

SDO Project (08/1710/153)

Information for choice: what people need, prefer and use

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Glossary and abbreviations

AFP blood test – alpha-fetoprotein blood test checks the level of AFP in a pregnant woman's blood to indicate whether the baby might have an abnormality e.g. neural tube defect or chromosomal abnormality

A level – advanced level academic school qualification

ARC - Antenatal Results and Choices voluntary organisation

AS level - Advanced Subsidiary level academic school qualification, the first part of the current A Level qualification

BEd – Bachelor of education degree qualification

CAPI – computer-assisted personal interviewing

CLRN – Comprehensive Local Research Network

CVS – chorionic villus sampling – an antenatal diagnostic test for chromosomal disorders in the fetus

DIPEX – Database of Personal Experiences of Health and Illness – the name of the charity that runs the Healthtalkonline website and the former name of Healthtalkonline

GCE – general certificate of education academic school qualification

GCSE general certificate of secondary education academic school qualification

GP- general practitioner

HE – higher education

HL – Hodgkin's lymphoma

ID- identification number or code

IRAS - Integrated Research Application System

MREC – Multi-centre Research Ethics Committee

NHL –non-Hodgkin's lymphoma

NHS – National Health Service

NIHR – National Institute for Health Research

NIHR CRN CC - National Institute for Health Research Clinical Research Network Coordinating Centre

NIHR CSP - National Institute for Health Research Coordinated System for gaining NHS Permission

NRS CC - NHS Research Scotland Coordinating Centre

OSOP – one-sheet-of-paper qualitative analysis method

PCRN - primary care research network

PCT – Primary Care Trust

R&D – Research and Development

REC – Research Ethics Committee

RM&G – Research management and governance – also known as R&D

SCT - sickle cell and thalassaemia collection of interviews carried out for the Healthtalkonline website

SDO - Service Delivery and Organisation programme of the National Institute for Health Research

SC - sickle cell disease, a haemoglobin disorder

SCE – Scottish Certificate of Education academic school qualification

SPCRN - Scottish Primary Care Research Network

SS - sickle cell anaemia, a haemoglobin disorder

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The Report

1 Introduction

1.1 *The commissioned research, aims and objectives*

Choice is at the heart of all Government health policies (1-5). The SDO's scoping review of the evidence on patient choice in the NHS, commissioned in 2004, suggested that: people want information but not necessarily for making choices; that people facing complex treatment choices often prefer decisions to be made on their behalf by a well-informed and trusted health professional; that wanting the option of choosing a distant hospital for non urgent care is limited to those situations where there is a long wait for a local hospital and there is a history of poor quality care; that wealthy and better educated people are likely to benefit most from choice; and that there is little evidence that giving people more choice will, in itself, improve quality of care (6). It is recognised that information is pivotal to people's experience of choice and self-management; to make optimal choices with confidence and to build on their existing self-management strategies people need the right information, at the right time with right support to use it (7). Lord Darzi's Next Stage Review (8) made it clear that the English NHS was to be focused as: "*an NHS that gives patients and the public more information **and** choice, works in partnership and has quality of care at its heart*" (page 7) (our emphasis).

SDO 08/1710/153 was commissioned in 2005. The brief called for research to understand the *types of information* that people take account of when making choices, the *format of information* that they prefer, and *whether preferences vary* systematically according to socio-economic status, ethnicity, gender and age. In responding to this brief we focused on two key types of information: 'general facts' and 'personal experience' information. By 'general facts' we mean research-based information about health care interventions and the risks and outcomes associated with them; medical knowledge that reflects consensus based on what has been observed among many patients/people; and other information that is widely accepted to be both reasonably reliable and fairly broadly applicable (e.g. statements of legal requirement or policy). By 'personal experience' information we mean information about the experiences of particular individuals, as communicated by themselves or others.

The research considered people's use of and preferences for information of these different types in the context of choices faced in relation to five, contrasting, exemplar health issues in stages 1 and 2 (antenatal screening, ending a pregnancy for fetal abnormality, screening for sickle cell disorder or

thalassaemia, caring for a person with dementia, and lymphoma) and three in stage 3 (antenatal screening, caring for a person with dementia, and lymphoma). The health issues were chosen to cover a range of types of choices (e.g. about screening, treatment, type and place of care) that have different implications, are faced by people at different life stages and in different states of health. We recognise that a choice of different health conditions, in which perhaps simpler decisions would be faced, would result in very different results than those presented here. Nevertheless, we aim to shed some light on the how people use and value information in decision making.

The research aims were:

1. To examine the kinds of information that people need, prefer and use in relation to choice;
2. To investigate their response to, and use of, different types of information available in different formats; and
3. To investigate whether views, preferences and reported use of different types and formats of information vary systematically according to socio-economic status, ethnicity, gender and age.

The research was undertaken in three stages to answer the following questions:

1. What do people see as 'choices' and how do they describe the choices they have experienced? (aim 1);
2. What types of information, information resources and information sources do people report seeking or using when they describe the choices they have faced? (aim 1);
3. What are people's views of, and preferences for, different types of information? (aim 1 and 2);
4. How do people respond to and consider the usefulness of information resources that present options/outcomes information and personal stories separately and in combination? (aim 2);
5. How are the views, preferences and reported use of different types and formats of information for each type of choice distributed across the population within socio-demographic groups? (aim 3);
6. Are there distinct types of people, patients or carers in relation to information use and choice? (aim 3).

1.2 The importance of health information to the NHS

Information is crucial for most of the key components of current health care policy, including informed consent, self care, and, especially for patient choice. Information is recognised to be important by patients and carers, who report needing different types of information for different purposes, but often struggle to access what they need (9). Various strategies have been proposed (and implemented) to improve the provision of health information to NHS

users including a 'Patient Information Bank', translating and interpreting services, NHS Direct Interactive, Health Direct, community based navigators and 'Information Prescriptions' (1). 'Information Prescriptions' (defined as "specific, evidence-based information to a specific patient, care-giver or consumer at just the right time to help them make a specific health decision or take a self-management action" (10) have been used for several years in innovative primary care settings in the UK and USA (11) and are endorsed by the UK-based Partnership on Long-term Conditions (12).

Since this project began NHS Choices has been launched as the single entry point for all information provided by the NHS in England (<http://www.nhs.uk/Pages/HomePage.aspx>). The site includes details of national and local services, health information on major topics, including health promotion, and multi-media content including filmed patients' experiences. A recent (2009) addition to NHS Choices has been the introduction of a 'trip advisor' section where people can add their opinions of an NHS Trust through rating scales and free comment sections.

1.3 Choice and information

While choice is central to UK health policy, and patients are expected to become more accustomed to the notion of choice 'as the Choice agenda rolls out' (2;3), as Fotaki et al (6) pointed out, desire for choice and involvement in decision making varies across patient groups, health care scenarios, and over time (13-15). Critics of the choice agenda express concern that imposing choice on patients could be as detrimental as imposing advice. For example, when asked to take responsibility for a choice on a life and death matter, 'figuring out which choice to make becomes a grave burden' and, if the choice turns out to be 'wrong', can lead to intense regret (16). A study of women with early stage breast cancer also observed that women used value-laden terms such as 'right' and 'wrong' when referring to treatment decisions, and showed that women did not always perceive the choice to undergo adjuvant therapy as a real choice because 'doing nothing was no choice' (17).

Previous research has shown that: the potential for exercising choice is not always recognised (17;18) when it is perceived it is not always wanted (19-22); patients' involvement in decision making can take a variety of forms (23;24); and people can feel involved or perceive themselves to have contributed to decision making even if they have not had a significant influence over the selection of a treatment (20;21;25). Nonetheless, there is a clear desire from the public and patients for more information: 80 percent of respondents to a community-based survey said they were likely to seek information on health problems (26); and studies continue to show that most patients with diverse conditions want, appreciate and value information about their treatment even if they do not want or expect choice (14;15;21;27). In summary, current evidence suggests that while information is a pre-requisite for making informed choices, patients value information for a range of reasons, even when it is not used to make choices; 'choice' may not be what matters most to patients in terms of their involvement in decision making.

1.4 Information of difference types and in different formats

Policy makers have recognised the need to provide information in different formats and, as we have seen, have proposed a range of approaches. Ellins and Coulter (26) reported a UK survey that suggested: most people (75%) sought health information from doctors and far fewer from nurses (22%), the internet (30%), printed material (23%), family and friends (19%), and newspaper and magazines (18%). However, these figures varied significantly by age, gender, ethnicity, socio-economic status and whether people had a long-term illness. Since our research began the internet has become even more central for health information and support; 70% of households now have access to the internet and less than 10% of the population are estimated to have neither direct, nor proxy, access to the internet; health information is the fastest growing area of reported internet use (28). Voluntary organisations, in particular, have recognised the role of special interest groups on social networking sites such as Facebook. The Facebook groups on long term conditions, such as asthma, now have many thousands of members, often far more than belong to the relevant voluntary organisations themselves.

1.5 Information of different types

1.5.1 Options/outcomes information

Generalisable, scientific information that systematically describes a range of options and the distribution of their outcomes across populations is widely recognised as important to support choice. Many of the information resources that have been produced for patients over the years have been criticised because they failed to identify options and neglected to provide scientific or research-based information about possible outcomes (29). Over the past decade, the NHS has made significant efforts to ensure that written health information resources for patients include 'evidence-based' information about the effectiveness of interventions in relation to options and outcomes (30; 31). However, when research based information on options and outcomes is not available information providers have to rely on other sources and often include medical knowledge based on consensus and other information that is widely accepted to be both reasonably reliable and fairly broadly applicable (e.g. statements of legal requirement or policy).

1.5.2 Personal experiential information

Another type of information that is increasingly recognised as important is personal experiential information. Many information resources now include personal accounts of illness and health decisions and internet sites often invite visitors to submit 'my story' type accounts of their experiences. The NHS Choices site features numerous video clips and links to sites based on patient's experiences (including www.healthtalkonline.org). Accounts of people's personal experiences can be compelling, more influential than

statistics and can serve a number of purposes. They can convey important social and emotional information (32), provide a backdrop for understandings of susceptibility to various illnesses such as heart disease (33-35), help make facts and figures meaningful to people and enable them to apply them to their own case by facilitating an 'imaginative leap' (for example to envisage what a particular health state would be like for them). Personal experiential information can help people to identify the significance of issues and to come to terms with particular problems (36). They can help people realise that they are not the only ones who are dealing with particular health issues, validate their health experiences, and alert them to issues to discuss with their own doctors and nurses. People who are faced with treatment choices for serious conditions increasingly turn to the internet to learn how others have made their decisions and to check that the options that have been offered to them are comprehensive (37). Patients and their families often want to know how others have made decisions and coped in similar situations (38; 39). However, despite the proliferation of the use of accounts of personal experiences in information resources their relevance in relation to the choice agenda remains unclear. On the one hand, these accounts of other people's experiences may be helpful, enabling people facing choices to think more clearly about "what it might be like" to follow different courses of action or to experience outcomes with which they are unfamiliar. On the other hand, as a study comparing the effects of providing different types and groupings of personal stories alongside 'options/outcomes' type information has shown, they can also have a distorting influence on decisions (40). In summary, personal experiences are integral to most people's experience of health and illness, but why they are compelling and how they are used in relation to other types of information remains poorly understood.

1.6 The structure of the report

We met the research aims and answered the research questions in three stages, each building upon the results of the previous stage. Section 2 describes the methods and results from stage 1, secondary analysis of transcripts of narrative interviews undertaken for the Healthtalkonline website concerning the five exemplar health issues, undertaken to meet aim 1 and answer research questions 1 and 2. Section 3 describes the methods and results from stage 2, extended focus group discussions and individual interviews with people facing or having faced the exemplar health issues, undertaken to meet aim 2 and answer research questions 3 and 4. Section 4 describes the methods and results from stage 3, a national survey of people facing or who have faced three of the exemplar health issues (antenatal screening, caring for someone with dementia and lymphoma treatments) undertaken to meet aim 3 and answer research questions 5 and 6. Finally, in section 4, we bring summarise the research from each stage; make some conclusions and policy recommendations.

2 Stage 1. Information that people need, prefer and use in relation to choice

2.1 *Aim and research question*

The aim of this stage of the project was: to examine the kinds of information that people need, prefer and use in relation to choice.

Associated research questions were:

- What do people see as 'choices' and how do they describe the choices they have experienced?
- What types of information, information resources and information sources do people report seeking or using when they describe the choices they have faced?

We addressed these through secondary analysis of interview transcripts undertaken with people who had experience of the five exemplar health issues (antenatal screening, ending a pregnancy for fetal abnormality, screening for sickle cell disorder or thalassaemia, caring for a person with dementia, and lymphoma). The interviews were originally collected and analysed by experienced social science researchers at the Oxford University Health Experiences Research Group (formerly DIPEX). The group use narrative and semi-structured interview methods to explore people's experiences, information and support needs. Using procedures approved by MREC, the interview transcripts were then reviewed by participants before being copyrighted to the University of Oxford. Extracts from the interviews and further analyses are also published on a website, run by the DIPEX charity (www.healthtalkonline.org). The full interview transcripts are available for secondary analysis, under licence from the University of Oxford. Here we describe our analytical approach and summarise the findings most relevant to the research questions.

2.2 *Methods*

2.2.1 **Order of analysis of collections**

Because we assumed that the order of the analysis would affect how the themes, coding and interpretation would develop we started with the most common and routine screening that people experience (antenatal screening), moved on to a less common screening experience (for sickle cell and thalassaemia) and then to the potential subsequent decision of whether to end a pregnancy. Experience of treatment decisions for people with lymphoma offered a complete contrast to decisions taken about pregnancy and we finished with an issue which affects people later in life (caring for someone with dementia) and which we felt would probably be the most complex in terms of decisions and choices.

2.2.2 Method of secondary analysis

The main researcher read and analysed all of the interviews in each of the five collections (a total of 184 interviews – see Table 1). In each collection a further two senior researchers from the project team read a minimum of seven to 10 interviews each and verified the completeness and accuracy of the analysis. As we became confident in our analytical approach and the accuracy and completeness of the analyses we reduced the number of checks; just over a quarter (49) of interview analyses were looked at by at least two researchers.

Table 1. Number and sex of interview respondents for secondary analysis studies

*Some respondents were interviewed jointly or were interviewed on more than one occasion therefore the number of interviews and the number of respondents may differ.

	Antenatal screening	Ending a pregnancy for fetal abnormality	Sickle cell and thalassaemia screening	Lymphoma	Carers of people with dementia
Number of interviews*	40	37	30	46	42
Number of respondents*	47	40	39	46	31
Number female	39	31	30	23	16
Number male	8	9	9	23	15

We drew on a number of qualitative methods including an adaptation of the 'framework approach' (a matrix based analytic method) developed by Ritchie and Spencer (41), and thematic analysis, including the OSOP method (42).

Using a table ('framework') for each individual transcript we noted the following:

- the decisions described in the transcripts (for all actual rather than hypothetical decisions)
- whether the decision was seen as a choice or not
- information type (e.g. personal experience, risk statistics, other people's experiences, GP attitude, success story, survival rate) and

format (e.g. leaflet, voluntary support group, website, verbal from nurse) used for the decision

- method and manner of information delivery (brief details of how, where, when, and by whom)
- evaluation of information (reaction to the information, their understanding of it and the impact it had on them)
- evaluation of decision (except for antenatal screening)
- any information gaps raised by the respondent.

We used direct quotes from the interviews in our modified framework approach to allow us to stay close to the data. See Table 2 for a template of a framework. The framework was adapted following analysis of the antenatal screening collection to the respondent's reflections (or evaluation) on their decision.

Table 2. Example of the analytical framework used for each interview transcript

Decision event	Seen as choice? (yes, no, unclear)	Information type & format	Method & manner of information delivery	Evaluation of information	Evaluation of decision	Information gaps
Decision 1	Data/evidence	Data/evidence	Data/evidence	Data/evidence	Data/evidence	Data/evidence
Decision 2	Data/evidence	Data/evidence	Data/evidence	Data/evidence	Data/evidence	Data/evidence
Decision 3 etc	Data/evidence	Data/evidence	Data/evidence	Data/evidence	Data/evidence	Data/evidence

Drawing on previous research, preliminary reviews of the data, and discussion with the original researchers and colleagues including a dementia care advisor, we focused on the most relevant decisions for each health issue. In antenatal screening these included decisions up to the time of birth; in the ending a pregnancy it included the decision to terminate; whether to see and hold the baby, have a post-mortem and a funeral; in sickle cell and thalassaemia it included screening and pregnancy decisions; in lymphoma it included the various treatment decisions, fertility and disclosure; in dementia interviews it included the decision about place of care, use and administration of drugs and sedation, and dealing with wandering.

We used an 'OSOP' ('one sheet of paper') analysis (42) to summarise data on decisions. This involved reading through each row of data relevant to a particular decision in each framework in turn and noting, on a single sheet of paper, all the different issues that were raised by the data extracts, along

with the relevant respondent IDs. When the OSOP was complete, we had a summary of all the issues for a particular decision and the IDs of the relevant respondents. The next step was to group the issues into broader themes (also known as axial coding). We created a descriptive summary of each OSOP.

2.2.3 Which decisions were analysed?

To maximise efficiency we selected OSOP analyses for decisions that were likely to yield relevant information to inform the stage 2 focus groups. We undertook analysis in relation to:

- antenatal screening: dating scan; 20 week scan; amniocentesis; chorionic villus sampling (CVS)
- sickle cell and thalassaemia: amniocentesis; CVS; decisions to end or continue a pregnancy
- ending a pregnancy: whether to see and hold the baby; post-event investigation (post-mortem, research, genetic causes); disclosure; whether and how to mark the baby's life/ death
- lymphoma: all treatment decisions
- dementia: place of care for the relative (own home, live-in care or residential care).

Where decisions were discussed by respondents in more than one collection (for example, decisions whether to have diagnostic tests in pregnancy was discussed by respondents in antenatal screening, sickle cell and thalassaemia and ending a pregnancy collections) we combined analyses. Finally, in the interests of brevity, only some analyses are summarised here, these are:

- decisions on ultrasound scanning in pregnancy
- decisions on diagnostic testing in pregnancy
- decisions on ending a pregnancy
- treatment decisions in lymphoma and
- place of care for carers of people with dementia.

Wherever relevant, for each of these analyses we present: whether the decision was seen as a choice; the relationships between choice and understanding or information used to make a decision; sources of information; and information gaps.

A paper based on our analysis of other decisions faced by people in the immediate aftermath of ending a pregnancy has already been published (43).

2.2.4 Limitations of using secondary data analysis

The qualitative data used for this analysis came from interviews in which use and sources of information were frequent topics, but decision making and choices were not always central to the research question. For example, while decision making was inevitably a key focus in the antenatal screening and termination collections, the carers of people with dementia study was designed to explore the ethical dilemmas facing carers. Although the use of unstructured, narrative interviewing produced much relevant data, there were inevitably some occasions where the original interviewer had not followed up

on issues that would have been of great interest to the current research questions on information to support choices.

On the positive side, we were able to analyse a data set that took many years of skilled researcher time to collect and which yielded a wealth of rich data on the topic; indeed this was rather more than even the original research team had anticipated.

The nature of the samples is also an important consideration for presenting the results: the studies aimed for diverse, maximum variation which sought unusual experiences as well as more conventional ones. In representing a wide range they did not aim to be numerically representative, thus it could be misleading to present the results numerically.

2.3 Findings

2.3.1 Ultrasound scanning in pregnancy: the 'dating' and 'anomaly' scan

The National Screening Committee emphasises that decisions to have any antenatal tests, including the 'dating' scan and more detailed 'anomaly' scan, and are to be made by women themselves. For example, in 'Screening tests for you and your baby' (44) they write: *"It is important that you understand the purpose and possible results of the screening tests before you make your decision."* (page 5).

The 'dating' scan (8- 14 weeks) estimates gestational age; it is not listed as a screening test by the NHS National Screening Committee. In some areas a nuchal translucency scan is also carried out (11- 13 weeks) to estimate probability of Down's syndrome. Respondents did not routinely distinguish between 'dating' and 'nuchal fold' scans in their descriptions. The 'anomaly' scan (18- 20 weeks) expects to pick up neural tube defects and some heart conditions.

As we have said, separate frameworks were initially developed for different interview collections, but given that the same decisions were discussed by respondents in several collections we combined data from antenatal screening, sickle cell and thalassaemia and ending a pregnancy collections. In this analysis, 40 antenatal screening interviews included 30 where respondents described experiences of the 'dating' scan in 57 different pregnancies; and 38 described their experience of the anomaly scan. The respondents had all been interviewed in 2004, either during pregnancy or (with two exceptions) within two years after a birth or a termination.

Was ultrasound scanning seen as a choice?

Accounts varied in relation to whether the ultrasound scans were seen as a choice. Those women who had decided against having any screening tests; or wanted all tests because problems had been found during screening in previous pregnancies; or who said that they wanted to have the scan so that they could see the baby implied that they had seen the decision as a choice.

Other women clearly recognised that there was a choice, but one that was given scant attention. A few women said that they had not been aware that the scan was a matter of choice, or had not been aware of this in their first pregnancy but had become aware that it was in later pregnancies. For example:

'It felt like something that everybody did as part of the process and that [pause]. I don't think it ever felt like something that you might choose not to do. [pause] I don't think there have been many things actually that have felt like they were your choice.' (AN01, age 32, talking about current pregnancy).

Choice and understanding of the purpose of ultrasound scans

Accounts suggested that some of the respondents had not fully understood that the 'dating' scan might uncover a problem; of these, none declined the test. They saw it as standard or routine, to get an image of the baby; some said they had been naïve about the scan. One woman said *"It was just simply at three months I was to have a scan, and that would tell me, like, how many weeks I was"* (AN34).

Other respondents had at least a partial understanding of the scan's potential to uncover 'problems' (such as multiple fetuses, miscarriage, or to see if 'something was wrong') but still talked of the scan as routine, for example, to confirm the pregnancy and as something to look forward to. One woman, whose second baby was diagnosed antenatally as having a hypoplastic left heart, said:

'On the whole I used to look forward to them, thinking, "Oh, you know, this is great. I'll get a chance to sort of see how the baby's developed" and, yeah, it's something positive' (AN04, age 41).

Only one talked of being told what would happen (AN34) and this respondent also spoke of her lack of knowledge about what the scan may find. She said:

'It's called a dating scan and you don't enter into any discussion beforehand about what they are actually looking for, and what can be picked up by a scan.' (AN34, age 26, has healthy baby of 7 months).

The potential consequence of treating the dating scan as routine was illustrated in accounts from women who had discovered serious problems. The following extract is from a woman who discovered that her pregnancy had not survived when she went for her scan.

'And then I just got called for the twelve week scan, and it said what it was about. But I just knew about other people all went for their scans, and they came back and they sent the pictures of their babies to everybody, and that was it. And I had no real concept of what ...what actually might happen as a result, and it was quite shocking.' (AN13, age 43, talking about current pregnancy).

Similarly, some respondents had no detailed understanding of the anomaly scan thinking that it was to 'check the baby was alright' or to 'see the baby'. For example, a woman who had a Down's syndrome child said:

'We hadn't really discussed what screening we would have. The first, with my first child I had what was on offer, which was the 20-week scan, and that was it basically. I probably had AFP blood tests, various things like that, but I don't know that I was actually aware I was actually being screened, because it is just what you do.' (AN12, age 37)

Of those who seemed to have little understanding of the purpose of the anomaly scan, none had had previous pregnancies and none refused to have it.

The NHS Antenatal and Neonatal Screening Programme sees information (and therefore understanding) as key to enable people to make informed choices about their participation in screening. Our analysis suggests that those respondents who demonstrated a detailed, or even partial, understanding of the scans were more likely to have also seen it as a choice. For example, AN16 described having a partial understanding of the purpose of the dating scan for her first pregnancy because she had been told about it at her booking visit with a midwife, she said *"they don't really look for anything at 12 weeks; they just do a dating scan at 12 weeks"*. However, by her third pregnancy her active choice to have a scan was clear:

'I was scanned at 13 weeks by a consultant, and the consultant was looking for anencephaly, and also they did the nuchal fold measurement at the back of the neck, ... because obviously that does a degree of Down syndrome, and they wanted to do that for me because of all the problems that I'd had in the past.' (AN16, age 23, ended first pregnancy at 20 weeks for anencephaly, talking about current pregnancy)

People for whom the scans were not seen as a choice appeared less well-informed than women who felt they had made a choice; they did not talk much about the scans or their understanding of it and listed fewer sources of information (see below).

Sources of information

For well-informed respondents the most influential source of information was often their own experience of earlier pregnancies. Those who had not had an earlier pregnancy often cited the experiences of friends. The few respondents who were also health professionals drew on this additional understanding. Other sources of knowledge were discussed in much less detail; midwives, general practitioners, sonographers and obstetricians were all mentioned, as were information sheets from a hospital and pregnancy books.

Information gaps

Of those respondents who seemed to have little understanding of the scans they had, some knew that their knowledge was patchy and said they would have liked to know more:

'I felt like I would have liked to know what an anomaly scan was [laughing] and what they were checking for. I mean, I knew they

were checking for problems with the organs and things like that. But I found it hard to follow the whole thing. I mean, I felt a little bit out of touch with what was going on. I would have liked more information about what they were doing.' (AN08, age 23, first pregnancy, pregnant at interview).

2.3.2 Diagnostic testing during pregnancy: chorionic villus sampling (CVS) and amniocentesis

A diagnostic test such as CVS and amniocentesis is offered if screening tests undertaken early in pregnancy (such as AFP blood tests, nuchal fold scans or sickle cell and thalassaemia genetic screening) suggests risk of fetal abnormality. National Screening Committee information resources explain that CVS can be undertaken from about 11 weeks of pregnancy in a specialist centre; amniocentesis can be undertaken from about 16 weeks of pregnancy. Neither test is routinely offered because they each carry a risk of miscarriage (around 1 percent) for amniocentesis and 1-2% for CVS).

Probably because the purpose of the tests are the same and both carry miscarriage risk, accounts of decision making in relation to CVS or amniocentesis were very similar. Eighteen respondents from the antenatal collection and 9 from the sickle cell (SCT) collection described facing the decision whether to have an amniocentesis; some experienced the decision more than once and in total we analysed 34 separate decisions.

Were diagnostic tests seen as a choice?

The diagnostic tests were seen as a choice by all but one respondent, although another felt it was not presented as a choice by health professionals. In an unusual example (SCT18) a woman, who had her first two children in France, said that her first child was found, postnatally, to have sickle cell anaemia (SS). She moved to London when she was pregnant with her third child and says that the tests, including amniocentesis, were performed without choice. She said that she did not argue but would not have had them done if she had perceived that she had a choice because of the anxiety involved in waiting for the result and making the decision about whether to terminate the pregnancy (which would have been contrary to her religious views).

Choice and understanding of diagnostic tests

In contrast to experiences with dating and anomaly scanning, all respondents seemed to understand the purpose of CVS and amniocentesis. Of the 48 decisions discussed, 24 involved deciding not to have the test.

Information, knowledge and values interacted to influence decisions. Religious beliefs that precluded the option of termination were particularly prominent in the SCT collection; if the child was unaffected by the condition this could reinforce beliefs:

Wife: 'They told me to have the test done while I was pregnant'

Husband: 'We said whatever happens will happen, we left it in the hands of Allah, and now everything worked out ok. Our daughter was fine' (SCT16, Bangladeshi couple, age 31 (wife) and 34 (husband)).

Sources of information

People's perceptions of the risk of fetal abnormality were based on risk information gained from screening tests and delivered by health professionals (here shortened to 'medical information') but also on experiential knowledge (such as having a family member with Down's). Understandings of risk from each source were brought together when respondents talked about decision making, neither were wholly rejected or accepted and both appeared influential in decisions made.

For example, despite both parents being carriers of thalassaemia, SCT21 did not have an amniocentesis in her first pregnancy. Her husband was from a family of six children in which both parents were carriers of thalassaemia but all children were healthy. This personal experience combined with the risk of miscarriage led to the decision not to have an amniocentesis in the first pregnancy:

'I also became pregnant very soon, and then she [the genetic counsellor] said that you are both carriers and you will have to get the baby checked. Then my husband said that both my mother- and father-in-law were both carriers, they had six well children, Mashallah. My husband said, "Don't worry, leave it, we don't want to have it checked."' (SCT21, age 31).

During the couple's next pregnancy the respondent's mother-in-law gave birth to a child with thalassaemia major. This influenced their decision to have a test in their own second pregnancy:

'Then my mother-in-lawbecame pregnant and she had a son, my young brother-in-law. He was major. He is approximately my son's peer. He was major, and we were scared. The second ... pregnancy I had it [the test] done, but I was late, because it was about four and a half months. I didn't even know I was pregnant. When I found out, I had checks, went to the city, had everything done. They said that your baby is major.' (SCT21, talking about her second pregnancy).

For a more detailed discussion of the interaction of experiential and other information sources in accounts of diagnostic testing during pregnancy see (France et al, in preparation – see Appendix 4).

As we have seen 'medical information' about the risks associated with amniocentesis was usually provided through health professionals. For respondents in the sickle cell and thalassaemia collection knowledge of their own carrier status was usually confirmed by genetic testing or antenatal parental carrier status testing. However, some did not seek carrier testing because their experiential knowledge of their own *health* led them to believe that they could not be genetic carriers of disease. For example one respondent talked of her partner's decision not to have testing for sickle cell:

'He [partner] said he's AA [i.e. not a carrier of the sickle cell gene] – that he's ok. I think, it's kind of believed to be AA is like when you're not weak, when you're not tired, you're not anaemic, you're active, so that, I mean, you're a big man with big broad shoulders, with big bones - you can do things that the women cannot do. So I think that, in his books, means not being sickle, not having the sickle trait.'
(SCT19, age 37, Nigerian, three children 9, 11 and 13).

People's awareness of what it is like to live with sickle cell disease, either the less severe (SC) or more severe (SS) variants was only based on personal experience. For example, SCT04 had a child with the less severe form of sickle cell (sickle cell disease or 'SC'). Her Christianity and her son's experience of good care contributed to her decision not to have diagnostic testing in her second pregnancy. She said:

'I'm just going to put everything in God's hands.And I'm not worried about anything, because I have no cause to worry. And then seeing the way my son has grown up here, and how he is, and I know that, you know, this baby's going to be fine, whatever the outcome. And there's a lot of people out there to help you, so I'm sure everything will be fine.' (SCT04, age 35, Nigerian, child aged 5).

Another couple who were both carriers of thalassaemia major did not know anyone else with the condition but had thought hard about the implications of having an affected child.

'I mean you just don't want the baby to live a life like that. Because it's, you know, our perspective on life is about fun and, you know, and doing things really. We just don't want it to live like that. Because in that situation I think - another experience we have is that because we, the family's very small. It's just me and my wife and my mother, so we don't have that extended family network to support the baby. Can you imagine when we died, you know, who's going to, where's his or her networks going to be? And if you're carrying a sickness, you know who's there for them? So it's that sort of thing that we can't sort of take the chance with.' (SCT13, male, age 31, Vietnamese, one baby).

Our analysis suggests that the relationship between experiential knowledge of the condition and decisions about diagnostic tests is not straightforward.

Information gaps

Most respondents did not mention any gaps of information needs when describing their amniocentesis decision. However, a few raised specific gaps. For example, faced with a high risk of genetic disorder, two people said they would have liked more information about the conditions their babies might experience. In her third pregnancy AN13 found the baby was at high risk of Down's; she felt there was nowhere to find out what it would be like to live with a Down's baby before deciding whether or not to have an amnio. The couple discussed above (SCT13) found waiting for the result very stressful. They were both carriers of thalassaemia, knew nothing of the disease and had

decided to terminate if the baby was affected. The husband wanted to know about other people's experiences of making the decision:

'Because organisations like, you know, the beta organisation, things like that, again it's more scientific. They don't give you the personal experience that you can phone, you know, get more like that. I don't want - I know the scientific detail. I just want to know how other people go, you know, go through it. But I want to understand how other couples like us faces the decision, their decision. How do they - what's their process like, you know? The thinking process? I mean, that's what I wanted to know, specifically. How did they arrive at their decision?' (SCT13, male).

AN24 said in her first pregnancy she had been unprepared for amniocentesis both in terms of the procedure and the meaning of the result. In a later pregnancy she said she was given conflicting information by consultants about how the position of the placenta might affect the risk of miscarriage.

2.3.3 Ending a pregnancy due to fetal abnormality

The discovery of fetal abnormality during pregnancy usually leads to termination. A systematic review of termination rates following prenatal diagnosis found that in the UK and elsewhere for Down's syndrome, termination rates in the 1990s were approximately 92%, for spina bifida they were 67%, anencephaly, 84%, Turner syndrome, 71%, and Klinefelter syndrome - 58% (45).

We had access to 48 transcripts which described facing the decision whether to end a pregnancy for fetal abnormality. Interviews were with 38 women, 6 men and 4 couples.

Was the decision to end a pregnancy seen as a choice?

Ending a pregnancy was almost always clearly described as a choice made by the woman or couple. In one account a Bangladeshi women told us that she had wanted to continue with the pregnancy but her mother and extended family made the decision for her to terminate. In some other examples the decision was seen as both a choice and no choice if the couple had been told that the baby could not survive. For example, EAP07 talks on the one hand about how she and her husband, having made the 'right decision' (implying choice) when they ended a pregnancy at 22-23 weeks because of multiple organ and limb defects discovered in the anomaly scans, but also suggests that there was no real choice:

'Basically you're killing your baby when you have a labour induced at that; I can't imagine how anyone could do it unless it was you don't have a choice.' (EAP07, female, age 38, ended pregnancy at 22-23 weeks for multiple organ and limb defects).

For most respondents the decision-making process was carried out within a short timeframe (usually because the abnormality was identified at a late stage in gestation). In some cases, the termination started on the same day as diagnosis/confirmation; one woman said that she later regretted the speed

with which she had proceeded to termination. Others had a period of weeks to decide, either because of the early stage at which the problem was identified or, because of the nature of the condition, termination could happen at a later stage.

Information used for decision making

The respondents describe a very wide range of medical and experiential information used in the decision to end a pregnancy. Among the most important information that people described in making a decision was the medical opinion that the baby's condition was 'incompatible with life' or fatal:

'And at that point he [the consultant] said, "This child cannot live". And so you, you know. And I think "incompatible with life" was an expression that, because that's not the expression that I would use, so that must have been phrased at some point.' (EAP 19, male, age 45, ended two pregnancies for Walker Warburg syndrome at 22 and 20 weeks).

Some couples, who knew that the child could survive, made their decision because they wanted to have a 'perfect' or 'normal' child. Other influences on the women's decisions included the partner's preferences or those expressed by the wider family; some thought that the child would have a poor quality of life; or feared that the baby would be very disabled. As for decisions on diagnostic testing, many described imagining what it might be like, for the child and the family, to live with the disability. In explaining their decisions respondents often drew on a mixture of reasons. For example:

'And then we just decided that looking at the whole situation... I mean, it would mean that I wouldn't be able to work, which I know isn't, it's perhaps a very selfish thing to say, but financially I cannot afford not to work, or I couldn't at the time. The effect it would have had on our other daughter and on the marriage. I mean we were looking at the whole picture. And I'd actually got an article out of a nursing magazine that I'd got off my sister about a child that had gone through all the different stages of operations, and I sort of read it and I, and I just knew that there was no way that we could put a child through that kind of suffering or ourselves, you know, for that matter. And so we decided we would go ahead with the termination.' (EAP09, female, age 33, ended pregnancy at 22 weeks for hypoplastic left heart).

Respondents' own experiences of caring for with disabled children were influential. A woman who already had a child with sickle cell disease decided to have an early termination because she felt strongly that she could not cope with another affected child. She did not wait to have a diagnostic test. She said:

'I spoke to her [my cousin] about when I found out that my child, my daughter's got sickle cell. She knows about it. Even when I was going to do the abortion she was like saying, "Are you sure you want to do it? Can't you just go in and do the [diagnostic] test and see? Maybe this child might not even have it [sickle cell anaemia]." And it's like,

and I was like, "I'm not even taking the risk. If the child has it or whatever, I don't even want to know any more. I just might as well just get rid of it and just, you know. I'm just worried that, that I'm so scared that I might be having" - even though they say it's like 1 in 4 chances to see if you've got sickle cell, I still didn't, don't want to.' (SCT11, female, age 30, from Sierra Leone, ended second pregnancy at around 11 weeks).

Sources of information

The information sources people used included information given by a range of health professionals (midwives, consultants, paediatricians, fetal cardiologists, obstetricians, genetic counsellors); from voluntary organisations and from friends; experiential knowledge (one's own and others'); pregnancy and medical books and magazines; websites; and ultrasound scan images.

The extent and sources of information used varied; some people actively sought out as much information as possible about their unborn baby's condition while others avoided getting further information on the condition.

Information gaps

All but two of the respondents identified gaps in their knowledge when describing how they decided whether or not to end a pregnancy. The diagnosis or prognosis for the baby was sometimes very uncertain, either because the condition was rare or because the diagnosis could only be made at a post-mortem. Parents understood that it was not possible to have this information at the time they were making their decision, but its absence was felt sharply and clearly contributed to their distress. However, other information gaps could have been met in a timely manner and appropriate format.

Aspects of the process of the termination were not always explained. Some women said that they did not know how, or at what point, the baby would die; some did not realise until after they had made their decision to terminate, that they would have to go through labour; many did not know what the labour would be like; or were not aware of the risks of surgical termination.

'So I phoned my midwife and this was the bit I hadn't researched, and she said, "Right, okay, I'll ring the labour ward and book you in." I said, "A labour ward?" She said, 'For the procedure,' I said, "Why do I need to go to the labour ward? Won't I go to the general ...?" "No," she said, "You do know what will happen, don't you?" And I said, "Yes, I'll have a general anaesthetic and it will all be done and " "No," she said, "You'll have to go through the labour," which I hadn't comprehended, that hadn't sunk in, although I knew it, I did know this but it hadn't, it hadn't, I hadn't realised it. ' (EAP09, female, age 33, ended pregnancy at 22 weeks for hypoplastic left heart).

Several respondents said they would have liked to have been told about the existence of support groups (Antenatal Results and Choices (ARC) was often mentioned) or given literature from these organisations at a time when it

could have been most useful. Rather unhelpfully, some women were given literature that included help in making the decision, either during or after the termination.

People's preferences for how much information they want and when they want it were immensely variable. Sometimes the amount of information was given in a short period of time was over-whelming, indigestible or given at a time of high emotion. Sometimes the details were unwanted e.g. some people did not want to know the details about the lethal injection as part of the termination process or did not wish to see photos of children with the abnormality. One woman describes how she found it hard to understand the nature of the problem despite repeated explanations:

'In retrospect, something I feel that would have been very helpful at the time would have been a tape-recording of what the doctor told us. Because you, you're having all this information given to you, you can't take it in because you're in complete shock but you're expected to, to act upon it.' (EAP09, female, age 33).

2.3.4 Treating lymphoma

Lymphoma is a cancer of the lymphatic system. There are two main types, Hodgkin's lymphoma (formally known as Hodgkin's disease) and non-Hodgkin's lymphoma (NHL). The main types of treatment for Hodgkin's lymphoma are chemotherapy and radiotherapy. People may need to have either of these, or a combination of both. Many people with Hodgkin's lymphoma can be cured, even when the lymphoma has spread to different areas of the body.

The main treatments for the different types of lymphoma are protocol driven. Cancerbackup information states that the multidisciplinary team of professionals will "decide the treatment that is best for you.....they will be able to advise you on the best course of action and plan your treatment." However, the Cancerbackup information also suggests that if two treatments are equally effective for the type and stage of lymphoma, patients may be offered a choice of treatments and advocates that people feel as well-informed as they can before making the decision.

We analysed interviews with 23 men and 23 women with Hodgkin's and non-Hodgkin's lymphoma at a variety of different stages and with different 'types' of the disease. The age range at the time of diagnosis is from 11 to 70 years of age.

Was treatment for lymphoma seen as a choice?

Respondents were usually asked in their interview if they had been *involved* in treatment decisions rather than if they saw such decisions as a choice. Many talked about choice in response to this question, or it was possible to infer whether or not they perceived a choice. One option, sometimes apparent in these accounts, was to decline treatment, although this was also characterised as not a 'real choice'. For example:

'I don't remember ever being given an option [about treatment decisions]' (LYM02, male, 70 at diagnosis, talking about having chemotherapy and radiotherapy).

'You just have the treatment. I did exactly what they [the doctors] wanted to' (LYM08[1], male, 42 at diagnosis, talking about having chemotherapy).

'It was very cut and dried. It wasn't sort of, "We'll offer you this, and we'll offer you that". It was radiotherapy to deal with the tumour in my eye.' (LYM10, female, 55 at diagnosis).

People's relationships with their health professionals and the trust they put in the advice they were given were important in determining the extent to which they felt involved. For example:

'I never felt that it was somebody being told this is what I had to have. Clearly I've grown over the years to put a lot of trust and faith in senior medical staff, but they do sit and talk you through it, and as I said to you earlier, that on all those occasions my wife joined me for those discussions, so that she feels she is inevitably part of that discussion. They've taken me through not just for that but what the alternatives are. And one of the alternatives this time was we do nothing but they don't recommend that, and clearly that's not something I'd buy into, but at least he went through three or four different alternatives as choices I had in terms of treatment. So I wasn't left to say this is the way it will be. Clearly there was a recommended course of action and that's the one that I have followed. But it has come through discussion to be honest' (LYM04, male, 49 at diagnosis, talking about having high dose chemotherapy plus stem cell transplant).

The range of treatments that were presented as a choice by people with lymphoma included chemotherapy; the decision to 'watch and wait'; surgery to remove tumours or damaged organs/ bones; new and risky treatments such as trial chemotherapy drugs, stem cell or bone marrow transplants. However, these treatments were also presented as no choice so it seemed to be the way in which treatment decisions were made rather than the nature of the treatment which seemed to influence whether the respondent thought that they had made a choice.

Respondents who considered having new, experimental or very high risk treatments (as is often the case in advanced lymphoma) were usually well aware that the choice was theirs. Some such treatments were offered as part of research trials requiring informed consent. Previous analysis has shown that while women offered antenatal screening did not always perceive they had a choice, those who were offered diagnostic screening all perceived a choice. Diagnostic screening also carried a risk so it is possible that health professionals seemed to make choices clearest when the perceived risk is greater.

Respondents often did not present their treatment as a choice if they were open to having treatment but health professionals said it was not suitable, was too risky or was not possible (e.g. due to lack of a stem cell donor); or when they deferred to their professional's knowledge or went along with their decision; or when there were no other treatment alternatives left.

'The consultant was very honest with me because I'd asked him to be so, and he said, "Well, basically you will die." So, realising that I didn't have any option I said that I would go ahead with it.' (LYM42, female, diagnosed at 42, talking about stem cell treatment).

Information sources

Most of the information the lymphoma patients accessed came from health professionals such as haematologists, oncologists, surgeons, nurses and sometimes a GP. Many people seemed to rely on health professionals as their main information source and the range of other sources seemed smaller than for other collections. Information from health professionals was usually verbal but they also sometimes provided leaflets and booklets.

It was notable that patients spoke less about using experiential information to help treatment decisions, only 10 people spoke about drawing on some sort of experiential knowledge in 13 treatment decisions. This included information about the effects of treatment on health and survival; the severity of the lymphoma (experiencing the size of lumps and other symptoms); and the process of treatment. People drew on friends' and family's experiences of cancer and treatments, especially chemotherapy. In many cases people may have been influenced by experiences of treatments for other cancers, or treatments that were no longer used. For example, LYM14 referred to her father who had lymphoma in his 40s:

'So we started the first day of chemo, of course approached with trepidation and all the rest of it, and, "How am I going to feel?" And all, really scared about the nausea because I think, because my father had cancer when I was a child and I'd known a lot of people having cancer through the years, and those who'd had chemo I knew nausea, I was anticipating nausea being a major problem.' (LYM14, female, 45 at diagnosis).

People sometimes used other's experiences of lymphoma, and awareness of what happened to them, to benchmark their own survival chances. For example, LYM15 was told she might have a high grade lymphoma and had to decide whether to have a tumour removed; she knew that Jackie Kennedy had died of high grade lymphoma

'I was aware from the book, and also by this time I'd been told that people with a low grade lymphoma can sometimes spring a high grade lymphoma which is very aggressive. That's what Jackie Kennedy died of, a high grade lymphoma. So it just shows that having all the money in the world doesn't help. But it's often cured as well.' (LYM15, female, 53 at initial diagnosis).

Those people who had had a recurrence inevitably drew on their own experiences of treatment when making their subsequent decision.

Some people did not want to seek out further information in addition to what the professionals told them. For example:

'But I'm sure some people asked loads of loads of questions, I didn't, I wasn't, I put my total faith in the people looking after me and I didn't ask a lot of questions, I didn't ask what cocktail, what drugs, you know, they told me what they were going to do and I just, you know.' (LYM11, male, age 38 at diagnosis, talking about stem cell transplant).

Other people did their own research and accessed information from voluntary organisations, books and the internet. Some said that they wanted more information than the health professionals were able or willing to give them; wanted to research new treatments, or verify the information or treatment recommendation they had been given.

One woman who wanted lots of information at the start of her illness researched a new treatment Rituximab. She felt that the local hospital was poor in giving her information so she looked on the internet and found out there was a clinical trial of Rituximab. She asked her doctor if she could be on the trial; she also called Cancerbackup's (voluntary organisation) phone helpline. She commented that even if they are willing, health professionals do not have time to tell her everything she would have liked to know:

"I was down apparently as, 'Asks a lot of questions'. You know, they knew that I was somebody who wanted to ask questions" (LYM38, female, age 60 at diagnosis).

A woman who was unhappy about being told she did not need treatment for her lymphoma and could not understand why, found a book 'Everyone's guide to cancer therapy' which she calls her 'bible'. She says fortunately she learnt from the book that her lymphoma was incurable but slow growing.

'Well I felt pretty bad about not having any treatment, I thought, "Why the hell not?" And in fact apart from them telling you ever so cheerily you don't need treatment, to which you privately think, you know, this is what drives people going off to whacky alternative therapists and charlatans. You know this, what looks like and may well be flagrant callousness and it's really because they don't have the guts to tell you that in the long term they can't cure you but they can give you for instance chemotherapy to debulk tumours and make life comfortable. And they don't tell you it's not curable', (LYM15, female, 53 at diagnosis).

People were sometimes frightened by information they came across. For example, LYM20 stopped his own research on the internet after reading about the 60 percent survival rate for his disease and LYM12[1] who avoided information on Hodgkin's after reading in an old medical encyclopaedia that it was fatal.

Information gaps

Many of the information gaps concerned unexpected side effects or unanticipated longer-term negative impacts of treatments.

'Mum sort of panicked because we didn't know what to expect and we didn't, like they say you're going to be sick but you don't think, "Oh I'm going to be literally just going to be throwing up nothing for seven hours continuously"' (LYM09, talking about chemo side-effects).

There seemed to be more information gaps on prognosis/ outcomes (such as the risks, long-term impact or efficacy of a treatment) for those who did not see their treatment as a choice compared to those who did see it as a choice. People who regarded their treatment as a choice appeared to have gathered more information on the process of the treatment.

2.3.5 Caring for someone with dementia: decisions on place of care

The decision on where a person with dementia should live is usually seen as the carer's responsibility. For example, Alzheimer's Scotland's "A Positive Choice" states: *"If you care for a person with dementia, there may come a point when you have to think about long-stay care. Perhaps it will be because of a crisis. Or perhaps you are starting to plan ahead. Either way, it can be a difficult and painful decision."*

We analysed interviews with 31 carers of relatives with dementia including 13 husbands caring for a wife; six women (including one ex-wife) caring for a male partner ; and one man caring for his male partner; two sons (one caring for his father, one for his mother); and nine daughters caring for a mother. The interviews included a variety of experiences of caring at home, at a geographical distance, in their own homes and in residential care. Twenty three had made the decision to use residential care; several others were considering it for the future.

Was place of care seen as a choice?

The majority of carers were clearly aware that the decision about place of care was a choice. Some were determined to care for their partner (or parent) at home as long as possible. People who had made the decision to move the person to residential care had usually found that they could no longer cope with the caring role and felt that the person would be better cared for in a home, or realised that they could no longer combine caring for a parent with raising their own young children. Sometimes, however, people said that they had not felt in control of the decision, for example one man became unable to cope when the care assistance broke down:

'The man [the care assistant] who was doing it, resigned at the New Year because the pay was so appalling, I mean he had a family, and they had no one, the, I'm not sure I can remember what the company was now, but they had no one to replace him and without

their help I could no longer cope with, with [him] and so he stayed at the [hospital],.’ (ALZ38, male, 52, caring for male partner).

Occasionally the choice may be removed – for example if the person with dementia is sectioned under the Mental Health Act. When the carer was no longer able to provide live-in or distance care, the care decision was often not portrayed as a choice. Other reasons that people suggested a lack of choice included changes in circumstances, deterioration in health or behaviour, or (as in the following example) physical aggression towards their spouse:

‘When you look at something and say ‘What’s the alternative?’ and there isn’t one, that’s easy isn’t it, that’s not a difficult, that’s not a difficult decision. You’ve made you know, you’ve recognised the reality of the situation is there isn’t another choice.’ (ALZ52, son providing distance care for his father until he went into a home).

All those who cared for their relative in their own home or community saw it as their choice to provide that care for their relative. A theme of reciprocity was particularly evident in the accounts of elderly husbands caring for their wives:

‘I never thought for a moment that I would [Uh], not do it. [Uh], she has looked after me with such devotion and love; it was little enough I could do in return to do the same for her. I, there was no decision to be made, that was it, you know.’ (ALZ07, husband providing live-in care for his wife).

Making decisions on behalf on one’s relative was often an ongoing process rather than a one-off event; a decision, such as whether to care for a relative by oneself or to use a care home, would have to be revisited perhaps on a number of occasions as the relative deteriorated and circumstances changed. Other decisions were often dealt with rather than considered. For example:

‘Because all the things like dealing with the DSS and the carers and stuff, I just did it. There weren’t no real decisions in that respect. It’s strange really trying to explain it. You spend over two years looking after somebody and doing all the things but when it comes to explaining what you done, it was just day-to-day and doesn’t take a lot of explaining. You know it doesn’t take a long procedure to do’ (ALZ08, elderly husband provided live-in care for his wife till her death).

Some respondents talked about the difficulty of having to take over decision making for their relative and how ill equipped they felt to make decisions on someone else’s behalf:

‘I think you brought the word ‘burden’ into it, I think, I think that is true, it’s the right word. That it becomes increasingly a burden to make these decisions for somebody else’s life and it does feel a bit like playing God. Because it’s, you don’t know whether you’re doing it, whether it would have been that person’s wish that you’ve made this decision. ... and the power that that creates, I mean it does, it does put you in a very powerful position. To be constantly in charge

of somebody else's life.' (ALZ09, 53, daughter provided distance care for her mother until she went into a home).

'And sometimes, one of the difficulties of my husband's disease is he cannot make decisions. He really, really can't make decisions and it's actually quite tough always making the decisions.' (ALZ21, 52, wife providing live-in care for her husband).

Information used for decision making

When making the decision about where one's relative with dementia should live (by him/herself at a distance, live-in by oneself, in a residential home), the majority of information for the decision was clearly based on their circumstances and experiences as a carer. This included: how the person was coping as a carer; the success or failure of care assistance such as respite care; the nature of the relationship with the person before their illness; the person's previous or current wishes; the stage of the illness and the person's behaviour; the impact of caring on the wider family; and other experiences of respite or residential care. The narratives included many accounts of worsening symptoms and difficulties coping. For example:

'That last year, for the rest of the family was awful, I think everybody suffered, we all suffered. You know, we'd have phone calls in the middle of the night so you were disturbed, sleep. And when she was here there would be disturbed sleep so it was...'. (ALZ09, 53, daughter provided distance care for her mother until she went into a home).

'And then within three days things got very, very bad again, she refused to eat or drink, I couldn't even get her even to drink a little milk and water and I felt I simply had to and so I rang up and they said 'Oh well if it's like that she'd better come in,' and they found a room for her somehow.' (ALZ60, 78, husband provided live-in care for his wife before she went into a home).

Sometimes a professional made a suggestion about a place of care, e.g. an old age psychiatrist might raise the possibility of a nursing home; or recommend ways that they might remain in their own home. The source of such information was most often health professionals such as psychiatrists, Community Psychiatric Nurses, psycho-geriatricians and consultants but also social workers, community care staff, friends, a solicitor and voluntary organisation staff. This tended to be the only information that professionals were reported as contributing to the decision, but it was sometimes cited as strong supporting evidence for the decision. However respondents sometimes struggled to know whether to trust the judgement of professionals if it conflicted with their own knowledge and instinct about the person they were caring for.

'every time she's in hospital, they try and force me to put her in a placement, in a rest home or a nursing home, "Isn't she too much for you now? Shouldn't you think about putting her in a placement?"
"No, I want her to come home because my mum has always wanted

to die at home. ' ' (ALZ12, 45, daughter providing live-in care for her mother).

Information gaps

In this collection of carers' experiences most respondents did not mention any information gaps regarding their decision about place of care. The gaps that were mentioned included information about how to finance the care, how to find respite care and at what stage of dementia it is best to move to residential care. Others wished that they had known what caring for someone with dementia would be like – especially in combination with other family responsibilities. Some found out about the help and support provided by the Alzheimer's Society when it was too late – echoing the tardiness with which voluntary sector information was provided in the Ending a Pregnancy collection.

2.4 Summary: addressing the research questions

2.4.1 What do people see as choices and how are choices experienced?

The extent to which respondents focused their accounts on choices, decisions, or dilemmas varied considerably in the different collections.

The routine procedures of antenatal scanning were not always spoken of as a choice. Those who did see it as a choice also spoke with much more understanding of the procedures whereas those who did not spoke of the routine, expected, nature of the experience. This understanding was usually accorded to personal experience rather than formal sources such as health professionals and leaflets, although these were also mentioned. In contrast, having a diagnostic test in pregnancy (CVS or amniocentesis) was always spoken of as a choice and seemed well understood by respondents. Ending a pregnancy due to fetal abnormality was nearly always described as a choice although some were ambivalent saying that although they had to make a decision, there was no real choice involved.

Whether treatment for lymphoma was spoken of as a choice depended not so much on the type of treatment as on the way respondents described the professionals talking about treatments with them. Often, in lymphoma, the treatments are heavily protocol-driven and it can seem that there is no real alternative, other than to refuse treatment (which felt like no choice). It was not necessarily the case that if a patient portrayed one of their treatment decisions as a choice then they would see all of their other treatments as a choice; sometimes a person saw one of their treatments as a choice then another of their treatments was not presented as a choice. However, as expected in the light of a life-threatening illness, some respondents made it clear that they did not always want a choice and preferred to trust their health professionals' expertise and clinical judgements. Even those who felt that they had always had a choice could talk of a trusted health professional who recommended a course of action.

Finally, the decisions on where to care for a family member with dementia were usually, though not always, presented by respondents as a choice that they were aware of making and sustaining. When there was a sudden change in circumstances, the person with dementia was 'sectioned', or when the carer themselves became ill, the decision to move the person into long-term residential care was often expressed as a loss of control and absence of choice.

2.4.2 What types of information, information sources and information resources do people report seeking or using in describing the choices they faced?

Respondents describe drawing on personal experiences of antenatal screening (their own or their friends') as their main source of knowledge for decisions and understanding in relation to ultrasound screening. A wide range of other information sources was also mentioned, including health professionals, books and information leaflets. For diagnostic tests it was possible to distinguish between 'medical' information about, for example, risk of a genetic condition and experiential 'information' or knowledge based on one's own or others' experiences of living with the condition, e.g. sickle cell disease. Both were presented as important in decision making about diagnostic tests; neither dominated and either could be discussed as important at any one decision point.

For ending a pregnancy due to fetal abnormality information to guide 'imagined futures' was important. This could be being told by health professionals that a baby would not live but also experiential knowledge about what it might be like to live with a particular condition. Knowledge and information combined with values and with personal circumstances to influence decisions which were all intensely personal. Some talked of an excess of information or poor timing.

As may be expected people with lymphoma relied heavily on information provided by health professionals and described a less extensive range of sources of information. Some clearly sought information; some avoided it; some found out more than they wanted. Experiential knowledge was less prominent in accounts though it still had a role; people drew on the experiences of friends, neighbours or celebrities' experiences to imagine what might happen to them (although sometimes this information was about another cancer or a different treatment regime and may have been misleading).

Finally, carers of people with dementia relied heavily on personal experience of what it was like to live with or care for the person. Equally, there was a strong sense of reciprocity, particularly between husbands and wives, in decisions about caring for someone at home. Health professionals and others sometimes seemed to have helped people to make the decision about residential care by pointing out that they had done enough and needed to look after their own health.

2.4.3 Relevance of these findings to others in similar situations

We checked that the findings summarised in sections 2.4.1 and 2.4.2 were relevant to people in similar situations by presenting summaries of findings for each condition in focus group discussions and individual interviews conducted in stage 2 of the research (described in section 3). Respondents said that the summaries rang true; they made sense. No dissenting views were expressed.

2.5 Implications for stage 2

The analyses confirmed that information gained through both one's own and others' experience can be important in decision making about choices faced. Its role seemed to be to help with 'imagined futures'; to suggest what would happen and how it would be. Of course people's own experiences are what they are; they cannot be influenced or changed or packaged into 'information'. However, as we have seen in section 1, others' experiences *can* be, and already are, collected and made available through formal sources in a variety of ways. Thus, in stage 2, we distinguished between two broad types of information that we call for convenience 'general facts' and 'personal experience', and further distinguished between personal experience presented in three different formats. Section 3 describes the methods and results from stage 2 of our research in more detail.

3 Stage 2. Response to different types of information and views about their use

The aim of this stage of the project was to investigate people's responses to different types of information and views about their use in relation to decision making. Our research questions were:

- What are people's views and preferences for different types of information?
- How do people respond to and consider the usefulness of information resources that present options/outcomes information and personal stories separately and in combination?

As we explain in section 3.1.2, in seeking resources to use to stimulate discussion it soon became clear that information about options/outcomes were not readily available for three of the five health issues. This led us instead to think of a broad distinction between two broad types of information that we called for convenience 'general facts' (compared to options/outcomes) and 'personal experience' (compared to personal stories) information.

Within the category of 'general facts' information, we were primarily interested in research-based information about the probabilities of different outcomes occurring with particular health care interventions, but we also considered information about health conditions and interventions for which there was a wide medical-scientific consensus (typically on the basis of repeated and aggregated observations among many patients/people), and broadly applicable statements of legal requirement or policy. We defined 'personal experience' information as information about what had happened to, or been thought or felt by, particular individuals. It could be communicated by those individuals or by others.

We addressed the research questions using focus group discussions and individual interviews with people who between them had personal experience of the five health issues (antenatal screening; antenatal testing for sickle cell or thalassaemia; ending a pregnancy for fetal abnormality; lymphoma; and caring for someone with dementia). We showed examples of different types of information and asked participants to discuss their usefulness in relation to health care decisions they had faced.

This stage of the project was approved by the Fife and Forth Valley Research Ethics Committee and the University of Stirling Department of Nursing and Midwifery Ethics Committee.

3.1 *Methods*

3.1.1 **Recruitment**

We recruited participants from two regions: central Scotland and Oxfordshire in southern England. We had planned to conduct all recruitment through

either general practices or hospitals, but because this proved problematic for various reasons we introduced additional strategies of recruiting via voluntary sector support organisations, advertisements in the local media and on the University of Stirling website. Information about the initial and additional recruitment approaches used for each health issue is provided below. Recruitment rates are summarised in Table 3.

Antenatal screening for Down's syndrome

Primary Care Research Networks helped to recruit participants through general practices. NHS R&D (governance) approval took almost four months to obtain in one region.

The National Childbirth Trust sent recruitment packs to potential participants. Press releases to local media resulted in some recruitment publicity in Forth Valley but not Oxfordshire. We advertised the study on the University of Stirling website.

Antenatal testing for sickle cell and thalassaemia

Because of the very low prevalence of sickle cell and thalassaemia in NHS Forth Valley we recruited people with this health issue only in the south of England. In Oxfordshire, women screened at one NHS Trust were mailed an invitation to join the study.

We approached relevant voluntary organisations about the study but received no response. We advertised twice in *The Metro* (London edition) and the *Evening Standard* newspapers.

Ending a pregnancy due to a fetal abnormality

In Oxfordshire, staff at one NHS Trust agreed to approach potential respondents on a face-to-face basis. Hospitals in NHS Forth valley declined to participate.

The Antenatal Results and Choices (ARC) organisation promoted the study through its online discussion board.

Lymphoma

Initial recruitment was as for antenatal screening for Down's syndrome.

We enlisted general practices in NHS Greater Glasgow and Clyde to help recruit people with lymphoma, and a Lymphoma Association support group in Thames Valley agreed to participate. We advertised as for antenatal screening for Down's syndrome.

Table 3. Recruitment routes and number of participants

Health issue	Recruitment approach	No. invitations sent	No. initial responses	No. participated	Total no. participants
Antenatal screening	NHS Forth valley GPs (7/54 agreed)	43	2	1	14 (3 focus groups including pilot)
	Oxfordshire PCT (4/7 GPs agreed)	55	9	4	
	Forth Valley adverts & press releases	n/a	11	9	
Antenatal testing for sickle cell & thalassaemia	John Radcliffe hospital Trust	20	2	2	12 (2 focus groups, 2 interviews)
	Oxford/London adverts	n/a	16	10	
Ending a pregnancy	John Radcliffe Hospital Trust	n/a	1	1	13 (2 focus groups, 2 interviews)
	ARC (Antenatal Results and choices)	n/a	8 (incl. 5 couples)	12	
Lymphoma	NHS Forth valley GPs (6/54 agreed)	4	1	1	10 (2 focus groups, 2 interviews)
	Oxfordshire PCT (2/15 GPs agreed)	14	5	5	
	NHS Greater Glasgow and Clyde GPs (3/12 agreed)	3	0	0	
	Forth Valley adverts & press releases	n/a	0	0	
	Lymphoma Association Support Groups	n/a	4	4	
Dementia carers	Adverts in press – Oxford/ London	n/a	16	10	13 (3 focus groups, 3 interviews)
	Oxfordshire PCT(2/10 GPs agreed)	11	4	4	
	Forth Valley adverts & press releases	n/a	2	1	
	Stirling Carers' Centre	29	10	5	

Caring for someone with dementia

Initial and additional recruitment strategies were as for antenatal screening for Down's syndrome. Stirling Carer's Centre helped recruit for this health issue.

When NHS or voluntary organisation staff identified potential participants they provided an information pack containing a letter of invitation from the relevant staff member or organisation; a participant information sheet; an initial consent form; and a reply-paid envelope. People interested in taking part in the research were asked to return the initial consent form to the research team. The researcher then contacted them by phone to arrange participation in a focus group discussion if possible or an individual interview if not. When potential participants contacted the research team in response to an advert, the researcher sent them a letter of invitation and a participant information sheet and re-contacted them about a week later to ask if they would like to participate and arrange a focus group discussion or individual interview if appropriate.

All participants completed a consent form before the interview or focus group discussion started. They were offered a £20 gift token as thanks for participation and travel expenses were paid if necessary.

3.1.2 Data collection

We carried out 12 focus groups (including one pilot) and nine individual interviews with a total of 62 people (see Table 3). The main change made after the pilot focus group was a reduction in the amount of material we presented to illustrate different types of information. Since the people who took part in the pilot met our eligibility criteria and their discussion provided useful insights, we included this group in our analysis.

Focus groups were held in university, voluntary organisation or commercially let meeting rooms, with an additional 'break out' room or space available where possible so participants could take time out if they got upset. Interviews were conducted either in participants' homes or meeting rooms.

We used several strategies to investigate how people used and perceived 'general facts' and 'personal experience' information, conducting each focus group or interview in four main stages:

- broad initial questions about uses of, and needs and preferences for, information when making decisions relating to their health issue;
- presentation and discussion of stimulus materials (see below) that provided examples of 'general facts' and 'personal experience' information (in different formats) relating related to:
 - one generally familiar decision; and
 - one decision specific to the focal health issue;
- discussion comparing 'general facts' and 'personal experience' information; and
- presentation and discussion of participants' views of a summary of findings from stage 1 of the study (see section 2.4.3).

At the start of interviews and group discussions, we acknowledged that participants might become upset as they remembered or thought about difficult situations and choices. We encouraged focus group participants to be respectful of each other and advised that if they did become upset, they could take a break away from the group (although some became emotional, none chose to take a break).

We sought consent to video and audio-record and transcribe the interviews and group discussions. Two dementia carers who were interviewed individually declined to be video-recorded, but all other interviews and group discussions were video and audio-recorded, and all were transcribed.

The stimulus materials

We developed six sets of stimulus materials to encourage participants to consider and compare 'general facts' and 'personal experience' information. For each of the five health issues, we used our Stage 1 findings to identify one decision likely to have been faced by most or all participants. We also identified a decision that might be familiar to participants with experience of different health issues so that we could look across the whole sample to better compare responses to 'personal experience' information presented in different formats.

The decisions selected for each health issue, are outlined in Table 4 with a note of the rationale for selecting them.

We had initially intended to use publicly available information resources in their entirety as stimulus materials, and to ask participants to read or look at certain sections of these. However, when we came to finalise our selection of materials we decided instead to provide only excerpts of 'general facts' and 'personal experiences' type information. Our primary concern was to find out what people thought about these two types of information rather than what they thought about particular resources. Some resources included both 'general facts' and 'personal experience' information (in varying combinations), and we were keen to ensure the two were clearly differentiated. We were also concerned to avoid participants spending most of their interview time reading, and to avoid overloading them with information. (We made the resources from which extracts were taken available afterwards for those who were interested).

Table 4. The decisions focused on for each health issue

Health issue	Decision	Rationale
Antenatal screening	Whether or not to have antenatal screening for Down's syndrome.	All pregnant women in the UK are offered some kind of screening for Down's syndrome (we did not focus on any specific test). Participants would have made their decisions about this (and received any test results) by the time we interviewed them.
Antenatal testing for sickle cell and thalassaemia	Whether or not to have an antenatal diagnostic test for sickle cell diseases or thalassaemia.	In the UK, all pregnant women who are known carriers are offered a diagnostic test (CVS or amniocentesis) if the baby's father is also a carrier. Participants would have made their decisions about this (and received any test results) before we interviewed them.
Ending a pregnancy	How to treat the remains of one's baby following termination due to fetal abnormality.	We were reluctant to look at information intended to support decision making about whether or not to end a pregnancy in case we inadvertently caused people to regret or question a particularly difficult and emotive decision. All women or couples who had ended a pregnancy would have faced decisions about whether or what form of funeral and/or memorial their baby would have.
Lymphoma	Whether or not to accept whatever treatment (including no treatment) was recommended after diagnosis.	This decision is faced by people diagnosed with any type of lymphoma. Recommendations usually reflect clinical guidelines.
Caring for a person with dementia	Where a relative with dementia would live.	This is a common important decision anticipated or faced (and sometimes revisited) by family carers whatever their caring circumstances.
All	Which, if any, methods of support to use in an attempt to stop smoking.	Although not everyone would have faced this decision personally, we thought the decision and options would be familiar, and probabilistic research-based information about outcomes was readily available.

For 'general facts' information, we had intended to select excerpts that presented research-based probabilistic information about options and outcomes relevant to the decisions of interest. This was relatively straightforward in the cases of antenatal screening for Down's syndrome and antenatal diagnostic testing for sickle cell or thalassaemia. However, it seemed less appropriate and less feasible for decisions about where a relative with dementia would live and whether and what kind of funeral to hold after ending a pregnancy because of fetal abnormality. Also, in the case of lymphoma treatment we were concerned about the potential lack of applicability of, and potential to cause distress to participants with, detailed probabilistic information about the survival rates associated with different treatments. For these health issues we therefore chose examples of non-statistical information about relevant options and consequences that did not make reference to the experiences of particular individuals.

For 'personal experiences' information we considered using summaries from the relevant health issue modules of the Healthtalkonline (formerly DIPEX) website. However, these summaries did not map directly on to the decisions we were focusing on (for example, there was no summary specifically describing carers' experiences of deciding where their relative with dementia should live). We therefore decided to show three excerpts, each based on one interviewee from HealthTalkOnline, which between them illustrated a range of experiences relating to the decision of interest.

We chose content relating primarily to experiences of options and their possible consequences, and sought to ensure that the excerpts included people who had chosen differently (for example, women who had and had not held a funeral after ending a pregnancy for fetal anomaly) and people with varied experiences and views of particular options.

For each health issue decision, and for the general quit smoking decision, we presented examples of 'personal experience' information in three formats: a story about an individual told (in writing) by a third person; directly quoted speech (in writing in a 'speech bubble'); and a video clip of a person telling their own story. All excerpts were selected from materials developed in the UK (see Table 5).

Overall, each focus group was shown one page of 'general facts' and three examples of 'personal experiences' relating to methods for stopping smoking, and three to four pages of 'general facts' and three examples of 'personal experiences' relevant to their health issue. (See Appendix 1 for examples of the materials).

We asked people what information they had used and what had influenced them in making their decision. After presenting the information resources we asked if this type of information was/ would have been useful for making their decision and why; if they saw any down sides to the types of information; their opinion of the formats; and how they prefer to get health information.

We decided against sending the stimulus material to participants in advance of their focus groups or interviews. We did not want to put people off attending by giving them 'preparation' work, and did not want people who had not read the material in advance to be disadvantaged in the discussions.

We used a structured PowerPoint slide presentation to show the stimulus material, but varied the order in which we presented 'general facts' and 'personal experience' to try to avoid the kind of bias that might arise if all groups were shown the same type of information first. Where possible we avoided reading the stimulus material aloud (to mimic the way people would usually receive this information and to avoid influencing participants' interpretations), but we did read the material in one group that included people with dyslexia. We provided printed A4-size copies of the slides so people could refer back to these during the discussions.

We explained to participants that the excerpts were intended only to illustrate types of information, not to provide comprehensive information.

Table 5. Information resources used to develop stimulus materials

Health issue	Resources
Antenatal screening	UK National Screening Committee, Screening Tests for you and your baby, 2008. (46) Healthtalkonline antenatal screening module. http://www.healthtalkonline.org/Pregnancy_children/Antenatal_Screening
Sickle cell and thalassaemia screening	UK National Screening Committee, Screening Tests for you and your baby, 2008.(47) Healthtalkonline sickle cell and thalassaemia screening module. http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia
Ending a pregnancy due to fetal abnormality	ARC (Antenatal Results and Choices), A handbook to be given to parents when an abnormality is diagnosed in their unborn baby, 2007. (48) Healthtalkonline ending a pregnancy for fetal abnormality module. http://www.healthtalkonline.org/Pregnancy_children/Ending_a_pregnancy_for_fetal_abnormality
Lymphoma	CancerBackup, Understanding Hodgkin Lymphoma, 7 th Edition, 2006.(49) CancerBackup, Understanding Non-Hodgkin Lymphoma, 11 th edition, 2007. (50) Healthtalkonline lymphoma module. http://www.healthtalkonline.org/Cancer/Lymphoma
Carers of people with dementia	Alzheimer Scotland, A Positive Choice – choosing long-stay care for a person with dementia, 2007. (51) Alzheimer's Society, Choices in Care, 2003. (52) Healthtalkonline caring for someone with dementia module. http://www.healthtalkonline.org/Nerves_and_brain/Carers_of_people_with_dementia
Stopping smoking	Information adapted from: NHS 'Go Smoke Free' website- http://gosmokefree.nhs.uk Cochrane reviews - The Cochrane Library http://www.mrw.interscience.wiley.com/cochrane

3.1.3 Analysis

We worked primarily from anonymised verbatim transcriptions of all 12 focus groups and nine individual interviews; video was used to check which excerpts people were referring to. One researcher (EF) read all of the 21 transcripts. Three other researchers (VE, RJ and SW) read a sample of three to five transcripts each (a total of eight transcripts, which covered all five health issues, were read by at least two researchers). Analysis then proceeded in four main steps.

Step 1

All four researchers agreed a broad initial coding framework based on the two research questions: what are people's views and preferences for different types of information? How do people respond to and consider the usefulness of information resources that present options/outcomes information and personal stories separately and in combination? Initial codes included:

- participant-identified information gaps

- positive/negative views of personal experience information
- positive/negative views of general facts
- preference for general facts
- preference for personal experience information
- interaction of/combining personal experience information and general facts
- other influences on decisions, e.g. religion, age, family circumstances.

These codes were applied systematically to all transcripts by EF using NVivo 7 software. This initial coding allowed us to bring together in NVivo 'reports' all the data relating, for example, to the ways in which people reported using 'general facts' and 'personal experience' information, and to comments about the value of these different types of information.

Working from these initial collations or 'reports', EF then produced a first summary analysis which was checked against the collations and a sample of transcripts by the other three researchers, then refined in discussion.

Step 2

The coding was refined to focus on participants' evaluation of (their views and preferences for), and what they said about the use and usefulness of, general facts and personal experience information distinguishing between these two types of information and between people's reactions to the stimulus material we provided on smoking; the stimulus material we provided on the five health issues; and examples people gave of their own prior use of information. We also coded data under the headings: information format preferences; and information source preferences. A further iteration of coding and analysis was then conducted.

Step 3

We then used 'OSOP' ('one sheet of paper') analyses (42) to summarise data on information use, perceived value, impact, and usefulness of the two types of information - personal experience information and general facts. This involved reading through each NVivo report in turn and noting, on a single sheet of paper (in this case actually an MS Word document), all the different issues that were raised by the data, along with the relevant transcript and individual respondent IDs. We then checked the transcripts to make sure no data had been missed in the NVivo reports and added into the OSOP any other relevant data. We completed three different OSOPs: one which noted all the different uses of, and evaluative statements about personal experience information; one which did the same with regard to general facts information; and one recording feedback on the formats of personal experience and general facts information. For this analysis, in contrast to stage 1, we adapted the OSOP to include verbatim quotes from transcripts to support the observations and identified issues.

Next we created a descriptive summary of each OSOP. When each OSOP was complete, we had a summary of all the issues relevant to the use of the two types of information (personal experience/general facts information) for all

five health issues and the IDs of the relevant respondents and focus groups. This allowed us to identify which issues were raised by those across all five health issues or only by those with particular health issues. The next step was to group the issues into broader themes (also known as axial coding).

Step 4

From the three OSOPs we generated broad themes relating to how information was used, valued and its impact – these were discussed and refined iteratively by the team who all read the relevant NVivo reports and the OSOPs. This involved developing the consideration of data relating to the use and perceived value of the different information types, and factors 'moderating' the use and perceived value of different types of information, checking for any key differences across the five health issues. This eventually resulted in the final list of themes:

- Recognising a decision - making it real/engagement with issue/ hitting home/appreciating significance of an issue
- Raise awareness of choice/options
- Emotional support
- Hope (giving or taking away)
- Feeling alone/not alone
- Feeling abnormal/not abnormal
- Raise awareness of what other people think and do
- Anticipate what the future might hold or what might happen
- Evaluate your decision or preferred or chosen option

Key moderators of information use and value we identified were:

- the trustworthiness of the person/ source of the information
- the representativeness of the information
- the personal relevance/ applicability of the information.
- These themes were then grouped under the relevant stages/phases of decision-making e.g. recognition and clarification of a problem; identification of potential solutions; appraisal of potential solutions; selection of a course of action; implementation of the chosen course of action; and evaluation of the solution adopted (53).

3.2 Findings

Participants had much to say that confirmed the importance of information in health-related contexts. We heard numerous concerns about information received (or not) from health care providers, and many mentions of attempts to find information from other sources. Most of the issues that participants raised were consistent with those highlighted in previous studies (for example, about having too little or too much information, about information being oversimplified or unduly complex, and about the inconsistency of information from different sources), and we will not rehearse these in detail here. Rather, we focus on our original findings relating to the aim of

investigating responses to, and uses of, different types and formats of information.

Participants seemed willing and able to distinguish 'general facts' and 'personal experience' information along the lines our descriptions and examples suggested, although, as we note below, these distinctions are not entirely clear-cut. In focus groups and individual interviews they talked about the uses they had made of examples of these two broad types of information in relation to health care decisions they had faced. They commented on the examples of information we presented, and some considered the value these might have had for them *if* they had been available when they faced the particular decisions that we focused on. Participants also discussed the value of 'general facts' and 'personal experience' information in relation to decisions more generally.

We have organised the rest of this section as follows. We consider first (3.2.1) the uses made of 'general facts' and 'personal experiences' information and how it is valued in relation to three key activities of decision making. It should be noted that respondents discussed learning from others' personal experiences in everyday encounters as well as from more formal sources.

In section 3.2.2, we look in more detail at what people say about what would moderate their use of 'general facts' and 'personal experience' information and/or the value derived from these.

In section 3.2.3, we consider people's responses to three different formats for presenting personal experience information.

Sections 3.2.1 and 3.2.2 draw on discussions relating to each of the five experienced health issues, and we note when particular uses or reasons for valuing information appeared more or less significant for particular health issues. Section 3.2.3 draws additionally on discussions relating to the information that all focus group participants were shown about ways of supporting smoking cessation.

3.2.1 Uses and value of information in relation to decision making

Although choice is sometimes regarded as a simple matter of making a selection from a given set of alternatives, a strong case can be made for conceptualising decision making in health care as a process (sometimes repeated in cycles) involving several activities: recognition and clarification of a problem; identification of potential solutions; appraisal of potential solutions; selection of a course of action; implementation of the chosen course of action; and evaluation of the solution adopted (53). Individuals might be involved in these activities in several ways (53), and might find different types of information useful to support their involvement across them.

In practice, the various activities of decision making do not always occur in a simple, chronologically linear sequence. They may vary in significance, and

they may not be readily separable as people talk about their decision-making experiences. Nonetheless, the idea of stages of decision making offers a helpful framework for introducing our main findings about the use and value of different types of information. We have organised our initial presentation of what people said about using 'general facts' and 'personal experience' types of information under three main headings relating to: recognising decisions are needed and identifying options; appraising options and making a selection; and evaluating and living with decisions made.

Some people who talked about considering several possible ways of dealing with a problem, or changing the way they managed health issues, did not describe what they were doing as choosing or decision making. This was most evident among relatives of people with dementia, who described seeking and using information as they tried to respond appropriately to the changing behaviours and needs of the person they cared for. We have included their comments about information use within the scope of our study. There was notably less discussion about the value of 'general facts' than about 'personal experience' information, perhaps because people were inclined to assume that 'general facts' would underpin decision making. In the sections below we summarise comments about the use of 'general facts' first, then consider how people suggest 'personal experience' information can add value (or not) to decision-making processes and experiences.

Recognising decisions are needed and identifying options

Decisions about health care can become necessary for a range of reasons, and people come in a variety of ways to recognise that they (will) need to accept, contribute to or make decisions about particular issues. Their prior awareness of health issues and familiarity with the kinds of decisions faced will vary, in part because of differential exposure (over time) to diverse examples of 'general facts' and 'personal experience' information. We did not try to ascertain when people had recognised that they faced decisions. However, some striking differences were evident in how people reported information from health care providers had enabled them (or not) to realise that potentially important decisions were being made or would be needed. It was also clear that people had varied expectations about their roles in health care decision making.

a) 'General facts' information

'General facts' about the kinds of problems associated with some health care situations strongly suggest that action is needed, so options must be identified and decisions made. For example, awareness that untreated lymphoma can be fatal and that treatments are available that can prolong survival often leads to a recognition when lymphoma is diagnosed that potential treatments need to be considered. The well-known fact that dementias can cause progressively severe deterioration in capability and result in people needing high levels of care often leads to a recognition that family members will need to consider where and by whom people with dementia might be cared for as the condition progresses.

For other situations, it may be health professionals' provision of 'general facts' about 'options' they are offering that first signals to people that a decision is needed. For example, pregnant women are usually told *that* particular antenatal screening tests are offered or recommended, then invited (more or less clearly) to make a choice. Women in this study, as in others, varied in their awareness of the 'general facts' behind health policy decisions to offer or recommend particular screening tests to particular groups of women - for example that some babies are born with particular health conditions, that this is more likely if the parents have certain identifiable risk factors, that these health conditions commonly have certain implications for the babies' and their families' lives, that some of these health conditions can be detected antenatally by screening and diagnostic tests, that these tests involve certain procedures and are associated with particular outcomes, and that parents whose babies are found to be at high risk of having particular conditions can be offered interventions to end the pregnancy. Their comments confirm that, depending in part on the selection of 'general facts' that health professionals present, the way in which the 'option' of screening is offered, women who are eligible for antenatal screening vary in the extent to which they think decisions about this need careful consideration on an individual basis.

While many of the 'general facts' about the existence of and rationale behind antenatal screening services are now quite widely known, other 'general facts' that may signal the need and/or set parameters for decision making are less well known. Information about options is more likely to be 'new' and useful to people who face decisions that are less familiar to them.

b) 'Personal experience' information

There were several examples in our data of people describing how 'personal experience' information had introduced them to the idea that they might need to make a decision. There were also examples of this kind of information making the need for a decision feel 'more real' than it had appeared on the basis of 'general facts' about options and outcomes, and/or prompting people to see a need to think carefully before choosing. For example, women in one focus group on antenatal screening commented that 'personal experiences' in the form of a story and speech bubble in which women described how they had only realised what antenatal screening was 'about' when they were told it had identified a possible problem with their unborn baby, alerted them to a need to think more carefully about the blood tests offered during pregnancy. (In previous pregnancies, health professionals appeared to assume they would have, or directed them towards, the tests on offer).

'I would agree with that statement that I didn't appreciate at the time the significance of the antenatal screening programme, because it's that way that the question is posed to you: "You'll be having the test, won't you?" (FGAN08, age 26-35)

'But then reading this bit where this person is saying, "I didn't appreciate quite the significance," and I think that would jolt me to think, "Oh right, this is a big deal then; it's not just another, you know, routine blood test, or just getting a check; there is actually something quite significant about that, and maybe I should think

about this a bit more". If I hadn't read that bit, then I might not have thought that about just getting that, the facts.' (FGAN03, age 26-35)

A man caring for his wife with dementia was also prompted by an extract of 'personal experience' information to realise that his future options might be constrained, and he might need to face up to the unwelcome possibility that his wife would need nursing home care in the future if his wife's condition deteriorated further:

'It's [the dementia] not going to go away. And there's not a lot I can do about it now. And I'm not prepared to put her into a home, but as we saw, the decision was taken out of the guy's hands. And what do you do then?' (FGDEM07, male, age 76)

There were also examples of people being alerted by 'personal experience' information to options they had not previously been aware of. For example, a video clip in which a woman discussed the funeral arrangements she made after ending a pregnancy suggested possibilities that some participants had not considered before:

'what she said about the little toy that she put in, that they had like a little... was it like a little rose? You wouldn't know from this [ARC booklet]... Not that you would choose the same, but you wouldn't know you could put those little personal things on because your baby has never been alive, hasn't been recognized. (FGEAP01, female, age 26-35)

People caring for relatives with dementia faced a changing variety of challenging situations, and options for dealing with these were not comprehensively considered in the 'general facts' type information they had received. These participants particularly obviously valued hearing about other carers' personal experiences – either via information media or more direct interpersonal discussion - because they could glean ideas about possible ways of dealing with the various practical problems that emerged over the course of their relatives' illnesses.

'often it's just very very small things. But listening to other people, you just maybe get wee, "ooh, we could do that, that way" or. So I think it's important.... you know, you draw from it.' (FGDEM09, female, age 61)

The above examples related to options that might be considered as self-, social-, or spiritual-care rather than more narrowly defined health care. We also heard examples of people being alerted by personal experience information to professionally-controlled health care interventions that they might have wanted to consider. For example, a participant in a lymphoma focus group said he had learned from others' accounts that chemotherapy could affect fertility and that he had not been told by health professionals about options for fertility preservation.

Appraising options and making a selection

The findings from this second stage of the study confirm what was evident from the first stage that people who are aware of several options often seek

information from various sources and draw on information of different types as they consider what to do. The only exception in our data, consistent with an observation made previously among Canadian women (54), was that some women who were adamant that they would not terminate their pregnancies did not want to consider information about antenatal screening and diagnostic tests.

a) 'General facts'

'General facts' about the available options and the likelihood of both desired and undesired outcomes occurring with these was often clearly recognised as useful by people faced with choices about whether or not to accept the health care interventions that were offered or recommended to them. For example, a man with lymphoma pointed out how information about the effects of chemotherapy on survival could support a decision to accept the treatment despite its difficult side effects:

'I appreciate having that sort of information and it definitely makes a difference, because if you were being handed information that said, you know, whatever you do doesn't make any difference for you, then you wouldn't go for the ordeal. But of course that [information] made it seem the reasonable decision to make.' (FGLYM10, male, age 38)

Some women also valued accurate information about options and outcomes when deciding whether to accept proffered antenatal screening or diagnostic tests.

'I wouldn't have known what the prevalence of Down's Syndrome was, so just having that, and having it written there as the age of the mother and looking at that as a risk factor, I think that was, yes that was important for me.' (antenatal group, FGAN11, age 26-35)

'I quite like having information like this especially when it has facts because the facts are like, gives you like a general picture of what you should expect or not expect, like where it says one or two [percent] would miscarry if you have a CVS and one would miscarry if you have an amniocentesis ... So I like having the facts, it's quite important so I can consider the risk involved yeah, and make up my mind is it worth it or not' (sickle cell interview, FGSC12, age 28)

There was little talk about information about options and outcomes as such in relation to decisions about whether, when and where to place relatives with dementia in residential care/nursing homes. These decisions generally seem to turn on a complex range of factors that are highly person- and context-specific. Those who have to make them think primarily about relationships and responsibilities, considering who can and who should take on which caring roles.

In addition, several participants commented that general facts information alone did not suffice for decision making. All of the specific health issue decisions that we focused on could be experienced as emotionally difficult,

and some people noted that probabilistic statistics could be frightening and confusing, and did not remove uncertainties about personal outcomes.

'how would you know whether you're in the 5 or in the 100? [Sic] In a sense it doesn't really help you as an individual because you don't know. You don't know whether you're going to be one of the 5 out of 100, or whether you going to be one of the 95 out of 100.'
(lymphoma interview, FGLYM05, female, age 44).

Not surprisingly then, some people talked about wanting and valuing supportive discussions and advice – from family and friends, others who had been in similar situations, or health professionals, to help them appraise their options and choose a course of action. We come back to this issue in section 3.3.

'I think with something like screening, the facts is one thing, what you're going to do with those facts is another and I think that's when people want the opportunity to talk it through with somebody and say, "Okay so the facts are here, this is where I'm at and, you know, can we talk about what we're going to do with the two of them?"'
(antenatal group, FGAN12, age 26-35).

b) 'Personal experience'

'Personal experience' information could also be used in various ways to help appraise options and make selections. Our data suggest it could serve a variety of purposes, including helping to: identify and focus on key issues; think what interventions and outcomes might be like; anticipate possible retrospective feelings about particular choices; identify and consider sources of decision support; and appraising own and others' approaches to decision making. We consider each of these purposes in turn. There were also examples in our data of people hearing particular stories that challenged their understanding (perhaps derived from limited 'general facts' information) of what outcomes were possible or likely; this, however, was by no means the most dominant or important reported use of 'personal experience' information in relation to appraising options and making a selection.

Identifying key issues

Some participants reported appreciatively that personal stories had helped (or might help) them "see" what was at stake in a decision and focus on key features of particular options. For example:

'I think when that woman on the video said, like her bottom line was that she decided she would rather have a baby with Down's than risk losing one that might be perfectly OK. I think things like that can help you to realise what the decision comes down to once you have got all that information' (antenatal group, FGAN02, age 36-45)

Thinking "what it might be like"

The potential of personal stories to help convey information about subjective experiences and facilitate understanding what it might be like to undergo

particular health care procedures or find oneself in a particular 'outcome' state was mentioned particularly by women discussing decisions about antenatal testing and the possibility of ending a pregnancy for fetal abnormality.

For example:

'It hits home. I mean she talks about the procedure being invasive and that it is, and the concerns about miscarriage, and I think something like this will get the point home straightaway.' (sickle cell group, FG SCT07, age 37)

Several women reported that reflections on the personal experiences of friends or family members who lived with screened-for conditions had featured strongly in their considerations – although they had apparently not been decisively influential. For example:

'if this baby is SS [has sickle cell anaemia], what would I do? I've lived the situation, I've seen my sister in pain for so many years. Would I want to terminate the pregnancy? It's my first pregnancy, I'm already looking forward to seeing, you know, I already had everything for the baby. Am I going to terminate it if it was SS? Or am I going to face seeing my own child going through the pain that I've seen my sister go through?' (sickle cell group, FG SCT06, age 34)

Anticipating retrospective feelings about particular choices

'Personal experience' information could also prompt people to consider how they might feel *after* making particular choices. For example, this woman had known she could have a funeral after ending a pregnancy, but had not been convinced at the time that she had a right to this. She reflected after seeing a video clip of a woman describing her funeral choices and how she felt about it that it might have been helpful to try to anticipate her future feelings.

'I knew and I was told what was available to me, but what I didn't didn't really think about was how whatever decision I made would affect me then or in the future. Had I seen something like this, I maybe would have would have thought differently.' (FGEAP03, age 40)

Identifying and considering sources of decision support

People also commented that they had gleaned ideas from personal stories about ways of accessing or enhancing decision support – from health professionals or elsewhere. For example:

'the video's quite helpful because he talked about how he talked it through with the consultants and they told him positives, negatives, just weighing up all the options and letting you know that you can have someone else in with you.' (lymphoma interview, FGLYM04, age 21).

Appraising own and others' approaches to decision making

Some participants were clearly interested to know what other people had chosen to do when faced with similar decisions, and their comments suggested they attended to the values and reasons that had influenced other people's choices. They variously considered their own decisional leanings and reasons in the light of comparisons with what other people had thought and done.

'I thought it would be useful to have facts and figures; it's useful to have someone to guide you through this but, to be honest, there is an element of "Oh what do people normally do then?"' (ending a pregnancy group, FGEAP07, male, age 36-45).

The value of 'personal experience' information resources in suggesting or serving as a sounding board for decisional reasoning was perhaps particularly important for people who lacked "live" access to others with experience of similar health issues. However, this was not restricted to people with rare conditions. Pregnancy is common, but many women prefer not to disclose their pregnancy in the first few months, so feel unable to talk to others about antenatal screening:

'It's often the time when you can't necessarily draw on experiences around you, because everybody differs in [the] time in which they tell people that they're pregnant, [laughter] so you can't always draw on people's experiences at that time; and it was only after I had told my friend that I was pregnant, that I'd said to her, "What did you do about the blood tests?"' (antenatal group, FGAN07, age 30).

People caring for relatives with dementia could learn from other people's stories that various options could be tried and they might work differently for different people. This woman appreciated realising that there was not one right choice:

'people at the group would say "Yes we've had to try that." "No it didn't work for us," and somebody else would say "Well it did for us," and, you know, so I got the feeling that there was no kind of hard and fast rule about what you had to do and it was okay to change and I was still on the right path if you like, whatever the right path is for that person. Because I mean I was always trying to do that right thing, you know, and the women at the group used to say to me there isn't a right answer or a wrong answer, it's just what's going to work for you.' (FGDEM13, female, age 64)

As several previous quotes have illustrated, people could think that information about other people's reasoning and choices could be useful *without* any assumption that they would necessarily be inclined to think the same way or make the same selection. Some people clearly rejected the idea that they should or would 'copycat' choices – particularly those of strangers:

'they are just people sharing their experiences, but there is nothing to say that we have to follow what they have done.' (antenatal group FGAN03, age 36).

'being given lots of examples of "Oh, this is what other people felt were right for them" didn't really help me to understand my own mind and actually I just felt a bit, sometimes a bit invaded by that and a bit of a sense of, yeah, like they were trying to sort of give me other people's feelings to kind of adapt, like adopt to take on myself. Which actually may have generated a bit of emotional stress' (ending a pregnancy interview, FGEAP05, male, age 26-35)

However, some people were concerned that 'personal experience' information could be inappropriately influential, particularly if 'personal experience' presentations came across as highly persuasive and/or the people facing decisions were in a state of turmoil.

'It's very persuasive isn't it and I suppose with that situation you could be very influenced in a way that you might not want to be, to that situation. I completely agree with her [woman on video] that it's more important for her to have a Down's baby than miscarry a normal baby [because of amniocentesis]. Whereas, I suppose if you haven't thought through what you think ethically about the decision, you might be swayed in a way that you might not want to be swayed' (antenatal group, FGAN01, age 26-35).

'I guess they might influence someone to make a decision just based on someone else's experience rather than their own. Because it's such a confusing time anyway that then you might just be like oh well - look they decided not to have a funeral and they were happy about that so let's just not have one. Whereas that might not... I don't know, I guess it might influence people to make a choice that isn't the right one for them because they were confused or something.' (ending a pregnancy group, FGEAP04, female, age 26-35).

Evaluating and living with decisions made

a) General facts

General facts were viewed as an important basis/support for guiding action, but they did not generate much comment relating to the 'later' activities of decision making.

b) 'Personal experience'

Discussion about 'personal experiences' information revealed that it could serve a number of useful purposes in the wake of having selected a course of action. Some of these were associated quite generally with coping with a health issue rather than just with addressing needs for decision support. In particular, feeling emotionally supported or optimistic on the basis of others' experiences was mentioned:

'I read a lot, people's experiences, bought books, went and bought it in books and it was like calming and making me feel like that no matter, people have been there and done that (sickle cell interview, FG SCT12, age 28).

'I've not done it in the case of my dad [with dementia]. But when my mum had a stroke I was on all the stroke sites, and the thing that drew me to the information about stroke was always the things that had people's experiences. I seemed to home in on them because I wanted to see that there was light at the end of the tunnel.' (carers' group, FGDEM05, female, age 46-55).

Accessing other people's experiences could help people feel 'less alone' in dealing with ongoing health issues and living with decisions made. For example, people caring for relatives with dementia described being reassured that their difficulties were not imagined, and deriving some hope from knowing that other people were coping. For example, one woman reflected on a story that we showed:

'it shows you that one isn't alone. You know that's the bottom line really, because I probably wouldn't share his conclusions somehow but knowing people are coping with what you have to cope with is reassuring.' (carers' group, FGDEM04, female, 50s)

Women who had ended a pregnancy for fetal abnormality could find it comforting to know that others had also chosen this difficult course of action which was particularly prone to generate blame and shame.

Some were unsuccessful in their attempt to find personal stories that would foster their particular hopes. For example, one woman struggled to find stories about women in their forties who had ended pregnancies for fetal abnormality but went on to have children.

In addition, there were several reports in our data of people identifying options that they might have wanted to pursue at points at which it was too late for them to choose them. Although some subsequently discovered that the options would not have been applicable or appropriate in their case, this experience could be very distressing. For example, one woman described having followed advice to initiate a medical termination of a pregnancy affected by Trisomy 9 then searching online for a bit of information about the condition:

'they [health professionals] basically told us that our baby had no chance of survival whatever happened... And then we went away and looked on the internet and there seemed to be a forum about Trisomy 9 which had lots of mothers with children with Trisomy 9 discussing their children. Which, then I was like "hang on a second, the hospital told us the baby couldn't survive!" And I'd already started taking the drugs to induce the labour. And then we... like, you know... I kind of broke out in a sweat in a panic, and was like "the internet seems to now be telling me that people with this condition are alive!" (FGEAP04, female, age 26-35).

3.2.2 Moderators of the use and value of information

The usefulness of both general facts and personal experience information depends on individual users and their context as well as on features of the information provided. In this section, we focus primarily on the features of

information resources that might moderate their usefulness and value, and on the ways in which health service providers might influence the usefulness of these (or examples of general facts or personal experience information that they offer directly in consultations).

In general terms, three interlinked issues were dominant in people's considerations: the accuracy of information; its personal relevance or applicability; and the values it reflects or the motives behind its provision. These issues were raised in relation to both 'general facts' and to 'personal experience' information, but the kinds of considerations that emerged were different for the two.

Accuracy

With 'general facts' information, participants raised concerns about the completeness of the range of possible options that were mentioned and the accuracy of information about the frequencies or likelihood of particular outcomes occurring with them. Some people noted that local variations in service provision mean that information produced at a national level may not accurately reflect the local situation (an issue which overlaps with concerns about the personal relevance of information).

With 'personal experience' information, the possibility that people might not be entirely truthful about what happened to them was only raised in the context of discussion of some of the (short) excerpts that we showed: a few participants thought that the stories or quotes had been 'made up' (see section 3.2.3). The possibility that individuals who recount their experiences include mention of (second hand) general facts that could be inaccurate is a different issue.

Participants raised two main concerns relating to the accuracy of 'personal experience' information (or its potential to support the development of a correct understanding of issues). First, a diverse array of individual experiences could be confusing:

'What I found a little bit confusing with personal experiences that they tend to go in all directions. Somebody felt pretty bad about going through that and someone else said, "You know, it's not that bad after all."' (lymphoma group, FGLYM10, male, age 38)

Second, the range of 'personal experiences' presented or available from a particular information (re)source might not accurately cover the range or reflect the distribution of experiences in the population. Some participants suggested that statistical representativeness was important, but some were concerned that this might present an undesirably negative picture (for example if it had been the case that fewer people recovered than died after treatment for lymphoma), and some were particularly keen to ensure that examples of people with rare experiences were included (to ensure they could find examples that were personally relevant – see below). Between them, their comments highlight key tensions in efforts to ensure 'balance' in the provision of personal experience information (55;56).

Personal relevance or applicability

Several participants, most notably those discussing decisions about caring for someone with dementia or being treated for lymphoma, noted that 'general facts' information was sometimes too generic, not detailed enough, or not well enough tailored to local services or personal circumstances to be clearly relevant or easily applicable to their case.

There was a suggestion in the data that, in order to be relevant, 'personal experiences' information needs to be about people who are similar enough to the recipient or the situations they face. People described needing to be able to identify with those whose experiences were presented, and some described going to some lengths to find information about people with similar health experiences and/or personal characteristics and circumstances.

'It was so personal and each person is so different it's quite hard to identify and to think, 'Well that's relevant to me.'" (Carers' group, FGDEM03, female, age 40s)

'I would have really loved to see what's really, to hear about someone who was really, really in my, you know a similar experience with mine [placenta praevia]. And know what they went through I really want to know wherever, yeah something very similar what I am going through. I would have loved to read about such a situation.' (Sickle cell interview, FG SCT12, age 28)

The parameters of how people determine personal relevance, whether it concerns their age, gender or observed ethnicity, or whether, as in the example above, it concerns people with very similar experiences could not be distinguished in our analysis. In any event, the assessments of relevance made are likely to be influenced by many smaller judgements and assumptions and idiosyncratic.

Values and motives behind the provision of information

Some participants regarded some information developers with suspicion and would want to know who had produced particular resources so they could be aware of potential biases:

FG03AN06F: 'I'd want to know like where, where does that website come from, you know, who is it sponsored by? Is it a government sponsored website? Where do they get their money to run, and what is their objective? You know, is it like... because a lot of them are kind... there are so many websites and stuff out there that you can choose and pick to look at, and you know, some of them are maybe sponsored by, you know, big corporations or something, which have an objective and are trying to steer you in a certain way.' (Antenatal group, FGAN06, age 36-45)

Some participants were also concerned that presentations of 'general facts' and/or 'personal experiences' were slanted to suit a particular agenda, and might (be designed to) lead people towards a particular choice, rather than whatever choice would be best for them. This could be because of the selective presentation of material (e.g. of statistics or of stories illustrating

particular issues and experiences) or because of the language used in the presentation. Women considering issues relating to antenatal testing noted that the 'general facts' information offered by NHS staff used language that assumed that having a baby with Down's syndrome, sickle cell diseases or thalassaemia was a bad thing.

'It says "the risk goes down with age," it talks about risk rather than chance so it depends on your views on Down's Syndrome if you see it as a risk.' (Antenatal group, FGAN12, age 26-35).

'I can think of far worse things than thalassaemia or sickle cell that my child could have, personally.' (Sickle cell group, FGSC07, age 37)

This tended to suggest an agenda that was pro-testing – and possibly pro-termination of affected babies. This kind of language could, of course, feature in 'personal experience' information, too, but this was not commented on in our data, and might be considered less problematic if 'personal experience' information is seen to derive from people with less position-related influence than health care staff, and because people can more readily elect to dismiss 'personal experience' information if they do not identify with those whose stories (and values) are presented.

3.2.3 Presentational formats

As described above, we showed examples of personal experience information relating to options for smoking cessation support and to health issue-specific decisions in three formats: a third person story, a direct quote, a video clip. People saw all three formats before discussing them.

Some of the comments that participants made in response to what they were shown related to the content and level of detail of the particular excerpts we presented, and to the artificiality of the presentation situation – with limited possibilities for checking or following up on information. People expressed concern, for example, that the stories were partial or incomplete, perhaps raising more questions than they answered. Some also commented on the absence of general facts that would have helped them put the personal experience in context.

'I think you need it backed up with facts because unless there's a longer story than that, that's actually on the internet, it raises more questions, I think, than it answers.' (Antenatal group, FGAN07, age 30)

This highlights the potential importance of the continuation of a 'mixed economy' of information provision in terms of providing access to different types of information.

In the sections below, we have been careful to focus on comments about the three particular formats considered rather than the meaning-supplying *content* of the information shown although we recognise that the two are linked.

Third person story or account

This format attracted relatively little comment, but both likes and dislikes were expressed and three people identified it as their preferred format.

Those who liked it found the format familiar and saw it as easier to read and understand than the direct quote in a speech bubble. A few commented that because it conveyed less information about the person involved than a video clip, it was easier for them to identify with the person in the story format (the reader could imagine what the person was like).

“Julie had decided to stop smoking”, that’s a bit more generic and yet it’s a story that gives you some insight to it. And, you know, it’s a bit like listening to the radio as opposed to watching TV; I can imagine who Julie is as opposed to there [on the video] I can see who the girl is and I’m thinking, “That’s not me.” (Ending a pregnancy group, FGEAP13, male).

One woman who thought that the story might be a composite summary of many people’s experiences found that appealing, seeing such processed information as perhaps more trustable than one individual’s experience.

‘I’m more used to receiving information in a way that has been more processed like that, you know, I feel that from, I don’t know, for whatever reason of my personal history that that’s the way that you should receive information so I feel I’m more likely to trust it, if that makes sense?’ (Lymphoma interview, FGLYM05, female, age 44).

People who disliked the written story format said they did not connect with it well.

‘I just thought it’s a bit, it’s third person, it’s like “Yeah, so what?” It’s just a personal thing. Fair enough it’s a story, but I’m a bit detached from it because it’s a story’. (Sickle cell group, FG SCT05, age 28).

And although we had explained that all the examples presented the stories of real individuals, some participants assumed it had been made up and were inclined to dismiss it as a result:

‘It’s a story, a story, and I can write everything [anything]’ (sickle cell group, FG SCT02, age 31)

‘[The story] kind of reminds me of charity letters and it says why you know? And you know straightaway they’ve made it up and it comes across as a bit artificial.’ (Carers’ interview, FGDEM04, female, age 50s)

Directly quoted speech

There were more criticisms than positive comments about this format. It was seen as less accessible than the video because it was hard to read or take in (we presented verbatim quotes from interview transcripts); it did not convey the emotion that the video could, and was seen as harder to relate to; and its

authenticity was doubted by people who thought it could have been made up or selected with a particular agenda in mind.

'I don't warm particularly towards the kind of written quote about people talking, because in, I always feel that it's a bit false or maybe it's, you know, maybe it is real but somehow, I don't know, you know, I'm a bit off put by the fact that its supposing to be a real person whereas I'd always wonder whether it was a real person or not.' (Lymphoma interview, FGLYM05, female, age 44).

'it feels like if something is written down, a quote somebody somewhere has chosen it, there has been an intermediary documenting it and yet there is an intermediary there [the video clip] because somebody is filming it, and chosen to film it and yet somehow that feels more...accessible for me.' (FGEAP01, female, age 26-35).

The people who reported liking the quotation gave similar reasons of flexibility of identification that were given for the third person story format:

'But people's stories, that kind of quote like that is great. Like that yes, somehow if it's so personal that it's a video of some one person you've either got to associate with them or you don't.' (Ending a pregnancy group, FGEAP07 male, age 36-45).

Video clip

The video clip generated the most discussion across the groups, and attracted much more positive than negative comment.

Being able to see and hear an individual talking on the video led some participants to talk about the video as having more 'impact', being more 'engaging', 'persuasive', 'moving', 'human' and 'real', to give a few examples. Having access to tone of voice, body language and what the person looked like allowed some people to identify with or relate to the individual more than when it was a written quote or story (if they felt empathy with the person); allowed them to judge that the clip was authentic and not made up or acted; and showed how the individual reacted or coped emotionally with a situation they were describing. The message seemed to come across more strongly and quickly in a video clip.

'There was more impact because you could see her expression, you could see sort of the tears welling up and all of that and you could hear it in her voice, that sort of thing. seeing something like that it makes you think a little bit more emotionally almost. You know you think "oh," whereas that [other format] is just writing.' (Ending a pregnancy group, FGEAP03, female age 40).

'It's like the body language from the video, you know, because people can say things and write things, but you only judge what they're saying with your body language, you know, it all adds up to

be a more powerful experience.’ (Sickle cell group, FGCT05, age 28).

Some people found the video more accessible and easier to use than written formats. A few of these people had told us they had dyslexia or found it hard to take in a lot of written material.

‘I had to read this [written format] a couple of times to really take it onboard, whereas that woman [on video] got through to me straight away.’ (Antenatal group, FGAN02, age 36-45).

‘And again, with me I’m dyslexic, so I have a job to read anyway.’ (Lymphoma group, FGLYM08, female, age 61).

The few negative comments about the video all related to the individuals who featured or the views and feelings they expressed. Several people said they did not identify with the individuals who were featured (mainly the young female smoker), and two focused on the level of emotion conveyed – one felt too little emotion was expressed by a woman in the video shown to the ending a pregnancy groups (others had opposing opinions about this), one felt that the strength of emotion displayed by a man in a video shown to carers’ groups was distressing.

3.3 Summary: addressing the research questions

3.3.1 What are people’s views and preferences for different types of information?

Respondents were both willing and able to distinguish between ‘general facts’ and ‘personal experiences’ information and to identify features of each that they valued for particular reasons in particular circumstances. However, it has to be said that the conceptual distinction between ‘general facts’ and ‘personal experiences’ was not always clear-cut. For example, there were examples of other people’s experiences of being *told* ‘general facts’ serving as a source of ‘second-hand general facts’ and of some ‘personal experience’ information recounted as if it were ‘general facts’.

Clear preferences were not always expressed and respondents tended to recognise a need to consider *both* general facts and personal experience information critically. They appreciated that there may be contingent deficiencies in any particular example of information provision (e.g. it may be inaccurate or misleading), that the applicability of information to individual situations varies, and that the motives behind information provision might be to lead people towards making a particular choice. There is support for a continued ‘mixed economy’ of provision of information, including provision of different types of information as well as different formats such as the use of video which may convey more information and be more accessible than written material alone.

3.3.2 How do people respond to and consider the usefulness of 'general facts' and 'personal experience' information?

There was a great deal of variation in terms of whether and to what extent respondents perceived particular types and formats of information useful; the value of any particular example of information provision depended on features of both that information and the potential user and their situation.

In addition, information was not the only support that people discussed needing. They highlighted the potential importance of social support and of opportunities to shape and refine their own views in the light of others'. Support for values clarification has been highlighted in the literature (57). Our research suggests that some forms of personal experience information could help with this.

While respondents talked of 'general facts' underpinning informed decisions, 'personal experience' information was seen to add value to 'general facts' in a number of important ways and to play a unique role in supporting decision-making. Table 6 summarises what both 'general facts' and 'personal experiences' information was said to be useful for in considering decisions. We have found that (some) people report making use of 'personal experiences' information in ways that are consistent with at least some understandings of what makes for a 'good' decision-making process (58), for instance, many people report assessing its personal relevance and applicability.

Table 6. Summary of the reasons for which 'general facts' and 'personal experiences' information was seen as useful.

	'General facts' information	'Personal experience' information
Recognising decisions are needed and identifying options	<p>Help understand situation, possible sequelae and their probabilities.</p> <p>Present options (between which one might or must choose).</p>	<p>Help understand situation, possible sequelae.</p> <p>Identify options (other people's stories sometimes include possibilities that were not offered as options).</p> <p>Help "get" the point that a decision is needed and/or important.</p>
Appraising options and making a selection	<p>Understand the likelihood of particular outcomes occurring with particular options.</p> <p>Inform a weighing up of the probabilities of particular benefits and harms occurring with different options.</p>	<p>Give examples of, and draw attention to, the kinds of outcomes that can occur with different options.</p> <p>Help "see" and focus on issues that are personally salient.</p> <p>Help appreciate and consider the kinds of subjective feel that might be associated with particular options and outcomes.</p> <p>Help consider what one might feel like after making particular selections.</p> <p>Help identify approaches to decision making: (a) decision support strategies invoked; (b) considerations used and reasoning applied.</p> <p>Help identify and consider the values and norms that particular other people apply when appraising these options (including people who seem more and less like me).</p> <p>Offer potential comparisons that facilitate reflection on and testing of one's own reasoning and decisional leanings.</p>
Evaluating and living with decisions	<p>Know when one's own experiences fall outside a likely range</p>	<p>Be prepared for possible emotional responses to choice made or outcome experienced.</p> <p>Recognise diversity of experience.</p> <p>Appreciate that one is not alone.</p> <p>Promote hope.</p>

3.4 Implications for stage 3

Stage 2 analysis confirmed that the distinction between 'general facts' and 'personal experience' information was reasonable and relevant to respondents. We continued to investigate this broad distinction in stage 3. The study was exploratory; it identified the potential value of different types of information and preferences for different formats. These deserved further exploration in a wider survey and preliminary analyses of the data were able to inform the drafting of both questions and response options for the stage 3 described in more detail in the next section. Finally, the study was too small to undertake systematic analyses of differences between the views and experiences of people from different demographic groups. However, we picked up some suggestions of potential age and gender differences in response to types of information that we determined to investigate further in stage 3 analyses.

4 Stage 3. Variation in views, preferences and reported use of different types and formats of information

The aim of this stage of the study was to investigate whether views, preferences and reported use of different types and formats of information varied systematically according to socio-economic status, ethnicity, gender and age. The original research questions were:

- How are the views, preferences and reported use of different types and formats of information for each type of choice distributed across the population within socio-demographic groups?
- Are there distinct types of people, patients or carers in relation to information use and choice?

We conducted a questionnaire survey in Scotland and the West Midlands of England with people who between them had personal experience of three contrasting health issues.

We focused on three, rather than five, health issues for two reasons: first, stage 1 analyses showed that responses to potential choices about screening and the value of experiential information were similar for respondents to antenatal screening, sickle cell disorder/thalassaemia and ending a pregnancy collections regardless of ethnicity; second, as section 3 has described, recruiting respondents to stage 2 focus groups for ending a pregnancy and sickle cell/thalassaemia presented a particular challenge. The sampling strategies used (advertisement in press and through support groups) were not appropriate for a large scale general population survey and no other NHS routes seemed possible. Therefore, with prior agreement from the funder, we focused resources on achieving good samples for the three remaining groups: antenatal screening; lymphoma treatments; and caring for someone with dementia.

Difficulties in recruitment and the considerable time taken to achieve NHS research management and governance (RM&G) approvals required further changes to protocol which were discussed at length with the funder. They are described in subsequent sections.

This stage of the project was approved by the University of Edinburgh's School of Social and Political Science Research Ethics Committee and by NHS Research Ethics Committee Scotland A REC. The data collection was subcontracted to the survey organisation GfK NOP.

4.1 Methods

4.1.1 Questionnaire development

The questionnaire was developed in three iterative stages. First, based on findings from stages 1 and 2 of the project, the project team discussed its aims and several draft versions of the questionnaire. Second, 16 cognitive interviews were conducted to determine respondents' understanding of concepts and questions and the 'workability' of the draft questionnaire. Finally, after further amendments, the questionnaire was piloted with 12 respondents by GfK NOP to check the implementation of the questionnaire and the sampling design. We briefly describe each of these stages.

Initial drafts – aims and focus

Our aim was to design a questionnaire to investigate views on and use of information for any health decisions so that the same questionnaire could be used across all three health issues. Because the approach had worked well in stage 2, we focused questions around a particular decision for each health issue: for antenatal screening, whether or not to have screening for Down's syndrome; for lymphoma, whether or not to have treatment (although we recognise that in practice this could be ambiguous or a series of decisions); and for dementia carers, whether a relative with dementia should live with them or in a care/nursing home (another 'decision' which could be ongoing over a considerable period of time). We were interested in the same two broad types of information as in previous stages, i.e. 'general facts' and 'personal experience' information (see section 3.1.2).

To address the aims and research questions for stage 3 the questionnaire covered:

- perception of choice regarding the 'decision';
- influences on the decision;
- use and usefulness of information of different types (personal experiences and 'general facts');
- whether they had all the information they felt they needed;
- when they needed information of different types;
- source of their information;
- which information formats they use and prefer;
- socio-demographic and background characteristics.

We designed the questionnaire to take about 30 minutes to complete in a face-to-face interview; initial wording and content of questions and statements were generated from stages 1 and 2 findings and was designed to follow a discursive 'conversation' with respondents.

The version of the questionnaire used for cognitive testing went through 13 full drafts within the project team. It contained 61 to 64 substantive questions depending on the health issue. Cards were used to remind respondents of response options and to provide examples of 'general facts' and 'personal

experience' information, specific to the health issue and developed from those used in stage 2.

Cognitive interviews

Respondents for cognitive interviews were prior participants in Stage 2 focus groups and interviews; they were sent a letter and an information sheet inviting them to return an initial consent form to the researcher if they were interested in taking part. Further antenatal respondents were recruited through the Forth Valley Real Nappy Network (the researcher attended two of their meetings, spoke to mothers and handed out flyers) and through personal contacts.

Sixteen interviews were conducted in central Scotland and the Thames Valley with three men and 13 women in March and April 2009. Six of the nine antenatal respondents were newly recruited; all of the dementia carers and people with lymphoma had previously taken part in Stage 2. The sample included: four dementia carers; three lymphoma patients; four pregnant women; and five women who had recently had a baby. One interview took place at the University of Stirling, the others in people's own homes. Most interviews lasted around 90 minutes and were audio-recorded; respondents received a £20 gift voucher as thanks for their help.

The cognitive interviews investigated understanding of questions, response options and general sense, or 'workability', of the questionnaire asking questions like: what do you think the question is asking? What are you thinking as you hear that question? You look a little uncertain, can you tell me why? In later interviews, more time was spent on questions and wording which had proved problematic in earlier interviews.

Both conceptual and practical problems with the questionnaire were identified. Table 7 illustrates these and describes the solutions enacted in the next draft.

Pilot interviews

So that we could test both the revised questionnaire and the procedures for data collection to be undertaken by our partner survey organisation, GfK NOP, the pilot was planned to be as similar as possible to the main survey. Women who had experience antenatal screening and people who were carers of people with dementia were recruited through general practices, facilitated by the Scottish Primary Care Research Network (SPCRN). People who had been treated for lymphoma in the last 10 years (but not less than 6 months ago) were recruited through a hospital in Greater Glasgow and Clyde. Sections 4.1.4 and 4.1.5 describe recruitment in more detail.

Twelve pilot interviews were conducted with a sample of those who had responded promptly to the invitation to participate. The sample included: four lymphoma patients; five dementia carers; and three women who had been offered antenatal screening. They were aged between their 30s and 70s and the majority were college or university educated. Piloting (including briefing, interviews and debriefing) took place over a two week period in late June/early July 2009. Interviews were carried out in respondents' homes or another location (a library) using computer assisted personal interviewing (CAPI); respondents received a £10 gift voucher as thanks for their help.

On the whole the questionnaire worked well. The problems raised by interviewers and their solutions implemented for the final version are described in Table 8.

Table 7. Summary of conceptual and practical problems and their solutions for the questionnaire identified through cognitive interviewing

Problems	Solutions
<i>Conceptual</i>	
'Involvement in' and 'influence over' a decision were not consistently differentiated or interpreted by different respondents and some respondents felt the terms meant the same as each other.	We gave a short definition of 'influenced': 'by influence we mean having an effect on what was decided'.
The distinction between 'general facts' and 'personal experience' was not obvious to respondents. For example, when asked what general facts were used to inform a decision it was clear that a respondent was talking about another's experience.	In the questionnaire it was dealt with by giving clearer definitions of 'general facts' and 'personal experience' information, more explicit instructions on some questions, and by removing or rewording questions as necessary.
An attempt to ask about the timing of receiving 'general facts' and 'personal experience' information and at which points it was useful was not understood.	The questions were revised to directly compare the importance of the two types of information and a further question asked about when, ideally, this would have been received.
<i>Practical</i>	
Response options for some questions were not mutually exclusive or balanced.	Options were clarified and balanced as needed.
The timeframe we were interested in was not always apparent.	We clarified whether we were interested in their views on information <i>at the time</i> or <i>in retrospect</i> .
Some problems with particular showcards of examples of types of information were observed.	Examples were changed, amended, or edited.

Table 8. Summary of problems and their solutions for questionnaire development identified through piloting

Problems	Solutions
<i>Timing</i>	
Interviews with most lymphoma and antenatal respondents took 25-30 minutes. Those with dementia carers took considerably longer because: the decision on where a relative should live was sensitive and emotional; the decision was not always seen as a choice or even as a decision.	Because the time was felt to be necessary for respondents and no-one had complained we did not attempt to shorten the questionnaire.
<i>Information examples</i>	
The examples from 'personal experiences' and 'general facts' were well understood; it took time and was repetitive to show the examples at two time points.	We decided to show the examples only at section C, just before they were referred to.
<i>Questions</i>	
In the dementia carer interviews the multiple repetition of the phrase 'the decision whether to live with you or somewhere else' was upsetting for some respondents.	The phrase was changed to 'the decision of where your relative should live'.
In the lymphoma interviews it was not clear if 'surgery' included biopsy/lump removal.	The wording was changed to specify these treatments.
In discussing preferences for different types of information the word 'prefer' was interpreted as 'favourite' by some respondents and while they would use them did not list them in responses because they weren't favourite. Others were indifferent to information type.	We added a response option: 'I have no preference either way' for each possible information format and gave additional response options 'I would use it, but I don't prefer it', 'I just don't use it', and 'I never thought about, or considered using it'.
In some questions interviewers had to search through response options.	They were reordered so the most frequent options were at the top of the list.
<i>Other changes</i>	
One lymphoma respondent wanted to donate their £10 gift voucher to cancer research.	We gave respondents the option to donate it to a charity of their choice.

The final version of the questionnaire, which was administered through CAPI, can be seen in Appendix 2. It has 63 questions in five sections.

Section A: An introduction to the questionnaire, the decision to be discussed, and background information on current circumstances, such as where a relative is living, number of children and pregnancies, and diagnosis and treatment of lymphoma.

Section B: The perception of choice in relation to: awareness that a choice was available, influence over decisions made, other people's involvement in the decision, who the decision was discussed with, whether respondents were given information and whether they felt their views were heard, and overall satisfaction with the decision process.

Section C: The provision and usefulness of information including, whether respondents had enough or wanted more. The distinction between 'general facts' and 'personal experiences' information was maintained and for each we sought views on how much they were given, whether it was enough/too much, whether and from where they sought information themselves, whether it was helpful in considering the decision, how useful it was for a variety of things (see question 19), and whether and why it was used in decision making.

Section D: The importance of the format in which information is provided (such as from professional staff, leaflets, books, the internet etc, see question 34b).

Section E: Socio-demographic information and access to, and use of, the internet.

4.1.2 Original plans for the sample

The survey aimed to recruit a stratified random sample of 300 respondents for each of the three health issues (900 in total) split evenly across Scotland and England (150 respondents per health issue per country). Sampling strategies would necessarily vary between health issues. For people who had been offered antenatal screening, and caring for someone with dementia the Scottish Primary Care Research Network and the primary care research networks (PCRN) in England agreed to recruit general practices. For people with lymphoma, the National Cancer Research Network in England and the Scottish Cancer Research Network agreed to recruit lymphoma centres.

The sample size was calculated on the basis of being able to establish a substantive difference (effect size) of 10 percent in the proportions between subpopulation groups, with 5 percent significance and 80 percent power, using a directional test. To allow for a low response rate we planned to over-sample by a factor of up to five (i.e. lists of up to 1500 per health issue were to be generated) in order to achieve the sample of 300.

However, extreme delays in gaining NHS research management and governance (RM&G) approval occurred, despite considerable effort from the research team (this process is described in Section 4.1.3), and slower than anticipated recruitment through primary care (described in Section 4.1.4)

required substantial changes to the sample. The problems we encountered and the approach we took to address them are described elsewhere (59). Here we summarise the time it took from ethical approval to recruitment before going on to describe recruitment in the following sections.

4.1.3 Ethics, research management and governance (RM&G) approval

Ethical approval

Ethical approval for the study from Scotland A Research Ethics Committee and NHS RM&G approvals was applied for in February 2009. Initial ethical approval was granted in March 2009.

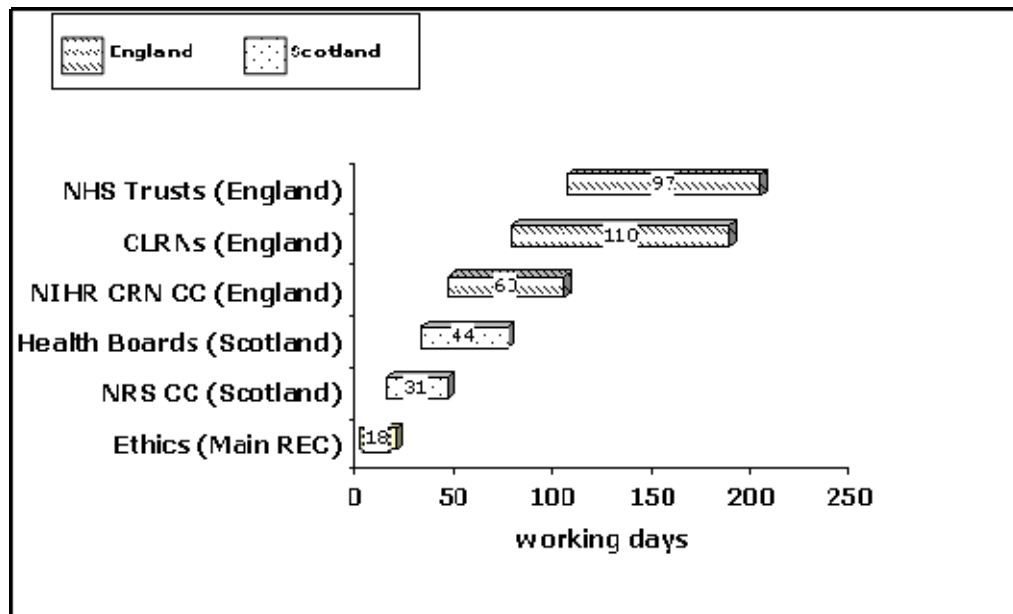
NHS RM&G approval

In Scotland RM&G approval was awarded from seven health boards over a period of 13 to 44 (median 15) working days after receipt of ethical approval (we collected primary care data from only five of these). Time taken between application for ethical approval and confirming all RM&G permissions in Scotland was 75 (median 46) working days.

In England, RM&G approval was asked for from seven local clinical research networks on behalf of 14 primary care trusts. We did not receive approval from any primary care trust in time for us to conduct fieldwork within the funding period of the award. Approval was requested from a further nine local clinical research networks on behalf of four acute and six foundation trusts but was received from only 5 acute and foundation trusts over a period of between 86 to 126 working days after receipt of ethical approval (median 103 days).

Delays were experienced at each stage of the process (see Figure 1). In summary, the time it took between being granted ethical approval until we were able to start fieldwork was approximately five calendar months.

Figure 1. Time taken for NHS Governance process for RM&G approvals and permission (excluding non-responses)



4.1.4 Recruitment and response: women offered antenatal screening and carers of people with dementia

Women offered antenatal screening and carers of people with dementia were identified through general practices in Scotland with the support of the SPCR. This involved a two-stage process of first recruiting general practices in six health board areas and then recruiting respondents.

Recruiting general practices

To maximise our chance of including ethnic minority participants and to control survey fieldwork costs, recruitment was focused in urban areas. To ensure that we had recruited practices in deprived as well as in affluent areas we targeted practices in the more deprived areas of NHS Greater Glasgow and Clyde, NHS Lothian and NHS Lanarkshire.

Recruitment of practices was slow and the number of practices we were able to recruit limited by the time we had available to complete the study to fulfil our contract with the funder. When recruitment through general practice proved so slow, alternative routes (e.g. antenatal screening centres, midwives and a variety of possible secondary care routes for dementia carers, e.g. psychiatrists, neurologists, community psychiatric nurses, admiral nurses) were investigated. However, because of the time it would take to get support from NHS staff, amended RM&G approvals, and to contact patients and carers this was not feasible within the timescales of the study.

Recruiting respondents

We knew from stage 2 of the study that general practice records do not always record pregnancies or their result (i.e. miscarriage, termination or live birth). Hence sampling was extended to include women who had recently had a baby as well as pregnant women. SPCRN staff searched practice registers for women who were 24+ weeks pregnant and for mothers with babies up to six months old (by identifying young babies and then identifying their mothers). It proved time-consuming and difficult to identify eligible women.

Identifying carers of people with dementia was even more complex. In Scotland, general practices are required to construct a list of all those caring for someone. However, we knew from stage 2 that practices do not routinely record who is being cared for or their diagnosis. SPCRN staff used three strategies to identify carers of people with dementia:

1. They examined lists of carers and used personal knowledge to try to identify those caring for a person with dementia; when necessary they contacted carers to ask whether they cared for a person with dementia.
2. They identified people with dementia from patient lists then searched medical records for other patients listed as living at the same address or postcode as the dementia patient (who would be considered a carer).
3. They identified people with dementia who lived in residential or nursing care homes from patient lists and wrote to managers of the relevant homes asking them to pass on a study invitation pack to the family carer of the named dementia patient in their care, if there was one.

General practitioners or practice managers checked and approved lists and excluded those ineligible or too ill to participate. Practice staff sent a letter of invitation, participant information sheet, initial consent form and reply-paid envelope to all remaining on the list. They were asked to return the initial consent form to the university if they were happy to be contacted by GfK NOP. Reminders were sent to non-responders by practice staff in NHS Greater Glasgow and Clyde, NHS Lothian and NHS Lanarkshire between two to three weeks after the initial invitation. It was not possible to send reminders in other health board areas, which is reflected in lower response and interview rates in these areas.

Response rates

Because of time constraints we stopped practice recruitment after just over five months (end of April to September 2009) summarises recruitment of both practices and respondents in each health board area. Twenty-six of the 123 (21%) practices approached were eventually recruited to the study with considerable variation by health board area. Reasons for non response or slow recruitment included: a lack of research orientation; the volume of research requests; more interest in studies more directly relevant to clinical practice; and, in parts of Scotland, the high demands on practices exacerbated by tourism in the summer (when we were recruiting) at a time of staff holidays and reliance on locums.

Table 9. Recruitment of general practices and respondents

Health Board	General practices		Women who experienced antenatal screening		Carers of people with dementia	
	Approached	Participated (%)	Approached	Interviewed (%)	Approached	Interviewed (%)
NHS Highland	11	0	0	0	0	0
NHS Tayside	23	2 (9)	59	2 (3%)	43	6 (14%)
NHS Grampian	17	5 (29)	198	17 (9%)	180	37 (21%)
NHS Greater Glasgow & Clyde	20	9 (45)	217	33 (15%)	167	28 (17%)
NHS Lanarkshire	40	5 (12.5)	116	16 (14%)	144	15 (10%)
NHS Lothian	12	5 (42)	156	14 (9%)	134	22 (16%)
Total	123	26 (21)	746	82	668	108

Table 10 shows that we were able to recruit practices in both high and low areas of deprivation in most health board areas.

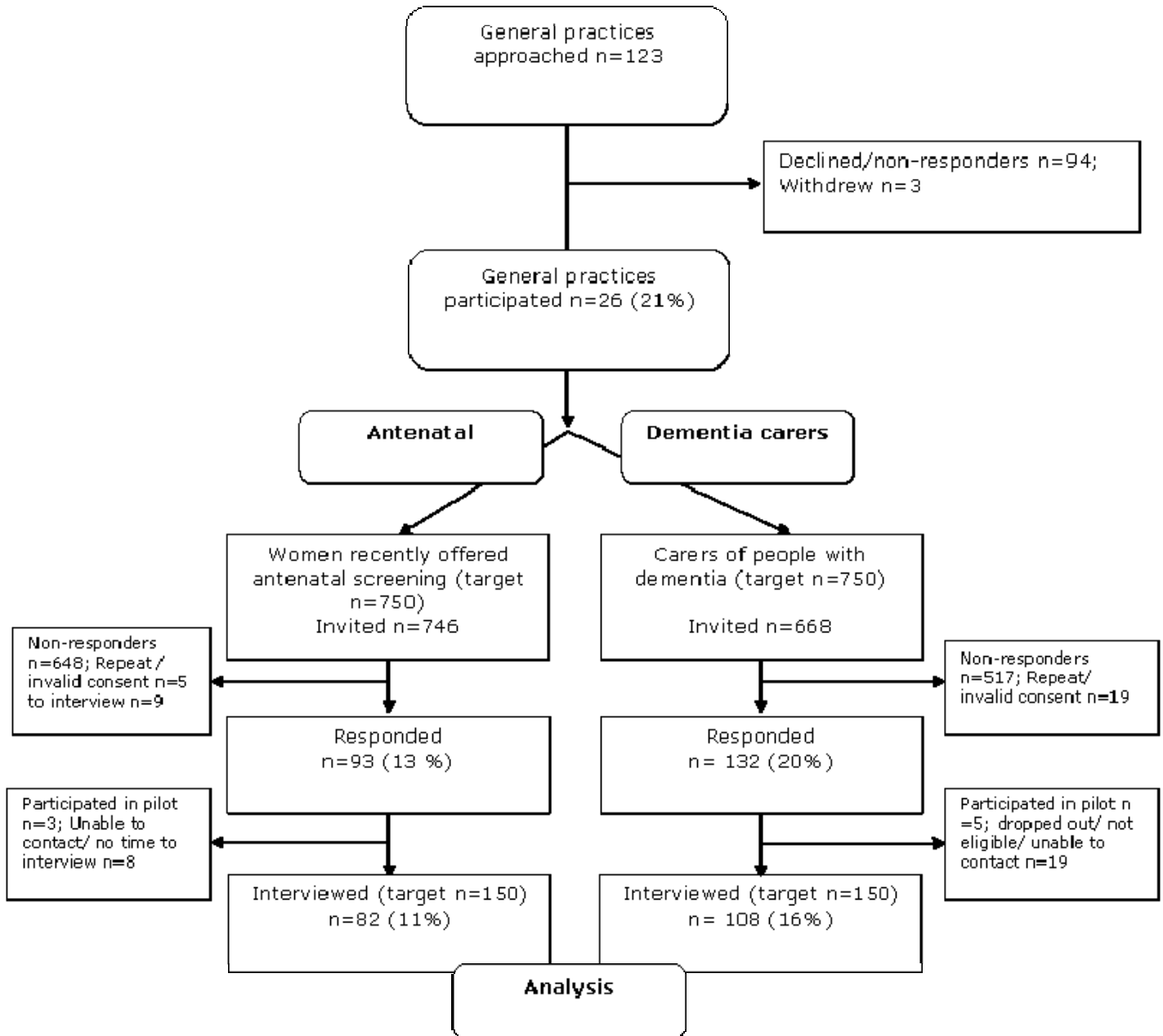
Table 10. Practice size and deprivation status of recruited practices

(Latest available figures from 30 Sept 2008 taken from ISD Scotland, 2009).

Health Board	Total no. of practices	No. of practices with >50% or more of patients in least deprived Quintiles (1&2)	No. of practices with ≥50% or more of patients in most deprived Quintiles (4&5)	Range of practice sizes (no. of patients)
Lothian	5	2	3	3,149 - 10,704
Lanarkshire	5	0	3	2,863 - 10,420
Aberdeen	5	3	2	4,485 - 13,910
Glasgow	9	2	6	2,459 - 8,867
Dundee	2	0	2	5,151 - 6,955

Figure 2 summarises response to the survey for women who experienced antenatal screening and carers of people with dementia. We had anticipated a low response rate (to achieve a sample of 150 per health issue we had planned to send 900 invitations; an estimated response rate of 16%); our pessimism proved well-founded. The time taken to recruit practices and the difficulties of identifying the sample from records led to a lower than expected number of invitations to be sent out (746 to women who experienced antenatal screening and 668 to carers of people with dementia). Response rates to invitations were 13% for women who experienced antenatal screening and 20% for carers of people with dementia.

Figure 2. Recruitment through the Scottish Primary Care research Network of general practices, women recently offered antenatal screening and carers of a person with dementia



4.1.5 Recruitment and response: people with lymphoma

Recruitment of people with lymphoma was again a two-stage process of first recruiting consultant support in lymphoma centres/clinics and then recruiting respondents.

Recruiting lymphoma centres/consultants

Prior to receiving RM&G and with the support of the Scottish Cancer Research Network and the English National Cancer Research Network consultants in seven Scottish and nine English lymphoma centres/clinics were approached to help recruit to the study.

Recruiting respondents

Consultants and their staff (e.g. research nurses) were asked to identify people with diagnosis of lymphoma within the past 10 years (but not the last six months) and to send an invitation pack (containing a letter of invitation, participant information sheet, initial consent form and reply-paid envelope) to a random sample of 125 (150 in one Scottish clinic). Patients were asked to return an initial consent form to the university if they were happy to be contacted by GfK NOP to take part in the research.

Response rates

Consultants in five (of seven approached) clinics in Scotland and seven (of nine approached) in England agreed to support the research. Reasons for declining to participate included not being able to meet study timescales and staffing shortages.

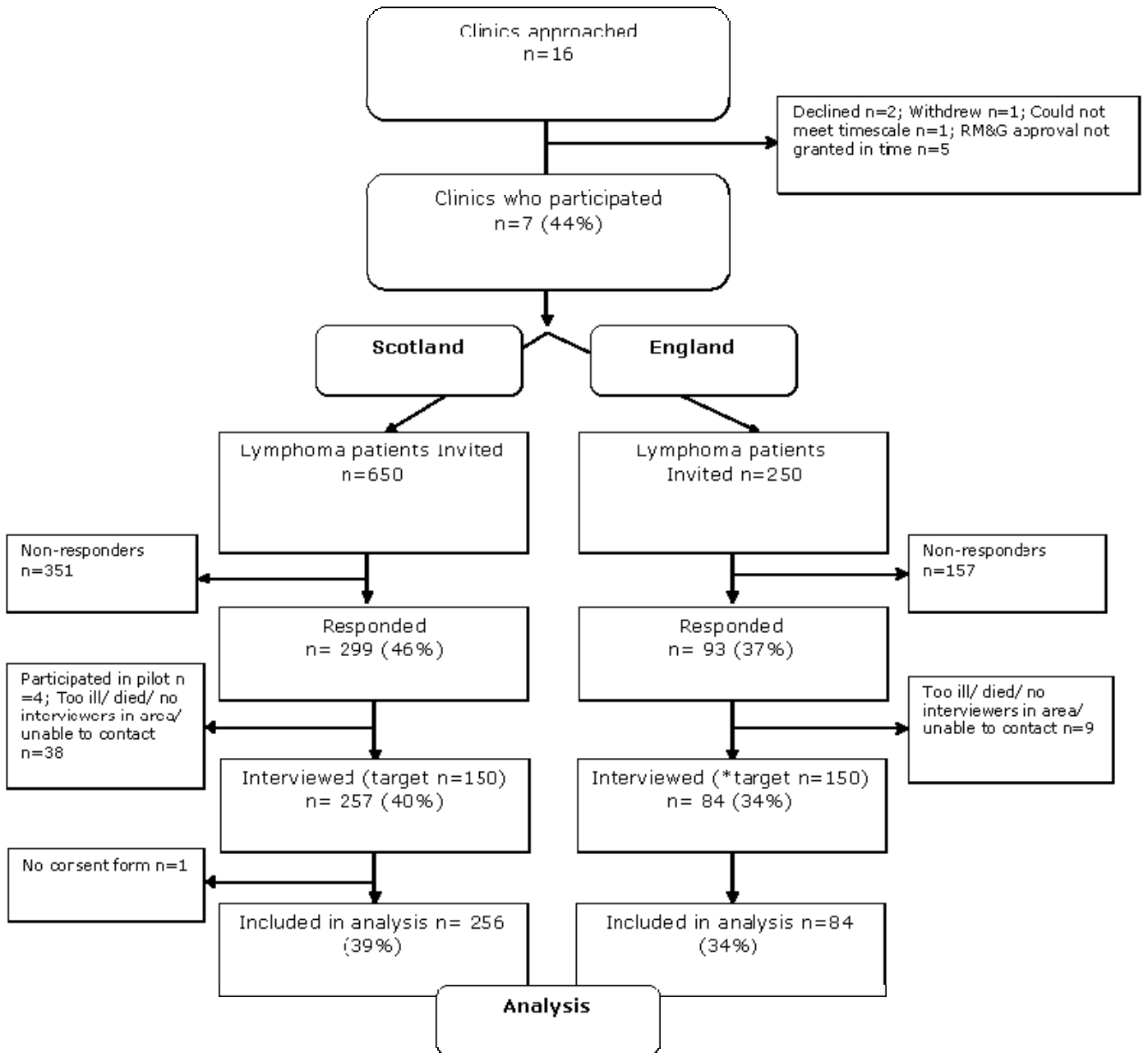
Despite the high level of support for the research from lymphoma centres (in noticeable contrast to low level of support from primary care) we were able to recruit in only two of the seven English clinics (both in large cities in the West Midlands). In four clinics non-recruitment was due to the delay in receiving RM&G approval within the timescale of the study. In one clinic it was because of their desire to have copies of completed consent forms to which we were unable to agree within the terms of our ethical approval; we were not able to resolve this issue by the time we had to stop recruitment.

Response rates for lymphoma recruitment in Scotland were higher than expected; they ranged between 42 and 54 percent with a total of 299 responses across cities in five health boards. Hence we were able to increase the sample size in Scotland to compensate for the reduced sample size in England. In England response rates were 28% and 46% with a total of 93 responses across two trusts. Figure 3 summarises the response to the survey of people with lymphoma and Table 11 details numbers interviewed in each area.

Table 11. Lymphoma patient recruitment and number interviewed

Health board/ NHS trust	Approached	Interviewed (%)
Tayside	125	64 (51%)
Highland	125	32 (26%)
Greater Glasgow & Clyde	125	44 (35%)
Lanarkshire	125	57 (46%)
Lothian	150	60 (40%)
Coventry & Warwickshire	125	52 (42%)
Heart of England (Birmingham)	125	32 (26%)
Total	850	341

Figure 3. Flow diagram of recruitment of clinics and lymphoma patients through the cancer research networks



4.1.6 Fieldwork

In Scotland, 17 GfK interviewers were briefed in August 2009. Interviews with people with lymphoma took place between August and October 2009; interviews with women offered antenatal screening and carers of people with dementia took place between September and November 2009.

In the West Midlands GfK interviewers were briefed in November 2009. Interviews took place in November and December 2009.

4.1.7 Weighting of data

In common with most social surveys, the respondents who participated are unlikely to match exactly those who were invited to take part. Weighting is applied to try to match the respondents to the survey to the overall population characteristics in order to better represent the wider population.

For women who had been offered antenatal screening for Down's syndrome, we compared the age and deprivation of our sample to population data for births in Scotland(60;61). Our sample had a lower proportion of younger and more deprived women, so we increased the weight given to the views of these women. (The overall sample numbers have been kept the same, rather than increasing the overall sample size, to avoid artificially deflating the standard errors).

For carers of people with dementia there are no official population statistics or estimates for Scotland. Furthermore, our survey profile is very similar in age and gender characteristics to a survey of unpaid carers in Scotland (62), therefore we have left the data unweighted, while noting its potential unrepresentativeness.

For lymphoma, there are prevalence statistics for age and gender, but not for deprivation. For people with a diagnosis of lymphoma in Scotland we compared our sample to ISD prevalence statistics for Hodgkin's (63), and non-Hodgkin's (64) lymphomas from 1984-2004. For non-Hodgkin's lymphoma (NHL), the gender proportions were similar but there was a smaller proportion of younger people in our sample and an over-representation of middle-aged people compared to the wider population. Therefore the weighting gives more weight to the younger age group and less weight to the middle-aged group. For Hodgkin's lymphoma (HL), our sample has lower proportions of males and younger people than the population of those with HL, therefore these groups were given increased weight.

For people in the West Midlands we compared our sample to the West Midlands Cancer Intelligence Unit 10-year prevalence figures (65). For NHL, we have re-weighted the sample numbers to reduce the proportion of males, boost the numbers of younger people and reduce the size of the middle-aged group to better reflect the true population proportions. For HL, our sample has lower proportions of males and middle aged people than the population therefore these groups were given more weighting.

In summary, as a result of weighting to relevant population samples, we are confident that the analyses shown in subsequent sections are broadly generalisable for antenatal screening and lymphoma. However, because no population data were available on characteristics of carers of people with dementia we were unable to weight our data; this means that we cannot be confident that our findings can be more widely generalisable to this group (although the sample is broadly similar to that obtained in another survey of carers (62)).

While the conditions were chosen for this research because they were experienced by people at different points in their lives, covered decisions related to health (antenatal screening) as well as illness (lymphoma) and family (carers of people with dementia) it is clear from analyses conducted in stages 1 and 2 that decisions are idiosyncratic and contingent on a wide range of personal and external circumstances. This means that the findings presented in subsequent sections cannot be generalised to other conditions or even to different decisions by people with the same conditions.

4.1.8 Data analysis

Descriptive statistics are presented in relation to: background details relating to the person's health issue; awareness of choice; the provision and usefulness of 'general facts' and 'personal experiences' information; and views on the format of information provided. All analyses, tables and figures present weighted data, from which statistical results provide generalisations to their respective populations.

Associations between the variables and the socio-demographic variables gender (where relevant), age, education and deprivation are investigated using chi-square (Pearson's or Fisher's Exact) tests of statistical significance and measures of strength based on the appropriate level of measurement. Because of the problems in recruitment described earlier and consequent reduction in sample size, it was not possible to investigate associations with ethnicity. In the case of people with lymphoma, some analyses were carried out to test the differences between people with Hodgkin's and non-Hodgkin's lymphoma, as well as between Scotland and the West Midlands.

Despite every attempt to reach the targeted samples, governance and recruitment difficulties meant that sample sizes, particularly for women making antenatal screening decisions and carers of people with dementia, meant it was usually necessary to combine categories of socio-demographic variables for analysis. This was done in two ways for different analyses. First, separate analysis of each health issue was undertaken with the largest number of categories possible for any particular test that did not offend one of the assumptions of the chi square test (i.e. no more than 20 percent of expected cell sizes less than 5). The categories used are as follows: for women who had been offered antenatal screening it was necessary to reduce education to two groups (graduates and non-graduates). Age groups were combined into three (18-24; 25-34; 35-44) or sometimes two (18-24; 25-44) groups. Deprivation was always combined into three groups (most affluent quintile, middle three quintiles, and least affluent quintile).

For carers of people with dementia, education was reduced to four groups (no formal qualifications; standard/GCSE/City & Guilds/etc.; Higher/GCE/Diplomas in HE/etc.; First degree/higher degrees). Age was combined into four (25-54; 55-64; 65-74; 75+), but sometimes three (25-54; 55-64; 65+) groups. Deprivation was combined into three groups (most affluent quintile, second and third most affluent quintiles, fourth and fifth most affluent quintiles).

Since the sample for people with lymphoma was larger, there was less need to combine categories, except in a very few instances. Education was combined into the same groups as for carers of people with dementia. The age group 18-25 was always combined with the 25-34 group for analysis. In quite a few cases (but not always) the 85+ age group was combined with the 75-84 age group to provide a 75+ category. Deprivation was left as five categories.

Second, when comparing results across the three health issues, we adopted a standard categorisation of the socio-demographic variables. For these analyses education was categorised very simply as graduates and non-graduates while deprivation categorised as the lowest two quintiles versus the highest, next to highest and middle quintiles.

While considerably simplifying the analyses this approach did allow some control over these characteristics when comparing across health issues. The relative lack of overlap between the age groups across all three health issues prevented any re-categorisation of this variable for the comparative analysis.

4.2 Findings

Given the delays in recruitment described in sections 4.1.3 and 4.1.4 the full dataset was available for analysis only in mid-January 2010. Here we present summary analyses to answer the research questions on views, preferences and use of information.

As for stage 2 data we distinguish use, views and preferences for 'general facts' and 'personal experiences' information, bringing out differences between them and between the views of respondents with different health issues where relevant. The questionnaire asked respondents to consider 'general facts' and 'personal experiences' information in relation to the particular decision they all had experience of; for this reason we asked first about use and then about views and preferences and we present the results in this order here. Differences in response related to gender, age, deprivation of the area in which respondents live and educational attainment are reported where significant associations were found. First we present the socio-demographic profile of respondents.

4.2.1 Socio-demographic profile of respondents

Table 12 summarises the socio-demographic profile of respondents. Other information is provided in Appendix 3.

Women who made antenatal screening decisions

The median age of respondents was 29 and they tended to have high educational attainment; none had no qualifications and many were highly qualified. There was a strong, positive association between educational attainment and age ($p < 0.001$; $\gamma = 0.578$) and between educational attainment and living in more affluent areas ($p = 0.047$; $\gamma = 0.444$). Nine per cent of the sample were from ethnic minority groups; most of these defined themselves as African, were highly educated, older, and lived in more affluent areas.

Half the women had one child currently, with a maximum of four, resulting from a maximum of six pregnancies. Very few (<6%) reported that they had not been told about or offered a screening test; unlike the stage 1 sample (for which maximum variation sampling was used) all remaining respondents said they knew what the tests were for. Nearly this entire sample (96%) used the internet and 97% had had access to it at home.

Carers of people with dementia

The median age of respondents was 63 and, as expected, there were more female respondents. Male respondents tended to be older (median 68 vs. 61; $p = 0.047$; Cramer's $V = 0.238$). There was a wide range of educational attainment but most respondents lived in the least deprived areas. There were no respondents from ethnic minority groups.

Fifty-three percent of respondents were caring for a parent; 36% caring for a partner; the remainder for other relatives. Men were more likely to be caring for a partner (56% vs. 28%; $p = 0.005$; $\phi = 0.272$) as were older people (Table 13). Thirty percent of respondents said they lived with their cared for relative, 56% that their relative lived in residential care. Living at home with the relative was more common among spouses (71% of spouses vs. 11% of other relatives) but this did not vary by gender.

Sixty-eight percent of respondents said they used the internet, which, as expected, varied with age (91% of 55-64 vs. 25% of 75+; $p < 0.001$; Cramer's $V = 0.552$), education (95% of those with degree vs. 24% of those with no formal education; $p < 0.001$; Cramer's $V = 0.505$) and deprivation of area in which they lived (73% of those in least deprived vs. 38% of those in most deprived quintiles; $p = 0.005$; Cramer's $V = 0.314$). Seventy percent of respondents had access to the internet at home.

People with lymphoma

Because the socio-demographic profiles and the proportions of those with Hodgkin's and non-Hodgkin's lymphoma were similar among respondents from Scotland and the West Midlands analysis was conducted on the combined sample.

As expected, the age distribution was different for those with Hodgkin's (median = 42) and non-Hodgkin's (median = 66) lymphoma. The treatment regimens are also different; as expected, those with Hodgkin's lymphoma were more likely to have chemotherapy (93.5% v 79.2%; $p = 0.014$;

phi=0.148) and radiotherapy (67.7% v 37.8%; $p < 0.001$; phi=0.238) than those with non-Hodgkin's lymphoma. Time since diagnosis averaged between two and five years, ranging from six months to ten years, reflecting our sampling design. There was a fair distribution of educational attainment but women were more likely to have no formal qualifications than men (38% v 22%) and less likely to be graduates (23% v 29%) ($p = 0.003$; Cramer's $V = 0.202$). There was a strong association between age and educational qualifications, with younger people more likely to have higher educational attainment (55% of 18-34, 42% of 35-44, 29% of 45-54, 29% of 55-64, 13% of 65-74, 16% of 75-84, 13% of 85+ had degree; $p < 0.001$; gamma=-0.382).

Sixty-three percent of respondents used the internet which, as expected, varied with age, educational attainment and deprivation of the area in which they lived. Seventy-one percent of respondents had access to the internet at home.

Figure 4. Age distribution for people with Hodgkin's and non-Hodgkin's lymphoma

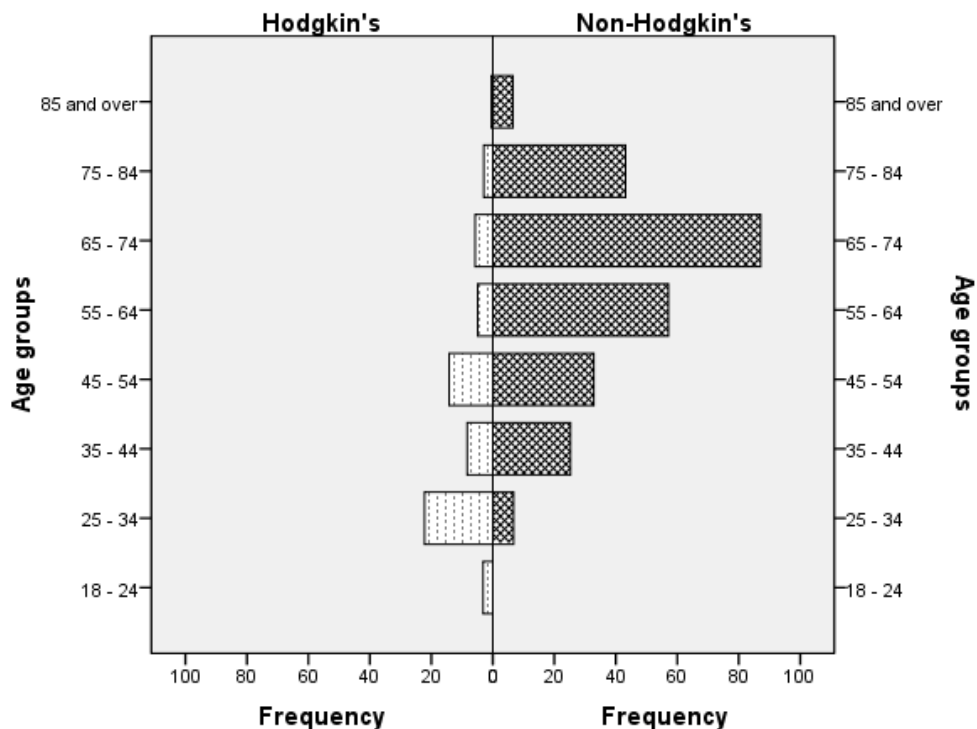


Table 12. Socio-demographic characteristics of the survey sample (%)

	Antenatal screening N=82	Caring for dementia N=108	Lymphoma N=340
Sex			
Male	-	35	51
Female	100	73	49
Age			
18-24	20	-	1
25-34	61	1	9
35-44	19	3	10
45-54	-	19	14
55-64	-	32	19
65-74	-	22	29
75-85	-	17	15
85+	-	6	2
Educational qualifications			
None	0	16	29
O level/GCSE / SCE Standard/Ordinary grades/trade apprenticeships	22	28	26
A/AS levels/ SCE higher/ Scottish Certificate	12	14	7
Diplomas in higher education/ other HE qualification	12	18	11
First degree (including BEd), Postgraduate Diplomas	33	17	16
Higher degree/postgraduate qualifications	20	3	10
Other/don't know	0	2	1
Deprivation of areas in which live (quintiles)			
1 (Least deprived)	19	51	29
2	18	17	25
3	12	13	19
4	23	11	15
5 (Most deprived)	29	8	12
Ethnicity			
White	91.4	100.0	98.5
Asian/Asian British	1.2	0.0	0.9
Black/Black British	7.4	0.0	0.6

Table 13. Association between carer's age and which relative carer of person with dementia was caring for (%)

(p<0.001; Cramer's V=0.840)

	25 – 54 n (%)	55 – 64 n (%)	65 – 74 n (%)	75+ n (%)	Total n
Spouse /partner	0 (0)	1 (3)	16 (67)	22 (96)	39 (37)
Other relative	25 (100)	33 (97)	8 (33)	1 (4)	67 (63)

4.2.2 Perception of choice

Respondents were asked about their perception of choice and their use of information for each of the decisions we were focusing on (screening for Down's syndrome; where a relative lives, and treatments for lymphoma). Asked whether at the time of the decision they were aware that they had a choice, 92% of women who had been offered antenatal screening, 54% of carers of people with dementia and 43% of those with lymphoma responded that they were clear they had a choice (p<0.001; Cramer's V=0.254). Being clear that they had a choice was associated with higher educational attainment among those with lymphoma (65% degree, 49% Highers/GCE etc., 36% fewer qualifications; p=0.001; gamma=0.267), but not for the other two health issues.

4.2.3 Use of information

Did respondents have enough information for their decision?

Respondents were asked to consider whether they felt they had enough information *in general* for their decision (Table 14). Responses varied by condition; 81% of women making antenatal screening decisions; 67% of carers of people with dementia and 78% of those with lymphoma reported they had as much information as they needed. Comparing those who felt they had enough (or too much) information with those who did not revealed a statistical difference between the health issues (p<0.001; Cramer's V=0.181), even when controlling for education and deprivation. However, stronger differences were observed between health issues for less deprived graduates (p<0.001; Cramer's V=0.418) and more deprived non-graduates (p=0.011; Cramer's V=0.217). Nearly 25% of carers of people with dementia reported that they had either needed more or that in general, the information was insufficient for their decision but less than 10% of the respondents with experience of other health issues suggested this was the case. People with Hodgkin's lymphoma were less likely to say that they had as much information as they needed (76% vs. 87% of those with non Hodgkin's lymphoma; p=0.007, Cramer's V=0.117). Expressing a need for more information was significantly associated with age for carers of people with dementia; 56% of those aged 25-54, 29% of those aged 55-64, 25% of those aged 65-74 and 22% of those aged 75+ reported they needed more information (p=0.039, Cramer's V=0.279).

Table 14. Whether respondents felt they had enough information for their decision (%)

	Antenatal screening N=82	Caring for dementia N=108	Lymphoma N=340
Yes, if anything, I felt swamped by it	4	0	5
Yes, I had as much information as I needed	81	67	78
Yes, although I felt I needed more	6	9	8
Not really, I definitely felt I needed more	7	11	5
Not at all, it was far too little	2	12	2
Don't know/can't remember	0	1	2

Those who would have liked more information were asked what kind of information they wanted. Using the framework of stages of decision making introduced in section 3, Table 15 shows that most responses related to *identifying or appraising options*. In particular 54% of carers of people with dementia said they wanted to know what the options were while 62% of those who had been offered antenatal screening and 74% of those with lymphoma said they had wanted to know what each option might lead on to.

Table 15. If would have liked more information for decision, what kinds? (% of those who wanted more information)

Statistical significance of differences between health issues given in brackets.

	Antenatal screening N=13	Caring for dementia N=35	Lymphoma N=51
<i>Identifying options</i>			
What the possible options were (p=0.206)	39	54	35
<i>Appraising options and making a selection</i>			
What each option might then involve or be like (p=0.073)	23	26	47
About what each option might lead on to later (p<0.001; Cramer's V=0.422)	62	29	74

Being given or finding 'general facts' information

Before asking whether respondents had used 'general facts' information, they were asked how much they had been given by professional staff (e.g. doctors, midwives, nurses or social workers) and their views on whether it was the right amount; Table 16 and Table 17 summarise the responses. As expected, those caring for people with dementia were more likely to say that they were given too little or far too little information from professional staff; currently professional staff are not allowed to recommend care homes to relatives and information on their quality can be very hard to find and evaluate.

Respondents were asked about how much 'general facts' information they found for themselves at the time of the decision. Given how little information is available it is not surprising that more carers of people with dementia reported seeking a lot or quite a lot of 'general facts' information themselves (30% of those who experienced antenatal screening, 50% of carers of people with dementia and 37% of those with lymphoma). As expected, reported seeking of 'general facts' information oneself was significantly more common among those with higher educational attainment for all health issues (percentages of those seeking a lot or quite a lot of information: antenatal screening - 7% non-graduates vs. 23% graduates, $p=0.016$; Cramer's $V=0.383$; carers of people with dementia - 3% no formal qualifications, 34% school qualifications, 14% graduates, $p=0.018$; $\gamma=-0.416$; lymphoma - 7% no formal qualifications, 16% with school qualifications, 14% of graduates, $p<0.001$; $\gamma=-0.381$) and with age for those with lymphoma and carers of people with dementia (percentages of those seeking a lot or quite a lot of information: carers of people with dementia - 17% 25-54, 22% 55-64, 8% 65-74, 4% 75+, $p=0.002$; $\gamma=0.516$; lymphoma - 6% 18-34, 6% 35-44, 2% 45-54, 2% 55-64, 2% 65-74, 1% 75+, $p<0.001$; $\gamma=0.376$). Among respondents with lymphoma reports of seeking 'general facts' information oneself was also more common among men (62% men vs. 50% women; $p<0.0001$, Cramer's $V=0.223$) and those with Hodgkin's rather than non-Hodgkin's lymphoma (80% Hodgkin's vs. 53% non-Hodgkin's; $p<0.001$; Cramer's $V=0.287$).

Table 16. How much 'general facts' information was given by professional staff (%)

(p<0.001; Cramer's V=0.298 (excluding 'don't know'))

	Antenatal screening N=82	Caring for dementia N=108	Lymphoma N=340
A lot	12	5	28
Quite a lot	39	36	45
Some, but not a lot	38	18	17
Very little	8	20	5
None at all	3	19	4
Don't know/can't remember	-	1	1

Table 17. Was the amount of 'general facts' information from professional staff enough? (% of those who received any 'general facts' information from professionals)

(p<0.001; Cramer's V=0.202 (excl. 'don't know'))

	Antenatal screening N=79	Caring for dementia N=86	Lymphoma N=325
Far too much/too much	0	2	6
Just right	77	57	81
Too little/far too little	22	40	12
Don't know/can't remember	0	1	1

Those who sought 'general facts' information were asked about sources. Table 18 shows that using the internet was more common among women making antenatal screening decisions (who were also younger and more educated) but was also reasonably high among carers of people with dementia and people with lymphoma. The differences between the health issues in use of the internet were present when controlling for education and deprivation. It is notable that between 20 and 30 percent of respondents reported that they had also sought 'general facts' information from family members, friends and relatives. This did not vary significantly between the health issues, even when controlling for education and deprivation.

Table 18. Where 'general facts' information was found for decisions (% respondents)

* multiple sources could be chosen

	Antenatal screening N=82	Caring for dementia N=107	Lymphoma N=352
Internet/website* (p<0.001; Cramer's V=0.350)	89	40	67
Books or journals* (p<0.001; Cramer's V=0.212)	23	3	21
Family, friends or relatives* (p=0.729)	20	29	24
Voluntary groups or patient organisations* (p=0.002; Cramer's V=0.184)	0	19	8

Using 'general facts' and 'personal experiences' information

We asked respondents if the 'general facts' information they had been given or sought was actually used by them when considering their decision. Table 19 summarises the responses. There is a significant difference between the health issues, even after controlling for education and deprivation. Of people with lymphoma 55% said that they had not used any 'general facts' information compared to 32% of women making antenatal screening decisions and 30% of carers of people with dementia (p<0.001; Cramer's V=0.216) .

Table 19. Using 'general facts' information to consider the decision (% of those who said they had 'general facts' information)

(p<0.001; Cramer's V=0.216 (excluding 'don't know'))

	Antenatal screening N=81	Caring for dementia N=98	Lymphoma N=332
No, did not use any	32	30	55
Yes, it formed part of information used	58	50	26
Yes, it was virtually the only information used	7	20	17
Don't know/can't remember	3	-	2

Furthermore, reporting use of 'general facts' for decision making varied by age for each health issue. Lower use was made of 'general facts' by women aged 18-24 making antenatal screening decisions (25% 18-24 vs. 73% 35-44, $p < 0.001$, Cramer's $V = 0.454$); carers aged 75 and over of people with dementia were less likely to use 'general facts' for their decision (88% 25-64, 60% 65-74, 34% 75+, $p < 0.001$, $\gamma = 0.449$); while for people with lymphoma, increased usage was more likely among those aged 35 to 54 (48% 18-34, 56% 35-54, 46% 55+, $p < 0.001$, Cramer's $V = 0.209$).

We asked respondents if the 'personal experiences' information they had been given or sought was actually used by them when considering their decision. In asking about the use of 'personal experiences' information in the questionnaire we asked respondents to include use of one's own ('things you have gone through or seen yourself') as well as others' ('experiences of friends or family or other people through work, family or friends') experiences. Table 20 summarises the response to being asked whether they had actually used 'personal experiences' information to help them consider the decision. People with lymphoma were much more likely to report *not* using any 'personal experiences' information for decision making than the other two groups (59% of people with lymphoma, 36% of women making antenatal screening decisions and 30% of carers of people with dementia). However, this is only statistically significantly different for the more deprived, non-graduates with lymphoma ($p < 0.001$; Cramer's $V = 0.734$).

Table 20. Using 'personal experiences' information to consider the decision (% of those who said they had 'personal experiences' information)

($p < 0.001$; Cramer's $V = 0.734$ (excluding 'don't know')).

	Antenatal screening N=70	Caring for dementia N=80	Lymphoma N=177
No, did not use any	36	30	59
Yes, it formed part of information used	57	53	36
Yes, it was virtually the only information used	7	18	5
Don't know/can't remember	-	-	0.6

As with reported use of 'general facts', reported use of 'personal experiences' information varied by age for each health issue. Lower use was made of 'personal experiences' information by women aged 18-24 making antenatal screening decisions (35% 18-24 vs. 59% 25-44, $p < 0.005$, Cramer's $V = 0.357$); carers aged 65 and over of people with dementia were less likely

to use 'personal experiences' information for their decision (64% 25-64, 37% 65+, $p < 0.039$, Cramer's $V = 0.248$); while for people with lymphoma, lower usage was likely among those aged 55 and over (28% 18-34, 37% 35-54, 14% 55+, $p < 0.003$, Cramer's $V = 0.198$).

Table 21 considers reports of use of either 'general facts' or 'personal experiences' information for decision making. It illustrates that facing a serious condition like lymphoma, the majority said they either did not use any information (probably because they relied on their health professionals' knowledge and treatment recommendations) or that they used only 'general facts'. In contrast, both 'general facts' and 'personal experiences' information were reported to have been used for those facing the non-life threatening decisions of whether to have antenatal screening for Down's syndrome or where a relative with dementia should live. These differences between the health issues are statistically significant ($p < 0.001$; Cramer's $V = 0.270$), and are similar regardless of education and deprivation levels.

Table 21. Using 'general facts' and/or 'personal experiences' information (%)

($p < 0.001$; Cramer's $V = 0.270$)

	Antenatal screening N=79	Caring for dementia N=98	Lymphoma N=326
Used only 'general facts'	29	30	31
Used only 'personal experiences'	17	13	8
Used both 'general facts' and 'personal experiences'	38	41	13
Used neither general facts' nor 'personal experiences'	16	16	48

Regarding use of information from *other people's* 'personal experiences' (i.e. excluding use of one's own prior personal experiences), 45% (37/82) of women making antenatal screening decisions, 40% (43/108) of carers of people with dementia but only 18% (60/340) of people with lymphoma used others' experiences in considering their decision. These differences are not surprising given the relative prevalence of each health issue in the wider population and thus the relative availability of others' personal experiences.

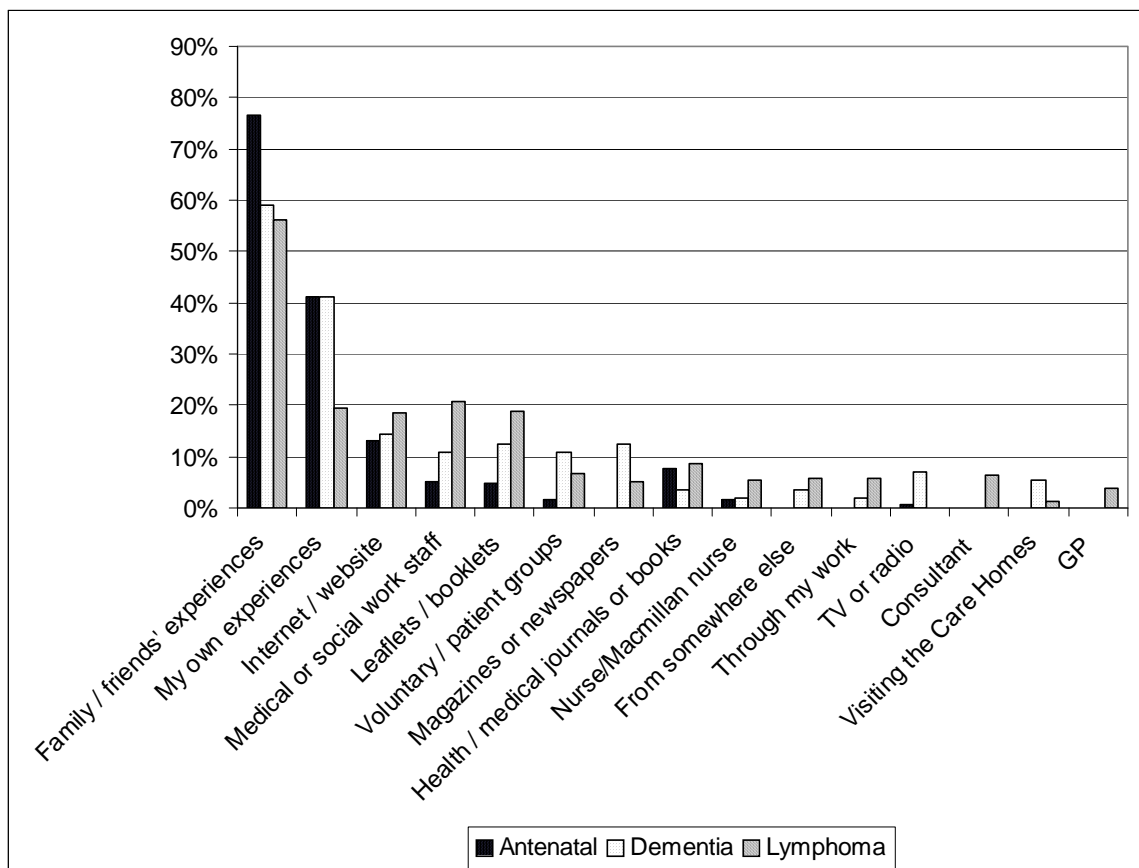
Sources of 'personal experiences' information

In terms of where respondents got information about other people's personal experiences, Figure 5 shows that drawing on the experiences of family, friends and relatives is common for respondents across all health issues. There is a tendency for women making antenatal screening decisions to be

more likely to get 'personal experiences' information from family and friends than are people with the other health issues ($p=0.053$), but this is not a statistically significant difference. Graduates with lymphoma were less likely than graduates with the other health issues (39% vs. 92% for pregnant women and 80% for carers of people with dementia) to get 'personal experiences' information from family or friends ($p<0.001$; Cramer's $V=0.524$), while more deprived carers of people with dementia were significantly less likely than those with other health issues (27% vs. 71% for women making antenatal screening decisions and 72% for people with lymphoma) to get personal experiences information from this source ($p=0.005$; Cramer's $V=0.365$).

Twenty-one percent of those with lymphoma who used 'personal experiences' information said that it came from their health or social work professionals whereas the proportion was lower for women making antenatal screening decisions (5%) and carers of people with dementia (11%) ($p=0.031$; Cramer's $V=0.202$). This may be because people with lymphoma have more opportunities to talk things over with their health professionals or possibly because health professionals had suggested people with lymphoma talk to other patients. Recommendations for mutual peer support are quite common in cancer care. The number of different sources of 'personal experiences' information was smaller for the most common health issue, antenatal screening, perhaps because it is so easily accessible from family and friends.

Figure 5. Sources of 'personal experiences' information for people across the health issues



Statistical differences also exist between people with lymphoma and women making antenatal screening decisions or carers of people with dementia in relation to how many reported having their own relevant personal experiences on which to draw ($p=0.013$). Otherwise the differences are too small or are based on too few responses to be able to distinguish any variation.

4.2.4 Views and value of 'general facts' and 'personal experiences' information

Respondents who reported using either 'general facts' or 'personal experiences' information in considering their decision were asked about their *views* and experiences and the *value* they had placed upon the information at the time.

Table 22 shows that 'general facts' and 'personal experiences' information were described as having helped in similar ways in recognising decisions and identifying options as well as in appraising options and making a selection. Positive views on the value of both 'general facts' and 'personal experiences' information tended to be lower for those with lymphoma; this may be because the treatment is largely protocol driven and while people may have been aware that they could refuse a particular, or indeed any, treatment they may not have felt that they really had a choice. Similarly, a lack of 'general facts' information for carers of people with dementia probably resulted in the lower levels of agreement with the statement that facts' could help suggest options and alternatives'.

However, neither 'general facts' nor 'personal experiences' information was reported as the most important influence on decisions. When asked the one thing that most influenced the decisions, 55% of people with lymphoma, 47% of carers of people with dementia and 8% antenatal women felt there was no real choice ($p<0.001$; Cramer's $V=0.358$), irrespective of level of education or deprivation. Twenty-five percent of people with lymphoma considered staff attitudes and views were the most influential while 20% of women making antenatal screening decisions were most likely to mention their previous personal experience as most influential.

Table 22. Views on why 'general facts' and 'personal experiences' information was useful in considering the decision (% of those who used 'general facts' or 'personal experiences' information)

'Stages of decision making' framework	Why 'general facts' useful % strongly agree or agree with statement			Why 'personal experiences' useful % strongly agree or agree with statement		
	Antenatal screening N=53	Caring for dementia N=69	Lymphoma N=139	Antenatal screening N=44	Caring for dementia N=56	Lymphoma N=71
GF: General Facts PE: Personal Experience CV: Cramer's V						
<i>Recognising decisions are needed and identifying options</i>						
It made me realise there was a choice about... GF: $p < 0.001$; CV=0.301 PE: $p < 0.001$; CV=0.404	88	74	53	87	80	45
It suggested options and alternatives GF: $p < 0.005$; CV=0.201 PE: $p < 0.001$; CV=0.330	65	53	40	70	68	35
It led me to think that I needed more information GF: $p = 0.001$; CV=0.225 PE: $p = 0.918$	40	62	36	42	40	44
<i>Appraising options and making a selection</i>						
It made me understand what each option might lead onto later GF: $p = 0.014$; CV=0.182 PE: $p = 0.002$; CV=0.267	85	65	81	89	84	63
It provided information on how I might cope or feel after the decision was made GF: $p < 0.001$; CV=0.363 PE: $p = 0.135$	48	37	77	76	58	71
It made me aware what each option might involve or be like GF: $p = 0.114$ PE: $p = 0.034$; CV=0.218	85	69	74	36	64	64
It helped me decide what to do GF: $p = 0.507$. PE: $p < 0.001$; CV=0.359	79	87	84	93	95	66
<i>Other/evaluating and living with the decision</i>						
It made me realise that I wasn't alone in dealing with this GF: $p < 0.001$; CV=0.343. PE: $p = 0.052$	53	75	79	98	82	89

4.2.5 Preferences for 'general facts' and/or 'personal experiences' information

While views on the value of 'general facts' and 'personal experiences' information were remarkably similar, when asked to *compare* the importance of each type of information against each other when making their decision Table 23 shows that differences between health issues emerged. There is a statistically significant difference between the health issues ($p < 0.001$; Cramer's $V = 0.391$), after excluding 'not applicable' and 'don't know' responses, even after controlling for education and deprivation. Seventy percent of respondents with lymphoma said that 'general facts' were either the only or the more important type of information compared to 43% of women making antenatal screening decisions and 21% of carers of people with dementia. On the other hand 27% of carers of people with dementia, 15% of women making antenatal screening decisions and 4% of people with lymphoma reported that 'personal experiences' information was either the only or the more important type of information while 27% of both women making antenatal screening decisions and carers of people with dementia said that 'general facts' and 'personal experiences' information were equally important.

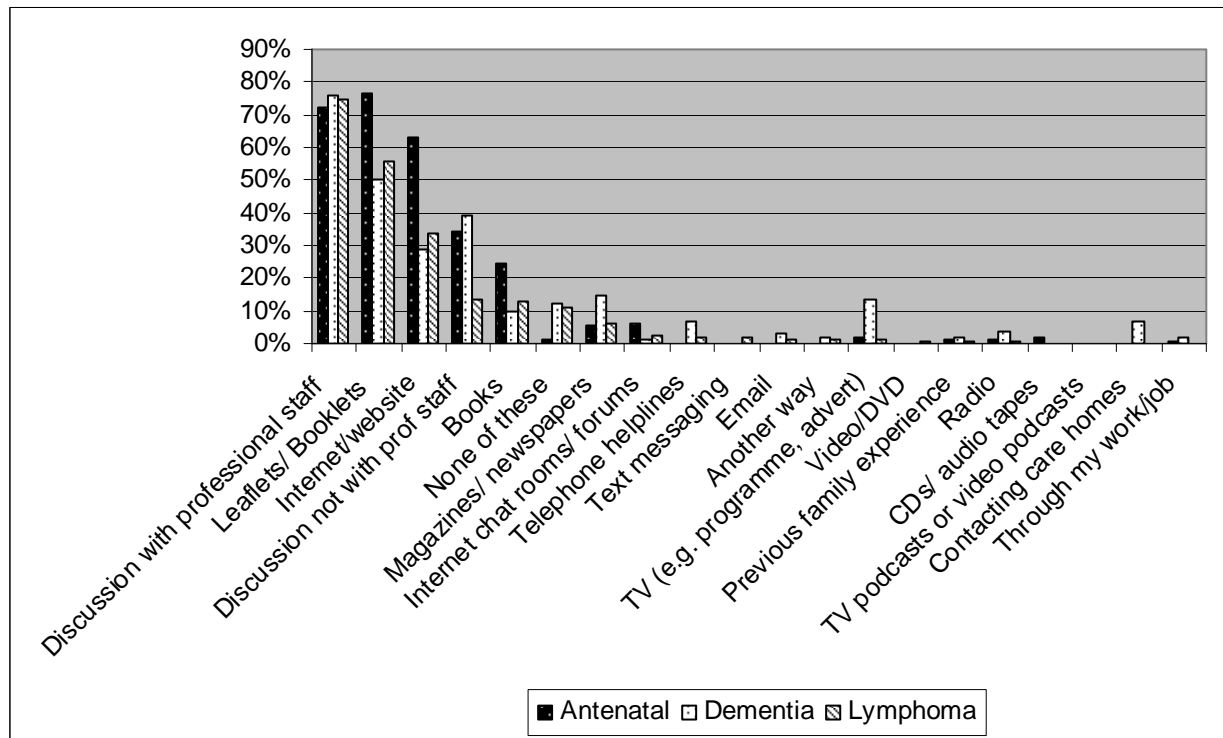
These differences are not surprising when one considers the differences in decisions faced; it makes sense that those facing the life threatening condition lymphoma said they relied only on 'general facts' in thinking about treatment decisions. We have seen in section Table 13 that nearly 25% of carers of people with dementia felt that they had either needed more information or that the information was insufficient for their decision, that they had wanted more 'general facts' information from professionals and that they had tried to find out more. They face a dearth of 'general facts' information about residential options; it is not surprising therefore that they relied on 'personal experiences' in thinking about where their relative should live. It is also possible that 'personal experiences' information is most highly valued in thinking about decisions that focus on values and personal relationships, such as antenatal screening and where a relative with dementia should live, rather than in decisions more readily guided by clinical expertise.

Table 23. The importance of 'general facts' and 'personal experiences' information compared to each other when thinking about the decision (%)

	Antenatal screening N=82	Caring for dementia N=108	Lymphoma N=340
'General facts' were the only important information	12	14	49
'General facts' were more important	31	7	21
They were both about equally important	27	27	12
'Personal experiences' were more important	15	20	3
'Personal experiences' were the only important information	0	7	1
I didn't think either type of information was important	5	10	6
Not applicable	10	14	8
Don't know	0	1	1

4.2.6 Preferences for source of information

Respondents were asked which ways of getting information they used for their decision (Figure 6). The figures show that the order of the top four sources of information varied across health issues. For women making antenatal screening decisions they were: leaflets and booklets (78% of responses), discussion with health professionals (72%), internet and websites (62%), discussion with someone else (34%); for carers of people with dementia they were: discussion with medical or social work staff (76%), leaflets and booklets (50%), discussion with someone else (40%) and internet/website (28%). For people with lymphoma they were: discussion with health professionals (75%), leaflets and booklets (56%), internet/websites (34%) and discussion with someone else (14%). The results clearly reflect the type of information that is available for each health issue and the time available to find it; we have seen that access and use of the internet was highest among women making antenatal screening decisions and these results reflect that. They also confirm that most people report that most of their information comes from interacting either with health or social care professionals, or from others in the wider community, or from leaflets/booklets.

Figure 6. Ways in which people got information for their decision

Statistical differences exist between health issues in relation to use of these sources of information: leaflets/booklets ($p < 0.001$; Cramer's $V = 0.171$), the internet ($p < 0.001$; Cramer's $V = 0.237$), and books ($p = 0.010$; Cramer's $V = 0.132$) which were all more popular among women making antenatal screening decisions; discussion with someone who is not a professional ($p < 0.001$; Cramer's $V = 0.273$), and magazines ($p = 0.021$; Cramer's $V = 0.122$) which were both more popular among carers of a person with dementia. Otherwise the differences are too small or are based on very few responses to be able to distinguish any variation.

Finally, respondents were asked which sources of information they would prefer to use and would not want to use, if they were to face the decision again (Figure 7, Figure 8). As might be expected, the sources that were not wanted differed from those that were preferred.

Overwhelmingly (over 90% of responses from each health issue) respondents said that they liked to receive information, face to face, from health and social work staff. However there were health issue-specific differences in the frequency with which people were willing to use other sources of information – particularly the internet ($p < 0.001$; Cramer's $V = 0.259$), which was more popular among women making antenatal screening decisions. While lymphoma patients and carers of people with dementia were both fairly evenly split between those who would prefer to use websites (40% and 43% respectively) and those who would not want to use the internet for information (43% and 48% respectively) the pattern was very different for women making antenatal screening decisions; 75% of them preferred

websites and only 15% said they would not want to use it. This difference reflects the different patterns of internet use in older and younger age groups,

Figure 7. Preferred sources of information for all health issues

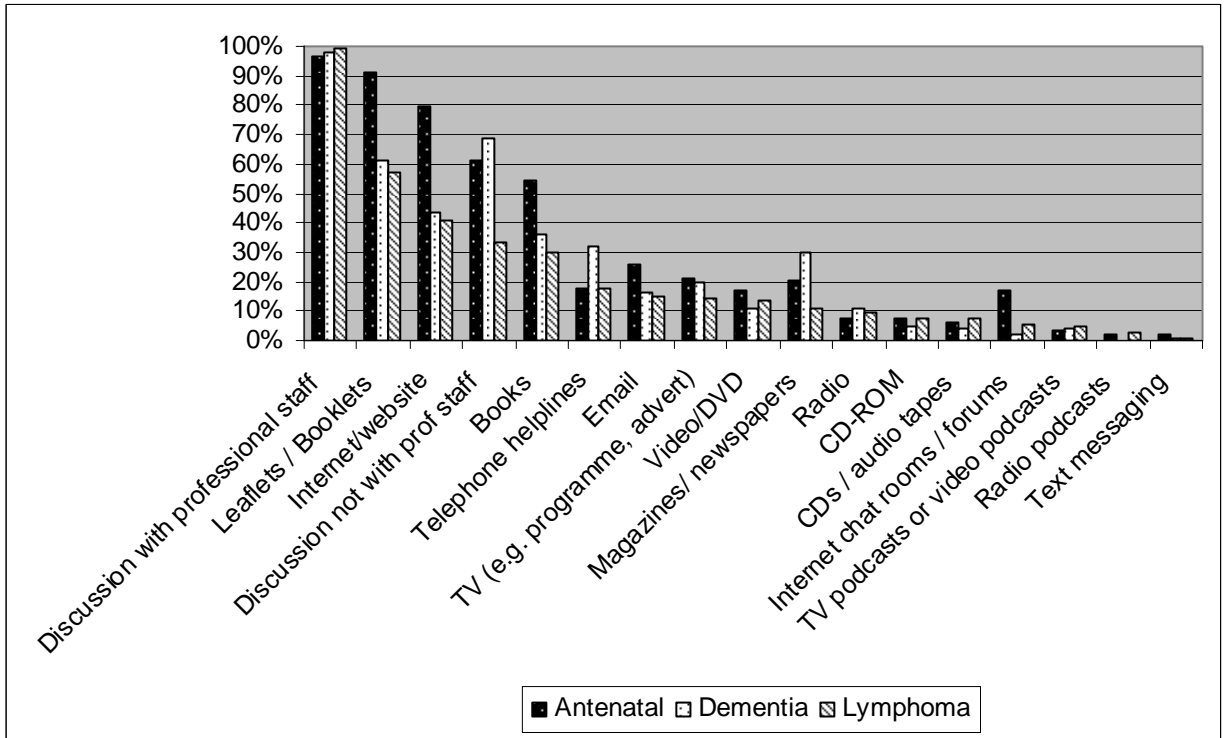
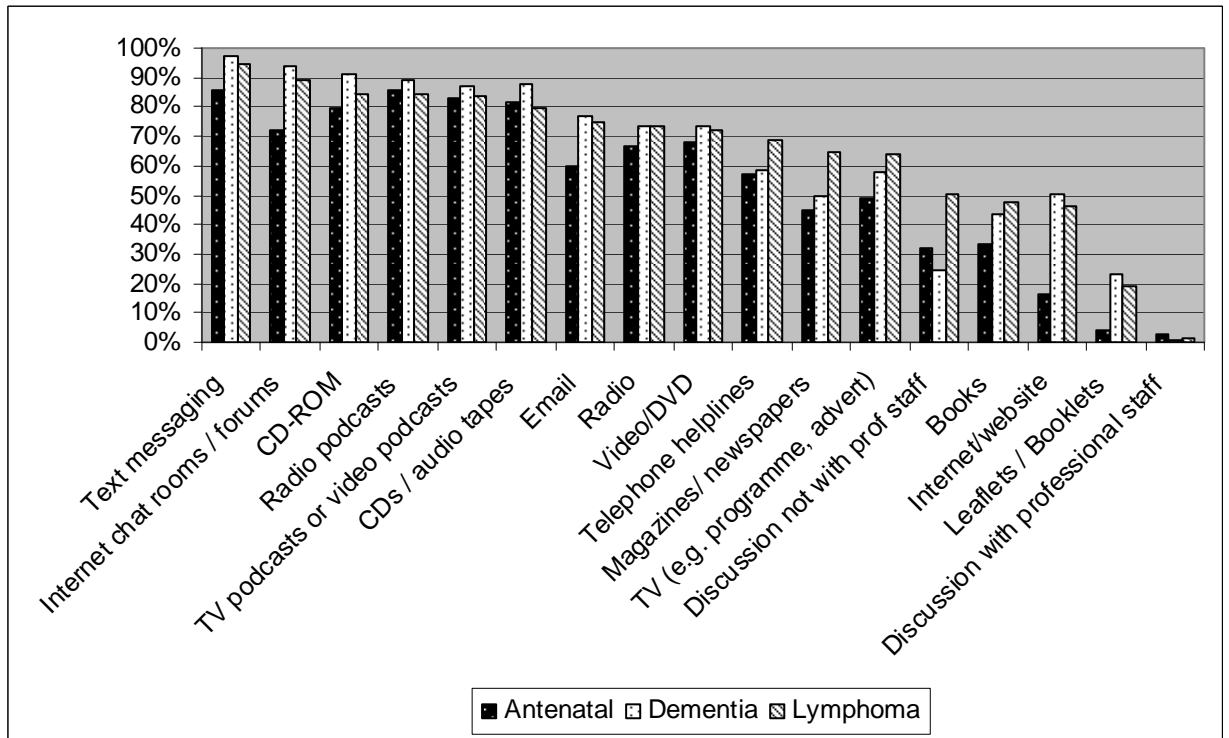


Figure 8. Sources that would not be wanted for all health issues



rather than education or deprivation level: in this sample nearly all of the women making antenatal screening decisions had internet access at home and were, on average, younger than the other two groups. However, the data do not suggest a lack of selectivity about which type of website they would use: there was a clear distinction in attitudes to using 'websites' as opposed to internet 'chat rooms' which were far less favoured as sources of information across all three groups. Thus only 5% of lymphoma patients, 2% of dementia carers and 16% of women making antenatal screening decisions reported that they would use internet chat rooms as a source of information. Internet chat rooms were more likely to be preferred by women making antenatal screening decisions ($p < 0.001$; Cramer's $V = 0.207$); this was partially related to their younger average age and higher education level.

Other statistically significant differences in preferences for information sources between respondents facing the different health issues included preferring leaflets/booklets ($p < 0.001$; Cramer's $V = 0.197$), which were more popular with women making antenatal screening decisions; again this was mainly an age-related factor, with some association with their higher education level, but not with deprivation level. Books were also more popular with women making antenatal screening decisions ($p = 0.004$; Cramer's $V = 0.168$), which was related to their overall higher education level. Magazines were less popular with people with lymphoma ($p < 0.001$; Cramer's $V = 0.240$); this was not related to levels of education or deprivation. Telephone helplines were more popular with carers of people with dementia ($p = 0.018$; Cramer's $V = 0.138$); this was unrelated to their education level or age. Preferring discussion with people who are not professional staff appeared to be less common among people with lymphoma ($p < 0.001$; Cramer's $V = 0.292$) (unrelated to their level of education, deprivation, or age), suggesting that these people in general have a stronger preference for professional advice.

4.3 Summary: Addressing the research questions

4.3.1 How are the views, preferences and reported use of different types and formats of information for each type of choice distributed across the population within socio-demographic groups?

In addressing this research question we have identified reported use, views and preferences for 'general facts' and 'personal experiences' information in the samples we were able to recruit to the study.

Analysis from stage 2 (reported in section 3) had suggested that while respondents talked of 'general facts' underpinning informed decisions, 'personal experience' information was seen to add value to 'general facts' in a number of important ways and to perform some unique functions. This analysis is broadly supported in the survey data for women making antenatal screening decisions and carers of people with dementia but not for people

with lymphoma who reported lower use of either 'general facts' or 'personal experiences' information in thinking about treatment decisions in general (probably because they are protocol-driven and made by or with clinician experts).

About two-thirds of women making antenatal screening decisions and carers of people with dementia reported using 'general facts' when thinking about their decision while two fifths of each reported using other people's 'personal experiences' information. However, about two fifths of women making antenatal screening decisions and carers of people with dementia reported using both 'general facts' and 'personal experiences' information (where personal experience information included use of one's own as well as others' 'personal experiences').

While there were considerable similarities in the reported value of each type of information, there was a suggestion that more respondents felt that 'personal experiences' information was useful for the 'imagined futures' of knowing how one might cope or feel after a decision was made and (for carers of people with dementia) being aware what each option might involve or be like. When asked to directly compare 'general facts' and 'personal experiences' information in considering their decision about a third of women making antenatal screening decisions and carers of people with dementia felt that they were equally important.

These data suggest that there is support for the continued 'mixed economy' of provision of different information types; that 'general facts' are important for all health issues but that in some circumstances, in our case exemplified by the 'value-based' or 'relationship-based' decisions, the addition of 'personal experiences' information may be of particular relevance. People who are facing rarer health issues for which there are few clinical protocols or those that involve decisions with a clear 'values' component may be in particular need of experience based information as well as facts.

Overwhelmingly, respondents reported getting information from discussion with health and social care professionals and expressed a preference to do so in the future; the role of interaction with trusted professionals continues to be important. Similarly, gaining information through discussion within the person's wider social circle continues to be valued; as Code (66) has suggested, most human knowledge comes through interaction.

The internet was a preferred source of information among women making antenatal screening decisions and also among younger carers of people with dementia. It is likely to be increasingly important as the population ages and younger cohorts become carers; the current investment in internet-based information is well advised.

Carers of people with dementia found it particularly hard to access information in general and 'general facts' information about where their relative should live in particular; they relied more heavily on 'personal experience' information than other groups. This was clearly not always a matter of choice and is illustrative of the particular, and frustrating, dearth of

information on residential care. Current policy initiatives to improve access to information for carers of people with dementia are well-founded.

The main variation in use, views and preferences for 'general facts' or 'personal experiences' information in terms of socio-economic variables was, as expected, by educational attainment and age and in the expected directions. Because we were not able to recruit many respondents from ethnic minority groups we were unable to examine variation in use, views and preferences by ethnicity.

4.3.2 Are there distinct types of people, patients or carers in relation to information use and choice?

The data suggest that the differences in information use and choice are more related to the different *types* of health issue and choice than they are to the type of person. While younger and better educated people may be more likely to report seeking information, of various types, respondents in all groups reported that they used, and valued, information from a wide variety of sources when facing choices.

We were interested to find that there were distinct patterns of use and preferences for information between the different health issues, suggesting that the respondents were indeed concentrating on the particular decision they were asked to think about rather than expressing their views of information per se. We were conscious that respondents might feel some sense of obligation to present themselves as the type of person who seeks their own information; if this happened it did not obscure the differences between conditions.

The results suggest that people draw on the sources of information that are available to them, but not without discrimination. Thus, interaction with health professionals remains important and is combined with information drawn from other sources including the internet, yet internet chat-rooms were far less favoured as a source of information in all three conditions. As Nettleton et al (67) reminds us the use of the internet for health information is contingent, embedded and embodied. This reinforces the current moves to increase signposting and accessibility of different types of information. This should include information through face-to-face interactions supported by easily accessed printed or internet resources.

5 Conclusions

SDO 08/1710/153 called for research to understand the *types of information* that people take account of when making choices, the *format* of information that they prefer, and whether preferences vary systematically according to socio-economic status, ethnicity, gender and age.

We have investigated these issues in a multi-method study conducted in three iterative stages in relation to exemplar health issues chosen to cover a range of types of choices, with different implications, faced by people at different life stages and in different states of health. In stages 1 and 2 we considered five health issues: antenatal screening, ending a pregnancy for fetal abnormality, screening for sickle cell disorder or thalassaemia, caring for a person with dementia, and lymphoma. In stage 3, we considered three: antenatal screening, caring for a person with dementia, and lymphoma. In stages 2 and 3 we focused attention on information in relation to particular decisions.

We considered two types of information: 'general facts' and 'personal experience' information. By 'general facts' we referred to research-based information about health care interventions and the risks and outcomes associated with them; medical knowledge that reflects consensus based on what has been observed among many patients/people; and other information that is widely accepted to be both reasonably reliable and fairly broadly applicable (e.g. statements of legal requirement or policy). By 'personal experience' information we referred to information about the experiences of particular individuals, as experienced or communicated by themselves or others.

In section 3 and 4 we also made use of a framework that sees decision making not as a set of one-off choices but as a process or cycle that involves: recognition and clarification of a problem; identification of potential solutions; appraisal of potential solutions; selection of a course of action; implementation of the chosen course of action; and evaluation of the solution adopted (53). It suggests that people are likely to find different kinds of information useful for different aspects of the process. We operationalised the framework to consider the usefulness or otherwise of 'general facts' and 'personal experiences' information when recognising decisions are needed; identifying options; appraising options; making a selection; and evaluating and living with decisions made.

The results of the project are being disseminated through peer-reviewed publication and conference presentations, listed in Appendix 4. In this section of the report we draw on these data to return to the specifics of the SDO call. We consider: what people see as choices and the information they report using; the *types of information* that people take account of when making choices; the *format* of information that they prefer; and whether preferences vary systematically across social groups. Finally, we consider the six policy-related research questions together and summarise our response to them.

5.1 Choice and information

Previous research has suggested that the experience of choice varies across patient groups and health care scenarios. (6;13-15). Secondary analysis of interviews conducted for www.healthtalkonline.org reported in section 2, and results from the survey of views reported in section 4, confirm and emphasise the point that perceptions of choice varied considerably between health issues and that the most likely explanations for this is the nature of the condition and related decision-making rather than any particular feature of people themselves.

Other studies in the UK and elsewhere have suggested that levels of informed choice regarding antenatal screening were low (54;68-70) or that some women perceived testing as routine or felt pressured to accept it (15;54;71). This research also found that the routine procedures of antenatal ultrasound scanning (which is one of the screening tests for fetal abnormality including Down's syndrome) were not always spoken of as a choice by respondents to Healthtalkonline interviews and that those that did see it as a choice also spoke with much more understanding of the procedures. However, almost all respondents to the stage 3 survey on screening for Down's syndrome reported that they were aware that they had a choice. This difference may be because communication of choice in antenatal screening has improved in the time since the Healthtalkonline interviews were conducted; certainly, the National Screening Committee emphasises that decisions to have any antenatal tests are to be made by women themselves and midwives are encouraged to make this clear to women (72). Alternatively the difference may reflect differences between the samples; the survey sample had, on average, high educational attainment and more highly educated people are more likely to seek information and thus be aware of their choice.

In contrast to a study in North America which found that women felt that the offer of an amniocentesis by health professionals was made with some 'authoritative power' so that they felt they could not or should not decline it (71), whether to have a diagnostic test in pregnancy (CVS or amniocentesis) was always spoken of as a choice and seemed well understood by Healthtalkonline interviewees. Similarly, Healthtalkonline respondents who had ended a pregnancy due to fetal abnormality nearly always described their decision as a choice although some were ambivalent, saying that although they had to make a decision, there was 'no real choice' involved. These findings are consistent with those in other qualitative research carried out in the USA (73;74), which found that couples who either terminated or continued with a pregnancy after diagnosis of a fetal abnormality 'constructed' or perceived choice in a variety of ways 'that located the moral agency for effecting these pregnancy outcomes either in themselves or elsewhere' (pp353)(73) in order to come to terms with their decision; or as a way to 'explain or explain away' (pp311) (74) their choices. In relation to these data we suggest that when decisions are risky, or value-laden, as is the case with antenatal diagnostic testing and ending a pregnancy due to fetal abnormality, health professionals understandably go to considerable lengths to explain the presence and nature of choices to be made whereas when decisions are

routine, not seen as risky and/ or protocol-driven, as is the case with routine screening for Down's syndrome, choice can be de-emphasised or be less likely to be perceived even if it is emphasised.

Carers of people with dementia, responding to both Healthtalkonline and survey interviews, varied as to whether they saw the decision of where their relative should live as a choice. When there was a sudden change in circumstances, the person with dementia was 'sectioned', or when the carer themselves became ill, the decision to move the person into long-term residential care was often expressed as a loss of control and absence of choice. Previous research has found that carers' decisions are often reactive, responding to a dynamic situation (75), and that they tend to reflect a weighing up of how much care is needed with their capacity to provide care (76-78).

However, fewer survey respondents with lymphoma than with other health issues reported that they were aware of a choice of treatment and whether treatment was spoken of as a choice in Healthtalkonline interviews with people with lymphoma depended not so much on the type of treatment as on the way respondents described the professionals talking about treatments with them. We know from a previous study that many women with breast cancer who were offered the choice between treatment or no treatment felt that this was not a meaningful choice (17). 'Doing nothing' is not an option because of the unspoken conviction that cancer should be 'fought'; a decision on treatment can be made by imagining a future self and how it would feel to live with the decision for which one felt culpable (79). We also know that people facing potential cancer treatment do not always recognise that they can exercise choice (17;18).

As expected in the light of a life-threatening illness, some respondents made it clear that they did not always want a choice and preferred to trust their health professionals' expertise and clinical judgements. Even those who felt that they had always had a choice could talk of a trusted health professional who recommended a course of action. This reliance on health professionals reflects research on shared-decision making models for life-threatening illnesses which maintains that many patients prefer not to assume full decision-making control (20-22;80;81). Similarly, other research on shared decision making in cancer which found that many people want their doctors to make treatment recommendations (17), but find it hard to get physicians to express an opinion (22), worked hard to 'reframe' decisions as joint or shared with physicians (79), or tried to understand physicians' recommendations from other information such as the ordering of options (82).

Whether survey respondents felt they had enough information *in general* for their decision also varied across health issues. Most women with experience of antenatal screening and people with lymphoma reported they had as much information as they needed whereas nearly a quarter of carers of people with dementia reported that they had either needed more or that in general, the information was insufficient for their decision. They felt they were given too little information of any type by professional staff and also reported seeking

more themselves compared to respondents with experience of other health issues. This dearth of information for carers of people with dementia is rightly recognised by both voluntary sector organisations and by governments in England and Scotland.

Survey respondents for all three health issues who would have liked more information most often wanted it to *identify or appraise options*. This is despite efforts by the NHS to provide written patient information on options and outcomes (30;31). Information was sought by respondents to both Healthtalkonline interviews and the survey from a wide range of sources including informal sources such as families and friends; O'Brien et al (82) also found that families and friends were important sources of advice following diagnosis of cancer and prior to any consultations to discuss treatments. Among survey respondents, using the internet was more common among women making antenatal screening decisions (who were also younger and more educated) but was also reasonably high among carers of people with dementia and people with lymphoma.

5.2 Type of information

5.2.1 The value of 'general facts' and 'personal experiences' information

Analysis of Healthtalkonline interviews presented in section 2 confirmed that people take account of both 'general facts' and 'personal experiences' information (gained through both one's own and others' experience) in decision making. The relative value and use of these two types of information was further explored in stages 2 and 3 of the project presented here in sections 3 and 4.

Respondents to focus group discussions and individual interviews (stage 2) were both willing and able to distinguish between 'general facts' and 'personal experiences' information and to identify features of each that they valued for particular reasons in particular circumstances. However, there was a great deal of variation in terms of whether and to what extent they found particular types of information useful; the value of any particular example of information provision depended on features of both that information and the potential user and their situation. The analysis suggested a range of things that 'general facts' and 'personal experience' information might be useful for at each stage of the decision-making process. The cognitive testing of the questionnaire for stage 3 (section 4) suggests that respondents to the survey may have found it more difficult to distinguish between 'general facts' and 'personal experiences' information when considering their decisions. However, they were willing to continue with the interviews and certainly were able to express clear preferences between them.

In *recognising decisions are needed and identifying options* the analysis suggested that both 'general facts' and 'personal experiences' information could be useful to help understand the situation and its possible sequelae and

to identify options, but that 'personal experiences' information would also help respondents 'get' the point that it was an important decision.

In *appraising options and making a selection* 'general facts' information might help with understanding the likelihood of particular outcomes and inform a weighing up of the probabilities whereas 'personal experiences' information might help one to: focus on issues that are personally salient; appreciate and consider the kinds of subjective feeling that might be associated with particular options and outcomes; consider what one might feel like after making particular selections; identify approaches to decision making; identify and consider the values and norms; help draw attention to the kinds of outcomes that can occur with different options; and offer potential comparisons that facilitate reflection on and testing of one's own reasoning and decisional leanings.

In *evaluating and living with decisions* 'personal experiences' information might help people be prepared for possible emotional responses to a choice made or outcome experienced; recognise diversity of experience; appreciate that one is not alone; and promote hope.

Respondents appreciated that there may be contingent deficiencies in any particular example of information provision (e.g. it may be inaccurate or misleading), that the applicability of information to individual situations varies, and that the motives behind information provision might be to lead people towards making a particular choice.

Some of these findings resonate with commentators who suggest, for example, that access to others' stories can help people understand the significance of an event (36), or researchers who suggest that online 'personal experiences' information can help people to learn how others' have managed (38) or that it is actively sought because of its personal relevance (39). Some of the range of reasons for which it is valued also resonate with the list of criteria suggested for rating internet interventions for long-term conditions(83). The information sources in both stage 2 and 3 were always presented alongside each other, and some of the reasons respondents reported they valued 'personal experiences' information reflect its distinctive nature compared to more generalised, 'factual' information. However, this does suggest that 'personal experiences' information does seem to have a unique role in supporting decision-making. We believe that it can support good-quality decision-making if presented carefully, despite some concerns over its potentially negative impacts, for example, when patient narratives or 'testimonials' are included in decision aids (84).

5.2.2 The use of 'general facts' and 'personal experiences' information

The nature of the health issue and decision faced was a major influence on whether respondents to the stage 3 survey reported using information that was available to them. Less than half of respondents with lymphoma reported using either 'general facts' or 'personal experiences' information in their treatment decision, although more than 80% of people making decisions

about antenatal screening and carers of people with dementia reported using either one or both types of information.

The value of types of information in different stages of decision making, suggested from analysis of stage 2 focus groups and individual interviews (see 5.2.1), was further investigated by asking survey respondents who had used either 'general facts' or 'personal experiences' information what the information had been helpful for. People with lymphoma were less positive about the value of either 'general facts' or 'personal experiences' information compared to respondents with experience of antenatal screening or carers of people with dementia. For the latter two groups, 'general facts' and 'personal experiences' information seemed to be valued for similar reasons, except that there was some indication that 'personal experiences' information was more likely to be reported as helpful for understanding *how one would cope* after the decision was made.

5.2.3 Preferences for 'general facts' or 'personal experience' information

Clear preferences were not always expressed between 'general facts' and 'personal experiences' information by respondents to stage 2 focus groups and individual interviews who tended to recognise a need to consider *both* 'general facts' and 'personal experiences' information critically. They appreciated that there may be contingent deficiencies in any particular example of information provision and that the applicability of information to individual situations varies.

In general, for women with experience of antenatal screening and carers of people with dementia, while 'general facts' were reported as underpinning decisions or as important in decisions, 'personal experiences' information was seen to add value to them and to perform some distinct roles/ functions. In stage 3 survey data about two fifths of women with experience of antenatal screening and half of carers of people with dementia reported that 'personal experiences' information was equally important or more important than 'general facts' information in making their decision. People with lymphoma, on the other hand, were much more likely to say they relied on 'general facts' only.

5.3 Format of information

Secondary analysis of Healthtalkonline interviews did not directly inform an understanding of preferences for the format of information provision although it was clear that respondents used information from a wide range of sources. This was confirmed in stage 3 survey data which showed a wide array of information sources and formats used by respondents but with an overwhelmingly clear preference to receive information, face to face, from health and social work professionals.

In stage 2, respondents were asked their preference for three different formats of 'personal experiences' information: a third person story, a direct

quote, a video clip. Respondents' views were mixed with no clear preferences stated; there were likes and dislikes about each format.

Those who liked the third person story (which was familiar from newspapers and magazines) saw it as easier to read and understand than the direct quote in a speech bubble and because one could imagine the characteristics of the person it was easier to identify with them. Some were concerned that it could be 'made up' for propaganda purposes while others thought that if it were a composite of people's experiences this would get over the problems of a single person's experiences being too influential.

There were more criticisms than positive comments about reported speech in a speech bubble. It was seen as less accessible than the video because it was hard to read or take in (we presented verbatim quotes from interview transcripts); it did not convey the emotion that the video could, and was seen as harder to relate to; and its authenticity was doubted by people who thought it could have been made up or selected with a particular agenda in mind.

Finally, the video clip generated the most discussion across the groups, and attracted much more positive than negative comment. Positive views were based on being able to see and hear an individual talking having more 'impact', being more 'engaging', 'persuasive', 'moving', 'human' and 'real'. This may be because the video clip carried more information; it gave access to tone of voice, body language and what the person looked like allowing some people to identify with or relate to the individual more than when it was a written quote or story (if they felt empathy with the person). Those who did not like this format said it was because they did not identify with the example, and were not able to feel empathy for their position.

There were health issue-specific differences in the frequency with which people were willing to use other sources of information – particularly the internet. While lymphoma patients and carers of people with dementia were both fairly evenly split between those who would prefer to use websites and those who would *not want* to use the internet for information the pattern was very different for women making antenatal screening decisions; three-quarters of them preferred the internet and only a minority said they would not want to use it. This difference largely reflects the different patterns of internet use in older and younger age groups: in this survey sample nearly all of the women making antenatal screening decisions had internet access at home and were, on average, younger than the other two groups.

In addition, respondents were selective about which type of website they would use: there was a clear distinction in attitudes to using 'websites' as opposed to internet 'chat rooms' which were far less favoured as sources of information across all three groups.

5.4 Variation in views and preferences across social groups

In the stage 3 survey we were able to investigate variations in use, views and preferences for 'general facts' or 'personal experiences' information by age, educational attainment, gender and the level of deprivation of the area in which people lived. The results were not surprising; most variation was found in reported use by age and educational attainment and in the expected direction (younger – but not the youngest - and better-educated people may be more likely to report seeking information). However, we could not distinguish variation in preference for type of information ('general facts' or 'personal experiences') or between format of information. Because we were not able to recruit many respondents from ethnic minority groups we were unable to examine variation in use, views and preferences by ethnicity.

5.5 Implications for policy, practice and research

The findings presented above have a number of implications for policy, practice and research, summarised here.

5.5.1 Implications for policy

Findings from all 3 stages confirm previous research which shows variability in the ways and extent to which people: (a) expect and prefer to be involved in decisions about their healthcare; (b) think they are offered choices by health care providers; (c) have options that they consider meaningful; and (d) receive or obtain, use and value information in thinking about decisions. Information was, of course, seen as critical for choice and decision-making but stage 1 analysis showed that it was also valued in its own right.

Respondents in stages 2 and 3 of the research were able and willing to distinguish between 'general facts' and 'personal experiences' information and said that both are important for decision-making. However, respondents also spoke of the need to be careful and discriminating in their use of both 'general facts' and 'personal experiences' information; people generally expected that 'general facts' information should underpin health care decisions but said that 'personal experiences' information could add value in various ways and may have a unique role in some circumstances.

Implication 1: Taken together these findings lend support to policy initiatives to provide high quality information on health care and efforts to: enhance the accessibility of different types of information (both 'general facts' and 'personal experiences'); to improve signposting to high quality information sources, and to facilitate appraisal of information quality. They also suggest that more emphasis could be placed on the provision of well-collected, balanced, information based on personal experience than is currently apparent.

Throughout our study we found that carers of people with dementia perceived a dearth of information when they needed to make decisions about where their relative should live.

Implication 2: These findings reinforce the importance of improving the availability and accessibility of information on particular health issues (such as dementia) or to support people facing particular types of decisions (such as where a relative should live).

Findings from the third stage of the study found, unsurprisingly, that the reported use and perceived value of both 'general facts' and 'personal experiences' information was higher among younger and more educated people. However, we also found surprisingly high levels of reported use of the internet for health information, even among older people facing difficult decisions (although internet 'chat rooms' were not rated highly as a source of information).

Implication 3: Taken together these findings suggest that current investment in internet-based information resources is well founded but that continued efforts to make this information accessible and relevant to all, regardless of social position, are justified.

The first and second stages of our study in particular highlighted the fact that people often need more than information about health care options and their implications to support them as they face decisions. Many people, particularly when faced with life-threatening illness, need help to interpret information, guide them through decisions, and provide emotional/moral support.

Implication 4: These findings suggest that policies and initiatives that emphasise the provision of information to support 'independent' choice-making by patients run the risk of overlooking the importance of supportive professional-patient interactions, and may lead to deterioration in decision quality and patient experience.

5.5.2 Implications for health professionals

Our findings indicate that people generally regard their health professionals as very important sources of information about health issues and think they should provide clear and honest information about their health care options. However, most people can and do also draw on information from other sources including the internet.

Implication 5: It is important for health professionals to be aware of and respond to the legitimate expectations that people have of health information providers but also to have opportunities to 'work with' patients to enhance their ability to make effective use of information from other sources.

Health professionals who have been encouraged to provide 'evidence based' information about health care options and their outcomes may not be aware of the potential value of 'personal experiences' information in relation to decision-making. Our study – especially stage 2 – highlighted the functions that information about personal experiences can serve in helping people to

recognise that decisions are needed and need thinking about, identifying options, appraising options (including identifying and reflecting on potentially relevant values and reasons), evaluating and living with decisions, and coping with ongoing health issues.

Implication 6: In recommending sources of information health professionals may like to consider that 'personal experiences' information may be particularly helpful to people in identifying and appraising options (including imagining what it might be like to live with a decision) and coping with an on-going health problem.

However, the study also found that people say they are critical and selective in using information for decisions. For example, they are aware of potential bias in information provision, where the provider may have 'an agenda' or vested interest in encouraging selection of a particular option.

Implication 7: This finding suggests that if health professionals do make recommendations to access information based on personal experience they should make it clear that they do not mean that particular individual stories should be used as exemplars to be copied.

As noted in the implications for policy, people facing complex and difficult health care decisions often have support needs that will not be met by information alone. The guidance and emotional support that can be derived from caring and facilitative interpersonal interactions with trusted health professionals remain important contributors to patients' decision-making experiences. This is probably particularly the case for people facing life-threatening illnesses (such as lymphoma), or emotionally difficult circumstances and decision situations for which the available information is complex and may seem contradictory (such as decisions about whether or not to end a pregnancy due to fetal abnormality, or where and how to ensure a relative with dementia is well cared for).

Implication 8: Information provision is important, but so are 'talking it through' and being a caring presence.

Finally, analysis of data from stage 1 and 3 showed considerable diversity in the extent to which people receive or obtain, use and value information in thinking about decisions; there was more variation in reported information use between health issues and decisions than in people's socio-demographic characteristics.

Implication 9: It is good to respond to individuals' own personal information needs which are more likely to be contingent on their health issues and the decisions they face rather than on their age, gender or socio-economic position.

5.5.3 Implications for research

We found that 'personal experiences' information had a number of valued uses in relation to decision-making. In the course of our investigation, it became increasingly apparent that 'personal experiences' information is highly

diverse, and includes, for example, information about experiences of health conditions, of the processes and outcomes associated with different healthcare interventions, and of making and reflecting on health-related decisions.

Implication 10: Further research could usefully investigate the uses and values of 'personal experiences' and 'general facts' information in a more differentiated way.

We have shown that people are careful and critical in their use of information but the internet means that access to many different 'new' types of information is proliferating. Little is known about how people using some of the new forms of health information such as patient and user reviews, ratings and feedback (as in the type comparisons found on travel websites such as 'Trip Advisor' - <http://www.tripadvisor.co.uk>) to help in the evaluation of NHS services or health information exchanges on social networking sites.

Implication 11: Research on whether and how people use tools such as patient and user reviews, ratings and feedback to make comparisons and decisions about health and health care (compared to similar tools used in their leisure pursuits) could usefully guide policies on provision and quality ratings.

While internet 'chat rooms' were not a highly rated source of information for respondents in our studies, internet use was surprisingly high, even among older respondents. Social networking groups related to health continue to proliferate and are likely to be a potent source of personal experiences information. Again, little is understood about their use, value or impact.

Implication 12: Detailed understanding of how participation in social networking health groups might influence views, and the ways in which they operate on behaviours, would help guide future policies and recommendations.

Respondents talked of decisions taken over time and through interaction with varying information sources and social and professional contacts.

Implication 13: A prospective study of the dynamic of health-related decision making and the influence of different kinds of information on outcomes at different time points could help professionals target informational support.

Finally, the new Government is keen that the NHS and social care agencies makes the most of existing sources of information by signposting and recommendations rather than direct provision.

Implication 14: Evaluation of the range of approaches to revised quality rating systems so that the information can be trusted and is user friendly will be important.

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Appendix 1. Focus group and interview stimulus material for Stage 2

Smoking examples

Personal experiences - Choosing how to stop smoking

Example

People's stories

Julie had decided to stop smoking after she watched her son pretending to smoke 'like his mummy'. She was shocked and decided that it was time to quit smoking for her health and to set a positive example for her children.

She had tried to give up several times in the past using just her own will power but had been unsuccessful. This time she went to her GP to find out about different ways of giving up smoking and was offered counselling and Nicotine Replacement Therapy.

She found that this combined approach worked for her and the counselling helped her to be strong when she was tempted to smoke.

Source: adapted from <http://gosmokefree.nhs.uk>

Personal experiences - Choosing how to stop smoking

Example

People talking (written quote)

"A year back I had a really nasty bout of bronchitis -it was just horrible, I felt terrible and the doctor said that smoking was part of the reason for me getting it so bad. I thought to myself, I've really got to give this up.

I thought I could do with all the help I could get so I got the nicotine gum, the patches, the plastic cigarette thing. I even thought about that hypnotherapy cos a friend had tried it, but in the end I didn't do that. For one it was pretty pricey and to be honest I wasn't convinced it'd work." male, 49

Personal experiences - Choosing how to stop smoking

Example

People talking (video)



Woman in her 20s talks about trying to stop smoking at first using nicotine patches and then stopping without help.

Smoking examples

General facts approach - Choosing how to stop smoking

Example

General facts approach

Choosing how to stop smoking

Options include

- Stop smoking without help
- Stop smoking using nicotine replacement therapy
- Stop smoking using individual counselling

Consequences include:

- The number of people who are successful in stopping smoking for at least 6 to 12 months are:
 - Up to 5 out of 100 for people who try to stop without help
 - Up to 8 out of 100 for people who use nicotine replacement therapy
 - Up to 14 out of 100 for people who use counselling

Source: *The Cochrane Library* <http://www.mrw.interscience.wiley.com/cochrane>

Lymphoma stimulus material for focus groups

General facts approach

Deciding on treatment (1)

The benefits and disadvantages of treatment (NHL & HL)
 Many people are concerned about the side effects that may occur with cancer treatments. Although treatments can cause side effects, these can usually be controlled with medicines. Some people ask what would happen if they did not have any treatment.

Treatment can be given for different reasons, and the potential benefits will vary for each person.

Source: *adapted from Cancer BACUP, 2006*

General facts approach

Deciding on treatment (2)

The benefits and disadvantages of treatment (NHL)
 Low-grade NHL is usually very sensitive to chemotherapy and radiotherapy, and treatment can reduce the amount of lymphoma (partial remission) or get rid of it for a time (complete remission). Many people with low-grade NHL can have the illness controlled for many years and can live an almost normal life for a lot of that time. Treatment can reduce symptoms and increase life expectancy for most people.

Source: *adapted from Cancer BACUP, 2006*

General facts approach

Deciding on treatment (3)

The benefits and disadvantages of treatment (NHL & HL)

Without treatment, high-grade NHL would usually get bigger and spread quite quickly, and most people would not live for much longer. Most of the side effects of treatment can be well controlled and the treatment is usually effective. A complete cure is possible for many people with high-grade NHL. Some people will find that their initial treatment does not work, and then another type of treatment will be used.

Many people with Hodgkin lymphoma will be cured with treatment.

Source: adapted from Cancer BACUP, 2006

Personal experiences

People's stories

When 34-year-old Lynne's Hodgkin's lymphoma came back she was convinced that she would need chemotherapy to treat it. She wanted to have children and was worried that it would make her infertile.

However, the specialists told her that they would treat her with radiotherapy. She was relieved that she did not need chemotherapy but was concerned about any side-effects of the radiotherapy.

She knew she could decide not to have treatment, but she didn't feel that was a real option. She went ahead with the treatment and found it less unpleasant than the first time she had experienced radiotherapy.

Personal experiences

People talking (written quote)

"I think the doctors said, 'This is what we will give you.' I don't think they said you can choose not to have it, but they said this is what we would suggest. And I think my mum said, 'Is there an alternative to chemotherapy, what if we don't have it?' They said basically it would get worse, go to my bone marrow and that will be it.

So I don't think we felt that there was any choice but I didn't feel resentful about that. I, rightly or wrongly, completely trusted them because they seemed so confident, and I think they are confident about Hodgkin's and the treatment you get for it. And everyone else was too so there wasn't a choice but it wasn't a problem."

Young woman diagnosed with Hodgkin's lymphoma at age 20

Personal experiences

People talking (video)



This man in his fifties talks about the treatment choices he had when his non-Hodgkin's lymphoma returned and about deciding whether to have treatment or not.

Transcript of video clip

“Interviewer: How were your treatment decisions made, did you ever feel that you were party to the decisions or was it a question of your consultants just saying this is what you've got to have, end of story?”

Patient: I never felt that I was somebody being told this is what I had to have. Clearly I've grown over the years to put a lot of trust and faith in senior medical staff, but they do sit and talk you through it, and as I said to you earlier, that on all those occasions my wife joined me for those discussions, so that she feels she is inevitably part of that discussion. They've taken me through not just for that but what the alternatives are. And one of the alternatives this time was we do nothing, but they don't recommend that, and clearly that's not something I'd buy into, but at least he went through three or four different alternatives as choices I had in terms of treatment. So I wasn't left to say this is the way it will be. Clearly there was a recommended course of action and that's the one that I have followed. But it has come through discussion to be honest.

Interviewer: Good.

Patient: But we have to recognise that I'm not a doctor therefore my understanding is more limited and I've grown to trust them, not dictated to. I think that's part of it.”

Appendix 2. Final questionnaire for Stage 3 survey

QUESTIONNAIRE

[Decision]

LYM – whether or not to have treatment for lymphoma

ANS – whether or not to have a screening test for Down's syndrome in your current or recent pregnancy

DEM – where the person with dementia lives and is cared for – with you, in their own home, or a residential care or nursing care home

[IN routing for DEM please say: 'about where your relative lives' and not the above full phrase]

While some of our questions are about what you remember happening around the decision, others allow you to give your opinions about the information concerning this specific decision.

You may remember from the letter that we sent to you that we said that there are many different kinds of information. Some provide facts and figures, some give information on what you or other people have been through or experienced. I will show you some examples of these types of information later in the interview.

'The first questions ask for a bit of background information.'

[Q1a to Q1c: DEM only]

1a. How is the person you are caring for related to you?

CODE ONE ONLY

The person with dementia is:

- My spouse / partner
- My mother (in law) / father (in law)
- Other relative
- Friend
- Neighbour
- Other (please specify)

1b. Where is s/he living at the moment?

CODE ONE ONLY

- At home with me
- In a residential care home or nursing care home
- In their own home
- Somewhere else (please specify)

1c. Has your relative ever had to move home as a result of having dementia?

- Yes [go to 1d]
- No [go to 1e]
- Don't know/ can't remember [go to 1e]

CAPI INSTRUCTION: Please remove the code given at Q1b as an option at Q1d and Q1f

1d. Where did your relative live [their main residence] before they lived [insert answer to qu1b]?

CODE ONE ONLY

- At home with me
- In their own home
- Somewhere else (please specify)

1e. Are there plans for your relative to move home in the next few weeks or months because of having dementia?

- Yes Go to Q1f
- No Go to Section B

1f. Where are they about to move to? READ OUT

- To live in my home with me
- A residential care home or nursing care home
- Somewhere else (please specify)

[Q2a to Q2f: ANS only]

2a. Can I just check, are you currently or have you recently been pregnant?

CODE ONE ONLY

Currently pregnant

Recently pregnant

2b. How many children have you had [*include live births only*]?

ENTER NUMBER OF CHILDREN

2c. How many pregnancies have you had in total including this one and any miscarriages, stillbirths, or terminations?

ENTER NUMBER OF PREGNANCIES

CAPI – For Q2d, Q2e, Q2g AND Q2i, USE THE FOLLOWING TEXT SUBSTITUTION:

If “Currently pregnant” at 2a, then please use the text substitution “this pregnancy”.

If “recently pregnant” at 2a, then please use the text substitution “your most recent pregnancy”

2d. For this/ your recent pregnancy have you had any care or contact during your pregnancy from the NHS in the UK?

PROMPT CODE ONE ONLY

- Yes
- No, I had private care in the UK
- No, I had overseas care
- No, I have had no care or contact at all during pregnancy [Go to Q2e]

2e. Why have you had no care or contact at all during pregnancy?

-I did not know I was pregnant [Thank and close]

-No care was available to me, or I did not know I could have any care during pregnancy [Thanks and close]

-I refused or decided I did not want care during pregnancy [continue with interview]

-I intend to have care at some point in the pregnancy but I am in the early stages of pregnancy at the moment or just found out that you are pregnant [continue with interview]

INTERVIEWER TO SAY 'A screening test for Down's Syndrome is a test that tells you how *likely* it is that your unborn baby will have the condition- it won't give a definite yes/ no answer. These tests often tell you whether you are 'low or high risk' or give you a figure such as '1 in 500' telling you how likely or unlikely it is that your baby will have the condition. The screening tests could be a blood test, a special scan looking at the back of the baby's neck (around 11-13 weeks), or both a scan and blood test'. We are *not* asking about the amniocentesis or Chorionic Villus Sampling (CVS) tests that give a definite yes/ no answer in the next 4 questions. This *is where a long fine needle is inserted through your belly or birth canal into your womb and a sample of cells or fluid is taken and tested.*

2f. For this/ your most recent pregnancy, were you offered or told you were having any screening tests for Down's syndrome?: We are *not* asking in the next 4 questions about the amniocentesis or Chorionic Villus Sampling (CVS) tests that give a definite yes/ no answer. This *is where a long fine needle is inserted through your belly or birth canal into your womb and a sample of cells or fluid is taken and tested.*

[Interviewer information: Some of the names for these different tests are (*do not read these out*): *nuchal scan/ nuchal translucency test, blood tests: double test, triple test, quadruple test, AFP (alphafetoprotein) test, serum screening; NT plus test, the combined test, CUB test, integrated test.*] CODE ONE ONLY

- Yes, I was offered tests - go to Q2g
- Yes, I was told I was having tests – go to Q2g
- No go to Q2h
- Don't know/ Can't remember go to Q2h

2g. At the time, were you aware these tests involved screening for Down's syndrome?

CODE ONE ONLY

- Yes
- No
- Don't know/ Can't remember

2h. Did you have any of the *screening* tests for Down's syndrome for this/ your most recent pregnancy? This would have been a blood test, a special scan looking at the back of the baby's neck (done around 11-13 weeks of pregnancy), or both the special scan and blood test. We are *not* asking here about the amniocentesis or Chorionic Villus Sampling (CVS) tests that give a definite yes/ no answer. This *is where a long fine needle is inserted through your belly or birth canal into your womb and a sample of cells or fluid is taken and tested.*

CODE ONE ONLY

- Yes [**Go to 2j**]
- No [**Go to 2i**]
- Don't know/ Can't remember **Go to 2j**

2i. Was a decision made - by you, a family member, or medical or social care staff - for you not to have any screening tests for Down's syndrome? CODE ONE ONLY

- Yes
- No
- Don't know/ Can't remember

ASK ALL

2j. Now I am going to ask you about amniocentesis and Chorionic Villus Sampling (CVS) tests which can tell you if your baby has Down's syndrome. This *is where a long fine needle is inserted through your belly or birth canal into your womb and a sample of cells or fluid is taken and tested,*

Did you have an amniocentesis or Chorionic Villus Sampling (CVS) to test for Down's syndrome or for another condition in this/ your most recent pregnancy? CODE ONE ONLY

- Yes
- No
- Don't know/ can't remember

IF NO OR DON'T KNOW AT all of 2f, 2 h and 2i – route these people to be asked these questions only: Q4, Q12 (&13), Q21 (&22a-22c), Q27 (&28a-28c), Q32, Q33, Q35 and then Q36-53 and Q54. Also interviewer to say, "because you have answered 'no' or 'don't know' to a number of these questions, this could mean that some of the following questions might not seem very relevant to you – please answer as best you can"

INTERVIEWER TO REPEAT 'I want to talk about the decision whether or not to have a *screening test* for Down's Syndrome - this is a test that tells you how *likely or unlikely* it is that your unborn baby will have the condition. We are *not* going to talk about tests such as amniocentesis or CVS which give a definite answer (as these are not available to all women). When answering the questions I'd like you to think about the decision whether or not to have a screening test in your recent/ current pregnancy. All of the questions ask about this/ your most recent pregnancy. We are *not* asking about the decision about *which* screening test to have if there was a choice.

[Q3a –Q3c: LYM only]

3a. Which form of lymphoma were you diagnosed with?

CODE ONE ONLY. INTERVIEWER CODE THE MOST RECENT DIAGNOSIS IF MORE THAN ONE.

- Hodgkin's
- Non-Hodgkin's
- Don't know

3b. When were you diagnosed?

CODE ONE ONLY. INTERVIEWER CODE THE MOST RECENT DIAGNOSIS IF MORE THAN ONE.

Less than 6 months ago

6 months but less than 12 months ago

1 year but less than 2 years ago

2 years but less than 5 years ago

5 years but less than 10 years ago

10 years ago or more

Don't know

3c. Have you had any of these treatments as part of your current or most recent treatment?

SHOWCARD A: CODE ALL THAT APPLY.

- Chemotherapy [GO TO Q4]
- Radiotherapy [GO TO Q4]
- Surgery, lump removal, biopsy [GO TO Q4]
- Stem cell or bone marrow treatment/ transplant [GO TO Q4]
- Any other treatment – please specify:[GO TO Q4]
- No treatment [GO TO Q3d]
- Don't know/ can't remember [GO TO Q4]

3d. Are you, or were you being actively monitored- this is sometimes called 'watch and wait' or 'watchful waiting'?

CODE ONE ONLY

- Yes
- No
- Don't know/ can't remember

INTERVIEWER TO SAY: When answering the questions please think about the most recent decision about whether to have treatment or not.

B] Perception of choice

CAPI –FOR SECTIONS B AND C, USE THE FOLLOWING TEXT SUBSTITUTIONS IN PLACE OF [DECISION X]:

LYM – “about whether to have treatment for lymphoma”

ANS – “about whether to have a screening test for Down’s syndrome”

DEM – “about whether your relative should live with you or somewhere else”

‘The next questions ask about the decision that was made [about x]’

4. At the time, were you aware that there was a choice [decision x] in your situation?

SHOWCARD B: CODE ONE ONLY

- No, I wasn’t aware that there was any choice to be made
- No, I didn’t think that you had a choice in my circumstances
- I had a vague idea that there was a choice
- Yes, I was clear that there was a choice
- Don’t know/ can’t remember

5. Looking back, how much influence do you feel you had over the decision that was made [decision x]? By ‘influence’ we mean having an effect on what was decided.

SHOWCARD C: CODE ONE ONLY

- A lot
- Quite a lot
- Some, but not a lot
- Very little
- None at all
- Don’t know/ can’t remember
- Not applicable

6. Who else, if anyone, influenced the decision that was made [decision x]? By 'influenced' we mean had an effect on what was decided.

SHOWCARD D (i/ii): CODE ALL THAT APPLY

- No one at all
- GP
- Hospital doctor/ consultant/ psychiatrist
- Midwife
- Nurse/ Community Psychiatric nurse (CPN)
- Social workers
- Any other medical or social work staff: Please specify:.....
- Spouse / partner
- Daughter / son
- Mother / father
- Other relative
- Friend
- Neighbour
- The person with dementia [DEM only]
- Someone else (please specify)
- Can't remember
- Not applicable

7. While the decision [x] was being made who, if anyone, did you discuss the decision with?

SHOWCARD E (i/ii): CODE ALL THAT APPLY.

- I didn't discuss it with anyone
- GP
- Hospital doctor/ consultant/ psychiatrist
- Midwife
- Nurse/ Community Psychiatric nurse (CPN)
- Social workers
- Any other medical or social work staff: Please specify:.....
- Spouse / partner
- Daughter / son
- Mother / father
- Other relative
- Friend
- Neighbour
- The person with dementia [DEM only]
- Someone else (please specify)
- Can't remember
- Not applicable

ASK ALL WHO ANSWERED MEDICAL OR SOCIAL WORK STAFF IE CODES 2 TO 7 AT Q6 OR Q7. OTHERS GO TO SECTION C

8. When talking to medical or social work staff [decision x], did they give you or tell you information for the decision.

CODE ONE ONLY

- yes
- no
- Don't know

9. When talking to medical or social work staff [decision x] , did they listen to your views about the decision?

CODE ONE ONLY

- yes
- no
- Don't know/ Can't remember

10. In what ways were the medical or social work staff involved in making the decision [about x]?

SHOWCARD F: CODE ONE ONLY

- The medical or social work staff made the decision, not me
- I (alone or with a relative/ friend) made the decision together with the medical or social work staff
- The medical or social work staff left the decision to me
- The medical or social work staff left the decision to someone else (not me).
- Not applicable - the medical or social work staff were not involved in the decision
- Don't know/ can't remember

IF CODE 4 AT Q10

Q10A Who, other than yourself, was the decision left to? Specify.

11. Given what you've said about the way the medical or social work staff acted, how happy or unhappy were you with the way the decision [about x] was made?

SHOWCARD G

CODE ONE ONLY

- Very happy
- Happy
- Neither happy nor unhappy
- Unhappy
- Very unhappy
- Can't remember / Don't know

C] Provision and usefulness of information

The next questions ask about information used in making or thinking about the decision [X]. Again the questions ask about [this/ your most recent pregnancy/ the most recent decision about whether to have treatment/ the most recent decision about where your relative lives]. We understand some people do not feel that they made a decision, or they feel that there was no decision to be made. Even if someone else made the decision, or you don't see it as a decision, you might have been given information to do with [whether to have treatment (LYM)/ whether to have screening (ANS)/ where your relative lives (DEM)], so please try to answer the questions as best you can.

12. Thinking about the decision [about x], looking back do you feel you had enough information?

SHOWCARD H

CODE ONE ONLY

- Yes; if anything, I felt swamped by it [Go to Q14
- Yes, I had as much information as I needed Go to Q14
- Yes, although I felt I needed more GO TO Q13
- Not really; I definitely felt I needed more GO TO Q13
- Not at all; it was far too little GO TO Q13
- Don't know/ can't remember GO TO Q14

13. Looking back, what kinds of information did you want more of for the decision [about x]?

SHOWCARD I

CODE ALL THAT APPLY

- Some more information about what the possible options were
- Some more information about what each option might then involve or be like
- Some information about what the each option might lead on to later
- Another kind of information (please specify)
- Don't know/ Can't remember

CAPI SHOW BOTH EXPLANATIONS BEFORE ANY ROTATION (SEE INSTRUCTION AFTER PERSONAL EXPERIENCE)

'At the start I explained we are interested in two types of information. One provides facts and figures on the different [LYM:treatment, ANS:_tests or DEM:_options] available to you and what the consequences or effects of those could be, which we are going to call 'General Facts'. General facts can come from medical or social work staff, books, the internet, leaflets etc.

INTERVIEWER HAND OVER EXAMPLE OF 'GENERAL FACTS' INFORMATION. ALLOW RESPONDENT TIME TO READ BEFORE CONTINUING.

Another type of information comes from people's personal experiences - by 'personal experiences' we mean both

- things you have gone through or seen yourself
- AND other people's descriptions or accounts of what has happened to them. This could be the experiences of your friends and family, or of other people that you have heard about in conversation, in magazines, newspapers, on the TV or radio.'

For example, [for LYM -] having lymphoma, knowing someone with the lymphoma or a similar condition through work, family or friends/ [for ANS -] in pregnancy, knowing someone who is pregnant or who has Down's syndrome or a similar condition through work, family or friends / [for DEM -] as a carer, knowing someone who is a carer, or who has dementia or a similar condition through work, family or friends].

INTERVIEWER HAND OVER EXAMPLE OF ANOTHER PERSON'S 'PERSONAL EXPERIENCES'. ALLOW RESPONDENT TIME TO READ BEFORE CONTINUING.

CAPI – THE NEXT SECTION IS MADE UP OF TWO DISTICT QUESTION GROUPS - *General Facts' (Q14 – Q22) and 'Personal Experience' information (Q23 – Q28). THE ORDER OF THESE GROUPS SHOULD BE RANDOMISED IE CAN HAVE EITHER GENERAL FACTS AND THEN PERSONAL EXPERIENCE OR PERSONAL EXPERIENCE THEN GENERAL FACTS*

I am going to start by asking you about (general facts/personal experience) information

14. At the time, how much 'General Facts' information for this decision [about x] were you given by medical or social work staff ?

SHOWCARD J

CODE ONE ONLY

- A lot GO TO Q15
- Quite a lot GO TO Q15
- Some, but not a lot GO TO Q15
- Very little GO TO Q15
- None at all GO TO Q16
- Don't know/ can't remember GO TO Q16

15. Was the amount of information you got from medical or social work staff:

READ OUT

CODE ONE ONLY

- Far too much
- Too much
- Just right
- Too little
- Far too little
- Don't know/ Can't remember

ASK ALL

16. At the time the decision [about x] was being made, how much 'General Facts' information did you find out for yourself? We do not mean information you got from medical or social work staff.

SHOWCARD K

CODE ONE ONLY

- A lot
- Quite a lot
- Some, but not a lot
- Very little
- None at all
- Don't know/ Can't remember

IF 'NONE AT ALL' OR 'DK/CAN'T REMEMBER' AT BOTH Q14 AND Q16 GO TO Q21.

IF NOT 'NONE AT ALL' OR 'DK/CAN'T REMEMBER' AT Q16, GO TO Q17

ALL OTHERS GO TO Q18

17. For this decision [about x], where did you get the 'General Facts' information that you found out for yourself? We do not mean information you got from medical or social work staff.

READ OUT: CODE ALL THAT APPLY

- Family member, relative or friend who is a medical or social worker
- Family member, relative, or friend who is/are not a medical or social worker
- Voluntary groups or patient organisations
- Internet / website
- TV or radio
- Magazines or newspapers
- Health/medical journals or books
- From somewhere else (please specify).....
- Don't know/ Can't remember

ALL EXCEPT THOSE WHO SAID 'NONE AT ALL' OR 'DK/CAN'T REMEMBER' AT BOTH Q14 AND Q16

18. Thinking about the 'general facts' information you were given or found out for yourself, did you *use* any of this 'General Facts' information to help you consider this decision [about x]?

If yes probe for code

- No, I didn't use any [GO TO Q20]
- Yes, it formed part of the information I used [GO TO Q19]
- Yes, it was virtually the only information I used [GO TO Q19]
- Don't know/ Can't remember [GO TO Q21]

ASK ALL WHO SAID CODES 2 AND 3 (Yes) AT Q18

19. I am going to read out some statements about what use 'general facts' information was to you for the decision [about x]. Please answer each statement by saying how strongly you agree or disagree with each one

SHOWCARD L

CODE ONE ONLY

(Strongly agree, agree, disagree, strongly disagree, don't know)

ROTATE STATEMENTS

'General facts' information was useful because.....:

- it made me realise I wasn't alone in dealing with this
- it led me to think that I needed more information
- it made me realise that there was a choice [about X]
- it suggested possible options and alternatives
- it helped me to decide what to do
- it made me aware what each option might involve or be like
- it made me understand what each option might lead on to later
- it provided information on how I might cope or feel after the decision was made

[GO TO Q21]

ASK OF THOSE WHO SAID CODE 1 AT Q18

20. I am going to read out some statements about why you might not have used 'general facts' information in thinking about this decision. Please answer each statement by saying how strongly you agree or disagree with each one.

SHOWCARD L

CODE ONE ONLY

(Strongly agree, agree, disagree, strongly disagree, don't know)

ROTATE STATEMENTS

I did not use 'general facts' information in thinking about this decision because:

- I felt there was no choice
- I had already made up my mind
- I was already well enough informed
- I didn't want any more information
- I found the information hard to use or difficult to understand
- it made me more confused as I found there were too many things to think about
- it didn't seem to relate to me in particular as it is based on what is typical for lots of other people
- I wanted to know how I would cope or feel afterwards but the information didn't tell me this
- I was concerned the information might influence me to make a decision I would regret

ASK ALL

21. Did you want more 'General Facts' than you had for thinking about [x]?

- No, I didn't want to know anything else [GO TO Q23]
- Yes- [GO TO Q22a]
- Don't know/ Can't remember [GO TO Q23]

ANSWER 22A IF CODE 2 (YES) AT Q21. OTHERS GO TO Q23

22a I am going to read out some statements about why you might have wanted more 'general facts' information for the decision about [x]. Please answer each statement by saying how strongly you agree or disagree with each one.

SHOWCARD L

CODE ONE ONLY

(Strongly agree, agree, disagree, strongly disagree, don't know)

ROTATE STATEMENTS

Looking back, for the decision about [X] I would have liked more 'general facts' information to know:

- that there was a choice
- what other options or alternatives there were
- what each option might involve or be like
- what each option might lead on to later
- how I might cope or feel after the decision was made

ASK ALL

22b. Were there any other reasons why you wanted more 'general facts' information?

Yes – go to Q22c

No – go to Q23

22c. What were they (specify the reason(s):.....

ASK ALL

The next few questions ask about [general facts/personal experiences] information

IF ON PERSONAL EXPERIENCE ROTATION THEN:

INTERVIEWER TO SAY:

This is information that comes from people's own experiences or other people's experiences'.

By 'personal experiences' we mean both

- things you have gone through or seen yourself
- AND other people's descriptions or accounts of what has happened to them. This could be the experiences of your friends and family, or of other people that you have heard about in conversation, in magazines, newspapers, on the TV or radio.'

For example, [for LYM –] having lymphoma, knowing someone with the lymphoma or a similar condition through work, family or friends/ [for ANS –] in pregnancy, knowing someone who is pregnant or someone who has Down's syndrome or a similar condition through work, family or friends / [for DEM –] as a carer, knowing someone who is a carer, or who has dementia or a similar condition through work, family or friends].

IF ON GENERAL FACTS ROTATION THEN:

"General Facts" provide facts and figures on the different [LYM: treatment, ANS: _tests or DEM: _options] available to you and what the consequences or effects of those could be. General facts can come from medical or social work staff, books, the internet, leaflets etc

INTERVIEWER TO SHOW EXAMPLE 1 (A/D/L), 2 (A/D/L) and 5 (A/D/L)/
EXAMPLE 3 (A/D/L), 4 (A/D/L) AND 5 (A/D/L) [dependent on rotation]

23. Did you *use* any 'Personal Experiences' information when thinking about [x]?
This could be information from your own experiences or other people's experiences.

READ OUT: CODE ONE ONLY.

- No, I didn't have any 'personal experiences' information for this decision [GO TO Q27]
- No, I didn't use any [GO TO Q26]
- Yes, it formed part of the information I used GO TO Q24
- Yes, it was virtually the only information I used GO TO Q24
- Can't remember/ Don't know [GO TO Q27]

24. Where did this 'Personal Experiences' information come from for thinking [about x]?

READ OUT: CODE ALL THAT APPLY

- My own previous personal experiences
- Experiences of family, relatives, or friends
- Voluntary groups or patient organisations
- Medical or social work staff (e.g. midwife, GP, consultant, Social worker). Please specify.....
- Internet / website
- TV or radio
- Leaflets / booklets
- Magazines or newspapers
- Health / medical journals or books
- From somewhere else (please specify).....
- Can't remember/ Don't know

25. I am going to read out some statements about what use 'Personal Experiences' information was to you in thinking [about x]).

Please answer each statement by saying how strongly you agree or disagree with each one.

SHOWCARD L

(Strongly agree, agree, disagree, strongly disagree, don't know)

ROTATE STATEMENTS

Think overall about the 'Personal Experiences' information you had.

Overall, 'Personal experiences' information was useful for the decision [about x] because:

- it made me realise I wasn't alone in dealing with this
- it led me to think that I needed more information
- it made me realise that there was a choice [about x]
- it suggested possible options and alternatives
- it helped me to decide what to do
- it made me aware of the things I needed to think about in making a decision
- it made me understand what each option might involve or be like
- it made me understand what each option might lead on to later
- it provided information on how I might cope or feel after the decision was made

[Go to Q27]

ASK OF THOSE WHO SAID CODE 2 AT Q23

26. I am going to read out some statements about why you might not have used 'Personal Experiences' information in thinking [about x]. Please answer each statement by saying how strongly you agree or disagree with each one.

SHOWCARD L

CODE ONE ONLY

(Strongly agree, agree, disagree, strongly disagree, don't know)

ROTATE STATEMENTS

I did not use 'personal experiences' information in thinking about this decision [about x] because...

- I felt there was no choice
- I had already made up my mind
- I was already well enough informed
- I only wanted factual information
- I didn't want any more information
- I was concerned the information might influence me to make a decision that I would regret
- I didn't think other people's personal experiences would be helpful in my situation

ASK ALL

27. Looking back, for the decision [about x] did you want more information than you had about other people's personal experiences (e.g. of treatment/screening/caring)?

- No, I didn't want any more personal experience information [GO TO Q29]
- Yes [GO TO Q28a]
- Don't know/Can't remember [GO TO Q29]

ASK ALL WHO SAID CODE 2/YES AT Q27

28a. I am going to read out some statements about why you might have wanted more information on other people's personal experiences for the decision [about x]. Please answer each statement by saying how strongly you agree or disagree with each one.

SHOWCARD L

CODE ONE ONLY

(Strongly agree, agree, disagree, strongly disagree, don't know)

ROTATE STATEMENTS

Looking back, for the decision [x] I would have liked more information on other people's 'personal experiences' to know:

- that there was a choice
- what other options or alternatives there were
- what each option might involve or be like
- what each option might lead on to later
- how I might cope or feel after the decision was made

28b. Are there any other reasons why you wanted more information on other people's personal experiences?

Yes – go to Q28c

No – go to Q29

28c. What are they (specify the reason(s):

ASK ALL

29. On balance, thinking about the decision [about x] that was made, how important to you were these two types of information, 'General Facts' and 'Personal Experiences', compared to each other?

SHOWCARD M: CODE ONE ONLY

- 'General Facts' were the only important information
- Although both were important, 'General Facts' were more important than 'Personal Experiences'
- They were both about equally important in making the decision
- Although both were important, 'Personal Experiences' were more important than 'General Facts'
- 'Personal Experiences' were the only important information
- I didn't think either type of information was important in making the decision
- Not applicable (I did not have the two types of information)
- Don't know

30. Looking back, when would it have been most useful to have information on other people's personal experiences?

READ OUT: CODE ONE ONLY.

- Before getting the 'General Facts'
- At the same time as getting the 'General Facts'
- After getting the 'General Facts'
- Don't know/ Not applicable

ASK ALL WHO FELT THEY INFLUENCED THE DECISION 'A LOT', 'QUITE A LOT', 'SOME, BUT NOT A LOT' OR 'VERY LITTLE' AT Q5

31. What is the one thing that you think most influenced your decision [about x]?

CODE ONE ONLY. DO NOT READ OUT

- My previous personal experience
- There was no real choice; it had to be done this way
- The attitudes or views of the medical or social work staff
- The attitudes or views of other people (not medical or social work staff) who are important to me
- Family circumstances [e.g. family size, have dependent children, etc.]
- Moral or religious beliefs
- 'General Facts' information
- 'Personal Experiences' information
- Another influence (please specify).....
- Not applicable- I was not involved in making the decision
- Don't know

ASK ALL

D]Format of information

We would now like you to consider the way in which information might be given to you.

32. How important is it for you to get 'General Facts' information for decisions about [insert decision] directly from medical or social work staff?

SHOW CARD N

CODE ONE ONLY

- Extremely important
- Very important
- Quite important
- Not particularly important
- Unimportant
- I do not want information as I don't want to be involved in decisions like this[Go to Q56]
- Don't know

33. For decisions [about x], how do you prefer to get information from medical or social work staff?

SHOWCARD O: CODE ONE ONLY

- I prefer to get be told directly by medical or social work staff
- I prefer to read, listen to it or watch a recording of the information
- I don't mind how I get the information as long as I get it
- I don't want information from medical or social work staff for this kind of decision
- Don't know

- 34a. Which of these ways of getting information, if any, have you used for the decision [about x]?

SHOWCARD P: CODE ALL THAT APPLY.

34b. For each way you have used, please tell me if you used it to get information on other people's 'personal experiences', or to get 'general facts' information, or both.

SHOWCARD X: CODE ALL THAT APPLY.

<u>Yes- used this way</u>	<u>Used for General Facts</u>	<u>Used for Personal Experience</u>	
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Leaflets / Booklets
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Books
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Magazines/ newspapers
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	TV (e.g. programme, advert)
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	TV podcasts or video podcasts
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Video/DVD
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Radio
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Radio podcasts
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Internet/website
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Email
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Internet chat rooms / forums
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	CDs / audio tapes
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Telephone helplines / telephone counselling
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	CD-ROM
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Text messaging
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Face-to-face conversation / discussion / counselling with medical or social work staff
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Face-to-face conversation / discussion / counselling with someone who is <u>not</u> medical or social work staff
<input checked="" type="checkbox"/>	None of these		
<input checked="" type="checkbox"/>	Another way – please specify.....		

35a. 'I am now going to read out a list of information sources that you might use if you were to face this decision about [x] again in the future. For each information source, can you please tell me whether you would prefer to use it, not want to use it, or have no preference either way?' SHOWCARD P – CODE ALL THAT APPLY

35b. For each way you would prefer to use, please tell me if you would use it to get information on other people's 'personal experiences', or to get 'general facts' information, or both.

SHOWCARD X ADD A DON'T KNOW TO Q35B TO EACH SCREEN

IF RESPONDS 'NO PREFERENCE', FOR A FORMAT THEN DO NOT ASK QU36 OR 36A FOR THAT FORMAT

<u>Prefer this way</u>	<u>Would not use</u>	<u>No preference one way or the other—</u> [Routing-do not ask Q36 & 36b]	<u>Would use for General Facts</u>	<u>Would use for Personal Experience</u>	
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Leaflets / Booklets
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Books
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Magazines/ newspapers
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	TV (e.g. programme, advert)
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	TV podcasts or video podcasts
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Video/DVD
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Radio
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Radio podcasts
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Internet/website
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Email
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Internet chat rooms / forums
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	CDs / audio tapes
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Telephone helplines / telephone counselling
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	CD-ROM
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Text messaging
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Face-to-face conversation / discussion / counselling with medical or social work staff
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Face-to-face conversation / discussion / counselling with someone who is <u>not</u> medical or social work staff
<input checked="" type="checkbox"/>					None of these [GO TO Q54]

<input type="checkbox"/> Another way – please specify (up to three other ways).....

36 - 56. I'm going to read you a list of the ways of getting information that you said you would prefer to use. For each, please tell me why you would prefer it?

ASK FOR ALL MENTIONED AT Q35

DO NOT READ OUT. CODE TO PRECODES AND CODE ALL THAT APPLY.

PROBE: Anything else?

PREFER

- I just like this way or usually use this way
- I find this one of the easiest ways to understand
- It offers the most up to date information
- It is easy to get hold of it or get access to it
- It provides just the right amount of information
- I believe that the information is accurate and true
- You can keep going back to it/ refer back to it
- You can ask for clarification/ ask what something means
- Other (please specify).....
- Don't know

36b-56b. I'm going to read you a list of the ways of getting information that you did NOT say you would prefer to use. For each, please tell me why you would not prefer it as a way of getting information?

ASK FOR ALL NOT MENTIONED AT Q35

DO NOT READ OUT. CODE TO PRECODES AND CODE ALL THAT APPLY.

PROBE: Anything else?

NOT PREFER

- I would use it, but I don't *prefer* it
- I just don't use it
- I never thought about, or considered using it
- I don't know what it is, or how it could be used to provide information
- I don't have a mobile phone
- I don't use the internet/ computers
- It does not provide enough information
- It provides too much information
- I don't trust the information is accurate or up to date
- The information might be made up
- I think the information might try to push me to make a particular decision [*biased*]
- It is difficult to get hold of it or get access to it
- Reading is difficult for me [*e.g. dyslexia, literacy difficulties, concentration problems*]
- I have eyesight problems [*blindness, poor vision*]
- I have language or communication difficulties [*e.g. not native English speaker*]
- Hearing is difficult for me [*deafness, hard of hearing*]

- I have problems using my hands [*e.g. to text, phone, type*]
- Other (please specify).....
- Don't know

57. *We asked you this at the start but now you have had time to think in detail about these things we'd like to ask you again: Overall, looking back do you feel you had enough information about this decision?*

SHOWCARD Q: CODE ONE ONLY

- Yes; if anything, I felt swamped by it
- Yes, I had as much information as I needed
- Yes, although I felt I needed more
- Not really; I definitely felt I needed more
- Not at all; it was far too little
- Don't know/can't remember

58. Overall, looking back do you feel it was easy to get hold of the information you needed?

SHOWCARD R: CODE ONE ONLY

- Yes, it was very easy to get hold of
- Yes, although it could have been even easier to get hold of
- Not really, although it wasn't difficult to get hold of
- No, it was rather difficult to get hold of
- No, it was too difficult to get hold of
- Not applicable - I didn't need any information
- Don't know/ Can't remember

E] Socio-demography

'The next few questions ask for a few personal details.'

59. Gender INTERVIEWER CODE

- Female
- Male

60. How old are you? SHOWCARD S

- 18 – 24
- 25 – 34
- 35 – 44
- 45 – 54
- 55 – 64
- 65 – 74
- 75 – 84
- 85 and over
- Refused

61. Which ethnic background do you consider yourself to belong to?
SHOW CARD T. CODE ONE ONLY

White:

- White British
- White Irish
- Any other White background

Mixed:

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed background

Asian or Asian British:

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background

Black or Black British:

- Caribbean
- African
- Any other Black background

Chinese or other ethnic group:

- Chinese
- Any other (please specify).....
- Refused

62. What is the highest level of qualification you have obtained?

SHOWCARD U. CODE ONE ONLY

- (1) No formal qualifications
- (2) O level/GCSE / SCE Standard/Ordinary grades, NVQ/SVQ/ GSVQ level 1 or 2/ GNVQ foundation or intermediate, BTEC/ SCOTVEC First/ General certificate, / General diploma, City and Guilds Part I/ RSA Stage I-III, SCOTVEC modules/ Junior Certificate
City and Guilds Craft/ Ordinary level/ Part II/ RSA Diploma
- (3) Trade Apprenticeships
- (4) A/AS levels/ SCE higher/ Scottish Certificate 6th Year Studies, NVQ/ SVQ/ GSVQ level 3/ GNVQ Advanced, ONC/ OND/ BTEC National,
City and Guilds Advanced Craft/ Final level/ Part III, RSA Advanced Diploma
- (5) Diplomas in higher education/ other HE qualification, HNC/ HND/ BTEC higher, Teaching qualifications for schools/ further education (below degree level), Nursing/ other medical qualifications (below degree level), RSA Higher Diploma
- (6) First degree (including BEd), Postgraduate Diplomas/ Certificates (including PGCE), Professional qualifications at Degree level
(eg chartered accountant/surveyor), NVQ/SVQ Level 4 or 5
- (7) Higher degree/postgraduate qualifications
- (8) Other qualifications including overseas
- (9) Don't know

60. Do you use the internet?

- Yes
- No

61. Do you have access to the internet at home, if you wanted to use it there?

- Yes
- No

62 Social Class questions

Which member of your household would you say is the Chief Income Earner?

Is the Chief Income Earner...

RELATED PERSONS:

1) If two equal incomes, take the elder person

2) If living as married treat as married and therefore related

If, for example a husband gets more in unemployment benefit that his working wife earns he is still Chief Income Earner.

UNRELATED PERSONS:

3) Take respondent as Chief Income Earner, eg flat sharer etc.

OCCUPATION OF CHIEF INCOME EARNER

Please ask and enter the occupation details for the Chief Income Earner

Job Title

Job Description

Industry

Number employed at location

Qualifications

IF Manager/Supervisor/Self-Employed, Number of People Responsible for

Respondent is in group...

[

- A [1]
- B [2]
- C1 [3]
- C2 [4]
- D [5]
- E [6]

CAPI ONLY ASK POSTCODE IF NOT ALREADY IN SAMPLE FILE

64. Postcode

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[Interviewer to fill in – do not ask unless you need to]

Appendix 3. Details of weighting of survey data in Stage 3 analyses

Weighting of data

In order to be able to generalise to the population of interest, apart from drawing samples on a random basis, it is good practice to attempt to ensure that the achieved sample is as close as possible in completeness to the intended sample and, in turn, to the structure of the population. There are three main causes of problems in this regard: disproportionate sampling designs, missing respondents and missing items within a questionnaire.

Stratification

In this study we stratified by health board area in Scotland, while problems in getting RM&G approvals in England meant that we had no choice but to limit our sampling to two lymphoma clinics. For the two samples recruited via primary care (pregnant women and carers of people with dementia), we focused on targeting general practices located in more urban environments, in order to maximise the chances of recruiting people from minority ethnic groups. These general practices were also split between the more deprived and the more affluent catchments in order to reflect income inequalities as a possible determinant of information use. In the case of lymphoma, the clinics are routinely based in urban centres due to their wide catchment populations. We have assumed that the five health board areas per health issue, in which the vast majority of the population lives, out of a total of fourteen such areas, are representative of the whole of Scotland.

For the two English clinics, one within an Acute Trust and the other within a Foundation Trust in contiguous areas in Birmingham and Coventry, we have assumed they are representative of the West Midlands only in England. Therefore, no consideration of disproportionate sampling has been applied to these data.

Missing respondents

The greatest distortion in surveys, arguably, is caused by the failure in getting all sample members to respond. Our sampling design, as detailed in the methodology, was based on simple random sampling within delineated time periods for people with lymphoma and antenatal women, and in relation to place of residence for carers. While reminders were used where possible, the achieved samples did not perfectly reflect the known characteristics of the populations from which they were drawn. In order to remedy this problem, weights were applied to the samples of people with

lymphoma and antenatal women, based on known population characteristics, while lack of population information for carers of people with dementia in Scotland meant that such weighting could not be applied to this sample.

In the case of our three health issue groups, the availability of population data is distinctly different for each. The best population data are available for births, giving information on age and deprivation within fairly specific spatial or administrative units. Data on lymphoma are fairly detailed, giving information on age and gender within Hodgkin's and non-Hodgkin's lymphomas, although not with deprivation. Data on unpaid carers of people with dementia are not available from official statistics, but rely on deriving likely proportions from current or recent surveys, themselves unlikely to reflect the true population proportions. Weights have been derived from a number of official statistical sources and are delineated as follows.

People with a diagnosis of lymphoma

This health issue has been considered separately for Scotland and England and separately for Hodgkin's (ICD-10 C81) and non-Hodgkin's (ICD-10 C82-C85) lymphoma due to the very different age profiles of each. Weighting has reflected the age by gender profiles of the prevalence of each type of lymphoma within each nation. No deprivation statistics are available for prevalence.

Scotland

In Scotland the data were drawn from the Information Services Division, part of NHS National Services Scotland. The data were based on the latest available (31/12/05) prevalence statistics for those surviving up to 20 years, broken down by age and gender, for Hodgkin's lymphoma (<http://www.isdscotland.org/isd/1473.html>) and non-Hodgkin's lymphoma (<http://www.isdscotland.org/isd/1483.html>). We have assumed that there are very few people with either lymphoma under the age of 18 (our lower limit for recruitment).

(a) Hodgkin's lymphoma

The ISD statistics show the following prevalence proportions of the total population:

ISD	Males		Females	
	n	%	n	%
Under 45	589	0.326	469	0.260
45-64	297	0.165	219	0.121
65+	118	0.065	113	0.063
All Ages	1,004	0.556	801	0.444

The equivalent respondent numbers in our sample are as follows, showing a rather different picture, having lower proportions of males and younger people than the population:

Study sample	Males		Females		Total
	n	%	n	%	
unweighted					n
18-44	4	0.09	15	0.32	19
45-64	11	0.23	8	0.17	19
65+	3	0.06	6	0.13	9
Total	18	0.38	29	0.62	47

Therefore, there is a clear need to re-weight the sample numbers to reflect the true population proportions. We can produce the weights for each cell in the matrix through calculating the values by dividing the population proportions by the sample proportions; viz.

Study sample	Males	Females
weighted		
18-44	3.834	0.814
45-64	0.703	0.713
65+	1.024	0.490

The weighted numbers now show the following distribution, giving much more weight to the younger age group and particularly for men.

Study sample

weighted	Males	Females	Total
18-44	15	12	28
45-64	8	6	13
65+	3	3	6
Total	26	21	47

(b) Non-Hodgkin's lymphoma

Here we follow the same process as with Hodgkin's lymphoma. The ISD statistics show the following prevalence proportions of the total population:

ISD	Males		Females	
	n	%	n	%
Under 45	441	0.080	244	0.044
45-64	1,042	0.190	874	0.159
65+	1,271	0.232	1,612	0.294
All Ages	2,754	0.502	2,730	0.498

The equivalent respondent numbers in our sample are as follows, showing very similar proportions for gender and older age, but a slightly lower proportion of younger people and a higher proportion of middle-aged than the population:

Study sample	Males		Females		Total
	n	%	n	%	n
18-44	9	0.05	5	0.03	14
45-64	42	0.22	39	0.20	81
65+	48	0.25	52	0.27	100
Total	99	0.51	96	0.49	195

Although the data are very similar to the population, to be consistent with the Hodgkin's lymphoma patients we have weighted the data, using the same approach:

Study sample

weighted	Males	Females
18-44	1.742	1.735
45-64	0.882	0.797
65+	0.942	1.102

The weighted numbers now show the following distribution for our sample, giving more weight to the younger age group and less weight to the middle aged group, while leaving the older age group and the gender proportions relatively untouched.

Study sample

weighted	Males	Females	Total
18-44	16	9	24
45-64	37	31	68
65+	45	57	103
Total	98	97	195

NB Some of our respondents (14) did not know which type of lymphoma they had been diagnosed with, in which case they have not been weighted.

England

In England the data were provided by the West Midlands Cancer Intelligence Unit (WMCIU) and are based on the prevalence statistics for those surviving up to 10 years, broken down by age and gender, for the latest available data (1/1/08) for Hodgkin's disease (ICD-10 C81) and non-Hodgkin's lymphoma (ICD-10 C82-C85) in Arden and Pan Birmingham Cancer Network, corresponding to our two hospital sites. Conditions such as lymphoma are likely to have a larger catchment area than the area in which the specialist clinics are based, but we have limited the interviews to those who live in the surrounding area.

The West Midlands Cancer Intelligence Unit was only able to produce prevalence statistics for 5 or 10 years survival and so, to be as consistent as possible with Scotland, we used the 10-year figures. This assumes that the relative proportions between each age and gender cell remain relatively unchanged over the 20 year period. While this might not be strictly true, it

is believed that the differences are unlikely to affect our weights in more than a marginal way. While the data were available for a more detailed breakdown of ages, we have kept to the same aggregated age-groups as for Scotland, since the sample cell sizes are very small. Even so, since we had not recruited any young men with Hodgkin's lymphoma, the weightings have excluded this sub-population, despite the fact that they are by far the largest population group in this region (34.9%). We have again assumed that there are very few people with either lymphoma under the age of 18 (our lower limit for recruitment).

(c) Hodgkin's Lymphoma

The Pan Birmingham and Arden statistics show the following prevalence proportions of the total population:

WMCIU Age groups	Males		Females	
	n	%	n	%
Under 45	193	0.349	147	0.266
45-64	83	0.150	54	0.098
65+	43	0.078	33	0.060
All Ages	319	0.577	234	0.423

The equivalent respondent numbers in our sample are as follows, showing a rather different picture, having lower proportions of males and middle aged people than the population:

Study sample unweighted	Males		Females		Total n
	n	%	n	%	
18-44	0	0.000	9	0.600	9
45-64	1	0.067	1	0.067	2
65+	1	0.067	3	0.200	4
Total	2	0.133	13	0.867	15

While there is a clear need to re-weight the sample numbers to reflect the true population proportions, the sample numbers are very small and care has to be taken in the analysis. Due to the lack of young men, the cell has been given a unitary weight. We can produce the weights for each cell in the matrix through calculating the values by dividing the population proportions by the sample proportions; viz.

Study sample

weighted	Males	Females
18-44	1.000	0.681
45-64	3.458	2.250
65+	1.792	0.458

The weighted numbers now show the following distribution, giving much more weight to the middle age group and particularly for men.

Study sample

weighted	Males	Females	Total
18-44	0	6	6
45-64	3	2	5
65+	2	1	3
Total	5	9	14

(d) Non-Hodgkin's lymphoma

Here, as before, we follow the same process as with Hodgkin's lymphoma. The prevalence statistics show the following proportions of the total population, following a very similar pattern to the Scotland data:

WMCIU	Males		Females	
	n	%	n	%
Under 45	150	0.071	104	0.049
45-64	406	0.192	317	0.150
65+	561	0.265	575	0.272

All Ages 1117 0.529 996 0.471

The equivalent respondent numbers in our sample are as follows, showing slightly higher proportions of males, as well as a lower proportion of younger people and a higher proportion of middle-aged than the population:

Study sample	Males		Females		Total
	n	%	n	%	
unweighted					N
18-44	2	0.031	2	0.031	4
45-64	21	0.328	12	0.188	33
65+	16	0.250	11	0.172	27
Total	39	0.609	25	0.391	64

Therefore, we have re-weighted the sample numbers to reduce the proportion of males and boost the numbers of younger people at the expense of the middle-aged group to better reflect the true population proportions. To be consistent with the Hodgkin's lymphoma patients, we have weighted the data, using the same approach:

Study sample	Males	Females
weighted		
18-44	2.272	1.575
45-64	0.586	0.800
65+	1.062	1.583

The weighted numbers now show the following distribution for our sample, giving less weight to males, more weight to the younger and older age groups, with a corresponding reduction in the middle aged group.

Study sample	Males	Females	Total
weighted			
18-44	5	4	9
45-64	12	9	21
65+	17	18	35

Total 34 31 65

NB Some of our respondents (5) did not know which type of lymphoma they had been diagnosed with, in which case they have not been weighted.

Antenatal screening for Down's syndrome

For this health issue we are able to consider population data for births in Scotland in 2008 (the latest year available) based on mothers' exact ages in General Register Office for Scotland (GRO) statistics , age bands (in Information Services Division of the NHS National Services Scotland (ISD) statistics), and deprivation (in ISD statistics) .

Although we have recorded age in our survey within fairly standard age bands, they do not correspond exactly with those provided in ISD. Unfortunately the GRO statistics are based on registered births in Scotland (wherever they were delivered), while ISD statistics only record births within NHS hospitals in Scotland. To get round this problem we have estimated the proportions in each individual age relative to the age bands to produce comparative proportions that correspond with our age bands.

The figures and relative proportions from the GRO statistics, based on the ISD age bands, that match our sample age bands, are as follows:

GRO aggregated numbers	Proportion of ISD group	
18 - 19	2,979	0.696
20 - 24	11373	1
25 - 29	16171	1
30 - 34	16028	1
35 - 39	10025	1
40 - 44	2044	0.956
45 - 54	95	0.044
Total (excl <18)	58,715	

The ISD figures by their age bands and deprivation quintiles are as follows for 2008 (the latest year available), having excluded those with unrecorded deprivation scores:

ISD	Deprivation Quintile					Total
	1 - Least Deprived	2	3	4	5 - Most Deprived	
Under 20	183	377	639	1060	1903	4162
20 - 24	736	1233	1787	2702	4260	10718
25 - 29	2020	2545	2974	3324	3907	14770
30 - 34	3486	3391	2994	2744	2525	15140
35 - 39	2610	2302	1827	1623	1380	9742
40+	530	459	361	306	293	1949
Total	9565	10307	10582	11759	14268	56481

Applying the GRO estimates, as above, produces the following birth figures for each deprivation quintile:

Age groups	1 - Least Deprived				5 - Most Deprived		Total
	1 - Least Deprived	2	3	4	5 - Most Deprived		
18 - 24	863	1495	2232	3440	5585	13616	
25 - 34	5506	5936	5968	6068	6432	29910	
35 - 44	3116	2741	2172	1915	1660	11604	
45 - 54	24	20	16	14	13	87	
Total	9509	10192	10388	11437	13690	55217	

Given that we have some missing cells in our sample, these needed to be excluded from the above figures before weighting could be applied; viz.

Age groups	1 - Least Deprived	2	3	4	5 - Most Deprived	Total
18 - 24	863	0	0	3440	5585	9888
25 - 34	5506	5936	5968	6068	6432	29910
35 - 44	3116	2741	0	1915	1660	9432
45 - 54	0	0	16	0	0	16
Total	9486	8677	5984	11423	13677	49247

NB Data are removed where the sample has no cases.

From these data we can derive the following proportions in each cell:

Age Group	1 - Least Deprived	2	3	4	5 - Most Deprived	Total
18 - 24	0.018	0.000	0.000	0.070	0.113	0.201
25 - 34	0.112	0.121	0.121	0.123	0.131	0.607
35 - 44	0.063	0.056	0.000	0.039	0.034	0.192
45 - 54	0.000	0.000	0.000	0.000	0.000	0.000
Total	0.193	0.176	0.122	0.232	0.278	1.000

Turning now to our sample, we have the following respondent numbers in each cell:

Study sample data

Age Group	1 - Least Deprived	2	3	4	5 - Most Deprived	Total
18 - 24	1	0	0	1	7	9
25 - 34	12	6	10	6	7	41
35 - 44	19	6	0	4	2	31
45 - 54	0	0	1	0	0	1
Total	32	12	11	11	16	82

The respective proportions for our sample are, therefore, as follows:

Study sample data proportions

Age Group	1 - Least Deprived	2	3	4	5 - Most Deprived	Total
18 - 24	0.012	0.000	0.000	0.012	0.085	0.110
25 - 34	0.146	0.073	0.122	0.073	0.085	0.500
35 - 44	0.232	0.073	0.000	0.049	0.024	0.378
45 - 54	0.000	0.000	0.012	0.000	0.000	0.012
Total	0.390	0.146	0.134	0.134	0.195	1.000

We can now derive the weights from the relative reciprocal values for each cell in the matrix, by dividing the estimated population proportions by the sample proportions:

Study sample weights

Age Group	1 - Least Deprived	2	3	4	5 - Most Deprived
18 - 24	1.438	1.000	1.000	5.728	1.328
25 - 34	0.764	1.647	0.994	1.684	1.530
35 - 44	0.273	0.761	1.000	0.797	1.382
45 - 54	1.000	1.000	0.027	1.000	1.000

NB Zero cells have been weighted as 1.

The result of this weighting of the data is to increase the weight given to the views of the younger and the more deprived women, at the expense of the older and the less deprived women. The following table shows the numbers that will appear in the analyses of this health issue:

Study sample data - weighted

Age Group	1 - Least Deprived	2	3	4	5 - Most Deprived	Age Group
18 - 24	1.438	0.000	0.000	5.728	9.299	16.465
25 - 34	9.168	9.884	9.937	10.104	10.710	49.803
35 - 44	5.189	4.563	0.000	3.189	2.764	15.706
45 - 54	0.000	0.000	0.027	0.000	0.000	0.027
Total	15.795	14.447	9.964	19.021	22.773	82.000

While these adjustments are intended to reflect the true weight of views in the population, the overall sample numbers have been kept the same, rather than increasing the overall sample size, to avoid artificially deflating the standard errors.

Carers of people with dementia

There are no official statistics on this category of carer in Scotland. While there have been surveys in recent years, most have been carried out through membership organisations; e.g. Alzheimer Scotland (85). In their survey in 2006 they found that 72% of carers were living with the person with dementia, compared to only 31% in our survey.

The only recent population-based survey that we have been able to locate is the OPM survey that was carried out for the Scottish Government in 2006 (62). Even this survey was recognised as being biased towards members of voluntary organisations. The following table shows the proportions of carers within a range of age-groups by gender (personal communication from OPM):

OPM	Male		Female		Total	
	n	%	n	%	n	%
18-24 yrs	2	1	2	0	4	1
25-34 yrs	0	0	3	1	3	0
34-44 yrs	2	1	37	7	39	5
45-59 yrs	53	27	173	33	226	32
60-69 yrs	48	25	134	26	182	25
70+ yrs	89	46	172	33	261	37
TOTAL (n)	194	100	521	100	715	100

Our sample has older male carers (median age = 69) compared to OPM (median = 68) and younger female carers (median = 61) compared to OPM (median = 63). Despite having a higher proportion of males in our sample (32% compared to 27%), overall the median age (63) was slightly lower than OPM (64). Overall, there is little difference between these samples, but that does not mean that our respondents are representative of the population.

Given the lack of reliable population estimates, coupled with the fact that our survey profile is very similar in age and gender characteristics to the OPM survey, we have decided to leave the data unweighted, while noting its potential unrepresentativeness.

Incomplete questionnaires

The problem of missing respondents in surveys is typically compounded by incomplete responses to the questionnaire or checklist. One of the advantages of face-to-face interviewing is that this problem can be minimised due to the ability to clarify issues when they are not understood, or to encourage respondents to provide an answer when they might otherwise be disinclined to do so. In this survey we were fortunate in having minimal missing responses, except where the questions might have been inapplicable. Since we routinely noted if respondents said they did not know the answer, we have been able to keep the lack of responses to a minimum.

Ideally such a problem of missing responses to items can be dealt with through the process of imputation. We have taken the position that when a respondent claims they do not know the answer this is indeed their opinion, rather than assuming any other response could be possible. The remaining items where no answer of any kind is recorded would, therefore, be the only candidates for imputing values. However, the proportion of missing answers

is so low that this has been considered to be unnecessary and, in any event, unlikely to impact on the final analysis. The only missing answers for reasons other than being inapplicable were, in fact, in the last section of the questionnaire under 'format of information', where respondents were asked to give a reason why they did or did not prefer one of the 17 formats presented. Not only was this a lengthy and somewhat tedious question, it was also at the end of the interview, when there would be likely to be a tiring effect.

Appendix 4. Project dissemination: publications and presentations

Published articles

Hunt, K., France, E., Ziebland, S., Field, K., Wyke, S. 'My brain couldn't move from planning a birth to planning a funeral': a qualitative study of parents' experiences of decisions after ending a pregnancy for fetal abnormality, *International Journal of Nursing Studies*, 46(8): 1111–1121, 2009.

Thompson, A.G.H. & France, E.F. One stop or full stop? The continuing challenges for researchers despite the new streamlined NHS research governance process. *BMC Health Services Research*, 10:124, 2010.

Submitted articles

France, E.F., Locock, L., Hunt, K., Ziebland, S. Field, K. and Wyke, S. Imagined futures: how experiential knowledge of disability affects parents' decision-making about fetal abnormality. First submitted on 12/10/09 to *Health Expectations*. Revisions submitted on 08/03/10. [Copy available on request]

Articles in preparation for submission to peer reviewed journals

France, E.F., Entwistle, V., Hunt, K., Jepson, R., Ziebland, S. and Wyke, S. How women draw on experiential and biomedical information when accounting for their antenatal screening decisions. Final draft in preparation for submission to *Social Science and Medicine*. [Copy available on request]

France, E.F., Entwistle, V., Jepson, R. & Wyke, S. How patients and carers use and evaluate experiential health information in relation to decision making. First draft in preparation for submission to *Patient Education and Counselling*. [Copy available on request]

List of presentations

France, E.F., Entwistle, V., Hunt, K., Jepson, R., Ziebland, S. and Wyke, S. The interaction between personal experience and professional knowledge in health decision making. *Research Unit in Health, Behaviour and Change, University of Edinburgh*, 12 May 2008

France, E.F., Locock, L., Field, K., Wyke, S., Hunt, K. & Ziebland, S. Antenatal screening and ending a pregnancy – parents' accounts of the impact of knowledge of disability on decisions. *The British Psychological Society Scottish Branch Annual Conference*, Stirling, December 2007.

France, E.F., Locock, L., Field, K., Wyke, S., Hunt, K. & Ziebland, S. Antenatal screening and ending a pregnancy – parents' accounts of the impact of knowledge of disability on decisions. *Nursing & Midwifery Department presentation, University of Stirling*, 18 March 2008

France, E.F., Locock, L., Field, K., Wyke, S., Hunt, K. & Ziebland, S. Antenatal screening and ending a pregnancy – parents' accounts of the impact of knowledge of disability on decisions. *Stirling University midwifery students, University of Stirling*, 21 April 2008

France, E. Wyke, S., Hunt, K., Ziebland, S., Entwistle, V. Patients' use of experiential knowledge in health decision making. *Alliance for Self Care Research Annual Research Seminar*, Carnoustie, 23 April 2008.

France, E.F., Wyke, S., Hunt, K., Ziebland, S., Entwistle, V. Patients' use of personal experience in health decision making, presentation at the *HSRN (Health Services Research Network) Developing Better Health Services conference*, Manchester 4-5 June 2008.

France, E.F., Wyke, S. Hunt, K., Ziebland, S. Entwistle, V. Patients' use of personal experience in antenatal decision making. *British Sociological Association Medical Sociology Conference*, Brighton, 4-6 Sept 2008.

Hunt, K. France, E., Ziebland, S., Field, K. & Wyke, S. 'My brain couldn't move from planning a birth to planning a funeral': parents' experiences of decisions after ending a pregnancy for fetal abnormality. *Enhancing Decision-Making in Healthcare Practice International Conference*, Stirling, 29th September 2009.

France, E.F., Entwistle, V., Jepson, R. & Wyke, S. How patients and carers use and evaluate experiential health information in relation to decision making. *Scottish School of Primary Care Conference*, Crieff, Scotland, 27-28 April 2010.

France, E.F., Entwistle, V., Jepson, R. & Wyke, S. How patients and carers use and evaluate experiential health information in relation to decision-making. *The Alliance for Self-Care Research Conference*, Stirling, 11-13 May 2010.

Conference abstracts accepted for oral presentations

France, E.F., Entwistle, V., Jepson, R. & Wyke, S. How patients and carers use and evaluate experiential health information in relation to decision making. Poster presentation. *European Association for Communication in Healthcare International Conference on Communication in Healthcare 2010*, Verona, Italy, 5-8 September 2010.

France, E.F., Entwistle, V., Jepson, R. & Wyke, S. 'Knowing people are coping with what you have to cope with is reassuring.' Why people use and value experiential health information. *The International Institute for Qualitative Methodology 16th Qualitative Health Research Conference*, Vancouver, Canada, 3-6 October 2010.

Thompson A, France E, Wyke S, Ziebland S, Hunt K, Entwistle V and Jepson R. The mirage of choice: now you see it, now you don't. *British Sociological Association Medical Sociology Group Annual Conference*, Durham, England, 1-3 September 2010.

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.