Web-based information for people with high blood pressure

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DECLARATION

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ABSTRACT

High blood pressure (HBP) is a chronic, multifactorial condition thought to affect 10-25% of the UK population. Two of its complications, heart disease and stroke, are among the highest causes of mortality and morbidity in developed and, increasingly, developing countries. Yet, poorly understood and asymptomatic, HBP has proved easy to ignore and remains under-diagnosed and sub-optimally managed.

Responsibility for managing BP is a debated issue. Underpinning this project is the concept of individual responsibility to actively participate in one's own health care. For people with HBP this involves permanent lifestyle modification, often combined with adherence to medication. The behaviour changes required for optimal self-care depend on the knowledge and motivation to sustain a perceived decline in quality of life in the absence of the clear rewards which a condition with alleviated symptoms would offer. The current overall picture is of poor adherence to BP-lowering behaviours and routines. Nevertheless, these behaviours are crucial to reducing BP and achieving healthy longevity - as such, their promotion is the aim of this project.

The emergence in recent years of the Web as a mass medium has brought with it opportunities for health promotion initiatives. As a one-to-many mode of communication, it offers a cost-effective way to maximise the scope of interventions while uniting an unprecedented number of different media. Despite this favourable channel, delivery of information about BP over the Web is fraught with pitfalls and, as reviewed in this project, its enormous potential has yet to be achieved.

The project began with the conception of a development methodology, and this was followed by a review of the medical and social aspects of HBP. A review tool was developed to evaluate existing HBP resources on the Web, an exercise which informed the approaches adopted and avoided in the project, and which continued for its duration to accommodate emerging resources. The climate for introducing a Web-based information resource for HBP was investigated through a review of Internet and computer use and a profile of the target user group. Meanwhile a framework for a BP information package was produced on the basis of findings from a survey of Camden and Islington health professionals, observation at a hypertension clinic and general practice surgery, and interviews with patients and practice nurses. This framework was submitted as a concept diagram for online validation by a group of general practitioners, after which the development of content began. Content was produced in a variety of media as appropriate to the subject material. A series of prototype cycles shaped a working version of the multimedia information package, named Pressure's Off, which was produced for the Web. This working version was validated by five health professionals, after which recruitment for a formative evaluation was carried in a hypertension clinic. The evaluation involved six participants, from whom structured feedback on selected sections of Pressure's Off was collected via observation and recorded interview. Recordings and field notes were transcribed, coded, and analysed for themes, and findings from this process fell into two categories. The first discussed responses and revision recommendations for each section, and the second explored contributions which offered valuable insight into the concerns of people using the Web to find information about HBP. Findings from the evaluation were considered in the context of the overall project process to generate conclusions and identify opportunities for future work.

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND AND MOTIVATION

Blood pressure (BP) refers to the pressure of blood in the arteries. The higher it is, the greater the risk it poses to circulatory health by overworking the heart and damaging the arteries. It is a key risk factor for heart attack and stroke, the major causes of mortality and morbidity in the UK. It is also a very complicated condition.

The precise mechanisms by which damage is sustained are diverse and poorly understood. Current theories suggest that the immediate cause of high blood pressure (HBP) may be any or all of peripheral resistance to blood flow in the arteries, particularly forceful heart beat, or increased blood volume. It is associated with a number of other mediating risk factors including obesity, animal fat, salt and alcohol intake, sedentary lifestyle, familial HBP, and low consumption of fruit and vegetables. Associated with industrialised regions of the world, HBP may affect 25% of the UK population; the precise value is difficult to determine because the condition is routinely under-diagnosed. It is known as the "silent killer" because, for many, the catastrophe of a heart attack or stroke is the first symptom of the insidious toll it exacts on the circulatory system. Because of this asymptomatic quality, individuals are unaware of the condition and consequently do not present at their GP surgery for attention. A "rule of halves" applies by which half of those with the condition have it diagnosed, half of those diagnosed are treated, and half of those treated achieve BP control considered optimal.

In Western Europe the UK has comparatively high death rate from circulatory disease – nearly twice that of its next-door-neighbour France (Department of Health, 1999).

To achieve optimal BP control continual self-care is crucial and has a number of aspects. To reduce the risk factors listed above most patients are advised to implement permanent changes to diet and lifestyle which, for many, have far reaching consequences and can feel drastic. Moreover, many patients can expect to be on BP lowering medication for the rest of their lives.

It is not surprising that BP control is poor in the UK (Beevers et al, 2002, p94), because there is a gulf between health professional recommendations and patient action. While medical professionals can be supported in offering the best available care, advice and information to their patients, they cannot be held responsible for its uptake by patients. So in exploring ways to improve BP control, focus has shifted to the individuals ultimately responsible for these changes – the patients

themselves. Hence the growing interest in informing patients, implicit in which is the assumption that information is a requirement for good self-care:

> "People can improve their own health, through physical activity, better diet and quitting smoking. Informing people about health risks can enable them to make lifestyle decisions."

> "People with long term health problems can also play a participating role in managing their condition with the necessary support and information."

> (Department of Health, 1999).

Embodied more tacitly here is the recognition that, confronted by rising health expectations and a shortfall in NHS funding, the government and medical professionals require the population to accept a degree of responsibility for its own physical wellbeing. Around this time originated the concept of the Expert Patient (Department of Health, 2001b), a programme for people with chronic conditions which promotes patients' role in managing their own disease.

Meanwhile, current concepts of the condition are subject to change. Researchers operating at the peripheries of what is known about HBP continue to expand the body of evidence; recent years have seen shifts in perspective which are beginning to impact on the paradigm by which HBP is identified and managed (Law et al, 2003a). In communicating these fast-evolving changes in best current evidence and practice, there is the need for a dissemination medium which is updateable, far-reaching, and inexpensive – criteria which are met with increasing effectiveness by the World Wide Web, now a mass medium present in over half of UK households (Office for National Statistics, 2003). The scope of the Web and its capacity to represent and manage information makes it well suited as a dissemination medium for this subject area. Its unprecedented unification of different media makes highly engaging presentations possible, while its potential for interactivity presents opportunities for rich learning experiences which synthesise information into applicable knowledge (Bloom, 1964).

To summarise, HBP is a widespread, complex, multifactorial condition with a rapidly evolving body of evidence. Participation of patients in their own care is strongly encouraged, and knowledge about the causes, consequences and management of the condition is a requirement for this participation. However, building this knowledge in patients, potentially resource intensive, is rarely undertaken in the health service and, in the absence of explanations, advice and directives prevail. This simplistic approach does not help patients to fully understand the implications of their diet and lifestyle modifications, and jeopardises the motivation to maintain healthy behaviours. This is the climate in which this project to inform people about HBP has developed, which aims to use the rapidly growing medium of the Web to meet information and knowledge needs.

1.1 AIMS

The project outcomes should support initiatives to reduce diseases of the circulatory system which are being implemented nationwide under the umbrella of the National Service Frameworks (Department of Health, 2000; Department of Health, 2001). In order to achieve this it is necessary to:

- identify the information needs of people with high blood pressure.

- develop a knowledge base on blood pressure which is evidence-based, current, and engaging, representing knowledge in a variety of media as appropriate.

- develop a dissemination medium which is accessible, acceptable, maintainable and cost effective.

- advance end users' knowledge about blood pressure

- encourage and motivate adherence to treatment strategies

- promote an active interest in end users' own cardiovascular health

1.2 OBJECTIVES

The objectives below are instrumental in achieving the aims set out above:

- analysis of the nature of BP and depth of the information required for effective self-management.

- review of current technology for the care of HBP in order to establish strengths and shortcomings.

- analysis of health-related behaviour and strategies to motivate change.

- a consultation to establish the needs of the patient and health professional and how support could be incorporated in day-to-day living and routine practice.

- design of an information package on BP to be distributed primarily over the Web which takes into account the requirements of different users.

- evaluation of the package in terms of ease of use, affective (emotional) responses, acceptability, and effectiveness.

1.3 ORGANISATION OF THESIS

Chapter 2 introduces the broad methodology developed to guide the research, with reference to needs-assessment, information package design and development, and evaluation. The domain of HBP is introduced in Chapter 3 including an introduction to the circulatory system and an overview of cardiovascular risk factors. Individual

BP management and control are considered with respect to medication and lifestyle; BP management at a population level is considered in Chapter 4, where concepts of health and models of health promotion are discussed as a basis on which to explore health promotion for HBP. The climate for health information on the Web is explored in Chapter 5, and opportunities for its use in improving management of BP are considered. The needs-assessment phase is reported in Chapter 6, which draws on patient and health professional perspectives to conceptualise care and identify information needs and strategies for support. In Chapter 7, design and development of the information package are described with respect to the creation of the knowledge base and its implementation for the Web. Evaluation of the prototype information package is reported in Chapter 8, followed by a discussion of findings and their implications in Chapter 9. Conclusions and opportunities for future research are outlined in Chapter 10.

CHAPTER 2: RESEARCH METHODOLOGY

This chapter outlines the methodology for designing, developing and evaluating Pressure's Off, a Web-based package for people with high blood pressure (HBP) and, in doing so, contextualises the rest of the thesis. It links the next three chapters, which provide essential background to the project, with those which follow, detailing the needs assessment, system design and development, evaluation, discussion, and future work.

Little on methodologies for developing health information packages exists in the literature, which tends to focus on development and evaluation (Berridge, 2002, p282). The model for this project, shown in Figure 2.1[1], draws on the work of Alessi and Trollip (2001, p410) on designing instructional systems, but omits several aspects of commercial projects, such as costing and promotion. Another foundation is the work of Berridge (2002) to produce an information package on diabetes for patients and health professionals.

Figure 2.1 presents the methodology developed prior to beginning work on Pressure's Off, an information package for a complex clinical domain. It covers the entire lifespan of the project and, although beyond the scope of this project, anticipates maintenance and advancement of the finished product. The linearity of Figure 2.1 maps broadly, but not directly, to the sections of this thesis. One area to note is the review of the blood pressure information sites, begun in the early stages of the project, but ongoing and consequently reported later in 7.2 as background to the design and development of Pressure's Off. Another area is the validation and/or evaluation of the design (interface) and assets, which is reported in 7.5 and 8, respectively. A further area to note is the distinction in the methodology between the process of validating the design and organisation of Pressure's Off (a matter of appropriateness) and that of validating the content (one of accuracy) – these parallel processes are reported in the same section, 7.5.

For convenience, each constituent part of the development methodology is presented in Figure 2.1 with the chapter section where the corresponding research methods undertaken in the project are reported. These constituent parts are discussed in turn below.

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[1] The red, circled numbers 1 and 2 in Figure 2.1 mark the two areas referred to in subsequent sections of the chapter (2.2 and 2.5).

Development methodology

Research method

TIME

EVALUATION & PROJECT MANAGEMENT

Review of domain

Chapters 3, 4, 5, 7.2 – HBP, health promotion, the Web

Needs assessment

Chapter 6 – questionnaire, observation, interview

Identify scope

Chapter 7.3.2 – framework as concept map

PLANNING

Knowledge framework — Validate

Chapter 7.3.2 – responses to framework

Knowledge base — Validate

Chapters 7.3.3, 7.4 – content production and validation

Prototype layout & structure — Evaluate usability & look+feel

Chapter 7.5, 8 – iterative design of structure and interface, evaluation

Finalise design

DESIGN

Produce or obtain assets | Design and integrate

Validate &/or evaluate

1

Chapters 7.3.4, 7.5.4 – description of assets, working version

Chapters 7.4, 7.5, 8 – validation of accuracy and approprateness, overall evaluation

Beta test

2

Final revisions

IMPLEMENTATION OF VERSION

MAINTENANCE

Technical support | Fix bugs | Collect feedback | Plan next version | Content management

Figure 2.1. Development methodology and research methods for Pressure's Off

2.1 PLANNING

The planning section includes a review of the domain, needs assessment, and finalisation of scope. The latter two areas are covered in subsequent chapters. The review is presented in detail below.

2.1.1 REVIEW OF PREVIOUS RESEARCH

The first activity of the project was a literature review which aimed to consolidate research in a domain spanning a number of disciplines. It was intended to inform the BP knowledge base, to give insight into health promotion policy and practice, to identify prior research and activity in the area, and to underpin the development of the research methodology. The review covered the academic press, books, proceedings and grey literature, and was carried out using bibliographic datasets and citation indices available via the Web.

Searches of Ovid Medline and PubMed were effective in identifying papers on HBP and related health care systems and services, and also yielded journal articles on educational interventions. This educational aspect was reinforced by interrogating the Educational Resources Information Centre (ERIC) and the British Education Index (BEI), which were used to source literature on the generic subject areas of computer-aided learning and patient education, as well as on BP and cardiovascular health in particular. An additional source of references in these subject areas, and a primary source for literature about the Web, was ISI Web of Knowledge. Grey literature was an important part of the review, and was identified by searching the sites of governments, media and other organisations.

The broad topic of Web-based information for people with HBP was searched using systematic combinations of the following keywords and keyword groups[2]:

- (patient OR health) AND (educat* OR inform* OR promot* OR "self care")

- "high blood pressure" OR hypertens* OR cardiovasc* OR circulatory

- Web OR "Web based" OR online OR Internet OR Internet based

- (computer OR Web OR Internet) AND (assisted OR aided OR based OR mediated) AND (learn* OR educat*)

- CAL OR CAE OR CBL OR CBE

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[2] These are presented for the purposes of this thesis using Boolean logic, * as a wild card, and a number of other printable elements such as speech marks and brackets. Use of these printable elements, as well as permutations involving capitalisation and hyphens, depended on the rules of the dataset searched.

More specific sub-topics, such as individual complications of HBP, or specific approaches to usability testing, were queried opportunistically throughout the project.

The literature review highlighted three important considerations about the domain. The first to emerge was a lack of provision in the area of cohesive health information specifically for HBP. Available information was found to be either insufficient in detail, or disaggregated into several related areas such as weight loss, looking after your heart, or healthy eating, where HBP is consequently de-emphasised. A second consideration was that, at the turbulent intersection of health, education and information and communication technology, the project domain is subject to rapid and irregular change caused by disruptive innovations such as the polypill (Section 3.7.2.1). A third, related consideration was the complexity of the domain. HBP is a multifactorial condition with no known cause and no clear path to achieving safe levels. Widespread across the population, irrespective of demographics such as ethnicity, age and educational achievement, this diversity brings with it corresponding variation in health-related behaviours and learning approaches, as well as variation in the context of use for an information package like Pressure's Off.

A second dimension to this review of previous activity was a search for existing Web- or computer-based resources for learning about HBP. This involved searching the Web, across search engines, for the duration of the project, using combinations of the keywords outlined above. Since existing tools for evaluating the quality of resources were inadequate, a review tool was developed to assess the scope, depth and interest, information quality criteria and Web quality criteria. Early in the project this search was practically fruitless - few information packages have been produced in the interim, still fewer of which are high quality.

Findings from the literature review are detailed in the next three chapters which cover the medical and social domain of HBP, approaches to health promotion for the condition, and the climate for health promotion on the Web. Findings from the review of Web- or computer-based resources are outlined in detail in section 7.2 where they provide context for the Pressure's Off system design and development.

2.1.2 NEEDS ASSESSMENT

The understanding that needs-assessment is an indispensable part of programme design is common to the disciplines of both health promotion and Web design. Due to the infinite variation in interventions and their contexts, no structured approach has been formalised so far, and consequently the types of needs assessment activities undertaken should be dictated by their objectives. In the design of Pressure's Off, the objectives were to identify the climate for introducing a Web-

based or computer-based information package, to ascertain which aspects of HBP should receive particular attention, and to gain insight into how the package would be used in practice. Consequently the needs assessment comprised different activities. Observations at a hypertension clinic and general practice were carried out to gain insight into working health care systems for BP and to gauge the variety of patient responses to these. Interviews with patients and practice nurses yielded first hand accounts of the issues affecting BP management. Through a survey of all general practices in the London boroughs of Camden and Islington, quantitative data about BP management and the climate for computer-based health information was gathered. This needs assessment is the subject of Chapter 6, and a related evaluation of existing web-based information resources can be found in Chapter 7.

2.1.3 SCOPE

On the basis of the findings from the literature review and needs assessment, a decision, discussed in Section 7.4, was made to produce a resource which unified the different aspects of HBP, which emphasised information on medication and lifestyle, and which could be used flexibly. In delineating the subject area for the purposes of this project, several sub-topics of HBP were omitted, including secondary causes and HBP in different sub-groups (for example, pregnant women, older people, people of African-Caribbean origin). Although resource limitations forced this decision, the omitted areas are important and have a place on an HBP information package.

2.2 KNOWLEDGE BASE DEVELOPMENT AND VALIDATION

The design phase of Pressure's Off began with a proposed framework for the knowledge base, based on decisions about its scope. This framework was produced as a concept map and validated over the Web by a group of GPs. Having finalised this framework, the knowledge base was built in corresponding units, initially using text - the most explicit, cost-effective and straightforward medium. Since validation involves a holistic analysis of presentation, context and content, a decision was therefore made to postpone formal validation, which involved volunteers, until media assets had been sourced or created. Thus validation was removed from its original position in the critical path of the project plan to a later stage (number 1 in Figure 2.1) where there was a danger that the repercussions of changes might be felt more strongly.

2.3 APPLICATION DESIGN AND IMPLEMENTATION

Concurrent with developing the media assets, design of the interface itself was undertaken. This began at a juncture when, having completed a textual knowledge base, the developer could be appropriately sensitive to its content. After an iterative design process involving three prototypes and evaluation cycles, a scheme was finalised.

2.4 CONTENT VALIDATION

Having finalised the integrated design and knowledge base, validation was then carried out by five volunteer health professionals, each of whom accepted one or more sections. Since the validators were geographically diverse, were not necessarily comfortable with computers, and needed to work flexibly, a creative approach to the validation was required to ensure that they could access the material and give feedback. To maximise opportunities, validator packs were prepared including a CD-ROM containing Pressure's Off and word-processed document files for each section – this allowed validators to read and make amendments on screen or in print. After changes had been fed into Pressure's Off, and with ethical approval, patients were approached for feedback.

2.5 EVALUATION

Although it is important that design be carried out in the strict order recommended for usability, resource limitations made this difficult during the development of Pressure's Off. As outlined in the Figure 2.1, evaluation was an ongoing process in the development of Pressure's Off, and involved a range of different stakeholders. However, gaining access to patients, the target end-users, was difficult, and a decision was made to use their rationed input for later evaluation (number **2** in the Figure 2.1), rather than at the earlier stages of development. Indeed, it was the scope and media variety of the maturing Pressure's Off which won the interest and involvement of the health professionals who eventually agreed to host the study and recruit the patients.

As discussed, evaluation should be continuous, to benchmark progress against the standards and requirements of stakeholders. In Pressure's Off, formative evaluation activities were carried out between each stage of development – namely the creation of the knowledge framework, the development of the knowledge base, and the package's design and development – and are described in the sections where these activities are reported. The evaluation by patients, as target users, is presented in a dedicated chapter (Chapter 8) because it was the most highly structured and yielded the richest data. Six patients were recruited from a London

hypertension clinic list by a Hypertension Nurse Specialist and spent 90 minutes with the researcher. Each completed a questionnaire on their health, their attitudes to computers, and their attitudes to self-care for HBP, as well as a ten item multiple choice test to identify their baseline knowledge. They were then observed and recorded using pre-specified areas of the package, for which they provided structured feedback.

2.6 SUMMARY

This chapter has presented an overview of the methodology for the broader research endeavour, including an outline of the design, development, and evaluation of Pressure's Off. Each of these elements of the project pathway is detailed in the following chapters, with emphasis on the several points of intersection between them.

CHAPTER 3: THE MEDICAL AND SOCIAL DOMAIN OF HIGH BLOOD PRESSURE

Blood pressure (BP) is the pressure of blood within the arteries. A certain amount of pressure is necessary for blood to travel around the body, flowing upwards against gravity from the heart to the brain, or from the feet up to the heart. BP must also be able to rise swiftly in response to stimuli - the "fight, fright or flight" nerve impulses, for example - allowing blood to be immediately targeted where needed. This elevation is achieved by increased peripheral resistance in the arteries. Poiseuille's formula (Purdy et al, 1995) estimates resistance as proportional to the fourth power of the radius of the vessel's lumen – this means that small changes in radius are amplified into significant changes in resistance.

BP is expressed as two numbers – for example, 140/90 mmHg. The first value, known as the systolic blood pressure (SBP), represents the maximum pressure during the heart beat cycle, when blood flow is most forceful. The second value, known as diastolic blood pressure (DBP), is the minimum pressure registered between heart beats. The unit of measurement, mmHg or millimetres of mercury, is a historical reference to the indirect measurement method developed in 1898 by Scipione Riva Rocci. Kilopascals may be used in future.

High blood pressure can be summed up as resistance in the arteries to the circulation of blood so that it takes more force to push the blood round the body and increases the workload of the heart. This strain eventually damages the heart and blood vessels.

Few authorities now take the threshold for HBP to be what is 'normal' for a given individual's age and sex, because in industrialised countries, average pressures are too high for health (Rodgers, 2003); a more contemporary approach refers to a threshold of 'safety'. The term hypertension – used to describe chronic, pathological BP elevation - is falling out of favour (Hart, 1997; Wald and Law, 2003) because it assumes an arbitary cut-off point, implies an established cause and, for many lay people, suggests stress or anxiety. Because of its multiplicity of causes and mechanisms, it has come to be described with increasing caution as a syndrome rather than a disease, and is known throughout this thesis as high blood pressure (HBP).

The overview of HBP below represents an extensive knowledge acquisition period necessary for this project. Without good knowledge of the epidemiology of HBP, the processes of the circulatory system and the effects of therapy upon it, any endeavour to provide or to evaluate support for patients will be over-simplified.

Although this introduction cannot possibly do justice to the vast complexity of HBP, it is nevertheless required to understand the subtlety and involvedness of its management and prevention.

3.1 KNOWLEDGE ACQUISITION

Medical knowledge is the heart of all health information packages. Knowledge itself is an elaborate concept, an accumulation of know-how, procedural rules, facts, skills, guidelines, understanding, prioritisation, application, common sense and experience. Awad (1996, p29) defines knowledge as "the sum total of our perceptive processes that helps us draw meaningful conclusions". The task of extracting and synthesising these elements as a knowledge base for a specialised field of interest falls to a knowledge engineer.

Knowledge engineers have a set of abilities comprising both non-technical and technical skills, through which data and information, the building blocks of knowledge, are incorporated into a schema - the cement. Non-technical skills are of an interpersonal, communication, analytical and organisational nature, and are applied to elicit and interpret expert knowledge from a variety of sources. Technical skills include domain-specific knowledge, computer technology, and evaluation strategies, which are applied to formalise and represent the knowledge base and to evaluate the design and development process.

The knowledge acquisition process involves exploring a variety of knowledge sources, and perfecting the emergent domain representation through a sequence of refinement cycles. Awad (1996, p144) advises that there is a preparation stage which is prerequisite to knowledge acquisition and illustrates this point with an anecdote about the development of a decision support system, the Diabetic Foot Advisor, which involved interviewing an orthopaedic surgeon. The surgeon specified a reading list and insisted that the knowledge engineer read every item prior to the interview, delaying the interview by seven weeks:

> "...but it paid off. Most of the sessions went without a hitch. The expert did not have to explain terminology or adjust any explanations to a more simplistic level for the knowledge engineer." (p145)

This example highlights the need for prior knowledge (Dalgarno, 2001) in order to take best advantage of time with subject experts - especially important when working with NHS health professionals, who are famously short of time and inundated with commitments. This chapter focuses on this prior knowledge. It is based on text-books in anatomy, physiology and pathology, and lent currency and context through journal publications and lectures. Rich and Knight (1991, p105) discuss the ensuing stage of knowledge acquisition. Only having gathered the facts, "truths in some relevant world... things we want to represent" is it possible to

proceed to "representations of facts in some chosen formalism" so that knowledge can be manipulated. They outline four criteria (p109) for effectively representing the knowledge in a given domain:

- Representational adequacy: the ability to represent with sufficient subtlety the diverse types of knowledge in a domain – for example time, procedures, or facts.

- Inferential adequacy: the ability to manipulate the representational structures to form, based on knowledge derived from the existing representation, dynamic new relationships between its elements.

- Acquisitional adequacy: the ability to acquire new information into the knowledge base.

- Inferential efficiency: the ability to flexibly integrate new information so that it is available to form dynamic new relationships

These criteria are particularly useful to keep in mind when representing the diverse elements of HBP, in all their interrelatedness.

Ultimately, the medical knowledge outlined below has been represented and schematised based on the input of subject experts. The resulting concept map, a branching diagram which fulfilled Rich's and Knight's aforementioned criteria, was circulated on an email discussion group and to members of a hypertension clinic team. It was further refined through interviews and observation of patients and health professionals. These activities are discussed in greater depth in the following chapters.

3.2 ANATOMY AND PHYSIOLOGY

As background for considering blood volume regulatory mechanisms, an introduction to the circulatory, or cardiovascular, system is needed. Usefully compared to a building's plumbing system, it comprises the heart and the blood vessels, which conduct blood around the body delivering nutrients and removing waste products for every living cell.

3.2.1 THE BLOOD VESSELS

A network of blood vessels forms the fabric of the circulatory system, which comprises two circuits. The oxygen-supplying pulmonary circuit is a closed loop between the heart and lungs, while the systemic circuit connects the heart to all other parts of the body. Blood vessels are broadly divided into arteries, which carry blood away from the heart, and veins, which return blood to the heart. Arteries and veins have distinct qualities, outlined below.

3.2.1.1 Arteries

Arteries bear the brunt of high blood pressure. Their structure must withstand the pressure of blood pumped strongly towards remote destinations. Leading directly from the heart, the aorta is the largest artery, its elastic walls able to accommodate the heart's high-pressure systemic output. The aorta branches repeatedly to form large arteries which share this elastic (compliant) quality. These branch in turn, becoming smaller, less elastic, and more muscular.

The smallest arteries, the arterioles, buffer the force of the blood flow with muscular sphincters. This buffering prevents damage to the capillaries, a network of miniscule blood vessels which branch from them. One cell thick, the permeable capillary walls allow the blood to deliver and collect oxygen, nutrients, hormones and waste to and from the fixed cells of the body. To perform this function, each blood cell comes into regular contact with each organ of the body, including the lungs, kidneys, liver, intestines and brain. From the capillaries, deoxygenated blood on its return to the heart flows into the system of veins.

3.2.1.2 Veins

Veins return blood to the heart. At their furthest point from the heart, capillaries merge as minute venules. Venules from the two circuits merge repeatedly, decreasing in number and increasing in size to culminate in two large veins which transport blood to the heart. Veins have thinner walls than arteries, with less elasticity and muscle. Because the pressure in the veins is usually lower and the blood tends to flow against gravity, larger veins contain valves which permit flow towards the heart while preventing it from falling back. Venous return must be balanced with cardiac output, and can be augmented by sympathetic nervous activity or by muscular contraction in the limbs during exercise, both of which decrease venous compliance and, consequently, increase pressure.

3.2.2 THE HEART

The heart muscle acts as a pump and comprises four chambers. The right atrium receives blood from the cells of the body (the systemic circuit), and passes it into the right ventricle. The right ventricle pumps blood to the lungs (on the pulmonary circuit) to pick up oxygen. The left atrium receives blood from the lungs and passes it into the left ventricle. The developed left ventricle contracts strongly to send blood around the body. A network of blood vessels, including the coronary arteries and veins, supplies the heart muscle with oxygen and nutrients and removes its waste products.

3.2.3 THE BLOOD

Blood is a mixture of cells and cell fragments with a diversity of functions. Their vehicle for transportation is plasma, a watery solution which also carries other substances. The components of blood are introduced below.

3.2.3.1 Red blood cells

The distinctive convex shape of red blood cells (erythrocytes) gives a large surface area ideal for their main function, the take-up and delivery of gases. Erythrocytes collect oxygen from the lungs and nutrients from other locations, and deliver them to every fixed cell of the body. From these fixed cells they remove the waste products of metabolism, such as carbon dioxide which they pass back to the lungs, and other products which are delivered to the kidneys or bowels. Unable to move on their own, they exist in watery plasma and depend on the action of the heart for circulation.

3.2.3.2 White blood cells

White blood cells are differentiated and have diverse functions related to the immune system. They are able to travel to their site of action, responding to chemical signs of foreign bodies.

3.2.3.3 Platelets

Fragments of large cells which are found in the bone marrow, platelets (or thrombocytes) are the smallest formed parts of the blood. With an important role in clotting, they can move to where they are needed. They form the bulk of any scab or clot and, as they bind together, release a chemical (seratonin) to constrict the blood vessels, restricting blood flow to the injured area and preventing blood loss. Chemicals which encourage growth of new tissue are also released, which help to save the blood vessels affected by the injury.

3.2.3.4 Plasma

The formed elements of the blood exist in a watery straw-coloured solution which allows them to be pumped round the body. Plasma contains other substances required for homeostasis – the hormones, antibodies, enzymes, proteins and metabolites which are needed to maintain mechanisms and states in the body (homeostasis). These include albumins needed to draw water from the tissues into the capillaries and so maintain blood volume and pressure, a variety of globulins which transport different fats and vitamins in the blood and function in immunity, and the clotting factor fibrinogen. The amount of plasma in the body can fluctuate to regulate the proportions of solutes such as sodium.

3.3 UK PREVALENCE OF HIGH BLOOD PRESSURE

The prevalence of HBP is certainly higher than the 25% suggested by official figures (Burt et al, 1995) for two reasons. One is that, unless special measures are taken, it is consistently under-detected in routine primary care practice (Beevers et al, 2001; Julius, 2000; Williams et al, 2004). The prevailing "rule of halves" (Figure 2) a term first coined in the 1960s, suggests that 50% of people with HBP are undetected and that detection itself does not guarantee BP control (National Institute of Clinical Excellence, 2004).
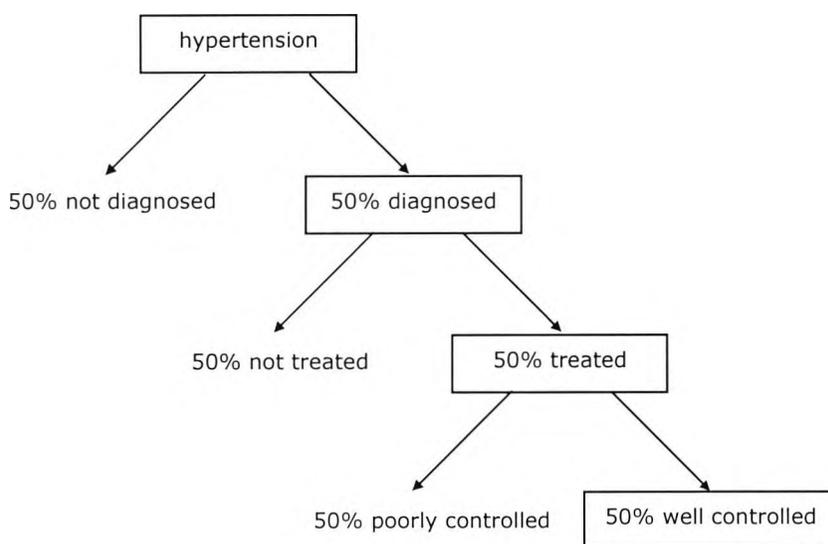
Figure 3.1 The "rule of halves" (After Beevers et al, 2002, p94)

The second reason is that the established thresholds for HBP have lately come to be considered as too high (Department of Health, 1998; Law et al, 2003); it is well known that risk of cardiovascular disease rises progressively across the entire BP distribution, including levels considered normotensive (Cutler et al, 1995, p253–270). In other words, there is no cut-off for risk. Consequently, the notions of hypertension and normotension may be gradually abandoned in favour of the concept of BP as a continuum.

According to the current WHO definition of hypertension (SBP>140 mmHg and DBP>90 mmHg or on medication) the Health Survey for England (Department of Health, 2002) identified a prevalence of 37.4% in men and in 33.8% in women. Hypertension increased with age in both sexes, rising in men from 13.8% in those aged 16-24 to 71.2% in those aged 75 and over. The corresponding figures for women were 4.5% and 78.8% respectively. Another model estimated that for 5.7 million UK adults aged over 16 years (12% of the population) BP is above 160/95mmHg, and for a further 10.3 million (21%) BP is in the established range for concern, between 140/90-160/95mmHg. Prevalence is higher in men than in

women up to age 55-64, while in the older age groups the opposite is true. Also classified as HBP is the phenomenon, known as isolated systolic hypertension, in which diastolic BP falls with age while systolic BP continues to rise.

The National Health and Nutrition Examination Survey in the USA (Hajjar and Kotchen, 2003) identified a 3.7% increase in incidence of HBP in the ten years since the previous survey and estimated that the condition affects nearly one third of the population. Other countries, notably Finland, have achieved a reduction in pressure across the population in the last decade through a mixture of individual and population interventions (Puska et al, 1996).

5% of elevated BP has a known origin, frequently one of several underlying conditions which cause the over-secretion of hormones, such as phaeochromocytoma, acromegaly or hyperthyroidism. Many pregnancies are complicated by HBP. Pregnancy-induced hypertension (PIH) develops with pregnancy and resolves afterwards. More threatening is preeclampsia, a rapidly progressive hypertensive condition which affects 10% of pregnancies, requiring urgent attention to protect mother and foetus. Still more serious is eclampsia, a rare condition affecting 4.9 in 10,000 maternities (Douglas and Redman, 1994) which features rapidly soaring BP and convulsions.

3.4 EPIDEMIOLOGY

HBP tends to cluster with other cardiovascular risk factors (Kannel 2000; Law et al, 2003) in a complex interplay which remains poorly understood. It is usual to assign these risk factors to either the non-modifiable or modifiable category; however, this approach can muddle the issue, fatalistically attributing risk to several states which have no direct relationship to BP. For example, age is often regarded as a non-modifiable risk factor, although elevated BP is not intrinsic to advanced age. Birth weight cannot itself be retrospectively adjusted, yet the predisposition to HBP conferred by low birth weight can be lessened. Diabetes cannot be cured, but blood sugar levels can be maintained at levels which do not pose cardiovascular risk. The assignment of socio-economic status as either a modifiable or non-modifiable risk factor would depend on the politics of the reader. For this reason, the distinction has been abandoned below in favour of an overview, below, of causal and preventative factors which, though not exhaustive, offers an insight into BP elevation.

3.4.1 AGE

Although HBP is not intrinsic to the ageing process, in industrialised countries BP tends to rise with advancing age. Rodgers (2003) summarises the association:

"Age is of course the best proxy for exposure to life, and life in developed countries at present almost inescapably entails long term exposure to major risks, such as excess intake of salt and saturated fat."

At birth average pressure is 50/70 mmHg followed by a sharp rise between two days and six weeks, after which pressure tends to stabilise until age four when it resumes its climb with no apparent fluctuations after adolescence. There is a discrepancy between the two pressures with systolic BP tending to rise progressively to an average of 140 mmHg by the seventh or eighth decade while the diastolic rise is less steep, with the average value stabilising or declining by the fifth decade.

BP tends to track; the higher the baseline, the steeper the increase over time. Observation of unacculturated, isolated populations suggests that societies acquire a disposition towards age-related increases in BP when they adopt an industrialised lifestyle (Carvalho et al, 1989; He et al, 1991).

As life expectancy increases, scientists will be able to study more accurately the prevalence of hypertension in the very elderly, which presently appears to fall away. This may be due to the susceptibility to death of those with HBP, leaving only healthy survivors, or possibly to a reduction in cardiac output with advancing age. (Beevers, 1982; Whelton, 1994).

3.4.2 ALCOHOL INTAKE

Alcohol has a direct pressor effect across the BP distribution and accounts for 5%-30% of all HBP (Friedman, 1982). Raised BP has been reported in 50% of alcoholics admitted into hospital (Alderman, 1994; Beevers, 1982). The mechanism of BP increase with alcohol consumption is not clear, but theories include sympathetic nervous activity, increases in plasma cortisol and activation of the renin angiotensin system. Reduced serum sodium brought about by diuresis (increased urine output) in heavy drinkers may stimulate the secretion of rennin, a precursor of raised pressure.

However, the correlation yields a J-shaped curve, suggesting that alcohol consumption of two drinks per day or less is likely to have a cardioprotective effect. This may be due to the psychological effects of moderate drinking as a means of relaxing and escaping stress, and increased high-density lipoprotein (good cholesterol) concentrations. Despite proclamations from the red wine industry, based on European mortality statistics which showed the lowest coronary heart disease (CHD) rates in France, Italy, Spain and other red wine-drinking countries, as long as the drink contains ethanol, its type does not matter.

Indirect effects of heavy drinking include the tendency for alcohol abusers to be less adherent to treatment and have poorer general health.

3.4.3 BIRTHWEIGHT

Birth weight, an outcome of genes, maternal nutrition, HBP and placental function, is inversely related to systolic pressure (Hardy et al, 2003). People with low birth weight have a predisposition to HBP and a number of other mediating cardiovascular risk factors. Maintaining a healthy weight can alleviate risk conferred by birth weight.

3.4.4 OVERWEIGHT

Despite a 33% decline in energy intake over the past twenty years[3] (DEFRA, 2001a), obesity and weight gain remain the most important determinants both of elevated BP and the development of other risk factors (Kannel, 2000), and frequently exists in patients with resistant HBP (Dror et al, 2002).

> "As a matter of fact, the clinical diagnosis 'essential hypertension'… is associated with obesity in over 50% of all hypertensive patients, whilst over 50% of the obese are hypertensive." (Sharma, 2002)

A ten-year follow-up study of 200,000 male and female participants, exploring the risks associated with being overweight (Field et al, 2001), found that risk of developing HBP increased with the degree of overweight in both men and women, though studies of the impact of duration of obesity on risk have produced variable findings (Hekimsoy and Okten, 2003). Distribution of surplus fat around the abdomen is an added risk factor (Okosun et al, 2000; Kannel, 2000). Although the strong association between obesity and HBP can be broadly explained by genetic and/or environmental factors which predispose to both conditions, the pathogenesis of HBP in obese people is poorly understood. Mechanisms by which obesity is hypothesised to act on BP include:

- an increase in blood volume (hypervolaemia) stimulating increased cardiac output, with a failure of the response mechanism to reduce vascular resistance appropriately (Reisin et al, 1983)

- stimulation of the renin–angiotensin–aldosterone system leading to increased vascular resistance (Tuck et al, 1991)

- increased salt intake as a feature of increased food intake, leading to an increase in blood volume (Tuck et al, 1991).

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[3] See the section on Physical Activity.

In spite of the recognition that weight loss has a positive effect on BP, clear recommendations for treating obese patients with HBP do not yet exist (Sharma, 2002).

3.4.5 DIABETES

Over 70% of patients with Type 2 diabetes have elevated BP (Beevers et al, 2001), and are at increased risk of developing macrovascular problems such as coronary artery disease. Elevated levels of blood sugar cause dysfunction in the lining of the arteries (Guerci et al, 2001), undermining elasticity and contributing to raised BP. A process known as glycosylation is implicated in this arterial damage (Aronson and Rayfield, 2002), a reaction between glucose and proteins or lipoproteins in the artery walls. Long lasting, stable protein structures evolve in the arteries which interfere with their activity and contribute to atherosclerosis. A further effect of elevated blood glucose is to increase the oxidation of LDL cholesterol, another feature of atherogenesis.

3.4.6 EDUCATION

Lower educational achievement has a negative impact on health in general (Lantz et al, 2001), including BP (Stamler et al, 1992; Stamler et al, 2000). Saounatsou and colleagues (2001) found a positive correlation between years of schooling and adherence to therapy. Panagiotakos and colleagues (2004) divided their sample into three categories of educational status: low (≤ 9 years schooling); medium (9-14 years); or high (university education). They report that participants in the medium and high categories had significantly lower diastolic and systolic BP than the least educated group.

3.4.7 ETHNICITY

The epidemiological data on prevalence of HBP across ethnic groups are inconclusive or contradictory. Two UK studies of adults (Department of Health, 1999b) and adolescents (De Giovanni et al, 1983) found little significant difference between ethnic minority and majority BP. In its investigation of the BP of minority ethnic groups in England, the Health Survey for England (1999) identified few significant differences between BP levels in the general population and those in 6 ethnic minority groups. However, in their review of British cross sectional studies of HBP variability, Lane and Yip (2001) found that, with some exceptions, most studies identified a high prevalence among South Asian and African-Caribbean groups.

It should be noted that using a common threshold to compare the BP of ethnic minority groups and those of the majority is misleading. This is because ethnic minority status can make individuals experience health problems which are different from those experienced by the general population in their country of

origin. For example, the age-standardised death rate from all causes in ICD 9 (the cardiovascular section of the International Classification of Disease) in 1994 accounted for 724.09 deaths per 100,000 in Chinese men and 518.78 in women. In the UK in 1998, these values were 581.26 and 377.16 respectively (World Health Organization, 2003a). Despite higher ICD 9 death rates in China than in the UK, the Health Survey for England (1999) identified slightly lower rates of cardiovascular disease in the Chinese group than in the general English population.

Variation across ethnic groups cannot be explained by current genetic theory since genetically similar individuals have BPs which vary according to their circumstances (Roberts and Maurer, 1977). Findings from maturing cohort studies incorporating a life course approach to chronic disease epidemiology (Aboderin et al, 2001; Kuh and Ben Shlomo, 2001) are beginning to illuminate a complex interaction of factors including housing, maternal education, working life, nutritional status and social exclusion. Current theory suggests that the action of ethnicity on BP is itself affected by individual or collective experience; ethnicity has both a direct and an indirect effect.

One thought-provoking example is the so-called Slavery Hypothesis, which evolved to explain high incidence of HBP in African Americans (Kaufman and Hall, 2003). Increasing evidence that sodium metabolism played a key role in blood volume regulation was extrapolated to theorise that African people had distinct and innate capacities for sodium retention which, though suited for the high temperatures of their origins, might prove maladaptive in other settings. This fitted uneasily with a parallel observation that incidence of HBP was low in Africa, while genetically similar African Americans experienced high incidence even in comparable climates. Efforts to accommodate the discrepancy came to focus on selection processes operating in the slave trade and in the transatlantic voyage. Blackburn and Prineas (1983) first articulated the hypothesis:

> "There are also hypothetical effects of genetic selection which could lead to an unusual population susceptibility to salt. Could an exaggerated hypertensive response to salt be related, for example, to selective effects in blacks of slavery? First came the forced recruitment of Africans from central, low salt-use areas; subsequently came a selective wastage from heat stress and salt and water deprivation during the brutal voyage across the sea. Among survivors, likely those most fit to withstand the acute stress, there followed an abrupt exposure to a poor quality diet with heavy salting on which the southeastern American slaves subsisted. Salt-saving renal-adrenal adaptations to a low salt environment, and selection, would be, by this idea, overwhelmed in the new salt-rich environment. Excess pressor responses to sodium might result not only from these sorts of selection processes, but from the stress of social dissonance among the slaves. But all these ideas too are broadly speculative."

The idea later became associated with its main proponent, Clarence Grim, and while defended as a serious and plausible scientific and historical proposition (Kaufman and Hall, 2003), is the subject of fierce debate.

3.4.8 FRUIT AND VEGETABLE INTAKE

The DASH diet (Sacks et al, 1995; Sacks et al, 2001) recommends a variety of fruit and vegetables, which confers a range of cardioprotective nutrients (Ness and Powles, 1997; Sacks et al, 1995; Sacks et al, 2001), namely:

- Vitamins, minerals and compounds with antioxidant properties, such as A, E, zinc, selenium, lycopene and flavonoids (John et al, 2002).

- Substances which reduce levels of the damaging amino acid homocysteine, such as folic acid (Boushey et al, 1995).

- The cardioprotective minerals potassium, calcium, and magnesium (Ascherio et al, 1998; Iso et al, 1999).

- Soluble fibre which reduces harmful low-density lipoproteins and helps to protect the artery walls (Ascherio et al, 1998).

It is known that storage and preparation of fruit and vegetables can affect their nutritional value (Institute of Food Research, 2003, p2; Warlaw and Kessel, 2002). For instance, it is important to use any cooking or storage water in the meal, since these are rich in vitamins which have leached out of the food. Chopping fruit and vegetables into small pieces causes oxygen to denature the vitamins exposed on the raw surfaces.

3.4.9 GENETIC PREDISPOSITION

BP is regulated by "numerous metabolic and structural characteristics of the cardiovascular, renal, nervous, and endocrine systems that involve the products of many genes" (Cardia et al, 2003). Current theory (Dennis, 2003) holds that among the three billion bases of the human genetic code is a diversity of markers which dictates an individual's susceptibility to various health conditions, including HBP. However, since each base is unremarkable and offers no clues to its characteristics, the identification of HBP susceptibility genes remains essentially random and noisy, based on searching for similarities in the genetic code between individuals with the condition (Dennis, 2003; Sharma and Jeunemaitre, 2000). Moreover, in the case of a multifactorial condition like HBP, several different genes are likely to be involved in the underlying cause. The professional community is now settled (Castellano et al, 2003; Ju et al, 2003; Marques et al, 2003) in its view that both genes and environment are implicated in HBP, but the complexity of the domain has prevented a full explanation up to now. Nevertheless, insight grows, and investigation of phaeochromocytoma (a relatively common hormone-emitting, BP-elevating tumour)

has identified its origin as monogenic, due to mutations in one of four phaeochromocytoma susceptibility genes (Dluhy, 2002). Discoveries like this make routine screening and individualised therapies for HBP likely prospects for the future.

3.4.10 HOMOCYSTEINE

Homocysteine is an amino acid with a function in tissue generation. A relatively newly recognised marker for cardiovascular disease, it is derived from foods containing animal protein, such as meat, milk and eggs. Raised levels - hyperhomocysteinaemia - have several known causes, including male sex, menopause, smoking, alcohol, heavy alcohol consumption, deficiencies of folic acid and vitamins B12 and B6, psoriasis and some sorts of medication. Raised levels are known to have multiple, damaging effects on the cardiovascular system including endothelial (artery lining) dysfunction, oxidisation of cholesterol leading to plaques, and a coagulant effect on blood (Mangoni et al, 2002).

3.4.11 HYPERCHOLESTEROLAEMIA

Cholesterol is a fatty substance found in every cell of the body and essential for digesting fats, strengthening cell membranes and making hormones. To travel round the body, cholesterol combines with proteins produced by the liver and intestines to form carriers called lipoproteins. Cholesterol is absorbed from diet (the exogenous cholesterol pathway) and enters the liver, from where it is secreted into the bloodstream (the endogenous cholesterol pathway). The liver secretes cholesterol as very low density lipoprotein (VLDL), which is broken down into two further types: low density lipoprotein (LDL), which picks up cholesterol and deposits it in the body cells; and high density lipoprotein (HDL), which gathers cholesterol from the body cells and transports it to the liver for elimination. Rather than overall cholesterol levels alone, the ratio of LDL to HDL cholesterol is a good indicator of cardiovascular risk, with higher LDL being more dangerous.

Cholesterol contributes to HBP when it oxidises and builds up on the lining of the large and medium-sized arteries as a constituent of atheromatous plaque blocking the lumen of the vessel, impeding flow, and causing a rise in BP. Evidence of the role of fats in atheroma includes: the predisposition in normal arteries to collect LDL compared with other plasma components; the prevalence of cholesterol and cholesterol in atheromatous plaques; and correlations between diet and clinical vascular disease.

The rough surface of the plaque can bring about a slowing of blood flow (stasis) and turbulence which causes local counter currents. Turbulence can cause blood cells to come into contact with, adhere to, and damage the endothelium, including platelets which release the hormone PDGF, (platelet derived growth factor), causing the

lesion to enlarge. Degeneration in the cells of the lesion cause it to become fibrous (sclerotic). Stasis impedes both the inflow of fresh blood carrying clotting inhibitors and the clearance of blood containing activated coagulation factors, important in both arteries and veins[4]. (Berne and Levy, 1990; Fox, 1996).

3.4.12 KIDNEY FUNCTION

Kidneys have an important role in regulating sodium concentration in the body, which they achieve by adjusting blood volume. Kidney abnormality or impairment is heavily implicated in HBP, which has been observed to follow the kidney from donor to transplant recipient (Roberts, 2001). It is beyond the scope of this thesis to do justice to the important and complicated impact of the kidneys on BP.

3.4.13 MEDICATION

Some medication can elevate BP, including those causing sodium retention, increased sympathomimetic activity and vasoconstriction. Oral contraceptives, drug withdrawal, and interaction with antihypertensive drugs can also cause BP to rise (Beevers et al, 2001). Vigilance is required on the part of health professionals to avoid the contribution of medication to HBP.

3.4.14 PHYSICAL INACTIVITY

Sedentary lifestyle is a risk factor for cardiovascular disease which clusters and interacts with others, obesity in particular. A dramatic decrease in energy intake over the past two decades has not resulted in a national reduction in BMI because energy expenditure has experienced an even greater decline (Law, 2004). In fact the benefits of physical exercise are wider than weight loss alone – it also lowers resting diastolic and systolic pressures proportional to the amount of exercise undertaken up to 90 minutes per week (Ishikawa-Takata et al, 2003). The American Heart Association recommends 40-60% of maximum heart rate for 30 minutes on most days[5]. (Fletcher et al, 1996).

3.4.15 SATURATED FAT INTAKE

Despite a 25% fall in the amount of meat consumed, the National Food Survey (DEFRA, 2001a) recorded a steep climb in consumption of food of animal origin between 1940 and 1960, and a related rise in intake of saturated fat corresponding

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[4] Under these conditions there is a risk of thrombosis, whereby a clot of blood develops on the lining of the affected artery. Clots can detach from the artery wall and become lodged, obstructing the blood flow. The clinical features of embolism depend on where in the circulation the obstruction is situated: cerebral embolism can cause stroke or transient ischaemic attacks (TIA), while gangrene can result from a clot in the arteries of a limb.

[5] The maximum heart rate is commonly (though controversially) held to be 220 minus ones age.

to the improved abilities of pastoralists to breed cattle for their meat or milk yields. Saturated fat in our diets is closely linked with high levels of LDL cholesterol which cause and interact with HBP and are a potent cardiovascular risk factor in their own right.

Despite this evidence, it was and remains important to the industry that all parts of the animal be profitable so, for example, when tallow candles were replaced by electric lighting, the redundant animal fats were diverted into the food chain. Malcolm Law (2004) comments with a measure of scepticism on the late trend of falling consumption of cream, butter, full fat milk and lard, observing that the fats have thus far remained hidden in the food chain as ingredients in prepared meat products, soups, sauces and convenience meals.

He notes (2004) that the unit of saturated fat is the animal carcass, rather than individual intake - "...so long as some people want low fat milk or lean steak, cheap, fatty food will become available and other people will buy it..." - and that it is important to legislate to remove the harmful substances, now relegated to by-product status, from the food chain.

3.4.16 SOCIOECONOMIC STATUS

It is well-established that people in lower socio-economic groups experience poorer health generally than those who are affluent (Lantz et al, 2001). There exists:

> "...a social gradient of health across the entire British population between 1911 and 1980, which persisted irrespective of all the major epidemiological changes that have occurred in British society over the 70-year period. In other words, whatever disease or illness kills people in Britain tends to kill poor people more than their better off counterparts". (Tsey et al, 2003).

In high income countries HBP is more prevalent in less affluent groups, where the incidence is higher (Hardy et al, 2003; Lang, 1998) and the condition is more likely to remain untreated (Bell et al, 2003, Lang, 1998). Lower income, poorer education and, to a lesser extent, ethnic minority – all of which are associated with lower socio-economic status, are generally acknowledged to be key mediating factors.

It is worth mentioning that, in contrast to low-income countries where HBP is regarded as a disease of affluence, the association between HBP and income in high-income countries has historically been inverse. In low-income countries, the less affluent are more likely, through necessity, to exist on a diet low in saturated fats, sugars and energy, higher in fruit and vegetables, and to have physically active occupations. Disturbingly, this is reversed as countries 'develop' (WHO, 2003, p4-5).

3.4.17 SODIUM INTAKE

Reducing salt intake can significantly lower BP (Sacks et al, 2001). The mechanism by which sodium elevates BP is poorly understood, but is believed to be associated

with poor kidney function. There is some evidence of a genetic component in the effects of sodium, in that normotensive children with hypertensive parents have more difficulty excreting sodium than those with normotensive parents (Roberts, 2001). There is a commercial aspect to salt intake (Roberts, 2001) which leads to conflict between health lobby groups such as the Consensus for Action on Salt and Health and those from the food industry such as the USA's Salt Institute. Salt is a cheap way to add flavour to prepared foods, which also allows them to be bulked out by other cheap ingredients such as water. Salt also increases thirst, leading to improved drink sales.

Current guidelines (British Hypertension Society, 2004; JNC 7, 2003; Williams, 2004) recommend adherence to a diet rich in food sources of magnesium, calcium and potassium and low in sodium. It has become known as the DASH diet, named after the study Dietary Approaches to Stop Hypertension (Sacks et al, 1995; Sacks et al, 2001) which confirmed the benefits of these nutrients.

3.5 SUMMARY OF EPIDEMIOLOGY

Some of the risk factors and mediating factors for HBP are outlined above, although it has not been possible to do them justice. The sketch serves to hint at an elemental feature of HBP – its interconnectedness with the environment, social circumstances, economic status, and heredity.

3.6 ASSESSMENT

Because of the complex interaction of mechanisms in HBP, total cardiovascular risk is influenced by more than just BP and, accordingly, therapy decisions and prognosis are based on an assessment of the factors influencing this risk (Beevers, 2001; Julius, 2000).

The first step in clinical assessment is to ascertain that BP elevation is sustained. This is achieved, ideally, by multiple measurements over a period of weeks or months. The British Hypertension Society guidelines (2004) recommend that two measurements should be taken on each of three or four separate occasions, at least two minutes apart, and in whichever arm higher pressure has been identified. The mean of the two readings is used unless there is a marked difference between them, in which case more measurements are needed. If raised BP is sustained in the clinic environment, ambulatory BP monitoring (ABPM) is often used to rule out "white coat hypertension" – BP elevation due to the emotional impact of the clinical environment. Along the same principle as ABPM, many surgeries now loan home monitoring devices to patients for a week or a fortnight to collect a series of readings at home.

During this period, a history and physical examination of the patient identify the causes and effects of the HBP (Beevers et al, 2001). History-taking explores medical history, family history, drug history, and social factors such as diet, lifestyle and occupation. General physical examination can reveal distinctive conditions which are underlying causes of HBP in 3-5% of cases, as well as noticeable signs of alcohol and tobacco use and raised lipids. Body mass index (BMI) is a calculation based on the patient's height and weight. Speed and variations in heart sounds may offer early clues about its health, and listening to breathing may identify wheezing which contraindicates use of beta-blockers. Ophthalmoscopy may reveal retinal and corneal states associated with malignant or accelerated HBP, or hyperlipidaemia. Examining the abdomen may disclose signs of liver disease associated with alcoholism, or inherited polycystic kidney disease associated with HBP. Assessment of the central nervous system may flag previous stroke.

If sustained HBP is confirmed, several investigations are carried out in every case. Blood biochemistry is investigated; serum sodium, calcium and potassium concentrations can flag a number of underlying causes of HBP, but may be confused by use of certain types of medication – thiazide diuretics or ACE inhibitors, for example. Raised serum creatinine indicates damage to target organs such as the kidneys. Raised serum uric acid may be an indication of frequent alcohol consumption, use of diuretics, or renal impairment. Raised serum cholesterol and triglycerides are synergistic risk factors to be treated in their own right, and may indicate use of diuretics or beta-blockers. Urinalysis is also carried out in every case, and may reveal protein or blood associated with renal disease, or glucose indicating diabetes. All patients are supposed to undergo echocardiography to screen for left ventricle hypertrophy (LVH) and provide a baseline of heart function with which subsequent changes can be identified. Selected patients will undergo second line investigations, such as echocardiogram, renal ultrasound, twenty-four hour urine collection, and thyroid function tests.

3.7 TREATMENT

BP-lowering treatment takes two broad approaches. Lifestyle modification is a first-line treatment initiated as soon as elevated BP is identified, and involving adjustment of diet and lifestyle. If BP does not respond to these measures, or if cardiovascular risk is critical, a wide choice of medication is available. Both approaches are discussed below.

3.7.1 DIET AND LIFESTYLE MEASURES

Newly diagnosed patients are counselled about their lifestyle with respect to their modifiable cardiovascular risk factors. They are advised to make some changes to

their diet, limiting intake of foods containing saturated fat, salt and, where applicable, energy, and increasing intake of those which provide potassium, antioxidants and soluble fibre. In practice, according to DASH diet principles (US Department of Health and Human Services, 1999), this means eating more fruit, vegetables and low-fat alternative dairy produce, and less animal fats, meat, packaged foods and savoury snacks. Physical activity is strongly but vaguely encouraged; it is difficult to find clear guidelines about intensity, but there is some consensus on the Web that effective exercise constitutes any sort of physical activity which brings the heart rate to between 60% and 85% of its maximum (controversially estimated as 220 minus ones age), increasing with fitness, with a recommended duration of at least 30 minutes and at least five times a week. In many cases information about losing weight, with the aim of achieving a body mass index (BMI) within the healthy range of 20-25, is given in the context of dietary and exercise advice. If patients smoke they are given strong advice to stop, ideally coupled with long-term support. Diet and lifestyle measures are considered in detail in the following chapter.

3.7.2 MEDICATION

Antihypertensive drug treatment is initiated if either BP is 160/100 mmHg or higher, there is a ten-year cardiovascular risk above 20%, if there is existing cardiovascular disease, or if there is target organ damage. The pharmacological treatment of HBP has recourse to a growing choice of medication. Current prescribing for HBP without known cause favours established drugs, with their larger evidence base, as first-line therapies. As new drugs pass into the formulary, they are the focus of high profile longitudinal studies which excite avid interest. Consequent changes to prescribing guidelines can create new markets and impact profoundly on health care budgets. A large number of trials have matured and more are underway (Black, 2001). Table 3.1 shows a brief summary of drug groups.

For optimal control, most patients need to be prescribed combinations of two or three antihypertensive drugs for the long term, hinging on a synergy known as the AB/CD algorithm (Williams et al, 2004), which states that drugs that inhibit the renin-angiotensin system - ACE inhibitors and angiotensin II receptor blockers (A) or beta-blockers (B) - should be logically combined with drugs which do not inhibit it - calcium channel blockers (C) or diuretics (D), as outlined in Figure 3.2.

	Indication		Contraindication	
Drug class	Compelling	Possible	Possible	Compelling
Alpha-blockers	Prostatism	Dyslipidaemia	Postural hypotension	Urinary incontinence
Angiotensin Converting Enzyme Inhibitors	Heart failure Left ventricular dysfunction. Type 1 diabetic nephropathy.	Chronic renal disease. Type II diabetic nephropathy.	Renal impairment. Peripheral vascular disease.	Pregnancy
Angiotensin II Receptor Antagonists	Cough induced by ACE inhibitor	Heart failure Intolerance of other antihypertensive drugs	Peripheral vascular disease	Pregnancy Renal vascular disease
Beta-blockers	Myocardial infarction Angina	Heart failure	Heart failure Dyslipidaemia Peripheral vascular disease.	Asthma or chronic obstructive pulmonary disease Heart block
Calcium antagonists	Isolated systolic hypertension in older patients Angina	Angina Older patients Myocardial infarction	Combination with beta-blockade	Heart block Heart failure
Thiazides	Older patients		Dyslipidaemia	Gout

Table 3.1. Major classes of antihypertensive drugs, their indications and contraindications. (After Beevers et al, 2001).
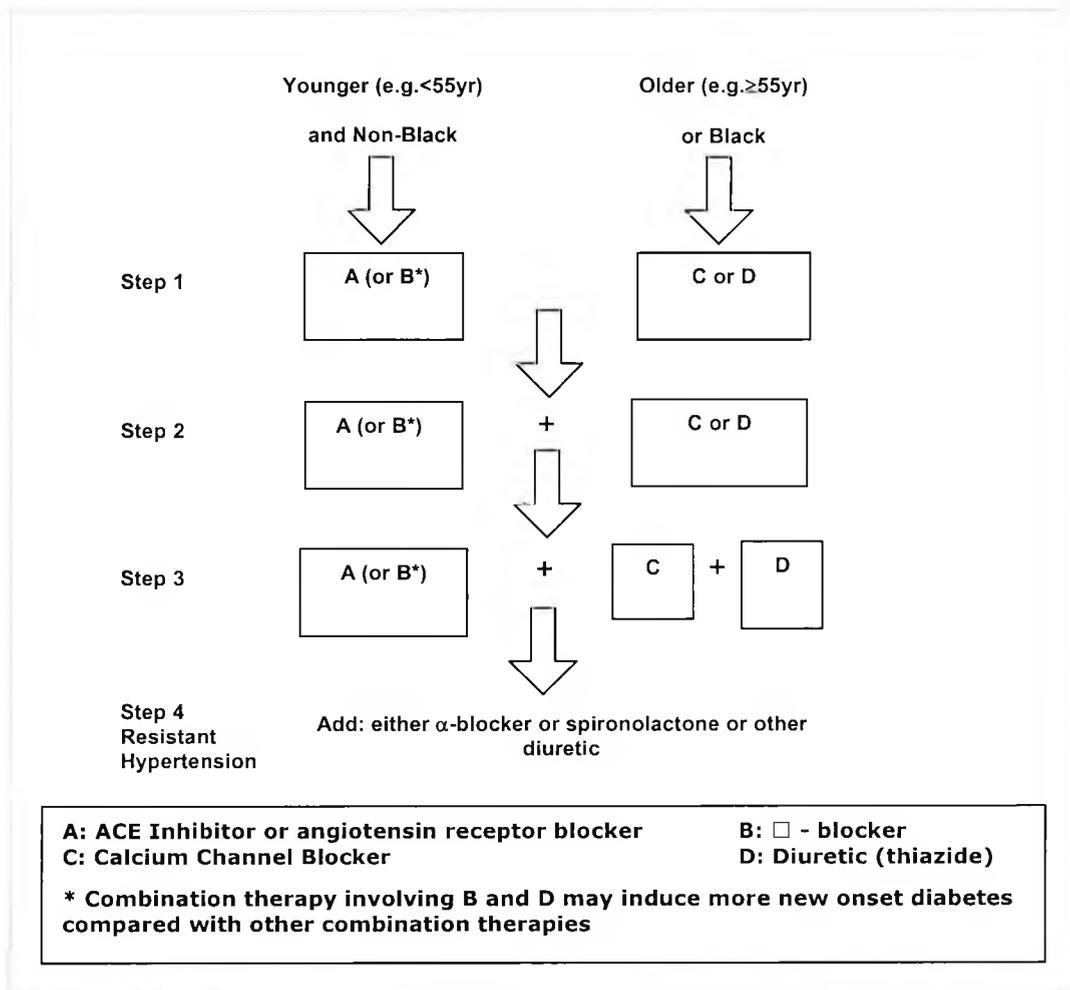
Figure 3.2. Indications for prescribing and combining BP lowering medication. (After Brown et al, 2003)

3.7.2.1 Polypill

A June 2003 issue of The British Medical Journal presented claims for a new intervention which would have "a greater impact on the prevention of disease in the Western world than any other known intervention." (Wald et al, 2003). The polypill, currently hypothetical, is promoted (Law, 2003b; Wald, 2003) as a magic bullet integrating several well established medications which are already often used together - three half-dose antihypertensive drugs, folic acid to combat homocysteine, the anticoagulant aspirin, and a statin to reduce cholesterol. The polypill promises to reduce cardiovascular disease by a massive 80%, causing few adverse effects. It is proposed, contentiously, that this medication be offered to everybody aged over fifty-five.

The editorial for the issue called for a debate about the extensive use of preventive medications (Rodgers, 2003), especially in people without manifest disease. As discussed in Section 4.3.1), this proposal represents a disturbingly medical approach to health protection which embodies deep pessimism about our ability as a society to alleviate the risk factors for cardiovascular disease. As its proponents would agree, the prospect of medicating everybody over fifty-five years old starkly highlights the failure of successive policy makers to reduce cardiovascular illness by other means. A further drawback to this approach is that it depends on good adherence to treatment which, as outlined in Section 3.7.2.2 below, is presently inadequate for BP-lowering interventions.

A sceptical view of the polypill presumes that it will gain acceptance if it represents the path of least resistance. It will demand little of its users – only to be taken daily with occasional prescription renewals. Its introduction will not harm the economy because it will not fuel, and may even dispel, mounting pressure to cut down on detrimental types of consumption such as junk-food, alcohol and cigarettes. Moreover, it will create an enormous and stable market for the medication.

Yet it could be argued that a significant attempt has yet to be made to alleviate these risk factors by non-medical means, and that a holistic approach incorporating legal and fiscal interventions, individual empowerment and infrastructure for healthy living could achieve a multitude of other health and social benefits besides cardiovascular improvements. Although such an approach to health promotion has hitherto been forestalled by the rhetoric that freedom of choice – in this context, the freedom to market and consume unhealthy lifestyles - is sacrosanct and to be upheld at all costs, there is an emergent consciousness that the ultimate choice, far narrower, is actually between a long-term healthy lifestyle or the likelihood of developing a range of health conditions associated with modern life – such as cancer, diabetes and depression - which a polypill cannot prevent. It may therefore

prove a mistake to characterise cardiovascular disease as the embodiment of the nation's ills and set about eliminating it in this manner – its attempted destruction may expose a range of other diseases with the same underlying causes.

3.7.2.2 Adherence to treatment

Adherence is the intersection of health care provision and health care uptake. According to the WHO definition (2003b, p3), it is "the extent to which a person's behaviour – taking medication, following a diet, and/or excecuting lifestyle changes, corresponds with agreed recommendations from a health care provider". Unlike compliance, which presumes obedience to an authority figure, the concept of adherence ("concordance" is also widely used) requires the patient's agreement and active partnership. It is notoriously difficult to measure, and a multi-method approach is usually the best strategy. Subjective ratings tend to overestimate adherence, personality traits are poor predictors, counting remaining dosage units or scrutinising pharmacy databases offer only basic information, biochemical measurement can be unreliable, and electronic devices such as medication event monitoring systems remain too expensive for widespread use. It is worth stating that nonadherence usually, but not without exception, precludes good BP control (Khalil and Elzubier 1997).

Adherence to BP lowering therapy is associated with better control and reduction in complications (Lucher et al, 1985). On the other hand, failure to adhere to recommendations, a widespread problem of great magnitude, has been identified as the main reason for poor BP control (National Lung, Heart and Blood Insitute, 1997; Waeber et al, 2000). In developed countries such as the US, around half of treated patients adhere; studies in China, the Gambia and the Seychelles identified 43%, 27% and 26% respectively and this lower rate is true of most developing countries (WHO, 2003b, p7). Patients are prone to absenting from health care systems for BP (Mapes, 1977), and those who persist are unlikely to achieve even the 80% threshold which passes for adherence to medication (WHO, 2003b, p108).

The solution lies in identifying and modifying the factors which impact on adherence. Social and economic variables have an impact, including ethnic minority status, war, and advanced age, which are associated with poor adherence. The health care system, in particular the relationship between the team and the patient, has an effect which is poorly understood. Each condition, patient and therapy regimen has its own actors relating to adherence. For HBP it is important that patients understand the condition, since it is asymptomatic and without frequent monitoring provides little feedback to reward good adherence. Lower socioeconomic status, associated with lower educational achievement which poorly equips individuals for the range of lifestyle decisions they must make from day to day, can

be supported through educational and behavioural interventions. Identifying the optimal drug tolerability and minimising the complexity of the regimen is crucial to promoting adherence by eliminating adverse effects and streamlining the process of taking the medication.

For HBP, adherence amounts to an understanding of the importance of therapy, how to participate rationally in therapy, how to deal with lapses and how to identify adverse effects and decide what to do about them. Individual ability to reflect on the nature and success of his or her adherence is also a positive attribute.

3.8 CARDIOVASCULAR RISK AND COMPLICATIONS

Cardiovascular risk rises throughout the entire BP range. For individuals between 40 and 70 years of age each increment of 20mmHg systolic or 10mmHg diastolic doubles the risk of CVD across the entire blood pressure range from 115/75mmHg to 185/115mmHg (Lewington et al, 2003). Complications - conditions and events caused by interruptions or restrictions in blood circulation - include heart disease, kidney disease and cerebrovascular disease. HBP is the certified cause of around 3,000 deaths per year, but is included on around 20,000 death certificates and is an important contributory factor in 50,000 deaths from stroke and 100,000 deaths from coronary heart disease (CHD) each year (Donaldson, 2001). Worldwide, systolic BP above 115 mmHg accounts for two-thirds of strokes and almost half of ischaemic heart disease (Murray et al, 2003). This amounts to 7 million premature deaths annually (WHO, 2002), and 23.6% of disability adjusted life years in more developed countries (Murray et al, 2003). He and MacGregor (2003) estimate that lowering systolic BP below 140mmHg would avert 125,600 strokes and ischaemic heart diseases annually, amounting to a reduction of nearly 63,000 deaths per year.

The fundamental mechanism by which elevated BP brings about complications is damage to the arteries, known as atherosclerosis and common to most vascular disease. Atherosclerosis is a hardening and loss of elasticity in the artery walls, the prevalence and severity of which increases with age in industrialised countries. Causes include trauma from the continuous pulse of blood at high pressure over time, damage to the artery lining over time by cigarette smoking, and fatty plaque deposited as occluding lesions on the damaged artery walls, causing turbulence and further trauma. Trauma usually affects the large arteries and not the veins since flow in the latter is steadier and at lower pressures. When an artery is affected by atherosclerosis it cannot stretch to incorporate the output from each systole; this means that blood is being forced through a narrower space and cannot reach its destination as easily. Poiseuille's Law (Section 3.1) comes into effect as the vessel

walls thicken, and in this way elevated BP becomes both a cause and effect of atherosclerosis.

The ensuing cardiovascular events can be thought of as blocking or bursting effects of HBP. Bursting effects are caused by increased peripheral resistance, stimulating increased cardiac output which leads to a corresponding increase in BP. Arterial aneurysm is a sac-like stretching of a vessel wall in response to the pressure, which eventually ruptures causing a haemorrhage in the vicinity. In the heart, sustained peripheral resistance generally causes the left ventricle to hypertrophy; like the muscles of a body builder it grows in size to cope with its workload, but instead becomes less flexible and ineffective at pumping blood. Heart failure is then likely, with an attendant pooling of blood in the lungs, legs and liver. Blocking effects have a number of manifestations. Sclerosed vessels gradually starve their target organs of oxygen and nutrients, causing ischaemic heart disease, kidney disease, and other conditions. Occlusions can also be caused by detached fragments of plaque lodging in a smaller artery and severing its blood supply – often manifest as embolic stroke or transient ischaemic attacks. Where blood flow is sluggish, due to atherosclerosis or heart failure, clots can develop inside blood vessels – for example, thrombotic stroke. The effects of atherosclerosis on the cardiovascular system are outlined in Figure 3.3.

Despite the evidence that HBP is implicated in these diseases and events, its role as a cardiovascular risk factor is complicated and vulnerable to a certain amount of speculation. Recent findings suggest that, as a risk factor for CHD (the most widely studied of the complications), HBP interacts multiplicatively with five others – elevated LDL cholesterol, obesity, diabetes, physical inactivity and smoking. This means that a person with all six risk factors is 729 times more likely to suffer a heart attack than a person with none (Law, 2004). This means that BP as a sole screening test for cardiovascular risk is a poor indicator.
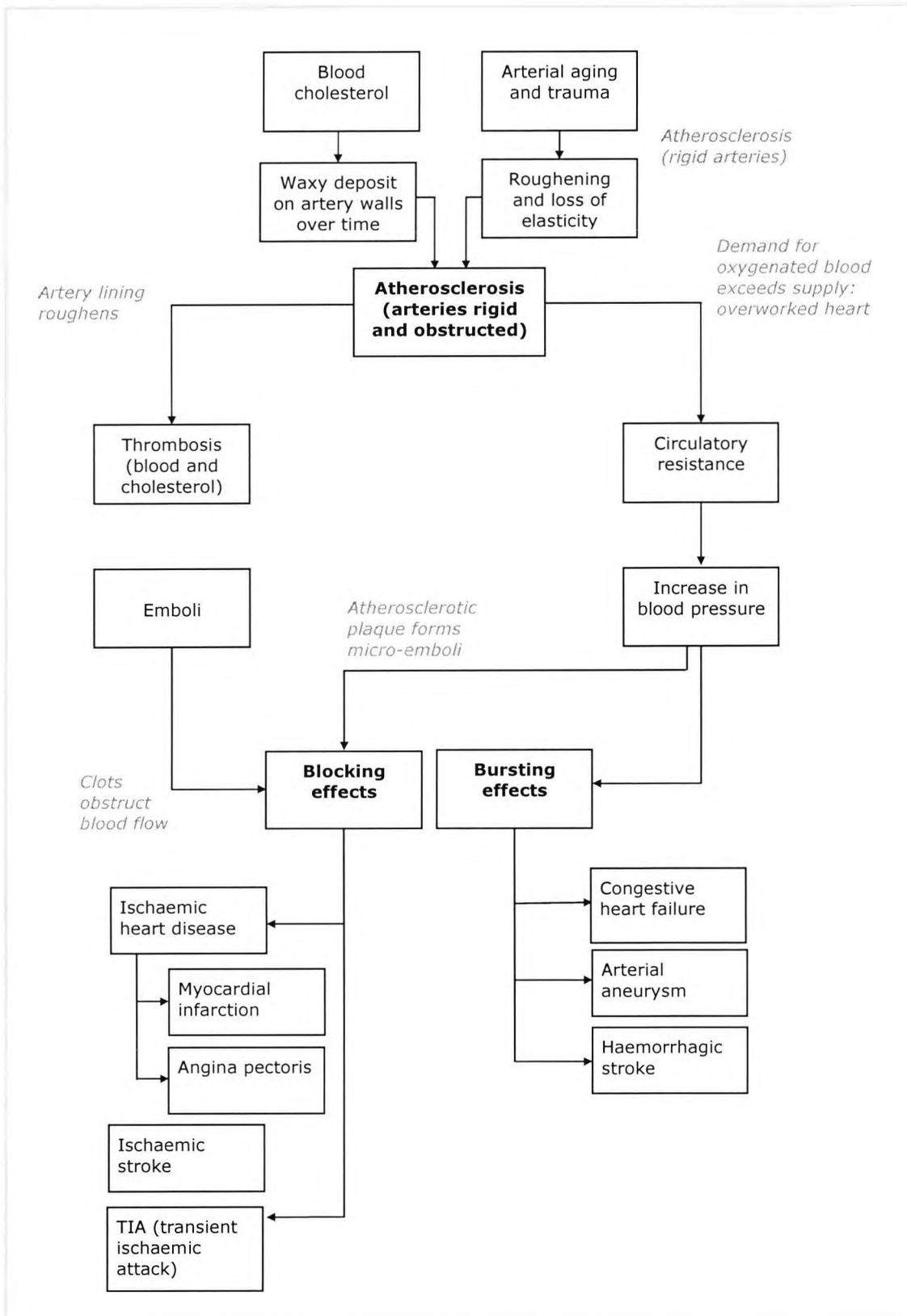
Figure 3.3 Effects of atherosclerosis on the cardiovascular system

3.9 COSTS

Data about the costs of HBP is not a product of standard audit practice, and is difficult to amalgamate. Economic information about this complex condition has to be painstakingly disaggregated from diverse administrative sources such as hospital

admissions, medical procedures, consultations and prescriptions, and synthesised through meta-analysis. Costs encompass antihypertensive drugs, laboratory tests and instrumental procedures, health professional visits for BP control, specialist visits, casualty visits, hospitalisation due to cardiovascular problems, rehabilitation and continuing care (Degli and Esposti, 2001). Less evident and still more difficult to quantify are the reductions in quality of life, income, and contribution, and the burdens of care and concern which descend on the friends and families of people who succumb to cardiovascular events.

3.9.1 COSTS TO LIFE AND HEALTH

The Office of Health Economics (OHE) (Yuen, 2001) collects statistics on consultations. In 2000 in the UK, 764 of every 10,000 patients consulting presented about "essential (primary) hypertension" (p50), compared to 254 for diabetes mellitus and 231 for all neoplasms. 2,109 of every 10,000 doctor consultations were for HBP, the highest for any disease. An estimated 8,234 million people consulted a GP about their circulatory system, compared to 15,705 million respiratory patients, 5,689 million patients with mental disorders, and 11,054 patients with skin or subcutaneous tissue disorders (p49). This is disproportionate to the threat posed by HBP suggesting, according to the rule of halves (Beevers et al, 2002, p94), that it is underrepresented in primary care. Of a total of 655,385 (Yuen, 2001, p36) deaths in 1998, diseases of the circulatory system were the leading cause, accounting for 258,240 deaths - about one third of the total (p37) - cancer led to a total of 148,584 deaths and external causes of injury accounted for 19,159. Within the circulatory disease category, "hypertensive disease" caused 3,471 deaths, CHD, 138,114, and cerebrovascular disease (strokes), 66,024. The complications of HBP - without which it cannot be meaningfully considered - overshadow most other conditions in their toll on life and health in the UK and other high-income countries.

3.9.2 SOCIAL COSTS

Among other dimensions, social costs affect quality of life, social role and vocational role, and have yet to be adequately calculated (Coyne et al, 2002).

For HBP, health related quality of life (HRQL, a concept outlined in Section 4.1.4) can be measured in terms of patient-reported outcomes for symptoms, dimensions of general well-being (psychological affective states), cognitive function, sexual function and sleep (Coyne et al, 2002). HRQL tends to be adversely affected by the identification of HBP, and its ensuing events. Diagnosis is often accompanied by feelings of fear, negative self-image and inadequacy (Battersby et al, 1995; Wagner and Strogatz, 1984). Early effects of medication can be uncomfortable, which is especially problematic considering the generally asymptomatic nature of

the condition - "the side effects of antihypertensive medication may be less well tolerated by patients than the unperceived effects of untreated hypertension" (Coyne et al, 2002), undermining adherence. Lifestyle modifications often pose an enormous challenge with few obvious rewards and can seem uncomfortable and joyless, a further threat to adherence. In short, for many, HBP is characterised by a sharp dislocation from a former, more comfortable life.

As calculated by the OHE (Yuen, 2001), of a total of 878,193 years of potential working life (up to age 65) lost to premature death, circulatory diseases accounted for 37%, the highest proportion (p35). By comparison, all neoplasms comprised 22% and suicide, 7% of lost years. Although by some accounts CHD mortality is in decline, the social class gradient for CHD mortality has become dramatically steeper over the past 20 years (Department of Health, 2000, p9), and death rates from heart disease among unskilled men are now three times greater than those among professional men.

3.9.3 HEALTH CARE COSTS

In 1995, the American Heart Association (Moser, 1998) estimated the annual cost of US BP care at $18.7 billion, including health care professionals, hospital and nursing homes, medication. Accounting for indirect costs brings the value to as high as $37.2 billion (Coyne et al, 2002). According to Hodgson and Cai (2001), medical spending attributed to HBP (ie including its comorbidities and complications) in the US accounts for 12.6% of total expenditure on health, including $22.8 billion for hypertension, $29.7 billion for cardiovascular complications, and $56.4 billion for other diagnoses. In 2001 in the UK, the National Health Service funded 90 million prescriptions for BP-lowering medication (National Institute of Clinical Excellence, 2004). This £840 million expenditure accounted for 15% of the total annual cost of all primary care drugs. Since the cardiovascular diseases to which HBP contributes cause 30% of all deaths and account for four million bed days (8% of NHS total capacity) annually, improving HBP management would have major beneficial resource implications for the NHS (National Institute for Clinical Excellence, 2004).

Not all spending can be considered an investment – in the treatment of HBP costs are often incurred without benefit, including labelling (stigma), ineffective lifestyle modification, switching medication and not treating to target pressures (Moser, 1998). Jonsson and colleagues (2003) identified four categories of health resource allocation: antihypertensive medication costs, hospitalisations, physician visits and side-effects. Their findings indicate that medication costs and visits (the two dominating costs which account for almost all expenditure), rise by 8% as target BPs are lowered from DBP 90 to 80 and treatment is more aggressive. These costs are not conclusively offset by the cost of hospitalisation, which tends to fall, but

non-significantly. Nonadherence, discussed in Section 3.7.2.2, results in poor outcomes and increased health costs.

3.10 SUMMARY

HBP is a complicated notion, the definition of which, never stable, is currently experiencing particularly forceful erosion. Health professionals experience difficulty aggregating its multiplicity into a working model they can use in practice and it is difficult to comprehend how patients, especially those taking the desirable participatory role, can find living with the condition any less challenging.

HBP exists alongside a large range of interrelated factors such as obesity and hypercholesterolaemia, but it is no longer safe to assume that it has an arbitary cut-off point, an established cause, nor a known mechanism. For this reason, decisions about medication for HBP continue to be based on informed generalisation, and patients who resist definition by given categories often pose resistant problems. HBP is one of the most important risk factors for the cardiovascular illness which devastates high-income and developing countries. However, directing all resources into BP reduction in the belief that this is the surest way to reduce cardiovascular risk has proved ineffective. BP lowering interventions must be combined with other measures such as education, dietary changes, physical activity, cholesterol reduction and smoking cessation. Moreover, BP should be persistently treated to optimal levels, which involves working more effectively to keep patients attending, involved, and adherent.

Lowering BP cannot be isolated and prosecuted as an end in itself. The true end – the reduction of cardiovascular illness – must be kept in sight at all times. For this reason, lowering BP demands a holistic approach as befits such a complex domain. HBP is rooted in several aspects of lifestyle prevalent in developed countries, and in combination these are root causes of many other diseases and conditions. A truly informative information package for HBP, therefore, cannot ignore the complexity of the condition; it must encompass, attempt to untangle, and clearly present, the numerous interrelated factors which impact upon it. These modifiable risk factors have such a far-reaching negative health impact that a corollary of undertaking this untangling exercise is the advancement of a broader understanding of several comprehensive health issues. The Polypill is touted as a magic bullet to prevent the vast majority of cardiovascular disease, and the enormity of its prospects cannot be underestimated. However, dietary and lifestyle changes, such as those recommended and explained in Pressure's Off, contribute to good health in a more meaningful, sustainable and far-reaching way.

CHAPTER 4: HEALTH PROMOTION AND HIGH BLOOD PRESSURE

Following the overview of high blood pressure (HBP) in the previous chapter, this chapter discusses health promotion for the condition, providing background and reasoning underpinning the strategies adopted for this research project. After considering the slippery concept of health, the features and goals of health promotion are outlined, and the theories behind different approaches are described with particular emphasis on health education as the chosen approach in this project. The evaluation of health promotion is covered, after which health promotion for HBP is considered in the context of adherence to diet, lifestyle and medication interventions and current shortcomings in each area. The chapter concludes by exploring the premise that information works – that it has a positive impact on the health of its consumers. As demonstrated by the frequent failure to convert health awareness into healthy behaviours, the assumption is not always borne out by experience.

4.1 CONCEPTS OF HEALTH

In order to discuss health promotion it is necessary to first identify the nature of health. This section explores the concepts of positive and negative health, and how health can be measured.

4.1.1 DEFINITION OF HEALTH

> "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (WHO, 1946)

To engage in the business of health promotion it is necessary to have a view of what health is. The origin of the word is heal, whole or hale, The concept has two meanings in everyday use – the presence of well-being and absence of infirmity. The WHO's definition, which has not changed since its inception, acknowledges these positive and negative aspects of health. However, it does not account for the fact that health may exist and alter along a continuum of relative states, may be subjective or socially determined, and may not represent a fixed relationship between infirmity and wellbeing.

4.1.2 NEGATIVE HEALTH

In their discussion of negative health, Downie and colleagues (1996, p10-18) examine different aspects of infirmity, including disease, illness, abnormality, disability, deformity, unwanted states and injury. A number of issues emerge, summarised below. There is a distinction between illness - a physical manifestation - and disease - an underlying pathology. People with HBP do not feel ill with the

disease, neither can they sensibly be said to *be* ill with it. Similarly, a person who *feels* ill may need to have their condition legitimated by a diagnosis before they can be said with confidence to *be* ill, because people who persist in their complaints in the absence of a diagnosis are often dismissed as hypochondriacs or malingerers. Only relatively recently have some illnesses such as depression gained legitimacy in the medical model prevalent in the developed world, with its residual tendencies towards mechanistic, reductionist approaches to illness (Naidoo and Wills, 1994, p7).

To be regarded as an illness or disease, a condition must be essentially progressive, allowing questions about whether the sufferer is getting better or worse. For example, blindness is an impairment which can be severely disabling, but since it is a fixed, non-progressive state it is not usually considered "unhealthy". A broken leg is an injury, and therefore both incapacitating and progressive, but the sufferer may simultaneously be in good health. Severity also has an impact on our perception of health – a person with psoriasis is not said to be in poor health unless the condition becomes acute or a systemic infection is picked up as a result. Asymptomatic diseases like HBP and early cancers, prior to diagnosis, do not impinge on a person's sense of their own well-being – they *feel* normal and the HBP is easy to ignore. On the other hand, some signs and symptoms such as the sarcopenia of advanced age are often regarded fatalistically - and increasing evidence (Abbott, 2004) suggests, wrongly - as normal, inevitable states rather than disorders. This discrepancy shows up in the ongoing debate to define HBP – "normal" BP in developed countries is much higher than is "healthy". A condition, such as HBP in advanced age, which is widely regarded as normal tends to be treated less aggressively (Dickerson and Brown, 1995), although current evidence suggests that most of the UK population would benefit from BP lowering interventions as they advance in age (Law et al, 2003). This reflection on the nature of negative health reveals challenges when defining positive health and the relationship between the two.

4.1.3 POSITIVE HEALTH

The WHO definition above regards health as a state of well-being. Well-being can be a subjective and unstructured state which exists in several dimensions including the social, political, environmental, physical and emotional, and to varying degrees from flimsy and transient to robust and enduring. The origins of subjective well-being are correspondingly widespread, may be short-term or hedonistic (Downie et al, 1996, p19), and consequently of spurious value to long-term health. Health promoters tend to operate with reference to a more objective, structured standard of well-being, rooted in the more durable concepts of autonomy and fitness described below.

Autonomy is concerned with the degree of control individuals have, or feel they have, in their lives, the lack of which is associated with feelings of powerlessness, depression and fatalism which threaten health and self-care. Autonomy can be promoted by empowerment, which itself has dual facets – individuals and their environment. Empowerment promotes in individuals the belief that people can control their circumstances, and enables and facilitates this control within society or the environment.

Fitness hinges on four physical, functional attributes known as the Four Ss: strength, stamina, suppleness and skills (Downie et al, 1996, p22; Age Concern, 2002). The presence or absence of these attributes, which can be lost or gained, can affect an individual in three ways. The foremost of these is the ability to look after one's own basic needs, summarised by the medical profession as the Activities of Daily Living and including washing, dressing and toileting. The second is a person's ability to meet their own standards or those set by their occupation. The third is the ability, as witnessed in body building and marathon running, to maximise the body's potential in terms of effectiveness or efficiency, as a means to an end or for its own sake.

Autonomy and fitness encompass well-being and form the positive aspects of health, and in terms of BP, they are crucial to an individual's ability and inclination to, namely, eat healthily, avoid smoking and excessive alcohol consumption, take regular exercise and, where indicated, take the medication prescribed.

4.1.4 MEASURING HEALTH

Health-related quality of life (HRQL) measures, such as those outlined below, are useful in evaluating HBP interventions (Coyne et al, 2002) the goal of which is to "reduce morbidity and mortality by the least intrusive means possible" (National Heart, Lung and Blood Institute, 1997).

Health is measured to assist planning, allocate resources and evaluate outcomes. As demonstrated by the previous sections, it is difficult to define health, and consequently it is most straightforward and, predictably, most common to measure health as a negative variable – the quality of *not* being diseased or ill (Naidoo and Wills, 1994, p46). However, this biomedical model (Prieto and Sacristán, 2003) yields statistics such as absences from work, the prevalence of a given disease, or mortality statistics – surrogate measures which do not offer insight into health.

To measure health positively, a number of different measures have been developed, based on the known correlation of a given indicator with health status. Health measures, such as height and birth-weight, for example, can be used as indicators of nutrition during childhood or gestation. Health behaviours such as exercise, consumption of fruit and vegetables, and uptake of a screening or

immunisation programme, can also be used as indicators. Environmental indicators are gathered by measuring aspects of the locality, such as air quality, housing and population density, while socio-economic indicators are concerned with disposable income and occupation.

Health status can also be measured subjectively, in terms of an individuals' perception of dimensions such as their own physical mobility, role limitations, pain, sleep, social isolation, emotional reaction and energy level, using generic quality of life instruments such as the Sickness Impact Profile, Nottingham Health Profile (Hunt and McEwan, 1980) and the Short Form 36 Health Survey (SF-36) (Ware et al, 1992). In evaluating interventions and rationing health care, the subjective considerations described above are embodied in the notion of the Quality Adjusted Life Year, or QALY. QALYs are arithmetical calculations of quantity and quality of life; the amount of time in a given health state is weighted by a score for that health state. Health states are calculated using subjective measures such as the EQ-5D questionnaire which can yield 245 distinct states, which have been weighted as values of 1 or lower (Phillips and Thompson, 2004); imperfect health is worth less than one and can have minus score, and death is equivalent to 0. One year lived in perfect health is worth 1 (expressed as 1 Year of Life x 1 Health State = 1 QALY); thus half a year lived in perfect health could be worth the same QALY as one year lived in health assessed as half of perfect (0.5 x 1 or 1 x 0.5).

4.2 DEFINITIONS AND GOALS OF HEALTH PROMOTION

Most definitions of health promotion incorporate two dimensions: the individual and their circumstances in a chicken-and-egg interaction. According to Naidoo and Wills (1994, p62):

"The process of attempting to promote health may include a whole range of interventions including:

- Those which foster healthy lifestyles

- Those which encourage access to services and involvement in health decisions

- Those which seek to promote an environment in which the healthy choice becomes the easier choice

- Those which educate about the body and keeping healthy"

The WHO (1984) reinforces the importance of social circumstances:

> "Health promotion has come to represent a unifying concept for those who recognize the need for change in the ways and conditions of living in order to promote health. Health promotion represents a mediating strategy between people and their environments, synthesizing personal choice and social responsibility in health to create a healthier future".

The Department of Health's Public Health Electronic Library glossary definition emphasises individual control:

> "The process of enabling people to increase control over and improve their health. As well as covering actions aimed at strengthening people's skills and capabilities, it also includes actions directed towards changing social, environmental conditions to prevent or to improve their impact on individual and public health."

The American Journal of Health Promotion's definition is holistic:

> "Health promotion is the science and art of helping people change their lifestyle to move toward a state of optimal health. Optimal health is defined as a balance of physical, emotional, social, spiritual, and intellectual health. Lifestyle change can be facilitated through a combination of efforts to enhance awareness, change behavior and create environments that support good health practices. Of the three, supportive environments will probably have the greatest impact in producing lasting change. " (1989).

In the above views, health promotion has a number of distinct and intersecting aspects encompassing the individual and social, educational and behavioural, mental and physical, enforced and elective.

The ultimate goal of health promotion is for people to flourish. It aims to take measures which not only prevent ill health but simultaneously promote positive health. It does not aim to enforce a culture of risk avoidance, an unfulfilling existence incompatible with health, but intead promotes a balanced and informed approach to life. Downie and colleagues summarise (1996, p26):

> "The overall goal of health promotion may be summed up as the balanced enhancement of physical, mental and social facets of positive health coupled with the prevention of physical, mental and social ill-health".

For the target group, behaviour change is a prerequisite of health, and health promotion practice is based on a number of theories of how to bring it about.

4.3 THEORIES AND MODELS OF HEALTH PROMOTION

Downie's model (Figure 4.1) shows a number of different approaches to health promotion – health education, health protection and prevention - and how they can overlap.
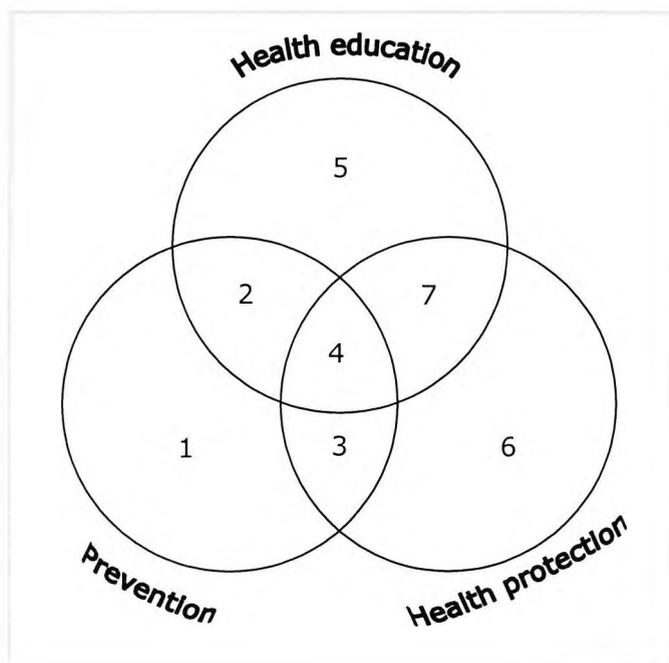
Figure 4.1. A model of health promotion (Downie et al, 1996, p59).

1. Preventive services such as screening for HBP

2. Preventive health education such as smoking cessation advice or behaviour change counselling.

3. Preventive health protection such as applying VAT to saturated fat

4. Health education, aimed at policy makers, for preventive health protection, such as lobbying to ban junk food advertising.

5. Positive health education, for example life skills work with young people or empowering communities.

6. Positive health protection, such as allocating funds to build attractive and accessible fitness facilities.

7. Health education, aimed at policy makers, for positive health protection, lobbying for healthy policy commitments such as subsidisation of fruit and vegetables.

A dichotomy has emerged between the voluntary and the authoritarian approaches. The voluntary approach upholds the freedom of choice of every individual, the view that 'the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others' (Mill, 1859). This explicitly rejects the demand for compliance, passivity, regulation or dependency from the client, in favour of those which involve negotiation, choice and empowerment (Naidoo and Wills, 1994, p92). In contrast, the authority approach is a top-down process based on the decisions of experts, seeking to define client needs and persuade them to take the 'right' decision (authorised by

the experts), for their own best interests. This is often incarnated as a straightforward transmission approach – health professional advises patient and expects or hopes that the information will somehow trigger a decision to adopt healthy behaviours. Although this model is cheap and so usually forms the basis of health promotion for BP, it is not effective on its own. The crucial issue is, does an individual have the right to make a wrong decision, or no decision, with respect to his or her health? On what is this right based – the ability, in utilitarian terms, of a state-funded health care system to fund the wrong decision, an appeal to inalienable human rights, or beliefs about whether there can be a 'right' choice?

The three aspects of health promotion introduced above are explored in the following sections, with particular emphasis on health education, the approach chosen for this project.

4.3.1 HEALTH PROTECTION

Health protection has included the construction of sewers to prevent cholera and typhoid epidemics, postnatal classes for new mothers, and Winter Fuel Payments to protect older people considered vulnerable to hypothermia. Two examples of health protection targeted at cardiovascular disease are discussed below.

Health taxes, also known as "ad valorem" or sin taxes are an example of fiscal control. They fall into preventative health protection category (see Figure 4.1), and are based on a well established inverse price/consumption relationship (Institute of Alcohol Studies, 2003; Lang et al, 2002). A discretionary tax is applied to a consumable and resentment is tempered with the pledge that the tax will be hypothecated – for health promotion or treatment of a given condition, for example. However, health is rarely if ever the only consideration in levying a tax (see Section 4.5.3 on Alcohol and Tobacco); governments also have obligations to local businesses, the developing world, and the economy in general - and, an additional concern, smuggling becomes more lucrative as taxes increase, undermining both health protection and revenue generation. Moreover, it is undesirable that the taxes come to be seen as significant revenue generators, as this undermines its health message. Consequently there is no coherent policy on differential taxation of goods according to their impact on health.

The Polypill, one current preventative medical intervention under consideration, has already been introduced in the thesis (Section 3.7.2.1). Law (2003a) and colleagues question the term "hypertension", arguing that living in a high income country poses a health risk of its own, and consequently almost any inhabitant would benefit from reducing his or her BP, regardless of its place on the national distribution. Having considered five policy options to achieve this reduction, they conclude that offering a combination of antihypertensive and other cardioprotective

drugs to all people aged over 55 was the approach which would have the most impact on mortality and morbidity. The anticipated impact of this intervention is enormous:

> "The Polypill strategy, based on a single daily pill containing six components as specified, would prevent 88% of heart attacks and 80% of strokes. About 1 in 3 people would directly benefit, each on average gaining 11-12 years of life without a heart attack or stroke (20 years in those aged 55-64)" (Wald et al, 2003).

This proposal represents a disturbingly medical approach to health protection and, as even proponents would agree, starkly highlights the failure of successive policy makers to reduce cardiovascular illness by other means.

4.3.2 PREVENTION

Prevention involves reducing the risk of an unwanted health state, and is a difficult concept to pin down. Some observers have attempted to divide it into primary, secondary or tertiary interventions. Downie (1996, p50-2) and colleagues criticise this classification on the basis that it blurs "the distinction between prevention and cure and palliation", and that its terminology is meaningless jargon. They suggest instead redefining prevention as four "foci":

1. Prevention of the onset or first manifestation of a disease process or some other first occurrence, through **risk reduction**

2. Prevention of the progression of a disease process or other unwanted state, through **early detection** when this favourably affects outcome.

3. Prevention of avoidable **complications** of an irreversible, manifest disease or some other unwanted state.

4. Prevention of the **recurrence** of an illness or other unwanted phenomenon.

This approach to risk reduction for HBP could include, for normotensive people, raising awareness about nutritional aspects of diet, improving school or workplace meals, and encouraging and enabling exercise. Early detection would entail routine BP and cholesterol monitoring. Where elevated BP is present, preventing complications would involve strategies to improve adherence to bp-lowering medication or a weight-loss plan, or rehabilitation after a cardiovascular event. Preventing recurrence might involve targeting treatment against the recurrence of a particular cardiovascular event, or maintenance of an achieved healthy BP.

4.3.3 HEALTH EDUCATION

The origins of modern health education lie in the public health movement of 19th Century, a response to the dramatic increase in epidemics in overcrowded industrial towns. Early efforts focused on sanitation and temperance, with promotion of immunisation beginning towards the middle of the century. After experimenting

with devolving responsibility to a local level, the Health Education Council was set up in 1968 as a strong central body overseeing mass media campaigns such as those to reduce smoking and promote family planning. Different incarnations of the Health Education Council over the years include the Health Education Authority, the Health Development Agency and Health Protection Agency.

In approaching health education, Draper and colleagues (1980) suggest a "tripartite typology" which comprises:

- education about the body and how to look after it, such as that offered by Pressure's Off and the Blood Pressure Association.

- education about access to and appropriate use of health services, such as that provided by the Doctor Patient Partnership.

- education about policies and processes, from the local to the international, which impact on health, a neglected area which is often left to a small number of independent-minded pioneers such as the Consensus for Action on Salt and Health.

In delivering this education, there are two main approaches – giving information as a means of enabling people to set their own health agendas, introduced below, and producing behaviour change, a complicated concept which is discussed at length below.

4.3.3.1 Information

Information is fundamental to all health education interventions. The focus on informing patients came about in recognition that, with rising incidence of chronic disease, patients could assume a key role in producing their own health and illness, and that encouraging this consumer culture could improve satisfaction, lessen dependence on health professionals and, ultimately, reduce demands on the health service (Coulter et al, 1998, p4). Information can be given on a number of different areas, always with the same aim: to empower patients to make informed decisions and choices, and become actively involved in their own health care (Department of Health, 1992). These are:

- **health promotion and disease prevention**, including concepts and practical skills such as understanding risk, awareness of the nutritional properties of different foods, and knowledge about safe ways to exercise

- information to support **treatment choices**

- information to **improve the effectiveness of clinical care**, such as advice on how to avoid ill effects of postural hypotension, which can be a side effect of antihypertensive medication.

It must be acknowledged that not every patient wishes to assume a partnership role in their health care, or is able to process and apply the prerequisite information. Examples include a person with cognitive impairments as the result of a stroke, or somebody who does not feel confident in their ability to make decisions, and would prefer to think of the doctor as the expert.

4.3.4 THEORIES OF BEHAVIOUR CHANGE

Some established theories of behaviour change are discussed below, which are parallel and, sometimes, interrelated. As a model, each is unavoidably reductionist, considering factors in isolation, failing to weight them responsively, and incapable of fully representing the complexities of human behaviour. However each has been, and is, influential on that branch of health promotion which focuses on the impact of individual behaviour on health, and in that respect offers important insight into managing a chronic disease. For a multifactorial condition like HBP, changing behaviour can significantly modify cardiovascular risk. In applying each model to reducing HBP, the goal would be to achieve changes to the several significant aspects of lifestyle and diet discussed in Section 4.5, as well as possibly initiating and maintaining a long-term course of medication which may need fine tuning to minimise adverse effects and maximise effectiveness.

4.3.4.1 Health belief model

Becker's (1987, p245-249) well established model suggests that, for behavioural change to occur, an individual must have an incentive to change, be aware of their own susceptibility to a threat, perceive sufficient severity in the threat ("cues to action"), recognise benefits – a reduction in the threat - of changing, and estimate their own "self-efficacy" equal to carrying out the change.

According to this model, as a precondition for change to reduce HBP, a person would need to have a clear awareness that, say, reducing sodium could achieve reductions in BP of over 5mmHg, as an incentive to change. He or she would also need to accept a susceptibility to the condition in the absence of symptoms, and that the condition is a threat in the form of increased cardiovascular risk. Demonstration of an increased risk of stroke and heart attack, possibly as a concrete value (Anderson et al, 1991), could address the severity criterion, consolidated with cues to action such as counselling sessions or reminders to attend monitoring appointments. A clear understanding of the benefits of, for example, curtailing alcohol or enduring early side effects, could help a person to persevere with healthy behaviours. The potential magnitude of the changes and the far-reaching impact they might have on life's routines could undermine self-efficacy; this could be safeguarded by setting achievable goals and planning for change to be achieved in increments, over time.

4.3.4.2 Theory of planned behaviour

The theory of planned behaviour (Ajzen, 1991) is based on the premise that the antecedents of action are perceived behaviour control (PBC) and intention. PBC refers to an individual's estimation of his or her own ability to perform a given action. Intention is defined as the presence and intensity of motivation to carry out a given action, and is an indicator of the effort an individual will dedicate to achieving that action. PBC enhances intention, since people tend to feel more positive about tasks they are confident about achieving (Kelley and Abraham, 2004). Setting priority goals and making specific plans to achieve them has been found to have a reinforcing effect on intentions.

For BP the emphasis would be on breaking an overarching goal into a more manageable series of objectives, prioritising these and planning the specifics of achieving them. For example, for a person who is physically inactive, exercise may emerge as a priority that would assist weight reduction as well as improving cardiovascular health. An achievable initial goal would be set to build confidence, for example, walking for a total of fifteen minutes each day. It would be useful to develop this with an exploration of exactly where exercise could best fit into the person's day-to-day routine, action-planning for different scenarios, to anticipate barriers to exercise and make the goals as concrete as possible.

4.3.4.3 Transtheoretical (stages of change) model

Procashka and DiClemente (1982) regard behaviour change as a process which they express in a model defining a sequence of stages through which an individual advances often in a cyclical way, until the change is accomplished and they exit.
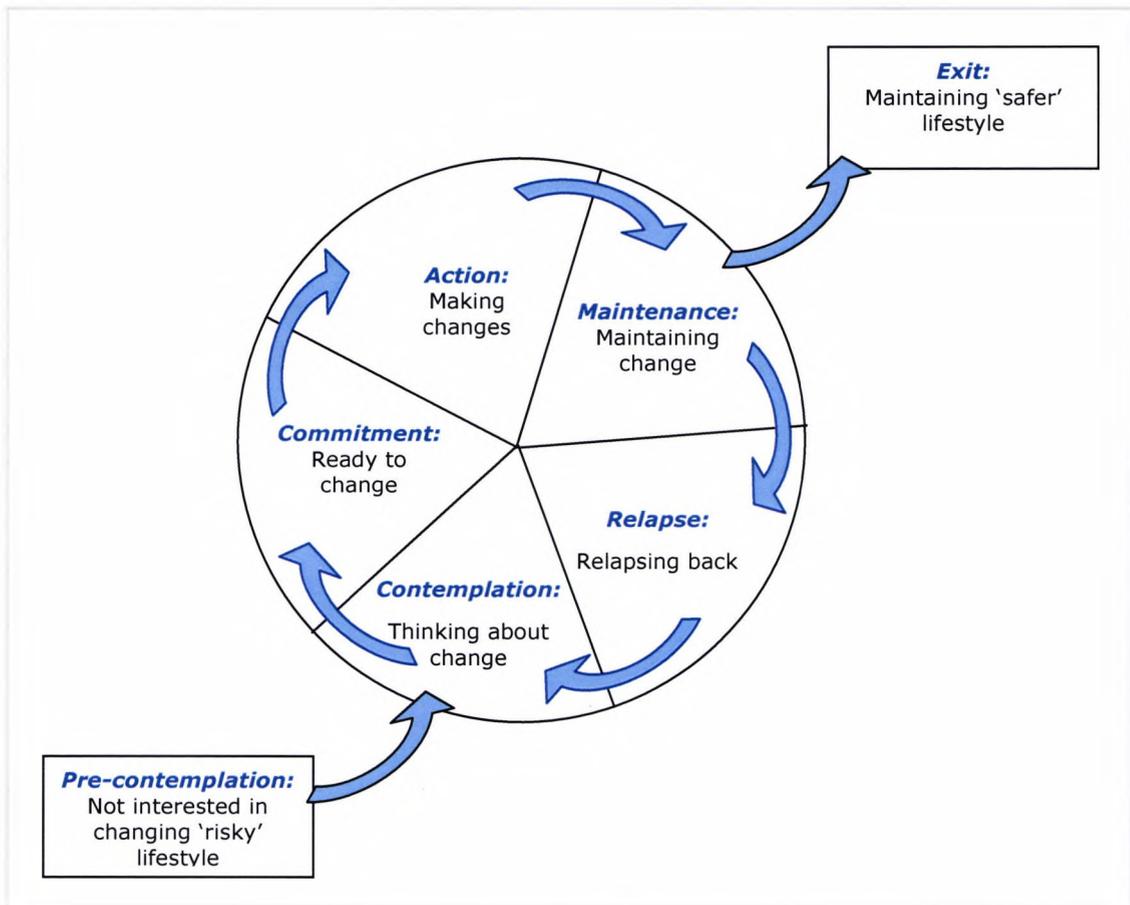
Figure 4.2. Stages of changing health behaviour. (Ewles and Simnett, 1999, p264, adapted from Neesham, 1993 and Prochaska and DiClemente, 1984)

During the pre-contemplation stage, the person is unaware that there is a problem and has no motivation to change. The contemplation stage occurs when a person becomes aware of the need to change a behaviour and motivation is triggered. From contemplation a person may eventually progress to the commitment stage, during which a decision is made to change, after which they enter the action stage where change is put into practice. Once change has been achieved, it is necessary to maintain it by resisting the desire to revert to the former habit. However, it is unusual to achieve effective maintenance and exit the cycle on the first attempt; most people tend to relapse. At this stage it is important to understand that past failure is no indication of future failure, and to then progress to the contemplation stage once again. The model is used to select health promotion interventions tailored to clients' positions in the sequence.

For HBP, passage into the contemplation stage may be triggered by a raised BP value or, if educational interventions are targeted upstream, individuals may develop an early awareness of the need for change. Educational, self-awareness or self-esteem interventions can be helpful in building a case for change during the contemplation stage, or reinforcing decisions reached in the commitment stage. For people in the action or maintenance stage, behavioural strategies may be more

helpful in supporting diet and lifestyle modifications or adjusting to the routine of medication.

4.3.4.4 Health Action Model

Tones' Health Action Model (Tones et al, 1990) gives priority to self-esteem – the attitudes a person holds to him/herself - as a crucial element of behaviour. He argues that people with a positive self-concept are more likely to be motivated to live healthily than people with a negative one, who are more likely to feel that the control they have over their behaviour is limited by circumstances or luck. For the latter, building self-esteem is crucial to increasing feelings of personal effectiveness before embarking on change.

As discussed, lifestyle changes to lower BP can be extremely challenging, requiring a firm self-belief that one is capable of achieving them. Empowerment could also encourage people to look beyond their own behaviour to modify their environments - for example requesting healthy meals at their work canteen, campaigning for an extended cycle path network.

4.3.5 SUMMARY OF HEALTH PROMOTION THEORIES

The above overview of health education shows that it is not necessarily the disinterested presentation of information it might appear to be. It can be seen as a way to involve people on the one hand, or for the state to evade responsibility, on the other. It can be offered to inform and empower, or it can be manipulated to persuade and even control. It can be deployed as a tool for experts to lever correct health behaviours, or it can be constructed by patients to inform a decision. It can involve a combination of the above approaches. Health promoters must have a clear idea of the goals of producing the information, and an awareness of the ethical implications of presenting it in different ways. With this in mind, the following section discusses how health promotion can be evaluated.

4.4 EVALUATION OF HEALTH PROMOTION

Where there are limitations on resources it is necessary to justify the ongoing funding of an activity. To be confident that a health promotion activity is bringing about the desired effect, evaluation is needed, demonstrating concrete results in keeping with evidence-based times:

> "Health care in the 21st century relies not only on individual medical skills, but also on the best information on the effectiveness of each intervention being accessible to practitioners, patients and policy makers." (Cochrane Library, undated).

Evaluation makes a vital contribution to policy by providing feedback, enabling accountability, informing decision-making, and promoting learning for

improvement. In a health promotion context, it is considered to be a formal activity "where appraisal is linked to original intentions and fed back into the planning process" (Naidoo and Wills, 1994, p282). As a formal activity, evaluation must be valid (measure what it intends to measure) and duplicable (yield the same results when repeated).

4.4.1 WHAT TO EVALUATE

Evaluation is targeted at predefined issues and questions, which tend to fall into the category of either efficiency, effectiveness or economy, known as the "three Es" Naidoo and Wills (1994, p282).

Efficiency is the extent to which the original objectives of a health promotion activity have been met. Objective measures are required - for example, comparative awareness of units of alcohol in people's chosen drinks before and after an intervention; comparative frequency of fruit being offered at workplace meetings; or changes in a person's understanding of how their medication works.

Effectiveness considers outcomes, and assesses whether the objectives addressed by an activity translate into to health improvements in a given area. Applying the criterion of effectiveness to the above examples would involve assessing the effect of increased awareness of units of alcohol on adherence to recommendations for alcohol intake; the effect of increased availability of fruit in this context on actual intake of fruit; the effect of insight into a drug's mode of action on adherence to that drug.

Economy involves a cost benefit analysis to determine whether the value of the activity exceeds the cost of putting it into practice. This can be problematic because it can involve comparing a monetary value with the more slippery values associated with health and happiness. Measurement of economy may consider the effects of raising alcohol awareness on people's cardiovascular health, as well as that of their liver, their occupational performance, the enjoyment they derive from socialising, takings of the leisure industry, alcohol-related accidents, and other corollaries. Offering costly perishable foods at meetings may incur extra expense in the absence of immediate benefits to a company and, where food is used to boost attendance at meetings, fruit may not represent sufficient enticement. The economic consequences of patients understanding how their medication works may be increased spending on medication, or may lead to people rejecting medication to the detriment of their health.

The above 3 Es are revisited in Chapter 8, where they are considered in the context of a framework to evaluate educational gains. As well as using comparative output measures to evaluate the three Es, there is usually pressure to tie impact to quantitative, objective measures such as performance indicators. It is also useful,

where possible, to benchmark against other competing activities (those adopting different approaches and, sometimes, different objectives to achieve similar outcomes) in order to gauge relative achievement and continue with the most worthwhile strategy.

4.4.2 TIMING

Health promotion activities can have several distinct effects as objectives, and these may emerge at different stages of the intervention or during the ensuing period. Deciding whether to adopt short-term or long-term evaluation strategies it is important to be aware of the time-related factors which could affect evaluation outcomes. Short-term and long-term evaluations can yield different results because impact can decay or accrue over time, or may be affected by the cessation of a programme. An activity's objectives and outcomes may relate to existing trends; it may impossible to distinguish the effects of the intervention from parallel developments, or the intervention may have the effect of hastening an outcome which would have transpired without it, but more gradually.

4.4.3 THE EVALUATOR

Ideal evaluators have three qualities: knowledge of the domain, the ability and inclination to deliver a disinterested assessment, and research skills. Regrettably it can be difficult to find these qualities coexisting, especially for smaller evaluation exercises, and in many cases they have proved mutually exclusive. In-house evaluation has a number of drawbacks: the evaluators, being closely involved with the designing the intervention, may not have research expertise, may find impartiality difficult, or may be affected by salience bias and filtered perception. On the other hand, insiders have a deep insight into the project, are likely to cost less and assimilate seamlessly. Out-sourcing evaluation increases confidence in an unbiased approach, can bring specific research expertise but, on the other hand, comes at an increased cost, may cause disturbance, and will demand a period of orientation. In many cases, resource limitations dominate the choice of evaluator.

4.4.4 DESIGN

Evaluation can be considered from process, impact and outcome perspectives. As Wills and Downie and colleagues point out (1996, p90) the remit of the evaluation may not suit the positivist methods prevalent in medical evaluation, but may favour more qualitative or naturalistic approaches, including log books, observation and interview.

Process evaluation is usually formative, being concerned with design and development issues. It aims to explore practicalities which will affect the replicability of the activity in a broader context (Weston et al, 1995). Process evaluation has been the principle approach in this project. **Impact evaluation**

tends to be defined as consequences of an activity observed during or immediately after an intervention, compared with **outcome evaluation**, which explores those emerging after an intervening period.

Output measures are be defined by the objectives of the health promotion activity and may include surveys, health indicators, attitude scales, self-esteem scales, cost-benefit analysis, and audit.

4.4.5 LIMITATIONS

The imperative to evaluate rigorously often finds itself in direct conflict with resource limitations. Difficult decisions about how, what, or even whether to evaluate, should be based on objective criteria. Evaluation might be crucial to the broader uptake of an activity, and may be governed by the demands of a requisitioning organisation. Health promoters may already have a settled belief about an intervention, and reject evaluation on the grounds that the ensuing cost and effort would be disproportionate to the value gained from evaluating. Evaluation may become an entirely academic exercise without the frameworks in place to feed findings back into the planning process, or broaden the target of an intervention.

4.5 HEALTH PROMOTION FOR HIGH BLOOD PRESSURE

The previous sections in this chapter have outlined theories and models of health promotion and discussed evaluation approaches. Against this background, health promotion for HBP is considered below.

Because of the tendency to regard HBP as the sum of its parts, a fragmented approach to health promotion for HBP has prevailed, with few exceptions[6]. Consequently, it is more productive to look for evidence of activity targeting various elements of diet and lifestyle rather than for holistic health promotion activity for HBP. For this reason, the following section is divided into sub-sections corresponding to the so-called modifiable risk factors which are targeted by health promoters.

4.5.1 DIET

For a patient with HBP in a high-income country, on frustration to self-care is the ubiquity of unhealthy food. As discussed in Chapter 3, contrary to earlier optimism there is some evidence that HBP is on the increase in the developed world. The investigators state that, after adjustment for age, ethnicity and sex, over half this

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[6] The Blood Pressure Association is one exception. Information on HBP elsewhere tends to subsumed into consumer health information on cardiovascular diseases, especially CHD and strokes.

increase is partially related to increase in body mass index, which was identified in the same survey (Flegal et al, 2002). With respect to health promotion, the following sections cover a number nutrients and food types which have been the focus of health promotion interventions to improve cardiovascular health. This review fed into decisions about the content to be included in Pressure's Off.

4.5.1.1 Sodium

The British Hypertension Society guidelines (2004, p13) report that a fall of 2-8 mmHg can be achieved by limiting sodium intake to 2.4g or less. Where sodium intake is excessive, the renin-angiotensin system dilutes the blood to protect its electrolyte balance, water is retained and the amount of blood in the body increases, bringing about a rise in BP. Reducing the current 9g average daily salt consumption in Britain by one third would reduce average BP by about 5mmHg systolic in people over 50 and thereby reduce the incidence of heart attack and strokes by about 15% and 22% respectively (Law et al, 2001). In 2003, the Scientific Advisory Committee on Nutrition published its report on salt and health (Scientific Advisory Committee on Nutrition, 2003) during which it reinforced the link between sodium and high blood pressure, and called for measures to reduce consumption of salt to 6g per day, a significant reduction for most.

Current shortcomings

75% of salt intake comes from processed foods (Nestle, 2002) and many of these, MacGregor and Sever (1996) point out, "have a salt concentration approaching or equal to that of sea water". As a nation we have developed a taste for salt, and reducing it can make food seem suddenly bland and unexciting; although this loss of flavour is temporary, without encouragement and reassurance, it can undermine many good intentions.

Most people have heard of the concept of hidden salt, but less are aware of the extent to which it has pervaded foods we perceive to be neutral or sweet in flavour such as bread, which contributed up to 22% to average salt intake in 2000 (DEFRA, 2001). As in the case of fruit and vegetables below, the recommendations are blurred and do not give clear goals. The distinction between sodium, implicated in blood pressure, and salt, which contains sodium (4g of salt gives 1.6g sodium) is unclear or meaningless for many people. Low salt alternatives are advertised as a solution to bland food, but these are not recommended since the potassium they contain can interfere with heart beat regulation.

4.5.1.2 Fruit and vegetables

The British Hypertension Society guidelines (2004, p13) report that a fall of 8-14 mmHg can be achieved through adopting a diet high in fruit and vegetables and low

in saturated fat. Fruit and vegetables are potentially abundant in phytochemicals which protect the cardiovascular system (Ness and Powles, 1997), including antioxidant vitamins, aspirin, potassium and calcium, as well as cardioprotective soluble fibre. Current recommendations advocate consumption of 5 portions of fruit and vegetables a day at the minimum, and most nutritionists would suggest considerably more. National campaigns to promote this target include the 5-A-Day Campaign and the National School Fruit Scheme. Larger supermarkets such as Sainsburys have included a conspicuous 5-A-Day logo on foods intended to help with identifying healthy processed foods.

At the local level, a number of awareness and behavioural strategies are being piloted. Steptoe and colleagues (2003) found that both nutritional and (particularly) behavioural counselling improved consumption of fruit and vegetables across incomes.

Current shortcomings

The 2002 National Diet and Nutrition survey estimated the mean number of fruit and vegetable portions consumed in the UK at 2.8 (Henderson et al, 2002), a little over half the minimum healthy amount. Out of the £600m spent annually on food in the UK, just £26m is spent on fruit and vegetables (Lang et al, 2002), and considering their high price, this represents a woefully small amount.

Although health promotion interventions for diet have been shown to be effective, there is regional and socio-economic variation in interpretation, implementation and success. This may be partly due to a continuing lack of confidence in the recomm ndations. Exactly what constitutes a portion is neither intuitive nor straightforward (WHO, 2003, p8; Department of Health, 2003) – fruit juice cannot count as more than one portion, ditto pulses - potatoes, though undeniably vegetable, are discounted entirely. The use of the portion concept, an artefact to assist lay understanding, is inadequate because it applies the same unit measurement to items whose different shapes and physical properties might interfere with calculations. Moreover, the effects of the preparation of fruit and vegetables on their health properties are little known (Institute of Food Research, 2003, p2); the relative health merits of tinned, frozen, fresh, pickled, raw and cooked foods are unclear. Also poorly understood are the changes undergone by nutrients during the storage, preparation and cooking process and, related to this, the benefits conferred by mature vegetables compared to those harvested young (Wardlaw and Kessel, 2002). Moreover, there is a phenomenon of disingenuous promotion, exploiting awareness about healthy eating to persuade people, especially parents, to buy fruit- or vegetable-based foods which also contain such high levels of sugar, salt or fats that their benefit to health is compromised or even

reversed (Associate Parliamentary Food and Health Forum, 2003). It must also be mentioned that the high price of fruit and vegetables demands difficult choices of those on lower incomes.

4.5.1.3 Junk food (saturated fat and sugars)

According to the British Hypertension Society (2004, p13), BP can be reduced by 5-10 mmHg per 10kg of body weight loss, and by a separate 8-14 mmHg through adopting a diet high in fruit and vegetables and low in saturated fat. Junk food is blamed for weight gain and obesity as well as high intake of saturated fats, trans fatty acids and sugars. BBC Radio 4's Moral Maze (BBC Radio 4, 2003) panel of discussants objected to the concept of fast-food consumers (often from lower socio-economic groups) as helpless victims without control or personal choice, requiring protection through legislation. A number of "witnesses" argued with their point of view, including Tim Lang, Professor at the City University's Department of Health Management and Food Policy and consultant to the WHO:

> "It's a moral issue in that people have to make choices and they're constrained by the circumstances within which they make choices … circumstances, culture, environment, messages, education, marketing, all of those sorts of things … anyone who thinks there's free will about diet is talking nonsense." (BBC Radio 4, 2003)

Protective behaviour on the part of the food industry is well-established (Schlosser, 2001). As observers have pointed out, "No government statement tells people to eat less" (Marwick, 2003) since this would erode an important economic interest. Meanwhile, the industry promotes the view that obesity is a private, not public, health problem which should be regulated by willpower, not legislation.

Nevertheless, the case against junk food is building. Organisations, health professionals, scientists and journalists have been releasing reports and recommendations in rapid succession, with the reduction in consumption of unhealthy food as their goal. At Princeton, Avena and Hoebel (2003) carried out research using rats which indicated that withdrawal from a high-sugar diet caused symptoms similar to withdrawal from use of addictive drugs. Wang (2001) suggested, on the basis of a comparison of PET scans in morbidly obese people and those with drug addictions, that people may overeat for similar reasons for which addicted people use drugs, and therefore cannot be expected to regulate their own consumption. Law and colleagues recommended that super-sizing be outlawed. Documentary-maker Morgan Spurlock recorded his demonstrably declining physical and emotional health during a month in which he existed exclusively on three meals a day from McDonalds (2004). Each release is well publicised and followed, as intended, by intense media coverage.

One review found that mixed educational and environmental interventions in workplaces can improve dietary habits, though not all have been (Hider, 2001). Portion or packet size reduction is another health protection measure under consideration, with McDonalds announcing a decision to phase out super-sizing in March 2004 (BBC News World Edition, 2004). Another, recommended by the British Medical Association is the introduction of a so-called "fat tax", the application of VAT to foods high in saturated fat. Regulation of proportions of unhealthy ingredients, bans on advertising unhealthy food, and the mandatory health warnings on packaging are also under consideration. Providing shoppers with electronic feedback about their purchases appears a promising supermarket-based intervention to reduce surplus energy intake.

Current shortcomings

The proportion of people in the UK with body mass index (BMI) of over 30 (the clinical definition of obesity) continues to rise, and in 1991 stood at 21% of men and 23% of women (Office for National Statistics, 2001). This proportion is as high as 30% for people with routine occupations.

Meanwhile, there is a divergence of opinion in the public health arena about which approach to diet modification should be adopted. The 1990s saw a trend towards the additive approach, with emphasis on adding healthy foods to a diet - for example the 5-A-Day campaign - rather than prohibiting unhealthy ones. The rationale behind this approach was the idea that a higher consumption of healthy foods would crowd out the unhealthy ones - consolidated by the argument that forbidding highly desirable but unhealthy foods was out of keeping with the times, not effective and led to negative self image. This has led to reluctance on the part of health promoters to pass negative judgement on aspects of their clients' diets, and a corresponding preference for promoting and positively reinforcing healthy behaviours.

There is little evidence that this approach improves outcomes, and moreover it has some unintended corollaries. It reinforces the prevailing view that self-restraint is an unreasonable and unachievable expectation, that health is something that can be 'consumed', and, in so doing, undermines the link between moderation and health which is so crucial for longevity in high-income countries. It also indulges a food industry strongly opposed to regulation, which continues to reject, suppress or overrule evidence about the health-eroding qualities of some of its most profitable products. Pressure from the extremely powerful US food lobby, representing a $1.3 trillion industry, has succeeded in diluting a number of US government health messages.

One was a recommendation to decrease meat consumption. The meat producers objected so the statement was replaced with the phrase, "choose meats, poultry and fish which will reduce saturated fat intake." Another was a call to reduce sugar intake. Under pressure from the sugar industry it was changed to "choose beverages and foods that limit your intake of sugar." Then it was further modified to "choose beverages and foods to moderate your intake of sugar." (Marwick, 2003).

On a national level, fiscally funded campaigns advising citizens to cut down on certain foods are rare because on many levels it is controversial for the state to intervene in the diet choices of the nation.

> "Clearly, it's not just about what government can do – at the end of the day what each of us puts in our mouths is a matter, generally, for personal decision, as it were, so we need to think about the way policy and framework and other issues interact with the choices that individuals make". Melanie Johnson – Public Health Minister (BBC Radio 4, 2004)

Food means more than nutrition, closely associated with leisure, luxury and relationships. The food industry has "work[ed] hard to convince us that limiting choices is what legislation is trying to accomplish" (Shell, 2003). Increasingly important to the economy, unhealthy foods continue to find their way to supermarket shelves, outlets and vending machines, pressurising state policy to assign regulation of obesity to the individual, a promotion of freedom of choice over health which epitomises the libertarian approach of that dominant exporter of consumer culture, the USA (Hutton, 2002).

4.5.2 PHYSICAL ACTIVITY

The British Hypertension Society guidelines (2004, p13) report that a fall of 4-9mmHg can be achieved through regular exercise. Current Health Development Agency (2003) recommendations are:

> "At least 30 minutes of physical activity on five or more days of the week. This physical activity should be of at least moderate intensity – similar to brisk walking. Activity can be taken in bouts of 10 to 15 minutes, allowing for accumulation of activity throughout the day. "

There are a number of available health promotion angles to achieve this goal. Towards health protection, one example of pro-health regulation[7] is the 2003 introduction of congestion charging in London coupled with a policy of building infrastructure to facilitate walking and cycling, which promises a 'major advance in public health' (Roberts, 2003). Fiscal measures to regulate motoring continue to meet with vigorous resistance, and the overall cost of motoring (including

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[7] The 2003 congestion charge was welcomed on health grounds by the London Cycling Campaign, Transport 2000, and Environmental Health News

purchase, maintenance, petrol and oil, and tax and insurance) has remained at or below its 1980 level in real terms, although fuel costs have risen in real terms by 6% (Office for National Statistics, 2002). On the health promotion front, there have been a number of initiatives to increase physical activity. In primary care, guidelines for 'exercise on prescription" were introduced in 2001, partly in response to the prioritisation of cardiovascular health (Department of Health, 1999), allowing GPs to refer patients for supervised courses at local leisure centres or gyms. Subsequently there has been an increase in use of motivational interviewing techniques and exercise programmes which have been shown to increase fitness (Petrella et al, 2003; Raina Elley, 2003) and lower BP (Raina Elley, 2003). Meanwhile the drive to inform and motivate continues predominantly via the medium of leaflets (Kelley and Abraham, 2004). At a national level, there have been a number of campaigns to promote exercise (Hillsdon et al, 2001) which have raised awareness and increased fitness.

Current shortcomings

The 1998 Health Survey for England identified that six out of ten men and seven out of ten women are not active enough to benefit their health and there is a general consensus that more must be done. The distance walked by British residents on the public highway has fallen since the 1980s, from 392 kilometres a year on average in 1985-86 to 305 kilometres in 1999-2001, (Office for National Statistics, 2004), and the average trip on foot is just 0.6 miles (Department for Transport, 2001). Car traffic has increased 83% between 1980 and 2001 (Office for National Statistics, 2002). As the service sector grows and industry shrinks, the nature of occupations in the UK tends towards the sedentary and fitness has declined. Participation in exercise for leisure is influenced by income, with higher earners more likely to be regular participants (Health Development Agency, undated). Barriers to sustainably integrating physical activity with everyday life are numerous, and both structural and attitudinal in nature. In urban settings, opportunities to take exercise which is free of charge, safe and convenient are often few. Meanwhile activity as a way of life has been undermined from a number of angles. There is a prevailing convenience culture abundant in labour-saving gadgets and avoidance of routine physical exertion as uncomfortable or undesirable. At the same time, safety fears about pollution, traffic and crime lead to increased car use for distances which could be walked or cycled in more favourable circumstances.

The guidelines on exercise are not clear, partly because there is an ongoing debate among health promoters about thresholds which are optimal on the one hand and realistic on the other; moreover a consensus has not yet been reached on exactly what constitutes exercise, how little is enough, what defines intensity, and whether the exercise has to be taken in one session to give maximum benefit. The

recommendation to take "at least 30 minutes of moderate intensity activity on five or more days of the week" is confusing jargon. The National Institute of Health Consensus Statement on Physical Activity and Cardiovascular Health (1995) states that "the appropriate type of activity is best determined by the individual's preferences and what will be sustained" and that "all people in the United States increase their regular physical activity to a level appropriate to their capacities, needs, and interest". Moreover, generic information on exercise is not appropriate for all health conditions – people with HBP should undertake isometric exercise such as weight lifting only with caution, since it can raise intra-abdominal pressure; some types of weight-bearing exercise recommended to protect bone-density are not intense enough to benefit the cardiovascular system. The absence of clear goals is an obstacle to both motivation and achievement.

4.5.3 ALCOHOL AND TOBACCO

Alcohol has a direct pressor effect across the BP distribution and accounts for 5%-30% of all HBP (Friedman, 1982). The British Hypertension Society guidelines (2004, p13) report that an average fall of 2-4mmHg can be achieved through limiting weekly alcohol intake to below 21 units for men and 14 for women. It is also extremely high in energy and contributes significantly to obesity. It also has deep-rooted cultural value in the UK and for many people is strongly associated with socialising. As such, it has been treated with caution by successive governments who approach health promotion predominantly fiscally, and with advice targeting at limiting the antisocial effects of binge drinking. In 2001, £6897 million was collected in revenue from alcohol (Institute of Alcohol Studies, 2003).

Despite an ill-defined relationship with HBP, smoking is invariably covered in all BP-lowering health promotion. Like alcohol, the government's attitude to smoking is ambivalent. During Labour's first term, excise duty on cigarettes increased by 30%, where it has remained (Institute for Fiscal Studies). In January 2003, 20 cigarettes retailed in the UK at £4.51, of which 67p was VAT, 99p was a health tax (artfully styled 'ad valorem') and £1.88 was specific – a total tax of £3.55 (Tobacco Manufacturers Association, 2003).

Current shortcomings

A third of men and a fifth of women exceeded their recommended daily amount of alcohol on at least one day in the previous week (p10), with a quarter of men exceeding eight units. It is desirable that people who drink alcohol be able to keep track of their consumption, and 81% of respondents to the General Household Survey (GHS) said they were familiar with the concept of units of alcohol (Office for National Statistics, 2002, p19), an improvement on the 1985 figure of 75%. However, from a health education perspective, serious shortcomings in knowledge

persist. Although total alcohol consumption did not vary between social class in the GHS, awareness of alcohol units did vary, with lower groupings again faring worse. About half the frequent beer drinkers and just under one third of the frequent wine drinkers were not aware of the number of units in their drink (Office for National Statistics, 2002, p22). When asked about the units in their drink of choice, 20% of frequent beer drinkers thought that one pint of beer equalled one unit – a significant underestimation. Moreover, 41% of frequent drinkers who had heard of daily recommended levels were unable to define them. 29% thought that the daily recommended amount for men was four units or more; 23% thought that three units or more fell within the recommendations for women. Findings on the public's knowledge of recommendations have not changed since 1997.

About a quarter of men and women smoked tobacco in 2002, a slightly higher prevalence than 2001 (Office for National Statistics, 2002b, p3) with people in manual jobs considerably more likely to smoke. Prevalence of smoking dropped during the 1980s, but levelled off during the 1990s. Tobacco has health implications which are more straightforward and therefore better understood throughout the population. Smoking was the most frequent response to a question (Office for National Statistics, 2002b, p 61) about causes of premature deaths. One sixth of respondents thought that living with a smoker would increase the risk of a list of conditions: asthma, lung cancer, heart disease, bronchitis, coughs and colds, and diabetes, which had been included in the list to identify whether knowledge or perceptions informed the response; the incorrect impression that smoking is a risk factor for diabetes suggested that perceptions, rather than knowledge, were prevalent. Current, regular smokers were less aware of the risks of passive smoking than never-regular ex-smokers.

Governmental policy towards alcohol and cigarettes clearly highlights its ambivalence to the fiscal approach. Despite the risk it poses to health at a number of levels, 2002 saw duty on alcohol frozen for the fifth successive budget "to strengthen the international competitiveness and domestic base of the UK spirits industry" (Inland Revenue, 2002), and small breweries were similarly supported with reduced rates of duty.

The Institute for Fiscal Studies (2004) summarises another dilemma from a revenue-orientated perspective:

> "Alcohol and tobacco duties are much less significant for the exchequer, and it is doubtful whether higher rates could raise much revenue. Once taxes are high enough, the revenue lost by discouraging people from buying the goods – or at least, from buying them legally in the UK – outweighs the extra tax paid on each item bought."

Indeed, an additional problem when retail prices rise is smuggling; it becomes easier to undercut authorised products, and consequently more lucrative to import

them illicitly, increasing the burden on the NHS without contributing financially. In the case of cigarettes, the IFS argues strangely that revenue from the 99p health tax, because it has been hypothecated for the NHS, could lead to an unmanageable surplus:

> "This pledge would constrain the government, since it would need to add to the NHS spending plans that are set out until March 2008 rather than use the revenue for any other purpose." (1994)

While it is not difficult to understand why the NHS should not come to rely on revenue over which the Government has no control, it is hard to comprehend why the money could not be spent on fixed-term, costed interventions or research. As a final note, the maximum revenue potential of a product is often dictated by political sensitivities rather than by ethics.

4.5.4 MEDICATION

Creating the circumstances for adherence to BP-lowering medication is a delicate exercise, because of the complex nature of the condition, the consequent varying mechanisms of its different drug groups, the asymptomatic nature of patients, and the rarity of finding the optimal medication, or combination, at the optimal dose, at the first attempt. In their Cochrane Review, Haynes and colleagues (2002) identified a number of adherence interventions used in chronic conditions. They included: instruction for patients in the form of oral and written material and programmed learning; increased communication and counselling in the form of compliance therapy, automated or personal follow-up by telephone, computer-assisted patient monitoring and counselling, and family intervention; convenience of care such as simplified dosing; increasing patient involvement in care through self-monitoring; reminders, including dose dispensing units, medication charts and individualised reminders; and positive reinforcement or rewards for improved adherence or treatment response.

For HBP, Sackett and colleagues reported no significant difference in adherence between patients receiving attention from a work-based occupational health professional, those receiving programmed instruction, and those receiving a combination (1975). Studies of complicated mixtures of several interventions improved adherence and clinical outcomes (Haynes et al, 1976; Logan et al, 1979). Becker (1986) experimented with convenience in the way drugs were packaged, but was unable to improve adherence. A computerised telephone monitoring system in conjunction with counselling achieved improvements only in those patients who had been non-adherent at baseline (Friedman et al, 1996).

Current shortcomings

Current strategies for improving adherence to medication are not achieving substantial improvements (Haynes et al, 1996; Haynes et al, 2002) and there is poor understanding of the reasons for this (Kjellgren et al, 1995), though it has been established that sociodemographic factors (such as age, sex, and social group) play only a small part. There is a need for innovative strategies, lack of which looms large as a reason for the failure to adequately control BP in more than two thirds of cases (Svensson et al, 2000). Svensson and colleagues (2000) found that reasons for non-adherence included adverse effects and the ensuing desire to regain quality of life, dislike of drugs, and, significantly, the misunderstanding that HBP was an intermittent condition. Interestingly, adherent patients gave less, and more vague, evidence of involvement in care than did non-adherent patients, who tended to use active reasoning. This involvement is to be encouraged, and indicates that a strategy of partnership and education to include non-adherent patients in decision-making about therapy could be effective. However, for several reasons, despite initiatives like the Doctor-Patient Partnership and the Medicines Partnership, this approach is proving difficult to work into current practice with its many contstraints and priorities. Consequently, the onus often remains on patients to ask the right questions (Ask About Medicines Week Executive, 2003), though it has been established that they often lack the self-assurance and recall to gather information from their doctor (Ley, 1988, p16), and have doubts about asking pharmacists (Lisper et al, 1997).

4.6 THE IMPORTANCE OF INFORMATION FOR HIGH BLOOD PRESSURE

As the previous sections have shown, optimal self-management is not intuitive but presupposes a level of knowledge about diet, lifestyle and medication beyond the information offered in most resources. The above catalogue of shortcomings and their implications confirms the need to address this inadequate provision. However, there are a number of caveats in presenting information to HBP patients. It is important to avoid provoking anxiety (Sims 1998, Montgomery et al, 2003), which has a negative effect on both health in general and BP in particular. Moreover, not every patient wishes or is able to be involved in their management or decision making in this way (Sims, 1998) and some may actively wish to defer responsibility to a health professional. Concerning the risks of treatment, Misselbrook and Armstrong (2001) report that the way information is presented has a significant impact on patients' decisions; they estimate that 92% would accept treatment justified using a relative risk reduction model, falling to 68% using a number

needed to treat model. This presentational influence on impact has relevance for the way evidence about diet and lifestyle modification is given.

Despite these caveats, HBP guidelines worldwide are unanimous in their assertion that patient information is a crucial part of effective management (Australian Heart Foundation, 2004; European Society of Hypertension Guidelines Committee, 2003; Joint National Committee on Prevention, Detection and Evaluation of High Blood Pressure, 2003; National Institute of Clinical Excellence, 2004; Touyz et al, 2004; Williams et al, 2004; World Health Organization, International Society of Hypertension Writing Group, 2003). A number of studies found that HBP patients also hold this view. Carney and colleagues (1993) found most HBP patients to be no more knowledgeable than normotensives, and reported that 70% of their sample wished to know more. Sims (1998) also found that the most common request of patients who wished to participate in their care was for more information, especially of an individualised nature. In their study of decision aids for patients, Montgomery and colleagues (2003) randomised 110 patients to either or both a complex decision aid (a decision tree about treatment, together with infor nation about their cardiovascular risk) and a simple decision aid (an off-the-shelf video and two information booklets). Patients showed, in the short term, less decisional conflict, more knowledge and a possible reduction in anxiety. In Germany education is an intrinsic part of treatment for both HBP and diabetic patients sanctioned since 1991 by a national disease management programme which is proving effective (Gruesser et al, 2003). Cuspidi and colleagues (2000) found that an educational group meeting was appreciated by patients, improved knowledge and improved adherence to treatment.

Education about HBP should therefore be viewed as an intervention in its own right (Grueninger, 1995). However, it is not a panacea and must be offered alongside more fundamental, and tricky, sociodemographic, political and economic interventions. Naidoo and Wills offer a strong warning about the victim-blaming tendencies inherent to an approach that embraces education as a total solution, unaccompanied by structural change:

> "In practice health education and health promotion have come to reflect different political orientations which can be characterized as the individual versus the structural approaches. What happens when the two concepts are polarized is that health education comes to be seen as a narrow field of activity which seeks to explain health status by reference to individual lifestyles and is a process largely determined by an expert. In its emphasis on personal responsibility, it sees a minimal role for the state and, this, has come to be associated with a conservative viewpoint" (1994, p78).

The motivation underpinning Pressure's Off is the knowledge that the prerequisites for health – especially cardiovascular health – are manifold:

> "The fundamental conditions and resources for health are peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity. Improvement in health requires a secure foundation in these basic prerequisites" (WHO, 1986)

This provision of education does not assume a denial of the other, more fundamental, preconditions for health. As an information resource, it does not seek eminence amongst these preconditions, but aims to contribute to the "supportive environment" for health referred to in the Ottawa Charter for Health Promotion (WHO, 1986) which includes "access to information, life skills and opportunities for making healthy choices". It acknowledges and aims to meet the need for a full resource which finally integrates information on the manifold influences on BP, cardiovascular context, medication, and lifestyle into a single package.

4.7 SUMMARY

The prerequisites for health range from basic human needs, across knowledge, healthy attitudes, and empowerment, to action. Approaches to promoting these take place on correspondingly varied levels using different methods dictated by political orientation, resources, power and influence, and evidence of effectiveness. In guarding against or managing a chronic condition such as HBP, which develops gradually over time and demands attentive self-care, education is a critical factor which, as demonstrated above, is deficient. The cardiovascular ill health in high-income countries is appalling, and requires a complex mixture of health promotion interventions to reverse the trend. However, the UK is a high-income country whose economy feeds on a free market and as such, a government-led, far-reaching strategy to make the healthy choice the easier choice is unlikely in the foreseeable future. In an environment abundant with modifiable risk factors for cardiovascular illness, knowledge is an essential ingredient of optimal self-care, combined with the empathy, encouragement and facilitation of health professionals. One intervention strongly indicated for HBP is a resource to address the continuing information deficits of people who need to look after their BP and, by implication, their cardiovascular system.

CHAPTER 5: CLIMATE FOR HEALTH INFORMATION ON THE INTERNET

An ongoing revolution is having a great impact on health care. The transformation is motivated by changing ideas about patient and health professional roles, and powered by advances in technology which have given us the Internet - an electronic network of computers and other digital devices which supports person-to-person communication and information retrieval (Anderson et al, 2003). From its origins in dot matrix text and monochrome, the Internet has evolved the Web, a medium which uniquely packages more modes of communication and forms of content than have ever been integrated before. This chapter exists to provide background and rationale for decisions made in the course of this project.

The background to personal computing has been effectively detailed elsewhere (Berridge, 2002). Wilson (1998) covers the history of computing in primary care up to 1998. Since 1998 policy, in the form of the National Programme for IT in the NHS (formerly the NHS Information Strategy) has brought about enormous growth in primary care computing equipment and infrastructure – facilitating, and sometimes crucial to, the diverse functions integral to modern health service provision. These include timely information for evidence-based practice, ordering investigations, electronic transmission of prescriptions, booking appointments, improving attendance and follow-up, continuing professional development, creating and sharing medical records, communication around referrals, and patient education, to name a few. One notable undertaking is the emerging electronic medical record, the goal of which is to build a single, enduring, longitudinal record for every citizen, replacing all others, available across sectors, and enabling the universally acknowledged goal of timely and seamless health and social care (Department of Health, 2005). Another significant development is NHS Direct, a nurse-led, telephone-based service, a response to the growth in requests for advice and information from members of the public.

This chapter outlines the current conditions for accessing the Internet, and explores the way people are using it for health information. Since the potential of the Internet is amplified for people in poor health who are vulnerable to social exclusion through low income, low mobility and the physical and emotional effects of illness, accessibility issues are considered in some depth below in a social and operational overview of the user.

Throughout this chapter a distinction is made between the Internet – the communications infrastructure which links network to network – and the Web – a way to access information within the medium of the Internet.

5.1 THE INTERNET IN UK HOUSEHOLDS

The scope of the Internet is expanding briskly in the UK. In 2002, an international survey showed individual computer uptake at 49% in the UK, and this proportion has certainly grown since. Meanwhile the Government, as part of its UK Online programme, plans to invest around £6 billion in e-services by March 2006 (National Audit Office, 2003), not as an end in itself, but to support other targets in health, social exclusion and life-long learning. Its current slogan is "Internet access for all who want it" (UK Online, 2003), an interestingly tacit reference to the resistance from some quarters to this information and communication revolution.

5.1.1 HOW MANY PEOPLE ACCESS THE INTERNET?

This is not as straightforward a question as it seems, since access is not a clear-cut concept – does it refer to unrestricted access at home or does it also encompass opportunities in workplaces, libraries and Internet cafes? According to the UK Expenditure and Food Survey, an estimated 11.9 million households had home Internet access between July and September 2003, amounting to 48% of all households (54% of households owned a computer). This represents sustained, significant increase in uptake since 1998, as shown in Figure 5.1.

Percentage of households with Internet access
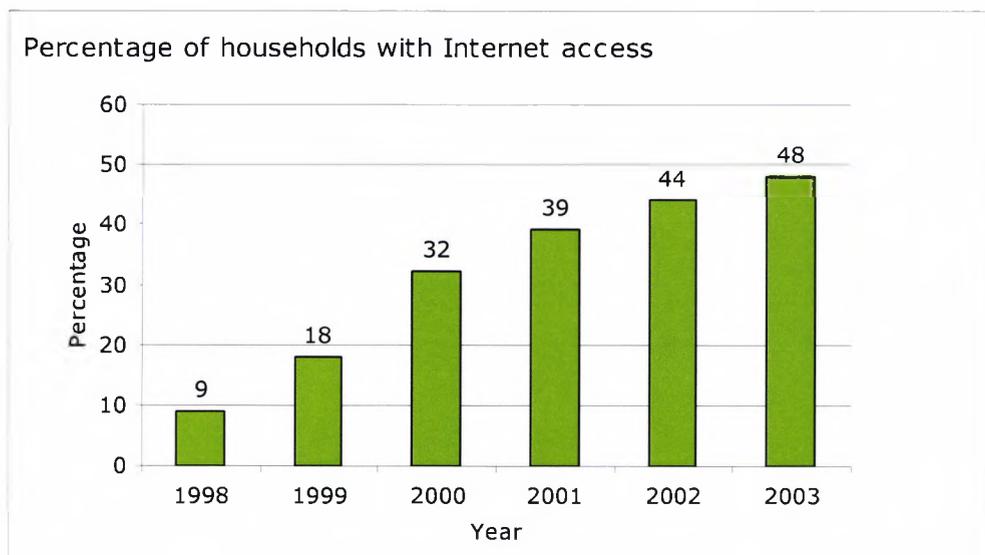
Figure 5.1. Percentage of households with Internet access (After: Office for National Statistics, 2003)

64% of British adults had ever used the Internet in September 2003, with 58% having used it in the three months prior to the interview (Office for National Statistics, 2003).

5.1.2 WHAT ARE THEIR CHARACTERISTICS?

In 2003, the percentage of people who had recently used the Internet decreased with age from 88% of people aged 16-24 to 16% of those over 65. However, this latter category is the fastest growing of all and it has been recognised (National

Audit Office, 2003) that, as a group, older people have a lot to gain by getting online. A small but significant gender difference has been identified, with 60% of men compared to 55% of women using the Internet in the previous three months. As is to be expected, Internet uptake grows according to household income; in July 2003 85% of the highest decile group had access at home, compared to 12% of the lowest decile (Office for National Statistics, 2003b). Throughout the UK, uptake is distributed quite closely around the mean (recorded here at 46%); the South-East leads at 52% and Northern Ireland, considerably less than other regions, stands at 35% (Office for National Statistics, 2003c).

5.1.3 HOW DO THEY CONNECT?

Although broadband's cost is prohibitive for less frequent home users, it is a growth service with government backing. Coverage – formerly patchy – extended to 95% of the population in 2004, and in September, with five million users, it outstripped dial-up for the first time (Wakefield, 2004).

In 2000, in response to a question about where UK adult users mainly accessed the Internet, 16% reported mainly connecting at work, 59% in their own home, 14% in another person's home, 6% in college or university, 2% at school, and 3% by other means, including libraries, government offices and Internet cafes (Office for National Statistics, 2000). For the proportion of adult home users in February 2003, computers continued to dominate as the preferred method for accessing the Internet (99%). Approximately 9% of adults who had ever used the Internet had done so using a mobile phone, while around 6% reported using Digital Television (Office for National Statistics, 2003d).

5.1.4 HOW OFTEN?

In 2003, the average UK use was ten hours per week (Office of the e-Envoy, 2003) and rising.

5.1.5 WHAT ARE THE BARRIERS TO WEB ACCESS?

UK Online (2003) claims that "pro-competitive pricing" has removed cost from the list of barriers to access. This is true to an extent – it is now possible to connect at home for the price of a local call. However, since, for some, terrestrial telephone line rental represents a significant outlay, lower income households, where mobile phone uptake was 62% in 2003 (Office for National Statistics, 2004b), have to think carefully about whether the costs of a land line can be justified or whether they should cancel their terrestrial service and rely exclusively on mobile phones. For those who connect by telephone from home, Internet calls charges can quickly mount up. Additionally, it is easy to forget the considerable outlay involved in

purchasing hardware and software; it is difficult to discover the price of the average computer, but Computer Buyer reviewed versatile[8] budget machines in May 2004 which were priced around the £500 mark. Moreover, to realise the full potential of the web – voice-video communication, moving images, and other high bandwidth material – broadband is required, for which there is a substantial monthly charge, currently rarely under £20.

Cost is not the only barrier – another is know-how. As Ben Shneiderman points out in his book on human issues in design (2002), much of the technology simply does not work adequately enough to retain and accommodate potential users who have little time or some trepidation. Despite his prediction that "the old computing is what computers can do; the new computing is about what people can do", the barriers endure. Technology can be extremely intimidating, and the psychological constructs of computer anxiety, computer dislike, and low computer self-efficacy are widespread affective responses which can have a negative impact on individual behaviour with computers.

This section has outlined exclusion *from* the Web – information exclusion *on* the web is discussed in the following section.

5.2 SOCIAL AND OPERATIONAL OVERVIEW OF USERS

It is an enduring paradox, expressed as the Inverse Care Law (Hart, 1971) that the very people who tend to be excluded are precisely those who are most vulnerable to ill health. In the UK, people who have low incomes, impaired vision or hearing, cognitive impairment, literacy problems, low educational achievement or who do not understand English are particularly susceptible to exclusion of many types, including activity, participation and information. Many of these factors are simultaneously risk factors for high blood pressure (HBP), and a number – for example, cognitive and visual impairment are associated with stroke, the survivors of which are often living with HBP.

The statement, attributed to Tim Berners Lee, that "the power of the Web is its universality. Access to everyone regardless of disability is an essential aspect" is often quoted on Web sites about disability. In acknowledgement of this enlightened aim, this section explores operational and social aspects of Web users with particular reference to the factors which contribute to or cause exclusion from the Web.

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[8] For example, the JAL Monarch 2600VS and peripherals, with 2.6GHz processor, 512Mb RAM, 120Gb hard drive, 128Mb graphics card, CD/DVD drive, 8 USB ports, several expansion slots, speakers and 56kb modem and MS Office-compatible software package.

5.2.1 SOCIAL DESCRIPTION OF THE USER

5.2.1.1 Experience with technology

Noyes and Baber (1999, p19) outline several attempts to categorise users in terms of their experience with a technology. These can be summarised as:

1. Naïve individuals with no experience of technology

2. Novice users with context-specific experience, for whom a new context would be a challenge demanding active transfer of knowledge.

3. Skilled users who are competent, proficient operators of technology, but who may rely on carrying out instructions by rote.

4. Expert users who also have knowledge about how the underlying system works.

Therefore, as the medium for interacting with the content in a resource, an interface must accommodate users across this range of aptitude. In his seminal book The Psychology of Everyday Things (1988, p188), Donald Norman outlines the fundamental principles which place a user at the centre of the design of robust, usable interfaces:

1. The alternative actions available at each stage should be clear.

2. The conceptual model of the system should be transparent.

3. The current state of the system should be apparent.

4. Natural, or intuitive, mappings between intentions and the required actions, between actions and effects, and between the visible information and the interpretation of the system state should be conformed to.

Adherence to these principles is key to a usable interface.

5.2.1.2 Income

In 2001, the distribution of wealth was skewed with the wealthiest 50% owning 95% of all marketable assets (Inland Revenue, 2001). Being one of the UK's many council or Housing Association tenants is the single best available predictor of being poor (Institute for Fiscal Studies, 1999). While Britain's median household income is £293 per week (before costs), the most prevalent income band, accounting for 1.8 million people, is £190-£200 per week, leaving little disposable income. Since a significant proportion of the population – those most vulnerable to health problems - cannot easily afford access to the Web at home, it is valid to question the Web as a primary medium for offering health information. However, it is unacceptable that these inequalities should prevent developers targeting information at people on low income. This amounts to resignation to the wealthiest continuing as principal beneficiaries of the technology, an attitude which effectively delays its spread

through other sections of society. Moreover, despite fears that technology is driving the demand for online health information, the real impetus is actually patients who have difficulty obtaining information from established channels, such as health professionals with their increasing pressures on time. In most cases, demand for a service precedes the infrastructure to deliver it, and creates demand for this infrastructure. The permeation of technology has happened in precisely this way, pioneered by wealthy enthusiasts on the bleeding edge and ultimately mainstreamed.

Nevertheless, to use the Web alone would exclude many people on low income; in order to avoid exclusion, Web-based information must be one of several different media in which health information is offered.

5.2.1.3 Language

Information providers for people with other first languages should assume a grasp of English which varies between fluency and complete incomprehension. The recent emphasis on patient involvement and informed consent obliges the health service to meet these language needs. In inner city locations, inhabited by the majority of ethnic minority communities in the UK, language can be a barrier to information only surmountable through the skills of communication support workers - translators and interpreters who specialise in health. These professionals need specific training, because there are a number of pitfalls in converting information from one language to another. All language is saturated with the idiom and metaphor of its culture; consequently, attempts to simply transliterate an original English language resource into another language are unlikely to succeed, since rendering of groups of words verbatim leads to loss of meaning. In any case, the original meaning may not be effective in the new context. Another concern is that different cultures may have different information needs which depend on aspects like diet, lifestyle, and attitudes to illness. Issues may be perceived as sensitive or embarrassing in some cultures, while unexceptional in others. These points also apply to graphical information.

In avoiding these translation pitfalls, there are a number of principles to consider (National Information Forum, 1998; p24, Doak et al, 1996; p67):

- treat ifferent language versions as distinct projects, aiming to create new materials developed in close partnership with the target community
- identify the variety of users within the target group, which may extend beyond the patient
- consider whether training is necessary for the staff who use the translators

- prepare an English language version specifically for translation, working with bilingual professionals to develop information in the language used by the community

- apply the principles of a readability formula such as Fry's (Fry, 1977) to produce language which:

    - uses short sentences

    - focuses on positive actions

    - avoids jargon and complicated vocabulary

- Pilot the translation in the target community before putting it into full operation, to ensure that it communicates effectively.

It is also worth considering that the media for delivering information may be valued differently across cultures. For example, in the West emphasis is placed on sharing understanding in print, which is considered definitive and trustworthy. In South Asian cultures, however,

> "...the best way of arriving at understanding is to develop a listening relationship with a person who understands. Written information may be questioned because there is always a possibility that it is only a flawed representation of the author's true understanding." (National Information Forum 1998, p12)

5.2.2 OPERATIONAL DESCRIPTION OF THE USER

The previous section considered a range of social circumstances which may affect users of Pressure's Off; this one explores how users interface with and process computer-based material. To begin with the lowest common denominator, the user is a member of class human and has a number of attributes in common with other members. The typical input and output channels of the human computer user are outlined below.

5.2.2.1 Vision

The visual processing system has capabilities and limitations which shape the design of graphical user interfaces (GUIs). Typically visual perception distinguishes brightness, colour, size, shape and depth. Under certain circumstances viewers make errors or generalisations which demonstrate that the way elements are grouped can influence their ability to isolate and process an individual element. One example is the Muller Lyer optical illusion (Figure 5.2) - when a line is attached to a conventional arrow head shape, there is a tendency to underestimate the length of the line. The opposite is true when the arrow head is inverted:
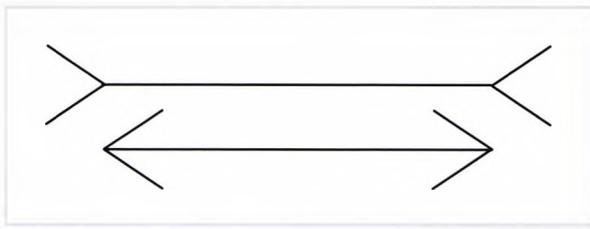
Figure 5.2. The Muller Lyer Optical Illusion.

Another is the Boynton illusion (Figure 5.3), which demonstrates a filling-in phenomenon in the brain. Although the two yellow areas appear identical when looked at closely, when viewed at a distance the shape of the right area appears to be defined by the black line:
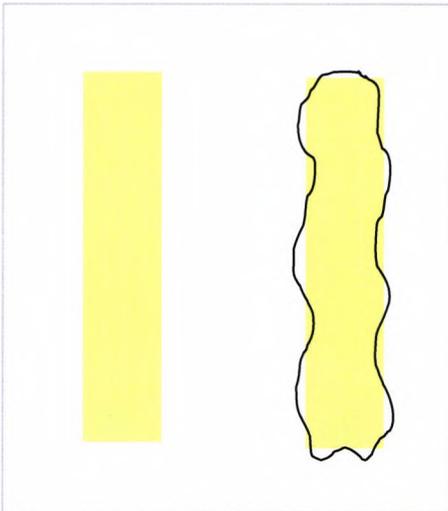
Figure 5.3. The Boyton Illusion

The ability of the eye to perceive shape enables the activity of reading, which can be divided into:

- perception of the visual pattern of the word

- decoding with reference to an internalised lexicon

- contextualising the word through syntactic and semantic analysis

When reading the eye jerks forward in *saccades* and, especially if the text is complicated, backwards in *regressions*. Perception takes place during the intermittent periods of fixation, where familiar words are recognised by shape and less familiar ones are decoded as a group of characters. The speed of reading is affected by a number of factors: font sizes between 9 and 12 point are effective, given proportional spacing between lines; line lengths between 2.3 and 5.2 inches are equally legible, legibility is increased by negative contrast of colours which provide increased luminance; removing word shape clues by using upper case or intricate fonts is detrimental to reading speed. There is evidence (Dix et al, 1993) that reading from a computer screen is slower than reading from a book, which

suggests that text on computer screens should be kept to a minimum in favour of more readily processed signals.

5.2.2.2 Impaired vision

Over 2 million people in the UK have sight problems (Royal National Institute for the Blind, 2004). Visual impairments include colour blindness, central-field vision loss (seeing only the edges of the visual field), tunnel vision (seeing only the centre of the visual field), and clouded vision. Colour blindness, an impaired ability to distinguish between different colours, affects 8% of males and 1% of females, who most commonly are unable to discriminate between green and red (Dix et al, 1993) (deuteranopia) and, less commonly, yellow and blue (tritanopia).

It could be argued that, of all users, the Web has the most potential for people with visual impairments. Online delivery can overcome many aspects of information exclusion experienced by this group, restricted in mobility and access to visual information. Using a screen reader - software which processes information on the screen and synthesises it as speech - software applications and documents can be accessed on a standard personal computer (PC) with enabled sound. For those with residual or partial vision it is possible, assuming accessible design, to customise the appearance and presentation of information by resizing text and adjusting contrast and colours.

However, for reasons discussed below, the actuality falls short of this potential. For screen reader users, the most fundamental issue is whether the screen reader can process the information. Graphics, used enthusiastically in many Web sites for decoration and layout as well as to relay information, are only amenable if descriptively tagged. Sites developed in Macromedia Flash are not screen reader friendly, although work is ongoing to improve this situation. Another important issue is sequence of information and internal navigation. By default, screen readers begin at the top left of a screen and progress down line by line. Unresponsive to the visual cues which a designer might deploy to draw users' attention to important information, screen readers can make using a Web site designed for sighted users monotonous. Navigation and sequence of information can improve the experience, by inserting invisible links allowing blind users to bypass, for example, repeated header or menu information. Other visual impairments may mean that users are colour blind or susceptible to glare from the screen, need a choice of background or text colours, or to be able to resize screen elements such as text.

There is a large amount of very specific information available to support designers in accommodating people with visual impairments.

5.2.2.3 Hearing

The ear processes changes in air pressure as sound. Optimal auditory perception distinguishes between different pitches, degrees of loudness, and timbre, as well as the direction from which the sound is coming. Neurons in different parts of the auditory system are alert to different frequencies, and can subtly differentiate at low frequencies. Filtering occurs but the ear is less accurate in making distinctions when the conflicting sounds are very loud (Dix et al, 1993). Auditory processing is quicker than reading, but with text the reader has the advantage of being able to process and reprocess at leisure.

In interface design, sounds are usually used to complement visual signals. However, auditory icons can be used to convey information without diverting the users' concentration to the sound source. Speech synthesis could be useful where functions (such as SAVE) do not have an analogous sound, and where long passages of text have to be read. Stimulating multiple senses as with the same information is an effective memory enhancer.

5.2.2.4 Impaired hearing

In the UK an estimated 9 million people are deaf or hard of hearing (Royal National Institute for the Deaf, 2004). Hearing impairments make it difficult or impossible to access audio information unless transcripts are made available. Conversely, the visual communication prevalent on the Web in the form of chat rooms and email discussion groups can be very enabling.

However, while the Web's origins are as a visual medium, it is increasingly an auditory one as well. Deaf users cannot use the audio track of video clips, nor can they use audio recordings such as lectures or music. A straightforward way to circumvent this is the addition of captions to audio or video tracks. Providing a transcript is not optimal - it is important that the caption is synchronised with other elements presented as text tracks running underneath the video or animation.

Where sound is used for background ambience on a Web page, or where the audio content cannot be captioned, so-called D-links can be used to provide a detailed media description. Audio should not be exclusively used for navigation cues and, if used at all, should be supplemented with a range other signals.

5.2.2.5 Haptic and proprioceptive perception

Across the skin there are receptors which respond to temperature variation, pain, and pressure. Haptic interface refers specifically to use of the hands to communicate with technology, and is a combination of tactile and kinaesthetic feedback to give a sense of an object's shape, size solidity, surface texture and composition (Noyes and Baber, 1999). Proprioception, the awareness of the various

parts of the body in space, is important to performance of routine functions; practice gives a touch typist an awareness of limb and finger positioning, and a perception of key position which is confirmed or denied by tactile feedback from the keyboard.

5.2.2.6 Motor function

Motor control is an important aspect of interacting with a computer. An action such as hitting a button in response to a prompt can be broken down into a number of processes. The stimulus of the prompt is received through receptors and transmitted to the brain, where it is processed and a response is generated. The brain sends impulses to the appropriate muscles which perform the action. Dix and colleagues (1993) divide these processes into reaction time, which depends on the sense through which the stimulus is received, and movement time, which depends on the physical particulars of the individual, their skill in the action. Speed and accuracy of movement should be taken into account in the design of the interactive system. Fitts' Law (Dix et al, 1993) defines time taken to hit a target as a function of the size of the target and the distance to be moved. This impacts on system design by necessitating menus arranged to reflect common patterns of use.

These input and output channels interact with the brain, which interprets the input signals and responds with its own output.

5.2.2.7 Impaired proprioceptive, haptic or motor function

Keyboards, computer mouse pointers and touch screens are the primary input devices on the Web, and sites tend to be designed for use with these by default. Anybody who has observed a new computer user grapple with a mouse for the first time is reminded that controlling it demands a certain level of coordination and dexterity, and this is also true for users interfacing with keyboards. Motor impairments may involve loss or absence of limbs, paralysis and or reduced coordination. The problems faced by users with motor impairments depend on the nature of the impairment. In patients with the cerebellar tremor common in multiple sclerosis, for example, a movement such as reaching toward and grasping an object becomes extremely difficult.

A range of alternative pointing devices is available. Head pointers can be an option for those with little or no limb mobility, but tend to be less precise than the mice pointers anticipated by many designers. Neural interfaces are slowly emerging as an option, including electrooculogram (EOG) which processes signals from eye movements, electromyogram (EMG) which processes muscle movements, and electroencephalogram (EEG) which distinguishes between different types of brainwave. Speech interfaces responding to voiced commands are also emerging.

In practice, graphical navigation systems need to be designed with sufficiently large target areas to allow users with limited dexterity or those using alternative pointing devices to position their pointer and activate the link. Clear visual feedback should be given when an action, such as activating a link, is performed. An additional point is that wheelchair users may be forced to take a position further from the screen than people with full motor function. All screen elements should be either configurable or large enough to be seen at a greater distance than standard.

5.2.2.8 Cognition

Cognition can be described as a person's ability to deal with time, space, quantity, quality and cause (Kylen, 1985).

An important aspect of cognition is working memory space (Baddeley, 1986), the current active system for temporarily storing and manipulating information needed in the execution of complex cognitive tasks such as learning, understanding and reasoning. The number of concepts an average user is capable of keeping in operation at any one time is estimated as 7 plus or minus 2, and this has implications for the design of interfaces and the way information is structure. The founder of this theory, George Miller (1956) summarises his findings:

> "...the span of absolute judgment and the span of immediate memory impose severe limitations on the amount of information that we are able to receive, process, and remember. By organizing the stimulus input simultaneously into several dimensions and successively into a sequence or chunks, we manage to break (or at least stretch) this informational bottleneck."

The demands made by different stimuli on working memory have come to be known as cognitive load (Kirschner, 2002). Cognitive load is determined by an interaction between the complexity of the task and the learner's cognitive ability, and therefore straddles both this section's operational description of the user and the social description in the previous section. For learners in an unfamiliar computer environment, contributors to cognitive load include the intrinsic factors to do with the complexity of the information itself, and the extrinsic factors concerned with the way it is structured and the medium through which it presented (Pollock et al, 2002). On principle, the cognitive load imposed by the extrinsic factors, such as the computer interface, should be minimised to free up working memory resources for the business of assimilating the proffered information into applicable knowledge.

The concept of variable working memory has afforded considerable insight into learning difficulties. Working memory space is held to be a fixed quality which cannot be improved and, although there are ways to compensate for low capacity, people with less working memory are at a disadvantage - especially when carrying out unfamiliar tasks in unfamiliar environments.

5.2.2.9 Impaired cognition

Cognitive disabilities include learning disabilities and intelligence deficits, often co-existing, and can affect, for example, people with Alzheimer's, dyslexia, or previous stroke. Problem areas for people with these sorts of disabilities include abstraction, symbolism, and reading comprehension.

Although available accessibility guidelines tend to be principally concerned with visual impairment, there is a growing body of evidence about effective design for different cognitive impairments. The most basic design rule is to take measures to maximise working memory space, a rule of thumb which is by no means restricted to cognitive impairment, but is generally applicable and useful in any design or development undertaking. To give a brief overview, this involves (adapted from Harrysson, 2003):

- ensuring that screen elements such as navigation controls are positioned prominently and consistently throughout, including a clear path back to the starting point.

- presenting no more than ten or fifteen items on a screen; keep presentation and layout simple and uncluttered.

- illustrating where possible, and representing categories consistently with graphical symbols.

- providing frequent and friendly feedback.

- displaying important information prominently.

5.2.2.10 Speech

Speech is a human output channel which system developers are beginning to exploit. One successful application is phonetic word processing which produces text output from speech input, based on a neural network grouping similar phonemes together. After an initial period of adjustment, voice recognition software can be trained to decipher the idiosyncrasies of the individual user. As a computer input channel, speech can be used to supplement or replace others - for example, when the user's hands are not available for data entry.

5.2.3 THE ROLE OF THE WEB IN REDUCING HANDICAP

The processes for producing information for people with different impairments are dependent on the delivery media chosen. The sections above focus on online delivery, a medium which offers unprecedented opportunities to avoid the digital segregation of people according to ability, allowing (with sufficient developer knowledge) the production of a single version which accommodates the maximum amount of impairments, an approach known as universal design. The potential of

the Web can help to highlight an important distinction, often blurred, between the concepts of impairment, disability and handicap. These are defined as follows (Bennett and Ebrahim, 1995, p4-5):

- impairment is the loss or abnormality of specific function as a result of pathology – for example tremor, blindness, muscular weakness, confusion

- disability is any resulting loss or restriction of activity, such as reduced activities of daily living or the inability to read smaller typefaces

- handicap is the disadvantage caused to the individual as a result of their disabilities – for example their no longer being able to maintain social contact outside the home, carry shopping, climb onto a bus.

According to the Labour Force Survey (2001), in 2001 there were 6.8 million people aged between 16 and 64 with a work-limiting disability in the UK – this is approximately 10% of the population and does not include older people in whom disability in prevalent. The definitions above suggest that we should consider these disabilities to be circumstantial rather than fatalistically regarding them as immutable. In other words, the factors which determine whether an *impaired* person becomes *handicapped* are often environmental, rather than inherent to a person's state or condition - modifying or adapting the disabling environmental factors can remove a given handicap. The Web has enormous potential in reducing the many handicaps and, if a site is well designed and configurable, with the help of adaptive technologies such as screen readers it can be accessed by people with a range of different physical and cognitive impairments including blindness, deafness, paralysis, and learning difficulties.

5.2.4 LEGAL AND ETHICAL OBLIGATIONS OF INFORMATION PROVIDERS

The Inverse Care Law (Hart, 1971) is the observation that availability of good medical care tends to vary inversely with need in a given population. In an effort to combat this, the UK has extended rights to disabled people in the form of the Disability Discrimination Act (1995) and its extensions (1999; 2004), the Human Rights Act (1998), and the Special Educational Needs and Disability Act (2001). The DDA implied that producers of information about "goods, facilities and services" which is inaccessible to certain users may be liable to legal action; SENDA later amended this to include educational rights. The Human Rights Act enshrines in law a number of human rights identified by the European Convention on Human rights as inalienable, including the right to education.

However, the nature of much legislation in this area remains globally opaque (Gibson, 2004). Consequently, few developers have fully exploited the potential to

include impaired users and, due to lack of skill and resources, many more have ignored it entirely, precipitating a landmark ruling in 2000, known as Maguire v. SOCOG (Institute on Independent Living, 2000). In this ruling the defendant, the Sydney Organizing Committee for the Olympic Games (whose evidence of undue burden did not stand up), was fined £20,000, an outcome which sent ripples through the Web-developing world and exposed an urgent need for clearer legislation. The intervening period has seen little improvement, and the 2004 Web Accessibility Study (Parsons, 2004) found 79% of 105 UK sites tested to be in breach of the law, with 40% of government sites similarly inaccessible.

In designing a usable, accessible interface, it is important to be aware of the actual and potential accessibility threshold for a user group, which may be dictated by the diversity of ability within the group or, increasingly, by the legal system. This awareness allows priorities to be drawn up where resource limitations impinge on developing a fully accessible site. However, in the absence of a precise legal bearing on accessibility requirements, it is incumbent on designers to accept ethical considerations as a driving force. The motivation for producing a health information resource - to assist as many people affected by the condition as possible – must be considered foremost. It is the obligation of the designer to ascertain if inclusive design techniques exist for circumventing a given accessibility problem and, if they do, to exploit them.

5.3 THE INTERNET FOR HEALTH INFORMATION

The social and operational circumstances of Web users have been described above. This section explores the climate in which people use the Web for obtaining health information.

5.3.1 BACKGROUND

Most of the exploratory work in the area of health information on the Web has been carried out in the USA, where patient consumer culture interacts with an enthusiastic uptake of Internet technologies. Anderson and colleagues (2003) outline the circumstances which cause patients to take to the Web. High-profile technological advances in medicine – primarily in acute care and infection control – create expectations in patients across all divisions of health care. If these cannot be met, the resulting frustration can lead to a desire in patients to take responsibility for their own health. There are concerns about the length of consultations (Freeman et al, 2002), and a lack of health professionals' time can lead to misunderstandings which affect adherence. It can also hinder physicians' acquiring and practising information management skills needed both to maintain best current practice and to evaluate material presented by patients.

Health care systems are under increasing pressure to cut costs and their transfer into market systems is a possibility if not an inevitability. Increasingly, individuals who directly contribute to the cost of their own health care become canny consumers looking for the best value for money. They also demand increased stringency of ethical and legal standards, part of a trend towards consumer protection, in acknowledgement that doctors can make mistakes.

The trend towards preventative medicine, in the form of media campaigns, for example, has contributed to general awareness in the population, and as the level of education attained in high-income countries continues to rise, the population becomes better equipped to understand and apply information about health. Meanwhile, the growth of the Web as an accessible and inexpensive information resource, and the enormous amount of health content it offers, encourages users to experiment with diagnosing and treating themselves. This in turn leads to increased demand for quality resources.

Anderson and colleagues assess health care consumers as dissatisfied, powerful and knowledgeable, and under these circumstances the Web is a catalyst for demand, offering an information and communication resource which is available round the clock throughout the year, which can be accessed from home without the delay of waiting for an appointment, which can be interrogated anonymously[9], which offers information pitched at different levels of expertise, and from which a second, third or tenth opinion can be sought without awkwardness.

Where health care providers exploit the power of the Internet, it has the potential to be far more than an information and communication resource. It can individualise a user's experience based on input data (American Heart Association, 2001; NHS Direct, 2004). It can be used as a secure repository for personal health information (NHS, 2003). Telemedicine projects continue to pioneer remote patient monitoring by collecting clinical data, either through peripheral devices (Home Health UK, 2000) which upload results, or remotely via voice and video where the patient is trained to use monitoring equipment and report to the doctor (Abdoh et al, 2003). Alarms and reminders to promote adherence can be automated using the Internet. In short, the Internet has enormous potential to support health.

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[9] This is not to be taken for granted, since matching health searches with other demographic information would represent a triumph of market research. If anonymity is valued, it will have to be actively safeguarded.

5.3.2 HOW MANY PEOPLE LOOK FOR HEALTH INFORMATION ON THE WEB?

According to a 2003 report from the Pew Internet & American Life Project (Fox and Fallows, 2003) searching for health information is the third most prevalent online activity in the USA after email (93%) and researching products prior to purchase (83%). 80% of adult Americans Internet users (equivalent to 93 million people or half of the population) have used the Web to get health or medical information, and Europe is not far behind (Eaton, 2002). This does not happen on a daily basis - about 6% of Internet users search for health or medical information on an average day, while 78% search every few months or less. The most prevalent health-related online activity is research on a specifc medical condition (63% of Internet users), followed by research on a treatment or procedure (47%), diet, nutrition and vitamins (44%), and exercise and fitness (36%).

5.3.3 WHAT ARE THEIR CHARACTERISTICS?

The Pew Internet and American Life Project (Fox and Fallows, 2003) reported that 85% of women, compared to 75% of men, have used the Internet for health information. Unsurprisingly, better-educated and higher-income Internet users were more likely to search for health information, as were those aged below 65 (80% compared to 70% of those aged over 65), white Americans (82% compared to 76% African Americans and 75% Hispanics), experienced Internet users (77% of those with 2-3 years' experience compared to 59% of those with less than one year) and those with a high speed connection (89% compared with 80% of dial-up users). Only 38% of disabled Americans went online, compared with 58% of the entire population.

Internet users can be broadly divided into three groups. Most health seekers (57%), in particular women and parents, stated that their last search was on behalf of somebody else, often to get factual information or guidance on care-giving. Disabled and chronically ill Internet users are very active, with 85% having searched for at least one health topic, compared with 63% of the total online population. The third group comprises those who take care of somebody in their household who is chronically ill or disabled.

5.3.4 HOW DO THEY USE THE WEB?

Fox and Fallows (2003) identified the following activities based on 2000 responses to an online questionnaire:

- Searching for health information at any time of the day or night.

- Researching a diagnosis or prescription.

- Preparing for surgery or finding out how best to recover from it.

- Getting tips from other caregivers and e-patients about dealing with a particular symptom.

- Giving and receiving emotional support.

- Keeping family and friends informed of a loved one's condition.

- Finding humour and even joy in a bad situation.

In-depth studies of how people with different conditions use the Web are few. From interviewing people with HIV/AIDs, Patricia Reeves (2001) identified three dimensions of the major concern for HIV positive Internet users, namely finding information: the range of available information, from general to specific; the currency of the information; the accessibility of the information. Other uses which emerged were social connections, activism and escaping, the latter two of which were unanticipated by the author. Ziebland and colleagues (2004), in their study of people with cancer and the Internet, identified round-the-clock access and privacy as main reasons for using the Web. Cancer patients reported researching their symptoms prior to seeking medical help. They refer to the Web during investigations to reassure about the tests, to prepare for results, and to make the most of consultations. After diagnosis, the Web is a source of online support, clarification, information about telling family members, information about treatment, and information about follow-up.

5.3.5 WHAT STRATEGIES ARE USED?

1	2	3	4	5
Consumer has a health question or issue and decides to seek information online.	Consumer chooses a search engine and types in a search item.	Search engine processes search and lists search results.	Consumer chooses from search results.	Consumer reviews website information.
Variables affecting results: Internet access Literacy Language	Variables affecting results: Search behaviour Assessments of credibility	Variables affecting results: Type of search engine Search algorithm Ranking algorithm Paid listings	Variables affecting results: Positioning of search results Consumer quality evaluation Expert evaluation of quality	Variables affecting results: Actual quality/accuracy of information Relevance to consumer needs Ability to comprehend

Figure 5.4. The process by which consumers seek health information online (After Greenberg et al, 2003).

Greenberg and colleagues (2003) attempt to identify and represent the stages of the process by which consumers seek online health information, shown in amended form below (Figure 5.4).

Fox and Fallows (2003) report:

> "The typical health seeker searches every few months or less. She starts at a search site, not a medical site, and visits two to five sites. She spends at least thirty minutes on a search. She feels reassured by advice that matches what she already knew about a condition and by statements that are repeated at more than one site. She is likely to turn away from sites that seem to be selling something or don't clearly identify the source of the information. And about one third of health seekers who find relevant information online bring it to their doctor for a final quality check."

They also note that only 25% of users are vigilant about always checking the reliability of the information they find.

THE FUTURE OF HEALTH INFORMATION ON THE INTERNET

The future of health on the Internet will be shaped by the requirements and characteristics of future patients. Jadad and colleagues (2003) consider the qualities of good patients of the future:

- bringing lists of questions to the consultation and expecting answers in clear terms

- knowing how involved they want to be in decisions about their health care

- having free access to their health record on paper or through electronic means, to use it or share it as they see fit

- requesting and receiving a second opinion whenever they face a major diagnosis or decisions about treatment

- using telephone, Internet, and other forms of communication to complement personal visits with members of the healthcare team

Far from the obedient, unquestioning patient of former times, this is very much a description of an engaged, critical, questioning presence on a health care team. These attitudes are also in keeping with the concept of the patient as consumer. However, this perspective fails to fully define a good patient, emphasising as it does patient rights and expectations without the reciprocity of considering the *contribution* a patient should make. Embodied in the concept of the "consumer" is the assumption that health can be achieved simply by accepting and absorbing it; in fact health cannot be acquired in this way but involves motivation, delayed gratification, and the denial of many impulses. It is difficult to comprehend how a person who does not manage to adhere to any or part of their blood pressure-lowering strategy could be considered a good patient solely on the basis that they

are well-informed and participating. In response to the shortcomings of the consumer outlook, Coulter (1999) outlines an evolving role for the patient as *partner* in health care:

> "Consumerism was strongly promoted in the 1980s as part of the market ideology which infused health policy in many countries. The problem with consumerism was that it encouraged people to make demands but failed to emphasise reciprocal responsibilities... Partnership has therefore replaced consumerism as a key plank of public policy. Official statements in the United Kingdom are peppered with the term, which is popular with politicians both because it evinces a warm glow but also because it emphasises mutual self help. The new emphasis is on shared information, shared evaluation, shared decision making, and shared responsibilities."

The future of health information on the Internet is likely to have two themes. One will be information *about* patients, in the form of the electronic health record (Department of Health, 2002), storing cradle-to-grave data centrally for timely, interoperable and secure delivery at point of care. The electronic health record promises to revolutionise care by smoothing the seams between its different sectors. The second theme will be information *for* patients. While the Internet remains a decentralised, anarchic publishing medium it is unlikely that the quality of health information, as defined by the criteria above, will improve as a proportion of the whole. Unsubstantiated commentary, speculative sales pitch and subjective narratives will abound as they do now, because the circumstances which prompt individuals to publish them – the drives to externalise, describe, convince, share, assist, or market - are enduring. For this reason, search engines must be scrutinised as the bodies who mediate what we discover on the mushrooming Web. Indeed, BBC News technology analyst Bill Thompson has recommended the instigation of 'OffSearch', the Office of Search Engines, to prevent Internet searches becoming exclusively directed the market and users open to exploitation (Thompson, 2003).

Underpinning the role of the future patient is *knowledge* of their health condition in context, without which their participation will be compromised. This fact alone is reason enough to make the Internet, the information highway, central to health care in the future; a correspondingly enormous amount of resources is being poured into connectivity and bandwidth (Department of Health, 2002). Add to this its unparalleled potential to bridge formerly insurmountable barriers of time, distance, and isolation, as well as its ever-improving capacity to digest vast amounts of information into manageable, relevant portions - its potential to serve patients and health care workers alike emerges as enormous.

5.4 THE QUALITY OF HEALTH INFORMATION ON THE WEB

Assuming the important role of the Web in patient participation, the quality of online health information is a particular concern. None of the quality concepts outlined below is specific to the Web and several, such as attribution and currency, have been borrowed from the world of print (Silberg et al, 1997). However, once again information technology has proved a catalyst – this time for quality, a growing demand in response to a decentralised, deregulated publishing medium. Indeed, never has publishing been so unrestricted. There are no pedantic demands from sales-minded, legally aware publishers. Contrast the convoluted chains of production, distribution and consumption in the print world with the instantaneity of the Web where it is possible for content to be uploaded by its authors and downloaded by its users in a matter of moments. It is no longer disastrous if inaccuracies are found in the content - they can be corrected with minimal cost and loss of face. And although the promise of information for the masses which is both free and high quality is extremely difficult to deliver, the Web has made publishing the least expensive part of the process. Anybody can publish anything.

These attributes of the Web are of great benefit to conscientious, thoughtful, rigorous health information providers and charlatans alike. They are, however, a mixed blessing for information consumers who are confronted with an inundation of health content of widely varied quality.

5.4.1 INITIATIVES TO DEFINE AND PROMOTE INFORMATION QUALITY

Although search engines are at the forefront of sifting high-quality information from poor, quality is complex and recognising it difficult to automate. For example, Google's trademarked PageRank technology orders its search results according to how many other sites have linked to that site, and weights the linking sites themselves in the same way. Although Google describes this approach as "uniquely democratic" (Google, 2002), susceptible as it is to confirmation bias and inclined against newer sites, it embodies the flaws of democracy as well as the strengths, and does not in itself guarantee quality.

A number of organisations have been created in response to alarm about amounts of "health-related frauds, myths, fads, and fallacies" (Barrett, 2004) which thrive in the unregulated medium of the Web, and doubts about the abilities of consumers to discriminate between poor and high quality information. None of these organisations, introduced below, has so far emerged as pre-eminent.

The Discern on the Internet Project, funded by the NHS Executive Research and Development Programme, originated with the aim of assisting patients and information providers in judging the quality of written information about treatment choices. The organisation has also developed guidelines for the production of health information. The project generated the Discern instrument, based on an agreed set of criteria.

The Centre for Health Information Quality (CHIQ), a charitable organisation established in 1997 by the NHS Executive to act as "a clearing house on all aspects of patient information, providing practical advice to the NHS and others on the production of good quality information for patients" (Help for Health Trust, 2002). Based at the Help for Health Trust in Winchester, it has been instrumental in the development of the government health information project NHSDirect Online. CHIQ aims to ensure that all available patient information is clear, evidence based, and involves patients throughout its production. The British Medical Association Patient Information Awards bases its criteria on CHIQ recommendations.

The Health On the Net (HON) Foundation has its origins in the telemedicine conference *The Use of the Internet and World-Wide Web for Telematics in Healthcare*, Geneva 1995. It is currently a non-governmental organisation with Special Consultative Status in the United Nations. The HON Code of Conduct (Health on the Net, 2002) is a set of voluntary rules designed to guide responsible self-regulation and ensure a reader always knows the source and the purpose of the information he or she is reading.

OMNI (Organised Medical Networked Information) is the health and biomedicine member of the BIOME service, a group of high profile information gateway developments funded by the JISC's (Joint Information Systems Committee) eLib programme. OMNI's approach is to select, according to a set of review guidelines, Internet resources for their quality and relevance to a particular target audience. The consequence of this effort is to improve the recall and especially the precision, of Internet searches for a particular group of users (OMNI, 2004a). The review guidelines (OMNI, 2004b) could be described as a manual and, using illustrative examples, offer technical skills for finding more about a Web site than is immediately apparent.

Other studies and organisations include Eysenbach and colleagues (2002), who conducted the first known review of the evaluation of quality of health information on the Web from which they developed an overview of quality criteria based on transparency, The Internet Healthcare Coalition who have a code of ethics (2003), and the British Healthcare Internet Association who have developed a set of quality standards for medical publishing on the Web (2002).

5.4.2 SYNTHESIS OF INFORMATION QUALITY CRITERIA

In order to produce a framework by which to review existing BP resources, and on which to base the development of Pressure's Off, the proliferating recommendations from the organisations introduced above are synthesised below into a working list of priorities. These are presented as a set of guidelines (Table 5.1). Since they are interrelated, it has been difficult to prioritise any single approach to presenting them – consequently they are listed in alphabetical order.

Theme	Underlying principle	Implications
Accessibility	The resource is readily available across the target user group, in suitable formats.	Consider alternative or additional formats such as leaflet, web-site, audio, video, CD-ROM etc. Consider need for information in other languages. Consider need for information accessible by people with impairments. **Consider structure, design and layout of the resource (navigability).** Where possible, submit resource to be considered for inclusion on national, regional and local databases. Develop using readability and accessibility tools.
Accuracy	The resource is complete, and based on the best available evidence.	Use reliable, evidence-based sources. Make the hierarchy of evidence clear.
Appropriateness	The resource communicates messages which are relevant both to its aims and to its target user group.	Define target user group clearly from the start, for example, on the front page of the resource. Design resource specifically for this audience and make aims explicit. Explain what the information is about. Explain what it is meant to cover and what it isn't. Explain who might find it useful. Consider need for more than one resource.
Attribution and accountability	The resource is attributable.	Ensure the information is balanced and unbiased. Ensure the author is named and their

		contact details are readily available.
		Disclose any affiliations of the author.
		Disclose identities of commercial and non-commercial organisations that have contributed funding, services or material.
		Provide references for source data for information and, where possible, links to those sources.
		Present advertising and other promotional material in a way that differentiates it from the original material. Display a brief description of the advertising policy adopted by the producers of the resource.
Complementarity	The resource avoids undermining established health care initiatives.	Design the resource to support, not replace, the relationship that exists between resource users and their health professionals.
Completeness	The information is complete, and acknowledges any gaps or areas of uncertainty.	Acknowledge areas of uncertainty. Outline interventions fully, describing risks, benefits and other effects. Make any gaps in the information explicit.
Confidentiality	If personal information about the user is collected, legal requirements must be honoured.	Where personal information about the user is collected, be explicit about how it will be used. Honour or exceed the legal requirements of medical or health information privacy which apply in the region.
Continuity	The information is presented in context with other resources.	Cross reference clearly to related resources. Ensure it is stated that the resource is part of a series where appropriate.
Currency	The information is up-to-date.	Ensure date of production is clearly indicated. Consider how quickly the information may become out-of-date and state expiry or review date. Ensure resources are in place to maintain currency. Consider advantages of electronic version of resource for particularly time-sensitive information. Ensure out-of-date information is removed from circulation.

Feedback	Feedback mechanisms should be provided	As well as providing details about a range of ways of contacting the authors, feedback should be actively encouraged.
Originality	Information has not already been produced for the same audience and in the same format	Identify similar resources with an early search of national, regional and local databases. Inform the information producing community about the new resource.
Readability	Words and sentences are readily understood.	Develop using readability tool such as Flesch, Gobbledegook, Plain English Campaign (http://www.plainenglish.co.uk/freepub.html) Ensure any obscure terminology is explained.
User involvement	The resource is designed in a user-centred way.	Ensure actual and potential members of the target audience are involved in all key stages of production.
Validity / reliability	The resource is either created or validated by subject experts. There is an editorial review process by subject experts.	Confirm that information is structured in a way appropriate to both its character and user expectations. Confirm that information is accurate, current, complete and appropriate.

Table 5.1. Synthesis of guidelines on reviewing or producing health information for patients

There is one recommendation which has not been included in the list above. The Health on the Net Code states that advice should only be given by medically trained and qualified professionals, reflecting concerns about accuracy, accountability, and the general appropriateness of information. However, the pressures on the health professionals involved in this project were such that their roles in content development were as advisors, critics and validators. This developer-led model has proved sustainable and effective (Vogel and Bennett, 2002; Wilmes et al, 2004) in the production of multimedia health information resources, development of which requires a diverse skill-set which cannot be assumed to exist in its entirety in either a health professional or a multimedia developer. Related to this, the item Validity/Reliability has been added, recommending that subject experts validate the content and structure of the resource. At the same time, "content is all", and subject experts as content providers tend to minimise the slippage and dilution of meaning inherent to more convoluted development processes.

5.4.3 WEB QUALITY CRITERIA

The above recommendations, largely borrowed from the print world, were conceived to surmount poor quality rather than to positively exploit advances in technology. While they are invaluable in identifying those sites which reach the minimum criteria for confidence, the *best* online health information resources are more than a sum of these recommendations. They use the Web to make themselves distinct from corresponding content available in hard copy, augmenting or offering alternatives rather than imitating it. Assuming minimum quality standards, a number of other important criteria are required to distinguish between adequate and superior online resources. No such guidelines from the health information community were identified, and one reason for this may be that recognising opportunities for learning technology, developing a new facility in response, and integrating this effectively, would vary enormously between subject areas, and would be difficult to standardise in a set of guidelines. To explore this further, a post was sent to the active, 539-member Medical Webmaster Discussion Group which prompted the following response:

> "Your question is a very intriguing permutation of our usual approaches to discussing quality issues, and I hope it generates a great deal of discussion. I think, ultimately, you hit the nail on the head when you said "maybe this sort of quality can't be reduced into a checklist. However, we do learn a lot from making the effort!" (Anderson, 2004)

In the absence of guidelines for high quality health information sites, a more general exploration of the criteria for good Web sites was carried out which included a review of criteria for Web awards. However, this exercise exposed a conceptual gulf between awards which recognise quality information – such as the category for Web sites in British Medical Association Patient Information Awards - and those which reward "latest and best cutting edge design", such as England's Favourite Web Site Awards (http://www.favouritewebsiteawards.com/) which has no health category. The famous USA Webby Awards (http://www.webbyawards.com/main/), which does have a health category which rightly prioritises content over design, lists further criteria as structure and navigation, visual design, functionality, interactivity, and overall experience.

The product of discussion with peers and colleagues, in person and in online communities, a further guideline for best exercising the technology is has been developed as part of this project.

Theme	Underlying principle	Implications
Function	The resource functions fully and seamlessly.	All elements work properly and function as advertised. Graceful degradation of any elements which fail to work.

Configurability	Opportunity to configure the look and feel of the resource.	The user can configure aspects of appearance, including background and font colours, font-size and layout.
Individualisability	Opportunities to tailor the presented information in a way that reduces "noise" and improves the "signal" should be taken.	Based on data which the user chooses to input, information can be targeted – this might mean highlighting certain points or removing irrelevant ones. The user can configure the degree of individualisation This targeting of information is transparent and explicit.
Interactivity	Where opportunities for the user to participate, rather than view are recognised in the subject area, opportunities are taken to build this participation into the resource.	Where appropriate, interactivity should be built into the resource. Opportunities are taken to give information and receive real-time tailored responses. Opportunities for discovery learning are taken, such as promoting understanding of a concept though graphical manipulation of its elements. Opportunities for self-testing are taken.
Searchability	Searchability is a fundamental advantage of computer based information over paper based equivalents.	The resource should be searchable. The search engine should be dynamic rather than static. The objects within the resource should be search-engine friendly, including the appropriate metadata and without distracters.
Use of multimedia	The full range of media is exploited as appropriate to the information to be communicated.	Multimedia is used appropriately to communicate effectively. Effort is made to make the multimedia accessible. Maximum control over the pace of presentation is given to the user. For example, long videos are broken into smaller units which lend themselves to index and metadata. If the information is intended to be used online (rather than printed off and taken away), reading from the screen should be minimised.

Table 5.2. Guidelines for exploiting new media in health information Web sites

To its users, content will always be the most important attribute of a site. Therefore the previously outlined quality criteria (Table 5.1) are a higher priority than the

guidelines above (Table 5.2) – in this way trustworthiness and accessibility – the fundamental attributes of an effective resource – take precedence.

5.5 WEB-BASED INFORMATION FOR PEOPLE WITH HIGH BLOOD PRESSURE

The previous section considered the Web as a medium for health information in general - the implications for people with HBP are considered below. For high-income countries which uphold consumption and choice as ways of life, information is one of the foundations of cardiovascular health. It has been reiterated several times in this thesis that HBP is a phenomenon with far-reaching causes as well as effects; as a consequence its management requires information with particular qualities.

As the following chapter illustrates, there is a great volume of potentially relevant information about HBP to be made available – too much to be condensed into a précis which could be absorbed in a single sitting. This has three implications, all of which suggest that the Web is well suited to this subject area. One is that the resource should be searchable so that users can target their information gathering rather than ploughing through in a linear way, or repeatedly thumbing between index and content. Another is that distribution of this large volume of information could be made inexpensive and feasible by physically transforming it from hard copy into online format. The third implication, also related to the volume of information, is that new ways of structuring it must be explored so that it is readily navigable and can be presented to best advantage.

As well as its magnitude, the information about BP is often qualitatively complex, abstract, or both. Some health information advisers from the era before the Web have recommended simplifying knowledge about a health condition into digest form which can be easily understood by any reader. This is representative of a tendency in health promoters to have low expectations about the level of detail which the end user can understand – a simplification strategy which can blur or undermine the message. For example, 5 portions of fruit and vegetables each day are recommended, yet there are a large number of related considerations, from type of fruit or vegetable eaten to the way they are stored and prepared, which significantly affects their nutritional value, but about which awareness is extremely low. It is increasingly recognised that the medium of communication can affect understanding, and although there are at present few studies of the relationship between comprehension of content and the medium by which it is communicated, the recommendation to keep things simple may need to be reviewed if patients are to be truly empowered. It may emerge that well-designed Web sites can reduce

extraneous cognitive load imposed on the user by corresponding paper material by freeing up working memory capacity to make the structure of the knowledge more transparent, by clearly delineating and contextualising units of knowledge, and by facilitating targeted information (Bannert M, 2002; Cawsey et al, 2000; Kirschner, 2002).

A further feature of complex or abstract knowledge is that it cannot always be effectively conveyed verbally. Especially powerful is the ability of multimedia messages to "explain the step-by-step operation of a cause-and-effect system in which a change in one part causes a change in another part" (Mayer and Moreno, 2002). The potential for demonstrating the behaviour of the cardiovascular system, the concept of HBP, or the progression of arterial degeneration is clear. Discovery based multimedia (Moreno, 2004) is another powerful learning medium based on the principle that learners should be facilitated in constructing mental models, on which understanding and knowledge are based. Multimedia offers the potential for learners to interact with objects by exploring, and manipulating to promote deep learning.

In developing this information package for BP there were several requirements. The underlying thinking was not merely to replace paper-based information, but to exploit opportunities offered by the new medium of the Web. Alan Dix (2001) recommends an approach to the transition from paper to a computer-based medium which aims for "translation" of content and recommends taking steps to avoid "transliteration". Transliteration is an easy trap which merely transfers existing user experiences into the new medium - for example, if a target user group is used to reading verbal information on paper, an obvious strategy is to transfer this verbal material wholesale onto the Web. Although there is some satisfaction to be gained that this approach makes the information more widely available and readily updateable, it ignores the fact that it is harder and generally more inconvenient to read from a screen than from paper. A more effective strategy, however, involves deconstructing an existing learning experience to identify or reaffirm learning objectives which may be tacit or have become obscure. Only when the learning objectives are explicit is it then appropriate to begin to build online learning experiences around them, from scratch. In this way it is possible to achieve "translation" as opposed to transliteration.

One opportunity offered by the Web was the prospect of using the navigational and search capability of the technology to fully represent the domain rather than taking the reductionist approach which is a practical necessity for paper-based patient information. Another prospect, since the Web is unprecedented and unsurpassed in the number of different media it unites, was the exploitation of this provision to shake off the restrictions of verbal information and static graphics which affect

content on paper. With reference to the knowledge base, it was clear that several areas could be better represented as animation or video. It was also clear that several areas of learning could benefit from the interactivity offered by the Web.

5.6 SUMMARY

This chapter has explored the climate for health information on the Web. It began by reviewing infrastructure – the uptake of the Web in the UK population – and found it conducive to delivering health messages, and improving year by year. After considering the enduring socio-economic problem of exclusion from the Web, the physical and cognitive problems of exclusion *on* the Web were investigated, together with strategies for overcoming them. Current and future approaches to Web-based health information were outlined, followed by an exploration of quality – its essence and practice – in which a synthesis of recommendations was presented. The perceived inadequacies of existing quality criteria, with their emphasis on print-world concerns, prompted the production of guidelines specifically for using the Web to best advantage. With these in mind, priorities for Web-based information for people with HBP were identified. This knowledge, together with the needs assessment described in the following chapter, informed the design and development of Pressure's Off.

CHAPTER 6: NEEDS ASSESSMENT

There is a general consensus that tools and applications designed to address the needs of a group of people should be developed in close partnership with target users and stakeholders. Needs assessment for Pressure's Off involved a number of activities to fulfil this requirement. Understanding the information needs of people with HBP was crucial to finalising the core knowledge base for the domain as well as identifying approaches to communicating this information to promote understanding and motivation. An understanding of the systems currently in place for giving information was also needed, including approaches to HBP education in principle, factors affecting its dispensation in practice, and the experiences of patients and practitioners. In exploring these issues, early quantitative questionnaire data were subsequently explored with more interpretive qualitative research methods, including observation and interview. Proponents of this type of qualitative research continue to struggle to achieve equal status with their empirical, "rigorous and scientific" (Taylor, 2002, p2) counterparts in the natural sciences. Since the research outlined in this thesis draws on qualitative approaches, the chapter begins with an overview of positivistic and post-positivistic research methods which includes the strengths and limitations of each. Following this, the approaches to needs assessment adopted for this project are described, beginning with a questionnaire which explored HBP in primary care sent to all general practices in a north east London borough. This questionnaire yielded a broad sketch of the research area, which was enhanced through observing interaction between health professionals and patients in a general practice and a hypertension clinic, as well as through interviews and conversations. After a discussion of the limitations of this needs assessment, the findings are summarised and a set of recommendations are presented.

6.1 POSITIVISTIC AND POST-POSITIVISTIC APPROACHES

All research is carried out using methodologies which can be broadly categorised as either positivistic or post-positivistic (Cohen et al, 2000). Positivistic methodologies are inductive and assume that the social world, like the inanimate world, can be objectively measured and defined. Post-positivistic methodologies reject this as reductionism, and adopt a hermeneutic approach which explains social phenomena from the perspective of their participants (Cohen et al, 2000; Savenye and Robinson, 1996, p1171-3). The needs assessment for Pressure's Off draws on post-positivistic methodologies, which have their critics and are sometimes denied equal

status with more empirical methods. For this reason, the rationale behind these approaches is described below.

6.1.1 POSITIVISM

As a coherent philosophy of social science, positivism had its origins in the early nineteenth century, when the French philosopher August Comte undertook an empirical investigation of society in the 'positive' terms of the natural sciences, subject to identical laws, theories, and methodological practices. Predating social science, positivism developed to measure the natural world and assumes that inquiry begins with a theoretical hypothesis which can be verified or falsified by reference to a body of empirical data (Lincoln and Guba, 1985, p333). Cohen and colleagues (2000, p8) summarise the ideology:

> "Following in the empiricist tradition, it limited inquiry and belief to what can be firmly established, … thus abandoning metaphysical and speculative attempts to gain knowledge by reason alone."

as does Avis (2003):

> "Positivism is frequently used to stand for the epistemological assumption that empirical science based on principles of verificationism, objectivity, and reproducibility is the foundation of all genuine knowledge."

So positivism holds that all phenomena have causes and effects which can be classified and quantified to form functional relationships from which generalisations of truth can be drawn.

6.1.2 POST-POSITIVISM

Criticism, originating in late nineteenth century Europe, of the positivistic approach to social science focused on the striking contrast between the tangled, idiosyncratic, unpredictability of human nature and the more consistent, regular behaviour of its environment. A leading figure of opposition was the poet and author William Blake:

> "Blake would have us understand that mechanistic science and the philosophy of materialism eliminate the concept of life itself. All they can do is to define life in terms of biochemistry, biophysics, vibrations, wavelengths, and so on; the reduce 'life' to conceivable measurement, but such a conception of life does not embrace the most evident element of all: that life can only be known by a living being, by inner experience. No matter how exact measurement can be, it can never give us an experience of life, for life cannot be weighed and measured on a physical scale." (Nesfield-Cookson, 1987, cited in Cohen et al, 2000, p17).

Others levelled criticism at positivism's claims for objectivity as the only secure foundation for knowledge. The Danish philosopher Soren Kierkegaard resisted quantification for its own sake, which he viewed as restrictive and impoverished. He sought instead to vindicate subjectivity as a valid perspective in the study of humans and, indeed, the sustenance of humanity itself. Among many others

Stevenson (2000, pp21) proposed that empirical findings are no less social constructs and should not be accepted as uncontroversial, complete facts independent of their theoretical, academic and political trappings Witness the Salem Witch Trials, Eugenics, and the rise, fall and probable resurrection of carbohydrates as a dietician-endorsed staple.

6.1.3 POSTPOSTIVIST RESEARCH METHODS

As an alternative to quantitative positivistic techniques, a number of qualitative research methodologies to explore human behaviour emerged; naturalistic, interpretive approaches which explore situations and phenomena through the eyes of their participants. Case studies are one such approach - specific, concrete instances which can offer insight into experiences of real people in real situations (Cohen et al, 2000, p181). Another, the ethnographic tradition involves the naturalistic observation of a subject or group of subjects going about their day-to-day practice, to produce a "slice of life" (Denzin and Lincoln, 1998, p15) situated account from an insider perspective. Direct consultation of users and stakeholders is an approach currently enjoying widespread uptake in the form of questionnaires, polls, interviews and focus groups. Direct interaction with research subjects can be a productive opportunity to develop intriguing themes or explain phenomena which have resisted interpretation.

The divergence in the positivist and postpositivist camps is highlighted by approaches to study design. Taking a positivistic approach, Kerlinger (1973, p300, cited in Lincoln and Guba, 1985, p221) demanded that variance be controlled by rigorous advance specification of a study, including hypotheses, variables, methods of data collection, modes of data analysis, and anticipated problems and responses. This methodology is a prevailing requirement for many research project proposals. It is, however, incompatible with the imperative of naturalistic inquiry - to allow the study design to unfold and evolve in response to its subjects and their environment. In this way the parameters of the research are more dictated by its subjects, rather than exclusively by their investigator. Naturalistic approaches assume that behaviour and data are socially situated and that, consequently, context is heavily implicated in the meaning of a given phenomenon - effect cannot be separated from cause. On the premise that researchers cannot define what they are looking for in advance, naturalistic researchers observe subjects as they go about their normal day-to-day activities, and in this way hope to build an authentic perspective from the point of view of the people studied.

Lincoln and Guba (1985, p38-43) outline the implications of this outlook for the design and practice of naturalistic research, which contrast sharply with positivistic practice. Research should take place in the natural setting, in recognition that

studying the "entity-in-context" yields the fullest understanding, and should use humans, the only instruments with sufficient subtlety, to collect data. The human investigator draws on tacit knowledge to interpret interaction in spoken and unspoken form. Purposive sampling is legitimised by the requirement that entities be considered in their contexts. Because a priori theory cannot anticipate the multiple realities of the data, data analysis is inductive and descriptive, taking account of the multiple influences which act on them; theory is grounded in the data rather than preconceived to be proved or disproved. The research design and its boundaries cannot be accurately anticipated or preordained, but must respond to an emerging focus, itself based on data as they collected over time. LeCompte et al (1984, p108), for example, note that methods are

> "...adjusted, expanded, modified, or restricted on the basis of information acquired during the mapping phase of field-work... Only after final withdrawal from the field can researchers specify the strategies they actually used for a particular study."

The outcomes of the research, its meanings and interpretations, are negotiated with its human sources, who are considered best placed to authorise an interpretation of their values. Only tentative attempts, if any, are made to extrapolate generalisations from the findings, which tend to be reported as case study rather than a reproducible, stable methodology.

6.1.4 TRUSTWORTHINESS OF POST-POSITIVISTIC RESEARCH

Confidence in trustworthiness is crucial to the uptake of published research, and is particularly important in qualitative research (Pope and Mays, 2000), which is hermeneutic in nature. Critics of qualitative research level the charge of relativism (Mays and Pope, 2000) at any approach which uncritically attributes authority to subjective reports and fails to acknowledge that they are intrinsically unrepresentative or incomplete, and so inadequate for generalising to build a complete explanation of a phenomenon. Another charge is lack of rigour, implying that post-positivistic research findings derive more from the researcher's interpretation than from the data themselves (Taylor, 2002, p3). The debate over meaning, or good interpretation, continues around the extent to which a researcher can transcend his or her own cultural horizons to obtain objective, rational knowledge of an external world, as it exists independently of the research process, and in the absence of an external norm (Lincoln and Guba, 1985, p14) against which to test it.

Triangulation is one approach to gaining reliable information about a single phenomenon by deploying multiple research methods. The concept of triangulation has its origins in land surveying, where it refers to the ability to locate a given point from two other points which are a known distance apart. In social science it refers

to the explanation of a feature or phenomenon from several different methods or points of reference. In this way it is hoped that a convergent validity of explanations will be achieved which leads both to a complete and objective understanding of the domain, and to a mutual confirmation of the validity of the methods used. Massey (1999) and others argue that the researcher must beware of the "spectre of positivism", which assumes a single social reality which can be mapped and represented in its entirety, when in fact, unlike topography, this cannot be taken for granted. Nevertheless, when applied to the area of user consultation for development of an information package like Pressure's Off, triangulation offers several advantages over a single methodology approach. Despite Massey's caveat, the stark fact remains that a developer who is unfamiliar with a given domain must identify and make generalisations about user needs in order to progress. In such unfamiliar circumstances, triangulating a number of different methods helps to build a detailed and multidimensional "working truth" about the target user group, rather than relying on a single – and therefore inadequate - snapshot.

Another issue in trustworthiness is the reproducibility of the research. Naturalistic fieldwork customarily makes extensive use of observational techniques for data collection which may be carried out over long periods of time. Context-giving artefacts, spoken word, documentation and audiovisual items are considered as data in terms of their capacity to contribute to a full representation of the entity studied. These methodologies must be used with caution and reported meticulously in order to avoid what Francis Wheen terms the "demolition of reality" (2004, p78). He fears the hegemony of deconstructionists like Jaques Derrida, who reject the notion of objective reality in favour of one that the world is

> "a socially constructed 'text' about which you can say just about anything you want as long as you say it murkily enough." (p81)

Since there are none of the traditional guarantees of validity and objectivity in much qualitative research, non-traditional criteria for trustworthiness should be offered by the investigator. For example, in his rejection of the concept of 'objective' observation, Fielding (2001, p155) discusses a test of 'congruence' or verifiability, whereby an observer should be able and prepared to impart the rules of engagement with an observed group to other would-be observers, allowing them to enter into the same setting and personally appreciate the validity of the original observer's analysis. Another way to reduce errors is known as respondent validation (Mays and Pope, 2000), whereby the investigator's account is compared to that of the original research participants, who are asked to respond to the findings.

In carrying out post-positivistic research methods responsibly – so that they can be held up for scrutiny - it is important to keep in mind that reality is not a subjective belief. Despite the susceptibility of the concept of high blood pressure (HBP) to categorical revisions, it is no less real and measurable, and rejecting its implications as merely putative clearly cannot bring about a reduction in - equally real - cardiovascular risk. Ultimately, the motivation behind any research exercise is to expose a new aspect of reality, hitherto unknown, which can withstand robust scrutiny and exist as a reliable basis for rational thoughts, plans and action.

With this in mind, the following section of the chapter describes the needs assessment for information on HBP, and the final section discusses its implications for the design and development of Pressure's Off.

6.2 BACKGROUND

Two factors have significant impact on information needs for HBP. Firstly, patients are asymptomatic, which makes it relatively easy to ignore the threat. The need for lifestyle modifications is consequently perceived as less urgent than for a complaint with insistent reminders in the form of symptoms. Secondly, HBP is chronic and can only be managed with lifelong vigilance. For many patients, looking after themselves involves continuous self-denial – and without the rewards of progress benchmarks or the prospect of an endpoint. These aspects of HBP, in the context of the health promotion approaches discussed in Chapter 4, suggest that information needs should be met through, on the one hand, description, explanation and reinforcement of practical information about diet, lifestyle and treatment and, on the other, sustained motivation and encouragement to put knowledge into practice.

In keeping with user-centred guidelines for the production of information for patients (Help for Health Trust, 2002; Duman, 2003), stakeholders and target users were involved in the production of Pressure's Off, as outlined in this chapter and Chapter 8 on evaluation. After the early HBP knowledge acquisition period (Section 3.1), the need for a survey of clinicians emerged as a way to link the theory of BP management with BP management in practice. To inform the design of a questionnaire and as part of the general needs assessment, arrangements were made to observe interaction between patients and clinicians in general practice and in a hospital-based hypertension clinic. Findings are described below at length, prior to a discussion about their implications.

6.3 SURVEY OF GENERAL PRACTICES

While motivated, self-assured patients are aware of gaps in their knowledge and can take measures to become informed, a larger section of people do not have

enough prior knowledge to identify what they need to know to manage their BP. For this reason a decision was made to survey health professionals, who have an overview of knowledge requirements, prior to prototyping the information package, with the aim of building a framework which could then be shown to patients for feedback.

6.3.1 QUESTIONNAIRE DESIGN

The questionnaire had dual aims. One aim was to establish the organisation of information provision in each practice, including which information was provided for HBP patients and how it was provided, to identify respondent assessment of the performance of their practice, and to determine whether information providers had received post-registration training in this area. The second aim was to establish the nature of information given to patients, including which areas were prioritised and how approaches varied between patients.

Because of the criteria for the questionnaire, which needed to be broad in scope, short in length and collect highly context-specific information, no complete instrument was available which fully met the research aims. Therefore questions were developed with reference to the aims of the questionnaire, based on the findings discussed earlier in this chapter. Individual question items which could not be found by searching the literature and existing questionnaires (Centre for Applied Social Surveys, 2004) were developed in-house. The self-completed questionnaire was designed according to established questionnaire design principles (Charlton, 2000; Cohen et al, 2000; McGibbon, 1997; Oppenheim, 1992; Gilbert, 2001).

Content validity – the relevance of the questionnaire items to the domain in general - was tested by circulating a draft to members of the Centre for Measurement and Information in Medicine and to health professionals enrolled on the Centre's MSc in Medical Informatics. Face validity – the precision of questions in measuring what each is intended to measure - was tested by piloting the questionnaire in 9 practices in Lambeth, Southwark and Lewisham, based on which a number of changes were made. Spaces for comments, formerly included with each question, had invariably been unused by respondents in the pilot. They were replaced with a general space for comments at the end of the questionnaire. The questionnaire was reduced to one piece of A4 paper by printing it double-sided, to minimise the chance that its length might deter respondents. A decision was made to allow anonymity, but respondents were encouraged to disclose their identity by offering each entry into a prize draw for £25 in either Marks and Spencer or book vouchers. To be able to receive this in the event of winning, they had to supply their contact details.

6.3.2 IDENTIFYING AND RECRUITING THE SAMPLE

At the stage of sending out the questionnaire, the practice nurse role was in the early days of its ascendance in chronic disease management. While nurses were being given increasing responsibility for management of HBP in primary care, the GP role was still key at all stages, and for this reason it was decided to send questionnaires to all GPs and practice nurses in one inner London borough.

Camden and Islington Health Authority (CIHA) was selected for the study due to its existing links with City University, the base for the project. It was anticipated that a number of health professionals would offer future input to the project, in which case the proximity of location would also be an advantage. Camden and Islington is also the health authority of the Caversham Group Practice with which links had already been established. CIHA was approached for contact details of all general practices under the administration of Camden and Islington Primary Care Trusts.

A decision was made to personalise the covering letter since, as health professionals, the intended recipients receive a large volume of post and would be more likely to take time to read a personal letter than a mail shot. Although the CIHA was able to supply GP names, it did not hold details of practice nurses. Each practice was therefore contacted by telephone to yield a list of 108 named practice nurses out of a total of 126.

126 practice nurses and 73 GPs were sent a pack containing:

- a covering letter introducing the project and announcing a prize draw for £25 in vouchers for Marks and Spenser's, books or music.
- the questionnaire, comprising 17 questions.
- "What is Computer-Aided Learning?", an overview for those unfamiliar with the concept, including comparisons with other learning media, screenshots and details about where to find examples.
- A prepaid envelope addressed to the principal investigator

6.3.3 RESPONSE RATE

There was an early discrepancy in response rate between nurses and GPs – the latter was extremely low. This is a recognised phenomenon (Kellerman and Herold, 2001; MacPherson and Bisset, 1995; Morris et al, 2001) which is especially prevalent in London (Morris et al, 2001). In their key role in the rapidly changing health care system, GPs are confronted with an unmanageable number of questionnaires and are prevented by limitations on time and resources from completing them all. This knowledge, along with resource limitations, suggested that following up the practice nurse responses rather than the GPs would represent the best use of time and resources. Practice nurses are increasingly the vanguard of

BP management in primary care (Kennedy, 2003). As the main point of contact for people with HBP, they are responsible for ensuring that patients are well informed, answering questions, and motivating lifestyle changes. They are well placed to observe fears, difficulties and gaps in knowledge, and are well seasoned in the effects of strategies for lifestyle modification.

To ensure the best possible response rate from the practice nurses, a follow-up letter was sent to those for whom there was no record of a returned form. There was a significant number of anonymous respondents at this stage and these nurses will have received a follow-up letter which may have been frustrating, not least because of the unreliability of the postal service in that area. For this reason a decision was made that the follow-up questionnaires should no longer have the option to be anonymous, and instead were labelled with each respondent's details. This meant that when a second follow-up was prepared, most of the non-respondents could be identified, but it may also have compromised the validity of some of the responses. Out of the 126 nurses surveyed 74 completed the questionnaire, a 59% response rate. The prize draw was won by a practice nurse from Mill Lane Medical Centre.

6.3.4 DATA ANALYSIS

Data were entered into a Microsoft Access database and explored using queries. Charts were generated by importing data into Microsoft Excel. Findings from the questionnaire are presented below, and the questionnaire can be found in Appendix 1. It is worth noting that, while giving invaluable insight, the questionnaire raised as many questions as it answered, highlighting the limited potential of questionnaires alone to explore the phenomena they identify. Consequently, the themes from the questionnaire, outlined below, were explored in more depth via the interviews and observation described in the following sections.

6.3.4.1 HBP education in practice

Q1: As a factor in good management of hypertension, how important do you consider patient education to be?

1
0
0
0
28
45

most important
very important
quite important
not very important
unimportant
null
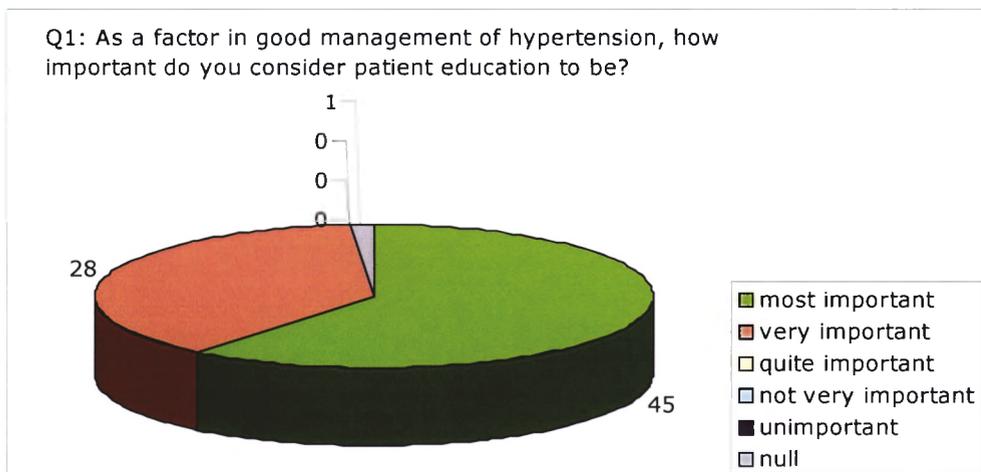
Figure 6.1 Importance of patient education

Responses to Question 1 indicated that approximately two thirds of respondents regarded education as the most important factor in management of HBP (Figure 6.1). The remainder of the sample considered it to be very important factor. This reflects the fact that knowledge is held to be fundamental or important to the attitudes and behaviours which mediate BP management.

Q2: What information does your practice routinely provide for each newly diagnosed hypertensive patient?
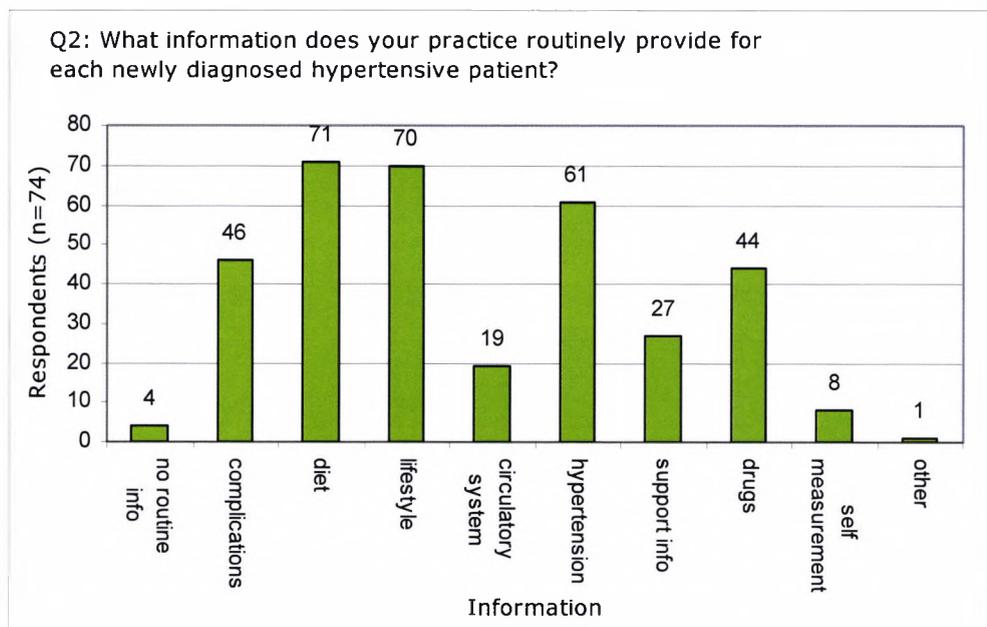
Figure 6.2 Information routinely provided for newly diagnosed hypertensive patients

Question 2 identified the information routinely given to newly diagnosed patients (Figure 6.2), information on diet and lifestyle was given by 90% of nurses. Although 82% gave routine information about HBP and 62% offered information on complications, only 26% offered background information on the circulatory system where these complications of HBP occur, risking a gap in knowledge.

5% of respondents reported that they did not offer routine information, suggesting either a highly responsive, personalised approach to informing patients, or the entire lack of a protocol for giving this type of information.

Surprisingly, 61% reported giving information on medication at the point of new diagnosis. In the ideal world of guidelines, BP is tracked from birth, and elevation is identified early or as it happens. It is therefore recommended that decisions about medication be preceded by diet and lifestyle interventions. The fact that information on medication was given at the stage of diagnosis in some practices may mean either that blood pressure tends to be appreciably - rather than slightly – elevated at diagnosis, or that this information is included on leaflets routinely given to new patients, or that the patients themselves tended to initiate a discussion about medication.

In Question 3, respondents were asked to rate six areas of knowledge on a five-point scale of importance (Figure 6.3). Lifestyle was considered to be by far the

most important area of knowledge, with only one respondent rating it lower than 4. Complications was the next most important area, followed by medication, which was valued slightly higher than knowledge of cardiovascular risk. At the time the questionnaire was completed, few respondents considered knowledge about self-measurement to be important, though this attitude may have changed in the intervening period. This suggests that, to fulfil the criterion of complementarity and reflect existing practice, Pressure's Off should provide full lifestyle information. However, this does not have to be to the detriment of other areas, since few or no respondents commented that any of the areas listed were inappropriate. Awareness of BP level over time was not considered a priority - this is interesting because, for patients with HBP, these measurements represent the only available feedback about their progress with managing the condition. Yet there is similar evidence from the hypertension clinic that health professionals are concerned about patients becoming fixated with their BP to the detriment of overall wellbeing, and will act to curtail self-measurement if it is seen to become all-consuming. This is a difficult, under-researched area with implications for self-care of many chronic conditions.
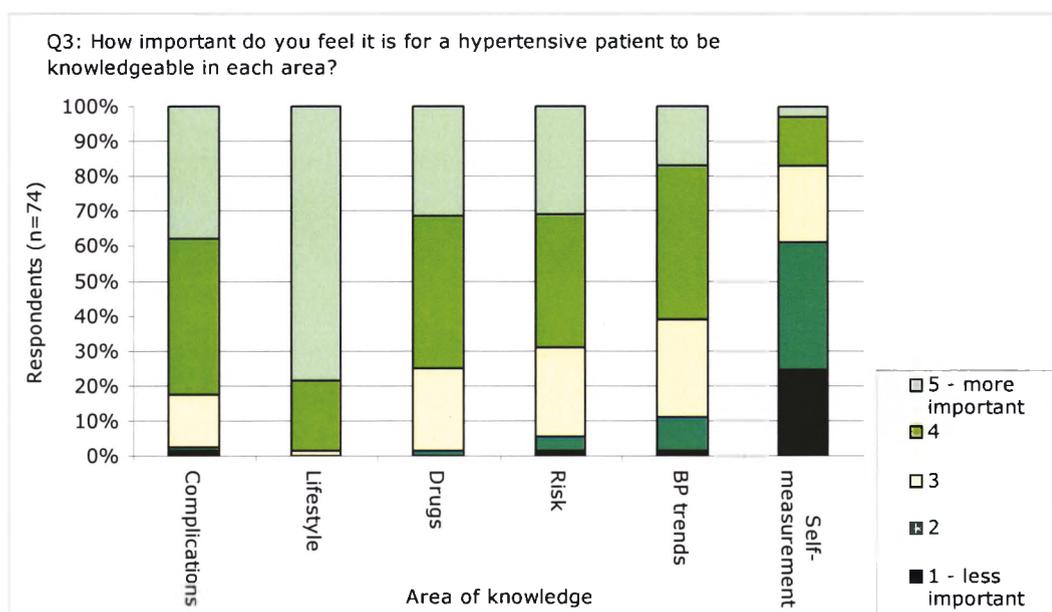
Figure 6.3. The importance of patients' knowledge different areas of hypertension.
Question 4 explored different modes of giving information (Figure 6.4). Face-to-face conversation with a nurse or a GP was perceived as most valuable. 80% of respondents assigned the highest or second highest category of importance to the GP talk and 92% assigned these to the nurse talk. This may be due the unequal proportions of GP and nurse respondents, but is also likely to reflect the developing role of practice nurses in informing patients. Information leaflets also had an important function in consolidating and reinforcing communications with the nurse or doctor. Out of all the categories of education, computer-aided learning was assigned the least important role in informing newly diagnosed patients about their

BP, and at the time only 7 respondents reported encountering any kind computer-based education for HBP patients.
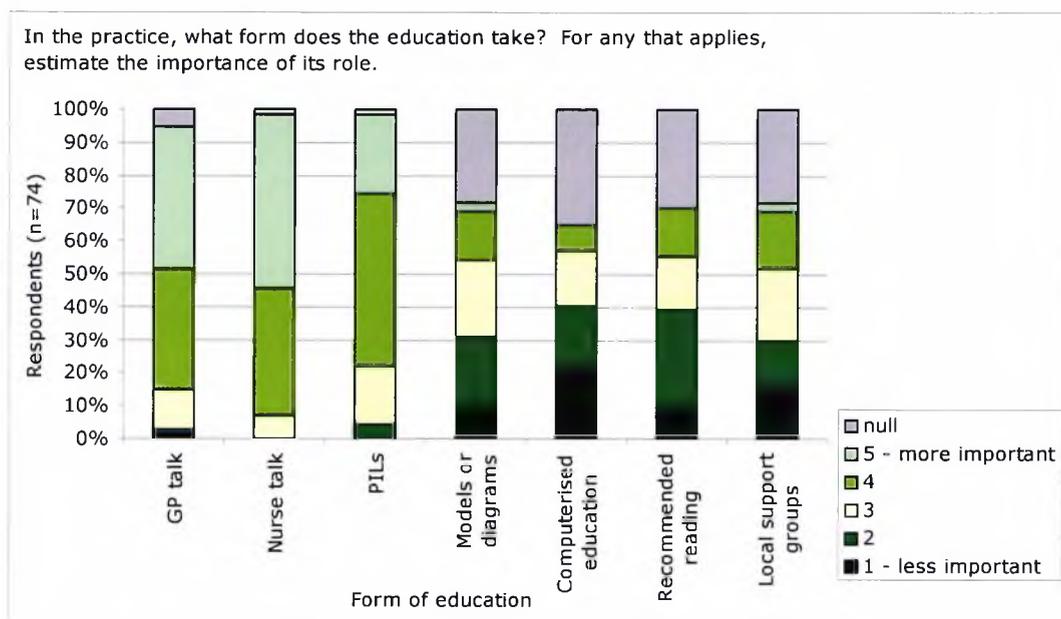
Figure 6.4 The importance of different modes of giving information

6.3.4.2 Training for education providers

In Question 6, respondents were asked about training of HBP education providers in their practice in the previous year (Figure 6.5) and the previous five years (Figure 6.6). 41% of respondents were confident that education providers had received training within the previous year. A conclusion can be drawn that about a third of respondents were unsure about the training status of their group of colleagues, and the construction of the question did not allow a response specific to their own situation. Another potentially invalidating factor is the question order, which may have confused respondents who had been trained in the previous year - they may conceivably have considered that a "Yes" for the question 5 precluded a "Yes" for the question 6. These respondents should have been filtered, omitting question 6 and proceeding to 7.

Q5: Have the providers of education for hypertensive patients in your practice been formally trained in providing education specifically for hypertensive patients within the last year?

3%

36%

41%

20%

- Yes
- No
- Not sure
- Null
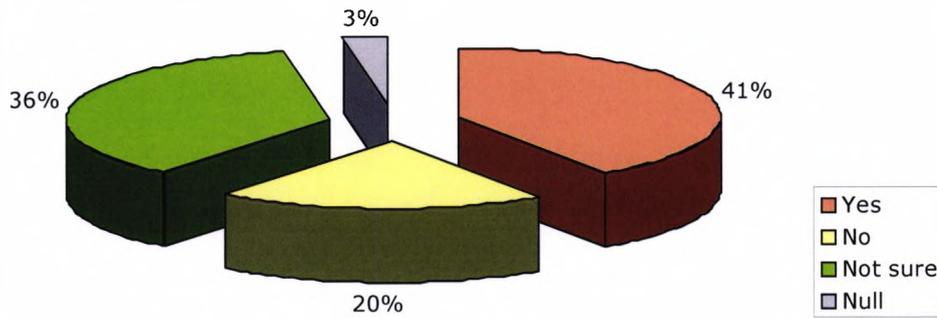
Figure 6.5 Training for high blood pressure information providers in the last year

Q6: Have the providers of education for hypertensive patients in your practice been formally trained in providing education specifically for hypertensive patients within the last 5 years?

7%

22%

60%

11%

- Yes
- No
- Not sure
- Null
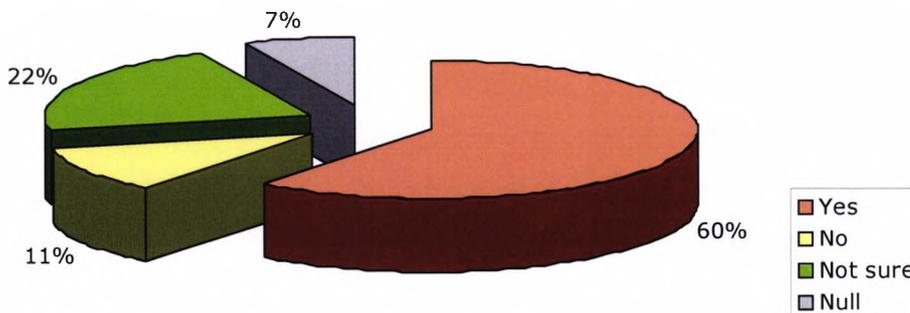
Figure 6.6 Training for high blood pressure information providers in the last five years

However, the overall profile confirms the existence and significant uptake of training for information providers.

6.3.4.3 Educational needs of patients

Question 7 (Figure 6.7) considered the different educational needs of patients. It was felt that these were most affected by individual aptitude. Social circumstances, ethnicity and age were also perceived as influential. Gender was considered important by nearly one third of respondents, a considerably smaller proportion than the other factors. Patients' own questions were not necessarily felt to imply differing information needs; this response may have been either because patients tend not to ask questions, or because they tend to ask the same basic ones, or even because of a view in the respondents that patients are not accurate judges of what they need to know.

124

Q7: Do you feel that individual patients have different educational needs, either in terms of the material covered or how it is delivered?

Y-axis: # respondents (n=74), X-axis: Factor

- social circumstances: 62
- aptitude: 65
- age: 58
- gender: 23
- ethnicity: 59
- patients' questions: 49
- psychological state: 58
- severity of risk factors: 55
- no different needs: 4
- other: 4
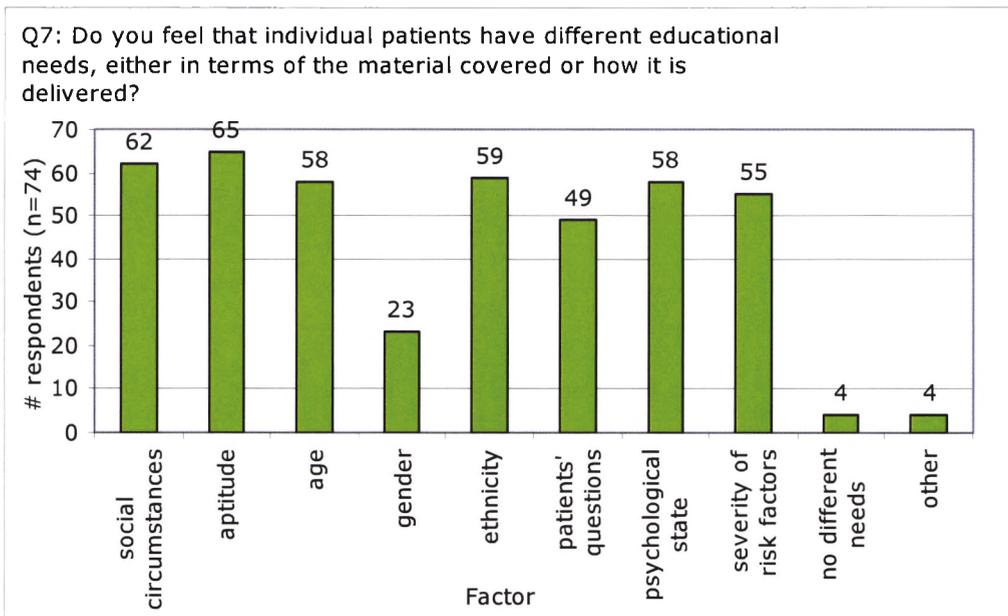
Figure 6.7 Factors affecting the educational needs of patients.

Although over half the respondents to Question 8 (Figure 6.8) regarded primary care as addressing these educational needs identified "quite well", a significant minority of 33% regarded these needs as "not very well" or "badly" met (Figure 6.8).

Q8: How well do you feel the needs you have specified above are addressed in primary care as a whole? (n=74)

- effectively: 3
- quite well: 42
- not very well: 22
- badly: 1
- null: 6
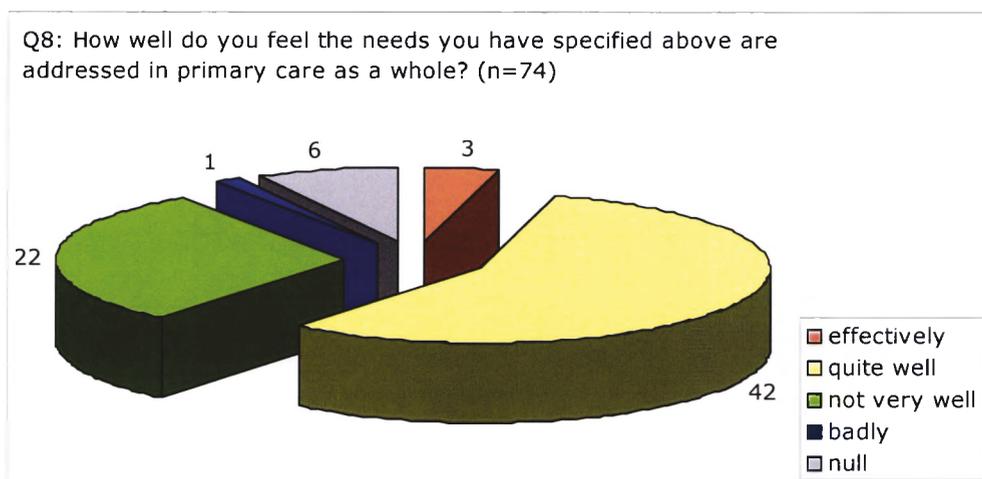
Figure 6.8 Performance in addressing information needs in primary care

In Question 9 respondents were asked whether their practice's approach to patient education varied between patients (Figure 6.9). Number and severity of risk factors had particular impact here. Patient questions, or lack of them had a smaller effect, and 21% responded that there was no difference of approach in their practice.

Q9: Does the approach to education vary between patients in your practice?

Focus categories: more risk factors (53), ask questions (25), do not ask questions (14), other (3), no difference (16). Respondents (n=74).
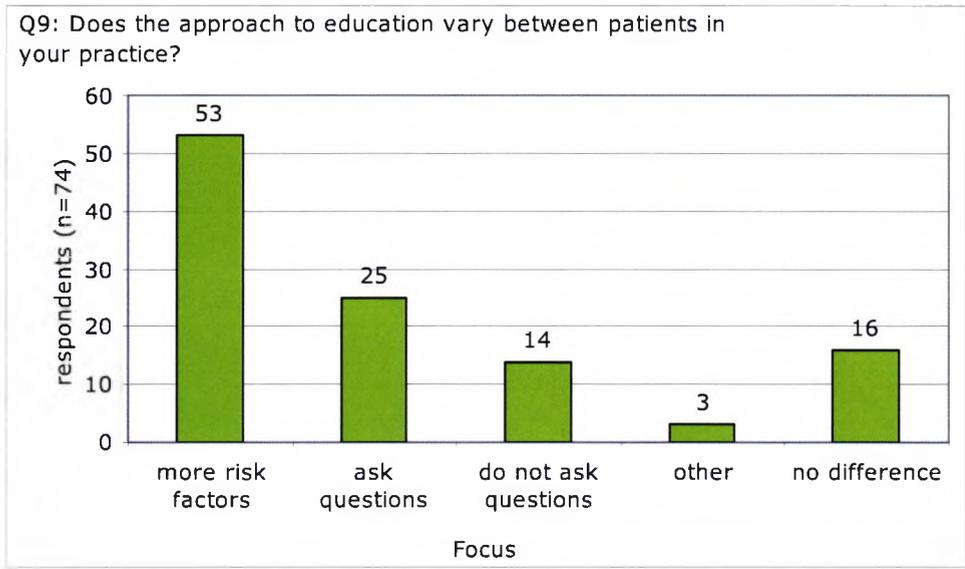
Figure 6.9 Variation in approaches to education in practice

In Question 10, respondents were asked to identify areas of the information that they would want to individualise between patients (Figure 6.10). 85% of respondents reported wishing to individualise a section on cardiovascular risk, and 66.2% could see the value of individualising information about side effects. The question does not offer insight into *how* respondents would like to individualise this information. For example, would it be considered useful to withhold the section on cardiovascular risk in its entirety, or would respondents prefer to customise it in terms of detail or risk factor?

Q14: Assuming the list below represents components of a hypertensive patient education program, identify the areas you might wish to individualise.

Area to be individualised: cardiovascular risk (63), blood pressure trends (52), side effects (49), feedback on performance (56), complications (56), progress (56), none (0), other (0). Respondents (n=74).
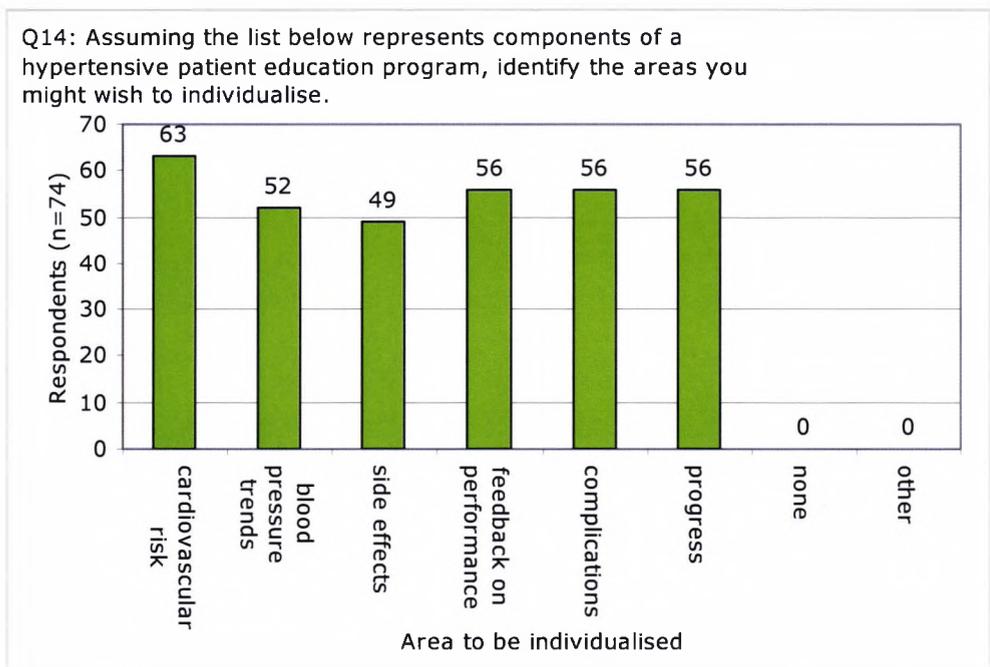
Figure 6.10 Areas for individualisation in a patient education programme.

6.3.4.4 Response to poorly controlled hypertension

A free text item, Question 10, revealed a variety of approaches to the question "If a hypertensive patient is not well controlled, what procedure is adopted in your practice?". Most responses were a single sentence in length.

In only one case was the approach reported as monitoring alone, and this was recognised by the respondent as an under-provision:

> "close monitoring only but little education or support … offered" (Respondent 1).

Referral to specialists or allied health professionals was frequently mentioned:

> "Generally they are referred - from nurse to GP then from GP to specialist" (Respondent 4).

> "Hospital referral, dietician referral, more education" (Respondent 21).

However, in most cases other interventions were instigated. Some emphasised medication:

> "Discussion re lifestyle, make sure taking drugs correctly. Set time limit by which improvement, if not, change drugs" (Respondent 33).

> "6 monthly medication & BP review" (Respondent 67).

> "To increase medication preferably a combination of drugs until target is achieved." (Respondent 42).

> "Drug compliance - find out if patient is taking prescribed medication." (Respondent 47).

> "We try different drugs / combinations of drugs and may, depending on other risk factors, refer to a cardiologist" Respondent 17).

Others prioritised information or education alongside monitoring:

> "More education." (Respondent 47).

> "Regular monitoring … and health education". (Respondent 43).

> "Give leaflets / education and give patient appointment to see nurses on regular basis" (Respondent 9).

> "blood pressure - awareness of complications. Regular monitoring 3-6 monthly. Importance of diet/exercise/alcohol/stress…" (Respondent 26).

Some mentioned a two-way communication approach where patients had a chance to discuss their attitudes as well as being informed:

> "Establish open relationship in which all factors may be discussed." (Respondent 25).

> "more regular monitoring with more chance for in depth discussion about medication compliance etc" (Respondent 48).

> "Discussion on diet, weight, smoking, exercise and relevant issues." (Respondent 49).

> "Offering information, reinforcing risk, exploration of patients ideas concerns and explanations and health beliefs" (Respondent 28).

Respondents were asked about the factors they perceived to be responsible for poor blood pressure control (Figure 6.11). Lifestyle was perceived to be the most

important factor contributing to poor BP control, with two thirds of respondents rating it in the top two categories of importance. Half the respondents attributed high importance to patients' poor understanding of the significance of their medication.

Q11: Factors perceived to be responsible for poor blood pressure control
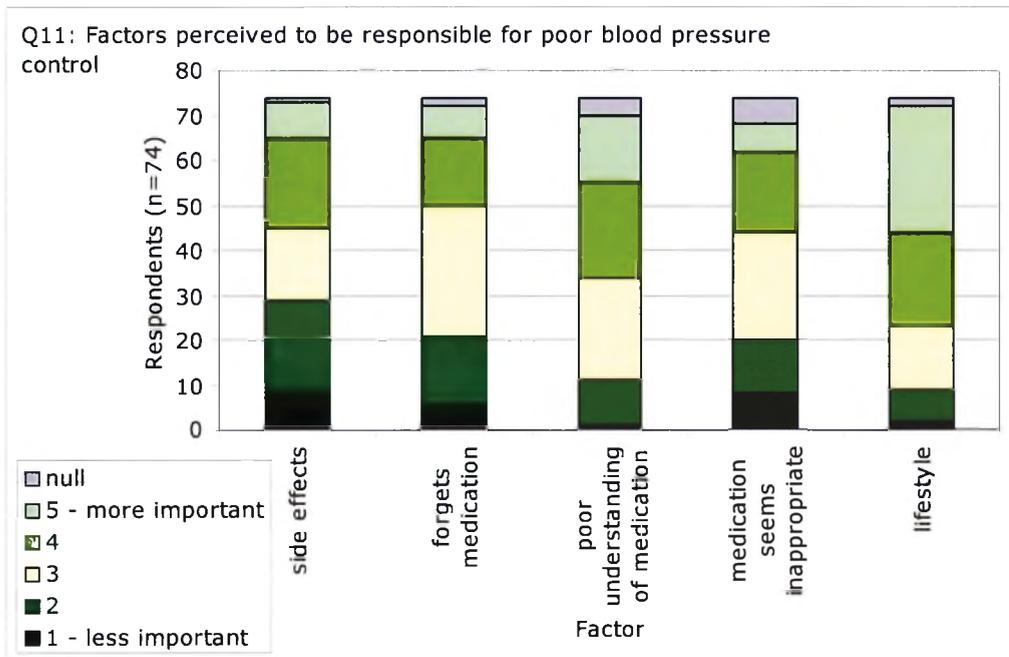
Figure 6.11: Factors perceived to be responsible for poor blood pressure control

6.3.4.5 Computer-based information for patients

Nine respondents (12%) had encountered computer-based information for patients (Question 12). 59% had a positive or very positive attitude to the concept (Figure 11). Respondents unfamiliar with the concept were asked to refer to an enclosed introduction to computer-aided learning. Over half of respondents were positive about computer-based education for patients with HBP.

What is your attitude to computerised education for hypertensive patients?
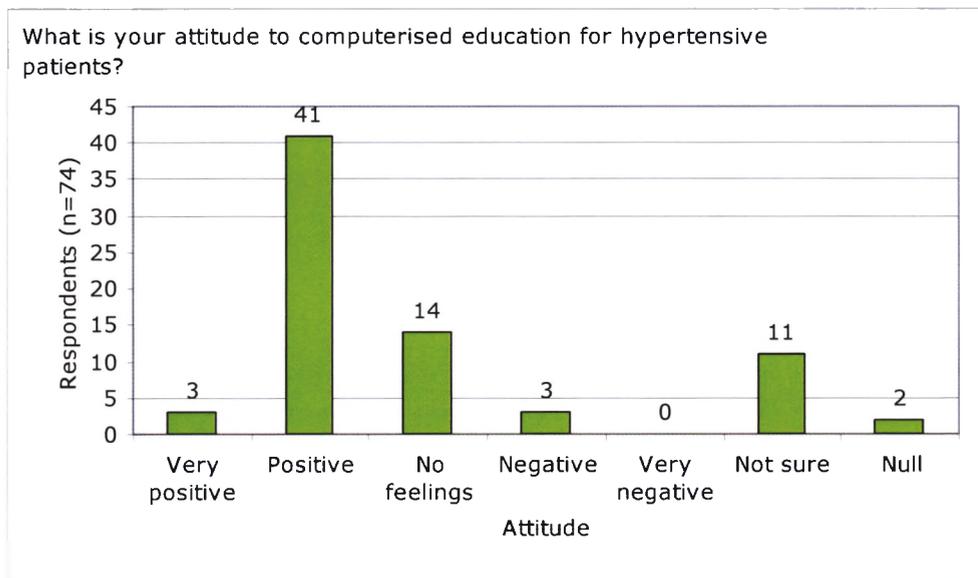
Figure 6.12: Attitudes to computer-based education for hypertensive patients

Questions 16 and 17 asked whether the respondent would be happy to be further involved in the project, and what kind of voucher they would prefer if they won the draw.

6.3.5 SUMMARY OF QUESTIONNAIRE FINDINGS

The responses presented above highlight the variability of approaches to managing HBP in practice. Largely missing from practice were the expensive behavioural approaches, introduced in Section 4.3.4, which have a positive effect on BP. Information tends to be given in face to face or in the form of leaflets, and is predominantly about HBP itself, its complications and diet and lifestyle interventions. Knowledge about lifestyle is flagged as a priority area for patients, while BP trends and self-measurements are less valued. Doubts about the effectiveness of current approaches to BP management are raised. Variation in patient needs is recognised by most respondents, who report individualising the education in response, and note that they would value the opportunity to do so with computer-based education. Encouragingly, although few of the respondents had encountered computer-based information for HBP, a large proportion were positive about the concept.

6.4 OBSERVATION

Two observations took place, the first at a general practice where opportunistic screening was performed and the second in a hypertension clinic where patients were monitored and diet and lifestyle counseling was given.

6.4.1 AFTERNOON SURGERY AT A GENERAL PRACTICE

The population prevalence of HBP afforded the opportunity to observe BP screening during a routine afternoon surgery at a Camden and Islington general practice. The GP mentioned that, among the other GPs in the practice, he was often allocated those patients with a psycho-social dimension to their poor health, because this was a particular strength of his. By common agreement his consultations were longer, enabling him to spend time talking with people about the range of circumstances outside their immediate physical health which might affect their well-being. He also mentioned that he planned carry out some opportunistic BP monitoring that afternoon specifically because he would be observed by a researcher interested in HBP. Patients' consent for the non-participative observation was requested.

Over the course of the surgery it was not always judged appropriate to monitor a patient's BP, a point also flagged by a practice nurse interviewee (section 6.5.2). For example, one patient presented in an emotional state incompatible with monitoring, because the resulting raised values would have added to that patient's

distress. Where it was considered appropriate, BP screenings were initiated in a matter of fact way – "While you're here, let's have a look at your blood pressure...". On this occasion, patients were evidently familiar with the procedure and began to adjust their clothing in anticipation. This GP took measurements in each arm, and the procedure took several minutes. Where values were high, the GP mildly noted the fact, and suggested that an appointment should be arranged with the nurse to check again in a week. In this practice, as in many others, the nurses were predominantly responsible for giving diet and lifestyle advice, and arrangements were made to interview two nurses from that practice (Section 6.5.2).

6.4.2 A HYPERTENSION CLINIC

The clinic is run in the Out Patients Department at a large London hospital, by a Consultant Clinical Pharmacologist and a Hypertension Nurse Specialist (HNS), and exists as a service for patients with HBP which has resisted management in the general practice setting. Patients attend each of two morning sessions, for new and follow-up patients. To the uninitiated observer, the difference between these sessions is subtle, lying in the increased knowledge about the patient based on investigations such as 24 hour monitoring or ECGs, and the reinforcement of diet and lifestyle knowledge and motivation. Similarities are probably due to the way information given in the first session is routinely reinforced in the second session by the HNS, during which similar aspects of diet and lifestyle are discussed. A new patient session and a follow-up session were observed. Patients were welcomed in the waiting room by the clinician, who sought consent for the session to be observed. The researcher was positioned in a corner where she would not obstruct proceedings, and maintained an entirely non-participative approach unless somebody directly initiated communication.

The consultation itself was deliberately informal and unhurried, to encourage an unreserved exchange of information between HNS and patient. BP was measured on two separate occasions using an automatic monitor, a process which was explained for new patients. Patients responded to set questions about aspects of diet and lifestyle, which triggered advice and explanations from the HNS, who also answered questions. Several patients were referred for investigations such as ECG or 24 hour BP monitoring, procedures which the HNS explained. Six consultations were observed, between twenty minutes and half an hour in duration, involving ethnically diverse patients, aged between twenty-something and seventy-nine, with varying comorbid conditions, who had been referred by their GPs. Themes emerging from these consultations are described below.

Four patients mentioned side effects of medication which had resulted in changes to their prescription. Despite this, they reported good adherence to their respective

medication regimens except in one case where Mr C admitted that although the current prescription was "the best pills so far", he did not take them regularly.

There were several barriers to physical activity. Mr C was taking medication for depression which, he said initially, prevented him from being active; later in the interview he referred to daily brisk walks, but this claim may have been intended to appease the HNS. Mrs D had given up Exercise on Prescription because "... it was boring and everybody had to wait for the older people in the group". She had recently enrolled in a gym. Mr B was living in secure accommodation and had limited autonomy – the HNS had to negotiate several aspects of his lifestyle with his carer. Mrs F's heart pain prevented her from taking much exercise – she could walk about fifty steps at a time after which she had to pause.

Neither was diet straightforward for these patients. Mr B had little notion of healthy eating, asking about crisps, "Isn't they good for me?". Moreover, his carer was in doubt about the quality of the food available on his unit, and disclosed that he felt intimidated by the caterers. Mr C's description of his diet, though exemplary in its moderation, contradicted his overweight appearance. Mrs D matter-of-factly described herself as "not an everyday fruit and vegetable person", and didn't buy fruit because "it goes off". When asked about his fruit and vegetable consumption, Mr E responded that he knew how much he should be eating but didn't always manage.

Only one of the patients, Mr E reported that he drank alcohol regularly. As a musician on tour, it was freely available and he was experiencing problems cutting down. He was also the only patient who disclosed that he smoked – about ten cigarettes a day, socially. The HNS approached advising him by reiterating that there were no easy solutions and to carry on trying to cut down slowly.

A large part of the interaction was dedicated to diet and lifestyle information. This took the form of the HNS asking each patient about their current habits, and linking her advice to their responses. She then initiated a second series of questions to address any outstanding areas, so that salt and savoury snacks, spreads, fruit and vegetables, meats, dairy products, smoking, alcohol, and exercise were all covered. She kept her advice concrete, relating it to foods and ingredients themselves rather than basing it on comparatively theoretical and potentially inaccessible concepts such as saturated fat or calcium, for example. Despite the relatively long appointment slot, the diversity of diet and lifestyle in a developed country like the UK made it difficult to cover the range of factors adequately.

Communication between general practice and the clinic was not always adequate, for a number of reasons. Since each patient record was recorded on paper and stored in Lloyd George folders, reading these could be a challenge, and omissions

made some GP therapy decisions hard to explain. Inevitably, there were frustrated and critical references to the practice of some unidentified GPs, while clinic staff evidently had very successful working relationships with others. Since GPs, clinic staff, and sometimes other health professionals, have parallel control over a single patient's medication, each consultation requires an advance, soap-opera style review of the notes previous consultations by other clinicians, and their subsequent therapy decisions. This review is supported with a request that each patient bring all their various medication, and its packaging, to the clinic. However, some persistent deficits in information were observed, which have been widely noted throughout the NHS, and which have to be accommodated by clinic staff.

Although there was a protocol for the consultations, the HNS exercised judgement about offering information and advice on a patient-by-patient basis. For example, Mrs A was upset and disappointed because, after some months trying to get pregnant, she had been advised against it until her BP was under control. She had recently started to take a centrally acting drug (one of the few indicated in pregnancy) from which she was suffering disruptive side effects relating to her energy levels and mood. Worse still, she thought she might be pregnant already. The HNS dispensed with lifestyle and diet advice for the session, directing her energies to comforting Mrs A and encouraging her to persist with the medication to establish whether the side effects were temporary.

These appointments were an opportunity for patients to become informed about factors in their diets and lifestyles which could help lower their BP. It was notably how quickly the appointment slot, which had seemed very long, passed when confronted with the volume of information to be covered. To include all the relevant topics it was necessary to pare them down to their essentials. The individual circumstances of these patients also impinged - most inconveniently, as it seemed at first - on the practical application of the advice they were given. As an outsider and lay person, this investigator gained invaluable insight into the gulf between information and healthy behaviour.

6.4.3 SUMMARY OF OBSERVATIONS

These observations provided an indispensable initiation to HBP in practice, introducing the researcher to diverse members of the target user group. The experience was invaluable in raising awareness about existing barriers to diet and lifestyle modifications. It also offered the opportunity to observe the BP measurement procedure, and patients' reactions to it.

6.5 INTERVIEW

Opportunistic conversations with people with HBP are integrated with transcripts and recordings from the Database of Individual Patient Experiences (DIPEx, 2002) to give insight into patients' experiences and attitudes, below. Themes emerging from interviews with two general practice nurses are discussed in the following section.

6.5.1 PEOPLE WITH HBP

Over the course of the project it has been possible to talk informally with a number of people with HBP. Some initiated conversations with the researcher when they became aware of the project and others were comfortable discussing the subject at the request of the researcher. Opportunistic and unstructured as these informal discussions have been, findings from them are integrated here with interview material from the Blood Pressure Module of the Database of Individual Patients' Experience (DIPEx, 2002), a series of interviews covering people's experience with different conditions, which have been used in research about diverse aspects of illness (Ziebland et al, 2004). The 18 interviews on BP available on the Web site are not offered in full but have been chunked, making them searchable, transcribable, and easy to download. Because this has made the sequencing of statements, the sampling processes, and the editing processes unclear, excerpts are included below to illustrate emerging themes rather than to encourage conclusions about the broader population.

One theme was how information was obtained. Although information in a health care setting has been shown (Ley, 1988, p7) to be a good way of enhancing satisfaction and consequently compliance, there is often slippage between what patients are told by health professionals, and what they understand. Ley (1988, p26) makes four points here:

- patients often do not understand the vocabulary used by the clinician
- patients often do not understand the substance of what they are told by a clinician
- what the clinician says is interpreted within the framework of the patients own ideas about the illness, and these often differ from accepted orthodox ideas
- patients tend to be reluctant to ask questions

This last point is exacerbated by mounting pressure on health professional time, expressed in the 6 minute consultation.

> "I would like to know more about high blood pressure, I've got a wonderful doctor - it isn't that he wouldn't tell me - he would if he had the time, but he hasn't got the time and I know that." (Interview 05, DIPEx, 2002).

The lack of knowledge about HBP is convincingly illustrated by DIPEx (2002). A large number of interviewees demonstrated a common misunderstanding about HBP, attributing the condition largely to stress:

> "I know even with me, at work people were surprised when they learnt I was in hospital and I had high blood pressure, because they thought I was stress free." (Interview 10).

> "...what do I cut out of my life in order for it to be less stressful? There are things I'm trying to reduce on my own, not physical stresses but mental stresses really." (Interview 12).

> "I do feel that I am a sort of hypertensive character." (Interview 15).

> "I felt at the time that that was probably because of the extra bit of stress and anxiety and that once that had passed it would go again. I didn't think that it was something to stay." (Interview 18).

> "I think the main thing is don't get stressed out, if you're not stressed out your blood pressure is not going to do too high." (Interview 20).

This has its roots in the term "hypertension" and its associations with anxiety and nervous energy. However, this overemphasis on stress has possible repercussions – the quest for a relaxed existence can lead to a fatalistic outlook, also evident in DIPEx, which may be in direct opposition to other goals such as weight or alcohol reduction and increased physical activity.

The imprecise nature of information was another theme. One 55 year old man (Interview 07, DIPEx, 2002) complained about a lack of specific guidance on diet:

> "And I wondered, 'Ah, yeah. I'll rush out and buy a dozen tins of herrings'. I'll see if that's any good for me. You could actually be eating a lot of wrong foods. On the other hand, you would know the right foods, if they told you. But they just say to stay away from chocolate and beer - all the favourite things."

Another (Interview 07, DIPEx, 2002) dismissed much information for lay people as useless:

> "I have looked things up on the Internet and it's amazing what you can gain from people and from research foundations. But if you sign onto [a web site] as a lay person, all you get is gobbledy-gook. If you turn round and say you are a doctor or a medical researcher and sign on you get access to far more technical libraries. You know, where you can actually look."

This suggests that the reductionist, simplistic approach to providing health information is of limited use for more inquiring or motivated people. For those unaware of the evolving nature of medical knowledge, the concept of best current practice, and the notion of coping with uncertainty, this can lead to a loss of confidence in *any* information: "It is hard really to know where the truth lies and I suspect they don't know really themselves." (Interview 07, DIPEx, 2002). Lack of certainty and perennial change in best current practice are a fact of life for any health professional, but can be profoundly unnerving and demotivating for lay people seeking categorical answers. On the other hand, in a conversation with the researcher, a 29 year old woman was dismayed to learn that, despite steps to

increase her fruit and vegetable intake, the way she routinely prepared them reduced their nutritional value. She believed that such specifics should not form part of official health messages because "most people" would be demoralised by the conditional clauses and reject the message entirely. Like a significant proportion of health promoters, she was in favour of mitigating the message in order to make a given behaviour change seem achievable.

Another theme was the tendency to ignore HBP, especially where reinforcement of diet, lifestyle and medication messages is undermined by lack of health professional time. One 29 year old man known to the researcher had done his best to forget about his elevated BP, which had not been followed up since its initial diagnosis. Some years later he was persuaded by his partner to ask his GP to for a BP measurement. On recording a reading of 160/110, the GP recommended that he make a hospital appointment to undergo a series of tests for target organ damage. The patient felt very alarmed, made a number of resolutions toward changing his diet and lifestyle and, soon afterwards, joined a gym. However, the alarm quickly faded to a background uneasiness and, reluctant to face the implications of HBP, he avoided making the hospital appointment or seeking further BP monitoring (nor was this followed up by the general practice). He admitted that he had been unable to stop smoking or curb his excessive alcohol consumption when out with friends.

His parents, a husband and wife, in their late fifties also have HBP, concerning which they have a sanguine outlook. This is reinforced by the longevity of the wife's father, who was enjoying a full life at a very advanced age with a heart bypass operation behind him. These two demonstrated an accepting attitude to HBP, and reported a similar outlook in their GP. If they took their medication as directed, which they achieved with the use of dosette boxes, they were inclined to consider their duties fulfilled. No urgency or anxiety about BP was apparent to the researcher. At the time of the interview they were both in the obese category and enthusiastic drinkers, neither of which they explicitly associated with BP.

A third area covered was the aftermath of a diagnosis of HBP. BP-lowering lifestyle modifications can seem at best tedious, and at worst unbearable. "It has taken over my life in so much that I can't do the things now that I want to do." (Patient 09, DIPEx, 2002). Encompassing alcohol intake and diet, they can be socially disrupting and lead to stigma – "I still think it's more of a taboo subject between people. It's quite a private thing." (Interview 07, DIPEx, 2002). For the unaccustomed, physical exercise can bring with it discomfort, loss of time, expense and, according to one obese female, exposure to ridicule. The emphasis on self-denial in some interpretations of health promotion can be joyless and incompatible with the current ethic of consumption and self-fulfilment which prevails in the mass media. In acknowledgement of this, recent years have seen movement towards an additive

approach in health promotion – stressing positive measures such as the benefits of eating certain foods – rather than focusing on proscribing unhealthy aspects of lifestyle and diet. However, there is no escaping the fact that for many people, looking after their BP effectively requires radical and far-reaching reform of their diet and lifestyle, for which substantial support should be given. Moreover, for some people a healthy lifestyle does not guarantee lower BP – an issue which re-emerges in Section 8.6.3.5 on personal responsibility:

> "One of the things I was a bit miffed about was I'd done all the right things: I've never smoked, I've kept my weight down, I take regular exercise, I eat a low fat diet and I have hypertension!" (Interview 01, DIPEx, 2002)

6.5.2 TWO PRACTICE NURSES

Two nurses at a Camden and Islington general practice were interviewed separately. The semi-structured interviews, lasting approximately thirty minutes were taped and transcribed, and the emerging themes are discussed below.

Several general patient attitudes to HBP were mentioned which can be broadly described as self-sufficient, in-denial and anxious. Motivated patients might

> "just want to come in, have their blood pressure checked, know that it's OK and go out, and if it isn't OK, they want to somebody to kind of direct them in the right direction and give them the appropriate advice." (Nurse 1, 2, 18-20).

Patients in denial resisted care, "some of them just want to ignore it I suppose – they don't come in for their blood pressure checks." (Nurse B, 3, 12-14). For a significant proportion of patients it was clear that they perceived their blood pressure as "a very worrying thing". (Nurse 1, 6, 11).

> "There are these people who just need the regular contact with someone who cares who can do physical measurements that make them feel almost like they feel that there is an intervention being made..." (Nurse A, 2, 6-8)

Care is taken not to exacerbate this anxiety, demonstrating a sensitivity and responsiveness on the part of health care practitioners to the varying needs of individual patients: "...you do have to be careful when discussing symptoms because you can terrify people..." (Nurse 1, 1, 51-3).

> "I think they tend to break them in gently to the idea that their blood pressure is higher than it should be. Because otherwise they go home in a complete panic thinking they're going to have a stroke or a seizure or something. (Nurse 2, 4, 40-3).

One dilemma which highlights the need for this kind of sensitivity is whether to warn patients in advance about adverse reactions to medication. On the one hand:

> "...you don't want to because other studies show that if you tell someone that this might happen you're increasing the likelihood that it will, and you want them to have successful treatment, for their benefit" (Nurse 1, 3, 21-34).

and on the other:

> "They should probably know the side effects of the tablets, because some of the tablets have got awful side effects, haven't they. I think they're often swapped around a bit because of the side effects, so I think that's important." (Nurse 2, 1, 9-11).

The solution is pragmatic – paper-based information is packaged with the medication, but a prior discussion about adverse effects is not necessarily initiated. Open questions are used in follow-up appointments to elicit signs and symptoms which could indicate adverse effects, and if these are present patients are referred back to the GP. An exception is made for sensitive conditions which might otherwise go undetected:

> "The one problem is the men don't often mention impotence and that is one where if they are having other side effects then before I refer them to the doctor I might mention it, because it can be a huge relief to them that you've asked them and they can be terribly worried and terribly distressed about it and not actually want to mention it, so I try and facilitate that." (Nurse 1, 3, 9-13).

In their pursuit of information, one nurse had observed that patients found practice nurses more approachable than doctors:

> "...the patients are trying to protect their doctor – they're lucky people these doctors, got so many people protecting them - they come to see the nurse – they don't want to bother the doctor, they seem so busy and this seems like such a silly little thing, and you get that across the board and not just in hypertension, but we do tend to see quite a bit of it in hypertension, and once they know we're here and we're accessible they do use us." (Nurse 1, 3, 2-7).

Inevitably, this valued accessibility is restricted by time:

> "I think patients will always ask lots of questions if you allow them to ask them. There are issues in primary care with time management and how you manage your time and how you facilitate the patients." (Nurse 1, 3, 54-7).

6.5.3 SUMMARY OF INTERVIEWS

Conversations and interviews with patients generate a number of themes which have increased the researcher's understanding of what it is like to live with HBP, and suggested several areas of HBP which cause difficulty for patients. The practice nurse interviews offered valuable insight into the practicalities of giving BP information to patients, and point to resource limitation which compromise the effectiveness of patient education, and which should be addressed.

6.6 LIMITATIONS OF THE NEEDS ASSESSMENT

The validity and reliability of the questionnaire research instrument are uncertain, a regrettably common problem (Boynton and Greenhalgh, 2004). Several flaws survived the pilot stage and a number of question items proved blunt instruments yielding inconclusive findings. Question 7 offered a number of options for factors affecting information needs - Question 9 then asked about how approaches to

giving information varied in *practice*, but neglected to offer the same set of options – a missed opportunity to compare theory and practice. Question 11, exploring the causes of poor BP control, offered a set of options which were skewed towards problems with medication, and may not have adequately reflected real life. Boynton and Greenhalgh (2004) recognise the problem here – at the time the questionnaire was designed, early in the project, the researcher was not familiar enough with the research area to predict the range of possible responses. It would have been a better idea to precede questionnaire design with a qualitative approach such as observation or interview – in fact the observations and interviews were pursued to address shortcomings of the questionnaire as well as to gain deeper insights.

Limitations of the interviews have already been discussed; drawing conclusions from the observations is also problematic. They are few in number, opportunistically sampled and, as snap shots at a single time and in a single place with its particular culture and approach, may be unrepresentative. Moreover, awareness of the presence of the investigator may have brought about a Hawthorne Effect, whereby the act of observing a phenomenon causes it to change.

Despite these limitations, triangulation of research methods has increased the reliability of findings from each approach. Although there are strict caveats about extrapolating findings to the broader population, these research approaches were the best instruments available for attempting to understand the complex phenomena of giving, receiving, and acting upon information about HBP.

6.7 DISCUSSION AND RECOMMENDATIONS

The themes arising from the interviews, survey and observation described above are reviewed below and, on the basis of these, a number of recommendations for Pressure's Off are made.

Many patients and all practitioners acknowledge that information is important both at the time of diagnosis and in response to poorly controlled HBP. Most practitioners were positive about using computers to deliver it, and only a very small minority were negative. **This indicates a favourable climate for introducing Web-based health information.**

A significant proportion of patients and practitioners feel that information needs are not well addressed currently. There is a lack of detailed information, although opinion is divided about how much detail to offer by default. Face-to-face consultation with a health professional – most likely a practice nurse - is currently the most widespread approach; yet even longer face-to-face appointment slots do not provide sufficient time for practitioners to cover the relevant information in detail. Consequently, misunderstandings occur and motivation is prone to wane.

There is a need to reinforce face-to-face health messages and, assuming a continuing lack of time on the part of health professionals, the Web is a promising medium in which to attempt this.

Regarding content, there was a clear consensus that diet and lifestyle information was most important, followed by BP and complications. BP trends and self measurement tended to be demoted. Practitioners tended to attribute poor BP control to lifestyle factors and, to a lesser extent, poor understanding of medication. **Information on lifestyle and medication should be emphasised and presented fully and creatively in Pressure's Off.**

Patients were vague about the information they required, but sensitive to the level of detail they received. Some were frustrated by a lack of detail, and others, by too much. **The information management capabilities of computers have the potential to address the issue of detail. Ways of stratifying information, to allow more or less detail as desired, should be investigated.**

In their interaction with patients, practitioners reported sensitivity to individual circumstances, and perceived educational needs to vary on a number of levels - particularly in response to aptitude, social circumstances, ethnicity, age, psychological state and risk factors. They welcomed the potential to individualise parts of a computerised information package. **Opportunities to individualise Pressure's Off should be taken.**

6.8 SUMMARY

The mixed methodology needs assessment involved triangulating findings from interviews with patients and health professionals, survey data, and observations in a clinic and general practice. The Web emerged as a viable complement to face-to-face counselling from a health professional which addresses their time limitations, and a medium with the potential to address the issue of levels of detail. Medication and lifestyle were highlighted as important and thorny issues in which both professionals and patients were most interested.

Despite the emerging limitations of each data-gathering approach, in combination they formed a robust basis on which to proceed. They also hugely enlightened the researcher, who was consequently well equipped to make decisions about the design and development of the information package, and the evaluation design, discussed in the following chapters.

CHAPTER 7: DESIGN AND DEVELOPMENT OF PRESSURE'S OFF

Based on the needs assessment described in the previous chapter, work on the knowledge base began. The domain was represented as a concept map, a framework from which to hang units of information. Both this framework and the information itself were validated by health professionals, ensuring the reliability of the information and its organisation. As the knowledge base took shape, the interface was developed in response. A usable, accessible interface was a priority for Pressure's Off, a resource for the Web, which could be described as Anglocentric, Western, superficially aesthetic and largely careless of users with impairments. However usable, accessible design is not a precise art since, as revealed in Chapters 5 and 6, very little about the target user can be taken for granted and, moreover, the delivery platforms (hardware, software and sundry Web technologies) are currently undergoing rapid change. For this reason, an overarching design aim was flexibility, in keeping with human-computer interaction (HCI) recommendations.

The concept of user centred design (UCD), the theory upon which the design and development of Pressure's Off are based, is described as background to this chapter. Here are introduced the different variables of a user's circumstances which underpin the UCD process described in the rest of the chapter. Variables which effect individual users have been discussed in Section 5.2; platform variables are discussed below as part of a more technical exploration of usability and accessibility, and ideas about the wider context of use are proposed. These concepts are introduced alongside the ensuing measures to incorporate their principles and implications into the design of the Pressure's Off interface. The chapter continues with a review of several Web sites for people with high blood pressure (HBP) with respect to scope and the quality indicators, outlined in Section 5.4, for information and the Web. This review forms the basis of the knowledge base, described next, including its scope, organisation, and a discussion about designing and producing the different media in which it is expressed. The chapter continues by describing the process by which the knowledge base was validated. The final section describes the design and development of the software (Appendix 4), with respect to interface, structure and media assets.

7.1 USER-CENTRED DESIGN

In response to the drivers of an increasingly sophisticated GUI (graphical user interface), the burgeoning up-take of ICT (information and communication

technology) for commerce and legislation for accessible design, there has been a corresponding trend towards user-centred design (Shneiderman, 2003). UCD is an overarching concept that makes users the focal point in the design of systems for their use. It identifies and schematises a user group's conscious and subconscious needs and expectations, and bases interface decisions on these metrics. In practice, UCD is interpreted in a number of different ways. In the commercial sector, it focuses on increasing sales and improving loyalty by improving a user's, or consumer's, experience (Donoghue, 2002). In teaching and learning communities, the focus is on creating environments conducive to constructing knowledge, and the debate continues about how this should be achieved (for example, Okan, 2003 and Salomon, 1998). The overarching concern of the accessibility lobby is to identify and publicise the needs imposed by a range of disabilities, and to ensure that user interfaces accommodate these needs (W3C, 2004).

UCD originated in a University of San Diego research laboratory, as a response to the so-called "human errors" that undermine even the most logically designed, theoretically sound system (Norman, 1988). It is an acknowledgement of the perennial slippage between designers' intentions, developers' implementations – no matter how rational - and the way end users perceive and interact with a system. Although, in common with many of the concepts covered in this thesis, there is no consensus on a definition for UCD, it is often represented as a user at the centre of a number of concentric circles symbolising aspects of user context from a local to global level (Figure 7.1).
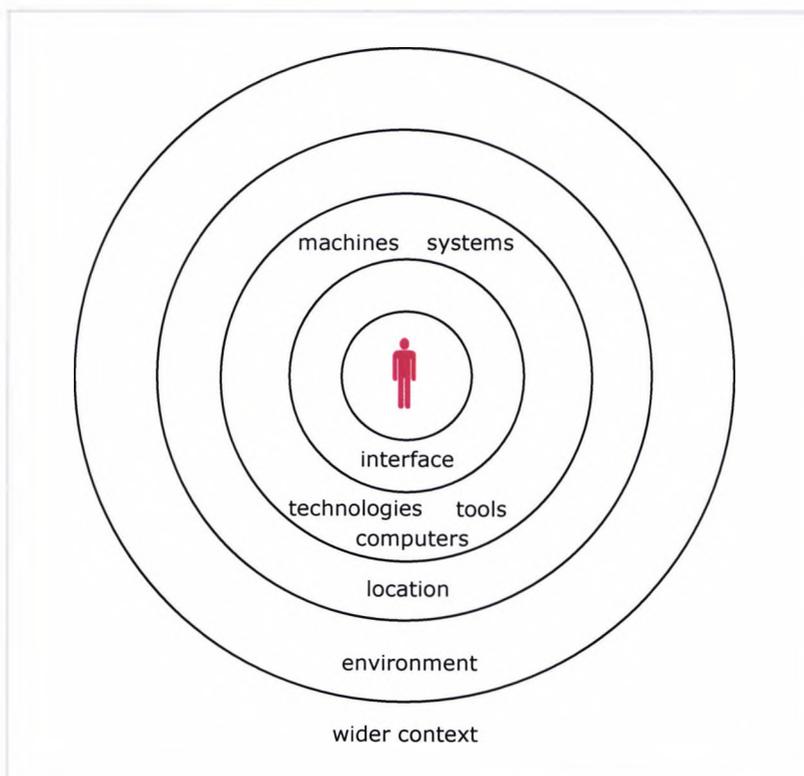
Figure 7.1. Representation of user-centred design

In practice, as Noyes and Baber (1999, pxii) note, UCD is a multidisciplinary activity in which, optimally, a team of professionals represents the interests of all stakeholders:

> "Such an approach requires frequent excursions into a wide spectrum of different research domains, methodologies and theories"

However, for the many lone developers on small-scale projects such as this one, it becomes necessary to take on several crucial roles informed by disciplines as diverse as graphic design, social science, cognitive psychology, and systems science. For this project, operating at the intersection of three volatile subject areas - education, health and technology – both broad and deep insights are required to keep UCD in sight.

An enduring debate among designers is whether UCD should actually involve user representatives at every stage of design. Participatory design can bring accurate information about tasks, opportunities for users to influence design decisions and the potential for increased user acceptance of the final system (Shneiderman, 1998, p109). However, as Nielsen (1993, p11-12) points out, users are not always able to predict how they will interact with putative future systems, and often have divergent opinions on the finer details of an interface. For example, Furnas and colleagues (1987) found that the chance of two people choosing the same name for a hitherto unnamed object is between 7% and 18%, which has implications for designing icons. Moreover, user involvement may lengthen the implementation period, can be costly, can antagonise those who are not involved (Shneiderman, 1998, p110), and, if the sample of participating users is not representative, can endanger application to a wider audience.

The approach adopted in Pressure's Off is described below.

7.1.1 USER-CENTRED DESIGN OF PRESSURE'S OFF

The design of Pressure's Off was conceived and implemented by a multidisciplinary researcher who, ideally, would have involved authentic end users at every stage to maximise user-centredness. However, access to patients was not straightforward, for reasons covered in Chapter 8 on Evaluation. It is often the case that access to a target user group is restricted (Smith and Dunckley, 2002), especially on smaller projects concerning health. It is an interesting observation that raising interest in the early stages of a project is difficult, since it requires a high degree of conceptualisation from those invited to participate. However, the emergence of a concrete product makes it much easier to excite interest and gain input – even in the presence of significant flaws - since people can interact with it, understand its strengths and weaknesses, and offer clear suggestions about how to improve it. Since it was correctly anticipated that arranging access to patients would be

challenging, a decision was made to prioritise the evaluation as the opportunity to seek direct input, and postpone approaching patients with HBP at the interface design stage.

As a contingency, a search was carried out for an available naturally occurring sample. Particularly desirable was an online support group of people with HBP, who would be able to conveniently access a site on which iterations of the interface could be posted, and offer instant feedback. None was identified, and one explanation of this is that people with HBP do not *suffer* with it, nor are there any specific remedies or practices which can resolve the condition. In short, people may not perceive there being much to discuss on the matter. As one patient remarked, "It's not a very sort of 'get together' thing like perhaps breast cancer or something might be in women where they would share experiences." (Interview 15, DIPEx, 2002). After an unsuccessful investigation, the search for a face-to-face group was abandoned on the basis that it would meet too infrequently to offer the immediate and frequent feedback required.

Consequently, a decision was made to evaluate the iterations of the interface opportunistically, an approach previously used by Berridge (2002). One potential confounding factor of this strategy was that members of a HBP group may have been more likely to regard themselves as stakeholders than the eventual evaluators and consequently may have given more attention and effort to the evaluation exercise. However, because of the qualities of HBP discussed in Chapter 3 – its prevalence, the heterogeneity of those who have it, and their tendency to overlook the condition - it is feasible that using a group without HBP had no effect on the design of Pressure's Off. Since usability was explored at this stage rather than responses to content and structure, an assumption is made that the absence of HBP in the individuals who participated during the design stage did not bear significantly on their input.

These UCD issues are discussed further over the course of the chapter.

7.2 REVIEW OF WEB-BASED INFORMATION FOR PEOPLE WITH HBP

There are few online resources for HBP which penetrate beyond a simplistic approach to the subject area. There is however an abundance of overviews and factsheet-type resources; interrogating the Web search engine google.co.uk for `information "high blood pressure"` yields a first screen dominated by links to textual fact sheets such as
http://www.medinfo.co.uk/conditions/hypertension.html,
http://www.netdoctor.co.uk/diseases/facts/hypertension.htm,

http://www.medic8.com/healthguide/articles/hibp.html,
http://www.hbpf.org.uk/highblood/index.cfm
http://www.patient.co.uk/selfhelp/.

Using this search string, a review of existing online HBP resources was carried out. Although the review was not exhaustive (the search generated 1,530,000 results), it represented an authentic approach to searching the Web which would be adopted by a real-world BP information seeker (Fox and Fallows, 2003). In reviewing existing resources for HBP, exclusion criteria eliminated:

- those which were not discrete sites or sub-sections of sites[10]
- those comprising less than 10 pages, since their scope and depth would be compromised
- those not in English, since no translator was available
- those not specifically about HBP – a strategy intended to eliminate fact sheets and general cardiovascular resources, and to focus on well-formed sites.

Surprisingly, sites excluded by these criteria include resources from esteemed sites which, because of their reputation, might be expected to be a first choice for information seekers. HBP sections on NHS Direct, the British Heart Foundation, and BBC Health were all excluded because of the small number of pages.

An overview of the sites identified is given below. This is followed by an outline of the review framework, prior to the review findings themselves.

7.2.1 OVERVIEW OF SITES REVIEWED

The BP Association (UK), http://www.bpassoc.org.uk

The BP Association, launched in October 2000, is based at the internationally renowned centre of excellence for blood pressure, St George's Hospital in Tooting, London. It is funded by the Department of Health as well as educational grants from a large number of pharmaceutical companies and other medical equipment suppliers, and has grown steadily in scope and depth since its inception. The site is mainly verbal with no multimedia or programmic elements found.

Your guide to lowering high blood pressure (National Heart, Lung, and Blood Institute, USA), http://www.nhlbi.nih.gov/hbp/index.html

This resource is one of a series of publications "for patients and the public" from the National Heart, Lung and Blood Institute, part of the USA's national institute of health. No background to the resource is apparent.

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[10] In the case of sub-sections, linked pages which resided outside that section but within the larger site were considered to be part of the resource.

High blood pressure (American Heart Association, USA),
http://www.americanheart.org/presenter.jhtml?identifier=2114

The AHA has an enormous site both in scope and breadth, and the sub–section reviewed below represents only a proportion of the total information on BP distributed throughout the site, not all of which is cross-referenced. No background to the resource is apparent.

Hypertension (Patient Education Institute, USA),
http://www.nlm.nih.gov/medlineplus/tutorials/hypertension.html

The Patient Education Institute has been producing interactive tutorials since 1995. It states that these are unbiased and evidence-based, but sources for the material are unclear, as are sources of funding for the Institute. The BP tutorial, an early multimedia site making full use of sound, is extremely simple, straightforward to use and conceptually easy to grasp.

High blood pressure centre (Mayo Clinic, USA)
http://www.mayoclinic.com/findinformation/conditioncenters/centers.cfm?objectid= 0000C07D-38AE-1B32-82D780C8D77A0000

Mayo Clinic is a charitable foundation with a particularly strong reputation in difficult medical conditions. It operates several clinics and hospitals across the USA where partnerships of doctors take responsibility for each case. Mayo maintains a comprehensive health information site of which the BP section is part. Sources of funding are unclear.

Dr Blood Pressure (USA) http://www.drbloodpressure.com/

A site of unknown origins and funding, its use of English suggests that it is a second language. The paucity of coverage of lifestyle suggests that it exists to channel people to the pages of its "partner" company which sells supplements and monitors.

Blood Pressure (Life Clinic, USA) http://www.lifeclinic.com/

Life clinic was created as an in-depth information source for chronic diseases, with a particular emphasis on HBP. It appears to be funded through sponsorship, advertising, and the sales of its vital signs monitors, which are installed in public places for use by the general public.

7.2.2 FRAMEWORK FOR THE REVIEW

The HBP Web site review framework, developed for this project, incorporates a number of quality indicators outlined previously in Sections 5.4.2 and 5.4.3. These are divided into three categories:

- Scope, Depth and Interest

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- Information Quality Criteria

- Web Quality Criteria.

Scope was marked out of 10, with 1 mark for inclusion of each of the following aspects of HBP, as identified in the knowledge acquisition period for Pressure's Off[11]: cardiovascular system context; definition of BP; measurement; causes and risk factors for HBP; complications; health care; medication; lifestyle; recommended resources; and a miscellaneous point available for other content. Because depth and interest are more qualitative, a second reviewer – a 30 year old man with elevated BP – was used and marks were based on the median. Each of the above 10 aspects of BP was awarded a mark out of 1 for **depth**, a concept which incorporated practicalities and level of detail. These were summed to give a second mark out of 10. The **interest** value of the resource was subjectively rated out of 10.

Information quality criteria draw on the synthesis of recommendations in Section 5.4.2. Without greater insight into the subject area and privileged access to the information provider, it has not been possible, with rigour, to weight the criteria below and so generate a numerical rating. However, it has sometimes been possible to determine when a site either fully meets or fully fails to meet a given criterion – these complete successes or failures are presented in either green font or red font respectively, while those aspects which are harder to evaluate are presented in orange. **Web quality criteria** are similarly assessed, according to the guidelines in Section 5.4.3. It should be emphasised that the *amount* of text in different colours is not an indication of the quality of the site, but is intended to flag good, poor and uncertain quality in different aspects of each site.

The review is arranged in tabular format below (Table 7.1), with a brief summary of performance against each criterion.

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[11] Each aspect has been identified as part of the core knowledge base for HBP; however, they do not cover secondary causes of HBP, BP in women and advanced age, and low BP, among other aspects.

7.2.3 REVIEW FINDINGS

Theme	Rating						
Title of online resource							
Name	BP Association **Information**	National Heart, Lung, and Blood Institute **Your Guide to Lowering BP**	American Heart Association **What is HBP?**	Patient education institute, USA **Interactive Health Tutorial: Hypertension**	Mayo Clinic, USA **HBP Centre**	**Dr Blood Pressure**	Life Clinic, USA **BP**
Scope / Depth and Interest (each out of 10)							
Cardiovascular system background	0.0 / 0.0	0.0 / 0.0	0.0 / 0.0	1.0 / 0.7	0.0 / 0.0	1.0 / 0.7	0.0 / 0.0
Description of BP	1.0 / 0.5	1.0 / 0.6	1.0 / 0.4	1.0 / 0.7	1.0 / 0.5	1.0 / 0.7	1.0 / 0.5
Measurement	1.0 / 0.7	1.0 / 0.6	0.0 / 0.0	1.0 / 0.3	1.0 / 0.8	1.0 / 0.6	1.0 / 0.4
Causes and risk factors for HBP	1.0 / 0.4	1.0 / 0.5	1.0 / 0.3	1.0 / 0.3	1.0 / 0.7	1.0 / 0.5	1.0 / 0.7
Complications	1.0 / 0.3	1.0 / 0.6	1.0 / 0.3	1.0 / 0.8	1.0 / 0.8	1.0 / 0.4	1.0 / 0.5
Health care	1.0 / 0.5	0.0 / 0.0	0.0 / 0.0	1.0 / 0.4	0.0 / 0.0	1.0 / 0.5	1.0 / 0.8
Medication	1.0 / 0.6	1.0 / 0.3	1.0 / 0.6	1.0 / 0.2	1.0 / 0.4	0.0 / 0.0	1.0 / 0.7
Lifestyle	1.0 / 0.7	1.0 / 0.9	1.0 / 0.4	1.0 / 0.4	1.0 / 0.8	1.0 / 0.1	1.0 / 0.8
Recommended resources	1.0 / 1.0	1.0 / 1.0	0.0 / 0.0	0.0 / 0.0	0.0 / 0.0	0.0 / 0.0	1.0 / 1.0
Miscellany	Included sections on low BP, pregnancy, FAQs and travel. 1.0 / 0.9	Strong on practicalities of self-care. Included "real life" accounts, and HBP in women. 1.0 / 0.9	A HBP pledge. Common misconceptions. Section on using hot tubs. Message for African Americans and women. 1.0 / 0.7	None. There is also a very informative tutorial on exercise in this series, but it is not flagged within the resource. 0.0 / 0.0	Questions and answer section. Coping skills. Glossary. Unique concerns ("delicate" topics). 1.0 / 0.9	None. 0.0 / 0.0	Food analyser. Pregnancy. 1.0 / 0.9
Total scope / depth	**9.0 / 5.6**	**8.0 / 6.4**	**6.0 / 2.7**	**8.0 / 3.8**	**6.0 / 4.9**	**7.0 / 3.5**	**9.0 / 5.3**

Interest	8.0	7.0	4.0	7.0	6.0	4.0	6.5
Total / 30	23.6	21.4	12.7	18.8	16.9	14.5	20.8
Information quality criteria							
Name	BP Association Information	National Heart, Lung, and Blood Institute	American Heart Association	Patient education institute, USA	Mayo Clinic, USA	Dr BP	Life Clinic, USA
Accessibility	Not fully accessible; Navigability generally good, but overview not available and structure unclear. Explicitly printable. Some orientation.	Not fully accessible; Navigation omissions. Overview available but does not correspond to the lengthy picklist menu on each page. Some orientation, but disorientating links outside the site necessitate use of browser Back button.	Not fully accessible. Uses JavaScript layers for navigation – accessibility problems. Small font - can't be resized. Overview is apparent for those who can access it. Arbitrary structure of information and presentation of menu. Slow-loading side-bar menu. Very disorganised section.	Resource entirely produced in Flash. Printable version, but as a PDF "blob" which is difficult for screenreaders. Overview and general orientation clear from menu. Within sections linear navigation only. Corresponding audio and textual content. Instructions for use. Web page not clearly titled.	Not fully accessible. Small font - can't be resized. Unexpected, large and complicated pop-up layers from menu. Overview and orientation unclear - have . Inexplicit navigation – easy to stray out of the BP section. Option to "format to print" on each page. Patchy, inconsistent navigation, subtle and disorientating changes in the menu between pages.	Not fully accessible. Menu is in an image map, but fully reproduced in text form below. Resizable text. Exceptional orientation and navigation are clear. Pages clearly titled.	Good accessibility. Orientation sometimes unclear because each page has been given one context which is hardwired into the sidebar, although that page may be linked to from other contexts. Overview present in the sidebar menu. Clear navigation. Printable version of each page. Programmic elements can interfere with menus.
Accuracy	News and research; sources are not always cited – few if any are fully cited, no hierarchy of evidence.	No sources are cited. Some inaccuracies identified.	No sources are cited.	No sources are cited.	Few sources are cited.	Incomplete citation of sources. Riddled with spelling and language errors. Ideosyncratic style and some maverick pieces of information. Confidence in	Not every source is cited. Provides digests of fully referenced research papers.

						accuracy undermined.	
Appropriateness	Clear for whom intended.	Clear for whom intended.	Unclear for whom intended.	Clear for whom intended.	Unclear for whom intended.	Clear for whom intended.	Clear for whom intended.
Attribution and accountability	No individual authors. Several different modes of contacting the BPA are offered. Link to Contact section on each page. Funding unclear.	No individual authors. Several different modes of contacting the NHLBI are offered. Link to Contact section on each page. Funding unclear.	No individual authors. Advertisements not clearly distinguished from content. Funding unclear.	No individual authors named, although named board of directors on a linked site. Links to several organisations given on every page – unclear which is responsible for the resource.	Advertisements clearly distinguished. No individual authors, but link introducing each significant staff member, with photo.	Funding unclear. No background to the organisation. In compliance with the HON code. Advertisements clearly distinguished. Spurious connection to commercial site – nature of relationship is not explicit.	No individual authors named. Funding unclear.
Complementarity	No claims beyond an information resource.	No claims beyond an information resource.	Includes a decision support tool to help patients make treatment decisions – US site.	No claims beyond an information resource.	US site with strong emphasis on patients choosing their own medication. Clear advertising and sponsorship policy.	No claims beyond an information resource.	No claims beyond an information resource.
Completeness	Some missing information; gaps in knowledge sometimes identified.	Some missing information; gaps in knowledge rarely identified.	Some missing information; gaps in knowledge rarely identified.	Simplistic approach; gaps in knowledge rarely identified.	Some missing information; gaps in knowledge rarely identified.	Some missing information; gaps in knowledge rarely identified.	No gaps in knowledge identified.
Confidentiality	No statement.	No statement.	Privacy statement and policy on collection and use of personal information available on each page.	No statement.	Privacy statement and policy on collection and use of personal information available on each page.	No statement.	Privacy policy on collection and use of personal information available on each page.

Continuity	Plenty of cross referencing with other resources.	Stands alone.	Continuity with AHA site – but very disorganised presentation.	Stands alone.	Continuity with Mayo Clinic site – some bleed between the HBP section and the rest of the site.	Stands alone.	Stands alone.
Currency	Full dates for last check and last update on each page.	Undated.	Year of publication on each page.	Undated.	Date of last update on each page.	Date of last update on each page – however the same date for all. This raises suspicion that the information is not being responsively updated.	Undated.
Feedback	Invited on front page and elsewhere.	Invited on front page.	Not actively invited. Contact details are clearly signalled.	Invited on each page.	Not actively invited. Contact details are clearly signalled.	Not actively invited. Contact facility available - no details – just a web form.	Contact details are clearly signalled on each page.
Originality	Originality in the scope of the information, and the authority of its source. Offers some original sections – eg on health insurance.	Some unusually practical features, such as sample exercise programme. Occasional very good use of graphics, some of which are interactive. Quiz.	Some unique interactive features. Textual information is generally unoriginal, but some ideosyncratic forays into eg hot-tub use.	Multimedia resource. Information itself is very simple. Unusually high ratio of illustration to text.	Little originality – Mayo's focus is in its broader reputation as a health provider, and on the scope of the rest of the site.	Little originality of material. Original tone - chatty and questioning.	Plenty of original material. Unusual digests of research papers.
Readability	Clear language, no unexplained jargon.	Clear language, no unexplained jargon.	Clear language, no unexplained jargon.	Basic language, no unexplained jargon.	Clear language, no unexplained jargon.	Exceptionally incorrect and unclear use of language, occasional spelling errors.	Clear language, no unexplained jargon.
User involvement	Refers to user involvement but does not define it.	No reference to user involvement.	No reference to user involvement.	No reference to user involvement.	No reference to user involvement.	No reference to user involvement.	No reference to user involvement.

Validity / reliability	Close work with the British Hypertension Society with access to leading experts in HBP.	Unclear.	Tool giving access to relevant BP research, but separate from other parts of the site. AHA is a reputable organisation.	Unclear.	Unclear.	Unclear. Health on the Net code verification seems inappropriate.	Unclear.
<td colspan="8" align="center">**Web quality criteria**</td>
Name	Blood Pressure Association Information	National Heart, Lung, and Blood Institute	American Heart Association	Patient Education Institute, USA	Mayo Clinic, USA	Dr Blood Pressure	Life Clinic, USA
Function	No failures identified.	No failures identified.	No failures identified.	No failures identified.	No failures identified.	No failures identified.	Some features don't work properly, or interfere with each other. Occasional dead links.
Configurability	Text resizable. Not permitted full configurability with user's own style sheet.	Some text resizable, some not. Not permitted full configurability with user's own style sheet.	None.	Sound can be adjusted, but no other configurability.	None.	Some text resizable, some not. Not permitted full configurability with user's own style sheet.	Text resizable. Not permitted full configurability with user's own style sheet.
Individualisation	None found.	None found.	A BP Profiler tool collects data and generates individualised information about medication or research.	None.	None.	None found.	None found.
Interactivity	None found.	Quiz.	BP profiler tool box responds to input data to generate user-specific	Questions and answers at intervals.	Quizzes on different aspects.	None found.	Food analyser. User's own health record. Risk calculator. User's saved articles.

			information. Quiz with feedback.				
Searchability	Yes, with results clearly presented	None.	Not within the resource, but across the wider AHA site	None.	Not within the resource, but across the wider AHA site	None found.	Yes, but failed to find pages for some basic keywords. Results are difficult for a user to process.
Multimedia	Text and still graphics only.	Text and still graphics only.	Text and still graphics only.	Sound used well. Some simple but effective animations. Many illustrations, some cosmetic – a necessary supplement to keep attention on the simplistic verbal material.	Video, but without metadata. 2 frames per second? Transcript is viewed separately, and stops video when link is clicked.	Text and a few still graphics only.	Text and a few still graphics only.

Table 7.1 Review of existing Web-based health information resources for people with HBP

7.2.4 DISCUSSION

Considering scope and depth, most sites were limited in the core areas identified for the review, although most included other areas, such as HBP in women. The Cardiovascular System Background was particularly prone to neglect, even in those larger sites where it was covered in other sections. One possible reason for this is the urge to mark out boundaries around the HBP subject area – perhaps under the assumption that otherwise users will be overwhelmed with information, or that users do not require this knowledge, or perhaps because it is awkward to extend the knowledge base to such an extent. Medication was another variably represented area, and no site offered information about how each medicine works. Additionally, there was a marked absence of practical skills – such as planning dietary modifications and physical activity - in most of the resources, which dealt fairly superficially with what are probably the most crucial aspects of self-care for HBP. It was interesting to note the cultural differences in some of the US resources which, in the absence of a default national health provision and the presence of variable health insurance premiums, explicitly provided support in selecting medication.

Most notable in terms of information quality is that no site fared consistently well or consistently poorly on the quality indicators – good practice was unevenly distributed within and across sites. This suggests that some criteria are easier to satisfy than others, and there are indications that this is the case for Readability and Function. Correspondingly, several criteria were widely neglected, including Accuracy, Configurability, Individualisability, and User Involvement – most developers find building these attributes into a resource a challenge. Elements of the accessibility were also underachieved – markedly, orientation and resizability of text. Only one site included a full date for both last check and last update. For time-sensitive areas, the date of the next check would also be reassuring. For the sites which include adverts, the imperative to control the layout of a page threatens accessbility.

Considering the quality of the Web implementation, it is poignant that the most ambitious site by far (Life Clinic) in terms of exploiting opportunities for dynamism was the only site which had problems with function – it was markedly less robust than the others and showed unsightly seams where, for example, the Shockwave cardiovascular risk calculator was included. This emphasises the point that successfully embedding multimedia and programmic elements involves considerable knowledge, skill and experience. The Interactive, Individualisable, and Multimedia features present were well-conceived, generally well-executed, and engaging to use. They also highlighted the continuing prevalence of text and static graphics in the resources. Searchability was variable – on one resource no results were found

for a keyword known to be present, and on another the large volume of results and their poor presentation undermined the usefulness of the Search facility.

To summarise, although most of these sites have at least one original and useful aspect, each could be improved. Currently, most sites struggle with the basic ingredients of information quality, and fail to fully and effectively exploit the medium of the Web. Opportunities to use multimedia to demonstrate difficult concepts and procedures have been particularly neglected, most noticeable in the several protracted descriptions of the BP measurement procedure. This suggests that most resource producers are using the Web prosaically as another mass medium for text and pictures, rather than as a unique fusion of media which can shake off the restrictions imposed by print. This is likely to be partly due to a lack of imagination and largely through necessity, since developing multimedia and interactivity is resource-intensive, skills-dependent, and involves significant front-loaded investment. Consequently, there are a number of ambitious ideas which have yet to be developed, including background to the cardiovascular system, local knowledge such as pathways through health care and exercise opportunities, and information about how medicines work. The findings from this review have been incorporated into the development of Pressure's Off, as described in the remaining sections of this chapter.

7.3 KNOWLEDGE BASE DEVELOPMENT

The production of the knowledge base involved activity in four areas. The first defined the scope of the resource and had as its output a concept map (Figure 7.2) an overview which was circulated among health professionals. The second area of activity involved populating this framework with knowledge. This knowledge was produced in verbal form by default, as the most straightforward and cost effective medium at the most explicit level of detail and, therefore, the most readily manipulable into other media as appropriate and as the opportunity arose. The third activity involved sourcing or producing the media assets and programmic elements. The fourth was the validation of Pressure's Off. Each activity is described below, after the following background section.

7.3.1 CONTEXT OF PRESSURE'S OFF

The content and approach of Pressure's Off as a health promotion intervention was conceived on the grounds that HBP is a complex interaction of many diverse factors, a poorly-managed condition about which there is a lack of information. Because of the complexity of the subject area, designers of paper-based information about HBP have been forced to choose between either confronting their readers with a large and daunting tome, or radically simplifying the subject area to

reduce its volume and preserve its impact. As a result, full and relevant information relating to self-care of HBP is rarely unified as one resource (an exception is *Blood Pressure at your Fingertips*, a 352-page book for patients by Julian Tudor Hart), but remains fragmented into its constituent parts – generic resources on diet, alcohol, exercise and smoking. Despite the advent, in the form of the Web, of a powerful tool for organising and navigating large volumes of information, this approach to HBP remains as a hang-over. In acknowledgement of this shortcoming is the growing recommendation for a strategy which looks beyond the condition itself to encompass its causes (Murray et al, 2003; Puska, 1996; WHO, 2003) so that HBP is

> "...seen in the context of more comprehensive approaches to the control of cardiovascular disease that focus on several inter-related risks to health including BP, cholesterol concentration, tobacco use, body-mass index, physical activity, diet, and diabetes" (Murray et al, 2003)

The Web offers exciting prospects for a holistic approach which is neither bulky nor linear.

This project did not have in-built collaboration with health service providers from the start. At the time the knowledge base needed to be shaped, links were not in place and the input of professionals had to be sought opportunistically. Health professionals are legendarily busy, and it is a feature of busy people that they are better placed to dissect and examine an existing idea than to generate new ideas of their own. For this reason, after a period of extensive reading the knowledge base was created within the department, to be validated externally by health professionals. A similar approach was adopted by Wilmes and colleagues (2004) to a health information package on Falls.

Computer-Aided Learning for Hypertensive Patients

Cardiovascular system
- Overview
  - Animation
  - Facts & Figures
- Blood
  - Function
  - Anatomy
  - Hypertension & blood
  - Facts & figures
  - Visual aids
- Blood vessels
  - Function
  - Anatomy
  - Hypertension & vessels
  - Facts & figures
  - Visual aids
- Heart
  - Function
  - Anatomy
  - Hypertension & heart
  - Facts & figures
  - Visual aids
- Your risk
  - Overview
  - Hypertension
  - Weight
  - Blood lipids
  - Salt (sodium)
  - Other conditions
  - Smoking
  - Alcohol
  - Exercise
  - Family history
  - Ethnicity
  - Rick calculation

Hypertension
- Overview
  - Spectrum
  - Prevalence
- Definition
  - Definition
  - Animation
- Causes
  - See Your risk
  - Secondary causes
- Symptoms
  - none
- Other medical conditions
  - Diabetes
  - Pregnancy
  - Heart problems
  - Previous CV event
  - Circulation problems
  - Kidney problems
  - Psycological problems
  - Other problems

At the doctor's
- Overview
- Diagnosis
  - Overview
  - Measurement
  - Lab test
  - Observation
- Prescribing
  - Overview
  - Considerations
    - Other conditions
    - Other medication
    - Side effects
    - Your wishes
  - Guidelines
- Long term
  - Maintaining control of BP
    - Measurement
    - Lifestyle
  - Chronic disease

Complications
- Heart attack
- Stroke
- Heart failure
- Angina
- Embolism
- Thrombosis
- TIA
- CAD
- LVH
- Heart disease
- Organ damage

Medication & Lifestyle
- Medication
  - Overview
  - Intro to pharmacology
  - Drug groups
    - Diuretics
    - Beta blockers
    - ACE Inhibitors
    - Calcium ch blockers
    - Vasodilators
    - Ang II rec antags
    - Centrally acting
    - Alpha blockers
  - Side effects
  - Taking medication long term
- Lifestyle
  - Overview
  - Weight
  - Healthy eating
  - Exercise
  - Smoking
  - Alcohol
  - Recreational drugs
  - Stress

Reference
- Glossary
- Recommended reading
- Support groups
- CAL references
- Tests & games
- Feedback

Figure 7.2 Scope of Pressure's Off

7.3.2 SCOPE

As discussed, HBP is an elusive concept. The simultaneous miscellany and interrelatedness of the elements of self-care has already been emphasised. One of the difficulties for information providers is that there is no universal hierarchy of diet and lifestyle changes for HBP – there is scant evidence to support categorically prioritising any of, say, saturated fat intake, fruit and vegetable intake, or exercise over each other. Therefore it is not appropriate or supportable to advise a patient "Exercise is top of the list for HBP" or "The most important thing is always saturated fat intake, followed by the fruit and vegetables".

Maybe it is the stubbornly comprehensive nature of the condition which has led to such paucity in the online provision of information about HBP - a paucity which does not reside in the *number* of resources, but in their scope and depth. The review of resources which begins this chapter marks a distinct lack of integration of the diverse factors which are needed for insight into cardiovascular health. It also finds a widespread lack of context; an absence of cardiovascular background, an interstitium by which to lend meaning and impact to what is otherwise a dislocated series of facts. Therefore underpinning the creation of the knowledge base for Pressure's Off was the motivation to map the subject area for patients in a way which simultaneously does justice to the scope of the domain and delineates its boundaries.

On the basis of the knowledge acquisition detailed in Chapter 3 and the needs-assessment research outlined in Chapter 6, the domain was mapped and presented as shown in Figure 7.2. This concept map was posted on a Web page, the URL of which was posted to the GP-UK email discussion list, a lively public group background to which can be found at http://www.jiscmail.ac.uk/lists/GP-UK.html (where the original and follow-up emails soliciting feedback can also be found). A Web form was created to collect feedback as responses to three questions covering scope, depth and structure. After one follow-up, a total of 12 health professionals from discussion group accessed the Web site. Significantly, there was little consensus in the changes proposed. Some omissions were identified but, reassuringly, no respondent identified a wrong inclusion. Although there were

concerns about the high level of detail proposed, a case for including this amount of information in a medium conducive to information management has already been made in Section 5.5. On the basis of these responses, and in the knowledge that the scope could be extended, a decision was made to pursue the next stage of knowledge base creation while opportunistically exploring the issues raised by GP-UK. Over the development period, the concept map was viewed by two health professional researchers on the ASCOT (Anglo-Scandinavian Cardiac Outcome Trial) study, the group of health professionals who validated the knowledge in Pressure's Off, a Hypertension Nurse Specialist from the Blood Pressure Association, and members of the hypertension clinic team. No problems with it were identified over this period.

7.3.3 PRODUCING THE KNOWLEDGE

Having defined the scope of Pressure's Off, work to populate this framework began. The content was produced according to guidelines from the Plain English Campaign (The Plain English Campaign, undated). Later, validators also gave feedback on phrasing.

There were several challenges, anticipated in the needs assessment. One was how to present information which accommodated motivated, educated users as well as those who preferred short advice, or were unwilling or unable to understand complex information. One option was to stratify information so that a concise version could then be supplemented with incrementally more detailed content. This was not fully achieved in Pressure's Off, requiring greater subject expert involvement in producing and organising the knowledge base than was available, and additional needs assessment. As outlined in the next chapter, this management of information was flagged by patients. For more on this necessary step of stratification, see the section on Future Work in Chapter 10.

Another related stratification issue, if Pressure's Off were to be used as both a reference and a more detailed information resource, was the need to avoid repeating definitions and similar phrases. One approach, adopted early, was the use of layers activated by a mouse-over to give glossary entries. This raised another dilemma – the activation of the mouseover demands a certain amount of manual dexterity, a potential accessibility problem. However the alternative way to obtain the material, on clicking, would demand that the

user clicked again to close it – frustrating, slow, and, if neglected, leading to a large number of open windows or layers. Since the motivation of providing this function was convenience, the click-minimising mouseover method was chosen for the interim while a fully accessible equivalent was sought, with glossary entries signalled by bold green text. This dilemma is typical of many others which occurred during the development of Pressure's Off, and indeed of software in general.

The knowledge production period generated over 120 separate files of content, roughly corresponding to nodes of the concept map.

7.3.4 PRODUCING THE ASSETS

It has already been pointed out that disseminating textual material over the Web has a number of important advantages over print, including scope, updateability and, if well designed, enhanced accessibility for some groups. However, the power of the Web lies in the opportunity to choose, from several available media and different degrees of interactivity, a way of presenting content which is best suited to the information and its purpose.

Several different strands of research in this area are united as a cognitive theory of multimedia learning, based on the idea that humans have separate visual and verbal processing systems and that these, as discussed in the section on cognition (5.2.2.8) are limited. When instructional messages are presented in graphical form, constructivist theory holds that a user selects features to form a visual mental model. Correspondingly, verbal information is incorporated into a verbal model. These models are then integrated with each other and with salient parts of the user's prior knowledge. Multimedia can prime these processes, and does so best when designed according to the following principles, based on a review of studies conducted by Mayer (1999). Firstly, this emphasises that multimedia have advantages over verbal material alone, and tend to guide learners towards appropriate mental models. Better transfer of facts into applicable knowledge is achieved through placing words and pictures close to each other on a screen – the **spatial contiguity** principle. To minimise working memory demand, the **temporal contiguity** principle suggests that corresponding verbal and illustrative material be presented simultaneously rather than successively and, according to the **visual split attention** principle, that verbal material should be presented as

narration rather than text. The **auditory split attention** principle cuts out ambient sounds from the audio material to assist the connection between words and illustrations. According to the **individual differences** principle, the effects of the above four principles are dependent on user prior knowledge and spatial ability. Multimedia may not be required for, or may even interfere with, messages intended for users with high prior knowledge Appropriate connections are more likely to be made where **chunking** is employed to break content into short units which do not overload working memory. This rationale also informs the **coherence** principle, which eliminates extraneous material from these units.

Developing the entire knowledge base in multimedia was beyond the scope of this project, taking many more hours of development time than were available. Therefore several key areas of Pressure's Off were selected for development according to the principles above. Their selection was in keeping with the principle of reusability, a granular approach to learning design whereby materials are disaggregated into stand-alone units which can be repurposed for different contexts (Duncan, 2003). Specific reasons for their selection are described below. Unless mentioned, no similar material was identified elsewhere at the time.

7.3.4.1 Interactive introduction to the heart

Cardiovascular system > The heart > Anatomy of the heart

The descriptions of the heart and the passage of blood through it are long-winded and demanding, and so benefit greatly from translation from verbal format into an interactive animation. Several interactive hearts are available on the Web, but the Pressure's Off version (Figure 7.3) unites a number of useful features. It demonstrates the heart's position in the body and connection to other organs, highlights the existence of a blood supply to the heart muscle, allows users to click on an area of the heart for an overview of that area, distinguishes the functions of the left and right heart with graphic effects, and animates the passage of blood through the chambers alongside a verbal description.

7.3.4.2 Calculate your Body Mass Index

Cardiovascular system > Risk > Calculate your BMI

This allows users to enter their height and weight in Imperial or Metric units, to convert them if they are curious, to generate a Body Mass Index (BMI), to read an analysis of the value, and to view their position in a chart showing the distribution of BMI. It permits users to experiment with different weight scenarios and so formulate goals.

7.3.4.3 What is blood pressure?

Blood pressure > High blood pressure > Overview of high blood pressure > What is blood pressure?

BP is a difficult concept to grasp, and it is important to make this asymptomatic condition, theoretical in so many patients' minds, as concrete as possible. This click-through animation shows that a certain amount of pressure in the arteries is required for blood to flow at all, demonstrates the elasticity of arteries, and emphasises that elevated pressure strains the artery walls.

7.3.4.4 Videos of the measurement process

Your healthcare > Measurement > Video

These videos were created early in the project to inform patients and possible student health professionals about the measurement process, which can be affected by the patient's state of mind, exertion prior to measurement, fullness of their bladder, clothing, position of their arm in relation to their heart and other factors. Verbal explanation is best accompanied by a demonstration. Video with voice-over covers preparation, fitting the cuff, checking the manometer, inflating the cuff, listening for the return of blood, and taking the measurement. Although the EU moved to outlaw mercury in 2000, there are no plans to restrict its use in the UK, and legacy mercury sphygmomanometers will be used for some years to come (Medicines and Healthcare Products Regulatory Agency, 2003). The first two videos covering preparation and fitting the cuff are also relevant for automatic monitors.

7.3.4.5 Overview of the consequences of high blood pressure

Consequences > Overview of the consequences of HBP

The development of arterial plaques is difficult to grasp and tedious to explain, but is nevertheless important because it highlights the interaction of HBP and blood lipids. As in the case of "What is BP", it is valuable to make the asymptomatic "furred up arteries" concrete and detailed. This click-through

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animation shows a labelled cross section of an artery and illustrates how damage from HBP allows blood lipids to find their way through its inner lining, damaging the layer of muscle beneath and triggering the healing process which stiffens the artery - atherosclerosis. It is somewhat simplified from its original version, on the explicit and substantiated advice of one of the validators.

7.3.4.6 Stroke

Consequences > Stroke

Stroke is a sub-section of the section on Consequences. Most people have heard of stroke, but do not have an understanding of the complications of HBP which cause it. As a major cause of death and disability it deserves attention, and an involved verbal explanation of the pathology of stroke can be neatly avoided with animation. This click-through animation shows how strokes can happen outside the brain through the development of clots on the artery walls (thrombosis) supplying it, or inside the brain when breakaway fragments of plaque lodge in its vessels. It shows how damage to the brain is localised to the parts "downstream" of the blockage.

7.3.4.7 Search for my medication

Medication & lifestyle > Medication > Find your medicine's drug group

In order to understand the action of a drug, it is necessary to know what drug group it is in. This search facility matches all BP lowering medication available in the UK with its drug group, and promotes strategic use of the section on how different drug groups work. The Blood Pressure Association was enthusiastic about this facility when it was demonstrated.

7.3.4.8 Food labelling

Medication & Lifestyle > Lifestyle > Healthy eating > Food labelling

Information is only one ingredient of the behaviour change which is ultimately needed for a healthier diet – however, as discussed in Section 4.5, it is a crucial one. Many people have only a basic awareness of the nutritional value of foods. Reading food labels is not intuitive but without this skill, applied in combination with knowledge about recommended daily intakes of a range of nutrients, it is impossible to make informed choices when shopping for food. This animated click-through game (Figure 7.4) introduces a scenario where a

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woman is shopping for dinner at the supermarket after work, keeping in mind recent advice from her practice nurse. The user compares four different pasta sauces by interacting with their nutritional value information labels. Clicking on different areas of each label gives detailed information about that nutrient, including its recommended daily intake and an analysis of its presence in that particular sauce. After an opportunity to compare all the options, the user is invited to select the healthiest option, and feedback is given on right and wrong choices.

7.3.4.9 Nutritional value

Medication & Lifestyle > Lifestyle > Healthy eating > Food labelling

Continuing the nutritional theme which is so important to HBP, this animated click-through game highlights the issue of hidden salt, fat and calories in foods by manipulating users' expectations. Users are asked to compare two items from a group of common snack foods in terms of fats, carbohydrates, fibre, energy and sodium. After answering questions about which they believe is higher in a given nutrient, feedback is given.

7.3.4.10 Blood pressure quiz

Find out more > Test yourself > Self-testing BP quiz

The immediacy of self-testing on the Web is popular with users and, where feedback is given, very useful. This ten-item multiple choice quiz was designed according to guidelines, with a simple stem in the positive mood and each distracter indistinguishable in form and content from the correct answer. The quiz tallies a user's score and gives feedback after each question. A printable summary is available at the end of the quiz.

The areas outlined above, with the exception of the videos, which were substituted for another section on understanding BP readings, were used during evaluation, as described in the following chapter.
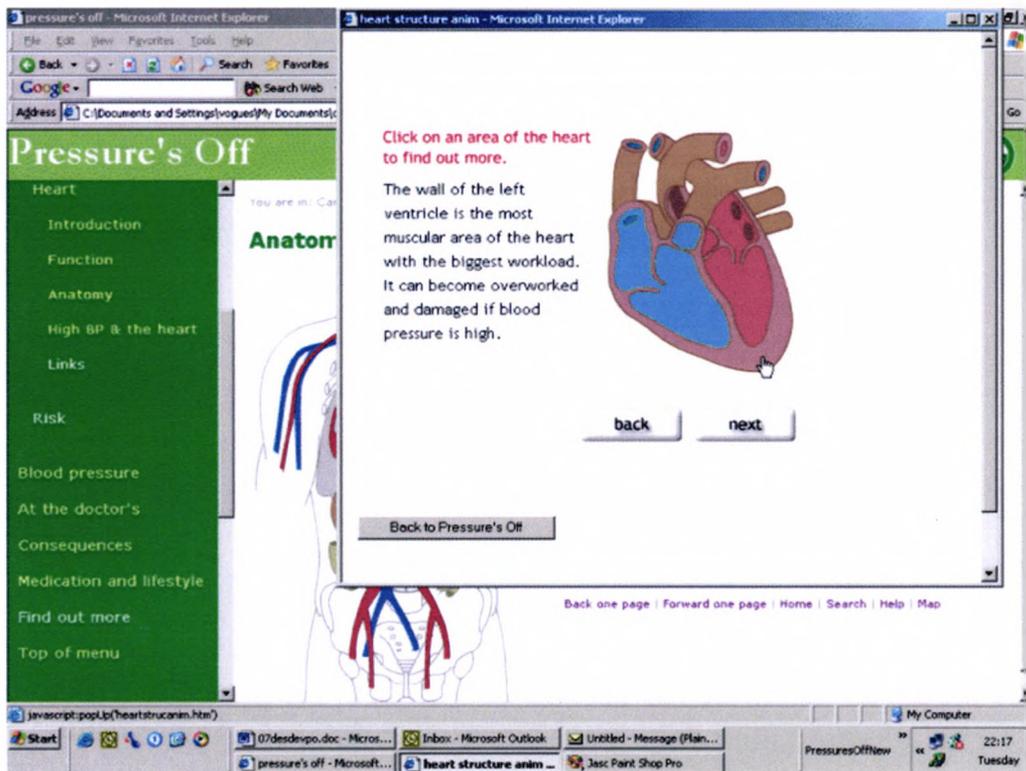
Figure 7.3. Animated introduction to the heart
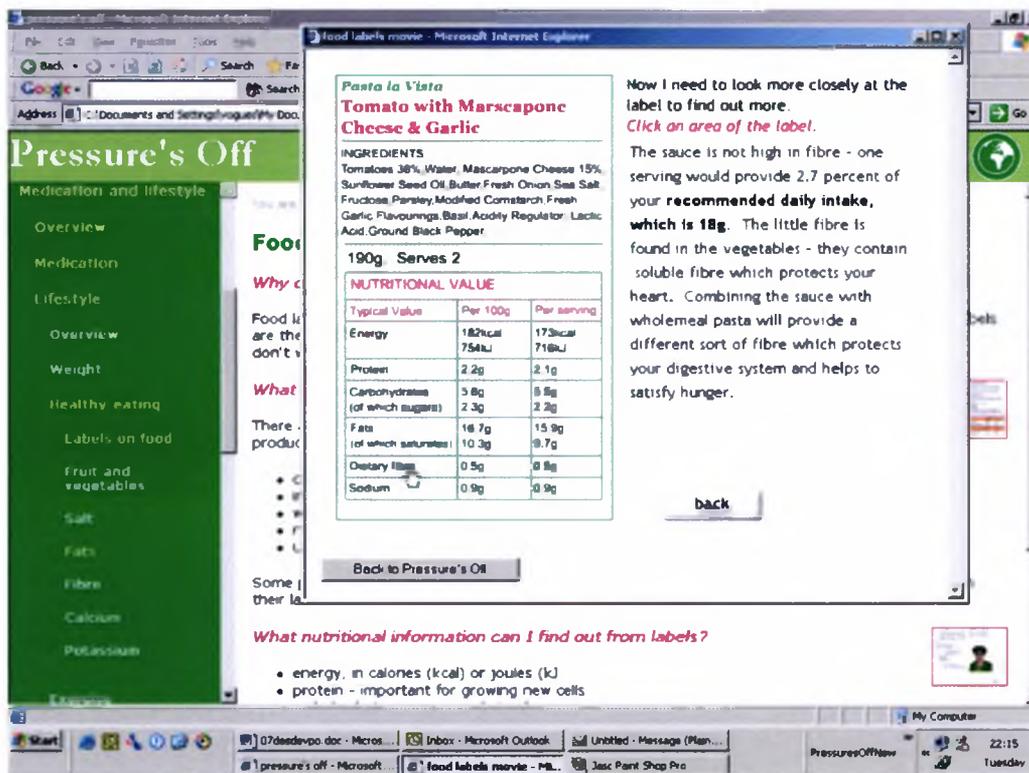
Figure 7.4. Food labeling game

7.4 CONTENT VALIDATION

In order to assure the reliability of content, a group of five practising health professionals carried out content validation. One validator was a Hypertension Nurse Specialist (HNS) at the hypertension clinic, and the other four were general practitioners who were known to the department. One had a senior academic role at Queen Mary (University of London) and is well-known for his work on HBP, a second worked in the aforementioned Camden and Islington practice, and the remaining two, based in Wandsworth and Launceton respectively, were enrolled on the MSc Medical Informatics course run by the Centre for Measurement and Information in Medicine. Recruiting the validators involved preparing the materials to be processed, contacting each validator individually by phone, email or in person, explaining the aim of the exercise, and giving clear indication of what would be involved.

As Berridge (2002) and Wilmes and colleagues (2004, p21) also found, participants (who volunteered their time) were unable to validate every section and moreover, in the absence of remuneration, their ease of inspecting the material proved crucial to their decision to undertake the validation exercise and their ability to carry it out. It was therefore a main priority to make the process as straightforward and unobjectionable as possible. Since the GPs opted to go through the content unaccompanied, allowing them flexibility in fitting the activity with their other commitments, a way to facilitate clear annotation of the content, impossible on the computer-based version, was required. Consequently, as well as the Web incarnation, Pressure's Off was divided into 5 top-level sections, each of which was extracted into 5 corresponding word-processed documents totalling 157 pages of text and images. Printed versions, on offer, had the added advantage of being portable and would not tie validators to a computer or require Internet access. However, validators were encouraged, if possible, to annotate the digital version using Microsoft Word's Track Changes tool, for which instructions were supplied in the covering letter, since this would facilitate amendments. The pack sent to each validator included:

- A covering letter

- The printed document(s), if requested, including table of contents, with 1.5 line spacing, line numbers, and a large right hand margin for free text feedback comments
- A CD-ROM containing Pressure's Off and the validation document file
- A printed concept map of Pressure's Off, for context.

Within the validation document, each section included:

- A breadcrumb trail for context – eg "You are in: The cardiovascular system > The heart > Anatomy
- Each section's title
- Content, including all text and static material such as images and tables
- For each section, three six-point, continuous, semantic differential scales, which had the corollary of indicating that a section had in fact been checked, as well as collecting qualitative feedback.

Validators were asked to circle an unnumbered interval on each scale, as shown in Figure 7.5 to demonstrate their confidence in the accuracy, completeness and appropriateness (Berridge, 2002) of the content, and were asked to support these with full comments.
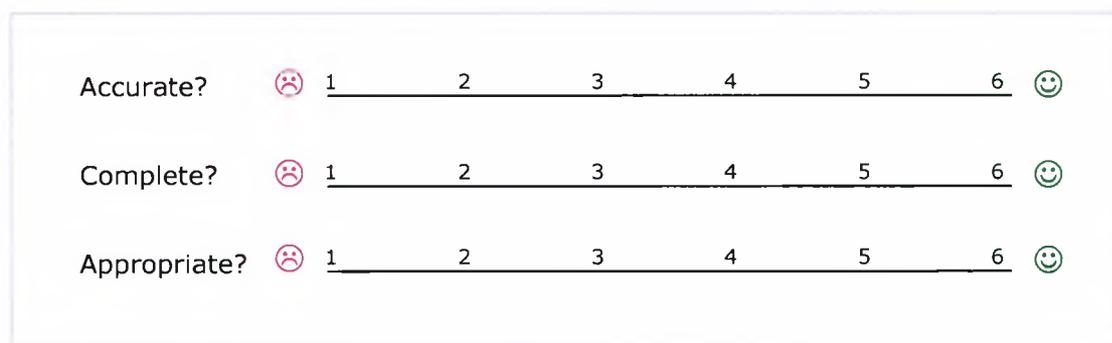
Figure 7.5. Sample scales for content validation

In practice, the four GP validators selected sections for validation on the basis of their expertise or interest. Three validators were able to carry out their activities by annotating the digital version, while one preferred to work on paper.

It emerged early in the process that that the validation approach was limited by the number of validators, recruited with difficulty and too few to generate the consensus needed to be fully confident about the validity of the resource.

The section on the Cardiovascular System and Complications were inspected by one validator, Blood Pressure, Medication and Lifestyle and At the Doctor's by two.

While maximum effort had been made to minimise the burden on the validators, all but one (the HNS, who validated all of the content) failed to inspect more than one section, citing lack of time as their reason. In the absence of the developer who would carry out the changes, comments were written or typed, a further limitation on input which had two negative effects. It led to difficulty explaining the responses to the scales – especially in a small number of instances where they were inconsistent with the comments - and it led to ambiguity about tracts of text which were not annotated - absence of comment could not be considered a positive signal of satisfaction with the content. However there was a third, positive, effect of this approach - a substantial volume of content, in the form of precise verbatim changes, was collected which surpassed what could have been achieved face-to-face. All validators demonstrated their interest with full and thoughtful responses within their section.

Because of the validation limitations outlined above, a content management strategy was devised to keep a record of the proposed changes and resulting actions. All comments were transcribed or copied into a document and labelled with the section to which they pertained. Proposed changes were included, noted as accepted or queried, along with scores from the scales. All input was attributed to its validator, who was anonymised and assigned a unique identifier (V01 – 05). A representative sample of the comments is below, with context (Figure 7.6).

There is evidence that [brand of margarine] is an effective way to lower your cholesterol – though it isn't the only way. "Some now refute this evidence. This is also advertising a particular brand, therefore we have legal issues if someone uses it and has problems."
(V03; BP > ...& cholesterol > High cholesterol and cholesterol lowering products)

"I wonder whether the info about the invasive method is of any value to the patient. It might even frighten them."
(V01; At the doctor's > Measurement > History of measurement)

"It is important to recognise that the need for medication does not in any way represent a failure on behalf of the patient. Some patients are left feeling that they have "failed to try hard enough" with the diet and lifestyle options as a result of which medication is needed. I always try to stress the fact that there is a big genetic component in hypertension which diet and lifestyle cannot address – thus not everyone begins from the same starting point. Similarly – medication is not an alternative to diet and lifestyle modification, which still needs to happen"
(V02; At the doctor's > Decisions about medication)

"Put CXR and ECG at the top of the list and echo third down – angiography, MRI etc are specialist investigations – more likely to be used if evidence of angina or heart failure exist rather than in isolated hypertension. If I read about (and expected to be referred for) angiography I would not go back to my GP."
(V02; At the doctor's > Tests > Tests on the heart

..diuretics mainly work by reducing the amount of blood in the body "Frightening!"
(V04; Medication & lifestyle > Medication > Introduction to medicine for HBP)

"...good idea to look up own drug"
(V04; Medication & lifestyle > Medication > Find out which group your medication belongs to)

Figure 7.6. Responses from validators

The consultant pharmacologist from the hypertension clinic also viewed the site, and the clinic's HNS took responsibility for a systematic inspection of the entire site prior to hosting the evaluation. She did not complete the scales but made extensive notes, and she and the consultant proposed changes which were discussed in a very productive morning's meeting with the developer.

Semantic differential scale scores for the three sections for which they were given are shown below in Tables 7.7, 7.8 and 7.9.

Aspect/Score	☹ ← satisfaction → ☺						Other	Total sections	Average
	1	2	3	4	5	6			
Accurate	-	-	-	1	20	2	0	23	5.0
Compete	-	-	-	7	12	4	0	23	4.9
Appropriate	-	2	1	3	8	9	0	23	4.9

Table 7.2 Scores for the BP section (V03)

Aspect/Score	☹ ← satisfaction → ☺						Other	Total sections	Average
	1	2	3	4	5	6			
Accurate	-	-	-	-	1	10	-	11	5.9
Compete	-	-	-	1	3	6	1	11	5.5
Appropriate	-	-	-	-	3	7	1	11	5.7

Table 7.3 Scores for the At the Doctor's section (V02)

Aspect/Score	☹ ← satisfaction → ☺						Other	Total sections	Average score
	1	2	3	4	5	6			
Accurate	-	1	4	5	3	1	-	14	3.6
Compete	-	1	2	5	6	-	-	14	4.1
Appropriate	-	1	-	3	9	1	-	14	4.6

Table 7.4 Scores for the Medication and Lifestyle section (V04)

Caution is needed in extrapolating from these scores, the products of three different validators. However, considering the distribution of scores within a section, the assumption can be made that the lower scores are more significant than the higher ones because they are likely to indicate concrete examples of inaccuracies, omissions or unsuitability, and can be substantiated. From this perspective, despite the lack of numbers to generate a consensus, there is still good reason to prioritise the accuracy and completeness of the Medication and Lifestyle section, which achieved notably lower scores. At the same time, the generally high averages are an encouraging indication that the knowledge base is close to achieving accuracy, completeness and appropriateness.

At the end of this phase of knowledge base development, the scope, structure and content of Pressure's Off had been conceived, shaped and validated. Meanwhile, work was ongoing to create the medium by which it would be delivered - this system design and development is discussed in the remainder of the chapter.

7.5 SYSTEM DESIGN AND DEVELOPMENT

Including users in the design of a package involves avoiding a number of pitfalls - users often lack the ability to imagine the ramifications of design decisions or comment on technical design specifications (Preece et al, 1994, p537). For these reasons it is good practice to base full-scale implementation efforts on the findings from evaluations of experimental designs. Known as prototypes, these are developed as cheap, quick samples of the features and functions of the proposed package to be tested with users, and are intended to be changed or discarded. In identifying this sample, Nielsen (1993, p95) identifies two dimensions of prototyping (Figure 7.7). Vertical prototyping is intended to explore functionality and can be tested in realistic circumstances. A vertical prototype demonstrates a limited number of features, but shows the depth of the resource. Developers gain insight into operation sequences – the way users would interact with the package for a given task in the real world. Building a vertical prototype is relatively labour intensive, and therefore it may be created as an evolutionary or incremental prototype which bridges the gap between specification and implementation (Preece et al, 1994, p541), intended to be built on rather than discarded. A horizontal prototype is intended to explore the features of a package, and involves creating a simulated interface which does not support the performance of real tasks but affords insight into the adequacy of the scope, look, and feel of a package. Because they are relatively quick and easy to produce, a number can be produced easily and discarded after evaluation. A prototype developed at the intersection of horizontal and vertical dimensions is known as a scenario. Scenarios involve paring down both functionality and features, and restrict their users to a single interaction with the material along a planned pathway. They are useful for anticipating how users will interact with a given part of the package, as well as gathering responses to the interface.
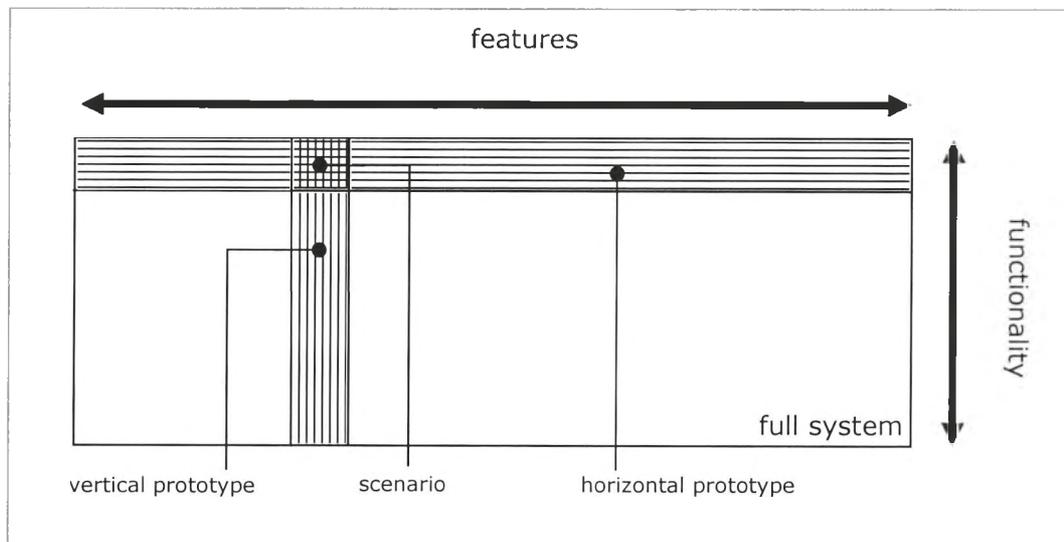
Figure 7.7. Two dimensions of prototyping. (After: Nielsen, 1993, pp95)

The horizontal prototyping approach was adopted for Pressure's Off, in the knowledge that its use would be voluntary by self-directed adult users rather than, say, a standard day-to-day activity at work requiring specific tasks to be carried out. Therefore look, feel and scope would be important to the potential user and a crucial factor in the uptake of the package. It was also important to prototype rapidly so that information on requirements and the adequacy of possible designs could be collected.

As mentioned earlier in this chapter, Web design often involves a trade-off between designer control and accessibility/usability. In their discussion of web design on limited resources, Straub and Gaddy (2003) distinguish between compensatory and non-compensatory decision-making. Compensatory decision making is a rational process by which all information on the alternative choices is systematically collected and a decision is made on the basis of an analysis of the deficits and benefits of each. This approach is time-intensive and complicated, and in practice many decisions are based on incomplete information or imperfect insight into the relative importance of attributes – a non-compensatory decision-making strategy known as 'satisficing' where the first adequate option to emerge is selected. The design of Pressure's Off has attempted to avoid satisficing, evident in the iterative design of the interface described below.

The Pressure's Off interface was developed to avoid challenging its users, and was not intended as a departure from existing conventions. The principle of

platform consistency holds that prior knowledge gained from other applications should equip a user in interacting with a given application. Pressure's Off draws on the established conventions of the Web to create an environment which existing Web users find familiar territory, and effort is made to orientate novice users using a number of strategies. Nevertheless, within these conventions many choices exist, each of which has its advantages and drawbacks. The evolution of the prototypes into a working interface is described below with explicit reference to the theoretical underpinnings which informed the design.

7.5.1 INTERFACE EVALUATION

The interface versions outlined below evolved through ongoing formative evaluation, required to guard against the assumptions and tacit knowledge of the developer leading to the creation of an esoteric, unusable system. Usability testing theory holds that users of different levels of expertise can give different insights about an interface. Therefore two categories of evaluator were actively sought. The interface was opportunistically and informally peer-reviewed by members of the department, competent or expert computer users with prior expectations arising from their insight into Web conventions, who could be expected to challenge the interface. However, as experts, these individuals might make intrepid inferences and cognitive leaps which would fail to register basic inadequacies. Therefore input from novice computer users was also solicited – these individuals might not fully exploit an interface but would register the shortcomings that could confront a Web beginner.

The evolution of the interface is described below with reference to three versions, culminating in the current, working version.

7.5.2 FIRST PROTOTYPE

A rapid prototype was developed, pictured in Figure 7.8.

Page title   Page heading   Filing metaphor for orientation and navigation   Fixed width, tabular layout

Fixed font size   Navigation controls: previous page; section menu; next page; search; index; front page; help; close.   Option for contextualised information on mouseover
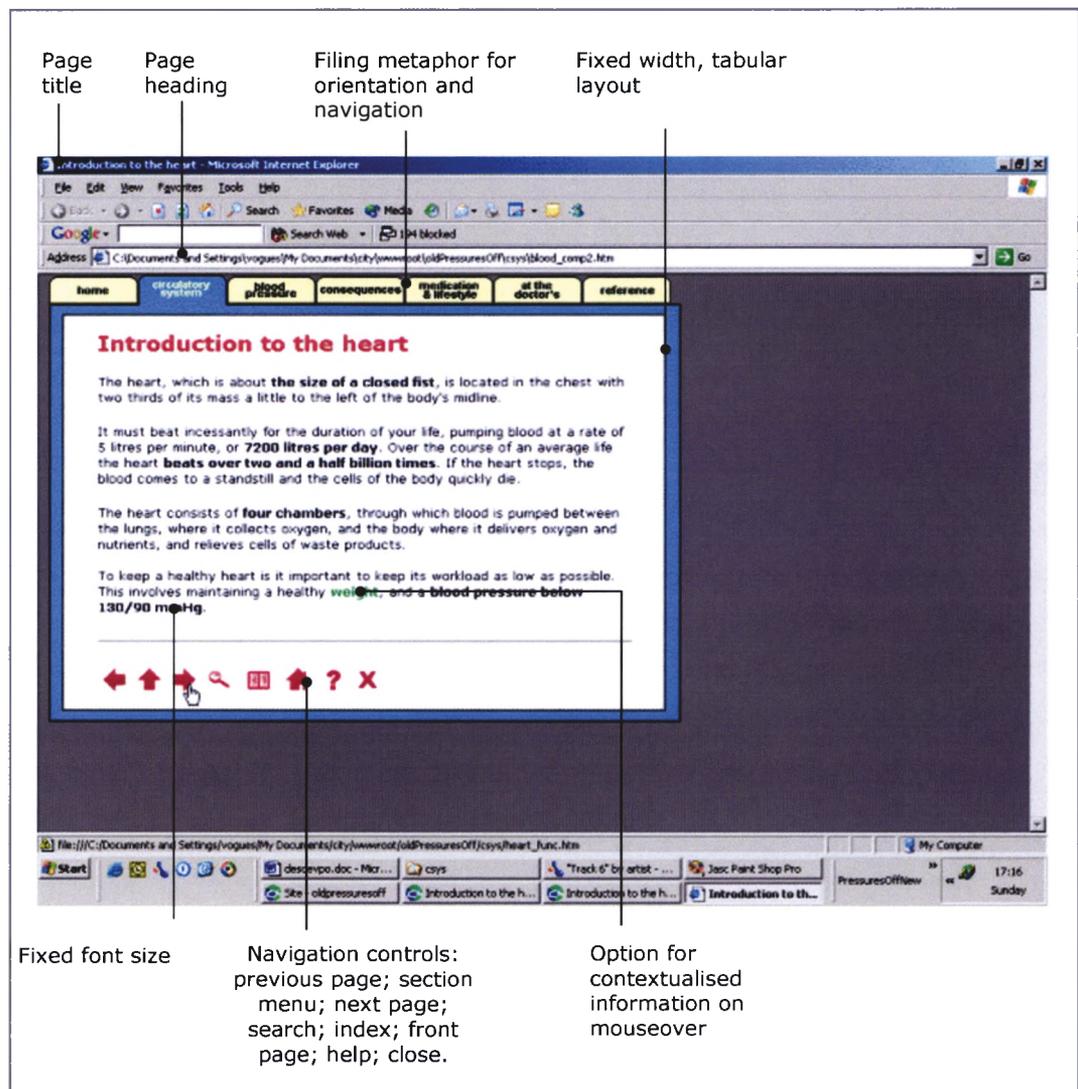
Figure 7.8. First version of Pressure's Off interface

The recent evolution of cascading style sheets (CSS) for layout (see the source code of http://www.e-envoy.gov.uk/ or http://www.smd.qmul.ac.uk/edudirect/epbl, for example) has not is now rivaling tables for screen layout on the Web. However, tables remain widespread on the Web (see the source code of http://news.bbc.co.uk/ and http://www.amazon.co.uk, for example), and Pressure's Off content had its origins inside a table with an absolute width to fit a 640x480 resolution. This width had the advantage of accommodating smaller screen sizes and lower resolutions, and catering for users' preference for smaller line lengths when reading from a screen (Dyson and Kipping, 1998; Youngman and Scharff, 1998). It had several disadvantages – namely subverting the purpose of

tables (ie to represent tabular data), presenting users with higher resolutions with a lot of empty screen, and preventing users who had invested in larger screens from taking advantage of them.

The font size was also fixed absolutely at 12pt. An advantage was that the lines were fixed at an optimally readable length (Dix et al, 1998, p22), and therefore it would be possible to predict the appearance of content above the fold (ie what is visible on the screen without scrolling) and design accordingly for, especially, novice users who often fail to scroll. Disadvantages included the inability to resize text, especially in older browsers, which might make the site illegible for some users.

To provide orientation and navigation, the top level sections of Pressure's Off were represented along the top of the screen, employing the well-used metaphor of a paper filing system which would resonate with the majority of users (Cates, 2002). This involved creating a set of illustrated "file dividers" which were saved as images and presented as links. An advantage of this strategy was that it presented a consistent representation of the available sections within Pressure's Off, with a clear message that it was possible toggle easily between each. Another advantage was basic orientation, communicated by the change in size and colour of a tab when a user would download a page from that section. Disadvantages concerned accessibility. The labels on each tab were necessarily small[12] because the tabs were images of a fixed size – this would pose problems for partially sighted users who were not routinely using screen readers. Additionally, these tabs were of limited value since they only offered top level access and orientation; further sub-menus or index pages would be required which would depart from the filing metaphor.

Along the bottom of each page are the navigation controls, including arrows for the Previous and Next pages, an arrow to the Section Menu, Search, Index, Home, Help and Close. One advantage of this approach is the consistent presentation of the navigation controls. Another is the use of icons, graphical metaphors which, if well designed, can be more easily processed by users than text (Cates, 2002). A third advantage was the Previous and Next facility,

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[12] Stylesheets have solved this problem in the intervening time since the first prototype was designed.

which would permit linear progress through the content, a way of scaffolding users who were field dependent or had little prior knowledge of the subject domain. One disadvantage was the questionable aptness of the choices of metaphor (such as the Up arrow for the Section Menu, or the open book for the Index). Ill chosen metaphors can confound the conceptualisation and, therefore, usability of a Web site (Hamilton et al, 2000). Another disadvantage was the potential for confusion with the Previous and Next buttons – the distinction between these hard-coded links and a browser's Back and Forward history buttons needed clarification.

7.5.3 SECOND PROTOTYPE
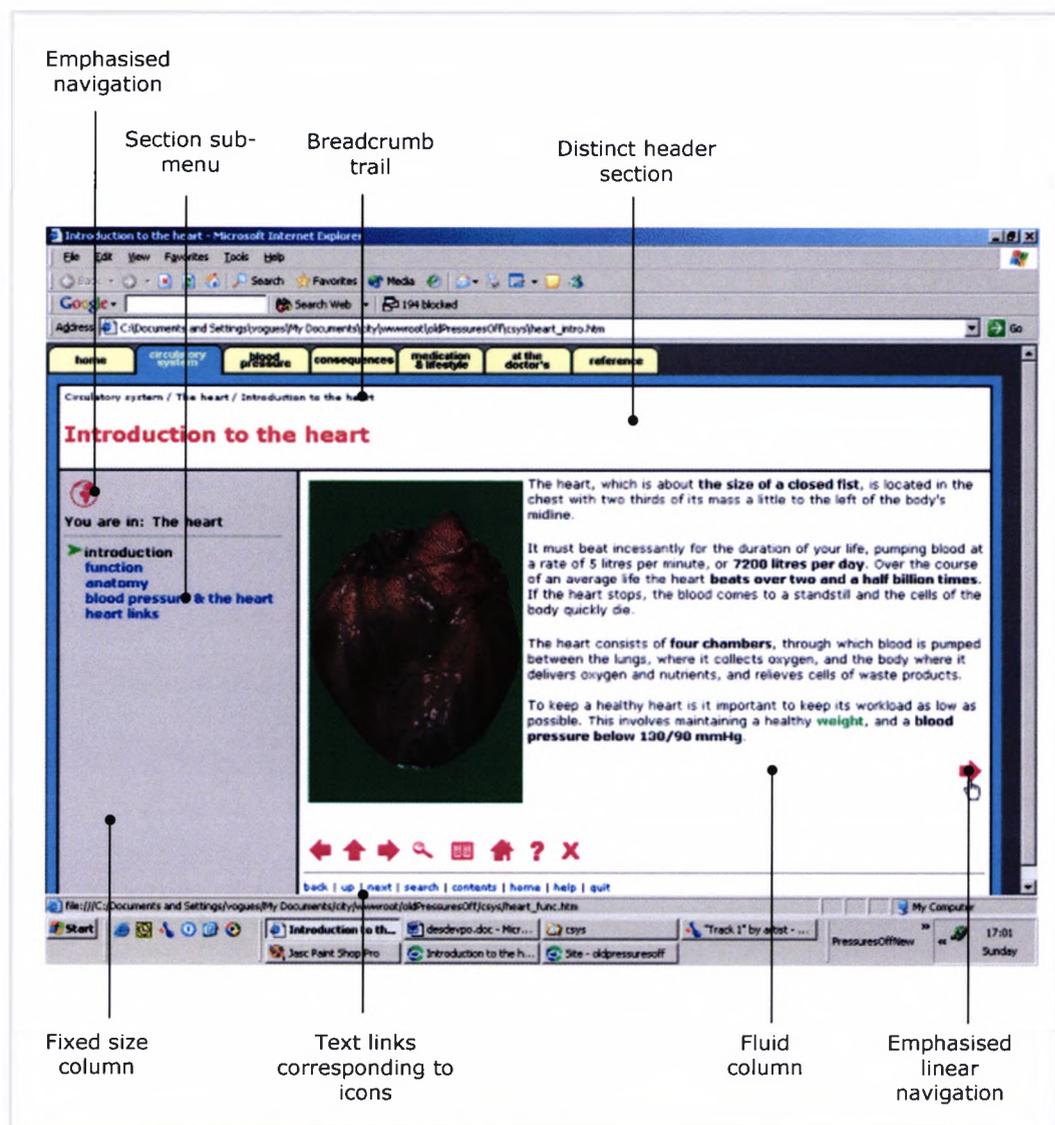
Figure 7.9 Second version of Pressure's Off interface

The second version is shown in Figure 7.9. This interface has acquired a further table column (known as a side bar) in which resides a second-level menu. The side-bar is fixed width and the text inside it is configured to wrap. The absolute width specification has the advantage of retaining its integrity on small screens or windows – key navigation and context material does not risk getting squeezed out of view in a horizontally scrolling window. A disadvantage is that, if users resize the text upwards, it could appear crammed into the fixed-size window. Additionally, although width can be controlled, height cannot. For longer pages, users scrolling downwards would be in danger of "losing" the menu. In addition, since Pressure's Off contains a large number of different sections, each of which contains several pages each of which in turn would require its own individual menu, this would involve either a large amount of redundant coding (with implications for maintenance) or the creation of many more templates than would be practicable.

There is reinforcement of orientation in the side bar which informs users, with a green arrowhead, which section they are looking at currently. A delineated header area contains a "breadcrumb trail" for orientation, detailing the context of the page being viewed, as well as the page title. These are both useful additions for which no drawbacks have been identified.

In acknowledgement of the complexity of the information structure, the Next arrow has been repeated in the body of the page. It is included as an option for users who wish to determine a linear route through the material which does not omit any pages. However, this scheme has the drawback that novice users may feel compelled to use the package in this way and lose confidence in the option to be selective and strategic.

Text links have been added to the navigation icons at the bottom of the page to clarify their meaning and as an accessibility criterion.

7.5.4 WORKING VERSION

After much deliberation about layout the following priorities emerged:

- Within Pressure's Off the principle of coherence (consistency and logic) should be upheld to give a transparent interface which impinges minimally on the user's consciousness

- An overview of the resource should be readily available which clarified both scope and sequence of information

- Redundant coding should be avoided to reduce maintenance overheads.
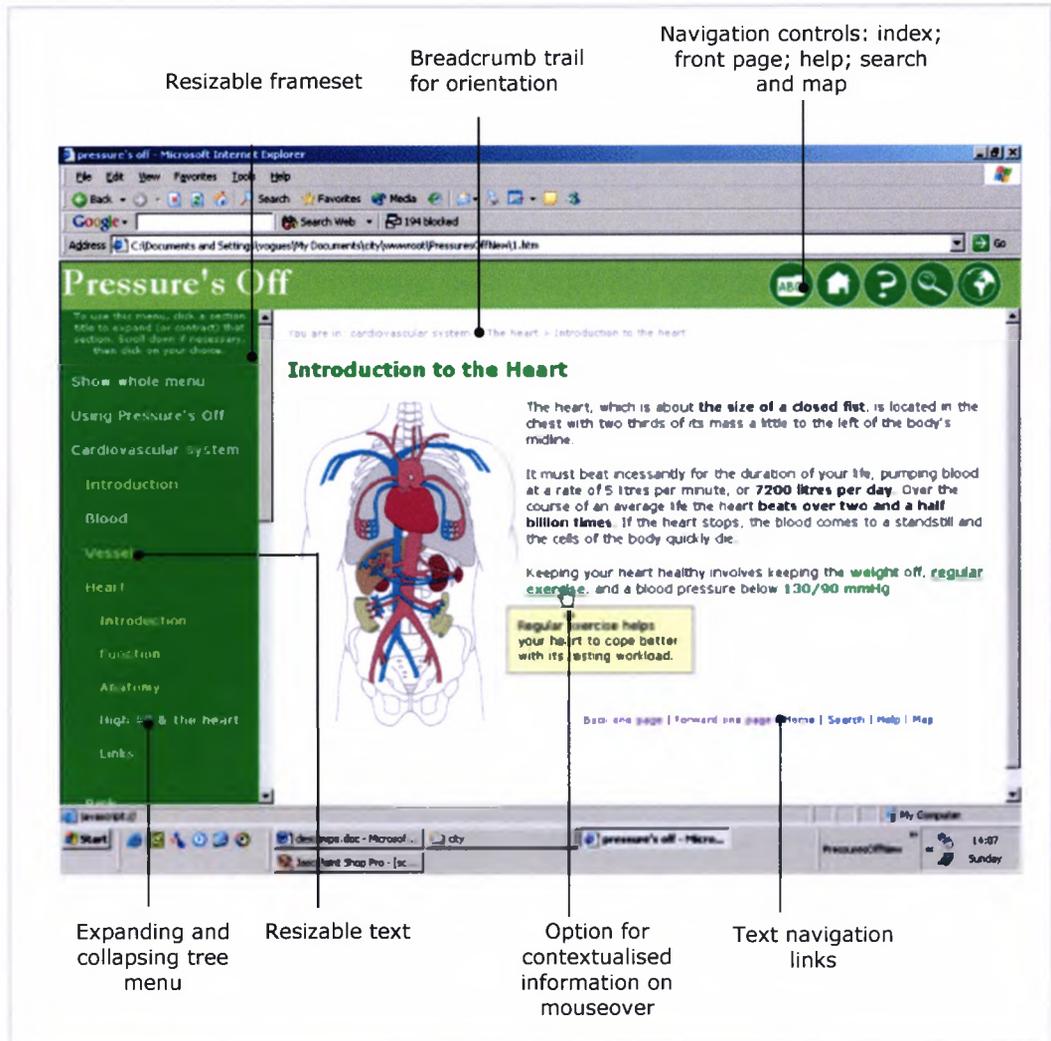
Figure 7.10 Third and working version of the Pressure's Off interface

To this end the tabular layout was abandoned in favour of a **frameset** (Figure 7.10). A frameset is a way to visually divide the computer screen into distinct areas that can be separately rewritten. The advantage here is that, regardless of scrolling in the **main content pages**, the **title bar** and **side bar** remain constant – a frame of reference, so to speak, and extremely useful for novice users. Thus the title bar can keep a number of elements constantly visible at the top of the screen, namely the title and the important Index, Home, Search, Help and Map navigation controls. Similarly, the side bar fixes the

menu in position, and this has an important advantage – the potential to give the menu a dual function as both navigation tool and overview of the site. However, making a decision about the scope and function of the menu was not straightforward - it was necessary to acknowledge an important debate about the nature of hypermedia - the linked units of information which constitute the Web. This debate is introduced below.

Despite its enthusiastic uptake, the use of hypermedia is controversial in learning theorist communities. Some constructivists have argued that the power of the Web lies in the complete learner control it can confer, which is "consistent with the constructivist principle that learners should be given the opportunity to discover knowledge through their own active exploration" (Dalgarno, 2001). Proponents of this theory of "cognitive flexibility" (Spiro and Jehng, 1990) contend that hypermedia allows complex and ill-structured material to be represented in a flexible way which makes it "possible to revisit the same material, at different times, in rearranged contexts, for different purposes and from different conceptual perspectives" (Balcytiene, 1999). This, in partnership with the critical thinking skills which some argue hypertext also fosters, is instrumental in developing intentional learning (metacognitive knowledge) in users – "a problem-solving framework for approaching learning, awareness of the functional potential of knowledge and strategies for identifying deficits in knowledge" (Balcytiene, 1999).

However, there are conflicting claims about hypermedia, and some argue that a "natural consequence of giving the user control of his [sic] progress through the hypertext" is the 'lost in hyperspace' phenomenon (Dix et al, 1998, p595). A related negative phenomenon, termed the "butterfly defect" (Salomon, 1998), arises when a Web user is seduced by indiscriminate use of links to explore in a tangential and haphazard manner which inhibits their organisation and construction of knowledge. Salomon highlights the difference between facts and ideas, and draws a distinction between *exploration*, a bottom-up unguided approach to information and *search*, which he considers to be top-down, metacognitively guided and goal directed - a more advanced and desirable approach for a learner. Both Greenfield (2004) and Salomon (1998) point to an affinity between cognitive webs and hypermedia ones, and raise concerns that the casually associationistic organisation of the Web could affect

learners' ways of thinking and the way their own webs of meaning develop. Salomon asks:

> "Could [learners'] cognitive webs of meaning come to reflect hypermedia characteristics, consisting of flimsy associationistic connections?" (1998)

Greenfield discusses her fears about the consequences - a descent from a critical, questioning existence to one where meaning is sacrificed to sensation – what she terms a "yuck wow culture". Preece and colleagues (1994, p320) also warn against the prevalent practice of presenting extensive navigational facilities in the absence of "a holistic picture of the information space" from which users can make meaning.

In view of this, hypertext has been used with caution in Pressure's Off, and an overview of the information has been included. The package aims to provide sufficient navigation alternatives to exploit the power of hypertext and avoid compromising freedom of movement, while simultaneously encouraging in-depth exploration as a meaningful and motivated decision on the user's part. One important consideration here is whether to make the **breadcrumb trail** clickable, allowing users to click back through the front pages of concentric sections. A decision was made not to add this functionality in Pressure's Off because it might invite users to navigate haphazardly and so contribute to disorientation and the butterfly defect. **Internal links** within Pressure's Off are generally avoided; although the user may be referred to a given section for background or extra information, links for this cross-referencing have not been included and the user must consciously navigate to a given page, which is intended to safeguard a metacognitive learning approach. Similarly, **external links** are used in dedicated Extra Information sections to direct users to resources which are explicitly outside Pressure's Off.

The side bar menu is anticipated as the principal way to access the content, and fulfils the function of both **menu** and **overview** by adopting a **tree structure**. The tree menu gives the impression of being a single page, but is in fact a separate page for each menu state. This strategy involved considerable redundancy of source code, but was necessary to guarantee accessibility by avoiding scripts which might not be compatible with some user agents. On entering the site, a user is presented with the collapsed menu

showing the top level sections, together with instructions for use. As each is menu item is clicked, it expands to show an indented sub menu containing either links to content pages or links to expand further indented sub menus. An option has been included to expand the whole section menu, giving an overview of the entire site – some 128 pages arranged over four levels. This representation, along with the Map, is intended to counteract Salomon's (1998) butterfly defect, and promote top-down goal-driven use of the information in Pressure's Off. At the same time it must be noted that a possible threat to this aim is the **Search facility**, which encourages users to view pages in isolation. However, Search was included to facilitate the use of Pressure's Off for reference, and in that respect is indispensable to a resource intended to be flexible.

One large drawback of the frameset scheme is that search engines index individual frames, ignoring their framesets. This increases the likelihood of **orphan pages** appearing in search engine results. One way of solving this problem is to include a script in each frame forcing it into a frameset – this means that when any individual page is opened, the frameset automatically loads as well. However, this poses problems for users who prefer not to use frames. Another way to circumnavigate the problem is to optimise each content page for use without frames – which is also an accessibility and usability requirement. In Pressure's Off each frame contains a set of navigation links at the bottom of the page, which means it can stand alone as an individual Web page from which users can access Search, Help, a Map and an Index. In the event of an orphan frame being opened for the first time, a user would be inclined to click on the Home link. The Home page is the only content page which is forced into a frameset – this means that when the Home link is activated, the user is presented with the entire context conferred by the menu and title bar, and can choose to remain within the frameset or open the next content page in a new window. Otherwise, there is little reason to activate the Home page, since it is an introductory page with a unique function. The working strategy is that currently in Pressure's Off the title bar, side bars, and home page are forced into the frameset and cannot be viewed in isolation, while the content pages remain flexible.

Screen readers cannot easily scan the contents of multiple frames. Some approach framesets by alerting the user and proceeding to process all the

frames as if they were a single page. There may be a keyboard shortcut which allows the reader to toggle between frames. Others, on registering the frameset, present users with a list of frames from which to select. One of the most important ways to make frames accessible is to give each frame a title – in Pressure's Off they are caller 'header', 'menu' and 'main document' – which makes it possible to communicate the purpose of each frame to the screen reader user. Within frames, since screen readers tackle a page by beginning top left and working down, a user could face the prospect of having to process repetitive content. One way to avoid this is to use "skip links" within pages, as recommended by a number of validation services, such as A-Prompt (http://aprompt.snow.utoronto.ca/index.html) to allow screen reader users to bypass repetitive content and access the substance of the page. In Pressure's Off, skip links link the critical junctures – such as orientation and navigation – in each frame.

Frames can confuse users who wish to **print** screens, since it is easy to inadvertently print out unintended frames. One solution is to add a Print script to each content page, encouraging users to adopt this route to printing.

Navigation icons reside in the title bar, where they benefit from its constant visibility. They are duplicated as **text links** at the bottom of each content page, where 'Back one page' and 'Forward one page' links are included which imitate the browser Back and Forward buttons' function.

Font-size is modifiable, and Pressure's Off is thought to work in all **browsers**.

This working version is not without flaws. However, it works robustly and this important quality allows it to fulfil its remit adequately. More on improving the interface can be found in the section on Future Work in Chapter 10.

7.6 DEVELOPMENT TOOLS

HTML pages were produced using Allaire Homesite for hand-coding templates and bespoke pages, and Macromedia Dreamweaver for subsequent development and content management. Images were created or edited using Jasc PaintShop Pro and Macromedia Flash, with some buttons being designed in Macromedia Fireworks. Animations and interactive sections were produced using Flash, video was recorded early in the project in a studio using an

analogue recorder, captured and edited with Adobe Premiere Version 6, exported as .avi versions for Apple's leading QuickTime Player. Other interactive elements such as the BMI calculator and the ten-item multiple choice quiz with feedback and score were created with Javascript.

7.7 SUMMARY

In keeping with user-centred design, development of Pressure's Off began with a specification of the subject area, used this to inform interface development, and finally progressed to eventually integrate the two. Developing the knowledge base involved an extensive research period to generate an overview of the subject area which was approved by health professionals, after which it was populated with verbal and multimedia learning objects. Technical development was a challenging exercise in which the only thing that could be taken for granted was diversity – of user and platform. Broad variation in the platform on which Pressure's Off would be used was recognised; usability and accessibility consequently emerged as particular concerns, demanding a flexible approach to design. In acknowledgement that the target user group defies categorisation, input into a UCD-grounded design process was sought from individuals of varying aptitude with computers. This input evolved a working interface for Pressure's Off through an iterative cycle of rapid, horizontal prototypes.

The result is a working comprehensive multimedia information package developed as Web site and also deliverable as a stand-alone resource on CD-ROM. The navigation is structured to allow linear or non-linear use, and the resource can also be used as a searchable reference. Correspondingly, the information itself has been broken down into meaningful units which are small enough to be digested but not so small as to atomise knowledge into a loose collection of dislocated facts. Multimedia has been used where possible and appropriate.

The following chapter describes the evaluation of Pressure's Off.

CHAPTER 8: EVALUATION

The approach to evaluating Pressure's Off was based on several factors. In contrast to the immediacy of blood glucose control or coping with an asthma attack, for high blood pressure (HBP) cause and effect are blurred and there are no dramatic returns on lifestyle interventions. This means that people with HBP explore information resources with questions about a variety of different circumstances and their bearing on BP. Another factor was the fact that layout and navigation in Pressure's Off draw on established conventions of the Web. As already mentioned, the Blood Pressure Association (BPA) site came into being in 2000, after this project had started. It was therefore necessary to closely observe BPA developments, communicate effectively, and diversify to avoid duplicating its work, which progressed rapidly. This approach has been successful, evidenced by the interest the BPA has shown in incorporating a number of Pressure's Off illustrations and interactive diagrams. For these reasons evaluation focused on a selection of sections distinct from other resources available.

As mentioned in Chapter 6 with regards to the needs assessment, obtaining patient involvement was a challenge and consequently reserved for the formative evaluation presented below. After considering the manifold contributions users could make to the development of Pressure's Off, a decision was made to design the evaluation from two perspectives. Target users would provide feedback about the ten areas of innovation mentioned above, with respect to usability, gains in knowledge and affective responses. However, during this rare opportunity to meet face-to-face with patients, it was anticipated that, as a result of the interview methods employed to collect this feedback, rich data would be incidentally collected about the issues which confront people with HBP, and how these are dealt with in life.

This chapter follows an established format beginning with an account of the methodology of the evaluation. Hermeneutic in character, qualitative research requires precise detailed reporting to equip readers to assess the value of its findings. Following this the evaluation procedures are outlined, after findings are presented and discussed in two sections. The first is concerned with reactions to the areas of Pressure's Off explored during the evaluation, and includes proposed improvements and their justifications. The second section

explores other themes arising during the discussion which offer insight into the experiences of people with HBP and are important considerations in designing information resources for this group. The chapter ends with conclusions drawn from the evaluation exercise.

8.1 AIMS

The "three Es" of evaluation – efficiency, effectiveness and economy – have been outlined in Section 4.4.1. Planning for the evaluation initially involved mapping these to the relevant aims of the research project, which were to:

- develop a dissemination medium which is accessible, acceptable, maintainable and cost effective

- engage end users

- advance end users' knowledge about BP

- encourage and motivate adherence to treatment strategies

- promote an active interest in end users' own cardiovascular health.

Consequently, the aims of the evaluation were ambitious, encompassing changes in knowledge and motivation as well as usability, affective considerations and usage, for the entire package. There were plans for an initial questionnaire for participants, followed by free and directed time using Pressure's Off, which would be video recorded. A pre- and post-test of blood pressure knowledge would be completed, with a follow-up a month later consisting of a knowledge test and questionnaire about motivation and behaviours. After conversations with several health professionals involved with HBP in a clinical and academic capacity, the assessments of motivational and behavioural changes were accepted as interesting but highly complex areas which lay beyond the scope of this project. Moreover practicalities also impinged - it would not be possible to standardise the experiences of each participant, which raised problems for testing changes in knowledge. As a voluntary learning experience which would not be assessed in real-life, it was not felt appropriate to set learning objectives for participants.

As a result the research questions were refined and, rather than a summative evaluation of user satisfaction, the finalised evaluation design came to focus on usability, interest, gains in understanding, and how sections of Pressure's

Off might be improved. As such, it aimed to collect qualitative responses to Pressure's Off, and sought opinions beyond those that could be polarised into good/bad, helpful/unhelpful. For this reason, apart from two questions comprising scales to summarise interest and understanding, free-ranging responses were elicited for each section which explored:

- affective considerations, encompassing general enjoyment, interest and motivation to continue or return which, it is well established, bring about more effective learning (Alessi and Trollip, 2001, p422)

- usability, a basic requirement (Nielsen, 1993)

- self-perceived improvements in understanding of a given aspect of HBP

- perceived omissions

- suggestions for changes.

It was anticipated that other insights about the experience of living with the condition would emerge during the evaluation and, since contact with patients was difficult to arrange, it was important to capture this and incorporate it into the development of Pressure's Off. This expectation informed the evaluation design, discussed below.

The findings were intended to form a basis for decisions about modifications. Suggestions for improvements were elicited from participants with open questions, rather than from a series of pre-defined options, and this approach raised questions about the criteria for making those changes which might only be suggested by a small proportion of the sample. In the context of this study, and in common with all software development, a decision was made that the developer had sufficient expertise and professional judgement to organise findings into plans for modifications, to identify those suggestions which were sound and feasible to implement. Working criteria for accepting suggestions from this small sample included the suggestions being additive (for example adding orientation, titles, navigation alternatives, rather than removing elements), providing information management solutions (for example layering information), or if definite, substantiated consensus emerged.

8.2 DESIGN

Based on the above aims, design of the evaluation was undertaken, as described below.

8.2.1 THEORETICAL BASES FOR THE EVALUATION DESIGN

Evaluation of educational materials can be categorised as summative or formative. Formative evaluation happens during the development process to benchmark progress and authorise decisions. Weston and colleagues summarise (1995):

> "The purpose of formative evaluation is to validate or ensure that the goals of the instruction are being achieved and to improve the instruction, if necessary, by means of identification and subsequent remediation of problematic aspects."

Summative evaluation, on the other hand, is carried out on a completed product and is concerned with evaluating learning and other outcomes according to a range of process and impact indicators. For this project, summative assessment would investigate changes in knowledge and behaviour, record patterns of use, and ultimately look for an associated reduction in cardiovascular illness and mortality.

Although the importance of outcomes cannot be overstated, it was important to carry out a process evaluation, introduced in Section 4.4.4, a broad exploratory study of Pressure's Off avoiding the premature restrictions of outcomes-related research questions. Michael Scriven, who first developed the concept of "goal-free evaluation" (1991), discussed the valuable formative function of observing, without agenda, the effects of a phenomenon, avoiding cues and filters introduced by considering the *aims* of that phenomenon. Kirkpatrick (1994) also argues that although goal-related outcomes evaluation are crucial in measuring the effectiveness of a phenomenon, this should be undertaken only after its prerequisites – such as usability and positive affective response - have been established.

These theories indicate that a descriptive approach would be appropriate at this stage of Pressure's Off's development, and a decision was made to design a qualitative study which would avoid restricting participants' responses. Ziebland and colleagues (2004) substantiate this approach:

> "A qualitative design facilitates understanding of an experience or phenomenon from the perspectives of the individuals who have 'lived' it. It accomplishes this by using the participants' own words, rather than numbers, to convey meaning."

It was nevertheless considered appropriate to standardise the way participant responses were collected rather than to adopt a purely naturalistic study design. This decision both responded to the specific challenges about the reliability and transferability of qualitative research findings discussed in Section 6.1.1.4, while allowing different participants' responses to be compared.

Although a large outcomes study of the "Three Es" (Section 4.4.1), incorporating effects such as behaviour change and changes in BP-related morbidity and mortality, would be ideal here, it is not only beyond the scope of this project, but has proved too ambitious an undertaking for many other health promotion evaluation studies. Nevertheless, it is important to consider how this study would contribute to a larger evaluation exercise should the opportunity be forthcoming. Kirkpatrick's four level evaluation model (1994), originally developed to evaluate training, usefully represents the elements which contribute to achieving the aims of a project. These elements - users' reactions, learning, transfer (behaviour change) and results - are presented by Kirkpatrick as a hierarchy (see Figure 8.1) where positive evaluation of each level is an important precursor to considering the level above. The Encyclopedia of Educational Technology (Hoffman, 2004) notes:

> "Thus, each successive level represents a more precise measure of the effectiveness of the training program, but at the same time requires a more rigorous and time-consuming analysis."
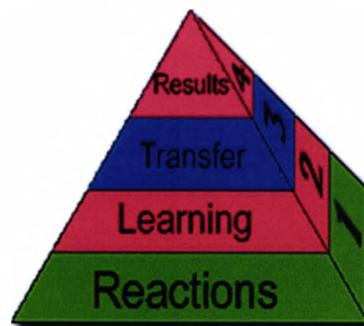
Figure 8.1 Kirkpatrick's four-level evaluation model (Hoffman, 2004)

Kirkpatrick's model is suitable for learning about self-care for HBP, which aims to achieve behavioural change. As such, it informed the scope of the study,

which focused the lower tiers of the hierarchy to explore affective considerations (Alessi and Trollip, p422) and elements of learning.

The details of the study design are described in the following sections.

8.2.2 STUDY LOCATION

Fixing the site of the study with members of the hypertension clinic team involved a decision about whether to make an appointment to visit participants in their own homes with a lap-top computer or, because appointments at the clinic are infrequent, to ask them to make a special trip to the hospital. The former had the two advantages that participants would be more likely to be at ease, and would be minimally inconvenienced by the experience. However, these were outweighed by two other considerations - the small screen size of a lap-top computer and the safety of the researcher and lap-top away from main roads in a high-crime area.

Participants were asked to come to the hospital at a mutually convenient time – in practice, this happened on the days which the clinic took place, which meant that the clinic team were on hand in case of incident. Apart from one session, which took place is the participant's home, the consultant's office with a personal computer was the location of the study.

8.2.3 ETHICAL APPROVAL

An ethical approval application was submitted to the East London and City Health Authority Research Ethics Committee. This was provisionally accepted with certain provisos which should be met before Chair's Action could be gained. For example, the committee demanded that audiovisual material collected from participants be destroyed on completion of the study, and stipulated some questionnaire modifications. Meanwhile, some over-ambitious features of the original protocol had been identified, and these were flagged in the request for Chair's Action, which was ultimately granted.

As the relative of a HBP patient, Participant 1's (P1's) session was able to take place prior to ethical approval being granted. Initially intended as a pilot, it confirmed a robust study design and collected good data which have been included in the findings. Although her responses to some questions reflected that she did not have HBP, they were included on the basis of the growing recognition that the majority of adults in industrialised countries would benefit

from lowering their BP, even if they are not above the current threshold for intervention (Law et al, 2003a). For this reason it was considered useful to observe the responses of people without HBP.

8.2.4 QUESTIONNAIRE DESIGN

Two questionnaires were designed. The first (Appendix 2) explored participants' health, their computer use and their attitudes to HBP. The second (Appendix 3) collected responses to each of the areas of Pressure's Off covered in the evaluation, and covered six aspects: interest, understanding, positive and negative responses, unanswered questions, and suggested improvements. In common with the needs assessment questionnaire outlined in Section 6.3, no existing instruments to collect the particular information required were identified, and consequently the question items were developed and validated in the department. It should be noted that the attitude scales were initially included as Likert scales since these would yield "sharp" data with a small sample. These were modified as visual analogue scales, as shown in Figure 8.2, at the request of the Ethics Committee. This was appropriate for measuring the intensity or magnitude of sensations and subjective feelings, and the relative strength of attitudes and opinions about specific stimuli.

Experiences validating the content for Pressure's Off (see section 7.4.5), during which input was limited by the need to write or type, informed the researcher's decision to mediate the questionnaire and take an audio recording of responses.

To safeguard the uniformity of experience for the group of participants, there was a hiatus in adjustments to Pressure's Off during the evaluation period, despite gathering consensus for a number of changes.
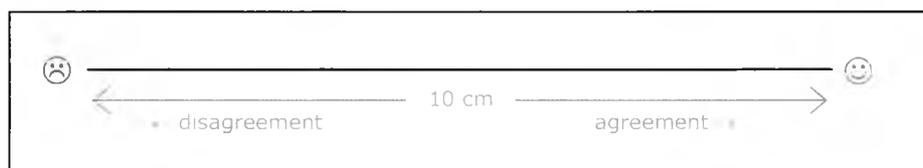
Figure 8.2 Example of the visual analogue scales used in the evaluation

8.2.5 KNOWLEDGE TEST DESIGN

A ten item multiple choice knowledge test was authored by the researcher (who had received relevant training) with four options for each item, one of which was correct. Its scope was the core knowledge around lifestyle without

which good self-care for HBP cannot be planned. It aimed to identify baseline knowledge in the participants prior to the session using Pressure's Off[13]. Although there are no post-test data to identify changes in knowledge (because the remit of these participants was to feed back on ten specific areas of the application) this objective knowledge assessment sheds light on participants' responses to the information in Pressure's Off, especially in combination with their perceived knowledge. For example, the demonstration of little prior knowledge in combination with little *reported* prior knowledge would suggest the potential to experience greater gains in knowledge during the session. The test results were also expected to expose patterns of knowledge in the sample which might suggest areas for development within Pressure's Off.

8.2.6 SELECTION OF AREAS OF PRESSURE'S OFF TO BE EVALUATED

The pilot session involved working through the sections in order, and this experience encouraged ruling out strict timescales. Since participants would interact with the material at different paces, it was important that each cover a range of sections rather than working through in order which would risk neglecting the later sections. Therefore a strategy was adopted whereby the excerpts to be viewed were randomly selected for each participant using the random number service available at http://www.random.org). There were occasions when timely Internet access was not available to generate this list; the participants were then asked to arrange the numbers 1 to 10 in any order and this list was used.

It was anticipated that in the event of some sections not receiving enough attention, these could be allotted to later participants. However, the supply of participants ended before all sections could be evaluated by an equal number of participants. A better strategy would have been to attempt to keep an even spread of participants over each section from the beginning, and to allot sections on a session-by-session basis.

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[13] After their session, each participant was given a sheet with the correct responses to the knowledge test, and commentary.

Section 5, *Videos of the Measurement Procedure*, was omitted since the method of measurement covered is not in use in the clinic.

8.2.7 SAMPLING

In order for the participants to engage fully with the information, they would ideally be experiencing health care for HBP. To recruit from this group staff at the hypertension clinic, where observations had already been carried out, were approached for their assistance. Recruitment was not a straightforward process. Gaining access to what are termed 'closed' or 'private' settings (Hornsby-Smith, 1993, p224-5) is always a challenge and in this project was dependent on "impression management" (Silverman, 2000, p198-9), being non-judgemental, and involving all stakeholders in the organisation offering access. As gatekeepers, the consultant and nurse specialist were understandably concerned to protect the interests of their patients, whom they regarded as potentially vulnerable. The clinic is in a disadvantaged London borough; many of its residents fare exceptionally poorly on several social and economic indicators including educational achievement, housing, and income. There is a high concentration of immigrants in the area, which can introduce language and cultural complications as well as the other difficulties implied by displacement and poverty. Consequently the strategies of either randomly sampling from the patient list, or approaching individuals before or after their clinic appointment were rejected on the grounds that those patients may feel singled out, under scrutiny and obliged to participate.

An acceptable strategy for the team was for the specialist nurse to mediate recruitment of a purposeful sample, contacting individuals opportunistically on the basis of the team's insight into that patient's circumstances and their capacity to participate in such a study. This judgement would be opaque, so particular reassurance was reiterated by the researcher that the study would welcome people of any age, any educational achievement and the entire range of computer experience.

According to a paper published by Robert Virzi (1992), 80% of all usability problems can be found with four or five users. Additionally, the first few users will most likely detect the biggest usability problems. Jakob Nielsen and Thomas Landauer (1993) provided further support for this theory when they found that the first five users will uncover about 70% of the major usability

problems and the next few users will find nearly all the remaining problems, up to about 85%. In this way the number eight passed into developer-lore as the minimum sample size for usability testing. In some contexts, for example e-commerce sites, more test participants are required, but for the purposes of usability testing an information package such as Pressure's Off, a target sample size of ten participants was set with the clinic team who carried out the recruiting.

Due to constraints – on recruiter time and in the form of the pool of patients whom they considered suitable for such a study – the eventual number of participants was six. This sample was smaller than hoped, but large enough to identify usability problems and contribute suggested improvements although, as expected for this small-scale study, saturation on this feedback was not ultimately reached.

8.2.8 SCHEDULE OF SESSION

The researcher sent the specialist nurse her diary as an excel spreadsheet, updated weekly, and based on this the sessions were arranged. It was felt that each session should take no longer than 90 minutes to avoid placing a burden on participants, who might be older, in poor health, or having to take time off from work.

In working through each section, the "think-aloud" technique was considered but rejected on the grounds that it would impose a considerable burden on participants who might be novice computer users. Instead, they were observed interacting with each section by the researcher, who responded to any comments they volunteered during the interaction and collected any outstanding responses after each section with a series of 8 set questions. These questions (Appendix 3) covered interest, self-reported improvements in understanding, positive and negative features, unanswered questions and suggested improvements.

The schedule for each session follows.

1. Administration and consent

Description: Review information sheet and obtain written consent to take part in the study and to be audio recorded.

Aims: Inform the participant

Duration: 10 minutes

2. Questionnaire 1 completed

Description: Written questionnaire (if necessary can be mediated by principal
investigator as amanuensis)

Aims: Collect details about age, sex, blood pressure history, attitudes
to and aptitude with computers, and attitudes towards managing
own blood pressure. A potential source of insight into
subsequent responses.

Duration: 10 minutes

3. Knowledge test completed

Description: Written 10 item multiple choice test.

Aims: To indicate baseline knowledge of high blood pressure prior to
viewing the information. A potential source of insight into
subsequent responses.

Duration: 10 minutes.

4. Session using Pressure's Off

Description: Researcher navigates to a given part of the information
package; participant takes control of the computer to interact
with it; participant responds to set questions.

Aims: To observe participants interacting with the material; to collect
feedback on content and usability.

Duration: Remaining time minus 10 minutes.

5. Close

Description: Participant is thanked and given the opportunity to comment
and ask questions.

Aims: -

Duration: 10 minutes.

8.3 PROFILE OF PARTICIPANTS

Early in the session and prior to using Pressure's Off, participants were profiled with a questionnaire covering demographic data, health status, attitudes to and aptitude with computers, and attitudes to using computers to acquire health information. They also completed a knowledge test. The participants were profiled because individual differences would have a bearing on their understanding of the information presented, the value they assign to it, and their consequent actions. In order to be effective, health promotion must identify and address all of these issues.

The group of participants comprised four women and two men, aged between 29 and 69 (mean age 48). One had not been diagnosed with HBP, but had been invited to participate because she had a close family member with the condition. They all currently or formerly had professional job roles in the public sector, including two former nurses. This educational status was an unanticipated feature which, while making the sample unrepresentative, also made possible unexpectedly perceptive and critical feedback which was enormously beneficial to Pressure's Off at this stage of development.

From the patients in the group, BP-related health status was collected from memory and notes on the "pink cards" administered by the clinic, which they were asked to bring. Responses are summarised in Table 8.1. Notably none had a known cause of their HBP. BP had fallen recently for three, although only one – P5 - could be described as within safe limits. Five participants had a computer at home, and four had access to the Internet.

Their attitudes to computers were collected using visual analogue scales to indicate agreement with four statements, findings from which are shown in Figure 8.3. Significantly, all demonstrated a high degree of acceptance of using a computer to find out about their health condition, despite considerable variation in confidence with the technology. Nevertheless all indicated strong preference for receiving information from a health professional rather than using a computer, congruent with findings from the needs assessment.

#	Question	Participants					
		P1	P2	P3	P4	P5	P6
7	Please w rite your height, if you know it (m)	1.56	1.84	1.64	1.77	1.73	1.57
8	Please w rite your w eight, if you know it (kg)	57.20	79.00	95.30	77.30	99.00	69.00
	(Calculated BMI)	23.5	23.3	35.6	24.8	33.2	28.0
9	Please w rite your last BP measurement if you know it.	presumed normal	150/94 mmHg MDT	149/80 mmHg	140/93 mmHg approx	120/80 mmHg	140/88 mmHg
10	If you are taking any medicine for your blood pressure, please w rite dow n their names if you know them	n/a	MRDoxazin 4mg/d; Perindopril 4mg/d; Amlodipine	Amlodipin e 10mg, Bendroflu azide 2.5	Diuretics	Estin 5mg/d, Atenolol, 50mg/bd	Lisinopril 10mg daily
11	As far as you know , have you ever had, or do you have now , any of the conditions listed opposite?	n/a	None	Embolism	None	I'm not sure (note: "chest pain")	None
12	Only 5% of people have a know n cause for their high blood pressure. To your know ledge, is your high blood pressure caused by another illness or condition?	n/a	No	No	No	No	None
13	Recently (in the past few readings) has your blood pressure gone up or dow n?	Not sure	No change	Dow n	Dow n	Dow n	Up

**Table 8.1. Participants' BP-related health status.**
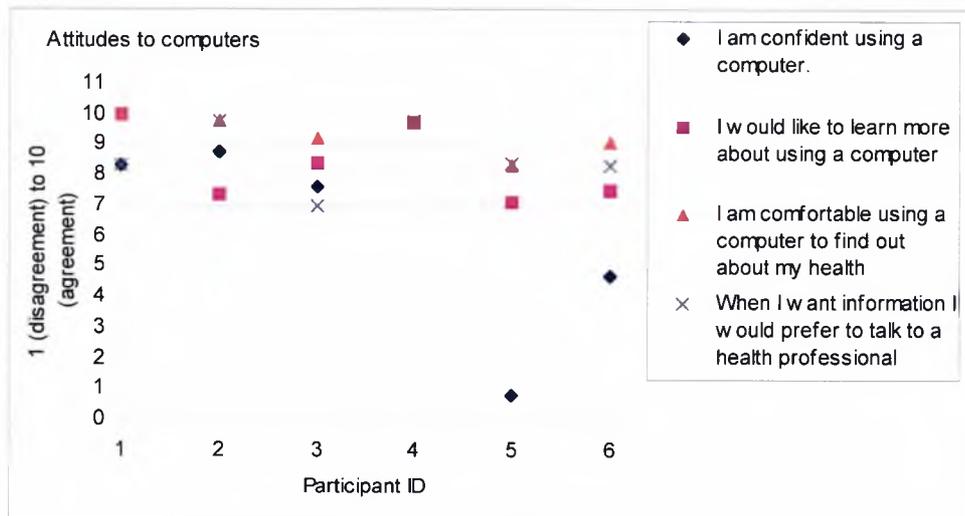
Figure 8.3 Participants' attitudes to computers

Similar scales were used to gauge participants' attitudes to their BP. Reliability here was safeguarded using a number of different items to measure the same

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concept – a recommended approach for internal consistency (de Vaus, 2002, p19). Findings from twelve items are presented below, grouped by theme[14].

Figure 8.4 shows attitudes to learning about BP. Unsurprisingly for this purposeful sample, all indicated strong disagreement with the statement about "I would prefer not to know very much" (mean: 0.4, range: 1.7). All strongly agreed that they would like to find out as much as they could (mean: 9.6, range: 0.8), but agreement with a similar statement "I would like to learn more" was significantly less (mean: 8.3, range: 2.5). On this basis it was initially assumed that participants might consider themselves already optimally informed about HBP, but the denial of a further statement "I believe I know enough about high blood pressure to keep it under control" showed that this was not the case – the mean here was just 3.0 with a range of 6.7. The inconsistency between the above two similar statements may therefore be due to the question order or wording – the idea of finding out as much as one can may have had a definitive appeal compared to the somewhat vaguer "learn more".

Learning about blood pressure

- ◆ I would like to learn more
- ■ I would prefer not to know very much
- ▲ I would like to find out as much as I can
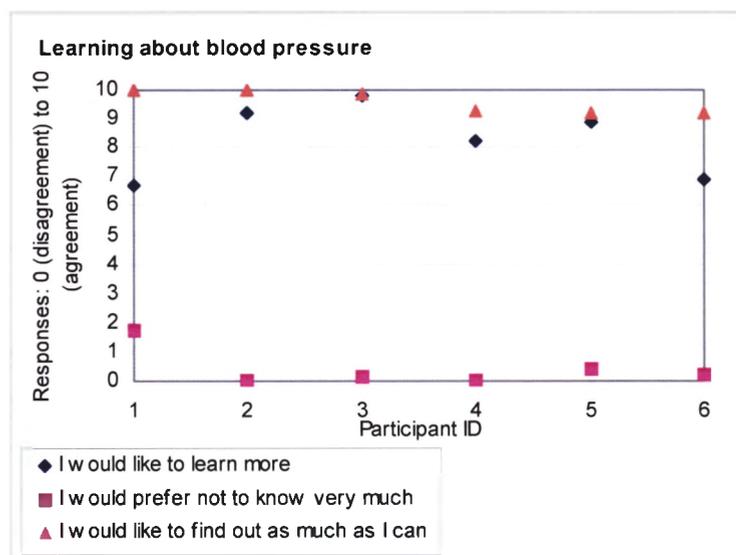
Figure 8.4 Attitudes to learning about blood pressure

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[14] Please note that, as labelled, the x axis is nominal not ordinal. In other words, it refers to individual participants (eg Participant 1, Participant 2, etc) and not the *number* of participants .

Thinking about blood pressure

Responses: 0 (disagreement) to 10 (agreement)

Legend:
◆ I am interested in my blood pressure
■ I would rather not think about my blood pressure at all
▲ I don't feel under much threat from my high blood pressure
✕ It's easy to forget about my blood pressure
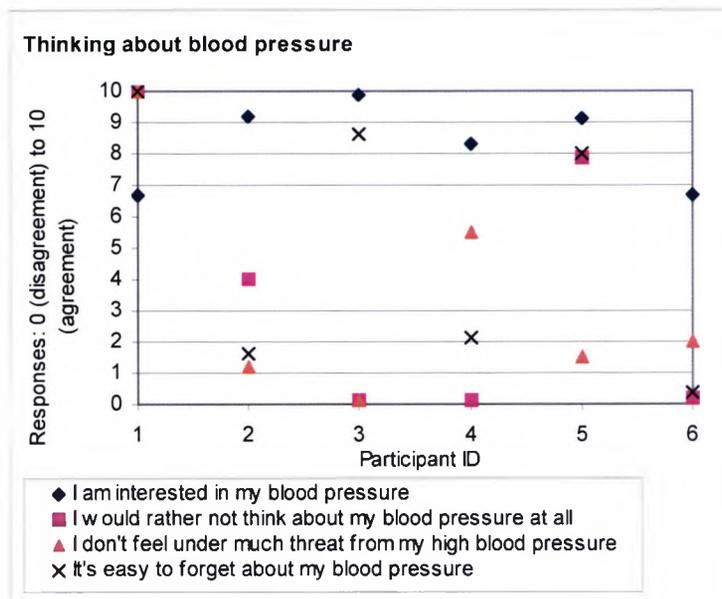
Figure 8.5 Attitudes to thinking about blood pressure

Figure 8.5 presents participants' attitudes to thinking about HBP. Although, again unsurprisingly, participants showed generally high interest in their BP (mean: 8.3, range: 3.2), responses to the statement "I would rather not think about my high blood pressure at all" were widely distributed (range 9.9), an array which reflects the paradox that thinking about ones own BP is rarely pleasant, but is nevertheless necessary for its ongoing management. A correlation was observed between the latter statement and the statement "It's easy to forget about my high blood pressure", which the small sample allowed P3 to significantly weaken. Also widely distributed, and correlating to the responses about the perceived threat of HBP (again weakened by a single response from P5), were responses to the statement "I don't feel under much threat from my high blood pressure" (mean: 3.4, range: 9.9). The overall picture is of a general ambivalence to considering BP on the part of those participants with HBP.
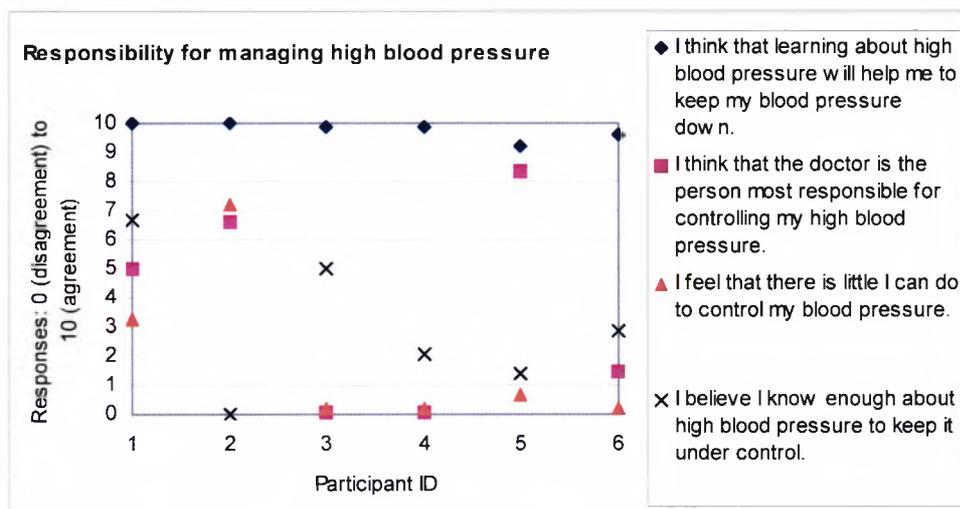
Figure 8.6 Attitudes about responsibility for high blood pressure

Figure 8.6 shows participants' perceptions about responsibility for HBP management. There was uncomplicated, strong agreement (mean: 9.8, range: 0.8) that learning about HBP would help with its management, congruent with their decision to participate, and with their educated, professional status. The self-reported adequacy of their individual BP knowledge proved more controversial, yielding a mean response of 3.0 and a range of 6.7. P1 was most confident in her knowledge, which may be a function of her "normotensive" status but which was also supported by a high score in the knowledge test. The flatly negative response from P2, who was in fact relatively knowledgeable and scored second highest on the knowledge test, may be explained by his HBP's resistance to treatment[15], which emerged during the session. Of particular interest is the perceived responsibility of the doctor, which divided the group, but which showed a marked correlation (r=0.55) with perceptions about individual power to control BP.

The knowledge test scores were interestingly low on the whole. It is worth observing that they expose knowledge shortcomings in patients considered to be motivated and educated, which raises interesting questions about the knowledge of less motivated and less educated patients. It must be stressed once again that, although these questions were intended to challenge participants, optimal self-care is practically impossible without the knowledge

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[15] This participant had a growing conviction that his blood pressure would resist all intervention, and that his knowledge and subsequent actions could not improve it.

they tested – this knowledge is required by anybody with HBP. The results are presented in Table 8.2 (for the complete test, see Appendix 6).

Qu				Points				Total
		P1	P2	P3	P4	P5	P6	
1	Eating fruit and vegetables helps to low er blood pressure because the:	1	1	1	1	0	0	4
2	Exercise is most useful for the cardiovascular system if it causes the heart to:	0	1	0	0	0	1	2
3	For people w ith high blood pressure w eight training:	1	0	0	0	0	0	1
4	For most people, the underlying cause of their blood pressure is:	0	1	0	1	0	1	3
5	High blood pressure affects the arteries by causing:	1	1	1	0	0	0	3
6	High blood pressure is a main risk factor for:	1	1	0	1	1	1	5
7	Current recommendations advise that our intake of alcohol should not be more than:	0	0	1	0	0	0	1
8	Current recommendations advise that our intake of salt should not be more than:	1	0	0	1	0	0	2
9	Smoking causes:	1	0	0	0	1	1	3
10	The medical name for high blood pressure is 'hypertension'. This is because:	1	1	0	1	1	1	5
Total		7	6	3	5	3	5	

Table 8.2 Knowledge test results: question stems and totals for each participant and question.

Despite recent sustained media coverage, and in keeping with the findings discussed in section 4.5.1.2, current recommendations for intake of salt and alcohol were unclear to participants, though the significance of alcohol in their health is not known since drinking habits were not elicited. Few were able to answer either question on exercise correctly. The mean score was 50% (maximum: 70%, minimum: 30%).

In summary, the above data collected via the questionnaire and knowledge test show a group of educated participants distributed across a forty-year age range, who are comfortable with the idea of using computers to find out about HBP. Their HBP, like the majority, has no known reason and is not well controlled. Although they firmly associate knowledge about HBP with good control, they may have knowledge shortcomings of which they are not necessarily aware, and which they are ambivalent about addressing. There is a grey area where their perceived responsibility for BP management ends and their doctor's begins, which may affect motivation to learn more and modify behaviour. They have individual differences have an undetermined effect on their response to Pressure's Off.

After this data collection, participants were observed and recorded using the sections of Pressure's Off as described below.

8.4 RECORDING AND TRANSCRIPTION OF OBSERVATION DATA

The interviews were recorded using an Olympus DS-330 digital voice recorder connected to an omnidirectional tripod-mounted microphone. The resulting files were then downloaded to a secure area of the server and transcribed verbatim using an Olympus AS-2000 PC transcription kit. The transcription of oral to written language is a difficult concept and a consequent deficit in transcript quality has been observed, including a high degree or error, omission and interpretation by the transcriber. The following steps (Poland, 2002, p629-49), borrowed from conversational analysis practices, are taken to safeguard transcription quality:

- A degree of non-verbal communication is noted:

    o Chronemic elements such as silences are transcribed as pauses with their duration in seconds, eg [pause 3 sec]

    o Hiatus in the interview is represented as a start time, and end time and a reason, eg [14:02-16:09 P2 describes breakfast today]

    o Short hesitation is represented as "..." or alternatively "uh", "er", "umm" and other variations

    o Paralinguistic communication such as laughing, sighing, interjections and held sounds are identified. Changes in tone which are not implied by the meaning of the sentence are interpreted by the researcher, eg [humourous sarcasm], and extra stress on words or phrases is denoted by italics.

    o Body language deemed significant by the researcher is noted.

- Areas of ambiguity are flagged with a question mark, a time and any hunches of the researcher, eg [?16:40 – I just had to go?].

- Interjections such as "Mm-hm" are included.

The completed transcripts comprised 78 pages at size 10 single-spaced font, and varied between 6 and 20 pages in length.

8.5 ANALYSING THE INTERVIEW DATA

This formative, exploratory study identified improvements to each individual area by eliciting qualitative responses to sections, rather than merely counting *instances* of positive comments, criticisms and suggested improvements. As such, the exercise aimed to improve a working version rather than provide a definitive evaluation of a finished product. On the basis of this evaluation, changes would be implemented, after which a beta evaluation could be carried out and a Version 1 released. This is discussed in more detail in Chapter 10 with regard to future work. Decisions had to be made about how data would be analysed to maximise relevance to this aim.

There are two main approaches to analysing interview data. One is a pre-specified procedure where each section of a transcript is attributed to one of the central research questions (Chioncel et al, 2003; Malterud, 2001). A more inductive approach, grounded in the interviews, allows the data themselves to suggest the codes and categories with which to interpret them (Malterud, 2001). As Heritage observes (1984, p243):

> "...analysis is strongly "data-driven" ... Correspondingly, there is a strong bias against *a priori* speculations about the orientations and motives of speakers ... Thus the empirical conduct of speakers is treated as the central resource out of which analysis may develop"

Because the evaluation was a valuable opportunity to gain further insight into patients' experiences, the researcher was receptive to a number of tangential comments, if they were judged relevant to the broader issues affecting the design of Pressure's Off. This approach generated rich data which were not well expressed by pre-defined codes relating to the questions and, moreover, there was a considerable amount of overlap between responses, making them difficult to delineate. For example, a participant might find an area interesting *because* they understood it, or might make extensive suggestions about improvements when asked about whether their understanding had been improved. Therefore it was considered appropriate to ground coding in the data themselves.

In the coding exercise, an early decision was made to treat each different set of responses to an excerpt as separate interviews, which allowed a corpus of responses to grow about each area examined. In parallel, however, to mop up

the many more general comments which would otherwise have been ignored, the interviews were also analysed as single entities.

The researcher open-coded the transcripts in a first pass exercise which generated a code book containing 66 codes in 6 categories: affective responses; interest; suggested improvements; understanding; unanswered questions and usability. To reduce subjectivity of interpretation, inconsistency, and errors, a second coder used the code book to carry out a spot check of the existing coding and inter-coder variability was resolved through discussion. The volume of data allowed coding using a word processor and spreadsheet package.

8.6 FINDINGS

In qualitative research with its hermeneutic approach to data analysis, reliability and validity must be demonstrated as in quantitative research. Among many valuable pieces of advice for the qualitative researcher, David Silverman (2000) warns:

> '...qualitative researchers, with their in-depth access to single cases, have to overcome a special temptation. How are they to convince themselves (and their audience) that their 'findings' are genuinely based on critical investigation of their data, and do not depend on a few well-chosen 'examples'?' (p176).

Or, as Nigel Edwards, Director of Policy at the NHS Federation remarked (2004), "The plural of anecdotes is not evidence". This potential pitfall of 'anecdotalism' is an important consideration in this project. As in the case of any software evaluation, this evaluation exercise had a formative purpose - to identify strengths and weaknesses in the sections covered with a view to improving them. The data presented below have been selected for inclusion on the basis that they are representative of phenomena observed during the exercise. Because of the wide-ranging nature of the comments data cannot be presented in full, but can be accessed in full on the accompanying CD-ROM (Appendix 4). Those presented below represent the processes undertaken, and have been strategically chosen and included on the basis of their noteworthiness, frequency of mention, saliency, or good sense.

The sections viewed, by whom, and the order in which they were viewed are summarised in Figure 8.9. Two sections – *What is Blood Pressure?* and

Nutritional Content of Foods were viewed once, and because the opportunistic recruitment effectively came to an end before saturation was reached, it was not possible to increase their viewing incidence. The number of sections covered by each participant, also shown in Figure 9.5, depended on the pace of their feedback.

	P1	P2	P3	P4	P5	P6
The heart	1	1				4
Body Mass Index	2	2	1	1		1
What is blood pressure?	3				1	2
Understanding the numbers	4					
Consequences of HBP	5		2	2	2	3
Stroke	6		3			5
Search for my medicine		3	4	4		
Understanding nutrional information	7	4	5	3		6
Nutritional content of foods	8					

Figure 8.7. Sections viewed (blue cells) and viewing order (red text)

Findings are divided into two areas – feedback on each area with a view to improving it, and more nuanced findings which offer insight into the reactions of people using the Web for information about HBP.

8.6.1 RESPONSES TO THE PRESSURE'S OFF AREAS COVERED

The study was based on participants' interaction with the selected areas of Pressure's Off, described in Section 7.4.3. Their responses to each section are outlined below, organised by category of response.

8.6.1.1 Excerpt 1: The heart

Number of evaluators: 3

Mean interest: 5.5 (1.6-10.0)

Mean improved understanding: 5.3 (0.6 – 10.0)

A number of enthusiastic **affective responses** were collected from P1 who showed particular enjoyment, while P6 voiced some discomfort about the amount of information presented in the section (See section 8.7.2.3). **Interest** in the section varied; P1 was intrigued while P2, who had familiarised himself with the heart after an irregular ECG, was unmoved by both the information and its presentation, describing himself as "a bit flippant about the heart" since it was now "not a particular focus". P6 was also indifferent, since information about the heart "wouldn't be the first thing" she would try to find out.

The section affected different participants' **understanding** differently. For P6, who perceived the information as peripheral to requirements, it "didn't hinder or particularly help", whereas for P2 "I don't think there was anything there I didn't know...". Both awarded low marks on the basis of their personal lack of gain from the section in combination with a general lack of interest in the subject area. P1 took the information on its own merits, showing no inclination to question its inclusion. She reiterated that the graphical and verbal presentation was very clear. The strategic use of animation was positively received by all participants. P6, who showed an early bias against any moving elements on the screen, remarked that the animation of blood flow through the heart "feels appropriate", while P2 "liked it when it moved" and P1 commented "...seeing the thing move, and uh... Yeah, I think that was really – really quite cool". P1 was also appreciative about the use of animation to shift focus from one area of the heart to another. P6 raised an issue about the labelling of the outside of the heart, which she found interfered with understanding because it "*diluted* the image", and which is discussed below as a suggested improvement.

There was one **unanswered question**, raised by P2, about why a healthy heart might appear unhealthy on an ECG. Since this was peripheral to the section, it was noted for future work on other areas of Pressure's Off. Two **usability** issues were raised. P2, who tended to scan screens rapidly, missed the instructions and without intervention would have experienced the section as a series of non-interactive screens. This raised the need for experimentation with ways of emphasising the navigation controls and instructions. In addition, P1 pointed out that her colour-blind father would have had difficulty distinguishing between the red and blue used to denote the different sides of the heart. This was not critical, however, since the information was not exclusively reliant on colour. **Suggested improvements** are summarised below.

Suggested improvement	Action
P2 pointed out that while you could activate text by clicking on some areas of the heart, you could not on others – the valves, for example.	As a consistency measure, labels to be available for all areas of the heart on clicking.

P6 suggested that the static labels on the external heart, which she found burdensome, should be replaced by labels activated by clicking. In fact this approach had already been adopted for the internal heart, on the basis that it more complicated.	As consistency measure, and to reduce cognitive load, to develop external heart labels to be activated by clicking.

8.6.1.2 Excerpt 2: Body Mass Index[16] (BMI)

Number of evaluators:	5
Mean interest:	5.6 (1.7 – 8.8)
Mean improved understanding:	4.4 (1.2 – 9.2)

The **affective responses** of P1 (BMI 23.5), P3 (BMI: 35.6) and P6 (BMI: 28.0) were connected with their discomfort about their weights, and as such are discussed in Section 8.7.2.4. Despite this, there was **interest** in the section. P2 was excited by the opportunity to experiment with weight-gain or weight-loss scenarios – "That's quite interesting actually". P4 also found the section "interesting". For P6, familiarity with the subject material, in which she was generally interested, tempered her interest in this particular case, a sentiment paraphrased by P2:

> Well, I suppose it's not uninteresting, at that level, but I think I had an idea of what that would be and that was why, um… (P2)

Those already familiar with the concept of BMI did not always report improved **understanding**. P2 had optimal BMI which, on the contrary, was for him another reason to be mystified about why he should be afflicted with HBP. P6 commented "I'm afraid that's… nothing I don't know, there." Moreover, in this section the problem with looking at individual sections out of context emerged. For example, P4 found the process of calculating his BMI something of an academic exercise, since it emerged that he had not grasped beforehand how his weight might affect his health: "I know what happens with my weight and how it fluctuates, but – again – I don't know if it's healthy or unhealthy". P1, who didn't perceive that there was "much to understand", found her

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[16] Although a rough measure of overweight which does not accommodate different body types, BMI is routinely used as an easily-calculated guide. The safe range is considered to be between 20 and 25.

understanding improved because the BMI calculator could, unusually, process Imperial units. Both P1 and P6 reiterated that the section's "clarity" was a positive point. P4 was the only participant with **unanswered questions**, and these demonstrated his aforementioned conceptual difficulties. He wanted to know what a safe weight was, suggesting that he had not grasped the implications of his height for his weight.

A number of **usability** issues were raised, many of which incidentally highlighted a tendency to overlook the instructions.

> MV: You said "Oh, I need to click" – could you see anywhere on the screen where you would have clicked if you needed to do a conversion?
>
> P2: I suppose I would have just expect to click here [on the word Imperial] to change from Imperial to metric – that's what I would have thought of doing.
>
> MV: Interesting – I've included something [the instructions] up there, but maybe it would be a good idea –
>
> P2: Well, also – well, I didn't read *that* [the instructions].

For this reason, and due to the amount of information on the page containing the tool, a proportion of users did not engage as planned with the most important screen elements. Most notably, encountering the Imperial area of the tool at the top of the page, two participants (P2, P4 and P6) were briefly discouraged, despite the corresponding Metric tool appearing directly below and also above 'the fold'. Moreover not every participant noticed the adjacent link to a conversion chart. No participant used the conversion chart, and only one (P6) acknowledged it on being prompted. Similarly, the graphical BMI chart which allows users to contextualise their BMI tended to be omitted (only P1 acknowledged it without prompting).

This section in particular shed highlighted the diverse approaches of different users to processing information on a screen, one taking the time to acquire an overview of a page before interacting with content:

> MV: Now I saw you hovered over the link [to the feedback] there –
>
> P4: Yes.
>
> MV: Were you tempted?
>
> P4: Yes I was –
>
> MV: What stopped you?
>
> P4: Um... what stopped me was... that um... I found that using computers it's generally worth your while... trying – getting to the

bottom of the page... *before* you start using the links, because they can lead you to place you don't wanna be.

while another tended to process pages serially:

"....part of my hesitation might have been that... I realised that – cos I was loo– what I saw first was the Imperial, um, measurement, and I actually realised that was going to take me longer to remember, my Imperial... statistics, than my Metric statistics – that's why I sort of looked at that first, and then my eyes went down to the metric one and I thought "I know – I know that one immediately"" (P6)

and another tended to be prioritise certain features and overlook others:

MV: There's Metric or Imperial.

P2: Yeah, I have to go Metric.

MV: Ok – was that clear to you? [he shakes his head] It wasn't...

P2: I thought I'd clicked something – what I looked at – I was looking to see 'Click on Imperial to change it' – does that make sense? [clicks and reads]. I'm overweight!

MV: [pause] Sorry?

P2: I'm not overweight – I can't be overweight!

MV: No, you're 23 point –

P2: 23 – sorry...

The need to scroll was vulnerable to oversight in this section and, since participants reliably scrolled through text elsewhere in Pressure's Off, this was interpreted as a function of the several discrete units of information on a single page.

It would be nice if they were a bit closer, so... that you could actually... you don't have to go up and down to see them. (P4)

I mean, obviously I had to scroll down, so – I – you know... I sort of had to reach over for the mouse and... (P6)

Mm. I don't need the metric – I can scroll down here...? (P3)

Well I think it's a difficulty with it being here [Metric under Imperial]. Because whenever you're looking at a Web page you scroll down so you could have – if Imperial and Metric were at the same level from that perspective, then it would have been easier to see. Because you tend to look down. (P2)

The form was not as intuitive for everyone as P4 asserted:

Yeah, yeah. I thought is was... intuitive – I – as a [profession] one of the things that we know is, if you want information, create empty boxes – people automatically fill them in, cos you've got empty boxes it intuitively leads you to what to do. (P4)

but depended on familiarity with the keyboard and with forms themselves. For example, P3 was observed in her attempt, lasting several seconds, to identify a key to enter the ½ symbol (common on typewriters but absent from computer keyboards).

Suggested improvement	Action
P2 and P4 suggested arranging the Metric and Imperial calculators so that they appeared simultaneously rather than serially.	Modify layout so that Metric and Imperial calculators appear side by side.
P6 suggested that the static labels on the external heart, which she found burdensome, should be replaced by labels activated by clicking. In fact this approach had already been adopted for the internal heart, on the basis that it is a better way to present complicated information.	As a consistency measure, and to reduce cognitive load, develop external heart labels to be activated by clicking.
Advocating for people who find it difficult to process graphs, P3 suggested a graphical depiction of BMI and the idea of progressively sized human silhouettes was generated. While this could be misleading as a replacement approach, it could be used in addition to the numeric scales to signal the purpose of each axis.	Design new chart with comparatively sized silhouettes at intervals along the height and weight axis, supplementing the numeric scales.
Implied improvement	**Action**
The tool was designed on a single page which presented many different types of information – instructions, forms, feedback and links to a conversion and BMI charts - serially. It emerged that not all users registered the crucial features on the screen as anticipated.	Split the tool into separate pages for each step – choosing Metric or Imperial, generating a BMI, obtaining feedback, and viewing BMI in context.
The instructions were repeatedly overlooked, subsumed into or eclipsed by the other screen	Emphasise instructions through font and layout.

elements.	
Different data entry for the forms would free users from the keyboard. This might involve an online keyboard including symbols such as 1/2.	Explore.

8.6.1.3 Excerpt 3: What is blood pressure?

Number of evaluators: 3

Mean interest: 7.1 (6.1 – 8.4)

Mean improved understanding: 5.8 (3.1 – 8.5)

Affective responses for this section were specific and were incorporated into other coding categories. P1 and P5 both reiterated their **interest** in the section. P1 was engaged by the animation:

> I do like the moving bits – they're cool. They just make it look more interesting, and just... Yeah, more interesting. (P1)

whereas P5 hinted at a sense of obligation beneath her interest, which is discussed in more depth in Section 8.7.2.5.

P6 reported found that the images interfered with her **understanding**, and generalised about her cognitive approach in her feedback:

> ... I know about myself – what – the way I learn and receive information... and... by the third image... I... really sort of in a way didn't want to look at the diagram, I just wanted to read the words... (P6)

Significantly, she revised this self-assessment for the following section:

> No, I think it's good. So all that stuff I said about the other picture... that I can't manage pictures... I found that picture very effective. (P6)

but without changing her mind about this section which remained low in her estimation because "I think it might have confused me a bit" (P6). A possible reason for this antipathy is a shortcoming in the way HBP is conceptualised in the section, which may have overridden the text and interfered with her understanding, as Mayer (1984) warns poorly chosen images can:

> P6: [pause] Um... wh... those arrows – I don't know why they're bothering me [laughs] you know – I mean, are they supposed to indicate the... the *strain* on the artery, or... I don't know – just... it's...
>
> MV: Mmm. Ok, let's think about that one – think about how we could improve it. Um [16:14 – tries to explain the concept using a number of ineffective metaphors "it's not even that simple" – 17:20] So thinking about those arrows, is there any way we could have illustrated that better, that you can think of?

P6: [pause 10 seconds] No...

MV: Maybe then you can tell me, what are those arrows saying to you?

P6: Um... I think it's saying to me... that there's pushing in all directions, sort of...

MV: And... what does that mean to you in relation to high blood pressure?

P6: Not a lot, actually. No.

MV: Mm. Mm.

P6: *But* – but the text is meaningful... to me. I can conceptualise it more easily... through reading and come up with the same sort of *idea* as some of the examples you've used... about that – about the force that's needed, and, and, pushing, rather than that picture...

As somebody already familiar with the physiology of HBP, P1 found the section "very clear" and commented with approval about the avoidance of "horrendous long words" and, with P6, the effective brevity of the text. P5's responses about her understanding involved reporting the contents of the section without sign that she had assimilated the knowledge, indicative of a task-driven (Marton and Saljo, 1984) learning approach - possibly adopted for a demanding situation. Indeed this participant's obvious relaxation at the close of the session implied an ongoing discomfort and tension over its duration, which had not been registered by the researcher at the time. Attempts by the researcher to probe her responses elicited repetition of Pressure's Off content without elaboration, indicating a surface approach (Bloom, 1964).

P1 had one **unanswered question** pertaining to the two parts of the BP value (eg 130/80 mmHg) but remarked that this was likely to answered elsewhere in Pressure's Off, which it is. However, it could be usefully incorporated into the animation. Moreover, this raised the issue of granularity and context, discussed in more detail in Section 8.7.2.7.

Regarding **usability**, the tendency of some users to overlook the instructions was noted. P5 filtered them out because:

I was concentrating on the sentence I was reading there, so I ignored it. (P5)

Another issue was orientation – P5 and P6 did not recognise immediately that they had finished the section:

P6: [whispers to herself] That's just back to the beginning.

MV: So you clicked on Again and then you noticed that you were back to the beginning.

P6: Yeah.

Additionally, P5 (viewing her first section) had to peer to read the screen and was forced to use her glasses, which she did not seem accustomed to wearing.

Suggested improvement	Action
P1 would have found it useful to see the separate points in blood flow at which the two BP readings were taken. This would usefully tie in with the section "Understanding the numbers", which covers the reason for the two values which make up each BP reading.	Incorporate the two separate moments when BP is recorded into the animation.
P6 had problems with the way BP was represented graphically, which did not make sense to her. Since this representation is a crucial part of Pressure's Off, it needs to be reconsidered.	Generate and test different graphical representations with target users.

Implied improvement	Action
The end of the section was not immediately clear to P5 and P6. Orientation in the form of a display to indicate current location in the context of the total number of screens.	Ensure that the Again button is distinct in location and appearance.
P6 experienced problems when she tried to click rapidly through the section. Any buttons activated during an executing animation were found to reload the scene until it had completed, after which the button could be used.	Make adjustments to the Flash timeline and the way the buttons are presented so that all visible buttons can be used.

8.6.1.4 Excerpt 4: Understanding the numbers

Number of evaluators: 1
Interest: 8.3
Improved understanding: 8.3

P1 was the only participant who saw this section. No general **affective responses** were coded; she marked the section high for **interest** although she was familiar with the way BP values are expressed:

> I can remember when I didn't know, and when I did find out, I was like "Oh! I didn't know that." And I found it really interesting because I never knew what the blood pressure was... (P1)

She felt that it promoted **understanding**, also rated highly, because it was "clearly written down and it's easy to read". However, in common with the previous section, she felt that there were some **unanswered questions** in the section:

> P1: [reads and clicks for 58 secs] Would it say... Would it ever be helpful to know what an average blood pressure should be though? Have you got...?
>
> MV: Mm.
>
> P1: Because my dad, when he got, when he first went to have his blood pressure – and it was tremendously high, it was like two-hundred-and-twenty over a hundred and something...
>
> MV: Ah.
>
> P1: A hundred and ninety, and he, he doesn't know what the average blood pressure number should be.
>
> MV: He doesn't know what he's aiming at.
>
> P1: No... and... he's not managed to find that as well, because he's retired and not very good at using the Internet. Would that come under that – it wouldn't really because this is just telling you about the numbers and, and what they are, which is...

Again, this raises interesting questions about approaches to making a resource which can be used both as a reference and as a more in-depth guide, which are discussed in Section 8.6.3.3. P1 in particular showed global cognitive traits which balked at the way the information in this section had been circumscribed. There were no **usability** issues – the verbal material which dominated this section was found to be clear and easy to read.

Suggested improvement	Action
P1 felt it was an omission not to emphasise the "average" or target BP. Since a main aim of Pressure's Off, congruent with guidelines, is to maintain BP below this level, it is important to reinforce the message.	Include the target BP values prominently.
The issue of illustrating a heavily textual page was raised. The suggestion from the previous section *What Is Blood Pressure?* to flag the diastolic and	The illustration mentioned adjacent to be duplicated in this section.

systolic pressures, at the relevant stages of the animated elastic artery is also relevant to this section.

Implied improvement	Action
P1 found the way the information had been divided into sections left much untold.	For this section and others, include a cross referencing system.

8.6.1.5 Excerpt 5: Videos of the measurement process

As explained above, these were omitted since they did not reflect practice at this particular clinic.

8.6.1.6 Excerpt 6: Overview of the consequences of high

Number of evaluators: 4
Mean interest: 9.2 (8.1 - 10.0)
Mean improved understanding: 9.1 (8.3 - 9.6)

This section excited some particularly positive **affective responses**. P1 found it "great", as did P4, while P6 reiterated that it was "good". As hoped, the way the subject area, which dealt with insidious arterial damage, was presented did not create discomfort:

> "It's not too gruesome it will frighten somebody. Cos some of the pictures can be a bit gruesome, can't they." (P1).

> I'm comfortable with it, and I feel... reasonably detached, actually (P6)

P3 and P6 expanded on the reasons for their **interest**, which emerged as strongly related to the personal relevance of the subject matter – resembling an emotional involvement:

> ...it's caused me some great difficulties in my life, so, I've got a vested interest in trying to understand it and you know contribute to controlling it, you know... (P6)

> [Sighs] Well, it's *informative*. It sort of... tells me what is going on in my body. Really... if my blood pressure isn't controlled, and the damage it can do to the different areas of my heart. (P3)

whereas for P4, interest was closely connected with changes in understanding and he gave the impression of a more dispassionate, academic interest:

> The reasons *for* that [interest] is it is the first time I've understood the process that eventually leads to high blood pressure. (P4)

This last statement raised an interesting issue related to **understanding**, inadvertently flagging a *misunderstanding* which emerged with probing. P4 had failed to register a crucial screen element - the title of the section. This resided in the window's title bar and P4's experience indicates that in this location it was vulnerable to being filtered out (see Section 5.2.2.1) of consciousness. This failure caused or contributed to his impression that the section explained the *causes* of HBP, when in fact the close link between atherosclerosis and HBP is poorly understood and probably cyclical. When explained, P4 found this challenging to conceptualise, and remarked:

> If I was ill and I had come to look at that site, I would feel... [pause 5 seconds] Yeah, I would feel that I had an understanding of everything except the point you made about the circular cause and effect. (P4)

He was also concerned about the ability of the wider target user group to grasp this concept:

> In the world, as far as *I* know... 99.5% of the world's population still believe in linear cause and effect, and the idea that there can be cyclical cause and effect is not really understood by most people – (P4)

This opinion is interesting because to understand the implications and mutually-perpetuating nature of arterial damage and HBP it is *necessary* to be comfortable with the concept of cyclical cause and effect. It is unclear how many of the other participants misunderstood, but P6's correct interpretation indicates that the information *would* be correctly grasped by a proportion of users as "the harm that can go on in... your arteries ... over a period, if you have high blood pressure".

P4 also had problems with the vocabulary, which he took time to illustrate by thinking aloud:

> P4: What else did I get – "damage to the elastic layer of artery" – I can understand that.
>
> MV: Ok.
>
> P4: "raised" – yes, get that – "
>
> MV: Mm.
>
> P4: fibrous" – fibrous? – "plaque"?
>
> MV: Hmm.
>
> P4: What is a plaque? "Lipid"? Well, fat, I'd imagine – "absorbed into cell". Which cell?

MV: Mm... Mm! Yeah – which cell – good point. Yeah, I could easily make that clear. Even if I put "into a cell" – that would be –

P4: That would – that would – yes – that would be okay, yes.

He considers here one of the largest passages (58 words), which troubled him considerably. Although as P6 points out: "I mean this is quite a big bit of text, I suppose [the introductory screen]... but mostly it's pretty small... ". Experiencing this passage at the beginning of the section was probably daunting. P3 also had problems with part of the passage describing the healing response implicated in arterial damage:

> I feel it's just been put in there. If I was going through an article and saw that, I would just think [wrinkles her nose] "Where has this come from", you know? (P3)

which suggests that the description may have had some omissions of reasoning, further contributing to P4's mystification. The thought processes evident in P4's thinking aloud imply that the cognitive load of the screen was too high for him to process and assimilate the information. Contributors to this situation are the amount of text, the technical vocabulary and embedded explanations, and the lack of "signposts", by which he meant the aforementioned inconspicuous title, explicitness that the section outlined a process, and contextualisation of each screen in this process.

The labelling in this section, such as it was, was singled out as effective and helpful by P1 and P3. P1, P4 and P6 were enthusiastic about the diagrams:

> P4: Well I liked the little pictures [chuckle] Oh, I loved the little pictures.
>
> MV: The pictures worked for you?
>
> P4: Yeah. Very good.

> I just think the diagrams are great – I really do. All the diagrams in this are great. (P1)

> Um [pause 3 sec] I think, you know, flipping what I said before – I actually found... pictures really useful in... um... the... visualising the um... the harm that can go on in... your arteries... um... you know, over, over a period, if you have high blood pressure. (P6)

For P4 and P6 particularly, the graphics were more useful than the text in contributing to their understanding. Both of these two were inclined to consider text and images in isolation rather than as working partners, implying a particular cognitive style or approach, discussed in Section 8.7.2.6. There

were a number of **unanswered questions**. P1, identified earlier as having a global approach to BP knowledge, would have liked to see details the implications of the arterial damage included in the section. P4 had questions about the relationship between arterial damage and BP, discussed above. P6 wondered at length about the pace at which the damage developed, which preoccupied her considerably, although she acknowledged that this would be difficult to quantify:

> P6: But... that isn't the first question I would want to ask – you know, it – but I think inevitably, if you've had high blood pressure for a period of time, you might be thinking "Well, I wonder where I'm at" [chuckles]
>
> MV: Mm.
>
> P6: In that stage – at that, that process. Um... uh... you know – because it is a concern that people have – if you've – if you do choose to take an interest and listen to what you're being told, you know, you, you might have a worry about... if and when you're going to become... ill.
>
> MV: Mm.
>
> P6: You know – further than the fact you've got high blood pressure, which in itself is a condition you hope to be able to control, whether you're actually going to have, you know, the consequences... and I know that somewhere along here [Pressure's Off menu] there's probably – they're going to tell you about those, you know, you think "God, I wonder if I look like that".
>
> MV: Mm.
>
> P6: So that, you know, it could – you could think "Well, how long has that... taken, for these layers to break down" –
>
> MV: Yes, I think that's a really good point actually.
>
> P6: But I'm sure it's really difficult to answer because of there must be so many contributing factors...

Related to this is the notion of reversibility, although P6 said she was not concerned by that – she was principally concerned with anticipating *when* complications might develop.

There were few **usability** issues. P4 emphasised the importance of clear "signposts" to help with pages accessed "out of context", as often happens on the Web. P3 exposed a problem with the Flash controls, which were not robust during some animations.

Suggested improvement	Action
P4 pointed out that because the section showed a process in a series of stages, the stages could be numbered. It was reinforced in discussion that this numbering could also serve to to contextualise the information and orientate the user.	Number each screen and include context (eg 2 of 4).
P4 did not register the title of the section (residing in the window's title bar) which caused or contributed to a misunderstanding. He suggested that the title be clearly included.	Titles to be clearly included in the body of the page.
Both P1, P3 and P4 felt that the normal artery should be labelled at the beginning of the sequence, rather than being left to "assumption" (P1).	Normal artery to be clearly defined at the beginning of the section.
Implied improvement	**Action**
In common with P6 in Excerpt 3, P3 experienced problems when she tried to click rapidly through the section. Any buttons activated during an executing animation were found to reload the animation until it had completed, after which the button could be used.	Make adjustments to the Flash timeline and the way the buttons are presented so that all visible buttons can be used.
P4 and P6 both experienced problems with the verbal material – specifically the vocabulary. P6 perceived this text as simultaneously difficult and necessary. This implies the need for explanation of difficult terms.	Consider solutions. Links to a glossary is the obvious choice here, but may interfere with users' concentration. Including a definition in the body of the text (the current approach) is liable to make the passages bulky and daunting. A third alternative is to include explanations in a dedicated a section of

	the window.
P6 flagged the concept of cyclical cause and effect as complicated, something to make more explicit	Include initial and summary screens which illustrate and reinforce the mutually-perpetuating relationship between HBP and atherosclerosis.
P1 felt that further damage to the arteries should be included, emphasising a point she had made earlier in Excerpt 4 about the difficulties in delineating BP information into separate units.	Cross reference with other material about blocking and bursting effects.

8.6.1.7 Excerpt 7: Stroke

Number of evaluators: 4
Mean interest: 9.0 (8.1 - 10.0)
Mean improved understanding: 8.8 (7.1 – 10.0)

P1's **affective responses** were positive – "That's really good that is – I liked that" – and she volunteered that the section wasn't too scary, which she attributed to the drawn illustrations:

> P1: That wasn't too scary.
>
> MV: You didn't think it was.
>
> P1: No! No – what I think's scary is when they have, you know, the real life pictures... of the, the blood, um, the arteries and that –
>
> MV: Ruptured –
>
> P1: But then some people might need that – they might need that little... kick up the backside.

Although the diagrams had been calculated to provide dispassionate illustration of a potentially life-threatening condition, P6 suggested that even the most unemotional portrayal could not override pre-existing fears in the observer:

> P6: I also know that it's something that people with high blood pressure are – can be at risk of... and I think I'm quite worried about it. Um... having had high blood pressure for, you know, a long time...
>
> MV: Mm...

P6: And I think I've got... really quite scared of it actually.

MV: Mm.

P6: So um... but – but the way I treat fear is always to try and find things out – even if um... um... yes, even if it's stuff I would rather not know about – it's a way of controlling my fear is to find things out about – about – about a subject.

This statement implies that others might not treat fear with such intrepidity, and rather may adopt avoidance tactics, or be upset by the content. P3 also made a statement which alerted the researcher to the impact of the section:

I tell you what... I would say that for someone who had no idea at all, I think this would be quite an eye-opener. (P3)

This suggests that the content is sensitive, which should be acknowledged within the section's introduction.

In common with Excerpt 6, **interest** scored highly and was expressed in either emotional or academic terms. P6's interest was strongly related to the section's relevance to her personal circumstances:

Yes – it has a sort of resonance for me, you know, it's got personally, um... it's something that... I want to... know about... (P6)

...it completely relates to me, my experience, so... I would want to know. (P6)

Although the information was not new to her, she was "glad it's there" (P6). In contrast, P5's interest had a more academic basis related to the different types of stroke:

MV: Going back to the first question about finding it interesting – what are your reasons?

P5: It explained the different types of stroke [28:15 – describes the different strokes – 28:40] the other one, it's likely that you can get over it partially.

She also related her interest to understanding – "It explains everything in detail – to a *layman*. You know, what exactly happening to your blood vessels. It explains." (P5). P1 "just found it really interesting", and mentioned the animations as a factor in this.

The section increased **understanding** of the subject area, which also scored highly. Again, the diagrams were well received:

Because I like the diagrams. I like... the detailed diagrams (P3)

P6: – I thought it was quite clear here... and um... that sort of image or bit of the brain sort of having – getting *deprived* and, and closing *off* and, you know, being possibly being damaged... or being damaged but then also maybe being damaged permanently – I thought that was illustrated quite well.

MV: Mm.

P6: And yet all it is this sort of load of spots in the head that's sort of... kind of shrivelled up and gone a bit pale – but I thought – I thought it was *good*.

Illustrating the processes leading to a stroke was valued for its contribution to conceptualising a complicated event:

What I like about the section is the detailed – the processes, the way you move from one process to the other, so you can follow it through. (P3)

Well, the diagram too helps one to understand. The diagram helps you to understand. It tells you about the blood vessels in the different parts of the brain – earlier on – I think the previous statement – and how a clot, you know... can block... the circulation, you see... (P5)

I think they're just so, um... Just so... easy to understand, bec – you know – nothing complicated – it's not, um... not lots of diagrams and not all – it's just showing you, it says "OK, you've got lots of blood vessels" but it's just showing the one, and it's clear and easy to understand and easy to follow. (P1)

P1 and P5 both found the distinction between the types of stroke illuminating. In common with her reaction to other excerpts, "once again, quite a lot of long or difficult words..." emerged as an issue for P6. Again, on probing, a preference surfaced that the technical words should be included rather than replaced:

MV: Long difficult words. Can you give me some examples?

P6: Err... [pause 5 sec]. Atheroma. But then you've put that in brackets and explained it straight away.

MV: Do you think we should have left out the term and put "small pieces of the build up on the artery wall... tend to break off"...?

P6: For me, I'd rather it was in there somewhere, but, but I think it's important to have an explanation for what it means. Because, you know, they're the names that doctors will use.

It is interesting that P6 found it difficult to substantiate her impression that the text was difficult to understand because of difficult words. P4 had a similar experience interacting with Excerpt 6. However, as Preece and colleagues neatly observe, users should feel that "it is the system that is being tested and not them" (1994, p350). It goes without saying that the *impression* that the

text is difficult poses the same threat to understanding as if it actually *were* difficult by some objective measure. Voluntary users of an information package should not be expected to persevere with complex material which could be simplified without loss of meaning. Nevertheless, the competing imperatives to represent complexity, minimise the volume of text, and deal with difficult vocabulary are evident here and are difficult to resolve.

P1 and P3 flagged some ambiguity which hinged on labelling:

> P1: But you know that's an artery and this is… You're going to have a bit of…
>
> MV: Because again, that's not labelled as a healthy artery, but I suppose, or any kind of artery – I tried to give it some context by having it coming out of the brain…
>
> P1: Well, you know that's an artery, don't you, and you know that this is a damaged one.

Although she reassured that she knew what was meant, it was clear that she had had to make an assumption in the light of vague information. P3 was succinctly definite:

> MV: Mm – what do think it needs?
>
> P3: Label it?
>
> MV: Label the arteries and pieces of plaque.
>
> P3: That's right.

There were **unanswered questions**. P6 appreciated the explanation of stroke, but at the same time mentioned her need for a more applicable, practical type of information – "…all my questions have always been about 'What can I do to stop it happening?'":

> People look at it for different reasons. And some people – maybe if it was a relative or something, and somebody had had a stroke – they might want to know that information. You know they might need that information to find out what it meant and what had happened. I mean maybe obviously they're going to once again, like me wanting to prevent it they're going to think "Well, are they going to get better? What can I do? How can I help them? Will they talk? Will they" – whatever it is that they're compromised with, but, um… there is the need for that, and uh… I think it is helpful, helpful to have it there. (P6)

This unresolved issue of delineating information is discussed below in the context of suggested improvements. The issue of fear is discussed in Section 8.6.3.4. **Usability** was generally found to be good, although a clearer distinction was needed between the consequences of thrombotic and embolic

strokes. These were presented with the reuse of a sequence of animation, creating brief but confusing feelings of déjà vu for P6:

> No – um I just - as I say there were, I mean in the way I was, I wasn't sure at one stage whether I was – the separation between the two kind of strokes – whether I'd missed a bit somewhere, and whether I'd um... you know carried on on a bit that I'd already had before... So but I was obviously, I mean you have... deliberately repeated the last two – (P6)

Suggested improvement	Action
P6 was confused by the reuse of a single piece of animation to illustrate the effects of two different types of stroke. This could be remedied by presenting the two types in separate and distinctive blood vessels.	Create a separate distinctive blood vessel for the second type of stroke.
Related to her confusion above, and in common with some comments made about Excerpt 6 which also illustrated a process, P6 suggested including some orientation in the form of "how many pages there are, and what you're on", as well as sub-headings.	Number each screen and include titles and context (eg 2 of 4).
P3 saw a clear need for more labelling to link the commentary and illustration.	Label each element as it is introduced.

Implied improvement	Action
P1 and P6 raised the issue of fear, but diverged in attitude. The former perceived the benefits of an emotional "kick up the backside" while the latter was often troubled by the prospect of stroke. The section needs to acknowledge the possibility that some users may experience discomfort when engaging with this content.	Provide an introductory screen containing an overview of the section, an acknowledgement that the content may make uncomfortable viewing, and details of support organisations.
P6 referred to the need for practical information for those who had experienced a stroke, as well as for those who were concerned with preventing one. This is beyond the scope of Pressure's Off - as a multifactorial condition with a number of	The exit strategy for Pressure's Off requires a way of building and maintaining lists of external resources

complications, it is challenging to represent these for stroke. However, in avoiding a reductive and simplistic approach it is important to be transparent and explicit about this difficulty by signposting, at the peripheries of the knowledge base, related knowledge and resources.	covering subjects arising from the core material.

8.6.1.8 Excerpt 8: Search for my medication

Number of evaluators:	3
Mean interest:	9.5 (9.5 – 9.6)
Mean improved understanding:	9.3 (9.1 – 9.5)

As evidenced by its high score on the visual analogue scales, the section was of great **interest** and received a particularly enthusiastic response from all participants.

> See, this is interesting me – all of this is interesting me... what all these are... apart from the diuretics. Because I just think these are probably bad medicine... (P2)
>
> Mm! Very interesting! (P4)

This was of interest because the section was exclusively text-based and, considering earlier feedback, offered little the researcher felt to be immediately engaging. Once again, reasons for interest were strongly related to understanding. **Understanding** was highly rated, which was also interesting since a number of participants had found even relatively small passages of text burdensome in former sections. Yet, in the absence of prompting, no participant reported being troubled by the text in this section.

On exploring this unexpectedly positive reaction, it emerged that the question-and-answer format was helpful:

> P4: Um... it – I thought that um by having the frequently asked questions, and the answers, that worked very well...
>
> MV: You seemed to get on better with the text in this section.
>
> P4: I did, because it is... uh... it's... The purpose of the text is uh explained as a headline before each piece of text...

This was significant, since P4 had been particularly outspoken in criticism of the amount and quality of verbal content in other sections. On probing it emerged that the way information was divided into manageable portions by

the question-and-answer format was key, and he had the impression that the sections on different drug groups were a "nice size".

Above all others, this section was valued for the changes in knowledge it brought about. When the researcher questioned whether the information was already well known, P2 (a more knowledgeable participant – see Table 8.2) volunteered "Well, no, this bit here looks new – um... I wasn't aware of that... so...". The other participants were of similar opinion:

> It's the "why am I taking them" and "how they work"... uh... which were particularly of interest... And uh, the "other information" at the bottom was also very interesting... (P4)

> P3: I think I've pretty much said it – I like this section because it tells you about the side effects – it also tells you exactly what your medication is doing for you, and so if there was anything else – for example, I knew all along that – there was one thing I certainly didn't know that I saw here – I'll tell you [39:05 digression about postural hypotension]
>
> MV: So you learnt something?
>
> P3: I learnt something.

> It provided information that, um, I found interesting... and which I didn't know before. (P4)

There were some **unanswered questions**. P3 referred to the variability of medication between ethnicities. P2's unanswered questions were so numerous, so reasoned, so illustrative, and so eloquently expressed that they are worth reproducing below:

> P2: So if I'm looking at this I'm – I mean I notice this dizziness – you might feel dizzy. What's that caused by? Why d'you feel dizzy? Is that lack of oxygen in the brain? What – what's causing that?
>
> MV: Good question.
>
> [36:25 – discuss ideas for graphically representing how drugs work - 37:20]
>
> P2: - and why does it affect my prostate gland, and my understanding – from some of the stuff I've read it tends to talk about the prostate gland first, and so... my guess would be that maybe it was developed in terms of the *prostate* gland, and then, then it was seen to, you know – so *why*... why – what's the link there? Um... You know – those are my sort of questions. And the other thing you see is like when you look at the other stuff that's in places like the BHS web site and stuff – what I'm clear about is that there's probably a need for um... How do these drugs interact with one-another? What is it that – why is it that, you know, an alpha blocker with a calcium channel blocker works, yeah?

[38:15 – more on his questions, and why shouldn't he have a time off medication to prove to himself whether it is working or not? The consultant told him that it would be unethical to endorse that; he is unsure whether to take things into his own hands – 39:30] For me... you know - I'm just looking for evidence – that's the sort of information I want from this. So I – you know – if that's having that effect on me and somehow it can be *shown* to me what it's doing to my body – cos it's not just that the disease has not symptoms, the *treatment* has no symptoms either. I mean, how do I measure – if I can't experience a measurement of my blood pressure being high – ie can't feel unwell... then obviously I can't experience the opposite either. I can't experience it being lower. So for me I think "Ok, I'd like some evidence here, you know – working premises – you try something, you measure what it does... and so for *me* it's – it is *unsatisfactory* I mean, you know, my, my mean... [40:45 – digression about how his BP hasn't changed in 2 years, through 5 different medications in different combinations, but he is encouraged to consider this a success of sorts, since it has not risen - 41:56] This is interesting though – I mean working out – what the hell's the difference between *those*? [42:33 - he looks at a list within a group, looks up his drugs - 42:59]

He also wanted to be shown, more controversially, about what the "cost implications are on the NHS and I want to be sure that that's not affecting my prescriptions".

P2 enjoyed the section, and yet it fell far short of offering the information he wanted. Considering his list of questions raises the important issue of withholding or disclosing sensitive information - thinking back to the needs assessment survey (Figure 6.10), a high proportion of the respondents stated that they would wish to individualise information from patient to patient.

The drug search engine raised some **usability** issues, some of which demonstrated the robustness of the design. The excerpt below shows P4 circumventing the search engine to find information specific to his drug group:

P4: It's Benza – begins with a B anyway.

MV: Let's see how you deal with this considering you don't know the name of the drug. [he clicks on Diuretics on the menu]. Ah, you would go straight to Diuretics.

P4: [he finds it in the list of drug names at the top of the Diuretics page] There it is – Benzo – Benz blub-lub-lub...

He looked for and found an alternative route to the information. However, for P3, the search engine's intolerance of spelling mistakes proved a problem:

MV: So thinking about that screen how could we make it more straightforward to use?

P3: You remember you said when I got here I put Amlodipine and I didn't spell it right... and it couldn't find any word – what was that for? [asking about the search configuration box]

MV: [40:50 – explains – 41:27] Do you think that needs to be labelled – that little section?

P3: Yes – it's just that I just thought "Oh put Isdin in" –

MV: You knew to do that – some patients wouldn't.

P3: No.

In addition, P2 mistook the list of drugs within each group for a list of links, and was frustrated that he was not able to click them to access information on individual drugs. The mistake appeared to be more wishful thinking than misleading design.

Suggested improvements	Action
P3 mentioned ethnicity in relation to different antihypertensive drug groups. Ethnicity has considerable influence over first line treatment, and could be included as a reason for a medication being prescribed. At the same time, because of the interaction of factors which dictate treatment choices, and because evidence continues to emerge, it is difficult to know how to include this information definitively.	Seek specialist advice.
In the absence of technology which could accommodate spelling mistakes, P3 would have appreciated a caveat that care must be taken entering the name of the drug into the search field.	Include caveat about precise spelling adjacent to search field. Look for solutions which can make inferences in the event of spelling errors.
P3 wanted to see the information represented "visually": Most people are visual – people are no longer... like before - they use computers a lot. People no longer look at the written word much now – I mean I come from a generation who looks at written word. And there are more younger people suffering with hypertension, isn't it? So you need to make it	Explore ways to present information about drug modes of action visually.

> more friendly... But if you do something to show how it works on the screen, it probably would help... something visual. (P3)

This would be complicated, since the mechanisms of drug action are often poorly understood. However, this uncertainty does not preclude the graphical representation of existing theories, with the appropriate caveats.

Implied improvements	Action
P2 and P3 would have valued 'evidence' about the different drugs. However, evidence is difficult to include in an appropriate way, since it assumes completeness and relevance as well as rigour (Milne et al, 2000). One approach would be to divide evidence into some priority areas - Men, Women, Older People, Ethnicities, Side Effects, for example - while being transparent that it has not been possible to represent *all* the evidence about a given drug.	Seek specialist advice about representing evidence. Experiment with a well-researched, widely-used drug such as bendrofluazide (a long established diuretic).

8.6.1.9 Excerpt 9: Interpreting nutritional information

Number of evaluators: 4 (P3 also viewed it briefly, on her initiative)

Mean interest: 7.4 (2.6-10.0)

Mean improved understanding: 5.0 (1.0 – 8.3)?

This section provoked interestingly diverse reactions. General **affective responses** from P1, P3 and P6 were positive – "excellent" (P1), "really good" (P1), "fascinating" (P3) and "good" (P6). Notably, these were from the women of the sample – although this sample is small, this is noteworthy because it supports findings from other studies on the subject of gender and diet. Possible explanations for which are discussed below.

Considering **interest** in the section, the women were receptive. In contrast, the two men gave the impression of resistance. P4 emitted a number of audible groans during this section, the only one of the session which provoked this reaction. P2 rated the section low on interest,

> MV: You said not very interesting – why is that?

P2: [long pause] Um... [more pause] I suppose I'm thinking about if I'm eating crap out of a jar from the supermarket then I know I'm not eating the best food I can. If I'm talking about eating healthily then I'm talking about... making food for myself. What would be – what I would do with one of these [79:40 – digression about how he would improve the sauce's nutritional value with his own additions and a little extra time – 80:22] I know that the stuff I'm buying in a jar at the supermarket is not particularly good for me – yes I could make some choices about it, but...

The flavour of his contributions on the section and his urge, evident throughout the discussion on the section, to discuss his own diet also suggested defensiveness, which he inadvertently reinforced with statements such as:

Yeah I suppose I would recognise that I'm not eating particularly well if I looked at it... (P2)

He claimed to be well aware of the nutritional content of packaged foods, remarking that he would not need to look at the labels but could get all the information he needed from looking at the ingredients list. However, he had already mentioned his surprise at the high quantity of salt in a well-known brand of vegetable juice – scanning the ingredients shows that salt and spices are the last, and therefore least, ingredients – he would have needed to consult the nutritional information to know that the sodium content was in fact high. P2 showed aversion to the content, though it appeared simultaneously to interest him, and this contradictory reaction suggests that he was not entirely comfortable with the subject material.

In contrast, the women found the section highly engaging – P3 asked to see it additional to her allocation – and rated it highly.

Although the small sample size makes it difficult to draw conclusions from this, two factors may be at play here. Firstly, the men were both within the ideal BMI range and may not have felt worried about their eating habits – a concern which mistakenly tends to fixate on weight rather than health. Secondly, women are more likely than men to be chronic dieters or restrained eaters (Liebman et al, 2001; Conti et al, 2004).

In terms of its effect on **understanding**, the two who found the section less useful did so for different reasons. P2 considered that he already understood the concepts: "It's just because I understand it, I think – it's not a criticism of

it". P4 was ambivalent. On the one hand, he felt the section contained important information:

> I think the thing that I like most is that it gives all the recommended daily intake and then it gives you information about particular foods... so that you should be able to relate the two to give you some idea about whether you're taking in the right amount or not. (P4)

but at the same time, he found it difficult to transform this information into knowledge: "The information was there but I couldn't assimilate it". On probing this statement an interesting inconsistency emerged, and it is worth including the following dialogue in full to illustrate the point that logical, rational presentation of health information is of limited use unless positive first impressions are secured first – the "hook" to ensure the user becomes engaged and continues with the section:

> P4: Yeah. [5 sec pause] Theeeeee... important point is highlighted. Um... I start reading from the top and by the time I've read two or three lines I'm pretty bored here [chuckles]. So again the important point should be at the top.
>
> MV: Ah-huh! Mm.
>
> P4: That should work in the same way as a newspaper article – when a journalist writes a newspaper article they write it with the important things at the beginning and the less important things further down so their editor can cut off... the boring bits –
>
> MV: Ok – so looking at this protein... in the Tomato and Mascarpone, which do you think – what order do you think the sentences should come?
>
> P4: Ok, ummm...
>
> MV: What is the most important thing? Considering that you've got four different sauces, and if I tell you now that this sentence [one of the recommended daily intake statements] happens –
>
> P4: In all –
>
> MV: - in all of them.
>
> P4: Yeah.
>
> MV: What's the most important thing to you?
>
> P4: The highlighted part is the most important. Um... then...
>
> MV: So you would rather know – you'd rather emphasise the generic piece of information rather than the bit of information that pertains to the sauce, which is...
>
> P4: Yeah. It's... true – though the reasons for that is what I'm looking for is advice on what to do. So it's not so much that I need to know that 14g gives one serving blah blah blah – what I'm looking for is... what do I do? And uh... this gives me the advice about what to do.

This intriguing swerve of reasoning at the very end of the excerpt seemed to perplex even the participant himself. He had not found the section conducive to his learning, but on trying to substantiate his reasons, they evaporated. This justification of the developer's rationale is a pyrrhic victory – in the real world this user, in the unlikely event that he chose to persist, would have had the impression that the section demanded perseverance. There were other concerns about the volume of information. Like P4, P6 was simultaneously concerned and approving about the volume of information, an ongoing theme in her contribution: "...good to have it there, but I think it takes quite a long time to remember it." P2, however, had hoped to be able to click on each individual ingredient for a list of evidence about its relationship with HBP – he favoured *more* information.

P4 made a number of suggestions which would help manage information for palatable presentation to people with his aversion to text and preference for graphics, discussed below.

P1 was unequivocal in her praise and, finding the subject difficult, found her understanding much improved:

> Yeah, like I say, it's a shame they don't have these in a supermarket, because they can be so confusing, the food labels... (P1)

There were no **unanswered questions**, which was probably related to the volume and comprehensiveness of information included.

Usability was found to be generally good, although the instruction to click on an area of the food label for more information was vulnerable to misinterpretation, and two participants thought they had completed the section before they had in fact reached the final page – this was not a critical error. In addition, not all areas of each label – such as the title of the sauce - were active, which was potentially confusing for users. Plans for addressing these shortcomings are included in Suggested Improvements, below.

Suggested improvements	Action
16% Fat (RDI 100g) P4 experienced trouble "assimilating" the core information about recommended daily intakes (RDI). To aid his understanding, he suggested representing these as "little men". Developing this idea with the researcher generated a plan for a new way of presenting nutrient content in the context of RDI. For example, the RDI of fat is 100g (men) and 75g (women). The 15.9g of fat in the tomato and mascarpone sauce represents around one sixth (men) or one fifth (women) of the RDI. A worked up example, for a man's total fat intake, is shown here.	Explore the design of male and female graphics to illustrate, with different proportions of shading from feet to head, the proportions of RDI foods contain for different nutrients.
P4 reported that he wanted to "carry this information away" and suggested a table which he could print out. The recommended daily intakes for each nutrient would lend themselves to tabular format.	Design and include a table of recommended daily intakes of BP-related nutrients for men and women.
P2 wanted to click on individual ingredients to find out more about the relationship of each to BP. However, the examples used in the section cannot be considered representative of food as a whole, as P6 illustrated: "I wouldn't say I never ever buy it – I have done, um… very rarely. I, I think a lot of people do". Moreover the evidence is not sufficient to support a separate page for each ingredient, which would cause significant ingredients to be lost among less significant ones. This approach would involve a considerable investment of time. However, for ingredients which are well-researched with respect to BP (which are therefore also likely to be widespread)	Provide clearly distinguished links for well-researched ingredients to pages outlining the effect they have on BP, with hierarchies of supporting evidence and references.

links to more information would be helpful.

P4 suggested converting the tabular summary of nutritional information for four pasta sauces into a graph so that it is better understood. This approach would convey the information with more immediacy. However, it would not reflect the way nutritional information is presented in real life. To replace the table with a graph would undermine the purpose of the section, which is to support acquisition of generic information processing skills rather than knowledge about four pasta sauces. Allowing users to toggle between the table and a graphical representation – possibly using P4's "little men", above would usefully encourage users to consider this numeric data as their respective proportions of RDIs.	Develop graphical version of tabular summary information about nutritional values.
"Click on *an* area of the label" should be changed to "Click on *any* area the label".	Change the instructions as adjacent.
Implied improvements	**Action**
P4 and P6 were concerned about the amount of information, although they did not suggest that it be reduced.	Experiment with colour and layout to present information more effectively.
After successfully identifying the healthiest sauce, P1 and P6 both failed to continue to the final screen.	On the correct sauce screen, include a Next as well as Back button to provide another path to the final screen and encourage users to progress.
When instructed to click on an area of the label, P4 started at the top left of the screen. This meant that he clicked non-productively on several elements – mostly section titles. He suggested clarifying exactly	Ensure that all label elements give feedback when clicked. For non-productive parts of the

what could be clicked on in the instructions. However, considering that many people skim the instructions, it would be more effective to make sure every element on a label gives feedback when clicked. For those which do not activate information, this feedback could usefully take the form of a pop-up message providing hints about the active parts of the label.

label, use this feedback to direct to the active areas.

8.6.1.10 Excerpt 10: Nutritional content of foods

Number of evaluators: 1
Interest: 10.0
Improved understanding: 8.3

Both a positive **affective response** and high **interest** were evident in the commentary that P1 gave as she worked through the section. She was clearly engaged, having "fun", and in an unprecedented state of high excitement which was significant since this was the last section she viewed and it would be reasonable to expect some fatigue at this stage of the session:

> Oh, I think the brie would have more fat in – oh no – it hasn't! Gosh… I don't like brie, but I like cheddar… that's not fair [chuckles]… "The harder the cheese, the more fat it contains." Oh, I didn't know that. (P1)

> Oh, I'm hoping it's the crackers, cos I like hot chocolate [laughs and clicks to find out]. Oh no!!! That's terrible! [clicks and reads] Gosh, I didn't know that. (P1)

As the above excerpts illustrate, the section contained many surprises which contributed to her high score on **understanding**. She also approved of the choice of foods covered:

> And like I say, you've picked things which are… comfort foods, and… things that you know you shouldn't really, sort of eat too much of. And then again, you'd be surprised to see that because you didn't know. (P1)

However it is worth noting that these snack foods might not be relevant to all users.

The section raised **unanswered questions** about recommended daily intakes (RDIs) for the nutrients covered, which are covered as suggested improvements below. Two **usability** issues were raised. When presented with

nutritional information for the foods covered in the section, P1 expected a similar approach to that in Excerpt 9 which allowed users to click on areas of the label. Fruitless attempts to click on each label led to disappointment. Another usability issue concerned the way information was activated, covered below in implied improvements.

Suggested improvements	Action
P1 wanted information about RDIs of the nutrients discussed in the section. This would be valuable in helping users to make sense of and apply the theoretical information in the section.	Include RDIs of the nutrients covered, accessed from a link on each screen of the section.
P1 expected to interact with the nutritional information about each food in the same way as she had with the nutritional information in the previous excerpt, which was similarly presented. However, since this section aims to debunk some common assumptions, rather than to inform the user about the notional nutritional values of notional products, this type of interaction is not appropriate. In order to make a distinction, it is necessary either to omit the nutritional values of each food or to present them differently.	Consult users further about this issue.

Implied improvements	Action
P1 initially tried to activate a link by clicking on the label to an image, which was not linked to an action. This caused momentary confusion.	Allow labels to activate links, as well as their associated images.

8.6.2 SUMMARY OF RESPONSES TO AREAS COVERED

The sections above summarise responses to a range of innovative areas of Pressure's Off. These were elicited in a standardised way which allowed comparison, improved validity and, most importantly, generated a number of actions through which those areas would be improved. The following sections explore other themes arising from the evaluation process, which are important considerations in designing information resources for people with HBP.

8.6.3 RESPONSES TO PRESSURE'S OFF AS A HEALTH PROMOTION INTERVENTION

This section considers a number of important factors, recurring as themes in the conversations with participants, which affect how information about BP is taken up by its recipients and gives insight about how it should be presented.

8.6.3.1 Personal relevance

Personal relevance emerged as an important factor, both in engaging users with the information and in encouraging them to take action.

Prior knowledge in users of their individual risk factors could make them less receptive. For example, P2 reported feeling "a bit flippant" about the heart because he had ruled it out as a concern. Similarly, he did not gain from finding out his Body Mass Index (BMI), because he knew that his weight was not a concern. At the same time, he believed that the BMI tool would be relevant for some users.

> "...it doesn't help me understand my blood pressure. That's not your fault – in the sense that... if I'd come up 30 and above I'd have internalised that as making some sense, because it empowers me, gives me something to do." (P2)

A belief in a body of core BP knowledge, which enhanced feelings of personal relevance, emerged. Discussing *Understanding the Numbers*, P1 voices an opinion which was also the basis of decisions about Pressure's Off content:

> I think if you've got high blood pressure, then you should know about these things.

However, also present is an underlying sense of obligation which hints that using provided information is not an inevitable consequence of approving its presence. P5 demonstrates a similar sense of obligation in her comments about the *Overview of High Blood Pressure*:

> MV: And so you're interested in high blood pressure?
>
> P5: Yes, I have to be... [laughs] if I'm involved...
>
> MV: Yes... as an involved patient?
>
> P5: Yes.

This flags a crucial distinction, important to all developers of health information, between satisfaction on a user's part that a piece of information is included, and actual engagement with that piece of information – this

corresponds to the distinction Procashka and DiClemente (1982) make between contemplation and commitment (see their Stages of Change Model, Section 4.3.3.2). This is an issue of sensitivity and specificity – ensuring that the users to whom a piece of information is relevant can engage with and extract meaning out of that piece of information, while avoiding alienating users for whom the information is not relevant. There were indications that this was achieved in parts of Pressure's Off:

> I just think um it's – there's lots of different bits of information, you don't have to choose to read them all – it – you, know, you, you could just read one bit and then go on to have a jar of sauce – not like the heart or the stroke, you know, where you should really – you feel you need to read right through to the end – you can just read one bit and it can still be of value to you. (P6, *Interpreting Nutritional Information*)

Ways to achieve the balance are discussed in the following chapter as opportunities for future work.

8.6.3.2 Scope of Pressure's Off

Related to personal relevance is the theme of scope – the range of information to be included in Pressure's Off.

As discussed, decisions about core knowledge were made early in the project. During the evaluation, the discussion came to focus on the relative merits of practical and theoretical knowledge. P6 voiced mixed feelings about including physiology is Pressure's Off, illustrated by a comment that the anatomy of the heart "wouldn't be the first thing" she would try to find out. Indeed, several participants professed to feel more positive about those items of information which they perceived could be put into practice than those which could not. Accordingly, *advice* tended to be more enthusiastically received than the *background* to the advice:

> "...all my questions have always been about "What can I do to stop it happening?" (P6, *Stroke*)

> ... what I'm looking for is advice on what to do. (P4, *Nutritional Content of Food*)

This attitude was interesting to observe in this sample of educated, questioning people who might be expected to resist uncritically following advice without fully understanding its implications. Indeed, the statistics on adherence, discussed in Section 3.7.2.2, suggest that patients are unlikely to follow the advice. The principle of the active patient (Section 4.3.3.1) suggests

that understanding the processes in their bodies is a necessary precursor to adherence.

This bias against theory and reflection and in favour of concrete facts and their application implies the hope, wish or assumption that the management of HBP is a matter of procedure, and that knowledge of these procedures is the most important precursor to good management. This attitude suggests a misunderstanding of BP and also denies or overlooks the many factors implicated in motivation and behaviour change (discussed in Chapter 4), one of which is the gap between theory and practice highlighted by Becker (1987, p245-249) and by Procashka and DiClemente (1982) in their Stages of Change Model (see Section 4.3.3.2), which Pressure's Off aims to bridge by promoting understanding. The heart is inextricably linked to BP, and without this knowledge BP management easily becomes an academic exercise without focus or immediacy. The prioritisation of applicable advice over theoretical knowledge is an unhelpful hierarchy, and this deduction is supported by the Blood Pressure Association's interest in the physiological sections of Pressure's Off.

8.6.3.3 Level of detail

Exploring issues around level of detail in more depth uncovered ambivalence about how much detail was required, or helpful, in Pressure's Off. P6 commented:

> Um... I mean, what a complex... organ it [the heart] is... perhaps that's
> – it just is, and that's, you know, you can't sort of just leave a bit off
> because it takes up too much space, and say "Oh, well we won't say
> that that's the left ventricle", or something, you know.

Interestingly, the concept of detail – or *depth* of information - could be eclipsed by the perceived *amount* of information and the initial impression this made on the participant:

> ...the fact that it's two and a half – what, two and a half *lines*... is fine
> for me. Err... three – once it gets to three lines, uhh... that for me
> becomes – (P4, *Search for my Medication*)

> Theeeeee... important point is highlighted. Um... I start reading from
> the top and by the time I've read two or three lines I'm pretty bored
> here [chuckles]. So again the important point should be at the top. (P4,
> *Interpreting Nutritional Information*)

> ...it's very clear again – you've just got a few lines there, nothing too
> complicated (P1, *What is Blood Pressure?*)

Rather than allowing the complexity of the information to dictate the amount presented, some participant feedback seemed to be based on the premise that, on principle, the content of each unit should be condensed into a few lines of text, implying a task-driven approach to learning. In contrast, P2 consistently demanded more information and never less.

Another aspect of detail was the vocabulary used. Again, this was controversial. While some participants were quick to query technical words:

> Ah... Um... [clicks and reads] It's interesting – it's very very interesting – I can look at the pictures and I'll understand the pictures, I look at the words and they mean bugger all [laughs]. (P4, *Overview of the Consequences of High Blood Pressure*)

there was a general feeling that they should be included:

> P6: Err... [pause 5 sec]. Atheroma. But then you've put that in brackets and explained it straight away.
>
> MV: Do you think we should have left out the term and put "small pieces of the build-up on the artery wall... tend to break off"...?
>
> P6: For me, I'd rather it was in there somewhere, but, but I think it's important to have an explanation for what it means. Because, you know, they're the names that doctors will use. (P6, Stroke)

Patients say they use health information practical information. They are informed and aware that they have a condition called high blood pressure, and they are informed about the measures they should take to minimise its exacerbation by environmental factors. However, the depth of response to *What is Blood Pressure?* and the positive reactions to *Overview of the Consequences of High Blood Pressure* – sections which are theoretical rather than practical - identified gaps in knowledge, even in the educated group who participated in the evaluation. This suggests that for many patients there two fundamental mysteries – what happens to blood inside the arteries and the particulars of how HBP affects the arteries. These mysteries have their origins in the lack of attention paid to the physiology and pathophysiology of HBP, as demonstrated in the resources reviewed in Chapter 7. This suggests that people with HBP are poorly equipped to connect their conceptualisation of BP with the diet and lifestyle measures they are advised to take. This is important, since transfer, or behaviour change, is encouraged by a full understanding about a phenomenon, which allows patients to elaborate, make inferences, and assimilate self-care into every day life. Without this

understanding, advice becomes a set of directives, regurgitated by patients as intentions which are too often unachieved.

Overall, it can be assumed that the level of detail required will vary from user to user and section to section. All of the reactions suggest once again that the careful stratification and "chunking" of information into units would be a useful way to accommodate the different requirements for detail. The Web offers unique opportunities here, one example of which is stratification of information demonstrated in the sections on *The Heart* and *Interpreting Nutritional Information* which allow the user to select or omit units of information.

8.6.3.4 Fear

P3 (BMI: 35.6) experienced a very powerful reaction when she saw herself in the obese zone of the chart which interfered with her objectivity:

> It's obvious – I'm not saying that I like it... because no-one likes things that are quite negative about themselves... (P3, *Body Mass Index*)

P1 (BMI: 23.5) and P6 (BMI: 28) both elaborated on this theme, mingling humour with the evident discomfort they felt at confronting their weight.

Reiterating her uneasiness, P3 explained that seeing things "visually" had "scared" her and made her realise that "if I don't do something I will keel over soon". Although the potential for this kind of discomfort had been covered in the information leaflet on which informed consent to participate was based, this was a concern for the researcher, even though it emerged that P3 considered this response constructive and motivating: "I need to take some control of my life".

Research into the use of fear in health promotion messages suggests that it should be used with caution, but that in judicious combination with recommendations and opportunities for action, fear can be an effective motivator (Chapman, 1999). Another source of discomfort which has been most notably exploited by the anti-tobacco lobby in the USA is known as the social norms approach (Berkowitz, 2004), which works to create the impression that certain behaviours are socially undesirable. This approach is based on the premise that social ideals are far more powerful a motivating factor than either health fears or health ideals; epidemiologist Geoffrey Rose (1981) writing at a time when there was 'a regrettable and continuing separation of the therapeutic and preventative roles in general practice',

recognised that 'social pressure brings immediate rewards for those who conform' and argued, again, that it far out-influences the recommendations or ominous predictions of health professionals.

Since these approaches are ethically sensitive, there are no plans to use either strategically in Pressure's Off unless there is clear evidence indicating its effectiveness in a given context, and appropriate expert guidance is available.

8.6.3.5 Personal responsibility

Figure 9.5 indicated that users strongly believed that learning about BP would help them keep it down. For P3, who flatly denied that responsibility for her BP lay with the doctor (Figure 9.5), maintaining it at a healthy level was her personal responsibility:

> Because I just feel that knowledge is power. And the more you know about how your body works, and what really is happening inside – because it is such a silent killer, really, and if you have detailed information like this then you can work from it and start looking at the way you take – I think, take an individual responsibility. That's what it does for you. (P3, *Stroke*)

However, P2, the most avid for information of all the participants, felt both that there was little he could do to control his BP and that responsibility lay ultimately with the doctor:

> ...you know, I'm not in control of this. I've got to say to someone else "Ok, I trust you, there you go... (P2, *Search for my Medication*)

It emerged during his session that he felt he had acted responsibly and done all he could, without success. He seemed buoyant in the face of his resistant HBP, but his situation raises questions about the proportion of patients who, through no fault of their own, find that their best efforts are insufficient to keep their BP under control. The practice of personal responsibility here implies perseverance on the assumption good health will inevitably prevail. To acknowledge that it may *not* prevail undermines the power of the message, and yet to ignore this possibility excludes those patients most in need of support. One of the Pressure's Off content validators, a GP, offers insight and an approach:

> Some patients are left feeling that they have "failed to try hard enough" with the diet and lifestyle options as a result of which medication is needed. I always try to stress the fact that there is a big genetic component in hypertension which diet and lifestyle cannot address – thus not everyone begins from the same starting point.

Similarly – medication is not an alternative to diet and lifestyle modification which still needs to happen.

By introducing the "genetic component" he absolves blame – however by simultaneously referring to "different starting points" he nurtures the motivation to persevere with diet, lifestyle and medication. So concerning personal responsibility, there are a number of points to emphasise: that self care is an individual affair which involves people taking action to keep their individual BPs as close to safe limits as they can; that BP is a continuum along which all reduction is beneficial; that what may appear to be an unresponsive HBP (because it is not falling below the 140/90mmHg threshold) may in fact be a BP that is maintained at significantly lower levels than it would be if the patient suspended their self-care.

8.6.3.6 Approaches to learning

Despite the remit of their involvement, which was to give feedback rather than to learn, a number of participants showed a desire to learn during the session. Consequently it was possible to observe individual differences in the approaches to learning over the course of the study, particularly evident in the statements coded under Personal Relevance. This is of interest because research into adult learning is not well explored in the context of health information, which focuses more on the ends of behaviour change rather than the means by which it is achieved. Notably, P2 showed marked strategic, goal-driven approaches (Entwistle, 1981; Marton and Saljo, 1984; Ramsden, 1992), denying current interest in the heart although it had once been an all-consuming focus for him. He had a medication-related learning goal in mind on agreeing to participate:

> P2: No no – what – I suppose – I don't know why other people might find themselves looking for more information about their heart. [08:25 – digression about why he looked for heart information, more on his ECG and echo – 09:14] I was looking for answers, really - how could a very healthy heart appear to be unhealthy.
>
> MV: So are you saying that when you go and look for information, it's with a target in mind? You wouldn't necessarily just casually browse through the background on high blood pressure...?
>
> P2: No no no – because I've done it – I *have* gone through web sites and I've gone through the British Hypertension Society web site and I did go onto the professional side and try to make sense of you know, and can basically track – I mean for *me*, the issue is understanding the medication. (P1;2;32-42)

P4 showed a similar goal-driven approach:

> ... what I'm looking for is advice on what to do. So it's not so much that I need to know that 14g gives one serving blah blah blah – what I'm looking for is... what do I do? And uh... this gives me the advice about what to do. (P4)

These participants had identified learning needs which might cause them to filter out other information as peripheral to these needs. On the other hand, surface - possibly task-driven – approaches (Entwistle, 1981; Marton and Saljo, 1984; Ramsden, 1992) were shown by a number of participants, who were observed to work diligently through sections without showing any critical engagement with the content. While a surface approach might be expected in this context, it was interesting to observe, and highlighted the possible pitfalls with information on prescription, and its premise that exposure to information brings about de facto improvements in knowledge.

8.6.3.7 Context of information

Some sections threw up unanswered questions which were related to the way the information had been organised, with each section intended to both stand alone and fit into a sequence:

> Um... Yes, but it doesn't tell you – oh, but it does say another section though, doesn't it (P1, *What is Blood Pressure?*)

> P4: Uh-huh – cos again, that's one of the things about going through a web site – you always end up – what, I dunno... but you end up reaching things out of...
>
> MV: Mm.
>
> P4: ...out of context. (*Consequences of HBP*)

These perceived omissions raised the issue of how - indeed, whether - information can be successfully presented to meet the requirements of both a reference resource and a more sequential learning package. Bloom's influential taxonomy of learning (1964) suggests that the most effective cognitive learning occurs when users are encouraged to apply, analyse, synthesise and evaluate knowledge. If each section in Pressure's Off is to stand alone, there is a tendency for concepts to become fragmented into disjointed facts where transmission of information replaces acquisition of knowledge (Friesen, 2004; Greenfield, 2004; Salomon, 1998).

This tendency needs to be addressed. As mentioned earlier in this chapter, cross-referencing between sections is one way to address the potential disjointedness, and these could take the form of a series of frequently-asked questions arising from each section and answered in others. To promote Bloom's higher forms of learning, each section would benefit from an activity which encouraged users to engage with the information - the Universities' Collaboration in e-Learning (UCeL, 2003) specifies that each learning object should include the presentation of information, an activity, an assessment and resources. Some parts of Pressure's Off – such as *Interpreting Nutritional Information* and *Body Mass Index* – are good examples of this practice.

8.6.3.8 Novice users

It was illuminating to observe P5 using the section – the first in her session – since she was a complete beginner with computers. A little about her experience is mentioned here as a reminder of how it feels to be a complete beginner at computing - a very remote memory for most developers.

P5 had particular problems with conceptualising the navigation:

> P5: So now I have to get there – is that right? [gestures to the top left of the monitor]
>
> MV: Is that what you'd want to click on to get another page?
>
> P5: Where it says Next – that window demonstrates that it's next... doesn't it?
>
> MV: Yes. If you wanted to see the previous page, where would you click?
>
> P5: The previous page would have to be this end, wouldn't it? [gestures to the other side of the monitor]
>
> MV: Ok, so –
>
> P5: I don't *know*, I'm just –
>
> MV: That's fine – it's fine – it's interesting to hear. Um... if you clicked on this button, where do you think you'd get to?
>
> P5: Which button – that one there?
>
> MV: Yes, this one that says "Back".
>
> P5: [pause 2 sec] Probably move up here [gestures to the top of the monitor].
>
> MV: And when you say "move up here"... um... are you imagining that the screens shuffle along this way?
>
> P5: I imagine that it comes down.

She had a prior impression of information reaching the screen from an area above the monitor, and disappearing beneath the monitor afterwards – a logical interpretation of the window metaphor and scrolling analogy. However, because the section was *not* presented as a scrollable document but as a series of separate screens navigated via Back and Next buttons, she struggled to incorporate the newer concept of navigation into her existing mental model. On the day, P5 was one of the less critical participants - a possible reason for this is the pressure of using a new technology under close scrutiny reducing her capacity to engage with the content. Nevertheless, as a novice user, observing her experience was illuminating for the developer and generated a number of ideas for improvements.

8.6.4 SUMMARY OF RESPONSES TO PRESSURE'S OFF AS A HEALTH PROMOTION INTERVENTION

The responses to each excerpt (Section 9.7.1) considered the content and design of Pressure's Off, whereas the themes outlined above have focused on the experiences and attitudes of the participants as members of the target user group. These have been illuminating and the light they shed gives clear insight into specific issues of presenting information to people with HBP.

8.7 LIMITATIONS OF THE EVALUATION

As already discussed, the sample size was smaller than ideal. Although approaching the minimum recommended for identifying usability issues, it did not lend itself to statistical analysis and could not fully explore the "three Es" of evaluation – efficiency, effectiveness and economy. Additionally the purposeful sample, comprising articulate, critical thinkers, was not representative of the broader population. It is understandable, considering the highly responsive, individualised information HBP patients receive in the clinic, that the consultant and nurse specialist would choose to put forward participants they knew to be psychologically equipped for any information. Advice on HBP is strongly rooted in delicate issues to do with way-of-life and, compared to the diabetes education modules produced by Berridge (2002), there was much less procedural information which could be encapsulated in simple, neutral directives, such as measuring blood sugar or injecting insulin. Therefore Berridge's strategy of approaching people in a clinic waiting room

was not available to this project. However, it should be noted that this limitation in representativeness has some advantages. The intrepid, analytical approach of most of the participants, many of whom assumed an advocate role for people less mentally capable than themselves, was of great benefit to the ongoing development of Pressure's Off, and appropriate to this stage of its development.

Another limitation was the time restriction which necessitated viewing excerpts in isolation. This led on some occasions to a perception that they contained omissions. This was mitigated with dialogue between the researcher and participant similar to the excerpt below:

> P4: Well, *how* that relates to blood pressure – like I have no idea if being very fat relates to blood pressure, or if being very thin is good, or - in relation to blood pressure – like I know it's good and bad in *other* things, but in relation to blood pressure... I don't know.
>
> MV: Ok – so in isolation it doesn't really help with blood pressure – I suppose that's the kind of *artificial* aspect of this evaluation cos I show you things in isolation but then I've got this section on weight um... and that's got some – (P4, *Excerpt 2: Body Mass Index*)

To accommodate this isolation, comments like P4's were assigned a code which flagged perceived omissions and noted whether these were in fact addressed elsewhere in Pressure's Off. As discussed, these perceived omissions offered pointers about usefully cross referencing between sections or adding to a given section.

In several cases, constructive suggestions for improving Pressure's Off were not forthcoming despite experiencing usability problems. For example, despite explaining that she hadn't initially noticed the Metric fields in the BMI calculation, P6 did not suggest improvements to layout. This suggests that a proportion of individuals are inclined to assume that responsibility for usability problems is theirs, rather than considering whether any aspect of the facility could be improved. It is therefore necessary for the researcher to be vigilant for usability problems, and to possess the skills to elicit both reasons and suggestions about how they could be solved – all without influencing a participant's response. On this basis a case emerged for separating the usability evaluation from the study of reactive responses and learning. The usability study could be carried out by readily available participants with a

range of expertise, and the findings to be incorporated before exploring reaction and learning with the specific target user group.

Figure 8.8 shows a summary of self-reported interest and improvements in understanding. A trend towards a more positive response can be observed along the x axis from left to right which, on checking the order in which sections were viewed, raises the possibility of bias in responses due to section order. It may mean that participants tended to warm to either the evaluation exercise, or Pressure's Off, or both, in the course of the session. It also suggests that interacting with Pressure's Off was an increasingly enjoyable experience.
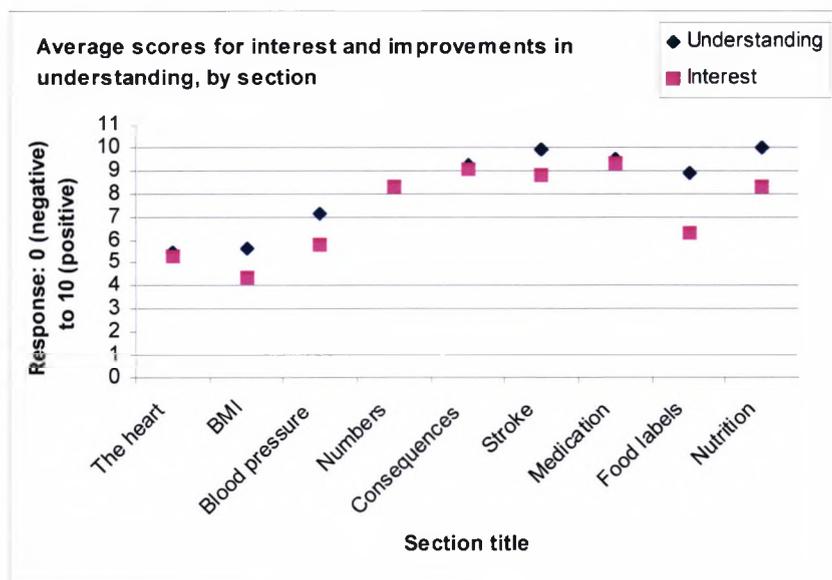
Figure 8.8 Average scores for interest and improvements in understanding, by section

8.8 SUMMARY

This chapter has described and discussed the methodology and findings from an encouraging, illuminating evaluation exercise, a detailed exploration of important sections of Pressure's Off with patients at a hypertension clinic. Information about the participants collected prior to viewing Pressure's Off sketched a group of people with shortcomings in their knowledge which were not necessarily recognised, who varied in their attitude to taking responsibility for BP management, which would be expected to affect motivation to learn more and modify behaviour.

Consequences of HBP, Stroke and Medication emerge as highly valued sections in terms of interest and understanding. The former two sections illustrated processes which the participants found highly interesting, in a way which they found clear, while the latter was felt to be particularly relevant to its evaluators. Conversely, the sections which were less well-received tended to be those whose relevance was not recognised.

Participants remained interested and engaged throughout the evaluation session. Rich feedback on each section, collected using rating scales and a semi-structured interview, yielded endorsements, insights, and a set of suggested and implied modifications for specific BP-related health and lifestyle resources. It also offered what are thought to be unprecedented insights into the experiences and attitudes of people with HBP using online health information. These helped to explain how the sections were perceived, and how they achieved - or could be modified to achieve - their aims.

Although primarily a formative exercise, this evaluation showed a number of very positive outcomes. Figure 8.8 above shows that the evaluated sections of Pressure's Off were highly engaging - a fundamental requirement if users are to be attracted and retained. It is also a requirement which, as shown in the review of resources in Section 7.2.3, is very hard to meet. Tellingly, the detailed explanations of the participants show that the appeal of Pressure's Off has its origins in both the content and the way it is presented, and this indicates that text, dynamic graphics and interactive features are generally working well in synthesis. Assuming that interest has been engaged, a health information resource must advance understanding. Figure 8.8 shows that improvements in understanding in Pressure's Off tended to surpass the respectable scores for interest in most sections. This is a highly significant and encouraging finding which confirms that Pressure's Off can improve the knowledge of educated users engaging with it on a critical level. At the same time, as participants commented, care must be taken to present information manageably for people with less aptitude – the comments have offered clear and feasible suggestions about how this can be achieved.

As such, there is every indication that Pressure's Off will, with the well-defined straightforward changes and additions outlined above, meet real-world information needs of users with high blood pressure.

CHAPTER 9: DISCUSSION

This thesis has presented developments underpinning the scope, design, development and evaluation of Pressure's Off, a Web-based information package for people with high blood pressure (HBP). The previous chapters have explored its context, developed and synthesised theories and approaches, detailed its production choices and processes, explored reactions of members of its target user group, and generated recommendations. This chapter has dual purposes. The first is to review the project and summarise the research. The second is to discuss the outcomes of the research and their implications, which will allow conclusions to be drawn about best practice in the area of Web-based information for people with HBP.

9.1 LOOKING BACK ON THE PROJECT

The complexities of HBP emerged slowly at first. The ongoing review of literature and resources uncovered few and superficial attempts at computer-based information resources, and this was mystifying since other health conditions – cancers, drug addiction and depression – were well and increasingly represented. What was different about HBP?

To shed light on this question, efforts were ongoing to engage the interest of health professionals, whose input as stakeholders and gatekeepers to patients would be crucial to the success of the project. Given the well-known time constraints on health professionals, it soon emerged that this input could only be obtained in the form of feedback on existing material, rather than the anticipated partnership in producing the knowledge base. This led to a dilemma for the researcher arising from a lack of subject knowledge, particularly at the outset of the project. The inevitable outcome was an extension to the period of knowledge acquisition which delayed the production of the prototype. However, once the prototype was completed and presented, the interest of health professionals was vastly improved, leading to increased confidence and effectiveness.

The knowledge acquisition phase was reminiscent of the proverbial blind men in their effort to make sense of the elephant[17] – BP was presented by different research camps in terms of sodium, alcohol, genes, lipids or other factors, yet its essence was and remains poorly understood. Many risk factors were acknowledged to contribute to a complex interaction of mechanisms – these were unique to each individual, could not be observed – they were hard to define or represent in any way other than two numbers and a unit of measurement – the BP value. Moreover, the implication of this value was also uncertain.

This complexity shed light on the paucity of resources, and raised the first of two fundamental questions for the project - whether to be faithful to this complexity or to embrace simplicity. Because many simplistic approaches to BP information had already been identified and found to have limited value, it seemed fitting to let the knowledge base boundaries evolve during the knowledge acquisition phase, governed by the knowledge itself. Notwithstanding ongoing excision and circumscription, the knowledge base was permitted to grow by design to a large size.

Feeding into the knowledge base were findings from the mixed-methodology needs assessment. Data from an initial questionnaire to local health professionals allowed areas of content to be prioritised and primed the researcher to design further investigations, namely observations of clinical episodes and interviews with health professionals and patients. As well as serving to shape the knowledge base, these findings were illuminating for the researcher, who was consequently well-equipped to make decisions about design of both the information package itself, and its evaluation. The output of the needs assessment was a list of recommendations for designing and developing an information package for HBP and, in combination with the knowledge acquisition phase, a conceptual framework dedicated to HBP information for lay people (Figure 7.2). After obtaining and working in feedback from health professionals on scope, depth, and structure, the implementation phase began.

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[17] Each blind man touched a different part of the elephant – the ear, the trunk, the flank – and based on his individual experience each reached a different assumption about the overall shape of an elephant.

Since multimedia development is particularly resource-intensive, implementing it throughout Pressure's Off was beyond the scope of this project. The decision to represent the complexity of the subject area led to a second question about which specific topics to prioritise for development. In 2000, the Blood Pressure Association was inaugurated, a registered charity run by specialist BP health professionals which, with its comprehensive Web site, rapidly covered the ground that this project had covered in the two preceding years. There was a clear need to diversify – to identify unmet information needs – and this incidentally provided an answer to the above question. Unmet needs and best practice were identified and substantiated through an ongoing review of existing resources. A tool was developed specifically for this review which united, for the first time, the concerns of information quality, Web site quality, and scope, depth and interest for the HBP subject area. This review clearly identified shortcomings in current resources, and allowed the researcher to prioritise ten areas of Pressure's Off, identified as important, unmet information needs, into which to channel extra time and effort.

Because of the perennial NHS security issues which, varying from Trust to Trust, impinge on what can be downloaded over the Internet, Pressure's Off was developed as a Web site which could stand alone on CD-ROM or hard disk, or be delivered over the Web. The first stage of development focused on the interface, which involved a series a prototype cycles. There were three main priorities here - usability, accessibility and appeal. Achieving these involved exercising delicate skill, know-how and judgement to identify and carry out the most appropriate trade-offs, investments and sacrifices. Once the interface had been finalised, it was populated with the illustrated knowledge base, and the ten priority areas were developed and integrated. Navigation and orientation tools in the form of a search facility, index, and site map were added.

A formative evaluation was carried out by patients from a hypertension clinic. An opportunistic sample recruited by the clinic team gave rich feedback on selected priority areas of Pressure's Off, covering affective responses, interest, understanding, strengths and weaknesses and suggested improvements. The mixture of quantitative and qualitative data collected was subjected to systematic coding and data analysis. Findings were divided into two types, those relating to the specific areas of Pressure's Off covered, and those which

gave insights about the motivations and approaches of BP information seekers. This evaluation exercise produced increased understanding about the strengths of the areas evaluated, which could be extrapolated to other areas of Pressure's Off. A further invaluable output was a list of suggested improvements which were assessed and worked into a series of concrete actions for future work.

Looking back on the challenges and achievements of the project affords insights about the methodology chosen and how it could be improved for the future.

9.2 OUTCOMES OF THE RESEARCH

The specific outcomes of the research, touched upon in the review above, are discussed below.

9.2.1 A REVIEW TOOL AND GUIDELINE FOR ONLINE HEALTH RESOURCES

Developed in response, on the one hand to the lack of quality information resources on HBP, and on the other hand to the inadequacy of existing tools for assessing their worth, the two quality assurance tools produced in this project were an outcome unanticipated by the project aims.

Considering the quality of health information on the Web, a review of quality assurance initiatives was carried out which identified a large number of guidelines (Section 5.4.1). Ironically, it was impossible to identify the best of these – each had at least one distinctive advantage over the others, and several were presented in a way which compromised their own guidelines[18]. In response to this proliferation of guidelines, the researcher amalgamated the points they raised as a synthesis (Section 5.4.2) incorporating the strengths of each while omitting their failings.

However, this new guideline was not felt to be adequate for the purposes of the review – it was effective in flagging bad practice but entirely ignored positive features. The guidelines on which it was based seemed to have been conceived to surmount poor quality rather than to actively exploit advances in

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[18]For example, the Discern Web site (http://www.discern.org.uk/) is undated.

technology. They are helpful in ensuring that a given site achieves the minimum criteria for confidence, but the *best* online health information resources are more than a sum of these recommendations. The best online resources should use the Web to distinguish themselves from corresponding hard copy or other material, rather than seeking to imitate it. For this reason, an extra module was created for the guideline explicitly to identify good quality in the design of online health information (Section 5.4.3).

Using the tool to review online health information allows the distinction of superior sites from those which are simply adequate and trustworthy. Applying it during the design and development of online health information helps to produce not only an accurate, current, complete, transparent and generally trustworthy site, but also one which exploits the distinct capabilities of the Web, including searchability, individualisation, accessibility, and multimedia.

These two tools were used both as guidelines to review existing online resources and to guide the design and development of Pressure's Off. With their emphasis, hitherto overlooked, on promoting best use of the Web as well as avoiding the pitfalls of producing online health information, they have a wide application beyond this project.

9.2.2 IMPROVEMENTS TO THE PROJECT METHODOLOGY

The methodology produced for this project, shown in Figure 2.1, was conceived in the early stages to guide and sequence stages of development. Subsequently, a similar approach was benchmarked in a successful £250,000 project proposal by the researcher to the Health Care Foundation to develop a web- and kiosk-based information package for older people about falls (Wilmes et al, 2004). Nevertheless, both projects suffered setbacks which had their roots in the difficulties encountered obtaining input from health professionals and target users in the absence of remuneration to attract and retain them and protect their time. The changes to the methodology, shown in Figure 9.1, relate to the crucial early stages of this type of project, where stakeholder input is secured.

In planning Pressure's Off, the researcher was reluctant to produce a prototype before extensive knowledge about HBP, health promotion and online health information had been acquired. This reluctance originated from a fear that a prototype which exposed domain ignorance risked alienating potential

project partners in the health care professions. As a result, the planning stage lasted longer than anticipated and the first prototype was produced later than hoped. However, in retrospect, this is easy to identify as a chicken-and-egg situation – it is an interesting observation that, without concrete examples of an intended product, raising interest in the early stages of a project is difficult and requires a high degree of conceptualisation, not to mention faith, from those solicited for their participation. In practice, as soon as the prototype was shown, health professionals warmed to the project. So for projects, such as this one and many others, which have little funding beyond the labour costs, the conclusion is drawn that even in the presence of significant flaws, an early, intelligently designed prototype which is transparent about its weaknesses would make it much easier to excite interest and gain input, allowing viewers to assume a critical role rather than a more challenging creative one. People can interact with the prototype, convey its strengths and weaknesses, and offer clear suggestions about how to improve it. In this respect early prototyping would have offered clear advantages in this project, and the project methodology, first presented in Figure 2.1, has been amended to reflect this (Figure 9.1). Since it is good practice to offer alternatives for comparison when seeking feedback (Krueger and Casey, 2000), more than one prototype is recommended, and since there would be an emphasis on speed, they would probably need to be produced as scenarios (Nielsen, 1993, pp95) as shown in Figure 7.7.

As the Planning section in Figure 7.7 acknowledges, identifying a clear need for the product in question through a needs assessment, and publicising this need, would also provide clear incentives for stakeholder input.
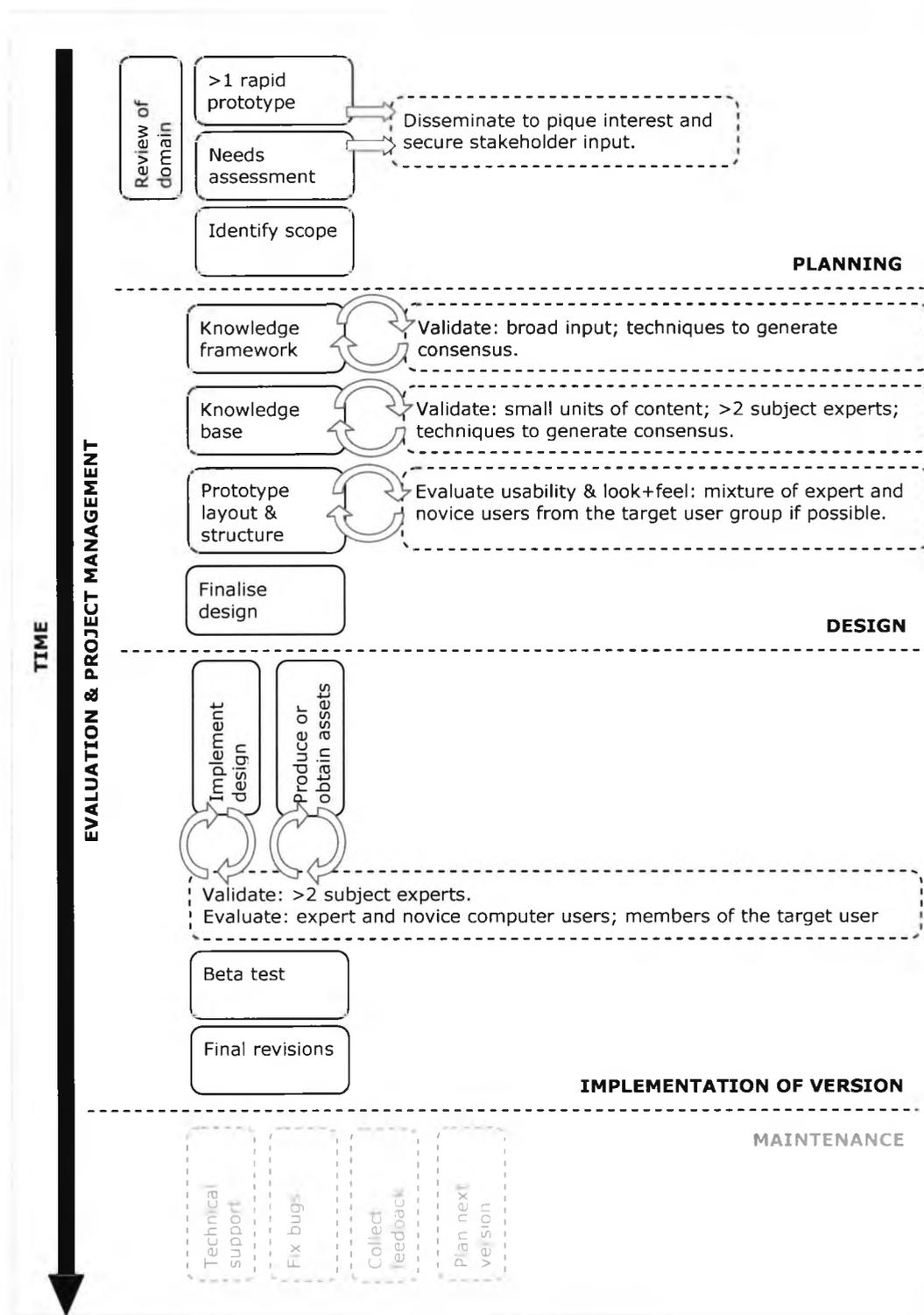
Figure 9.1 Amended design and development methodology for online health information

A further change to the methodology (first presented in Figure 2.1) can be seen at the Design stage, where the instructions to validate and evaluate have been modified. Since the product must meet real-world needs, the initial crucial validation of the knowledge framework should be as broad as possible in its scope, involving as many stakeholders as possible. However, in a poorly-defined subject area like HBP, the agreement necessary to proceed has proved elusive, so consensus-generating techniques, such as Delphi, may be indicated (Jones and Hunter, 1999). Validating the subject knowledge is a matter for groups of subject experts. It is important to recognise that most doctors combine a keen awareness of the gaps in their own knowledge with an evidence-based philosophy (Epstein, 2004). As such, they feel trepidation when asked to comment outside their immediate area of expertise – especially if the results will be presented to patients. Moreover, in response to the unmanageable growth of medical knowledge, doctors increasingly operate in multidisciplinary teams, a way of organising care which hinges on distributed cognition. Therefore as indicated in Figure 9.1, it is necessary to divide the knowledge base into constituent units, and to validate these with relevant subject experts, be they cardiologists, nurse specialists, dieticians, or physiologists. At this stage, it would be helpful if not essential to reinforce outcomes and deadlines by paying validators.

The final change, also in the Design phase of Figure 9.1, explicitly involves both expert users and novices in the evaluation of the prototype. As discussed in Section 7.5.1, competent or expert computer users are more likely to challenge an interface than novices. However, as experts, these individuals might fail to register basic inadequacies. On the other hand, novices might not fully exploit an interface but are more likely to register the shortcomings which could undermine a Web beginner.

It is anticipated that implementing the above changes at the critical early stages of a project should enable the latter activities – shown in the Implementation phase - to proceed according to plan.

9.2.3 KNOWLEDGE BASE

A knowledge base for patient information about BP has been developed. Its framework has been represented as a concept map, a precedent for which has not been identified. One explanation for this is that the knowledge in other

resources has evolved over time and has not been formalised as a map. Another is that, where subject experts have been responsible for specifying a resource, their knowledge has been tacit, taken for granted, and not made explicit. Nevertheless, a map such as this is very important for conceptualising and structuring the information – appropriate information architecture increases the usability of online resources for users with some prior subject area knowledge (Gauss and Urbas, 2003; Last et al, 2001). Moreover, it streamlines and controls the future development of the knowledge base, encouraging validators to flag gaps and, having identified these, to suggest the most appropriate point within the existing structure for the additions.

The knowledge base is not exhaustive, as demonstrated by the review of resources presented in Section 7.2.3 but effectively represents the body of knowledge which health professionals consider core to self-care for HBP.

The framework discussed above was almost fully populated with detailed information. The rationale for prioritising a selection of areas for multimedia development has been presented. The remainder of the knowledge base was developed in verbal form – although this textual medium is not optimal for the Web, considering the resource limitations in this project, it was the most appropriate format. For minimal outlay of resources, verbal representation of knowledge affords a particularly high level of detail. In this respect the paragraphs of text in Pressure's Off, which are not ideal for presenting health information online, can be somewhat rehabilitated as the "stem cells" of multimedia - units of raw undifferentiated information which, while already adequate for communicating information, are also available to be developed into any other more computer-friendly medium as the opportunity arises. It is far more demanding to, say, modify a picture of a heart into verbal form than vice versa. As a final point on the subject of text, accessibility requirements stipulate that text alternatives exist for all graphical material – in the case of Pressure's Off, they exist in advance.

9.2.4 THE PRESSURE'S OFF PROTOTYPE

The Pressure's Off prototype is a unique contribution which unites several very helpful features. One is the exceptionally user-friendly partnership of index, menu and search engine. Search engines are useful to users with prior knowledge who know what they wish to find. Indices can provide useful

triggers for those who may have a vague notion of the term they wish to find, but lack the accuracy required by a search engine – useful for complicated drug names, for example. The menu, which unfolds to show the entire structure of Pressure's Off as a site map, is the final partner, offering context and orientation which promotes subject area understanding (Gauss and Urbas, 2003; Last et al, 2001). In this respect, Pressure's Off is a truly flexible resource which can be used for in-depth learning or for quick reference.

The *information* in Pressure's Off is not its most significant contribution, although it is a useful one. The unification of the different factors in HBP – the physiology, risk factors, health care, complications and treatment – was a highly innovative approach at the beginning of the project – an approach which is validated by the Blood Pressure Association's similar strategy. The true innovation in the prototype, which distinguishes it from other available resources, is the combination of a sufficient level of detail with interactive, multimedia presentation which, as presented in Chapter 8, patients found both highly engaging and helpful to understanding.

9.3 LIMITATIONS OF THE PROJECT

This project existed at the intersection of three rapidly changing domains – health, education and information technology and, as such, limitations were inevitable.

This pace of change represented a particular challenge. Several innovative design and development tools emerged over the course of the project, the legal requirements of information providers were under review, and the advent and rapid expansion of the Blood Pressure Association resource forced several changes of direction. In this respect, this project experienced the common pitfalls which affect many such projects, demanding constant vigilance and a flexible, creative response.

Although the sample of patients who evaluated Pressure's Off approached the group size of eight held sufficient to identify the majority of usability issues, it was smaller than ideal and saturation was not reached. This was unavoidable, since recruitment was the preserve of the clinic team, and restricted by their prior commitments. Opportunistically sampled, it cannot be claimed that the selected patients were representative. However, their background as public

sector professionals enabled insights and creativity of response which a representative sample in the area may not have been able to offer.

Related to this, Pressure's Off cannot fully meet the needs of those hardest affected by the Inverse Care Law (Hart, 1971). As part of a growing range of health promotion interventions for HBP, it was intended to effectively exploit advances in technology to broaden the scope and depth of these interventions for the growing number of Web users. Considering usability, P5's experience as a novice user highlighted several design features which were not as intuitive as hoped. A number of concerns were also raised about the complexity of the material which suggested that the information management capabilities of the Web had not been employed to full advantage.

Pressure's Off is not yet ready to be made publicly accessible over the Web. For the purposes of the prototype, some proprietary images were used for which permission has not yet been obtained. The validation exercise was not conclusive, leaving target users vulnerable to information which is not fully accurate, complete and current. Not all of the sources of information have been made explicit – references need to be supplied in each section in order to meet the projects' own rigorous quality criteria. Plans are currently underway to develop the content in Pressure's Off further in partnership with the Blood Pressure Association (see Appendix 7).

9.4 SUMMARY

The Joint Information System Committee's Project Management Infokit humourously presents a typical project scenario (Figure 9.2, after JISC, undated).

What the user wanted:

What the budget allowed for:

What the timescale allowed for:

What the technician designed:

What the user finally got:
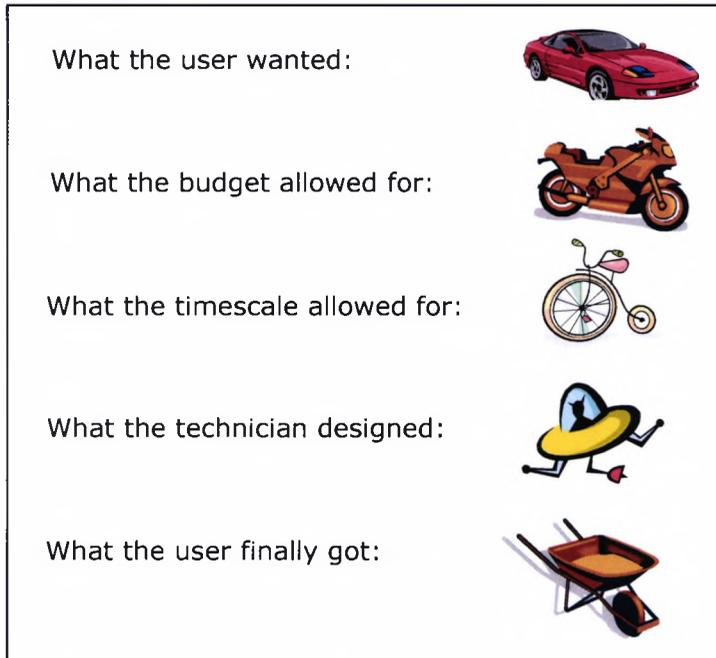
Figure 9.2 A typical project scenario

Using this analogy, Pressure's Off offers its target user group far more than a wheelbarrow. Pressure's Off could be compared to a prototype car for which, through road testing, a set of improvements have been identified - a clear path to becoming a luxury-end model. The framework and knowledge base exist as a robust chassis and durable body. Inside, the dashboard is functional and has some innovative features. Designed as extendable, additional work on the priority features identified by its test-drivers would build in the upgraded specification of a luxury model. Fixtures and fittings are ergonomically sound and, again, with extra attention could feel luxurious. Most importantly, Pressure's Off is not like the spacecraft above – on the contrary, it relates well to its aims and like a basic model car will carry its passengers to their destination efficiently and in relative comfort.

CHAPTER 10: CONCLUSIONS AND OPPORTUNITIES FOR FUTURE RESEARCH

The previous chapters of this thesis have presented the knowledge underpinning Pressure's Off, explored its context, developed and synthesised theories and approaches, detailed its production choices and processes, explored reactions of members of its target user group and generated recommendations. This chapter has dual purposes. One is to summarise the achievements of the research and its contribution to the body of knowledge about the subject area, allowing conclusions to be drawn about best practice in the area of web-based information for people with high blood pressure (HBP). Building on these conclusions, the chapter's other purpose is to outline recommendations for ongoing work.

10.1 SUMMARY OF ACHIEVEMENTS

The achievements summarised below are mapped to the aims of the project.

The project aimed to **identify the information needs of people with HBP**. It achieved this through a multi-method needs assessment exercise, findings from which were built upon through careful data collection and analysis during the prototype evaluation.

The project aimed to develop a way to **disseminate information about HBP which was accessible, acceptable, maintainable and cost effective**. The medium of the Web presented opportunities to meet each of these criteria. The priority of accessibility was identified through an operational description of the target user group, and met using fluid layout and formatting, alternative ways of presenting information, clear signals, and the separation of content from layout and formatting which allows the seamless accommodation of user agents. A review of Internet uptake in the UK indicated that the Web as a dissemination medium was highly and increasingly acceptable. It also flagged a disadvantaged group who did not have Web access and risked exclusion. Access was broadened by creating Pressure's Off as a stand-alone Web site to

be served on the Web or distributed on CD-ROM, and by presenting information in readily printable units.

To meet the aim of **advancing end users' knowledge** about BP, gaps in knowledge were first identified through background reading and the needs assessment – significant, widespread shortcomings which were confirmed by a knowledge test during the evaluation. On the basis of these findings, resources to address these gaps in knowledge were produced. Participants in the evaluation reported that after working through these resources, their knowledge was significantly improved.

All material for Pressure's Off was created with the aim of **encouraging and motivating adherence to treatment strategies**, and informed by theories of behaviour change and motivation identified in the literature review. Although it proved beyond the scope of the project to explore changes in motivation and adherence, which would require an impact study, the strategies adopted for this project were well aligned with those of professional bodies such as the Blood Pressure Association, which work towards similar aims.

To meet the aim of **promoting an active interest in end users' own cardiovascular health**, theories about learning were applied to the design and development of the content in Pressure's Off. Participants in the evaluation reported a high level of interest in the sections they worked through. Further work is needed to ascertain whether this engagement endures subsequently as a active concern about cardiovascular health.

10.2 SUMMARY OF CONTRIBUTIONS

This thesis presents a research project to meet shortcomings in patients' knowledge about their high blood pressure by exploiting advances in technology. Its contributions in this area are summarised below:

1. A review tool and guideline for online health resources which helps to distinguish superior sites from adequate, trustworthy ones, and which helps to produce not only accurate, current, complete, transparent and reliable sites, but also encourages exploitation of the distinct capabilities of the Web.

2. Improvements to the project methodology for small-scale projects. These include prototyping as early as possible to stimulate stakeholder interest in the project and enable true user-centred design, as well as specific validation strategies.

3. A comprehensive, detailed knowledge base which contributes to the skills and information required for effective self-management of high blood pressure. It comprises a validated framework which is populated with aggregated units of knowledge and information in a variety of media.

4. The Pressure's Off prototype, including sections prioritised for development, which evaluation participants found to be highly engaging and informative.

10.3 PRIORITIES FOR FURTHER DEVELOPMENT

The research carried out for this project raised a number of priorities for future development, summarised below.

10.3.1 HIERARCHIES OF EVIDENCE

Regarding the second information need for evidence, as Milne and colleagues (2000) comment, evidence-based information, much in demand with these participants, is something of a holy grail:

> 'An important issue for busy people preparing consumer health information is the ease with which rigorous, relevant, and complete information can be found. In searching for the evidence on which to base consumer health information the question remains whether it is possible to draw on the information from related systematic reviews (therefore maximising rigour) found by careful searching (maximising relevance) and covering a wide enough area (maximising completeness). Only if all three possibilities are pursued can patient information be evidence based.'

As indicated in the information quality criteria (Section 5.4.2) and confirmed by patient feedback (Section 8.6.1.8), it might therefore be useful to approach evidence in a scalable way, by dividing it into priority areas suggested by a representative sample of patients. Sections such as Men, Women, Ethnicity, Side Effects, Pregnancy, Heart Failure and others could be populated with

evidence included on the basis of a high ranking in an appropriate hierarchy. For example, double blind randomised controlled trials with no heterogeneity and a confidence interval (CI) all on one side of the threshold number needed to treat[19] (NNT) would gain the highest possible ranking (Evans, 2003), while there would also be a place for opinions from respected sources, and descriptive studies. In the Pressure's Off evaluation the interest was constant but the questions diverse. This approach would allow patients to focus on their area of interest and avoiding information overload.

10.3.2 INFORMATION MANAGEMENT

An excess of information combined with poor presentation can undermine health messages. Where information is complex, as it often is in the case of HBP, particular attention should be paid to presentation. The uniquely dynamic information management capabilities of the Web – layering, searching and retrieving, zooming and panning - should be fully exploited to display content flexibly and in "chunks" which can be easily processed.

10.3.3 CONTENT

Considering content in Pressure's Off, one of the most promising areas for development identified by patients and health professionals is the section on medication. One of the great surprises arising from the evaluation is the strong interest shown in the text-based section on medication and the desire for more information – these overcame an intolerance of tracts of text which had prevailed for former sections. Representing medication is an extremely sensitive area into which, for fear of upsetting or misleading patients and ultimately discouraging adherence, few have ventured. However, poor adherence to medication is a powerful driver for further research in this area. The findings from this evaluation suggest that engaging interest and demystifying medication could promote adherence, and good communication between patients and health professionals. Participants in this study referred to information needs in two areas: how medication works and the evidence supporting its use.

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[19] A population measure of the effectiveness of an intervention, NNT is the number of patients who have to be treated in order to prevent one event occurring.

Representing a drug's mode of action is difficult, since its impact on the body's equilibrium can be complex and widely multifactorial. For example, beta-blockers reduce cardiac output and sympathetic nervous system activity, and also have a poorly explained lowering effect on plasma renin, an enzyme which can bring about an increase in BP. In addition, they can cause adverse effects such as bronchospasm, lethargy and sexual dysfunction. Using a range of media to represent these modes of action for patients would be an exciting challenge.

10.3.4 INDIVIDUALISATION

The needs assessment identified the value of individualisation. Two categories of individualisation are discussed below, one concerning dynamic response of Pressure's Off to each user, and related to the information management above, and the other concerning the expansion of the Pressure's Off knowledge base to include a diversity of users.

Over the course of the project, advances in technology emerged which would allow the Web version of Pressure's Off to respond dynamically to its users. However, authors and developers have been slow to exploit these in online health information, persisting with the old paradigms which prioritise information and content. Roger Schank (2004) draws a parallel with the earliest days of cinema, when the most groundbreaking use most film makers could imagine for cameras was to record theatre productions to be screened in auditoria. While information remains a cornerstone of self-care for HBP, the new medium of the Web offers many other opportunities for learning experiences (Riva, 2002).

Java's servlet technology (Sun Microsystems, 2004) presents one such opportunity, allowing screens to be aggregated from granular units of content. In this way, using data were collected (on a voluntary basis) from patients at the beginning of their initial session using Pressure's Off, servlet technology in combination with a set of rules could respond by, for example, creating an individual home page for each user containing links to those areas of Pressure's Off most suitable for their circumstances. Another use of servlets is to slot in units of content "on the fly". For example, if a given user input a body mass index (BMI) which the system flagged as above the healthy threshold, the information in the BMI page could be updated to focus on

personalised information relating to weight loss and risk for the given BMI range.

The second area of individualisation is concerned with diversity. As discussed in 3.4.7, people with ethnic minority status, which is strongly related to social circumstances, often fare poorly on several health indicators and can be particularly vulnerable to HBP. In equitably providing health information for different ethnic groups, language is the most immediate concern, and issues around translation have been detailed in Section 5.2.1.3. However, there is a diversity of approaches to illness across cultures and, correspondingly, health care is organised in different ways. In this country, a particularly mechanistic approach to the body and health prevails (Naidoo and Wills, 1994, p7) which has traditionally neglected the spiritual aspects of health valued in some other cultures. Moreover, it is important to avoid an inadvertent Anglocentric presentation – for example, failing to represent diversity in illustrations of people or foods - which can interfere with the way health messages are received by people from other cultures. The solution here is to aim for either neutrality or diversity of representation, as appropriate to the content.

10.3.5 EVALUATION

The aim of Pressure's Off is to equip people with the knowledge and skills to care for their BP. The lower levels of Kirkpatrick's (1994) four level evaluation model have been evaluated to the satisfaction of target users in the evaluation described in Chapter 8. After completing a working version of Pressure's Off, summative evaluation should be carried out, over time and with a representative sample, to provide evidence about its effects, whether it achieves its aims to promote healthy behaviours, and whether its benefits outweigh its costs. Both impact and outcome evaluation will be required; impact evaluation explores the consequences of an activity observed during or immediately after an intervention, and outcome evaluation explores those emerging after an intervening period.

10.3.6 OPPORTUNITIES TO CARRY OUT FURTHER WORK

There is a tendency for a large proportion of doctorate projects to sink into obscurity in the absence of an exit strategy. As part of the exit strategy for Pressure's Off, opportunities for carrying out the aforementioned future work were explored. One promising prospect has arisen from the good relations

established between the researcher and the Blood Pressure Association (BPA). While parallel endeavours, with their attendant diversification and creativity, can be extremely productive, in the area of health promotion they can also dilute resources and, consequently, messages. There are opportunities to build on the work done for Pressure's Off in partnership with the BPA in which the organisation's subject area expertise, sustainable funding model, national profile, and geographical proximity will be crucial. The organisation has shown interest in a number of Pressure's Off sections, and these will be further developed by the BPA and the researcher for inclusion on the BPA's web site (Appendix 7). The hypertension clinic team, who made such an central contribution to the project, concur. It is satisfying that, via this conduit, this Economic and Social Research Council (ESRC) funded project will be able to make a unique contribution which addresses specific unmet BP information needs as well as a number of the ESRC's thematic priorities (ESRC, 2000). Arrangements are underway for the researcher to become involved with the imminent redesign of the BPA web site, an exciting prospect.

10.4 FINAL WORDS

Health promotion for high blood pressure is an under-researched subject in which this project – the scoping, design, development and evaluation of a Web-based information package – has made a unique contribution. It has identified and prioritised user needs, addressed the complexities inherent to producing information for a multifactorial condition, effectively distinguished itself from other projects in the domain, and succeeded in producing a package rich in innovative resources, which users reported engaged their interest and promoted their understanding.

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APPENDIX 1: QUESTIONNAIRE TO CAMDEN AND ISLINGTON HEALTH PROFESSIONALS

About patient education

As a factor in good management of hypertension, how important do you consider patient education to be?

Most important ☐
Very important ☐
Quite important ☐
Not very important ☐
Unimportant ☐

What information does your practice routinely provide for each newly diagnosed hypertensive patient?

Indicate any which apply.

No routine information ☐
Information about complications of hypertension ☐
Diet information ☐
Lifestyle information (e.g. smoking, exercise) ☐
Information about the circulatory system ☐
Information about hypertension ☐
Local support information (e.g. diet or exercise groups) ☐
Drugs - how they work, their side effects etc ☐
Advice about self-measurement ☐
Other (please specify on the page provided) ☐

Consider the following areas of hypertension management. How important do you feel it is for a hypertensive patient to be knowledgeable in each area?

Circle a number. You can assign the same number to different areas.

Complications of hypertension   less 1   2   3   4   5 more

Lifestyle modification   1   2   3   4   5

Drug information   1   2   3   4   5

Cardiovascular risk assessment   1   2   3   4   5

Individual's blood pressure trends   1   2   3   4   5

Self measurement   1   2   3   4   5

In the practice, what form does the education take? For any that applies, estimate the importance of its role.

Circle a number or leave blank. You can assign the same number for different areas.

Talk with GP   less 1   2   3   4   5   more

Talk with nurse   1   2   3   4   5

Patient information leaflets   1   2   3   4   5

Models or diagrams   1   2   3   4   5

Computerised education   1   2   3   4   5

Recommended reading   1   2   3   4   5

Local support groups   1   2   3   4   5

Have the providers of education for hypertensive patients in your practice been formally trained in providing education *specifically for hypertensive patients* within the last year?

Yes   ☐
No   ☐
Not sure   ☐

Within the last five years?

Yes   ☐
No   ☐
Not sure   ☐

About the Patient

Do you feel that individual patients have different educational needs, either in terms of the material covered or how it is delivered? Indicate any factor you feel may be significant.

Social circumstances ☐
Your assessment of patient's aptitude ☐
Age ☐
Gender ☐
Ethnicity ☐
Patient's questions ☐
Severity of risk factors ☐
Psychological state ☐
No different needs ☐
Other (please specify on the page provided) ☐

How well do you feel the needs you have specified above are addressed in primary care as a whole?

Effectively ☐
Quite well ☐
Not very well ☐
Badly ☐

Does the approach to education vary between patients in your practice? Indicate any difference that applies.

Focus on patients with more risk factors ☐
Focus on patients who ask questions ☐
Focus on patients who do not ask questions ☐
Other focus (please specify on page the provided) ☐
No difference between patients ☐

If a hypertensive patient at your practice is not well controlled, what procedure is adopted in your practice?

_____

_____

_____

_____

_____

_____

For the proportion of patients whose hypertension is poorly controlled, estimate the extent to which the following factors are responsible.

Circle a number. You can assign the same number to more than one point.

less   1   2   3   4   5   more

Side effects prevent patient from
taking medication

1   2   3   4   5

Patient regularly forgets to take
medication

1   2   3   4   5

Patient does not understand the
importance of the medication

1   2   3   4   5

The medication seems inadequate /
inappropriate to the patient

1   2   3   4   5

Patient's lifestyle

1   2   3   4   5

About computerised education

Have you ever encountered a *computerised* education system for patients?

If you are not familiar with the concept of computerised education please refer to Introduction to Computer-Aided Learning (enclosed).

Yes   ☐
No   ☐

Name and nature of system:

_____

_____

_____

What is your attitude to computerised education for hypertensive patients?

Very positive   ☐
Positive   ☐
No feelings   ☐
Negative   ☐
Very negative   ☐
Not sure   ☐

Would you, as a health care professional, want the opportunity to individualise a computerised education program for different patients?

Yes   □
No   □
Not sure   □

Assuming the list below represents components of a hypertensive patient education program, identify the areas you might wish to individualise.

Individual's cardiovascular risk assessment	□
Individual's blood pressure trends	□
Information on side effects for a certain drug	□
Feedback for the individual in their management of blood pressure	□
Information on the complications of hypertension	□
Progress of patient	□
None of the above	□
Other (please specify on the page provided)	□

About you

Would you be happy to be further involved in this project with regard to evaluating the patient education?

If 'Yes' please supply your name and address below

Yes   □
No   □
Not sure   □

What kind of voucher would you prefer?

Marks & Spensers voucher   □
Book voucher   □
Music voucher   □

Thank you for your time and interest.

Your comments

Input from health care professionals is valuable to this project. Please use this space for:

- **additional comments for any of the questions**

- **comments on patient education and computer-aided learning**

Your contribution is much appreciated.

[lined space for respondent comments]

APPENDIX 2: EVALUATION PRE-SESSION QUESTIONNAIRE

Please note that the visual analogue scales were 10cm in length in the originals, but have been shortened for presentation in this thesis.

Questionnaire: you and computers, your health, and learning about blood pressure

Thank you for participating in this evaluation of Pressure's Off, information on high blood pressure. We would like to find out some background information about you, which will give us clues about how different people use Pressure's Off. Your input will help to improve it.

Your opinion is important. Please answer the questions below as fully as you can.

1. What is your name? *This information will be anonymised only seen by the principal investigator and members of the research team.*	
2. What is your date of birth? *Please write.*	
3. What is your occupation, if you have one? *Please write.*	

You and computers

We would like to find out how you feel about computers. We'd also like to reassure that there are no wrong answers.

4. Please indicate whether you agree or disagree with the following statements. *Make a mark on the scale underneath*	I am confident using a computer. ☹ ———————————————— ☺

each statement. ☺ = *agree* ☹ = *disagree*	I would like to learn more about using a computer. ☹ ──────────────────────────── ☺
	I am comfortable with the idea of using a computer to find information about my health condition. ☹ ──────────────────────────── ☺
	When I want information about my health condition, I would prefer to talk to a health professional than to use a computer. ☹ ──────────────────────────── ☺
5. Do you have access to a computer at home? *Please tick one box or write.*	No computer ☐ PC ☐ Apple machine ☐ Laptop ☐ Palmtop ☐ Other *(please describe)* --
6. Do you have Internet access at home? *Please tick one box.*	Yes ☐ No ☐

Your health

We would like to find out some information about your health. You may not know the answers to any of the following questions, and that will not be a problem.

7. Please write your *height*, if you know it. *You can answer in metres OR in feet and inches.*	-------- metres **OR** -------- feet, -------- inches.
8. Please write your *weight*, if you know it. *You can answer in kilos OR in stone and pounds.*	-------- kilos **OR** -------- stone, -------- pounds
9. Please write your last *blood pressure* measurement, if you know it.	-------- / -------- mmHg
10. If you are taking any *medicine* for your blood pressure,	

please write down their names if you know them. *You can refer to your pink card, if you have it with you. If you don't have your pink card and you can't remember, that is not a problem.*	-- -- -- -- -- -- --
11. To your knowledge, have you ever had, or do you have now, any of the conditions listed opposite? *Please tick any box which applies.*	Heart attack ☐ Heart failure ☐ Heart disease ☐ Left ventricle hypertrophy ☐ Stroke ☐ Angina ☐ TIA ☐ Embolism ☐ Thrombosis ☐ I'm not sure ☐ Other *(please describe)* -- --
12. Only 5% of people have a known cause for their high blood pressure. To your knowledge, is your high blood pressure is caused by another illness or condition? *Please tick any box which applies.*	Yes ☐ No ☐ Not sure ☐
13. Recently (in the past few readings), has your blood pressure gone up or down? *Please tick any box which applies.*	Up ☐ Down ☐ No change ☐ I'm not sure ☐

How you feel about your blood pressure

We would like to find out how you feel about your blood pressure. We'd also like to reassure you once again that there are no wrong answers.

14. Please let us know how you feel about the following statements. *Make a mark on the scale underneath each statement.* ☺ = agree ☹ = disagree	I am interested in my blood pressure. ☹ ————————————————————— ☺
	I would like to know more ☹ ————————————————————— ☺
	I would prefer not to know very much ☹ ————————————————————— ☺
	I would like the doctor or nurse to tell me everything I need to know. ☹ ————————————————————— ☺
	I would like to find out as much as I can. ☹ ————————————————————— ☺
	I think that learning about high blood pressure will help me to keep my blood pressure down. ☹ ————————————————————— ☺
	I think that the doctor is the person most responsible for controlling my high blood pressure. ☹ ————————————————————— ☺
	I feel that there is little I can do to control my blood pressure. ☹ ————————————————————— ☺
	I don't feel under much threat from my high blood pressure. ☹ ————————————————————— ☺
	I would rather not think about my blood pressure at all. ☹ ————————————————————— ☺
	It's easy to forget about my blood pressure. ☹ ————————————————————— ☺
	I believe I know enough about high blood pressure to keep it under control. ☹ ————————————————————— ☺

Thank you

APPENDIX 3: EVALUATION QUESTIONS

The same set of questions was asked for each section selected for the evaluation. An example is below.

Description	Pop-up window containing interactive animation outlining the anatomy of the heart.
Path	Cardiovascular system > The heart > Anatomy of the heart
Notes	
01	Did you find this section interesting? ☹ _____ ☺ Make a mark on the line. ☺ = More interesting ☹ = *Less interesting*
	What are the reasons for this response (Q01)?
02	Did you find that it helped your understanding of an issue to do with high blood pressure? ☹ _____ ☺ Make a mark on the line. ☺ = More helpful ☹ = *Less helpful*
	What are the reasons for this response (Q02)?
03	Is there anything you particularly like about the section?
	Why do you like that part?
04	Is there any part of the section which doesn't work for you?
	Why don't you like that part?
05	After looking at the section, do you have any unanswered questions on the subject?
	What are your questions?
06	How could we improve it?

APPENDIX 5: EVALUATION CODEBOOK

The codes below were used to analyse the transcripts of the recorded evaluation sessions.

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Affective responses   ar
Approval   ar-al
Discomfort   ar-df
Enjoyment   ar-et
Excitement   ar-ex
Humour   ar-hr
Tone   ar-te

Interest   it
Animation   it-an
Enjoy learning (general)   it-el
Graphics   it-gs
Interest   it-it
Personal relevance   it-pr

Understanding   ug
General   ug-ge
Clarity   ug-ge-cy
Compar. info sources   ug-ge-co
Conceptualisation   ug-ge-cn
Effective   ug-ge-ee
Error   ug-ge-er
Misunderstood   ug-ge-md
New knowledge   ug-ge-nk
Omission   ug-ge-on
Graphical   ug-gl
Animation   ug-gl-an
Graphics   ug-gl-gs
Labelling   ug-gl-lg
Verbal   ug-vl
Amount   ug-vl-at
Clarity   ug-vl-cy
Jargon   ug-vl-jt
Reading experience   ug-vl-re

Suggested improvements si
General   si-ge
Concept   si-ge-ct

Information   si-ge-in
Graphical   si-gl
Graphics   si-gl-gt
Labelling   si-gl-bl
Layering of info   si-gl-li
Interface   si-ie
Instructions   si-ie-is
Layout   si-ie-lt
Orientation   si-ie-on
Navigation   si-ie-nn
Verbal   si-vl
Detail   si-vl-dl
Jargon/technical vocab   si-vl-jt

Unanswered questions   uq
Covered elsewhere in PO   ug-ce
Remained unanswered   ug-ra
Resolved on review   ug-rr

Usability   uy
Ease of use (general)   uy-eu
Experimentation needed   uy-ep
Instructions   uy-in
Orientation   uy-ou
Physical position   uy-pp
Unsure how to proceed   uy-up
Layout   uy-lt
Layout clarity   uy-lt-lc
Register elements   uy-lt-re
User error   uy-er
Pop-up window   uy-er-pw
Closed window inadvertentl uy-er-cw
Failed to click   uy-er-fc
Mis-clicked   uy-er-mc
Vision   uy-vn

APPENDIX 6: BLOOD PRESSURE

KNOWLEDGE TEST

1. Eating fruit and vegetables helps to lower blood pressure because they:

A	are low in both simple and complex sugars.	☐
B	do not contain artificial additives.	☐
C	contain substances which help keep the arteries free from build-up.	✓
D	are low in energy (calories).	☐

Fruit and vegetables are rich in substances, including vitamins, minerals, soluble fibre and naturally-occurring aspirin, which keep the arteries free from build-up. None of the other options - calories, additives or sugar - are particularly true of fruit and veg, and nor do these have a direct effect on blood pressure.

2. Exercise is most useful for the cardiovascular system if it causes the heart to:

A	beat at twice its normal resting rate.	☐
B	beat at 50%-75% of its maximum rate.	✓
C	pump at 50 - 75 beats per minute.	☐
D	pump at three times its normal resting rate.	☐

The cardiovascular benefit from exercise is based on maximum heart rate, which varies from person to person, depending on age and fitness. As a guide, our maximum heart rate is about 220 minus our age. During exercise, our target zone should be between half and three-quarters of this, building up slowly over a number of months.

3. For people with high blood pressure weight training:

A	should involve raising your arms above shoulder level to improve circulation.	☐
B	risks over-working the heart muscle.	✓
C	causes a short-term fall in blood pressure.	☐
D	should not exceed 80% of your body weight.	☐

Weight training is a type of isometric exercise - involving lifting and holding. There is some evidence that sustained contraction of the large muscles during this type of exercise limits the amount of oxygen that reaches the heart. It is not recommended for high blood pressure.

4. For most people, the underlying cause of their blood pressure is:

A	a hormone imbalance.	☐
B	not known.	✓
C	being overweight.	☐
D	alcohol-related.	☐

In 95% of cases, there is no known cause of high blood pressure. Certain hormones, overweight and alcohol can all contribute to or cause high blood pressure, but for most people, none is a single cause.

5. High blood pressure affects the arteries by causing:

A	a stiffening and narrowing of the artery walls.	✓
B	a rise in fats in the blood which leads to a build-up on the artery walls.	☐
C	an increase in blood volume leading to overcrowding of the cirulatory system.	☐
D	wearing away of the artery walls, which become thin and at risk of tearing.	☐

High blood pressure does not itself cause a rise in blood fats (lipids) nor an increase in blood volume - though reducing blood lipids and blood volume can sometimes help to lower blood pressure. Neither does it cause the blood vessels to wear away - instead the artery walls respond to damage from high blood pressure by stiffening and losing their elastic ability to stretch with each heartbeat.

6. High blood pressure is a main risk factor for:

A	hypothermia.	☐
B	irregular heart beat.	☐
C	heart disease.	✓
D	asthma.	☐

Neither hypothermia (a drop in body temperature), nor asthma (a tightening of the airways), nor irregular heart beat, are related to high blood pressure. High blood pressure is a main cause of heart disease, which is one of the largest causes of death and disability in the UK.

7. Current recommendations advise that our intake of alcohol should not be more than:

A	4 units in a day for men, 3 for women, with at least 2 alcohol-free days each week.	✓
B	21 units in a week for men, and 14 for women, with at least 3 alcohol-free days in a row.	❏
C	2 units in a day for men and 1.5 for women, with at least 3 alcohol-free days each week.	❏
D	21 units in a week for men, 14 for women if beer or spirits are drunk, or 28 units in a day for men and 21 for women if red wine is drunk, with 3 alcohol-free days each week.	❏

Based on the most recent evidence, the correct answer is A. For men, 4 units is equivalent to 2 pints or beer, or 4 single measures of spirits, or 4 small glasses of wine. For women, 3 units is equivalent to 1.5 pints of beer, or 3 single measures of spirits, or 3 small glasses of wine. While this amount of alcohol is not thought to increase our cardiovascular risk, it may increase risk of other health and social problems.

8. Current recommendations advise that our intake of salt should not be more than:

A	4g a week.	❏
B	10g a day.	❏
C	10g a week.	❏
D	4g a day.	✓

According to the Consensus for Action on Salt and Health, we should aim for a maximum 4g of salt each day - the average person eats about 9g. The salt in our diet is sprinkled on at the table, added during cooking, or hidden in processed foods, ready meals, and sweet and savoury snacks.

9. Smoking causes:

A	damage to artery walls due to toxins in tobacco.	✓
B	a sustained rise in blood pressure, putting strain on the heart.	❏
C	a gradual increase in platelets in the blood, causing it to stick to the artery walls.	❏
D	a long-term increase in heart rate, putting strain on the heart.	❏

Smoking is not associated with an increase in blood platelets, an increase in heartbeat, nor an increase in blood pressure. Toxins in tobacco are known to damage the artery walls.

10. The medical name for high blood pressure is 'hypertension'. This is because:

A	it was believed to affect people who feel tense or anxious.	☐
B	it was believed to be caused by increased tension or tightening of the arteries.	✓
C	it was believed to bring about an increase in feelings of tension or anxiety.	☐
D	blood vessels react to higher pressures by tensing.	☐

The tension in 'hypertension' refers to a tightening in the arteries rather than a state of mind. This tension or tightening was believed to be a cause, and not an effect, of high blood pressure. Some people argue that the term 'hypertension' is misleading, because it implies that hypertension has one cause - a tightening of the arteries - when in fact this is not the only cause.

Thanks for taking part.

APPENDIX 7: BLOOD PRESSURE ASSOCIATION CORRESPONDENCE

BLOOD
PRESSURE
ASSOCIATION

15 September 2004

To whom it may concern

Mira Vogel approached the Blood Pressure Association part way through her thesis, seeking feedback and information regarding the Pressure's Off web site. I was very impressed by the quality of Mira's work, both in terms of content and technological skill and asked whether the BPA might be able to make use of some parts of the web site and some of the tools for the public that she has developed.

Subsequently I have met again with Mira to discuss this further and have agreed that Mira will help us to further develop our own web site, volunteering her time and expertise. Mira will be helping us to make the web site more accessible and improving the content as well as using some of the excellent tools that Mira has developed during her thesis, such as the medicines search engine, the information on food labelling and the animated anatomical and physiological diagrams.

I hope that by doing this the work that Mira has undertaken for her thesis will provide real and lasting benefit to people with high blood pressure.

Yours sincerely,

Sarah Ransome
Information and Support Manager

FIGHTING BLOOD PRESSURE TO BEAT STROKE AND HEART DISEASE