Lay attitudes towards cardiovascular risk in the context of screening, prevention, and trial participation

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Declaration

I hereby declare

i) That this thesis has been composed by myself

ii) That the work presented within this thesis is my own unless otherwise stated

iii) That this work has not been submitted for any other degree or professional qualification

Helen Eborall
June 2004

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For my Grandad

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Abstract

Background: This study expands the understanding of lay attitudes towards, and perceptions of cardiovascular risk by exploring beliefs in the context of a large trial of screening and prevention in a 'healthy' population.

Aims: To investigate public attitudes towards screening for cardiovascular risk, prevention of cardiovascular disease (in particular aspirin as a preventive medication), and participation in a preventive research trial.

Methods: Participants were members of a healthy population (50-79 years) invited to attend screening for asymptomatic atherosclerosis, some of whom were subsequently invited to participate in a randomised control trial assessing the efficacy of aspirin in preventing cardiovascular events. The study sample included those who had not attended screening, those who were ineligible for the trial, those who had declined to participate in the trial, as well as trial participants. Semi-structured qualitative interviews and focus groups were conducted and transcribed verbatim. Transcripts were analysed inductively and interpretatively for emergent themes.

Findings: Attitudes and beliefs varied both between and within groups of participants from different stages and situations from the screening and trial process. Prominent themes included:

Screening attendance: Participants discussed their own attitudes often as distinct from those of 'known' or 'general' others. Salient explanations of barriers included fatalism, optimistic bias, denial and disinterest. The common phrase "what's not broken, you don't fix" seemed to imply a low risk perception for asymptomatic conditions. Conversely participants who were positive about screening attendance, due to the benefits of early diagnosis, implied individual responsibility, but often in hindsight.

Screening experience: An 'at risk' result often mismatched expectations, and provoked varying reactions: some participants maintained prior beliefs about personal health and risk, seeking alternative explanations; others reinterpreted their pre-screening beliefs. Key influences on participants' reactions included the nurse-

participant dialogue, understanding, and perceptions of the novel screening measurement (ankle-arm blood pressure ratio). An 'at risk' result led many to trial participation, a few declined seeking guaranteed medication, and others took no action.

Preventive medicine: Attitudes and behaviour appeared to contradict: prevention was typically described as "better than cure", and aspirin emerged as a favoured drug with assumptions of trust, safety, and low perceived risk. But a prevailing tendency and preference for avoiding medication, and lack of awareness of aspirin as a possible preventive drug for heart disease, inhibited the appeal of engaging in such practice, particularly until the condition was symptomatic and/or medication was deemed "necessary".

Trial Participation: Participants' accounts revealed a wide range of influences on trial participation. When considering benefits and drawbacks of the trial, attitudes expressed ranged from feelings about personal gain or loss, to altruistic attitudes. The trial tablet was central to many participants' attitudes, which were rooted in beliefs about aspirin specifically and medication in general. Misunderstandings were common regarding the purpose, concept and procedure of the RCT, the selection criteria and screening measure. Whilst there was some recognition of the need for the trial and its required randomisation process, preference for the active drug was overwhelming, and discontent focused on the commitment as well as the idea of being a 'guinea pig'. A major role in the decision to participate seemed to be played by perceptions of personal susceptibility to cardiovascular risk.

Conclusion:

The present study demonstrates the salience of the concept of cardiovascular risk in members of a general public population, and how this underlay attitudes towards screening and prevention, and participation in a preventive research trial. A multitude of factors were shown to contribute to people's perception of risk, amidst the complex context of personal and situational factors in which people make decisions about their health. However, a definite 'marker' of risk seemed particularly necessary; the asymptomatic nature of atherosclerosis, and lack of awareness of the screening measure emerged as particularly important contributors to low perceived

risk. The findings have implications for, and can inform, the promotion of preventive health for asymptomatic conditions. Furthermore, the findings about attitudes towards, and understanding of, trial participation have implications for those conducting research trials particularly regarding informed consent.

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Chapter 1: Introduction

Background

Cardiovascular disease is the main cause of mortality, and one of the largest causes of morbidity in Britain, accounting for four out of ten of all deaths; coronary heart disease (CHD) alone accounts for half of these (most result from a heart attack) and a quarter are due to stroke (British Heart Foundation, 2003). CHD is the most common cause of premature death. Whilst death rates from CHD have reduced significantly over the past few years, morbidity from CHD has risen by a quarter in older people over the past 15 years (BHF, 2003). UK CHD death rates are amongst the highest in the world and within Britain the highest rates are in Scotland and the North of England. For manual workers, the death rate remains much higher than non-manual workers and the rate is also falling much more slowly (BHF, 2003).

Concerning risk factors for heart disease, unhealthy lifestyle remains a problem in Britain despite health promotion campaigns: 29% of men and 25% of women smoke, the habit is more common in manual workers (35% of men and 30% of women) and in Scotland (BHF, 2003). The average diet is still considered too unhealthy, typically involving an excessive intake of saturated fat and salt, and insufficient intake of fruit and vegetables, particularly in those with lower incomes, and in Scotland, the North of England and Northern Ireland (BHF, 2003). The recommended amount of weekly physical activity (to lower CHD risk) is carried out by just 37% men and 25% women in the UK; this and the unhealthy diet contribute to rapidly increasing rates of overweight (45% of men, 34% of women) and obesity (20% of men, 19% of women). Regarding physiological risk factors, approximately 40% of British adults have high blood pressure (or are receiving treatment for high blood pressure), 67% have blood cholesterol levels above the recommended level (BHF, 2003), around 3% of British adults have diagnosed diabetes which is on the increase and a further 2% are thought to have undiagnosed diabetes (Diabetes UK, 2003; BHF, 2003).

The prevalence of heart disease and associated risk factors is a huge problem in Scotland in particular; Scotland's high rate of heart disease has been attributed to

smoking, poor diet and poverty (NHS Scotland, 2003a). The Scottish Executive has identified reducing coronary heart disease and stroke as a national priority and is aiming to halve the number of deaths from these conditions in people under 75 by 2010 as outlined in the white paper 'Towards a healthier Scotland' (1999; NHS Scotland, 2003). NHS Health Scotland (formerly Health Education Board for Scotland or HEBS) has conducted numerous campaigns relating to reducing key lifestyle risk factors such as smoking. Secondary prevention strategies in practice include rehabilitation, training on lifestyle behaviour change and stress management for survivors of cardiovascular and cerebrovascular events, for example use of the Heart Manual (Lewin, Robertson, Cay et al., 1992). Community based projects such as 'Have a Heart Paisley' are incorporating many smaller prevention projects, both secondary and primary (NHS Scotland, 2003b).

Secondary prevention deals with individuals with established clinical disease, but this group accounts for just 20% of cardiovascular events whilst the majority of such events occur in those individuals who are considered 'healthy' (Rose, 1992). Thus, primary prevention is vital for reducing the incidence of cardiovascular disease, and presents a huge challenge for public health (Price, Fowkes, Murray et al., 1997). Current primary prevention in the general public consists of identifying and prescribing appropriate treatment for those with established cardiovascular risk factors: high cholesterol, high blood pressure and smoking, usually through General Practice (Sleight, 1991; Kannel, 1987). However criticisms of this approach include first, that it has an ineffective cost-benefit ratio, and second, that it overlooks those who despite having lower or average risk on these factors will still experience cardiovascular disease (Price et al., 1997). Thus other potential indicators of risk in the 'healthy' population have been researched; these include sub-clinical atherosclerosis which has been found to be associated with increased risk of cardiovascular events in this population (Leng, Fowkes, Lee, et al., 1997; Kuller, Shemanski, Psaty, et al., 1995; Criqui, Langer, Fronkek, et al., 1992; Kornitzer, Dramaix, Sobolski, et al., 1995; Ogren, Hedblad, Isacsson, et al., 1995). Atherosclerosis is the narrowing of the arteries due to fatty plaques developing on the inner artery walls which eventually obstruct blood flow and is the principal cause of

coronary heart disease, stroke and circulatory disease in the legs (Oxford Medical Dictionary, 1998; Fowkes, Housley, MacIntyre, et al., 1988).

The most effective and simplest method of identifying asymptomatic atherosclerosis is with the ankle brachial pressure index (ABPI). This is a measure of the ratio of the systolic blood pressure in the ankle to that in the arm (Price et al., 1997). This non-invasive measure has high patient acceptability, and is reliable and accurate (Leng at al., 1997; Ouriel, McDonnel, Metz, et al., 1982; Yao, Hobbs & Irvine, 1969; Fowkes et al., 1988). It has been found to be a good predictor of both increased mortality and future cardiovascular events (Kornitzer, et al., 1995; Vogt, Cauley, Newman, et al., 1993). In the Edinburgh Artery Study (a cohort study of the general population aged 55-74 years), amongst participants with a low ABPI (≤ 0.9) the incidence of cardiovascular events was 30% compared to 17% amongst those with an ABPI greater than 0.9. The ABPI was not only a good predictor of cardiovascular events but improved the prediction beyond that of conventional risk factors; the authors explain that the low index reflects the combined effect of various risk factors over time and that once atherosclerosis has developed, it is a better predictor than any single risk factor (Leng, et al., 1997). The most interesting finding was that in participants with no risk factors (non-smokers, normal cholesterol and blood pressure) those with a low ABPI (≤ 0.9) had a 23.1% chance of a cardiovascular event compared to 7.9% in those with an ABPI greater than 0.9 (Leng, et al., 1997).

The ABPI therefore could be a particularly useful measure for GPs to carry out in the conduct of an assessment of other cardiovascular risk factors in their patients: it would indicate patients who would require further monitoring and who could benefit from preventive treatment (Leng, et al., 1997). One treatment currently used widely in secondary prevention is antiplatelets such as aspirin; these drugs have been found to reduce the rate of cardiovascular events in those with angina, and reduce by a third the rate of further cardiovascular events in those who have had a heart attack, stroke or transient ischaemic attack (Antiplatelet Trialists' Collaboration, 1994). Research has shown that a high dose of aspirin is not needed; low doses seem to be of the same efficacy in reducing the rate of further cardiovascular events (Hirsch, Dalen, Fuster,

et al., 1992). Furthermore, lower doses should cause less gastrointestinal problems (Levy, 1974). Until recently, there has been a lack of research into the use of antiplatelets in those with asymptomatic atherosclerosis, i.e. as a preventive drug.

The Aspirin for Asymptomatic Atherosclerosis (AAA) Trial

A large randomised control trial is currently assessing the efficacy of low dose aspirin (100mg/daily) in members of the 'healthy' population identified with asymptomatic atherosclerosis according to a low ABPI measure. 165,832 people (50 to 79-year-olds with no history of cardiovascular disease, identified through GP records) in Lanarkshire, Glasgow and Edinburgh were sent a letter inviting them to reply if they were interested in attending a screening with the ABPI at a research clinic, 48,015 (29%) replied and 42,767 (26%) were sent an appointment for a screening (which they could change if inconvenient). 28,980 (17.5%) people were screened, 4715 (16.3%) of these had a low ABPI ($\leq$0.95) and of these 437 were not eligible (due to previous heart disease, allergy to aspirin and other diseases and conditions), 164 were excluded by their GP, and 764 declined to join the trial. 3350 people were entered into the double blind RCT where they have been randomised to receive either aspirin or a placebo for the duration of the trial (Stewart, Douglas, Price et al., *in progress*)[1]. See Figure 1 depicting the AAA trial process.

The first trial entrants began the trial in May 1998 and due to the lengthy screening process across the three areas the final screenings were carried out in December 2001. The final participants therefore began the trial medication in January 2002. At the start of the trial, participants were invited to remain in the trial for 5 years. However, due to an event rate lower than anticipated, fitting with the incidence of heart disease in Scotland dropping (NHS Scotland 2003a), the trial has now been extended to minimum 8 year participation, or until a clear result is attained before this point. At the time of writing (January 2004) approximately 2200 participants are still taking their trial medication, other participants have stopped, the most common reasons being starting on aspirin or medication contraindicating to aspirin (GP prescribed or in some cases self prescribed), side effects attributed to the trial

[1] For further information about the AAA trial, contact Prof F G R Fowkes

medication, cardiovascular related event, 'other' medical reasons or 'changing their mind'.

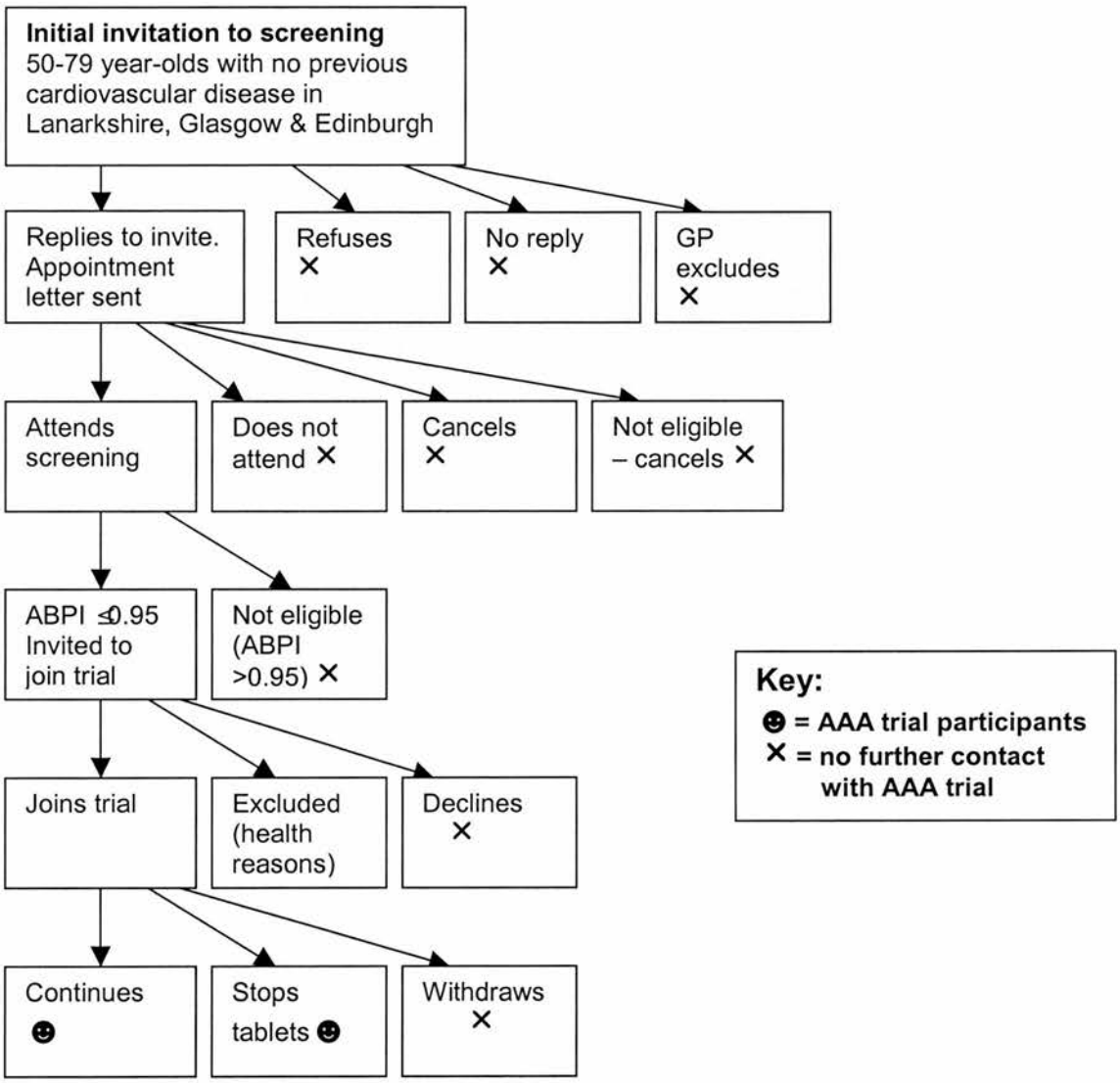

Figure 1: Different groups involved in the AAA trial

Research aims

A screening and prevention process such as that being tested in the AAA trial raises many issues in addition to the epidemiological and clinical issues that are the focus of the trial. Should the trial have a successful outcome, a similar screening and prevention programme may well be conducted in the general population. However, successful implementation (for example in a primary care setting) requires knowledge about the public's health relevant attitudes, beliefs and practices. For example, would people want to attend such a screening? The screening uptake rate in the AAA trial demonstrates that there are many individuals who do not take up such an invitation; 82.5% of those sent the first invitation letter and 32% of those who were sent an appointment did not attend. Second, how would people react to the diagnosis of a low ABPI, or a healthy ABPI? Third, what would people think about taking an aspirin as a preventive drug? In particular would a preventive drug like aspirin have more appeal than making other lifestyle changes such as stopping smoking? Furthermore, understanding all these issues in the context of trial participation could be a useful elaboration of epidemiological focus. For example, what would people think about participating in such a trial? How do they feel about the randomisation of aspirin and placebo?

Awareness of these issues led the principal investigator of the AAA trial (Prof Fowkes) and a medical sociologist (Dr Cunningham-Burley) to apply for funding from the Chief Scientist Office, Scottish Executive, to enable this research to be conducted through a PhD studentship. The overall aims were to explore the healthy lay public's attitudes towards and beliefs about screening for cardiovascular risk, aspirin as a preventive medication for heart disease and participation in a preventive research trial. More specifically, the aims that I outlined at the start of the project were:

- Explore attitudes towards attending screening for cardiovascular risk in both individuals who attended and who declined
- Explore reactions to the screening and ABPI result, and perceptions of personal cardiovascular risk

- Investigate attitudes towards preventive medicine, in particular aspirin, in relation to future cardiovascular events, and attitudes towards preventive medicine in comparison to making other lifestyle changes
- Investigate attitudes towards participating in a double blind randomised control trial of preventive medicine

Alongside these runs the aim to further develop research into lay beliefs about cardiovascular risk within a novel context.

The study was conducted in an interdisciplinary environment; knowledge of epidemiological, sociological, psychological and health services research were drawn upon to develop the project. The project involved interviewing individuals within the population invited to the AAA screening who were at different stages in the screening and trial process; the timeline of the trial (and staggered screening process) enabled a diverse range of participants to be included; from those recently attending screening to those several years into the trial. The AAA trial and the population invited to it, have provided an ideal opportunity and site to explore the wider context of screening, health beliefs and practices, and trial participation. It is hoped that the findings will help both shape the practice of clinical trials in the future and inform the development of prevention programmes such as screening.

Thesis outline

The current thesis reports on this work and is structured as follows. The literature review in Chapter 2 covers relevant literature from various disciplines relevant to the research aims. The chapter is divided into five sections: First, I cover literature on lay beliefs about heart disease and cardiovascular risk including the existence of lay epidemiology and use of explanatory models to account for the occurrence of heart disease, and its relation to perceptions of personal cardiovascular risk. Second, I outline research on attitudes to screening covering influences on screening uptake, lay meanings of screening, and the psychological impact of screening. The third section covers literature exploring lay beliefs about medication, from research on (non)-compliance to that which places lay ideas about medication in the context of risk. In the fourth section I cover literature relevant to public participation in

research. The first half considers the many potential influences on the decision to participate, the second half considers the concept of altruism. The fifth and final section is a brief overview of literature on risk perception, a theme which underlies research in this area and links the diverse aims of the research and analysis of data.

Chapter 3 outlines the methodological approach taken and process engaged in to conduct the research. First, concerning the research design, I outline the purpose of the research, the research questions, the choice of methodology and approach. Next I describe the initial phase of the research including the pilot work and topic guide development. The main fieldwork is then discussed incorporating sampling, recruitment, ethics and reflexivity. This is followed by describing the analytical approach and conduct.

Chapter 4: The first findings chapter focuses on participants' attitudes towards the screening. Starting with barriers, I present and discuss four particularly salient phrases in participants' accounts that seem to reflect or represent beliefs that appear to contribute to screening non-attendance. These phrases seem to be used as cultural shorthands of shared lay knowledge and beliefs. I explore how participants' accounts of their own attitudes compare with the attitudes they impute to other people. This moves the discussion onto individuals' rights versus responsibilities regarding screening and preventive health. Participants' beliefs about benefits of screening are then considered, linking back to discussion of prior expectations of screening, and whether expectations are met at the actual screening. Leading onto the screening experience, I present how people appear to make sense of the screening result, in particular where expectation-reality mismatch has occurred, and the role of the research nurse in participants' interpretations. Finally reactions to a low risk result are examined.

When discussing screening and preventive health, a phrase which was prominent in many individuals' accounts was "prevention is better than cure." Chapter 5 focuses on beliefs about prevention and preventive medicine, exploring what people say they *think* about prevention and what they say they *do* about prevention. First I present

how some participants' accounts emphasise the attitude that "prevention *is* better than cure". Then I demonstrate and discuss why for other participants, "prevention is better than cure, *but*..." Despite citing the phrase, these people's accounts provide reasons against engaging in active prevention, in particular preventive medication use. I next explore how aspirin appears to be considered as different to other medication. Finally I present participants' attitudes towards the use of preventive medication as opposed to lifestyle change.

Chapter 6 presents and examines participants' attitudes towards participating in the AAA trial. The first section explores the emergence of a spectrum of altruistic attitudes in participants' accounts about participation. The second section examines views about the risks and benefits of participating. This includes attitudes towards the RCT procedure, and incentives, barriers and reactions to experiences in the trial. Third, misunderstandings of the trial are presented and discussed.

An underlying theme which emerges in chapters 4, 5 and 6 is perception of cardiovascular risk. Chapter 7 presents further data relating to participants' views about cardiovascular risk perception. The focus is on risk factors including family history of heart disease, lifestyle, Scottish identity and clinical measures of cardiovascular risk, and how participants applied these risk factors to themselves and others.

In Chapter 8, I discuss the data presented in the previous chapters with a particular focus on the emerged importance of risk perception and its relation to participants' attitudes towards screening, prevention and trial participation. The first two sections discuss the relation between risk perception and screening. First, screening attendance and second, reactions to the screening experience. The third section discusses how participants' views about aspirin as a preventive medication relate to both perceived cardiovascular risk and perceived risk from medication. The fourth section discusses the interrelationship between these two perceptions and attitudes towards participating in the AAA trial. Finally, I will focus more generally on the notion of risk and how the research findings have contributed to knowledge about

risk in health research. To conclude, I will discuss implications of the findings for screening and prevention programmes, clinical trials, and for further research.

Chapter 2: Literature review

Introduction

The overall context of the research, and its specific aims, led to a literature search spanning several disciplines, reflecting the interdisciplinary approach to the study. The areas of literature I chose to focus on at the outset included: attitudes towards screening and prevention (including preventive medication), trial participation, and cardiovascular risk. This search spanned several disciplines, particularly health psychology, and medical sociology, also medical ethics, epidemiology, and anthropology. The development of the literature search and the progression of the fieldwork led to searching further areas that I considered relevant. Overall the literature covered falls into five sections as outlined below. These are large bodies of literature, thus, my aim in this chapter is to outline a broad range of research and perspectives within each area.

- **Part I: Beliefs about heart disease and cardiovascular risk.** Due to the focus of the AAA trial screening, I felt it important to search for literature on people's attitudes towards cardiovascular risk and heart disease to provide a grounding in the disease/condition area. This led predominantly to medical sociological research on lay beliefs of heart disease, its aetiology, development and risk factors.
- **Part II: Attitudes towards screening.** A large amount of research in the health psychology literature has investigated attitudes towards screening focusing mainly on cancers, largely concerning influences on uptake and the psychological impact of screening. Debates in the medical literature regarding the ethics of screening, and sociological research placing screening in the context of risk and exploring lay meanings of screening provided further perspectives.
- **Part III: Beliefs about medication.** Searches revealed little literature focusing on attitudes towards *preventive* medication specifically, however both health psychology and sociology literatures have considered beliefs about medication (general or other specific types). The psychological perspective has largely focused on compliance to prescribed medication and demonstrated the

development and application of models for predicting and explaining medication-taking behaviour. Qualitative sociological research has explored lay meanings of medication and related these to the concept of risk.

- **Part IV: Attitudes towards research participation**. Initially, searching for relevant literature regarding attitudes towards trial participation led me to studies of influences on uptake in the epidemiological and medical journals, and a few recent qualitative studies from the social sciences. I also consulted social psychology research for a perspective on possible social influences on the decision to participate. However, the fieldwork itself led me to consult a further body of literature not considered at the outset – that concerning altruism and pro-social behaviour from sociology, anthropology and social psychology.
- **Part V: Risk.** The theme of risk runs through the four preceding areas, thus, I decided to consult a number of key pieces of psychological and sociological literature to provide a grounding in different perspectives on risk, to enable consideration of heart disease, screening, prevention and participation in the context of risk.

Part I: Beliefs about heart disease and cardiovascular risk

In this initial section, I cover literature on beliefs about heart disease and cardiovascular risk. I begin by outlining findings of a key piece of ethnographic research in medical sociology which illustrated the process of lay epidemiology and use of the 'coronary candidacy' model in lay accounts of coronary events, and how awareness of fallibilities and fatalism related to lay people's ideas about risk factors. I move on to cover findings of this and other literature on beliefs about risk factors including family history and gender, the application of risk factors to oneself generally and retrospectively, and the interplay with behaviour.

Lay epidemiology and coronary candidacy

There has been a long tradition of research on lay health beliefs in medical sociology (for example, Pill & Stott, 1982, 1985; Calnan, 1987; Blaxter, 1990; Backett & Davison, 1992, 1995*)*. This in-depth work has led research to a deeper understanding of the lay public's understandings and beliefs about illnesses, their aetiology and treatment. More recently, heart disease has been the subject of a few prominent research studies, not least because it is one of the major causes of mortality and has been the focus of a range of public health and health promotion initiatives. Ethnographic research into lay beliefs about heart disease in South Wales by Davison, Davey-Smith and Frankel (1991) demonstrated the existence of an explanatory model widely used by people to account for coronary heart disease: coronary candidacy. This cultural mechanism is described as developing through the process of 'lay epidemiology' which the authors define as:

> "a scheme in which the individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and the public arena, as well as from formal and informal evidence arising from other sources, such as television and magazines..." (Frankel, Davison & Davey-Smith 1991, pp428).

Input from experience and observation of family, friends and self, health professionals, the media and official bodies, is incorporated into the resulting explanatory theory of coronary candidacy: the type of person likely to have heart problems based on physical,

social and personal criteria (Davison et al., 1991). Physical factors include those who are overweight, unfit, those with a red/flushed face complexion or grey pallor, social factors comprise family history of heart disease, occupation (mental stress from work responsibility and pressure, physical stress from manual labour, poor work environmental conditions, sedentary work) and geographical residence. Finally personal factors cover behaviour (bad lifestyle) and nature (excessive worriers and anger) (Davison et al., 1991). Constructs such as the coronary candidate serve to explain the occurrence of adverse events: "how and why did this happen to this person at this time?" (question posed by Rose, 1985; Davison et al., 1991). In the case of coronary candidacy, Davison and colleagues describe four uses: regarding other people it is used to both predict and retrospectively explain heart disease morbidity and mortality, similarly regarding personal contemplation, it is used to predict one's own risk of developing heart disease and retrospectively explain it (Davison et al 1991).

Whilst there is often an overlap between factors in the theories developed through lay epidemiology and professional epidemiological opinion (for example Davison and colleagues found almost universal knowledge of the risk factors for heart disease promoted by health education (Davison, Frankel & Davey-Smith, 1992)), the lay epidemiologist notes several fallibilities in the medical professional model. Thus to the lay epidemiologist coronary candidacy status is not regarded as straightforward, whilst it increases one's risk it does not guarantee heart disease incidence. Experience and awareness of anomalies are evident and need accounting for: two particular extreme anomalies being the 'unwarranted survivor' typically described as a drinking, smoking, unfit old man who lives to a ripe old age, and the anomalous death of a young, healthy jogger who 'drops down dead' (Davison et al., 1991). Thus the randomness of heart disease is recognised and incorporated into the model. This is linked with fatalistic feelings within lay beliefs about heart disease but Davison et al. (1991) emphasise the distinction between the fatalistic feelings they found and Pill and Stott's (1981) fatalist-lifestylist dichotomy which implies ignorance. Rather, the authors regard a fatalistic component of the lay epidemiologist's theory as "the realistic recognition that some

barriers exist on the road which may not be surmountable through personal, individual effort" (Davison et al 1992, pp679). There are various such influences on health beyond the individual's control including personal factors (such as heredity), the social environment and the physical environment, all of which have a complex relationship with an individuals' lifestyle and health status (see Davison et al., 1991). However a fourth external influence noted in people's beliefs is regarded as less modifiable: the influence of fate, chance, luck in attempting to explain inability to find a causal link for heart disease in their family (Davison et al., 1991; see also Preston, 1997).

The research by Davison et al. (1991) further highlights the prevention paradox originally noted by Rose (1981). This paradox is inherent in population strategies of preventive health promotion and may therefore limit their effectiveness in producing behavioural modification for example regarding coronary prevention. Population strategies aim to shift the whole distribution of risk factors, reducing the mean towards lower risk; as compared to high risk strategies which aim to target and curtail those at the top end of the risk distribution. Whilst benefiting the population as a whole, on an individual level there is little gain, this is the prevention paradox (Rose, 1981; Davison et al., 1991; Hunt & Emslie, 2001). Davison et al. (1991) suggest that lay awareness of the prevention paradox, in the context of broad health promotion messages about reducing risk factors for heart disease, contributes to mistrust of expert advice (Davison et al., 1991; Hunt & Emslie, 2001). Scepticism arising from contradictory medical advice has been shown to contribute to low motivation to behaviour change (Nic Gabhainn, Kelleher, Naughton et al., 1999). Health promotion in these contexts may be working against lay and popular culture, and is therefore unlikely to succeed (Backett & Davison, 1992).

Lay beliefs about heart attacks

Further research (for example Hunt & Emslie, 2001, in Scotland) extended understanding of issues around the coronary candidacy model. First the belief that a heart attack would be 'a good way to go' was common (Emslie, Hunt & Watt, 2001),

this builds upon observations in the research in South Wales that a heart attack was regarded as a status symbol, and evidence of success achieved through hard work (Davison et al., 1991). Also contributing to its preferable status is the widespread belief of a heart attack as sudden, dramatic and fatal (Ruston, Clayton & Calnan, 1998). It is perceived as desirable for its quickness in young deaths and naturalness in old age deaths; this belief ignores the possibility of surviving with a disability, despite the large percentage of heart attack survivors and the experience of this in family members (Emslie et al., 2001). Regarding vascular disease, heart attacks seem to be regarded as favourable to strokes, which tend to be considered more disabling (Carroll, Naylor, Marsden & Dornan, 2003). In people's comparisons with cancer, heart disease is reported as much less feared (Nic Gabhainn et al., 1999; MacFarlane & Kelleher, 2002).

Lay views on cardiovascular risk factors and aetiology

Family history

Davison, Frankel and Davey-Smith (1989) highlighted the major role played by heredity in lay beliefs about heart disease aetiology. Emslie and colleagues' study focused particularly on family history, and found a common belief that health-damaging factors in one's past (family history, past health damaging behaviours) could not be undone by modifying one's behaviour at a 'late' stage in one's life (Emslie, Hunt & Watt, 2000). Ambivalence was apparent in discussions of these risk factors and in assessing personal risk from these past 'legacies' (Hunt, Emslie & Watt, 2000). Heredity or genes were mentioned spontaneously as a cause of heart disease by two thirds of participants in the Scottish study. Again ambivalence and uncertainty prevailed in discussions of family history of heart disease as a risk factor; there were difficulties in defining a premature death and categorisation of a 'family history'. Recognition of a family history did not always lead to perception of a *personal* risk depending on one's perceived resemblance to different 'sides' of one's family (Hunt et al., 2000). Thus family history could be perceived and interpreted in various ways, therefore not lending complete support to the existence of fatalism in the population regarding heart disease.

Gender

Emslie and colleagues note how the coronary candidacy ignores gender, other than generally considering women at less risk than men; they argue that gender is a key element of the construct (Emslie et al., 2001). Accounts of those with heart problems, *and* the anomalies, are of men. To initiate mention of female cases, discussions were moved towards family members; descriptions of male relatives focused on sudden fatal heart attacks whereas with female relatives less dramatic imagery was used and they focused on limiting illness (Emslie et al., 2001). The authors elaborate on this finding in the context of wider debates about gender and health in medical sociology, for example mechanical metaphors of the male body contrasted against the organic and natural female body in medical and cultural discourse (Emslie et al., 2001).

Ruston and Clayton (2002) explored the low levels of perceived vulnerability to coronary heart disease in women, including those who had experienced a CHD related event. Participants were found to engage in three strategies of minimising risk perceived: first, attributing risky lifestyle to men. Second, subjectively manipulating the potential threat arising from their personal risk factors; risk factors that contributed to a man's candidacy were regarded as less relevant for a woman, indeed some were regarded as beneficial, thus were discounted when women applied them to themselves. Third, over-emphasising the importance of social position in relation to risk; the traditional role of the male breadwinner was associated with stress and physical strain whereas that of the female housewife was regarded as morally healthy and cardio-protective. Furthermore, a woman adopting a man's traditional breadwinning role was seen as placing herself at increased risk (Ruston & Clayton, 2002). This and Emslie et al.'s findings have implications for understanding the beliefs, awareness and practices amongst women and men in the general population, and amongst the medical and research community.

Established and experienced cardiovascular risk

So far the research discussed has focused on the beliefs of the general public. Other research has explored the beliefs of specific groups of people who have a high

cardiovascular risk. Type 2 diabetes is a major risk factor for cardiovascular disease (Stamler, Vaccaro, Neaton, et al., 1993; Simons & Simons, 1998; Diabetes UK, 2003). A recent qualitative study of people with diabetes including half with and half without cardiovascular disease found only a minority associated diabetes with increased cardiovascular risk, particularly in those who had no cardiovascular disease themselves; furthermore when assessing their individual risk the majority rated their risk as low (Carroll et al., 2003). Participants generally weighed up quality against length of life when considering lifestyle changes relating to long term health gain; whereas those with cardiovascular disease regarded the long term gains highly, those without disease referred to the short term benefits of their 'bad' lifestyle behaviours more favourably (Carroll et al., 2003).

People who have experienced heart disease, heart attacks and/or cardiovascular related problems have been the focus of much research; these individuals provide the opportunity for researchers to explore retrospective beliefs about cardiovascular risk before, and current beliefs after an event. As described above, a widespread belief is the image of a heart attack as a sudden, dramatic, fatal event involving chest pain (Davison et al., 1991; Emslie et al., 2001). Many heart attack survivors reportedly shared these expectations prior to the event (Ruston et al., 1998). Such expectations could have negative consequences for survival and prognosis: in terms of symptoms, research has found that when symptoms experienced were generally considered 'typical' for a heart attack (chest pain, radiating pain, collapse), individuals were less likely to delay in seeking medical help than those who experienced 'atypical' symptoms (including shortness of breath, nausea, faintness, sweats). A mismatch of individuals' *own* expectations and experience was also associated with delay (Horne, James, Petrie, et al., 2000). A recent study found that, despite awareness of one's own risk and experiences of heart attacks in one's family, this did not guarantee acting 'appropriately' upon the experience of one's own symptoms. Again misinterpretation and disregard of symptoms was common (Brink, Karlson & Hallberg, 2002). Regarding prior beliefs about personal risk, heart attack victims who sought medical help within four hours of their attack were

more likely to have higher prior perceptions of personal risk of a heart attack then those who delayed seeking care (Ruston et al., 1998). Similarly, disregard and endurance of symptoms has been explained as due to illusions of invulnerability despite objective risk indicators (Brink et al., 2002).

Wiles (1998) explored how patients made sense of their heart attack after the experience interviewing them soon after the event and several months later. Initial shock and disbelief were expressed both at having the heart attack and surviving it, again demonstrating lack of prior perceived personal risk, and prior expectations about a sudden fatal event. Interestingly, lack of perceived risk continued for some: around a third made a full recovery but no longer considered themselves as having heart disease; those who did not make a full recovery reinterpreted their event as more serious and sought attempts to explain its aetiology (Wiles, 1998). An additional finding related to the information given about likely recovery time: the author pointed out that such information is derived from epidemiology and thus based on population data and averages. This is used by health professionals without realising patients' tendency to interpret it as personally relevant, thus decreasing trust in health professionals and possibly giving up lifestyle change when the expected (average) recovery is not reached (Wiles, 1998).

Several studies highlight the association of patients' illness perceptions to their attendance at cardiac rehabilitation and their recovery; in particular belief in control of the illness and belief in aetiology from lifestyle was associated with higher attendance at rehabilitation (Petrie, Weinman, Sharpe et al., 1996; Cooper, Lloyd, Weinman, et al., 1999).

In summary, the research covered in this section has demonstrated the complexity involved in people's understandings and beliefs about heart disease and their perceptions of cardiovascular risk (in everyday life, during an event and after surviving an event). Through the process of lay epidemiology, information and messages from health

professionals, health promotion and media sources are observed and noted, as is personal experience and that of others conveyed in conversations or publicised through the media. The resulting model of coronary candidacy is used in predicting and accounting for cardiovascular risk and events. Lay awareness of fallibilities in the relationship between risk factors and events contributes to fatalistic attitudes, and explains people's feelings about behaviour related to lifestyle risk factors. Research has shown distinctions in the way risk factors are applied to oneself in comparison to others, demonstrating methods of minimising personal perceived risk. The interplay between personal perceptions of risk and expectations and ideas about cardiac events and symptoms has consequences regarding behaviour and action upon experiencing an event. All this has implications regarding motivation to engage in a preventive lifestyle. The focus of the work reported in this thesis will expand this area to focus on the relationship between lay beliefs about perceived cardiovascular risk and attitudes towards screening and prevention regarding heart disease.

Part II: Attitudes towards screening

In this section, I cover some of the literature on attitudes towards screening within three main parts. First, I discuss research literature investigating influences on screening uptake. This is mainly quantitative research and comprises analyses of sociodemographics and social cognition models including criticism of this approach. I then draw upon qualitative research that challenges the perspective of the public health experts contrasting it with that of the meanings lay people hold about screening. Third, I consider the literature on the psychological impact of screening and screening results.

Current screening programmes

Before discussing the literature it is useful to consider a definition of screening:

> "a public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications" (National Screening Committee, 2003)

In addition, by identifying and alerting those who are at risk for a certain condition, screening can help bring about reduction in unhealthy behaviour contributing to an individual's risk status (Pitts, 1996). Screening's overall aim is reducing disease incidence, morbidity and mortality; it is either primary prevention involving screening for risk factors (such as cardiovascular risk) or secondary prevention involving screening for presence of disease (for example cancers). Tertiary screening and prevention also exists, for example sensorineural deafness (Jepson, Clegg, Forbes, et al., 2000), but will not be covered here. In the UK there are currently national screening programmes for breast cancer and cervical cancer; all GP registered women aged between 25 and 64 years (cervical) and 50 and 64 years (breast) are currently offered regular screening. For other cancers, such as colorectal, pilot screening programmes have been carried out and recommendations for national screening programmes have been made (NHS, 2003). There is also antenatal and neonatal screening. The Department of Health has recently

allocated funding to the NHS National Screening Committee for the Diabetes, Heart Disease and Stroke Prevention Project to engage in screening and intervention programmes for these conditions (NHS, 2003).

Attitudes towards screening attendance

Despite the apparent benefits of screening, many people do not take up screening opportunities when invited; often these are those in the most 'at risk' groups (Nielson & Jones, 1998). Therefore factors that potentially influence screening uptake have been the focus of a large amount of research. The majority of these studies has focused on cervical and breast cancer screening as these screening programmes have been underway for several decades thus providing populations to be studied.

Sociodemographical factors

Initially research investigated the importance of sociodemographics in determining uptake. As Britain becomes increasingly diverse in ethnicity, culture and religion, these have been investigated as potential determinants of screening uptake. A systematic review reported that the majority of studies of breast and cervical cancer uptake found no significant association with ethnic origin, although a few studies found higher uptake in black women (Jepson et al., 2000). However, qualitative research has identified cultural beliefs that inhibit screening uptake; Underwood, Shaikha and Bakr (1991) identified Islamic beliefs that inhibited women from engaging in breast and cervical cancer screening. First, the belief that lives were controlled by Allah (God) thus it is God's will if someone is sick, so while willing to seek care when ill, preventive check-ups are uncommon. Interestingly another study (Holschneider, Felix, Satmary, et al., 1999) found the same belief in Latino women in the US. A second Islamic belief prevents women from exposing their body to men other than family; women described avoiding physical examinations by male doctors, they lacked confidence in health professionals' respect of their cultural values regarding this issues and thus avoided attending at all (Underwood et al., 1991).

Screening uptake has been found to be lower in those from more deprived socioeconomic backgrounds (for example Harper, 1993; Neilson & Jones, 1998; Bostick, Sprafka, Virnig, et al., 1994; Friedman, Webb, Richards, et al., 1999; Gatrell, Garnett, Rigby, et al., 1998; Pelfrene, Bleyen & De Backer, 1998; Lagerlund, Maxwell, Bastani, et al., 2002). A systematic review found that a majority of US studies reported those with health insurance (an indicator of higher socioeconomic status) were more likely to attend mammograms than those without (Jepson et al., 2000). Research has focussed on identifying and targeting barriers and perceptions that are more pronounced in lower socioeconomic groups (for example Orbell, 1996; Wardle, Williamson, McCaffery, et al., 2003). Level of education has been investigated as a potential determinant of screening uptake, however a systematic review found no association in the majority of studies (Jepson et al., 2000).

Knowledge and understanding

Research has focused on misunderstanding as a potential barrier to screening uptake. Neilson and Jones (1998) following up women who had declined a GP invitation to cervical screening, found that the invitation letter had failed to explain the purpose of the test; a quarter of the decliners wanted to know more about the purpose and the meaning of the results. Further misunderstandings involved misperceptions of causes of cancers (for example, McKie, 1993; Mouchawar, Byers, Cutter, et al., 1999). A major issue of misunderstanding is the view that whilst asymptomatic screening is unnecessary (McCaffery, Borril, Williamson, et al., 2001), and that symptoms would be required to initiate screening attendance (McKie 1993); such misunderstandings are problematic for chronic conditions as once symptomatic, prognosis is often fatal (Pitts, 1996; McCaffery et al., 2001). A second important aspect that is crucial for screening programmes is provision of sufficient explanation of the possibility of false results, i.e. both false positive and false negative results. This will be discussed further within the psychological impact section.

Whilst it is important that invitations should be clear and informative, some past health promotion campaigns have assumed that understanding and knowledge of risk would be sufficient in provoking behaviour, such as screening uptake, but such decisions are much more complex involving many factors as discussed in the following sections.

Invitations to attend

The GP can have a significant influence on an individual's screening uptake (Rakowksi, Dube, Marcus, et al., 1992); opportunistic invitations during GP consultations for other reasons can produce a high percentage of screening uptake (Norman, 1993). Influences on a GP to make an opportunistic invite include their own beliefs and family history (Woo, Cook, Weisberg, et al., 1985; Marteau & Johnston, 1990), and national policies such as GP targets for cervical cancer screening (McKie, 1993) and GP contracts. Such policies are not always adhered to by GPs (Frolkis, Zyzanski, Schwarz, et al., 1998; Norman, 1993) or can lead to insensitivity and controversy (McKie, 1993). Norman (1993) found no difference in percentage uptake for general heath checks between opportunistic invites (using tagged patient records) and postal invitations; however, the latter generated greater coverage. Invitation letters containing an appointment time generally produced greater screening uptake than open invites, but the latter invoked more satisfaction with type of approach (Norman & Conner 1992; Williams & Vessey 1989; Wilson & Leeming 1987).

McCaffery et al (2001) point out a hurdle for 'new' screening programmes; all female non participants in a colorectal screening programme reported having attended cervical and breast cancer screenings, one of the explanations being that these had become routine (which fits with the latest UK attendance figures of approximately 81% and 75% respectively) whereas bowel cancer screening being novel probably entails stronger intention (McCaffery et al., 2001).

Health beliefs and social cognition models

Whilst pinpointing sociodemographic factors associated with screening uptake may be useful, as particular barriers associated with certain groups can be targeted, psychologists have focused on cognitive factors and models that explain how cognitions are related to health behaviours: social cognition models (SCMs). These are variables that can potentially be changed and can mediate the effects of other factors (Conner & Norman, 1995). The two SCMs that have been most widely applied to preventive health behaviour are the health belief model (HBM) and the theory of planned behaviour (TPB). The HBM (Rosenstock, 1966; 1974; Becker, Haefner & Maiman, 1977), an expectancy-value model specific to health related behaviours, comprises of components relating to four key beliefs: perceived susceptibility to a health event, perceived severity of the condition and its consequences, and perceived benefits and costs of the related health behaviour. A review of the HBM (Harrison, Mullen & Green, 1992) reported these four variables as typically significant predictors, however effect sizes were small. The TPB (Ajzen 1985; 1988; 1991) and its predecessor the theory of reasoned action (Fishbein and Ajzen, 1975; Ajzen & Fishbein, 1980) which also developed from expectancy-value theory, holds that the main determinant of volitional behaviour is the intention to engage in that behaviour (Conner & Sparks, 1995). Behavioural intention is determined by one's attitude towards the behaviour, subjective norms (the belief about whether significant others think one should engage in the behaviour), and perceived behavioural control (the perceived ease or difficulty of performing the behaviour.

Reviews and meta-analyses of research applying social cognition models to predict screening intentions and behaviour have found generally poor predictions, and focused on intentions or past behaviour, rather than measuring actual screening uptake (Godin & Kok, 1996; Harrison et al., 1992). This has been tackled (Bish, Sutton & Golombok, 2000) with a prospective study of cervical screening uptake investigating the predictive use of the HBM and TPB with an added measure of anticipated affect. However, neither model was found to account for a significant proportion of variance in the behaviour i.e. a significant predictor of screening uptake. The TPB was a good predictor of screening

intentions, in particular the attitude component showing that women's attitudes are a good predictor of their intention (Bish et al., 2000). The most useful component of the HBM was perceived susceptibility. Explaining the findings the authors note that questionnaires assess only a 'proxy measure' of an intention and are often hypothetical, whereas decisions regarding screening in reality are less likely to follow a habitual response, involving different thoughts and influences each time (Bish et al., 2000).

Further criticism of social cognition models include the failure to acknowledge emotional influences and responses which are likely to be heightened when waiting for results that could include diagnosis of a disease such as cancer (McCaffery et al., 2001). Sutton (1998) noted that while SCMs are designed to predict behaviour, much of the variance in behaviour remains unexplained. This unexplained variance led Ogden (2003) to question the conclusions of studies applying SCMs which give support to the models despite low levels of explained variance, rather than using the data to challenge the models. She notes how authors' explanations included poor operationalisation of the models, problems with the population used or the behaviour of focus, or advocating extension of the models (Ogden, 2003). She further criticises the focus on analytic rather than synthetic truths in the models' operationalisation, and suggests that rather than accessing cognitions, SCM questionnaires could be creating or changing cognitions (Ogden, 2003).

Other criticism of applying SCMs to attitudes towards this and other areas includes overestimation of the significance of cognition and calculation involved; the assumption that individuals are rational and autonomous ignores the lived and embodied experience of screening, which extends beyond cognitive processing to the wider social context in which decisions take place (Howson, 1998). Furthermore, if rational processing *does* take place, only a decision to attend is considered a 'rational' choice. Howson (1998) contests the expectation that the public *should* choose to attend screening, and that non-attendance or not deciding are often regarded as "failure in one's social duty to maintain

health and well being" so shifting the responsibility onto the individual (Howson, 1998; Greco, 1993; Singleton, 1995).

Lay meanings of screening

Surveillance and the risky self

Howson (1998) places screening in the context of surveillance by medical culture to monitor and eliminate risk of disease but argues that this contributes towards a generalisation of risk, development of risk consciousness and the 'risky self' (Howson, 1998; Ogden, 1995). Lupton (1993) notes that while people have a right to know their risk, should they not also have a right *not* to know their risk?

Uncertainty and reliability

Duncan, Hart and Scoular (2001a) describe the disparity between expert and lay definitions of certainty of screening tests: medical opinion is based on probabilistic reasoning applicable to the population whereas the layperson is concerned with prediction and control of individual health. People generally attend screening to ascertain their disease-free status (Posner & Vessey, 2001). Women in Howson's (1998) study reported attending cervical screening for 'peace of mind', not because they perceived themselves to be at risk. Duncan et al. (2001a) state how this expert-lay mismatch is not due to public misunderstanding, rather a result of the way screening is presented. For example, cervical screening is considered a triumphant medical progress: safe, simple and successful, with no mention of side effects and accuracy of the test (Howson, 1998). But her participants talked with great anxiety about the reliability of the screening test (for example from media reports and others' experiences of missed or misinterpreted results resulting in disease and death); even a 'normal' result would leave them in doubt. Uncertainty may thus not be alleviated by screening and may even be exacerbated reinforcing their sense of risk, not just from the disease but from the test itself (Howson, 1998).

Discussing chlamydia, Duncan et al. (2001a) warn how scepticism of screening's ability to control future health may impact upon uptake, and may lead to anxiety in women arising from this uncertainty. They advocate presenting screening to the public in a way that acknowledges the uncertainties (Duncan et al., 2001a). Furthermore, dissatisfaction is not confined to the public, as many health professionals display concern over the ethics of recruitment strategies (Duncan et al., 2001a). Recent articles and letters in the British Medical Journal have outlined the negative side of screening programmes, and debated honesty in informing the public of the limitations of screening (for example Austoker, 1999; Kmietowicz, 2000).

Psychological impact of screening

It is important to consider the psychological impact of screening, not only as a potential influence on future screening attendance (Wardle, Pernet & Stephens, 1995), but also because screening programmes aim to benefit health. Thus, any costs including psychological harm must be considered. People usually consider themselves healthy before being offered screening; health tends not to be thought about until our own health or that of someone close to us deteriorates (Shickle & Chadwick, 1994). Shickle and Chadwick (1994) suggest that to be offered screening casts doubt over our 'healthiness' and can provoke anxiety until a negative (healthy) test result is received. The authors describe this state as the 'worried well'. Receipt of a screening invitation itself has been associated with anxiety (Nathoo, 1988). Applying optimistic bias to attitudes towards screening (when people perceive their risk of getting ill as lower than those around them – discussed in Part V) would predict people to expect a negative (healthy) test result. Indeed as mentioned, Howson's (1998) participants reported attending cervical screening for reassurance rather than anticipating any risk. If these expectations are not matched and a positive result is actually received, it is likely that anxiety both general and specific to the condition will be generated. Raised anxiety has been found in women receiving positive cervical cancer screening results compared to negative (Wardle et al., 1995). Research has shown varying amounts of adverse psychological effects of screening.

Positive results bring about the transition from being a 'well' person, through potentially ill, to 'ill' (Duncan et al., 2001a). Duncan et al. (2001a) criticise research for concentrating on cognitive processes and ignoring the 'lived experience' of those attending screening and obtaining results. Focusing on the meanings people attach to the situation, they draw upon Bury's (1982) concept of 'risk to meanings' whereby the uncertainty from living with a chronic illness challenges our ability to maintain culturally ordered meanings (Duncan et al., 2001a). They argue that managing meanings and risk to meanings are central to women's accounts of chlamydia diagnoses; once diagnosed, participants reinterpreted their meanings to maintain their 'nice' image thus minimising threat to their identity (Duncan et al., 2001a).

Receipt of a positive result could increase anxiety through feelings of being 'labelled' with a condition. Certain conditions are associated with stereotypical images of the type of person susceptible, sometimes involving stigma for example from sexually transmitted diseases or conditions associated with risk from sexual activity such as cervical cancer (Posner & Vessey, 1988; Wardle et al., 1995). Such stigma will add to the impact of being diagnosed with the condition, for example shock, distress and anxiety in women diagnosed with chlamydia (Duncan, Hart, Scoular, et al., 2001b). Regarding other conditions detection and labelling of hypertension has been associated with reduced well being, more psychological distress and other psychosocial effects (for example Irvine, Garner, Olmsted, et al., 1989). High cholesterol detection was not found to have such adverse psychosocial effects, except slightly increased worry about cholesterol (Irvine & Logan, 1994). The authors propose several explanations for this distinction. First, focusing on the role of perceived control, high cholesterol control and treatment could be viewed as more under individual control and optimistic bias could be operating. Second, high cholesterol has been perceived as less symptomatic, thus an individual's expectations regarding symptoms may be more salient than anticipated consequences at this point (Irvine & Logan, 1994).

In addition to 'positive' results, uncertainty can also arise from 'abnormal' or 'inconclusive' results that request recall for a further test; this process and its uncertainty could increase psychological morbidity (Lerman, Trock, Rimer, et al., 1991). Comparing women with negative results and two severity levels of abnormal results from a mammogram, Lerman et al. (1991) found those with both levels of abnormal result reported more worry about breast cancer than those with normal results. Overall the negative psychological impact increased with level of suspicion of mammogram, and this impact persisted after the women had had further tests ruling out cancer, suggesting increased perception of personal risk (Lerman et al., 1991).

This highlights the issue of false positive results. Whilst *attendance* at breast screening was not found to increase anxiety, Sutton and colleagues (Sutton, Saidi, Bickler, et al., 1995) found that women who received positive results (later found to be false positives) reported significantly more anxiety at the stage of receiving the results letter than those with negative results. The authors also note how the false positives reported higher anxiety at earlier stages in the process (being screened and awaiting results) and reported more discomfort than the negatives. As anxiety was reported retrospectively, this indicates that the experience of receiving a positive result coloured their memory of earlier stages in the screening (Sutton et al., 1995). With no interference from retrospective reporting, another study (Sandin, Chorot, Valiente, et al., 2002) comparing women attending for a regular breast cancer screening with those recalled for further screening, found women in the recalled group had higher levels of specific worry, fear and thoughts about breast cancer. However, the negative impact was not found to persist following notification of a negative result contrasting Lerman et al. (1991). Several authors have advocated minimising uncertainty by reducing the time delay of awaiting results and recall screening (Lerman et al., 1991; Wardle et al., 1995).

It is important to consider lay understandings of results. Regarding cancers, 'abnormal' results which require further testing do not equate to diagnosis of cancer (as discussed above many turn out to be false positives); misunderstanding of 'pre-cancer' and

'premalignancy' has been discussed in the literature as a cause of distress (Wardle et al., 1995; Wardle et al., 2003) highlighting the need for adequate explanations to participants of these results (Duncan et al., 2001b). Regarding screening for cardiovascular risk factors, the issue is slightly different in that most such risk factors are along a scale with different cut off points above which indicate varying levels of increased risk.

Positive results are not always accepted. Irvine and Logan (1994) found that over half the men in their study who were told they had high cholesterol did not accept it. Denial could have different consequences; it could be linked with positive affect and well-being. However, in this study deniers had more negative attitudes towards health behaviour change, so made less changes and improved their cholesterol less than those who accepted the label (Irvine & Logan, 1994).

Negative (healthy) screening results can also have psychological impact. This can be positive, for example providing reassurance of prior beliefs about personal health and lack of risk, as demonstrated by Howson (1998) regarding negative cervical screening results. Perceived risk and worry has been found to reduce post screening, for example in a colorectal cancer screening programme (Wardle et al., 2003), in which transient emotional benefits were also apparent. A positive effect demonstrated in a cardiovascular risk screening programme was a significant change in behaviour by men identified as high risk particularly regarding diet. Although promising, the authors acknowledged that as changes were assessed only in the short term, they may not have been maintained in the long term (Tymstra & Bieleman, 1987).

However, negative results can also have a more worrying impact through false reassurance of healthiness. Tymstra and Bieleman (1987) described this as the 'certificate of health' effect; almost half of the participants who received 'healthy' results (cardiovascular risk factors) agreed that the result was proof of no need to change their lifestyle, despite the fact that these men engaged in the same amount of 'unhealthy'

behaviour as the other respondents and engaged in less care about their diet. In another cardiovascular screening and intervention programme, the intervention group's perceptions of current health shifted in a positive direction after one year matching objective measures of reduced cholesterol and weight, however their perceived ability to reduce risk of future heart attacks decreased (Marteau, Kinmouth, Thompson, et al., 1996). The authors suggest this may be from complacency with the level of objective risk that participants had achieved, despite this reduction being modest, indicating that the intervention had generated false reassurance.

As mentioned previously it is crucial to ensure participants' correct understanding of screening results, in particular that 'normal' or 'negative' results are not understood as very low risk as opposed to no risk whatsoever (Marteau, Senior & Sasieni, 2001). Marteau et al. (2001) found that when manipulating presentation of cervical screening results in a hypothetical situation, adding one accompanying sentence, "low risk of having or developing cervical cancer in the next five years", resulted in a marked increase in understanding of residual risk thus avoiding false reassurance. The perception that screening has given a 'clean bill of health' has also been shown in those who did not receive a 'healthy' result; in an annual screening assessment for elderly people McIntosh and Power (1993) found such misperceptions in large numbers of those whose objective screening result placed them in the medium or high health risk groups.

To summarise, this part of the literature review has presented an overview of some of the key research into attitudes towards screening. Literature focusing on influences on uptake was outlined incorporating sociodemographic factors, knowledge, triggers, and application of social cognition models. Whilst of some use predicting uptake, criticism of these approaches included the amount of variance left unexplained. Literature exploring lay meanings of screening was outlined, highlighting feelings of uncertainty and risk associated with the experience of receiving an invite, attending the screening and interpreting the results. Finally, literature concerning the psychological impact of

screening was covered illustrating the effects of positive, uncertain and negative screening results.

Part III: Beliefs about medication

In this section I present an overview of literature which has investigated people's beliefs about medication. I begin by highlighting an issue which provoked the majority of this research, namely non-compliance to prescribed medication. I outline how psychological research has applied and developed models to investigate beliefs related to compliance. I then discuss implications of the terms 'compliance' and 'adherence', and criticism of the dominance of this issue in research about attitudes to medication. Next, from the medical sociology literature, some qualitative research is outlined which explores people's ideas about medication and aspects of the doctor-patient interaction in the prescribing situation. Finally I consider literature which places patients' ideas about medication within the wider social context incorporating the notion of risk.

Medication and compliance

The focus of the majority of research investigating patients' attitudes towards medication has been compliance, or rather *non*-compliance, to prescribed medication. Non-compliance/adherence to medication has been estimated as up to 50% (Sackett & Snow, 1979; Meichenbaum & Turk, 1987) added to which is the large amount of prescriptions not redeemed which in one study was 14.5% (Beardon, McGilchrist, McKendrick, et al., 1993). Non-adherence is more than simply not taking the medication; it involves altering the dose, frequency and/or duration of the prescribed regimen (Conrad, 1985). The potential adverse consequences of non-adherence are both at the individual level, with obvious adverse effects to an individual's health and illness, and at the population level, for example treatment resistant variants of viruses and infections (for example HIV) developing rapidly from under or irregular dosage (Kalichman, Ramachandran & Catz, 1999), along with monetary costs to society from prescription wastage and hospital readmissions (Kent & Yellowlees, 1994).

Research, particularly in psychology, has investigated non-adherence with the aim of tackling this huge challenge to health care (Horne, Weinman & Hankins, 1999; Horne, 1993); potential contributing factors investigated have been sociodemographics, illness

type and medication type. Certain conditions and their required medication were identified as less likely to be associated with adherence, for example asymptomatic illnesses when treatment is preventive and lengthy/indefinite (Rand, 1993). Various models have been applied to the area including social cognition models such as the TPB (described in Part II) (Fishbein & Ajzen, 1980; Ajzen, 1985, 1991) and HBM (Rosenstock, 1974; Becker et al., 1977). Particular components of these models have been associated with adherence rates (see Horne et al., 1999). Stage models such as the precaution adoption process model have shown some use in this area (Weinstein, 1988).

The self regulation model (SRM) (Leventhal, Diefenbach & Leventhal, 1992), a hybrid of the social cognition models and stage models (Brewer, Chapman, Brownlee, et al., 2002), proposes that individuals' illness cognitions comprise of five attributes which the SRM questionnaire items measure: First, the 'identity or symptoms' assess individuals' labelling and somatic experience. Second, 'consequences' assesses their expectations of the illness and the risks it may pose for other/further complications/events. Third, 'timeline' assesses the likely duration and course of the illness. The fourth assesses perceptions of 'cause', and the final attribute assessed is 'controllability and cure' (Leventhal, et al., 1992; Brewer et al., 2002). The SRM can conceptualise non-adherence as a coping mechanism for dealing with the illness threat (Leventhal, Meyer & Nerenz, 1980; Leventhal, Benyamini, Brownlee, et al., 1997), this decision being guided by beliefs about the five illness attributes above (Horne et al., 1999). The SRM has shown some use in predicting adherence in hypertensive patients (Meyer, Leventhal & Gutmann, 1985), and asthmatics (Jessop & Rutter, 2003), and in explaining adherence in patients with high cholesterol (Brewer et al., 2002). For example, the latter found that those with a model of hypercholesterolaemia similar to an 'expert model' (in particular in terms of the consequences, symptoms and timeline) demonstrated more adherence and control of their cholesterol (Brewer et al., 2002). However that those with an expert-like model of their illness show better adherence implies that an expert, i.e. biomedical model, of an illness is superior and that patients should be encouraged to hold the same model. This belittles and does not acknowledge the patient's own beliefs, meanings and

explanations about the illness and more importantly the medication. Furthermore in these studies a large proportion of variance in adherence was still left unexplained.

A further criticism of the SRM is the focus on the patient's beliefs about *illness*, whilst their beliefs about *medication* are perhaps more relevant (Horne et al., 1999). Horne et al., (1999) found that whilst studies that have investigated patients' representations of medicines indicated that certain representations seem to be common across different illnesses, different questionnaires had been used making a systematic comparison of findings a difficult task. This provoked the development of a model with the aim of comparing beliefs about medication in general with beliefs about specific medicines, investigating the distribution of these beliefs, and how the two sets of beliefs relate to one another and to adherence behaviour: The Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 1999). The development drew upon interviews with patients and qualitative research (for example: Britten, 1994; Fallsberg, 1991; Lorish, Richards & Brown, 1990; Morgan & Watkins, 1988; Conrad, 1985). The resulting BMQ comprises of two scales: The 'BMQ-specific' assesses an individual's views on their prescribed medicines; participants rate (on a 5-point scale) their agreement with statements about dependency, adverse effects, and efficacy of their medication. The 'BMQ-general' similarly requires participants to rate their agreement with statements about medications in general such as doctors' overuse and trust in medication, addictiveness, harm and safety (Horne et al., 1999).

Horne and Weinman (1999) used the BMQ to investigate adherence in four illness groups (asthma, renal, cardiac and oncology patients). Medication beliefs were found to be the strongest predictor of adherence (stronger than demographics and illness type). Whilst the majority of patients believed their medication was necessary for maintaining their health, a third had strong concerns about the potential adverse side effects, furthermore stronger concerns were associated with lower reported adherence (Horne & Weinman, 1999). The authors found that the necessity-concerns differential was more strongly related to adherence than either construct alone. They propose that this implies

a cost-benefit analysis of concerns versus necessity, and that this is a possible mechanism by which beliefs about medication influence adherence behaviour. This mechanism could be an explicit, deliberate strategy to minimise harm from medication, or implicit, relating to perceived (un)importance of the medication resulting in forgetting to medicate (Horne & Weinman, 1999). Interesting distinctions between illness groups were also found; the asthmatic and cardiac patients reported less adherence. The authors suggest that whilst this could be simply linked with these patients' high concerns-necessity differential, it could also be related to symptomatology and perceived association between medication use and presence/absence of symptoms (Horne & Weinman, 1999). A further explanation could relate to perceived severity of the different illnesses; as previously described heart disease tends to be much less feared than cancer.

Whilst the BMQ can provide an insight into lay beliefs of medication and is useful for gaining an overview into the medication beliefs of different patient/illness groups on a large scale and predicting adherence, a sizeable amount of variance in adherence behaviour is left unexplained in many of the studies which have applied it. Sociological qualitative research on patients' views about medication has shifted the focus away from adherence, and whilst findings support constructs identified by BMQ research, this research has extended our understanding of this area by considering the wider context in which the individual makes decisions about medication. This will be discussed shortly, however, at this point it seems appropriate to discuss criticisms expressed about several aspects of compliance research.

Criticism of a focus on 'compliance'

Use of the term 'compliance' in this context has received much criticism as it implies obedience to doctors' orders and paints a negative picture of patients who are not fully committed to their prescribed routine as 'deviant' (Shumaker, Schron & Ochrene, 1990; Mullen, 1997; Conrad, 1985). Simultaneous to the move away from the paternalistic model of the doctor-patient relationship, this movement (advocated by the Royal Pharmaceutical company's working party on medicine, 1997) rejects the term

'compliance' and even 'adherence' in favour of 'concordance' or 'therapeutic alliance' which imply more of a partnership in the relationship (Marinker, 1997; Mullen, 1997). However, a change in terminology is useless without an accompanying change in culture, in particular in the prescribing relationship (Marinker, 1997). To the consultation, the doctor brings medical knowledge, and the patient brings their beliefs about health, illness and medicine, both should be equally influential on the outcome (Marinker, 1997). The barriers to achieving concordance are ample, the requirements of such a cultural change involve re-training, public awareness, and of course longer consultations (and thus increased funding and resources) (Marinker, 1997; Mullen, 1997). Research is already investigating and developing methods/models for creating concordant decision making in prescribing relationships, such as Dowell and Hudson (1997).

Conrad (1985) criticised research for locating the problem of non-compliance in the doctor-patient interaction or the patient's knowledge and/or beliefs, instead advocating a patient-centred approach where the "meanings for everyday life are more salient..[]..for understanding why people alter their prescribed routines" (Conrad, 1985, pp.29). Conrad (1985) argued that patients were active agents in their treatment rather than the passive recipients expected by the medically centred perspective. The epileptic patients in Conrad's study spoke about developing their own medication practice, often engaging in a similar method of 'trial and error' which they regarded the doctor as doing, and testing the medication. They regarded their behaviour as self-regulation rather than non-compliance for various reasons, summarised by Conrad as an attempt to assert control over a condition which appears out of control (Conrad, 1985).

Patients' ideas about medication

Britten (1994) criticises the research literature for paying too much attention to adherence and insufficient attention to patients' *ideas* about medication. In a qualitative study of patients' ideas about medicines, Britten explored and explained non-adherence within a wider context: First, patients' views of the properties of medicines were

discussed including some positive beliefs, for example the acceptability of longstanding medication, and many negative views of medicines such as their harm and unnaturalness. She also identified more elaborate beliefs such as the doctor using medication to treat the symptom not the cause. Second, patients' orientations to medicine were identified; both positive and negative features were found including preference to avoid medication until necessary and as a last resort, plus fears of shame and labelling as 'ill'. Third, patients expressed views on appropriate use versus actual use of medication. Patients who were more adherent tended to have positive orientations, however, situational and contextual influences were important, sometimes involving judgements about value and balancing of risks and benefits, or influenced by the doctor-patient relationship. From her findings, Britten (1994) argued that doctors should not assume that medicines are always the most acceptable treatment and that assessing a patient's orientation to medication can help address concerns and deal with adherence issues.

Britten's (1994) study was among the pieces of research which Horne and colleagues (1999) mention as informing the development of the BMQ. A more recent qualitative study of hypertensive patients (Benson & Britten, 2002) revealed themes fitting with the BMQ components: patients discussed both specific and general reservations about their medication, and a large proportion mentioned balancing these reservations against their positive perceptions about the medication. However, the study added further insights and explanations behind their beliefs: patients discussed the role of their past, both previous adverse experiences from medicines and the lasting family value of being brought up to avoid drugs. The past experience with their doctor comprising trust had a positive effect on some: other positive factors included achieving a positive outcome, making them feel better and gaining 'peace of mind' from their medication. Despite general dislike of medication, some was accepted due to absence of a practical alternative, or sometimes regarded as minimal compared to more damaging drugs such as steroids (Benson & Britten, 2002).

A recent qualitative study addressed the issue of views specific to preventive medication for asymptomatic risk (Lewis, Robinson & Wilkinson, 2003); a hypothetical drug was presented to both patients and health professionals to explore the minimum benefit people believed would justify daily drug treatment for preventing heart attacks. Similar to the cost-benefit analysis discussed previously, many expressed their need for information about side effects which they would weigh up against the benefits, and most lay people expressed desire for shared decision making in the prescribing decision. Perhaps not surprisingly, in discussing the concept of minimum absolute benefit required to be met by the hypothetical drug over 10 years, doctors would accept a smaller benefit (10% or less), nurses slightly higher and lay people's acceptable benefit ranged from 10 to 99% (Lewis et al., 2003). This indicates the idealistic expectations of medications that lay people seem to hold.

The prescribing relationship

Although one criticism of non-compliance research was locating the problem in the doctor-patient interaction and communication, the role of the doctor and their discourse in the consultation appears to be influential on the patient's subsequent medication taking behaviour: Britten (1994) demonstrated how some patients took "whatever their doctor prescribed" without questioning, perhaps due to their faith in the doctor. Benson and Britten (2002)'s study emphasises the importance of the doctor's discourse on a patient's weighing up of reservations and benefits of medication. Insufficient communication in the doctor-patient interaction continues to be a problem; Britten and colleagues (Britten, Stephenson, Barry, et al., 2000) studied consultations, interviewed both parties and discovered many misunderstandings in prescribing decisions arising from communication failure such as lack of exchange of relevant information (in both directions), conflicting information from other sources, insufficient explanation and factors about the relationship itself. A movement towards shared decision making would be needed to tackle these problems; the authors discuss whose responsibility it should be to improve communication. They argue that while both sides can change, the power imbalance inherent in consultations leans towards placing the responsibility on the

doctor to encourage patients to express their views and beliefs (Britten et al., 2000). Dowell and Hudson (1997) developed a therapeutic decision model through qualitative work with patients as a strategy for GPs to explore patients' beliefs within the consultation. This had promising results; over half the patients seemed to improve their management of their condition (Dowell, Jones, & Snadden, 2002). Despite various limitations, the findings demonstrate the benefits of investing in time exploring patients' beliefs.

Medication and risk

The qualitative research outlined so far has explored people's beliefs about medication and extended our understanding of explanations behind beliefs about medication. In the same way that beliefs about illness are formed through lay epidemiology, input from personal experience of medication use, that of family and friends, advice from doctors and pharmacists, media coverage, promotions from pharmaceutical companies, and national policy/recommendations is incorporated into beliefs about medication.

The sociological literature places lay beliefs about medication within the area of risk. Bissell and colleagues (Bissell, Ward & Noyce, 2001, pp. 6) point out how the focus of risk research in sociology has been on 'high-level' risks and has "by-passed those more mundane dimensions of health and health-related behaviours which perhaps more concretely characterise lay people's engagement with science and scientific medicine". These authors highlight interpretation of risk information as a key area in risk perception; applying Beck's theory, considering the speed at which information about risk promulgates and how reflexive the area is, the difficulty is in the establishment of factual information which people can evaluate, and this results in multiple competing sources of 'expert' information (Bissell et al., 2001; Beck, 1992).

In addition, sociological research has concentrated on the difference between the beliefs of patients and health professionals about prescribed medication. Research has shown how patients continually reassess their medication's efficacy (Donovan & Blake, 1992).

The difference between lay and professional beliefs reflects a growing critique by an increasingly assertive public, inquisitive of scientific medicine and its guidance (Vaughan & Seifart 1992; Williams, Popay & Bissell, 1995). Bissell and colleagues (2001) use Giddens' (1991) writings on public mistrust of expertise in late modernity to explain the active nature of trust which must be won and constantly be renegotiated with the lay public. 'Lay reskilling' (rejection or alteration of various technologies) has emerged from both the mistrust and the acknowledged limitations of science (Bissell et al., 2001).

Bissell et al. (2001) explored lay beliefs about non-prescription medicines using qualitative methods, and had the unforeseen opportunity to do this before and after a 'scare' surrounding a non-prescriptive medication. Before the scare there was much emphasis on benefits of medication in people's accounts and many did not consider risks, assuming that a medicine's position in the pharmacy as a non-prescriptive indicated its safety. These beliefs seem incompatible with risk society theories suggesting that the taking of non-prescription medicine receives little reflexive thought. After the scare, however, there was great awareness of the uncertainty of medical knowledge, and concerns over future risks. The authors proposed, therefore, that regarding lay beliefs of *non*-prescriptive medicines, mistrust of expertise, reflexivity and lay reskilling are not as pervasive as suggested in the theories of Giddens and Beck, but are more occasional and emerge in response to specific health scares. A further finding was that participants continued to buy and use the implicated medicine after the scare; they acknowledged the risk and simultaneously displayed faith in medicine. Participants' continued use was not about lack of understanding about the risks, rather it showed their dependence on the medicine for therapeutic use (Bissell et al., 2001).

The dynamic nature of risk perception and related beliefs emphasise the importance of qualitative, ideally longitudinal, methods in this area as these methods are able to explore dynamic changes in ideas about risk over time (Bissell et al. 2001).

In summary, this section has outlined literature investigating people's attitudes towards medication. Whilst literature focusing on compliance has received criticism, it has identified factors and beliefs that contribute towards patients' views about use of prescribed medication, and has recommended investing more time exploring these beliefs with patients in general practice consultations. Exploration through qualitative research has expanded knowledge of patients' insights and explanations behind their medication-related beliefs, and has demonstrated the relationship with people's (dynamic) perceptions of risk. Less is known, however, about people's ideas and beliefs about *preventive* medication, particularly related to asymptomatic conditions, although literature has indicated that ideas about its necessity are likely to differ from medication for ongoing and symptomatic conditions. Similarly, aspirin itself has received little attention.

Part IV: Research participation

The literature referred to in this section spans several disciplines: medicine and epidemiology, medical ethics, social psychology, sociobiology and sociology. I begin by outlining research into influences on (primarily medical) research participation including demographics and perceived benefits and barriers. Focusing on the randomised control trial (RCT) procedure I next present research into lay understanding of participation. Research investigating the influence of the media and the medical community is covered, including mention of the role change for clinicians involved in trials. The social context and social influences on participation decisions are then considered. The second half of this section was provoked by my fieldwork in which the expression of altruism was salient and led me to explore a different area of literature. Drawing from key texts in sociobiology, social psychology and sociology, I explore how 'altruistic' behaviour has been examined and discussed in the context of behaviour relevant to research participation.

Research participation 1

Influences on participation uptake

The literature covering public attitudes towards research participation has generally focused on the public's interest (or not) in participating in clinical research and the potential influences on an individual's decision to participate; it has been largely quantitative such as questionnaire based studies of trial participants (Madsen, Holm, Davidsen, et al., 2000), or hypothetical questions involving the general public (Purdy, Finkelstein, Fletcher, et al., 2000) and those not typically invited to participate in trials (Fouad, Partridge, Green, et al., 2000). In hypothetical situations, studies have reported positive opinion towards participation, however the ability of hypothetical scenarios to represent 'real' participation decisions can be questioned (Featherstone & Donovan, 2002). Much of the early research into attitudes towards participation can also be questioned ethically, as the aim was often to increase accrual rates in trials (Ross, Grant, Counsell, et al., 1999).

Early research in this area highlights sociodemographic factors as an important influence on clinical trial participation, particularly regarding barriers; certain barriers are more pronounced for the more disadvantaged such as transport, and financial and time constraints. In America, the situation is further complicated by the medical cost system; the disadvantaged worry that their medical insurance may not cover research participation, conversely this same group may participate as a means of obtaining free health care and attention (Merz, 2000). Regarding ethnic minorities, mistrust of medical research remains salient in the African-American community from unethical medical practice such as the Tuskegee Syphilis Experiment (Fouad et al., 2000; Skrabanek, 1990). Other barriers against participation reported include inconvenience, too much time commitment required, and worries about side effects of treatment (Schwarz & Fox, 1995; Bevan, Chee, McGhee, et al., 1993).

Regarding benefits, both overt and more subtle personal benefits are likely to be influential (Madsen et al., 2000). The question of offering incentives has received much ethical debate as pharmaceutical company run research usually offers financial incentives whereas NHS/Charity/University run trials are less likely to offer overt incentives, particularly financial. In a survey of HMO members (US) over 40% reported they would be more likely to participate in medical research if there was a financial incentive, however, a working group (including members of the lay public) set up to discuss participation issues reported that incentives should not be the driving force and that they may be inappropriate (Fouad et al., 2000). Regarding less overt benefits, time and attention given to patients involved in RCTs can create a feeling of being medically monitored and cared for which would not be received otherwise, even in the placebo group (Madsen et al., 2000). The mere presence of a health professional may suffice to provide a form of placebo effect in itself (Elander & Hermeren, 1995); single physician designs which provide doctor continuity can further increase satisfaction (Madsen et al., 2000). For some, the 50% possibility of access to a new medication has been reported as sufficient reason to participate, others regard participating as doing something active for oneself and one's condition (Madsen et al., 2000).

Past experience of trials is likely to be important. Positive experiences are likely to increase favourable opinion of future participation; such reported benefits include increased knowledge about one's health problem, longer clinician contact, having one's opinion valued, the feeling of being a 'hand picked' patient and the opportunity to meet others with the same condition (Madsen et al., 2000; Purdy et al., 2000; Wynne, 1989). Adverse trial experiences that could dissuade from future participation include lack of feedback of results, uncomfortable or invasive procedures such as endoscopies or blood samples, radiation, length of time involved in the trial, and finally non-disclosure agreements about bad experiences in the trial (pharmaceutical company trials) (Madsen et al., 2000; Fouad et al., 2000; Merz, 2000). Further, procedural aspects of the RCT can cause discontent; in particular the randomisation of treatment arms (Madden, 1994).

Informed consent from participants is a legal requirement for all medical research participation. Participant information must be clear and thorough covering the purpose of the research, the procedures, drugs, duration, follow up involved, also the possible outcomes and side effects. In addition, any randomisation and placebo involved should be outlined and the purpose explained (Snowdon, Garcia & Elbourne, 1997). Medical Research Ethics Committees must approve participant information. Information leaflets and consent forms have been criticised for being cluttered with legal and medical jargon (Wogalter, Howe, Sifuentes, et al., 1999). In the past, the majority of consent forms had readability scores only slightly lower than medical journals (Morrow, 1980); revising such forms to improve understanding of the subject matter and the actual message increased perception of choice and better overall understanding in recipients (Bjorn, Rossel & Holm, 1999). Other improvements include making forms more informal, information more accessible, less time pressure, and oral presentation of the contents or a follow up phone call to ensure understanding (Wogalter et al., 1999; Davis, Holcombe, Berkel, et al., 1998; Edwards, Braunholtz, Lilford, et al., 1998). Particular effort should be made to make information clear when research includes groups who may have more difficulty understanding, for example older (75+) participants showed a worse grasp of

the RCT procedure than younger participants in a comparison of two trials (Bjorn et al., 1999). Information should not be limited to the recruitment and consent phase of a trial; feedback and explanation of results is equally important (Purdy et al., 2000).

Understanding the RCT procedure

In studies which examined perceptions of the RCT process, only a few respondents explained their non-participation as due to the placebo and trial procedure (Schwarz & Fox, 1995; Mohanna & Tunna, 1999); however people's understanding of RCTs is likely to influence their attitude. Participants' understanding of the procedure and purpose must be ensured. RCTs have widespread acceptance as the most efficient way to enhance knowledge about medical treatment when a state of clinical (or collective) equipoise exists i.e. when there is clinical uncertainty amongst doctors about the best treatment in a given medical situation (Snowdon et al., 1997; Robinson, Kerr, Stevens, et al., 2003). Participants are randomised to a treatment arm for both ethical and scientific purposes (Robinson et al., 2003). Due to the state of equipoise, it is ethical to only allocate treatment at random. Furthermore scientifically, selection bias is avoided through random allocation thus maximising impartial results and increasing bona fide knowledge (Schulz, Chalmers, Hayes, et al., 1995; Robinson et al., 2003). Double blinding (neither participants, clinicians nor researchers know any participant's treatment identity) further minimises selection bias.

The concept of blinding can be difficult to grasp, as people want to know what is being done to them (Madsen et al., 2000; Purdy et al., 2000) and anxiety arising from such uncertainty could alter a patient's prognosis (Baum, 1990). Patients whose health does not improve may drop out of the trial in order to get better medication, altering the reliability of the research (Elander & Hermeren, 1995) or may experience such improvement or side effects that they correctly guess their medication, effectively unblinding the study as far as the participant is concerned (De Deyn & D'Hooge, 1996).

Participants' awareness and understanding of the randomisation concept and its purpose has been the focus of a few recent studies. Much confusion regarding randomisation and its aims was found in a study of parents of babies who had been entered into a neonatal trial of treatments for respiratory failure (Snowdon et al., 1997), also in men invited to participate in a benign prostate trial, who verbally acknowledged the confusion they felt (Featherstone & Donovan, 2002). Misunderstandings arose from the word 'trial' (relating to its use in other situations like trial period) and the method of treatment allocation. Although analogies such as 'tossing a coin' or 'lottery' were common in the babies' parents' accounts indicating comprehension, more detailed inquiry revealed very different beliefs of how treatment was allocated, in particular therapeutic determination depending on individual needs (Snowdon et al., 1997). Similarly, Appelbaum and colleagues (Appelbaum, Roth & Lidz, 1982) found a third of psychiatric participant-patients shared this misunderstanding, as did over half of Featherstone and Donovan's (2002) participants, which Appelbaum et al. (1982) termed 'therapeutic misconception'. Use of a computer in the allocation process was acknowledged but there was confusion over the computer's role and on what basis it made decisions, rather than awareness of its use as a randomisation tool. Men in the prostate trial, despite showing fairly good understanding and recall of the trial design (in particular randomisation), struggled to make sense of the concept and accept it (Featherstone & Donovan, 2002). Participants in both this and the parents' study engaged in several approaches of trying to make sense of the randomisation, such as becoming distrustful of the trial, or conversely becoming trusting of the doctors or turning to fate or destiny. In both, randomisation was sometimes attributed to ideas about rationing of treatment due to lack of available clinical resources, or as an ethical resolution to remove responsibility from someone making a decision (Snowdon et al., 1997). Parents rationalised the concept, for example in hindsight reporting that randomisation had led to them avoiding risks from the experimental treatment or by minimising chance (by discussing the influence of higher powers or God) (Snowdon et al., 1997). The majority expressed a strong preference for the experimental treatment and expressed few concerns about its potential risks (awareness of its use overseas further added to this). This led to the belief that

randomisation was unfair and to expressions of moral overtones about being owed the experimental treatment (Snowdon et al., 1997).

As demonstrated, despite sometimes actively trying to make sense of the purpose of randomisation, participants' explanations do not show accurate understanding of clinical equipoise (Robinson et al., 2003; Featherstone & Donovan 1998, 2002). MRECs now have guidelines for producing trial participant information containing a descriptive statement explaining clinical equipoise and random allocation (Robinson et al., 2003). However Appelbaum et al (1982; Appelbaum, Roth, Lidz et al., 1986) argue that explanations of equipoise may make little difference due to the prevailing lay assumption that a doctor will always act in the patient's best interest. Considering these findings, Robinson et al. (2003) explored public understanding and assumptions relating to random allocation and clinical equipoise in RCTs through a series of studies using hypothetical scenarios and highlighted three main sources of misunderstanding: First, many participants could not accept that an individual doctor, or doctors collectively, could be totally unsure about which of two treatments is best. Second, the idea of a doctor suggesting treatment allocation at random was considered unacceptable, and third, participants did not regard random allocation as producing more knowledge than allocation by choice or matching (Robinson et al., 2003). The findings indicate that descriptive information about equipoise and random allocation can be difficult to make sense of (Robinson et al., 2003), supporting earlier findings. However, the need for accurate comprehension of equipoise, randomisation and change from standard doctor-patient roles is crucial for informed consent (Appelbaum et al., 1982; Featherstone & Donovan, 2002; BMJ Editorial, 1995), and could reduce anxiety caused by confusion (Snowdon et al., 1997).

Social influence and social context

Participation is influenced by 'others' at different levels. The media is in a powerful position. While it is without question that coverage of severe unethical conduct in research should make headline news, and the media is quick to highlight this (for

example concern over payments to doctors or institutions for enrolling patients), it is rare to see equally high profile coverage of *good* ethical practice (Madsen et al., 2000; Fouad et al., 2000; Merz, 2000). Another less personal influence by a third party is the role of Medical Research Ethic Committees whose approval must be sought for running any medical trial. Linked with this is the importance of perceived safety of a trial, endorsement by an authority including MRECs and LRECs (local) or even the church has been found to increase participants' perceptions of safety (Madsen et al., 2000; Purdy et al., 2000; Fouad et al., 2000). Distrust of medicine or hospitals are reported reasons for non-participation (Schwarz & Fox, 1995; Bevan et al., 1993).

On a more personal level, health care professionals are often the gatekeepers for access to potential research populations. Approval by a known or trusted GP can contribute to perceived safety (Fouad, et al., 2000; Daugherty, Ratain, Grochowski, et al., 1995). Referrals depend on appreciation of the need for the particular trial, time to counsel patients, information, and adequate assessment of a potential participant's preferences regarding participation (Fouad et al., 2000; Featherstone & Donovan, 2002). In addition, there is conflict between the role of clinician and of scientist, and between the goals of therapy and of research (Elander & Hermeren, 1995; De Deyn & D'Hooge, 1996; Groudine & Lumb, 1997). A doctor's Hippocratic obligation to apply all existing knowledge to providing patients with the best possible treatment may be contested by scientific obligation to acquire new knowledge to benefit future patients (De Deyn & D'Hooge, 1997; Hellman & Hellman, 1991). By referring a patient to an RCT, a doctor cannot guarantee the patient will receive the best treatment (Groudine & Lumb, 1997). The role change from providing individualised care to the role of researcher can lead to poor compliance or non participation from the doctor (Snowdon et al., 2003). However, RCTs are the only method of reducing the number of ineffective drugs (De Deyn & D'Hooge, 1996).

The context of consenting to participate must be considered. The illness or condition that the trial is concerned with will alter the situational context in which the decision to

participate is made; trials for life threatening conditions are likely to add anxiety and urgency to the participation decision. For example in the trial studied by Snowdon et al (2003), parents of babies with high risk of death were forced to make a quick decision when under great anxiety and without the time to consider all the information, which included novel concepts such as randomisation.

Considering the social context, the hospital setting itself is likely to be influential. Grisso (1996) applied Goffman's (1961) concept of the 'total institution' to institutional members (for example hospital residents, students, prisoners) and officials (doctors, professors, prison officers) when considering research participation in such settings. The officials maintain superiority and members become socialised, losing their personal identity, altering expectations and decisions about life and social interaction (Grisso, 1996). Grisso (1996) questioned the likelihood of an institutionally socialised member dropping member identity and thinking autonomously when asked by an official to participate in something even if presented as something entirely voluntary.

The social psychology literature can help explain reasons for consenting to participate by considering the huge body of research into social influence, 'norms', and conformity. Whilst too large an area to discuss in detail here, a few key research findings can be considered. Asch (1951, 1952, 1956) demonstrated the ease with which people conformed on unambiguous tasks to the incorrect answers of a majority (stooges who were pretending to be fellow participants) whereas on the identical task in isolation, conformity was almost entirely removed. Criticism of the lack of perceived consequences in Asch's studies was one factor leading to Milgram's infamous obedience experiments in which the presence of an authority figure induced 65% participants to administer what they believed to be electric shocks (increasing in severity) to their supposed fellow participant (a stooge) upon every incorrect answer in a staged learning experiment, despite cries of pain and eventual silence. This demonstrated the high rate of obedience to an authority (Milgram, 1963, 1974; Hogg & Vaughan, 1995). Further social influences found to increase compliance that could be applied to participation

include reciprocity and guilt. The 'reciprocity principle' proposes that if we do others a favour they will feel obliged to reciprocate (Isen and Levin 1972). Guilt arousal has also been shown to increase compliance (for example Carlsmith & Gross 1969).

Combining the social context and social influences summarised in the previous few paragraphs, if a member (socialised into member status) witnesses fellow members consent to the request of a researcher (fitting the role of an official), and considering the ease with which people have been shown to conform and obey, compliance to researchers' requests is likely to be high (Grisso, 1996). Requests for participation are not uncommon in 'institutions' such as medical settings. In such settings there exists what Grisso terms a "normative power residual: a shared expectancy about generalised power arrangements and modes of influence in interactions between officials and members of the institution" (Grisso, 1996). Despite moves towards a more consumer-oriented health care service, patients may still tend to assume a fairly passive role within the institutional context, where decision-making may not be truly individual.

Research Participation 2

Altruism

In the first half of this section I have outlined research into influences on participation, moving towards considering the situational and social context within which individuals make such decisions. The second half focuses on a different social influence: altruism. Altruism was mentioned in the quantitative studies (Madsen et al., 2000; Purdy et al., 2000; Fouad et al., 2000) but in no great detail. The salience of expressions of altruism in my participants provoked me to consult further literature (not considered at the outset of the current research) on altruism in social psychology and sociology.

Altruism is defined in the Oxford dictionary as: "selfless concern for the wellbeing of others" and as applied to zoology, "behaviour of an animal that benefits another at its own expense." Rapport and Maggs (2002) stress the difficulty in finding a clear single definition for altruism, as definitions range from completely unconditional giving to

more mutually beneficial acts. Reciprocal altruism is considered the form of altruism most appropriate to human behaviour (Trivers, 1971; Rapport & Maggs, 2002). Dawkins' influential book "The selfish gene" proposes that we will only engage in behaviours which benefit our genes. Thus altruistic behaviour will only occur if we recognise something of ourselves (familiarity or similarity) in the recipient of the pro-social behaviour, thus benefiting genes of ours also present in the recipient (Rapport & Maggs, 2002). Badcock (1986) refers to this as 'kin altruism'. Pro-social behaviour for an altruistic motive with no benefit to the actor or to their genes, and to the actor's expense, is termed 'induced altruism' by Badcock (1986). This does not occur in the animal kingdom as it goes against natural selection (Rapport & Maggs, 2002). Such self sacrifice seems idiosyncratic to humankind.

Bierhoff (2002) argues that altruism can be defined depending on the ultimate goal of the behaviour; true altruism is when the ultimate goal is reduction of suffering in another individual, alongside which any benefits to oneself are merely unintended consequences. There is ongoing debate, however, over the existence of true selflessness. Sociobiology and social psychology share the belief that people are basically egoistic (Bierhoff, 2002). Some even argue that selfless acts are actually disguised forms of self seeking behaviour (Hobbes, 1968 cited in Page, 1996), thus questioning whether the ultimate goal of pro-social behaviour is ever truly altruistic. However, Haddow (2002) argues that such discussions lack distinction between selfishness and self-interest:

> "worthy of note, is that individuals can often pursue their own self-interest, without necessarily being selfish. Individuals who are selfish, by contrast, will necessarily be pursuing their own self-interest, often to the detriment of others." (Haddow, 2002, ch. 4, pp. 6).

Social psychologists have attempted to break down apparently altruistic behaviour into different motivating pathways. Bierhoff (2002) describes pathways which Batson (1991) proposed lead to pro-social behaviour, demonstrating how benefits are derived from seemingly altruistic behaviour. First, egoistic motivation involves self-reward, for example self-congratulation for one's responsible behaviour. Second, motivation to

attain negative state relief; engaging in the behaviour elevates one's mood or reduces personal distress from the situation. Third, motivation to avoid negative consequences such as personal feelings of guilt or social rejection, i.e. the behaviour increases either one's own positive self-evaluation or that of others. Finally, perspective taking and empathy can motivate the behaviour, which could be argued as the closest to 'real' altruism. These different motivating factors are not exclusive, they could exert an influence both individually or through combination with each other (Bierhoff, 2002). Individuals can also have mixed motives, altruistic and non-altruistic (Haddow, 2002).

Explanations for pro-social behaviour in social psychology led to the development of the empathy-altruism hypothesis which, along with alternative hypotheses, has been tested by instructing participants to consider hypothetical situations and manipulating factors hypothesised to influence pro-social behaviour. The empathy-altruism hypothesis states that perspective taking (through attachment to the other (kinship, friendship, or romantic); similarity to the other, familiarity with the situation, or feeling sorry for the other) leads to empathic concern which in turn motivates altruistic behaviour (Bierhoff, 2002; Rapport & Maggs, 2002). Various challenges to the hypothesis have further developed it, for example the proposal that perspective taking alone is insufficient and rather that empathic emotion is the crucial factor which remains stronger than others such as personal distress (Bierhoff, 2002). Cialdini and colleagues (Cialdini, Brown, Lewis, et al., 1997) challenged the existence of empathy instead arguing for 'felt oneness' (a non altruistic motivating factor) whereby a high level of identification with the recipient is suggested to blur the distinction between self and other, and thus also between selfishness and selflessness, leading to felt oneness and consequently pro-social behaviour. Thus the empathy which leads to altruism actually results from self-other merging (Cialdini et al., 1997), demonstrating accordance with the selfish gene theory (Bierhoff, 2002). Bierhoff (2002) combines Batson's empathy-altruism hypothesis, Cialdini et al.'s 'felt oneness' and Hoffman (2000)'s developmental theory of empathic distress and empathy, concluding that:

> "whether focusing on self or victim, the actor's emotional responses are part of a biologically pre-wired behavioural system which unfolds from an undifferentiatied egocentrism into a dichotomy of personal distress and empathic concern" (Bierhoff, 2002, pp.213)

Once developed, the ultimate goal of the behaviour will reveal whether the motivation is altruistic or egoistic (Bierhoff, 2002).

The above theories from social psychology are useful in considering the pathways to 'altruistic' behaviour and whether that behaviour is 'truly' altruistic. Other work has applied the concept of altruism and explored it within the context of 'real' situations. Titmuss's influential book, 'The gift relationship', in 1970, explored altruism within the context of blood donation and the wider health and welfare systems. His main contention was that the UK blood donation system ran entirely on altruism through the donation of blood by unpaid volunteers and was a safer and more efficient system, in addition to being more moral, than the privatised market system in the US. He also argued that a move from a voluntary system would change the nature of society. His work was an important argument against economists at the time, who were advocating a change to a market system. It is also thought that his work provoked a change to a voluntary system in the US (Oakley & Ashton, 1997).

Titmuss described donors by dividing them into (8) types according to the motivation attributed to them; as these descriptions were of the US system the typologies related to how money affected people's motivations. For example, those for whom cash is the main motivation, those with more reciprocal motivations such as 'paying back' for blood received in the past, or those who saw it as a 'pre-deposit' to insure future needs of self or family members (Titmuss, 1970). He described all donors in the British system under 'voluntary community donor':

> "This type is the closest approximation in social reality to the abstract concept of a 'free human gift'. The primary characteristics of such donations are: the absence of tangible immediate rewards in monetary or non-monetary forms; the absence of penalties, financial or otherwise; and the knowledge among donors

> that their donations are for unnamed strangers without distinction of age, sex, medical condition, income, class, religion or ethnic group." (Titmuss, 1970)

As part of a survey of UK donors, Titmuss included an open question of why donors had first decided to donate and categorised the responses. The largest group of responses (26.4%) he classified as altruistic, comprising those who reported a general desire to help and those who were more specific about particular groups in society. The second and third largest reported reasons were responding to an appeal either general (18%) or a personal appeal from someone known to the individual (13.2%). Reciprocity for blood received personally or by known others (either already received or contemplating future need) made up 9.8% of responses. Titmuss (1970) himself acknowledged methodological problems of the survey and stated that caution should be taken regarding the findings and whether they can be interpreted as showing individuals' true motivations. However, he argued that the three most common motives provide support and context to his proposition of blood donation fitting a gift relationship (Titmuss, 1970; Oakley & Ashton, 1997).

Titmuss used Mauss' (1954) writings on gift exchange theory to inform these ideas. Mauss' gift exchange theory derived from studying indigenous cultures as an example of pre-capitalist society. The political economy paradigm in social science proposed that gift-giving in pre-capitalist societies was the pervading economic transaction, whereas capitalism replaced this moral exchange system with one of market-exchange, whereby transactions became monetary based and temporary between unknown individuals and incurred no lasting debt (Polanyi, 1957). Mauss (1954) wrote how the exchange system that existed in pre-capitalist societies ran according to gift-giving: the gift was crucial for creating and enhancing solidarity in society, the transactions were more than simply economic exchanges and rather than being voluntary they were part of a tripartite system of obligations: to give, to receive and to reciprocate. Unlike in market exchange where parties leave the transaction with no debt, the gift exchange system formed and conserved social bonds (Mauss, 1954).

Titmuss (1970) applied the analogy regarding the UK blood donation system as a gift exchange system, but departed from Mauss in that there are no obligations to give or receive with the gift of blood, rather voluntariness and altruism are considered the driving forces of the system, with no reciprocal expectations. Some critics focus on this absence of obligation and reciprocity which are central components of gift exchange theory (for example, Leach, 1971; Frow, 1996, cited in Tutton, 2002). Can gift-giving ever be unreciprocated and engaged in solely for an 'other'? (Haddow, 2002). Frow (1996, cited in Tutton, 2002) argued that 'gifts are precisely not *objects* at all, but transactions and social relations'. Gifts without expectation of reciprocity, i.e. through altruism, invalidate gift exchange theory and require an alternative explanation, and proving that no reciprocation is expected is itself difficult (Haddow, 2002).

Tutton (2002) discusses the work of Titmuss and Mauss relating it to blood donation in a different context (genetic research). He argues that while it is the same substance, donated through the same scientific procedure, the donated blood's use and purpose incurs different motivations. He argues that gift exchange applied to blood donation in this context is more complex and the outcome less transparent to the donor; the gift changes from the blood as a substance for therapeutic purposes to the genetic information which can be extracted from it (Tutton, 2002). Gift exchange theory fits well as Tutton found more expectations of reciprocity; participants were keen to learn more about their own genetic ancestry as well as contributing to furthering knowledge of the society's genetic ancestry as a whole.

Haddow (2002) questioned whether gift exchange theory could be applied to another donation system: organ donation. Similar to blood donation, the UK organ donation system runs according to voluntariness and anonymity with no reciprocal expectations (Haddow, 2002). Haddow (2002) argues that the assumption by many that families donate through altruism does not account for the variety of forms and reasons different individuals in society have for giving. As discussed earlier, social psychologists have attempted to explain motivations behind pro-social behaviour, this is generally carried

out through engaging participants in hypothetical scenarios or through behavioural observation. However, individuals' accounts of their reasons for their behaviour should not be rejected. Haddow (2002) criticises those who deem these untrustworthy, instead emphasising the importance of listening to individuals' own interpretations of the underlying reasons for their actions.

The second half of this section has drawn from key texts in different disciplines which have explored and attempted to explain the concept of altruism and how it has been studied in the context of behaviours relevant to research participation. Titmuss saw the need to ask donors themselves their reasons for donating, and Haddow presents a strong argument for listening to the accounts of donors themselves. It is questionable whether we can establish individuals' true motivations (or even whether such motivations exist) or the ultimate goals of their behaviour from their accounts, and therefore whether we can find evidence for 'true' altruism. However, individuals' presentations of their own interpretations of their behaviour will provide useful insights, in the case of this study, in relation to research participation. As discussed in the first half of this section, there have been relatively few qualitative studies with research participants, or with participants who have declined to participate. There is a clear need for listening to and interpreting the accounts of such individuals.

Part IV of the literature review has outlined many potential influences on research participation ranging from aspects and understandings of the trial procedure, to social and contextual influences and altruism. One could however question the ethics of research that attempts to understand lay reasons for and against participation. Whilst such research is useful and important, particularly as some advocate lay involvement in implementation of trials (Hanley, Truesdale, King, et al., 2001), the question remains of whether the findings could be used to exploit the public, and manipulate them into participating. By discussing their reasons for and against participating in research, people believe that their opinion is being sought and valued, and even as researchers we hope that the study will help trials to be more sensitive to participants' needs. However,

once published, the findings could potentially be used by any researcher, with the explicit aim of increasing participation rates. It is hoped that this is not the case, rather that the findings will be useful in developing more ethical practice relating to informed consent and provision of information.

Part V: Risk

In all four preceding sections of the literature review there has been reference to risk perception, for example in discussing perceptions of cardiovascular risk, influences on screening uptake and attitudes towards medication. The literature on risk is immense and multidisciplinary (Gabe, 1995). In this final section I outline some of the literature, mainly from psychology and sociology, which I consider most relevant to risk in the context of preventive health. I begin by focussing on control, considering the distinction made in the literature between externally and internally imposed risks, and how these and associated issues (such as risk management, responsibility and blame) relate to risk perception. Next, the discussion focuses on research into the process of risk perception including optimistic bias and the weighing up of costs and benefits. Finally, I refer back to the research that explores lay meanings of cardiovascular risk covered in Part I.

Control

The notion of risk has become the subject of much attention, theorising and research due to the increased awareness of risk in modern society, in particular arising from knowledge about risks from technology and from lifestyle (Lupton, 1993). These two sources of risk are often discussed and distinguished in terms of the extent of control the individual has relative to the source; the former being controlled externally (for example environmental hazards beyond the individual's control) and the latter internally (for example 'risky' behaviour such as smoking). Both sources of risk have implications for the individual's health and illness, however perception of the respective risk is proposed to differ relating to perceived control (Pidgeon, 2001). In the public health arena, Frankel et al. (1991) demonstrated this distinction using the example of two differing risk scares from egg consumption: salmonella and cholesterol; the former, associated with fairly instant serious illness from one egg (beyond the individual's control), was perceived as more risky than the latter for which consumption over a number of years increases one's risk of a chronic disease (individual's choice and control regarding the quantity consumed). Controllability is related to the voluntariness associated with the risk source; we willingly take risks such as engaging in dangerous sports, even though

such activities may be a thousand times more risky than involuntary risks which we find less acceptable (Starr, 1969; Denscombe, 1993).

Externally imposed risks

Linked with control is the issue of risk management for which we rely upon the government and experts. Before managing a risk, the level of risk is assessed with the aim of measuring it (quantitatively). This enables comparison with the risk of harm from different sources in order to allow rational decision-making regarding management of the source (Gabe, 1995). Inherent in this approach is the assumption that all risks can be measured, and there is an optimism about risk management (Gabe, 1995.). Slovic (2000) argues that our perception and acceptance of externally imposed risks is associated with our perception of the efficacy of their management, for example we perceive dangerous animals in zoos to be managed more effectively than technological risks. In addition, within technological risks, chemicals and radioactivity are potential risk sources in both industrial and medical situations, but people tend to accept prescribed medicines and X-rays attributing them with much benefit and low risk, whereas pesticides and nuclear power were less accepted and considered much lower benefit and higher risk (Slovic, 1992; Gabe 1995). Slovic (2000) explains this distinction by emphasising the importance of the risk management agency; people tend to have more trust in medical risk managers (GPs) than in technological risk managers (government). Gabe (1993) describes how the deterioration of trust in expert authorities has provoked much sociological writing. The dominance of authority regarding interpretation of risks has now been replaced and is undermined by an increasingly critical public (Giddens, 1991); Gabe (1993) relates this change to Beck's (1992) concept of a risk society and notes that:

> "Social and economic processes have created global, nuclear, chemical, genetic and ecological hazards for which there is no satisfactory aftercare. These structural features reinforce the need for trust in expert authority at the very time that increasing reflexivity and a growing recognition in the indeterminate status of knowledge about risk work to undermine it." (Gabe, 1993, pp.11)

The general public depend on the government and experts not only for risk management but also for information about risks, as the public itself does not have the expertise to do the job (Lupton, 1993). External environmental and technological hazards, and the associated lack of personal control, often elicit anger in the lay public and mistrust towards authorities (Lupton, 1993; Gabe, 1995). The government's response to this 'crisis in confidence' has led to the birth of risk communication, which aims to find ways of bringing the public and the experts into alignment (Kasperson, Jhavari & Kasperson, 2001; Gabe, 1995).

But, whilst we rely on experts, campaigners and the media for risk information, Lupton (1993) points out that such mediators have their own agenda and may distort facts in order to influence opinion. Psychological research produced the 'social amplification' process model of the information flow in risk communication; it highlighted the news media's controlling role in dramatising and framing the source of risk by selecting 'facts', altering the language used, and by interpreting the social meaning of the risk (Kasperson et al., 2001). Less trust in the risk managers is proposed to increase social amplification (Kasperson et al., 2001); whilst trust is easily destroyed, its creation and rebuilding is a long difficult process (Slovic, 2000). Slovic (2000) thus argues that risk communication has not yet succeeded in its aims.

Internal/self control

Regarding risks under our own control, there has been increasing emphasis over the past few decades on the role our lifestyle plays in increasing our risk of various diseases. Risk factors are identified and their relative risks calculated by epidemiology. This informs the government who may then instigate or encourage health promotion campaigns to warn the public of the risks with the aim of motivating them to change their behaviour (Lupton, 1993; Gabe, 1995). In the context of heart disease, campaigns have advised us to reduce behaviours that increase cardiovascular risk: smoking, a diet high in fat and salt and a sedentary lifestyle. The assumption that knowledge and awareness about the risks associated with such activities will lead to behaviour change

has received much criticism (for example Lupton, 1993; Gabe, 1995). Criticisms include failure to take into account the impact of people's social circumstances, also the assumption of rationality in people's behaviour (Lupton, 1993). However, some programmes promote behavioural change through specific inetrventions, rather that just providing knowledge about risk. In addition, Lupton (1993) questions whether public communication of risk is always desirable and in the public's best interest and whether the ethical implications of such communication are considered thoroughly. Whilst accepting the valuable aims of government health promotion campaigns, i.e. promoting and improving the population's health, Lupton (1993) also challenges the risk discourse in such campaigns for being paternalistic and removing the individual's autonomy; she criticises the emphasis on danger rather than safety. She asks whether individuals should have the right *not* to be continually bombarded with reminders of risk and vulnerability (Lupton, 1993).

Lupton (1993) explains how individual responsibility is invoked at two levels: for the individual's personal health; and for 'the good of society', as those whose behavioural choices increase their risk of illness or disease cost rather than contribute towards society. In addition to acting on information about risks relating to lifestyle, individuals are encouraged to assess their level of risk for major diseases through health risk appraisals such as screenings. A problem of such appraisals is the application of epidemiological data (of population averages) to estimates of individual risk (Lupton, 1993); as mentioned in Part I when discussing beliefs about heart disease, people can regard these estimates as definite and incongruence with reality may lead to uncertainty and anxiety (Wiles, 1998; Davison et al, 1991).

Associated with control and trust is the issue of blame. Slovic (2000) notes how experts blame the public for 'risky' lifestyle choices, while the public blames the authorities for technological and environmental risks. A risk's categorisation as internal or external will influence moral judgements about blame and responsibility (Lupton, 1993), fitting with the earlier noted association between voluntariness and acceptability. Blame then leads

to a further distinction within externally imposed risks; man-made risks (for example from technological sources) are less accepted than natural risks such as volcanoes and floods as for the latter, there is no-one to blame (Denscombe, 1993), as supported by insurance policies which categorise such events as 'acts of God'.

Lay risk perception

Pidgeon (2001, pp. 231) advocates that:

> "to understand understandings of risk, we need to go beyond simple one-way efforts to improve public understanding of science. Scientists need to understand the public as much as the public needs to understand science".

As mentioned earlier, risk assessment by experts is through rational and quantitative methods; much psychological research into lay perception of risk assumes rational cognitive processing in the individual too (Lupton, 1993). Denscombe (1993) describes research investigating *how* people perceive risk i.e. what methods they use to interpret risk information. For example, 'heuristics' are discussed as facilitators of the process: this model proposes that rather than considering new risk information in depth each time it is received, novel information is interpreted by comparison with knowledge about more familiar risks (Kahneman & Tversky, 1982; Denscombe, 1993). Factors proposed as particularly important in this process are as follows (Denscombe, 1993): the 'dread factor' or severity of harm anticipated from the incident or behaviour; the vividness of the risk, i.e. the ease with which it can be imagined, influenced by experience and knowledge of the risk; the frequency of risk, whereby increased exposure to the risk source reduces the expectation of resulting harm; the tendency to ignore risks with particularly low probability, and a sense of invulnerability (Denscombe, 1993).

The final key aspect outlined above is more commonly referred to as optimistic bias or unrealistic optimism and has been the focus of much attention. When evaluating, consciously or unconsciously, our level of perceived risk of experiencing a negative event, there is a tendency to believe that our chances are less than average (and higher than average when perceiving our risk of experiencing a positive event). Whilst on an

individual level this could plausibly be an accurate perception, if a group of people collectively perceive this, systematic error is occurring and this is what is known as unrealistic optimism (Weinstein, 1980; 1982). Applied to health, participants rated their personal perceived risk of experiencing 75% of problems listed (including heart attacks, cancer, addictions etc.) as lower than how they rated the risk in their peers (Weinstein, 1982; 1987).

Fitting with the influence of control as discussed earlier, factors reported as contributing to optimistic bias were related to perceived self control over the event (personal actions and psychological attributes), whereas external factors (hereditary and environmental) were not associated with such unrealistic optimism (Weinstein, 1984). Characteristics reported as affecting the level of bias included: the belief that if the problem has not yet appeared, there will be exemption from future risk; that individual action could prevent the problem; that the hazard is perceived as infrequent and that lack of experience with the hazard (Weinstein, 1987). It is interesting to note the overlap between the influences on optimistic bias and the key aspects of heuristics outlined previously, and that whilst presented as distinct factors in the heuristics, optimistic bias research regards them as interlinked.

Optimistic bias is associated with perceived self control over a negative event, therefore increases self efficacy, i.e. the perceived ability to change behaviour. Such bias should logically strengthen intentions to act, however, most positive illusions about risk instead tend to *weaken* these intentions (Taylor & Gollwitzer, 1995) and precautionary behaviour is inhibited by the reluctance to acknowledge personal vulnerability (Weinstein & Lyon, 1999). Optimistic bias thus tends to be regarded as maladaptive regarding health consequences (Weinstein, 1989), but it can also lead to beneficial effects; optimism has been associated with less depression (Alloy & Ahrens, 1987) and positive well being (McKenna, 1993). Potential health benefits from optimistic bias however, will depend on the nature of the source of risk; whereas optimism may help heart disease patients maintain health enhancing behaviours and improve their quality of

life, optimism which leads to rejection of the risks of drug abuse could be fatal (Weinstein, 1989; McKenna, 1993). Regarding some illnesses, people may actually overestimate their risks; when estimating their *absolute* risk of breast and prostate cancer, people *over*estimated personal risk, however, they still regarded their personal risk as lower than that of other people so comparatively were still showing optimistic bias (Clarke, Lovegrove, Williams, et al., 2000).

Research has indicated the functioning of a personalised cost-benefit analysis system through which people's attitudes towards risk are formulated (Kahneman & Tversky, 1982; Denscombe, 1993). This is linked to tolerance of risks; risks are accepted if the benefit is considered worthwhile. Such analysis is proposed to extend beyond the individual level, to consideration of whether both the costs are shared equally by those who benefit (Slovic, Fischoff & Lichenstein, 1980; Denscombe, 1993). Risky behaviour has been explained in terms of the anticipated rewards gained from the behaviour (Heimer, 1988). However, the benefit has also been argued as arising from the *act* of risk taking itself which serves to fulfil inner psychological needs, thus suggesting experience of benefits regardless of the anticipated consequences of the behaviour (Denscombe, 1993).

The theories of risk perception outlined including optimistic bias and weighing up of costs and benefits are useful in demonstrating important influences. However, the assumption of rational cognitive processing in individuals, and the (generally quantitative) methods used to assess lay risk perception, have been criticised for not accounting for the social and cultural context in which people live and act (Lupton, 1993). Social psychology has demonstrated the extent to which the situational context can influence the risks we are willing to take (Denscombe, 1993); group situations tend to increase our acceptance through a normalising of risks and reduction of fear as demonstrated in the conformity and obedience studies (Asch 1951, 1952, 1956; Milgram, 1963, 1974; as mentioned earlier in the 'participation' section of the literature review).

Interpretative social research has examined lay perceptions of risk and risk behaviour within the context of the social circumstances surrounding their lives and explored the relationship between the perceptions of risk of the layperson and the expert (Gabe, 1993). An example is the work of Davison et al. (1991) outlined in Part I which described the development of lay perceptions of cardiovascular risk through lay epidemiology, a process where input from various sources and experiences led to an explanatory theory for predicting and accounting for cardiovascular events, and demonstrated the existence of fatalism.

Part V ends the literature review by focusing on a notion referred to in the four preceding sections. It covered research on the relationship between control and risk including externally imposed risk and its management, internally controlled risk and individuals responsibility. Explanations of lay risk perception outlined were use of heuristics, optimistic bias, weighing up of costs and benefits, and finally, reference was made to the social and contextual circumstances within which lay perceptions of risk develop.

Summary: Chapter 2

In this chapter I have outlined literature that I considered relevant to the aims and context of the research. In Part I, I described existing literature on people's understandings and beliefs about heart disease and cardiovascular risk including the process through which these beliefs are proposed to form and be applied to predict and account for cardiovascular events in oneself and others. In Part II, I outlined research from different disciplines into attitudes towards screening; this overview covered literature on influences on uptake, the impact of screening and associated meanings. As a background to investigating people's attitudes towards preventive medication, part III outlined research into attitudes towards medication (general and other types). In Part IV I described literature from several disciplines that I considered relevant to investigating

attitudes towards trial participation incorporating literature focusing on this specifically, as well as literature regarding the potential social context and influences affecting a decision to participate, and literature on altruism. Due to a theme of risk referred to in the four preceding sections, Part V outlined perspectives on risk from psychological and sociological literature that I considered relevant to the research context.

Chapter 3: Methods

Introduction

In this chapter I will present an overview of the methodological approach and process I took and engaged in to conduct the research for this thesis. I begin by discussing the design and plan of the research including the purpose of the research, the research questions, the choice of methodological approach and research methods. I then describe the initial phase of the research encompassing the pilot work and development of the topic guide. Moving on to discussion of the main fieldwork, I describe the sampling and recruitment, research ethics and discuss particulars of the data generation process including reflexivity and strengths and weaknesses. Finally, I outline my approach to the data analysis.

Purpose of the research

In the literature review chapter I highlighted areas where I felt gaps existed and where a different methodological approach to the research areas could explore attitudes towards and beliefs about the screening and prevention of heart disease, and about research participation. In summary, first the psychological research literature into attitudes towards screening attendance has been largely quantitative applying social cognition models to investigate people's intentions to attend. This has been useful for predicting uptake, but a couple of qualitative studies have demonstrated a more complex picture behind people's decisions to attend screening, and some qualitative sociological literature has explored in more depth lay meaning and beliefs about screening and the particular diseases. The focus has largely been on diseases such as cancer, but other research has illustrated the many factors contributing to lay meanings of heart disease including the process of lay epidemiology indicating that attitudes towards screening for heart disease would be equally complex. Second, research into beliefs about medication has included psychological studies leading to the development and application of theories and models to investigate attitudes, usually focusing on compliance to prescribed medications. Sociological research has also investigated compliance and has explored beliefs and meanings about risk of medication. However, preventive medication specifically has received little attention from either discipline. Thirdly, research into attitudes towards participating in RCTs

has again been largely quantitative and usually with the aim of increasing uptake. A couple of recent qualitative studies of trial participants' attitudes and beliefs have revealed confusion and misconceptions regarding RCT procedure; the trials in focus involved overt differences between the treatment arms rather than use of medication and placebo, thus the placebo and preventive nature of the AAA trial provides a novel focus for research.

From my review of the literature therefore I have not only outlined gaps in the literature which provoked the development of the aims of the present research, but I have also highlighted the initial basis for adopting a qualitative approach. Such an approach is most appropriate to investigating these research areas, as will be discussed in further detail in the following section.

Mason (1996) recommends acknowledging other purposes behind research, and in addition to the purpose outlined above it is important to consider additional interests. Considering the perspective from epidemiology, two areas of the findings will be of direct interest. The first is developing knowledge of why people would (not) attend screening for heart disease and whether they would take aspirin as a preventive medication for heart disease, with the ultimate aim of gauging public opinion because successful implementation of such a screening and prevention programme will depend on the attitudes of the general public. This is linked with the purpose and interest of a third party: the funding body, as the implementation of successful screening and prevention programme would have the overall aim of reducing heart disease in Scotland. A second line of interest to the epidemiologist focuses on increasing knowledge of why people do or do not participate in RCTs and considering how such information could inform and improve the running of research trials. This raises important ethical issues which will be discussed in the ethics section below.

Choosing a research methodology:

In the initial stages of planning a piece of research, Mason (1996) advocates asking oneself questions about the research to identify and outline the ontological and

epistemological position and the broad research area. From the answers, along with defining the intellectual puzzle, the research questions can be more clearly defined:

Ontology: The nature of the phenomena that I wanted to investigate were people's attitudes, beliefs, understandings, interpretations, accounts, experiences. I believe these to be held individually, and also to exist in the interactions between individuals.

Epistemology: What represents knowledge and evidence of these phenomena? How can one access their knowledge and evidence? From my perspective, obtaining and analysing people's accounts would be the most appropriate way; accounts could be generated through qualitative interviews, either individually or in a group. Although Mason (1996) warns that interviews will provide *recounts* of experiences, and access to how people present and account their attitudes and beliefs; from this perspective, it is not possible to get inside a person's mind. In accessing such accounts, attitudes and beliefs are treated as interpretations and versions. In my analysis I aim to demonstrate this wider interpretative and cultural context.

The research questions can now be clearly defined as follows:

- What are people's attitudes towards attending screening for the risks for heart disease? What are their explanations behind their decision to attend or not? What are people's attitudes towards the ABPI measure? What were people's reactions to the screening result? What are people's perceptions of their personal risk of heart disease?
- What are people's attitudes towards using preventive medication for heart disease? What are people's views about aspirin specifically?
- What are people's attitudes towards participating in a RCT? What are people's explanations behind their decision to participate or not?

Coherence of research methodology to research questions

Defining my approach to the research and the research questions led to the decision to conduct qualitative interviews to generate data, allowing me to explore people's accounts and explanations of their attitudes and experiences relevant to the topic area

and research questions. There are different types of qualitative interview and so it was essential to consider the appropriateness and potential contribution of these on several levels. First, considering the degree of structure to the interview, it was decided that a semi-structured approach with open ended questions would ensure the interview covered the research questions whilst encouraging a more informal 'conversational' style, allowing participants to answer in the way they wanted and encouraging depth (Burgess, 1984; Mason, 1996). A second level of consideration was concerning individual and/or group interviews. It was decided that both methods could address the research questions in the desired way, as both methods allow participants to address the subject matter in their own terms through the use of open ended questions on a topic guide (Crabtree, Yanoshik, Miller, et al., 1993). However, the methods could also complement one another by generating different data; useful contributions of the two approaches will now be briefly highlighted. I will not compare the two approaches in terms of advantages and disadvantages per se, rather I will outline a number of ways in which each method can contribute to achieving the overall research aims through different types of data.

Regarding the data generated, individual interviews can reach more depth, whereas focus groups can reach greater breadth; in an interview the researcher can engage in deeper probing thus can clarify meanings more easily (Crabtree et al., 1993), whereas broader data can be generated in a focus group due to the range of attitude and experience of the participants. The unit of analysis differs: interviews can focus on the individual, their understanding and thus how individuals differ regarding the subject matter, whereas focus groups are useful for exploring shared cultural understandings of a group of people (Crabtree et al., 1993) and provide an opportunity to observe how a group consensus is achieved, how disagreements are handled and follow the stages in a reasoning process (Barbour, 1995). Focus groups can also be used to compare individuals' attitudes directly 'in situ' as opposed to later theorising (Kitzinger, 1995; Morgan, 1997). Kitzinger (1995) points out that focus groups can capitalise on the communication of the group to generate data and when such group dynamics work well this can lead the research in unexpected directions. In addition, focus group participants are not forced to express an instant

opinion, they have time to think whilst fellow participants talk and can remain silent when they choose (Barbour, 1995). A group setting may be intimidating for some individuals, particularly those who may lack the confidence to voice disagreement (Michell, 1999).

Altogether the choice of integrating two methods reflects the desire to explore the research questions in both great depth and breadth, to investigate understandings and beliefs of individuals in addition to exploring shared understandings, and to maximise the diversity of people participating.

Pilot work

Pilot focus groups were conducted for several reasons, first for initial exploration of the research questions and development of the topic guide, and second to develop my own moderating and interviewing skills. It was also important to work out ideas about appropriate group composition, size and organisational issues of the focus groups in particular. I will therefore discuss how the pilot work helped contribute to the development of the research within the context of these two key phases in the following sections ('development of the topic guide' and 'sampling and recruitment'). First I will present an overview of the pilot work: the recruitment, conduct and reflection. I conducted three pilot focus group discussions.

Pilot focus groups A & B: The first two focus groups were conducted with members of a retired persons' organisation outside the catchment area for the trial. None of the members had any prior knowledge of the trial. I attended a meeting of the group with an academic who had been invited to speak at their meeting about heart health promotion. I distributed information leaflets and gave a brief presentation of the purpose of my research, and invited those interested in participating in a pilot focus group to indicate their interest by providing their phone number. I subsequently arranged two focus groups (group A consisted of one male and five females, group B of one male and three females) which I conducted with an assistant moderator who took notes and detailed the sequence of talk (see later for explanation of sequence of talk). Each discussion lasted approximately 30 minutes.

A few points should be noted about the participants in the first pilot groups. First, participants' unfamiliarity with the AAA trial and the ABPI measure meant that detailed explanation of the screening and trial was necessary, and the focus of the discussion was a hypothetical scenario rather than a situation that participants had experienced themselves. Post focus group discussions with my assistant moderator brought my attention to the way in which I presented the screening and trial to participants. She pointed out that when describing the efficacy of the ABPI and introducing the idea of aspirin as a preventive medication, I should take care to present unbiased information, thus not swaying people's opinions. This provoked me to reflect on the potential impact of being seen as a member of the trial team on participants' discourse. Second, most participants were middle class and fairly well educated; I felt therefore that the discussion may have missed issues which were more salient to those from different backgrounds. Despite these two important points, the first two pilot studies generated useful themes that contributed to the development of the topic guide.

Pilot focus group C: For the third pilot focus group I contacted a charity who organised 'self-help' groups for people with heart conditions, including those who have experienced heart attacks, strokes and angina. Unlike the first pilot groups, I conducted this focus group during one of their regular meetings, thus had no control over the group composition and size, nor the location which proved to be a problem as the group consisted of eleven people along a long dining table in a fairly noisy canteen. In addition, I had no assistant moderator to take notes. All these difficulties were noted and actively avoided when organising the main fieldwork. However, the group composition was useful as the topic of heart disease was highly salient to all members. Furthermore, as members lived within the catchment area for the trial, there was some awareness of the trial and a few had acquaintances who were trial participants. The majority of participants were from more disadvantaged backgrounds than the first pilot groups, thus I felt this expanded the range of people and opinion, further contributing to the development of the topic guide.

It should also be noted that in all the pilot focus groups, participants were known to each other as they met on a regular basis. Advantages of such naturally occurring groups include participants being more confident in challenging each other's beliefs and practices based on previous experience (Kitzinger, 1995), but existing dynamics and hierarchies could also prevent disclosure by some members (Kitzinger, 1995) and participants may not explain issues which they assume to be already known by the rest of the group (Krueger, 1994; Morgan, 1997). In pilot group A, status within the organisation seemed to have had an impact: a couple of participants were clearly dominant which seemed to inhibit one participant from expressing her views. Conversely in pilot group C familiarity seemed to help as participants often prompted each other to mention particular experiences, and their history as a cardiac rehabilitation group seemed to have creating a comfortable environment for discussing personal health issues.

Development of the topic guide

As previously mentioned, the initial topic guide was developed from the research questions, which were formed as a result of studying literature relevant to the area and the gaps that I identified as particular aspects to investigate. The initial topic guide was used as a basis for the pilot focus groups (see appendix A5.2.1). As discussed above, one of the key aspects that I changed as a result of the pilot studies was to ensure my presentation of the trial and the ABPI measure was factual but unbiased. However, with the exception of group 5 in the main fieldwork, participants' awareness of the trial meant that an explanation of the trial was not necessary; rather than discussing a hypothetical situation participants were able to discuss their own experience of the screening and trial. Questions on the topic guide for the main fieldwork were adapted to address this; the same basic topic guide was used for individual interviews and focus groups (appendix A5.2.2-A5.2.6), but it was adapted according to the participants' stage in the trial process. For example, pilot group participants were asked, "Why do you think people would/wouldn't attend the screening? Group 5 were asked, "What were your reasons for not attending the screening?" Other participants were asked, "What were your reasons for attending the screening?"

The basic topic guide was split into three broad topic areas: screening, aspirin as a preventive medicine, and trial participation. There were several (7-10) questions for each topic area, however often one question provoked discussion which covered several of these questions. Additional questions and probes were made in response to each participant's discourse. In some interviews, the order of topics discussed followed the order on my topic guide (screening first, aspirin second, trial third). This was more common in my first interviews where I was less confident and skilled in the semi-structured approach, and also with interviewees who were less talkative and went into less depth. However, as the study progressed, I rarely asked questions in the order as shown on the topic guide, rather the list of questions served to provide me with example questions to ask and as a back up when stuck for how to further explore a participant's response. In many interviews, particularly as I became more experienced, the nature of the overlap between the three topics or the extent to which

the participant saw them as being enmeshed/linked tended to lead to a less ordered and more merged discussion. In individual interviews, I felt the flexibility of the topic guide approach encouraged more control for the participant and avoided disrupting the flow (Burgess, 1984). Similarly, in focus groups, I was keen to let participants' discussion with each other be as natural as possible, thus I tried to explore issues that were raised through probing and encouraging participants to probe each other, without dominating the direction of the discussion whilst trying to keep the discussion in one of the three main areas to allow full exploration before moving onto a different area. As I developed more skill throughout the fieldwork and reached total familiarity with the topic areas and questions I wanted to cover, I rarely looked at the topic guide other than towards the end of the interview to check that I had covered all question areas with the participant. Therefore, the topic guide became more of an 'aide mémoire' (Burgess, 1984).

The first area focused on screening; with all participants I began the interview/focus group with the question, "Thinking back to when you first received the invite to attend the screening, what were your initial thoughts?" The nature in which the discussion proceeded and unfolded depended on a participant's response to the initial question. There was a wide range of responses to this initial question, for example mentions of keenness to check one's own health led to discussion centring on the screening and perceptions of risk, whereas mentions of altruistic feelings led to a focus on the trial. Often participants mentioned several aspects simultaneously, or in focus groups different participants mentioned different issues in response to one question, in this case I tried to note (actually or mentally) the issue I wished to pick up on later whilst pursuing one avenue first.

The topic guide further developed over the course of the fieldwork in response to attitudes that were expressed and themes that emerged in earlier interviews. For example, I often presented participants with previous participants' views (anonymously) to explore agreement or disagreement. For example if a participant expressed willingness to participate I often said, "some people have said to me that they wouldn't enter the trial if they could not guarantee getting the aspirin, what do

you think about that?" Using views attributed to others has several potential effects: it can provoke expression of attitudes towards other people's views, which can in turn reveal more about participants' own views, also it may indicate to the participant the acceptability of expressing certain attitudes that they may have been too hesitant to express themselves. A further development resulting from the fieldwork was in the way I asked certain questions and presented particular issues. For example, one participant challenged me by commenting that I seemed to be implying responsibility to attend the screening. This challenge drew my awareness to adding a question addressing this issue: "do you think people should attend screening?"

When I felt that the interview/focus group had covered all the research questions, I glanced through the topic guide to check for any questions which had not been covered and in this case raised these questions. I reminded participants of the purpose of the research and the issues I had wanted to cover, and asked if they felt that there was anything relevant that we had omitted (Krueger, 1994; Morgan, 1997), often this provoked further response and discussion (see ending template, appendix A5.3).

In addition to the topic guides, for the focus groups I prepared copies of newspaper headlines about aspirin as stimulus material, five focusing on positive properties such as use for heart disease and five focusing on negative properties such as potential risks (see appendix A5.4); such stimuli can be useful in generating discussion (Kitzinger, 1994). In focus groups comprising trial participants (1a, 1b and 2), I did not use the material as participants' discussion flowed particularly well and also covered the issues that the stimuli may have provoked. These participants had experience of the trial tablet, thus the possibility of aspirin, and most could express their opinion about aspirin referring to their experience. In the remaining focus groups the stimuli may not have led to a more lengthy discussion on these issues than a question, whereas in focus group 4a, which comprised of only 3 participants, I felt it helped to extend the discussion somewhat.

Sampling and recruitment

The research questions I wanted to address guided my decision about whom I wanted to interview. Unlike quantitative research, qualitative research does not aim to access a representative sample; rather purposive sampling allows targeting of people of particular interest and relevance to the research, and exploring the diversity of the intended population (Mason, 1996; Barbour, 2001). Through the sampling I engaged in, I aimed to reflect different relationships to the screening and trial, to explore a range and diversity of views. Studying the AAA trial process led me to identify different stages throughout the whole screening and trial process at which I wanted to recruit participants. I was in the fortunate position that when I started my recruitment the trial had been screening and recruiting for two years; over half the intended number of participants were enrolled into the trial and screening and recruiting was still underway. Therefore, I could potentially reach participants ranging from those who had been in the trial for two years to those who had just been screened, hopefully exploring different perspectives. The five stages I identified are shown in Figure 3.1.

Group 1: Trial participants (including a range from those who had recently started the trial to those who had been participating for over two years)

Group 2: Trial participants who had stopped the trial medication (due to side effects, cardiovascular events or other reasons) but who were still receiving annual follow up by the trial team

Group 3: Individuals who had attended the screening, were eligible to enter the trial but had declined to participate

Group 4: Individuals who had attended the screening but were ineligible to enter the trial (normal ABPI)

Group 5: Individuals who had been invited to the screening but had not attended

A key to the groups will be displayed as a footer on all pages of the data chapters

Figure 3.1: Groups of participants in the present research relating to different stages in the AAA screening and trial process

Reaching participants in each of the five groups identified would allow exploration of the research questions. Attitudes could be compared and contrasted within and between groups. Regarding screening, the decision to attend could be explored through group 1 to 4 participants' explanations for attending and group 5 participants' explanations for not attending. In groups 1 to 4, reaction to the screening result could be explored, including reaction to a low ABPI (groups 1 to 3) and a healthy ABPI (group 4). Regarding attitudes towards trial participation and aspirin as a preventive medication, group 1 and 2 participants' experiences of the trial can be explored including their attitudes towards aspirin, the placebo, and the RCT process, as can the attitudes of group 3 including their explanations for declining to participate.

Considering the time scale of the research, my views on the number of interviews I could feasibly carry out and the amount of data I could feasibly analyse, my initial aim was to interview approximately ten participants and conduct two focus groups within each of these five groups. The number of participants I interviewed according to group are shown in Figure 3.2. I used slightly different approaches for the recruitment of the five different groups (for details of the recruitment process see appendix A2).

	Individual Interviews	Focus groups (number of participants in each)
Group 1	9	2 groups (9; 7)
Group 2	11	1 group (6)
Group 3	11	-
Group 4	9	2 groups (3; 6)
Group 5	6	-

Figure 3.2: Number of participants according to group

Regarding the focus groups, I chose to conduct separate focus groups in each of the separate groups outlined above i.e. not mixing people from different stages of the trial. I wanted homogeneity regarding trial stage as I felt this would facilitate the discussion (Morgan & Krueger, 1993) because mixing those from different 'stages'

could have had negative consequences; for example mixing those with different levels of risk seemed inappropriate, likewise mixing trial participants and non-participants.

Additional criteria were considered when recruiting participants to maximise the diversity of participants in terms of area of residence, social class, gender and age. The trial was being carried out across three health boards, therefore I was keen to include a roughly equal number of participants from each health board area. Regarding social class I used participants' postcodes to work out their DEPCAT[2] (Carstairs & Morris, 1991) score, and when recruiting for individual interviews, I attempted to include participants from the entire range of DEPCAT score. Within focus groups, I originally planned to achieve homogeneity regarding social class as I felt this would facilitate interaction and minimise any hierarchical, and potentially inhibiting, dynamic, but this proved to be a difficult logistical task, thus participants came from a mix of backgrounds. Regarding gender I recruited roughly half male and half female participants and the age of participants ranged from 52 to 78. (See Figures 3.3-3.4 for participants' demographic details). Pseudonyms have been used throughout the thesis to protect participants' anonymity.

Figure 3.3: Participant details: Individual interviews

Participant pseudonym and group identifier	Gender	Age	Carstairs DEPCAT score[2] 1 = most affluent 7 = most deprived
Wendy1	F	55	4
Keith1	M	59	3
Monica1	F	66	4
Richard1	M	54	5
Imogen1	F	61	1
Gordon1	M	67	7
Hamish1	M	70	7
Fergus1	M	72	5
Moira1	F	53	4
Hilary2	F	77	2
Fred2	M	62	3

[2] Carstairs DEPCAT variables, derived from combining variables from small area census data, represent levels of relative affluence and deprivation in small geographic localities (postcode sectors) in Scotland ranging from 1=most affluent to 7=most deprived (McLoone, 2000).

Alison2	F	55	3
Warren2	M	72	5
Marie2	F	77	5
Peter2	M	55	3
Joe2	M	56	3
Harold2	M	63	7
Martha2	F	65	6
Jennifer2	F	61	4
Amy2	F	76	3
Isaac3	M	58	2
Eleanor3	F	62	2
Mandy3	F	59	2
Morag3	F	64	1
Graham3	M	58	5
Miriam3	F	73	1
Paul3	M	63	4
Geoff3	M	68	1
Isobel3	F	60	4
Patricia3	F	61	2
Rebecca3	F	73	6
Dennis4	M	75	2
Daniel4	M	54	1
Craig4	M	54	2
Maureen4	F	53	1
Owen4	M	52	6
Nancy4	F	69	1
Molly4	F	75	2
Joyce4	F	54	6
Ted4	M	77	1
Audrey5	F	72	3
Michelle5	F	63	3
Timothy5	M	61?	4
Jack5	M	66	4
Susan5	F	53	2
Mildred5	F	65	2

Figure 3.4: Participant details: Focus groups

Focus group participant pseudonym and focus group number	**Gender**	**Age**	**Carstairs DEPCAT Score 1 = most affluent 7 = most deprived**
1a			
Alice	F	65	3
David	M	71	1
Jen	F	65	1
Julie	F	56	3

Aileen	F	67	2
Alf	M	74	2
Rod	M	53	2
Andrew	M	59	5
Bob	M	70	5
1b			
Yvonne	F	72	1
Anita	F	74	7
Lorraine	F	52	4
Nigel	M	64	6
Maive	F	67	4
Wayne	M	69	3
Henry	M	67	3
2			
Emma	F	70	5
Ursula	F	61	1
Beatrice	F	75	4
Cath	F	63	-
Ella	F	70	-
Deirdre	F	68	-
4a			
Wilf	M	65	6
Janice	F	70	1
Colette	F	52	3
4b			
Lucy	F	57	2
Nora	F	55	2
Jed	M	57	2
Elsie	F	60	-
Harriet	F	61	-
Melanie	F	64	-

Offering potential participants the choice between an individual interview and a focus group discussion hopefully contributed to minimising some barriers against participating. Individuals who were less mobile could opt for an interview in their own home, and a couple of individuals expressed preference for an individual interview due to shyness. Reasons given for a preference for a focus group included feeling that they would not have enough to say in an individual interview, and intrigue about meeting other trial participants. Convenience was not only an additional influence on the method of interview opted for, but also a particularly pertinent issue when attempting to arrange focus groups to suit the maximum number

of available and interested potential participants. All but one interviewee attended individual interviews (possibly as I minimised non-attendance by offering to conduct interviews in the individual's home or workplace if preferred). However, several people failed to attend their scheduled focus group, one focus group in particular which unfortunately happened to be on a day with extremely bad weather. In anticipation of some non-attendance I tended to over-recruit slightly when arranging focus groups (Morgan, 1995; Krueger, 1994). Another influencing factor on participation, common to most research, was self-selection; in addition to those who failed to turn up at focus groups, there were many people who declined to participate during the recruitment phase by declining the invitation from the research nurse (groups 1-4) or not responding to the letter (group 5).

Thus, my sample cannot be assumed to be representative of the population from which I recruited nor, of course, of the general population, but this is rarely an aim in qualitative research (Mays & Pope, 1995; Barbour, 2001). Rather, I aimed to interview a diverse range of people and thus hopefully explore a diverse range of opinion, which I believe I achieved. My regret at lacking the exploration and thus opinion of those who did not want to attend the screening was in some way compensated by some participants' discussions of their friends and family who do/did not attend screenings.

The decision to stop recruiting was made for several reasons: I had reached close to the number of interviews and focus groups I had aimed for. Second, I felt that I had reached theoretical saturation (Strauss & Corbin, 1990) as no new themes appeared to be emerging in the interviews. Thirdly, during the week of my last scheduled interviews, unforeseen changes in the trial organisation meant that trial staff and research nurses were preoccupied with a pressing matter and I felt that adding to their workload was inappropriate, in particular considering the large amount of help they had already given to my recruitment.

Ethics

Two approaches were taken when considering the ethical issues involved in the research: one formal and one informal.

Gaining formal ethical approval

Application for ethical approval for the research was requested in the form of application for amendment to the main RCT. A letter of application detailing the proposed aims, methods and recruitment procedures was sent to the Local Research Ethics Committee in each of the three health board areas where the trial was being conducted. Two of the LRECs requested further information, therefore a more detailed overview of the research, along with details of the likely topic content of the interviews and example questions, and the recruitment letters and participant information sheet were sent in reply. Ethical approval was granted by the three health boards for access to groups 1-4. However, there was further problems with access to group 5 (those who had not attended the screening). One LREC granted approval. For the second LREC, this group were removed from the application as this health board had recently brought in changes to access as a result of the Data Protection Act. In the third health board area, the LREC approved my access to this group, but the health board then brought in changes to the recruitment process for the main trial team regarding the storage of data, which in turn prevented my access to the data I would require in order to invite screening non-attendees to my research.

Informal ethical considerations

Ethical issues were considered when planning the recruitment of participants. The information sheet (given to screening attendees and trial participants and sent to non-attendees and trial decliners) explained the purpose of the study, emphasised lack of obligation to participate, and lack of effect of their decision upon their treatment in the main trial and/or any other health care. The research process was explained, the choice of interview type (individual or group), location, and time was offered, and confidentiality and anonymity were assured. In addition, where a research nurse was involved in the recruitment, she answered any queries individuals had regarding the study. Individuals had further opportunity to discuss the study and decline when I

telephoned them. I began each interview by outlining the purpose of my research, overview of the topics that I wanted to discuss, and how the findings would be used (Burgess, 1984). I explained the process to the participant including recording, transcribing, and anonymising transcripts; participants were asked if they were happy to be recorded; all participants agreed. I asked participants to read a consent form (see appendix), which they were then invited to sign if they agreed. Participants were informed that they could stop the interview at any time.

Regarding focus groups, I administered consent forms as participants arrived. When introducing the discussion I checked consent to record with all participants. I explained confidentiality from my perspective and asked participants to respect each other's confidentiality. The issue of confidentiality is more compromised in the group setting of a focus group, as there is no guarantee that fellow participants will maintain confidentiality (Morgan & Krueger, 1993; Kitzinger, 1995). However, Michell (1999) points out that in the case of bringing people together for the sole purpose of a research focus group, the assumption is that participants will not meet again and thus providing anonymity post event. This could not be guaranteed, particularly when participants lived in the same area, hence the importance of asking participants to respect each other's confidentiality.

I undertook a MSc course module in ethical and political issues in social research, which led me to consider ethical issues and implications of my research. As highlighted earlier when considering other purposes and interests in my research, there is a potential ethical problem as to how the research findings could be used, for example to increase uptake of research participation. This is a particular problem as this is one of my criticisms of existing research into attitudes towards RCTs. It is hoped that rather than using the findings to manipulate individuals in order to improve uptake, those conducting trials will consider the beliefs, attitudes and meanings lay people hold about trial participation, in particular concerning aspects where confusion and misunderstandings may arise, in order to ensure informed consent and acceptability to the public.

Main fieldwork overview

Individual interviews ranged from 25 to 90 minutes, the majority lasted 35 to 45 minutes. Focus group discussions ranged from 45 to 75 minutes. Focus group participants were given a name label to aid the memories of myself, my assistant moderator, and their fellow participants. I also introduced ground rules of the focus group (see appendix A5.1.1), such as avoiding talking simultaneously; the template for these and the introduction was developed referring to Krueger (1994) and Morgan (1997). To facilitate transcription the assistant moderator noted the sequence of talk of the discussion: each time a participant spoke, she noted the participant's name and either the initial few words spoken or key words in their comment. In addition, she noted other expressions such as non verbal utterances (for example "hmm"), and some body language, such as head nodding.

I recruited and interviewed participants group by group, from the five stages of the trial process I identified (for further details regarding recruitment refer to appendix A2). I conducted the fieldwork in several stages of batches of interviews interspersed with transcribing and preliminary analysis as follows. In the first batch, my fieldwork included participants of groups 5, 4 and some from group 3. I began transcribing the interviews as soon after conducting them as possible, and followed this first stage of fieldwork by completing all transcribing, making notes simultaneously, and subsequently carrying out some preliminary analysis of the data. I then conducted my second batch of fieldwork including the remainder of group 3, group 1, and group2. I transcribed the second batch of interviews, made further notes and developed my analysis, although still at a preliminary phase. Further analysis followed this; the analytical approach and process will be described shortly

Reflexivity

Consideration of the impact of the researcher on the data generated is encouraged in qualitative research. Such reflexivity contributes to presenting the transparency of the research process and the potential impact on the data of the researcher (Mays & Pope, 1995; Richards & Emslie, 2000). Other literature, however, has warned about being over reflexive if it detracts focus from the research participants (Finlay, 2002).

Richards and Emslie (2000) explored and discussed the impact of the researcher's presentation to their interviewees, comparing interviewees' reactions to a medical doctor doing research with a university researcher, and amongst their findings concluded that "who participants *think* you are affects what you get told". In addition to considering how participants saw me possibly having an impact on the generation of data, I regarded how I presented myself to participants as crucial for establishing a good rapport in the interviews, aimed at encouraging openness in participants' accounts and putting them at ease in expressing their views. By engaging in small talk prior to the interview, I attempted to begin building a rapport. There is debate in the literature over the increased benefits of a shared identity between researcher, whilst it can increase rapport and thus improve the amount and content of what is disclosed (Jones, 1991), sharing some identity does not necessarily guarantee the researcher 'insider' status (Burgess 1984; Jones 1991). Obviously, similarities between myself and the participants were often fairly minimal: my participants were aged between 52 and 78, mainly Scottish, about half were male and few were familiar with academic social research, whereas I was a female, English PhD student in my mid twenties. Although who I was undoubtedly will have affected the research relationship and data generated, and certain attributes prompted questioning by participants (in particular about my origins), I did not feel that who I was, prevented participants' discussion or disclosure. Indeed the lack of shared identity or understanding may have been enabling.

For some of the interviews conducted in Lanarkshire I used a hire car to travel to participants' homes which were spread over a large area with less public transport and in some cases these were in fairly disadvantaged areas. I felt it important to emphasise that the car was indeed on hire as I felt that arriving in a brand new car would give participants a false impression about my status, and where possible I used public transport. My presentation as a PhD student was written on my letter and information sheets, however I did not explicitly emphasise this when meeting participants and discussed it only if participants asked. In some cases I felt that this persona possibly increased participation. Several participants mentioned keenness to help a PhD student, some mentioned how their own children were at university or

that they themselves had engaged in postgraduate study, and some were keen to enquire more about my research and career.

Some participants mistook me for a doctor, in which case I corrected them, particularly as interviews often included discussion about doctors, in particular participants' GPs. I explicitly mentioned in my introduction to all interviews that I was not a member of the trial staff, with the aim of encouraging them to voice any negative views about the trial. In some cases however, particularly the focus groups, it appeared that I was being regarded as a representative of the trial (one participant used the phrase "the face of the trial") to which they could voice grievances. This was difficult, as although I tried to emphasise my independence, I did answer participants' queries about the trial process wherever I could, which probably contributed to an identity as a trial representative to some extent.

Data management and analysis

Choosing an approach to the analysis

There are many approaches to analysing qualitative data across and within the different disciplines of social research; when planning the research I studied different ones, which thus informed my approach to the analysis without following a particular prescriptive approach exactly. It was important to ensure that my approach to the analysis followed on from, and fitted in with, my approach to the generation of data. My reasoning for the use of qualitative methodology came from the ontological position and epistemological position as discussed earlier; I wanted to explore people's attitudes, beliefs, understandings and interpretations of the topic matter, and felt that through qualitative interviews and focus groups, data about these could be generated (Mason, 1996). I was keen that the findings generated by, and the theory produced from, the research should of course be grounded in the data, therefore I adopted an inductive and interpretive approach to the analysis, which Mason (1996) describes as a 'theory comes last' view:

> "The researcher will develop theoretical propositions or explanations out of the data, in a process which is commonly seen as moving from the particular to the general" (Mason, 1996, pp.142).

This approach has roots in Glaser and Strauss's (1967) grounded theorising:

> "A grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory stand in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather one begins with an area of study and what is relevant to that area is allowed to emerge" (Strauss & Corbin, 1990, pp.23)

As previously described in the overview of my research process, preliminary analysis followed the first batch of fieldwork and informed the second batch, in some cases allowing emergent themes from the first batch to be further explored in the second (Chamberlain, 1999).

The interviews were semi-structured around a topic guide which, as described previously, was formed initially from the research questions. It is important to acknowledge the influence of the relevant literature that informed the generation of the research questions. Similarly, the potential influence of my knowledge of the literature on my analysis of the data must be acknowledged (Strauss & Corbin, 1990). Whilst not specifically looking for previously documented models, theories or concepts, evidence of these was bound to occur. For example, whilst I did not specifically look for evidence of a concept such as 'optimistic bias' when exploring the data, the concept emerged as an important theme concerning participants' explanations for (not) attending screening. However, I did not use existing theories or models in a deductive way, nor did I use the data to test theories or models. In a multidisciplinary context, my data could investigate existing conceptualisations, including specific models or theories, and identify strengths and weaknesses.

All interviews were recorded (with participants' permission) using digital recording equipment; I then fully transcribed the interviews. I completed all transcription work myself as I believed it to be an important part of the preliminary analysis. While transcribing the interviews I made notes of interesting points and themes. The interview transcripts were printed out and read several times interpretively (Mason, 1996); I made detailed notes upon the printed transcripts of emerging themes.

After transcribing the first batch of interviews I engaged in preliminary analysis using my notes on the transcripts regarding the emergence of themes, named the themes, and began to build a picture of similarities and differences in the way participants discussed each theme, and how these themes related to each other. From this, I produced a written overview of how I saw the themes at this point. This summary helped inform the second batch of interviews.

The same approach of recording, transcribing, printing, reading, and making detailed notes was conducted on the second batch of interviews. Participants in the second batch included those from stages of the trial in which I had not yet interviewed people, thus new themes emerged. I conducted further preliminary analysis on the second batch, which further developed themes from the initial analysis and led to emergence and naming of new themes. A more detailed and more complex picture could be built and a more detailed overview of themes was produced.

At this point I organised the themes into several broad groups. The themes and my organisation of them led to development of the coding framework whereby groups of themes became 'trees' with 'parent', 'child' and 'sibling' codes (see appendix A6 for coding framework). Transcripts were entered onto QSR NUD*IST vivo (NVivo) software and coded using the framework. The NVivo package facilitated storage and retrieval of coded text. Taking one theme at a time I ran a search on NVivo to retrieve every section of transcript coded with the theme. I compared and contrasted different participants' discourse, noted similarities and deviant cases, and referred back to the original transcripts where necessary. I studied the differences and similarities between the different discourses coded by the code, formed ideas about how these related to each other and developed interpretations. I then created a structure for the presentation of the themes and their relation to one another, thus building the structure of each thesis chapter

Regarding the focus group discussions, I adopted a similar approach: I transcribed the discussions with the added aid of the sequence of talk produced by my assistant moderator to help identify which participant was speaking and provided extra notes

such as some comments on body language. I engaged in the same analytical process detailed above for analysis of the interviews regarding noting the emergence of themes. In addition, I studied the transcripts for interaction and dialogue between participants to explore how shared understandings and interpretations of the topics developed; how participants presented different stories/cases and the group used these to form conclusions. For example, when discussing the relative importance of different cardiovascular risk factors, participants in one focus group took turns to present different cases of individuals' lifestyle and health, eventually coming to an apparent group consensus. Furthermore I studied how challenges and disagreements were handled and what they revealed. For example, in one focus group one participant challenged another regarding their respective attitudes towards medication and the trial tablet. In the data presented in the following chapters, I do use some quotes from individual focus group participants but wherever possible and appropriate, I use extracts of dialogue from several participants.

Reliability of method, validity of data and generalisability of analyses

The process of making detailed notes during transcription and on the printed transcripts, which led to the emergence and depicting of themes and eventually to the coding framework, then using the framework to code the transcripts on NVivo ensured rigour in the analysis. This was further ensured by going back and forth between the transcripts and the retrieval reports when writing the chapters.

Validity of the data generation methods was enhanced by using both individual interviews and focus groups to explore the intellectual puzzles in a rounded and multi-faceted approach (Mason, 1996). Explanation of the research process including acknowledgement of the impact of both the background literature and my own potential impact as an interviewer, along with the extracts of dialogue presented in the following chapters demonstrate the interpretation process in a transparent manner.

Regarding generalisability of the findings, as previously mentioned, qualitative research rarely aims to achieve a representative sample thus empirical generalisation

to the wider population is not applicable (Mason, 1996). However the range and diversity of participants and their opinions indicates that the research findings will be useful and informative for those planning and implementing preventive health initiatives particularly involving screening and preventive medication use, and concerning cardiovascular risk and adults in this age range.

Chapter summary

This chapter has described the methodological approach and process involved in the research for this thesis. From the initial research aims to the final analysis, I have outlined the decisions I made and the work I conducted throughout all stages of the research process, in a reflexive and transparent manner.

In the following four chapters I will present data and my interpretations. The chapters relate to the groups of themes that emerged in the analysis: Chapter 4: 'Perspectives on screening for cardiovascular risk' presents analysis of data coded by the 'screening' tree. Chapter 5: 'Attitudes towards prevention and preventive medication' covers data coded by the 'medication' tree. Chapter 6: 'Attitudes towards participation in the randomised control trial' analyses data coded by both the 'Altruism-self benefit' and the 'Participation influences' tree. Chapter 7: 'Perception of cardiovascular risk' uses data coded by the 'Risk perception' tree.

Chapter 4:
Perspectives on screening for cardiovascular risk

Introduction

As outlined in the literature review, the literature on screening has been largely quantitative investigating sociodemographic factors and also applying social cognition models with the aim of explaining and predicting uptake. More recently, qualitative research has explored lay perspectives and also the psychological impact of screening and screening results. Due to current screening programmes mostly involving cancers, the majority of research has investigated attitudes towards and impact of cancer screening; there is less literature investigating attitudes and beliefs about screening for cardiovascular risk.

The present qualitative research enabled exploration of participants' accounts of beliefs about cardiovascular risk, screening attendance, and experience, and explanations behind these beliefs. Although it may be possible to identify costs, benefits and rational decision making in some people's discussions about screening, the present chapter situates the decision to attend screening within the context of personal, cultural, and social circumstances.

This chapter begins by exploring respondent accounts about non-attendance at screening, i.e. barriers to screening attendance. I have tried to progress beyond outlining these barriers, to examine participants' explanations behind them. These explanations included accounts of beliefs about health, illness, preventive health and the health service, and more specifically heart disease and screening. As the fieldwork progressed, it became apparent that a few key phrases were ubiquitous in the accounts of participants across the different groups, phrases that seemed to capture these beliefs about barriers. The first part of this chapter explores four key phrases. I then reflect on how participants used these phrases and beliefs to discuss their own or others' attitudes and behaviour. Exploration of the expressed attitudes towards other people's beliefs moves the discussion onto consideration of the rights versus responsibilities of the individual regarding screening. The following section

examines participants' beliefs about the benefits of screening, again further exploring the explanations behind these beliefs, and examining whether beliefs are particular to the different groups that comprised the sample of respondents in this study. The final section focuses on the screening experience, in particular exploring reactions and interpretations of participants' pre-screening expectations and their actual screening result, and the factors that seemed to underlie these interpretations.

Barriers & beliefs

"It won't happen to me"

> "there's also the aspect about this, "it's not gonna happen to me, it's not gonna happen to me", and we all think that way" David focus group 1a (71yrs)

> "...well I hadnae thought about it much you know, I hadn't put much attention to it. Heart attacks and cancers and things like that happen to other people" Timothy5 (61yrs)

When discussing reasons for non-attendance at screening, the quotes above were common in participants' accounts, echoing the work by Weinstein and others on optimistic bias, including use of the exact phrase, "it won't happen to me" (Weinstein, 1984) as discussed in the literature review (Weinstein, 1980; 1982; 1984; 1987). To recall, optimistic bias refers to when evaluating, consciously or unconsciously, our level of perceived risk of experiencing a negative illness event such as a heart attack or cancer, we tend to believe our chances are lower, thus more favourable, than the average person (Weinstein, 1980; 1982; 1987). As demonstrated in the above quotes, such optimistic bias was implied by many participants in the present research either when describing their own feelings, past and present, or the attitudes of other people.

As discussed earlier, in some illness circumstances optimistic bias could in fact improve health, for example positive well being helping heart disease sufferers to maintain health enhancing behaviours (Weinstein, 1989; McKenna, 1993). However with regard to preventive health behaviour and in this case screening, if optimistic bias inhibits screening attendance, this will largely be maladaptive, as any

asymptomatic risk factor will remain undetected. However, as the subsequent chapter (on prevention) will argue, it is not only the screening, but also the choice of behaviour *following* screening which influences health outcome.

The work of Weinstein and others has documented and quantified optimistic bias and investigated its expression relating to different circumstances. In the present research I explored the background behind this belief in individuals' accounts; in particular, the extent to which it seemed to be a shared belief (perhaps influenced by culture) with little reasoning behind it, or a belief based on personal reasons; and these feelings were then investigated.

Many participants considered optimistic bias regarding heart disease as a normal and acceptable attitude to have, and many admitted thinking in this way themselves. In the first quote at the start of the chapter, D's use of the pronoun 'we' demonstrates his assumption of the attitude's shared nature. Participants who assured that they did not hold this attitude now often described holding it in the past, for example Mildred5 (65yrs) described her attitude before she experienced a heart attack:

> Mildred5: yeah, I was fortunate really 'cause I got a warning
> HE: yeah
> Mildred5: and they take me into hospital right away but I had cousins and they just died, 'click' you know
> HE: so it didn't make you think that you might have one?
> Mildred5: no I'd think "it won't happen to me" eh? I mean don't you really?

Participants sometimes spoke about incidents (usually heart attacks) which triggered their sudden rejection of optimistic bias, rather forcing them to face the fact that "it *can* happen to you".

> Imogen1 (61yrs): erm well I think that if there's heart condition in your family I think you're more aware of it, and you change your lifestyle, whereas you hear somebody, if we were well and my husband was well and he'd had no surgery and somebody passed [away] who had had, I would say that's a shame for them but I wouldn't, I wouldn't think well I'll have to do something about it so that that doesn't happen to me, you see, it's got to come to you, it's got to come to your door before your realise, it isn't next door, it's here. You could be there, "oh it just happens to everybody else" but it doesn't, it happens to you.

Speaking with hindsight, Imogen1 explained how now she realised that heart attacks can and do happen to people like herself, but emphasised that this realisation had occurred only after her husband's heart attack had happened. So, it seems that until a heart attack occurs either personally or to a close 'other', people are more likely to continue being unrealistically optimistic.

In the quotes so far, participants demonstrated the normality and acceptability of optimistic bias. However, not all participants agreed; some criticised this as typical of apathy about health, which they considered widespread:

> Aileen (focus group 1a, 67yrs): I think the attitude would be "don't care", I think that's what I think people would be "it won't happen to me, I'm not bothered", yeah apathy...I think it's like breast screening, the girl there told me that most people don't turn up, they don't even bother to go, so they've got the opportunity and they don't take it and I think that it would be the same for the heart, that's what I think

The above participant struggled to understand why people did not take up the opportunity. Others were less harsh but expressed concern over the implications of such an attitude; Craig4 felt that more individual responsibility was something that should be encouraged to initiate more realistic risk perception:

> Craig4 (54yrs): ... I mean I think um as with any medical condition you've got an uphill battle persuading the general public that it has to be taken seriously and that there was a bit on this morning, all this publicity over diabetes as it happens, you know
> HE: yeah
> Craig4: um, and I mean I think there's a lot of "it'll never happen to me" syndrome as with all these serious medical conditions, so um you have to somehow take the public on board, and um make them aware of the fact and try to coerce them into taking some kind of positive...or at least keeping a lookout on their own condition and so on, and maybe having regular health checks and so on, just to make sure that everything's going along as it should. You know I think not many people do that

Participants' emphasis on individual responsibility is discussed later in the chapter.

The application of social cognition models assumes *rational* thought processing in decision-making. However, there is a tendency, in the literature, to treat only a decision to *attend* screening as rational, whilst a decision *not* to attend or not deciding tends to be considered irrational (Howson, 1998). Optimistic bias, due to its

unrealistic nature, could be regarded as irrational. But in a small number of cases in the present research, such as Geoff3 quoted below, some rational thought processing, involving analysis of his likely risk, did indeed seem to have been carried out, or at least this is how he accounted for his attitude. This analysis, prior to later discovering actual increased risk, had resulted in optimism:

> Geoff3 (68yrs): no, no I never thought about my health. As I say I couldn't understand why people were ill and various things, unfortunately I lost two or three of my agents through heart attacks and things like that. But it never actually dawned on me that it could happen to me or something. They were peers of mine as well so I'd known 'em many years and suddenly they weren't there. We had always been used to looking ahead and saying, "oh well so-and-so's gone but he was another twenty years or thirty years older, when it started getting closer and closer, and then you start looking behind you and discover people are going, then you say "oh hell"
> HE: did that make you think about your own risk of having a heart attack?
> Geoff3: not particularly but, I'd say, "it won't happen to me"
> HE: why did you think that?
> Geoff3: 'cause I can analyse, I'm an engineer
> HE: yeah
> Geoff3: and I'm paid, or I was trained to analyse and write down all the pros and cons in what they call a SWOT analysis. I was doing that before it was even called the SWOT analysis but that's beside the point. And er I did this analysis, analysed everything I was thinking about and felt I had no need to- I was active...

So in Geoff3's case, it could be argued that, the attitude: "it won't happen to me" implies more realistic, than unrealistic, optimism as he explained his analysis of his own risk according to cardiovascular risk factors. However, whilst he gave examples of risk factors for which he rated himself less at risk than others (exercise and stress) he failed to include other contributing factors, such as diet, which elsewhere in the interview he admitted had been rich and not terribly healthy in the past. So, maybe his optimism was indeed more biased than he argued, yet perhaps he wanted to appear as rational and leading a healthy lifestyle.

A further contributory factor to optimistic bias seemed to be age; generally other than anecdotes about anomalies, people talked about heart attacks happening to older people than themselves, so it seems that as long as a person feels young enough they are less likely to consider themselves a candidate for a heart attack:

> Ted4 (77yrs):...I think the younger you are, I'm at the stage where I think 50's young, er yeah you think "I'm OK so I don't think I need to go into this". Especially if you happen to be of the feeling that you're invincible (laughs) and nothing like this is gonna happen to you. I think that would be about it.

Some people were not as sympathetic to younger age being an excuse and felt that a healthy lifestyle should start younger than 50, although this was often said with hindsight. Expressing such attitudes with hindsight was common, for example Michelle5 asserted her keenness to attend screening to discover any risk, insisted that she would have attended invited screenings at a younger age and criticised others for not wanting to know, for example:

> Michelle5 (63yrs):...I can't understand why people wouldn't want to know

And later:

> Michelle5: I think there are still a lot of people who...I think they're wrong, 'cause I would rather know personally

However, whilst initially explaining others' non attendance as resulting from optimistic bias, she continued by revealing that she too had shared this attitude prior to having her heart attack:

> HE:...you said you probably would have gone because you're the type of person who wants to know but generally people do you think-
> Michelle5: "it's not gonna happen to me"
> HE: yeah do you think that's a problem as well 'cause people don't think-
> Michelle5: yeah...I mean before I had my first heart attack, I did feel tired, but I was just putting it down to- I was busy in my work and er I was getting older you know...but when I looked back on it I did feel tired I couldn't be bothered doing things, I'm still a bit like that (laughter)...but er maybe that was a sort of sign and I didn't realise.

Michelle5 had not attended the ABPI screening as she had suffered from a heart attack and thus was ineligible; her husband had attended.

To summarise, optimistic bias was a common and understandable explanation for screening non-attendance, particularly at the younger end of the age range amongst the participants in this study, and was often discussed with hindsight, with a subsequent change in attitude typically after an event or diagnosis.

"If it's gonna happen, it's gonna happen"

Unrealistic optimism relates to one's beliefs about future health and low personal susceptibility. In a way, this belief could be considered fatalistic: a person believes that a heart attack is unlikely to happen to them so they are less likely to do anything about checking the accuracy of their perceived invulnerability. A more explicit kind of fatalistic belief discussed in people's accounts as inhibiting screening attendance is epitomised by the phrase "if it's gonna happen, it's gonna happen", for example:

> Aileen (focus group 1a, 67yrs): well I've got two friends, they're widows, and they got invited to go up and they immediately said, "oh we don't want to know if there's something wrong with us forget it, forget it"...()... they don't go for breast screening, anything, they don't go, "if it's gonnae happen, it's gonnae happen" that was their attitude

As this quote demonstrates, fatalism is a problem for screening attendance: if people are fatalistic regarding illness, they are unlikely to see the benefit in finding out if they are at risk. Alternatively, perceived inevitability coupled with a sense of unpreventability may not entice preventive health behaviour and lifestyle change.

Fatalism was usually discussed when contemplating why *other* people did not attend screening. Indeed, it was particularly common when discussing 'known others' as demonstrated in the above quote. Similarly:

> Patricia3 (61yrs): no I think, some people have this outlook, "well if it's gonna happen, it's gonna happen" but I think- I know in Glasgow they are particularly bad for that, they just don't want to know. My sister had never gone for a screening
> HE: really?
> Patricia3: and I've gone on and on and on at her and she said, "no I'm not going" she's just- her attitude is, "if it's there, it's there and that's it". But she's really- I can't understand, 'cause otherwise she's quite intelligent

Patricia3 found it hard to understand her sister's fatalism, which she deemed inconsistent with her intelligence and awareness. This seems to echo assumptions of some early health promotion campaigns where raised awareness was expected to initiate action.

On the whole there were very few instances of individuals admitting fatalistic beliefs themselves; one of the few examples involved focus group 1a participants. David

compared and reflected on his own beliefs with those expressed by a fellow participant

> David (71yrs): I've got a sister and she's 83, and she's like a wee gazelle...a retired school headmistress, er my father died when he was about 76, my mother about the same age, just of natural causes, just died. I'm the same age as Bob and I reckon all the time I've got now is a bonus, cause I've had my three score and ten, and I'm philosophical about it, I- if I'm gonna die, I'm gonna die. While I will not live recklessly, so I will die of something natural, that's my attitude towards it I suppose

Later...

> David: and it ends up you go back to, "when you've gotta go, you've gotta go", there's a certain inevitability as Bob said, after we're born, we are gonna die eventually (focus group 1a)

In the next example, Alison2 justified her fatalistic attitude through acknowledging awareness of the randomness of heart attacks, and the fallibility of publicised risk factors in predicting *all* cardiovascular events, echoing the work of Davison et al. (1991) and Hunt and Emslie (2001) on awareness of the prevention paradox in lay epidemiology:

> Alison2 (55yrs): well everybody's at risk, nobody knows- I don't think anybody knows really do they that they-
> Sister: it's not foremost in front of your mind is it?
> Alison2: no it's not, that's what I say, just plod on and that's it I mean nobody can truly say, "it can't happen to me" I don't think, because it could do. I never even think about, "could I have heart attack, could I have this, could I have other?" I just feel what has to be, will be...

Similarly, many participants gave examples of randomness and anomalies that could have contributed to fatalistic beliefs, for example this extract from focus group 1a:

> Jen (64yrs): and yet look at the number of people who smoked and they're 90, and they're fine
> David (71yrs): that's right
> Andrew (59yrs): and you get them young athletes, and football players, that drop dead with a heart attack when they're 19 or 20
> David: that's right, my 83 year old sister, she smokes
> ?: really
> David: over 20 a day
> Jen: my grandfather smoked till he was 90,
> Andrew: that's what they say innit, winning the lottery
> Jen: and he liked his nip of whisky every night

A particular case referred to in this focus group and in a few individual interviews, involved a local 22-year-old footballer who had died of a heart attack very recently. This served as a vivid example of a seemingly anomalous and random event, something also identified in the lay epidemiology of Davison et al.'s (1991) participants.

Interestingly, one participant's realisation of randomness had a different effect: it heightened his awareness of potential risk and lessened any reassurance from test results:

> HE: oh right, did that- was that quite reassuring to have those tests?
> Peter2 (55yrs): I suppose in a way but you know you just don't know what's round the corner you know, you just don't know. I mean it could be a stroke, it could be a heart attack, anything. I remember one of the wee cleaners in the fire station, and she was a wee thin woman and that and she'd been in there for years and one day she was just (clicks) like that, heart attack, massive heart attack and that was her dead, but obviously you don't know what her diet was and don't know her history or anything like that but that was...

So, for Peter2, fatalism persisted despite 'healthy' results. Such awareness of the random and anomalous nature of cardiovascular events may have contributed to fatalism regarding cardiovascular risk perception, however these expressions of personally fatalistic attitudes were not discussed in relation to screening, rather in relation to general cardiovascular risk perception and had not inhibited screening attendance in these cases. So, it is possible that fatalism related to cardiovascular risk would not necessarily influence screening attendance. Generally, fatalism was more commonly used when talking about other people's non-attendance at screening, as illustrated by the first quotes in this section, and was usually viewed as an ignorant attitude that was hard to understand.

"Don't want to know"

Those who did not share unrealistically optimistic and/or fatalistic attitudes sometimes rendered these attitudes as denial, often using the analogy of the ostrich burying its head in the sand:

> Eleanor3 (62yrs): but in the same token, if you do go and there is problem, it will be dealt with before you lose your life. It really pays, the earlier you

attend to it. It's like this as well, I think you know burying your head in the sand, if you face up to it and I think that's- some people don't.
HE: yeah
Eleanor3: and I think that's why they don't take part 'cause they don't really want to know, they just keep their fingers crossed that they're alright.

"Don't want to know" was a common explanation given for non-attendance at screening, again predominantly when discussing others' attitudes. When explored further, several explanations behind this attitude emerged. A first explanation expressed by several participants of why 'others' did not want to know was the idea that non-attendees were simply not interested in their own health and body.

Peter2 (55yrs): really I think there's enough advertising and- but I think really...it's getting through to people, and the biggest majority of people just not interested, they're not interested, they don't care.

A couple of participants emphasised the difference between themselves and others with regard to this explanation:

HE:...do you know any reasons why people don't go
Gordon1 (67yrs): well again, they're nae interested in their health or something, there must be something that- whereas I was really keen when I find out cause I know I'm getting tested

A second explanation of not wanting to know was due to the possibility that screening would reveal bad news:

Yvonne (focus group 1b, 72yrs): well I've got a brother-in-law who's the same age as I am and has the same doctor, and I got the letter and I said, "I've got this thing to go to" and I had a date and he said "Oh I got one of those", but he said, "not me", that was it, I said, "why?", "no reason", he said, "I'm not going"
HE: why do you think?
Yvonne: he didn't want to know, he didn't want to find out if there was anything wrong with him, I'm sure that was it. But you know, "it'll be good you know", but no that was the end of the conversation he said, "no I'm not going" and he didn't attend, and I couldn't understand that

In this quote, the participant found it hard to understand why her brother would not want to know if there was something wrong with him as she herself could only see the benefits of finding a risk if there was one. Other participants were less forgiving:

Nancy4 (69yrs): I think [screening's] a great idea, I think it's probably unfortunate the uptake that you'll have...er judging by um the breast screening uptake, you know which is not as high as it should be, so you know...()...

HE: do you think that's the main reason people don't attend?
Nancy4: they just can't be bothered for one thing, er and people say silly things like "I'd rather not know" and things like that you know, um I would think these are the main reasons.

Similarly, fear was often given as both a possible and actual reason for not wanting to know and thus non-attendance. For example:

Jack5 (66yrs): well I think the fear element comes into it where they don't want to- if they've got something that they don't want to know about it. It's crazy I know, but a lot of people are like that...that er if they feel alright reasonably alright they won't do it and they're quite happy about that, they don't want to know anything...it's crazy I know but that's behind a lot of people's thinking.

Whilst Jack5 deemed such fear to be crazy, others simply deemed it "wrong". These participants struggled to understand how people could let their fear prevent them from wanting to discover if they were at risk. Other participants expressed their own fear of heart disease, and some of these who did not share this fear personally could sympathise with those who did:

Ted4 (77yrs): I think people probably have a fear of having these kind of tests because- because it might throw up something they would rather put off, I think that certainly. There's aspects of that come into it I think as well, maybe even when I was that time when I was- I could have this big survey where I was gonna be investigated, although I said I had a medical not long before, I think there were aspects of "I don't want to know in case maybe they're gonna find I've got cancer or something like that you know" and that is a fear, I think it's a natural fear

A couple of participants had experienced fear themselves but had forced themselves to attend because to them, the benefit of discovering the risk outweighed the fear:

HE:...why do you think people don't come to this type of thing?
Mandy3 (59yrs): afraid? Or they don't have a family history, and they don't really think they're affected at all and maybe if they do have but they're a wee bit afraid of what they might learn
HE: yeah...but you didn't think that?
Mandy3: I was apprehensive yeah I thought maybe they're gonna find out that I've got something wrong with my heart or something you know, I was apprehensive but I felt I wanted to do it

So, although she described being afraid when attending screenings, Mandy3 realised that she would rather know if there was something wrong so there could be something done about it. A few participants, including Mandy3, disclosed fears that

they or their relatives had, not specific to screening, but which contributed to non-attendance including fear of contact with the medical profession, hospitals and needles.

Participants who compared heart disease with other illnesses admitted to having a much stronger fear of cancer. For a few, this meant that they attended the present screening but were too afraid to attend cancer screenings (Jennifer2 below), whereas others attended cancer screenings but insufficient fear of heart disease seemed to inhibit attendance at the present screening (Isaac3 below):

> HE:...there's a large percentage of people () who don't come
> Jennifer2 (61yrs): who don't go, I don't understand that, maybe because they feel healthy and say, "I'm healthy and that's that" whereas they should have gone and, I mean I would go even if it was somebody who came along for cancer tae because if it was anything along the lines I would go y'know, see because I think aye we're needing breakthroughs from heart disease and cancer and that
> HE: do you go for other screenings, have you been for the sort of cancer screenings?
> Jennifer2: no, no, never, no
> HE: have you not been?
> Jennifer2: ashamed to say, no I'll no' go. And I should go because my daughter she's 39, and she actually went, she had a lump and they found out she's got it's calcium, right doon here has broke away from bones and that can go cancerous over night so she's going like every two month to get mammogram every two month, so noo I think they're gonna do a big biopsy and I don't know why because they say they're gonna take biopsies, they're getting wee bits o' scar that they're wanting this big bit, so I don't know what first but she gets called back every time she goes they phone, "will you come back over?" so this is hanging over her and they're right, I should go and I think that's what's making me frightened to go
> HE: what because she's got something
> Jennifer2: uh huh, that's frightened me
> HE: yeah
> Jennifer2: and I mean, just how you are that is. I think that my Mum having it tae an' that, that was a wee bit...frightened o' that
> HE: how do you see that as different like to going for a screening for heart disease?
> Jennifer2: I don't know, I've got more a dread, more a fear of cancer than of heart attacks, aye aye, I have

So Jennifer2 began by expressing feelings of individual responsibility to attend all screenings and declared her own keenness to attend all offered screenings, emphasising her desire to help contribute to medical knowledge, mentioning both

heart disease and cancer. However, she later admitted not attending cancer screenings, and, as her reasoning unfolded, she divulged fear arising from cancer scares and the experience of cancer in two first degree relatives. Whilst not specifically mentioning the importance of heredity in her fear at this point in the interview, the vividness of the experience seemed to be sufficiently daunting. Conversely, Isaac3 explained how a similar distinction between heart disease and cancer had manifested in the opposite behaviour in his wife:

> HE: I was just wondering how you can get- how you could get someone like your wife, or if people don't want to go, they don't want to go
> Isaac3 (58yrs): they don't want to go, you could have er this and that and then yet the well woman clinics, she (his wife) goes to that
> HE: oh right, so how does she see that as different?
> Isaac3: I don't know, it's probably something to do with maybe they read more about it and everything, you know breast cancer, smear tests and all that I think maybe that keeps them sort of saying "yeah it's good I'll go for that" whereas the heart side I don't think people really look at it in the same way, I don't know why but "it'll never happen to me".

The distinction between fear of heart disease and cancer echoes previous literature (for example Nic Gabhainn et al., 1999; MacFarlane & Kelleher, 2002). Also including the preference for dropping dead of a heart attack over lingering on with cancer, which is problematic as heart disease often entails 'lingering on' of a different kind with severe disability (Emslie et al. 2001).

A further explanation behind not wanting to know came from a contradictory belief to unrealistic optimism: a couple of participants suggested that non-attendance could stem from fear arising from people's awareness that they *are* likely to be at increased risk of heart disease due to their lifestyle or family history:

> Owen4 (52yrs): I would obviously have been a bit anxious and a bit depressed I suppose but obviously I'd still be grateful that it had been picked up and I certainly hope that wouldn't be a discouragement for people from going but I do understand that for some people it might be- that some people if they have a suspicion that they maybe are not as healthy as they are maybe don't want to go to the screening programme and have that confirmed.

So, more along the lines of: "it *will* happen to me", not knowing one's risk (which the screening test would reveal) may be a method of avoiding anxiety: as the well known saying goes, "ignorance is bliss". Similarly, that screening could lead to bad

news which would in turn might require unwanted lifestyle behavioural change, was suggested as another reason behind not wanting to know. For example in focus group 2:

> Cath (63yrs): no I think it was what you (Emma) were saying about fear going on because of that time you went and you had- well was speaking to another friend who's about my age and she said she just enjoys life, and she just enjoys her wine and whatever and her food and she's put on a bit of weight and all the rest of it, but she said, "I just don't want to know if I've got high blood pressure, I don't want to know", it's like they're blocking out and they just want to live the way they want to live, they don't particularly bother about changing their- they would have to change a lot but they want to enjoy, and they say, "if I drop dead tomorrow, fine" she says, um you know that's their attitude
> Ursula (61yrs): it is an attitude
> Cath: whereas other people
> Ursula: and there's lots of people like that
> Cath: a lot of people like that yeah
> Ursula: they live for the moment
> Cath: yes, I had a friend who was diabetic and he didn't stop drinking and he didn't stop his lifestyle and I think he thought, "well, it's too late now, I'm" he was in his 50s and he just carried on just drinking and
> Ursula: that's young 50
> Cath: smoking and exactly, but it was like, "oh well, I'm enjoying life and I don't want to stop" and he didn't and he died at 66, but that goes to show you that it was in the attitude, the problem

A few participants admitted that they were reluctant to change their lifestyle, for example in the following extract from focus group 1a, one participant maintains this attitude even when challenged by another focus group member:

> Andrew (59yrs): that's exactly what I was like, … I've not gone changing my life, I still smoke, I've not stopped, I still smoke, I've not stopped drinking, I always eat the same things and I eat what's nae good for you, cause these health foods and that I don't like 'em. Putting it quite bluntly, I dinnae eat to look after my heart, I eat what I like
> David (71yrs): he's gonna die happy
> (laughter)
> Julie (56yrs): but do you not think that it gives you the opportunity to change, the opportunity to change if you want to change?
> Andrew: it probably does
> Julie: it makes you aware, which surely it's a good thing
> Andrew: I'm aware of the fact, but there's nothing wrong with heart, there's nothing wrong with it…

In the above extract, whilst advocating individual responsibility regarding lifestyle change, Julie questioned Andrew's refusal to make such changes, but Andrew's

desire to lead an enjoyable life seems resistant to challenge. (Equally resistant to change is his risk perception, as despite a low ABPI he saw no problem with his heart; this will be discussed further in later chapters). Other participants were more judgmental when discussing the reluctance of others to change their lifestyle, and sometimes spoke stereotypically about people's lack of education, believing such low awareness to be the root of non-attendance:

> Lorraine (focus group 1b, 52yrs, DEPCAT 4): and again that depends on you being in the group of society that knows that what you do...()...I think a lot of people are frightened of going to doctors and you get that across the board, but then there's also a group who feel perhaps because of their lack of education and whatever that they won't understand what health professionals say to them. Nobody here's gonna be like that but there are people- I've been in hospital quite a lot over the years and it's always struck me that each time I go in I think yeah well I know the system and I know how to play it. But there are other people there that don't know, they don't understand the words, they don't understand the terminology, they're living in a sort of...institution that they're not used to and it makes them frightened and so the minute they get out they don't want to go back, they don't want to follow up, they don't want to go and see a nurse, they don't want to go and see anybody, just wish it away, and it's fear and it's lack of education in any case

Another participant, less judgmental, expressed her concern about the impact of socio-economic circumstances, acknowledging the difficulties of lifestyle change for people from more socially disadvantaged backgrounds:

> Moira1 (53yrs, DEPCAT 4): well I think that's partly to do with the fact that one doesn't necessarily want to know, if you see what I mean, I think it's- and I recognise that syndrome that's the head in the sand thing, particularly if you've got it in the family. Also I think, it's this my nervousness about having the high blood pressure, if you know that your behaviour could potentially be contributing to ill health, so if you smoke heavily or you're drinking too much or you're overweight, or all three, or whatever, you think "ooh God, do I really want to face up" because that might make me feel "god I've got to change" or confirm what I know in my heart of hearts, I'm really very unhealthy...()...and you see somewhere like Glasgow where there are huge pockets of deprivation, huge, huge pockets, and you think, well I don't blame anyone for saying "sod off, I don't want to know". It's people like me that can afford their nice organic food and the olive oil, that get all terribly good and conscientious

Moira1 did not advocate individual blame and responsibility, rather she realised the wider impact of social and cultural circumstances with particular referral to the

context in Glasgow. Similarly, several participants felt that a rejection of a healthy lifestyle was embedded in Glaswegian culture:

> HE: so you think people don't want to know, why do you think that is?
> Daniel4 (54yrs, DEPCAT 1): yes Glasgow, anyway and I'm from Glasgow, they are set in their ways
> HE: uh huh
> Daniel4: Instead of going home and cooking a good meal at night, they'll go and buy a fish supper, and that doesn't help heart disease...OK I like fish supper, it's nice, but now that I'm retired and I've sort of learned...that there's more than fish suppers

> Isobel3 (60yrs, DEPCAT 4): ...they may think that to come along they may be curtailed, and the first thing, especially with heart I think everybody thinks, "Oh, can't drink", so I would think in a Glaswegian population like their drink! So they would rather not know, and give up their drink until it was totally at death's door, I would think that is- or give up the smoking, you'll get that, "they'll want me to give up smoke and drink and I'm not going 'o"! They would see it as being maybe lectured

These participants recognised the difficulty of encouraging lifestyle change within the context of Glaswegian culture.

Although generally critical of the "don't want to know" attitude, and/or being keen to discover their own risk, participants were familiar with this seemingly common attitude and drew upon experiences and conversations with known others to propose explanations behind it and its potentially inhibitory effect on screening attendance.

"What's not broken, you don't fix"

> Timothy5 (61yrs): no that was this thing with cancer it happens to other people...it's the same as a heart attack
> HE: do you think that most people think like that, that's why they wouldn't get checked up for-
> Timothy5: aye- 'what's not broken you don't fix' you know, that's just the way it is... it's not like er...it's not like what you call it plant maintenance thing

In this quote, Timothy5 sums up a further common and seemingly logical belief: why bother fixing something that is not broken? In relation to preventive health, as long as we feel well why would we attend a doctor? Timothy5 also points out that this is unlike the way we look after other 'mechanical' systems that are regularly checked for faults. Although seemingly logical, this attitude may affect the likelihood of

detection and treatment of asymptomatic illnesses and conditions. Serious illnesses such as many cancers tend to be asymptomatic for a long duration, once symptoms appear the illness may be quite advanced. Regarding risk factors for heart disease, individuals can live for years without knowing that they have high cholesterol, high blood pressure or furring of the arteries.

For some people this was a logical attitude; they regarded checking an apparently well functioning system as pointless or unnecessary, as the following example illustrates:

> Keith1 (59yrs):...I must have had poor circulation anyway even from then. I don't know if my blood pressure was- 'cause no-one ever checked your blood pressure then. I mean it's like everything, if there's something wrong you'd have done something about it, if there wasn't, you just left it.
>
> Cath (focus group 2, 63yrs): I tend to just go when I need to, I don't normally go for check ups for unnecessary reasons

In particular, participants often said that as long as they felt fit or healthy, they would not go for any check up; usually a key incident was required to provoke regular checks:

> HE: ...if you'd received a letter then inviting you, what do you think you would have done, do you think you would have gone or not?
> Susan5 (53yrs): I wouldn't have gone
> HE: why not?
> Susan5: I would say, "I'm healthy"...that's just the only answer, I wouldn't have gone...but now I've got all this I would do
> HE: do you think a lot of people think that because...because you felt healthy and was it because you felt...?
> Susan5: yeah I felt alright...I can't answer for other people I don't know, there's a lot of people that love going to the doctor (laughs)...the doctor said "You will come back", I said "aye I'll see you in two years"
> HE: you yourself wouldn't have gone
> Susan5: I wouldn't have gone then, no
> HE: so what age do you think you maybe would have gone? If none of what-if you hadn't found out all this blood pressure business that you have
> Susan5: I wouldn't have gone
> HE: you wouldn't go
> Susan5: no
> HE: just as long as?
> Susan5: long as felt alright...that's stupid isn't it? I mean you should go and get a check up there, if I hadn't gone for my skin I wouldn't have found

> out...but that is the truth, to be honest with you, I just want to say the truth that's only way you're gonnae get answers

However for a few, even a low ABPI result in the present screening, or surviving a heart attack did not encourage regular check ups:

> HE: would you go for a check up now [after low ABPI] yourself at the doctor in say a year's time again a sort of heart check up to follow it up or?
> Morag3 (64yrs): I don't think I would go unless I felt I had problems

> HE: do you go the doctor regularly now [post heart attack] for like check ups and things?
> Harold2 (63yrs): not really no, just if I feel something
> HE: do you go for any check ups on your blood pressure?
> Harold2: no, not really no. If I found, if I feel as if I would go and if I-, I mean that's why you get repeat prescriptions and you don't need to go 'o the doctor you know, you just hand it in

This attitude relates to participants' general attitude towards consulting their GP. Some implied there was a tough mentality, particularly in older people, which led people to wait until a condition had progressed to severity before getting help

> Gordon1 (67yrs):...so I believe in going to the, aye, I'm quite safe going to that 'cause I know they're testing my blood, so I think they should be- everybody should, especially when they get older, go for a regular check up anyway. 'Cause my mother died and there was a lot of older ones in their days because they didnae go to their doctor.

It seemed that for some people, consulting the doctor signified 'giving in' to illness whereas avoiding the doctor demonstrated one's healthiness. This echoes findings of Blaxter and Paterson (1982): their older participants explained tendency not to consult due to preference for 'mind over matter' models of cure and not wasting doctors' time, relating to both emphasising their strong character and fatalistic views of illness. Similarly for Cornwell's (1984) participants, admitting ill health had negative moral connotations and demonstrated one's moral failings. Linked with this tough mentality, participants in the current research often distanced themselves from those who they considered consulted the doctor *too* much who were regarded negatively and were often referred to as "hypochondriacs", again echoing Cornwell's (1984) findings.

> Dennis4 (75yrs): well I was fairly fit, I mean I walk pretty often, I play golf, I wasn't like unwell or anything like that

HE: uh huh...() do you think a lot of people are like you and you know ignore the first one (invite)?
Dennis4: I think so, because unless you're a hypochondriac
HE: yes
Dennis4:...you let things ride I mean I just let things ride.

Monica1 (66yrs) stated how this was particularly true of older people, that they consulted for unimportant instances. This contrasts with Gordon1's view above, regarding 'older' people:

> Monica1: I wouldn't like to waste the doctor's time and I think that there are a lot of elderly people () and they're never away from the doctor, and as you say and I happened to say to one of them as well, "I'm getting really deaf", I had a mastoid years ago, getting really deaf in that ear you know, but I'm not doing anything about it. If it gets infected or discharges I go and get my drops. [This older woman said,] "you know I've been like that as well, I was away to the hospital, you know I went to the doctor's demanding that I see a consultant". I said, "for heaven's sake" you know, to me that's time wasting, because if you're 84, everybody gets dull hearing at 84, you know...

Others were less concerned with being perceived as hypochondriacs, and like Monica1 above, they were more concerned about not wasting their doctor's time, often due to an awareness that doctors are overworked.

Some participants expressed their awareness of why the "not broken, won't fix it" attitude was a particular problem for heart disease, as they felt that the earlier that problems are identified, the better:

> Patricia3 (61yrs): People are lazy too, they think, "well if I'm alright at the moment, why do I need to go?" they don't sort of see that anything that's ongoing that hasn't had symptoms at the moment can be picked up and save lots of big problems later on

The asymptomatic nature of heart disease was considered dangerous and concerning by some:

> Keith1 (59yrs):...The thing is that it's a disease you can get, you don't know you have it, there's nothing- it's not like you're- when you get the flu and you've got a sniffly cold and there's something wrong with you, but you have high blood pressure and you can be perfectly OK, it's not till it's got to the point where it's really done all the damage that you usually know the effects of it. So without really checking people earlier on, there's no way really you can stop them getting the effects of it.

The participants in focus group 2 concluded that it was a "silent killer". A few participants pointed out that if symptoms were waited for, it could be too late as the symptom could be a heart attack itself

> Craig4 (54yrs): You wouldn't, I don't think, think to go along to your doctor and say "I'll have my blood pressure checked" so er and that's exactly what happened to my friend I mean he had no reason to believe that- people don't know about high blood pressure- he had no reason to believe that and then suddenly bang!

With this in mind, some participants recounted fortunate discoveries of an asymptomatic risk, usually high blood pressure, diagnosed by chance, perhaps while consulting the doctor for a separate reason, when registering at a new doctor's or through an opportunistic check in the workplace. For example:

> Ted4 (77yrs): and from the tests, which were given- taken at the time, they found out I was diabetic, but the point is if I'd been still with the old doctor I would never have known, you see this is the thing so it's a wee bit worrying that to think that people you know can go through life like that and that it's only just via chance, such as a doctor retiring that you find out by going to another doctor who does tests.
> HE: would you feel it'd be better to have sort of regular check ups?
> Ted4: well this is a example, you know, a regular screening would take the place of somebody having to find out things by like having to go to another doctor.

Prior to these 'chance' diagnoses these participants had considered themselves in good health and their tendency not to consult until symptomatic would not have led to such a lucky discovery. Such instances thus led to concern and the realisation that the asymptomatic nature of heart related risk factors does not fit with normal consulting behaviour at present.

Considering the background to typical (non-) consulting behaviour, and lack of preventive health consultations, participants attributed this widespread attitude to British (and in particular Scottish) culture. A few participants compared this culture with other countries where regular check-ups are commonplace; a couple of participants mentioned the apparently efficient systems in the North Americas and others described experiences in other European countries:

> Owen4 (52yrs): But we don't have a culture in the UK, in Scotland, about regular medical check ups, I mean that's part of the difficulty. Er I mean I know it's easy to- it's almost fashionable to say but I do contrast even the

kind of visit to the GP I would normally have, and I have no problem with the service I get from the GP is absolutely excellent when I require it but er, but the kind of approach in a standard appointment with my GP compared to the unfortunately very odd time I've had to use health service abroad. Er because I've been- er I had a number of doctor appointments when I was in France and the service was, I mean, was superb in terms of time, in terms of going through all the routine medical stuff while you were there, and I know from a previous occasion some years back my wife had to go to the doctor in France when on holiday and I mean again the service was excellent in that way- you know everything but everything is checked in terms of blood pressure and so on.
HE: when you turn up for something else?
Owen4: when you turn up, I mean nothing remotely connected with that kind of issue but it's almost like a standard thing that they do now. That is not unconnected with the differentiation of the health service and the way that it's funded and so on and what-have-you but you'll know more about that than I do I would imagine, but it certainly does contrast with you know the feeling sometimes that you're kind of rushed with appointments at the doctors here but I have to say I think that again we need to work to establish the culture where all parties in the health service- in the health business here- the doctor on the one hand and the patients on the other you know are quite happy for people to come and get preventive health checks.

This explanation removes the responsibility from the individual, and the required change is regarding to be at a higher level, i.e. the health service. A few participants felt that such a change should entail incorporation of more preventive health:

Henry (focus group 1b, 67yrs): talking about these things, I think this is one of the big failures of the National Health Service, in that they don't do an awful lot of preventative checks...if you intend to get an MOT, if you want to call it that, every year or six months, they could catch an awful lot of illnesses long before you know people have nearly died because it doesn't show until the last minute.

This idea of regular "MOT" checks was suggested by many participants, for example Keith1 explicitly used the analogy of the car MOT to illustrate his feelings of illogicality regarding the lack of preventive health:

Keith1 (59yrs):...I was in my mid fifties when I'd seen the doctor and I thought "well [my father] started to have problems then, when he was in his late fifties". So I just thought, "well I'll ask him about it". A lot of times, a lot of doctors don't really check you out as such. I feel it's a bit strange that you- I bought a car, and after it's 3 years old, it's got to be checked every year after that. Now, they go on about how much this costs the National Health, the cost of treating people, but is prevention not better than cure? Would it be not better if people were given, when you can after a certain age or

> something- was it 65 or 70 or something like that, you can have your doctor give you a yearly MOT if you want 'o call it.

It is interesting to note that Keith1 made this suggestion as it demonstrates how participants' attitudes regarding preventive health change over time; earlier he was quoted describing his "not broken, don't fix it" attitude which he said he held prior to discovering his high blood pressure and low ABPI.

In some participants' GP practices, regular health checks were offered through '75+' clinics and 'well woman/man' clinics. However, this varied with different practices and continuation of such clinics depended on uptake. Such discussions in focus groups led to a discovery amongst participants of inconsistencies between different practices. This led some to feel almost cheated regarding provision at their particular practice:

> Rod (focus group 1a, 53yrs): my GP started er probably 6 or 7 year ago erm...it was a 'well man' clinic, I think you went once a year and they took blood and you gave urine samples, took the blood pressure etc etc etc, but it was like this we were sent a letter, and it was- you were given you know "from the week beginning the 6th to the 13th" and got it sorted it out between things and such and such and it was purely voluntary, but general apathy so they ended it,
> HE: did you go?
> Rod: of course I did
> Jen (65yrs): you'd never get that in our surgery ever
> Aileen (67yrs): you're lucky if you see a doctor

I asked participants what age they thought cardiovascular related screening should start. Fifty was considered particularly appropriate by many participants as it was deemed a physical milestone after which health problems increased. For others, it was regarded as a psychological milestone, a turning point at which they began to think more about their health and lifestyle, a marker of an older age at which more careful and sensible lifestyle was required:

> Morag3 (64yrs): ...I think 50 is probably quite a good age because for most people it's when you get the beginnings of um little things perhaps going wrong and you begin to realise that you're not as young as you once were

> Joe2 (56yrs):...I would have thought that...well any sensible person getting to the age of 50 is beginning to think, and beginning to waken up to stop doing stupid things like too much drink or too much this or too many excesses of any kind, er and I think that your health is just part of that as well

A large number of participants felt that the starting point should be earlier for example 40, due to the realisation that heart attacks can occur before 50, however this was predominantly expressed in hindsight. Some of these through further consideration, admitted the unlikelihood of attending at 40 themselves. Furthermore 50 was considered too young for some due to the dominance of work and family commitments at this age. Also at 50, the "not broken, won't fix it" attitude was considered more pronounced as most 50-year-olds will still feel fit and healthy.

> HE:...do you think you would have attended at 50, thinking back to when you were 50 if you'd got the same letter then?
> Fred2 (62yrs): no I don't think so, no, erm thinking back, at 50 year old I don't think I would have bothered, I wouldn't have taken it up, no
> HE: why's that?
> Fred2: er, because at that time I had no concerns or such like for it, I just wouldn't have bothered with it you know and I'd probably never have read an article if I'd seen something I would have just by-passed it, but because of the last time, because I was over 60 and such like, I said to myself, "well maybe I should get myself checked out" you know
> HE: did you see 60 as some kind of milestone?
> Fred2: well yes I did you know 60 you know, and with not attending the doctor or going for any check ups, er I said well, "this is a way of having it checked" you know

So for Fred2 (62yrs), 60 was a more appropriate age. Another participant discussed the idea of a cut off age at the older end too:

> Richard1 (54yrs):... unless you're one of these unfortunate people that are gonnae get a heart attack when they're 35, but they're a very small minority aren't they? Not a lot of people you know. I would have thought 50 to- 40 to 60 would be a good screening age, I mean I maybe sound ageist but I can't see the point of people worrying about things like heart disease when they're over 70. You know why bother?! (laughs)

As previously mentioned, access was given as a difficulty regarding screening attendance particularly referring to the fifties:

> Henry (focus group 1b, 67yrs): well man clinics, if you're working, are no use, cause they're all held in working hours
> HE: right yeah,
> Henry: so you can't take time off work to go to 'em, so if you can't attend these things
> HE: so they could have evening clinics?
> Henry: or even Saturday mornings, but they don't

However, other participants regarded such reasons as an excuse for not wanting to attend:

> Isaac3 (58yrs): yeah well my wife got one, she said "no I'm not going", and I said "it'd be worth it, you know you'd find out" but no she didn't
> HE: why was that?
> Isaac3: oh she saw it as, "no I'd have to get time off my work and it wouldn't be suitable" and I said "well, we'd make sure it was a morning", she only works part time in the afternoons, so we'd make sure it was a morning, "no, no, she said, too much hassle" (laughing)
> HE: do you think that's her real reasons or
> Isaac3: I'm not too sure to be honest (laughing) not too sure, I think partly that was the reason, no it was gonna be awkward to fit it in, but er yes, she might have just been like a lot of people "I don't want to find anything"

At a different level of consideration, participants usually recognised implications for the NHS of regular MOT style checks for everyone:

> HE: so you used to get checked at work
> Amy2's husband (77yrs?): aye, aye cause you were either in BUPA or NPP, something like that and they checked you out once a year...but I didnae know that you could do what she [friend] did, go once a year and get this sort of over all
> HE: I think you'd have to pay
> Amy2 (76yrs): aye it was a hundred pounds or something or two hundred pounds so
> HE: do you think things like that should be available through the GP?
> Amy2: I suppose it would be- what would the National Health say about that?! (laughs)

A further implication related to cost in terms of doctor time required for carrying out MOT checks. Participants' awareness of the already overburdened GP workload led many to comment that GPs have insufficient time to treat ill people, let alone the healthy, and the difficult task of encouraging people to come would increase work:

> Ted4 (77yrs): no I still think that people as I say should get more help from the doctor but then doctors are claiming that they're overworked and very little time for this kind of extra...it's very hard to get them on doing this, which is treating healthy people isn't it? You're talking about those who are already healthy so they'll continue to be healthy but then they don't go to the doctor in the first place so where does that leave you?

Some participants questioned whether doctors themselves would regard health check-ups appropriate use of their time:

> Isaac3 (58yrs): I think the private funded ones I think are maybe better because people accept this, it's not like the doctor sort of saying "come along", you go I think of your own volition to these, it's a case of well you can go or you can turn it down. You get a full personal report of your own. Um if you go to the doctor, I think nowadays you probably could ask for a report but I've never ever went to the doctor and asked for a full medical, er...I don't know if they even see that as what they should be doing to be honest.

Furthermore, a few felt that their request for a check up might be rejected and that they would feel as if they were making a fuss about nothing; this was backed up by experience, for example Geoff3 recounted asking his GP:

> Geoff3 (68yrs): no I once put my own practice to the test
> HE: oh really?
> Geoff3: yeah I was about 55 at the time, I knew what I was in my work and I said, "I really think at this age, it's time you gave me a full medical assessment" and the fellow says, "what do you want that for, you look healthy"
> HE: really?
> Geoff3: yeah and that was that, I didn't push it, but I felt that between 50 and 55 people should be going on these things to see if they can catch now what might be a problem when they're 65, 70.

In focus group 1a participants had a discussion about the potential impact of regular MOTs on doctors' schedules and one participant reflected on the influence of obligation:

> David (71yrs):...You'd be just going through life having medical check ups just in case you're gonna get something dreadful you know, you might even get leprosy ...or brittle bones, I mean when do you check?
> Rod (53yrs): you check once a year, if you can
> David: MOT, yeah an MOT every year or two years or, but then the whole system would clog up and everybody would just be going for MOTs all the time
> Bob (70yrs): you only get an MOT (car) because it's compulsory, if it wasn't compulsory...

This was an interesting realisation about the probable uptake of non-compulsory regular 'MOT' health checks.

The reported tendency to consult once symptomatic is problematic for the asymptomatic nature of heart related risk such atherosclerosis. Many participants believed changes in the health care system, including more preventive health care

such as MOT style checks starting at an appropriate age, could possibly tackle this but recognised many additional barriers. Generally, with the realisation that a line has to be drawn at some point, either 50 or retirement were considered appropriate starting points for offering such screening, and earlier check ups were suggested for those with a family history of heart disease. As discussed earlier, for many participants their positive attitude towards screening and 'MOTs' was expressed with hindsight and many admitted this. Their accounts of the belief that "what's not broken, you don't fix" and their views about current consulting culture are useful for those considering the planning and delivery preventive health checks of this kind.

In summary, the first part of this chapter has focused on explanations for non-attendance at screening, i.e. barriers, which I have presented, illustrated and explored centring on four key phrases which sum up these 'barrier beliefs': "it won't happen to me," "if it's gonna happen, it's gonna happen," "I don't want to know" and "what's not broken, you don't fix". The ubiquity of these key phrases in participants' accounts across groups suggest that the phrases operate as cultural shorthands for shared lay knowledge, and have significant lay meaning. The following section reflects on the associated meanings, focusing on whose attitude or behaviour the phrases were being used to describe.

Whose attitude?: Individual rights versus responsibilities

The key phrases discussed so far, and the beliefs and attitudes underlying them, were used in participants' accounts to explain behaviour of themselves currently, themselves in the past, other people in general and known others. Whose behaviour and/or belief was being described seemed to be related to the participant's attitude towards that belief in terms of its acceptability. In participants' accounts of their own attitudes and behaviour both past and present, explanations justifying the attitude allowed further exploration of the background to the attitude; distinctions between past and present beliefs illustrated how people's attitudes change with time and according to situation, life circumstances and health events. Accounts of the attitudes of 'known others' were particularly interesting as they entailed explanations revealed

in conversations with these relatives or friends rather than speculations about others in general, and participants' accounts often included their own comparison between the attitudes of themselves and the 'known other'. In some instances, particular groups of others were discussed; a few participants generalised about the less educated or more socially disadvantaged. Others, while attributing particular attitudes to certain social groups, discussed this in recognition of the impact of people's surrounding social and cultural context, with particular reference to deprivation in Glasgow.

To recap, the majority of participants who introduced the "what's not broken, you don't fix" attitude could empathise with it and embedded it in wider discussions about British culture, particularly the health service. An optimistic bias was evident when describing attitudes of both self and others; concerning their self such optimism was present in beliefs reported as existing prior to a cardiovascular event or risk diagnosis. Thus, the majority of participants could empathise with the belief even if no longer thinking that way themselves; those who did not, criticised those holding this attitude for a lack of personal responsibility. Whilst a few participants had fatalistic attitudes ("if it's gonna happen, it's gonna happen") regarding health and cardiovascular events, fatalism as a reason for screening non-attendance was predominantly used to describe the reasoning of other people and in particular known others such as relatives who reportedly had revealed this attitude in conversation with the participant. Similarly non-attendance due to denial ("don't want to know") and fear were common suggestions of other people's behaviour; participants who disclosed fear themselves had still attended screening. Overall discussions of fatalism and denial as explanations for non-attendance were fairly negative, and an implication of individual responsibility ran through many accounts.

Implied individual responsibility, both to lead a healthy lifestyle and to attend screening highlighted an interesting argument: that of the rights of the individual versus their responsibilities. As mentioned earlier, some health promotion campaigns in the past focused on the individual's responsibility for their own health with less emphasis on the complexity of the sociocultural context in which individuals live and

make decisions about their health. Some of the examples discussed earlier, for example regarding criticism of optimistic bias, implied that people had a duty and responsibility to attend screening (for example Craig4); when asked explicitly, a few participants did express such a view. The following participant went further by suggesting that such screenings should be mandatory:

> Gordon1 (67yrs, DEPCAT 7):...must be hard because people's no' interested and that's where I come back again- I'm interested but there's a lot no' interested, you find that, they're not bothered aboot their health, ken what I mean, they just dinnae bother. And it would be hard but there should be a test where you had to go, whether you like it or not, maybe once a year or you know, everybody, and that would take a lot of money, a lot o' expense.

A couple of participants felt that people should realise how lucky they are to have the opportunity and therefore should demonstrate responsibility in appreciation:

> Eleanor3 (62yrs, DEPCAT 2):...I always have gone for smears and mammograms and I think we're lucky in this country that we do get the opportunity, in some countries they don't, I think we're lucky that the facilities are there

Not all participants shared such views; in fact one participant challenged me for implying responsibility:

> HE:... I mean do you think that this sort of screening check I mean realistically do you think you can get to people if they don't want to go
> Ted4 (77yrs, DEPCAT 1): well you must know, or something you'll appreciate, when people are ill they start to think "we should have the checks" and all this but when people are not, you know they don't think this is necessary....()...Especially if you happen to be of the feeling that you're invincible (laughs) and nothing like this is gonna happen to you. I think that would be about it. I get a feeling that I know you don't really mean this but *you seem to be feeling that people should do this*
> HE: oh no not at all, I mean I'm just putting questions to you
> Ted4: but then because it's obviously, it's commendable that people you know think about this, but it's not also- you know it's understandable why they don't
> *(my emphasis)*

A closer look at Ted4's account revealed instances where he himself implies an emphasis on individual responsibility, however the above quote demonstrates his understanding and appreciation of reasons for non-attendance. Ted4's interview however did lead me to reconsider my own stance on this issue, and examine whether my questions or discourse which were intended to be neutral were in fact

implying only benefits of screening attendance. For the remaining interviews, I introduced a question to allow me to address this issue explicitly rather than ruminating over implications in people's accounts: "do you think people *should* attend such screenings?" However participants possibly still regarded me as representing the trial and thus holding the view that people should attend.

The notion of responsibility can be further examined with regard to whom the responsibility is directed. Howson (1998) discussed the idea of one's social responsibility to maintain one's health; on other words a responsibility to society to keep oneself healthy and thus reduce the burden on the NHS. A couple of participants did express this kind of stance. For example Imogen1 expressed strong criticism regarding unhealthy lifestyle:

> Imogen1 (61yrs, DEPCAT 1):. I mean some people are as I say they have their own life, they've got to live their life as they want, you know but I feel that erm...maybe I should say this but if they continue and they still expect the medical treatment, like my husband I mean he was- I mean somebody said to him when he was in the hospital waiting for this surgery, "had he won the pools or something?" because this surgery was thousands and thousands of pounds, you know and he worried a little bit about that, because somebody had wanted to be done, and they weren't getting it done and they felt like he was taking their- he was going in first
> HE: really?
> Imogen1: yes, um this was and he was a counsellor of some sort
> HE: oh right
> Imogen1: at the time, I mean we- we know it's a lot of money to have this surgery, but I mean that I feel that, it somebody has this and then they come out, and then they have this surgery, you know the doctors put them right and then they come out and they go straight back to the lifestyle they had before, I mean to me it's wrong, but you see you can't tell people how to live, they have to choose, but I don't think they should expect for people, you know doctors and everything, to help them if they are not gonna do their part
> HE: uh huh
> Imogen1: I feel really strongly about it, you know it annoys me when I hear of people having- they're having the surgery and then they just go back to the way they lived before and they abuse it

The fact that Imogen1's husband's life was saved by his heart operation had led to feelings of responsibility to lead a healthy lifestyle afterwards. She criticised people who returned to an unhealthy lifestyle after such operations for their lack of appreciation for life-saving care, and raised the issue that there is always someone

else on a waiting list for the same operation who could be more deserving. She recognised the right to personal choice regarding lifestyle but personally felt that responsibility and gratitude were more important.

A different type of responsibility expressed by a couple of participants was one's responsibility to one's family:

> Janice (focus group 4a, 70yrs, DEPCAT 1): I was thinking of my son, there's more a history of his father's side as well as my side

For this participant, joining the trial was regarded as synonymous with attending the screening, her reasoning being her son's future health. Whilst implying altruistic reasoning (discussed further in the participation chapter), this also seems to be linked with feelings of responsibility towards a specific other, i.e. her son. This relates to findings of Hallowell (1999) regarding feelings of responsibility in women with hereditary breast and ovarian cancer towards other family members. However, the issues were different for Hallowell's participants in that the risk identified was genetic.

In contrast to the individual responsibility perspective, a few participants pointed out that screening is not compulsory, so individuals have a right not to attend. As Lupton (1993) argued, people should have as much right *not* to know their risk as they do to know it. Some participants recognised this right not to attend:

> Graham3 (58yrs, DEPCAT 5): we're all different, that's the problem, and a lot of people um, they don't want to know certain things. Which is fine, that's their prerogative

But Graham3's acknowledgement of this right was not without criticism::

> HE:...do you think that everybody should go and get the check?
> Graham3: well they should do but again what with the modern world we're living in, they'd probably think it's a breach of their civil rights or something like that, you'd fight to get anything nowadays, you know it's crazy. Course they should, I mean everybody, I mean it's a short life

The debate between individual rights and responsibilities echoes debates in the media in recent years regarding unhealthy lifestyles, for example whether smokers should be allowed heart and lung transplants, and alcoholics allowed liver transplants. The NHS and government funding become central to these debates; there are those that

pertain that money is better spent on individuals with healthy lifestyles or who are willing to change their lifestyles. But once again this ignores consideration of the sociocultural influences on lifestyle and associated difficulties, particularly the costs incurred in changing their lifestyle.

Benefits & beliefs

The previous section focused on the explanations, i.e. barriers, behind people's non-attendance at the ABPI screening; it is interesting also to explore explanations of why people *did* attend. When considering their reactions to receiving the invitation to the screening many participants said that they had felt positive about attending and had regarded it as a good opportunity to check for any problems.

> HE: when you first received the invite, what were your initial reactions to getting the letter to attend the screening?
> Morag3 (64yrs): I think screening is a good exercise and therefore I was quite happy to participate

> Hilary2 (77yrs): well I thought it was a good idea to get everything (laughs) you know, know what's wrong and what-have-you, if there is anything wrong

Often people who were positive about the ABPI screening were positive about screenings in general and gave examples of other screenings they had attended; usually women mentioned attending breast and cervical screening. Describing it as a good opportunity was expressed at various age ranges; those in their 50s, particularly men, were generally not offered regular health checks unless workplace health checks were available, for example:

> Richard1 (54yrs):...when you went there initially was that they do a check up for you anyway which is something- well I don't suppose many folk of my age would bother to get check ups to be honest. So that was quite useful, I mean I've had them at work anyway cause of they did that at work

Likewise men in this age range often said that they had not seen their own doctor for a while:

> Fred2 (62yrs):...I really just went to see if I was reasonably fit, if I had anything to worry about, my heart condition or anything like that you know? Aye so that's why I went along
> (later)...well to me at that time you know when I was over 60, and as I say, you know just repeating myself, I'd had no previous check ups or I hadn't been ill for a long long time, not even ill, unwell, so I just decided that I

would take up that you know, and that's all you know, and it's not what I thought was gonna be in it

In some cases the screening was reported as having happened at a particularly relevant and convenient time in their lives as they were experiencing some concerns about their heart.

HE:...when you first received the invite to the screening, what were your initial reactions?
Mandy3 (59yrs): it came just at the right time because I was having problems, I was a bit worried about my heart and
HE: problems with your heart?
Mandy3: well yeah things just didn't seem quite right and I thought "ooh that's come at a very apt moment",

Consequently, another advantage mentioned by many was the earlier a problem was identified the better as some action could be taken:

HE: so what made you come along then?
Craig4 (54yrs): well I had got this letter and I mean I don't mind being screened I mean I suppose it's better to know that there's something wrong than go on in the happy delusion that there isn't you know because if there was for instance high blood pressure or something at that then treatment could be given for that sort of thing so before it got too dangerous.

However, of those participants quoted above from groups 1, 2 and 3 who were positive about attending the screening, none viewed themselves as being at great risk despite all having a low ABPI. This could explain such positive attitudes towards the screening, i.e. because they felt that nothing of great concern was found. Their positive views focussed on *attending* the screening but they did not perceive the ABPI result significant.

Craig4's quote above was representative of group 4; generally most of this group voiced very positive views about attending the screening and alleged that they would have wanted to find out if they were at risk. When considering the alternative scenario of receiving an 'at risk' ABPI result, some said they would have accepted the result without too much concern, others admitted that an 'at risk' result would have induced fear and/or provoked lifestyle change:

HE:...how do you think you would have felt?
Joyce4 (54yrs): I would have felt quite frightened actually
HE: yeah

> Joyce4: I think I would have...'cause I wasn't really expecting anything adverse so I think I would have got quite a fright

Regardless of their feelings towards the result, group 4 participants were all keen to attend. But as far as the screening and ABPI, this group were all labelled 'healthy'. The positive attitudes expressed in the interview could have been swayed by this 'healthy' result. Indeed Craig4 admitted that this could be the case:

> HE:...how do you think you would have felt?
> Craig4 (54yrs): um...well I would I suppose- I don't- that's hard to say really um...I think I would have been fairly philosophical about it, I mean I think I tend to be a bit that way um and um...maybe I would have wanted to know that. I think if you're going to go into a screening programme like this, you have to be prepared to be told whatever it is that's going to show up at, you wouldn't expect to have something concealed from you or whatever or...yeah I think- I don't think I would have been terribly- but maybe that's coloured by the fact that I suspected I wasn't going to be given any bad news anyway so I don't really know.

Group4's screening result met their expectations, i.e. that they were 'healthy'. So for Group 4, attending the screening seemed to serve as reassurance that they were healthy, i.e. reassurance that their pre-screening beliefs about their health were met. This echoes Howson's (1998) finding that women attended cervical screening for reassurance of their 'healthiness' rather than anticipation of being at risk.

As mentioned in the literature review, reported unintended consequences of screening have included false reassurance or a 'certificate of health' effect (for example Tymstra and Bieleman, 1987), whereby a 'healthy' result was used as a green light to continue to engage in an unhealthy lifestyle. This was rare in the present research but there were a couple of cases, for example Joyce4's reaction to her 'healthy' ABPI result:

> Joyce4 (54yrs): the main advantage was being told I certainly wasn't at risk

However, elsewhere in her interview Joyce4 admitted that she smoked and could pay more attention to eating a healthy diet and exercise, all known heart risk factors which she said she would have changed if she had received an 'at risk' result. So whilst demonstrating awareness of the riskiness of her lifestyle, as far as she could tell, there was no risk at this point as the clinical measure revealed no risk, leading her to maintain perceptions of healthiness and no change in behaviour. This

introduces an issue which will be further discussed in the risk perception chapter - that many people seemed to consider a clinical measure of risk a more significant marker of risk than well known risk factors such as lifestyle behaviours.

Interestingly, 'healthy' results did not always lead to reassurance; as quoted earlier when discussing fatalism, Peter2 (55yrs) recounting his feelings after regular medical checks at work, showed how his awareness of the randomness of illnesses such as heart disease inhibited any reassurance from receiving a healthy result.

Other than the Group4 examples above, the quotes earlier of positive attitudes to screening focussed on *attending* the screening. Thus, it was interesting to explore whether attitudes towards the screening had changed *after* receiving the screening result, in particular when, unlike group 4, people's expectations did not match their actual screening result.

The screening experience

Positive reactions

Positive reactions were not confined to the 'not at risk' group, in fact a few of those identified with a low ABPI said that they were glad to discover this:

> HE: and how did you feel when you found out that this sort of measure-?
> Gordon1 (67yrs): well I was quite happy Helen because if they find oot, that's another one, just like my high blood pressure, and then the other thing Helen, they test your blood.

As a cholesterol measure was also carried out at the screening, a few participants were glad to discover their high cholesterol, which led to treatment:

> Alice (focus group 1a, 65yrs): I've not got anything wrong with me except they discovered my cholesterol was high and that obviously benefited me, you know, cause I wouldn't have known that...gone along in ignorance

Although this participant expressed no concern about her low ABPI result. Another participant in the same focus group, glad of being informed of her low ABPI, had regarded it as a trigger to make changes to their lifestyle:

> Julie (focus group 1a, 56yrs): yes I was pleased, my husband actually got one as well, and he thought it was an excellent idea that we should go and attend.

> And he attended and er he was in for about 5 minutes and told he had a heart of an ox! And I was in about an hour (laughter), so I think it's an excellent idea, it makes you aware, I didn't have any problems that I thought before, and now we're starting to think of diet, exercise etc

Expectation-reality mismatch

However despite a handful of positive reactions to the 'at risk' result, not all participants shared this attitude, particularly those who had expected not to be at risk. Many were shocked at their result:

> HE: and did you think you'd be in the sort of at risk group or?
> Geoff3 (68yrs): no, I thought my wife would have been more at risk than me
> HE: oh right, did she go as well then?
> Geoff3: yeah we both went aye. But when I heard she was clear, I hit the roof! (laughs)

This raises an ethical issue concerning the potential impact of an 'at risk' screening result on a participant previously believing themselves to be healthy, in particular whether any anxiety results and whether measures are taken to deal with this. In focus group 1a participants reflected on reacting to the result and the subsequent identity change:

> Bob (70yrs): I think one of the things that hits you is when you go to screening first and you discover that you are slightly different to millions of other normal people going about, you do start and say, "oh I didn't know there was something wrong", and you have this attitude that you are- you have now something wrong with you
> HE: do you feel like that?
> Bob: well you feel like there's something happened and yet you didn't, you were never conscious about it, and it just made you think about heart and the future
> Andrew (59yrs): it's not that you're different to the other bodies, it's just that you ken [know] and they dinnae
> (laughter)

Andrew's comment, although made in jest, maybe helped the focus group normalise the diagnosis of a low ABPI, and deal with the fact that they had no prior knowledge of it, and even minimise the amount of risk perceived.

Searching for an explanation

For many, there was a mismatch between their expectation of the screening result and their actual result, as demonstrated by Geoff3 above. This appeared to lead

participants to search for an explanation of the result and risk, which in some cases meant reflecting on their prior beliefs about their health and level of risk. In some cases participants seemed to maintain pre-screening beliefs, and turned to alternative explanations for the unexpected screening result, for example:

> HE:. What were your expectations about um what would be found, the results of this screening?
> Morag3 (64yrs): ...I think I expected that I would be clearly in the category which they did not want
> HE: right
> Morag3: because I consider myself to be a fairly healthy person for my age
> HE: yeah
> Morag3: and I was a little disappointed when I was borderline. My reading was actually 9.5, and so I was given the option of either taking part or declining to take part.....
> HE: and how did you react when she said you were borderline? Cause you said you weren't expecting to-
> Morag3: no, I said I was disappointed that I was borderline, I had expected to be classed as too healthy to be required, but um...she did say that it could be a slightly false reading because I had walked from Princes Street to the Royal which is uphill
> HE: yeah
> Morag3: and when you're going for anything like that, you are slightly apprehensive, and she said the reading was so marginally under that on another day it might have been marginally over

Morag3 drew upon two alternative explanations for her low ABPI, first the activity of walking uphill to the screening, and second anxiety regarding clinical measures demonstrating awareness of the concept of 'white-coat hypertension'. However, as the ABPI is a ratio of the ankle blood pressure to the brachial blood pressure, the result is unaffected by anxiety or activity unlike standard blood pressure measure. Therefore, these explanations are inaccurate and problematic, indicating that she lacked awareness of the meaning of the ABPI (this will be discussed shortly).

In a few other cases, participants initially sought explanations similar to Morag3 indicating low acceptance of the result, however as the interview progressed, the participant appeared to think wider and considered further contributing factors and explanations. For example Keith1 initially spoke about the possible influence of anxiety on the result, but later concluded that his poor circulation fitted in with the findings:

> Keith1 (59yrs): yeah, but another thing I feel is that 'white coat hypertension' as they call it, is one of the things and invariably, it's like anything, if you go and it was slightly up the previous time, the next time you go, you can actually push it up a little bit higher without thinking you know. And I feel it's pity they can't just check your blood pressure unknowingly to you, you know like just er when you come in the door and wave a scanner past you "yes you're OK" you know, something like that.
> (later)...since I've been young, my feet have always been cold, I mean I go cold quite quickly, so I've always had poor circulation in my feet, so I don't know if that's maybe that could be because my blood pressure is slightly higher

A further group of participants who accepted the screening result despite an expectation-reality mismatch reinterpreted rather than maintained their pre-screening beliefs and sought explanations for this mismatch drawing on their awareness of risk factors, for example increasing age:

> HE: yeah, yeah. And how did you actually feel when she said you were eligible, that you had um this indicator?
> Miriam3 (73yrs): no, er, I wasn't concerned because it appeared to be very slight and er...so er something's bound to show up when you get to get to my age, you can't just slide through

Also heredity:

> Mandy3 (59yrs): I felt a bit panicky inside to be quite honest...something inevitable, cause I think I've always felt that this is going to be an inevitable happening in my life you know cause my mum died when she was 59 and I'm 59, all my life I kept thinking 59, 59, I'm nearly out of it but I think you know I've still got a couple of months to go. But you know I've always had that feeling because it's in my family and strangely enough about two or three years ago I was talking to my younger sister and she said about 59, she obviously thinks the same way you know

Building explanations entailing risk factors beyond the individual's control such as age and heredity may have helped participants accept the result and minimise the amount of risk perceived or personal responsibility for it. Further risk factors drawn upon to explain the result involved factors under the individual's control, such as the contribution of an unhealthy lifestyle:

> Isobel3 (60yrs):...and it wasn't in my script in my head to be told that- I knew my blood pressure was low, but when I asked why, it was to do this foot, that the interviewer had found had been to do with circulation. And it was to do with me being an ex-smoker, which had made furring of the arteries. And I did find that quite frightening...()... I just felt shocked that really- because my father had two strokes and my mother had had a stroke,

so it was- hearing that there was low circulatory problems and I didn't want to be their age with their problems and it sort of projected me forward which I hadn't thought about

Perceptions of the ABPI

As indicated, in several cases it became clear that the participant believed there was no problem with their ABPI despite it actually being low. For example:

> Fred2 (62yrs): ...I also think I was- I'm positive that both feet readings were the same, but being at the age I was, and I smoke
> HE: oh right
> Fred2: er...and the lady at the time said, "well you know we'll put you on the trial" sort of thing. I think the smoking had something to do with it you know.

Similarly, in two focus groups misunderstanding became apparent regarding the ABPI measure and its meaning. Some participants could not recall being told, some being adamant about this. In focus group 1b, my questioning about the measure led to the following discussion:

> Lorraine (52yrs): I'm not sure I was particularly aware of this, at all, I mean I do remember being told at the time that the pressure was slightly lower there, but I never attached any significance to it at all
> HE: uh huh
> Nigel (64yrs): has everybody who came on this been told that, it seems to be the case that I thought blood pressure as being low.
> HE: what it is is that the ankle pressure's lower than the arm, there's a certain level at which they invited you to come into the trial
> Nigel: so everybody in this [focus group] will have this
> Yvonne (72yrs): they didn't tell me that
> Lorraine: no I wasn't aware of that at all
> Yvonne: I just [remember being] told that the ankle blood pressure was slightly low

Similarly in focus group 1a, there were a few participants who had not been under the impression that the low ABPI was an indicator of any type of risk for example:

> Alice (focus group 1a, 65yrs): I was told to cut out butter, sugar, you know those cheese and all the things you normally eat. But I have done, it's not really drastic, and apparently it's going down, so that's good. But nobody ever said I was at risk, and nobody ever said anything about anything, so...

These were difficult situations for me as moderator because within the focus groups participants remembered different aspects and held different beliefs about the measure and the screening dialogue; in both focus group 1a and 1b these conflicting accounts collectively led to concern and feelings that they had not been told the truth.

Similarly, in a few individual interviews participants were adamant they were not told about the ABPI:

> Joe2 (56yrs):...I was interested in what they might find, I was interested when they took the blood pressure, cause normally it was just round here, but it was round the ankles and er they didn't tell you what they find
> HE: pardon?
> Joe2: they don't tell you what they find, well I certainly don't remember them telling me anything about what they found, but at the time I was getting it done I was down the doctors anyway and I knew it was, by his check I knew it was fairly standard so...but aye I was just interested to see and to take part
> HE: yeah cause the ankle one which may have been explained at the time, but it was like, if this one's lower than that one, it means that there's slight furring of the arteries and the beginnings of slowing of circulation which is predictor of very future heart problems and you can't really remember them saying anything about that?
> Joe2: I don't remember coming away from that being alarmed
> HE: right
> Joe2: and I would have been tuned in to- I'd have been tuned in to that

Such instances were difficult as I wanted to avoid causing anxiety; I probed to explore their understanding but did not correct them. They knew that I was not clinically trained. However, I was able to feed back my concerns to the trial team while maintaining anonymity. A common misunderstanding that emerged in many participants' accounts was the confusion of the ABPI measure with standard blood pressure, for example Isaac3:

> HE:...so how did you actually feel when she actually said that [low ABPI result]?
> Isaac3 (58yrs): ah it didn't really worry me because the doctor had already said that
> HE: yeah
> Isaac3: you know he said "we've gotta get your blood pressure down, cause," he says, "you're OK but in later years that could lead to big problems, we've gotta get it down now". () So it didn't make a lot of difference, having said that if I hadn't been to the doctor yeah I might have been a bit more alarmed.

One participant did not connect the ABPI with cardiovascular risk:

> Andrew (focus group 1a, 59yrs): I'm aware of the fact, but there's nothing wrong with heart

Some participants did not perceive the ABPI as a serious risk. For a few this was probably because as above, they either misunderstood the meaning or did not recall being told. There are several additional explanations for not rating the ABPI a

significant risk: the ABPI is still a novel and not widely known clinical measure. Whilst participants were familiar with standard measures of blood pressure and cholesterol, only one participant in the study had heard of the ABPI prior to the screening. For those not accustomed to medical terminology the ABPI may be a difficult concept to grasp. For a few participants the little importance attributed to the ABPI was furthered by their interpretations of their own GP's behaviour:

> HE: so it didn't like alarm you- it didn't make you-?
> Wendy1 (55yrs): no it was good to know, it was good to know but my doctor's never put me on any tablets or anything so he must think I'm alright.

So whilst not actually discussing the ABPI with her GP, the fact that her GP has never carried out the test led her to not rate it as important. Another participant (Graham3) wondered why the ABPI had not been found when he had a heart check-up at the hospital. The following participant probably mixed up his GP's reaction to the test result and the cholesterol result (also taken at the screening):

> Nigel (focus group 1b, 64yrs): the first time, my doctor got a letter with all the results and so did I, and it said in mine, I had to go and see my doctor, I can't remember what was...anyway, I duly went out to the doctor and said, "what does this mean?" and he said, "it depends on the laboratory that's done the test," he said, "and I wouldn't worry about it", whatever it was, I mean it was something like, a hundredth of a point above the aver- you know something

So discussion with their GP regarding the cholesterol result had become associated with the ABPI measure, leading them to not rate the ABPI as significant. Another participant reported his GP dismissing the measure:

> HE: did you tell your own GP about the result and that you were in this trial?
> Warren2 (72yrs): yes, I think I did, um...I think he just poo-pooed it, he said, "that's nothing", you know I mean he knows me well, he knew my medical records and you know, and "that's nothing untoward", that was his response

These quotes demonstrate the potential influence of dialogue with health professionals on risk perception. For other participants, perception of the research nurse's attitude seemed to influence reaction to the result:

> Peter2 (55yrs): slightly lower that was she said aye slightly lower in the ankle than it was elsewhere, er and I certainly have noticed er a few years ago I found my feet were always warm now they're getting a wee bit colder. I mean they're no' cold freezing, you know.
> HE: how did you feel when she told you that at the time?

> Peter2: it didn't really bother me because she say well you're- I don't think it was giving her any cause for concern sort o' thing

Indeed the influence of the nurse-participant dialogue emerged as particularly salient in participants' discussion and interpretation of the screening experience. Where a mismatch occurred between expected and actual screening result, it appears that one method of minimising the level of risk perceived was by utilising particular words and phrases as used by the research nurse. For example, there are two cases of this in the following quote:

> Isaac3 (58yrs): um...no I was quite- when she explained why they were doing the ankle, I thought "ah well" and she did the first reading and it was quite high, and then she did sort of the other eg and the other arm and everything but she said "I'll do the other one again" so she redid it, and it had fallen so she said "sometimes you get a false reading the first time you do it", and she was very pleased with what the results were, they weren't too bad at all, I can't remember what they were now but they were borderline for going on the trial anyway

First, Isaac3 had picked up from the nurse's reaction that she was pleased with the result, indicating that he interpreted no great risk. Second, he remembered the nurse's comment that the result could have been due to a 'false reading', again minimising the amount of risk perceived. Phrases, such as "marginal" and "just one ankle" were common when describing the ABPI result, for example focus group 1a participants discussed their result:

> Bob (70yrs): when the nurse at the screening was doing the blood test- the blood pressure test, three were OK and one was off
> Jen (65yrs): I was the same
> David (71yrs): it was just like one ankle?
> Bob: one ankle
> Jen: that's the way I was

However even "just one ankle" still means atherosclerosis in one leg. A similar term used by a considerable number of participants was "borderline"; the majority of these were from group 3 (eligible but declined). For a few of these participants, "borderline" status was further emphasised in their accounts by describing how the research nurse had highlighted the choice involved due to this status:

> Morag3 (64yrs): and I was a little disappointed when I was borderline. My reading was actually 9.5, and so I was given the option of either taking part or declining to take part.

Perhaps participants held onto their alleged borderline status as a method of minimising the risk perceived. As the influence of the nurse-participant dialogue emerged as particularly salient, I discussed certain findings with the research nurses themselves, in particular participants' common use of the term "borderline". "Borderline" was decided upon by the research team as a term to use to avoid causing anxiety, because it was advisable to avoid using the word "risk" whilst explaining the meaning of the ABPI result. It is an interesting point for health professionals to consider when choosing words to use when explaining medical procedures, condition and results to the public. People will often pick up and remember key words when making sense of the dialogue. A potential follow up piece of research could focus more on the nurse-participant dialogue in such situations. In illustrating and discussing the misunderstandings of the ABPI result, it is important to emphasise that I am not imputing blame on either the research nurse or the participant. Rather I am emphasising that in situations involving clinical measures that may be complex and novel to the participant, it is likely that the participant will draw upon their dialogue with the nurse when reflecting on the meaning of their result, and use this in making their own interpretations. It is important that those conducting screening programmes consider this issue and the wider issue of information and understanding.

Often it could indeed have been the case that a participant's perception of borderline status regarding their ABPI was in fact correct. However this introduces further discussion relating to clinical measures involving a choice of 'cut-off' point. Many clinical measures such as the ABPI or cholesterol fall along a continuum of low risk to high risk; cut off points are determined by epidemiological research and are necessary for clinicians when making decisions about their patients' health care. The general public however may regard such 'cut off' points as black and white, i.e. at risk or not at risk, rather than an informed indication of level risk. This will be discussed further in the risk perception chapter.

Summary: perspectives on screening

This first data chapter has explored participants' accounts of the ABPI screening. Firstly focusing on screening attendance, discussions of explanations for non-attendance led to the emergence of four salient phrases signifying four key beliefs regarded as inhibiting attendance. The ubiquity of these phrases indicated their operation as cultural shorthands of shared lay knowledge; lay meanings of, and attitudes towards, the phrases were discussed particularly in relation to their perceived acceptability. Participants' accounts demonstrated how perceptions of the ABPI screening were influenced by feelings towards health, illness and preventive health in general, and more specifically heart disease and screening. Furthermore, the analysis has demonstrated the complexity of the context within which decisions about attending such a screening are made in terms of personal, social and cultural circumstances. Whilst reasons for attendance were explained when discussing and comparing non-attendance, these were then explored further explicitly. The final part of the chapter explored the screening experience. Reactions to the screening result were examined, in particular relating to whether the result matched participants' expectations or not. Interpretations of the screening result were explored along with factors that emerged as particularly important in these interpretations including perceptions of the ABPI and the nurse-participant dialogue.

Screening programmes require that individuals identified as at risk are "more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications" (National Screening Committee, 2003). Thus, in addition to exploring individuals' beliefs about screening, their accounts of beliefs about the associated prevention programme will reveal more. The following chapter thus explores participants' beliefs about the prevention of heart disease with particular focus on preventive medicine and aspirin.

Chapter 5:
Attitudes towards prevention and preventive medication:

Introduction

The present chapter explores participants' attitudes towards the prevention of heart disease, with particular attention to preventive medication and aspirin. In addition to exploring participants' accounts of their attitudes, it explores accounts of their behaviour related to preventive health. The two often appear to be contradictory, thus explanations behind the idea of engaging or not in active prevention and preventive medication use are further examined and discussed. Salient issues covered include views about medication including side effects and managing without, dependency, necessity, the role of the GP, aspirin specific attributes and the idea of preventive medication as an alternative to lifestyle change.

Prevention *is* better than cure

When discussing attitudes towards screening and preventive health, a phrase that appeared in participants' accounts across all groups was "prevention is better than cure"; often these exact words were used, as some of the later quotes will demonstrate, or the same meaning was implied. For example, when discussing preventive health and regular check-ups, the following participant discussed benefits of catching something early:

> Rebecca3 (73yrs): it's best to have some kind of knowledge of if there's anything wrong with you, then you can catch it

Likewise when specifically discussing screening, the following participant summed up her opinion:

> Cath (focus group 4a, 63yrs): glad to hear it now rather than wait another 10 years or something

In addition to the benefits of prevention to the individuals, the same phrase was applied to potential benefits at a societal level:

> Keith1 (59yrs): now they go on about how much this costs the National Health, but is prevention not better than cure?

Furthermore, the phrase was common when considering preventive medication:

> Amy2 (76yrs): I think everybody should take a preventive thing, better prevent it than try and cure it...

Some participants like Amy2 above felt a preventive approach should be generic; others applied the notion to those with a specific risk:

> Daniel4 (54yrs): well prevention's better than cure...um if you find out you've got the lower count in your ankles and you're told to take it and you don't take it then more fool you for not doing it

Often, as in the two quotes above, such expressions implied an emphasis on prevention being the right thing that one 'should' do; a few participants went further explicitly voicing this as a duty, for example:

> Fergus1 (72yrs):...er I'd keep 'em up, yeah, I mean if it prevented it, if it prolongs your life, then obviously you haven't got a choice have you?

So, echoing the discussion in the previous chapter, the notion of responsibility was implicit in many participants' expressed views about prevention.

For some participants who expressed such positive views about prevention, the remainder of their accounts reinforced this preventive attitude with examples of their own attempts to engage in preventive behaviour. For example, Moira1 stated a firm belief in prevention and in the rest of her interview talked about her own healthy lifestyle and recognition of the need for prevention programmes such as free healthy school meals to improve the health of those who were not as well off as herself. In addition, as mentioned in the screening chapter, Group4 members often advocated a preventive approach in many ways, but were in a different position to other participants due to their ineligibility and 'healthy' screening result. Thus, the 'prevention is better than cure' type views expressed by this group could possibly be accounted for by their own low risk, as acknowledged by Craig4:

> Craig4 (54yrs): well...not I mean I always think prevention's better than cure, um, but...yeah I mean obviously my views on this would be tempered by what

> my circumstances were at any given time, um and er...that's what life is about, you're continually making choices and you're reviewing who you are and so on, and so yes I would have to review that in future if there was some imminent danger, yeah.

In addition, as discussed in the screening chapter, many participants expressed positive attitudes towards prevention in hindsight. For example, applying the idea of preventive medication to another condition, Imogen1 talked about how she wished she could have taken medication to prevent the conditions that she now had:

> Imogen1 (61yrs):...I mean I wish I had been able to take something to stop me having this thyroid problem, for having the blood pressure problem, it would be great if you could sort of say, "if you take this, it'll stop you:...

However when looking more closely at other individuals who voiced the 'prevention is better than cure' adage, and reading the rest of their accounts, it became clear that this view was not confined to group 4 members, or to 'active preventive' participants like Moira1, or to those talking in hindsight. Rather, this view was expressed by participants across all groups including those with a low ABPI, many of whom were not engaging in the ideal preventive lifestyle. Furthermore, when discussing actual behaviour a different picture to 'prevention is better than cure' emerged.

Prevention is better than cure, *but*

More often than not, descriptions of actual behaviour contradicted the attitude stated by the participant that 'prevention is better than cure'. Quotes from Graham3 (eligible but declined to participate, aged 58yrs) demonstrate this contradiction; the following quotes are all from the same interview with him:

> "oh aye, aye because I mean prevention's better than cure isn't it, as they say" *(when discussing screening)*

> "and I thought, well if it's not serious. Which might sound stupid, I'm not going to bother" *(when discussing the ABPI and the trial)*

> "I've weathered the storm this long you know which again is silly" *(when discussing the effect of smoking on his health)*

"it's a bit late in the day, I won't bother with it" *(when discussing giving up smoking)*

In the above quotes, Graham3 indicated several explanations behind not engaging in active prevention despite clearly stating that 'prevention is better than cure'; his reasoning included low perceived risk and severity from the ABPI result and feeling that he was too old to start anything preventive, particularly as his smoking had not yet had any noticeable effects on his health as far as he was concerned. However referring to his decisions as "stupid" and "silly" suggest that he felt he *ought* to be engaging in active prevention.

Similarly to Graham3, despite voicing the belief that 'prevention is better than cure', many participants' accounts revealed seemingly contradictory behaviour but also provided explanations behind this apparent contradiction, particularly regarding (not) engaging in preventive medication use. The remainder of this chapter outlines and discusses participants' explanations behind, and views about, engaging (or not) in preventive medication: The next four sections focus on different aspects of medication including side effects, avoidance, dependency and necessity. The following section considers the reported effect of the doctor-patient relationship on attitudes towards medication.

Views about medication: Chemicals and side effects

Many participants expressed dislike about medication due to the idea of chemicals or unnatural substances entering their body, for example:

HE: have you got any reason for (disliking medication)?
Monica1 (66yrs): no, no, I just er- like my father always used to say to me, if I had something wrong with me, I'd rather cut it out than put things in my system, you know, so I don't know.

Avoiding medicines was a preference Monica1 had picked up from her father; Craig4 gave a detailed account of what lay behind similar feelings:

Craig4 (54yrs): I tend not to like taking medications of any description, I prefer to keep chemicals out of my body if at all possible

HE: why is that?
Craig4: um I just think that they create imbalances and often taking medication can lead to complications, something else down the line, um I prefer as far as possible to let my body fight its own battles and.... Having said that, I have diabetes and have to take insulin, so you know the exception proves the rule really you know but- but that's something I tolerate, but I don't like- I mean I- my mother and her generation um I think ran to the doctor when they sniffed you know and um I think...she had terrible problems with allergies at one time, and she was on medications for this, that and the next thing you know and...I used to say to her "what are all these things doing to you? Is this not what's causing this?" "Oh, no no no" and she was screened and she had this long long list of things that she was alleged to be allergic to and I mean it was virtually being allergic to the world and you know, now all that came to a sudden end when she had the stroke and all medication were stopped, and gradually built up again and whatever she has now, this irritation has not recurred. I mean I think all the way down the line, it was the cocktail of drugs that she was on you know, and she would go along to the doctor and say "I've got this and I've got this" and he would give her another pill you know and I used to say " do they never say to you, "what else do you take?" or is there any risk that this could react badly with that or whatever" so my response to this is um don't have anything unless you absolutely have to you know, keep it all in your system

Linked to dislike of the idea of chemicals entering the body was concern about side effects both anticipated and experienced. As Craig4 explained, he had watched his mother experience an increasing amount of adverse side effects from medication, which in turn required further medication to counteract the side effects; the experience had led him to avoid all medication other than that which he considered vital to survival. Peter2 described a similar scenario:

Peter2 (55yrs): As I say my wife she takes- she hasn't always kept the best of health and medication, if you're taking a lot, it knocks the hell out your stomach sort o' thing you know, the more medication you take, depending, it depends on your constitution. Some people tend to have problems with their stomach other people don't, er she the medication that she's been taking, certain medication she just can't cope with, it knocks hell out of her stomach, and she's got to take Zantac and things like that for it, is that right... she's got to take that for her stomach and as I say well, the more medication you take, is it gonna come up with something else. Given the choice, I'd rather not take medication full stop.

Peter2 felt that the occurrence and severity of side effects depended on the individual, but like Craig4 the experience of watching someone close suffer had led him to strive to avoid the risk of such suffering himself by avoiding medicines wherever possible.

Participants in focus group 2, however, seemed to think that side effects were not dependent on the individual, but could happen to anyone. Most of this focus group had, in fact, experienced side effects to at least one medication and several had experienced side effects attributed to the trial tablet, which may have contributed to their beliefs:

> Ursula (61yrs): um and everything's bad for you, to a certain degree
> Ella (70yrs): oh yeah that's right
> Ursula: any medicine
> Cath (63yrs): any medicine
> Ursula: are bad for you, you know. If you can go through life without having to take anything, you're very lucky, right. Anyone, anyone can go through life without some kind of- they've all got side effects
> Ella: yeah

Generally, the idea of unnatural chemicals entering the body and the potential side effects was given as an explanation behind many participants' dislike and avoidance of medication, and more specifically the rejection by many of preventive medication.

Side effects of aspirin

Regarding side effects of aspirin specifically, almost all participants were aware of at least one potential side effect. Many participants spoke of their awareness of severe effects such as stomach ulcers and bleeds, for example:

> Morag3 (64yrs): well I'm a little worried about aspirin because it has side effects, you can have internal bleeding, um if you have the beginnings of ulcer developing inside you then it can cause problems, and so I would be wary of taking it for no reason if I didn't require to take it...()... people might think that it's quite safe to take, if they've been taking it all their lives for headaches
> HE: yeah
> Morag3: but if you read the small print in the packet, the instructions, you become more wary about taking any kind of medication um indefinitely.

Some suspected their susceptibility to such side effects, thus actively avoided aspirin:

> Isaac3 (58yrs): ...it was a doctor many many many years ago, when I was about 20 I think
> HE: oh right?
> Isaac3: and he said then, I think I had tummy problems and he said avoid aspirin if you can
> HE: yeah

Isaac3: affects the lining your stomach and all this so I don't know medically if that's true or not but er ever since then I've tried to avoid aspirin

Several participants weighed up the potential adverse side effects against the potential benefits, leading to different conclusions; Craig4 felt the cons were greater:

Craig4 (54yrs): no but I mean I know it can I suppose it depends on the dose and your own metabolism, I know it can be a bit severe on the stomach, so um yeah...so it's the same story, while you're maybe curing one thing, what are you doing to the other

In contrast, more participants felt that the benefits outweighed the costs, for example:

Imogen1 (61yrs): ...that sort of can cause ulcers...you know of the stomach, and there's a little niggle, when I was getting this indigestion, I've got to admit I did- I thought about that, you know...but there again I think there's a risk with all tablets. You know I feel there is, there's a side effect with everything, you know.
HE: so it doesn't worry you?
Imogen1: just this little niggle, but as I say it seems as if that's going away so it's perhaps just been you know. But it wouldn't stop me- if at the end of the trial, they said, "now look we feel that an aspirin would benefit you", it wouldn't stop me. [I wouldn't] say, "well I'm not going to take the aspirin because of that".
HE: you'd try it
Imogen1: yeah because I feel, well if I had an ulcer, they could sort of do something about that, but if I had a heart attack, there would be no point, I probably wouldn't be here, you know, you've got to weigh the pros and cons.

Imogen1's explanation represented the conclusion of several participants: that for the life-saving benefits of aspirin, the risk of experiencing adverse side effects was worth taking and tolerating, and could be appropriately managed. Richard1 came to the same conclusion, further adding that susceptibility to side effects would occur in a minority only:

Richard1 (54yrs): but the good effects tend to be about things which are actually dealing with- ameliorating things which are life threatening
HE: yeah
Richard1: whereas the bad effects either tend to be about things which are not life threatening like they're bad for your stomach, or they're about things that um happen to so few people that it's hardly worth considering,...()...Um so no I mean bad effect don't get me excited because mostly they're either minor, or you'll know about them anyway you know most cases you know, it's not like the first time a two-year-old eats a peanut, it's people or adults mostly that are gonna be exposed to it. The really nasty effect of anything like that would happen to a child. By the time you're an adult, with common things like aspirin, there must

have been a across your system more than once, you'll have a fair idea, I mean there are people that are allergic to aspirin in various sorts of ways as far as I understand, but you know people certainly get upset stomachs from them, and these people don't take an aspirin

Others emphasised the distinction they had made between themselves and more 'susceptible' others who for example "had had stomach trouble for years". There seemed to be some indication of an optimistic bias emerging in these participants' accounts, however as discussed earlier, rather than such optimism being considered unrealistic, comparison of the risk factors associated with these 'susceptible' others and themselves may have led to a well thought out conclusion. Or, lack of occurrence of any adverse effects whilst taking aspirin seemed to contribute to low perceived susceptibility to adverse side effects, or made the issue less salient:

Hamish1 (70yrs): well I'd heard there's still problems...aspirin affecting your stomach, you know, your bleeding or something like that. That is because of a friend of a family, who'd ulcers, and he was always taking aspirin somehow or other to alleviate his problems but I think they were increasing his problem, 'cause I think his stomach was getting burnt you know, I don't know about the blood, heard that he was coughing blood out and that but that was aspirin he was taking. Which I suppose should have been the last thing he was taking...()...
HE: the fact that you had an ulcer, and that you know that aspirin affects ulcers and stuff, does that not affect that your
Hamish1: no, I'm sure right away I would have found some sort of a side effect, you know like the bleeding of the stomach, and you know wait a minute, this could be the aspirin that's bringing this on, in which case I would have gone back.

Discussion about side effects in focus group 1b was the first time some participants had considered the possibility of side effects and led some to realise minor effects that they had previously not noticed, which seemed to cause some amusement:

HE: has anyone- do you know about side effects of aspirin
Lorraine (52yrs): bruising more easily
Maive (67yrs): your stomach, damage to your stomach
Anita (74yrs): bruising more easily...I'm just listening to L saying bruising more easily...well I've got a big bruise there
(Laughter)
Nigel (64yrs): that's one of things that I've started to notice small bruises, and never gave it a thought
(Laughter)

Anita: it's not painful
(laughter)
HE: so has anyone got any concerns about side effects?
Wayne (69yrs): I never gave it a second thought till today
(laughter)

A few participants felt the dosage was high enough to cause problems, despite the 100mg dosage being considered low in medical terms, for example:

> Molly4 (75yrs): and half an aspirin a day is quite a lot of medication to put into your body isn't it?

In contrast, others felt the low dosage was a reason to not be concerned about side effects:

> Geoff3 (68yrs): I mean it's a small quantity of aspirin, it's not gonna cut the lining of my stomach up I don't think so, or anything like that.

In focus group 1a, discussion about the low dosage involved in the active trial tablet seemed to help participants build a reassuring group consensus of low risk:

> David (71yrs): but the pills we take, they're just wee pills, they're not like the aspirin you get in the chemist are they, so there's less chance of getting a bleed or whatever from taking one of those, even a series of them, a number of them, less chance of
> Julie (56yrs): it's a low dosage that we are actually
> David: well they're very very small aren't they?
> Alf (74yrs): it's a third isn't it?
> David: it's a third is it? Aye, it's a third so there's a fair amount of- two thirds less chance of being affected I would think, I don't know

As these were trial participants, conferring with others and building a group consensus of low risk may have helped reassure each individual of low risk from their trial tablet given the 50% possibility that it was aspirin. Focus group 4b participants were in a different position due to their healthy result and lack of aspirin use, so may have considered the risks of aspirin differently. But a similarly safe picture of aspirin emerged; again the low dosage seemed to contribute, as did aspirin's place as a longstanding medication which needed no advertising compared to the mistrust of new and advertised drugs:

HE: how about Lucy's point about aspirin being sort of a common you know commonplace medication, do you think that makes a difference to how you think about it?
Elsie (60yrs): I would say possibly it is because there's always been aspirin and you do probably have proper faith in it:
Lucy (57yrs): 'cause you know what it is,
Elsie: rather than if you take something different
Melanie (64yrs): yet it's contra indicated in certain things like duodenal ulcer and things so you would need to watch that but it's a low dosage so is shouldn't be
Lucy: it's been there forever, it was always "just take an aspirin", you don't see it causing any harm particularly that's it, and because it's not sort of promoted as well like all these Hedex and all these things, they don't have a big campaign on TV for aspirin, you never see that, because aspirin's OK, and yet as you say it could have a side effect on some- maybe another condition that you had.

In addition to the low dosage, participants gave other solutions for minimising potential side effects including sugar-coated tablets, soluble aspirin and avoiding the drug on an empty stomach.

Following discussion about side effects in both focus groups 4a and 4b, very similar conclusions were reached, for example as summed up by a participant in 4a:

Wilf (65yrs): An aspirin a day's not gonna kill you

There was agreement and certainty regarding this conclusion in both of these focus groups. Such assumptions about aspirin's safety ran through many participants' accounts, for example:

Eleanor3 (62yrs): well given that it's a tried and tested drug that you would have been taking, I mean obviously it's a small dose you'd be taking wasn't it? So really they...certainly wouldn't do you any harm, one way or the other, well if anything it would possibly do good, given what they'd discovered. So but as I say if it had been something, if they'd said to have come and it was a drug they were just testing, that would've been different but given it was aspirin, I wouldn't have had a problem with it one way other...

The emergence of assumptions about aspirin's safety will be further discussed in the participation chapter, as this assumption seemed to play a role in the (low) risk generally perceived in relation to the trial tablet.

Generally, despite much awareness of the possibility of side effects from aspirin, more participants felt that the benefits outweighed the costs. The possibility of side effects was minimised due to lack of their occurrence, creative solutions for preventing them, or optimistic bias; assumptions about aspirin's safety prevailed.

Views about medication: Never taken medication

A further reason for avoiding medication came from the feeling that having never been in the habit of taking medication, many participants did not want to start at this point in their life. For example:

> Fred2 (62yrs): just purely er...probably 'cause I was quite naïve in quite a number of things, as I said earlier I'd never taken, I'm not in the habit of taking any kind of tablets you know I couldn't tell you the difference between them, a disprin and an aspirin you know, so I said "Och if I've went through you know 60 years of my life without taking anything like that, I'm just gonna leave it, not take it" and I decided that you know

Fred2 implied that his lack of medication use over the years was naïve, whereas most other participants who spoke about never using medication emphasised this as something they seemed to be proud of:

> Eleanor3 (62yrs):...I have been very lucky through my life, I've been a very healthy person and I've never ever- in fact I don't know when I took an aspirin last (laughs), I really don't, anything I mean I just don't ever take pain killers, don't have any need to take pain killers or anything like that, aspirin or panadol or any of these things

Eleanor3 seemed to be using her lack of medication use over the years to reinforce her identity as a healthy person; Monica1 emphasised similar 'healthiness' by distinguishing herself from others who do use medication:

> Monica1 (66yrs): I don't like to take pills if I can help it you know, even headache pills, you know. If I got- if I had it all day and I was forced to take, I'd take a paracetemol, that's the only medication I would ever use, ordinarily...()... I'm not a pill popper, like some people with their six bottles

This distinction and the choice of words indicate the negative connotations participants like Monica1 associated with people who take medication. It seems that the use of medication, like consulting the doctor as mentioned in the screening chapter, signifies an

illness identity; participants like Monica1 and Eleanor3 seemed to be distancing their own identity from this and through this possibly emphasising a tough mentality. This echoes attitudes of the women in Blaxter and Paterson's (1982) cross generational study (as mentioned in the previous chapter), where illness was considered a state of moral malaise, in particular in one's reaction to symptoms. The women presented themselves as not giving in to illness or letting it disturb their functioning, and those who did were regarded negatively. Regarding attitudes towards medication, older women in particular preferred to rely on 'mind over matter' models of cure rather than using medicines, which emphasised their strength of character (Blaxter and Paterson, 1982). Similar beliefs seem to apply to medicine use in the present study; Eleanor3 continued to describe how during a period when she was required to take medication, she waited until the pain was unbearable before resorting to taking the prescribed medication:

> Eleanor3:...I had my gall bladder out and of course I was given pain killers...well I took...it did say take every four hours or something like that...which I didn't do, I mean if I had been absolute- if it had been unbearable I would have taken them, but I don't believe in taking things, just keep swallowing pills unless...it's absolutely necessary. You know I just think I just don't think it's necessary. If I can deal with it, I mean if I'd been rolling about on the floor or something I'd have taken them but I thought- well sometimes when it was really bad, I'd take a couple but I mean I'd never at any point did I take two every four hours, I mean I'd just take maybe a couple and then maybe at bedtime another couple so I could get some sleep or something. I just don't believe in putting a lot of stuff into your body unless it's...

For some participants who emphasised this attitude, further probing revealed actual medication use, for example:

> Rebecca3 (73yrs): see because I like to know what I'm taking, and as I say I don't take any other tablets, unless the doctor prescribes, even in the winter months, if you've got a cold, you don't take nothing for it
> HE: do you take any medication now at all?
> Rebecca3: no, I only take my erm...water tablet, my blood pressure tablet, and my two inhalers.

Rebecca3 initially replied that she took no medication but then described how she 'only' took four lots. Like other participants she had managed most of her life without medication and seemed to struggle with the fact that she now had four ongoing items to

take so she appeared to try to minimise the significance of these medications when answering the question. Similarly Monica1 (quoted above) took thyroxin and the trial tablet despite her emphasis on not being a pill popper; her acceptance of these medicines was linked with beliefs about necessity (this will be discussed in more detail shortly).

A couple of participants felt that, as they had managed all their life without medication, they were too old to begin a course of preventive medicine at this 'late stage', as shown in quotes from Graham3 (58yrs) and Fred2 (62yrs) earlier in the section. Warren2 (71yrs) shared this attitude and reflected how with hindsight, after an event or once a condition has become evident and symptomatic, it is easy to see the benefit of taking preventive medication:

> HE: so how do you feel yourself about preventive medication?
> Warren2: um well (laughs) I suppose given that I'm 71 now um, I suppose I think it's late in the day for preventive medicine in you know with a person like myself with more often than not it's, you know, it's after the event has happened that you start taking these things, you know my youngest son's wife, her father, now he takes that (glucosamine) and he takes cod liver oil, but he sees that as preventive you know that he won't suffer from arthritis or whatever when he's older, you know and I think to myself, "yeah, if I'd thought about this when I was 30 or 40" you know I played cricket four or five times a week you know, "I might have done the same thing", arthritis and- you know my attitude to that is I'm paying for all the years of sport that I spent, and you do suffer wear and tear and you know lots of athletes suffer from the same thing. Yeah I suppose you don't think about that when you're young, it's only when you're older.

Warren2 considered himself too old at 71 to begin preventive medication, implying a fatalistic attitude in that he felt that whatever he does from this age onwards is unlikely to have an influence on his health. In contrast, elsewhere in his interview he refers to 71 as too young to be taking medication:

> Warren2: I prefer to avoid medication to be honest, you know
> HE: is there any reason for that?
> Warren2: um...I don't know I suppose that's a general...reaction, you know I don't want to be taking tablets if I can avoid it, um and I suppose like perhaps when I'm older I'll have to but rather not at the moment...()...I don't want to be dependent upon medication

His account thus implied that regarding medication avoidance, age was less of an issue than fear of dependency.

Views about medication: Dependency

Fear of dependency on medication was divulged by a few participants; as with Warren2, this tended to be divulged following several other reasons for medication avoidance. For example, Mandy3 (59yrs) firstly explained her dislike of medication as due to side effects and spoke about only medicating in severe pain, similar to those quoted previously. She referred to herself in a negative light for this behaviour (elsewhere in the interview described herself as a 'bad diabetic'). However, she eventually revealed her dislike of the feeling of being dependent and controlled by medication:

> Mandy3: I've been terrible all my life and I don't like taking any medication
> HE: why is that?
> Mandy3: I don't know what it is, I won't take a headache tablet or anything until I'm forced to do it at the last minute, I mean I've got arthritis, I've got pains in my hips and everything and I only take it when it's you know...(indicates severe pain) and I know you're supposed to take it regularly to keep it down but I don't. But I'm also um...what do you call it...opiate intolerant
> HE: oh right
> Mandy3: so I have problems in hospital with um...anaesthetics and things like that, so maybe I don't know it's something to do with that
> HE: so you don't like taking unless it's necessary
> Mandy3: yeah mm...but I am now because...I'm accepting that things are going wrong now and I really have to take my blood pressure tablets and if it was an aspirin to prevent, then I would do that as well, and I have to take my insulin because if I could do without that I wouldn't have that either, you know I think- for many years again I've had problems having to take this insulin but er, just reconciled with the fact I don't like taking things like that and having to do it...
> HE: do you still feel like you don't like taking them?
> Mandy3: I don't like taking things like that...the insulin is four times a day (). I cope with it, the physical aspect has never been any problem, it's the mental aspect of it you know it controls you sort of thing and I don't want to take it
> HE: is that what you mean about it controlling- you haven't got control over
> Mandy3: I've always thought that about the insulin yeah but I'm trying to get it under control just now, struggle, but er I don't know what it is, it's just a part of my make-up that I'm so reluctant to take things.

Despite seeming ashamed of her negative feelings towards medication she talked about how she was trying to turn around the feeling of control with herself being the

controller. This seemed to be a way of accepting and coping with having to take medication.

Similarly to how participants described witnessing loved ones' adverse side effects leading them to avoid medication themselves, the experience of watching her husband become dependent on medication over the year had led Jennifer2 (61yrs) to actively avoid any course of medication that she considered could be addictive:

> Jennifer2: I don't like taking medication. I must be honest, I don't like taking medication.
> HE: is there any reason behind that at all?
> Jennifer2: I really don't know but I don't- I maybe it's because I've watched my husband- he started off wi' asthma, chronic asthma, he's never smoked, it runs in his family and I've watched him over the years how he's went and now...he's just really done, he's a done man, and he's taken like heart his heart's not working right and everything through the stress of the asthma all his days an' that. And when I was told to use inhalers I wouldn't, I've never ever used them, because...my husband used to say they're like dummy to a baby, once you get them you get used to them and you cannae do without them, and therefore I'll no' take them
> HE: so is it the addictive thing you're
> Jennifer2: aye, that's what, aye, I just when the time really came if I had to, fine but no, and there I've got away with years and years without using them, I've never used them and that's the reason, just cause once you start, you cannae stop, that's how I feel
> HE: so how do you feel if like when you go back to the doctor in a month and if he puts you on some tablets for your blood pressure or something,
> Jennifer2: no, I would take them because I've got a fright aye, that's different when you've had a fright, you would aye I would definitely take them because I don't like the way I'm feeling

An interesting point about Jennifer2's responses above is the contrast of dependency with the notion of necessity; despite her fear of dependency leading to active avoidance of medication, she said that if a point came when she 'had to' take medication then she would take it. Indeed she was willing to participate in the trial, thus accepting the trial tablet.

Views about medication: Necessity

Martha2 (65yrs): see nobody likes taking pills but if you've got to, you've got to

The notion of necessity seemed to override reasons for disliking medication in many participants and led them to accept the idea of taking it. For example in focus group2, earlier quoted as concluding that all medication causes side effects, participants also expressed that adverse side effects had to be tolerated if a medication was considered necessary:

> Ursula (61yrs): I think so, I just think any medicine taken long enough is bad for you, it all has some side effects, all has some, but it all depends if you're living longer and you know, if you have to take it, you take it, and deal with the side effects, you just have to, my husband's on different things, he has to take them, even with side effects.

What contributed to a medication acquiring status as a necessity? I explored participants' accounts for their meanings of necessity. When describing medication as necessary common phrases were used such as "keeping my blood thin" and keeping the condition "under control". Life saving attributes were also used, for example "keeping me going", "surviving on pills" and:

> Harold2 (63yrs): I don't mind, not if it's helping me you know if it's keeping me alive

Some participants gave more sophisticated explanations of their meanings of necessity, for example due to their awareness of the condition and prognosis if left untreated:

> Keith1 (59yrs): well it's a- it's the only remedy if you want to call it, rather than as you say arteries and veins, it's the only way really I'm gonna try and keep on top of the problem. I mean if you let the problem go too hard or too high, I mean my father, they reckoned, he had hardening arteries all over the body and he died, and this is the root cause of high blood pressure would be. But er, it's the only way I can see at this moment in time, how to do it.

Martha2's view about necessity was related to her acceptance of increasing age:

> Martha2 (65yrs): At one point it was 7! Um I was a bit- not concerned but I felt, oh you know this is what old age is all about probably, but er, I got used to taking them and I just take them every morning and that's it, and if you've got to take them to keep you going, then you do it

HE: is that the way you see it?
Martha2: that's they way, yes, uh huh, I mean if I didn't need- I'd be happy to do without them, but obviously I need them so

The importance of the notion of necessity in overriding participants' other dislikes about medication included wanting to avoid side effects and dependency, has been illustrated. Exploration of participants' meanings of necessity highlighted the interrelated issue of perceived severity of illness or condition, which will now be discussed.

When does a 'risk' become a condition?

The question of the point at which a medication is perceived as necessary seemed to be embedded within the wider issue of when an increased risk becomes perceived as a condition or even an illness. Regarding the current situation, this is again linked to people's perceptions of the ABPI. Participants generally seemed to consider high blood pressure and high cholesterol as conditions requiring medication for control, whereas the ABPI did not appear to be thought of in the same way. The screening chapter demonstrated how many participants did not consider the ABPI as a significant risk; consequently for many participants it was not considered a sufficient risk to require medication. Warren2 sums up this attitude:

Warren2 (71yrs): I think if it had been medication that I needed to take, I would have taken it.

The lack of risk perceived to be associated with a low ABPI is illustrated by Peter2, who whilst advocating the benefit of being able to identify people with atherosclerosis, showed no awareness of his own low ABPI indicating this, thus saw no point in medicating:

Peter2 (55yrs):...you know as well as I do everybody's make up is entirely different, some people are more prone to arteries furring than other people, er and I would say if you can detect the people who are more prone to furring arteries, if that was the case for me and I knew I was going to fur up quite easily, I would take the aspirin to help stop that
HE: but did you not think this measure you had was enough to sort of indicate that?
Peter2: er aye no, I wouldn't have said so, unless I could really feel-

These quotes re-emphasise the lack of a perception of risk currently associated with the ABPI as discussed in the previous chapter, and highlight a problem for interventions that may involve preventive medication for atherosclerosis and similar asymtomatic conditions.

The following dialogue extract from focus group 1b shows an insightful discussion about distinct types of medication relating to the distinction between illness types:

> Wayne (69yrs): well I don't take medication, *because if you're taking medication, there's something wrong with you, you're ill*, so I don't...I'm on these decongestant tablets...
> Maive (67yrs): medicine may give you a better quality of life
> Yvonne (72yrs): that's right, but I wouldn't take like- medicine that I know people that are "go and buy this from the chemist, it's good for you", you know all kinds of things you get from you know- over the counter in the chemist, but I wouldn't do that, *if I needed medicine and I got it from the doctor, good enough I'll take it* and I'll follow the instructions and take it you know correctly. *But not to take medication for the sake of it.* I'm OK, I've got good health so I don't need prescription medicine, I haven't had prescription medicine for three years anyway 'cause my diary's been clear. But I've had prescription medicine in the past and fair enough I mean I'm happy to take it because it does make you better.
> Lorraine (52yrs): I've got a thyroid deficiency so I'm on a dose of thyroxin
> Yvonne: *ah but that's helping you*
> Lorraine: but it's yeah, but having said that I didn't even know I had a deficiency so um *whether it counts as an illness or not*, as this gentlemen over here (W) was saying, but er you know
> HE: do you see that as kind of different?
> Lorraine: yeah uh huh, I don't honestly think about it very much, but I mean I know what this lady means about not taking medicine for the sake of it but it's just I wouldn't give a thought to taking any medicine, whether I needed it
> Yvonne: *you're getting that for a reason*
> Lorraine: uh huh yes
> Yvonne: that's different but I seem to know many people that have cod liver oil, buy as much stuff out the chemist for this and that
> *(italics: my emphasis)*

This dialogue about medication and necessity brings together several issues covered in this chapter, demonstrating various problems regarding the perception of preventive medication. First, as discussed previously, participants made associations between medication and an 'ill identity', which seemed to have negative connotations and was

something participants wanted to avoid. Second, distinctions were made between different kinds of medication: prescription medication for an acute and presumably symptomatic episode of illness was regarded as necessary, as was medication for an ongoing and less symptomatic condition (thyroid deficiency) which was referred to as 'helping' and 'for a reason'. However, medicines recommended as being 'good for you' or 'for the sake of it', which seemed to be how they viewed preventive medicines, were not considered necessary. The comment, "you're getting that for a reason" is interesting; it seems that only established illnesses were being considered as 'reason' for medication use, and but conditions where preventive medication could help were not included in this reasoning. Participants seemed to be working together to build a model of different levels of medication and illness and their related necessity; the resulting model treated medications that participants themselves were taking as necessary, so once again possibly helping participants to maintain perceptions of healthiness and avoid an 'illness identity'. Lorraine's insightful question regarding a thyroid deficiency's status as an illness, particularly as prior to discovering it she had no awareness of having a 'condition', further adds to the complicated perceptions of 'silent' conditions.

Views about medication: The doctor-patient relationship

Continuing the discussion of necessity, some participants' acceptance of medication and views about its necessity seemed to be influenced by their GP. In several cases, in the event of a GP prescribing a medication, the participant then seemed to deem the particular medication necessary, despite prior reluctance they had about it given their dislike of medication. For example:

> Fred2 (62yrs): well I'm not keen on that either but for no reason you know because I really don't know a lot about er medicines or even medication you know, I mean if the doctor gives me antibiotics that's different thing you know, then I'll take the course I'm gi'en, er but I'm always reluctant even to take them you know. But it's just something that I went through all my life you know doing you know er I'd rather- maybe it sounds stupid but I'd rather put up with headache than take a paracetemol or something you know, I just don't fancy having these things in my body sort of thing you know and that's all
> HE: you said like if the doctor prescribes something, that's slightly different

> Fred2: well yes, I know- because if I go 'o the doctor, you know to find out what's wrong with me you know maybe a chest infection
> HE: yeah
> Fred2: well if I go to find out why I've got it such like, he tells me why I've got it but to cure it...he's got to give me these antibiotics then you know I go 'o the doctor who I trust then I've gotta take them you know reluctantly but I take them you know. Um...so I know it sounds stupid but that's the way it is you know

Participants who had this attitude often said they would take whatever their doctor prescribed, often like Fred2 quoted above, mentioning their faith and trust in their GP or the assumption that the GP must know best, or at least know a great deal more than their self. One participant emphasised several times during her interview how good her doctor was:

> Susan5 (53yrs): whatever she says, I'll do, you know so I don't really know anything about aspirin, I just take it, she said "take two a day" and that's it...()...and she said I've got to take two, I don't understand that but I just do what she say because she's good, I trust her...()...Well as I say I trust the doctor, she's a good doctor, um and she is really concerned about your health, it's not just a doctor who says "take this, take that" you know without thinking so I do trust her...()... I know what I'm doing as I say I trust the doctor, she's obviously cleverer than I am and she knows that's what I should take so that's it.

For Susan5, knowing the reasoning for her medication was less important than her trust in her GP's knowledge and advice. Blaxter and Paterson (1982) found this attitude common in their older participants who expected their doctor to be simultaneously a family friend and an unquestioned expert. Isaac3's faith in his GP was so strong that despite anticipated adverse side effects to aspirin given his past experience, as quoted earlier, he said he would still be willing to try aspirin if his doctor suggested it:

> Isaac3 (58yrs): I just go with what the doctor puts me on really...if he said 'ah I wanna put you on aspirin', yeah I would probably say, 'we'll try it'...

So, for a fair number of participants, their GP's advice could override their preference for avoiding medication. Where it was appropriate, I asked participants if they would consider asking their GP about the idea of starting aspirin as a preventive medication. One participant (Geoff3) had done this upon discovering his low ABPI, rather than entering the trial (his case will be discussed in the trial participation chapter).

Geoff3 (68yrs): and when I found out you knew I was at risk, but you were prepared to put me on a dummy pill
HE: uh huh
Geoff3: I said get lost, and rather than on aspirin, they can't tell you what you were on. So I walked out of the trial at that stage and I went to my own doctor
HE: and did you?
Geoff3: I spoke to him and told him what was happening, and he said, "do you want to go on aspirin?" and I said "well it sounds like I might have to". I'd sooner be on it rather nothing, so I have the 75mg aspirin.

Such behaviour was considered wrong or inappropriate by other participants, for example:

Ted4 (77yrs): I'd be wary of doing that, I feel that'd be a negative reaction, if I was coming to him for advice and then I'm more or less telling him what he should be saying you know...

Ted4 felt such an action would be inappropriate considering the roles embedded in the relationship he had with his GP; requesting a certain medication or even making suggestions was not considered within his patient role. Similarly Gordon1 felt that a doctor's 'permission' had to be granted before taking any medication, as shown in the following dialogue between him and his wife

Gordon1 (67yrs): well yes I would take it by myself but they say you've gotta get the doctor to get permission first, cause if I need it, I would need to find out if I needed it and I would take it then, you cannae take it, it tells you in the paper years ago, you've gotta go 'o the doctor then find out, then he gives you permission. But aye I was certainly take it if it helps, if you find out it helps, nae problem, I think everybody would do that really
Wife: my sister and her man take half an aspirin each
Gordon1: ah but did they ask for permission from the doctor?
Wife: I never asked them

So compared with Geoff3 who seemed to have a more partnership style patient-doctor relationship, other participants tended to be more passive, whether accepting their GP's advice without question, or waiting for their GP to make recommendations.

Self-medicating

A different type of active choice discussed by some participants was self-medicating. Regarding aspirin, one participant had started self-medicating in a preventive way after discovering her low ABPI at the screening:

> HE: so what did you do after that, did you decide to go on aspirin yourself?
> Patricia3 (61yrs): yeah I take my aspirin, I take a soluble aspirin most days
> HE: and did you go to the doctor?
> Patricia3: no
> HE: no, oh right
> Patricia3: no I actually- I got them in- I buy them in Superdrug, and I just take one you know dissolved in water, most days, you know maybe 5 times a week
> HE: yeah uh huh, and you haven't told your GP or anything
> Patricia3: no I haven't been to see the GP for quite a long time
> HE: oh right
> Patricia3: so I keep meaning, I keep thinking about it and saying maybe I should go along and see him cause maybe I should be taking 'coateds if I'm going to take them as regular as that
> HE: what size of aspirin are you taking?
> Patricia3: just I think it's 500 mg soluble...so I mean I think probably aspirin does make a difference

So Patricia3 had not felt the need to consult her GP about her self-medicating until the interview, when she considered checking with him at some point. She took soluble aspirin and had considered sugar-coated aspirin too, as she was conscious of the possible side effects on her stomach; the dosage she was taking however was particularly high. Craig4 described how a doctor friend self-medicated aspirin in a preventive nature:

> Craig4 (54yrs): oddly enough I have a doctor friend who I know takes a quarter of an aspirin every day, which she's got no cause to believe that there's any necessity for this but
> HE: has she had heart problems?
> Craig4: no
> HE: oh right
> Craig4: well I think she's just scared of having heart problems you know and um that's her response to that is to
> HE: interesting
> Criag4: yes uh huh
> HE: there seem to be a lot of people who are on aspirin after heart problems, after a heart attack, but
> Craig4: but they don't bother beforehand, yeah...yes but then this is obviously a highly informed person who's doing this

Craig4 emphasised this friend's knowledge and experience from being a GP herself, implying that she must have good reason for taking aspirin preventively despite having stated no clear necessity for this action. Following a discussion about awareness and use of aspirin in focus group 2, one participant questioned fellow participants about preventive self-medicating:

> Emma (70yrs): well I suppose we've read a lot about the supposed benefits of aspirin, but have any of us here actually decided, 'well off my own back, I'll take an aspirin'?
> Deirdre (68yrs): my friend has
> Cath (63yrs): my cousin has
> Emma: I mean I've often thought about it, then I thought, 'well I've not been told to do it, I'm not going to'

Her conclusion related once again to the absence of being directed to take the drug, presumably by her GP, which had dissuaded her from any further consideration of self-medicating.

In summary, participants spoke about known others who self medicated with aspirin in a preventive way and some considered doing this themselves, but with the exception of one participant, consideration was as far as they had gone. The influence of a GP prescribing, recommending or approving aspirin as a preventive medication seemed more influential and seemed to be related to perceived necessity.

Aspirin- a special case?

Participants' views about preventive medication were not only embedded in their beliefs about medication in general; it became evident that many participants held attitudes about aspirin specifically which appeared to have a large influence on their views about using the drug as a preventive drug and/or entering the trial. Of course, the study was about the trial and aspirin, so attitudes towards these were explicitly explored. This section examines participants' views about aspirin and its attributes, and argues that as attitudes towards aspirin often differed from attitudes towards medication in general,

many participants seem to treat aspirin as a special case. This section highlights perceived attributes of aspirin that probably contributed to this differential attitude.

Awareness of aspirin: Old wives' tales and current hearsay

Awareness of the benefits of aspirin emerged as not only a recent trend; some participants spoke of older relatives who had sworn by daily aspirin:

> Monica1 (66yrs): my mother always had an aspirin you know every day
> HE: did she?
> Monica1: uh huh, I mean and that was for years and years and years
> HE: what made her do that?
> Monica1: I don't know, it was just something that she seemed to know was good for her and she used to take it uh huh, yeah, soluble, she used to take, she used to get a little water

> Emma (focus group 2, 70yrs): my husband's parents always took half an aspirin every night... and his father was 96 when he died and his mother was 89, and they always took it, it was the first that I'd ever heard anybody taking it, and they always took it...

Participants who mentioned such "old wives' tales" seemed to feel there was some truth in them, as they attributed these relatives' long lives to the daily aspirin they took. Furthermore, they talked about relatives 'knowing' that daily aspirin was good for them but not knowing *why*. Some participants who mentioned current recommendations of taking aspirin for 'general health' seemed similarly unclear, for example:

> Bob (focus group 1a, 70yrs): aspirin's been on the go for many many years, it was used for most things before all the modern drugs
> Julie (56yrs): 'cause in magazines it sometimes tells you over a certain age you should take an aspirin, not specifically for heart disease but just for general health
> Bob: (in agreement) general health

Awareness of aspirin: cardiovascular related uses

A couple of participants were bemused by the discovery of aspirin's use for heart disease given its long history as a general household drug; Graham3 described how aspirin had been used for a multitude of ailments over the years and found its heart related benefits amusing:

Graham3 (58yrs):...aspirin, as I say, it's funny how all of a sudden it's became this great medication for heart problems.... I don't think it's a thing I've ever taken really in my life
HE: no
Graham3: well not ever having a sore head, I wouldnae need to
HE: uh huh
Graham3: it was always- when I was a youngster there was always a bottle of aspirin in everybody's sort of house you know? Like what the murdering stuff now that everybody seems to have you know? Ibuprofen or whatever it is, paracetemol, that's the one, everybody seems to have them in their house, but in my day it was aspirin
HE: yeah yeah
Graham3: so if they were taking it for sore heads...they wouldn't be able to die in a heart attack (laughing).

More often than not, participants' discussion of current recommendations showed some awareness, albeit vague, of the reasoning behind the advice:

Alison2 (55yrs): no I read t' paper and you know health pages even in books (magazines), you know and I found it and even in America they've done this aspirin thing different places as of 'ere and now they're saying that more people should be taking aspirin aren't they?...()...I did read in the paper that they're now saying that it could be a factor that more people to take it would prevent er heart thing like

Such hearsay seemed to originate from the media; participants usually referred to having read some recommendations but often acknowledged that their understanding was vague:

HE: where did [your awareness of aspirin's use for heart disease] come from?
Warren2 (71yrs): well I suppose I've read articles in the papers, I'd heard it on the television, um saying that aspirin- common aspirin, as they talk about it, was found to be helpful in um treating heart conditions and I think it was to do with preventing clots and thinning of the blood and something like that
HE: yeah
Warren2: so that's how vague I am about it, but I was aware

Other participants showed greater awareness of the research:

Isaac3 (58yrs): yes I've read in the paper sort of reports and that on it, so I have read that there was research being done, they were trialing aspirin and they were getting a fairly good success rate back out of it, the implications were that it was successful.

One of the main properties of aspirin which participants talked about was its ability to thin the blood or to stop the blood clotting as demonstrated by Warren2 above. Ted4 explained his awareness of atherosclerosis and aspirin's blood thinning ability but struggled to grasp a full understanding:

> Ted4 (77yrs): well does the aspirin thin the blood, is that what happens?
> HE: er...yeah...
> Ted4: well that's my layman's impression of what the aspirin would do, preventing obviously preventing clotting which you could also get from the furring up of the arteries as well so that could be smoking. I can't see that the aspirin is- you know the furring up of the arteries is like, this is in my mind, I might have heard but I don't think the message has got through about the aspirin too much no I don't think so

One participant discussed how aspirin's use as a blood-thinner replaced the old wives' tale of whisky (or brandy)'s use for the same purpose:

> Gordon1 (67yrs): but they did discover what you're saying Helen, the heart, definitely it thins the blood, but mind we're going back in the olden days again, all the older ones, they're living longer now, but some of them did live for a long time, in fact cross there (over the road) they're all in their nineties. But they all took their tipple, you know
> HE: oh yeah?
> Wife: oh yeah
> Gordon1: whisky, rum and brandy, and that was the secret because it thinned the blood.
> HE: oh right
> Gordon1: and they're strong going to this day, now they've discovered aspirin thins the blood
> Wife: but you get maere pleasure out of the whisky!

When describing awareness of aspirin's heart related uses, a commonly discussed issue which participants themselves had engaged in was the prevention of deep vein thrombosis (DVT):

> Morag3 (64yrs): I sometimes have taken aspirin myself
> HE: oh?
> Morag3: I take it if I'm going to be flying on a long journey
> HE: yeah
> Morag3: I would buy junior aspirin or something equivalent to that and take it for that

Awareness of aspirin's use for preventing deep vein thrombosis while flying was probably due to the recent media coverage of the debate; one participant was aware that this was still an area where further research was required:

> Keith1 (59yrs): I don't know I mean, we're going on holiday shortly and what happens is the wife is on- you know you get the deep vein thrombosis, travelling in planes and that, so she said to the doctor, she was there this morning, saying "what about taking some aspirin you know before I go?", and he says, "well take it if you want an' all but the jury's still out on whether it is effective or not effective

Keith1's comment demonstrates how some people were more sceptical than simply accepting the latest recommendation publicised through the media, preferring to wait for further research findings, again seeking advice from their trusted GP.

Another use that had received media coverage several years previously that some participants spoke about was aspirin's use for a heart attack.

> Lucy (focus group 4b, 57yrs):...in fact there was period where I carried an aspirin in my handbag, there must have been something on the television or so...(laughter)... and if you know you came upon someone who'd obviously had a heart attack and you're waiting for the ambulance you were supposed to put an aspirin under their tongue right? I carried one around until it became all crumbly and disgusting (laughter). You know perhaps er should I mean is that a thing to do? I mean do you happen to know that, supposing you come upon somebody you know the chances are and they're having a heart attack

Lucy pointed out that she had seen this on television and others spoke how they 'had heard' this advice without being specific as to the source, interestingly another participant said she had been advised this on a first aid course she had attended. Participants often talked about people they knew who were on prescribed aspirin for established heart conditions such as angina or after a heart attack, for example the following dialogue took place in focus group 1b:

> HE: so about aspirin generally, were you aware of aspirin's use with heart disease and things before this?
> Nigel (64yrs): I was, my wife's got angina
> HE: oh right
> Nigel: she takes the aspirin every day, she has to
> HE: oh right uh huh

Nigel: so I knew about aspirin and heart problems, it thins the blood
Wayne (69yrs): I've got a pal had a bypass and he's now on an aspirin every day. Just keeps the blood thin
HE: how about other people?
Yvonne (72yrs): my husband he had a heart attack...um '94 that's about 8 years ago, and he takes 2 75mg dispersible aspirin every morning, so I know about that, cause he kept saying, "well you should take it", but I don't take any- I'm not taking any aspirin.

Few participants had heard of the idea of using aspirin specifically as a preventive medicine (other than preventing DVT); only a couple of participants mentioned preventive use when I asked them if they knew of people who took aspirin, and there was some awareness through the media:

Molly4 (75yrs): well I just hear of it occasionally, I don't think I know of anybody personally, but you hear of people mentioning and of course interviews and so on are on television and radio um that they're doing- that they take half an aspirin a day just a case it help you know, I think it's a good thing

Most participants, however, did not seem to distinguish between aspirin's use as a preventive medication, and its use for established heart conditions. A few explicitly stated their assumption that aspirin's benefits had been proven, and thus questioned the need for more research:

Beatrice (focus group 2, 75yrs): I thought aspirin had been a proven blood thinner and so was accepted as such, and most people, once they've had a stroke, heart attack, anything like that without complications in the digestive system are given a daily aspirin at this moment

Awareness of positive attributes and adverse side effects came from personal experience, knowledge of others' experiences and the media. For a couple of participants, the mixed messages appearing in the media led to feelings of uncertainty about aspirin:

Miriam3 (73yrs): yes, I mean I've read about it in the press or heard about it on television, and there are always people who are very much in favour and there are some who've said they didn't think it made any difference, so there's a big variation in opinions isn't there?
HE: do you have an opinion on it yourself from all that that you've read and seen?

Miriam3: no not particularly, er...I'm not just quite sure what part the aspirin plays in it

Others spoke about ignoring the media's take on the situation:

Richard1 (54yrs):...you know what the papers are like with risk, they'll no-journalists have no conception of risk
HE: yeah
Richard1: you know any tiny thing that goes wrong with something, journalists will make a big fuss about it as if the whole planet's gonna die of it tomorrow you know. Um so it's I'm sure if there'd been any of that kind of risk with aspirin, it'd long since been all over the newspapers, so there isn't [one].

To summarise, aspirin's place as a longstanding medication and awareness of current recommendations led to perceptions of its benefits for general health. Commonly discussed attributes were blood thinning and clot preventing, and there was awareness of its use as a preventive drug for DVT and as a treatment drug for heart attacks and angina; its potential use for preventing heart disease was less well known. Aspirin's longstanding status probably contributed to its widely perceived safety as discussed earlier. Generally across the sample, trust in aspirin and its benefits was widespread. As discussed, for many participants, despite knowledge of potential adverse effects, these were clearly outweighed by very positive views about aspirin. For some, such positive views seemed to override dislike of medication, which seemed to lead to aspirin being treated as a special case.

Some participants talked explicitly about their faith and trust in the drug, for example participants who were on aspirin (and had not entered or were no longer in the trial):

Jack5 (66yrs):...I've spoken to other chaps about my age and there's a few that are on it and er...I'm quite happy to be on it, I feel very confident about it, I feel it's a strange thing but I feel it's a real help the aspirin because it's had such good reports and er
HE: reports, where?
Jack5: well in the newspapers, you're reading the Daily Mail for instance and certain days they've got health sections and er there's been write-ups about it, how various tests have been done and it's proved itself over a number of years, it's not just it's only come lately sort of thing, and so I feel confident about using the aspirin I feel it's a real help and er there's no side effects of any of the tablets I take so

For two participants, their faith in aspirin was so strong that despite having a second heart attack since being on daily aspirin their faith continued, for example:

> Timothy5 (61yrs): no well ur I take it faithfully every day because I believe it does good you know, I believe it does me good you know so...it didnae stop me having another...angina pain or anything like that but

Some participants mentioned how they preferred aspirin to other drugs. Regarding painkillers, it was regarded as more trustworthy for its comparative safety (earlier Graham3 was quoted as comparing it to ibuprofen which he described as "murdering stuff") and lack of advertisement (focus group 4b). Regarding cardiovascular treatment, a couple of participants who were on prescribed warfarin expressed their keenness to switch to aspirin. Often participants who disliked medication generally had more acceptance of aspirin, for example Mandy3 who had no clear reason for this preference:

> Mandy3 (59yrs): actually of all the things like paracetemols and things like that in- I've always in the past taken aspirin for pain, recently I'm taking brufen but aspirin's always the one I would take but I do have problems
> HE: do you?
> Mandy3: yeah, I only take aspirin very occasionally, but that was always my preferred um painkiller
> HE: why's that?
> Mandy3: I never felt right- well it's probably imagination paracetemol and things I've never I don't know it just didn't seem right, whereas aspirin didn't seem to affect me in the way, make me feel that you know *there's something more right when I take an aspirin*
> *(italics: my emphasis)*

Similarly, Susan5 admitted not taking other items of her prescribed medication but she faithfully, albeit reluctantly, took her prescribed aspirin:

> Susan5 (53yrs): yeah it's gone down uh huh, since I've been on the high blood pressure tablets and the aspirin it's...one thing though mind you it was up and she gave me other tablets which I don't take...er water tablet I think they're water tablets, it wouldn't be any good showing you if you're not a medic, but anyway I just take the high blood pressure and the aspirin, I know the aspirin- I think that does do you good

For some participants, dislike of medication in general applied to their views on aspirin too. However for a large number, certain favourable attributes of aspirin contributed to a

perception of aspirin as a preferred medication that seemed to be treated as a special case. This is important when considering the use of aspirin as a preventive medicine, as it seems that for certain people starting a course of aspirin for a preventive purpose would be preferable to taking other drugs. However, lack of awareness of aspirin specifically for preventing heart disease and general reluctance to engage in preventive medication use may form a huge barrier for the promotion of aspirin in this way. Once again, this reluctance seems to relate to low perception of cardiovascular risk in particular regarding the ABPI.

Preventive medication: an alternative strategy?

Given that the preventive method being investigated in the trial was preventive medication rather than lifestyle behaviour changes such as stopping smoking, an issue of particular interest was investigating people's opinions on the idea of preventive medication as an alternative to making changes to their lifestyle. Considering the picture of aspirin which has emerged and been discussed so far in this chapter as a seemingly 'special case' for many participants, I was interested to explore people's attitudes towards the idea of taking daily aspirin and their views on an 'unhealthy' lifestyle. I was particularly interested in whether preventive aspirin might be views as an alternative to lifestyle change as a strategy for preventing heart disease. In a few interviews, the participant brought up this idea themselves, for example by discussing people who engaged in taking aspirin and continuing an unhealthy lifestyle.

> Joe2 (56yrs): my wife's mother, she took it- she had heart problems as well... er and she always took an aspirin and she had great faith in that and it kept her going for years despite her smoking and everything

Where participants did not raise this issue, I asked their opinion of preventive medication as an alternative strategy. A few participants could see the potential success of the strategy, particularly as they felt that promoting lifestyle change was not successful, for example:

> Richard1 (54yrs): I mean I think it's perfectly feasible, if something proves- if you work on the assumption that people are not gonna change their lifestyle and

people are going to- I think you have to start from that assumption because the fact of the matter is, they're not having success changing people's lifestyles yet, well not seriously, so if you say, "well if you do continue to smoke and drink and do all the things that are bad for you, then at least take this aspirin, it'll help a bit"

Similarly participants could see how such a strategy would appeal to the general public:

Isobel3 (60yrs): I think it's wonderful because I know that if a lot of people who will benefit from that, for the simple reason that they can pop an aspirin or pop a pill...they do that and still continue to have fish and chips and all the food that they take (). So that type of person, it's wonderful for. I'm quite happy to deny myself the fish and chips, the meat, um and things, and discipline myself to what I think is necessary. But years ago that would probably considered a prank! The majority of people, your 7 out of 10 people are quite happy to go along, take 4 or 5 medicinal things from the doctor, instead of an alternate lifestyle and food.

Isobel3 felt that an aspirin could be 'easy' solution for people who do not want to change their lifestyle, but regarding her own health, would not have considered it, rather preferring a holistic approach. Similarly, a couple of participants favoured a holistic approach to prevention, but suggested that preventive medication could be offered alongside promotion of lifestyle change, for example:

Owen4 (52yrs): I mean I think at the end of the day if people have any vulnerability to these things, it's entirely reasonable that we should try and give them the preventative medicine, particularly if it's going to be a preventative medicine which doesn't have any dramatic negative side effects. Er and without sounding like some kind of new age person, I mean that at the same time it's important to stress the holistic approach to things and that you know- absolutely fine to use the chemical remedy but you know you try and use the personal lifestyle approach to things as well, not that I'm trying to be holier than thou 'cause I mean my wife still does not by any means! But I think you try to balance the two things.
HE: that's one things actually that I was going to come onto...()...what do you think about aspirin as an alternative to these ways of reducing risk factors
Owen4: I think things should be as complementary rather than as alternatives
HE: yeah...so would it appeal to people who don't want to give up smoking?
Owen4: well I think that I wouldn't remotely suggest that you don't encourage folk to take aspirin if they're not prepared to look at their own lifestyle but I think you could use getting onto the aspirin as a means of trying to persuade them also to look at their own lifestyle.

Interestingly, one participant revealed how she engaged in this strategy herself:

HE: because in a way you're kind of doing this approach, "if I stop smoking I'd reduce my chances of heart problems, but then again I could take this aspirin" so do you think that it helps?
Patricia3 (61yrs): not really, no I don't really believe that, I think the main thing is to stop smoking, would be the main thing. I take the aspirin really because I can't stop smoking, I have tried it and I should try it, I will try again, and I hope that it'll- I don't take the aspirin so I can go on smoking, I take the aspirin because I smoke and I hope that it might reduce the chances you know of a heart attack. But in my own mind I probably realise that smoking does so much damage it probably won't help, but it's worth a try

However despite doing this herself, rather than regarding it a good strategy, Patricia3 felt that it was wrong, probably ineffective and that stopping smoking would be preferable. Interesting to note is the distinction she made between taking aspirin *so she could continue* smoking, and taking aspirin *because* she smoked; she emphasised that she did the latter as a way of coping with her lack of success at quitting but her ultimate aim was to quit the smoking.

Richard1 (quoted above) felt that the medical profession would consider preventive medication wrong, and that anything that allowed people to continue their unhealthy but pleasurable behaviours would not be encouraged in British culture:

Richard1:...my impression is that the medical profession do not like to advertise preventive medicine, on the grounds that if you do so, you might encourage people to think that you can just keep taking the risks and take the preventive medicine and that will reduce the risk, 'cause you don't actually see that happening on any front, they tell you not to do things, you can keep on doing it and this will help, and I think there's a great um sort of resistance and it must come from medical profession 'cause I cannae see where else it's coming from, to that kind of approach. I mean it may be a sort of cultural thing in- in the UK that the proper thing to do is to cut out doing the things that you find pleasurable, rather than to start doing something which will ameliorate the effects of doing something pleasurable. I mean I could see somebody doing a campaign like that in Italy, where people have got different attitudes. But I can't actually see it in this country, or in the States for example, 'cause it's this puritan ethic that you get which says basically, "good things are bad for you, therefore you should cut the things that you enjoy doing out to improve your health" rather than say, "keep on doing all the bad things that you do but um-um take this as well".

Several participants questioned the medical effectiveness of such a strategy:

> Peter2 (55yrs): as you say, if it is preventative, yeah I would think it'd be a good thing you know. If you were eating chips every day, or smoking many cigarettes a day, yeah I suppose it would
> HE: do you think it would?
> Peter2: er would an aspirin...counteract all the side effects of all the fat intake and things like that? If it did help it would be good, it would be great, I mean aye you could indulge your vices and then take an aspirin and feel better sort o' thing.

Joe2 also questioned the efficacy, believing that such a preventive strategy for heart disease could not be so simple (which I was not trying to imply):

> Joe2 (56yrs):...- there's no quick fix for anything, it needs to be god forbid, a lifetime thing of taking whatever but you should certainly have one eye on that if you like to just prevent things happening to you

Others felt that it would be pointless or a waste of time, and not dealing with the root of the problem, for example:

> Ursula (focus group 2, 61yrs): well it's like fighting one thing against the other, if you're taking something that's rotten for you and they say, 'well just take an aspirin anyway", OK it might help but you're really defeating the cause if you're all still doing the wrong things, but if it helps, well...

Similarly, many participants were adamant that encouraging such a strategy would be promoting the wrong message and would encourage people to continue and/or engage in an unhealthy lifestyle:

> Mandy3 (59yrs): mm... but that would be the wrong attitude I suppose...but um a bit daft cause it's no cure and if they still continue to smoke or whatever then eventually the aspirin I don't think is going to be of any use

> Daniel4 (54yrs): someone who's in drinking a lot at night, eating all greasy foods, stodgy foods, you can't say to him, "don't go and do any exercise, don't bother changing your diet, just take the aspirin", what good are you gonna do? No the all three must go along in tandem

Such strong attitudes were expressed by a large number of participants. To them, the idea of preventive medication as an alternative strategy to lifestyle change was wrong; rather they advocated changing to a healthier lifestyle and generally felt that the onus should be on promoting healthier lifestyles once again invoking individual

responsibility. Some participants found the idea completely ridiculous: the following quote (from pilot study a) sums up this attitude and adds a particular Scottish context:

> Greg: what have a deep fried mars bar and an aspirin?
> (Laughter)
> Jon: and have twenty fags at the same time

Interestingly, despite the majority of participants advocating lifestyle change rather than preventive medication to prevent disease, many who voiced this attitude actually engaged in 'unhealthy' behaviour themselves, for example Joyce4 (a smoker):

> Joyce4 (54yrs): I don't know if it would work if you didn't, I think you would have to change your lifestyle slightly if you were susceptible I would think you'd have to do the whole thing yeah I don't think taking an aspirin and carrying on the way
> HE: how about with the smoking?
> Joyce4: think I could take an aspirin and it would...no I would say no, I think you'd have to do the whole thing

As discussed in the screening chapter, Joyce4 did not perceive much risk from her smoking and thus distinguished herself from those who she referred to as susceptible. Similarly Fergus1, a smoker and trial participant himself, seemed to attribute blame to smokers and felt that the trial was to benefit those with healthy lifestyles:

> Fergus1 (72yrs): well I don't think that's proper is it, I don't think that's right you know what I mean. Er the aspirin trial I suppose it's to help people that havenae smoked and still have heart problems you know what I mean, smoking's just a side issue, I know it doesn't help your heart...but the aspirin trial is I suppose, for people that don't smoke or drink even you know

It was surprising that so many people felt that such a strategy was wrong, in particular participants who admitted to engaging in unhealthy behaviours themselves. It was also interesting to consider the few individuals who did see the benefit of such a strategy; these tended to be individuals who led particularly healthy lifestyles themselves (such as one of the initial quotes from Isobel3), but perhaps could recognise the difficulties of lifestyle change for other people.

To summarise, whilst a few participants could see the benefits of a drug that could be taken to help prevent cardiovascular disease, thus requiring less emphasis on a healthy

lifestyle, the majority of participants rejected the idea of promoting preventive medication without making changes to lifestyle. The majority opinion was that once diagnosed with a risk, one should change one's whole lifestyle; this often seemed to be based on disapproval of encouraging unhealthy lifestyle or due to the belief that without lifestyle change, the drug would have little effect. Generally, a large emphasis on individual responsibility was again apparent when discussing this issue. This view was also prevalent amongst those who led unhealthy lifestyles themselves.

Summary and conclusions: Attitudes towards prevention and preventive medication

It is useful to consider the findings in this chapter and their implications for a prevention programme (as being trialed) involving aspirin for heart disease. On the surface, a positive attitude towards prevention was common as illustrated by widespread use of phrases such as "prevention is better than cure". However, participants' accounts revealed lifestyles that seemed to contradict this attitude; further analytical exploration revealed reasons and explanations behind this apparent contradiction including preference for avoiding medication, and only medicating when 'necessary', usually meaning once symptomatic or on a doctor's diagnosis and advice.

It is interesting to consider why the phrase "prevention is better than cure" is so prevalent in participants' accounts, despite not being matched completely by their own health related lifestyles. Participants may truly believe it as an ideal or they may not, they may be reciting it like a mantra as an initial response to questions about preventive health. Such a question is difficult to answer from people's accounts alone but regardless it is interesting to reflect on use of the phrase; as a well-known and used phrase, it seems to have become an 'old wives' tale' itself. However, whilst in the past it may be have been used to refer to lay beliefs about avoidance of illness, for example by wrapping oneself up in warm clothes in the winter to avoid catching a chill, in current society with health promotion emphasising preventive health and personal responsibility, together with the existence and promotion of preventive medication, the phrase has become

particularly pertinent. While people may ideally believe that prevention is better than cure, when it comes to behaviours such as taking daily aspirin for the rest of one's life to prevent heart disease, engaging in this behaviour is not straightforward as there are many factors (as illustrated in this chapter) which will have an influence on such a decision, both consciously and unconsciously.

From participants' attitudes towards aspirin, a picture emerged of the drug being considered a 'special case' due to properties such as its place as a longstanding medication and awareness of its benefits, which contributed to trust, faith and a low perceived risk. Thus, promoting aspirin as a preventive medication would probably have more success than other, less familiar, drugs. However, lack of awareness of its specific use as a preventive drug for heart disease and a general unwillingness to engage in preventive medication use when asymptomatic may well be a major barrier. The idea of preventive medication as an alternative to improving one's lifestyle was regarded as a useful approach by a few participants who could see the possible appeal to 'other people'. But the majority, including those with unhealthy lifestyles themselves, felt that such an approach was wrong and that once diagnosed a person should engage in a more holistic approach.

Finally, participants' attitudes towards aspirin as preventive medication for heart disease could be summed up as 'prevention is better than cure, *but*...' Despite apparent positive attitudes towards prevention as typified by common use of the phrase 'prevention is better than cure', invocation of individual responsibility and a favoured opinion of aspirin, the low perceived risk from atherosclerosis whilst asymptomatic and lack of perceived risk from the ABPI measure demonstrate the difficulty there may be in promoting this preventive method.

However, rather than paint a completely negative picture for such a possible prevention programme, the chapter has revealed areas of interest for those promoting such programmes. As explained, participants' accounts of prevention and preventive

medication and explanations behind their views, revealed varying personal and contextual influences on their views. Certain factors such as the GP's role in participants' views about the necessity of medication (and in the perceived risk of the condition), and the favourable view of aspirin help to tailor promotion of prevention programmes. Nonetheless, the widespread assumption of aspirin's safety should be considered and patients should be fully informed of the risks alongside the benefits. Awareness of asymptomatic atherosclerosis and the ABPI measure, whilst difficult, is an important challenge for public health and health promotion.

Chapter 6:

Gullible guinea pigs or good gift-givers?:

Attitudes towards participation in the randomised control trial

Introduction

This part of the thesis presents and explores participants' attitudes towards participating in the AAA research trial. The first section outlines and discusses the altruistic attitudes and self dominant views which emerged in participants' discussions about the trial and their decision about participating. The second section explores participants' views on the potential benefits and risks from participating in the trial. This includes attitudes towards aspects of the randomised control trial procedure, in particular the placebo and blinding, reactions to trial experiences such as side effects, views on the trial tablet, and their beliefs about incentives and barriers. Finally participants (mis)understandings of the trial are discussed.

Part 1:

For oneself or for others?: Altruism and self benefit

In the first interview carried out in the present research, Michelle5 (ineligible for trial due to prior heart attacks), spoke about her keenness to participate in research, giving the example of volunteering for a different trial whilst waiting for a heart operation. Her reasoning, *"well if I can help them in any way, 'cause I've had a lot of help from the hospitals*", was the first example of altruism that emerged in the research. In many of the interviews that followed, altruism was expressed in people's accounts of their decision-making making it a salient issue for analysis. Sometimes it was presented in terms of reciprocity like Michelle5, but there were various other explanations all of which will be discussed in the present chapter. Conversely, self-benefit in individuals' reasoning was equally salient in accounts. However, the altruism and self dominance which emerged was not a dichotomous categorisation, rather it appeared that the two fell at ends of a spectrum of varying dimensions. Furthermore, seemingly opposing dimensions along the spectrum could be salient to the same individual, sometimes at different points of time due to situational context, but also within the same decision making process.

This section will work through different 'dimensions' of the altruism-self benefit spectrum which were expressed in the accounts. Apparent influences behind these beliefs will be discussed. Social psychology attempts to explain the pathways and the motivating factors leading to pro-social behaviour, including altruism. In the present research it is dangerous to attribute motivations to people's decisions as often this was not elaborated on in such detail; second it is also possible that situational factors within the individual interview and focus group environment were influential on how participants expressed their beliefs; and third, interviews and focus groups produce *accounts* of motivations and opinions only, not what actually happens in a participant's mind. So possible influencing factors will be discussed whilst acknowledging this.

Altruism

There was evidence of altruism in many participants' accounts, sometimes this was explicitly discussed and in other cases it was more subtle in their discourse. A few participants mentioned their altruistic feelings almost immediately in response to the initial interview question about their thoughts on receiving the first screening invitation, however with others the altruism emerged later in the interview as they talked in more depth. Furthermore, the altruism talked about was not uniform across all individuals, rather the explanations given and context in which it was discussed could be broken down in the following ways:

Firstly, some participants spoke about 'general' altruistic feelings such as the hope that their participation would help contribute to research and thus other people in general, as summed up in the following quote:

> Hamish1 (70yrs): basically if it was anything that was gonnae help people in general, you know…I was quite happy to get involved sort of thing

Other participants were slightly more specific about wanting to help 'ill people', and many spoke about helping people in the future or helping advances in medical science. A few people mentioned how benefit to the future generations was more important than to themselves:

> Patricia3 (61yrs): I'm quite happy to take part in any research that will improve things and maybe help in the future, even if it doesn't help people at the moment...()...things that you might gain or learn from this group, you might be able to apply to people in the future, I'm quite happy if that's the case.

Only one participant explicitly used the term altruism:

> Moira1 (53yrs): well to be quite honest, altruism, I mean you know, somebody saying this could be really helpful. I appreciate that members of my family have died in the past, albeit not at a young age, of heart disease, so why not? It's not taking up much of my time

A second form of altruistic expression that emerged seemed to have more of a moral tone to it; the most common example of this was describing participating as a "good thing" to do and "worthwhile":

> Craig4 (54yrs): Um and on a wider perspective, yes um I think these things are for the greater good really, you have to find out what's- what works and what doesn't work, yeah, yeah.

> Miriam3 (73yrs): well I thought someone wanted help looking into er...heart problems and I wasn't particularly tied as far as time and whatnot, so I would go along and if it was any help, it would be time well spent

> Janice (focus group 4a, 70yrs): but as I say my main motivation was to volunteer and be useful

The term 'good' was used by many participants regarding trial participation. In addition to doing a 'good' thing, the feeling that one has done good and been a good person may have other effects such as receiving positive evaluation and/or avoiding social rejection by oneself and others. Evaluation by oneself could involve the idea of one's conscience. Conscience was something which Molly4 (75yrs) brought up when I probed about her mention of altruistic motivation:

> HE: I think right at the beginning you mentioned benefits for the wider society as well
> Molly4: mm
> HE: do you think that's quite important?
> Molly4: oh yes, you couldn't have a conscience and never think that

Batson (1991) used the idea of personal and social evaluation in his proposed pathways leading to pro-social behaviour - that we experience feelings of self-reward for our responsible behaviour. It is possible that a participant's emphasis on

participation being a 'good' thing to do could be altruistic or could signify more self-dominated motivation. Also the research setting may have influenced the expression of altruistic attitudes, as it is possible that participants may have wanted such positive evaluation from myself in the interviewer setting or from other participants in the focus group setting. However, the expression of self-dominant attitudes was equally abundant. Regarding one's conscience, a different pathway proposes that pro-social behaviour can alleviate guilt (Batson, 1991).

> Imogen1 (61yrs): ...I almost feel as though if I do this, it's helping somebody somewhere

Another kind of altruism apparent in several accounts was the naming of specific 'others' as the imagined recipients of the benefits from the research; these were children or more often grandchildren. For example in focus group 4a:

> HE: what are the advantages in taking part in such a trial?
> Colette (52yrs): It helps further advance medical science, there must be something
> Janice (70yrs): that's what my reasoning behind it, that there is money to do these things and you've got to have people to take part in them
> Wilf (65yrs): well I would say the same reason, I mean after all, if we've got families, it's for everyone's benefit
> HE: do you see any benefits for yourself as well?
> Janice: I was more thinking of my son, I suppose it could be... but I was more...
> Colette:...no I think when you get to this age, if you're [ill], you're [ill] anyway
> Janice: I was thinking very much of my son, there's more a history on his father's side as well as my side

Badcock's (1996) kin altruism proposed that if people can identify with the recipient of their prosocial behaviour, through familiarity or similarity, they are more likely to act prosocially. Dawkins' (1989) selfish gene theory suggests that it is the survival of the gene which is most important; similarity with the imagined recipient indicates that they share similar genes thus improved health in the recipient means survival of the giver's gene. However, attributing such motivating factors behind people's altruistic participation according to psychological and sociobiological theory here is suggestive.

When participants mentioned their offspring, in addition to wanting to help research that would lead to advances in medicine from which their offspring could benefit, they also seemed to imply a notion of responsibility. For example, the following participant, aware of his family history of heart disease, worried about the impact of the family history on his children:

> Jed (focus group 4b, 57yrs): that's probably true I mean I'm not a very frequent visitor of the doctor but I think like with my wife having heart disease in my family, both my parents died () of heart attacks...massive heart attacks, so if you can learn and help in the research about the illness () which you can pass onto your children

Naming specific others who may benefit keeps the issue personal to the individual; often people described how heart disease was already a particularly salient issue to them due to personal experience.

Personal context

The experience of a close 'other' having a heart attack or heart disease tended to increase the salience of the disease to the individual and was often mentioned as a reason for participation and/or screening attendance. Such 'others' were usually the individual's spouse, other family members and sometimes their peers. This salience initiated action for two predominant reasons: altruism or personal benefit, or a combination of the two. Regarding altruism, witnessing someone else suffering sometimes led to wanting to help prevent others enduring a similar suffering. On the personal side, the experience seemed to motivate behaviour aimed at preventing suffering in oneself. Joe2 summed this up nicely when asked about his initial thoughts on the screening invitation:

> Joe2 (56yrs): I didn't have a problem with it, my father died of a heart attack very suddenly and so anything at all that was a) gonna help me and b) could help somebody else, then I was quite happy to go with that. Er my mother, she was taking tablets for high blood pressure and I also take tablets for high blood pressure, so yes heart disease is something you think about.

The following extract from Focus Group 2 shows how personal context of different types influenced the decisions of this group of women:

> HE:...so it's about a year and a half ago since your screenings so I just wanted you to think back to when you first got that invitation to screening, and what your initial thoughts were on attending and getting that letter

Deirdre (68yrs): well my husband died of a stroke, and I thought if it was going to help anyone else, that's why I attended
Cath (63yrs): and I was just interested in it because um I had high blood pressure and I thought, it'd be good to get a check out for my health you know perhaps it's better than perhaps just going the doctor or something so that's another reason why I thought it was a good thing
Ella (70yrs): my husband had had two bypasses and erm apart from that, I was quite happy to do anything that might help research as well as perhaps help myself, but I didn't know whether it would help because I didn't know what I was taking
Emma (70yrs): well my mother's family all had strokes, so I actually felt it was good for me, and I'd never been to the doctors for anything like that for cholesterol or anything so, I was quite happy to
Ursula (61yrs): My husband takes aspirin as well, cause he had angina…a lot better now but he was put on aspirin as well as beta-blockers and other things you know, so I felt that I wanted to do my bit!

These 5 women all spoke about personal context but this motivated them in slightly different ways: For three (Deirdre, Ella and Ursula) the personal context was the experience of their husband: Deirdre spoke of altruistic reasoning; Ella gave both altruistic and self beneficial reasons and Ursula's reasoning is unclear although comments later in the discussion imply a fairly altruistic attitude. Where the personal context was a family history, Emma and Cath (who explained her family history later in the focus group) spoke of the benefits to themselves. Perhaps there is a greater underlying perception of personal risk when there is family history of heart disease rather than witnessing the disease in one's spouse.

A few participants were unfortunate to have witnessed heart problems in both their biological family and their spouse, for example:

Nancy4 (69yrs): well, my sister, my parents, my husband and everything so obviously I'm conscious of it my blood pressure
HE: so you've got a history of high blood pressure or heart problems in the family then?
Nancy4: well my mother had a very bad stroke at the age of 60, survived for twenty years after that, but had a very bad stroke at 60 and minor strokes after that. Er my father had a heart attack followed by a stroke, and then followed by a stroke,…well I mean he was, he was into his mid 70s by then I think
HE: did this make you
Nancy4: So I'm conscious of it, there's a hereditary factor somewhere there yes

The cumulative experiences had made Nancy4 equally keen to check her own health and participate for the benefit of others. In focus group 4a Janice (70yrs) had a similar history, she repeatedly stated how her willingness to help the British Heart Foundation arose predominantly from her husband's death:

> Janice: well I contribute to the British Heart Foundation and I thought "well what's the point of giving money if they can't get people to take part in the things", so I decided that I would take part because I've heard they do trials etc, it's the first time I've been asked to take part in one
> HE: is there any reason you contribute to the British Heart Foundation?
> Janice: yes, my husband dropped dead

A different family experience concerned participants' siblings; Maureen4's altruistic feelings arose from the recent death of her sister, when I asked how she saw herself with regard to heart disease, altruistic feelings emerged:

> Maureen4 (53yrs): I think um...I'm OK you know, I kind of don't think about it um because I was diagnosed with breast cancer four years ago so that's kind of more relevant than sort of heart disease, but in saying that eight weeks ago my sister died of a heart attack, she's just- she'd been with me on the Monday and she was perfectly fit and fine and healthy and on the Tuesday she was getting ready to go to a keep fit class and collapsed and died.
> HE: gosh
> Maureen4: and she had the blood pressure like I did, you know she had kind of like um high blood pressure but when she was put on medication she was fine, she'd no symptoms of heart disease whatsoever and yet her post mortem said she had ischaemic heart disease, so that's kind of worrying.
> HE: so did she think her blood pressure was under control?
> Maureen4: uh huh yeah
> HE: and how old was she?
> Maureen4: 69 but she was a very very fit 69, yeah, and she went to keep fit and she went to bowling and you know she was really sensible about her diet
> HE: that was quite a shock for you then
> Maureen4: pretty sad
> HE: did that sort of change how you felt about your own health
> Maureen4: probably not, I don't really you know give it much thought you know but I think it made me more aware that well I should come here today and sort of help in whatever way I can you know

Initially, there appeared to be a pattern whereby family history of heart disease seemed to lead to interest in the trial for checking one's own health, and heart events in a spouse seemed to lead to more altruistic motivations, but the picture was not so straightforward. Altogether it is evident in the accounts of people I interviewed that

increased salience of heart disease from witnessing it in significant others served as trigger to participate in the trial, regardless of who the imagined beneficiaries were.

As demonstrated in the screening chapter, experiencing heart disease in significant others led some participants to assess their own risk compared to that 'other', and in some cases to take action in the form of showing interest in the trial, either for a personal health check, for helping towards research aimed at preventing the disease in other people, or both. However personal context also led to no action in a few cases, as comparative analysis of their own risk with that of family members or peers could result in distinctions between themselves and others regarding lifestyle, available medical treatment, genetics and so on. For example, Geoff3 (68yrs) described cardiovascular episodes in his peers but comparative risk perception increased his optimism.

Reciprocity

One of the most strongly expressed altruism resulting from personal context was in Imogen1's account; she explicitly described how witnessing much heart disease in close family members led to her participation:

> Imogen1 (61yrs): yes I mean well my mother died at 53 with a coronary, and my brother was 60, my father had about three or four heart attacks, but he lived till he was 83 so it was a stroke that killed him () and then of course my husband had major heart surgeries so he had his first heart attack at 46, so anything that- if it would help- anything that I can give to them, to stop anybody else- I mean you think of your grandchildren…

In addition to wanting to help prevent the disease in future generations, she expressed immense gratitude for the life-saving heart surgery and care her husband received

> Imogen1: he was about 46 when he had his first heart attack, and then he was 50-there again () when he had open heart surgery at the hospital, but at first they thought he would have to have a heart transplant, cause it was so bad but they kept him in for about two months to build him up, to prepare him for the surgery and when they sort of done whatever tests they'd done, () And in an ideal situation, for him not to have any more medication, but sadly six weeks later, when he went back for the check ups, they had to take him back in, and put him back on these drugs. But, it kept him alive
> HE: and how is he now?

Imogen1: well he's slowly getting...he's not as good as he would like to be. I mean we're talking 16 years
HE: yeah
Imogen1: I mean that's marvellous, I mean they've kept him alive, they've given him life for 16 years and that's marvellous. And there's always something new

Thus her own participation was due to strong reciprocal altruism.

Imogen1:...and to me this is something, you know if you can learn from other people, it goes back to your grandchildren, it can help them perhaps
HE: so was that your main reason for taking part in the trial for future for other people?
Imogen1: yes it's for future of other people, and um...this might sound silly but it's a thank you for all that they've done for my family
HE: yeah yeah
Imogen1: you know for my husband. As I say I mean it's because the research that probably went into that they've done this for my husband which they probably wouldn't have known about if somebody else not come up about it. You know if it hadn't these- sort of when people went on to these trials for these new drugs which he's gone onto. I mean he wouldn't be here today. I don't think so anyway, if he hadn't have had the surgery"

Later in the interview she talked about the cost involved with heart operations which reinforced her desire to 'pay back' something to the NHS; her husband's post operation lifestyle behaviour changes are another way of demonstrating appreciation. Other participants expressed similar gratitude, however resulting from care received personally, for example:

HE: do you see any advantages of going into the trial?
Mandy3 (59yrs): er...I can't really except they might pick up something quicker but I think basically because it came at the time that it did, but also I was up- you know I have had- been in hospital a few times and I felt well this is a very small way maybe putting something back into the health service you know but it's nothing much but I thought "well yeah I could possibly do this"

There may have been some guilt involved with Mandy3, as elsewhere in the interview she spoke about being a "bad diabetic" in the past and not adhering to her medication so perhaps she felt guilty for having received treatment that she could have avoided.

A further reciprocity expressed by some a couple of participants was directed towards their respective GPs, for example:

HE:...so I just want to start by thinking about when you first received the invite to screening, what did you think when you got it?
Maureen4 (53yrs): I was a bit surprised but I thought well, I assumed that it was my GP that had put my name forward and I thought because he's been so good to me then I would just come along

The cases above show that where personal context of heart disease has involved a great deal of medical care and attention, feelings of reciprocity can provoke action in such as trial participation. Titmuss (1970) found that reciprocity for blood received personally or by known others was the reason given by approximately a tenth of donors in his research. In addition to focussing on care already received, this also incorporated contemplation of future care needed, so the altruism presented earlier in the chapter such as wanting to help people in the future and one's grandchildren could also fit under the umbrella of reciprocity.

Mutual benefits

There was evidence of further reciprocal systems; many participants spoke of how they believed or hoped that their participation would benefit both them self and others.

Molly4 (75yrs): I was just quite interested to take part in anything that might help, me *and* others

Fergus1 (72yrs): I mean every little helps, () if this aspirin trial comes- throws up something to help people in the future, myself included, I'm doing well you know.

Fergus1's idea was that both parties (self and others) would benefit in the same way, through improvements in cardiovascular medicine. Others distinguished between the types of benefit to each party: their personal benefits were the screening and health check up, and other people would benefit from the research results. For example:

Hilary2 (77yrs): well I thought it was a good idea to get everything (laughs) you know, know what's wrong and what-have-you, if there is anything wrong
HE: and what were your expectations about-what did you think they might find or not find or-
Hilary2: not really, I just thought I was trying these things just for research

A further way of thinking about benefits to self and others expressed by Monica1 (66yrs) and Martha2 (65yrs) was the belief that in the worst case scenario at least one party will benefit:

HE: how did that make you feel (ABPI result)?
Martha2: different (pressures) uh huh, you've just got to accept it and you know, and as I thought well I'll go ahead with the trial and if it doesn't help me, it helps someone in the future

Moira1 (53yrs) pointed out that it was unlikely that she would have thought of taking aspirin herself, so by participating her health would either stay the same as before (if on placebo) or possibly benefit (if on aspirin)

Moira1:...as far as I'm concerned, I wouldn't be taking an aspirin a day anyway so what's the harm? If I am taking one, so be it, but if I'm not, it's not as if I would have anyway.

A different reciprocal system expressed by some was a system of give and take where action preceded benefit, as opposed to reciprocal action for benefit (care) already received:

Julie (focus group 1a, 56yrs): but that's the reason we went on it as well, we could be on placebo or an aspirin, it was research, we hope that we're being helped at the same time

Sometimes, underlying this, there seemed to be an attitude that in today's society, no benefit comes without cost:

Lorraine (52yrs): well it was on the basis that somebody's got to do it you know?
HE: yeah
Lorraine: and I think I'd be er happy to take advantage of any results or you know, you've got to give something to get something
HE: uh huh
Lorraine: it doesn't seem like much of a hardship (focus group1b)

Isaac3 similarly described the trial as a "two way thing" and drew an analogy with trials of new equipment in his workplace:

Isaac3 (58yrs): I've always been keen to help, even in my job, an outside body and that, if somebody said well we want to trial this particular object in your place of work () if you don't give people opportunities to research stuff and that, then you're never gonna advance. () also you're gonna benefit as well because there's advantages to the company () if it improved your production methods great. And this, well if it improves your health then great yeah.

A further reciprocal system that emerged in a few participants' accounts was less altruistic, but rather a form of loaded reciprocity whereby the pro-social behaviour was talked in terms of bargaining power to attain a reward of some sort. For

example, a member of focus group 1a felt she deserved some reward for her altruistic behaviour:

> Alice (65yrs): I hate to think that I've done all this goody-goody bit...stopped smoking...took a year to stop, but I've stopped smoking, and I've changed all the food ideas to the ways it suggests in the book...and if I'm not on the aspirin, I'm on the placebo...I would be...(acts angry)

Similarly a focus group 1b member talked about the reward he wanted for his participation:

> Henry (67yrs):...I think if we're good enough to do this for them, they should make sure that we get feedback

Reciprocity, mutual benefits to self and others, and more 'loaded' reciprocity could all be regarded as exchange systems. Similarly to Titmuss's (1970) exploration of altruism applied to blood donation, there was no obligation to participate in the trial, and voluntariness and altruism seemed to drive the behaviour of some participants according to their accounts. But, as discussed in this last section, other participants regarded their participation in reciprocal terms and some had reciprocal expectations, which echoes Tutton's (2002) findings regarding blood donation for genetic research.

Altogether, this section has demonstrated different types of altruistic attitude that were expressed by trial participants regarding participating in the AAA trial. Participants' explanations behind these attitudes ranged from the non-specific to particular experiences that had provoked such feelings. Social psychology is interested in exploring the motivations behind apparent altruistic behaviour, and the behaviour could be examined in terms of an exchange system in social anthropology. Regardless of their 'true' motivations, participants' accounts and interpretations of the reasons for their own behaviour are useful and important to listen to and examine. Many participants displayed more self-dominant attitudes, and the subsequent section will explore how the benefits and risks to self were dominant aspects for many when contemplating participation. However, the emergence of altruistic expressions revealed useful and interesting findings regarding participants' explanations and reasons for participating, for example the importance of personal context and/or experience in contributing to their altruistic accounts.

Part 2:

Personal benefits and potential risks

Whilst the last section has demonstrated how altruism and reciprocal exchange emerged as particularly salient in many participants discussions of their views about participating, when contemplating the effects on oneself (both benefits and potential adverse effects) aspects of the trial procedure were central to these discussions. This section explores aspects of the trial and whether they were regarded as benefits or disbenefits of participation.

The RCT

The placebo

Individuals discussed pros and cons of the trial, which could have been weighed up against each other, although not necessarily in a conscious manner, in a decision about participating. Much of the discussion of cons centred on dislike of the RCT procedure and its requirements. The predominant reason arose from the ubiquitous assumption of aspirin's efficacy applied to cardiovascular health that ran through most participants' accounts; many participants thus voiced a clear preference for the aspirin over the placebo rather than the actual 50% chance in the trial.

> Julie (focus group 1a, 56yrs): if you thought you were on a dummy tablet and there is a chance that you can avoid a heart attack by taking an aspirin a day, you would want to go onto an aspirin a day

Some explained further reasoning behind this assumption: Richard1 (54yrs), knowledgeable about conducting RCTs due to his occupation and experience, felt that the trial would not be being conducted unless there was strong evidence for aspirin's benefits.

> HE: what are your feelings about the fact that you're taking this tablet and you don't know whether it's aspirin or the placebo?
> Richard1: well I suppose I would have liked to have known that it was the aspirin rather than the placebo because obviously I do know that the reason they're doing this trial is basically because there are recognised health effects of taking aspirin, um I know the purpose of this trial is not so much erm to add further proof to the original sort of evidence () yeah, I think it's partly that but I think it's also what they're trying to prove in this trial more than anything else is that the aspirin might help prevent heart disease ever materialise in the first place

HE: yeah
Richard1: and I think from what I've read, there's some evidence to suggest that that in fact is the case and they wouldn't be doing the trial on this scale if they didn't think that was the case
HE: yeah
Richard1: I mean really the purpose of the trial is to get absolute definite proof
HE: uh huh yeah
Richard1: that's why you need such a big trial, so from that point of view, it's obviously nicer to think, "well I'm taking the aspirin", and therefore I'm actually involved in active prevention

So Richard1's belief emanates from his informed perspective that unless there was good evidence for aspirin's efficacy in prevention, the trial would not be in process. Unlike other participants, he also noted the distinction between aspirin's use post heart condition from its potential preventive use being tested.

As discussed in the prevention chapter there seemed to be great faith in aspirin amongst some participants; this faith was the explanation given for a few participants' actual or hypothetical declining:

HE:...so what do you think about that at all, about the trial?
Jack5 (66yrs): well I don't know if that would be such a good idea, in a sense I feel confident about the aspirin and I don't think I'd like the idea of me personally if I took a dummy pill
HE: yeah?
Jack5: er, I'd feel uneasy about that, that's with me personally, I feel uneasy about that because er to be quite honest with you I've a great confidence in the aspirin because it's had such a good write up over a number of years and it's been proved through tests and various things that I don't think I'd be too keen on that idea...as I say purely because if I ended up with the dummy pill, I'd just, you know...
HE: you'd?
Jack5: I know it's mind over matter, but the same token I () no I wouldn't be getting the benefit as I feel confident just now with the aspirin, quite happy with it you know

Although emphasising his faith in aspirin (he is on GP-prescribed aspirin), Jack5 also implied that in a trial situation one's mind is more influential than the drug, which could perhaps make the placebo work, but personally his faith in aspirin would inhibit him from taking a chance at not being on aspirin. Similarly, many group 4 members (ineligible for the trial) admitted that given the choice to enter the trial, they would have acted on their preference for actual aspirin and declined to participate:

> Maureen4 (53yrs): Yeah I'm not really- I'm not a great um- I'm not in favour of placebos, I think if people are going to do a research trial then I know you have to have half and half, but I think it's unfair and I think it's unfair to the people who perhaps might benefit from being on the actual drug and yet they're just taking sugary- you know sugary tablets. So no if I'd...if I'd gone on your trial, if my results had been that I'd had to go on your trial I'd have gone out and bought aspirin and chucked your placebo in the bin (laughter). You know if you're asking for honesty then that's what I'd have done.

And many of these participants seemed to feel that such a preference would be a shared view:

> Dennis4 (75yrs): I think if they're- I think there would be quite a lot would be 'cause once they know that they've got er the lower blood pressure in their legs, they'd be worried about it

Others shared the preference, but said that a *preference* was the extent of their feeling:

> Owen4 (52yrs): But yes like everybody else, if I was going into the trial, I would rather be one of the folk who got the real medication rather than phoney stuff you know, but I still think it's- I would be prepared to take that risk I think.

Of those who were eligible for the trial, this assumption about and preference for actual aspirin was acted upon in various ways: Firstly, as mentioned in the prevention chapter, Geoff3 declined to participate in the trial and consulted his own GP for prescribed aspirin. The following quote shows more details of his views after being invited to participate in the trial:

> Geoff3 (68yrs): I tried to analyse what it was and analyse what you were offering under the aspirin trial
> HE: uh huh
> Geoff3: and when I found out you knew I was at risk, but you were prepared to put me on a dummy pill
> HE: uh huh
> Geoff3: I said get lost, and rather than on aspirin, they can't tell you what you were on. So I walked out of the trial at that stage and I went to my own doctor
> HE: and did you-?
> Geoff3: I spoke to him and told him what was happening, and he said, "do you want to go on aspirin?" and I said, "well it sounds like I might have to". I'd sooner be on it rather nothing, so I have the 75mg aspirin
> HE: right so you went and got it
> Geoff3: yeah, I wasn't gonna walk away and do nothing and find out I was liable for a stroke or er heart attack or something
> HE: and the main reason was that this trial- you didn't wanna be on the dummy pill?

> Geoff3: uh huh, that was the only reason, I wasn't gonna take a 50:50 chance of not being on the aspirin, and find out you know 6 months down or 6 years down the road I got hit, that's not on ()...er but you know I didn't expect to be in the trial, I wasn't expecting it...and when they said, "you did" I said, "no, I'm not gonna be a guinea pig, if I need something, I want it."

Also, as suggested by Maureen4 above, he explained that if he had entered the trial he would have self-prescribed aspirin instead of taking the trial tablet:

> Geoff3: ...'cause they hit the roof when they said come on the trial and I said "yes but I'll be taking aspirin as well" (laughs). You know I was quite prepared to get a 300mg aspirin and cut it in four and have a quarter a day.

Also mentioned in the prevention chapter was the case of Patricia3 (61yrs) who, like Geoff3, held a strong preference for aspirin and thus declined the trial, but rather than consult her GP she self prescribed aspirin:

> HE: yeah, yeah, uh huh...so when the nurse asked you, your main reason was because you didn't want to take the placebo
> Patricia3: yeah
> HE: so what did you do after that, did you decide to go on aspirin yourself?
> Patricia3: yeah I take my aspirin, I take a soluble aspirin most days
> HE: and did you go to the doctor?
> Patricia3: no
> HE: no, oh right
> Patricia3: no I actually- I got them in- I buy them in Superdrug, and I just take one you know dissolved in water, most days, you know maybe 5 times a week

These two participants demonstrated how their strong attitudes and preference for aspirin had led them to decline the trial in favour of guaranteed aspirin. Although a minority in the present study, as noted earlier this attitude was shared albeit hypothetically by some of Group4. However for Geoff3 and Patricia3, a further contributing factor towards their decision was perceived risk from the ABPI result. In contrast, a couple of individuals who declined to participate, due to apparent dislike of the chance of receiving the placebo, did not self prescribe or consult their GP for aspirin but took no action. This seemed to be linked with lower risk perception from the ABPI:

> Morag3 (64yrs): the reason I declined to take part was simply that when I learned that I might be taking a placebo for five years, I felt that I didn't want to participate
> HE: uh huh, OK...so you really didn't want that, you felt- what were your sort of main reasons for not wanting

Morag3: I felt it was a waste of time
HE: yeah
Morag3: it was something that I was going to have to remember to do, and remember to check up upon and I wouldn't know whether I was taking aspirin or whether I was taking a placebo and I just decided for that reason not to go for it
HE: yeah uh huh, so if it had been say you'd definitely have got the aspirin, would you have
Morag3: I think I would have tried it yes

Morag3's low risk perception from the ABPI was discussed in the screening chapter; she also had a strong dislike of medication so it is not surprising that she declined. It is interesting therefore that her reason given for declining was dislike of the chance of receiving the placebo, and that if guaranteed aspirin she claimed she would have participated.

Interestingly, such assumptions about aspirin's efficacy and dislike of the possibility of receiving the placebo were also expressed by many adherent trial participants. For example, trial participants in focus group 1a highlighted their perceived unfairness of the RCT procedure:

Bob (70yrs): going back to the original concept of this trial, I'm using the word 'trial', you go in and you do the screening and they find that there's some difference in one leg and they say to you, "would you like to go in this trial? you'll be given a tablet which you take every day for so many years". Now they tell you, you don't know whether it's an aspirin tablet or whether it's a placebo, so for five years, you've got furring up of the arteries and you're taking a placebo, what other remedies are there to catch you if your situation deteriorates? It seems a bit strange you see, if you're gonna get the placebo and I'm gonna get the tablet,
HE: that's one of the reasons for today is to find out what you think about that
Julie (56yrs): yes that's the one thing that I disagree with, I think if you are made aware that you are at risk, and you're put on an aspirin or a placebo, you really want to know what you are on because you would probably want to go on the aspirin if you thought you were on the placebo
Bob: sorry I think the converse of that is that if you know you're on the placebo, you won't take your tablets, you know if it's just a wee sugary pill

This raises questions about these participants' reasons for participating, if they disagreed with the process of the RCT. Perhaps their involvement with this part of the study was the first time they had voiced their opinions about the trial process, and

in particular in the focus group situations, the first time they had discussed it with other participants.

Some participants' preference for aspirin led them to question the need for the trial, as they assumed aspirin was already 'proven' in its treatment of heart disease. For example in focus group 1b:

> Maive (67yrs): what is it they think that aspirin does? Thin the blood?
> Lorraine (52yrs): I think that's the only thing that's slightly surprised me about this trial, was that I thought that was pretty well accepted

Similarly a few participants with this belief thus felt the RCT method was unfair, for example:

> Maureen4 (53yrs):...I also think that you know, if you're gonna do something, why don't you just do it, you know I mean, we know statistically what the rate of heart disease is in this country and therefore if you're trying to reduce it or eliminate it which you never will, but if you're trying to reduce it then why not give everybody a fighting chance, you know if you really believe that aspirin works then why not let everybody have it? I mean it's one of the cheapest drugs on the market isn't it? And if it reduces the cost of people being in coronary care units, for whatever length of time, you know then it would sort of like be economically sound in the end, but I don't know. I mean I know you have to do trials, but I mean aspirin has been going on for years now hasn't it? It's not a new thing.

Robinson et al. (2003) found that people were reluctant to accept either the idea of equipoise (the basis for RCTs, that clinicians can be completely unsure which of two treatments is best), or randomisation for determining treatment choice in trials. In the present research, participants' own beliefs about the drug in question (their assumptions about aspirin's efficacy) probably contributed to similar thinking, i.e. reluctance to accept that equipoise exists regarding aspirin as a preventive medicine and not acknowledging that this was a different use for aspirin, in turn contributing to their questioning of the need for the trial.

Blinding

A further aspect of the trial that caused some discontent was the blinding involved. The AAA trial follows double blind procedure, i.e. neither the participants nor the research team know any participant's tablet identity. Some participants would have preferred to know what medication they were taking; one participant described the

blinding as "scary". Other participants were less bothered but described being intrigued about their tablet identity, and some took this further by attempting to guess their medication. Julie (focus group 1a, 56yrs) misunderstood the double blinding element, and assumed the research team were aware of the tablet identity so tried to trick the nurse into revealing the medication identity:

> Julie:...and I have also enquired if you go on holiday now you don't know if you're on aspirin or not, but this DVT, you would want to take an aspirin before you went, so I asked the nurse, "do you take an aspirin?", () you know trying to catch her out, am I on it or not?...

Later in the focus group she mentioned other attempts to guess:

> Julie: I've even tried chewing it as well and to me it tastes like aspirin
> David: you could go and find a friendly scientist and he'll test it for you
> Julie: it's just curiosity I think, being curious

However, as Julie's curiosity had not deterred her participation. Other participants, initially intrigued, seemed to lose interest as trial duration progressed:

> Keith1 (59yrs): ...first it worried me but I thought, "well am I taking something that I could be just as well not be taking?" you know? But er I dunno...if it is aspirin or if it's not aspirin, I couldn't actually tell you. but like a lot of these things, it all depends how mentally you feel about it.
> HE: yeah, how do you feel about taking it now?
> Keith1: well at first I wondered about it, if it was or if it wasn't aspirin
> HE: yeah
> Keith1: and since then, it's just something that you do every day, so you just end up, it gradually goes into the (habit) with time, you just do it anyway you know

Several participants, whilst happy with the blinding process, expressed a desire to know the tablet identity at the end:

> Jennifer2 (61yrs): no that didnae bother me that, 'cause it was quite exciting that in fact, when I'd got to the end I'd've been quite happy 'o (to) know what I had been on and to see if they had found a difference, I would have liked to have found out, with somebody who'd the opposite for the two o' (of) us to see what the ootcome was, if the dummy was all in the mind in other words.

Other participants wanted their GP to know the identity of their trial medication; in this extract from focus group 1b Henry expressed concern over the quality of care his GP would be able to provide without knowing the tablet's identity:

> Yvonne (72yrs): but I don't think the doctor knows whether you're on the
> Maive (67yrs): no

Lorraine (52yrs): but probably take into account that you may be taking a dose of aspirin every day as part of this you know, presumed if he was going to prescribe something else for you
Henry (67yrs): that's a point, if people are on aspirin, and they shouldn't be for some medical reason, I think the doctor at least should know about it, so if the doctor doesn't know, I think that's wrong, I didn't appreciate that, I just assumed that they were told, as I've never seen the doctor
HE: the doctor knows that there's a possibility that you're on the aspirin or the placebo
Henry: but that could change his attitude to what he's giving me if he knows- if he's got to guess that you're on aspirin or not, he'll give you a different medicine for some things. I think the doctors should know.

This demonstrates how some participants seemed to think that the trial situation altered the standard duty of care in a doctor-patient relationship from a doctor's duty to provide the best treatment. A participant from focus group 1a was particularly articulate in expressing this viewpoint:

David (71yrs): but on the other side of the coin that Bob was talking about, if the AAA trial people know that I'm at risk, if they're all doctors, are they not obliged to take some action in order to save my life, to reduce that risk in which case they should not give me a placebo, they should give me aspirin
Others: (some agreement)
David: are they not obliged to, if I'm a doctor, my job is to say, "right, I have a duty, I took the Hippocratic oath so you are at risk so have an aspirin"

Later...

David: there was a bit a paper that said, "you may get some benefit out of this trial or you may not", one of the very first bits of paper we got. In other words that was their back up, to say that, "we know you're at risk and we're not giving you an aspirin, we're giving you a placebo"
Bob (70yrs): a get-out clause
David: that's right, from our side, that's catch 22, that they know I'm at risk but they're giving me a placebo, but they should be in fact treating me

In the above quote, David voiced awareness of a doctor's Hippocratic obligation to care; this echoes debate in medical journals regarding the distinction between the doctor-patient relationship in a standard care setting and that in a research setting and the associated conflict between the duty of therapy and the duty to contribute to research beneficial to wider society (De Deyn & D'Hooge, 1997; Elander & Hermeren, 1995; Groudine & Lumb, 1997; Hellman & Hellman, 1991). Whilst being particularly vocal in expressing this opinion and demonstrating his knowledge, David was an adherent trial participant, again raising a question of why he chose and continued to participate. It was my impression that David enjoyed engaging in

discussions and may have been trying to elicit responses from other participants by voicing such strong and provocative statements (particularly useful in focus groups research). Whilst generating a good critical discussion, this did not seem to lead to any significant discontent with the trial; certainly none of the focus group participants seemed sufficiently provoked to end their participation. But it demonstrated that it is not only doctors and researchers who deliberate over how research trials alter doctor-patient relationships.

It has been demonstrated elsewhere that many trial participants still expect the standard doctor-patient role to exist, which can lead to confusion over their beliefs about how their treatment was determined (Featherstone & Donovan, 2002; Snowdon et al., 1997; Heaven, 2003).

The Trial Procedure

Evidence for some discontent with the trial emerged in focus group 1b where the setting evoked perceptions of inconsistencies in the trial procedure, mainly due to individuals' misunderstandings or poor recall when comparing the information and contact that they had received:

> Nigel (64yrs): it doesn't seem to be very consistent then does it? Different results for different people
> Yvonne (72yrs): but the last two years the doctor also got the- you know he got the same letter as I did
> Nigel: yeah but Henry's had nothing...I'm just into the programme so
> Yvonne: but there was nothing this year, but talking about getting feedback, when I started I don't know about you, I was told that er I probably wouldn't know what the results was, and it would be after 5 years
> Nigel: that's what I was told as well

A few individuals raised questions about the research and procedure, in particular statistical analysis. In focus group 1a, David brought up the case of possible confounding variables

> David (71yrs): the case that he (Rod) gave, he didn't give up his drink, he didn't give up his smoking, he didn't give up the type of food he was eating, now...had he done so...how do you know, and if he was taking- he's actually taking aspirin, how do you know which was the one that saved his life so to speak, giving it up or the aspirin?

Owen4 wondered how analysis would account for non-adherence:

> Owen4 (52yrs): I think the main difficulty I would have found I suspect is in the statistical- not your statistical but the statisticians in the actual trial will have to deal with is you know the proof that people have stopped taking them. It's just so easy I think when you're doing something regular like that to forget for a day, to be somewhere out of your normal routine and you don't have it with you you know that kind of thing, but that's not my problem, it's my observation

Peter2 was generally suspicious of the way in which trials are analysed:

> Peter2 (55yrs): well I think there is a lot of confusion comes out about it, and from these figures that these people go on, do they interpret them the right way or are there two or three different ways of interpreting the figures, do they always get the interpretation right? I mean and I don't know, I'm only saying, is this the case?

These participants' questioning of the day-to-day running of the trial and its analysis, had not inhibited any of them from wanting and/or continuing to participate.

As demonstrated above, disagreement with the trial process and of the potential danger of not receiving the aspirin was expressed in both focus groups comprising adherent trial participants. When considering possible reasons for participation despite expressed discontent, it became apparent from examining the discourse used that whilst participants were aware that there was a 50% chance, some participants seemed to believe that they were actually receiving the aspirin. In fact some even referred to the tablet as aspirin, for example this member of focus group 1b:

> ...I certainly don't see any disadvantages because so far I've done nothing, you know I've been twice and this today and just take an aspirin a day

This was sometimes the case even when the participant had indicated a good understanding of the RCT process; Gordon1 discussed his understanding of the trial and the blinding, however, later in the interview he referred to the tablet as aspirin:

> Gordon1 (67yrs): So every morning I get up, Helen, I go 'o (to) the shops and I come back, and I take these pills, and I take that aspirin pill every morning,...

Gordon1's use of the words "that aspirin pill" could have been a simple way of describing the trial tablet rather than actually believing it was aspirin because the trial literature advised participants to treat the tablet as aspirin for example any pain relief

medication taken should not contain aspirin. Some participants spoke about doing this:

> Imogen1 (61yrs): I just take it that it is an aspirin, I treat it as an aspirin, and if I take any other medication I make sure there's no aspirin in it, just to make sure, but I don't know and I'm quite happy with it

But Gordon1's subsequent sentence implies that despite acknowledging an understanding of the trial process he appeared to believe not only that he was receiving aspirin but that he was therefore benefiting:

> Gordon1 (67yrs):...I think it's- the main thing is it's helping you, this aspirin tablet you'll see it's keeping the old ticker going and I think that's a- yes aye I would say that I'm quite happy.

Some participants even admitted that they believed they were receiving aspirin; one therefore realised he cannot have really thought about it:

> HE: how did you feel about the fact that you didn't know whether you were taking aspirin or the dummy pill?
> Warren2 (72yrs): I suppose I just presumed to myself that it would be aspirin, yeah yeah
> HE: cause some people say they don't like the idea of not knowing, and some people say they wouldn't want to go in because they wanted the aspirin
> Warren2: I don't know that I felt that, I just thought, "it probably is aspirin"...which suggests I didn't think too hard about it

This finding may be indicating evidence of a kind of optimistic bias; whilst participants were aware that there is a 50% chance of being on the aspirin, there may be a tendency to think that they were in the half receiving aspirin. As Richard1 commented before, he found it preferable to think that he was involved in active prevention. Whether it is more misconception or optimistic bias, it is an important issue relating to informed consent (discussed further in the misunderstanding section).

Contrary to those who voiced discontent with the RCT procedure, many participants accepted the idea, often due to their awareness of it being the most efficient way of conducting a trial and subsequently improving medicine.

> Owen4 (52yrs): well I mean that's one of these ethical questions that I mean you will never solve, because it's very difficult to run any kind of medical trial without having some kind of placebo side to it, er I suppose it's something that we would wish to try and limit as much as possible but it's

like many aspects of medical research there are bits of that you might not be entirely comfortable with in terms of ethics but until there's some better way of doing it you're stuck with it.

In interviews where people did not express the preference for aspirin over placebo, I put this perspective to them by saying, "some people have said to me that they wouldn't want to participate because they wouldn't want to get the placebo, what do you think?" Some participants could understand this viewpoint but realised the need for the process:

> Janice (focus group 4a, 70yrs): I had a wee passing thought about the people that were on the placebo might not do as well as the ones on the aspirin...but um I know they've got to do it that way and it's got to be blind but I just thought I wonder if it might have saved someone's life, just a passing thought as I say it wouldn't change my taking part in it. But my- if there was someone out there whose life could have been saved by the aspirin and they weren't taking that

Others disagreed completely probably due to their willingness to help:

> Molly4 (75yrs): oh no, no, that wouldn't cross my mind at all. I'd be happy at the end to know I'd only had a placebo

A few participants were very critical of those who expressed discontent with the idea of the placebo, Craig4 (54yrs) described this as "an extremely blinkered point of view", and Daniel4 (54yrs) implied it was ignorant:

> HE: are you happy with the chance of getting the drug and not getting the drug?
> Daniel4: yeah, that's a chance you take
> HE: yeah
> Daniel4: you know that not everybody in the trial is gonna get the drug, you know that, if you don't you haven't read a paper or read anything or seen the television, the news. To think "well I'm in the trial, I'm gonna get this tablet" you may as well be in cloud cuckoo land. You should know that it's a 50/50 chance of getting the pill or getting the other one.

Moira1 commented similarly regarding the blinding aspect:

> Moira1 (53yrs): well then there's no trial, that's the whole point, you cannot do a proper trial like that without absolute blind dishing out of samples, I totally appreciate that. I mean no, no, no, I can understand why they say that but if you're want things, medical research to advance, as far as I'm concerned, I wouldn't be taking an aspirin a day anyway so what's the harm?

Others accepted the process as requirements for successful research, for example Keith1 contemplated his reaction to discovering the tablet identity at the end:

> Keith1 (59yrs): "you mean I've been taking chalk for five years?!"
> HE: how do you think you'd feel if you found that out?
> Keith1: well somebody's got to take the placebo

A couple of participants specifically stated how they would have been happy to be a guinea pig, invoking altruism again:

> Timothy5 (61yrs): no, I don't think there's any disadvantage...I cannae see any disadvantage but the simple reason is...you might not know any of the results or anything like that because somebody else is doing the research-doing the groundwork and you're just one of the guinea pigs for it. But it wouldn't make any difference to me, whether I had been taking a placebo or an aspirin...it wouldn't have made much difference to me

Some participants seemed indifferent about the trial tablet. The following extract from focus group 1a illustrates contrasting opinions of trial participants:

> HE: do you see [the trial tablet] as different or the same?
> Alice (65yrs): no it's just another pill to take in the morning
> (laughter)
> Alice: another one of those white things you swallow them, I just take them and that's it
> HE: how do you feel about taking like that number of pills?
> Alice: it doesn't bother me, there's three- you have to take them two of them er- I forget what they're for...()...they're only white pills, there's nothing to stop you- they're small, they're not big pills, so you just have a cup of coffee and that's it, you'll live for another day
> Bob (70yrs): but you must believe that they're gonna do you some good?
> Alice: not the aspirin one because I don't think it's aspirin, I honestly do not think it is, it doesn't taste like it and as far as I'm concerned it's not
> Bob: you see I consider that it is an aspirin, I'm hoping it is an aspirin, I have a positive attitude towards it, if it is an aspirin, then it's gonna do me some good, otherwise I wouldn't take it, I wouldn't be in the trial
> Alice: well it doesn't bother me, it's just another pill
> Bob: well I could never, I'm sorry I could never have that attitude that it's just another pill
> Alice: nothing bothers me about my health
> Bob: but you must have a reason for taking it, if you've got a headache you would take a wee paracetomol or something
> Alice: but that's a pain and that's different
> Bob: something's gonna happen
> Alice: yeah pain's different, but I've not got any pain
> Bob: but if you've got cholesterol, say you've got high cholesterol
> Alice: uh huh

Bob: and you're taking a tablet, then surely you imagine that that tablet's gonna be beneficial for you or you wouldn't take it other wise
Alice: I honestly don't think about it
Bob: you don't think about that
Julie (56yrs): I'm the same as you (to Bob), I hope it's doing me good
Aileen: so do I
Bob: I find that pretty strange (to Alice)
Alice: it's just the whole thing is- goes over the top of my head, I really don't think about my health at all, it's only when somebody says, "do something", that I do it, but quite honestly, I don't think about it at all

Altogether, I have illustrated the varying attitudes participants had regarding the RCT procedure, in particular regarding the placebo and blinding, and how participants explained these as important in their decisions regarding participation. As demonstrated, for some participants discontent with aspects of the trial procedure overrode their altruistic feelings, but others participated despite expressing similar disgruntlement. For the majority, assumptions about aspirin's efficacy seemed to underlay their attitudes.

Adverse trial experiences: side effects and events

I was intrigued to know the feelings of any group2 participants who had stopped trial medication due to a cardiovascular event; in particular if they had made subsequent conclusions about their tablet identity and whether this had changed their opinion about the RCT and its process. For example, if they held assumptions about aspirin's benefits, their event may have led them to conclude that they had been receiving the placebo and maybe thus blaming of the trial for not preventing their event. Contrary to this, I found no blaming of this sort by the participants I interviewed. Harold2, who experienced a heart attack one year into the trial, spoke of how he accepted the trial process:

HE: so how did you feel about that, about going into the trial?
Harold2 (63yrs): no I was glad in a sense, I was glad in the sense that they found something that maybe, you know you don't know if you're taking the real aspirin or the dummy aspirin, I felt in a sense that it was helping you know, till I actually took the heart attack you know
HE: 'cause some people say they don't um you know that not knowing whether they've got the aspirin or the dummy pill
Harold2: uh huh
HE: um some people have said to me, "oh no I wouldn't wanna go in the trial because of you know I want the aspirin"

Harold2: it didn't bother me that much, no I didn't bother
HE: did you ever, did you ever wonder which you were on?
Harold2: did I?
HE: did you- did it ever go through your mind trying to work out whether you were on the aspirin or the dummy pill?
Harold2: no. well sometimes, as I say it didn't bother me so I just took them and I sometimes I'd say I wonder if this is the dummy I'm taking but it didn't bother me you know, ()
HE: did it change how you felt about the trial after having the heart attack?
Harold2: in what sense, do you mean whether the trial contributed?
HE: um or that…
Harold2: I thought maybe the trial to me in a way highlighted it, my heart was bad you know
HE: yeah
Harold2: no I didn't blame anything on the trial, no, I felt that after all if it was gonna do it, then it was gonna happen you know…

Even when probed, Harold2 refused to attribute blame for his heart attack to the trial, despite his comment, "I felt in a sense that it was helping you know, till I actually took the heart attack", instead he indicated a fatalistic view about his event. Harold2 was the only participant in the present study who had experienced a cardiovascular event and thus stopped the trial tablets due to the medication he required (including aspirin) post event. A handful of group 2 participants had experienced less severe changes in their cardiovascular health such as angina or raised blood pressure, which had led to them requiring prescribed aspirin or warfarin thus stopping the trial tablet. Like Harold2, these participants expressed no regret regarding participation and largely spoke altruistically.

As discussed, underlying the majority of participants' discussion about the trial, particularly the preference for the aspirin over the placebo, was the assumption of aspirin's efficacy. However alongside this was an additional assumption that aspirin could only be beneficial, i.e. there was little discussion of the potential risks of being allocated the aspirin rather than the placebo. I was thus interested to hear reactions of participants who had experienced side effects since starting the trial tablets.
Side effects experienced included effects typical of aspirin such as bruising and heartburn, but in addition people reported more peculiar ailments that they attributed to the tablets, such as tongue tingling, knee swelling and general aches and pains. With the advice of trial staff and their GP, those experiencing possible side effects

stopped and restarted the medication to test whether the trial tablet was the cause or not. Participants in focus group 2 compared their side effects:

> Cath (63yrs): I was taking it and I kept saying, "I can't be ill, I don't even know what it is", I stopped it and started it on two occasions and did find that I was waking up at night with a slight gnawing feeling in the stomach and
> Ursula (61yrs): I was exactly the same
> Cath: did you have the same? Well that's good to know yeah
> Ursula: yes, yes exactly the same
> Cath: cause I think I was surprised because as a child I took aspirin and through my life and I never had any problems but I did have it there

Later:

> Ella (70yrs): I stopped whatever it was because I got this tingling in the front of my tongue, and um when I stopped taking whatever it was, that stopped
> HE: interesting side effect
> Ella: I mean I don't know what I was on and at one point I said to the doctor, "was on I aspirin?" and he said, "well I don't know", so er but anyway but when I stopped whatever it was, this stopped

Regarding effects such as bruising and aches and pains, people tended to tolerate these and continue on the trial, echoing attitudes as outlined in the prevention chapter that mild side effects of aspirin were worth tolerating in favour of the potential benefits:

> Julie (focus group1a, 56yrs): I just thought, "well if I am on the aspirin, it's obviously doing me good" like the side effects, you just put up with them

Discussed earlier was Julie's curiosity regarding the identity of the tablet; her side effects had led her to further speculation. A fellow focus group participant described a scenario that had provided evidence for similar speculating:

> Alf (74yrs): I'm not sure if I may be on the aspirin, because just over a month ago I was in for a hernia operation, and before going in we got three sides of (paper) telling us all about the operation before and after, and one of the things they said was there might be bruising around- if you are on aspirin, if you're taking aspirin, there might be bruising around the area the operation cuts. Well I didn't- they said the bruising wouldn't be painful, I had quite a bit of bruising, it wasn't painful but it make me wonder if I may be on the aspirin.

But as a fellow participant jokingly pointed out:

> Andrew (59yrs): I think there's better ways (of finding out the identity) than going for a hernia operation!

Similarly to group 2 who had experienced a cardiovascular event, I was interested to hear the views of group 2 who had stopped the trial tablet due to side effects, which in some cases had involved a great deal of pain for example Alison2's experience:

> Alison2 (55yrs): I really felt I'd got gall bladder trouble again because it was from here right through into me kidneys and really severe. So I went to my GP, and she just checked round and said straight away, "don't take anymore, and ring Aspirin (trial) and tell them" and that was it, she gave me a course of tablets which- I had to go back, which the pain had eased, it was still there but nothing like it had been so she said, "give another fortnight and see, and if everything's OK don't come back". Well it had gone altogether then but she never actually said what it were causing, she just said she thought it could be causing some damage to me liver or kidneys, you know, not me stomach, so that was it, so now I've got one of these things round me neck that says I'm allergic to aspirin (...)
> HE: uh huh...so once you got it sorted out, how did you feel about the trial then?
> Alison2: I felt like well I've let them down, but at same time your health does come first and if that tablet aspirin were gonna kill me!
> HE: did you feel angry for getting the symptoms that you got?
> Alison2: no, no, because you go into it and you do know what you're doing I mean that were it, it were just one of them things, there's some people as you know who've started with it and they've still no problem.

Of the participants I spoke to who had stopped the trial medication due to adverse side effects, not one blamed the trial or regretted participating. Instead, like Alison2, they tended to speak of their disappointment at letting the trial down, indicating more altruism. One participant who had experienced moderate side effects was keen to restart and did so after the interview.

Participants who had not experienced side effects themselves commonly spoke of reassurance they felt due to the provision of information regarding possible side effects and the existence of safeguards in place for dealing with adverse events. For example participants in focus group 1a showed awareness of side effects to look out for and action to take if these are experienced:

> Aileen (67yrs): if it causes bleeding
> Andrew (59yrs): bleeding in the stomach
> David (71yrs): but now we're taking it once a day for five years
> Julie (56yrs): yeah but it's warning you that if you have any of these symptoms
> Aileen: it's on your sheet
> Julie: you stop taking it

> Andrew: and they always ask you when you go back
> Aileen: I've got a friend who...and she started this tablet the same as me and she suddenly started to bleed and they took her off it immediately about a fortnight ago, and they said it could be a side effect, but they did lots of tests, but immediately they took her off the aspirin

One participant explained how she had specifically enquired what to do in the event of a side effect. In addition to trial participants monitoring their own health and symptoms, a couple of participants discussed reassurance from regular monitoring by the research nurses:

> Richard1 (54yrs): And I know basically it's just as statistical study, and as long as you're given the checks so somebody was gonna say...well I assume, maybe I'm being too generous to them but I assume that if they noticed that I was actually looking seriously, likely to get seriously ill, they would tell me to go and see a doctor, rather than just keep me on the study and see if I kicked the bucket! (laughs) erm that might be unfair to them, maybe they're much more callous than I think, frankly I don't think so, I think that would have been the case, so provided that they're giving you the checks, it means that they're...you know they're not gonna be letting you carry on doing something like that if you're health was in any way deteriorating, at least I imagine they wouldn't.

These findings indicate that the provision of full information regarding action to take if experiencing possible side effects or events, in addition to being a requirement for informed consent in a trial, can also contribute to perceived safety. The issue of informed consent was brought up by only one participant; Owen4 expressed the importance of clarity in the screening letter:

> Owen4 (52yrs):...I would imagine that what would make a difference would be that you successfully strike up the balance between making it reasonably straightforward to follow the letter and the purpose and the research, and at the same time giving enough information treating people as responsible adults er 'cause I think people are probably are prepared to participate in research as long as they are sure what it's about. But at the same time they don't necessarily want several pages out The Lancet to read before they sign up for it, and I have to say that's a difficult balance to strike. ()...Um so I think as well as long as the people...somebody in the trial knows that clearly that they may be taking something which is completely useless er and that they may be therefore getting the protection that somebody else is getting, that's their business as long as they are fully informed, it's informed consent that matters.

Inherent in discussion about safeguards is the trust that participants demonstrated in the trial; similar trust related to the trial tablet:

Martha2 (65yrs): to take it, it's not gonna give you- they're not gonna give you anything that's gonna do you any harm so, just take it

Whilst participants' views about medication and aspirin were discussed in the prevention chapter, it is interesting to explore their attitudes specifically regarding the trial tablet. So far in this chapter, it has been demonstrated how for many participants, their trust in aspirin, and its perceived efficacy and safety, led them to express discontent with the RCT process due to their preference for aspirin over the placebo.

This trust in aspirin manifested in an additional few ways: the fact that the tablet would either be a placebo or aspirin and nothing else seemed to contribute to trust in the trial, particularly in comparison to the idea of a trial for a 'new' drug, for example:

Eleanor3 (62yrs): obviously it would depend what it was, but like taking a pill, obviously as long as I kind of know that it wouldn't be doing me any harm so, you know so, if it was a trial for something like a new drug that they were testing, you know I think I would uh huh make it a bit different, but I mean given that it was either aspirin or a placebo
HE: do you that's something- do you think that the fact that aspirin's been around for such a long time has an influence?
Eleanor3: well given that it's a tried and tested drug that you would have been taking, I mean obviously it's a small dose you'd be taking wasn't it? So really they...certainly wouldn't do you any harm, one way or the other, well if anything it would possibly do good, given what they'd discovered. So but as I say if it had been something, if they'd said to have come and it was a drug they were just testing, that would've been different but given it was aspirin, I wouldn't have had a problem with it one way other

Also for some participants who expressed a general dislike for medication (due to reasons discussed in the prevention chapter), their willingness to participate seemed to be related to their trust in aspirin. For example, the following participant described how her sister disliked the idea of medication and did not want to start on cholesterol tablets, but she happily participated in the trial:

Elsie (focus group 4b, 60yrs):...I think I would be the same I don't think I would like to take tablets, I could obviously if I had to, if you've tried
HE: is that...'cause obviously she's still taking the trial taking the trial tablets so does that not bother her?
Elsie: no, she's happy to take them
HE: why is that different?

Elsie: well I think again it's because it's aspirin, I think if it was anything else I think...or it's possibly aspirin

For other participants who expressed a dislike of medication in general, there were other reasons given for their willingness to take the trial tablet. For example Monica1 quoted in the prevention chapter as emphasising that she was "not a pill popper", had a favourable attitude towards the trial tablet

Monica1 (66yrs):...I don't like to take pills if I can help it you know, even headache pills, you know. If I got- if I had it all day and I was forced to take, I'd take a paracetemol, that's the only medication I would ever use, ordinarily.
HE: how do you see about the trial tablet as compared with that, if you don't like taking medication, but do you mind taking that?
Monica1: I don't mind taking that, because it's supposed to be helpful hopefully

So despite having avoided medication for most of her life, Monica1 thought that she could benefit from the trial tablet, implying that she probably hoped it was aspirin. For Alison2, who used the same phrase to emphasise her non-"pill popper" status, altruism overrode her dislike of medication that had arisen from medication she was required to take for another condition:

Alison2 (55yrs): it's the side effects of both the tablets, the ones for me neck, that I take, they just knock me out completely, I feel like "phhh I've got to get up" you know and you're so lethargic and same with the painkillers, you just feel like you're in a dream walking, you see things going about you but that's the only way I can describe it now and that's reason why I won't take them on a regular basis, plus fact that I think is you keep popping 'em, your immune system breaks down and then you waste of time because you just don't get any better do you? that's my system of working, probably wrong way
HE: did you- but you were still quite happy to take the trial medication?
Alison2: yes
HE: did you see that in a different way?
Alison2: I just felt that it could be helping other people

So beliefs about aspirin's safety and efficacy as well as altruism overrode several participants' avoidance of medication and led to willingness to take the trial tablet.

For some participants, dislike of medication led to declining to participate, as discussed in the prevention chapter, explanations included fear of anticipated side effects and dislike of chemicals. Isobel3 strongly disliked conventional medicine,

thus the prospect of five years of medication into her body had dissuaded her, despite her keenness to attend screening and interest in the research:

> Isobel3 (60yrs):... so when it was explained to me that it was the research for 5 years and I hadn't even thought about it, and I thought, "no I'll try and take care of myself other ways"
> HE: oh right, so you decided not to go into the trial
> Isobel3: yeah
> HE: how did you decide to take care of yourself as you say?
> Isobel3: well I take supplements, um I'm also vegetarian anyway, so I thought I would increase my fruit and veg... I take oils, I read a lot of health supplements, I also attend an Ayuverdic doctor. That's a Hindu, herbalism but it's there since much much longer, so I attend him

Interestingly, she expressed similar distrust as to the placebo as she pointed out that its ingredients were not clear and was unhappy taking *anything* without knowing more about it.

Altogether, participants' reflections regarding their experience of events and side effects whilst participating in the AAA trial generally indicated positive opinion, for example, little blame for any adverse experiences. Trust in the trial expressed by these participants seemed to be often linked to trust in aspirin, which reflects the findings discussed in the prevention chapter, and whilst for some, general dislike of medication applied to the trial tablet, for others it was treated differently.

Benefits and incentives of participation

On the whole, when asked about reasons for participating and benefits of the trial, participants referred to benefits of the screening and focussed on these rather than benefits of the trial itself, for example:

> Amy2 (76yrs): no, as I say I think it's a good thing that people get the opportunity to go into these things, so there must be a lot of people who are found out er you know, they could do with their help, no I think it's a good thing

When asked specifically about advantages of the trial, one participant who had declined to enter the trial felt that the screening in fact was the *only* benefit of the trial.

> Morag3 (64yrs): well I wasn't aware that there was anything else other than perhaps a check up and intermediate interview

However, several participants saw additional benefits to the initial screening, most commonly having one's health and reaction to the tablets monitored over the 5 years duration:

> Monica1 (66yrs): I thought that's good because um I thought to myself "this'll, it screens my health for the next five years and other aspects of it as well you know" and I thought "well it's a good thing to do"

For others, this ongoing monitoring was less specific to heart health but simply someone keeping an eye on their general health:

> Harriet (focus group 4b, 61yrs): you'd feel like somebody was watching you or you know somebody you know...somebody would be checking on you, whereas you might not have gone for this test, you might not go to the doctor every few months

An additional benefit mentioned by a handful of participants was their increased awareness about their cardiovascular health, which served as a warning giving them the chance to take steps to reduce that risk by making lifestyle changes:

> Julie (focus group 1a, 56yrs): there are people that I know and you're not talking about a relative you're helping, you're thinking of yourself and I think you're also given the opportunity in this five year period, that if you are on a placebo, you've got a chance to do something else, you've got a chance to improve your diet, get fit, you've still got an option, you can still improve yourself in five years, even if you're not on the aspirin, you've been given the opportunity or a warning that you're susceptible

Whilst Julie regarded this as an opportunity to make changes, the tone was slightly different in the following participant's statement, who emphasised responsibility which she would have felt to actively reduce her risk had she been at risk:

> Lucy (focus group 4b, 57yrs):...I expect that people that take part in the trial, that would be me...I would also be conscious of the fact that I should be watching my lifestyle at the same time. I think-I wouldn't know as you say which I was on whether I was on aspirin or not but the fact I was taking part in a trial like that, I think I would find some- there would be some responsibility on me to do the best...I could for myself. So in a kind of way people who are on it are doing themselves a favour I would say

Another participant implied that people who failed to take this opportunity would be foolish:

> Daniel4 (54yrs): if you look after yourself, you know you've got starting- the arteries are starting to fur up, if you're told they're starting to fur up, "how can I help? How can I do this? How can I assist in getting rid of it or easing

it?" you say "well you might be on this tablet...but what else can I do?" and if you don't do it, then...

Regarding more overt incentives to participate, one participant's non-participation was due to lack of expenses or financial compensation being offered (Paul3). Discussion in the literature however has found that financial incentive tends not to increase uptake (Fouad et al., 2000); certainly Paul3 was one of only two participants who voiced the opinion that financial incentives were appropriate. The second, Susan5, could not imagine why people would happily take the chance of receiving the placebo with no reward as such:

> Susan5 (53yrs): I don't like this dummy pill, you either know you're taking something or you're not
> HE: yeah
> Susan5: so if someone's gonnae give you something say either it's aspirin or it's not
> HE: people know that they could be on either so it's not like people have been lied to, but they go in knowing that they...but you wouldn't want...
> Susan5: no way, nobody's gonnae say to me "it might be this and might be that" not for me
> HE: can you see any advantages at all?
> Susan5: a wee bit er...it may be a stupid person thought they were taking something, no I don't agree...it'd just need to be a no for that one
> HE: that's fine. There are a lot of people in this trial so a lot of people are doing that I mean why do you think-
> Susan5: are they getting paid?
> HE: no
> Susan5: (laughs), they're off their head (laughs) sorry

However the majority did not agree; rather some stated how financial incentives would be wrong and perhaps entice the wrong type of person, for example in focus group 4a:

> Wilf (65yrs): no well I was thinking more of what you said earlier when you were talking about incentives and I was thinking about a pal of mine who regularly goes and gets him 50 pound a day at (name) University where they do er things like research, so obviously it must have been- it must be an incentive, and at (name of University) they sent it to a lot of people who would like to go into these studies but to me it would become a wrong reason
> HE: yeah does money alter things?
> Janice: but then if they were suitable people
> Wilf: well this guy's young, I mean he's in his thirties, he said "well I need some money so I'll just go along here, I'm fit and healthy, the doctor approves, he goes along to day care and they do studies for this that and the

other, and he's gets 50 pound a day, he comes out in a couple of weeks with a big bundle of money...he can't walk but!
(laughter)

Maureen4 (53yrs) talked with regret about participating in trials in the past for money when she was younger and fitter:

Maureen4: well I've been involved in drug trials before, yeah when I worked in (hospital), nurses used to volunteer to go in trials, 'cause they used to get paid for it (laughter), but no not for a long time
HE: how do you think about that- people being paid for it?
Maureen4: I think it's obscene actually, I mean I think we did it as student nurses because you were broke you know but I think a lot of people took things that hadn't a bloomin' clue what they were taking, and um a lot of people were quite ill, but they really didn't care that they were ill as long as they got the cash you know and I think that's bad. I think it attracts perhaps people you know that maybe not want to be involved in the trial in the first place, but money's very attractive isn't it?
HE: yeah. I mean there's no money involved in this trial...
Maureen4: yeah if you'd just sent out a hundred letters saying "if you come here we'll pay you one hundred pounds" you'd have a queue outside the door (laughter). But whether or not that's the right kind of thing you want to do, I don't think it's right you know.

So money had been an attractive incentive to a younger, fitter and less well off Maureen4 but being 53 now, she regretted it as she realised the risks involved with these past drug trials and shared the belief that money attracted the wrong type of person. This is interesting, given she had been attracted by money in the past.

Audrey5 described being offered expenses for a trial in the past and discussed how it seemed morally wrong to her to even claim expenses emphasising her altruistic intentions:

Audrey5 (72yrs): well some people do it for medical knowledge and some people do it for something different, because I discovered- here's another example, I discovered after I'd finished with Dr C and Mrs C, I didn't realise at the beginning that Mrs C she asked the consultants we should be getting paid for it, she said at the end, I said, "oh I don't have any expenses not at all" and she said, "you must have expenses", "no", I said, "I don't, cause it wasn't that far and at that time I was quite fit, now I understood afterwards when she did tell me, I was sent some flowers and some chocolates as a gift, cause of course some of them were putting in 50, 70 pounds expenses from the travelling point, they were taking taxis up and taxis back and it's quite expensive, and they were entitled to their expenses as you know, but I didn't want expenses, I was helping somebody else, (...) perhaps people would think, "I'll make something out of this too" you know, I don't know

Participants who emphasise their altruistic reasoning as distinct from others' participation for incentives are interesting; these participants could be indeed getting some reward from presenting themselves as altruistic. This moral discussion about money inciting the wrong type of person to participate is interesting; the idea that financial incentives would attract the 'wrong' sort of person echoes Titmuss's (1970) discussion of paid blood donation attracting unsuitable people, however Titmuss was referring to blood donation, which is a different situation in that the suitability (and healthiness) of the blood is crucial, whereas in the current situation, if a trial participant is eligible and adheres to the trial requirements, their reasons for participating whether for incentives or for altruism will not affect their contribution to the trial and their 'suitability'.

A couple of individuals found it hard to imagine people who *would* want to participate:

> Ted4 (77yrs): well my initial thoughts are if you were in the half where you were taking the placebo, well you know that would have a negative impression because if I thought I was doing something which wasn't really anything, I wouldn't feel very happy about it. And yet I know what you're talking about, you have to have some way of compar-of getting comparisons, but if I knew I was on the placebo, then why should I be doing that? Clinically I can understand why you're doing it, but you wouldn't surely find that many people would be happy to know that they were taking something that wasn't doing-

He elaborated to say how he found it hard to imagine people who would be this altruistic, which is interesting to contrast against the altruism expressed by many participants as discussed earlier:

> Ted4: unless there are a lot of public spirited individuals who would do that, I still feel it difficult to believe that somebody who was pretty old, would think along these lines. I'm sure that when they're getting very old, they're thinking only of things which are going to be improving their condition, rather than something which improves somebody else's. but er I know you can't tell lies or anything like that, you can't do that kind of thing, and I'm glad to hear there are people that take it up

His difficulty of imagining sufficient numbers of altruistic people led him to suggest lying to increase recruitment!:

> Ted4: I think you have to do it, I suppose you have to do it irrespective of the feelings of the individual because you'd have to do it by stealth you know

because how are you gonna get the information otherwise? You have to do make comparisons with one and the other, er I think you would have to be a wee bit unfair by you know playing down the fact that people might not be taking anything to get the information you want. That would- which in the long run would benefit society if you like generally, I think you couldn't be paying too much attention to the feelings of- you might have to tell lies (laughs)
HE: you can't do that!
Ted4: I know you can't but how else are you gonna get it?

Ted4 appeared fairly altruistic himself, he spoke of his interest in social research as he had conducted research and was keen to participate in this interview study, and said his initial interest in the trial was due to wanting to help. However he seemed to have a negative impression of other people's attitudes, and thought that generally people would not be sufficiently altruistic to participate. Maureen4, after honestly admitting how she herself would have discarded the trial tablets and bought her own aspirin, and regretting paid participation in the past, continued by suggesting that other people's participation was not altruistic but due to either lack of initiative to make their own decisions or to poor awareness and misunderstanding:

Maureen4 (53yrs): But I think a lot of people that come you know, they won't have this sort of gall to do that you know they'll just take what they've been given because well this is what the nurse or the doctor says you're to have, you know
HE: so do you think they don't really understand it they just do as they're told
Maureen4: I think they're just like you know little sheep, led, but uh huh I think any trial you know people are very willing to sort of think "well we're helping" you know but in actual fact they're not really totally aware of the consequences that from all this, if half of them who are on the trial have got you know high blood pressure, and they're not being given- they're being given the placebo, then I think they're probably not fully aware that you know- you're not doing them one bit of good so why bother coming?

Similarly Timothy5 indicated that participants probably believe they are receiving the active drug and that emphasising the possibility of the placebo would decrease participation rates:

HE: and what do you think about the fact that you've got half a chance of getting an aspirin and half a chance of getting a dummy pill?
Timothy5 (61yrs): as long as you don't know it doesn't make any difference.
HE: uh huh
Timothy5: 'cause nine times out of ten people will believe that they're getting an aspirin
HE: yeah

> Timothy5: so...if you're happy enough doing that then yeah...but if somebody hinted for one minute you were just getting a wee sugary tablet..."waste of time this"

Timothy5's insight about people believing they are receiving the aspirin reflects the finding discussed earlier that some participants do indeed imply this misconception. The last three quotes have shown perspectives of those who were not trial participants. Their impressions of trial participants are interesting; altruism was considered an unlikely reason for participation as opposed to being 'sheep-like' or having poor awareness. This contrasts with the beneficial reasons given by participants discussed earlier in the section.

Barriers: commitment and convenience

Costs of the trial that were discussed related to the commitment, 'hassle' or inconvenience seen by some to result from participating. For example, duration of the trial process was sometimes regarded as inhibiting:

> Miriam3 (73yrs): well she (nurse) explained the business about the tablet and it would be a whatsit- a pretend one or a real one, and then she said for 5 years, and then I decided I wasn't joining
> HE: right yeah
> Miriam3: the thought of this going on for 5 years, seemed to me seemed a long time, I didn't want to commit myself
> HE: no, no
> Miriam3: live for the present

Ted4 pointed out that duration would be a particular problem if recruiting people at the older age end of the age spectrum:

> Ted4 (77yrs): I think it would also depend how old you were, maybe if you were 50, you wouldn't, if you were getting on in life and coming up towards 80 I don't think you would talk about some 5 year plan, you might not even do the five years but no I think you would again it would depend how old you were. A younger person might be quite happy to do that, someone who was advance-what's advanced age now? The 93 year old- how do you think she would respond to that? Because in 5 years she'll not be here- well she might be...
> ()... the thing is that it's 5 years, it's such a long time that's the thing, it's not as if you're saying "do this for the next two to three weeks" but you're asking someone 5 years

Conversely Fergus1 (aged 71 at trial entry) looked on the invitation to participate for 5 years as a positive statement about his health:

> Fergus1: Er I didn't take it on board it was a trial, and I had to think about the period, so when they said last year this trial would last over 5 years, I said, "thanks for the vote of confidence you know!"

Five years was thus regarded as too much of a commitment by some; it was interesting to pinpoint what participants viewed as this commitment involving. At the younger end of the age spectrum a busy life, thus no time to participate, was regarded as a valid reason by several participants. For example:

> Molly4 (75yrs): Well it wouldn't have been simple 'cause I was still teaching and I went on till 60 or so, so it wouldn't have been so easy, it would just be a lack of time, it wouldn't be- I know you're saying you go on till the evening. Well I think your lifestyle makes it more difficult at that time to attend something else...

Another participant described accessing the hospital as too much 'hassle'. Thus the reasons given reflect the barriers against attending screening as discussed in the screening chapter. And similar to earlier discussions, other participants regarded 'not having time' as a lame excuse for non-participation. For example in focus group 1a, one participant challenged another on this issue:

> Julie (56yrs): or it could be that they have such a busy life that they don't want to get involved in something, it takes up too much time
> Andrew (59yrs): what taking a tablet every morning?
> Julie: no but you've got to come to every six months, you've got to go for your check up and things like that

In actual fact, after screening and baseline visits, all the trial required was annual clinic visits as Richard1 was well aware:

> Richard1 (54yrs):...and it's not all that inconvenient, I mean you get in the habit of taking the pills every day, and um you know going once a year, to keep in touch with them isn't exactly a burden you know. So it's just something you do you know, it's relative and if people want 'o do it, they'll do it.

A few participants said they had trouble remembering to take the tablet and in a couple of cases this had led to dropping out of the trial, for example:

> Peter2 (55yrs): the only reason I stopped was simply because I kept forgetting to take the tablets you know and it's just I take brufen now and again for my ills and that and I even forget to take it in the morning before going 'o work

> sort o' thing you know, so I'm getting to the stage that they're calling myself Al for Alzheimer you know cause I'm getting terrible forgetful. And I mean it would just be a sort o' sham for me to say, "I've been taking it when I haven't" you know. I think trials are- they are good things you know…

So despite emphasising their positive attitude towards research trials, Peter2 and Warren2 stopped the trial tablets due to their apparent difficulty remembering. Warren2 distinguished between this and lack of commitment, perhaps in attempt to justify his dropping out of the trial:

> Warren2 (72yrs): simply because I wasn't good at taking a tablet each day, you know. I think if it had been medication that I needed to take, I would have taken it
> HE: right
> Warren2: and that sounds as though I wasn't committed, but I was when I started certainly, but you know I'd go to take them and "goodness me, I haven't taken them this week" it was just something that didn't imprint itself on me and I mean I take tablets every morning now, um and they're not medication, they're dietary supplements

Warren2's quote once again implies perceived lack of necessity associated with the trial tablet and the low ABPI as previously discussed.

To a couple of participants, it appeared that it was the lack of disadvantages or hassle involved in the trial that persuaded them to participate, i.e. they could not see a reason *not* to participate. For example:

> Martha2 (65yrs):…when they said they would put me on the trial and you know I thought, "well fine, It's not gonna affect me- the way I live or what I do

> Marie2 (77yrs):I mean I was perfectly fit myself and I thought, "why shouldn't I go in?".

So for a few of these participants then, it was not the case that any benefits persuaded them to participate, rather the lack of strong reason for why not to participate or that they accepted participating without much thought.

The last two sections have illustrated participants' ideas about the benefits and barriers of participating in the AAA trial. At one end of the spectrum some participants felt that the benefits of the trial, both to self and others, prevailed over

the costs. For example, when asked about disadvantages of participating, Craig4's attitude was:

> Craig4 (54yrs):...of being in a trial? Um these would be grossly outweighed by the advantages I'd say

Conversely, Geoff3 (68yrs) who could only see risk and no benefit from participating:

> Geoff3: no, I don't see any advantage to me. Advantage to the researchers, yes. They can say "oh look that fellow died and he was on the dummy pill, maybe if he'd been on the right pill he wouldn't have died". So I see the benefit there, but I'm not prepared to be a blind guinea pig.

These are two extreme viewpoints; the chapter has demonstrated the wide range of opinions ranging from altruism to self-dominance, and attitudes about the pros and cons of participating. The Health Belief Model (Rosenstock, 1966; 1974; Becker et al., 1977) proposes that individuals weigh up barriers and benefits (along with perceived severity and susceptibility, and health motivation) when making decisions about carrying out a health related behaviour. Although criticised for assuming that rational thought processing takes place, and for ignoring the context in which people form beliefs about their health, it is apparent in the accounts of people in the present research that specific benefits and barriers are indeed mentioned when discussing attitudes towards participating in the trial. Referring back to Geoff3 for example, he explicitly described the cost-benefit analysis he had carried out when deciding to participate or not. For others there was less evidence for a cost-benefit analysis as such, rather certain aspects (for example dislike of medication, wanting to help others) appeared to dominate over others in their personal decision to participate, whilst still acknowledging and discussing less dominant factors. Also included in the HBM is the perception of risk and severity; as indicated in the chapter so far, participants' perceptions (high and low) of cardiovascular risk and risk from aspirin appeared to underlie many participants' participation decisions. This will be explored further in the subsequent chapters.

Part 3:

(Mis)understandings concerning participation

In the chapter so far, many misunderstandings have emerged. This section highlights those outlined so far, adding further instances not yet discussed.

Selection criteria for the trial

In the screening chapter I outlined the common misunderstandings and/or recall difficulties that emerged regarding the ABPI measure and its meaning; I demonstrated how many participants did not consider the ABPI a significant risk, and the impact that the screening experience, in particular the nurse-participant dialogue, appeared to have had on this risk perception. As the selection criteria for the trial was a low ABPI, participants' perceptions and understandings of the ABPI consequently related to their attitude towards participating in the trial.

It also emerged that many participants misunderstood the selection criteria for the trial and believed their invitation to, and subsequent eligibility for the trial as due to different reasons than the ABPI measure. A couple of participants assumed that family history of heart disease had led to their initial invitation:

> Alice (focus group 1a, 65yrs): I presumed the doctor had put me in for the screening because of my mother and father, both of them died of heart attacks, well my Mum had a stroke but you know what I mean, anyway so I presumed that was why I had been put in for it

Regarding eligibility assessed at the screening, a few participants believed high cholesterol was the reason for this:

> David (focus group1a, 71yrs): After the very first screening, the AAA people sent a report to my doctor...I had occasion to see him about two or three weeks later on another matter, and I brought this up, he said, "oh yes we've just got the report, you've got slightly high cholesterol now," he said something like .5 above, he said, "but they've only just lowered that level about a year or so ago". So had I been the same level and took that test the year before, then I would not be sitting here today. 'cause they just recently lowered it to whatever it is now

Not only did David misunderstand the selection criteria for the trial, but he also perceived little risk after discussing his cholesterol with his GP. Another common

mistake was to assume that high blood pressure was the determining factor for inclusion:

> Keith1 (59yrs): well it didn't really bother me, I mean they were inquiring you know if I was- it was my own doctor actually I think who got in touch with, and I take it their idea being is to try and get people who'd get in touch with their doctors and people who have raised blood pressure would be the people they would want to see, you know people who didn't have it, they wouldn't be bothering. So I take it that was how they got in touch with me.

Interestingly, a few participants felt that the research nurse's opinion of their lifestyle had swayed their inclusion; Monica1 felt that her healthy lifestyle had led to her being included:

> Monica1 (66yrs): I had no problems with that, she said to me I was on the borderline
> HE: right
> Monica1: right she said "but I think I'll include you, in the trial", I was just- I forget what figures they used, er and I was just on it
> HE: right
> Monica1: or just about on it, you know I wasn't way off you know, and she said "I think I'll include you in it", I don't know why she decided that, when it wasn't over you know. Possibly because of what I was telling maybe because I tried to help myself, she thought "I'll give her the benefit" or whatever.

Contrary to Monica1's healthy lifestyle, Fred2 felt that his smoking had contributed to his inclusion:

> Fred2 (62yrs): I did, she- I also think I was- I'm positive that both feet readings were the same, but being at the age I was, and I smoke
> HE: oh right
> Fred2: er...and the lady at the time said, "well you know we'll put you on the trial" sort of thing, I think the smoking had something to do with it you know

The choice of words used by a few participants when discussing eligibility appeared to indicate that they regarded their eligibility in a positive light:

> Wendy1 (55yrs): well I was glad I got accepted 'cause they say maybe you're not gonna be accepted, and I was glad I got accepted, I was quite happy about that

> David (focus group 1a, 71yrs): my wife and I both received the invitation at the same time, we both went down to the western general, and I was selected and she wasn't

The following participant expressed similarly positive opinions on being included in the trial and showed awareness that the trial recruited from a 'healthy' population. However, she seemed to still consider herself healthy after having a low ABPI and thus included in the trial, again indicating low risk perception from the ABPI result:

> Lorraine (focus group 1b, 52yrs): I think I was quite pleased whenever I got the initial letter out because the sort of person they were looking for was sort of you know basically quite healthy...

RCT procedure

As outlined earlier it emerged that some participants did not fully comprehend the RCT procedure. As previously mentioned, a couple of participants misunderstood the double blinding, believing instead that the research nurse and other health professionals knew the identity of their medication. Regarding the randomisation process, a few participants demonstrated awareness, but many despite indicating an awareness of the randomisation, appeared to believe that they personally were receiving the aspirin. This echoes previous literature where participants could seemingly accurately describe how treatments are allocated at random whilst simultaneously demonstrating inconsistent beliefs regarding their own treatment allocation for example allocation thought to result from symptoms or other criteria (Featherstone & Donovan, 1998; 2002; Snowdon et al., 1997).

A common misconception was that the trial followed a crossover RCT procedure, i.e. that each participant would receive periods of the aspirin and periods of the placebo. Alison2 seemed to think this, however her involvement in a previous trial, possibly a crossover design, probably contributed to her belief:

> Alison2 (55yrs): no I mean I knew that I were gonna be given a dummy as well as aspirin

Gordon1 too seemed to think the design was a crossover, and as discussed earlier misunderstood the need for the trial due to his assumption of aspirin's proven efficacy:

> Gordon1 (67yrs): that's right. So I take that faithfully all the time but as I say it's some's aspirins and some's blank tablets, I don't know what that's for. They should just keep you on aspirin and see how your blood pressure

HE: yeah I was going to say, how do you feel about that? Because obviously this is a trial and what they're doing is like half the people are on aspirin and half are on-
Gordon1: that's right, so you don't know what you're on, which
HE: so how do you feel about that?
Gordon1: well I think it should just be aspirin only, you know so you ken that you're taking it and then but they must have a reason, but they're half, they put in half

Harold2's account is interesting as it revealed inconsistencies in his understanding as he contradicted himself at several points in the interview; it could be the case that he was attempting to reinterpret his prior thoughts about the trial having had a heart attack, or it could be that the interview process itself led him think about the trial in more depth than he had before. At points in the interview he spoke about how he thought the aspirin might help him, so despite appearing to understand the RCT process he may have believed that he was on aspirin, as quoted earlier:

Harold2 (63yrs): no I was glad in a sense, I was glad in a sense that they found something that maybe, you know, you don't know if you're taking the real aspirin or the dummy aspirin, I felt in a sense that it was helping you know, till I actually took the heart attack you know

Then maybe trying to justify why he had a heart attack despite being on the 'aspirin', he talked about aspirin not being able to 'cure' all heart attacks:

Harold2: I thought I was helping, in a sense that the aspirin would have- I don't know cured you or anything, I don't think they could cure heart attacks, whether it would have prevented me having a heart attack. But I took it you know

Later he considered the idea that he may have been on the placebo which could explain why he still had the heart attack (so making the assumption about aspirin's efficacy), but he then showed that his understanding of the RCT process was not entirely accurate after all, similarly to Gordon1 he seemed to think the trial was a crossover design.

Harold2: But now I'm sorry that I never maybe took an aspirin 'cause it could have prevented () No I didn't- it didn't bother me taking aspirin but then again maybe it did bother me 'cause I was taking the dummy and it didn't help! But you're getting some aspirin some of the time so it must have been helping me.

These seemingly contrary quotes in Harold2's account implies that he struggled trying to grasp the concept of the trial procedure, and demonstrates how the concept can be difficult to understand for a member of the general public, indeed for anyone with no knowledge of medical research. There was a wide range of educational level in the participants in the study, and misunderstandings and/or assumptions were revealed in some participants even at the upper level.

I discussed the findings of misunderstandings with the research nurses. They told me how at annual clinic visits it was apparent that participants had forgotten aspects of the trial (such as those misunderstandings covered above); they pointed out that five years, or even one year, is a long time for people to remember details particularly medical details which were often novel to them. The nurses explained the ABPI and details of the trial to participants, and administer participant-friendly information documents, but questioned how they could guarantee that each individual had completely understood and would remember.

These misunderstandings are a concern regarding the issue of informed consent, in particular raise the issue of the difficulty of guaranteeing informed consent from the initial screening *throughout* the duration of the trial.

Summary: Attitudes towards participation in the randomised control trial

The AAA trial provided the opportunity to explore attitudes and experiences of members of a healthy population alongside an ongoing large RCT for preventive medicine. The present chapter has outlined and discussed the diversity of participants' attitudes to general and specific aspects of the research trial. The first section demonstrated the emergence of altruism in participants' accounts, and explored the different explanations given for these feelings. The second section focused on more self-dominant attitudes including the potential personal benefits and costs regarding aspects of the RCT procedure. Also illustrated were assumptions, misunderstandings and ideas about risk perception implied in participants' accounts.

Altogether the chapter has demonstrated the large number of different aspects, issues and feelings that appeared to influence the decision to participate in the AAA trial. Furthermore, the quotes used have illustrated how participants can have seemingly opposing opinions regarding the costs and benefits of the trial, further demonstrating the complexity of the decision. In some cases, weighing up the multiple pros and cons, whether consciously or not, became straightforward, for example the case of Alison2: this participant expressed clear altruistic views about participating and had participated in previous trials, she disliked medication but was willing to take the trial tablet for research. However a severe reaction attributed to the trial tablet led to her having to stop the medication because, *"at the end of the day, your health's got to come first"*. Similarly other participants explained how their attitudes changed over time according to different experiences.

For some participants, their attitudes appeared to change and contradict within the interview leading to further examination of their transcripts. Sometimes this seemed to reflect misunderstanding for example the case of Harold2, but for others such as Maureen4 (quoted in many parts of this chapter), it further demonstrated the multitude of experiences that could contribute to the decisions of some participants.
In addition, the emergence of misunderstandings regarding the trial raised the issue of the difficulty in guaranteeing informed consent throughout the trial duration, despite ethically approved participant-friendly documentation and training of research staff with participant contact. This is a serious issue that should be considered further by those running research trials and the medical community.

Chapter 7:
Perception of cardiovascular risk

Introduction

Regarding participants' attitudes towards screening, prevention and AAA trial participation, a key underlying theme that emerged was participants' perception of cardiovascular risk. This final data chapter will present further analysis specifically relating to participants' cardiovascular risk perception.

The data in this chapter emerged in two different ways: first, interview questions included, "did/do you see yourself as the type of person to have heart disease?" and/or "who do you see as the type of person to have heart disease?" Thus these formed direct questions about cardiovascular risk. Second, from participants' comments and discussion about screening, prevention and participation, their feelings about cardiovascular risk emerged in a subtler manner.

The chapter is split into sections relating to different risk factors. First, family history of the disease is discussed, exploring how participants perceived this as affecting their risk and the comparisons they made between themselves and affected others including peer comparisons; this was a particularly salient issue. The second group of risk factors discussed concerns lifestyle, in particular focusing on the risk perceived by those who continue to engage in 'unhealthy' behaviours. Third, the idea of heart disease being a particular problem for Scotland is considered. The final section highlights attitudes towards clinical diagnoses of cardiovascular risk factors.

Family history of cardiovascular disease, and self-others comparisons

Family history of heart disease or heredity was particularly salient in many participants' accounts; some members implied it was the most important risk factor. Discussion in focus group 2 returned to this several times. For example, the following extract was part of a discussion about causes of cardiovascular risk; participants gave examples where lifestyle and physical build appeared to be irrelevant, which led them to conclude that genes could overpower other factors:

Cath (63yrs): there's a lot more to it than just eating and drinking and lifestyle and whether you're overweight or whether you know, there's a lot to it you know. 'Cause my mother who was overweight, well she struggled with her weight most of her life, had no problems with high blood pressure or high cholesterol, and my father who wasn't overweight, he had all these things you know
Ursula (61yrs): is it in the genes?
Others: mmm (agreement from other focus group participants)
Emma (70yrs): that's what my doctor said, "you can help everything but not your genes", what can you do?

Later, participants presented descriptions of relatives, their cardiovascular health and their lifestyle; participants seemed to use the cases to build a theory of lifestyle being overridden by heredity. The following extract begins with the last case described:

Emma: my husband takes full cream and everything like that and he gets up in the morning and goes to bed at night and there's nothing ever wrong with him, and he's got more energy than I have
Ursula: he's very lucky, very lucky
Emma: he says he comes from good stock! (laughs)
Ursula: he's not far from wrong that's probably right, he comes from good stock, there is a lot to that.
HE: do you think any of it *is* luck?
Ursula: it's got a lot to do with your family and as you say if the family has had certain things you know, erm for my dad it was a heart attack, my mum was cancer, erm
Ella (70yrs): well my father I said, my husband has had two bypasses, his mother died of a heart problem, his aunts died of heart problems you know
Emma: yes
Ursula: it's in the family
Cath: I do think that even though you have a tendency to these things, you can help yourself, you know I would say you can, I do believe that, that you can take exercise and eat healthily and you can try and relax as often as possible and I think that does help

The examples participants gave contributed to their conclusion of the dominance of genes over lifestyle; only one participant in the group (Cath) seemed to think that lifestyle could intervene, whereas the other participants seemed to equate heredity with a degree of inevitability. In another focus group (1a), where similar conclusions were being reached, there was also some recognition that heredity was not the only risk:

David (71yrs): yeah but other people who are not from families with heart disease, do die of heart disease

Applying the same belief to her own perceived risk, Morag3 implied that due to no family history of heart disease, she had no reason to worry about her low ABPI:

> Morag3 (64yrs): ...I imagine that people who have a concern about their health might well want to participate regardless of whether it's aspirin or placebo. I think people where there's a history in their family of strokes and high blood pressure, may have more concern than I had.

In contrast to the cases of people with unhealthy lifestyles not being at risk due to "coming from good stock", Imogen1 presented cases of those who despite leading healthy lives were afflicted, which she found unfair:

> Imogen1 (61yrs):...but as I say I never smoked and my mother never smoked, and you see my brother never smoked, but you see they both had heart attacks.
> HE: yeah
> Imogen1: I see people-
> HE: how old were they?
> Imogen1: my mother was 53 and my brother was 60. I mean I can never understand when I see people how they abuse their body by- you know you see them drinking, I'm- fair enough you can have a drink, don't misunderstand me I don't- people have to live their life, do what they want to, but when you think how they abuse their bodies you know.

Some participants were concerned due to their own family history of heart disease, but others regarded such worrying as unnecessary:

> HE: how about like, some people talk about family history of heart related problems, have you got anything in your family?
> Martha2 (65yrs): well my brother had a heart attack three years ago, when he was um 70, er he didn't know he'd had it...()...And my mother died of a heart attack when she was 77..()...but she'd asthma and bronchitis, lots of chest complaints
> HE: so had that influenced the way you thought about your own risk?
> Martha2: no, not really, no, family history, medical history does...it's there but I don't think it does to dwell on these sort of things, you just you know everyone's different.

Whilst Martha2 felt that individual differences could counteract heredity, a few participants went further emphasising particular differences between themselves and affected family members which they seemed to use to minimise their personal risk perception. Echoing previous findings (Davison et al., 1989), distinctions were made regarding individuals' 'build': for example, in focus group 1b, participants were discussing whether they had a family history of heart disease. Lorraine contemplated her husband's family history:

> Lorraine (52yrs):...my father-in-law and one brother-in-law, but interestingly enough, they probably, they're different physical types if you know what I mean, my husband and his other brother are much more like their mother, so I don't know whether that has something to do with it

A more common distinction related to lifestyle, in particular participants whose relatives smoked. For example Keith1 distinguished himself from his father regarding two lifestyle risk factors, smoking and stressful work:

> Keith1 (59yrs):...I mean he used to go down and started working in the pub at nine in the morning, I mean he didn't get back home until about 11, well he came home during the day, after he'd shut you know when it was- he used to come home, so it was quite a long period of work. He smoked as well which didn't help, I mean he smoked- I mean people knew smoking was bad for them thirty, forty years ago but people didn't- weren't informed, told. () So I've never smoked or- my mother smoked, my sister smoked, my father smoked, but I never had any desire to smoke, I don't like the smell of it and various things...()...But anyway so what happened was he'd sort of had these problems, and he had three or four strokes or three or four heart attacks, he died of that eventually. So it was I was at the doctors and I thought, "well, are these things gonna happen to me?" I mean they're all saying genes are passed from each other to each other so that was it so he took my blood pressure

Despite the distinction between his own and his father's lifestyle, he reported both his father's history and events in his peers as influential on his decision to get a check up. When I asked him which he thought was the most significant, similarly to the discussions quoted above, he concluded that family history was most dominant:

> Keith1: well I would say the biggest risk factor is the genes
> HE: yeah
> Keith1: I mean what is hereditary, you can try and, you can't change it, but you can try and do something about it, but I don't know really if your genes are built that way, that your family have all heart problems or whatever that you can do much more about it. You can try and modify your lifestyle and various other things, but I don't think I suppose what you might do, you might cull all things but there's no way you can avoid it.

Echoing the findings of Emslie et al. (2001) there was a tendency not to attribute 'old age' heart attacks to family history, thereby providing another method of distinguishing between oneself and affected family members. For example:

> Morag3 (64yrs):...I was interested in the study because both my parents died from strokes
> HE: right
> Morag3: but then well not my father- I wouldn't have described him as elderly although he was early seventies, my mother was towards mid eighties,

and an aunt, dies two years ago from stroke, again she was late eighties so you can't really comment on that
HE: so you feel it wasn't really family history
Morag3: well they weren't young people to die

A few participants concluded that there was little to worry about regarding family history despite providing examples of a couple of cases of heart disease and some strokes. For example:

HE: yeah um...you mentioned before that your Dad had a heart attack
Alison2 (55yrs): he died of heart trouble
HE: so have you got any other heart disease in the family?
Alison2: no
HE: how about your grandparents?
Alison2: there was only Grandma (maternal) who had a dickie heart, my mum did tell me when I went on this, um she had a problem with heart but nothing drastic, I mean she died of cerebral haemorrhage, as did me other Grandma and me Grandad (paternal) he didn't die, he just had a stroke didn't he, it weren't heart with him?
Sister: it were Parkinson's wan't it? what about Grandad (maternal)
Alison2: I think it were just a stroke weren't it?
Sister: I can't remember now
Alison2: but it definitely wasn't heart, you know I mean even me dad's brother it were cancer, as is with his sisters weren't it?

Alison2 did not seem to see a connection between heart disease and stroke despite the shared risk factors. In reflection this could have indeed been due to the terms I used in questions, and my tendency to use the phrase 'heart problems' to reflect local vernacular.

Generational comparisons

Participants often distinguished between themselves and other family members by noting the differences between generations regarding cardiovascular risk factors; in particular when discussing diet, many participants reflected on the post wartime diet. Some now blamed this for current cardiovascular risk, for example Dennis4 attributed his wife's premature stroke to a high fat diet during her schooling:

Dennis4 (75yrs): my wife's been on aspirin for years, well it'd be about mid thirties
HE: oh right
Dennis4: it was the furring up of the arteries...and thinking back she had a lot of milk and beef dripping as a child...and it could have been something to do with it

Later…

> Dennis4: I think in my wife's case, it caught up with her…her diet as a school child. You know quite a lot of milk…as a school-, you know they used to give you a third of a pint of milk er free with your morning break and they went on until years after the war, they still…But I mean…we always liked milk, there were some boys who wouldn't take it so we'd have an extra one often (laughs)…but I mean…the wartime diet was quite good…quite a lot of suet puddings to fill you up, dumplings and suet puddings

A couple of participants noted how current dietary advice contradicted many of the recommendations in the post war diet, for example:

> Graham3 (58yrs): I find diet's a bit harm- because here's another thing again looking back on life, when I was at school we were always taught that the healthy way- to be healthy was er farm produce…butter, eggs, cheese, milk, and now these are the things that are, "don't eat these things" you know, "cholesterol"

However, the majority of participants who discussed the post war diet considered it *healthier* than the diet that they attributed to younger generations. For example focus group 1b concluded that rationing was healthy, similarly focus group 1a:

> Jen (65yrs): that's what we were brought up to isn't it? Healthy diet
> Julie (56yrs): and I think after the war as well, the diet was healthy because it was minimum
> Aileen (67yrs): yeah the diet's worse now I think
> Jen: I mean I still like my mince and potatoes
> Julie: and two veg!
> Jen: I like anything that's homemade
> Julie: but I think the youngsters as well, I mean they're working all day and they're going home, they're not want to start doing that like we did at home, when we were children, they've not got time.

Some maintained this viewpoint even after discovering high risk attributed to their diet. For example Wendy1 who had recently changed her diet drastically including cutting down from two eggs a day to two a week due to discovering high cholesterol:

> HE: 'cause some people I've spoken to talked about the post-war diet, and you know you were encouraged to eat eggs and butter and these things
> Wendy1 (55yrs): in saying that, we were lean, we were healthy because it was dieticians that arranged it for the nation and you got your amount for your week…

Participants often commented on the sedentary lifestyle of younger people today compared to the very active lives they led when young; often they felt this activity

had counteracted the high fat diet at the time. Several participants felt that the whole 'way of life' had evolved into an unhealthy one, for example:

> Alison2 (55yrs): I think it's worse yeah. I mean we were told dinner time were 'ere, you sat down, you ate what you had in front o' you. You had (proper) meals and nowadays everything seems fast food, I mean when you're shopping, you've only got to look in somebody's trolly, and the biggest majority of stuff is there square boxes that you just plonk in microwave...and a lot of young ones don't even know how to put a proper meal together or even do a stew. So I feel that food wise, a lot of young ones, they're more at risk aren't they?

Many participants emphasised the benefit of a 'haeme made' (home made) diet, in particular traditional home made Scottish soups, which they regarded as healthier than what today's generation cook and eat. Many, like Alison2, felt that today's generation's inability to make home made food was a particular contributor to the dietary problems, and thus heart disease. These participants seemed to be associating healthiness with the morality of putting all the work in oneself as much as the quality of the ingredients, echoing Ruston and Clayton (2002) and Blaxter and Paterson (1982).

On the contrary, other participants felt that younger people today were healthier, for example Gordon1 and his wife compared themselves to foreign students they had hosted and their own children. This was linked to awareness of food and health that was seen as much more publicised than when participants themselves were younger:

> Gordon1 (67yrs): so yes, the younguns what we're saying is, the younger ones are starting to get maere health conscious...()...aye, tell you this Helen, I'll say about when I was in the- we didnae care about this, aye we know now but we didn't know at the time, at that stage. Cause we were what you'd say
> Wife: ignorant
> Gordon1: aye well we had tellies just, but it's a wee bit maere broadcast now you know, it's on television
> Wife: well there's more health on the TV

Peer comparison

Several male participants commonly talked about how hearing about heart attacks in their peers had provoked sudden assessment of their personal risk. Typically they referred to friends from their past such as school friends which may have particularly

personalised the event due to the shared age. This experience had made a few of these men worry, it made Peter2 re-evaluate his lifestyle:

> Peter2 (55yrs): I never really thought, you know it's one of these things, I've known people that I went to school with that have died early, as a matter of fact I bumped into a fellow I used to know months ago and he was talking about these four guys that we used know, you know when we were 18, 19, 20 and that, and they're dead, various things, one was a heart attack, it does, it comes home to you and you say "well I'm at that age", and you don't know what's round the corner sort of thing you know
> HE: did it make you think about your own health that?
> Peter2: er well aye I suppose it did I mean I always was conscious that maybe you shouldn't eat too many fatty things you know what I mean cause I know it's not good for you…

However these participants typically distinguished themselves from the affected peers for example regarding lifestyle, thus reducing their own risk perceived:

> Warren2 (72yrs): but not, but not heart attacks. I mean the older you get, the more people you see that die before you, from heart attacks, um we moved in here 5 years and there was a young guy, 40, and he helped us with all the outside decorating and inside decorating when we moved in 5 years ago, and he took a heart attack at 40 you know and died. So I see heart attacks but strokes are much more common I think, so
> HE: so has that been in your sort of friendship group or in your family or?
> Warren2: friendship group, yeah, friendship group and um, but that's only one, that's only one, but I suppose I tend to think of strokes as being much more common than heart conditions
> HE: when this has happened did this made you um sort of re-evaluate your own risk of stroke at all?
> Warren2: probably and again I suppose I had the feeling that I'm less likely to suffer from them than a lot of my peers um simply because of the fact you know of my past lifestyle

To summarise, comparisons with others were often made when people considered and discussed cardiovascular risk. Due to the salience of family history in people's ideas about the aetiology of heart disease, participants often reflected on this and generally seemed to conclude either that there was or was not family history of risk in their own family. For those who considered themselves to have a family history, this was often mentioned as being in their thoughts when contemplating attending screening. However when applying perceived family history to their own personal risk, participants often made distinctions between themselves and the affected family members regarding physical type, lifestyle or differences associated with differing generations, often minimising their personal risk perception. Similarly while

cardiovascular events in peers were discussed as provoking analysis of one's own risk due to the shared age, distinctions which were often made regarding lifestyle seemed to minimise personal risk perceived.

Lifestyle

Many participants described in detail the healthiness of their current lifestyle. For many of the women this was associated with being conscious of keeping their weight under control which had been part of their lifestyle for a number of years. Many other participants discussed their current healthy lifestyle in comparison to an unhealthy lifestyle they had led in the past; the change had typically having been triggered by a cardiovascular event, a diagnosis, or another life change such as retirement. Whilst these participants' views on cardiovascular risk were interesting and important, I was particularly interested in hearing from participants who still engaged in 'unhealthy' behaviours, regarding their attitudes towards the risk arising from continuing to engage in such lifestyle. A couple of participants pointed out that 'unhealthy' behaviours were enjoyable:

> Andrew (focus group1a, 59yrs): ...surprised me that I was so healthy cause I smoke like a chimney and drink like a fish
> (laughter)

Later...

> Andrew: I've not gone changing my life, I still smoke, I've not stopped, I still smoke, I've not stopped drinking, I always eat the same things and I eat what's nae good for you, cause these health foods and that I don't like 'em. Putting it quite bluntly, I dinnae eat to look after my heart, I eat what I like
> David: he's gonna die happy
> (laughter)

In focus group settings, disclosure of unhealthy behaviours was often accompanied by laughter from fellow participants. There was only one instance where a participant challenged another on their lifestyle, the rest of the time the setting may have seemed a comfortable place to admit unhealthy habits.

A few participants weighed up the potential risk from aspects of their lifestyle against wanting to enjoy life, for example:

> Richard1 (54yrs): ...I think I'd a fair idea what the risks were already and I knew I was taking a certain amount of risks, I'd given up smoking a long time ago

HE: oh have you?
Richard1: oh yeah I don't smoke, I haven't smoked since I was er in my thirties and er...but that was partly because it was silly, it was costing me a lot of money, you know...but er I don't actually think I'm a terrible excessive lifestyle so I don't think I've a really high risk, I've probably got more risk than I need to have, I could keep fit or I could eat better, there's no question about that, but um actually I've got this strange idea that you might as well enjoy life while you've got it, and um the idea that you should sort of drag on living like a monk or a nun thirty or forty years, just so that you can manage another 10 years when you're 80 strikes me as being a pretty stupid way to live! (laughs) you know it's I mean different people see things differently but that tends to be my approach to things you know. If you cannae enjoy it, you might as well not be there, you know, so. That's maybe not answering your questions but...

Richard1 seemed to see the possible effects of lifestyle as concerning the older end of the age spectrum rather than affecting health at his age (50s); some fatalism emerged in his account:

HE: so do you see not yourself as the type of person to get heart disease or?
Richard1: well I wouldn't say that, no, I'm the right age group, and I eat far too much, I eat all the wrong things so yeah I mean- but I'm not really bothered with heart disease in that sense, you've got to die of something you know! (laughs) frankly I think I'd rather die of heart disease than some lingering cancer, and it strikes me that if you survive long enough you die of cancer eventually anyway! I mean that's the bottom line you know, you either die of something else or you die of cancer. But you know you're gonna die of something some day, I mean even when you live to 101, you eventually kick the bucket don't you! (laughs)
HE: so do you see heart disease as a kind of favourable, preferable
Richard1: it's relatively preferable way to go, it's quick...in general, I mean if you get a stroke obviously it's (not) but you know but um you know a straight forward heart attack, most folk would die of that pretty quickly you know.

Richard1's view of regarding heart disease as preferable echoes findings of Emslie et al. (2001), demonstrating the lack of severity associated with heart disease for many, and illustrating another reason for not wanting to make lifestyle changes. Some participants who happily admitted engaging in several unhealthy behaviours were quite critical of people who did lead healthy lifestyles such as vegans and 'health freaks', for example Alison2 happily admitted unhealthy aspects of her diet. Comparing herself with her health conscious friend she saw no benefit, only negative effects from her friend's lifestyle, which she seemed to use to justify her own lifestyle:

Alison2 (55yrs): well I eat- my sister thinks I'm a pig! (laughter) no I always have a cooked meal every day, if not a cooked meal, a salad, er there's fruit, I eat fruit, er I always have to have a pudding after everything, which is best part o' meal which can be anything- apple pie, custard, cream
Sister: half a gateau
Alison2: half a gateau! Meringues! And I'm always a nibbler, bars of chocolate, sweets, and I just drink coffee, very rare do I drink water, unless I'm taking tablets. As I say I just eat what I want
H and you feel OK about that?
Alison2: yeah, I mean I don't feel ill, but I'm eating more chocolate and sweet stuff than probably what I should do, but I do get me veg and me fruit every day
HE: uh huh, how about um do you smoke at all?
Alison2: yeah I do smoke yeah
HE: so with all these things put together I mean did you expect to have some sort of um risk of heart disease
Alison2: no not really
HE: or where do you see yourself compared to other people?
Alison2: I look sometimes at my friend who I go swimming with, she takes a lot of these what do you call 'em? From health food shops
Sister: oh heath things, that word, there's a special word she uses
HE: what like vitamins?
Alison2: is it organic? No not organic
HE: what homeopathic things or something?
Alison2: something to do with like natural stuff and what-have-you, and she always seems to be aching or tired or something, you know vitamin C tablets and what-have-you, and I don't take any vitamins or anything except just eat me food, and she watches everything on her diet because of her weight and also cholesterol. She never eats potatoes, always pastas and stuff like that and chocolate no sweet stuff, she'll have a yoghurt, but she eats a lot of fruit and stuff, but during winter time especially she's always really achy and what-have-you, and I always feel, well why take all that stuff if it's not doing you any good?

Echoing Davison et al. (1992), some participants drew upon fatalism and lay awareness of anomalous deaths and survivals to point out fallibility in the direct lifestyle-heart disease link, proposing that this awareness could be a reason for many people to continue an unhealthy lifestyle:

Yvonne (focus group 4b, 72yrs): the west of Scotland diet you know, I dare say, well I think we've got the second highest heart disease rate in Europe or something like that, so there must be something in it
Lorraine (52yrs): I think as you're saying though, it's not as clear cut as that, and what's easy is to point the finger at the lifestyle, if it wasn't for the fact that I'm sure all of you sitting round here can give you examples where there's they would say this was not the case. So I think people tend to get a little bit, "oh what the hell"

(laughter)
Wayne (69yrs): eating healthy foods has a lot to do with it...
Lorraine: but I'm meaning, you know it's not quite as simple as that, the correlations between the two things

A few participants implied that as their unhealthy lifestyle had not yet had a (noticeable) effect on their health, they saw no need to change, particularly when they had 'got away with it' for so long:

Fergus1 (72yrs): ...I drink and smoke, and I do all the things that are wrong, and every time I go for a- my wife- every time I go for a medical, er I come back from the medical, the doctor, I come back and I tell her, "how d'you get on?", I might leave the house with house with a wheezy chest and all that and this, and when I come back, say "my heart's fine, my chest is clear, my blood pressure's OK" and she's totally amazed, she' totally amazed at the whole thing. I'm the one that should be ill, you know
HE: so have you ever thought you know you say you do all the wrong things, have you ever thought therefore that you might be susceptible for heart disease?
Fergus1: not really no, it's too late to think about that isn't it? Erm no, no. Och aye, everybody thinks about it you know but, it's not- to be honest with you, it's not gonna stop me. I tried stopping- we both tried to stop smoking. I do drink to excess sometimes, you know, er...not just late now, you know

There were a handful of participants who shared this attitude of knowing the potential consequences of their lifestyle but due to no symptoms or clinical diagnosis of effects on their health, they were unmotivated to change. In some cases, even a diagnosis of increased risk did not motivate change, for example Alison2's raised cholesterol result:

HE: so how did you- what did you do to try and lower that- did you go on medication or anything?
Alison2 (55yrs): no, nothing. She told me- she asked me about my dairy intake, and er if I have butter on anything, I have lurpak and I have butter on! So you can see you teeth in it and if I have cheese, I have cheese. And she suggested I just stop having butter altogether, and I says, "well I can't eat bread with margarine on" I had enough eating bread dry when I had gall bladder troubles so- I honestly didn't do anything, I didn't go on to a diet or anything, I just ate me chocolate as usual! Me cream buns, I kept me butter on and everything and when I went back, it were bang on- in fact it were under what it should be, so that were it. naughty girl!

Alison2's view on her lifestyle was backed up by her second cholesterol test result that was lower despite making no changes to her diet. I asked Fred2 (aged 62) what would make him quit smoking, it seemed it would require a major event:

> Fred2 (62yrs): I don't know, it's funny that you should say that you know I keep looking to the future and saying oh you know, "what can happen that would make me stop?" Apart from maybe taking a heart attack you know, and then someone saying, "right you know, because it's smoking related, you've got to stop." But er no, I don't know um I keep looking for some purpose to say, "well that's it, you know I'll stop." So I've not reached that decision yet.

A few participants justified continuing an unhealthy behaviour as they concluded that the rest of their lifestyle was healthy so they could 'get away' with one risk factor, for example:

> HE: does it make you think about your risks of heart disease, do you ever think about that about smoking's effect?
> Beatrice (focus group 2, 75yrs): yes! But that's all I do!
> (laughter from other participants)
> Beatrice: of course you know about it, you read The Lancet, you read articles, you read, you know their findings and various drugs...

A couple of participants whilst aware of the risks from the lifestyle that they engaged in, seemed unable to apply this to themselves:

> Harold2 (63yrs): well here you know I said this before, I really can't understand why I took a heart attack, in the sense that I'd always worked, but then again I look back on my life, I think maybe the smoking and maybe taking a drink didn't help, you know because I was always active you know and I worked 7 days a week and you know
> HE: what is the sort of person that you see as the type of person that would have a heart attack different to yourself?
> Harold2: well, that's a good question in the sense that er...I would say a person that doesn't work, and smokes and drinks, and he's not getting any exercise, as I say I was always active in the sense that I felt when I was smoking and drinking I was getting it out o' my system
> HE: yeah
> Harold2: you know you can sweat drink out your system but I don't think you can sweat smoke. I think that my main concern I think is the smoking contributes to my heart attack rather than the diet because as I say I was off the drink for a year, when I took the heart attack you know. I don't think I live any kind o' life that would contribute to my heart attack in a sense you know except when I was smoking and drinking, but then again as I say it was 9 year after that I took that, but maybe it was a build up you know, you know in a sense that it was coming and I didn't know it, no

As illustrated, despite stating the main cardiovascular risk factors as smoking, drinking and being unemployed, and admitting that these factors applied to himself, Harold2 still questioned why he had a heart attack.

Altogether all participants showed an awareness of the risks of engaging in smoking, drinking, eating unhealthily and not being active. However, those that reportedly continued to engage in one or several of these behaviours provided justification or explanation for their behaviour ranging from awareness that certain individuals can 'get away' with such lifestyle without noticeable effect on their health, to admitting that engaging in such behaviours is enjoyable.

Scottish Identity

Many participants spoke about heart disease being a particular problem for Scotland, thus the Scottish identity was often regarded as increasing one's risk, or more often as an explanation of one's risk. Where participants did not raise this issue, I introduced the issue. In most cases the Scottish lifestyle, in particular diet, was seen as central to the problem, for example in focus group 1a:

> Aileen (67yrs, DEPCAT 2): but it's such a problem in Scotland isn't it, heart? (agreement)
> HE: do you think that- have you got any reasons for that?
> Aileen: diet, diet
> David (71yrs, DEPCAT 1): Scotch pies
> Aileen: pies
> Andrew (59yrs, DEPCAT 5): they say it's diet but we also drink a lot
> Aileen: we lived in England for 30 years, and we came back and I was on the bus going through Glasgow and the thing I noticed more than anything else was how fat people are, not everybody obviously, but the number of overweight people that I saw in Glasgow. Not just in Glasgow but I think this is something in Scotland

Other participants saw the diet as embedded in the culture:

> Richard1 (54yrs, DEPCAT 5): it's to do with diet, um I would think that's probably true, you know we don't eat a lot of things that help ameliorate it, but we do eat a lot of things that exacerbate it, you know I feel that's right you know. If we eat fish, we fry it in batter, and probably do it in lard or something like that, you know it's that kind of thing you know, I'm sure that's right. I wouldn't eat a lot of the sort of things that are probably better for you. and the lower income, the less likely we are to do it. You know I think that's probably true in the North of England to a certain extent as well. Um it's- its just traditional diets.

Similarly other participants felt that diet, and lifestyle, was passed on through families:

Miriam3 (73yrs, DEPCAT 1): aye there's hardly a week goes by then they're on about the bad diet and...
HE: what do you think about that?
Miriam3: I think that they're just bad habits, that they're brought up to have greasy chips and burgers and it's handed down from father to son, um I dare say it all started in the days when- there are lots of the foods that we take for granted now- just weren't available

Later...

Miriam3: I think it's what they've inherited...I think it's what they've inherited, poverty um lack of experience...I think they smoke more cigarettes than anybody else

Another participant and her husband reflected on the lifestyle that they had been brought up on, suggested a further explanation: the industrial history:

Amy2's husband (DEPCAT 3): generally as regards the West of Scotland I think there was always a bad diet we had in the West of Scotland, we were all the same, you know eating sliced sausage and bacon and egg and
Amy2: my mother used to say, "oh aye, the fat's good for your tubes!" (laughs) she didnae tell me it was blocking up my tubes
Husband: and fish and chips and things like that
HE: yeah
Husband: and the lifestyle generally you know
Amy2: go for a drink
Husband: heavy drinking, heavy smoking
Amy2: aye
Husband: and besides that, when it was an industrial area, it had all the pollution here
HE: yeah
Husband: you know so it's clean now but when we had all the ironworks and steel works and coal mines and coal fires

Whilst these two saw the environmental effects of the industrial history as important, another participant suggested the industrial history as affecting the pace of life and thus lifestyle:

Daniel4 (54yrs, DEPCAT 1):...they must do something in the west of Scotland, because the west of Scotland is bad
HE: yeah?
Daniel4: really, because it's an old industrial idea, they work shift work, eat at all hours, drink heavily, and that hasn't changed. The west of Scotland- the difference in between the west of Scotland and the east um, life's a lot slower on the east, the west of Scotland is what we call a rat race, they're always rushing about to get here to get this done

A fair number of participants attributed the Scottish diet to the climate; participants spoke about healthy food (typically salad) not providing sufficient warmth on a cold

Scottish winter evening, rather large helpings of hot meaty meals or fish suppers were needed. Similarly drinks of tea were seen as preferable to water. Interestingly a couple of participants felt that the climate had a more direct influence on physical health:

> HE: you mentioned before, about the Scottish diet and stuff, do you think that's a particular problem in Scotland?
> Monica1 (66yrs, DEPCAT 4): well I think the weather might have something to do with it as well, you know all the damp that we get, you know they say that's not very good for you. That and that's chest and heart I suppose you know.

Many participants regarded the bad Scottish diet as immersed in the widespread poverty particularly in Glasgow:

> HE: you said about the West of Scotland diet and so do you think that's all linked in?
> Moira1 (53yrs, DEPCAT 4): yes I do, I know that you know the deep fried mars bar joke tends to be overplayed, I also know that even in my lifetime, I mean when I was a little girl you just didn't see things like courgettes, they just weren't there. Um so in that sense I think um the lifestyle, the diet, the heavy smoking, the addiction to sweeties because we also have an appalling er record for tooth decay, that's really bad. Um there is a lifestyle there and I do think it's heavily linked with poverty, whatever anyone says, of course it's linked with poverty, it's linked with a lack of hope about having some kind of reasonable future in terms of employment and so on and so forth.
> HE: 'cause people talk about the Scottish diet, but the West of Scotland…?
> Moira1: I think it is possibly particularly the West of Scotland, and I think it's not everywhere in the West of Scotland, but I think Glasgow's one of these cities where you can lead a very pleasant middle class life and you don't need to see the nasty bits, if you see what I mean, you don't have to confront them and it's therefore perfectly possible to forget about them if you see what I mean.

A couple of participants went into great depth when discussing the influence of poverty on the lifestyle in deprived parts of Scotland, for example Owen4:

> Owen4 (52yrs, DEPCAT 6 but occupation suggests more advantaged):…And I think (the trial)'s just useful from the point of view in a further sense of getting the public to relate to medical research and the importance of it, and in the context of Scotland with the very sad medical history that we have as a nation you know I mean so it's even more important.
> HE: A few people have mentioned this Scottish thing about health and what- do you have any sort of opinions about that- why do you think it is?
> Owen4: well it's a deep seated cultural pheno- issue but er I mean I don't think it's gonna change overnight, I just hope that in the context of um what

has been achieved in other parts of Europe in terms of improving health that you know that we in Scotland could do the same.

Owen4 continued to go into great detail about the measures that Glasgow city council were undertaking and his opinion of them, but also mistakes he believed they had made, such as closure of swimming pools in schools. These extracts illustrate his points:

> Owen4: And I think that it's very easy for people like myself who're sitting there in their middle class lifestyle with a reasonable income and their kind of family and personal background, to take a family to places where they can learn to swim and where they can get exercise and encourage them to do it. I think it's very easy for folk in that situation to overlook the fact that for many people in Glasgow, given their personal and financial circumstances and their family circumstances, that they can't do that, they don't have the background in doing it, so you have to provide sports facilities and exercise facilities as conveniently to people as you can.

Later...

> Er you know because again it seems to be that these messages have got home to the more articulate better educated wealthier section of the community anyway, but they havenae got to the more deprived and disadvantaged section of the community in the same way and that raises the question that can you ever really solve all the problems in the health sector in Glasgow and parts of Scotland without solving the social problems that make people disregard their health in the first place. I'll shut up there!

Altogether whilst heart disease was seen as a particular problem in Scotland due to the typical 'unhealthy' lifestyle among other factors, the problem was seen as complex and embedded within historical, cultural and social issues, particularly relating to poverty, which were seen as very difficult to change, and an issue for those at the policy making level. However, several participants may have used the Scottish identity as an explanation for their own increased risk so as to remove some personal responsibility.

Clinically diagnosed risk

Several participants implied they would wait for a clinical diagnosis of risk or a condition considered a risk factor for cardiovascular disease before changing their behaviour. An example quoted in the screening chapter was Joyce4 who, despite being a smoker and admitting she could make other improvements to her lifestyle, considered herself at no risk due to a normal ABPI. For these participants there was

an implication of having 'got away with' their unhealthy lifestyle as there was no symptomatic or diagnostic indication that the lifestyle had had a physical effect.

Many participants seemed to treat clinical measures of blood pressure and cholesterol as a black and white issue: a cut off point above which was 'risk', and below which was 'no risk'. Several participants seemed to be particularly focused on the numbers, for example:

> Amy2 (76yrs): and very last thing at night, they said to me my cholesterol was 7.5, I think and I thought, "my cholesterol's never been 7.5" but I mean it had been 6.5, we got it down slightly but I now realise why I'm on it, I mean Dr C said to me, "well...your cholesterol comes from what you eat, and the rest of it is what you make in yourself" because when the two of us went onto a [diet] to- you know this was a while back, about the cholesterol, he [husband] went down and mine went up (laughs), so I thought, "well now I can understand why his maybe went down and mine went up because I'm making it"... so I take a tablet at night, pravastatin....So they give me a blood test every so often, er can check up whether- I don't know how they count it you know, if it's getting to high and so on
> HE: and how's that now, has it levelled off?
> Amy2: no, it hasn't nearly levelled off they never said it levelled off, but it's not going up high enough to take me off this stuff. I don't like- well I like taking the pravastatin because it certainly brings it down, my cholesterol's now down to 5.5...which is acceptable.

Focusing on the numbers of the results may have emanated from participants' GPs' use of the numbers:

> Graham3 (58yrs): I have a lot of time for my doctor I mean he's very meticulous... if you're one digit out, he will try and get that digit down to normal. He says "while you're here I'll just check your blood pressure and that "oh my God" he says, "that's far too high" and took blood sample and what-have-you, urine sample, made provisions for me to go to the (hospital)

A couple of participants spoke about these measures as being directly related to behaviour, for example Rebecca3 felt her blood pressure revealed how she had been behaving:

> Rebecca3 (73yrs): ...I go down to the surgery, I think I'm down there next month, sometime and erm she always takes my blood-, the nurse always takes my blood pressure, and then she might say- well the last time I was down there about 3 weeks ago...
> HE: uh huh

> Rebecca3: ...and I was just the same as I was the time before, but slightly a little bit up. Because if it's natural, I've been a good girl, but because it's up a bit, I haven't been very good! (laughs) this is our little joke you know.

Despite many treating cut-off points as black and white, members of focus group 4b discussed how there seemed to be inconsistency between the cut off points that different doctors used for diagnosis:

> Lucy (57yrs): so do you not check up every so often?
> Harriet (61yrs): I go maybe every 6 months I go...I used not- I never asked the number, it would just be "oh that's alright" and now it's like "well um what's the number?" then I realised what the numbers were, because what one doctor says is not always the same as another, one doctor might think that 140 over whatever 95 is fine whereas another doctor might think "well no it's not" 'cause they've done that before, one said totally different to another, you thought you were quite- but I wasn't at all. So I think there is a quite a wide difference in how doctors see blood pressure, I don't know maybe I was just confused I don't know about that
> Jed (57yrs): I always thought that it was fairly factual, that there was a clear-cut distinction that whether your blood pressure was low or high

Another participant noted how practice guidelines seemed to change regarding blood pressure monitoring:

> Keith (59yrs):...my wife, she's had to go for an ECG, because the doctor has changed their ideas about blood pressure at the practice, I mean before I- I went three or four times over a period of time, and they actually average out of things are done or not done. But now it seems that they send them off for an ECG, I think she's had her cholesterol checked, her blood was checked I think as well. I don't know all what they've done but they've done all that before. She said to the doctor about it, and he had said "well things have moved on a bit and we've changed our ideas. Before, if there was something wrong with you, "here you are, here's a pill" that's it. Now their idea is they want to check to see if there is something else wrong.

Such observations of perceived inconsistency and change could have reduced faith in such clinical measures, however the majority of participants who spoke about having the measures taken seemed to maintain trust in their GP's clinical judgement. Thus the idea of being diagnosed as having high blood pressure or not, i.e. as a black and white issue, seemed to prevail, and generally most treated such diagnoses seriously, considering it a risk and saw the need for prescribed medication.

ABPI:

In the screening chapter when presenting participants' differing reactions to their ABPI result, I illustrated how many participants had not treated the measure as a significant indicator of risk. To reiterate, several participants had misunderstood and/or did not recall the meaning of the measure, and others had confused the ABPI with standard blood pressure. Several participants, particularly those who had not anticipated being at risk, searched for alternative explanations for the result, and many latched onto phrases used by the research nurse such as "borderline" which seemed to help them minimise the amount of risk perceived from the ABPI.

Low significance of the ABPI, and thus low perceived risk from a low ABPI, was probably due to it being a novel measure compared to clinical measures of blood pressure and cholesterol. There were mixed understandings of what the ABPI measured and how this related to cardiovascular risk. Several participants struggled to make sense of the condition of atherosclerosis; Jennifer2 complained that it was not adequately explained:

> Jennifer2 (61yrs): all I'd like to have known was more myself about the furring of the arteries, because you werenae really told anything when you went there, they just done it, I heard for myself, she said, "did you hear that, there was a slow block" you could hear the block and then it was slow, so she says you're a candidate- but I'd like to have known, has it not got any other bit that's furring because, does you doctor know you go 'o that?

A few participants reported awareness of having poor circulation for many years and wondered whether and how this related to their low ABPI:

> Keith1 (59yrs): I mean since I've been young, my feet have always been cold, I mean I go cold quite quickly, so I've always had poor circulation in my feet, so I don't know if that's maybe that could be because my blood pressure is slightly higher?

Some made a link between the ABPI and their already diagnosed high blood pressure, for example:

> Cath (focus group 2, 63yrs): I was surprised because um I didn't expect to have any tendency to that because I'd always been quite physical active and you know and I was just surprised, but then I thought, "well if I've had high blood pressure for a while that would be the cause of it, the furring of the arteries

A few realised the impact of their lifestyle on the condition, for example a couple talked of the effect of a high fat diet on the arteries and a few participants realised the impact of their smoking:

> Peter2 (55yrs): I can always remember my father saying that "it greases your tubes", what he didn't know was that it furs up your tubes!

> Patricia3 (61yrs): ...when the girl told me that I did have erm arteriosclerosis in my foot, um then I was quite happy to take aspirin, but had I gone onto the trial and been given a placebo then I wouldn't have had that benefit
> HE: uh huh, so what um you said you were expecting to get this, why was that?
> Patricia3 well more or less because of the fact that I smoke...age group, and because of the fact I smoke.

Despite awareness of the condition, some participants expressed little concern:

> Peter2 (55yrs): I was hoping I would be alright, I think it was alright other than er I believe she told me that as I did smoke at one time sort o' thing you know because of that, I know smoking causes bad circulation
> HE: yeah so it was slightly lower?
> Peter2: slightly lower, that was she said aye slightly lower in the ankle than it was elsewhere, er and I certainly have noticed er a few years ago I found my feet were always warm now they're getting a wee bit colder. I mean they're no' cold freezing, you know.
> HE: how did you feel when she told you that at the time?
> Peter2: it didn't really bother me because she say well you're- I don't think it was giving her any cause for concern sort o' thing

But later in his interview Peter2 distinguished himself from those whom he considered prone to furring of the arteries implying lack of true awareness.

Overall there seemed to be much variation in participants' understandings of the ABPI and atherosclerosis. Some participants showed awareness of the link between lifestyle and furring of the arteries, and tried to make sense of the link with blood pressure, whereas many others struggled. In comparison to treating more widely known measures (blood pressure and cholesterol) as black and white issues with diagnostic cut off points signifying increased risk, participants seemed to focus more on the grey area regarding their ABPI diagnosis, for example as mentioned in the screening chapter, their "borderline status". This may have been related to their uncertainty regarding its meaning.

Summary: perception of cardiovascular risk

In this final data chapter I have presented factors that contributed to participants' ideas about cardiovascular risk, and how they seemed to use these factors to assess their personal risk. Family history of heart disease emerged as a particularly dominant risk factor; for many heredity appeared to be equated with inevitability. However, when applying this to one's own perceived risk, distinctions were often drawn between oneself and affected family members. Similarly, distinctions were made when comparing oneself to affected peers, often focusing on lifestyle differences. Awareness of the behaviours that increase cardiovascular risk was omnipresent; continuation of such behaviours was explained in terms of enjoyment, awareness of fallibility in the lifestyle-heart disease link, and lack of personal risk from lack of noticeable physical effects or significant diagnoses. Lifestyle was seen by some as embedded in Scottish culture and/or widespread poverty around Glasgow. The Scottish climate and industrial history were proposed as having both direct and indirect effects on health. Clinical diagnoses of blood pressure and cholesterol were generally accepted as markers of cardiovascular risk, indicated by numerical values. With the ABPI, participants focused on the grey area around a diagnosis of risk; this could have been related to the novelty of the measure and uncertainty regarding its meaning and the condition of atherosclerosis.

Chapter 8: Discussion

Introduction

A central underlying theme in participants' accounts when discussing screening, prevention, trial participation and cardiovascular health was that of risk; the risk that participants perceived seemed to be related to their decisions and/or actions, or certainly in their accounts of these. In this chapter, I will draw together the analyses of risk perception in the data chapters to highlight its importance in participants' reports of their behaviour regarding screening, preventing heart disease and participating in the AAA trial, and relate this to existing relevant literature.

Perceived cardiovascular risk was not the only risk that emerged as important regarding attitudes towards screening and prevention; perceived risk from medication, in particular aspirin also emerged as salient. This chapter will first focus on participants' perceptions of cardiovascular risk and how this related to attitudes towards screening attendance. Second, I will discuss the relationship between these perceptions of risk and participants' reactions to the screening experience. Third, I will discuss how participants' views about preventive medication related to their perceived cardiovascular risk and perceived risk from medication, in particular aspirin, and the interplay between these two risks. I will discuss how these two risks and their interrelationship related to attitudes towards participation in the AAA trial. Finally I will focus more generally on the notion of risk and its usefulness as a concept in research. To conclude, I will discuss implications of the findings for screening and prevention programmes and clinical trials, and for further research in a similar context.

Perceived risk and screening attendance

As demonstrated, 'at risk' results were often unanticipated; various other reasons were given for screening attendance. Exploring accounts and explanations revealed factors that seem to contribute to participants' ideas about cardiovascular risk, the type of

person regarded as susceptible to this risk, and whether they considered themselves at risk or not.

Davison et al.'s (1991) research into lay beliefs about heart disease identified and explored the notion of lay epidemiology: a dynamic process through which people interpret health risks by observing, discussing and noting cases of heart disease in their social network and as publicised through the media, resulting in an explanatory theory of the type of person likely to experience heart disease: a 'coronary candidate' (Frankel et al., 1991). Coronary candidacy comprised physical factors, social, occupational and environmental factors, and personal factors, but also the importance of family history of heart disease (Davison et al 1989; Emslie et al., 2000). Incorporated into coronary candidacy were noted fallibilities including unwarranted survivors, anomalous deaths, and recognition of the randomness of heart disease. Awareness of these fallibilities contributed to fatalistic feelings about heart disease (Davison et al., 1991) and challenged the efforts of health promotion.

As demonstrated in the data chapters, a very similar picture emerged in the present research in terms of participants' ideas about a typical coronary candidate. There was, however, a difference between the context of this and previous research: the present research explored participants' ideas about cardiovascular risk within the context of a screening programme and a preventive medicine trial, thus both the context, the population (people invited to screening), and the topics covered in the interviews (screening, preventive medication and the AAA trial) placed a different angle on the topic, despite still focussing on heart disease.

Davison et al. (1991) described how the coronary candidacy mechanism operated in four ways: retrospective explanation of other people's cardiovascular illness or death, retrospective explanation of one's own cardiovascular illness, prediction of other people's cardiovascular illness or death, and assessment of one's own risk of cardiovascular illness or death. The latter is particularly pertinent to the context of the

present research; the activity of assessing one's own risk of cardiovascular disease appeared to have been provoked or at least heightened by the invitation to a screening. From participants' accounts, the main factors that emerged of their ideas about coronary candidacy will now be discussed and I will consider how these appeared to relate to their own expectations of risk and screening attendance.

Family history

Family history of heart disease and the influence of genes were discussed by many participants, many of whom appeared to regard this as the most dominant factor, generally equating heredity with inevitability. Those who reported having heart disease "in the family" gave this as a common reason for screening attendance. Some participants with no perceived personal family history mentioned not needing to be as concerned about other risk factors (such as the ABPI) as those with. Furthermore "coming from good stock", i.e. from a family of "long livers", was regarded as an advantage; participants described such individuals as fortunate due to their apparent ability to "get away" with unhealthy behaviours. Participants were divided about the extent to which they believed lifestyle could counteract the power of heredity.

These findings echo those of Emslie et al. (2001) and Davison et al. (1989) who found heredity spontaneously mentioned by two thirds and a third (respectively) of their participants as an important determinant of heart disease and health status (respectively). Davison et al. (1989) divided participants' views of how heredity operated into three groups of meaning regarding what was inherited: discrete physical attributes, one's constitution, personality and behaviour. Participants in the present research seemed to imply similar meanings; genetic dominance was particularly common possibly due to the increasing amount of media coverage of genetic influence, for example the surge of media articles surrounding the human genome project. Regarding one's constitution, length of life was significant for some who reported wondering if "history would repeat itself". Inheriting personality was less discussed, but the idea of 'inheriting' behaviour

featured particularly when discussing the typical Scottish diet, demonstrating a cultural component to notions of heredity.

In a quantitative study, Hunt et al. (2000) reported that people who perceived themselves as having a family history of heart disease were more likely to perceive themselves at risk personally and to see behavioural factors as important in the development of this disease. However, qualitative research by the same researchers revealed that perceiving oneself to have a family history did not always lead to perceived personal risk and was not a straightforward dichotomous construct (Emslie et al., 2001). Factors that complicated predictive ability included making distinctions between the risk applied to one's family as a whole and to oneself personally, looking for patterns in the number of affected relatives, and discounting 'elderly' cardiovascular deaths. Similarly, Davison et al. (1989) found that participants described two different sides of their family, and individuals as "taking after" one or the other side. Thus, despite evidence of a family history of a disease, an individual's personal risk seemed to depend on their perceived similarity to the affected side. This was further complicated if individuals were regarded as taking after one side regarding one factor (such as build), but the other side regarding a different factor (such as temperament) (Davison et al., 1989). As discussed, there was evidence for most of these ideas in participants in the present research; assessing family history of a disease and its perceived relevance to each individual appeared to be a complex process. However, participants usually seemed to have reached a conclusion of either perceiving having a family history of the disease or not. Furthermore, assessing one's own family history seemed to be subjective; events and cases seemed to be interpreted in a way that fits with how a participant wanted to perceive them, thus could reinforce their low risk perception or their feelings of inevitability. The presence of family history was thus subject to very different interpretations.

Regarding perceived family history's relation to behaviour, Davison et al (1989) suggested four possible ways in which those who have assessed their own personal risk of inherited heart disease could apply their conclusion to decisions about lifestyle. Those

who perceive an inherited risk could a) decide to engage in a healthy lifestyle to prevent further increasing their risk, or b) decide that due to their risk there is no point engaging in a healthy lifestyle. Those who perceive no inherited risk could a) decide to engage in a healthy lifestyle to maintain low risk, or b) feel that their lack of inherited risk will allow them to get away with an unhealthy lifestyle. These were not proposed as discrete, explicit and conscious decision making processes, rather that the logic of these conclusions is echoed in discussions of their thoughts on family history (Davison et al., 1989). Similar logic was apparent in accounts of several participants in the present research.

Fatalism

Fallibilities of the coronary candidacy, outlined by Davison et al. (1991), emerged in participants' accounts in the present research illustrated by similar examples. The recent death of a local young footballer served as a particularly salient case that participants used to demonstrate the randomness of heart disease and an unwarranted death, and several cases were presented fitting the '90-year-old fat smoker' (unwarranted survivor). Whilst fatalism was proposed as inhibiting screening attendance in 'others', for participants who demonstrated fatalism in their own accounts, it had not inhibited attendance. It did however appear to contribute to ideas about personal susceptibility; for some, "not knowing what lies round the corner" seemed to justify maintaining unhealthy behaviours.

More subtle indications of fatalistic beliefs in the form of recognition of influences that individual effort cannot overcome included luck or chance, genes, the social environment and the physical environment (Davison et al, 1991). Perceived genetic dominance has been discussed. Assessment of one's own family history of heart disease can lead an individual to realistic perceptions of their own risk, but believing that heredity is an influence insurmountable through individual effort demonstrates fatalism, and, as mentioned, could inhibit preventive behaviours thus increasing one's risk further. Also, any cardiovascular events that occur are likely to be attributed to heredity rather

than personal behaviour. Regarding the social and physical environment, Scottish identity emerged as a commonly discussed risk factor. Socially, poverty (in particular around Glasgow) and the constraints upon lifestyle that it brings was brought up; participants described social disadvantage as extremely difficult for those affected to escape, without effective policy intervention at the local or national level. Thus, while not talking fatalistically about their own life, they recognised the potential impact on the more disadvantaged. Physically, the cold, damp, and dark climate was given as a reason for the high prevalence of heart disease in Scotland, both as a direct influence on health (although it was not clear exactly how), but also indirect through a diet higher in fat and volume to keep one warm. This seemed to be brought up in a fatalistic manner. Furthermore, the West of Scotland's industrial history was suggested by some as influencing inhabitants' health both directly and indirectly through lifestyle, with no clear operational explanation.

Lifestyle

All participants demonstrated awareness of lifestyle behaviours that increased cardiovascular risk. However, this did not mean that all participants followed this advice; it is a well documented finding that awareness of the risks from lifestyle is rarely sufficient in provoking lifestyle change alone (for example Lupton, 1993; Gabe, 1995). Many participants reported improving their lifestyle since they retired, had reached their fifties or sixties, or after a cardiovascular related diagnosis or event, and several admitted they could make further improvements. Others continued to engage in one or more unhealthy behaviours, explaining this as due to enjoyment and awareness that the behaviour was not the only risk and would not necessarily lead to a cardiac event. Others referred to "getting away with" unhealthy behaviours and having "lasted this long" without noticeable effects on their physical health.

The importance of the social and cultural context of upbringing emerged in generational comparisons of lifestyles. When reflecting on the post-war diet and rationing, some participants realised the likelihood that the dairy products in this past diet probably

contributed to their current high cholesterol and furring of arteries. Others deemed it healthier than today's generation's typical diet. Further generation differences focused on the benefits of "haeme (home) made" food compared to today's culture of 'ready meals'. Echoing Ruston and Clayton (2002), this seemed to be related to ideas about morality: the act of working hard to produce a homemade meal seemed to be equated with healthiness.

Age

Despite many participants advocating cardiovascular risk screening at age 50 (or 40), being fifty plus did not necessarily mean that participants considered themselves a candidate. Cardiovascular events in the 70s and 80s seemed to be explained due to "old age" rather than family history or other risk factors, echoing previous work (Rogers et al., 2000; Emslie et al., 2001). A few participants explained their own diagnosed increased cardiovascular risk as due to their increasing age. So it seemed that age was used more to explain events and diagnoses retrospectively rather than as a risk factor to consider in ideas of likely candidates.

Despite widespread awareness of cardiovascular risk factors as illustrated, several participants did not seem to apply this awareness to themselves, thus not considering themselves at risk. The screening chapter demonstrated several key beliefs that relate to risk perception that appeared to have influenced screening attendance: fatalism (as discussed), optimistic bias, denial and perceived lack of necessity.

Optimistic bias and perceived cardiovascular risk

As demonstrated, optimistic bias regarding heart disease was common in participants' accounts of their own beliefs (usually referring to their past beliefs) or the known or suspected beliefs of others. Optimistic bias is a difficult barrier for health promotion to overcome. The asymptomatic nature of the indicators of cardiovascular risk could contribute to or reinforce this belief, as lack of experience of a particular illness has been associated with optimistic bias regarding that illness (Weinstein, 1987). Ideas about

coronary candidacy are likely to reinforce optimistic bias if a typical candidate is perceived as distinct from how an individual views themselves. Indeed, some participants described comparing themselves with others, which often seemed to have led to a belief along the lines of, "it happened to them, but it won't happen to me". Such self-other comparisons included participants distinguishing themselves from affected family members by attributing events to other risk factors that they perceived not to share themselves. Also participants reported cardiovascular events in their peers of the same age as having triggered personal risk assessment, but they typically perceived themselves as leading a healthier lifestyle than the affected peers, or attributed events to non-shared factors such as family history.

Optimistic bias may have led participants to search for factors on which they could distinguish themselves from affected family members or peers, or conversely such comparative assessment may have led to optimistic bias. Such optimism, however, may not have always been unrealistic, participants may have been fairly accurate in their comparisons. Other participants' personal risk assessment led to *high* perceived risk. Applying optimistic bias to screening, it seemed to have inhibited participants from attending other health checks, and some 'known others' from attending the AAA screening. It thus remains a barrier for health promotion and screening uptake.

Denial, avoidance and lack of perceived necessity

Not wanting to know one's cardiovascular risk was suggested by many participants as a reason for non-attendance at screening, usually when discussing other people, both in general and specific cases. "Not wanting to know" was suggested as masking suspected increased risk, thus denial could prevent facing the reality of one's risk. The analysis also suggested that such avoidance was related to unwillingness to make changes to one's lifestyle.

Participants described, often with hindsight, how the asymptomatic nature of undiagnosed cardiovascular risk inhibited screening attendance. Most participants saw

the benefits of regular 'MOT' style check-ups but consulting a GP to check on one's health whilst asymptomatic is not a typical consulting style in Britain; rather consulting requires symptoms. Non-attendees at bowel cancer screening (McCaffery et al., 2001) reported two consequences of lack of symptoms: perceived lack of necessity of screening, and avoidance of thinking about the illness thus preventing psychological harm. So in fitting with other conditions and research, it seems that as long as one feels healthy, worrying is considered unnecessary and, borrowing another common phrase, "ignorance is bliss". Furthermore, participants talked negatively and distinguished themselves from frequent consulters or "hypochondriacs" seemingly to emphasise their own healthiness, echoing Blaxter and Paterson (1982) and the connection between health status and moral worth.

To summarise this section, the present research demonstrated evidence of a very similar coronary candidacy mechanism to that depicted in previous research (Davison et al., 1989, 1991; Emslie et al., 2000, 2001; Hunt et al., 2000, 2001; Hunt & Emslie, 2001). Risk factors particularly salient in participants' accounts included personal factors (especially family history of heart disease and lifestyle), social factors (particularly Scottish identity) and physical factors, awareness of the randomness of the disease was also incorporated. Participants drew upon these factors when considering and discussing their own perceived risk, but there was variety regarding which particular factors different participants drew upon and in the importance attributed to each factor. Beliefs which participants reported as inhibiting screening attendance both in themselves (past or present) and in others included optimistic bias, fatalism, denial, avoidance and lack of perceived necessity. These beliefs seemed to serve to minimise the level of perceived risk. Some participants reported engaging in such personal risk assessment as a result of a trigger such as a cardiovascular event or diagnosis in an acquaintance, relative or personally. When the experience was that of a known other, participants often compared themselves with the affected individual regarding risk factors. For others, risk assessment seemed to have been provoked by being invited and/or attending the screening; for example a few participants reported not having considered their risk of

heart disease prior to the screening. This points to the possibility that being invited to screening, regardless of whether one attends or not, could increase worry and anxiety from the personal risk assessment the invitation may provoke. Thus, whilst the goal of screening is to improve physical health, it also has the potential to cause psychological harm. Shickle and Chadwick (1994) writing on the ethics of screening stated that screening casts doubt over our 'healthiness' and has the potential to provoke anxiety until a healthy result is received.

Perceived risk and the screening experience

This section moves on to participants' reactions to and interpretations of the screening experience and result; these were related to their expectations and perceptions risk discussed in the first section.

Participants who received a 'healthy' ABPI result were very positive about screening in general and their AAA trial screening experience possibly met their expectations of their healthiness. Some of these reported receiving the reassurance that they had sought, rather than having anticipated any personal risk echoing previous research (Howson, 1998). For a few, a 'certificate of health' effect was apparent, i.e. a healthy result provided 'false reassurance' and a green light to continue their unhealthy lifestyle (Tymstra & Bieleman, 1987). Thus, despite awareness of the riskiness of their lifestyle, the fact of no noticeable physical effect of their behaviour had led to little perceived risk. Awareness of unwarranted survivors may have contributed to feelings of personal invulnerability.

Thus, for some participants, a clinical diagnoses of risk seemed necessary to provoke personal risk perception and is perceived differently from riskiness of unhealthy behaviours. This highlights the problem of asymptomatic conditions such as atherosclerosis: the tendency to wait for a clinical diagnosis before perceiving oneself at risk, added to the tendency not to consult one's GP for a clinical measure unless

symptomatic, is dangerous due to the fact that conditions such as atherosclerosis can progress to a severe level whilst asymptomatic. Furthermore, without symptoms or a clinical diagnosis, some individuals will see less need to change from an unhealthy lifestyle, thus their maintenance of smoking and other behaviours that increase cardiovascular risk, will continue to increase their risk.

The importance of pre-screening beliefs was highlighted. Some participants who had not anticipated being at risk, in reflection, appeared to re-interpret their pre-screening beliefs and perceptions about their healthiness and risk to find plausible explanations for their unexpected result. Some realised the contribution of their lifestyle, past and/or present thus acknowledging some responsibility. Others drew upon more fatalistic explanations such as heredity or increasing age, perhaps easier than admitting personal responsibility and blame. Many participants maintained their pre-screening low perceptions of risk despite receiving a low ABPI; for example drawing upon alternative (false) explanations. Lack of significance attributed to the ABPI can be explained in terms of issues with recall and understanding of the measure or of atherosclerosis, factors about the screening experience, in particular the nurse-participant dialogue, and perceived attitudes of a nurse or GP. Aspects of the nurse-participant dialogue that were latched on to, such as a "borderline" ABPI, indicated that these participants seemed to be using these particular memories to minimise the risk perceived from their result. This highlights the issue and difficulty of ensuring that participants are fully informed of their risk. Regarding communicating screening results to the participant, the middle ground of ensuring full comprehension of the meaning of the result without causing anxiety seems to be a difficult task.

Duncan et al. (2001) discussed how women who were diagnosed with Chlamydia through screening reinterpreted their meanings of the disease to maintain their image and avoid stigmatisation. Whilst atherosclerosis and cardiovascular risk lack the same type of stigmatisation as a sexually transmitted disease, there may be some stigma. Previous research (for example: Blaxter and Paterson, 1982; Cornwell, 1984)

demonstrated the negative connotations associated with being an ill person and the moral significance attached to maintaining one's healthy status. Thus, by maintaining an image as a healthy individual, individuals avoid such negative social evaluation. Being labelled "hypertensive" has been associated with increased psychological distress (Irvine et al., 1989), but less adverse effects were reported from labelling with high cholesterol (Irvine and Logan 1994). The distinction was suggested as relating to differences between the associated perceived control of each condition, with cholesterol regarded as more under the individual's control (Irvine and Logan, 1994). In the present research, there seemed to be mixed views about perceived control over atherosclerosis. Regarding causality, there was awareness that lifestyle factors under individual control can cause furring of the arteries, but there was also a high perceived dominance of heredity, environment and culture, typically seen as beyond the individual's control.

Current screening available includes national cancer screening programmes, and general health check-ups in the workplace or at 'well man/woman' clinics at surgeries. A couple of participants divulged having more fear of cancer than of heart disease, echoing previous research (Emslie et al., 2001; Nic Gabhainn et al., 1999; MacFarlane & Kelleher, 2002). Despite awareness of the randomness of heart disease, it may still be regarded as more under individual control than cancer in terms of risk factors, and so less feared.

Comparisons of perceptions of the ABPI with other clinical measures revealed interesting meanings and interpretations of the different measures amongst research participants. Regarding cholesterol and blood pressure, both were generally perceived as indicating significant risk, participants seemed to treat cut off points as a black and white issue, despite the continuum along which measures fall. In contrast, for the majority, the ABPI measure was a novel concept, and there was confusion in people's knowledge of atherosclerosis, in particular regarding the link between circulation and the heart. Rather than black and white, there was more emphasis on the grey area around the cut off point. It is probably the case that acceptance of the ABPI as a marker of cardiovascular risk

and increased awareness of atherosclerosis will take time to filter into lay knowledge; use of the measure in general practice would increase awareness, and the present findings imply that use by a known GP would increase its perceived significance. Participants knew that this ABPI screening was part of a trial, which may have had implications regarding their perception of the measure; this awareness and the novelty of the measure may have led to the perception that the measure was on trial and thus not considered significant.

This section discussed how pre-screening beliefs were an important factor in participants' reactions to the screening and their result. When the screening result met expectations, these beliefs persisted, and false reassurance was found in a minority. There was a variety of effect on risk perception in those who experienced a mismatch between their expectations and result: risk perception changed in some, by reinterpreting their prior beliefs to make sense of their low ABPI. Others maintained their pre-screening beliefs about their healthiness, drawing upon alternative ('false') explanations for their result. Aspects of the screening experience such as the nurse-participant dialogue seemed to minimise their perception of personal cardiovascular risk. Participants' meanings of the ABPI result can explain why many did not see it as a significant risk. Risk was often not perceived until diagnosed by a clinical measure. But whilst measures of blood pressure and cholesterol were accepted as signifying a risk which required treatment or lifestyle change, the ABPI was less accepted. The novelty of the ABPI, in particular its lack of use in current primary care, appeared to contribute to its lack of perceived significance. In addition, atherosclerosis appeared not to be regarded as overly concerning particular in comparison to diseases such as cancer.

Prevention, preventive medication and perceived risk

The first two sections discussed how participants' attitudes to screening and their reaction to and interpretation of the screening experience related to and was embedded within their perceived cardiovascular risk. This section discusses how participants'

perceived risk appeared to relate to their views about prevention, in particular aspirin as a preventive medication. Rather than focusing on perceptions of cardiovascular risk only, perceived risk from medication and the possible conflict between these two areas of perceived risk are also considered.

Perceived risk from medication

I demonstrated earlier how despite voicing phrases such as, "prevention is better than cure" regarding heart disease, many participants' accounts revealed lifestyles that differed from this, rather indicating a "prevention is better than cure, *but*" viewpoint. Central to this there seemed to be a dislike of medication. This related to perceived risks from medication relating to one's physical health, well being and social appearance. First, participants discussed potential adverse side effects from medication. While some participants felt that adverse effects depended on the particular drug, the dose and the individual's "constitution", others considered all medicines harmful. This echoes findings from research on patients' meanings of medication, particularly when exploring adherence and non-adherence to medication, for example negative properties of medication (Britten, 1994). Second, some expressed fear of the risk of becoming dependent on medication. Third, for many participants, medication seemed to signify transformation from a well person to an ill one, which had negative connotations, was thus a risk to be avoided. Britten (1994) identified fear of shame and labelling as 'ill' as the negative orientations her participants had towards medication; Blaxter and Paterson (1982) found that women presented themselves as not giving in to illness, and preferring to avoid medication in favour of a 'mind over matter' approach to cure. Similarly, many participants in the current research distinguished themselves from "pill poppers" about whom they expressed negative attitudes; they seemed keen to be regarded as healthy, which could be related to positive social and moral evaluation.

Perceived risk from aspirin

Most participants showed awareness of at least one possible risk from aspirin in the form of specific side effects to aspirin or risks of medication in general. For some participants,

the possibility of side effects (with and without knowledge of personal susceptibility) was sufficient risk to lead to avoidance of aspirin. Many others appeared to regard aspirin as a 'special case'; contributors to this included its status as a longstanding and common drug, old wives' tales and current hearsay about its benefits. Associated with this apparent special status seemed to be low risk perception. For some, risk was lessened due to the low dose, soluble or sugar-coated forms of the drug. For others, optimistic bias seemed to explain their low perceived personal risk as they talked about side effects happening only to those people who were 'susceptible', and distanced themselves from this group.

Bissell et al.'s (2001) study of reactions to a scare with a non-prescriptive medication led the authors to conclude that regarding non-prescriptive medicine, there is more trust, lay reskilling and reflexivity than risk society theories would suggest, rather than that specific health scares lead to occasional episodes of such thinking. Aspirin is both a non-prescriptive and a prescriptive medication; its over-the-counter status seemed to contribute to its perceived safety by participants. Whilst unlike Bissell et al.'s (2001) research, interviews were not carried out before and after a real scare so it was impossible to investigate participants' direct reactions to a scare, however, participants did mention 'scares' publicised through the media. Some participants emphasised their continuing faith in the benefits of aspirin whilst indicating awareness of publicised scares. Similarly Bissell et al. (2001) reported how participants continued to use the hayfever medication following the scare due to their belief in the therapeutic benefits. Media coverage of possible risks from aspirin had contributed to increased awareness, however, such instances did not seem to have led to great concern. Indeed, some participants were quite critical of the media's take on health risks particularly regarding mixed messages and reported discounting such information in favour of an "a little of everything in moderation" approach. Applying lay epidemiology to beliefs about aspirin, the data demonstrated how input came from participants' own experience and that of their family or friends, their GP's attitude, and media coverage. Multiple sources of

competing information can create difficulties for the layperson in establishing the 'real facts', particularly when sources are 'expert' (Bissell et al., 2001).

Cardiovascular risk versus risk from aspirin

For some participants, willingness to take aspirin despite dislike of medication may have resulted from weighing up the potential risks and benefits of aspirin against the potential risks and benefits of *not* taking aspirin. Such deliberation was explicitly discussed in a few participants' accounts. The situation of increased cardiovascular risk seemed to outweigh the potential risks from medication for some participants who normally would have actively avoided medication. Britten's (1994) participants similarly reported balancing risks and benefits when making decisions about appropriate use of medication; she emphasised the importance of situational and contextual influences on this process.

Perceptions of the necessity of medication emerged as what seemed to be the deciding factor regarding acceptance of medication. Participants had particular ideas regarding necessary medication, such as that which kept them alive, whereas medication described as being taken "for the sake of it" and people associated with this such as "hypochondriacs", seemed to be frowned upon, including use of over-the-counter medication such as vitamins and some preventive drugs. Generally, ongoing conditions, including high blood pressure and high cholesterol, and acute symptomatic episodes were deemed necessary, but for many atherosclerosis as diagnosed by the ABPI was not. The idea of preventive medication use as an alternative to making changes to one's lifestyle was rejected by the majority of participants. Rather, once diagnosed with a risk it was generally considered that one should change all aspects of one's lifestyle, again emphasising the necessity of a clinically diagnosed risk to provoke preventive behaviour, including medication use. Perceptions of necessity seemed to be influenced by participants' GP, linked to trust and faith, again echoing Britten's (1994) participants, several of whom reported taking "whatever the doctor prescribed". Other research has described the increasingly assertive and inquisitive public as less trusting and more

critical of medicine (Vaughan & Seifart., 1992; Williams et al.,1995); Bissell et al. (2001) regarded mistrust and awareness of science's limitations as giving rise to lay reskilling. In the current research some participants displayed mistrust towards medication, but there was little expression of mistrust of doctors.

This section has discussed the relationship between participants' perceived risk (both cardiovascular and from aspirin) and their views about prevention of heart disease, specifically aspirin as a preventive medication. Seemingly positive views towards prevention of heart disease were compromised by perceived risks from medication. Despite these views, willingness to take aspirin revealed the drug's seemingly special status as safe and trusted, and from weighing up cardiovascular risk against risk from aspirin, the latter typically was regarded as more controllable in the event of its occurrence. Risks of aspirin, as publicised through the media, had increased awareness but had generally not led to great concern. Ideas about necessity, which related to participants' meanings of the ABPI measure, emerged as a critical factor in the weighing up process.

Distinctions from previous literature regarding lay attitudes towards medication (such as Britten, 1994; Bissell et al., 2001; Benson & Britten, 2002) include both the preventive purpose of the medication and also the trial situation of this current research. Despite many participants' assumptions, aspirin's efficacy in preventing cardiovascular events in those with a low ABPI remains unknown until the results of the AAA trial are known. This presents a different situation in that whilst participants may indeed weigh up their ideas and perceptions about risks from aspirin against cardiovascular risks without aspirin, the actual risks are still to be quantified.

Trial participation and risk perception

The previous section discussed participants' attitudes towards taking aspirin as a preventive medication in terms of how this related to their perceptions of cardiovascular

risk, perceptions of risk from aspirin and the interplay and weighing up of the two types of risk perception. Attitudes towards participating in the AAA trial were rooted in the same beliefs and perceptions of risk, with additional factors such as altruistic feelings adding to the potential influences on an individual's decision to participate. This section will discuss how participants' perception of risk, both cardiovascular and from aspirin, appeared to affect participants' decision regarding participation in the trial, and how the two perceptions were weighed up against each other and against other factors.

Participation decision and weighing up risks

For many participants, attitudes towards trial participation were embedded in their perceptions of personal risk. In considering this relationship, it is useful to reflect on the different decisions participants made and compare and contrast the perceptions between those who made different decisions. However, in doing so, it is evident that there was no straightforward pattern between level of perceived cardiovascular risk and decision made; indeed two participants could perceive very similar personal cardiovascular risk but make opposing decisions, and two participants who made the same decision could hold very different perceptions of risk. I will consider participants' attitudes by dividing them into groups depending on their decision regarding participation and their perceived risk.

For participants who received a low ABPI but declined to participate, explanations were varied and revealed differing perceptions of personal risk. For a couple of participants the discovery of their low ABPI provoked the perception of increased risk for which the trial situation offered them no solution, so rather than enter the trial they engaged in alternative solutions. For a few of these, perceived cardiovascular risk was high compared with potential risk from aspirin, thus they sought aspirin themselves. For others, heightened perceived cardiovascular risk was equalled by a high perceived risk from aspirin, so rather than declining to participate for the purpose of guaranteeing receiving aspirin, they declined, in order to avoid any possibility of receiving aspirin. So, for these participants, high perceived cardiovascular risk appeared to lead to declining to

participate in the trial, but choice of subsequent action seemed to be affected by perceived risk from aspirin. At the other end of the spectrum, participants declined to participate in the trial, or stopped taking the trial tablets, due to *lack* of significant risk perceived from their low ABPI result. Unlike those described above, they neither made changes to their lifestyle nor sought medication. Their own explanations included being too late for any action given their age, perceived invulnerability and dislike of medication.

Moving onto those who chose to participate in the trial, some of these perceived significant risk from their low ABPI. Contrasting their accounts and views with the participants described above (for whom perceived risk had led to declining) revealed apparent differences between the two groups' understandings of the trial procedure. Those who had declined demonstrated a more accurate comprehension of the RCT process (including the randomisation of treatment allocation) than some of those who chose to participate. This implies that some participants who perceived high risk from their low ABPI may have believed they were benefiting from their participation and that their risk was being controlled through believing they were receiving the aspirin. Other trial participants indicated little significant risk perceived from their low ABPI. Rather, their reasons for participation included altruistic feelings, recognition of need for the trial, a "why not?" attitude, and the belief that the trial tablet would at best help their health. The lack of significant perceived risk from the low ABPI raises the possibility that given a more accurate understanding, these participants may have chosen to decline to enter. The willingness of this group to take the trial tablet also indicated they felt little or no perceived risk from aspirin.

Altogether there was no straightforward relationship between perceived risk and decision to participate. Whilst a participant's decision regarding participation was related to and explained in terms of level of perceived cardiovascular risk, the relationship between the two differed from participant to participant. Furthermore, the decision was also related to perceived risk from aspirin, and other factors including

understanding of the trial and altruistic feelings. The decision was thus very complex. The wide range in perceptions of risk from the ABPI within those who were diagnosed with a low ABPI further emphasises the importance of effectively communicating the meaning of novel clinical measures such as the ABPI to the layperson.

Preference for aspirin

As described above, some participants disliked the randomisation element to RCTs; many participants revealed a preference for the aspirin over the placebo. This preference was acted on by some in a variety of ways, or for others it remained a preference not acted upon; action appeared to be related to participants' personal perceived risk (both cardiovascular and from aspirin).

As discussed, the strongest preference for aspirin over the placebo was demonstrated by a couple of participants who were eligible for the trial but declined to participate, rather seeking aspirin themselves. Previous literature has found only a small number of participants to explain their non-participation in trials as due to dislike of the placebo and trial procedure (Schwarz & Fox, 1995; Mohanna & Tunna, 1999), however another qualitative study found a strong preference for the experimental treatment expressed by those actually participating (Snowdon et al., 1997). The preference for aspirin over the placebo was expressed by and emerged in the accounts of AAA trial participants; these same individuals reported taking their trial medication and mentioned no intention to stop, despite this preference. There are several possible explanations for their continued participation. First, many of these participants seemed to perceive little risk from their low ABPI result, so the preference for aspirin may have been regarded as requiring action only in the case of perceived high risk. Second, despite showing apparent awareness of the 50% chance of receiving aspirin, some participants implied that they believed that they personally were receiving the aspirin. For some, their suspicion had been reinforced by the occurrence of minor side effects such as increased bruising. Similar 'therapeutic misconceptions' have been reported in previous qualitative studies of trial participation (Appelbaum et al., 1982; Snowdon et al., 1997; Featherstone &

Donovan, 2002). Participants in a prostate trial demonstrated awareness of the trial design but struggled to accept and make sense of it (Featherstone & Donovan, 2002). This was echoed in the accounts of AAA trial participants, some of whom seemed to demonstrate a good understanding of the RCT design but elsewhere in their account implied otherwise.

Expressing that one was owed the aspirin due to willingness to participate and one's "good" nature echoed moral overtones about being owed the experimental treatment expressed by parents of neonatal babies in a trial (Snowdon et al., 1997). Believing that one is receiving the aspirin may be a method of making sense of the unfairness perceived about the RCT procedure.

Assumptions about aspirin

The commonly expressed preference for aspirin revealed the ubiquity of two assumptions about aspirin: its efficacy regarding cardiovascular health and its safety. Regarding the former, many participants had not distinguished between aspirin's use for established heart conditions and that being tested in the trial, i.e. as a preventive medication in those with early atherosclerosis. This assumption led a couple of participants to question the need for the trial. However, until the results from the AAA trial are analysed and reported, the efficacy of aspirin as a preventive medication for those with atherosclerosis as diagnosed by a low ABPI remains unquantified. So this assumption made by many participants, albeit common, remains unproven. The ubiquity of the assumption of efficacy of the experimental treatment relates to misunderstandings of clinical equipoise (Featherstone & Donovan, 1998; 2002; Robinson et al., 2003). Even with a full explanation of the state of clinical equipoise, people found the possibility of clinical uncertainty amongst doctors about the best treatment unacceptable (Robinson et al., 2003); the assumption that the doctor will always act in the patient's best interest seems to prevail (Appelbaum et al., 1982; 1986). However, one participant's comment that unless epidemiologists had a strong suspicion of aspirin's

efficacy for this particular use, the trial would not be in process, may indeed be well-founded; does clinical equipoise really exist in this particular situation?

As noted earlier, assumptions of aspirin's perceived safety seemed to have arisen from views of its longstanding and common status, old wives' tales and current hearsay. Its longstanding status certainly seemed to have influenced participation in some cases: a couple of participants commented on how they would have been more wary about participating in a trial of a new and unknown drug. Snowdon et al. (1997) also found few concerns about risk of the experimental treatment in the parents' trial, which unlike aspirin, was a treatment new to the UK; parents did, however, report awareness of the treatment's use overseas and the trial was a potential life and death situation unlike the preventive nature of the AAA trial.

As discussed earlier, when explicitly weighing up the risks from aspirin against cardiovascular risk, several participants stated that the potential risks from the trial tablet could be dealt with if they occurred. This indicates that in addition to perceived safety and trust in aspirin, participants' accounts implied trust in the trial itself, including monitoring and safeguards in place to deal with adverse effects or events. Snowdon et al. (1997) suggested that the trust in the trial that their participants demonstrated could have been one way of making sense of the randomisation process which the majority considered unfair; the same could apply to AAA trial participants. Other perceptions of trust were directed to one's GP, similarly GP approval has been reported as contributing to perceived safety of past trials (Fouad et al., 2000; Daugherty et al., 1995). Others indicated trust in the University as an institution running the trial or the British Heart Foundation funding the trial, in particular compared to drug companies for whom much mistrust was expressed.

Adverse effects attributed to the trial tablet or cardiovascular events had apparently not affected participants' trust in the trial; neither blame on the trial nor a negative attitude towards aspirin was expressed by any of those affected. Similarly, participants who had

stopped the trial medication due to changes in their cardiovascular health, expressed no blame on the trial for not having prevented their event. Thus, it seemed that trust in the trial was strong and prevailed. Expressions of mistrust in the trial included dissatisfaction with the blinding element and perceived inconsistencies in the running of the trial. Similarly to randomisation and equipoise, blinding has previously been reported as a difficult concept for people to grasp and thus may provoke discontent (Madsen et al., 2000; Purdy et al., 2000).

A risk of medication outlined earlier was its association with an ill identity; preference to maintain one's healthy identity thus preventing negative social evaluation related to medication avoidance. Despite implying this attitude, several were keen to participate in the trial and willing to take the trial tablet. It is possible that the trial tablet could be distinguished from other medication due to its trial tablet status; indeed participating in a trial may be regarded as increasing positive social evaluation if one emphasises one's altruism, although social psychologists would argue that the term altruism no longer applies due to more personally oriented motivation. This demonstrates how apparent altruism may help a participant cope with an otherwise perceived risk.

Altruism and risk

As demonstrated in the participation chapter, altruistic feelings emerged in participants' discussions about trial participation. Considering how such feelings related to perceived risk, some participants seemed happy with the potential risks involved in the trial due to their willingness to help or recognition of the need for the trial; these participants were either prepared to take the risk of entering the trial, or did not perceive it as sufficiently risky to not participate. However, perceived risk might have been a stronger influence than altruism; altruism seemed to last as long as participants perceived no risk to themselves, but an event signifying risk resulted in consideration of one's own health dominating over helping others. Thus, it seemed that whilst altruism can be an important influence on the decision to participate in a trial, participation should not jeopardise one's own health.

This section has discussed how the risk participants perceived, both of heart disease and from aspirin, and their weighing up of these two risks against each other and against other factors, related to their attitude towards participating in the trial. As demonstrated, no straightforward relationship between level of perceived risk and participation decision was evident, rather the relationship emerged as complex, and differed from participant to participant. Discontent with the placebo, blinding and widespread preference for the aspirin revealed pervasive assumptions about aspirin's efficacy and safety. Evidence of these assumptions in adherent trial participants implied a lack of acknowledgement of the reality of the RCT procedure, in particular randomisation, therapeutic misconceptions, and a lack of acceptance of participants' own low ABPI. Meaning of the ABPI and comprehension of the RCT process were important; there was a wide range of understanding of both which has implications concerning informed consent. Altruistic attitudes were reported as influencing participation, however only as long as personal health was not jeopardised it seemed. When personal risk reached a significant level, concerns about participants' own health dominated.

Risk

In this final section, I will draw together discussion from the preceding sections to focus on how the present research and its findings have contributed to knowledge about risk.

Existence of cardiovascular risk

The research has demonstrated that the concept of cardiovascular risk existed and was salient for the participants in this study; it is clearly a notion about which people have ideas and opinions. The findings have provided support for previous work on lay beliefs of heart disease including the notions of lay epidemiology, the 'coronary candidacy' and awareness of fallibilities of the concept. The data has demonstrated that a multitude of factors contribute to people's ideas about cardiovascular risk, and that certain factors

appear to be weighted more than others in terms of their relative importance, but this differs from individual to individual. Also illustrated were evident differences in how individuals apply risk factors to themselves when engaging in risk assessment compared to when assessing cardiovascular risk in others.

Markers of risk

Although a multitude of factors are considered when assessing likely cardiovascular risk in oneself and others, it seems that a definite marker is required to provide a significant acknowledgement of personal risk. The most common of these markers is experiencing a cardiovascular event, such as a heart attack or angina. The second group of markers involve receiving a diagnosis from a clinical measure. However, at present, whilst measures of high blood pressure and high cholesterol are largely associated with such significance, the ABPI measure is more likely to be met with ambivalence and uncertainty.

Minimising risk perceived

In addition to factors that contribute towards perceptions of cardiovascular risk, other factors minimise the level of risk perceived and instead contribute to perceptions of invulnerability. The well-documented phenomenon of optimistic bias, our tendency to believe that we are less likely to suffer from health problems than our peers, is one of such factors. Fatalism regarding health problems, supported by awareness of fallibilities of the coronary candidacy and the randomness of heart disease, is another factor. Denial and avoidance of contemplating or acknowledging likely cardiovascular risk are further contributors. The asymptomatic nature of conditions of increased cardiovascular risk, such as atherosclerosis, can support optimistic bias, denial and avoidance, and enhance feelings of lack of perceived necessity of testing our perceived risk, for example with a clinical measure. Beliefs about our healthiness and likely risk can be strong; anything that maintains and supports our beliefs is likely to be more welcome than something that threatens this perception, which is more likely to be avoided or rejected.

The impact of risk perception

The data has demonstrated the importance of risk and its perception in people's attitudes and decisions about preventive health.

- *on attitudes towards screening*

Regarding screening for cardiovascular risk, the strength of pre-screening perceptions of risk may mean that diagnoses of an 'at risk' result may not be accepted. Such a mismatch may lead to a search for alternative explanations for the risk indicated by the clinical measure as a way of minimising the level of threat perceived. Although voicing the benefits of such a screening, and willingly attending, people may not consider 'risky' results significant.

- *on attitudes towards preventive medication*

Again, although voicing positive attitudes towards the identification of cardiovascular risk and engaging in active prevention of heart disease, unless significant risk is perceived (through an event or diagnosis), preventive behaviour in the form of medication taking may not be welcomed. Where a diagnosis of risk *is* accepted, the level of risk perceived is likely to be weighed up against the level of risk perceived from suggested solutions such as medication recommended. Perceived risk from medication can include risks to one's physical and psychological health and one's social appearance. In comparison to less well-known drugs, aspirin will be more accepted due to its perceived safety and efficacy.

- *on attitudes towards participation in trials*

The findings have expanded knowledge regarding beliefs and understandings of participation in clinical trials; both the trial's preventive nature and use of a well-known drug in a RCT provided a novel situation for qualitative research. Supporting previous research into different types of trials, elements of the RCT principles and procedures such as equipoise, randomisation and blinding are evidently hard for some people to make sense of and accept. Perceptions of risk seem to dominate decisions regarding

participation; here both cardiovascular risk and risk from aspirin, were considered and weighed up against each other, as well as other factors such as altruism acting as an influence. The relationship between the level of perceived risk and the decision to participate is complex; similar levels of perceived risk may lead to different decisions, and other factors including understanding will have an impact. Perceived risk appears to dominate over other factors; here altruism was an apparent and strong influence, but was overridden when perceived personal risk was heightened.

The concept of risk has been the subject of an immense amount of research and writing across many disciplines. Chapter 2 outlined selected literature on risk spanning several disciplines reflecting the interdisciplinary approach to the present research. The increasing awareness of risk in modern society (as noted by researchers such as Lupton, 1993, and Gabe, 1995) highlights the need to understand public understandings of risk. The present research studied lay accounts of risk to explore the associated meanings; it 'borrowed' concepts of risk from both psychology and sociology in trying to understand these meanings. The data presented in this thesis demonstrated how a risk defined by epidemiology, and useful for preventive medicine, was received and considered by members of the public, as they were invited to participate in screening and a trial.

Implications

Implications for preventive health

- The beliefs, perceptions and meanings people hold about personal cardiovascular risk may be strong and somewhat resistant to challenges. Preventive health programmes should recognise potential 'barrier beliefs' related to these perceptions that may exist and may inhibit preventive behaviour (such as screening attendance) including: optimistic bias, fatalism, avoidance, and lack of perceived necessity, which are heightened in the case of asymptomatic conditions. Preventive health initiatives should work with and address these feelings, both at the stage of inviting people to screening and during the

screening experience, particularly when explaining the meaning of the screening result.

- The potential negative effects of screening should be considered. A positive (at risk) result may induce feelings of labelling and stigma, and may threaten an individual's identity as a healthy person. A negative (healthy) result may inhibit change to a healthier lifestyle.
- Use of medication in a preventive manner will be met not only by barriers relating to perceptions of personal risk, but also barriers relating to perceived risk from medication. Such beliefs may lead to 'non-adherence' to prescribed preventive medication. Again, these beliefs should be recognised, and time dedicated to working with and addressing these within the practitioner-patient encounter. It may be the case that, for some patients, preventive medication is not an ideal approach.

Implications for clinical trials

- The findings highlight the importance of ensuring informed consent not only at the point of ascertaining eligibility and making the decision to participate, but also *throughout* the duration of the trial. Informed consent should ensure understanding of the purpose of the research (including the concept of equipoise), understanding of the RCT process (including randomisation and double blinding), and awareness of the potential risks involved and procedures in place to deal with adverse events.
- The research has revealed many reasons given for participating in the AAA trial. It would be unethical for those recruiting into trials to use the findings to manipulate uptake by focusing on these, and thus overshadowing potential risks involved in the trial. However, the findings could point to certain groups of people who may be keen to participate, for example those for whom the focus of the research has a particular personal context.
- More importantly, the findings about attitudes towards particular aspects of the trial process can inform those running trials of how to develop trials that are

sensitive to people's expectations and needs, for example the provision of monitoring and health checks, and to make the informed consent process more robust and meaningful.

Implications for research

- The present research has demonstrated the benefits of an interdisciplinary approach to investigating an important public health issue. Furthermore, it has highlighted how qualitative research can make valid contributions to public health research alongside randomised control trials.
- Future research in this area would ideally find ways of reaching people who do not attend screening to which they are invited, within the constraints of current data protection law.
- A longitudinal study of people's experiences throughout screening and trial processes would further knowledge of the dynamic nature of risk perception; such research could explore people's perceptions prior to being invited to screening, upon receipt of a screening invite, and after a screening result. Similarly trial participants' beliefs could be explored at several stages throughout the process of a trial from the initial decision to participate to after the end of the trial.

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Appendix

A1 Details of recruitment process of the 5 groups (presented in the chronological order in which I recruited the groups):

Group5: People who had not attended the screening.

It was important to start recruitment with this group as soon as possible due to the ethical constraints limiting my access: Due to the introduction of the Data protection Act (ref), amongst other considerations, in two of the three health boards I was prevented from contacting people who had not attended the screening. In one of the two this was not anticipated as approval had originally been granted; however, later changes to the running of the trial prevented my access to the data used to access potential recruits. Although the third health board granted approval of access to this group of people, this health board covered the area where the trial had began screening two years previously and screening had finished in this area approximately ten months prior to the start of my fieldwork. The main difficulty therefore in attempting to recruit in this area was the length of time which had elapsed since receiving the invite to the trial: for people who had either refused to attend screening, not replied to the invite or not attended their appointment, ten months was presumably a long period of time to remember something which they had been invited to, but not attended. I posted out 213 invites (the last batch of people invited to screening in this area). From this I received 9 positive replies who I then contacted; I arranged interviews with 6 of these respondents and conducted all of these in participants' own homes. Of the remaining three, two could not be contacted and one stated preference for a focus group which could not be carried out due to low response. Of these six participants, not one would have been eligible for the trial regardless of their ABPI as three had heart conditions and two were on medication contraindicating to aspirin, and one was on prescribed aspirin. Therefore none of the participants were people who had simply not wanted to attend the screening.

Recruitment of group 5 was therefore frustrating and disappointing, particularly as I felt that this group of people could have informed one of the research questions: why do people not attend screening for heart disease? In my initial naivety when beginning the research I believed I could access this group of people, but later

reflection led to the conclusion that people who do not wish to attend screening and/or participate in a research trial are probably similarly unlikely to wish to be interviewed on the subject.

Group 4: People who had attended the screening but were not eligible for the trial (normal ABPI).

The screening appointment process was as follows: From the trial office, invites to the screening were posted in batches working through different general practices, and appointments were made upon receipt of the reply slip, therefore those attending screening appointments within the same week or so tended to be from the same area. Therefore it was possible, with the help of the trial office staff, to identify from the screening appointment lists, weeks when attendees were from areas with different DEPCAT scores. In addition to the trial office staff, the research nurses were the key gatekeepers in recruiting of this group of participants. Using the DEPCAT information, when I started recruiting from this group we chose a 3 week period and during this period at one clinic the research nurses asked every attendee who received a normal ABPI if they would be interested in participating in my interview study. Individuals were given information leaflets. If the attendee expressed an interest, the nurse provided me with the individual's name and phone number. I subsequently contacted the individual to check their interest, ascertain preference for interview or focus group and arrange a date, time and place convenient to them. The research nurses and I continued this process until I arranged ten interviews and two focus groups. I carried out nine interviews (all but one were carried out at the same location as the clinic, the remaining one was in the participant's office at their request). I conducted two focus groups also at the clinic, one comprised of three participants (there were several non-attendees) and one six participants.

Group 3: People who had attended the screening, were eligible to enter the trial but had declined to participate.

To recruit this group, with the help of the trial office staff, I used the trial database to identify attendees who had been eligible for the trial but had declined to participate (either by informing the research nurse when invited to participate, or by deciding

not to participate and cancelling their baseline clinic visit). As this was a relatively small proportion of attendees, I wrote to all those fulfilling the criteria over a period of 3 months explaining the purpose of my research in a letter and information sheet inviting them to participate in my interview study. If interested, they were asked to send the reply slip to me and upon receipt of the reply I contacted each individual to arrange an interview. Due to the smaller numbers of people fulfilling this criteria and interested, and the responders being spread across two cities and a wide range of areas within the cities, I did not manage to arrange a focus group of participants within this group, but arranged and conducted eleven individual interviews (six in a research clinic, one in my office and four in participants' homes).

Group 1: Adherent trial participants.

This was one of the easiest groups to recruit from and the research nurses were again crucial in recruiting trial participants. During a 3 week period research nurses invited all participants attending for an annual clinic visit, to participate in my interview study. Those interested were given an information leaflet and their name and details were passed onto me, I then contacted them to ensure interest, ascertain choice of interview type and arrange a date, time and place for their interview or focus group. I was keen to interview trial participants with a wide range of time in the trial and my participants ranged from those who had been in the trial three years to three months. I interviewed nine trial participants (five in their home or workplace, three at my office and one in the research clinic). I also conducted two focus groups, one in the research clinic in one health board area, the other in a University location in a different health board area.

Group 2: Trial participants who had stopped the trial medication but were still receiving annual follow up by the trial.

The research nurses were once again crucial to recruiting this group. Participants who are no longer taking the trial tablet receive an annual telephone call from the research nurse to check any changes in their health and medication; monthly lists of follow up telephone calls are produced corresponding to the month participants would have been due for their annual clinic visit. All participants receiving their

annual follow up telephone call during one month were invited at the end of the call to participate in my interview study. Names of those interested were passed onto me, I then contacted them, checked their interest, ascertained their preference for interview type and arranged a convenient interview. I conducted eleven individual interviews (ten in participants' homes and one in my office) and one focus group in a University location.

A2 Recruitment letters and participant information sheets

A2.1: Letter to Group 5

Dear [participant name]

We recently wrote to you, inviting you to take part in a research trial to combat heart disease in Scotland. We understand that you did not wish to take part in the study and respect your decision.

However, I would like to invite you to take part in an interview study which is a separate part of the Aspirin trial. I am a Ph.D. student based in the Department of Public Health Sciences of the University of Edinburgh and I am carrying out this research under the supervision of Professor Fowkes and Dr. Cunningham-Burley. **This part of the study aims to understand people's attitudes towards heart disease, screening and use of aspirin. I am particularly interested in hearing the opinions of people who did not want to take part in the trial, as their views about these issues are especially important.**

The enclosed leaflet contains further information about this study which is called the Public Attitudes study. You can take part in either an individual interview or a focus group where 6-8 people discuss issues together. Interviews will be carried out at a venue convenient to you or in your own home and will last for approximately one hour. Focus groups will also be carried out at a venue convenient to you and the other participants and will last for approximately an hour and a half. If you are interested in taking part please complete the reply slip below and return it in the reply paid envelope; you will then be allocated to either an interview or a focus group unless you have stated a particular preference.

I would like to point out that you are under no obligation to take part in this additional interview. Please complete the attached reply slip and return to me in the enclosed reply-paid envelope.

If you have any questions or wish to discuss this additional study please do not hesitate to contact me on **0131 650 3242** and I will be happy to give you more information.

I hope that you will be able to help me and look forward to hearing from you.

Yours sincerely,

Helen Eborall
Ph.D. Student

[name & ID no.]

Public Attitudes study

Please tick **one** box (□):

☐ I am interested in taking part in the **Public Attitudes study** and I can be contacted on……..(Tel. No.)

If interested in taking part, please circle **one** of the following:
interview / focus group / no preference

☐ I do not wish to take part in the **Public Attitudes study**

It would be useful if you could also tell us your reasons for not taking part in the **Aspirin trial**:

Please tick **one** box (□):

☐ My GP has prescribed daily aspirin
☐ I take daily aspirin myself (non GP prescribed)
☐ Aspirin would interfere with my other medication/medical conditions
☐ I could not commit to the time involved in the trial
☐ I was not interested in taking part
☐ Other reason
(pleasespecify)……

Signed…….. Date…….

Please reply to: Public Attitudes study, AAA Trial, Public Health Sciences, Medical School, Teviot Place, Edinburgh EH8 9AG

A2.2 Letter to Group 4

Dear [Participant name]

Thank you for your recent interest in the Aspirin research trial by attending the Kelvin Hall clinic. After measuring the pressure in your ankle and arm, you were not eligible to take part in the trial.

However, I would like to invite you to take part in an interview study which is a separate part of the Aspirin trial. I am a Ph.D. student based in the Department of Public Health Sciences of the University of Edinburgh and I am carrying out this research under the supervision of Professor Fowkes and Dr. Cunningham-Burley. **This part of the study aims to understand people's attitudes towards heart disease, screening and use of aspirin. I am particularly interested in hearing the opinions of people who attended the research clinic for screening.**

The enclosed leaflet contains further information about this study which is called the Public Attitudes study. You can take part in either an individual interview or a focus group where 6-8 people discuss issues together. Interviews will be carried out at a venue convenient to you or in your own home and will last for approximately one hour. Focus groups will also be carried out at a venue convenient to you and the other participants and will last for approximately an hour and a half. If you are interested in taking part please complete the reply slip below and return it in the reply paid envelope; you will then be allocated to either an interview or a focus group unless you have stated a particular preference.

I would like to point out that you are under no obligation to take part in this additional interview.

If you have any questions or wish to discuss this additional study please do not hesitate to contact me on **0131 650 3242** and I will be happy to give you more information.

I hope that you will be able to help me and look forward to hearing from you.

Yours sincerely,

Helen Eborall
Ph.D. Student

.....

[name & ID no.]
Please tick **one** box (□):

☐ I am interested in taking part and I can be contacted on.....(Tel. No.)

If interested in taking part, please circle **one** of the following:
interview / focus group / no preference

☐ I do not wish to take part

Signed..... Date.....

Please reply to: Public Attitudes study, AAA Trial, Public Health Sciences, Medical School, Teviot Place, Edinburgh EH8 9AG

A2.3 Letter to Group 3

Dear [participant name]

Thank you for your recent interest in the Aspirin research trial by attending the Kelvinhall clinic. You were eligible to take part in the trial, but decided against it for medical or other reasons and we respect your decision.

However, I would like to invite you to take part in an interview study which is a separate part of the Aspirin trial. I am a Ph.D. student based in the Department of Public Health Sciences of the University of Edinburgh and I am carrying out this research under the supervision of Professor Fowkes and Dr. Cunningham-Burley. **This part of the study aims to understand people's attitudes towards heart disease, screening and use of aspirin. I am particularly interested in hearing the opinions of people who attended the research clinic for screening and decided not to take part, as their views about these issues are especially important.**

The enclosed leaflet contains further information about this study which is called the Public Attitudes study. You can take part in either an individual interview or a focus group where 6-8 people discuss issues together. Interviews will be carried out at a venue convenient to you or in your own home and will last for approximately one hour. Focus groups will also be carried out at a venue convenient to you and the other participants and will last for approximately an hour and a half. If you are interested in taking part please complete the reply slip below and return it in the reply paid envelope; you will then be allocated to either an interview or a focus group unless you have stated a particular preference.

I would like to point out that you are under no obligation to take part in this additional interview.

If you have any questions or wish to discuss this additional study please do not hesitate to contact me on **0131 650 3242** and I will be happy to give you more information.

I hope that you will be able to help me and look forward to hearing from you.

Yours sincerely,

Helen Eborall
Ph.D. Student

.....
(name & ID no.)
Please tick **one** box (☐):
☐ I am interested in taking part and I can be contacted on.....(Tel. No.)

If interested in taking part, please circle **one** of the following:
interview / focus group / no preference

☐ I do not wish to take part

Signed..... Date.....

Please reply to: Public Attitudes study, AAA Trial, Public Health Sciences, Medical School, Teviot Place, Edinburgh EH8 9AG

A2.4 Letter to Group 2

Dear

I am writing to invite you to take part in a small interview study which is being carried out alongside the Aspirin (AAA) trial. I am a Ph.D. student based in the Department of Public Health Sciences of the University of Edinburgh and I am carrying out this research under the supervision of Professor Fowkes and Dr. Cunningham-Burley. **This part of the study aims to understand people's attitudes towards heart disease, screening and use of aspirin, and aims to include people from various stages of the trial.** You have restarted your trial medication after a period without taking it; I am particularly interested in hearing the views and experiences of people like yourself.

The enclosed leaflet contains further information about this Public Attitudes Study. This study involves one visit only. You can take part in either an individual interview or a focus group. Interviews will be carried out in your own home or at a venue convenient to you and will last for approximately 30-45 minutes. Focus groups will also be carried out at a venue convenient for those involved and will last for approximately an hour. If you are interested in taking part please complete the reply slip below and return it in the reply paid envelope, and I will phone you to arrange a suitable date and time.

I would like to point out that you are under no obligation to take part in this additional interview.

If you have any questions or wish to discuss this additional study please do not hesitate to contact me on **0131 650 3242** and I will be happy to give you more information.

I hope that you will be able to help me and look forward to hearing from you.

Yours sincerely,

Helen Eborall
Ph.D. Student

.....
(name & ID no.)

Please tick **one** box (□):

□ I am interested in taking part and I can be contacted on.....(Tel. No.)

If interested in taking part, please circle **one** of the following:

interview / focus group / no preference

□ I do not wish to take part

Signed..... Date.....

Please reply to: Public Attitudes study, AAA Trial, Public Health Sciences, Medical School, Teviot Place, Edinburgh EH8 9AG

A2.6 Participant Information sheet

Tackling Heart Disease in Scotland
The Scottish Aspirin Trial

Information sheet
Public attitudes study

Purpose of the study
The Aspirin Trial is currently testing the effectiveness of aspirin in preventing future heart problems amongst those identified by measuring their ankle blood pressure. However, it is also important to know what people themselves think about heart disease, its prevention, screening and research in order that their needs can be more effectively met by the health service. **We want to know what you think.**

To do this we will be carrying out interviews and focus groups with a wide range of people.

What will it involve?
You will take part in **either** an individual interview or a focus group

Individual interview: This will involve just you and the researcher (Helen Eborall). The interview will be carried out at a venue convenient for you or in your own home, and will last for approximately one hour. These will be informal with general questions about your views on heart health and attitudes towards heart disease, its prevention, and what you think about the use of aspirin. There are no right or wrong answers and all opinions are welcome!

Confidentiality is assured. If you have no objections, the interview will be tape-recorded; only the researcher will have access to the tape and once she has transcribed the interview she will wipe the tape. The transcripts of all the participants will be used to produce the study findings. Names and any other identifying information will be removed from the transcript so no individual will be identifiable.

You can stop the interview and/or the recording at any point.

Focus group: This will involve a group discussion between 6-8 people and the researcher. It will be carried out at a venue convenient for those involved, and will last for approximately an hour and a half. Similar to the individual interviews, the focus group will be informal with general discussion about heart health and people's attitudes towards heart disease, its prevention and the use of aspirin. Again, there are no right or wrong answers and all opinions are welcome.

Confidentiality is assured. If participants have no objections, the discussion will be tape-recorded; only the researcher will have access to the tape and once she has transcribed the interview she will wipe the tape. Names and any other identifying information will be removed from the transcript so single individuals will not be identifiable in research reports.

Should a participant wish to, he/she can leave the focus group at any point.

What will happen with the research findings?
The findings from the interviews and focus groups will form the basis of a Ph.D. (research degree) and will lead to publications in scientific journals. If you are interested in reading the research findings, you will be able to contact the researcher.

Further information
If you have any questions or wish to discuss this study, you are welcome to contact me (Helen Eborall) on **0131 650 3242**

A3.1 Participant consent form: individual interviews

INFORMED CONSENT FOR PARTICIPATION IN AN INTERVIEW ON SCREENING AND PREVENTION OF HEART DISEASE

This interview is part of the research involved in my Ph.D. The purpose of the interview is to explore understandings and beliefs about heart disease, its screening and prevention, and research participation.

I will conduct the interview on [date]. The interview will be recorded with the participant's permission and the recording will be transcribed and analysed by myself. Names will be removed and the data will be made anonymous.

There are no foreseeable risks in this research but should any discomfort arise regarding material addressed in this interview participants should contact me.

Helen Eborall,
Department of Public Health Sciences, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG Telephone: 0131 650 3242 Email: Helen.Eborall@ed.ac.uk

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I agree to participate in this research project and I understand that:

- The time required for this interview will be around 30-60 minutes.
- The nature of my participation will be an interview on the topic of "Screening and prevention of heart disease".
- My participation is entirely voluntary and I may terminate my involvement at any time.
- At the time of the interview my permission will be sought to record the interview.
- All my data will be kept confidential by the researcher; names and identifying features will be removed from the resulting transcript.
- Data will be used to form the basis of a Ph.D. (research degree) and will lead to publications in scientific journals.
- If I have questions or need to talk about matters arising from the interview at any stage I can contact Helen Eborall at the above address.

Signed Date

A3.2 Participant consent form: focus groups

INFORMED CONSENT FOR PARTICIPATION IN FOCUS GROUP ON SCREENING AND PREVENTION OF HEART DISEASE

This focus group is part of the research involved in my Ph.D. The purpose of the focus group is to explore understandings and beliefs about heart disease, its screening and prevention, and research participation.

I will conduct the focus group on [date]. The discussion will be recorded with the participants' permission and the recording will be transcribed and analysed by myself. Names will be removed and the data will be made anonymous.

There are no foreseeable risks in this research but should any discomfort arise regarding material addressed in this interview participants should contact me.

Helen Eborall,
Department of Public Health Sciences, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG Telephone: 0131 650 3242 Email: Helen.Eborall@ed.ac.uk

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I agree to participate in this research project and I understand that:

- The time required for this focus group will be around 1 to 1½ hours.
- The nature of my participation will be a focus group on the topic of "Screening and prevention of heart disease".
- My participation is entirely voluntary and I may terminate my involvement at any time.
- At the time of the focus group my permission will be sought to record the discussion.
- All my data will be kept confidential by the researcher; names and identifying features will be removed from the resulting transcript.
- Data will be used to form the basis of a Ph.D. (research degree) and will lead to publications in scientific journals.
- If I have questions or need to talk about matters arising from the interview at any stage I can contact Helen Eborall at the above address.

Signed Date

A4: Interview and focus group documents

A4.1.1: Introduction template for focus groups

Welcome and thank you all for taking the time to join this discussion on 'screening and prevention of heart disease'.

Introduce myself

- Me: moderating the discussion
- [assistant moderator] will be assisting me and taking notes

Purpose of research and use of results

- I would like to find out more about people's attitudes towards screening and prevention of heart disease, and participation in research trials. I am doing similar focus groups and interviews with participants and non-participants at all stages of the Aspirin trial in Edinburgh, Glasgow and Lanarkshire.

Why you were selected

- You were all selected because...[*for example for group 2:* you have all been participants in the Aspirin trial, but are no longer taking the trial medication for varying reasons]

Importance of all contributions - differing opinions

- There are no right or wrong answers but rather differing points of view. Please feel free to share your opinions, even if it differs from what others have said.

Check consent to record

Ground rules

Before we begin I'd like to introduce some ground rules.
The aim is to generate a discussion between you however I would ask that you please...

- **speak up**
- only **one person should talk at a time**.
- I'm **recording** the session because I don't want to miss any of your comments.
- Please **avoid engaging in side conversations** between neighbours.
- I would like everyone to participate **without one member dominating**.
- As mentioned in the consent form, **confidentiality** is completely assured. Names will not be used in the writing up of the research
- I would ask you to **respect each other's privacy**.
- Would anyone like to **add any** ground rules?

The session will last for about an hour
To start with could you introduce yourselves to me one by one.

A4.1.2 Introduction template for individual interviews

Thank you for participating

Introduce me

Purpose of research and use of results
I would like to find out more about people's attitudes towards screening and prevention of heart disease. I am doing similar interviews and focus groups with participants and non-participants of the Aspirin trial in Edinburgh, Glasgow and Lanarkshire.

Why you were selected
[*For example for group 3:*] I'm particularly interested in people who did not take part in the trial.

Importance of all opinions
There are no right or wrong answers but rather differing points of view. Please feel free to share your opinions.

Check consent to record

Timing
The session will last between half an hour and an hour

A4.2.1 Pilot topic guide

Part 1: Explanation of screening process:

- "healthy" population (50-79)
- ABPI

- *Who do see as the type of person likely to be at risk of having heart problems?*
- *What do you think about the idea of screening the population?*
- *Do you think many people would attend the screening appointment if invited?*
- *What sort of people do you think would attend/not attend the screening?*
- *(Why would people want/not want to know their risk level?)*
- *How did you think people would react when told by the nurse they are in the 'high-risk' group (or not in the 'high-risk' group?)*

Part 2: Explanation of use of **low dose** aspirin as preventive medication

- *Has anyone heard of aspirin being used to **treat** heart problems? What do you think about this?*
- *Has anyone heard of aspirin being used to **prevent** heart problems? What do you think about this?*
- *Do you know of any risks involved with taking aspirin?*
- *What do you think about daily aspirin compared with other recommendations for reducing risk of heart problems, for example stopping smoking or doing exercise?*
- *How do you think people would feel? And would it affect other behaviours eg. diet?*

Part 3: Explanation of RCT

- 50% chance aspirin/dummy pill, blinding, randomisation

- *Do you think people would participate in the trial? Why?*
- *People taking part in the trial do not know whether they are taking aspirin or a dummy pill. What do you think about this?*
- *What do you think are the advantages and disadvantages of taking part in this trial?*

A4.2.2 Topic guide for group 5 participants

1: Screening

- *What did you think when you received the invite?*
- *Do you think many people would attend the screening appointment if invited?*
- *What sort of people do you think would attend/not attend the screening? And why?*
- *What do you think about the idea of screening the population?*
- *(Why would people want/not want to know their risk level?)*
- *How did you think you would have felt if you had attended the screening and the nurse told you that you had early signs of future heart problems?*
- *Do/did you see yourself as the type of person likely to be at risk of having heart problems?*

2: Aspirin as preventive medication

- *Have you heard of aspirin being used to **treat** heart problems? What do you think about this?*
- *Have you heard of aspirin being used to **prevent** heart problems? What do you think about this?*
- *You take/are prescribed aspirin, why is this? How do you feel about this?*
- *You can't take aspirin, how do you feel about this?*
- *Do you know of any risks involved with taking aspirin?*
- *What do you think about daily aspirin compared with other recommendations for reducing risk of heart problems, for example stopping smoking or doing exercise?*
- *How do you think people would feel? And would it affect other behaviours eg. diet?*

3: Research participation

- *Would you have been interested in taking part in the trial if you could have done?*
- *Do you think people would participate in the trial? Why?*
- *People taking part in the trial do not know whether they are taking aspirin or a dummy pill. What do you think about this?*
- *What do you think are the advantages and disadvantages of taking part in this trial?*

A4.2.3 Topic guide for group 4 participants

1: Screening

- ***What did you think when you received the invite?***
- ***What were your expectations about when you attended***
- ***What do you think about the idea of screening the healthy population?***
- ***And about the age range 50-75?***
- *Do you think many people would attend the screening appointment if invited?*
- *What sort of people do you think would attend/not attend the screening? And why?*
- *(Why would people want/not want to know their risk level?)*
- ***How did you feel during your screening appointment?***
- ***How did you think you would have felt if the nurse told you that you had early signs of future heart problems?***
- ***How did you feel when you were told you were not eligible (too healthy) to go into the trial?***
- ***Do/did you see yourself as the type of person likely to be at risk of having heart problems?***

2: Aspirin as preventive medication

- ***Have you heard of aspirin being used to <u>treat</u> heart problems?*** *What do you think about this?*
- ***Have you heard of aspirin being used to <u>prevent</u> heart problems?*** *What do you think about this?*
- *Do you know of people who take aspirin?*
- ***Would you take aspirin if you considered yourself at risk of future heart problems?***
- ***Do you know of any risks involved with taking aspirin?***
  - ***Newspaper headlines- articles***
- *How does aspirin compare to any other medication that you take/or know of?*
- *What do you think about daily aspirin compared with other recommendations for reducing risk of heart problems, for example stopping smoking or doing exercise?*
- *How do you think people would feel? And would it affect other behaviours eg. diet?*

3: Research participation

explain trial process

- ***If you had been eligible, would you have been interested in taking part in the trial?***
- *Do you think people would participate in the trial? Why?*
- *People taking part in the trial do not know whether they are taking aspirin or a dummy pill. What do you think about this?*
- *Have you been involved with a similar trial?*
- *What do you think are the advantages and disadvantages of taking part in this trial?*

A4.2.4 Topic guide for group 3 participants

1: Screening

- ***What did you think when you received the invite?***
- ***What were your reasons for deciding to attend?***
- ***What were your expectations about when you attended?***
- ***What do you think about the idea of screening the healthy population?***
- ***And about the age range 50-75?***
- *Do you think many people would attend the screening appointment if invited?*
- *What sort of people do you think would attend/not attend the screening? And why?*
- *(Why would people want/not want to know their risk level?)*
- ***How did you feel during your screening appointment?***
- ***How did you feel when the nurse told you you were eligible for the trial/had early signs of future heart problems?***
- ***Do/did you see yourself as the type of person likely to be at risk of having heart problems?***

2: Aspirin as preventive medication

- ***Have you heard of aspirin being used to treat heart problems?*** *What do you think about this?*
- ***Have you heard of aspirin being used to prevent heart problems?*** *What do you think about this?*
- *Do you know of people who take aspirin?*
- ***Would you take aspirin (now that you have early signs of future heart problems)?***
- ***Do you know of any risks involved with taking aspirin?***
- *How does aspirin compare to any other medication that you take/or know of?*
- *What do you think about daily aspirin compared with other recommendations for reducing risk of heart problems, for example stopping smoking or doing exercise?*
- *How do you think people would feel? And would it affect other behaviours eg. diet?*

3: Research participation

- ***Why did you decide not to take part in the trial?***
- *Do you think people would participate in the trial? Why?*
- *People taking part in the trial do not know whether they are taking aspirin or a dummy pill. What do you think about this?*
- *Have you been involved with a similar trial?*
- *What do you think are the advantages and disadvantages of taking part in this trial?*

A4.2.5 Topic guide for group 1 participants

1: Screening

- ***What did you think when you received the invite?***
- ***What were your expectations about when you attended?***
- ***What do you think about the idea of screening the healthy population?***
- ***And about the age range 50-75?***
- *Do you think many people would attend the screening appointment if invited?*
- *What sort of people do you think would attend/not attend the screening? And why?*
- *(Why would people want/not want to know their risk level?)*
- ***How did you feel during your screening appointment?***
- ***How did you feel when you were told you were eligible to go into the trial?***
- ***Do/did you see yourself as the type of person likely to be at risk of having heart problems? Why?***

2: Aspirin as preventive medication

- ***Had you heard of aspirin being used to <u>treat</u> heart problems?*** *What do you think about this?*
- ***Had you heard of aspirin being used to <u>prevent</u> heart problems?*** *What do you think about this?*
- *Did you know of people who take aspirin?*
- *Do you know people now who take aspirin?*
- ***Do you know of any risks involved with taking aspirin?***
  - ***Newspaper headlines- articles***
- *How does aspirin compare to any other medication that you take/or know of?*
- *What do you think about daily aspirin compared with other recommendations for reducing risk of heart problems, for example stopping smoking or doing exercise?*
- *How do you think people would feel? And would it affect other behaviours eg. diet?*

3: Research participation

- *How do you feel about being part of this aspirin trial?*
- *What were you reasons for participating in the trial?*
- *How do you feel about taking this tablet for 5 years?*
- *How do you feel about not knowing whether the tablet is aspirin or a dummy pill?*
- *What do you think are the advantages of taking part in this trial?*
- *What do you think are the disadvantages of taking part in this trial?*
- *Have you been involved with a similar trial?*

A4.2.6 Topic guide for group 2 participants

1: Screening

- ***What did you think when you received the invite?***
- ***What were your expectations about when you attended?***
- ***What do you think about the idea of screening the healthy population?***
- ***And about the age range 50-75?***
- *Do you think many people would attend the screening appointment if invited?*
- *What sort of people do you think would attend/not attend the screening? And why?*
- *(Why would people want/not want to know their risk level?)*
- ***How did you feel during your screening appointment?***
- ***How did you feel when you were told you were eligible to go into the trial?***
- ***Previously did you see yourself as the type of person likely to be at risk of having heart problems? Why?***
- ***And now, how do you feel about your level of risk of heart problems?***

2: Aspirin as preventive medication

- ***Had you heard of aspirin being used to treat heart problems?*** *What do you think about this?*
- ***Had you heard of aspirin being used to prevent heart problems?*** *What do you think about this?*
- *Did you know of people who take aspirin?*
- *Do you know people now who take aspirin?*
- ***Do you know of any risks involved with taking aspirin?***
  - ***Newspaper headlines- articles***
- *Do you take any medication?*
- *How does aspirin compare to any other medication that you take/or know of?*
- *What do you think about daily aspirin compared with other recommendations for reducing risk of heart problems, for example stopping smoking or doing exercise?*
- *How do you think people would feel? And would it affect other behaviours eg. diet?*

3: Research participation

- *How did you feel about being part of this aspirin trial?*
- *What were you reasons for participating in the trial?*
- *How did you feel about taking this tablet for 5 years?*
- *How did you feel about not knowing whether the tablet is aspirin or a dummy pill?*
- *What were your reasons for stopping the trial medication? How did you feel about this? Did it change your opinions about the trial in any way?*
- *What do you think are the advantages of taking part in this trial?*
- *What do you think are the disadvantages of taking part in this trial?*
- *Have you been involved with a similar trial?*

A4.3 Template for ending interviews and focus groups

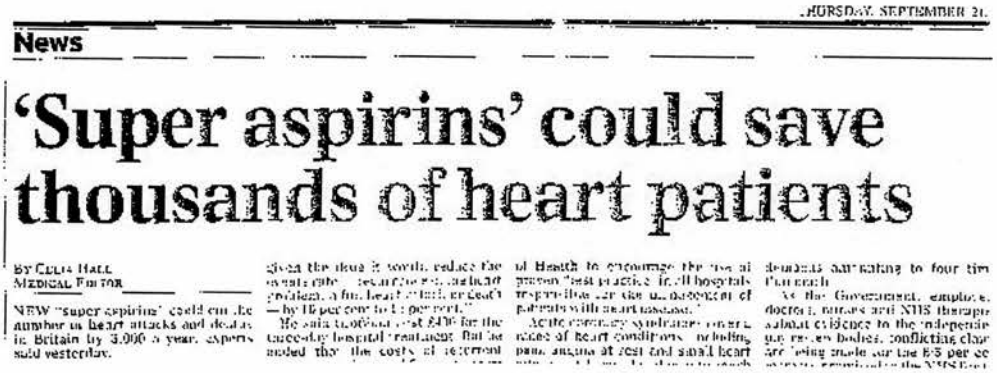
Ending:

- Summarise main opinions brought up then: *Would you say that was a fair summary?*

- *The purpose of today's interview/focus group was to help me to identify the most important issues regarding screening and prevention of heart disease. Have I missed anything?*

A4.4 Stimulus material for focus groups

A4.4.1



THURSDAY, SEPTEMBER 21,

News

'Super aspirins' could save thousands of heart patients

BY CELIA HALL
MEDICAL EDITOR

NEW "super aspirins" could cut the number of heart attacks and deaths in Britain by 5,000 a year, experts said yesterday.

given the drug it would reduce the overall rate ... heart disease, cardiac problem, a fatal heart attack or death — by 10 per cent to 15 per cent."

He said it would cost £470 for the succeeding hospital treatment that included the costs of deterrent

of Health to encourage the use of proven "best practice in all hospitals responsible for the management of patients with heart disease."

Acute coronary syndrome covers a range of heart conditions, including pain, angina at rest and small heart

doctors, nurses and NHS therapis about evidence to the independe guidelines bodies, conflicting clair are being made on the 8·5 per ce

A4.4.2

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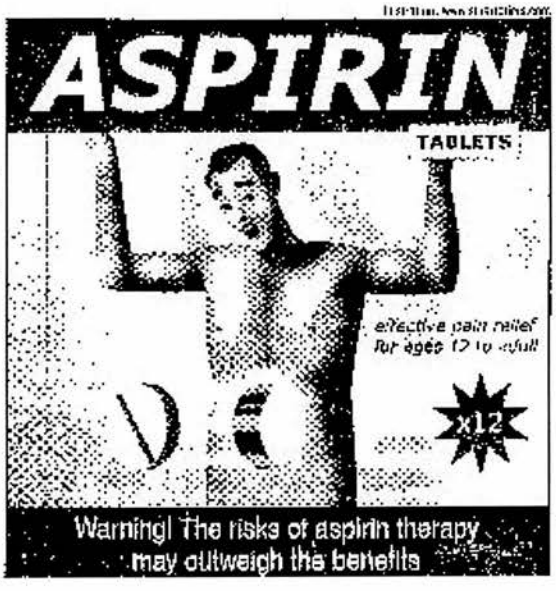
Phil Hammond

THE EXPRESS DOCTOR – ON CALL EVERY TUESDAY

Beware the hidden risks of our favourite cure-all

Even healthy people have been urged to take an aspirin a day — but new research advises caution



DOES An aspirin a day keep the doctor away? It's a seductively simple message and cheaper than an apple. Over the past two decades an estimated 58 million people in America alone have swallowed aspirin in the hope that it will keep them alive longer.

In the UK low aspirin has received some rave reviews. Back in 1995 Dr Richard Peto, Professor of Statistics at Oxford University told a conference that a daily aspirin would save the lives of at least 7,000 people a year in Britain — and 300,000 worldwide — if it was given following heart attacks and some strokes.

Ironically, the fact that it often still isn't used is probably because it's so cheap and familiar.

All women after the menopause should take it regardless.

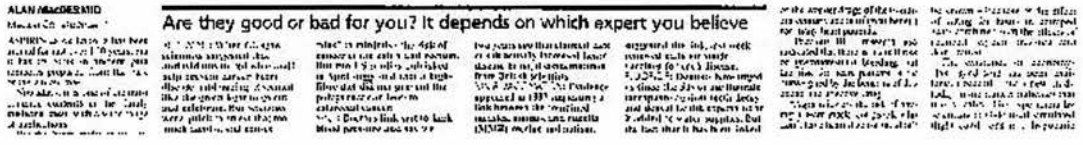
Heart disease and strokes are common and worth preventing, but not at any price. The latest research, published in the BMJ, suggests that if you are completely healthy the risk of ulceration or bleeding from the stomach by taking a daily aspirin outweighs the possible benefits.

In an overview of 24 trials with 43,000 participants comparing a daily aspirin to a placebo over a year or more, the risk of a bleed from the gut was 2.47 per cent in the treatment group, compared with 1.42 per cent in the placebo group. This extra risk often occurred with the low dose and modified release types of aspirin that are supposed to reduce it.

UK researchers concluded

A4.4.3

Wonder drug can still be a killer



ALAN MACDERMID

Are they good or bad for you? It depends on which expert you believe

A4.4.4

Daily aspirin dose 'can do more harm than good'

patients who are being considered for daily aspirin.

Professor Tom Meade, director of the Medical Research Council's Epi[illegible] and Medical Care Unit

'Wonderdrug': Thousands take aspirin daily believing it prevents heart disease

DAILY MAIL 28/4/98

How aspirin trial could offer hope to thousands

By MARIE SHARP

ONE of the biggest ever medical trials is to take place in Scotland to find out if aspirin can cut down on heart deaths.

More than 40,000 people will be asked to join the fered heart attacks or other coronary problems.

But it is now thought that prescribing it for patients considered at risk could pre- does have an impact on stopping the disease progressing then we could be reducing the number of victims of heart attacks and strokes by 150,000 over five years.

'Aspirin is a relatively cheap worst incidence of heart disease in the country, and Scotland is considered one of the unhealthiest nations in Europe.

Researchers will recruit candidates over the next few doses of aspirin and others dummy pills.

The long-term research aims to discover whether aspirin helps. Dr Cudmore said: 'Aspirin thins the blood and this is thought to be

New risks in aspirin revealed

DOCTORS are being urged to think again before persuading patients threatened by heart disease to take a daily dose of aspirin.

The advice comes from researchers who found that, even at very low doses, long-term use of the drug carried a risk of internal bleeding.

Aspirin is used to help people with heart problems because it can prevent blood clots.

[illegible] results of 24

Aspirir
Dange
to hea
patien

Even the Romans knew the wonder of aspirin

By Janet Boyle

IT'S a busy Monday morning when Mum collapses in agony, pain searing through her

Patients will be divided into two groups with one being asked to take a low dose aspirin every day and the others given a placebo. Results will show which groups suffer fewer heart attacks and strokes. The results should be known around 2006.

Aspirin may also be particularly

Aspirin study could prevent heart deaths

£1m trial for 3000 in sickest parts of Scotland

RAYMOND DUNCAN

RESEARCH in Scotland to test the effect of aspirin on people at high risk of heart disease even-

It is estimated that the Scottish trial could reduce the number of new cases of cardiovascular heart disease in those who are over the

Side-effects raise fears over aspirin heart cure

ALAN MacDERMID
Medical Correspondent

ASPIRIN, hailed as a . mple method of helping prever.t heart disease or stroke, has been discov-

are published today in the British Medical Journal.

They found that gastrointestinal haemorrhage occurred in 2.3% of patients taking doses even below 163mg per day. There is a 12%

A4.4.10

Lanarkshire chosen for aspirin study

NEW WEAPON IN FIGHT AGAINST HEART DISEASE?

HE effects of the humble aspirin on heart sease and strokes are to be studied during a de-scale trial in Lanarkshire, the heart ıense capital of Scotland.

Some 20,000 middle-aged men and women Hamilton, Motherwell and the Monklands a are to be screened during the trial, the first its kind in Britain.

By Wendy Fenemore

The £1 million project is being funded by the British Heart Foundation and the Scottish Office, with support from Lanarkshire Health Board.

It will be co-ordinated by the University of Edinburgh's Department of Public Health Sciences.

Lanarkshire has an unenviable record of coronary heart disease, with almost 20 per cent. more cases than the Scottish average.

In 1996, the year of the most recent figures, coronary heart disease claimed the lives of no fewer than 1655 people in Lanarkshire.

Appendix 5: Coding framework

Screening

Good opportunity
Screening described as good opportunity or similar

'MOT'/health check
"MOT" analogy, general health checks, workplace check-ups

Prevention is better than cure
Use of phrase "prevention is better than cure" or similar meaning

Benefits
Other benefits including non-specific

Individual responsibility versus individual rights
Talk of one's duty to attend screening, or conversely the right to not attend

Age
Screening associated with being a certain age

Denial and fear versus keen to know
Mention of phrases such as, "it won't happen to me" and "don't want to know", or conversely expressing interest in finding out one's risk

Asymptomatic/"not broken, won't fix"
Use of phrases such as "not broken, so don't fix it" and mention of the asymptomatic nature of conditions such as atherosclerosis

Inevitability/fatalism
Use of phrases such as, "what's going to happen, will happen" and "you've got to die of something"

Barriers
Mention of factors that inhibit screening attendance

Other screenings
Talk of screenings for cancers and other conditions

Medication

General

Dependence
Talk of dependence on medication or issues about control

'Alien'
Medication described as an alien substance in body, unnatural, or creating imbalances

Trust/mistrust
Mention of trust and mistrust of medication

Habit
Medication-taking described as becoming a habit

Like/dislike
Expressions of like or dislike of medication

Side effects
Discussion of side effects of medication

GP influence
Talk of the impact of one's GP on one's medication-taking

Preventive

"Prevention is better than cure"
Use of this phrase or similar, and linked accounts of behaviour that supports or contradicts this attitude

Preventive medicine as alternative
Comments about the idea of preventive medication as an alternative strategy to behavioural change such as stopping smoking

Aspirin

Discussion about aspirin specifically

Side effects
Discussion of side effects of aspirin

Trial tablet comparison

Comparison of the trial tablet with other medication

Contradiction
Trial tablet accepted despite general dislike of medication

Necessity

Comments regarding the point at which medication becomes a necessity

Current medication

Description of medication one is currently taking/prescribed

Altruism-Self benefit

Altruism
Overt mention of altruism by self or others, or altruistic implied through discourse

Duty/goodness
Talk of duty, implications of morality, or descriptions of action being a "good" thing to do

Recognition of need for research
Demonstration of awareness of need for research, trial and RCT process

Acceptance
Acceptance of participation without great thought, no specific benefits or barriers, 'muted' altruism

Reciprocity

- **Care received**
  Talk of appreciation for care received
- **'Loaded' reciprocity**
  Implications of anticipating care needed or some reward in return for participation

Mutual benefits
Mention of the benefits to both self and others from participating

Personal benefit
Talk of the benefits to oneself from participating

Self dominant
Discussion of the potential risks to oneself from participating

Participation 'influences'

Altruism
Altruism given as a reason for participation

Personal context
Mention of experience of heart disease in one's family, spouse or peers as provoking participation

Prior trial experience
Discussion of participating in previous trials

Trust

GP
Talk of trust in one's GP provoking participation
Trial
Expressions of trust in the trial

Positive trial attributes

Health check
Health checks received in the trial described as beneficial
Monitoring
Feeling of one's health being monitored throughout trial
Informed consent
Opinions on the issue of informed consent
Safeguards
Talk of the safeguards in place to catch events and side effects
RCT OK
Positive opinions expressed about RCT process
Awareness
Trial described as having improved awareness of one's own health

Barriers to trial participation

Age
Attitude that one is too old to participate
Duration
Duration of trial regarded as too long
Dislike of medication

Medication in general
Dislike of medication inhibiting participation
Aspirin in particular
Concerns expressed about side effects of aspirin
Side effects of trial tablet
Description of side effects experienced from trial tablet

Continued over

Barriers to trial participation *(continued)*

Dislike RCT process
Discontent with randomisation, blinding and placebo

Question research
Questioning of the need for the research, reliability of the process and analysis

Financial incentives
Lack of financial compensation for participating

Commitment
Dislike at the idea of the commitment involved in the trial

Convenience
Talk of the convenience/hassle or conversely the inconvenience involved in the trial

Other barriers
Mention of other barriers

Neutral trial attributes

Tablet ID
Talk of intrigue and guessing of the trial tablet's identity

Understandings
Discussion and implications of understandings and misunderstandings of the trial and RCT process

AAA trial experience
Descriptions of experiences in the trial including side effects and events

Risk perception

Perceived risk and participation decisions

No risk perceived, participate

No risk perceived, decline

Risk perceived, participate

Risk perceived, decline

Screening experience
Discussion of risk perceived from the screening experience, including the nurse-participant dialogue and terms such as "borderline" and "marginal"

Reaction to screening result
Description of one's reaction to one's screening result

Risk perception from clinical measures
Discussion and implications of risk perceived from measure including blood pressure, cholesterol, and the ABPI

Reaction to discovery of other risk
Description of one's reaction to discovery of high cholesterol or blood pressure and similar

Family history
Mention of family history of disease in relation to perceived personal risk

Lifestyle
Discussion of one's lifestyle, and the relation of lifestyle to cardiovascular risk

Scottish identity
Mention of 'being Scottish' and its relation to cardiovascular risk, including Scottish culture, and the impact of poverty

Age
Mention of the relation of age to cardiovascular risk

Psychosocial
Mention of the relation of factors such as stress and anxiety to cardiovascular risk

Comparison with others
Comparisons of oneself

Physical attributes
Weight, flushed complexion

Symptoms
Pangs, pains, pressure, headache, tightness in chest, breathless

Continued over

Risk perception *(continued)*

Fatalism
Discussion of fatalism regarding disease, or implications of fatalistic attitude

Lay epidemiology
Discussion echoing this concept

Randomness
Mention of the randomness of heart disease