, an interview will take place in a quiet room in Ascot Centre. The interview is likely to last around 90 minutes. Before the interview, the researcher will explain how the interview will run and at the end of the interview there will be an opportunity for you to ask questions. The interview will be audio recorded so that the researcher can write down what you said word-for-word following the interview and analysed later on. The interview will explore your experiences of having atrial fibrillation and what influenced your decision to accept or refuse warfarin as your blood thinning medication.

Expenses and payments

We will reimburse your travel expenses (bus fare, taxi, fuel allowance and parking) for your visit to the hospital to take part in the interview

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks to you in taking part in this study. This study is exploring your experiences about living with atrial fibrillation and your decision to accept or refuse warfarin. However, since we would like you to talk about your AF and blood thinning therapy, we understand that issues may arise that may be upsetting. The researcher is experienced in dealing with sensitive issues and will let you decide whether or not to carry on with the interview should you become upset. The researcher will debrief you at the end of the interview and give you contact numbers if you would need to discuss your feelings or your treatment further.

What are the possible benefits of taking part?

We cannot promise that the study will have any benefits. However qualitative interviews give the participants an opportunity to have their voices and problems heard. Thus the interview in itself may help you think about your condition, its treatment and anything else related to your atrial fibrillation.

What happens when the research study stops?

At the end of the study, what you said in the interview will be written down word for word so that we can look at it in more detail later on. If you would like to know about the results of the study you are free to ask for a copy of a summary of findings.

What if there is a problem?

If you experience any problems or have any concerns, please contact one of the people listed in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering taking part, please read the additional information in Part 2 before making any decision.

Part 2

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

You can withdraw from the study at any point during the interview and up to two weeks following it.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to one of the researchers who will do their best to answer your questions (contact Mr. Christian Borg Xuereb (0121-507-5053), Dr. Rachel Shaw (0121-204-4050), or Dr. Deirdre Lane (0121-507-5080). If you remain unsatisfied and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital Complaints and Litigation Department on 0121-507-4346.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence than you may have grounds for a legal action for compensation against *Sandwell and West Birmingham Hospitals NHS Trust* but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

If you join the study, some parts of the data collected for the study may be used as direct quotes in the results section of any published material. However, your name will not appear anywhere in the research and any material that can lead to your identity will not appear anywhere in the results or any publishable material. A pseudonym will be used instead of your real name in the study. The data may also be looked at by representatives of regulatory authorities and by people authorised to check that the study is being carried out correctly. However, we all have a duty of confidentiality to you as a research participant and no identifiable material will be disclosed.

What will happen to the information I give?

As mentioned above, all information that is collected about you during the course of the research will be kept strictly confidential. The content of the interviews will be kept in a secure location within the hospital and data stored on computers will be anonymised (using your assigned pseudonym) and the computers will be password protected. Only the researchers will have access to this data.

What will happen to the results of the research study?

At the end of the study, we hope to publish the results. You will not be identified in any report or publication. If you wish, we will send you a summary of our findings.

Who is organising and funding the research?

This research is being organised by Aston University and the Centre for Cardiovascular Studies, City Hospital. The study is being funded by Aston University to cover the running costs of the study. No payments will be made to members of staff involved in this study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being, and dignity. This study has been reviewed by the South Birmingham Research Ethics Committee and the Aston University LHS Ethics Board.

Further information and contact details

If you have any questions about the study, please call the person listed below. They will answer your questions or give you advice.

Chief Investigator:	Mr. Christian Borg Xuereb	0121-507-5053
	Dr. Rachel Shaw	0121-204-4050
	Dr. Deirdre Lane	0121-507-5080

If you have any concerns about this study, please call Balvinder Baines (R&D department on 0121-507-4946).

Thank you for taking the time to read this Patient Information Sheet and considering whether to take part in the study.

Appendix D: Physician Participant Information Sheet

Participant Information Sheet

Part 1

Main Study title: Patients' and physicians' experiences of atrial fibrillation and anticoagulant therapy: a qualitative journey

Study 2: Physicians' experiences of warfarin prescription

Dear Doctor

We would like to invite you to take part in this qualitative study. Before you decide it is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. **Part 1** deals with the information about the purpose of this study and what will happen to you if you take part. **Part 2** gives you more detailed information about the conduct of the study. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of this study is to describe the experiences and perceptions of doctors in prescribing warfarin to discover what influences their decisions to prescribe warfarin to patients with atrial fibrillation. Case scenarios will also be used to encourage discussion. This study will also explore whether your clinical experience (years in practice and/or specialist training) influences your warfarin prescription.

Why have I been invited?

You have been asked to take part in this research study because you had previous experience in deciding whether or not to prescribe warfarin to patients with atrial fibrillation. This study will explore what experiences and perceptions influenced your decision in prescribing warfarin or not to AF patients and therefore your experiences are invaluable to this study.

Do I have to take part?

It is up to you to decide whether or not to take part in the study. We will describe the study and go through this information sheet, which we will then give to you to read. We will then ask you to sign a consent form to show that you have agreed to take part. If you decide to take part, you are still free to change your mind at any time during the interview or up to two weeks following it and stop taking part in the study, and you do not have to give a reason.

What will happen to me if I take part?

After you have signed the consent form, an interview will take place in a quiet room wherever you feel most comfortable. This can either be in the ASCOT centre, City Hospital, or at Aston University or in your own office. The interview is likely to last around 90 minutes. The interview will be audio recorded so that it can be transcribed verbatim and analysed later on. The interview will explore your experiences and what influences you when you decide to prescribe someone with warfarin or not. Case scenarios will also be explored during the interview to facilitate discussion.

Expenses and payments

You will have your travel expenses (taxi fare or fuel allowance and parking) reimbursed if you have to come to City hospital or Aston University for the interview.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks to you in taking part in this study. This study is exploring your perception and experiences in prescribing warfarin to patients with atrial fibrillation. However, you may be concerned about confidentiality or divulgement of details. This issue is tackled in Part 2. The researcher will debrief you at the end of the interview and give you contact numbers if you need to discuss these feelings further.

What are the possible benefits of taking part?

There are no benefits to you in taking part. However qualitative interviews give the participants an opportunity to have their voices and challenges or problems heard. Thus the interview in itself may help you to reflect on your experiences and professional decision-making with regards to AF and anticoagulation therapy.

What happens when the research study stops?

At the end of the study, the interviews will be transcribed verbatim and analysed using qualitative analysis. If you would like to know about the results of the study you are free to ask for a copy of the summarised findings.

What if there is a problem?

Any complaint about the way you have been treated during the study or any possible harm you might suffer as a result of taking part will be addressed. The detailed information about this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2**What will happen if I don't want to carry on with the study?**

You can withdraw from the study at any point during the interview and up to two weeks following it without giving a reason.

What if there is a problem?

If you have any concerns about any aspect of this study, you should ask to speak to one of the researchers who will do their best to answer your questions

(contact Mr. Christian Borg Xuereb (0121-507-5053) or Dr. Rachel Shaw (0121-204-4050) or Dr. Deirdre Lane (0121-507-5080). If you remain unsatisfied and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital Complaints and Litigation Department on 0121-507-4346.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence than you may have grounds for a legal action for compensation against *Sandwell and West Birmingham Hospitals NHS Trust* but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

If you join the study, some parts of the data collected for the study may be used as direct quotes in the results section of any published material. However, your name will not appear anywhere in the research and any material that can lead to your identity will not appear anywhere in the results or any publishable material. A pseudonym will be used instead of your real name in the study. The data may also be looked at by representatives of regulatory authorities and by people authorised to check that the study is being carried out correctly. However, we all have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

What will happen to the information I give?

As mentioned above, all information that is collected about you during the course of the research will be kept strictly confidential. The transcribed interviews will be kept in a secure location within the hospital and data stored on computers will be anonymised (using your assigned pseudonym) and the computers will be password protected. Only the researchers will have access to this data.

What will happen to the results of the research study?

At the end of the study, we hope to publish the results. You will not be identified in any report or publication. If you wish, we will send you a summary of our findings.

Who is organising and funding the research?

This research is being organised by Aston University and the Centre for Cardiovascular Studies, City Hospital. The study is being funded by Aston University to cover the running costs of the study. No payments will be made to members of staff involved in this study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being, and dignity. This study has been reviewed by the South Birmingham Research Ethics Committee and the Aston University LHS Ethics Board.

Further information and contact details

If you have any questions about the study, please call the person listed below. They will answer your questions or give you advice.

Chief Investigator:	Mr. Christian Borg Xuereb	0121-507-5053
	Dr. Rachel Shaw	0121-204-4050
	Dr. Deirdre Lane	0121-507-5080

If you have any concerns about this study, please call Balvinder Baines (R&D department on 0121-507-4946).

Thank you for taking the time to read this Participant's Information Sheet and considering whether to take part in the study.

Appendix E: Patient Consent Form

CONSENT FORM

Title of Main Project: Patients' and physicians' experiences of atrial fibrillation and anticoagulant therapy: a qualitative journey

Study 1: Patients' experiences of warfarin

Name of Researchers: Mr. C Borg Xuereb, Dr. R.L. Shaw, Dr D.A. Lane, Dr. H.M. Pattison, Professor GYH Lip

1. I confirm that I have read and understood the information sheet dated 24/08/09 ver. 2 for the above study. I have had the opportunity to consider the information, ask 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 understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from QED, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records.

4. I agree to take part in the above study.

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature

1 copy for patient; 1 copy for researcher; 1 copy to be kept in hospital notes

Appendix F: Physician Consent Form

CONSENT FORM

Title of Main Project: Patients' and physicians' experiences of atrial fibrillation and anticoagulant therapy: a qualitative journey

Study 2: Physicians' experiences of warfarin prescription

Name of Researchers: Mr. C Borg Xuereb, Dr. R.L. Shaw, Dr D.A. Lane, Dr. H.M. Pattison, Professor GYH Lip

1. I confirm that I have read and understood the information sheet dated 24/08/09 (ver. 2) for the above study. I have had the opportunity to consider the information, ask 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 understand that relevant sections of data collected during the study may be looked at by individuals from QED, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.

4. I agree to take part in the above study.

Name of Physician	Date	Signature
Name of Person taking consent	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature

1 copy for physician; 1 copy for researcher; 1 copy to be kept in hospital notes

Appendix G: Patient Debrief Form

Debrief form

Title of Main Project: Patients' and physicians' psychological experiences of atrial fibrillation and anticoagulant therapy: a qualitative journey

Study 1: Patients' experiences of warfarin acceptance and/or refusal

Researchers: Mr. C. Borg Xuereb, Dr. R.L. Shaw, Dr. D.A. Lane, Dr. H. Pattison, Prof G.Y.H. Lip

Thank you for taking part in this interview. The purpose of this interview was to explore your perceptions and experiences that had an influence on you when you accepted/refused warfarin as your blood thinning medication. The data collected from these interviews will be transcribed verbatim for analysis. If you wish to withdraw your data from the study please contact Mr. Borg Xuereb, Dr. Shaw or Dr. Lane (details below) within two weeks of the interview. If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings, please do not hesitate to contact us.

Thank you very much for your participation

Mr. Christian Borg Xuereb

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Dr. Rachel Shaw

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Dr. Deirdre Lane

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Tel: +44 (0) 121 507 5080 (Department PA)

Appendix H: Physician Debrief Form

Debrief form

Title of Main Project: Patients' and physicians' psychological experiences of atrial fibrillation and anticoagulant therapy: a qualitative journey

Study 2: Physicians' experiences of warfarin prescription

Researchers: Mr. C. Borg Xuereb, Dr. R.L. Shaw, Dr. D.A. Lane, Dr. H. Pattison, Prof G.Y.H. Lip

Thank you for taking part in this interview. The purpose of this interview was to explore your perceptions and experiences that have an influence on warfarin prescription. The data collected from these interviews will be transcribed verbatim for analysis. If you wish to withdraw your data from the study please contact Mr. Borg Xuereb, Dr. Shaw or Dr. Lane (details below) within two weeks of the interview. If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings, please do not hesitate to contact us.

Thank you very much for your participation

Mr. Christian Borg Xuereb

Email: christian.borgxuereb@swbh.nhs.uk

Tel: +44 (0) 121 507 5053

Dr. Rachel Shaw

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Dr. Deirdre Lane

Email: deirdre.lane@swbh.nhs.uk

Tel: +44 (0) 121 507 5080 (Department PA)

Appendix I: Study 1 Full Interview Schedules

Refused OAC

Thank you for accepting to take part in this study.

1. Can you tell me something about yourself?
 - a. How old are you?
 - b. Are you currently employed?
 - c. Where do you work?
 - d. If retired:
 - i. What was your work before you retired?
 - ii. How long have you been retired?
2. Can you tell me something about your family?
 - a. Married?
 - b. Children?
 - c. Pets?
3. What is your everyday life like?
 - a. Any hobbies?
 - b. Social activities?
 - c. Lifestyle?
4. What is your general health status?
 - a. Physical, emotional, social, mental and spiritual
5. Can you tell me about your heart condition?
 - a. What does it do to you?
 - b. What does it do to your body?
6. How does it affect your everyday life?
 - a. How do you feel about it?
 - b. Do you experience any health challenges because of AF?
 - i. If yes: Can you tell me about these experiences?
 - c. Do you have any concerns or fears about this condition?
 - i. If yes: Can you tell me about your concerns or fears?
7. Can you tell me how you got to know about your heart condition?
8. Can you speak about your experience during the consultation with the doctor?
9. What did you feel when you were told you had AF?
10. What was your family reaction when you told them about AF?
11. Do you think that AF had an effect on your quality of life?
 - a. If yes:
 - i. What changes do you think it had on you?
Physical, emotional, social, mental, everyday experiences / health?
 - ii. How has the diagnosis affected your everyday life experiences?
 - iii. Were there any changes you had to make in your everyday life from before you knew you had AF?
12. What did you feel when you were told you had to start warfarin?
 - a. Do you know what warfarin is for?
 - b. Do you know what a stroke is?

13. What experiences influenced you in declining warfarin as your blood thinning medication?
 - a. Have you ever heard any rumours about warfarin?
 - i. If yes: What do you feel about this issue?
 14. How do you feel about the fact that you decided to decline to take this medicine?
 15. Did you tell your family about warfarin?
 16. What was your family reaction when you told them about warfarin?
 - a. What about when you told them you declined warfarin as your blood thinning medication?
 17. Do you think that warfarin could have had an effect on your quality of life?
 - a. If yes: What effects do you think it could have had?
 1. Physical, emotional, social, mental, spiritual perspective?
 18. Can you speak about the support you were offered if any?
 - a. Have you asked anyone to help you?
 - b. Family/Friends?
 - c. How did this make you feel?
 19. Did you search for any information about your condition and warfarin on the internet or in the library?
 - a. What sort of information did you find?
 - b. How did this make you feel?
 20. Do you know other people that have AF and refused warfarin as well?
 - a. Have you talked to them?
 - b. How does this make you feel?
 21. Do you know other people that have AF and are taking warfarin?
 - a. Have you talked to them?
 - b. What do they say about warfarin?
 - c. How does this make you feel?
 22. How are you doing without warfarin?
 - a. Do you think you made the right choice or not?
 23. Looking back at what we talked about, is there anything you wish to add about your experience?
- Thank you for your patience

Discontinued OAC

Thank you for accepting to take part in this study.

1. Can you tell me something about yourself?
 - a. How old are you?
 - b. Are you currently employed?
 - c. Where do you work?
 - d. If retired: What was your work before you retired?
 1. How long have you been retired?
2. Can you tell me something about your family?
 - a. Married?
 - b. Children?
 - c. Pets?
3. What is your everyday life like?
 - a. Any hobbies?
 - b. Social activities?
 - c. Lifestyle?
4. What is your general health status?
 - a. Physical, emotional, social, mental and spiritual
5. Can you tell me about your heart condition?
 - a. What does it do to you?
 - b. What does it do to your body?
6. How does it affect your everyday life?
 - a. How do you feel about it?
 - b. Do you experience any health challenges because of AF?
 - i. If yes: Can you tell me about these experiences?
 - c. Do you have any concerns or fears about this condition?
 - i. If yes: Can you tell me about your concerns or fears?
7. Can you tell me how you got to know about your heart condition?
8. Can you speak about your experience during the consultation with the doctor?
9. What did you feel when you were told you had AF?
10. What was your family reaction when you told them about AF?
11. Do you think that AF had an effect on your quality of life?
 - a. If yes: What changes do you think it had on you?
 1. Physical, emotional, social, mental, everyday experiences / health?
 - ii. How has the diagnosis affected your everyday life experiences?
 - iii. Were there any changes you had to make in your everyday life from before you knew you had AF?
12. What did you feel when you were told you had to start warfarin?
 - a. Do you know what warfarin is for?
 - b. Do you know what a stroke is?
13. How did you feel while you were taking warfarin?
14. Did you tell your family about warfarin?
15. What was your family reaction when you told them about warfarin?
16. Do you think that warfarin could have had an effect on your quality of life?
 - a. If yes: What effects do you think it could have had?

1. Physical, emotional, social, mental, spiritual perspective?
17. Can you speak about the support you were offered if any?
 - a. Have you asked anyone to help you?
 - b. Family/Friends?
 - c. How did this make you feel?
18. What experiences influenced you to discontinue warfarin as your blood thinning medication?
 - a. Have you ever heard any rumours about warfarin?
 - i. If yes: What do you feel about this issue?
19. How do you feel about the fact that you decided to discontinue this medicine?
20. Did you tell your family about warfarin?
21. What was your family reaction when you told them that you were going to discontinue warfarin as your blood thinning medication?
22. Can you speak about the support you were offered after you decided to discontinue warfarin? if any?
 - a. Have you asked anyone to help you?
 - b. Family/Friends?
 - c. How did this make you feel?
23. Did you search for any information about your condition and warfarin?
 - a. What sort of information did you find?
 - b. How did this make you feel?
24. Do you know other people that have AF and discontinued warfarin as well?
 - a. Have you talked to them?
 - b. How does this make you feel?
25. Do you know other people that have AF and are taking warfarin?
 - a. Have you talked to them?
 - b. What do they say about warfarin?
 - c. How does this make you feel?
26. How are you doing now that you discontinued warfarin as your blood thinning medication?
 - a. Do you think you made the right choice or not?
27. Looking back at what we talked about, is there anything you wish to add about your experience?

Thank you for your patience

Accepted OAC

Thank you for accepting to take part in this study.

1. Can you tell me something about yourself?
 - a. How old are you?
 - b. Are you currently employed?
 - c. Where do you work?
 - d. If retired: What was your work before you retired?
How long have you been retired?
2. Can you tell me something about your family?
 - a. Married?
 - b. Children?
 - c. Pets?
3. What is your everyday life like?
 - a. Any hobbies?
 - b. Social activities?
 - c. Lifestyle?
4. What is your general health status?
 - a. Physical, emotional, social, mental and spiritual
5. Can you tell me about your heart condition?
 - a. What does it do to you?
 - b. What does it do to your body?
6. How does it affect your everyday life?
 - a. How do you feel about it?
 - b. Do you experience any health challenges because of AF?
 - i. If yes: Can you tell me about these experiences?
 - c. Do you have any concerns or fears about this condition?
 - i. If yes: Can you tell me about your concerns or fears?
7. Can you tell me how you got to know about your heart condition?
8. Can you speak about your experience during the consultation with the doctor?
9. What did you feel when you were told you had AF?
10. What was your family reaction when you told them about AF?
11. Do you think that AF will have an effect on your quality of life?
 - a. If yes:
 - i. What changes do you think it will have on you?
Physical, emotional, social, mental, spiritual
everyday experiences / health?
 - ii. How has the diagnosis affected your everyday life experiences?
 - iii. Where there any changes you had to make in your everyday life from before you knew you had AF?
12. What did you feel when you were told you needed to start warfarin?
 - a. Do you know what warfarin is for?
 - b. Do you know what a stroke is?
13. Where you offered the chance to refuse warfarin as your blood thinning medication?
14. What experiences do you think influenced you in accepting warfarin as your blood thinning medication?

15. How do you feel about the fact that now you are taking this medicine every day?
 - a. Have you ever heard any rumours about warfarin?
 - i. If yes: What do you feel about this issue?
16. Did you tell your family about warfarin?
17. What was your family reaction when you told them about warfarin?
18. Do you think that warfarin had an effect on your quality of life?
 - a. If yes:
 - i. What effects do you think it will have?
Physical, emotional, social, mental, spiritual perspective?
 - ii. How will you adapt to these changes?
 - b. Where there any changes in your everyday experiences since you started taking warfarin?
19. Can you speak about the support you were offered if any, following diagnosis of this condition?
 - a. Have you asked anyone to help you?
 - b. Family/Friends?
 - c. How did this make you feel?
20. Do you know other people that have AF and are taking warfarin as well?
 - a. Have you talked to them?
 - b. How does this make you feel?
21. Looking back at what we talked about, is there anything you wish to add about your experience?
22. Thank you for your patience

Appendix J: Study 2 Full Interview Schedule

Thank you for accepting to take part in this study.

1. Can you tell me something about yourself?
 - a. How old are you?
 - b. How long have you been practising?
2. Can you tell me something about your line of work?
 - a. What type of patients do you visit?
 - b. Did you have any specialised training in the field of AF?
 - c. What do you think about warfarin?
3. Can you speak about your experiences during the first consultation with an AF patient?
 - a. From your experience, what would be going through the patients' mind at that moment?
 - b. How do you think they feel?
4. From your experience, how would you explain atrial fibrillation to a patient?
 - a. From your experience, what would be going through the patients' mind at that moment?
 - b. How do you think they feel?
5. What kind of questions or concerns do you usually get from patients when you tell them that they have AF?
 - a. Do you have any specific experiences you would like to share?
6. Can you tell me about your experiences when you tell an AF patient that they need to start warfarin as their anticoagulant therapy?
 - a. From your experience, what would be going through the patients' mind at that moment?
 - b. How do you think they feel?
7. From your experience, how would you explain warfarin to a patient in lay man terms?
 - a. Do you talk about risk?
8. From your experience, what kind of questions or concerns do the patients put forward after telling them about warfarin?
9. How do you deal with a situation where you do not agree with the patient's decision?
10. Could you take me through your thought process when deciding to prescribe warfarin to patients with AF?

- a. Could you share some actual case experiences that you had during your career?
11. What experiences would influence your decision in prescribing warfarin or not to patients with AF?
- a. Are there any experiences related to case scenarios that you could talk to me about?
12. I have brought with me some case scenarios of AF patients, could you go through them one by one and explain to me your thoughts about their situation?
- a. What do you think would be going through the mind of the patient?
 - b. Would you prescribe warfarin?
 - c. Why?
13. What barriers do you think physicians face when prescribing warfarin?
- a. Did you experience any of these barriers?
14. How could warfarin use be improved?
15. Looking back at what we talked about, is there anything you wish to add about your experience?
16. Thank you for your patience

Appendix K: Case scenarios used in physician interviews

From: Watson, T & Lip, G.Y.H. (2006). Management of Atrial Fibrillation. *Herz*, 31(9), 849-856.

Case 1



Case 2



Case 3



Short Cases

From: Gattellari, M., Worthington, J. M., Zwar, N. A. & Middleton, S. (2008b). The management of non-valvular atrial fibrillation (NVAf) in Australian general practice: bridging the evidence-practice gap. A national, representative postal survey. *BMC Family Practice*, 9, 62.



Appendix L: An example of the data analysis from part of the transcript of an interview with a general practitioner

he addresses ① by doing ② + ③

ASYMPTOMATIC VS SYMPTOMATIC

FOLLOW UPS / PATIENT REL/ MOMETIME WITH PATIENT

IRREGULARITY OF AF → LACK OF AWARENESS

ASSUMPTION TOO

PROBING

① PATIENTS FORGET WHAT THEY'RE TOLD IN CONSULTATION 125
 126 know everything else you say to them... they almost forget... then you ask them
 127 I'm sure that if they walk out the door and see someone else and asks them, so
 128 what did the doctor say, they would say, my heart is beating irregularly, I don't
 129 remember anything else. So you again, you telling them some profound news
 130 which they may or may not be expecting. Erm its important to gage their
 131 understanding and erm, trying to get their understanding back from them and
 132 erm... as appropriate I would always try to follow them up myself or one of the
 133 other specialist.

② PATIENT UNDERSTANDING DURING/AFTER CONSULTATION 130
 131 R- So kind of erm... do you use any, any kind of... personal way how to
 132 explain it? not all diagnosis? educational material

③ UNDERSTAND THE PATIENT UNDERSTANDING 133
 134 M - I'm one that I use a lot of erm... erm leaflets and such which I print off
 135 from the internet. So I would say most of my consultations... certainly every
 136 NEW patient that I see with a particular diagnosis, I generally will always print
 137 something off. And it gives them an opportunity to just reads something that
 138 erm... is kind of vetted by a medical professional as it where. As opposed to just
 139 going on the internet and trying to log on to some random website. And it gives
 140 them to opportunity to sort of read that, digest that, or get it read to them if they
 141 don't read English... and then come back with questions. I tend to do that rather
 142 than draw

143 R - do you manage to find information which is language specific...
 144 M - no its always English. We've tried this in our dermatology clinic, erm...
 145 sorry started to digress a bit using that as an example
 146 R - no its ok
 147 M - we've erm started to translate one of our main conditions like eczema and
 148 things into some of the other languages. But actually most of my patients are...
 149 who cannot speak English, they cannot read in their first language either. Most
 150 of them. Generally they are illiterate. So it's pointless. So in that sense, what I
 151 tend to do is give them the English version and give it to a friend or family
 152 members to translate.
 153

→ PATIENT EDUCATION IN CONSULTATION
 → INITIAL SHOCK
 → COMM SKILLS (PROBING)
 → TIME/RELATIONSHIP

→ EDUCATIONAL MATERIAL
 → INTERNET AS HOW ORANCE (SAFETY) CONCERN
 → TIME/RELATIONSHIP

→ LANGUAGE BARRIER
 LITERACY
 → FAMILY SUPPORT

EXPLORING ISSUE OF LANGUAGE SINCE he used internet LITERACY HAS LOW CLEVEL
 RESULTS FROM SIMPLE EXPERIMENT? NO GAVEU P! IMP OF INCREASING LITERACY?

AS PROVIDED BY THE EXPERT * INTERNET HAS QUESTIONABLE INFORMATION

PROVIDING INFORMATION HIMSELF

TRYING TO look into more depth how he addresses ①

IMP TO GAGE

his perception of patient's perception of consultation

ASSUMING

HE IS ASSUMING THAT THEY WILL UNDERSTAND @ HOME

why? why not draw us well? why did he mention drawing, IS IT NOT TO TAKE TIME FROM CONSULTATION

he assumed the illiterate and done question leaflets?!

6

Appendix M: An example of the table grouping verbatim extracts according to sub-themes from the general physician’s experience of the consultation

Sub-Theme	Explanation	Quote Interpretation	Quote
<p><i>Explaining information without the use of medical jargon and reassuring the patient</i></p>	<p>General Physicians, like cardiologists, emphasise the importance of describing information in lay man terms. Furthermore, explaining information in lay man terms helps in reassuring the patient that the illness can be controlled. This</p>	<p>Nilan reassures the patient that AF is a common disturbance. This alleviates the initial anxiety of the patient when receiving medical news on his heart. Furthermore, he informs his patients about both the actual name of the disturbance and a more common name that more easily describes the condition.</p> <p>Balu pointed out that information to the patient needs to be conveyed in a way that can be easily understood by the patient. Additionally, like Manpal, he commented that</p>	<p>I mean generally I say, you have an abnormal heart rhythm. In a normal person, the heart is beating at regular intervals. In you the heart is not beating at regular intervals, so that’s why your heart beat has become irregular and it’s not an uncommon rhythm disturbance. It’s very common as people grow older. Erm there is a medical term for this, what we call as atrial fibrillation or in simple lay terms, irregular heart rhythm. (Nilan)</p> <p>Well mhm... you have got to explain it to them in their own simple, basic language... that due to various reasons or a particular reason, your heart beat is irregular. Now it is very difficult to predict whether this is going to be temporary or permanent, but we are</p>

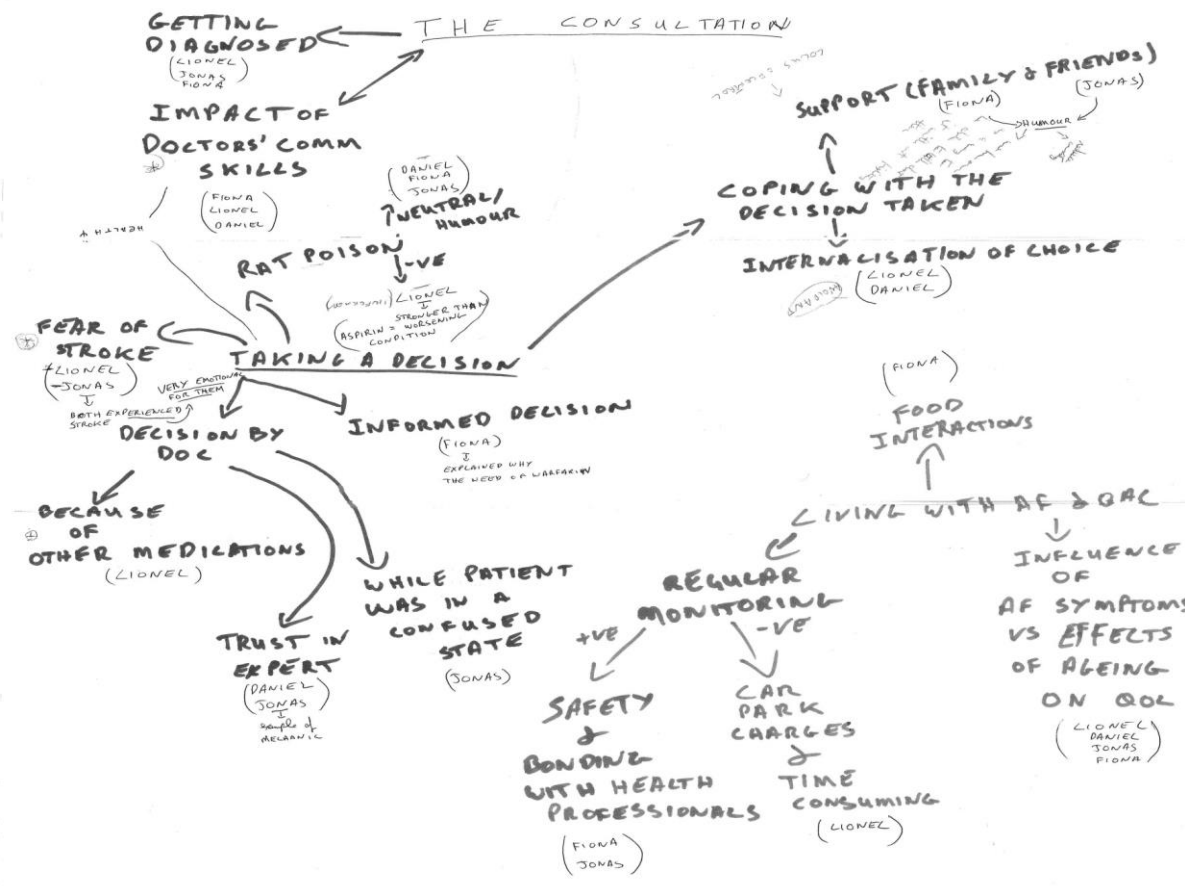
	<p>helps in overcoming the anxiety built when receiving the bad news.</p>	<p>although this illness has its difficulties, he assures the patient about the safety of care.</p> <p>Furthermore this assurance is seen in Balu's next quote, where he strives to alleviate the patients' concerns.</p> <p>Tom also focuses his consultation on patient reassurance. At every stage where he gives information which could cause anxiety to the patient, he balances it out by normalising the issue of the irregularity of the heartbeat. Furthermore, he assures the patient that both the AF and the clotting of the blood can be controlled.</p>	<p>going to find the cause for it (Balu)</p> <p>Is my heart failing, that's one of the common questions they ask... erm and you've got to explain, no your heart is not failing, its just that the synchronisation and the beating is not as regular as it should be. (Balu)</p> <p>The heart is beating irregularly, it's not a regular pattern. And that's fine. It could have been doing that for years, but there are problems with that. Sometimes it goes too fast in that pattern, so we have to slow it down a bit so we may use tablets for that. The other problem is, while its being irregular, it can slightly increase your chance of getting clots. Not necessarily happen... most people don't but it slightly increases your chance and we think you would need a blood thinning included. That's the simple way I</p>
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		<p>On being prompted, he provides a rationale for why reassurance is an integral part of the consultation. He argues that providing only information on AF without reassuring the patients on the safety of treatment, can lead to stress and anxiety on the patient.</p> <p>Similar to Nilan, Tom also assures his patients by telling them that AF is sometimes part of the normal ageing process</p> <p>Manpal relieves the anxiety of his patients by assuring them that AF can have treatment.</p> <p>Manpal also argues that it is</p>	<p>describe it. (Tom)</p> <p>R – So kind of... from what you told me before, it's like trying to keep the situation calm, reassuring the patient on the treatment?</p> <p>T – Yes... I don't want them to go away thinking that they're certain to have a clot and a stroke. Certainly, the warfarin keeps away. You know I say there is a risk, but it's not a definite thing. (Tom)</p> <p>Some of them we just tell them we just don't know. It's the wiring of the heart getting older and not staying in a regular pattern any more. (Tom)</p> <p>AF is a condition which can be reversible, may not be reversible but can have treatment (Manpal)</p> <p>If the family wants to speak to me, I am happy to</p>
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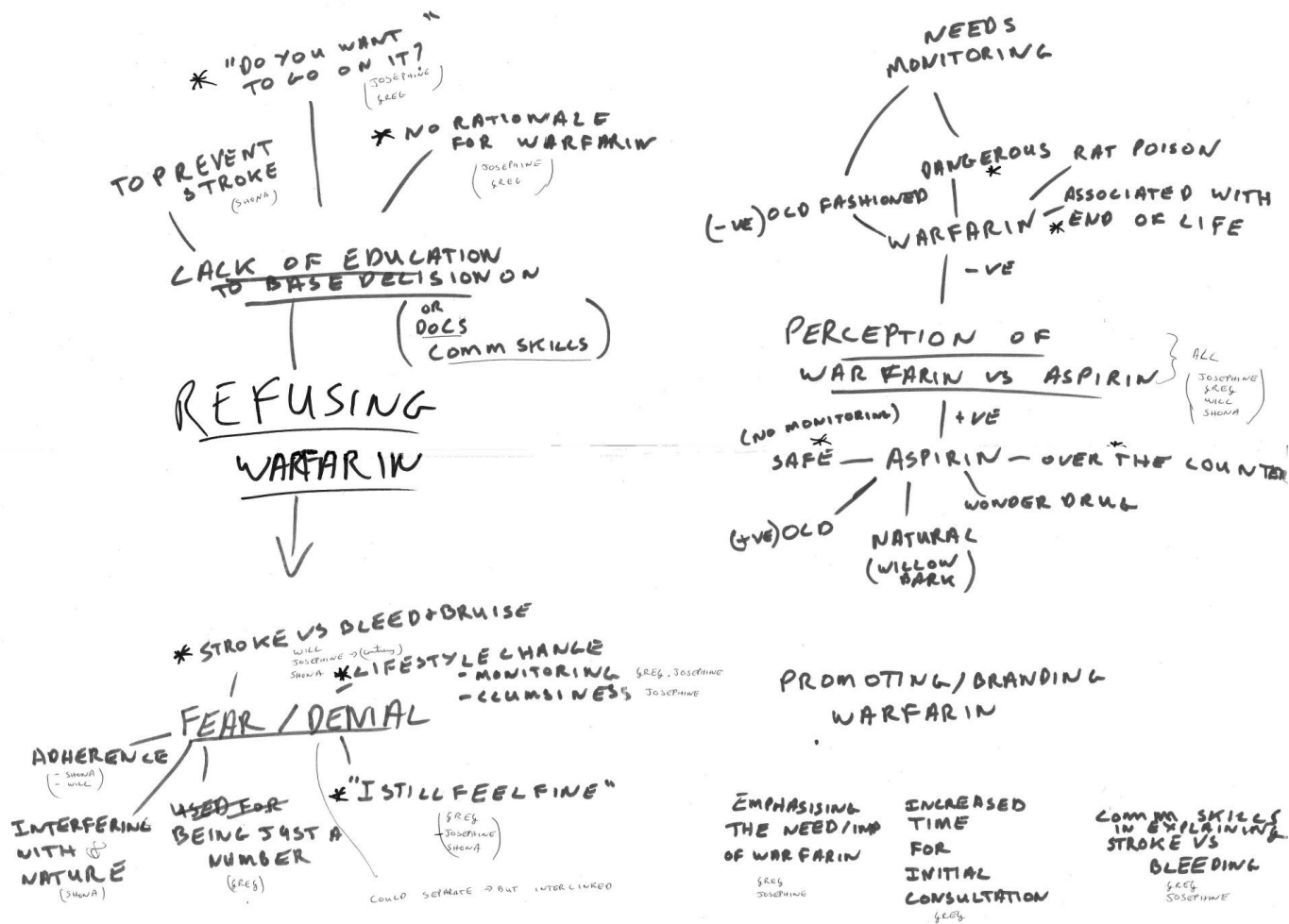
	<p>important to give family members an opportunity to discuss issues. This provides an opportunity to strengthen the patient-physician relationship. In addition, as one can note, on providing an emphasis on the “and I do” phrase, he is showing that this is an important aspect in medical consultations.</p>	<p>speak to them. I have a junior medical team staff who also speaks to family and relatives as well. AND I DO encourage them to do so. (Manpal)</p>
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Appendix N: Scans of Study 1 Mind Map Models

Mind map model of the patients who accepted OAC



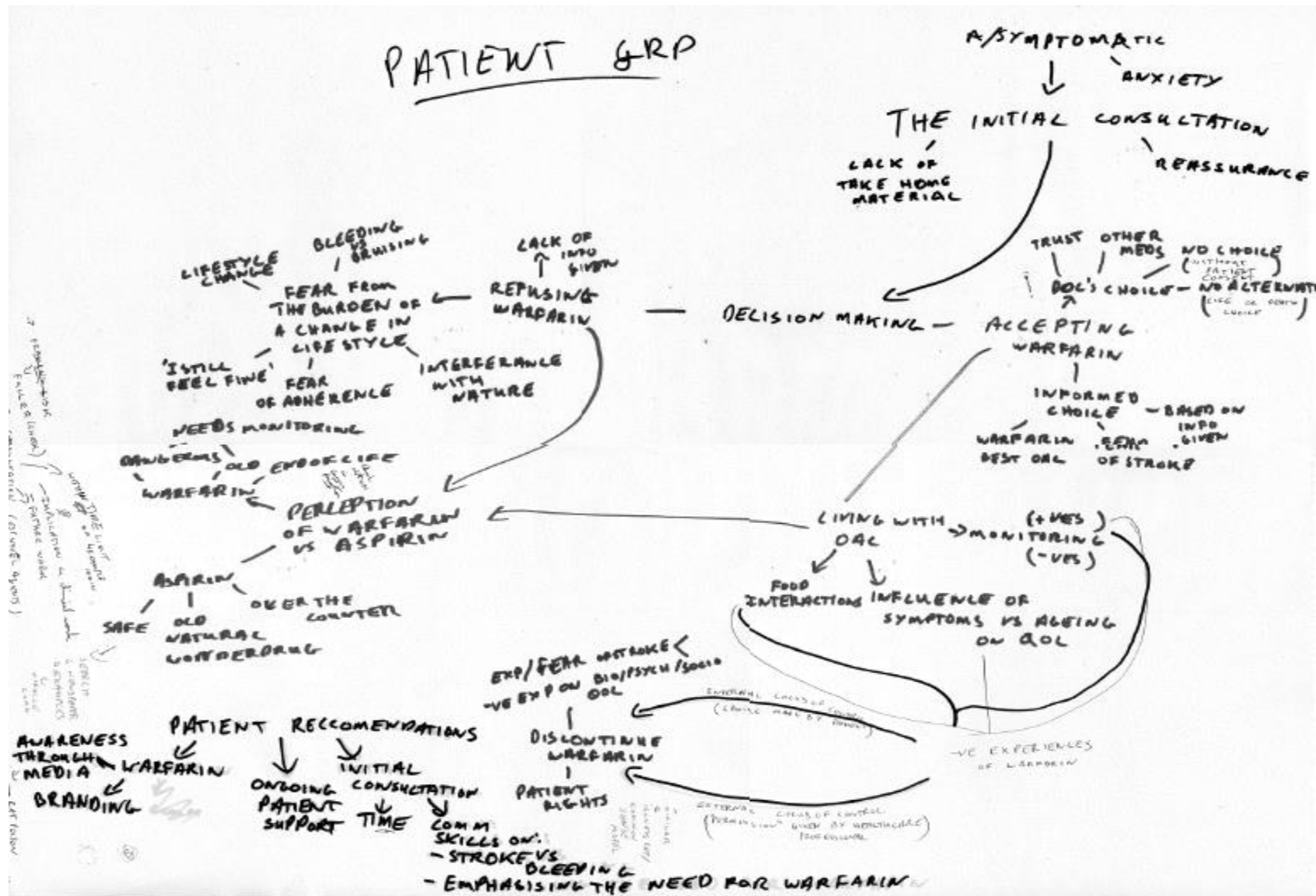
Mind map model of the patients who refused OAC



Mind map model of the patients who discontinued OAC

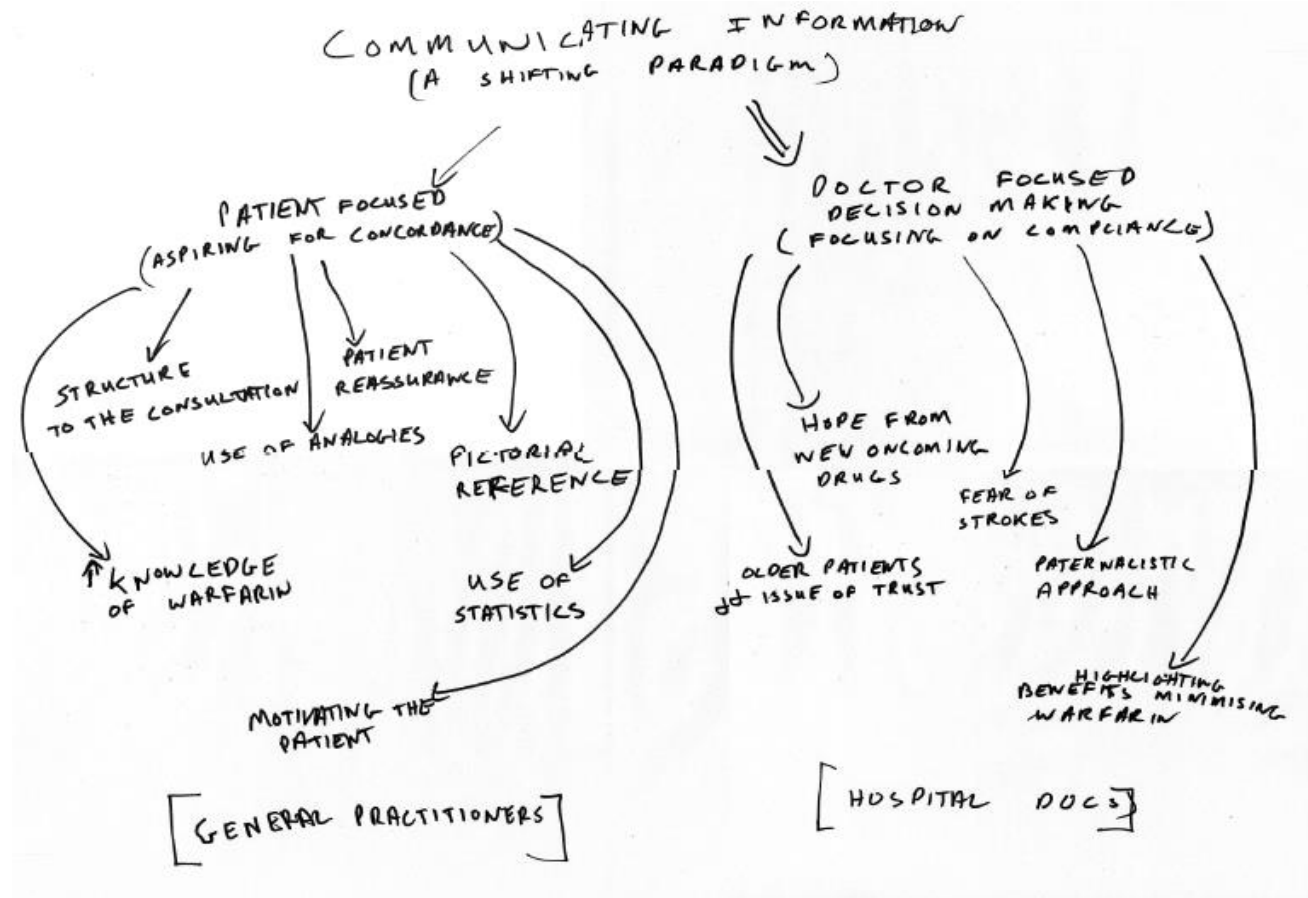


Final mind map model of the three patient groups in Study 1



Appendix O: Scans of Study 2 Physicians Mind Map Model

Mind map model of first overarching theme in study 2: Communicating Information, A shifting paradigm



Mind map model of second overarching theme in study 2: Challenges with OAC prescription for AF

