

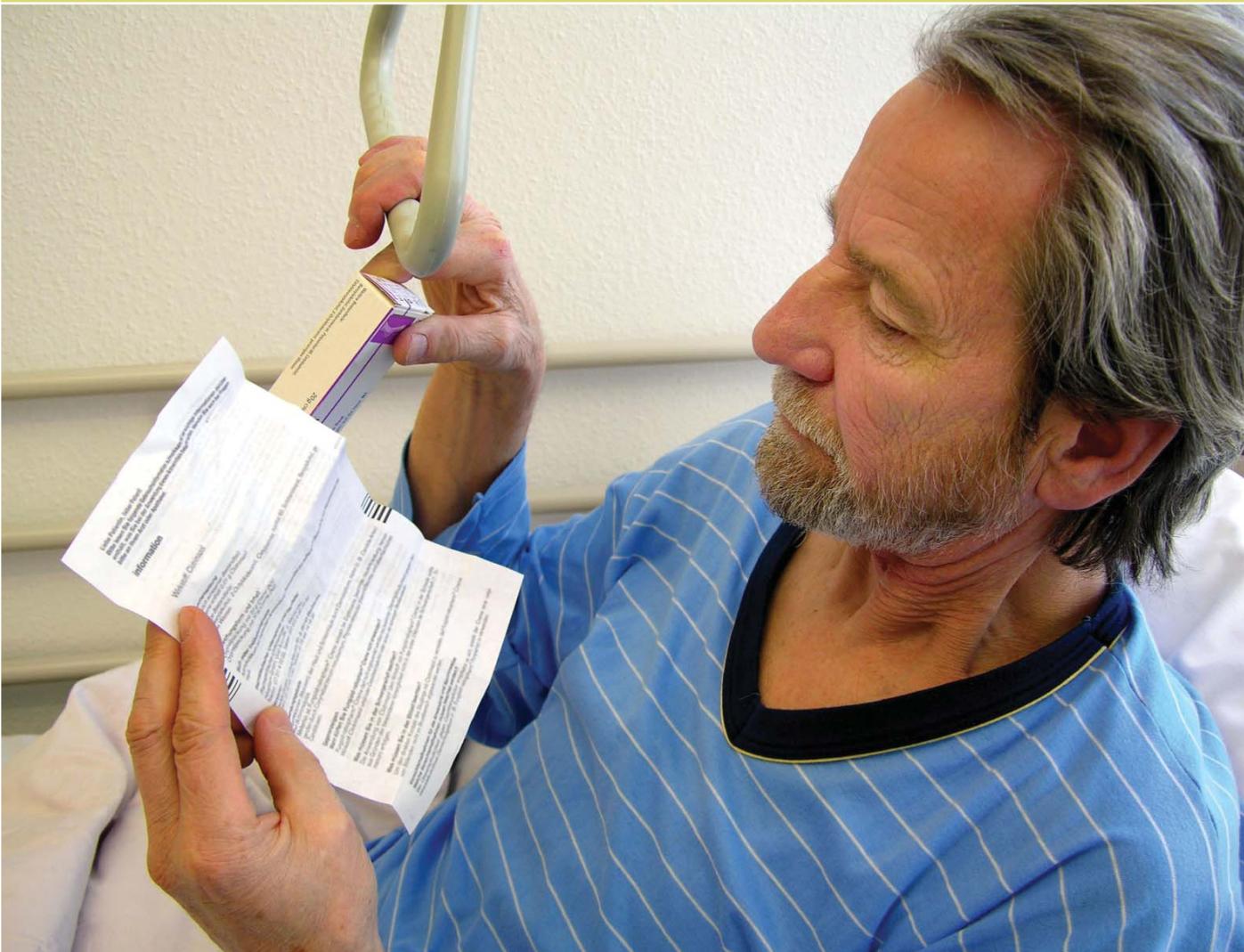


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Research report

Literacy, learning and health

Uta Papen and Sue Walters
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Executive summary

This study examines relationships between literacy, learning and health, and sets out to answer the following questions:

1. What are the literacy, language and numeracy demands placed on people in health-care settings?
2. What are the difficulties that adult literacy, language and numeracy (ALLN) students experience when accessing health-related information and when dealing with texts such as registration or consent forms? What strategies do they use to overcome these?
3. How do ALLN students find out about any health matters that concern them? What sources of information do they use – for example do they read magazines, watch TV or use the internet?
4. How do teachers and students think of and respond to health as a topic for ALLN?

The health-care system was found to have oral language demands for ALLN students, who needed to communicate with receptionists, dentists, nurses, pharmacists and doctors. This was especially true of ESOL students, who had problems with vocabulary and local accents, and some of whom felt that people didn't always have time to explain things in detail. But it could also be a problem for other ALLN students, who sometimes felt that doctors could do more to explain specialised terms and avoid medical jargon.

The health-care system was also found to place many literacy demands on ALLN students, in the form of leaflets, forms, letters, medicine packaging and inserts, and hospital signage. Some were asked to keep diaries and records, and others were invited to write down questions.

In addition to specific language and literacy demands, the ESOL students also had the task of familiarising themselves with the English health-care system.

Students were found to use a variety of strategies to cope with the difficulties they faced when engaging with the health-care system. Writing things down in preparation for consultations, taking dictionaries on visits to the doctor, reading leaflets whilst drawing on prior experience and knowledge, checking family medical books, and doing research on the internet, were some of the methods used.

One of the commonest ways of dealing with the demands of reading and understanding texts, was through using other people who were better able to read and understand English texts, who had an understanding of certain diseases, or who were more familiar with the working processes and structures of the health system. This process is known as brokering or mediation. Brokers or mediators might be friends, family, key workers or health professionals.

Judging from the views of both teachers and students involved in this study, Skills for Life literacy and ESOL classes offer opportunities for students to learn how to benefit from health-care services and how to access and understand health-related information. There is a need for such learning, especially for ESOL learners.

Although not a frequent topic in ALLN classes, health appears to have a regular place in ESOL Entry level classes. A major obstacle to the greater use of health as a topic in literacy and ESOL classes is the sensitive and personal nature of health. Gender, age and ethnic differences can make it difficult to share personal health experiences and/or concerns in the classroom context. However, it was found that the students in this study benefited from having health as a topic in the classroom in the following ways:

- Orientation to the UK health-care system (i.e. understanding how the system works and what is available);
- Access to health care (e.g. being able to make an appointment with a GP, being able to register with a dentist, using NHS Direct, going online to look up information on health websites);
- Increasing awareness (e.g. about health issues, nutrition, people's rights in relation to health);
- Improving their general speaking and listening abilities, their spelling and their understanding of grammar.

There is a list of suggestions for practitioners who are interested in using health in their programmes in Chapter 8 of this report (see p. 58).

1 Introduction

Health has always been a concern for adult literacy, language (ESOL) and numeracy programmes. Teachers are aware that students' poor health can negatively affect their learning and that they may drop out of programmes because of ill health. But dealing with ill health and disease can also create new learning demands and some people, who suffer from long-term or chronic disease, find that learning and the social contact that comes with attendance of classes offer relief and distraction from their illness (James 2001). It is also widely agreed that improved health is part of the wider benefits of learning (Schuller et al. 2004).

Despite this general interest in the relation between health and literacy, in England there has been very little research about what precise health-related learning needs and interests students in ALLN classes have. We know little about how ALLN students deal with the reading and writing they have to do as patients in a surgery or hospital. How do ALLN students cope with the literacy demands of health-care settings? This was one of the questions this study tried to address.

The overall aim of this study, that spanned a period of two years and eight months, was to examine how literacy, learning and health are related to each other. By literacy we mean reading, writing and engaging with written texts, for example signage at a hospital or a patient information leaflet. We have included 'learning' in our study title, because we assume that dealing with ill health can lead to people learning about new things and developing new skills. This could, for example, be learning about a specific disease or learning to use the internet to find out information about medication. In this study we wanted to understand how people who are (or have been) ill see the literacy demands of health care. Thus we were interested in *patients'* views, not the doctors' or the nurses' perspectives. The people who took part in our study were students in adult literacy and ESOL classes across the north-west of England. When we interviewed them, we asked them about their experiences as patients. Our aim was to identify and describe what written texts they came across in health-care settings, how they engaged with these, what difficulties they might have experienced and what other sources of information they drew on. A second aim of our study was to examine the role of health as a topic in literacy and ESOL classes.

1.1 Research questions

The specific research questions our study aimed to address were as follows:

1. What are the literacy, language and numeracy demands placed upon people in health-care settings?

2. What are the difficulties ALLN students experience when accessing health-related information and when dealing with texts such as registration or consent forms? What strategies do they use to overcome these?
3. How do ALLN students find out about any health matters that concern them? What sources of information do they use – for example do they read magazines and/or watch TV or do they use the internet?
4. What are teachers' and students' perceptions of and experiences with health as a topic for ALLN?

1.2 The policy context: Skills for Life and recent health policies

The introduction of the Skills for Life strategy in 2001 has led to a significant change in adult literacy, numeracy and ESOL policy in Britain. The development of national curricula is one of these. Health topics are frequently suggested in the new curricula as content for teaching literacy, language and numeracy.

Skills for Life acknowledges that health and dealing with ill health are central concerns for many adult learners. Skills for Life also explicitly aims to address the challenges created by the growth of the knowledge economy and the spread of information technology. Both have profound effects on the knowledge and skills available and necessary for people to operate successfully, not only at the workplace but in the various roles they occupy as members of the society. Patients are affected by the growth in knowledge and information technology. They are nowadays confronted with a range of written documents, many using technical language and/or being presented in complex formats.

Health care has become increasingly technology-based and it relies on highly specialised knowledge that is not easily communicated to patients. The health services are aware of this challenge and in recent years, the Department of Health has shown increasing commitment to improved patient education and health information. A series of policy reports, white papers and initiatives documents this. The publication of the Acheson Report in 1998 (HMSO 1998), summarising the results of an independent inquiry into health inequalities, marked the beginning of the Department of Health's efforts to improve the public's knowledge and access to information about health issues. The government's white paper *Saving lives: Our healthier nation* (Department of Health 1999) outlined a public health strategy for England, aiming to tackle health inequalities through the provision of public and patient health education and information. As part of the new strategy, NHS Direct, a telephone information and advice service, and the Expert Patient Programme (EPP), a self-management programme for patients with long-term conditions, were introduced. More recently, NHS Online, a web resource for patients, was launched.

Since the launch of Skills for Life, the Department of Health has developed specific initiatives to improve basic education within the NHS, i.e. for its own staff. Individual trusts and NHS organisations have introduced programmes offering literacy, numeracy and ESOL classes to its employees. New initiatives to improve patients' health literacy are the national 'Skilled for Health Demonstration Programme', which was launched in January 2003 by the Department of Health, the Department for Education and Skills and the charity ContinYou; and the 'National Health Literacy Collaboration', managed by the National Consumer Council, who in 2004 published an important report of health literacy (National Consumer Council 2004).

2 How we define health literacy

In this chapter, we explain the concept of health literacy that informs our study. This is how A. Muro from the El Paso Community College in the US defines health literacy:

Health literacy is the ability to understand, access and use health-related tools and services available in a given location. Some people may think of health literacy as simply the ability to decode health-related text. However, this is a narrow definition. Rather, health literacy has to do with the social and cultural practices that individuals and groups may engage in, in the process of understanding, accessing and using health-related tools and services.

(World Education, <http://www.worlded.org/us/health/lincs>)

Muro's definition is useful because it allows us to see that health literacy includes several dimensions and depends on different factors. We will explain why.

Muro begins by talking about the ability to understand health-related tools and services. By this he means, for example, being able to read a medicine bottle or to understand indications and dosage. This is the common way of understanding what literacy is about: the (cognitive) ability to code and decode letters and to understand words and sentences. Many health educators and medical researchers think of literacy as a skill and different tests have been developed to measure patients' health literacy (see for example Parker et al. 1995, see also Papen 2008). Such tests show wide differences in people's ability to, for example, understand medical terms. Studies in several countries confirm that different parts of the population have greater or lesser difficulties accessing and benefiting from health information (for the UK see Black et al. 1980, HMSO 1998, National Consumer Council 2004; for the US see Pamuk et al. 1998; for Canada see Health Canada 1999; and for Australia see Harris et al. 1999). In our research, we wanted to look in more detail at the kind of difficulties people experience with health information and how we can explain these.

As the above definition suggests, health literacy has to do with the 'ability' to access, comprehend and make use of health-related information. The question, however, is how we define this ability and what we think are the factors that contribute to it. Health literacy tests can give us approximate indications of people's general ability to understand written health information. But they cannot tell us much about how particular patients in particular circumstances deploy their literacy resources to access and understand health information. They cannot offer any insights into how concretely a lack of literacy (in the sense of, for example, an inability to understand a particular word in a leaflet or a question on a form) affects patients' health care.

In order to understand what role health literacy plays in particular episodes of disease or ill health, we need to take account of more than the patient's theoretical reading and writing skills. We need to understand the context: this includes the person's personal background, the social and institutional practices of health care (including the relationship between doctor and patient), the cultural practices of looking after one's health, as well as the emotional aspects of dealing with ill health. Talking to literacy and ESOL students in our study, we could see that all these factors played a role in their health literacy. In our research, we therefore needed a concept of health literacy that would allow us to take account of these social and cultural factors. Muro's definition makes this possible.

Another way of looking at health literacy – and literacy more generally – is to think of it as social practices: as *activities* which are always embedded in specific situations and contexts and whose actual shape and meaning can only be understood within these contexts (see Street 1993, 1995, 1999; Barton 2006; Barton and Hamilton 1998; Baynham 1995; Gee 1996; Papen 2005). This understanding of literacy matches how Muro, in his above definition, conceptualises health literacy. The main merit of a social practices view of literacy for our study is that it allows us to attend to the concrete social situations where people draw on their literacy to accomplish specific activities and fulfil particular goals.

Many contemporary social practices rely heavily on the use of written language. Health-care practices are no exception. Patient information leaflets or brochures are a good example of the kind of written text frequently used in health care. If you turn to Chapters 5 and 6 of this report, you will see numerous examples of the essential role written texts play in the interaction between doctors and patients and in the provision of health care more generally. This is not to suggest, however, that in health-care situations spoken language is of no importance. In almost any social situation, the use of a piece of writing includes 'talk around text' (Moss 1996).

To summarise our position, in this study we have adopted a concept of health that includes cognitive aspects (skills), social relations and context as well as the emotional and psychological side of health and health care (Dray and Papen 2004, Papen 2008). Following Muro, we suggest that health literacy depends on a variety of factors, including social status, age, gender, ethnicity, geographical space, the health-care system itself, etc. In our study, we have tried to take account of all these factors. Furthermore, our research pays particular attention to patients' own information-seeking practices. These are an important part of their health literacy. Many of these take place outside the medical encounter. Patients' reactions to information received and their strategies to find out more are important if we want to understand patients' health literacy. There is very little research on patients' own literacy practices. The National Consumer Council's (2004) recent position paper on health literacy acknowledges this gap. This is all the more important as we do not know much about the status of these practices in the institutional domain. For the patient, whether their own knowledge (whatever its source) is acknowledged or accepted by their health-care provider can be crucial. Literacy is linked to knowledge and power. The consultant's view on a specific case is usually given authority. By contrast, the patients' own ideas and the written sources they draw on may easily be disqualified – magazine articles are not scientific, there is no 'evidence' that herbal medicine works, many internet sites serve commercial purposes and what the neighbour has experienced cannot be taken as clinical experience (Freebody and Freiberg 1997).

3 Researching health literacy – how we found out about patients’ health literacy practices

This report is the product of a research project that included a variety of research methods – from a quantitative survey to in-depth qualitative work with individual ALLN students and teachers. The study covered a range of settings or ‘field sites’, as we call them, all of which are located in the north-west of England. In this chapter, we illustrate briefly how we collected and analysed our data.

The project can be roughly divided into three phases, each of which focused on different aspects of our research agenda. Each phase can also be distinguished by the number of participants involved and the level of detail at which we studied specific contexts and individual people’s experiences. However, there was significant overlap between the three phases and at times we simultaneously engaged in activities relating to two or even all three phases.

The study is inspired by ethnographic methodology. This means that we investigated literacy in ‘real-life’ settings: we tried to understand how people experience health literacy in concrete situations, in which they engage with texts. An ethnographic perspective also means that the researcher looks at a specific phenomenon in a holistic way, the aim being to understand the variety of factors involved in the activity. Our main focus was the participants’ (ALLN students’ and teachers’) perspectives on literacy in relation to their health and health care. Traditionally, ethnography requires the researcher to develop close contacts with the study participants and to observe them in their everyday life. This takes time and limits the number of people a study can include. Because our study was the first of its kind in the UK, we wanted to involve as many people as possible, but we also wanted to understand their experiences in detail. This was a logical consequence of our understanding of health literacy (see Chapter 2). We tried to address these contradictory demands by working with different people at different levels of intensity. We will explain below how this worked.

3.1 Research activities

We began our study with a survey into the role of health as a topic in literacy, numeracy and ESOL classes. In line with the regional focus of our study, we included further education colleges, adult and community colleges and other providers of adult literacy, numeracy and ESOL in the north-west of England, including Greater Manchester, Liverpool and parts of West Yorkshire. In total, 45 teachers completed our questionnaire. The majority of these were teachers of literacy and/or ESOL, while only a small number of numeracy teachers responded. We summarise the main findings of our survey in Chapter 7 of this report.

The survey allowed us to gain a general insight into the role of health as a topic in adult literacy, numeracy and ESOL classes. It confirmed that many students deal with health problems. On the basis of what we had learned from the survey, we now wanted to learn more about:

- the students' own experiences with reading and writing in relation to their own or their family's health;
- the presence or absence of health as a topic in selected ALLN classes and the reasons for this.

These were the aims of the second (and third, see further below) phase of our study (see Chapter 1, research questions). To achieve these aims, we needed to take a closer look at what was happening in ALLN classes and we needed to talk to individual students about their own health literacy practices. Therefore for the second and third phase of our research we used interviews, informal conversations and observations in students' homes and in health-care settings.

Altogether, we worked in seven literacy and ESOL classes and we interviewed 45 students and 10 teachers. We selected our classes on the basis of the survey, relying on existing contacts with providers in the area. We tried to include a numeracy class in our research, but were unsuccessful. This was because few numeracy classes include health in their curriculum. When approaching a college to get permission to conduct research in its classes, we found that literacy and ESOL coordinators and teachers thought of our research as interesting and useful, but not so numeracy teachers.

Each of us spent between 4–7 months working with a specific class, trying to visit the class once a week and interviewing as many students as had agreed to work with us. We also interviewed the teachers of these classes. In one of our sites (Lancaster), a teacher-researcher conducted 10 interviews with ESOL learners from three classes (all of which she was teaching herself).

3.1.1 Research activities in Phase 2

Classroom observations

The main aim of our classroom observations was to gain more insights into the topics addressed in the survey (see above and Chapter 7). The survey had indicated that overall health was not a frequent topic in ALLN classes. This was also the case in most of the classes we observed.

Teacher interviews

We used the teacher interviews to pursue the same questions we had already asked in the survey. We summarise our insights from the teacher interviews in Chapter 7.

Student interviews

The main purpose of our student interviews was to help us gain an understanding of the students' own reading and writing (i.e. literacy) practices in relation to health. We were particularly interested in finding out about students' experiences with the NHS and with specific situations that involve the use of written texts. But we wanted to avoid concentrating on deficits and difficulties only. One of our primary interests in this study was to identify students' (patients') own strategies in dealing with health literacy practices. A second purpose of the student interviews was to ask them about the role of health as a topic in the class they attended.

With a few exceptions, the students we interviewed were adults from the literacy and ESOL classes we attended. All of them had consented to be interviewed after an initial phase of several weeks in which as researchers we had visited their class regularly. Most interviews took place in the college prior to or after a lesson, in a classroom, an interview room or in the college's cafeteria. Other students invited us to interview them in their homes or offered to meet up with us in a public venue. Interviews usually took between 30 minutes and an hour, in some cases longer. The majority of the interviews were tape-recorded and later transcribed. However, some informants did not like the conversation to be taped. In these cases, we relied on our own notes. All interviews were organised and coded using the data analysis software N6 and we offered all our informants the opportunity to read and comment on their transcript. Few took up this offer.

A significant number of our informants were second language speakers. Depending on their degree of proficiency in English, we interviewed them in English or made use of an interpreter. In some cases, we were unable to find an interpreter who could work in the student's language and thus had to conduct the interview in English, although it would have been preferable to enable the respondent to speak in their own language. Among the first languages spoken by our informants were French, Spanish, Chinese, Polish and Urdu.

The interviews followed a schedule of questions which we used flexibly, so that there was enough space to take account of individual respondents' particular issues. We started the interview with background information on the person and when and why they had come to the literacy or ESOL class. After this introduction, we asked the students to recall a recent experience with a doctor or other health-care provider and what kind of reading and writing this involved. We used a series of questions to prompt a discussion of various texts and their experiences with these. For example, we asked about patient leaflets, prescriptions, package inserts, signage, etc. If the student was ill at the time we interviewed them or had recently been sick, the interview often focused on this particular health episode. We encouraged the respondent to remember everything that had happened throughout this episode and what reading and writing it had involved. Our 'best' interviews in terms of understanding the role of literacy in relation to health and health care were those that involved respondents suffering from chronic and, at times, serious illnesses. In a way, this is not a surprise: chronic, long-term or serious illnesses require frequent and regular visits to doctors and nurses, thus offering plenty of opportunity for encounters with written texts. Long-term or chronic illnesses, as we found, also made our respondents search for information themselves, using books or the internet or relying on friends and neighbours for support. We describe these experiences with health literacy in Chapters 5 and 6.

Some of our interviews were less 'productive' because the informant had not been ill or had only had minor health problems that were relatively easy to address and therefore had less need to engage with health literacy. But we also learned from these interviews. We understood that many of our informants had sufficient experience with common diseases to be able to deal with them without needing any additional information and that in these cases they might for example ignore package inserts.

In the final part of each interview, we asked our respondents about the role of health as a topic in the literacy or ESOL class they attended. We will explain in more detail in Chapter 7 what students told us.

3.1.2 Research activities in Phase 3

The 45 students interviewed in Phase 2 made up our 'larger' pool of informants, the majority of whom we interviewed only once. With others, although no formal follow-up interview was conducted, informal conversations allowed us to pursue some of the issues raised in the interview.

Phase 3 presented a continuation of Phase 2. Its main aim was to develop a better understanding of individual students' health literacy practices and their experiences with the health-care system. In order to achieve this we asked some of the students, who were already involved in Phase 2, to continue to work with us and to be interviewed again. We also hoped to be able to accompany them on their visits to health-care practitioners and/or to visit them in their homes. Five individuals consented to take part in Phase 3 – to be our 'close-ups'. The insights we gained from them and their experience present our five detailed case studies. They included repeated informal contact and interviews and in some cases visits to the students' home to discuss specific practices (such as how to know what medication to take when) or specific texts. Several of the close-ups shared their experiences of specific texts with us e.g. a leaflet. Two informants allowed us to accompany them on visits to the hospital or to a health-care practitioner.

3.2 Data analysis

Our method of data analysis followed a simple procedure: we read and re-read all our data in the light of the research questions. Based on this, we identified a series of themes – codes, as we call them – and sub-themes and we marked these in our transcripts. The main purpose of this exercise was to identify the themes that most closely reflected our informants' experiences. Once we had identified these codes, we read our data again, this time to find additional topics, which did not closely relate to our research questions, but covered additional issues brought up by our informants. To facilitate the process of coding and the organisation of our data along the codes, we used the computer software N6.

The first group of codes we used were about the literacy and numeracy demands of the health-care system (see research question 1). Reading through the interview transcripts and our field notes, we identified a range of written documents our informants had come across in their dealings with health-care providers. Our codes refer to these. For example, we identified codes such 'Literacy demands: leaflets' or 'Literacy demands: forms'. Chapter 5 is structured around these codes. Whenever we discuss a demand, we also describe the difficulties people told us they had with it. Our informants did not speak much about numeracy demands. Issues such as measuring and remembering the right dose of a medication to take were mentioned, but not felt to pose any problem. Only one informant described in some detail to us how he organised his tray of medication to take every day (see Chapter 6). In addition to the list of written language demands, we created a code for oral language demands. These were mentioned mainly by ESOL students, but it was obvious that for these students the ability to, for example, describe their symptoms to a doctor could present a problem.

The second set of codes we identified covers the strategies our informants used when dealing with the literacy and language demands of the health-care system (see research question 2). This set of codes includes issues such as people's reading strategies (e.g. reading with a dictionary), the use of mediators (other people helping with the reading of a

document) or ignoring the written text and relying on oral information instead. These issues are discussed in detail in Chapter 6.

The third set of codes covers the additional sources of information our informants drew on. By this we mean information that had not been given to them by a doctor or nurse, but which they had found themselves or which had been given to them by other people (e.g. friends). This set of codes relates to research question 3.

The fourth and fifth sets of codes address the role of health as a topic in ALLN classes (see research question 4). We asked all the student in our study about health topics in their classes, how useful they were and what else they might have wanted to learn about health and health care in their classes. We asked the teachers similar questions, but added to these their experiences as teachers when using health in their lessons. Here, we have included codes such as what specific aspects of health were discussed in class, how teachers saw the importance and usefulness of health as a topic for ALLN, etc. These codes closely relate to the content of the survey (see Phase 1 above).

3.3 Difficulties and limitations

In carrying out this research, we faced a number of difficulties and we had to adapt our original research design accordingly.

We had originally planned to find our study participants in GP surgeries rather than in ALLN classes. We soon had to abandon this idea. In the first months of the project we approached a number of surgeries in Lancaster with a request to take part in our study. We asked to be allowed to approach patients in the waiting room to seek their interest in our study. None of the surgeries approved of our idea for various reasons. Most practice managers simply rejected the idea because they felt it would disrupt their work. Others told us that we were very unlikely to find anybody willing to talk to us and that the surgery had ethical objections to our plan. Several surgeries explained that without prior approval from the local Trust, we could not work on their premises. This presented us with a dilemma. The Trust's Research and Ethics officers had explained to us that we were very unlikely to gain research permission for our project if we couldn't include in our application the names of surgeries and GPs willing to collaborate with us and to allow us on to their premises.

We were forced to change our study. As explained above, instead of finding our participants in surgeries, we focused entirely on students who we met in literacy and ESOL classes. In some ways, this solved our problems of access. However, there still remained difficulties with our study. Phase 3 involved no more than five students and contrary to what we had hoped for, only two of them allowed us to accompany them on their visit to a doctor. There are several reasons for this. Time constraints were one factor. Developing the kind of close and personal relationship necessary for the informant to share personal experiences regarding one's own health and well-being requires a considerable amount of time. In some cases, the student's unease in the wake of a situation that was likely to be private and intimate and could even be embarrassing, stopped them from inviting a relative stranger to accompany them. Most of our informants did not go to see the doctor on their own, but were accompanied by a family member or close friend. Our presence was felt to be unnecessary. Health is a sensitive and personal topic and some of our respondents dealt with very serious and long-term diseases. Literacy can also be a sensitive issue and some of the students were conscious of their own

skills deficits and embarrassed to talk to us (the researchers), who they perceived to be highly educated people.

As a consequence of these difficulties, we relied mostly on our informants' accounts of their visits to health-care professionals. With a few exceptions, we were unable to compare their accounts with what we ourselves were able to observe during a visit. We would have very much appreciated the opportunity to make such comparisons and they would have increased the validity of our findings. However, the reflective accounts of our informants' experience on their own provide many valuable insights into their experiences with literacy in relation to their health. This is particularly important for those amongst our informants who suffered from serious and long-term diseases. Some of these offered detailed stories of difficult and highly private moments and distressing experiences. Their stories are very revealing in terms of the role literacy played in how they dealt with these.

4 The study participants

4.1 Students

The following tables list all the 45 people who were interviewed in Phase 2 and 3 of our project. With the exception of two, all of them were students in literacy or ESOL classes. The people who participated in Phase 3 are: Peter (and his mother Margaret), Anna, Pamela, Shanaz and Kate.

Fourteen of our informants were men and 31 were women. Eighteen of our informants attended literacy classes and 26 were students in ESOL classes. The names given below are not the students' real names, but pseudonyms that either we or they chose to preserve their anonymity. Under employment, where occupation is given in brackets, this indicates employment in last job if unemployed, or before retirement or moving to the UK. The number in brackets after the country of origin indicates how many years the student has been living in the UK if they were born outside the UK.

Halifax Literacy

Name	Sex	Age	Employment/profession	Country of origin
George	M	40–50	Unemployed (gardener)	UK
Jeff	M	43	Unemployed (casual, manual)	UK
Shanaz	F	50s	Housewife	Pakistan/UK (31)

Preston Outreach Literacy

Name	Sex	Age	Employment/profession	Country of origin
Jing	F	30s	Chip shop counter assistant	Macau (8)
Jon	M	39	School caretaker	UK
Kate	F	45	Retired due to illness (marketing manager, bar work)	UK
Kathleen	F	50s	Retired (shop assistant)	UK
Lesley	F	Late 40s	Clerk	UK
Pamela	F	35	Cleaner (NHS)	UK
Peter	M	54	Retired (switchboard operator)	UK

Halifax ESOL Class

Name	Sex	Age	Employment	Country of origin
Abdul	M	29	Unemployed doctor	Sudan (less than 1 year)
Fouad	M	3	Works in restaurant	Algeria/France (less than 1 year)
Jalil	M	30s	Unemployed (artist)	Iran (1)
Mark	M	30	Student	Albania (3)
Mehdi	M	23	Works in restaurant	Iran (2)
Navid	M	32	Unemployed	Afghanistan (3)
Sediq	M	30s	Factory worker	Afghanistan

Preston ESOL Outreach

Name	Sex	Age	Employment	Country of origin
Razia	F	70s	Retired (primary teacher in Pakistan, housewife in the UK)	Pakistan (41)

Lancaster ESOL

Name	Sex	Age	Employment	Country of origin
Albena	F	31	Care assistant (nurse)	Bulgaria (2.5)
Amel	F	—	—	N. Africa
Anastasia	F	—	Housewife (doctor)	Russia (4)
Anna	F	30	Administrative manager	Poland (1.5)
Dipta	F	26	Henna painting	India (1)
Elisabeth	F	31	Unemployed	France
Fatima	F	37	Unemployed (architect)	Morocco (less than 1 year)
Gaspar	M	33	Chicken factory worker	Angola
Grace	F	28	Unemployed (PR)	China
Lin	F	35	Unemployed	Malaysia
Maria	F	35	Executive secretary	Brazil (5.5)
Sonia	F	38	Unemployed (bank employee)	Poland (1.5)
Wanda	F	34	Care assistant (nurse)	Poland (less than 1 year)
Zohreh	F	29	Housewife (nurse)	

Bolton ESOL

Name	Sex	Age	Employment	Country of origin
Fauzia	F	20s	Housewife	Pakistan (1)
Karima	F	26	Cleaner (dental nurse)	Iran (1.5)
Li	M	38	Chef	China (11)
Petra	F	21	Au pair	Czech Republic (1)

Lancaster Family Outreach

Name	Sex	Age	Employment	Country of origin
Debbie	F	20s	Housewife	UK
Gary	M	50	Retired (car mechanic)	UK
Joyce	F	55	Retired (ran a B&B)	UK
Karen	F	75	Shop manager/Children's nanny	UK
Muriel	F	27	Fast-food restaurant worker	UK
Sharon	F	30s	Housewife	UK
Yuree	F	—	Housewife	Thailand (3)

4.2 Teachers

Below is a list of the teachers we interviewed in depth. Those in bold are teachers whose classes we observed. Anita, Shirley and Wendy are teachers who participated in our survey. We got to know Sylvia, an ESOL coordinator, through our contact with the college in Bolton.

	Name	Class	No. of years teaching
1	Jane	Halifax Literacy	12
2	Trish (support teacher in Jane's class)	Halifax Literacy	5
3	Wendy	Manchester ESOL	24
4	Julie	Halifax ESOL	6
5	Joshua	Preston Outreach Literacy and Preston Outreach ESOL	New to literacy, 10 years ESOL
6	Sophie (support teacher in Joshua's literacy class)	Preston Outreach Literacy	14
7	Sylvia	Bolton ESOL	10
8	Scarlet	Bolton ESOL	20
9	Anita	Chorley Literacy	15
10	Shirley	Chorley Literacy	3
11	Louise	Lancaster ESOL	6
12	Pat	Lancaster Outreach Family Literacy	-

5 Demands and difficulties

In this chapter, we discuss the language and literacy demands that our informants told us about and the kinds of difficulties they experienced. Our focus in this chapter (and in the study overall) is on literacy demands. By this we mean the demands of having to read, write or act upon specific health texts. Much communication in health-care settings is mediated by written texts and as patients we may, for example, be asked to follow instructions or guidance provided by a leaflet. Our informants' experiences confirm this. We may also have to write, for example, when completing a form to register with a surgery. Again, this matches our informants' experiences. In addition to these reading and writing requirements of the health-care system, we have found that many of our informants use written texts (for example websites or health books) when trying to find information about a specific disease or treatment. We discuss our study participants' own information-seeking strategies in Chapter 6.

We have organised the following sections and sub-sections according to the type of documents and the difficulties our informants told us about. The order in which we discuss these reflects the frequency with which they were mentioned in our interviews and the detail in which they were discussed. It is important to explain here that although many informants told us about the literacy demands that they encountered when being ill, these demands did not always create difficulties for them. To some extent, this may be because people were embarrassed to admit their difficulties. From others we understood that they were perfectly satisfied with the parts of the text they understood and had found important enough to read. Many others successfully drew on their own resources and strategies to deal with challenging literacy demands. We describe these strategies in Chapter 6.

Although our interviews focused on the literacy demands of the health-care system, the demands of listening and speaking were brought up in particular by ESOL students and we therefore discuss them in a separate section.

5.1 The oral language demands of the health-care system

Elisabeth: I went with my husband.

Researcher: Right.

Elisabeth: But it was still difficult for the doctor to understand me and I can't understand the doctor as well.

Researcher: What happened?

Elisabeth: I just try to speak with my hands to explain. I took everything about my diabetes and took some things to show them. I took everything and it was a shock because it was impossible, I said, 'Well how can I explain? I don't know'.

This extract from our interview with Elisabeth, an ESOL student in Lancaster, reveals the common language demands of a consultation with a health-care professional. Elisabeth is describing her first meeting with her new doctor after she had moved to Lancaster. She had to tell him about her symptoms, explain her chronic health condition, give background information and be able to understand what the doctor asked and explained. Elisabeth was aware that both her doctor and she struggled to understand each other. The above short extract also demonstrates the manner in which speech is bound up with text and vice versa. While Elisabeth struggled to explain her diabetes to her new doctor she also showed him all her notes and records about her condition, which she had brought with her as an additional way of trying to communicate with him.

Nearly all the ESOL students in our study (Lin, Elisabeth, Gaspar and Grace in Lancaster; Li, Petra and Karima in Bolton; Mark, Navid and Shanz in Halifax; and Razia and Jing in Preston) told us about the need to communicate with receptionists, dentists, nurses, pharmacists and doctors. Anna and Lin specifically mentioned that they lacked the appropriate vocabulary to be able to express what they wanted to say to their doctors. Elisabeth also revealed how, because of her level of English, she was unable to assert herself to get a dentist's appointment over the phone. Navid, who had to attend the outpatient department of his hospital, explained how in the 'big' hospital there was no time for people to explain things to him in detail. Mehdi and Jalil, ESOL students in Halifax, also mentioned the difficulty in understanding local accents. In Chapter 6, we will describe some of the strategies these ESOL students used to overcome their difficulties with the oral language demands of the health-care system.

It was not only the ESOL students who mentioned the need to be able to talk to and understand health-care personnel. Kathleen, a British woman in her early 50s who had just started attending the outreach pre-GCSE Literacy class run by Preston College, struggled with the language used by consultants.

Kathleen: I mean I know what it is now, but I didn't before. You're thinking, 'What?' You know, there are always people, well, you know, suppose it is to make them feel important? I don't know. Because the doctors come out with these big words don't they? You know what I mean? And it does make them feel and look important and anyway, and this is how they put it, and there was one doctor that actually did ... but I already knew what it was then and he'd said, 'Aka ...' What is it?

Researcher: Oesophagus.

Kathleen: That's it. Yeah. Yeah. And he said that and I looked at him, and he also knew what I was thinking but, he already knew, and then he looked at me, and he turned round, and he said, 'gut'.

The above extract demonstrates the oral language demands of health-care contexts. Kathleen talked about how she was unable to understand and remember the specialised language the consultants used. It became one of her aims as a learner in the literacy class to be able to take part in conversations with doctors.

In the following extracts, Kathleen talked about the moment when she and her husband were told by the consultants that his cancer was terminal.

And so you know, and then I turned round, because they don't just do it once I have to admit, they don't just do it once, you know what I mean? They tell you about three or four

times and you know, you're thinking, 'Well, I'm trying to get my head round this, you know, and you keep – like a woodpecker. Keep pecking'. You know, like that, until at the finish, I think that were about the third time, and I just turned round, I said, 'Look can we just leave it there?' I said, 'You know, till we get our heads round it a bit like?'

Well that, I can't, it's like anything else really in a way, your kind of like, you're brain dead in a way, really, in a way, and even now some of the things that were said will never come back to me.

So, but it's what they tell you really in a way, they just stand there and I don't know what they expect you to say really, in a way. They just stand there and your life drains from you ... You know and you look at them and you think to yourself, 'Oh well what do you expect me to say?' You know what I mean? They look at you like you're on cloud ... well not cloud nine but you've got ... your mind's gone. You're goo-goo. You know what I mean? And they're looking at you and you're thinking to yourself, 'Well what do you want me to do? Jump up and down?' You know, they're the surgeons. They're the people who deal with it all the day. Have you got words to say to us? ... And then they just turned round and said like that well it's not the end, you know what I mean like? We'll make sure you've some quality of life, you know. You're standing there, you're thinking well what's that to me? You know what I mean? So I think they try and tell you too much.

Kathleen graphically explains how her husband and herself were in a state of shock and were not able to take in all the information that the consultants were trying to give them. She describes how being on the receiving end of all this information felt, how difficult it was to be told the same things repeatedly and to find words to say in order to carry on the consultation with the surgeons. We can see here the importance of emotion and affective issues in relation to health literacy. We will discuss this issue more fully in Chapter 6.

5.2 The literacy demands of the health-care system

Doctor's surgeries, hospitals and clinics are full of texts. Leaflets, posters and charts fill walls and tabletops. Buildings, rooms and corridors have signs giving directions and room names and numbers. Consultations with health personnel involve forms, records, charts, diagrams, prescriptions, instruction sheets and computers. We can speak of health-care environments as 'textually mediated environments' (Smith 1999) in the sense that texts are an important component of how information is conveyed in such spaces (for an example of the kind of texts commonly used in health-care settings see Figure 5.1). However, to what extent individual patients have to engage with any of these texts varies greatly and many of the written documents can be ignored. On one of our visits accompanying Anna to see her consultant, we noticed that of the many leaflets and posters displayed in the waiting room, none were consulted by any of the waiting patients. The only text that Anna had to use was the invitation for the appointment she had received.

Figure 5.1: Please think

NEXT TIME YOU ORDER YOUR REPEAT PRESCRIPTION

PLEASE THINK!!!

- please only order what you need
- don't automatically tick all the boxes on your repeat prescription form
- tell your GP if you have stopped taking any of your medication
- in Darlington tens of thousands of pounds are wasted each year from repeat medication that is never taken by patients
- please help us reduce this wastage so that the money can be spent on other important health services such as hip replacements and heart operations for the people of Darlington

In the following sections we discuss the main texts our informants had spoken about. These were:

- Leaflets
- Forms
- Letters
- Medicine packaging and inserts
- Signage in hospitals
- Keeping diaries and records
- Writing down questions.

We discuss our informants' experiences with these texts in the order given above, reflecting the frequency and detail with which they were discussed in our interviews. Leaflets and forms were the most commonly mentioned texts. In addition to the texts listed above, the study participants also mentioned menu cards, recipes and one informant mentioned an invoice from her dentist. Because none of the study participants described any difficulties understanding these, we do not discuss these here.

The majority of the texts listed above required our informants to read in order to understand and take action in relation to their content. This included working out the meaning of words and sentences, retaining the information they contain, and finding ways of keeping and organising texts. Other demands include being able to rate the usefulness of specific pieces of information, being able to write and spell sufficiently and in a form legible to others in order to complete forms, being able to write down questions and make notes or keep a diary.

5.2.1 Leaflets

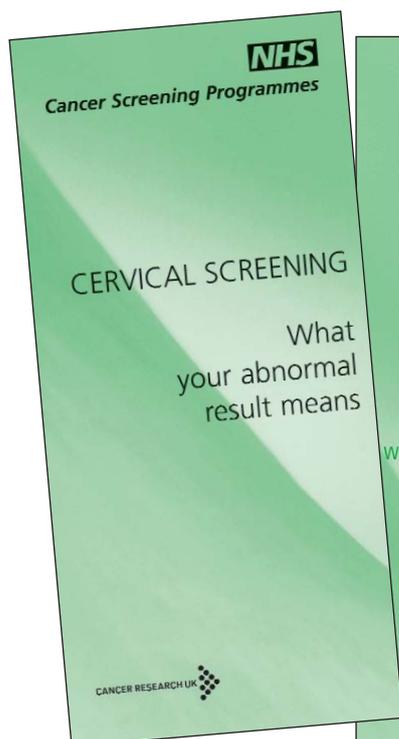
The type of leaflets that people told us about included:

- Hospital orientation leaflets – telling people what to expect from their hospital appointment or procedure, how to prepare for it and how to find their way to the treatment room;
- Leaflets about illnesses or health problems;
- Leaflets about screening services; and
- Leaflets about the health-care system – explaining how the local provision works and what services are available.

Dealing confidently with leaflets – Anna, Dipta and Lesley

We have chosen Anna, Dipta and Lesley's examples because we want to show that not all of our informants encountered significant difficulties with the leaflets they had been given. Some of our informants felt well informed by the written texts they had received. Anna is an ESOL student from Poland and she is one of our close-ups. After her cervical smear test, she received a letter explaining its results. Her results were 'abnormal' and mentioned changes to some cells. Such changes, as the letter explained, are called 'moderate dyskariosis'. In the same envelope, she also received a leaflet entitled 'What your abnormal result means' (see Figure 5.2). The leaflet further explained what it meant to have had an 'abnormal' result. It also describes a further examination, called a colposcopy, which the patient may receive. In several interviews with Anna, she explained to us how she reacted to the letters and leaflets and how she felt about the way her GP, and later her consultant, communicated with her. She was highly positive about the way she had been informed. The leaflet in particular satisfied all her information needs. When she visited the consultant, she was asked to raise any questions she had. However, she felt she had been so well informed already, that she almost had no need for further questions. But she appreciated being given the opportunity.

Figure 5.2: What your abnormal result means



NHS
Cancer Screening Programmes

CERVICAL SCREENING
What your abnormal result means

You have had an abnormal result from your cervical screening test. Cervical screening is designed to pick up minor changes before any problems develop, and almost certainly that is what the test has done for you.

An abnormal result is not unusual: about 1 in 20 women have test results that show some abnormality. It is important to remember that it is extremely rare for an abnormality found at screening to be cancer. Nearly all abnormal results show no more than small changes in cells. These act as an early warning sign that, over time, cervical cancer may develop.

What does my result mean?

An abnormal result usually means that small changes have been found in the cells on the cervix (the neck of the womb). The name given to these changes is **dyskariosis**. In many cases these changes return to normal by themselves. But sometimes the changes become worse and could lead to cancer in the future. In such cases it is necessary to have a further examination which will show if treatment is needed. Treatment is simple and virtually 100 per cent effective.

Fortunately, it usually takes many years for cancer of the cervix to develop. So it is very rare, especially in women who have regular cervical screening, for an abnormal result to show that cancer has already developed.

What causes an abnormal result?

Changes in the cells of the cervix are often associated with the Human Papilloma Virus (HPV), which is transmitted by sexual intercourse. There are over 100 types of this virus, and certain types are linked with nearly all cases of cervical cancer. Most women are infected with HPV at some point in their lives, but most infections disappear without the need for treatment. Even women with 'high risk' HPVs rarely go on to develop cervical cancer. HPV often shows no symptoms. It is therefore possible that you may have had the virus for many years without knowing about it, or a partner may have been infected many years ago and, again, not know.

What happens now?

For many women their abnormal result will show **borderline changes or mild dyskariosis**. These are small changes which often return to normal by themselves.

The areas of changed cells are known as cervical intraepithelial neoplasia, or **CIN**. Mild dyskariosis is associated with the grade CIN 1. These changes are not cancer, and in most cases do not lead to cancer in the future.

It is safe to give the small changes a chance to return to normal by themselves without having immediate treatment. If you have a test result showing borderline changes or mild dyskariosis your doctor will often ask you to return for a repeat screening test in around six months' time, but you may be referred for colposcopy (see below). If the repeat test is normal, you will be asked to have two more tests at six-monthly intervals to be sure that the cells are still healthy. If they are healthy, you will then go back to receiving routine screening invitations as before. If your repeat test still shows borderline changes or mild dyskariosis, you may be referred to a clinic for a further examination – called colposcopy.

For some women their result will show **moderate or severe dyskariosis**. These areas of changed cells are associated with the grades CIN 2 and CIN 3.

Even with CIN 2 or CIN 3 grade changes, it is unlikely that you have cancer. However, these changes are less likely to

Figure 5.2: What your abnormal result means contd.

<p>return to normal by themselves and usually need treatment.</p> <p>To decide whether you need treatment, a colposcopy examination will be carried out to investigate the cervix in detail. It is important that these changes are checked now, in case they become more serious in the future.</p> <p>What is colposcopy?</p> <p>This is a simple examination at a colposcopy clinic that allows the doctor to decide if you need treatment.</p> <p>An instrument called a colposcope is used. This is a type of microscope or magnifying glass which lets the doctor look more closely at the changes on your cervix. It does not touch you or go inside you. The examination is very similar to the screening test, so women may find it a bit uncomfortable.</p> <p>If you need colposcopy, make sure you receive the leaflet Cervical Screening: The colposcopy examination.</p> <p>What about treatment?</p> <p>If you need treatment following colposcopy you will usually be treated as an outpatient and there will be no need for you to stay in hospital.</p> <p>Treatment is nearly always 100 per cent successful. The area of changed cells will be removed from the cervix.</p>	<p>The method for this will vary from clinic to clinic, but it is a simple procedure and will be carried out under local anaesthetic.</p> <p>What follow-up will I need?</p> <p>If you do need treatment, you will be asked to have two follow up screening tests at around six-monthly intervals afterwards, to check that all the abnormal cells have been removed. If these check ups are normal, you will be advised to have tests every year for up to nine years. Assuming no further problems occur in that time, you will then go back to your usual screening interval of once every three to five years (depending on your age).</p> <p>What about sex?</p> <p>Sex does not make any abnormality worse, and you cannot pass on abnormal cells to your partner. Enjoy sex as usual, but you should use an effective contraceptive.</p> <p>It is important not to get pregnant until your abnormality is dealt with, as the hormones produced during pregnancy make treatment more difficult.</p> <p>Colposcopy will have no effect on your future fertility. The colposcopist will discuss with you the possible effect that</p>	<p>treatment may have if you become pregnant in the future. Pregnant women needing treatment may be advised to wait until after the birth of their baby.</p> <p>Further information</p> <p>If you have any questions regarding your condition or if you feel worried at all, do not hesitate to phone or make an appointment with your GP, who will be happy to talk to you.</p> <p>Summary</p> <ul style="list-style-type: none"> ● About 1 in 20 women have an abnormal cervical screening result, so it is not particularly unusual. ● Nearly all abnormal tests show no more than small changes in the cells on the cervix. These changes would probably never develop into cancer, but it is sensible to monitor them. ● Treatment, if needed, is simple and virtually 100 per cent effective. You will usually be treated as an outpatient. The colposcopist will discuss any effects treatment may have on pregnancy. ● You can have sex again within a few weeks of treatment. ● Having an abnormal screening result does not affect your ability to have children.
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In part, Anna's confidence in dealing with her condition and any information she received about it can be explained by the fact that she had had similar 'abnormal' results when she still lived in Poland. Back then, she had informed herself about the possible meanings of such results and the risk of cancer developing. Thus, as a patient in England, she was already well informed about her situation. However, since she now had to operate in English (of which she had a very good command), she did not understand every word of the texts she was given. But she didn't see this as a significant problem hindering her from making sense of their content. She simply looked up the words she did not know or she asked her (British) husband. There were some words that she had known, but whose meaning did not make sense in the context of her condition. An example is the word 'moderate'. She was familiar with it from listening to the weather report, but was not sure what 'moderate' meant in relation to her test. Another example was the word 'intercourse', which she had not heard before.

When Anna received her test result, she was worried and upset. But despite the difficulties she experienced with particular words, she emphasised that overall she found the written information she received very useful. This is significant because, as Figure 5.2 shows, the language and grammar of the leaflet are relatively complex. Many modal verbs are used (i.e. verbs which indicate possibility rather than certainty), indicating the author's need to warn readers of the possibility that the abnormal results could be a sign of cervical cancer without unduly frightening them. A range of adverbs are used to the same effect: 'usually', 'sometimes', 'almost', 'certainly' for example. When we asked Anna how she felt about this style, she was very understanding, explaining that the writer of the leaflet had no choice but to use modal verbs and vague adjectives, because when a woman receives this leaflet, it simply is not clear whether she has a cause for concern or not.

An additional factor in Anna's case was her trust in her consultant and her reliance on her husband, not only for help with words but also for emotional support. We experienced Anna as a very confident woman, who actively sought information and who, as far as we were able to

tell, did not hesitate to raise questions about her diagnosis and treatment. This is evident from her accounts of her conversations with her consultants, but also from how she communicated with us.

Dipta's experience presents us with a similar scenario. Dipta, another ESOL student in Lancaster, told us that she did not find a flu vaccination leaflet difficult to read because she was already familiar with the information it contained. In Chapter 6, Section 6.4, we will discuss in more detail how our informants relied on previous knowledge and experience in order to understand any information they received.

Lesley, a literacy student, also told us about how informed she had felt by the leaflets that she had been given by her doctor.

And there's plenty of information when you go to the doctor's, you know, various things, like because now I'm menopausal, when I went to discuss with her about it, you know, she gave me all sorts of like leaflets, go away, read this, type of thing, you know. Where I work there's a lot of ladies who are a similar age and they didn't have that information.

Lesley felt that she got what she wanted from the leaflets

Experiencing difficulties: Grace

Grace, a Chinese ESOL student, had been given a leaflet about cervical cancer screening provisions for women. She had great difficulties understanding this text. Not being fully certain what the leaflet was about, she asked her husband for advice. He, however, suggested that it was not necessary for her to take up the offer of screening. In this instance, we can see how Grace was made vulnerable in this situation, through her lack of vocabulary and her dependency on her (British born, English speaking) husband. The advice given by her husband meant that she did not make use of a facility that was freely available to her and that is an important preventative measure. Grace had kept the screening leaflet and she told us that she hoped to read it and understand it for herself as her English improved through her attendance at the ESOL class.

In all of our informants' accounts we could see that leaflets were nearly always given out or used in relation to oral information and/or in addition to other written texts. Listening to Anna telling us about her various visits to her GP and her consultant and remembering her prior experiences in Poland, it became clear that any written information she read was not consumed in isolation. The same is true for many other informants. Leaflets were usually handed out at the end of a consultation and often this was to support an explanation, which had been made orally. Other leaflets were sent together with an appointment letter. Thus, when the students in our research read a particular text, they did so in the light of other information they had received, be it orally or in writing. This means that whether they could understand and make sense of a specific text did not just depend on this text alone, but on all other information they had obtained and other knowledge they possessed (see also Chapter 6). This shows us that whether a text is 'readable' or not cannot be judged on the basis of assumed levels of health literacy alone. We always need to take account of the context and the reader's individual situation. We need to look at everything the person is doing in relation to making sense of and coming to terms with their illness. Furthermore, we need to include any conversations between patient and doctor which may have added to the patient's knowledge and understanding of her situation. Our data shows this. If Anna felt well informed and did not struggle with the complex language used in the written texts she had received and consulted,

this was in part due to her good command of English and her knowledge of her condition. So we can say that in part it was an effect of her good health literacy and her good general (English) literacy. But it was also an effect of her doctors' willingness and ability to successfully communicate with her, the support received from her husband and many other factors.

5.2.2 Forms

The various forms that our informants told us about were registration, consent and claims forms. Three of our informants spoke about disability or benefit claim forms. These forms constituted a significant literacy demand for them.

Gary told us that his wife filled in all of his forms, although he was responsible for other reading and writing in relation to his health, for example, keeping a record of his blood sugar levels and dealing with appointment letters and cards.

Peter and Kate commented on the size of the forms and the difficulty presented by the repetitious nature of the information being asked for.

Peter: And you're sort of repeating yourself a lot because they are like books basically.

Kate: They call them forms. They're not forms, they're booklets.

Kate: (My husband) got all the forms for Invalidity, Invalidity Care, Disability Allowance and Carer's Allowance, Mobility Allowance and all that lot. Everything came in and they're not forms. They're hopeless! Absolute, absolute nightmare. They are unreal, and it's like when we started filling in disabilities forms, oh, nightmare. It was like you'd start off with the first page and by the time you'd got to your third page it were all what you'd said on the first page, so to me it's a load of baloney. Do you know what I mean? And what you have to go into and what you have to tell them and all the rest of it. Why can't they just bring up your information on the screen? We are in 2000. You know what I mean? And go, 'Well yes, she is, yes it is an illness, yes it's the other thing?' You know what I mean? And just go, 'Yes, well she is genuine?' You know, 'she's not skiving'.

Kate: (It's) hard work filling in forms and like when you didn't understand them and they're like gooblygook questions.

Kate suffered from lupus, a severe and chronic illness. She was unable to complete the forms herself because she felt so defeated by her illness and by the nature of the forms. Her husband took on this task, working collaboratively with her. However, even her husband found the literacy demands of the forms challenging and this led to tensions between husband and wife as they tried to answer the questions on the form. They eventually asked neighbours for help and when this failed Kate's husband took the forms to the Welfare Rights Shop. As Kate commented, the information about her illness and disabilities that the forms were asking for, was already available in her medical record and she could not see why this record could not be used to prove that she was genuinely ill. Thus part of the 'demand' in this situation was for the repeating of information that in Kate's mind already existed in a professionally recognised and validated form in another domain.

Kate and her husband also found it difficult to gather together the (specialist) information that was required by the disability forms, as her illness was a rare one. The demand here was for

identifying and being able to use the specialist language of her illness.

Kate also spoke of the problems she and her husband faced in spelling well enough to complete the form. Where she wanted to use words like 'depression', which she felt expressed her identity and situation appropriately and which she thought of as a 'big' word, she was left using words like 'fed up' as she couldn't find out how to spell 'depression'.

If it wasn't for my husband and for my sister doing all the form writing I don't know what I'd have done, because I couldn't have done it. I couldn't have done it at all, because I find the questions very intimidating. The spelling for me is intimidating because, like I say, I want to write big words and I can't, so I always go for little words, so anybody picking up that form will think, 'Oh, she's thick'. You know what I mean? It's insolence, I don't care what they do. You know what I mean? Well she's really expressed herself, hasn't she? You know what I mean? Because I do it myself. I say, 'Oh, has a five year old written this?'

Kate attempted to use newspapers and magazines to look up the spelling of words, but she was not successful. It was only when she attended the literacy class that she acquired a dictionary for the first time.

Kate's experience with the benefit claims form made her feel powerless as she couldn't express herself in the way she wanted. Her struggle to express herself in ways she deemed appropriate for the medical context made her painfully aware of her own lack of literacy.

5.2.3 Letters

Several of our informants told us about letters they had received in relation to their health care. Some of the ESOL students who were refugees were sent an appointment letter from a doctor's surgery soon after they had arrived in the country.

Other informants received appointment letters from their hospital consultants or invitations to screens and routine tests. Most of them were contacted in writing about the results. In some cases, patients could choose whether to be contacted by telephone or receive a letter.

None of the students we interviewed reported any problems understanding these kinds of letters. But we have reasons to believe that some students did have difficulties with letters. Several of their teachers told us that students bring such letters into the college and ask for help with understanding them (see Chapter 7).

5.2.4 Medicine packaging and inserts

Nearly all of our informants had at some point been prescribed medicines or had bought over-the-counter medicines to deal with a health problem. When doing so they either needed to deal with a prescription form (see below) and/or with the text provided on the medicine packaging and on the insert inside.

Margaret, the mother of Peter, a literacy student in the Preston outreach class, always carefully read each of the medicine inserts for the medication that she and her son were prescribed, checking that the medicines did not clash with other pills they were taking. On one occasion, Margaret had found that the nicotine patches she had been prescribed by her doctor should not be taken by someone, like herself, with diabetes. Thus she had to decide between two conflicting pieces of information: her doctor's advice and the instruction given on the insert. This is an example of a difficulty that can arise when two pieces of information do

not add up. We will return to Margaret's experience in Chapter 6.

We specifically asked our respondents about the information written on the boxes or labels of their medicines and the information provided by the manufacturer on the inserts inside the boxes. Many of our informants appeared to have no difficulties with boxes and labels or they asked others to help them with the reading (see also Chapter 6). Others, however, struggled. On one occasion Sonia was not sure whether she had to take her pills before eating or together with her food. Gaspar, an ESOL student from Angola, said he could not understand labels and inserts. But he also explained that both his GP and his pharmacist instructed him orally on how to take his medication and what to be aware of. Other respondents expressed similar views. They were satisfied with the instructions given by the doctor and did not see a need to read the inserts. Others read only part of the information provided.

5.2.5 Signage and maps

We were interested in how the people in our study found their way around hospitals, as these environments are often vast – as one respondent reported 'maze-like' – places. Information about where to go is generally provided through signage and maps. Patients attending an outpatients clinic, as many of our respondents had done, need to be able to find their way independently to the correct area of the hospital using maps provided with their appointment letters or using the signs and/or maps in place in the hospital.

Some of our respondents (including Pamela, Gaspar, Grace and Kate) found the hospital signage easy to follow. Anna and Jing relied on the maps that they had been sent together with their appointment letters. Gary's hospital used coloured lines to lead outpatients from the hospital entrance to the correct reception. The appointment card was printed in the same colour as the line to be followed. By following the colours, Gary had no need to use other written signage or maps.

Other respondents relied on the support of friends or asked the people working in the hospital for directions. In that way, they 'avoided' the literacy demands of map reading and signs. Lesley and Lin both asked a receptionist or nurse for oral directions when they attended the outpatients department. Peter said that if he did get stuck he used 'the tongue in my head'. When Mark, an ESOL student from Halifax, went to the hospital for the first time, a friend helped him find his way. Grace took a friend along to a Family Planning Clinic to help her find her way but she also asked the receptionist for directions.

5.2.6 Diaries and records

Some of our informants had been asked by their consultants to keep a record of their health.

Peter had to keep a record of his digestive system. Gary had to check and keep a record of his blood sugar levels. Although both were given instructions about what to record, neither received guidance on how to write down the information they gathered.

Kate had been asked by her psychiatrist to write about herself and how she felt about her illness. But because of her difficulty with spelling she was impeded in doing this.

It was like depression. I couldn't write that, so I'd do it my way. You know what I mean? And then I'd look at it and then I'd think, no, that doesn't look right, but it was like big words ... I couldn't do it. It was in my head. This story was in my head and I just couldn't put it down on paper, so I'd use an alternative word ... You know, instead of using a big

word like 'I was really depressed', I would put, 'I was fed up', you know, but I really wanted to put 'depressed'.

Just as with her claim forms (see above), Kate felt she could not use the words she wanted when writing her diary and therefore was not able to express herself, or describe herself in the way she wished even in this most intimate, self-reflective context. This made her feel disempowered.

5.2.7 Writing down questions

Kathleen: They used to turn around and say if you've got questions you want to ask, write them down. And half the time I couldn't write it down. ... I found that hard reading because the questions I wanted to ask I couldn't write them down. I could write it down but sometimes it's really bad, you can't read it.

Kathleen's husband's cancer specialist advised her to write down any questions they had about his diagnosis and treatment and which they would want to ask him at their next meeting. Kathleen tried to do this, but was not able to spell all the words she wanted to use in her questions, and so when she came to consult the questions she had written down, she couldn't make sense of them.

5.3 Demands and difficulties relating to the health-care system

In addition to the more specific language and literacy demands which we discussed in the previous sections, the ESOL students in our study had to familiarise themselves with the English health-care system.

In Chapter 6, we will show that most ESOL students relied on their families, friends and community organisations to support them in negotiating their way around health-care provision. In their ESOL class, they learned about the NHS and how to get access to doctors (see Chapter 7).

A related difficulty was the need to 'translate' between different health-care contexts. As already mentioned, Anna received treatment for some abnormalities in the cell structure that had been found in a smear test. She had had similar test results while she was still living in Poland. But she told us that she couldn't find out whether her tests in Poland had been better or worse than her more recent results. In England she was told that she would have to have a colposcopy examination. She was uncertain whether this was the same as the examination that she had previously had in Poland.

Gaspar, an ESOL student from Angola, faced a similar problem with regard to the medication that he had been taking for a long time in Angola and Portugal. His English doctor did not recognise the name of the pills he had been prescribed in Portugal.

5.4 Conclusions

In this chapter we have discussed the literacy demands of health-care settings. We have considered a variety of texts our informants had to deal with. We also addressed oral

language demands. Numeracy demands were mentioned very rarely. One of the few examples was from Gary who needed to measure and record his blood sugar levels regularly.

One of the issues that emerged from considering the oral language and literacy demands and difficulties of health care is that there is an affective side to health literacy. Some of our informants faced difficult news or had to understand a test result that could indicate something serious. In such situations, patients are required to take 'informed decisions' and they are often given a written text to help them make these decisions. It is of course important for patients to understand the information they are offered. But 'understanding' here is about more than decoding the words in the text. It requires dealing with the information at an emotional level and deciding how to act. Some of our informants felt that busy doctors and hospital staff didn't give them the time they needed to understand and take in what they were told or invited to read.

The difficulties our study participants told us about suggest a number of things literacy and ESOL teachers can do to help students be more confident in their dealings with health information. ESOL classes clearly have a role to play in helping students acquire the vocabulary that is needed to describe symptoms to a doctor. The ESOL teachers in our study were already offering such lessons and their students confirmed how much they had benefitted from these. A more general point arising from our discussions with literacy and ESOL students relates to confidence. By this we mean the confidence to speak to health professionals, the confidence to ask questions or to take a leaflet back to a doctor with a request for clarification. Literacy and ESOL classes can support students in becoming more assertive when dealing with health professionals. Role plays for example, simulating the 'formal' and potentially disempowering context of health care, can be used to develop strategies for 'talking back' and raising questions in communication with doctors. We will come back to these suggestions for teaching in the conclusions to the report.

In the next chapter, we present the expertise and enterprise of people in dealing with the demands and difficulties they encounter in taking care of their health and that of others. Teachers can build on such strategies in their lessons.

6 Strategies for dealing with the literacy and language demands of health care

In the previous chapter we outlined the literacy and oral language demands and difficulties of health-care settings our informants told us about. In this chapter we discuss the strategies they used in order to deal with these demands and difficulties. We have structured the chapter following the codes we identified when reading through our data (see Chapter 3). The content of Chapter 6 responds in particular to research question 3.

6.1 Strategies for dealing with the oral language demands of health-care settings

In the previous chapter, we explained that many of the ESOL students participating in our study had difficulties explaining their symptoms. In order to overcome these, some of them wrote things down in preparation for their visit. Others took dictionaries with them to the doctor.

Before going to the surgery, Elisabeth wrote down some of the points she wanted to tell her doctor about. Sonia and Jing both used dictionaries to write down words to use when explaining their symptoms. Sonia prepared a list of words and phrases in advance of her appointments to use as prompts when talking to her GP. Jing used her dictionary to write down words for her doctor to read. Gaspar used a phrase book before he went to see his GP. He always took the phrase book with him to the surgery.

Other respondents prepared themselves for medical examinations by reading about the test they were to undergo and what it involved. Pamela searched the internet to find out what was involved in a colonoscopy that her husband had to have. She made notes of what she read. Anna read all of the leaflets that she was provided with by her doctor's surgery in advance of the various tests that she needed to have. Before going to the doctor, Jon, another literacy student, looked things up in a family medical book.

Peter, already mentioned in Chapter 5, prepared himself for all of his hospital appointments by making and keeping up to date a list of all the medication that he was taking (see Figure 6.1). He did the same for Margaret, his mother.

Margaret: Well Peter has written my list down because when you go to the hospital they say bring your medication. Now you'll see the big boxes out there that Peter has now (referring to all the boxes of tablets in the kitchen that were for Peter). They'll say are you on so and so? I said well you should know that, you give me them.

Figure 6.1: Peter's list of his medication

<u>LIST OF CURRENT MEDICATION</u>	
2	Mesalazine 500mg tablets twice a day
1	Doxazosin 4mg capsule a day
1	Finasteride 5mg tablet a day
1	Codeine Phosphate 30mg tablet 4 times a day
1	Bendrofluazide 2/5mg tablet a day
1	Simvastatin 20mg tablet a day
1	Lamotrigine 50mg ¹⁰⁰ tablet twice a day
1	Perindopril 2mg tablet a day
2	Azathioprine 50mg tablets a day
1	25mg tablet a day

6.2 Strategies for dealing with texts

In this section, we focus on the particular strategies our informants used in order to deal with the texts they encountered in relation to their health. We found that these strategies could be divided into the following:

- using dictionaries and phrase books to understand leaflets and other texts;
- reading a text in the light of previous information or experience;
- using a reading mediator (we will deal with this strategy in Section 6.3).

6.2.1 Using dictionaries and phrase books

One of the demands that we noted in the previous chapter was the need to read and understand leaflets, forms and letters received from health-care providers. Many of the ESOL students we interviewed used dictionaries (dual-language or English-only dictionaries) to help them understand words and phrases they did not know.

Anna bought a Polish-English medical dictionary to help her with the leaflets she was given by her doctor. She used this and a general dictionary to look up words, such as 'intercourse', that were unfamiliar to her (see Chapter 5). Sonia, Karima and Sediq managed to complete their registration forms with the help of their dictionaries. Zohreh, an ESOL student in Lancaster, used a dictionary to read the inserts in medicine boxes and to understand the printouts that her GP had given her. Her dictionary also helped her make sense of the information that she was given by her health centre about vaccinations for her young daughter.

Kate (see Chapter 5) used a dictionary to look up spellings whilst she and her husband were

filling in one of the disability claim forms. But having to work with the dictionary led to frustration and tension. It was much quicker and easier to go to the Welfare Rights Shop.

Kate: I mean yeah, I do have dictionaries, but by the time we've got the dictionaries out and he's had a bloody go at me, you get frustrated and it's not worth it because by the time he's had his blooming tantrum and I can't be bothered with him, we don't get nothing done.

Researcher: Okay.

Kate: So the majority of the time I go to my sister or we go to the One Stop Shop in Leyland which is the Welfare Rights.

6.2.2 Reading a text in the light of previous information or experience

Successful readers bring what they already know to the reading of a text. Our informants read texts that they had received, or found for themselves, in the light of their prior knowledge and experience.

Dipta already knew about flu vaccinations and thus had no difficulties understanding the information contained in the leaflet she had received from her surgery. Mehdi, an ESOL student in Halifax, knew about the medicines on sale in the pharmacy because he had seen them advertised on the television. He recognised them, because they were also available in his home country.

How our informants read leaflets and other written health texts also depended on what their doctor or nurse had already told them about the illness or treatment in question. Leaflets were often given to support or extend oral information. As mentioned already, for some of our informants this meant that they did not see the need to consult the written information they were given in any detail, as they were happy with what their doctor had told them. For others, the important point was that the doctor's oral explanations helped them make sense of at least parts of the information. This also partly explains why many of our informants told us they didn't have any difficulties with the leaflets they had received. In their view, it wasn't necessary to comprehend every word.

6.3 Drawing on social networks and accomplishing literacy tasks collaboratively

One of the commonest ways the people in our study coped with the demands of reading and understanding texts, was through using other people who could read and understand English texts better than they could, who had better understanding of certain diseases or who were more familiar with the working processes and structures of the health system. This we refer to as brokering or mediation. Mediation is a term commonly used to refer to 'a person who makes his or her literacy skills available to others, on a formal or informal basis, for them to accomplish specific literacy purposes' (Baynham 1995: 59–60, see also Baynham and Masing 2000, Jones 2000). The same process can also be called 'brokering' (Robins 1996).

Many of our informants described the ways in which they were able to call on other people as a resource. Our respondents were often members of rich social networks through which they were able to access the support and information they needed. While we could argue that the use of mediators is a sign of the fragility of people's literacy skills, the accounts of mediation

that we present in the following pages lead us to suggest that mediation, rather than being a weakness, should be regarded a strength. Being able to identify and make use of appropriate mediators is one of the expert ways in which people deal with the literacy and language demands of health-care settings.

6.3.1 Family mediators

Dipta provides us with a good example of how a family network works. The first time she had to go to the doctor in England she was scared and asked her mother-in-law to go with her, even though she did not know very much English. Later, her father-in-law went to the pharmacy to buy medication for her, and her London based sister-in-law passed on the name of a drug that Dipta might find helpful.

Other interviews with ESOL students revealed similar scenarios. Jalil asked his daughter to help him read the instructions for his medication. Razia, an ESOL student in the Preston outreach class, asked her son for help with reading medicine packet inserts. Mehdi's father accompanied him to the doctor and dentist, as he spoke more English than Mehdi and was more familiar with the local accent. Mehdi's mother went to the pharmacy to buy him some medicine for his cold and she read the dosage and contraindications for him. A neighbour, also from Iran, passed on information about dentists and gave them several dentists' telephone numbers when Mehdi needed to register with one.

Family networks are not necessarily stable and when a partner died or left a relationship other mediators had to be found to take over their role. When Razia first came to live in England her husband always went with her to the surgery. He also went into hospital with her when she had her first baby. Since she became a widow, Razia relied on her son, as well as other family members and friends, to read medicine packaging for her. Jing told us that when her son moved away she had to start asking her daughter for help with the vocabulary she needed when talking to her doctor.

The examples of literacy mediation which we have described so far, all concern ESOL students who by virtue of the fact that they were still learning English and developing their knowledge of the health sector, frequently relied on family members. We found that literacy students operated as much within social networks of support as did the ESOL students. Kate, for example, relied on her husband and her sister to help her read the forms she had been sent to fill in as well as to read inserts. The wives of Gary and Jon both helped their husbands with writing tasks. Jon's wife could tell him the correct spellings of words, whilst Gary's wife filled in his disability claims forms for him. She read the questions on the form out, Gary answered, and then she wrote down what he had said. Gary thought of himself as 'not a very good writer', so he was happy to let his wife do the writing on his behalf. Both George's and Kate's sisters wrote on their behalf to professional support associations in order to get more information about their chronic illnesses. Kate's sister undertook many other literacy tasks for Kate, alongside other members of the family who also acted as mediators. These will be discussed later in this section.

Peter and his mother Margaret are a good example of how two family members collaboratively deal with health issues. We have already mentioned how Margaret checked all of Peter's medications for him to make sure they could be taken together. This was partly because Peter had a visual impairment and reading the small print on medicine inserts was a huge task for him.

Peter: My mother is very helpful ... because when you get tablets or creams they've got instructions on the box, but also inside, they've got about what you can take with them ... and so she reads a lot of that for me, which is useful, because I mean you don't always do it. I mean at the moment I'm taking eighteen tablets a day ... she always does that. I tend to be a bit lazy.

Peter and Margaret also supported each other in dealings with their consultants. They had helped each other make a personal list of their medication (see above). Both were involved in writing the lists. Margaret copied down the names of the medication for each of them in big letters on a piece of paper. Peter then typed this list using his PC and printed it out. Margaret kept her list in her handbag. Margaret also phoned Peter regularly to check that he had taken his pills. She bought him a special tray for organising his tablets into morning, lunchtime and evening dosages for the week. At the beginning of each week, they sat together to arrange the tray. Margaret set out the tablets and checked the inserts to make sure that Peter could take the various tablets together. Peter then placed the tablets in the right section in the tray.

Kate's family provided a great deal of support and mediated many of the demands and difficulties that Kate faced in relation to her health and dealing with the chronic disease of lupus. Kate's account of her family's role as literacy mediators provides us with a rich example of how literacy support is achieved within a family. Crucially, her experience also shows that literacy mediation goes far beyond help with understanding specific words, sentences or leaflets, but includes advice in terms of where to find support and how to seek help (for example from specialists). It includes much needed emotional support in dealing with experiences of disease, which can affect the person both physiologically and psychologically.

When she was first diagnosed with lupus, Kate did not know anything about the disease. But she trusted her doctor and she did not want to know too much about what was happening to her. However, after five years of living with lupus, Kate found herself bedridden and very ill and felt strongly that her doctors were not treating her condition properly.

Feeling let down by her consultant, Kate turned to her sister Jenny for information and support. On the internet Jenny found the websites of the Lupus Foundation of America and Lupus UK. Both contained a great deal of information about the symptoms of lupus and its treatment. Jenny printed off this information and gave it to Kate, who organised it into a folder to be at hand for reading when she felt able to do so. Through the sites Jenny also found out about an alternative health treatment for lupus that she told Kate about and ordered on her behalf. She compiled a list of the names and addresses of all the health experts who were mentioned on the websites and wrote to all of them. Jenny found two doctors in the UK who specialised in the treatment of lupus. Through writing to Kate's GP she got appointments with them.

Kate was seen by both of these doctors and at the time of the interview was being treated by one of them.

We can see here the important role that a family member played in mediating the demands and difficulties that Kate faced in relation to her health. But Jenny also provided important emotional support.

Kate: I wouldn't do without her, and she wouldn't do without me, and I suppose when she saw me in the state that I were in, it were like she shook me up and I shook her up and we both got on with it and we enjoyed doing it, because it's something to do together, if you know what I mean.

Sue: Okay, so the kind of dealing with this lupus thing, is actually something you did together, it brought you together.

Kate: Yeah. Yeah. And I mean like I say, I couldn't work a computer, I couldn't have done, I don't even know how to turn the bloody thing on, you know what I mean? But we go round and we have lunch and we talk and we talk about family and we talk about problems and we talk about you know, like things you wouldn't talk to your husband about. And the kids are not there so you can have a moan about them and then she'll say, 'How are you doing?' and, 'When's your next appointment?'. So we'll go a bit into that, and then like if she's messing about on computer she'll go, 'Oh, I've got another bit of a snippet information'. You know what I mean? But I think we exhausted everything on the internet.

It is also noticeable in Kate's account how the literacy tasks related to her conditions are seen as *jointly accomplished* by Kate and her sister or other family members. As she says here, 'it's something we do together'. This reminds us of Peter and Margaret's sharing of tasks.

6.3.2 Friends as mediators

Friends also played a key part in people's social networks in relation to health. Li asked his friends to translate the words his doctor had written down for him. Mehdi, Razia and Mark (who is from Albania and now living in Halifax) all said that they asked friends to help them read the inserts in their medicine boxes, to check for dosages and contraindications. Mark's girlfriend helped him fill in his new patient registration form. An Albanian friend who had lived in England for some time helped him find a dentist.

When her husband was diagnosed with terminal cancer, Kathleen was able to talk to her church friends. Kathleen's friends provided her with important emotional support. Peter belonged to the same church as Kathleen and it was Peter who told her about the literacy class and supported her in coming along.

Some of our respondents were able to access the support of friends who had professional expertise. For example, Wanda, a Polish ESOL student, got information from her work colleagues in the health-care sector about how to get registered as a nurse in the UK. Lin's friend was a Chinese translator for the police. This friend was able to help Lin register with a doctor, make appointments, get information about health issues and she translated for her during consultations.

6.3.3 Key workers and health professionals as mediators

The people in our study also called on health professionals and social workers for support. In section 6.2.2, we have already mentioned that doctors and nurses provided a mediating role by orally explaining the content of leaflets and other texts. Others wrote down important information for their patients. When Anna's consultant explained the test procedure to her, he drew an image of a uterus on paper so that she could understand what he was about to do. Jon's doctor showed him what was causing his back pain by using a chart of a skeleton. In both these cases, health professionals used visuals to support their explanations.

A nurse at Gaspar's hospital explained to him the importance of taking his medication every day and the consequences of not doing so. Before coming to England, Gaspar had already used the same medication for many years. But he had not taken it regularly. Pamela's nurse had shown her how to use her inhaler, so she felt no need to read the instructions that came with it.

The above scenarios show that for the people in our study, the literacy demands of the health-care system were often reduced or removed through the support of various types of mediators. Thus, some patients did not engage with a lot of written texts. Mediators often turned texts into oral language. For example, when forms had to be filled out, they took on the writing, so that the patient only had to answer orally. This practice was mentioned by George, Jeff, Navid and Kate.

Jeff was a student attending the literacy class in Halifax. He described himself as an alcoholic who suffered from depression and was disabled. He was in his early 40s and did not work. He was helped in his daily life by a number of support workers from a variety of organisations in addition to his GP. He lived in sheltered housing where he had access to continuous support. Once a month, he went to Dashline, a drugs and drinking support organisation. He also attended a day centre once a week for people with learning difficulties and mental health issues. He also regularly went to AA meetings and he relied on the support of other AA members in his day-to-day life. Once a month Jeff could access respite care services and he met with his psychiatrist every three months.

Despite experiencing many health problems, Jeff rarely mentioned dealing with texts during our interview. This was because Jeff was plugged into a network of support workers and professionals who took care of any literacy demands or turned the texts that he needed to deal with into oral language.

Researcher: Do you ever have to fill in any forms when you go to these various places (meaning the respite care, the day centres, the psychiatrists etc)?

Jeff: No I don't fill in forms. They (referring to his key workers) do that, all I do is sign it.

Researcher: So do you ever read any of those things they put in the medicine packets, you know all those information...?

Jeff: No but me key workers does sometimes.

Researcher: So they do it for you?

Jeff: Yes because the writing is so small I can't see the writing, so they do it for me.

It became very clear through the course of the interview that Jeff's support workers (his key workers, as he calls them) removed any need on his part to engage directly with texts. Jeff was happy with this.

Researcher: So actually there is quite a lot of information available to you from all these different people. And do you get most of the information and find out about things through talking or do they give you things to read?

Jeff: They give you through talking.

Researcher: Through talking, and do you prefer that?

Jeff: Yeah

We can see from the above extracts of our conversation with Jeff that he was dealing mostly with people and not texts. There was no need for him to read leaflets or forms, nor to use books or to search for information on the internet. He only engaged with texts collaboratively through other people.

6.3.4 Conclusions: Relying on mediators and collaboration – two important literacy strategies

The support provided by mediators included mediating writing tasks, mediating information, providing emotional support, helping with physical tasks and checking up on a family member. Our examples show that the role of mediators goes far beyond 'reading', 'writing' or 'translating' in the narrow sense of these terms. In addition to offering crucial support in dealing with specific skills gaps, literacy mediators help to make sense of the broader experience of being ill, of suffering pain, of dealing with health-care providers, of taking medication and undergoing treatment. Mediators can also intervene in the power relations that exist between health-care providers and patients. Feeling unable to express oneself properly (in writing or orally) can exacerbate patients' feeling of lack of power and their inability to assert themselves in the face of a system of 'experts' and expert technologies. Mediators, be they friends, families or social workers, can mitigate these feelings by speaking or writing on behalf of the patient.

The examples that we described above show that patients draw on others to help them in situations where their own communication skills are not enough. In so doing, they can accomplish more than they would be able to do on their own. Through mediators and social networks, people's literacy and language abilities are shared and for the individual this often means that their own literacy repertoire is extended.

Although in the majority of the cases we found, social networks 'worked' and mediators empowered patients, having to rely on mediators can also put the patient at a disadvantage. How, for example, does Jeff get by when none of his support workers are around? Because of her husband's advice, Grace missed an important preventative measure (see Chapter 5, Section 5.2.1). There are also situations in which social support is not available. When Pamela had a miscarriage she found that people, even close family members, did not want to speak about it.

6.4 Calling on previous experience

Earlier in this chapter, we suggested that our informants read leaflets and other texts in the light of any information they had gained through other sources. In this section, we look at how the people in our study called on previous experiences in their lives in order to take care of their health. People carry with them through life the insights and knowledge gained from previous health episodes, and they apply what they have learned in one context or through one particular incidence to new situations. Our ESOL informants, particularly, often reminded us that they had experience and knowledge of dealing with health issues, medication and health texts gained before they had come to England.

Mehdi for example knew a lot about treating a cold and using painkillers. Because the same painkillers he bought in England were also available in Iran, he did not have a problem reading their names or knowing how many to take. Zohreh found the booklet she was given in the UK about pregnancy, and the information she received about smear tests, easy to read because she had already had a baby in Iran and had had smear tests before. She was familiar with the kinds of topics the booklet touched on and able to call on this knowledge when reading it.

Anna called on the information she had received in Poland about the tests she had undergone and her doctors' subsequent responses to the test results. Her comments about reading and understanding the leaflets show the expert way in which she drew on this previous experience (see Chapter 5).

However, as we have explained in Chapter 5, there can be problems in 'translating' between two different health-care systems and thus prior knowledge cannot always be relied upon.

6.5 Seeking out information

Many of our informants sought out additional information to advice received from their health-care provider. They searched for information and advice in books, on the internet, in magazines and on television. In this section we discuss which sources of information people drew on and how they went about finding it.

6.5.1?Using books and the internet

Several of our informants used books either in conjunction with the internet or on their own. In Jon's family, when somebody was ill and needed to see a doctor, they first used a family health book 'to get an idea of what it's about'. Jon said about the information he found in the book 'it's not a lot, it's only a page, but it's very basic ... it's very sort of condensed' whereas the internet, 'now that's a minefield'.

When Jon's teenage daughter was diagnosed with a thyroid problem, he went on to the internet to find out more about her condition and to reconcile some conflicting information. According to his family health book, people with his daughter's condition are expected to gain weight. But his daughter was losing weight and Jon and his wife were extremely worried that she was not eating properly. On the internet, he learned that in 10 per cent of all cases, patients don't gain but lose weight. This put his mind at rest. This example shows that although Jon clearly didn't find the internet an easy resource, he nevertheless managed to get from it what he needed.

Fouad also used both books and the internet to find out about health issues. He had already done this when he still lived in Algeria and France. If he wasn't satisfied with what he found in a book, he used the internet. He suggested that the internet is more up-to-date. Like Jon, he used it to supplement and check the information he found in books. For Fouad, books were for reading carefully, while the internet was for checking information he had found elsewhere.

Unlike some of the other students in our study, Pamela could not find what she looked for in the library. Pamela had had two miscarriages and wanted to find out her chances of having another. The only books she could find were pregnancy books and they only contained a few lines about miscarriage.

Pamela also felt unable to ask for information:

I think it can be a bit of a taboo thing as well, miscarriage. I don't think it's the kind of thing you can do, go to the library, and ask for books on miscarriages. There is this look of horror on people's faces ... You can't ask 'I want to know why I had a miscarriage. I want to know if it will happen again.' They'd think I was a mad woman.

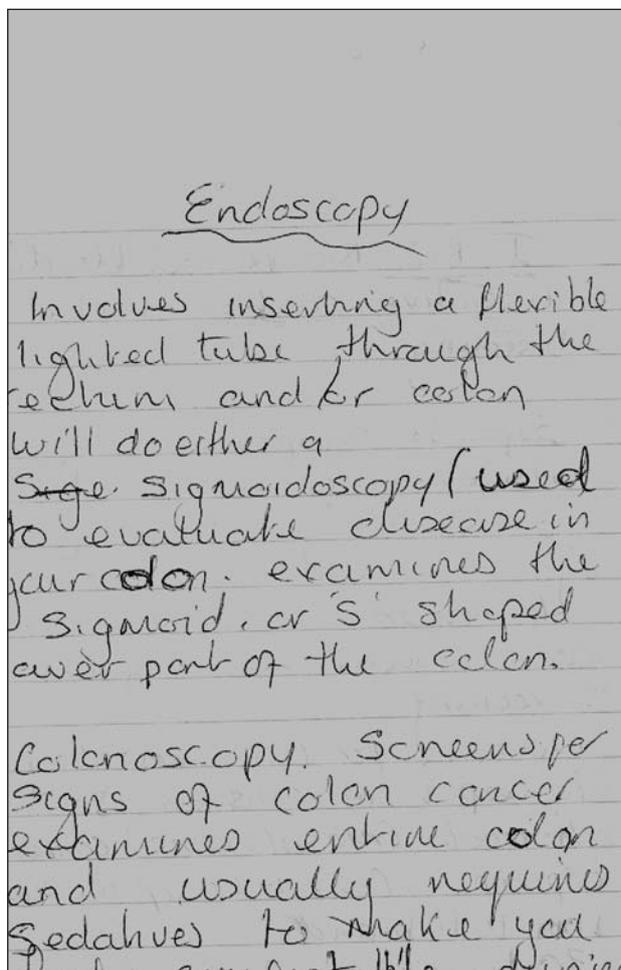
Pamela then decided to search the internet and she found that:

No one laughs at you on the internet.

Pamela also looked up information about tests, such as endoscopy and colonoscopy, that her husband had to have and made notes on what she found out (see Fig. 6.2 below). Again she found the internet extremely useful.

And it's telling you, I mean you can go to the doctor, and be told you have got that and you can have that, but they don't tell you everything, but this gives you much more information, you know, why have you been sent for this test and what are they looking for, what are they going to do and ...

Figure 6.2: Pamela's notes on endoscopy



The internet also offers a specific resource for ESOL learners, because they can search pages written in English and in their own language. This was mentioned by several of our respondents.

6.5.2 Using magazines and television

Shanaz (an ESOL learner from Pakistan) watched television programmes about healthy eating and how the right diet can help one to stay healthy and cure illnesses on Zee TV (a cable channel of South Asian programmes). Sometimes she read about such things in magazines.

Razia, another Pakistani woman, also read about health issues in magazines. Both women bought magazines written in Urdu. The only other person to mention getting information from a magazine was Peter who had used a men's lifestyle magazine (that he had bought for an assignment in his literacy class) to check whether he was underweight or not. Other informants did not trust magazines. According to Kathleen, newspapers and magazines were 'a load of tripe because I don't believe anything that's in them really' and a waste of money.

Several of our informants mentioned finding television a source of information. Mehdi chose a cold medicine to buy because he had seen it advertised on the television. Pamela said that she sometimes learned about 'things that you can do and where to go and what have you' through the television. Li sometimes watched Chinese television which had programmes about health. Kathleen had learnt from television about eating fruit and vegetables every day.

No-one spoke of finding the radio a useful source of information although one informant had heard an advertisement on the local radio station for a physiotherapist who she then called.

6.6 Rejecting or ignoring information

The previous sections have shown that many of our informants actively engaged with the information they received from their health-care providers. Others even sought additional advice from sources such as books, magazines, TV and the internet. However, not everybody reacted in the same way. Some of our informants did not read the leaflets and other information given to them by their doctors or nurses. Neither did they turn to other (written) sources of information about their condition. Often this was because they were content with their doctor's diagnosis and the information they had received. George, for example, did not bother to read the additional information that he received from the British Epilepsy Society. He was happy to rely on what his doctor and specialist had told him. Peter was also content to accept his doctor's diagnosis and the information he provided. Gary did not search for additional information subsequent to his doctor's decisions and diagnosis.

In the following sections, we offer additional reasons to explain when and why informants ignored or rejected the information they were provided with. We also explain why they did not actively seek additional information. Listening to what our informants told us revealed that their behaviour was guided by complex reasons and could not easily be explained by a lack of literacy or by them having 'the wrong attitude'.

6.6.1 Rejecting information: lack of trust in health professionals

Earlier in this chapter, we talked about Peter and his mother Margaret, who both had to take a large amount of tablets each day. Peter had ulcerative colitis, but also suffered from regular fits which could only be controlled by continuous medication. His mother had diabetes, asthma, osteoporosis and a heart problem.

Margaret always read the labels and the inserts of any medication that she or her son were prescribed. She was particularly concerned with making sure that any medication she took would not have any adverse effects on her condition as a diabetic.

Margaret tended not to trust medical professionals. She was known by one of Peter's consultants as the one who has 'twenty questions'. Interestingly enough, this particular doctor was the only one she thought well of. In her view, he was 'a really good man', because 'he does explain' and he 'kept on getting messages to me'. Other doctors, however, in particular their GPs, did not respond to her questions and concerns:

'But you don't get, they don't give you any explanation what they are for. What we want to know is why don't they tell people when you're prescribed a drug, why don't they tell, I always ask what's the side effects? You don't get any answers'.

Margaret's comments about their doctors show their lack of response to her attempts to inform herself and be in control. It was partly this failure of the doctors to engage with her concerns that lead her to reject some of the advice she was given. This is illustrated by an incident, which she recounted when we met up with her in her son's house. Her GP had prescribed her nicotine patches to help her stop smoking. However, when she read the package insert, she found out that the patches were not recommended for use by diabetics. When she queried her GP about what she had read, his response was that they 'don't bother' with this. What he meant was that she could ignore the product leaflet. But Margaret decided to trust the company that had produced the patches and did not use them.

Another example of a patient consciously rejecting professional medical advice was revealed to us by Kate who, like Peter and Margaret, had to take many different tablets. Instead of taking her medication throughout the day, as prescribed, she took all her tablets together at night when going to bed. Her reason for ignoring the instructions was that she simply felt much better when taking her pills at night. Some of her medication, which she was supposed to take in the morning, made her shake so badly that she couldn't even make herself a hot drink or prepare food. She preferred to take this drug at night.

6.6.2 Lack of confidence and fear

We have already described Kate's situation earlier in this chapter. For the first five years of her illness, Kate was treated by a consultant whom she trusted. She was content to follow his advice and she did not want any further information about lupus other than what she was told by him. She did not read any leaflets he had given her.

The following quote from Kate shows that initial trust in her doctors was not the only reason why she did not read about her condition.

Kate: Because I'm not clever, that's why, honest to God, I'm not clever. I find it very difficult in reading certain things.

Her self-perception was such that she did not think that she was 'clever enough' to look things up in books.

Kate also feared what she might find out. From the beginning, she had not wanted to read the leaflets that her doctor gave her, because she feared their content:

K: Because what was in the leaflets was me. And it was like looking at me on paper and it was upsetting and depressing.

Kate's words show that if she ignored information offered to her, she did so because of the emotional distress this could cause. She also avoided the information that other members of her family passed on to her.

Kate: ... and the family then got into it, ... and my dad and everybody, and it was like at one stage too overpowering for me because everybody kept chucking all these, and it wasn't good information, it was always bad information. There was nothing good coming out of it, it was always like oh my God, I am going to die of it It was all information relevant to the illness, but it were information that I didn't want because every time I read it, it was my symptoms.

Her resistance to information grew when her illness became worse. Instead, as we described above, Kate put her sister in charge. This meant that she did not have to directly confront herself with any information about lupus. Kate had requested that her sister (and other members of her family) only pass on what she termed, 'the happy moments of everything', that is information that would make her feel hopeful, positive and happy. She did not want to hear about what she had termed 'the depressive sides of her illness'.

Putting her sister in charge also meant that Kate could rely on somebody whose abilities she fully trusted. Her sister, Kate explained, was 'very clever'. For Kate, her sister was the right person to do the searches, to talk to doctors and to read through any information she had found.

Kate's reaction was not unusual. Several of our informants worried about knowing too much. When Dipta found a lump in her breast and after her GP told her that there was nothing to worry about, she did not search for more information. Like Kate she feared this would only make her worry. She wanted to stop being anxious. Commenting on how they felt when her husband was diagnosed with cancer, Kathleen expressed similar feelings. Talking about the medication he had to take, she explained:

If you get medication and you know you have to have that medication, you're for anything. And the side effects, you don't read them. I don't. Because if you read them you start worrying about what pains you might get while you're on this and you're thinking oh it's because I'm taking them. If you don't know, you can't imagine can you?

When we asked Kathleen whether she had ever been to the library to find out more about her husband's illness, she explained that she might be too frightened to do such a thing anyway, because 'it's the same as anything else really in a way, a little knowledge can be bad'.

Kathleen was also concerned that she might misunderstand the information provided. She wasn't worried about her reading abilities in the same way as Kate, but she also felt:

This is what the doctor is there for, even if you don't always get much help from doctors – but they study things.

Here she expressed her confidence in the doctor's knowledge.

6.6.3 Trying to control the flow and timing of information

In Chapter 5, we have already mentioned Kathleen and her husband's difficulties in talking with their consultant. When Kathleen's husband was tested for cancer, the moment the examination had been carried out, his consultant confronted him and his wife with the diagnosis. The tumor was located in the liver and was inoperable. They were then given a leaflet with more information about his (terminal) cancer. They also received information about chemotherapy. Back at home, her husband immediately put this leaflet in a drawer and he did not read it for a week. Kathleen, in support of her husband's reaction, and because she understood his reasons and feelings, ignored the leaflet until her husband had read it after a week had passed.

Kathleen's story raises the issue of how and when information is provided. Kathleen describes the insistence of the doctors on giving information right away, 'like woodpeckers'. But this is not what she and her husband wanted, they wanted to know in their own time.

At a later stage, during a meeting with one of their consultants, Kathleen was able to react more assertively in the face of information she was not ready to receive:

At the finish I turned around and said to the doctor we don't want to know that yet. You want to take it gradually, you know, you don't want it thrown at you like that you know.

From the above examples of when and why patients reject or ignore health information, we can say that a lack of literacy or a lack of confidence in one's own reading, writing and information skills, is only one amongst several reasons which stop patients from reading leaflets or searching for information elsewhere. In the face of potentially threatening news and distressing experiences, some patients desire more information whereas others reject it. Others prefer to put a mediator in charge. Amongst those who had a good relationship with their doctor, many felt no need for further information. For others, the important thing was to be able to control the flow of information being offered.

6.7 Conclusions

In this chapter we have discussed the various strategies our informants used in order to deal with the literacy and language demands of the health-care system. The most striking point we take away from the experiences summarised in this chapter is that in their attempts to deal with what was happening to them, the people in our study drew on a broad range of strategies and skills, allowing them to access health information and make sense of their experiences. Mediators and social networks play an important role in relation to health literacy. Following other researchers (Maddox 2007, Saldanha 2005), we suggest that literacy skills are often distributed amongst groups of people. In the face of literacy demands, individuals draw on the resources available through others in their social environment and they are thereby able to extend and enhance their own literacy skills. This is an important finding for ALLN classes. Teachers can organise class exercises on the topic of networks and support and they can engage students in researching their own (literacy-related) social networks. This means that students would identify the mediators they draw on, think about how well this strategy works and who else could be a good resource. Relying on literacy mediators is a very common practice and it is not limited to people with limited English or literacy skills. It is relevant for all areas of life, not just health, and is particularly important for people's ability to deal with institutional contexts and bureaucratic texts. The aim of this exercise would be to make

students aware of this resource, find ways to enhance it and discuss ways of making greater use of 'high-level' mediators (Papen 2007). These are people who are 'experts' in specific literacy practices and they are not necessarily part of a person's immediate social network. They can be public service workers, social workers, community workers or people in the neighbourhood who are known to be good at dealing with paperwork.

A second key finding emerging from the chapter is that dealing with ill health frequently engages students in informal and self-directed learning. When people deal with episodes of ill health and disease, they engage with a range of literacy and language practices – in so doing, they acquire new literacy and language skills. For example, the ESOL students (and some literacy students) in our study learned new words, terms and phrases or they learned to understand terms which they were familiar with but which take on a different meaning when used in the medical context. Others learned how to use, and practiced using, dictionaries and the internet. They carried out searches, skim read and assessed the usefulness of information. In so doing, they became more experienced in making informed judgements about any information they found. Such abilities and strategies are crucial not only in relation to health matters, but to many other contexts also. Working to improve and extend the above listed strategies is an important contribution ALLN classes can make and are already making.

Apart from acquiring literacy and language skills (of the kind listed above), some of the people in our study learned a lot about the specific disease or condition they were suffering from. Learning then, can be seen as an important part of dealing with ill health. However, we are aware that the experience of disease, rather than triggering the need for learning, can also lead to passivity and paralysis in the wake of experiences that include psychological and physical suffering.

It is important to point out that the strategies our informants used were not always successful. Using dictionaries and phrase books, searching for information in books and on the internet and drawing on mediators did not always produce the desired outcomes. Kate and her husband for example did not find using a dictionary a successful strategy, as it led to tension between them. Other examples mentioned earlier revealed that mediators cannot always be trusted to give appropriate advice and that dependence on outside support can in some cases leave the patient vulnerable. These examples show that people's abilities to cope with the literacy and language demands of health-care systems vary enormously and depend on factors relating to their own self as well as to the social environment they are part of. ALLN classes, as suggested above, can play a role in supporting students' resources and we will come back to this point in the conclusions. Before we do so, in the following chapter, we discuss the insights from our classroom observations and teacher interviews.

7 Teachers' perspectives on health in relation to ALLN and the Skills For Life curriculum

In addition to understanding students' experiences with literacy in relation to health, our study had set out to examine the role of health as a topic in literacy, language and numeracy classes (see research question 4, Chapter 1). We wanted to find out about the role of health in ALLN programmes, as well as what teachers' and students' experiences of health as a topic were.

In order to address these questions, we drew on several sources of data. We began with a small survey among ALLN teachers in the north-west of England (Phase 1 of our project, see Chapter 3). Additional data is drawn from observations in the seven classrooms that we visited throughout Phase 2 and 3 of the research. We interviewed the teachers of these classes and asked them the same questions that were raised in the survey. We also asked our 45 student informants about their experiences with health as a topic in the classes they attended. In the following sections, we report on our findings from these three sources of data. We begin with a brief summary of the survey.

7.1 The survey

The aim of the survey was to explore the role of health as a topic in ALLN classes. More particularly, we wanted to know to what extent health is used, whether it is a frequent or rare topic and what teachers' experiences with it are. We also asked teachers what they know about their students' health and how it relates to their learning. Forty-five teachers responded to our questionnaire.

With regards to students' health, the questionnaire responses showed us that health problems are present in many ALLN students' lives. Ill health often prevents students from making full use of the opportunities for learning available to them. It affects students' attendance and concentration and it can be the reason for students leaving the class.

Nearly all the teachers responding to our questionnaire expressed the view that students had learning needs in relation to health and health care. But very few teachers in our survey used health regularly as a topic in classes. Those who did were mostly ESOL teachers who organised a term or a series of sessions on health-related questions in their Entry level classes. Overall, we found that health was only used occasionally and in some classes it was not used at all.

There are many reasons explaining the low presence of health as a topic in the classes whose

teachers took part in the survey. Some teachers said they do not use health because it is not related to the aims of the course. This may also be the reason why few numeracy teachers responded to our questionnaire. Of the 45 teachers who completed our questionnaire, only three were numeracy teachers, while six taught both literacy and numeracy. Other teachers explained that while they were aware of students' health problems, they did not feel that students' wanted to talk about health issues in the class. Health is a sensitive topic, teachers explained, and it is also very personal. The teachers who included health in their classes focused not on specific diseases, but on the procedures and practices of using the health-care system. By this they meant things like how to register with a doctor or make an appointment, how to find a dentist, how to understand the dosage prescribed by the doctor, etc. Other teachers focused on general topics such as diet and nutrition, exercise and stress or child and family health. These topics were deemed suitable because of their more general nature.

Some teachers explained that their lack of experience and knowledge on health topics stopped them from using it more often as a topic in class. One teacher remarked that she would worry about giving wrong advice. Furthermore, several teachers indicated that the class composition prevented them from discussing any health issues in detail. These teachers taught large groups mixed in terms of gender, age and ethnicity and they felt that most health topics were too sensitive to be addressed in such a group. They also explained that it was difficult to find health topics which interested all learners.

As far as the benefits of using health as a topic are concerned, teachers in the survey mentioned the relevance of health for learners' lives, thus creating opportunities to build close links between learning in class and everyday uses of reading and writing. This was emphasised in particular by ESOL teachers. These teachers used authentic materials such as leaflets or inserts. Learning about health and the health-care system was believed to be empowering for students. At the same time, health topics allowed teachers to practice many general speaking, listening, reading and writing skills.

A detailed report of the survey and its findings can be found in Papen and Walters 2005.

7.2 Insights from our teacher interviews, classroom observations and conversations with learners

Before we report our findings, we present a brief description of the classes we worked in. They varied in terms of the background of the students attending, the levels and the way in which lessons were taught.

Type of class and teacher	Level	Frequency of class meeting	Student routes into the classes
Preston Outreach Literacy (Joshua)	Entry 1 to 2	Once a week (morning)	First class students had joined.
Preston Outreach ESOL (Joshua)	Entry 1 upwards (mixed ability)	Once a week (afternoon)	First class students had joined (no progression routes out).
Halifax Literacy (Jane)	Pre-entry to Level 2	Once a week (morning)	First class students had joined.
Halifax ESOL (Julie)	Entry 2	4 times a week	Before joining this class, many students had attended an Entry level 1 class.
Lancaster Family Literacy (Pat)	Mixed ability	Once a week (morning and for some afternoon)	First class students had joined.
Lancaster ESOL (Louise)	Entry 2 to Level 2	3 times a week	For most students this was the first class they had joined. Some of the Level 1 and Level 2 students had attended Entry level classes earlier.
Bolton ESOL (Scarlet)	Entry 1b	3 times a week	First class students had joined.

We now briefly describe all the classes whose teachers we interviewed (see Chapter 4, Section 4.2).

The literacy classes

Jane's class was mainly made up of students with special needs who were under the age of 20 plus three older students, one of whom was an ESOL student, Shanaz. She did not wish to attend the available ESOL class because it was a predominantly male class. Jane's class was a mixed ability class with students working at Entry level 1 and 2 and Levels 1 and 2. Joshua's outreach literacy class was made up of older students (over 30 years old) who wanted to improve their reading and writing. The class was held in a community centre in a small working class town close to the M6. The course was a pre-GSCE level class and had one ESOL student, Jing, who attended because the location of the class was convenient for her. Pat taught an outreach family literacy class in a white working class area in Lancashire. The students in the class were the parents, guardians or grandparents of children attending the primary school in which the class met. The age range was between 25 and 75. All of these classes were taught through whole class teaching, where the teacher taught the whole group together before setting tasks for individuals and groups to complete. Anita and Shirley taught Entry level literacy classes. Students worked on their own individual work plans supported by the teacher. There was no whole class teaching in these two classes.

The ESOL classes

Wendy's Entry level class was made up predominantly of Somali women. Wendy's students tended to have had little previous educational experience. Sylvia, Scarlet and Julie provided mostly for asylum-seekers and refugees from a number of different countries with a range of cultural, linguistic and educational backgrounds together with students who had come to learn English because they had settled in England due to marriage or for work, either alone or with a partner. The students in Louise's class in Lancaster were also of different linguistic and cultural backgrounds. Most of them were either spouses of people working or studying at Lancaster University, new immigrants from Eastern European countries or women of Indian background who had come to England as a result of marriage. Joshua's ESOL class was a mixed ability group attended by women of Bangladeshi, Pakistani and Indian origin living in a particular area of Preston. The women were aged between mid-20s and 80, most had lived in England for many years and they had attended the class for a number of years.

7.2.1 Students' health problems

According to the teachers we interviewed, ill-health affected many of their students and had consequences for their learning. Both literacy and ESOL teachers spoke about mental health issues such as stress, depression and anxiety.

Sylvia, the ESOL Co-ordinator at Bolton College, spoke at length about the stress and depression many of the ESOL students, in particular those who are asylum-seekers, suffered from. Many also had to cope with physical injuries sustained in their home countries, and now that they lived in England, they had to face the daily uncertainty of life as asylum-seekers.

Poor health was an issue for other students as well. The elderly women who attended the Preston Outreach ESOL class were frequently absent due to health problems connected with old age. Their younger colleagues were absent when they needed to take care of their children. Chronic health conditions such as diabetes, heart problems and back pain were frequent amongst the students in the Lancaster family literacy class.

Some of the teachers in our study explained that they were not always aware of their students' health problems, because they didn't know them well enough and because health was a personal issue students didn't necessarily talk about. Joshua knew about mobility issues and operations that kept his students away. But it was only through our interviews with the students that he became aware that two of his students had suffered from severe depression and one was coping with the emotional aspects of having lost two babies through miscarriage.

While several teachers explained that health problems could result in infrequent attendance, others felt that their students came to class even when they were ill. Pat told us that despite having to cope with a range of serious health problems, her students rarely missed a class.

7.2.2 Learning needs and motivations

Many of the ESOL teachers we interviewed were certain that their students had learning needs in relation to their health. ESOL teachers believed health to be a vital topic to cover in their lessons. By contrast, the literacy teachers in our study did not see health as a vital topic. Joshua felt that the most important thing for his students was improving their spelling, whilst Jane explained that her students wanted to broaden their horizons, but had no interest in health as a topic.

We asked the teachers in our study what they knew about their students' motivation to attend classes. Beginning with the ESOL teachers, Wendy explained that her students came to the classes because what was covered was important to their lives and a matter of 'survival'. The women in Sophie's ESOL class wanted to be able to go to the doctor on their own and not rely on their husbands. Julie believed that her students came into class because they needed to improve their English in order to be able to work and live in the UK. She thought that health was a motivating factor for those amongst them who were parents who had to take care of their children and speak enough English to be able to communicate with health-care professionals.

When we asked the students about their reasons for attending ESOL or literacy classes, most mentioned needing to learn English or to improve their reading or writing in order to find work or to get the qualifications they required in order to get the kind of job they wanted. For example, Pamela wanted to get her GCSE English so that she could start training to be a

midwife. Jon wanted to improve his reading and writing because he had struggled to keep his portfolio on a child development class he had been taking. Fouad wanted to learn English so that he could meet people and get a job in Halifax.

Other students mentioned reasons related to their mental or physical health, although these reasons were not as numerous. Jeff found that attending his literacy class helped him not to drink as he was not allowed into the college if he was drunk. For Sediq, who had suffered from depression, attending his ESOL class stopped him from being alone and it kept him busy. George had joined the literacy class when his parents, who he had lived with, had died as it gave him something to do.

7.2.3 Health as a topic in literacy and ESOL classes

Health was mostly a topic used by ESOL teachers. It played a much lesser role in literacy classes. The literacy teachers like Jane, Anita, Shirley and Pat, who did not use health as a topic in their classrooms, chose not to do so for a variety of reasons. Anita and Shirley did not cover health as a topic to any extent because their teaching was based around students following their own individually chosen programmes. Only one student had decided to work on a health topic. This student wanted to be able to read and spell the words that appeared on the insert that came with her medication. Pat explained that the main reason her students attended was because they wanted to know more about their children's literacy learning in school.

The only literacy teacher who covered health in his class was Joshua. In his literacy class, health provided the key theme for the class for two terms. He used materials connected to beauty and fitness as a stimulus for literacy work. The class also looked at leaflets about salt intake, healthy eating, looking after your heart, smoking and AIDS. They used information about plastic surgery, downloaded and printed off from various websites, and discussed Body Shop products and their marketing. None of these topics were directly linked to any concerns or issues that the students themselves raised in the classroom.

Returning to the ESOL teachers who participated in our study, the topics they focused on were the same as those mentioned by the ESOL teachers who completed our questionnaire survey (see Papen and Walters 2005). These were diet and nutrition, child and family health, exercise and stress, and going to the doctor. In our conversations with them, the ESOL teachers emphasised the importance of helping students to learn how to talk to health-care professionals. They also highlighted any themes relating to students' need to understand and navigate the health-care system. Overall, ESOL teachers focused more on health-care procedures and the practicalities of accessing health care than on specific diseases.

What the teachers told us about health topics in class was confirmed by students we interviewed. Topics that the ESOL students remembered having learned about included making an appointment with a doctor, describing symptoms, going to the pharmacy and buying medicine, healthy eating, common illnesses and their treatment, how the NHS works and how to use NHS Direct. Students from Joshua's class talked about how they had learnt about HIV and healthy eating.

We can see from the above that, with some exceptions, health was not a regular topic in the classes included in our study. However, it tended to have a relatively prominent place with ESOL beginners (Entry level). But even in these classes, it was usually dealt with for a short period of time only, usually a few weeks. Later on it might come up again as an occasional topic, but none that would take up substantial amounts of lesson time. As a topic, health

could also enter the classroom when students brought in health texts that they needed help with. Wendy and Scarlet remembered being asked for help with appointment letters from the hospital. These examples confirm what we suggested in Chapter 5: that health texts, such as appointment letters, can pose challenges to literacy and ESOL students, and that they are part of the literacy demands of the health system that patients are faced with when ill.

Sylvia, who also remembered a few situations when students asked her for help with specific letters, suggested that the majority of her students thought of their health issues as private business and would not necessarily ask for their teacher's help. Because she respected their wish for these things to be kept private, she helped those who approached her individually. But she did not discuss an individual student's letter with the whole group. Julie mentioned the role of literacy mediators in relation to health texts. She was certain that most of her students found help amongst their family or friends. This echoes our findings from Chapter 6. Julie also added that the students in her classroom did not share or discuss their health problems in class.

7.2.4 Teaching materials

The teachers who used health as a topic drew on authentic (real-life) materials in their lessons. Wendy, for example, used appointment cards, medicine packets and blood pressure machines in the classroom. She also brought in different kinds of food when covering healthy eating with the class, because 'the more they can see the real thing the better'.

Other teachers shared this philosophy. Scarlet used a box of medicines and flyers from different health centres. Louise used various health texts and medicine bottles and their inserts so that students could practice identifying the correct dosage. She encouraged her higher-level students to go online and use health-related websites. Sylvia used prescription forms and medicine bottles. Julie used bandages and thermometers in the classroom. Joshua used a flyer about the flu vaccination for reading and comprehension with his ESOL class, and Body Shop products with his literacy class. Many teachers also downloaded information from websites, including NHS Direct, to use with their students. In addition to real-life materials, some of the teachers also made their own worksheets or used Skills For Life materials for teaching about health (see Section 7.4.).

7.3 The usefulness and appropriateness of health as a topic

7.3.1 Benefits of learning about health

We have already touched on some of the ways in which teachers found health a useful topic, in particular for ESOL students. In this section, we will pursue this discussion adding the views of several other teachers.

Louise spoke eloquently of the importance of using health as a topic in her ESOL classroom and the effect it could have on students.

I think it's a kind of a milestone for some students, ESOL students, the first time they manage to go to the doctor's on their own and actually negotiate it and manage to get their message across.

Sylvia found the topic of health 'oozing' with opportunities to learn particular functions of English. She was aware of the opportunities that health as a topic can provide towards

covering the more general curriculum aims of Skills for Life. Wendy, by contrast, echoing the views of many other teachers, thought primarily about how teaching about health could help learners deal better with their own health problems. She believed that by covering health with her class small illnesses and 'common or garden' problems could be dealt with and prevented from becoming serious illnesses.

The teachers' positive views on the impact that learning about health had on their students was confirmed by the students we interviewed. Many felt that they had benefited from what they had learnt about health in class, in particular in terms of how to access services and deal with the health-care system. Mehdi was grateful that he now knew how to make an appointment and how to talk to his GP. Navid added that he could now take care of his wife and daughter by making appointments for them and accompanying them to the surgery. Several of Joshua's students found the health topics they had discussed in class very useful. Kate, for example, explained that she had learnt about 'Five-a-Day' in class and that as a result she had made some changes in what she cooked for herself and her family at home.

However, Pamela, who attended the same class, thought that health was too personal a topic to be appropriate for a literacy class. She felt that too much time had been spent on health topics.

Despite being generally happy with what they had learned about health and health care in their classes, very few students expressed an interest in learning more about health in their literacy and ESOL classes. Even when a student said that they would have liked to deal with health topics in greater detail, they themselves showed an awareness of the sensitive nature of the topic and the difficulties that this could cause in the classroom. Dipta, for example, was interested in learning more about cancer or meningitis. But she was aware that these might be difficult topics to discuss and suggested that while she had no problem talking to the researcher about these, she would struggle to do the same in class.

It is important to note that both the teachers responding to our survey, as well as those we interviewed, agreed that despite its relevance to learners' lives, health was not a topic to use too often and for too long a period. This leads us to the next topic we discussed with the teachers in our study.

7.3.2 Difficulties with health as a topic

For most of the teachers in our study, including those who took part in the survey, health is not an easy topic to deal with in classes. The age range and mix of genders in classes meant that it was difficult to talk about some health topics, because these were too sensitive and personal.

In Jane's view, it was a good idea to use the class to raise students' awareness of specific issues and resources such as NHS Direct, but she did not think that covering other themes was appropriate. A similar point was made by Sylvia who explained that dealing with the health system in the classroom was straightforward, while looking at specific diseases could be too personal. Several other teachers shared this view. They did not discuss specific diseases or life-style issues, because they were aware that these could cause discomfort and embarrassment for their students. There was a particular problem for female students, who might not want to talk about their symptoms in a mixed ESOL class. In an all-women's group this might be different. Sylvia mentioned that in the past many classes had been women only and this had allowed teachers to cover issues such as pregnancy.

Another reason why health is a difficult topic is because for many learners, the class is the place where they want to get away from their problems and concerns. They want 'time out' as one of the teachers explained. This point was confirmed by several of the students we interviewed.

Finally, several teachers commented on the fact that they did not know enough about particular health topics. Anita told us quite emphatically that a reason why she would be wary of using health as a topic in the classroom was that she was not a health practitioner.

7.4 The Skills for Life curriculum

Even though health was not a particularly regular topic in the classroom, the teachers we interviewed found that when they worked on health-related topics, this supported the more general aims of Skills for Life in terms of speaking, listening, reading and writing. Sylvia pointed out how useful health was as a topic in ESOL classes as it allowed her to teach many aspects of the English language, all of which were part of the Skills for Life curriculum aims.

More generally, the teachers in our study spoke favourably about the curriculum and told us that they used it as a framework for their work. No-one felt that they could not include health-related work to the extent that they had before the curriculum was introduced. On the other hand, the new curricula did not invite any of the teachers in our study to give health topics a greater role in their class. Thus it seems that Skills for Life has had little effect on whether and how health is used in literacy and ESOL classes. This concerns both the teachers in the survey as well as those we interviewed.

Any Skills for Life materials relating to health were mostly found to be very useful. However, Anita, Shirley and Jane, who worked with mixed ability classes (Entry level 1 to Level 2) found that the materials did not allow them to differentiate easily for their students and were therefore of limited use. Wendy had to adjust the Skills for Life materials on food and healthy eating to represent the eating habits and diets of the Somali women in her class. Arising out of this though was an opportunity for the women in the class to share what they knew and to use their knowledge in order to create a cookbook. Joshua based his scheme of work on the Skills for Life curriculum but used his own materials.

7.5 Conclusions

Judging from the views of both teachers and students involved in our study, Skills for Life literacy and ESOL classes offer opportunities for students to learn how to benefit from health-care services and how to access and understand health-related information. There is a need for such learning, especially for ESOL learners.

Overall, however, health is not a frequent topic in ALLN classes, although it appears to have a regular place in ESOL Entry level classes. Major obstacles to the greater use of health as a topic in literacy and ESOL classes are the sensitive and personal nature of health issues and the class composition. Gender, age and ethnic differences make it difficult to share personal health experiences or concerns. One of the literacy teachers in our study spent several weeks working with his class on lifestyle issues such as healthy eating. But he was an exception and even he excluded more difficult topics such alcohol and drugs.

The teachers who worked on health issues in their classes used a wide range of real-life health texts with students in the classroom. These are the kinds of texts that students told us they were encountering in health-care settings (see Chapters 5 and 6), for example patient information leaflets.

To summarise, we can say that the students in our study benefited from health as a topic in the classroom in the following ways:

- Orientation to the UK health-care system (i.e. understanding how the system works and what is available);
- Access to health care (e.g. being able to make an appointment with a GP, being able to register with a dentist, using NHS Direct, going online to look up information on health websites);
- Increasing awareness (e.g. about health issues, nutrition, ethical issues with regard to health, people's rights in relation to health);
- Improving their general speaking and listening abilities, their spelling and their understanding of grammar.

Students were also able to use their classrooms as places in which to:

- alleviate isolation and alienation
- build social networks and collaborative links
- keep busy
- get personal help from teachers.

8 Conclusions

In this report we have summarised the findings from our study on literacy, learning and health. We have discussed how literacy and ESOL students deal with the literacy and language demands of the health-care system and the role adult basic education classes can play in relation to improving students' health literacy.

In our study, we have tried to look at health literacy in a broad way, thinking of it as activities people engage with in relation to their health. In so doing, we have looked beyond patients' ability to make sense of certain words or follow instructions. We have tried to understand the broader context of their experience as patients and more generally as people being ill. In order to achieve this, we have included in our analysis – as much as this was possible – the context of health care itself. We have placed particular emphasis on our informants' personal contexts and social networks and on the way they draw on others, be they family members or friends, to deal with illness and its emotional effects.

We found in our study that health-care processes are often highly 'textually-mediated'. The texts and the knowledge people are asked to engage with can be complex and can challenge the literacy of most people. Several students told us in detail about difficulties with the literacy demands of health-care settings they experienced. The stories allowed us to see that health literacy – as the ability to make sense and engage with health information – does not depend solely on somebody's reading and writing skills. The people in our study had different reasons for engaging or not engaging with health information. Some said they lacked the confidence to do so, because they were not 'clever' enough. Many others were perfectly happy with the oral information they had been given by their health-care providers. Others felt too ill to do much or simply did not want to know. Those in our study who did not engage with health texts and failed to seek information in addition to what their doctors had told them should not automatically be dismissed as 'disengaged' patients who suffer from the wrong attitude and lack health literacy.

Our study has shown that even those amongst our informants who faced major difficulties had many strategies to overcome these. In Chapter 6 we reported on a range of such strategies. The use of literacy mediators stood out as a common and often successful practice. This leads us to suggest that health literacy is often 'distributed' (Saldanha 2005, Maddox 2007). By this we mean that it is not simply a property or an attribute of an individual (who is assumed to have a certain level of health literacy). Health literacy is shared knowledge and understanding, it resides in the family, the neighbourhood and the social network of a patient. An individual's health literacy could thus be seen as the sum of what she knows and is able to do on her own and what she is able to achieve with the support from friends, family and other significant people in her environment.

The following is a list of suggestions for practitioners who are interested in using health in their programmes. With these suggestions, we aim to show that understanding students' own ways of using literacy in relation to their health offers various ways forward in developing new strategies for teaching and learning. Such strategies, while focusing on enhancing students' ability to deal with the literacy and language demands of ill health and disease in an empowered and informed way, have the potential to also improve students' general reading and writing abilities.

- If literacy, numeracy and ESOL teachers want to make health a more central topic of their teaching, they need to be aware of how students deal with ill health and what difficulties they encounter. In order to achieve this, tutors can create learning units involving their students in researching their own reading and writing activities in relation to health. Students can together (in class) look at the kinds of texts they were asked to engage with and share their experiences. At the same time, students can identify the strategies they have used. For example, students might report on how they used dictionaries to understand leaflets or to prepare themselves for a visit to the doctor (see Chapter 6). Others might report on how they searched the internet. The class could then work on how to improve these strategies and maximise their benefit. Teachers should, however, be aware of the potentially sensitive nature of health topics and its reliance on students' willingness to share their experiences. It may be a good idea for the teacher to ask for recent experiences with *common illnesses*.
- Students can research their own social networks and identify the resources they draw on. Teachers can create exercises for students to map their networks and to identify the role different members take in terms of literacy mediation. The aim of this exercise is to make students aware of resources they have and how to support and possibly extend these. Literacy mediators are a common resource for everybody and their importance is not limited to health contexts. Drawing on others for support is an essential generic skill.
- Many of the students in our research lacked confidence vis-à-vis health professionals. ALLN classes are good places to work on assertiveness and confidence building. Role plays are an ideal way to simulate the social contexts of, for example, hospital visits or medical examinations and how patients can develop strategies to look after their interests with greater confidence.
- Students could also explore how readable different health materials are. They could identify what kind of knowledge is required (specialised or everyday), what type of language is used (expert or everyday language), whether the layout, formatting and use of graphics supports or impede understanding and how both patients and health professionals are being described (are patients represented as passive, while the professionals are taking decisions?). Such activities, which are inspired by the method of critical language awareness and critical discourse analysis developed by linguists, have been found to work well with adult students.
- Because health is a sensitive and personal issue, it can be a difficult topic for ALLN, in particular when a class includes learners from different age, gender, class and ethnic backgrounds. ALLN programmes that wish to make health a central topic are more likely to succeed if addressed to specific groups, for example women of a certain age, mothers with young children, pregnant women or people sharing similar health concerns and thus having a common interest.

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