THE INFORMATION NEEDS OF CHRONICALLY ILL OR PHYSICALLY DISABLED CHILDREN AND ADOLESCENTS

NHS 1639 3.99 BB/TS

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ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

Project title   Identification of the information needs of chronically ill or physically disabled children and adolescents, and development of recommendations for good practice. (MCH:16-12)

Lead researcher   Dr Bryony Beresford, Research Fellow, Social Policy Research Unit.

Project findings
Objectives
1.   To identify the information needs of chronically ill and physically disabled children and adolescents; including information relating to the condition and its management, as well as information about the impact of the condition on other aspects of the young person's life.

2.   To work with the research participants to develop recommendations for good practice in the provision of information to children and adolescents.

Design
This was a qualitative study involving individual interviews and group discussion meetings. Participants were interviewed in their homes before attending two group meetings with other young people of a similar age and with the same medical condition. The conditions included in the project were chosen to represent most of medical and psychosocial issues that are likely to be experienced by a young person with any chronic medical condition. The methodological and ethical issues encountered during the research are considered in detail in the project report.

Setting
The focus of the research was the information needs of young people who have a chronic medical condition. Data covered NHS care settings, family homes and other social situations.

Participants
A total of 63 young people were involved with the project: 27 boys and 36 girls. The young people fell into one of two age bands, 10-12 years (n=29) and 14-16 years (n=34). The young people had one of five medical conditions: juvenile chronic arthritis (n=17); cystic fibrosis (n=11), diabetes (n=12), epilepsy (n=10) and Duchenne muscular dystrophy (n=13). Participants for each condition were selected from a single site. Four hospitals, located in different areas of the United Kingdom, were used to recruit the sample.

Results
Young people with a chronic medical condition have wide-ranging information needs which this project has described and categorised into either medical or psychosocial information needs. Psychosocial information needs are derived from the need to manage the impacts of the condition on the emotional, social, educational and future aspects of a young person's life. Participants described these sorts of information need as being of equal importance as medical information in how they manage living with a chronic medical condition. Areas of medical information need included: the condition; general human biology; treatments; tests and investigations; managing an exacerbation; lifestyle factors; current research and health service and other sources of statutory support. Psychosocial information needs related to managing or dealing with: negative emotions; physical symptoms; parents; peers; school life and restrictions; as well as maintaining a positive attitude and planning for the future. Whilst an awareness of these potential areas of information need is very important, it is impossible to be prescriptive about what a particular young person with a chronic medical condition needs to know, and when. Differences in coping style, the

perceived content of a piece of information, and experience of, or exposure to, condition relevant situations were key factors influencing the sorts of information young people wanted to have and when it was needed.

Meeting the information needs of this group requires a holistic and individualistic approach to identifying and responding to information needs. A number of sources of information need to be available in order to meet the range of information needs. These include health professionals, parents, and other young people with the condition. Current sources of written information were regarded as being of limited value, and participants generated ideas to improve the quality of written information for young people. Help lines were not seen as an appropriate information source for these young people, but in the future the Internet may well play a role in meeting medical and psychosocial information needs. The role of health professionals, particularly doctors, both as a source of information and as a 'sign post' to other information resources, was often jeopardised by poor communication between doctors and young people. The research identified as series of practical, communication and social issues which promoted or hindered doctor-young person communication.

Conclusions
In order that young people with a chronic medical condition can optimally manage day to day life, their medical and psychosocial information needs have to be addressed. Significant barriers currently exist to this being achieved. These include ineffective patterns of communication between young people and health professionals and an apparent lack of awareness on the part of health professionals of the psychosocial information needs of their patients. In addition, systems to promote contact between young people with the same condition - a key resource in terms of psychosocial information - need to be put in place.

Relevance to the NHS
Provision of information to patients is a key feature of health service policy, and lies alongside a commitment to promote working partnerships between health professionals and patients. The findings of this project are pertinent to these policy and practice goals. First, information needs extend beyond relevant medical facts to include information which enables an individual to deal with the psycho-social impacts of having a chronic medical condition. Meeting psychosocial information needs will require enabling and facilitating contact between young people with the same condition. Second, this project revealed clear evidence of the difficulties children and adolescents can face in terms of using their doctors as an information resource. Any intervention aimed at improving this situation would, we suggest, require challenging health professionals' attitudes towards childhood and adolescence as well as communication skills interventions.

Dissemination
Target audience
Policy-makers - local and national, health practitioners, relevant voluntary bodies, medical and health services education and the research community.

Dissemination activities to date
1. 'What I Need to Know: the information needs of physically disabled and chronically ill children', Paper presented at the tenth annual meeting of the European Academy of Childhood Disability (Helsinki, June 1998)

2. Doing research with disabled children and young people: a view from 'backstage', Workshop session at conference 'Changing Community and Primary Care: Research, Policy and Practice', Nuffield Community Care Studies Unit, University of Leicester (Leicester, October 1998)

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CHAPTER ONE
BACKGROUND

1.1   INTRODUCTION

In this chapter we provide relevant background information, and thereby argue our case for the need to explore the information needs of children and adolescents with a chronic medical condition, and to identify ways which will ensure that these needs can be better met. We begin by presenting the policy context: legislation and policy directives which have a bearing on this study include health service policy, and national and international policy about children and their rights. We follow this by a review of previous research which is relevant to this study, and we draw attention to a number of limitations of this work. This discussion is followed by a description of two theoretical constructs - the process model of stress and coping, and patient empowerment - which we have used to direct the way we have conceived and researched information need. We then move on to report what is known about the various sources of information a child or adolescent may use - again the research is limited and where appropriate we use research with adults to illustrate our arguments. The penultimate section of the chapter draws together the arguments and evidence and provides an overview of the rationale and aims of the research presented in this report.

1.2   POLICY CONTEXT

There are three distinct areas of policy relevant to this project. The first concerns National Health Service (NHS) policy on providing information to patients. The second is policy about children's welfare, which in the UK is essentially the 1989 Children Act and the 1995 Children (Scotland) Act. Finally, there is international policy on children's rights. Each of these will be discussed in turn.

Health service policy

The provision of information to patients is central to government policy on health services. The document 'The National Health Service: a service with ambitions' describes its first objective as promoting a well-informed public, stating:

> Knowledge about health, illness, symptoms and treatment gives people more control over their circumstances, and helps them to access and use services effectively. People need good quality information..... if a condition is diagnosed, to understand the implications and to take part in decisions about treatment and care.
> (Department of Health, Cm 3425, 1996a)

Being informed is central to decision-making, and there is an increasing emphasis on patient involvement in decision making (The Patients Network, 1996), a philosophy embodied in the Patient Partnership Strategy (Department of Health, 1996b). Accurate, up-to-date and complete information about a medical condition, its treatment and management, as well as available support services, is needed for patients to fully share in decision-making (Richards, 1998; Coulter, 1998), and is indeed one of the rights set down in The Patient's Charter (Department of Health, 1996c). But it is recognised that this is not something that is easy to achieve in practice. Complaints to the Health Service Ombudsman often relate to lack of information, poor communication and a 'perceived absence of real partnership in decision-making' (Department of Health, 1996b, p3). It has been acknowledged that further research is needed into how to best meet patients' information needs (Blaxter, 1995).

What is very apparent from all this documentation is the lack of any consideration of these issues in relation to the information needs of children and adolescents, and what the notion of 'patient partnership' means for this group. The NHS directive 'Patient Partnership' fleetingly mentions children once, stating that they are one of a number of diverse groups with whom engaging in effective patient partnership will be 'particularly challenging' (Department of Health, 1996b, p8). An NHS charter on services for children and young people (Department of Health, 1996d) states that children and their parents have a *right* to information about treatments, and can *expect* to be involved in discussions and decisions about treatment. It also states that 'Discussions with your child will be at the right level for his or her age and understanding' (p13). The research literature we present later in this chapter would suggest that this well-meaning statement in no way reflects what seems to be happening in practice.

Finally, policy related to service evaluation and planning is another area which involves issues of information need. The NHS and Community Care Act (1990) requires that the views of services users should be sought in the identification of needs and the evaluation of services. This consultation should include children and adolescent users. For any process of consultation to be more than tokenistic, children and adolescents need sufficient information about services and their condition to be empowered to be involved in developing efficient and appropriate support services.

Policy about children
There has been a radical shift in thinking about children's involvement in determining what happens to them. Key legislation relating to children in the UK - the 1989 Children Act and the 1995 Children (Scotland) Act - both stress the importance of seeking the child's views on matters relating to his or her welfare, and in decisions about the provision of welfare services. As has

been argued, proper consultation and effective decision-making requires all parties involved being informed about their situation, options and possible consequences. Although the main substance of the Children Act (1989) mainly concerns the Court and social service departments, its philosophy of consultation and involvement of children in decision-making has implications for the way children and adolescents are treated in health service settings (Department of Health, 1991).

International policy: the UN Convention on the Rights of the Child
Article 12 of the United Nations Convention on the Rights of the Child states that children have the right to say what they think about anything which affects them and that what they say must be listened to carefully. Of the 54 Articles enshrined in this convention, article 12 is defined as one of the *fundamental* rights of the child. This piece of international policy relating to children is, for this project, particularly relevant to the way we went about doing the research. In Chapter Two we describe how we tried to ensure that the child's voice was heard in this project.

That aside, this Convention again challenges traditional conceptions of children as 'seen and not heard', and is aligned with current writing on the way children are perceived (Beresford, 1997). Previously children have been conceived, and treated, as passive recipients of events impinging on their lives. The new model of childhood recasts children as actively involved in managing and responding to the events and situations in which they find themselves (for example, Prout and James, 1990; Brannen and O'Brien, 1995; also Titterton, 1992). It not only raises a challenge for researchers to respond to the need to work directly with children, it also challenges practitioners to critically evaluate how they work and interact with children and adolescents, and possibly to redefine the role into which they cast children.

1.3 THE RESEARCH LITERATURE

1.3.1 The focus of previous research

There is a substantial body of research on patient knowledge and education. It is, however, limited in two fundamental ways. First, and almost without exception, previous research has been solely concerned with knowledge about the condition and associated treatments or investigative procedures. The second, and related, limitation is that the focus of research has been to explore the relationship between levels of knowledge and certain medical criteria, such as adherence to a treatment regime, control of the condition, and reactions to, or recovery from, surgery or other invasive procedures. Thus, much research in this area is characterised by its highly medicalised approach, with a focus solely on levels of knowledge about a disease or condition and how that relates to one or more medical outcomes. Such outcomes also tend to be those which are seen as desirable by health professionals. What is significant about much of

this work is that level of knowledge has not emerged as as strong a predictor of adherence or disease outcome as was envisaged (for example, Anderson, 1996; Coates and Boore, 1996).

In order to refocus future research we would argue that two important issues need to be addressed. First, the existing work on levels of knowledge needs to be balanced by discovering the *perceived* information needs of individuals with a chronic medical condition. Second, any such work needs to take a holistic approach. It should not be assumed that having a medical condition only generates a need for information about the condition and its management. Rather information needs related to all aspects of an individual's life which may be affected by the condition need to be explored and described (Kyngas and Barlow, 1995).

1.3.2 Research on children's information needs

Work on children and adolescents' levels of knowledge about their condition and its management was reviewed by Eiser (1990) who concluded that young people 'can be poorly informed about many aspects of their condition' (p83). However, such research was addressing a different question to the one posed by this project, which is: what do young people say they *need* to know?

There is little previous research which has focused on this issue, and existing work has tended to look at medical information needs - particularly of children and young people with cancer. These studies have found that children and young people with cancer have very similar medical information needs to adults with cancer (Cassileth *et al.*, 1980; Levensen *et al.*, 1982; Pfefferbaum and Levenson, 1982). In the most recent of these studies, Ellis and Leventhal (1993) explored the information needs of 50 children, aged between eight and 17 years, with cancer and their parents. The study focused on medical information needs, that is what the children wanted to know about the diagnosis, treatments and prognosis. Overall, the study found that children wanted to be fully informed about their disease and its treatment. Information about prognosis and the side effects of therapy were key concerns. The older children also reported information needs related to the risks of 'secondaries' and infertility. The study found discrepancies between what parents wanted their children to know and what the children said they wanted to know, with many parents wanting adverse information to be withheld from the child. Most of the children taking part in the study reported that the best way of meeting their information needs was through talking to their doctor. Less than one in ten children said they preferred written information to discussions with their doctor. A consultation exercise carried out by the Council for Disabled Children and reported by Russell (1998) with young disabled people with on-going health care needs reveals similar wishes for complete and accurate information about the medical condition and treatment options - including the risks and all the possible outcomes.

Individual differences in the need for information

There is evidence, however, from other pieces of research which questions whether *all* young people want to know everything about their condition and its management. Phipps and Srivastava (1997) highlighted an apparent contradiction between policies of open communication in clinical practice and the relatively low levels of information held by children with cancer. Phipps and Srivastava argue that this may be a result of children not wanting to know, rather than not being given appropriate and understandable information. What is important here is that information was not being withheld - rather the children were choosing to repress or ignore it. Differences in the way a child chooses to cope or manage their situation may therefore influence their need for, and use of, information. This is an idea we shall return to later.

1.4   DEFINING INFORMATION

The term 'information' is frequently used yet rarely defined. Dervin *et al.* (1980) argued that information is anything that a person finds informing. The critical feature of this apparently simplistic definition is that information cannot be pre-determined or defined objectively. Baker and Connor (1994) develop this argument:

> ...information is situationally, temporally, and personally bound. What is information to one person may not be to another; what a person found informing at one time, he or she might not in another situation. Viewed from this perspective, any given set of information needs may be unique.
> (p37)

This definition of information is markedly different from the way information has been defined both by researchers and practitioners involved in observing or meeting patients' information needs (Baker and Connor, 1994).

A shift to a more patient-centred approach to identifying information needs is clearly necessary both in research and practice (Frederikson, 1995; Baker and Connor; 1994; Weinman, 1990). There is a mismatch between patients' and doctors' beliefs about patients' concerns and information needs (for example, Beeney *et al.*, 1996). In particular, the emphasis placed on providing medical information to the exclusion of information related to psychosocial issues is a source of dissatisfaction to parents and patients (for example, Frederikson, 1995), including children and young people with chronic medical conditions (for example, Shaw *et al.*, 1997). Furthermore, in the same way as health professionals cannot predict a patient's information needs, parents cannot assume they know what their son or daughter needs to know about his or her medical condition.

1.5   THE ROLE OF INFORMATION: THEORETICAL PERSPECTIVES

So far we have described how the role of information within the medical or health care setting has been conceived in terms of health outcomes. Outcomes which, we have argued, are driven by the goals or concerns of health professionals rather than patients. Research and practice has also assumed that only information about the condition and its management is relevant to this process (Anderson, 1995). However, what has become apparent is that this model, on its own, holds limited predictive power. It also fails to take a holistic approach to chronic medical conditions and their impact on individuals' lives. A further limitation of this work is that it has made assumptions about what patients' information needs are, failing to consult with patients themselves about all the information needs that arise from having chronic medical condition.

In this section we present two complementary perspectives to understanding the role of information for individuals with a chronic medical condition. The first model is the well-established psychological model of stress and coping (Lazarus and Folkman, 1984). This model allows us to explore, at an individual level, both the range of information needs that may exist, and the ways in which information is a critical factor in determining the overall adjustment of a child or adolescent with a chronic medical condition. Its individualistic approach also offers a means of understanding individual differences in the types and degree of information need experienced.

The second perspective is drawn from medical-sociological literature and is concerned with the notion of 'patient empowerment'. As with the psychological model of stress and coping, its fundamental tenet is that individuals, patients in this case, actively manage and deal with their condition on a day to day basis. The concept of patient empowerment is central to current philosophies in the health care provision and, in particular, the notion of patients as partners with professionals in their health care (Richards, 1998). We would also argue that individual empowerment is particularly salient during adolescence when attaining independence and personal responsibility are key developmental 'tasks' (for example, Coleman, 1992). It is therefore clearly important that this research project should incorporate this notion into its approach. The patient empowerment paradigm also challenges, though, we believe in a limited way, traditional ways of thinking about the role of information, and argues that information needs are more disparate than that covered in previous research.

1.5.1 The process model of stress and coping

The process model of stress and coping was developed over a period of years by Richard Lazarus and Susan Folkman (for example, Folkman and Lazarus 1980; Lazarus and Folkman, 1984) and is now widely accepted as a powerful and valid way of understanding the relationship between stress and an individual's adjustment. The model has been applied to numerous fields of

research, including the experience of chronic illness during childhood and adolescence (for example, LaGreca *et al*., 1992). We will now briefly describe the process model of stress and coping. After that we will discuss the way the model can offer a framework for understanding the impact of a chronic medical condition on an individual, and the role of information in supporting his or her on-going adaptation and adjustment.

An overview of the process model of stress and coping
Figure 1 presents the process model of stress and coping. This figure shows that there are two basic components to the coping process. These are *appraisal* and the use of *coping strategies*. Both these aspects of the coping process are influenced by factors known collectively as *coping resources*, which comprise both personal or internal variables and socio-ecological or external variables.

Primary appraisal is the process by which an individual evaluates the significance of an event or situation in terms of its impact on his or her well-being. If the situation is judged to be either harmful, a threat or a challenge, then it is a stressor (Lazarus and Folkman, 1984). This process of primary appraisal is idiosyncratic. It is dependent on the individual's unique set of personal and socio-ecological resources which influence the appraisal process. This means that no event or situation can be objectively defined as a stressor. If an event is appraised as stressful, an individual has to make decisions about what to do. *Secondary appraisal* is the process of evaluating coping options and coping resources. This appraisal will also be influenced by the availability or perceived adequacy of personal and socio-ecological coping resources, and an assessment of the predicted effect of a coping strategy on the stressor. Following the deployment of a coping strategy, a process of *reappraisal* occurs. If the individual no longer appraises a situation as stressful, then the coping process will halt. If, the situation remains stressful then the individual will need to decide on the next course of action, and the coping process will continue.

Coping strategies are all efforts - both successful and unsuccessful - which an individual uses to master or manage a stressor. Coping strategies have two major functions: regulation of distressing emotions, described as *emotion-focused coping;* and management of the source of stress which is known as *problem-focused coping*.

Figure 1.1: The process model of stress and coping

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                        │   POTENTIAL STRESSOR    │◄──────────────┐
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                                    ▼                             │
         ┌────────►┌─────────────────────────────────┐◄──────┐   │
         │         │       PRIMARY APPRAISAL         │       │   │
         │         │  What is the meaning of this    │       │   │
         │         │           event?                │       │   │
         │         │  How will it affect my          │       │   │
         │         │        well-being?              │       │   │
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   │   EVENT   │ │          │ │  EVENT   │ │    EVENT      │  │   │
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   ┌───────────────────┐              ┌──────────────────┐  │   │
   │  SOCIO-ECOLOGICAL  │              │    PERSONAL      │  │   │
   │  COPING RESOURCES  │              │ COPING RESOURCES │  │   │
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POTENTIAL STRESSOR

PRIMARY APPRAISAL
What is the meaning of this event?
How will it affect my well-being?

EVENT IRRELEVANT

EVENT STRESSFUL
Threat
Harm   Challenge

EVENT BENIGN-POSITIVE

SOCIO-ECOLOGICAL COPING RESOURCES

PERSONAL COPING RESOURCES

SECONDARY APPRAISAL
What can I do?
What will it cost?
What do I expect the outcome to be?

COPING STRATEGIES
Problem-focused strategies   Emotion-focused strategies

OUTCOME

REAPPRAISAL
Has the stress changed?
Am I feeling better?

The processes of appraisal and coping are influenced by a group of factors known as *coping resources* and these fall into one of two groups: personal and socio-ecological resources. As the term implies, socio-ecological coping resources are located in the individual's environment - and include social support, financial and practical resources. Personal coping resources include physical health, morale, sense of control, personality factors, problem-solving skills, knowledge and beliefs. Differences in the coping resources available to individuals mean that considerable differences in coping are found between individuals who are ostensibly facing the same or similar stressor.

Chronic medical conditions as sources of stress: the need for a holistic approach

Cohen and Lazarus (1979) suggested a framework around which the stressors of a chronic illness could be understood in terms of threats. They argued that the stressors arising from having a chronic medical condition are wide-ranging. Cohen and Lazarus categorised these threats as follows:

1. Threats to life and fears of dying itself

2. Threats to bodily integrity and comfort (from illness, the diagnostic procedures, or the medical treatment itself)
   (i) Bodily injury or disability
   (ii) Permanent physical changes
   (iii) Physical pain, discomfort, and other negative symptoms of illness or treatment
   (iv) Incapacitation

3. Threats to one's self-concept and future plans
   (i) Necessity to alter one's self-image
   (ii) Uncertainty about the course of the illness and about one's future
   (iii) Endangering life goals and values
   (iv) Loss of autonomy and control

4. Threats to one's emotional equilibrium that is, the necessity to deal with feelings of anxiety, anger, and other emotions that come about as a result of the other stresses described

5. Threats to the fulfilment of customary social roles and activities
   (i) Separation from family, friends, and other social supports - physical or perceived
   (ii) Loss of social roles
   (iii) Necessity to depend on others

6. Threats involving the need to adjust to a new physical or social environment
   (i) Adjustment to hospital setting
   (ii) Problems in understanding medical terminology and customs
   (iii) Necessity for decision-making in stressful and unfamiliar situations
   (p229)

Although Cohen and Lazarus developed these categories based primarily on literature drawn from research with adults they are, on the whole, equally applicable to children and adolescents (Beresford, 1992). It is likely that this list of threats is incomplete. However, it does serve to demonstrate the wide variety of stressors that a child or adolescent with a chronic medical condition may have to deal with. Indeed, research on late childhood and adolescence would suggest that threats to self-concept and independence are likely to be particularly salient (for example, Eiser, 1993; Kyngas and Barlow, 1995; Cote, 1996). What is especially significant about this model is that Cohen and Lazarus acknowledge that threats may be located within social, environmental, emotional or psychological contexts. This point has since been reiterated. Eiser (1990) argued for the need for research to move away from focusing solely medical information to adopting a holistic approach to understanding information need:

> ....it is possible that the real limitation ..is the assumption that critical information that children need relates to 'facts' about disease and treatment. ... this focus on facts is at the expense of other information that is at least equally important to children - how they view themselves and maintain self-confidence and esteem; how they explain their illness to others and integrate treatments with social and personal aspects of life-styles.
> (Eiser, 1990, p 92)

Indeed Wallander and Varni (1992), in their review of research evidence, argued that psychosocial factors, as opposed to medical or physical status, exert a more powerful effect on the adjustment of children and adolescents with chronic medical conditions.

Information as a coping resource

In the previous section we argued that chronic medical conditions can cause stressors to arise in all aspects of an individual's life. Here we look at the role of information in the coping process. There is a reasonable amount known the role of information in preparing children for aversive medical procedures and surgery. Overall, this work suggests that being given or seeking out information is related to positive outcomes such as lower levels of distress before, during and after the procedure (for example, Tarnow and Gustein, 1983; Hubert *et al*., 1986; Melamed, 1992). More specifically, Peterson and Toler's (1986) work on children's information-seeking behaviours before surgery showed that children who seek information use what they have learnt to plan how they will respond to the situation they face. However, medical treatments form only a small part of the stressors associated with having a chronic medical condition. We would argue that information contributes to the coping resources available to an individual in a number of ways.

First, information is implicated in a number of personal coping resources. Research has shown, for instance, that the degree to which individuals feel in control of their lives moderates the

effectiveness of their coping efforts (for example, Seligman, 1975; Janis,1983). Feeling well-informed about what to expect from a source of stress makes a key contribution to this sense of control (for example, Weitz, 1991), and decreases anxiety (for example, Miller *et al.*, 1989). Van Veldhuizen and Last's (1991) work found a positive association between providing related medical information to children with cancer and their emotional adjustment. In arguing that information is an important coping resource, they conclude that:

> Using information obtained about the disease, the child is able to understand the situation better, increasing the feeling of control and motivating the child to cooperate with treatment.
> (p 235)

Information also allows the individuals to construct a framework by which they will understand their situation. In terms of knowledge and beliefs about a medical condition, in the absence of accurate or complete information, patients will 'fill the conceptual vacuum' (Voeller and Rothenberg, 1973, p1075) with their own interpretations and fantasies.

Lack of information may preclude an individual using coping resources that are available. In terms of the focus of this study, it could be argued that not knowing about things such as sources of social support, entitlements to various forms of statutory support, knowledge of a range of problem-solving skills and alternative ways to deal with difficult situations or distressing emotions will all influence the coping process. This list is not-exhaustive, indeed one of the purposes of this project is to describe the type and range of information needs a child or adolescent with a chronic medical condition may have. However, it does clearly show the range of *non-medical* information needs a child or young person may have. In recognising the wide variety of information needs that may exist, it is far more aligned to Dervin *et al.*'s (1980) individualistic and subjective definition of information. Adopting this definition within the context of the process model of stress and coping enables us to move forward research on information needs of paediatric and adolescent populations.

Information-seeking as a coping strategy
So far we have described information as a coping resource, and we have identified a number of types of information which are relevant to this discussion. Information-seeking is one of the most frequently used coping strategies. Seeking information may help an individual to make greater sense of their situation and/or may be used to identify possible solutions or outcomes. In this sense, information-seeking is seen as a problem-focused coping strategy and may well be followed or accompanied by other coping strategies.

It is important to also recognise that information seeking may also be used as an emotion-focused

coping strategy. The activity of information-seeking may reduce an individual's sense of dependence and loss of control by allowing them to feel that they are 'doing something' about their condition (Conrad, 1987).

Understanding individual differences in information need

As noted above, appraisal, coping resources and coping strategies differ between individuals. In addition, because an individual's coping resources fluctuate over time (Folkman, Schaefer and Lazarus, 1979), differences in ways of coping with the same or a similar stressor by an individual also occur.

In essence, this means that the process model of stress and coping is able to explain differences between, and within, individuals in terms of their need for information. First, differences in preferred ways of coping will generate different levels of information need:

> ....some patients cope by becoming very actively involved with their treatment
> and are helped by being given relatively detailed information whereas others cope
> in a more 'avoidant' manner and may find detailed information unhelpful or
> distressing.
> (Weinman, 1990, p304)

Furthermore, the nature of the stressor may mean that information-seeking coping strategies would not necessarily be effective. This is especially true in aversive situations which are uncontrollable. Research with adults with HIV and children with cancer suggests that, in some instances, information-seeking may be counterproductive and unhelpful, causing a loss of hope and a lowering of morale (for example, Weitz; 1991; Phipps and Srivastava, 1997).

1.5.2 Empowerment: the role of information

The notion of 'empowerment' has been increasingly used in a variety of contexts since the early 1980's. It has been used with reference to individuals, groups, organisations and communities (Dunst, Trivette and LaPointe, 1994), and its rhetoric can be found in many health care and health delivery policies. Caution has been expressed over the extent to which individual responsibility is over-emphasised within the notion of empowerment, in the absence of recognising the need for structures to be in place which enable and support empowerment (Anderson, 1996). Whilst acknowledging the validity of these concerns, the notion of empowerment remains an important concept and one that is particularly relevant when considering the role of information in the adjustment and well-being of children and young people with a chronic illness or physical disability.

'Patient empowerment' is a term that is often misunderstood, being interpreted as meaning a shift

from a controlling parent-child type relationship between a doctor and patient to a *laissez faire* parent-child type relationship (Bradley and Gamsu, 1995). In actual fact, true empowerment involves changing parent-child type relationships to become relationships between equals - a partnership - involving two-way communication between patients and health professionals. Empowerment recasts patients from a passive and dependent role to a role in which they actively manage their health care on a day to day basis, and their own expertise and knowledge regarding their condition is recognised and valued by professionals.

Within the field of management of chronic illness, the notion of patient empowerment can be traced back to the work and writing of Robert Anderson (for example, Anderson, 1995). Anderson questioned the effectiveness of traditional medical approaches to managing illness in which health professionals assume full charge and responsibility for the treatment of an illness, and in which patients are expected to follow a lifestyle dictated by health professionals. He cited the high levels of non-compliance to treatment regimes among adults with diabetes as an example of the apparent failure of this approach, arguing that:

> ...the traditional medical model simply does not fit the reality of daily diabetes care. Furthermore, attempts to force diabetes care into the traditional medical model have resulted in a significant amount of frustration for both patients and health care professionals. The most salient expression of this frustration is the substantial literature on patient non-compliance.
> (Anderson, 1995, p 413)

The degree to which an empowerment approach to the care of diabetes can be applied in practice has been tested using a randomized controlled trial (Anderson *et al.*,1995). The authors concluded that 'patient empowerment is an effective approach to developing educational interventions for addressing the psychosocial aspects of living with diabetes. Furthermore, patient empowerment is conducive to improving blood glucose control. In an ideal setting, patient education would address equally blood glucose management and the psychosocial challenges of living with diabetes' (p943).

Information has a central role to play in patient empowerment. It enables individuals to make informed choices about living with and managing their condition. Information relevant to patient empowerment is wide-ranging. It should encompass individuals' needs to be well informed about their condition and its management, to be self-aware, and to know about sources of support, problem-solving and other coping skills (Feste, 1991; 1992; Anderson *et al.*, 1995).

While Anderson (1995) questions whether the notion of patient empowerment is applicable to

all conditions, we would argue that this is the case especially if a holistic approach is taken to understanding of the impact of a illness on an individual's life. While most chronic illnesses may not require such an intrusive treatment regime as diabetes, all individuals still face the daily task of having to 'fit' any restrictions or requirements that a condition may impose into their day to day lives. For example, a girl with epilepsy may have to decide whether if it is safe to cycle a couple of miles to a friend's house; or a young man with arthritis will have to weigh up the costs and benefits of taking part in a school sponsored walk.

The notion of patient empowerment is clearly a positive and useful one. We would argue, however, that some of the assumptions or assertions it makes are misplaced or incomplete. For instance, most writers and researchers in this area have focused on the role of health professionals as 'educators'. Yet in doing so they have omitted to acknowledge in any direct way the difficulties of achieving effective communication between health professionals and patients. In addition, others would argue, and we would agree, that there are other, equally important, sources of information especially with respect to psychosocial information needs. In particular, the potential role to be played by other people with the same condition (Barlow, 1993; Barlow and Harrison, 1996). We discuss both these issues in the following section.

1.6   SOURCES OF INFORMATION

1.6.1   Health professionals

Health professionals are a key source of information about a medical condition, its treatment and day to day management. One of the main roles of doctors is that of communicating information. Indeed there is a substantial literature on doctor-patient communication. A number of well received 'good practice' texts on doctor - patient communication have been written which have drawn on this research (for example, Tate, 1997; Roter and Hall, 1993), and improving doctors' communication skills continues to be a significant training issue (General Medical Council, 1991, 1993; Hargie *et al*., 1998). Yet the majority of these texts have a striking omission: they fail to mention communicating with children and adolescents - either in situations where a parent is also present or where doctor is seeing an unaccompanied adolescent. This directly reflects the lack research into this particular aspect of doctor-patient communication, where communication between health professionals and young people is discussed this tends to be in relation to counselling (for example, Edwards and Davis, 1997).

Research into communication within paediatric settings has, in the main, focused on communication between the parent and doctor (for example, Pantell *et al*., 1982). A handful of studies have explored the child's contribution during a consultation with a GP or hospital consultant.   Comparative   analysis   of   videotaped   recordings   of   doctor-parent-child

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communication in GP settings in the Netherlands in the late 1970's and late 1980's suggests that, within that country, children's contributions during these encounters have increased (Meeuwesen and Kaptein, 1996). This appears to be both a product of changes in doctors' behaviours and a greater level of confidence among children to speak for themselves. However, Meeuwesen and Kaptein do note that these changes, or improvements, are small.

A similar picture emerges from studies of paediatric outpatient appointments. Of these, Dulmen's (1998) work - conducted in the Netherlands - is the most rigorous, and its findings are similar to of a number of small scale studies carried out in the United States (Arnston and Philipsborn, 1982; Pantell *et al*., 1982; Worobey *et al*., 1987). Dulmen found that while doctors may ask children questions, both about their health and more general psychosocial issues, when it comes to providing information doctors address the parent. The reasons for this apparently contradictory behaviour of paediatricians are largely unexplored, though Korsch and Aley (1973) suggest that paediatricians may not feel confident about communicating with children or fear it may take too much time (also Levinson, 1997).

A further barrier to satisfactory doctor-child communication may be a lack of awareness on the part of the doctor of the need to take into account the child's level of cognitive development. Work carried out in the United States by Perrin and Perrin (1983) found that health professionals tend to over-estimate a young child's understanding of illness and underestimate older children's understanding. Perrin and Perrin conclude:

> ...[health] professionals do not operate with an intuitive sense about cognitive development. We suspect that instead they see school-age children as generally the same, with minor variations in their size, motor capabilities, and language. ... It seems reasonable to expect that what adults think about children's abilities will influence their behaviour toward children, the kinds of demands they make, the kinds of explanations they provide, and the ways in which they try to teach children.
> (p877-78)

This issue is further complicated by the fact that levels of cognitive development do not follow a fixed, predictable course according to the child's age. Berry *et al.*'s (1993) study of conceptions of illness held by children with juvenile rheumatoid arthritis found that a significant number of children were functioning below the level expected for their age. An implication of this finding in terms of information provision is that each child's developmental status needs to be assessed, rather than relying on indicators such as age and familiarity with the disease and its treatment.

In addition, it is now recognised that it is not possible to use age to predict the concepts of health

and illness held by a child. Work in this area suggests that personal experiences and social factors significantly influence a child's understanding of his or her condition, as opposed to factors such as age (Eiser, 1990). Again this seems to advocate an individualistic approach to communication between health professionals and young people.

Dulmen's (1998) study also highlighted the problem of the triadic nature of the doctor-parent-child encounter. The proportion of verbal contributions from the paediatricians was similar to that observed in diadic patient - doctor encounters (that is, around 60 per cent). This, it was argued, 'may suggest that the child's participation in the encounter does not occur at the expense of the paediatrician but at the expense of the parent' (p566). This may partly account for Dulmen's finding that parents frequently answered questions directed at the child, which could be interpreted in terms of the parent needing to communicate and receive information from the doctor, as well as reflecting the power relationships that exist within families (Aronsson and Rundstrom, 1988). Clearly this is an area which needs further research, especially since there does not appear to be any UK based work on this.

Aside from the lack of observational research into what currently happens during consultations between a doctor, parent and child, even less is known about what children and young people (and their parents) *want* to happen during such appointments. Some recent consultation exercises with groups of children and young people have identified a number of issues and concerns (for example, McNulty and Turner, 1998). These consultations involved children and young people with a range of experiences or contact with health services and have included some with chronic medical conditions and physical disabilities. One example is work carried out for Portsmouth and South East Hampshire Health Commission by Doorbar (1995) which found that most of the young people's concerns about health care related to communication. In particular, Doobar reports that the young people wanted health professionals to be friendly and honest, and to listen and provide information which was 'jargon-free'. They also wanted the opportunity to see a doctor without a parent. The need to provide information verbally accompanied by written, pictorial, or audio/audio-visual information was also emphasised (Doorbar, 1996).

Finally, much of this discussion has focused on doctors, and communication during out-patient appointments. There is a dearth of research into the role of other health professionals in providing information to children and adolescents with a chronic medical condition. Many conditions require the input of physiotherapists and occupational therapists. In the course of diagnosis and on-going monitoring of a condition, it likely that other specialists (for example, neurologists, surgeons) will be consulted. A child or adolescent may also have contact with radiographers, clinic, ward and specialist nurses (for example, epilepsy and diabetic specialist

nurses, community paediatric nurses).   As yet, the role of these health professionals as information sources has not been explored.   In addition, there does not seem to be any work on communication between doctors and young people during in-patient episodes.

1.6.2   Parents

Parents are a key source of support and information for children with a chronic medical condition, especially during pre-adolescent years (for example, Cavet, 1998). Research suggests that most adolescents gradually reduce their demand and needs for support and information from their parents (LaGreca *et al.*, 1995; Olsen and Sutton, 1998; Vaux, 1985).

As we described earlier, the pattern of communication observed during paediatric appointments shows that paediatricians regard parents as a conduit of information between themselves and the child.   Some studies have found a high correlation between parents and children's understanding of the child's condition (for example, Nolan *et al.*, 1986).   However, other research suggests that parents' and patients' *attitudes* about management of the condition are unrelated, with discrepancies between the two parties becoming more marked during adolescence (Strube *et al.*, 1991).   This questions the effectiveness of parents as an information source, certainly among teenage children.

Studies have shown that levels of knowledge among parents about aspects of their child's condition or its management can vary enormously (for example, Beresford, 1992; Hoare and Kerley, 1991; Stewart *et al.*, 1998), and that parents can perceive themselves as poorly informed with unmet information needs (Coulter and Koester, 1985).   Indeed the difficulties that seem to exist in terms of communication between the child and doctor may also be experienced by parents.   Half the parents in Stewart *et al*'s (1998) study of children with epilepsy reported that outpatient appointments were of little or no use, problems with communicating with doctors and the lack of written information were highlighted.

1.6.3   Written information

As with other aspects of the literature we have reviewed here, work on the role of written information is mainly concerned with the impact of written information on adherence to medication or other treatment regimes. It therefore presents only a partial picture of the ways individuals may be using written information, and does not explore the wider range of information needs that could be, at least partially, addressed through leaflets or books.

Research on adult understanding and recall of medical information has consistently shown that providing information verbally is insufficient, and that adults want verbal information to be

complemented or supplemented by written information (Weinman, 1990). Weinman's review of research into the impact of written information reveals that written information can increase knowledge but its benefit to an individual is dependent on reading ability and, as we have discussed earlier, that individual's preferred way of coping - specifically, the amount of information he or she wants or needs.

Quite a lot of work has also been done on the content of information leaflets - in particular their so-called readability (McLaughlin, 1969). For example, Smith *et al.* (1998) evaluated 168 different information leaflets on asthma. They found that the majority of leaflets required high levels of reader comprehension skills, and that more than a third were inaccurate or provided incomplete or out-of-date information. These findings are similar to those of studies which have evaluated information leaflets for other chronic conditions (for example, Coutler, 1998).

As with so many areas of literature we have reviewed, there does not appear to be any work on children and adolescents' use of written information, and its suitability and accessibility for these age groups. We do not know, therefore, whether the research evidence amassed from adult 'patient information' research can, or cannot, also be applied to the paediatric population.

Finally, the fact that written information is an important resource, that it supports patient empowerment, and yet much of it is of poor quality or inaccessible, has prompted the setting up of the Centre for Health Information Quality (CHiQ) as a 'clearing house for patient information'. Established in 1997, CHiQ has laid down three key criteria for information leaflets: they must be easy to read, they must be based on evidence, and they must be developed with individuals who have that condition. With regard to this last criterion, we would argue that involving individuals with a medical condition in the design of information leaflets will also lead to a much wider range of information being included - dealing with the medical *and* psychosocial aspects.

1.6.4   Audio-visual material

Videos providing information about a medical condition are becoming increasingly available, and many of the voluntary organisations produce them (Hill, 1997). While there is, as yet, little evaluation of their role in providing information to adults, the early signs are positive (Weinman, 1990).

For children and adolescents, videos are a very familiar medium through which information is obtained. They are, for example, frequently used as teaching aids within schools. Holzheimer *et al.* (1998) explored the effectiveness of using an asthma education video tape and a picture

book to teach young children (aged two - five years) with asthma about their condition and its management. They found that children who had used the video tape *and* the picture book had greatest increases in knowledge, and acquired the information sooner, than the children who used either the video or the book. In addition, the picture book was found to be more effective than the video. Holzheimer *et al.* and others (for example, Jenkinson *et al.*, 1988) argue that one reason why books are more effective than videos or audio cassettes may be that individuals can control the pace at which they work through a book:

> The book allows parents to direct children's attention to content areas in which knowledge may be lacking, to review relevant information and subsequently reinforce the messages. In contrast, parents and children have no control over the pace at which educational messages are presented in the video tape, and thus have limited opportunity to reinforce relevant content.
> (p95)

It may be the case, however, that among older children audio-visual material becomes more or equally effective. Certainly in terms of recall, van der Molen and van der Voot (1997) found that conveying children's news stories audiovisually was more effective than using a printed version. Another explanation for this may be the very different nature of the information being conveyed.

A number of videos also exist which focus on the psychosocial aspects of living with a certain medical condition - some of which are specifically for children and adolescents. These, too, can be a source of information - about social, educational and personal factors which may be affected by having a particular condition. The use and effectiveness of these sorts of videos has not, however, been evaluated.

1.6.5 Help lines

Most of the national voluntary organisations concerned with the more common medical conditions provide a telephone help line service offering support and information, and the use of these help lines by adults (and carers) is continually increasing (Broadstock and Borland, 1998; Clode, 1998). There is some research into the use of help lines by adults with medical conditions, especially cancer. Overall this research has shown that help lines can be an effective way of obtaining information which is specific and relevant to an individual's concerns (for example, Anderson *et al.*, 1992), and which can then be used to assist decision-making, planning and problem-solving (Manfredi *et al.*, 1993; Marcus *et al.*, 1993). They may also be used as a resource for emotion-focused coping efforts (Broadstock and Barland, 1998). Clearly, help lines can be an important source of information to adults, whether the same applies to children and young people is not known. However, the impression of staff within voluntary organisations is that children and adolescents are not using their help lines (Bairstow, 1998; Harrison, 1998).

1.6.6   Peers with the same or similar condition

There is little acknowledgement in the literature of the role that other young people with the same condition may play as an information source. Peer modelling films have been used to help prepare children for hospital admission and to demonstrate self-administration of insulin injections (Shute and Paton, 1990; Gross *et al.*, 1985). However, a more direct use of peer support groups as a means of learning and sharing information among children and adolescents is rarely mentioned in patient education research and literature.

More general research on the functions of support groups or self-help groups reveals that they play an important role as an information source - especially for practical or social, as opposed to medical, information (for example, Beresford, 1994). Groups of physically disabled young people have described the benefits of sharing experiences and solutions (Barlow, 1993), particularly providing information to group members about dealing with problems and difficulties related to their condition (Russell, 1998; also Cavet, 1998). Similarly, a number of studies of children with cancer describe the self-reported value of support groups as, among other things, a source of information (Lansdown and Goldman, 1988; Hockenberry-Eaton and Minick, 1994).

1.6.7   The Internet

A recent newspaper article described the Internet as 'bursting with health information' (Burne, 1998), ranging from basic factual information to the findings of latest research. There are also a growing number of Web-based support groups where information and experiences can be exchanged. It is clear that the Internet represents a significant new resource which will become increasingly accessible to anyone seeking information about a medical condition and its management. However, there are concerns both about the accuracy of the information available, and the problems of lay interpretation of complex medical or pharmacological research.

At the moment, the Internet does not feature in the research literature on information provision to children and adolescents with a chronic medical condition. However, within two or three years all schools in the United Kingdom will have access to the Internet. The experiences of children and young people using the Internet to access medical information or support and information from peers will need to be monitored and examined.

1.7   RATIONALE FOR THE PRESENT STUDY

Access to information about their condition and its impact on their lives is a key need for children and adolescents who are chronically ill or who have a physical disability. Research suggests that being well informed is central to a number of processes. First, information is a key

element of empowerment, by which children can exercise greater control and choice in their lives. Second, information is critical to the process of coping with a condition on a day to day, long-term basis. Within this process, information acts as a resource, both in the way situations and events are perceived, and to the coping options that are available to an individual. The degree to which an individual is able to cope effectively impacts on overall adjustment to having a chronic medical condition, and on indicators of mental and physical health. In past, the concept of patient information needs has been driven by the assumptions and 'health outcome' agendas of medical research, and needs have largely been defined in terms of knowledge of the medical condition and its treatment or management. Any psycho-social information needs have been largely ignored - both with respect to research *and* practice. Furthermore, there is evidence to suggest that opportunities for meeting information needs may be very limited for children and adolescents. Information that is available tends to focus purely on medical information needs. In addition, children's roles in interactions with health professionals are typically confined to those of information provider, rather than information receiver.

The objective of the present study was to work directly with chronically ill and physically disabled children and adolescents in order to identify their past, current and future information needs, and their experiences of seeking information. The project then worked with the project participants to identify ways in which their information needs could be better met.

1.8   STRUCTURE OF THE REPORT

The remainder of this report is structured as follows. Chapter Two describes the research design, recruitment procedures, methods and details about the sample. In this chapter we also reflect on our experiences of using the different methods we employed. The chapter concludes with a report of the children's and adolescents' experiences of taking part in the project. Chapters Three and Four are devoted to reporting the findings of the study. We begin in Chapter Three by describing the children's and adolescents' information needs and the factors which affected what, and how much, they needed to know. Chapter Four deals with the children's and adolescent's reports of their sources and experiences of getting information, as well as reporting the young people's recommendations with respect to meeting their information needs. Finally, Chapter Five discusses the policy and practice implications of the findings from this study, and points to areas of further research.

CHAPTER TWO
RESEARCH DESIGN AND METHODS

2.1   BACKGROUND

Over recent years there has been a significant shift in the way research about children and adolescents is carried out (Beresford, 1997). Previously, it had been argued that children are an unreliable and invalid source of data. However, research has consistently shown that children are as reliable as adults, and are able to form and express opinions at a young age (for example, McGurk and Glachan, 1988; Williamson and Butler, 1994). Failures of earlier research to engage with children meaningfully is now seen as due to the use of inappropriate research design and methodologies (for example, Fine and Sandstrom, 1988; Backett and Alexander, 1991). Furthermore, we now know that adults cannot be used as proxy-informants. Children and adults experience events and situations differently, and as a result their needs and opinions arising from that situation also differ (Beresford, 1997).

As well as the position being taken by academics with respect to the need to carry research *with*, as opposed to *on* children, the fact that children have a right to express their views about issues related to them places an obligation on researchers to enable children and young people to have voice in projects which are about them (Beresford, 1997).

It was therefore very important that this project was designed in such a way that enabled children adolescents with a chronic illness or physical disability to express their views and opinions, both about their information needs and the ways that information should be provided. It was equally important that by taking part in the project, the young people were treated as more than just sources of data. Ideally, we wanted them to find that participating in the project was an empowering, enjoyable and beneficial. This project used these principles to inform all aspects of the research design and methods we used.

2.2   THE RESEARCH TEAM

During the data collection phase the research team consisted of researchers (Bryony Beresford and Patricia Sloper) and four interviewers. The interviewers were recruited to the project to carry out individual home interviews and to assist at the group meetings. A single interviewer worked with all participants with the same condition and in the same age group. That interviewer was then involved in planning, attending and facilitating the group meetings of those participants, along with one of the researchers. All the interviewers attended a two-day training workshop and received supervision from the researchers while they were carrying out the interviews.

2.3   OVERVIEW OF RESEARCH DESIGN

In summary, the project worked with children and adolescents with one of five chronic medical conditions: juvenile chronic arthritis, cystic fibrosis, diabetes, epilepsy and Duchenne muscular dystrophy. Each participant was interviewed at home and then attended two group meetings with other individuals of about the same age and with the same condition. The two key aims of the project were:

i)   To identify the information needs of chronically ill and physically disabled children and adolescents. This included information relating to the condition and its management, as well as information about the impact of the condition on other aspects of the young person's life. Methods used for this phase of the project included a literature review, individual interviews, and group meetings which incorporated a series of group tasks and activities.

ii)   To work with the research participants to develop recommendations for good practice in the provision of information to children and adolescents. This aim was achieved through group discussion meetings which involved a number of different tasks and activities.

2.3.1 Characteristics of the sample

Medical conditions included in the project

Although we expected that certain information needs would be specific to particular conditions, the conditions we chose to include in this study represent most of the issues and experiences which are likely to generate information needs. This, we believe, enables the findings from this study to be applied to other chronic medical conditions.

Cystic fibrosis was included in the project because it is a life-threatening condition, and its management demands a rigorous treatment regime of physiotherapy, medication and diet adherence. Young people with cystic fibrosis are likely to require inpatient treatment at least once or twice a year. In terms of the impact on an individual's social and emotional life, cystic fibrosis can affect physical appearance and the development of secondary sexual characteristics is often delayed. The condition is also likely to predispose the child to more than usual bouts of illness. The genetic nature of the condition means that there are also reproductive issues, and for boys infertility is likely to be a future problem. Cystic fibrosis is usually diagnosed within days or weeks of birth. There have been significant improvements in the medical management of the condition, and life expectancy is now much greater with many surviving beyond early adulthood. However, in some cases there can be a rapid and unexpected deterioration during the teenage years.

Although *juvenile chronic arthritis* is not life-threatening, it has severe long-term consequences if the condition is not well managed and adherence to treatments is poor. A treatment programme may include physiotherapy, wearing splints, operations, medication and exercises. Arthritis can also affect physical appearance and mobility and, as a result, employment opportunities. Finally, including arthritis in the study allowed us to explore issues related to pain and pain management. Juvenile chronic arthritis can occur from birth up to about 18 years of age. Prognosis varies according to the type of arthritis - some children will 'grow out' of the condition. Providing a definite prognosis can be difficult.

Diabetes was the third condition included. Assuming control of the monitoring and treatment regime necessary to remain healthy is a key issue for older children and adolescents. Diabetes places limits on lifestyle, especially in terms of diet, exercise and consumption of alcohol. Control of diabetes is often compromised during puberty and adolescence because of hormonal changes and rapid growth. For girls, issues related to having children may need to be faced as diabetes can cause problems in pregnancy. Having diabetes may also limit career and employment options. Insulin-dependent diabetes can onset at any age.

We chose *epilepsy* as our fourth condition because it is arguably the most stigmatised chronic condition. Although episodic, it also imposes significantly on life-style. There are restrictions in terms of employment, driving, alcohol consumption and certain activities may need to be avoided (for example, disco/strobe lights, excessive computer use) or should not be carried out alone (for example, swimming). As with the other conditions, a regular course of medication is usually necessary. The onset of epilepsy can occur from birth onwards, and in many cases the cause of the epilepsy cannot be established. As with arthritis, some types of epilepsy only occur during childhood - however, providing a diagnosis and prognosis is often difficult.

Finally, and at the request of the R&D Initiative's executive committee, *Duchenne muscular dystrophy* was represented in this study. Duchenne muscular dystrophy is a life-limiting condition characterised by increasing physical impairment and weakness, and hence growing care needs and dependency. The onset of symptoms is usually before the age of five years with progressive deterioration over a number of years. The condition cannot be treated, though its symptoms - muscle weakness - are managed by physiotherapy, splints, body braces and operations (usually on the back and feet). Duchenne muscular dystrophy is a genetic condition which only affects boys.

Ages represented in the project

Feeling confident about being able to manage the condition and its impact on day to day life and lifestyle becomes increasing important as children grow up and begin to assume autonomy and seek independence. This generates information needs that will vary according to the child's age or life cycle stage (Garrison and McQuiston, 1989). We chose to focus on two age groups - 10 to 12 years, and 14 to 16 years (at the time of recruitment to the project) - which represented stages at which there are likely to be increased demands for information about the condition and its impact on the child's or adolescent's life. Around the age of 10 to 12 years many children take over management of some aspects of the daily treatment regime, it is also when they will be transferring to secondary school and approaching puberty and adolescence. Different issues face 14 to 16 year olds including deciding about further education and/or employment, negotiating with parents for increased autonomy and independence, transfer from paediatric to adult services, relationships and sexual issues, and beginning to think about leaving home.

Proposed sample size
The sample therefore consisted of ten groups - two groups (younger and older) for each of the five conditions. The project aimed to recruit between eight and ten young people to each group thus yielding a sample size of about eighty. Details of the actual sample recruited to the project can be found in section 2.7.

2.4   RECRUITMENT
The sample was recruited through clinic lists at four hospitals. Given that the methodology included group discussions, it was necessary that, for each condition, all participants were recruited from the same hospital. Participants with arthritis were recruited from a hospital in the South East. The participants with muscular dystrophy and epilepsy were recruited from a single hospital in the North West of England. The young people with diabetes and cystic fibrosis were recruited from two different hospitals in the North East.

Ethical permission was obtained from the relevant ethics committees once the sites had been identified. The consultant(s) responsible for the clinics contacted potential families by letter (see Appendix 1), enclosing an age appropriate project information leaflet for the potential participant and a parents' project information leaflet (see Appendix 2). The letter invited families to return a contact form (Appendix 3) to the research team if they wished to be contacted by the research team with a view to taking part in the project. Reminder letters were sent to families who had not responded within a month of the initial letter.

Responses to contact forms were followed up by the interviewer responsible for that condition, and an arrangement made to visit the family.

2.4.1 Response rates

Response rates to the invitation to take part in the project are shown in Table 2.1.

Table 2.1: Response rates

Condition	No. of families invited to take part in project	Contact forms returned n (%)	Agreed to participate in study
Arthritis	37	19 (51%)	17 (46%)
Cystic Fibrosis	32	12 (37%)	11 (34%)
Diabetes	22	12 (54%)	12 (54%)
Epilepsy	not known	12	10
Muscular dystrophy	31	13 (42%)	13 (42%)

There were a variety for reasons why a few families decided not to take part in the project following our initial telephone contact with them. In the majority of cases it did not relate to the project itself.

For the conditions where we do have figures for response rate it ranged between 37 per cent and 54 per cent. This yielded a total sample of 63 young people. The final sample site was slightly less than we had originally predicted, but reflects lower than expected sampling pools at the various recruitment sites, rather than just poor response rates to the project.

2.5   OBTAINING CONSENT

Consent to take part in the project was obtained from the participant and a parent during the home visit. Prior to seeking consent, the interviewer provided further details about the project, answered questions and checked that both the parent and young person had read their information leaflet. A copy of the consent form can be found in Appendix 4.

All families who had requested a home visit by an interviewer consented to take part in the study. The interviewer re-checked consent with the participant (in the absence of a parent) before beginning the individual interview which immediately followed the introductory meeting.

The project took an on-going approach to consent. Thus all participants were told on a number of occasions that it was acceptable both not to answer any questions if they did not want to, and to withdraw from the project at any time.

2.6   ENCOURAGING PARTICIPATION

The researchers were aware that most children and adolescents would be reluctant to attend a meeting where they might not know anyone else, and be asked to discuss what might be quite sensitive issues. A number of aspects of the research design focused on encouraging participation in the project.

First, the groups consisted of other young people of a similar age and with the same condition. Second, clear information was provided at the recruitment stage, and the benefits of taking part - such as a greater knowledge of their condition, meeting others with the condition, and the chance to 'have a say' in the ways services are provided - were emphasised. Third, a payment in the form of a gift token (£10 for the younger age group, £15 for the older age group) was given at the end of both group meetings. Finally, prior to the group meetings each participant was visited by a member of the research team. This visit meant that participants knew there would be at least one familiar face at the first group meeting.

2.7   THE SAMPLE

A total of 63 young people were recruited to the study, 27 boys and 36 girls. The younger age group consisted of 13 boys and 16 girls (total = 29); while the older age group (14-16 years) contained 14 boys and 20 girls (total = 34). Table 2.2 shows a breakdown of the sample by age band and condition. As these figures show, recruitment of boys and the younger age group was more difficult.

Table 2.2: The sample

	Younger age group (10-12 yrs)		Older age group (14-16 yrs)	
	Boys	Girls	Boys	Girls
Juvenile Chronic Arthritis	2	4	3	8
Cystic fibrosis	1	4	3	3
Diabetes	-	7	2	3
Epilepsy	2	1	1	6
Muscular dystrophy	8	n/a	5	n/a
TOTAL	13	16	14	20

2.7.1 Participation in the different stages of the project

Participation in the project involved an individual interview and two group meetings. Although all participants were interviewed individually, not all attended both or even one group meeting.

Table 2.3 summarises participation in different stages of the project.

It was particularly difficult to arrange the group meetings for the young people with cystic fibrosis and muscular dystrophy. For the young people with cystic fibrosis, a problem was that in the management of this condition, families and health professionals are keen that contact should not occur between young people who are growing a particular infection (*Pseudomonas cepacia*) and those who are not growing the infection. As a result the decision was taken to form 'growers' and 'non-growers' groups, rather than splitting the sample by age. A number of practical difficulties meant that the first non-growers group meeting was cancelled.

For the group meetings for those with muscular dystrophy, the difficulty lay in a reluctance among the many of the young people to attend a group meeting. Only two of the older boys were able, or wanted, to attend the first group meeting, and it was felt that this was not sufficient to hold a group meeting. For the second group meeting, very few wanted, or were able, to attend and so a mixed age group meeting was held.

All the young people with either cystic fibrosis of muscular dystrophy who did not attend the first group meeting were invited to take part in a second individual interview which covered the same issues as were discussed at the group meeting. All young people with cystic fibrosis, and four of the eight with muscular dystrophy, agreed to a second interview.

Among the other conditions, attendance at the group meetings was very good and we were particularly pleased with high attendance rates at the second wave of group meetings, where some drop off might have been predicted. As would be expected, illness or hospitalisation was the most common reason for non-attendance. For one or two, other commitments such as weekend jobs or school, meant they could not attend a meeting.

Table 2.3: Participation in different stages of the project

	Individual interview	1st Group meeting	2nd group meeting
Arthritis 10-12 yrs	6	4	3
Arthritis 14- 16 yrs	11	10	8
Cystic fibrosis 10- 12 yrs	5	'growers' gp: 3	'growers' gp: 6
Cystic fibrosis 14 - 16 yrs	6		'non-growers' gp: 3
Diabetes 10-12 yrs	7	6	7
Diabetes 14-16 yrs	5	4	3
Epilepsy 10-12 yrs	3	3	3
Epilepsy 14-16 yrs	7	7	6
Muscular dystrophy 10-12 yrs	8	5	3
Muscular dystrophy 14-16 yrs	5	no meeting	
Total	63	42	42

2.8   METHODS

A *literature review* was carried out over the course of the project the findings of which are reported in the previous chapter.

For data collection, the project used qualitative research techniques for two key reasons. First, where little is known about a particular population, and assumptions cannot be made about what constitute the key issues or factors, the research task must be one of identification, description and interpretation (Neuman, 1991). Such a task requires qualitative techniques. Second, qualitative techniques offer a more direct voice to those involved with research (Prout and James, 1990), and are less likely to preclude participation by those with physical or other impairments, or the younger age groups (Beresford, 1997). The qualitative methods used in this project were individual interviews and group discussions. Various techniques were used to facilitate communication in both contexts. The group meetings were held at venues in or close to the hospital from which the participants had been recruited.

2.8.1 Individual interviews

Once a family had expressed an interest in taking part in the project, an arrangement was made for a home visit. The purpose of the home visit was three-fold. First, it provided an opportunity

for the child or adolescent and his/her parent(s) to meet a member of the research team before giving consent to take part in the project. Second, it meant that the young person would know at least one person when they came to the first group meeting. Third, assuming consent had been obtained, an individual interview could be conducted with the participant. The individual interviews were used to provide details about participants' knowledge and understanding of their condition; its treatment and management; the perceived impact of their condition on their lives; experiences getting information - both from health professionals and other sources, and areas of unmet information need. An example of the topic guide used for the individual interviews can be found in Appendix 5.

2.8.2 First round of group meetings

The first round of group meetings followed as soon as possible after all the individual interviews for a group had been completed. The aim of the meeting was to obtain as complete as possible picture of the participants' perceived past, current and future information needs. It was also important that time was spent at the beginning of the meeting facilitating the group to 'form' - a process which is necessary in order for any group to work effectively together (Clarkson, 1995). We chose to facilitate these first meetings around various interactive activities. Thus the meetings were quite closely organised and were not dependent on more unstructured open discussion of issues. The general format of these meetings was as follows:

- Welcome and introductions
- Explaining the purpose of the meeting
- Warming up exercise I: sharing feelings about being in a group (round group exercise)
- Warming up exercise II: each participant told their story of their medical condition
- Feedback to group on our interpretations of individual interview data on participants' medical information needs using visual aids
- Time for reflection, feedback and adding to the list of medical information needs through an interactive exercise
- Scenario exercise: participants worked either as a whole group, or in small groups if the group was large. This was an interactive exercise in which the groups discussed a series of scenarios about an imaginary young person with their condition; for each scenario the group had to decide what the individual would need to know to manage or resolve that situation
- Closing session.

All groups had at least one break during the meeting, and the meeting lasted between 1.5 and 3 hours.

2.8.3 Second round of group meetings

The second group meeting was concerned with exploring the participants' experiences of getting information, and identifying ways in which their information needs could be better met. We chose the adopt an iterative process to planning and developing the focus and content of these meetings. Thus what had emerged in a previous meeting informed how we ran, and what we covered, in a subsequent meeting. We used more 'adventurous' methods (for example, role play) and imposed less of a structure in the second meetings, thus allowing more time for open discussion between group members. This is because we were confident that the groups had 'formed' sufficiently during the first meeting to be able to respond to this sort of approach.

Listed below are the issues covered within the second round of group meetings, the methods used to facilitate discussion around each issue are in brackets:
- Doctor - parent - child communication (role play, brainstorm)
- Currently used and preferred sources of information (group mapping exercise, group discussion)
- Identification of appropriate information sources for different information needs (group mapping exercise, group discussion)
- Barriers to using various information sources (group mapping exercise, group discussion)
- Written information (design-a-leaflet exercise, group discussion)
- Diabetic camps (sharing of individual accounts, group discussion).

The duration of the second group meetings was similar to the first group meetings.

2.8.4 Other methods used with the boys with muscular dystrophy

Promoting discussion at the first group meeting for the boys with muscular dystrophy proved to be particularly difficult. This was partly due to the widely differing levels of cognitive ability and concentration within the group, even though they were within the same age range. A further factor, that was also noticeable in interviews, was the extreme reticence, and shyness, of some participants. Whilst the group did warm up slowly at the first meeting, and most of the group contributed to discussion, two quickly lost concentration and interest, and then tended to distract those who wished to carry on with further discussion.

Numbers willing to attend group meetings were low, and we therefore decided to hold only one meeting in the second stage and to divide participants into small groups based on levels of concentration and cognitive ability. Activities which did not require a lot of verbal input, such as responding to statements by 'posting' responses, were planned to supplement the more verbal activities used in other condition groups. Statements concerning how they might like their

information needs to be met were drawn up, based on information from interviews and from the other groups. Participants could then post cards into 'yes' or 'no' boxes to indicate their response. On the day, only three boys were able or willing to attend. These were some of the more verbally confident boys in the sample, but even so were clearly uncomfortable with activities such as role play. We therefore used 'posting' boxes for a non-verbal activity. This activity received a very positive response and through it we were able to move on to a mapping exercise and promote some discussion within the group.

As so few boys attended this second session, we converted the posting exercise into a postal questionnaire to give non-attenders a chance to have an input to recommendations regarding how they would like their information needs to be met. This was sent to all ten non-attenders; five responded.

2.9   ANALYSIS

Permission was sought to tape-record all individual interviews and group discussion meetings. A small number of participants did not want their interviews to be tape-recorded, in these instances the interviewer made notes during the interview which were then written up immediately after the interview. All the tape-recorded interviews were transcribed. The individual interview material was analysed using the framework or charting method (Ritchie and Spencer, 1994). Charting is a manual approach to managing and analysing qualitative data. The first stage involves coding of the transcripts according to a series of analytical categories. Next the data from the verbatim material is gathered onto a series of charts - one for each analytical category. The chart does not contain verbatim text but rather a synthesis of what was said accompanied by a reference to where it can be found in a transcript. Data are entered on the chart so that reading across a chart provides information about a particular subject, while reading down a chart enables comparisons to be made across the sample. The charts are then used to identify over-arching themes in order to understand the research findings and report them in a meaningful, yet concise, way.

The findings from the analysis of the individual interviews with respect to information needs were reported back to participants during the first group meetings. One of the tasks at those meetings was to ask for feedback from participants about the way that individual interview data had been interpreted, and to give the opportunity for participants to add further information needs.

The tape-recordings of the group meetings, and those interviews with participants who were

unable to attend the first group meeting, were treated differently. Notes were made from the tape-recordings, and these notes, along with other materials collected during activities carried out in a meeting formed the meetings' data. A similar charting method was used for the material gathered during the group meetings according the different themes and issues that the various groups had worked on.

For the analysis, we treated the data we had collected as a single set of data, as opposed to five different sets of data (ie. the five conditions). There were two main reasons for doing this. First, some of the issues being explored in this project are likely to be influenced by factors located within the clinics from which the young people were recruited (for example, practices in information provision; characteristics of key health professionals which may influence quality of communication with patients) (see Drotar, 1994). Thus any effects that might be ascribed to the nature of the condition might, in fact, be caused by aspects of the clinic and professionals who work there. Second, in an earlier section we described our rationale for choosing the five conditions represented in this project. We were particularly keen that, *taken together*, most of the issues, difficulties, stresses and predicaments that a young person with any chronic illness or physical disability may face would be represented in these conditions. Our argument was that this would enable the findings from this project to be generalised.

Finally, although we treated the interview and group meeting material as a single data set, we did explore the effects of condition-related factors on young people's information needs and their experiences of having those needs met. Such factors included duration of the condition, age of onset, treatment requirements, and prognosis.

2.10   SUPPORT FOR THE CHILDREN AND ADOLESCENTS TAKING PART IN THE STUDY

At the stage of designing this piece of work, we recognised that involvement in this project might raise issues or reveal needs for those children and adolescents taking part. Thus prior to the fieldwork stage the following support strategies were set in place.

2.10.1 Help packs

First, at the time of the individual interview, each participant was given a 'help pack'. This included cards bearing the telephone numbers (day and evening) of the research team, their project advisor (see below), and the help line numbers for appropriate voluntary organisations; and a pre-paid envelope addressed to the research team.

2.10.2 Project advisors

Second, workers skilled in providing information and counselling to children and adolescents with specific medical conditions were 'recruited' to the project. Known as 'project advisors', their role was to be an independent (of the research team) source of information or support to project participants - through telephone or personal contact. For three conditions (epilepsy, diabetes and muscular dystrophy), specialist clinic nurses or a hospital based advisor were used. For the other two conditions, workers from major voluntary organisations (Cystic Fibrosis Trust and Lady Hoare Trust) were 'recruited'. The project advisors were provided with information about the project through telephone contact and written material. Each was provided with a protocol for dealing with a situation in which they were significantly concerned for the child's welfare (see Appendix 6). We had originally planned for the advisors to be present at each of the group meetings. However, by the time of the second meeting the researchers felt that it would be unnecessary for the advisors to be present. This was mainly due to the strength of the rapport which had developed between the research team and the participants. It was felt that should the situation arise, it would more appropriate for a member of the research team to provide initial support and advice rather than pass the young person on to another, relatively strange, face. We discuss this issue further below.

2.10.3 Written information

At each of the group meetings a sample of relevant information leaflets was on display. Participants (and their families) were encouraged to look at them and request their own copies. After each meeting the researchers then obtained and distributed information leaflets requested.

2.10.4 Use of the support mechanisms

Members of the research team who conducted the individual home interviews reported that the help packs were received positively, and when asked about them at the second group meetings most participants said they knew where they had kept theirs. However, aside from some phone calls about practical issues linked to attending a group meeting, the research team was not contacted by any of the participants. Similarly, only one of the project advisors was contacted by a participant. This concerned a request for information about statutory benefit entitlements. The information leaflets were extremely popular. Virtually all participants who attended a group meeting requested at least one information leaflet.

How should we interpret this response by participants to the sources of support offered by the project? As we report in the following section, we believe that apart from a small number of participants, the children and young people enjoyed taking part in this project. For the great majority, the opportunity for contact and discussion with others in a similar situation was a very positive and informative experience. Many participants used the group meetings - both during

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discussions and breaks - to ask questions, both of each other and the research team. Before the project got underway we could not predict how our relationship with the participants would develop, and for this reason decided to have project advisors available. In the event, we were pleasantly surprised by the openness and warm rapport that developed - especially over the course of the two group meetings. Given this level of rapport, we believe it would been very unlikely that the young people would have used a project advisor (whom the participants might have met once or twice but did not 'know') instead of a member of the research team as a source of support. The exception here might have been the boys with muscular dystrophy, where there was less contact with the research team and the project advisor was well known to most of the families.

2.11   PARTICIPANTS EXPERIENCES OF TAKING PART IN THE PROJECT

At the end of each second group discussion meeting, we asked the children and young people to complete a brief questionnaire about their experiences of taking part in the project. Two versions of the evaluation questionnaire were used (see Appendix 7). For the boys with muscular dystrophy, many of whom had difficulties with writing, we used fixed-response questions which only required ticking boxes, while the remainder were given a questionnaire which asked participants to write down their responses to a series of questions. The questions covered reasons for taking part, usefulness of the information leaflet, what parts of the project they enjoyed most and which had been least enjoyable, and, finally, what the research team could have done to prevent the latter. The fixed-response questions used for boys with muscular dystrophy were derived from the responses of young people in the other groups. Those children and young people who were unable to attend the second group discussion meeting were sent the questionnaire. An overall response rate of 72 per cent was obtained.

This evaluation questionnaire was a crude attempt to begin to explore an issue about which very little is known: that is, the experiences of taking part in a research project. This evaluation did not form part of the project 'proper', and the idea to use this project as an opportunity to explore young people's experience of a research project was only formed towards the end of the project. Indeed, its main purpose was that it could be used to inform future practice within our research unit with respect to research with young people. We have chosen to report it here because we believe it offers useful insights. In terms of future projects we carry out, we will certainly be mindful of the sorts of issues that were covered by the responses given on the questionnaire.
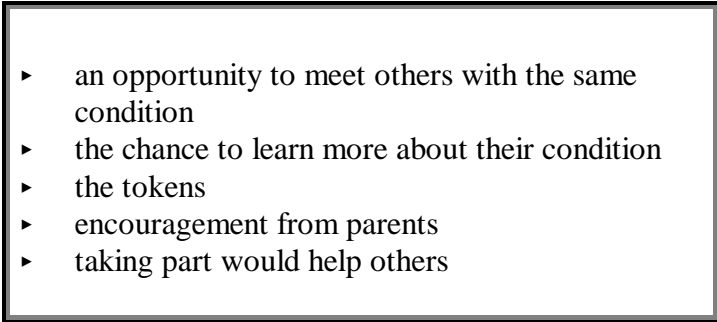
We will briefly report responses given on the questionnaire about why the young people took part in the study, the perceived benefits of taking part, and negative or difficult experiences. Aside from the boys with muscular dystrophy, most of the participants completed the

questionnaire soon or immediately after the second group meeting. Thus responses were likely to more reflect experiences of the group meetings rather than the earlier individual interviews.

2.11.1 Reasons for participating

Figure 2.1 summarises the reported reasons for taking part in the project. The most common reason given was that participation was seen as an opportunity to meet others of similar age who had the same condition. Thus for the majority of participants, the group meetings were an incentive to take part in the project. Other reasons for taking part included the chance to learn more about their condition, being encouraged to do so by parents and a sense that taking part would help others. While only a few participants stated that the tokens we 'paid' participants were the reason for joining the study, conversations with the young people over the course of the project suggest to us that when initially deciding to take part in the study the tokens *were* an incentive. By the end of the project, when participants had experienced the benefits of taking part (described below), the importance of the tokens to most of the participants was reduced, and this was reflected in their responses on the evaluation questionnaire.

Figure 2.1: Reasons given for taking part in the project

> ▸ an opportunity to meet others with the same condition
> ▸ the chance to learn more about their condition
> ▸ the tokens
> ▸ encouragement from parents
> ▸ taking part would help others
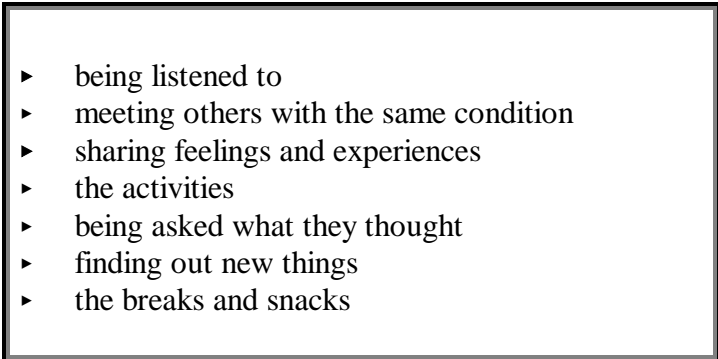
2.11.2 Positive aspects of participation

Figure 2.2 lists what the participants had enjoyed about taking part in the project. In terms of what had been good about taking part in the project, the most frequently reported benefits were meeting others with the same condition, and sharing feelings and experiences. For the boys with muscular dystrophy, many of whom did not attend a group meeting, having their views listened to was seen as a positive experience. The evaluation questionnaire also asked the young people to nominate the activity they had enjoyed most during the group meetings. Some participants made a general statement about enjoying discussions, while others made a specific choice about their favourite activity. Those who had taken part in role play activities often reported this activity as the most enjoyable. However, it is important and interesting to note that for each activity carried out in a group meeting, at least one participant stated that it was the activity he

or she had enjoyed most.

Figure 2.2: Things participants enjoyed about taking part

> ▸ being listened to
> ▸ meeting others with the same condition
> ▸ sharing feelings and experiences
> ▸ the activities
> ▸ being asked what they thought
> ▸ finding out new things
> ▸ the breaks and snacks
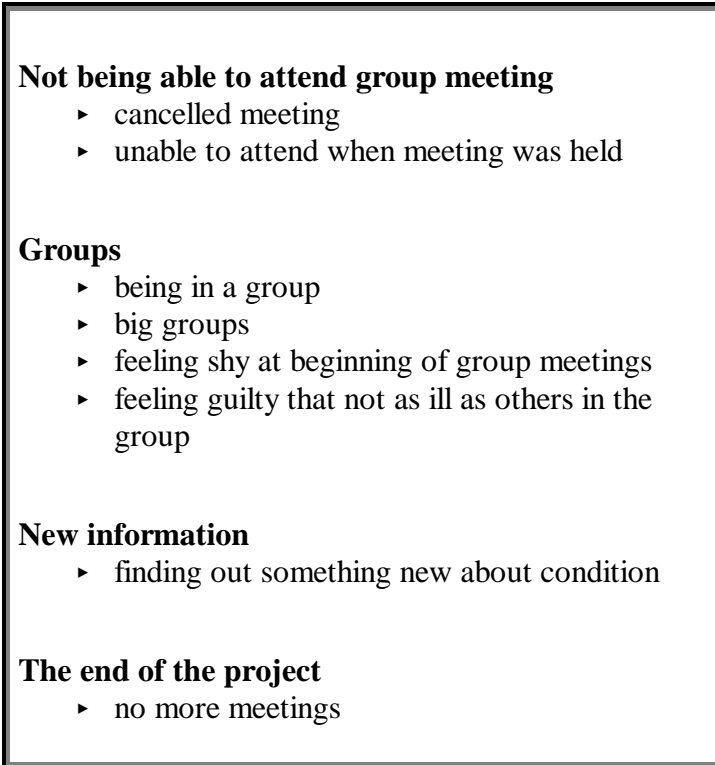
2.11.3 Negative experiences

Finally, Figure 2.3 shows what the children and young people did not like about being involved in the project. These negative or difficult experiences can be divided into four separate categories.

The first category concerns not being able to attend a group meeting either because the meeting had been cancelled (which happened on two occasions) or because the date of a meeting was unsuitable for an individual participant. Second, a small number of participants found some aspect of the group meeting difficult - though in most cases this was a short-term difficulty, such as feeling shy at the beginning of the meeting. Although most of our groups consisted of six or fewer young people, one group contained ten participants. Some of the younger participants in that group reported that being in such a big group was difficult, but enjoyed the sessions when the group was divided into three small groups. One participant said that meeting others with more severe forms of his condition had made him feel guilty.

Third, while a number of children and young people reported that learning new things had been a positive aspect of taking part in the study, in one instance a participant learnt a significant negative fact about his condition from another young person during a meeting. This was perhaps an inevitable consequence of group meetings where levels of knowledge varied across group members, and one which the researchers could not prevent happening. Finally, a number of participants were sad that the project only involved two meetings and no further meetings were planned.

Figure 2.3: What the children and young people did not like about the project

Not being able to attend group meeting
- ‣ cancelled meeting
- ‣ unable to attend when meeting was held

Groups
- ‣ being in a group
- ‣ big groups
- ‣ feeling shy at beginning of group meetings
- ‣ feeling guilty that not as ill as others in the group

New information
- ‣ finding out something new about condition

The end of the project
- ‣ no more meetings

2.12 REFLECTIONS ON THE RESEARCH TEAM'S EXPERIENCES OF THE FIELDWORK PHASE

2.12.1 Offer more than one way of being involved in a project

For some a key reason for taking part in this project was the chance to meet others with the same condition. However, we have already reported that almost all the boys with muscular dystrophy did not want, or were very reluctant, to take part in group meetings, *yet* wanted to be involved in the project. Furthermore, it may be that other children and young people who were invited to take part in the project, but refused, were put off by the fact that it involved taking part in group meetings.

While we were able in this project to respond to this difficulty when it occurred by offering further individual interviews and/or postal questionnaires, our experiences raise an important question about the way certain methods may act to exclude possible participants. Within the literature, it is quantitative methods that tend to be criticised as excluding certain groups, including children and disabled people (for example, Ferguson *et al.*, 1992). Yet it is now clear to us that qualitative research techniques, especially group situations, can themselves act as a deterrent to possible participants.

One response to this would be to offer a number of ways of participating in a research project, which is what we ended up doing in this project in an *ad hoc* manner. In addition, consultation with individuals representing the population who are the focus of research during the planning stages of a research project may reveal potential difficulties with proposed methods.

2.12.2 Taking account of the physical implications of the condition

Although the team was diligent in learning about the medical conditions with which they would be working, in retrospect we feel that even more time should have been spend 'translating' the medical facts into thinking about what that will mean in terms of how a child or young person would look, or what they would be able to do. In three of the five conditions represented in the study (arthritis, cystic fibrosis and muscular dystrophy) physical appearance may be affected. Arthritis and cystic fibrosis can restrict growth and may cause restrict normal weight gain. Alternatively, the use of steroids for treating arthritis can lead to overweight and a 'bloated' appearance. Boys with muscular dystrophy experience increasing physical disabilities, and all of the boys in this project used wheelchairs. As researchers we had been careful to consider the physical (and cognitive) manifestations of a condition when deciding what activities to include during the group meetings. What was equally important, however, was to consider our own reactions to meeting some of the participants because of the risk that our subconscious reaction when, for example, faced with a small and frail 15 year old with arthritis or cystic fibrosis would be to treat her like an eight year old child.

2.12.3 The value of more than one time of contact

When this project was originally designed, a number of different phases of data collection (initial individual interview and then two group meetings) were planned in order to collect all the data we needed. In addition, this repeated contact meant that the research team got to know the project participants, and vice versa, much more than through a single meeting, and the participants met with other members of their group on more than one occasion. This promoted communication within the project because of the levels of rapport developed. In addition to increasingly open exchanges, two other benefits were observed. First, it was possible to discuss and consider particular issues with participants on more than one occasion, enabling the research team to develop and explore certain ideas with participants. Second, it offered more than one opportunity for participants to recall and report their needs and experiences. Thus, on one or two occasions, a particular information need only emerged during the second group meeting.

CHAPTER THREE
INFORMATION NEEDS

3.1 INTRODUCTION

The findings of the project are reported in this and the next chapter. In this chapter we will describe the information needs identified by the project. Chapter Four provides an account of participants' experiences of seeking and obtaining information, and their suggestions for improving the extent to which their information needs are met.

This was not a study of the levels of knowledge or information held by participants. Instead it was concerned with finding out what the participants thought that young people with a chronic medical condition need to know in order to manage their condition and deal with living with it on a day-to-day basis. Overall, the types of information identified by participants within the different condition groups were broadly similar, and any differences in the types of information can be accounted for in terms of the specific characteristics of the conditions. We have categorised these information needs into two groups: medical information needs and psycho-social information needs. These information needs will be described in the following sections. Finally, while our findings suggest common areas of information need both between conditions and between individuals, we did find differences in how much the young people wanted to know - especially with respect to medical information needs. This chapter will therefore conclude by reporting our findings on the factors which appeared to influence how much information individuals wanted.

3.2 INFORMATION NEEDS
3.2.1 Medical information

The areas of medical information need for young people with a chronic medical condition are summarised in Figure 3.1.

Figure 3.1: Areas of medical information need

- The condition
- General human biology
- Treatments
- Tests and investigations
- Managing an exacerbation
- Lifestyle factors
- Current research
- Health service and other sources of statutory support

The condition

Information about the condition identified as being important included facts about aetiology, physiology/pathology, symptoms, effects of the condition on the body, prognosis and/or outcomes, and any genetic/hereditary issues. For the young people it was important to have sufficient information to make sense of what was happening to or inside their bodies. This young person is talking about epilepsy:

> I want to know but I don't. I don't know why it happens.
> (Girl with epilepsy, age 15)[1]

Particular difficulties seemed to centre on questions which did not have an answer - issues such as aetiology and prognosis. The young people found it hard to integrate or assimilate 'unknowns' into their concept of their condition.

General human biology

A knowledge of relevant human biology helped the young people to generate a concept of their condition. Thus a number spoke about the value of school science lessons in furthering their understanding of their condition. A particular issue for many participants was information about genetics. This was salient to understanding advances in treatments, understanding aetiology and issues associated with having children.

Treatments and therapies

Understanding about treatments and therapies usually builds on knowledge about the condition itself. Here information needs centred around knowing the correct way to administer treatments or therapies, dealing with missing a dose of medication, managing a treatment regime in non-typical circumstances and understanding the effects of the treatments/therapies and why they are needed. This participant was questioning the apparent contradictory purpose of her treatments - physiotherapy and splints:

> Why do you have to wear splints when you've got to keep everything moving?
> (Girl with arthritis, age 15)

Times when the type of drug or dosage were changed were often times of anxiety and needed explanation, as did the continued use of a drug when it had no apparent effect on the condition. A number of young people raised questions about combining drug regimes for their condition with treatments for acute illnesses and, among some of the older girls, contraceptive drugs.

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[1] Where possible the sex and age of the participant, along with their condition, will be stated following a quote. In some cases where quotes have been drawn from group discussion meetings this has not been possible. In these instances, the identity of the group will be stated.

Another major area of information need within this concerned the side-effects of medication. Some participants felt that information about this was being withheld from them:

> They [drugs] have side effects. They tell your parents but they don't tell you.
> (Girl with arthritis, age 14)

The final area of information need here related to having operations and being an inpatient. Young people wanted to know why an operation was being done, what it was expected to achieve and what the operation involved. In addition, they wanted to know how they would feel directly after the operation and have some idea about the period of recovery. In terms of being an inpatient, practical issues were raised such as keeping up with school work and hospital practice with respect to parents staying overnight.

Tests and investigations

The *purpose* and *procedures involved* in diagnostic and monitoring tests and/or investigations, and the *results* (and what they mean) was the fourth area of information need. All three aspects are important, and participants particularly highlighted the importance of knowing what a result 'meant', both in terms of their own health/condition and/or against general 'yardsticks'.

> G: You know when they do an EEG.... did they ever tell you really what those little zig-zigs mean?
> B: It's your brain waves..
> G: Well I know that! But what do they mean?
> B: Well, it's just showing the pattern!
> G: But does that mean it's alright, or does it mean there's something wrong with your head?
> B: I think they'd be bigger if there was something wrong.
> (Girl and boy with epilepsy, both age 15)

In the following extract a boy with muscular dystrophy is explaining about his back X-rays, it clear that for him, an important part of the understanding the X-ray is how his back compares to others with his condition:

> ... to see if my back goes straight because it goes funny. It goes all wrong because I don't stand up, don't walk. .... I think my spine's like a curve [but] it's better than other people's spines they said.
> (Boy with muscular dystrophy, age 11)

Managing an exacerbation or deterioration in the condition or its management

For most of the conditions represented in this project, exacerbations or transitory deteriorations in the condition would be expected. As well as knowing how to manage and treat these 'crises'

at home, participants said they also needed to know under what circumstances they should get in touch with their doctor at the hospital.

Lifestyle factors

In many cases, the activities and lifestyle that a young person adopts can affect how well the condition is controlled, its severity, and long-term prognosis. The different conditions represented in this study impose different restrictions and knowing what these constraints are, *and* the reasons for them, are a key information need. Among the older age group, drinking alcohol and knowing how to fit their treatment regime around their increasingly spontaneous lifestyles were points raised by a number of young people. In addition, knowing how to manage feelings of general malaise and tiredness was another concern raised by participants, the question being whether to rest or to try to continue normal activities.

In most cases day to day lifestyle decisions involved drawing on medical and psychosocial information needs. We will therefore further discuss the role of medical information in daily decision making in a later section about restrictions on lifestyle caused by the condition.

Current research

Some of the participants were very interested in current research into their condition, especially if it had implications for future treatments or management of the condition. In many instances, being knowledgeable about their condition will not mean that a young person is able to understand ground-breaking research being carried out which is relevant to their condition. An example here came from the young people with cystic fibrosis many of whom had heard through the popular media about recent advances in genetic engineering which came to the headlines at the birth of the cloned sheep 'Dolly'. The media coverage of this included reference to implications in the treatment of cystic fibrosis. However, none of the participants understood what this scientific breakthrough meant in terms of how their condition might be treated in the future.

Health service and other sources of statutory support

Service information needs relate to what young people need to know about the professionals involved in their treatment; aspects of service organisation - notably the transfer from paediatric to adult services, and availability of, and entitlements to, statutory support. Many of the young people in this project had contact with a number of health professionals, though awareness of the particular role or area of expertise of these various individuals was sometimes lacking. The older age group were particularly concerned about who would be responsible for their treatment and where their condition would be managed in the future, and whether they would have to start

paying for their medication. Entitlements to statutory support vary between conditions and with the severity of the condition. They are, however, an important issue with respect to making plans for the future. Information about disability benefits and support for independent mobility are two key features of statutory support which are relevant to young people with chronic medical conditions.

3.2.2 Unmet medical information needs

Different conditions 'carry' different amounts of information. There is less to know about epilepsy and its management, for example, than there is about cystic fibrosis. In terms of medical information needs, there were differences among participants - especially between the older and younger age groups - with respect to how much they knew and understood about their condition and its management. Comparing across the different conditions represented in this study, it was clear that the children and young people with certain conditions had a better and fuller understanding of their condition compared to other condition groups.

Given the design and parameters of this project it would not be appropriate to draw any hard and fast conclusions from this observation. While it may reflect differing clinic/hospital practice in terms of providing information, it is unlikely that this is the sole factor operating here. For instance, the aetiology and physiology of some conditions make them harder to describe (and understand) than other conditions. Contact with health professionals, a key source of information, varies enormously according to the type of condition, both in terms of frequency of outpatient appointments as well as inpatient episodes. Thus while those with cystic fibrosis were attending clinic as often as every six weeks and were likely to be on the ward at least twice a year, for those with epilepsy an outpatient appointment once or twice a year was all that was required in terms of the managing and monitoring the condition. There are therefore considerable differences in the number of possible opportunities young people have for asking questions and receiving information. In addition, perhaps because of the need for a high level of self-management, young people with conditions such as diabetes and cystic fibrosis, appeared to be better informed.

However, the degree to which a young person felt well informed about their condition did not directly relate to the extent of perceived unmet medical information needs. Apparently well informed participants still said they had unanswered questions about their condition and its management. The difference between poorly informed and well informed participants lay in the fact that the poorly informed participants had medical information needs that were very basic and 'broad brush', while the more informed young people tended to have specific concerns.

While differences were observed between condition groups, certain areas of medical information need were reported by two or more groups as ones that remained unmet. These were: side effects of treatments, prognosis of condition and long-term impact on other body functions, genetic issues, and the provision and organisation of adult services.

3.2.3 Psycho-social information needs

Psycho-social information needs are very different from medical information needs. It could be argued that medical information needs can, to a greater or lesser extent, be 'deduced' from the condition. Thus, if X has this condition he or she is likely to need or want to know about A, B, C and so on. In contrast, psycho-social information needs arise from an individual's own experience of his or her condition, and its impact on all aspects of his or her life. Here the 'information need' relates to role that information or knowledge can play in enabling a young person to deal with the situations and emotions that result from having a chronic medical condition. In the course of the project, the young people revealed how their conditions impinged on or affected the emotional, social and educational aspects of their daily lives, as well as their plans and aspirations for the future.

The young people involved in this project believed meeting psycho-social information needs was as important as meeting medical information needs. For instance, during the initial individual interviews we asked the young people what someone newly diagnosed with their condition needed to know. The great majority of participants talked about the importance of that person knowing how to *live with* the condition, as opposed to giving them information *about* the condition. In addition, it was very striking that throughout the project the young people emphasised their desire to meet and talk with others with their condition in order to find out how they managed the impact of being a child or adolescent with a chronic medical condition.

> I'd like to ask someone who has epilepsy - what do they do for fun?
> (Girl with epilepsy, age 15)

Figure 3.2 summarises the psychosocial issues experienced by the young people. While some of these issues are unique to those with a chronic medical condition, others will be experienced by any child or adolescent. However, with respect to the latter, the presence of the condition is likely to exacerbate or magnify the issue. The information needs that these sorts of issues generate are two-fold. First, in some instances, the child or adolescent may need to know, in advance, that a particular issue, feeling or situation is likely to be experienced. Second, and to use the concepts introduced in Chapter One, the young person will have to cope with these issues. That will require coping resources - one of which is knowledge or information. This will

include information about the condition, health and other support services, the experiences of others with the same condition, ways of coping, problem-solving skills and so on.

Figure 3.2: Psycho-social issues faced by participants

> ► Negative emotions ► Managing at school
> ► Physical symptoms ► Other social situations
> ► Unanswered questions ► Restrictions
> ► Parents ► Keeping going
> ► Peers ► The future

Negative emotions

Participants reported a range of negative emotions which were consequences of having a chronic medical condition. Knowing how to deal with these negative emotions is an important information need. These emotions included: sadness, anxiety, frustration, anger, self-dislike, feeling left out, feeling different, feeling lonely, and feeling embarrassed. Sometimes these negative emotions were directly caused by what the young person knew about the condition.

> ... there's always a thought in the back of your mind - like when you're lying awake at night: "I have a life-threatening disease and no one knows when I will die".
> (Boy with cystic fibrosis, age 14)

Or it was simply the fact that the young person did not want to have the condition, because of its symptoms or perceived impact on their life. A number of young people reported being unhappy about their bodies in some way, such as being smaller than peers, being underweight or overweight, and having visible scars. These physical manifestations of the condition, or the side effects of treatment, served to make the young person feel 'different'. Physical impairments also served to make a young person feel 'different'.

Living with physical symptoms

The physical symptoms of a condition - pain, stiffness, illness, infections, as well as the side effects of medication, such as nausea - are another aspect of having a chronic medical condition which a young person needs to learn how to manage and deal with, especially when there is no way of alleviating the symptom.

> B: ...everyday pain I just deal with myself. Just pop an extra pill now and again if it get worse.
> G: .... if you start making a big deal out of it, it just gets worse.
> (Boy, age 15, and girl, age 16, with arthritis)

Living with unanswered questions

Having a chronic medical condition almost always entails living with unanswered questions. These include questions about the cause of the condition, prognosis of the condition, future health, as well as less specific questions such as 'Why Me?'.

> Why did it happen to me, just like that?
> (Boy with epilepsy, age 12)

Living with unanswered questions can generate uncertainty and a sense of lack of control. They can also be very preoccupying. Thus an important issue that many young people will therefore face is finding ways to manage that uncertainty.

Parents

In the following chapter, we will describe the important role parents play in supporting and informing children and adolescents with a chronic medical condition. However, and not unexpectedly, parents could also be a significant source of stress and conflict. One young person said her diabetes 'was another thing they can get on to me about' (girl with diabetes, age 15). The particular issues that the young people said they had to deal with included over-protectiveness, negotiating greater independence, and taking over full responsibility for managing the condition.

Peers

Dealing with issues and situations related to peers were prominent in the young people's accounts. A lot of the participants reported being teased, laughed at or ostracised by peers on account of their condition - this was most likely to happen when returning to school after diagnosis or when moving from primary to secondary school. Among those recently diagnosed, many felt that they should have been warned by health professionals about the possibility that their peers may react negatively towards them.

> When I first got diabetes everyone just went: "Oh, keep away from her - you can catch it." And in the playground they kept away. And when I went and stood next to them they moved away.
> (Girl with diabetes, age 11)

Alternatively, some participants believed *their* sense of being different from their peers prevented them from 'normal' interactions with friends. One young man with muscular dystrophy said that he kept 'distance from his friends' and:

> I never ask anybody if they want to meet me in town because I always think they'll say 'no'; so that's very hard because I know that some of them would agree, but....

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(Boy with muscular dystrophy, age 17)

Many of the participants said they found telling peers about their condition difficult.

I don't want them to ask me. They should know.
(Group meeting, 10-12 year olds with muscular dystrophy)

This was especially true with respect to telling classmates as opposed to telling close friends.

....you don't tell them straight away. Kids don't understand.
(Boy with muscular dystrophy, age 17)

The young people talked about not knowing what to say and how much detail to give, or whether to tell their peers at all:

The worse thing about having epilepsy is if I'm having my tablets and my friends are at my house They say "What's that for?". And I've got to say "..because I've got a headache" or something.
(Boy with epilepsy, age 11)

In addition, in circumstances where they were meeting new people, the question of when to tell also needed to be addressed. This extract is taken from when some young people with arthritis were discussing how a fictitious character with arthritis should manage changing school:

She would have to decide for herself what she was going to say. Maybe if she knows quite a lot about it she'd be able to work out what she was going to say - be quite concise.
(Group meeting, 10-12 yr olds with arthritis)

Finally, other difficulties with peers included not being believed (that they had a medical condition), and friends being over-protective.

Managing at school

Participants reported two particular issues related to managing at school. First was the problem of keeping up with school work. Sickness, in-patient episodes, clinic visits and any physical disabilities all affected the young people's ability to keep up with their school work. The second issue related to the way they were treated by teachers. Some participants reported experiences of teachers not believing them about their symptoms, others reported being excluded from activities which they wanted to take part in and, finally, there were the circumstances where teachers were perceived as being over-protective towards the young person.

Other social situations

Difficult experiences in other social situations included being stared at by strangers and, again,

not being believed and being fussed over.

>People think you're different, but you're not.
>(Girl with cystic fibrosis, age 15)

Restrictions and missing out

Almost all participants experienced restrictions on the activities they could do. This was either because of the effects of the condition on their physical abilities, or because treating or managing the condition meant that certain activities were 'forbidden'.

>All the things other kids my age find easy [I find] very hard.... very frustrating sometimes.
>(Boy with muscular dystrophy, age 17)

The demands of a treatment regime also cut into some young people's leisure time. As well as missing out on the actual activity, these restrictions also affected the time spent with their friends. Some participants reported that they had lost friends because they could not join in their peers' games and activities.

>I don't think parents realise that if you don't do these things you think that you are being left behind. It's because your friends are doing them that you want to do them, because you don't want to be any different from your friends.
>(Girl with epilepsy, age 15)

An important aspect of managing restrictions was the need to make decisions about whether or not to do an activity, and in many instances this demanded medical and psychosocial information. We found this to be an issue particularly among the older participants where the need for independence and to keep up with peers may well conflict with advice given to them by health professionals about what are 'safe' activities.

>Doctors don't understand that you're a teenager and you want to do teenage things. They don't understand that, and that gets me frustrated more than anything else.
>(Girl with epilepsy, age 15)

>My physio said to me the other day "You really should wear [these sorts of] shoes all the time otherwise when you're about fifty you'll get backache". And I thought I really don't care if I'm fifty and get backache. I'd rather get to fifty and have backache than walk about in terrible shoes which I hate when I'm a teenager.
>(Girl with arthritis, age 16)

Some young people talked about the risks they took in terms of the things they sometimes chose

to do. They believed that, ideally, the risks they took should be based on informed decision-making.

> You have a choice whether you do it or not. With all the information you've got you make a decision - am I or am I not going to do it.
> (Boy with cystic fibrosis, age 14)

> G: Sometimes I do something that I know I will feel the effects of next week or whatever. I know when I do it that I will, but I still choose to do it...
> B: You think otherwise you won't do anything
> G: You'll still get flare-ups and aches and pains, but you think I might as well enjoy the in-between bits.
> (Girl, age 16, and boy, age 15, with arthritis)

In the following two extracts, the young people are discussing a hypothetical situation in which a young person is having to make a decision about whether to do a 'risky' or restricted activity. These quotes also give an insight into the young people's own experiences of having to make similar decisions:

> .... He needs to know everything about it [epilepsy, the activity] so if he is taking a risk, he's got good reasoning.
> (Group meeting, 14-16 year olds with epilepsy)

> Maybe he should go away for a week with school and get home and spend them whole week in bed. *He* has to balance it - whether he thinks it is worth it.
> (Group meeting, 14 - 16 year olds with arthritis)

In the circumstances of some of the young people, making a choice was not even a possibility. In these cases, dealing with restrictions might mean finding out about other activities in which they can take part. In addition, they will have deal with the emotional distress that can occur from not being able to join in. These young people are describing the emotions they experience when they cannot take part:

> 'It hurt [emotionally] and I cry.'
> (Boy with muscular dystrophy, age 10)

> G: "Jealous" is a good word. When other people do things that you can't, you feel really angry and stuff because you can't do it.
> B: Yes, sometimes I feel like punching them. Yes, because they can do things that I'm not allowed or can't...
> (Girl and boy with arthritis, both age 12)

Keeping going

Most participants emphasised the importance of keeping going and not letting the condition 'take over' their lives. Achieving this may involve practical time-organisation skills but also positive thought processes or cognitions about the situation. These young people were discussing the importance of a positive approach to their mental and physical well-being:

> G1: If you're thinking "Why me?" and not coping then it's going to be harder for you to get better.
> G2: If you just give up, stop doing everything, stay in all the time...
> G1: ...mmmm, it's going to harder for you to get better.
> (Girls with arthritis ages 15 and 16)

> If you think "I'm going to die soon because I've got a very bad disease and I'm not very well at all", then you will die soon, and you'll have a very bad chest and all that.
> (Boy with cystic fibrosis, age 14)

The future

Finally, participants described the issues that they faced in terms of their plans for the future. Although most frequently mentioned by young people from the older age group, some of the younger participants also mentioned concerns about their later teenage years and early adulthood. These issues ranged from: having to make decisions about schooling and careers; thinking about leaving home; issues related to long-term relationships including, for some, concerns about handling intimate sexual relationships; and the effects of their condition on having children. While most participants were not actively dealing with most of these issues, they were concerned about them and many were wanting to make plans or have future goals which were realistic.

> Sometimes I'm scared. Because you've got it so if you ever have children will they get it? And they [doctors] say "no", but I've seen articles where people with epilepsy have had children who have got it.
> (Girl with epilepsy, age 15)

Being well-informed about their condition, legal issues (for example, driving and career restrictions), and statutory welfare and support services, as well as knowing about young adults with the condition who have achieved similar goals, appear to be important resources for decisions around future planning.

3.2 FACTORS INFLUENCING HOW MUCH THE YOUNG PEOPLE WANTED TO KNOW

When this project was originally conceived it was thought that it may be possible to map out young people's information needs according to their age. This has not been possible, not because of any short-comings of the methodology, but because of the considerable individual

differences both between young people's needs for information, and when that information is needed. Through our analysis of the data collected during the course of this project we have identified two over-arching factors which appear to influence both how much the young people wanted to know and when information needs were likely to be generated. These factors were individuals' preferred ways of coping and condition-relevant experiences.

Ways of coping

Two different aspects of coping style influence the need for information. First, is the point on the information-seeking continuum where an individual tends to fall regardless of the nature of the stressful situation. Thus in our sample, it possible to identify those young people who actively sought out information about their condition. This was manifest in a number of ways. Their knowledge of their condition tended to be more detailed, for example, they knew relevant statistics, the names and dosages of their medications and tended to use more medical jargon. They were likely to have obtained library books about their condition and watched television programmes which featured their condition. As described in Chapter One, information-seeking is not just an activity which is carried out in order to cope actively with a problem or stressor. The process of getting information also serves to offer a greater sense of control to an individual, and therefore also mediates against negative emotions such as anxiety.

Second, it appeared to us that some young people were deliberately choosing not to seek out further information about their condition. This was particularly so among the boys with muscular dystrophy, many of whom said that while they wanted to know about the operations they might need, they did not want to know anything more about their condition *per se*. As we reported in Chapter Two, communicating with the boys with muscular dystrophy was often difficult and it was not possible, and may well not have been appropriate, to explore with them their reasons for avoiding information. Sadly, with muscular dystrophy there is no good news, the condition is life-limiting and the physical deterioration leads to increased frailty and dependency. Avoiding such information may well be an effective coping mechanism for these boys. A number of boys mentioned their hopes that a cure would be found for muscular dystrophy, but emphasised that in the light of the present situation as regards treatment they did not really want to know about their own future.

However, it is important to contrast these observations with the accounts of some of the young people with cystic fibrosis. Again this is a life-limiting condition, and though the average life-expectancy is greater than for muscular dystrophy, increasing ill-health, dependency on oxygen and major surgery (heart and lung transplants) may have to be faced. Yet among the older age group, most talked openly about the fact that their condition was life-limiting, and wanted to

know about what the future held in terms of treatment options:

> I think it's good for people my age to talk about heart and lung transplants, but it needs to be handled carefully.
> (Boy with cystic fibrosis, age 14)

> I think when I'm about 25 I would like to know how long I will live. Because I would like to know; I wouldn't like to go all of a sudden because I want to achieve some things.
> (Boy with cystic fibrosis, age 16)

We would be reluctant to ascribe the differences we observed in this project between the participants with muscular dystrophy and those with cystic fibrosis purely in terms of condition-related factors. Instead, we would argue that again these findings highlight individual differences, and the fact that these will affect what a young person will want to know about the adverse effects or implications of their condition.

Condition-relevant experiences

The second factor affecting degree of information need related to young people's experiences of 'events' or circumstances which were, in some way, relevant to their condition and which then could generate information needs. They included events such as changes in the severity of the condition or its symptoms, changes to treatment or the introduction of new treatments, and changes in the provision of health services. In addition, changes and new experiences related to psycho-social development also generated information needs (for example, changing school, the evolving nature of their relationships with parents and peers, impending school leaving age, driving age). While some of these psycho-social 'events' do follow a developmental pattern and are broadly age-related, we found considerable differences between young people of the same age in terms of their psychosocial development. A good example here is the wide age range in which young people begin to have more intimate relationships. Finally, it is not necessarily possible to predict whether or not an event will generate an information need. A number of factors will the influence the meaning of an 'event' to an individual, including a young person's beliefs and life aims.

In some instances, the young people did not experience an 'event' themselves, instead they had heard about or observed something which then generated an information need. For example, a number of the young people with cystic fibrosis knew of someone else (a sibling, someone else at school) with the condition who had died. This event meant that questions about their future emerged or resurfaced and needed to be addressed.

CHAPTER FOUR
ACCESSING INFORMATION - EXPERIENCES
AND RECOMMENDATIONS

4.1   INTRODUCTION

This chapter is concerned with reporting the participants' experiences of seeking and obtaining information and their ideas about how better to enable access to the information sources they would like to use.

We begin by giving an brief overview of where the young people said they went for information about medical and psychosocial issues. The rest of the chapter will be devoted to looking in detail at the participants' experiences of using some of these information sources, and/or the barriers that exist to such sources being used. The sources covered will be health professionals, parents, written or audio-visual information, others with the same condition, help lines, the Internet, friends and education professionals. Where relevant, we shall report the suggestions or recommendations that the young people made with respect to using an information source.

4.2   PREFERRED INFORMATION SOURCES USED OR WANTED BY PARTICIPANTS

During the second wave of group meetings a number of groups undertook a mapping exercise to show their current preferred sources of information, and information sources that they would like to have access to. During this mapping exercise we distinguished between various medical and psychosocial information needs. Figure 4.1 summarises the findings from this mapping exercise. The first four in each column were the most commonly mentioned preferred information sources. The sources printed in italics, indicates an information source not generally being used but seen as a *potentially* useful resource. The main, and not unexpected, finding was the difference between medical and psychosocial information needs in terms of what were perceived as useful or appropriate sources of information.

Figure 4.1: Actual and potential sources of information

Medical information needs	Psychosocial information needs
Doctor at hospital Parents Book/leaflet Other health professional	Parents *Someone else with condition* Friends *Support group*
Someone else with condition Specialist worker from voluntary organisation General practitioner (GP) *Help line* *The Internet*	Other family members Teacher Specialist careers advisor Book/leaflet Health professionals School nurse *The Internet ('chat rooms')* *Help line* School support worker

4.2.1 Medical information needs: sources of information

The sorts of medical information sources that the young people were currently using, or had used in the past, varied according to condition. This mainly reflected differences between conditions with respect to the number of health professionals they were in contact with. Along with health professionals, other key sources of medical information were parents and books or leaflets. Using someone else with the condition as a source of medical information was less frequently mentioned, and is obviously dependent on the opportunities to meet others with the condition. In recognition of the need for specialist knowledge, only a handful reported that they used their GP as a source of medical information. Finally, two potentially useful sources of information were identified - help lines and the Internet. Only one or two participants had actually had an experience of using these information sources.

4.2.2 Psychosocial information needs: sources of information

The information sources used by participants to address psychosocial information needs were different. Health professionals and written information were rarely mentioned as a resource, apart from information needs related to future situations - such as career choices and having children. Rather it was family and friends, as well as others of about the same age with the condition, which were nominated most frequently by the young people as where they would go

to finding out about how to deal with a psychosocial issue or situation. As mentioned above, however, not all participants currently had opportunities to meet others with their condition.

4.3   HEALTH PROFESSIONALS

All participants regarded health professionals, and especially their consultant or other hospital doctors, as an important source of medical information. Doctors were consistently nominated as the best person to go to with a question related to medical information need. While some participants spoke very positively about their experiences of seeking and obtaining information from health professionals, for others difficulties and barriers existed which meant that they could not or did not exploit health professionals as a means of meeting an information need.

The majority of our discussions with participants focussed on their experiences of communicating with doctors. This was driven by their belief that doctors are the ideal source of medical information. However, we would argue that the implications of many of the findings reported here are equally pertinent to other health professionals involved in the care of children and adolescents with chronic illnesses or physical disabilities.

4.3.1   Experiences of seeking information from health professionals

In this section we report participants' experiences of seeking information from health professionals. Most participants reported both positive and negative experiences. We focus first on the difficulties the participants had experienced, and then go on to discuss the factors that promote or hinder communication, drawing on examples of good practice, as well as difficulties.

Receiving incomplete information

A number of participants felt their doctor had not been entirely honest with them on at least one occasion, or had only provided partial information on a particular topic.

> It seems to take a lot of persuading to get the doctors to tell you everything that's
> going on.
> (Boy with arthritis, age 15)

This seemed to particularly occur in relation to providing information about side effects of medication - a frequently reported concern. For example, the some of the girls with epilepsy reported that their doctors had denied that weight gain and hair loss were side effects of their medication. However, they did not believe doctors' denials and thought that doctors said this to ensure adherence to the drug regime.

A consequence of finding out that information had been withheld or that they had been misled was that the trust a young person had in his or her doctor was eroded. This can result from withholding apparently unimportant information as well as in relation to more significant information. For a young person who has experienced this, the question remains in their minds of whether other information is also being withheld from them.

Conflicting advice between health professionals
A few participants reported that they had been given different advice about the same issue by different health professionals. This tended to be in relation to life-style issues, such as limits with respect to alcohol. In most cases, the doctor tended to offer more 'liberal' advice while other health professionals offered more 'black and white', textbook advice.

Confidence in doctors' knowledge
A lack of confidence in doctors' explanations was particularly noticeable among the participants with epilepsy and muscular dystrophy. Of the conditions included in this study, epilepsy and muscular dystrophy are the two with most uncertainties. With epilepsy, it is often difficult to pinpoint the aetiology; and the course and prognosis of epilepsy and muscular dystrophy can be unpredictable. As a result doctors cannot give very definite or specific answers to questions.

For the young people with epilepsy, this seemed to generate a lack confidence and a frustration in their doctors' inabilities to give them any answers:

> I do ask my doctor but they don't know. They probably know as much as I do which is nothing. I get very mad at them....why can't they answer my questions? (Girl with epilepsy, age 15)

Not understanding what is being said
A number of participants reported problems understanding some of the information given to them by the doctors. They felt that doctors 'should use simple language' (boy with muscular dystrophy, age 17) and not 'big, medical words' (boy with arthritis, age 16). One young person said that when he asked a question, his doctor responded in 'doctor language' (boy with muscular dystrophy, age 16).

Being refused information
Another, more unusual, experience was to be refused information. One participant recalled that the doctor's response to her question about wanting to have children was: 'You don't need to know that now!'. This sort of response does not encourage open communication:

I'm always being told, 'Don't worry!'. But I'm not. I'm just asking. It puts me off asking questions.
(Girl with arthritis, age 14)

G: When I quiz the doctors about things that are wrong with me they don't tend to want to tell me, as if to say: 'Well, you know, you're still quite young - you don't need to know'.
Int: .... and how does that make you feel about it, about talking to them?
G: You just avoid asking questions, don't you? You don't want to ask them anymore, it's like, 'Oh, I'll just find it some other way'.
(Girl with cystic fibrosis, age 14)

Being excluded

Some of the younger participants reported being excluded from consultations which consisted of a dialogue between the doctor and parent.

The main thing is that people talk over me. I try not to be mad, but it does get up my nose a bit.
(Girl with cystic fibrosis, age 11)

An older participant recalled how she felt when she was excluded as a child. It was clearly a very disempowering experience.

When I was younger I didn't get talked to. I didn't see the point of listening, I didn't understand. I'd be there so they could examine me.
(Girl with cystic fibrosis, age 14)

4.3.2 Factors that promote or hinder communication between young people and health professionals

For a young person to use a health professional as an information source requires free and open communication between individuals. Thus before looking at what this project has revealed with respect to the barriers to seeking information from health professionals, we shall report what we found out about factors which promote or hinder communication between young people and health professionals.

Rapport between young person and health professional

The extent to which participants reported a positive rapport with a health professional influenced the way they were able to communicate. The factors involved in promoting good rapport are likely to be numerous and the process complex. We found that different young people described their relationship with the same health professional in contrasting ways. One participant could be positive about a certain doctor while another participant reported finding the same doctor very difficult to talk to. Our findings suggest that it is more than just a question of some doctors being

good at developing a rapport with their patients while others are not. Analysis of our data implicate the following as factors which are pertinent to engendering rapport between health professionals and young people: duration and frequency of contact, gender, professional status, and perceived approach to patients.

First, *duration and frequency of contact* is a key factor. The majority of participants in this project reported that they found communication with someone they had not met before problematic. For example, a number of participants mentioned that they were finding it difficult to talk to a newly appointed specialist diabetic nurse because they hadn't 'got used to her yet' (girl with diabetes, age 12). Where participants had contact with a number of health professionals, they chose to talk to ones who they felt they knew.

There were considerable differences within our sample with respect to the duration and frequency of their contact with health professionals. Some participants had known their doctor for as long as they could remember, others were only recently diagnosed or attended clinics where they were seen by a different doctor at each appointment. Participants who saw a different doctor each time they attended clinic identified this as a real barrier to communication

> It would be better just to have one doctor so we could move on to different parts
> of epilepsy instead of getting the same questions again and again.
> (Girl with epilepsy, age 15)

A number of the girls taking part in this project said they found it difficult to talk to *male doctors*. This was a barrier not just to feeling unable to ask specific questions, but also in terms of more general interaction during an outpatient appointments.

Participants, especially the younger age group, were very conscious of *doctors' status*. This perceived status was often seen as a sufficient explanation as to why a young person found it difficult to talk to his or her doctor, and it was difficult to elicit underlying attitudes and beliefs about 'doctors'. However, for some doctors' status was a powerful inhibitor of communication:

> 'Speaking to the doctor is nerve wracking'
> (Girl with diabetes, age 11)

The approach doctors and other health professionals take to the care and management of an individual case can be divided into a *condition-centred and person-centred approaches*. A condition-centred approach tended to result in the young person feeling that the doctor was not concerned or interested in them as an individual.

> He's more interested in what's happening inside me than what I'm going to ask.
> (Girl with diabetes, age 10)

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You see her more as a doctor dealing with your treatment rather than other aspects of your arthritis.
(Girl with arthritis, age 14)

They don't write that sort of thing [difficulties sleeping] down - they only write the medical side of it down.
(Girl with epilepsy, age 15)

This contrasts with one participant's description of his physiotherapist:

She's brilliant, totally interested in me, all the attention on me.
(Boy with arthritis, age 16)

Where doctors adopt a person-centred approach this may well influence the way they talk to young people, with a greater appreciation of the need to use understandable language. For example, two boys with muscular dystrophy, who were very satisfied with the information they had received from their doctors, attributed this to the way their doctors related to them:

He was great, explained things really simply. I could understand it all.
(Boy with muscular dystrophy, age 13)

This same boy contrasted the doctor he is referring to above with another doctor who:

.... doesn't talk at my level. He ignores me and talks to mum.

Practical aspects of a consultation
Certain features of a typical outpatient consultation work against promoting positive and effective communication between young people and their doctors.

Ideally, an encounter between a patient and his/her doctor involves a two-way exchange of information. Participants with conditions *where a wide range of symptoms and/or physiological functions need to be monitored* (for example, cystic fibrosis) reported that outpatient appointments tend to be dominated by them (or their parents) providing information.

I don't ask a lot of questions. Mum and dad don't ask a lot either - they just answer a lot of questions.
(Girl with cystic fibrosis, age 12)

A number of participants complained about *brevity of their clinic appointments*. A sense that the doctor was in a rush was identified as something that made it difficult to talk to doctors. This reflects the way that doctors tend to control a consultation. Where a condition-centred approach is taken, especially perhaps in circumstances where the condition is stable, the possibility that a patient might have a question can remain unacknowledged.

Generally speaking, participants preferred that *as few people as possible* were present during

consultations with their doctor:

> ... it's only him, me and mum in there, so I wouldn't be embarrassed about asking
> a silly question.
> (Girl with epilepsy, age 15)

In particular, almost all participants who experienced out-patient appointments where student doctors were present said they found their presence inhibiting.

> You don't tell the doctor anything because you don't want them [student doctors]
> to hear.
> (Girl with arthritis, age 14)

Finally, and very briefly, *the way questions are asked* is important to promoting good communication. General or non-specific questions are difficult to respond to, as one participant put it:

> 'How are you?' is not a good question!
> (Girl with diabetes, age 11)

Young person factors

It is important to acknowledge that the reasons behind difficulties in communication between young people and their doctors cannot be located exclusively in doctors' attitudes and behaviour. Aspects of the young person's personality and their social skills can also play a role.

For some participants*, shyness and lack of confidence* made asking questions or talking to their doctor difficult. While many of the factors described above may exaggerate a young person's lack of confidence or shyness, aspects of a young person's personality (for example, extrovert versus introvert) can in themselves affect the ease by which a doctor and child or adolescent can communicate.

> I'm normally quiet - I never know what to say.
> (Girl with diabetes, age 12)

> It's hard to ask questions if you don't know what to say, or if you're a bit shy.
> I didn't know how to say it. I got all in a muddle.'
> (Girl with cystic fibrosis, age 12)

> I'm a bit of a quiet person so don't ask these things. Quite often I just wonder
> these things.
> (Girl with arthritis, age 15)

Among our sample, it was mainly those in the younger age group, as well as some of the older

girls, who were likely to report that shyness or a lack of confidence meant they felt unable to question their doctor. For a minority, the idea of doing so was, for want of a better word, quite frightening:

> I would ask but I'm shy - not got the guts to.....
> (Boy with epilepsy, age 11)

A number mentioned the problem of *not knowing how to ask questions*. This difficulty was more pronounced the more sensitive the issue.

> I don't really know how to approach things.
> (Girl with arthritis, age 13)

Parents

There were a two main ways in which *the presence of parents* during an outpatient appointment acted as a barrier to communication between a child/adolescent and his or her doctor. First, some participants reported that their parents dominated the appointment, making it difficult for the young person to contribute to the interaction. This does not necessarily reflect parents' desires to thwart their child's attempts at joining in the interaction with the doctor, rather parents' often have concerns and questions that need addressing. There may therefore be conflicting demands on the doctor's attention, and in such circumstances the more skilled and confident individual (probably the parent) is likely to win.

> I go to see him but not sure why 'cos Mum talks about things.
> (Girl with epilepsy, age 10)

Second, participants reported that doctors tended to direct questions at their parents, as opposed to themselves. In other words, a parent's presence deflects the doctors' attention away from the young person. In Chapter One we argued that doctors may find communicating with parents easier than talking with children and adolescents, and hence take the easy option during appointments attended by the child and parent. Within our sample, the younger age group were more likely to report this pattern of interaction during clinic visits, though it was experienced by some of the older adolescents as well.

> Some doctors still think that dad or mum is more important than me, and they
> have to talk to them instead of me. But it's no good talking to them. I'm the one
> with the cough.
> (Girl with cystic fibrosis, age 11)

We also found examples, however, where *parents were a source of support* to their child when seeing a health professional. When asked to name any factors which made it easier to ask their doctor a question, some participants said that their parents being with them was important. Indeed a few of the young people in the project said they and their parents planned what

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questions to ask before their outpatient appointments. Others, especially those from the younger age group, reported that they 'used' their parents to ask questions to their doctor on their behalf, or their parents helped them to ask questions.

Managing communication between doctors, parent, and young people: messages from the project participants

In response to the issues which we have just reported, we used two of the second wave of group meetings to focus specifically on issues related to managing communication between a doctor, parent and young person. Figure 4.2 summarises the messages that participants had for each individual involved in this context. Given the remit and time constraints of the project this 'messages' exercise formed only a small part of the work done by the groups and it is therefore likely to be incomplete and require expanding and refining. However, these messages are useful and interesting in themselves. First, they highlight the roles and responsibilities of all the individuals involved in such an encounter - both in terms of what they do, and how they behave to others. Second, they question the function or purpose of outpatient appointments - especially with respect to the information needs of parents and young people. Third, they highlight the skills that different individuals may need to acquire or develop in order to optimise communication.

Figure 4.2: Messages from project participants about managing doctor/parent/young person communication

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MESSAGES TO DOCTORS
- ▸ the young person should be in control
- ▸ direct questions to the young person
- ▸ young people might like to see their doctor without their parents
- ▸ young people might have questions they do not want to ask in front of their parents
- ▸ remember that the young person might be shy
- ▸ keep trying to speak to the young person
- ▸ young people want a choice about whether their parents are with them

MESSAGES TO PARENTS
- ▸ let the young person answer for him/herself
- ▸ understand that it is hard for young people to ask questions
- ▸ check beforehand whether your child wants to ask any questions
- ▸ don't try and control the situation
- ▸ the young person should be in control
- ▸ parents can't be 'in on' everything - young people might want to see the doctor alone
- ▸ trust your child to be truthful
- ▸ remember: who is the appointment for? You or your child?

MESSAGES TO YOUNG PEOPLE
- ▸ (try to) speak up more
- ▸ think about what you might want to say/ask beforehand
- ▸ tell your parents before the appointment that you want to take control, that you want to ask questions

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4.3.3 Barriers to obtaining information from health professionals

Personal or sensitive information needs

Even among those who were very positive about their relationship with their doctor or another health professional, there was an acknowledgement that there were some intimate or personal things that they could not talk to their doctor about. The sorts of questions at issue here varied between conditions. In some cases this related to questions about lifestyle, one participant said that asking his doctor about drinking was 'the lowest' he would go (boy with diabetes, age 15). For others - especially those with life threatening conditions - questions about their future health might be difficult to ask.

...if [when I'm older] I've still got CF and I do less stuff [physio], will my lungs

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and openings start closing? This is quite a big worry, but I don't talk to anyone
about it.
(Girl with cystic fibrosis, age 12)

It is likely that questions that are difficult to ask are also the most troubling:

It's easy to ask questions about things that don't bother me.
(Boy with cystic fibrosis, age 14)

It is important to remember that, for some young people, the presence of a parent may also inhibit discussions about personal or sensitive issues.

Potential negative consequences of asking a question

If a child or adolescent believed that asking a question would result in a negative consequence, they were less likely to ask it. For example, in conditions where an exacerbation of the condition might require hospitalisation, a few of our participants reported that they did not ask questions because they were worried that it might reveal symptoms which would result in them having to be admitted. At a different level, some participants mentioned that a reason for not asking about something (for example, drinking alcohol, taking part in certain activities) was because they might not want to hear the answer.

Some young people with muscular dystrophy felt ambivalent about asking questions where the answer may be negative, particularly with regard to the progression of their condition.

Sometimes I think the question would be hard for the doctors, and the answer
might not be a nice answer. I might not want to know it.... one day I might get
so weak I can't move.... I might like to know but it might make me sad, so I don't
want to know. I'll just wait until it happens and I'll manage it.
(Boy with muscular dystrophy, age 10)

Asking a question means admitting poor adherence or other disapproved of behaviours

In certain circumstances, wanting to ask a question may require a young person to admit to or reveal behaviours or activities that may be "forbidden" or discouraged by health professionals (and/or parents). This would include issues related to compliance or management of the condition and lifestyle. Information needs related to these issues were unlikely to be raised with health professionals who might condemn or reprimand. One young person in the project described how she felt she could talk to her physiotherapist about anything because she had got 'beyond the stage of pretending about adherence' (Girl with arthritis, age 16). Another described his doctor as:

The sort of person you could tell anything, not the sort to tell you off for it.
(Boy with diabetes, age 15)

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Not remembering the answer

Another barrier to using health professionals as an information source is that even after an answer has been provided, the young person forgets or does not take in what has been said. This is not an uncommon difficulty in doctor-patient communication, particularly in situations where people are anxious or upset. However, in our sample two groups might be particularly at risk for not remembering information that has been given to them. First, for some young people with epilepsy, seizure activity may interrupt attention and affect memory. Second, some degree of learning difficulty often occurs among boys with muscular dystrophy - this may affect their ability to understand and retain information.

Forgetting to ask questions

Earlier we described how some of the children and adolescents in this project found consultations with their doctor an awkward, and even frightening, event. It is hardly surprising, therefore, that some participants reported that they forgot to ask questions during their out-patient appointments.

4.3.4   When I see my doctor I want....: issues voiced by participants

In this final section on health professionals as an information source we directly report participants' wishes about what should happen when they see their doctor, see Figure 4.3. We obtained these data during the 'brain storming' sessions which followed after a role play exercise in which participants acted out a 'nightmare' or 'perfect' outpatient appointment. Many of the points or concerns listed here summarise or reinforce the findings we have already reported. Almost all the points made by participants were agreed upon unanimously. However, for two points - marked with an asterix in the figure - there was not consensus.

Figure 4.3: When I go to see my doctor, I want......

I want.....	.... but I don't want....
About the people present.... ▸ ..to know who I'm going to see. ▸ ..to see the same doctor every time. ▸ ..a helpful doctor. ▸ ..to be introduced to everyone. ▸ ..to choose whether my parents are there. *Feelings* ▸ ..to feel comfortable, at ease. ▸ ..my doctor to be cheerful. *Communication* ▸ ..to be able to talk to my doctor. ▸ ..to be able to ask questions. ▸ ..my doctor to use easy words, not 'posh' words. ▸ ..my doctor to believe what I say. ▸ ..my doctor to talk to and to answer to me and not my mum. ▸ ..to be listened to - my questions and opinions. ▸ ..to feel that my doctor understands what I am saying. *Getting information* ▸ ..things to be explained clearly. ▸ ..to be given advice. ▸ ..to have more detailed answers*. ▸ ..sometimes having something written down would help. ▸ ..sometimes drawings help to me understand.	*About the people present* ▸ ..other [student] doctors in the room. ▸ ..lots of people there. ▸ ..to see a different doctor each time. *Feelings* ▸ ..to be treated like an example of a disease. *Communication* ▸ ..to be ignored. ▸ ..to be treated as a kid. ▸ ..to be criticised. ▸ ..to be talked down to. ▸ ..to have to repeat the same information at each appointment. *Getting information* ▸ ..the doctor to say I can't do something. ▸ ..to hear about things that might happen in the future*. *And....* ▸ ..to have to get undressed if I don't need to. ▸ ..to have to wait for ages.

4.4   PARENTS AS AN INFORMATION SOURCE

As we reported at the beginning of this chapter, parents emerged as a key resource with respect to both medical *and* psychosocial information needs, see Figure 4.1. Here we will be focussing on parents role as a source of medical information, though we would argue that most of the barriers to using parents as an information source with respect to medical needs also applies to psychosocial needs.

In Chapter One we reported research which suggested that doctors tend to regard parents as a conduit of medical information between themselves and the young people they are treating. However, other research questions the extent to which parents may remain an important source of medical information as a child moves into adolescence. The findings from this project suggest a number of factors may influence the role parents play in meeting their children's medical information needs, and it is likely that many of these factors are inter-related or will interact.

4.4.1   Factors affecting young people's use of parents as an information source

Age at diagnosis

For children diagnosed at birth or as young children, parents are likely to be a key source of medical information. At diagnosis, time would have been spent with the parents explaining all aspects of the condition. This information would then be imparted to the child by the parents. For some conditions this may occur over a number of years. In the course of this project, some of the parents told us that they had not yet told their child (even those in the older age group) about all the implications of their condition.

In contrast, an older child or adolescent newly diagnosed will be given information directly by health professionals, thus establishing from the outset a different pattern of interaction and communication. A good example in this project was the children and adolescents with diabetes. The practice of their diabetic unit was to ensure that all newly diagnosed children above eight or so years of age were skilled in monitoring their blood sugars and administrating their insulin before being discharged. They were taught to do this directly by health professionals.

Duration of condition

While parents may be a key source of information relating to the basic facts about a condition after diagnosis or as a child becomes aware of his/her condition, the information needs of a young person who has been diagnosed for a while may be more specific or detailed. Parents may not be able to respond to questions about new treatments or the changing implications of the condition as the child grows up.

Age

Age, or stage in the life cycle, was another factor influencing whether or not participants used their parents as an information source, and reflects the differences between parent-child and parent-adolescent relationships. Thus overall, the younger participants reported that if they had any questions about their condition, they would ask their parents - usually their mother.

> I would always ask me mum if I needed to know something - I know her, she's my mum.
> (Girl with diabetes, age 11)

Among the older age group, and in some cases beginning to emerge in the younger groups, the dynamics of the parent-child/adolescent relationship meant that information exchange was difficult. For example, among the older group with diabetes, the condition and its management was a source of conflict and secrecy within some families. This meant that any concerns or questions were not expressed in front of parents. This quote gives some insight into the tensions that can exist between young people and their parents around issues related to the management of a chronic illness:

> My dad thinks I don't know anything. He thinks he knows everything about diabetes and I know nothing.
> (Girl with diabetes, age 15)

Parental involvement in day-to-day care and treatments
Where parents, regardless of the young person's age, were involved in providing care, therapies, or supporting the young person in administrating treatments, the young people were more likely to nominate their parents as source of medical information.

Parents' limited knowledge
The final factor which influenced whether the young people used their parents as a source of information centred on their perceptions of their parents' level of knowledge. Some participants believed that their parents did not know any more (or sometimes less) about their condition than themselves, which meant that parents were not viewed as an information source. This was found among younger and older participants - but especially among older participants where most had taken over management of their condition, or where the young person attended clinic appointments by themselves:

> I'm not sure about my Mum and Dad being helpful because I don't think they know very much, although they like to think they do.
> (Girl with cystic fibrosis, age 15)

4.5 WRITTEN AND AUDIO-VISUAL INFORMATION
The written and audio-visual information resources reported to us by participants were

predominantly concerned with providing medical, as opposed to psychosocial, information.

4.5.1 Access

The majority of participants could recall reading an information leaflet about their condition. A smaller proportion had also seen a video. However, across the sample ways of accessing written and/or audio-visual information were mixed. Use of written information - usually short 'books' or leaflets - was far more common than video- or audio-tapes. There certainly seemed to be differences between conditions and/or sites as to the extent to which the provision of written information was part of the care and support offered during a clinic visit. Even within clinics, some young people reported being given leaflets and so on, while others had not received them. Overall, written/audio-visual information was obtained from a doctor or other health professional, or had been picked up during a visit to their hospital. A minority reported 'sending off' for information, and in these cases it was the parents who actually undertook to obtain books or leaflets in this way. Finally, in some instances, a perceived lack of good or appropriate written information about a condition had precluded workers from offering written information to families.

4.5.2 Usefulness of written (and audio-visual) information

With one or two exceptions, participants in this project said they found the information leaflets they had read useful, though some commented that they were either 'too babyish' or 'written for adults'. However, their use as a source of information was seen as being rather limited - many of the young people mentioned the fact that all the leaflets they had read covered the same things.

> You never do seem to find a lot on the subject. The books aren't much use because they are written for adults so you can't understand a word of what they are saying. Really what we need is a book for children - to understand it.
> (Group meeting, 14-16 year olds with epilepsy)

Participants believed they were a good source of basic information about their condition, and the pictures, diagrams and/or statistics commonly provided in such materials were particularly useful. In terms of providing information related to psychosocial issues and future decisions (for example, careers), a number of the young people said they had enjoyed reading about others with their condition who had achieved the same sorts of things that they were aiming to do.

However, when it came to any specific, idiosyncratic question a young person might have, written material was deemed by participants as an inappropriate or ineffective information source.

> ....[Leaflets are] OK for vaguer information.
> (Girl with cystic fibrosis, age 14)

....[With many questions] you need to give them the specifics of your life....and you can't do that with a book.
(Boy with epilepsy, age 15)

Our overriding finding here was that the young people in this project preferred to speak to someone, rather than read something:

You get more out of a person.
(Boy with epilepsy, age 12)

There were differences between individuals as to whether they felt they might use written information in the future. Obviously this decision would be informed by their existing experiences of written information. However, it is also important to remember that individuals will differ in terms of their preferred medium for receiving information, and their need to seek information.

Only one participant reported a 'bad' experience from reading about his condition. In this instance he had learnt that one of the implications of his condition was low rates of male fertility. He has was angry about the way he had found out about this, describing it as being ' plastered on the middle page' (boy with cystic fibrosis, age 16) of a voluntary organisation's newsletter. While his anger was directed at the health professionals whom, he believed, had wrongly withheld this information from him, this does raise the issue of the appropriateness of providing sensitive information in written form when it has not been preceded by that information being given verbally - either by a parent or health professional.

Finally, aside from the young people with diabetes who were given a videotape to watch at the time of diagnosis, very few other participants had seen, or were interested in seeing, a videotape about their condition. One young person with epilepsy who had seen a video said it was not very helpful:

'you could tell it wasn't a real fit.'
(Boy with epilepsy, age 12)

4.5.3   Other forms of written or audio-visual information

Participants from a number of the conditions represented in this study reported that they had found general *human biology textbooks* particularly useful in helping them to understand more about their condition. Usually they had come across such books at school. One young person with arthritis, for example, described finding a diagram and photograph of an X-ray of a hip replacement. She recalled that this had enabled her, for the first time, to visualise what arthritis was, and what her own impending hip replacement operation would involve.

The *popular media* - newspapers and television programmes - were another reported source of information. In particular, they appear to be where the participants found out about advances in research or treatments they did not know about. For instance, a number of participants with cystic fibrosis mentioned that they had read or heard about gene therapy as a possible future treatment, and a couple of the young people with epilepsy had heard about neuro-surgery as a treatment option. The consequence of learning something new through the general media was that it provoked the need for more specific and detailed information which may not have been produced. Certainly, a number of participants with cystic fibrosis stated that they would like to have a leaflet about gene therapy.

4.5.4 Participants recommendations about the provision of written information

Despite individual differences in the use of written information, there was a clear consensus that written information should be available. During the course of some of the second group meetings, participants worked on an exercise to elucidate their recommendations about the provision of information. These are summarised in Figure 4.4.

Figure 4.4: Participants recommendations about written information

Availability of written information
    Written information should be offered to young people - rather than them having to seek it out or send off for it. It should not cost anything.

The type of information
    Three types of information should be provided through booklets: facts, advice and real-life histories. In many cases the three can complement each other. For instance, facts about a treatment can be accompanied by advice about fitting the regime into day to day life, as well as one or two individuals' accounts of their experiences of that treatment.

The extent of information provided
    Participants could not agree on whether written information about all aspects of their condition should be made available, in particular whether 'bad news' should be included.
    Participants did agree that age could not be used as an indicator of how much information to provide: some children and adolescents would want to know everything about their condition while others would not.

Authors
    Doctors with a specialist knowledge and young people with the condition should be involved in writing material. It might also be appropriate to include parents as well.

Age-appropriate
    It should be available in a number of age-appropriate versions. Adolescents do not want to have to use leaflets that are too 'babyish' or written for adults.

Presentation
    A balance needs to be drawn between making an information booklet look appealing and accessible, and it conveying a sense that it contains accurate and useful information. Colour printing and the use of photographs add credence.

Conveying information
    The language used should be understandable and not too scientific. The information should be presented in a manageable way - for example, through the use of bullet points. Pictures and diagrams should be used as much as possible.

Tenor
    Participants thought that written information should be presented positively but with sensitivity.

A resource section
    It is important that the follow-up information and details of other resources are given including:
- Telephone numbers: help lines, talk clubs
- Information about how to contact others with the same condition, eg. penfriend schemes
- Addresses of Internet sites
- Support services that are available, including voluntary organisations
- Bibliography of further information

4.6 OTHER YOUNG PEOPLE WITH THE SAME CONDITION

Virtually all the participants in this project said they wanted contact with other young people with the same condition. While almost all reported that their friends were a key resource in enabling them to deal with psycho-social issues related to having a medical condition, they also acknowledged that, for some issues, it would be easier to talk with another young person with their condition. This young person is describing her experience of attending one of the project's group meetings:

> I've met some people who I find it easier to talk to about my epilepsy than my friends at home. And it's been nice talking to people.
> (Girl with epilepsy, age 15)

Most reported that, aside from taking part in the project, they did not currently have contact with anyone of their age with the same condition, though contact was more likely among some conditions. The young people with cystic fibrosis, diabetes and arthritis were most likely to have met others with their condition. With respect to cystic fibrosis and arthritis, contact with others had been established during inpatient stays, though owing to risks of infection this is discouraged among the young people with cystic fibrosis. For the young people with diabetes, they had either met others through going on a 'diabetic camp' or through social evenings organised by the clinic. However, even among those who had had some contact with others, very few said that among their friends was another person with their condition.

Meeting various information needs was one reason for wanting to get to know others with the same condition. This included medical and psychosocial information needs.

> If we had a support group then you'd probably talk about your contraception and your driving and stuff like that there.
> (Girl with epilepsy, age 15)

> You could learn from different people's experiences. I mean if someone's had an operation or something - like a transplant - you might want to hear about that.
> (Girl with cystic fibrosis, age 14)

> [..finding out about] what they can do, [things] we thought we couldn't do.
> (Boy with muscular dystrophy, age 12)

At the end of each group meeting we asked participants to tell the group how they were feeling. Many of these remarks were about the value of meeting others with the same condition. These quotes highlight the importance to young people of simply knowing that there are other young people in the same sort of situation.

> Now I know there's people who feel the same.
> (Girl with epilepsy, age 10)

I feel a lot better because I know about what people feel about having diabetes.
(Girl with diabetes, age 12)

I feel better now because I know other people are going through the same thing as me, and I don't feel as alone.
(Girl with epilepsy, age 15)

A number of participants said they would value the chance to talk to young adults with their condition, and to hear about how they negotiated the transition from school to employment.

I'd like to talk to somebody a bit older than me that's got a job, who's been to college and got a job, just to find out what it's like. There's more chance of me talking to her than me mum about certain things.
(Girl with epilepsy, age 15)

4.6.1 Types of contact

Participants had a number of suggestions about different ways in which contact between young people with the same condition could occur. They included group meetings, one to one contact, pen friends; E-mail; and 'chat rooms' on the Internet. There were differences between participants as to their preferred means of contact - especially with respect to group versus individual contact.

Group meetings

Participants had very clear views about what group meetings should be like. The term 'support group' was felt to be very stigmatizing: membership meant that an individual had something wrong with them and had no other sources of support. This exchange between two young people during one of the group meetings demonstrates this well:

G: Yes, it's the idea of, like this woman sitting in front and saying "What shall we explore today?"
B: Everyone crying on each others shoulders!
G: ....and "How do you feel about this?"
B: They would be almost more depressed than you.
G: Yeah, you get this idea of people standing up and saying: "Hi, my name's Jane and I'm an arthritic"
B: It's almost like there's something wrong with us, like the AA - Alcoholics Anonymous.
G: Yeah, and it means you're not coping with it as well...... A support group is what you go to if you're not coping.
(Girl and boy with arthritis, ages 16 and 15)

Overall, participants wanted the opportunity to meet with others in an informal and social setting where their condition was not the focus, but the opportunity was there to make friends and share experiences.

...so if you wanted to talk about you could, but it wasn't the focus.
(Boy with arthritis, age 14)

They did not want their parents to attend the 'meetings'. However, some participants thought that it would be helpful to invite doctors or specialist nurses to some 'meetings' in order to obtain detailed medical information. While there were differences of opinion as to how frequently such a group should meet, there was agreement that it should be regular and long-term.

Contact between individuals
Participants believed that contact between individuals did not necessarily have to be on a face-to-face basis. Contact by letter, telephone or via the Internet were other suggestions, and these sorts of alternatives overcome the problem of geographical distance between individuals.

4.6.2 Facilitating contact
The young people in this project agreed that initiating contact with someone else or joining a group would be very difficult. They felt that clinic staff or school nurses could play a role in helping young people get in touch with each other. In terms of making joining a group easier, they suggested that an existing member of the group could make a home visit beforehand. While some of the participants said they would prefer on-going contact with just one individual, they did acknowledge that a group situation would be a good way of 'finding' that person.

Finally, the practice of offering activity weekends or holidays for people with diabetes, so-called 'diabetic camps', is another model of facilitating contact between individuals with the same condition. A number of the children and adolescents with diabetes in this project had been on one or more 'diabetic camps'. Overall they were seen as a very positive experience. Among the perceived benefits were the opportunity to find out more about managing the condition, to share feelings and experiences, and, in some cases, to develop friendships which were maintained after returning home.

4.7   OTHER INFORMATION SOURCES
4.7.1 Help lines
Within our sample only one young person had used a help line, and this was with respect to seeking information related to career decisions. We asked participants their views about using help lines and the following issues emerged.

A lot of the young people did not know whether a help line existed for their condition. In fact, all the conditions represented in this study do have help lines - most of which have a designated

young people's worker. While a number thought a help line was a good idea in principle, they did not feel that they would ever use one, or if they did it would be their last resort. In general the participants spoke about help lines in terms of providing help with knowing how to deal with psychosocial issues as opposed to providing medical information. Two barriers to using a help line were identified. First, a number of participants said that telephoning someone they did not know would be a highly unusual, and for some 'nerve-wracking', experience: it would be difficult to know what to say, especially if the call was about something personal or distressing. However, others felt that the anonymity offered by a help line was an advantage and might allow them to talk openly about issues they were concerned about. Second, some perceived a certain stigma attached to having to use a help line:

Makes you sound as if you're not stable or something, that you've got no friends.
(Girl with cystic fibrosis, age 15)

Finally, a couple of young people mentioned that in some situations other help lines might be more appropriate, for example the bullying help line.

4.7.2 The Internet
The Internet was identified as a potential resource. We reported above that the Internet was seen as a possible means of making contact with others with the same condition. Participants also nominated the Internet as a source of medical information. However, among our sample none had used the Internet as an information source, and only very few said they access to it.

4.7.3 Education professionals
With respect to psychosocial information needs a number of education professionals were mentioned by participants, including teachers and specialist careers advisors. In the main this related to information needs around career decisions. However, a few named their teacher or school support worker as someone who helped them with knowing how to deal with negative emotions and problems with classmates. Finally, one young person reported that her school nurse had been useful in knowing how to deal with problems with classmates.

4.7.4 Friends as an information source
It is important to highlight here the role that friends played in helping the young people find ways of dealing with negative emotions and difficult social situations. As one participant said: 'I can talk to my friends about anything. They know everything about me' (girl with cystic fibrosis, age 15). While we shall not be dwelling much on this finding here, it does serve to remind us about the 'mainstream' social support networks that children and adolescents with a chronic illness have, and their importance as a source of information and advice about how to deal with

emotional and social issues. However, it is also necessary to point out that one or two young people had not told their friends about their condition - in these instances, this important resource will not be available.

CHAPTER FIVE
OVERVIEW AND DISCUSSION OF IMPLICATIONS

5.1   INTRODUCTION

The purpose of this final chapter is to summarise and discuss the findings of the project within theoretical, practice and policy contexts. First, however, we present a brief overview of the strengths and limitations of the project, particularly focusing on the extent to which the findings can be applied to all children and adolescents with a chronic medical condition. The chapter concludes with a number of suggestions for further research which arise from the findings, or limitations, of this project.

5.2   STRENGTHS AND LIMITATIONS OF THE PROJECT

Before moving on to consider the implications of the findings of this project, it is important to discuss the extent to which our results could be applied both to others with the conditions represented in this study, and more widely across all children and adolescents with a chronic medical condition.

In Chapter Two we outlined the reasons for selecting the conditions represented in this study. Our aim was that the findings of this project could be used to inform how to meet the information needs of most young people with chronic conditions. Thus the conditions were selected in order to represent as many as possible of the issues - medical and psychosocial - that any young person with a chronic medical condition may face. The different conditions also represented differences in terms of the frequency of contact with health professionals, the number of health professionals typically seen, the frequency (if any) of inpatient episodes and the use of young people's clinics.

In terms of the actual sample we worked with on this project, a number of factors favour the argument that our findings can be applied across most paediatric populations. The young people involved came from different socio-economic backgrounds and had differing levels of educational ability. The sample was drawn from a number of sites throughout England, and within each condition, a range of severity and duration of the condition was represented. In addition, it was very apparent that among the participants, some were very well-informed about their condition, while others were less well-informed. Finally, as has been reported in a previous chapter, we found considerable individual differences within our sample in terms of what they said they wanted or needed to know.

In summary then, we would argue that the project recruited and worked with a wide range of

young people, and in terms of qualitative research, it is this lack of bias in the sample which is critical to the extent to which the findings can be applied (Mays and Pope, 1995). Further features of the research which add to the rigour of this project are that we worked directly with children and adolescents, in many cases over two or three separate occasions, and that a range of methods and techniques was used to facilitate, and corroborate, our exploration of the young people's information needs and the ways these needs can be met.

Limitations

In terms of applying the findings of this project, a key limitation is that the project worked within two age bands - 10 to 12 years and 14 to 16 years. These age bands were deliberately chosen as they were thought to represent periods of significant change and therefore may be times of increased information need. In addition, we chose only to include young people who had been diagnosed for at least a year, and among participants with a life-limiting condition, none were at the end stage of their condition. Next, in terms of the sample recruited to the project only four (out of 63) young people were from minority ethnic groups, and two of these young people and their parents used English as their first language. Finally, this project did not work with young people with severe learning difficulties.

This therefore leaves a number of groups within the population of young people with a chronic medical condition who were not represented in this project, and therefore applying the findings of this project to these groups should be limited and circumspect. First are those who have been recently diagnosed. Second are younger children, and, third, are those in late adolescence. The fourth main group are young people who are terminally ill. Fifth, this project has not addressed the information needs, and ways to meet these needs, of young people who do not use English as their first language. In addition, we have not been able to explore the effect of race in terms of meeting information need. The final group to whom we cannot assume these findings are applicable are those young people with a chronic medical condition who have learning disabilities.

5.3   OVERVIEW OF FINDINGS

The aim of this project was to identify the information needs of young people with a chronic medical condition, and to explore how these information needs can be best met. The background to this project was that very little was known about the information needs of young people, *per se*; and what was known was limited to facts and information about the condition. Through direct consultation with young people with a chronic medical condition, we identified two categories of information need: medical information needs and psychosocial information needs.

5.3.1   Medical information needs

Medical information included information about the condition, its treatment and day-to-day management, dealing with exacerbations, and diagnostic or monitoring tests and investigations. Knowledge about any dietary or activity restrictions was also highlighted, especially the reason for such restrictions. The young people talked about the importance of having an understanding of relevant human biology, and the need to know about (and be able to understand) current research into their condition. The final group of medical information needs included the support available from health and other statutory agencies, as well as entitlements to welfare provision, both at the present time and in the future. The sorts of medical information needs identified by this project are broadly similar to those identified both by research with adults (for example, Pfefferbaum and Levenson, 1982) and the limited work which has involved young people (for example, Russell, 1998; Ellis and Leventhal, 1993).

Across this range of information needs, it was clear that the young people wanted information that enabled them to make sense of their situation. Thus the importance of a knowledge of basic human biology was flagged up as providing a necessary context to understanding the actual condition. Another example is that in terms of information about tests and investigation, what was often most important was knowing what their results meant relative to others with the same condition. While it was not the purpose of this project to establish and compare levels of knowledge across individuals or conditions, it was clear that the participants involved in the project included those who were very well-informed about their condition and those who were not. However, both groups reported unmet information needs. The less informed young people had very basic questions about their condition, while the well-informed participants had more detailed and specific questions.

5.3.2   Psychosocial information needs

Psychosocial information needs are generated by a young person having to deal with or manage feelings, events and circumstances caused - directly or indirectly - by the condition. The participants in this project believed that knowing how to live with their condition was as important as knowing about the condition *per se*. In line with previous research (for example, Perrin and Maclean, 1988; Kazak, 1989; Beresford, 1992), this project has demonstrated the wide-ranging impact of a chronic medical condition on a child or adolescent's life.

The issues that may need to be faced include: dealing with negative emotions; living with the physical symptoms of the condition; living with unanswered questions; managing social relationships and difficulties - with parents and peers; managing at school; dealing with restrictions imposed on lifestyle; maintaining positive attitudes; and planning for the future.

Coping effectively with these situations draws on information as a coping resource in two main ways. First, information about the condition, and about health and other support services, will be needed. Second, knowledge about appropriate or effective ways of coping will need to be employed, for instance problem solving skills and the experiences and strategies used by others with the same condition can be used by an individual in deciding how to cope with a stressful situation.

5.3.3 Factors influencing the degree of information need

In course of this project it became very clear that, while it had been possible to identify information needs, considerable individual differences existed in what young people wanted to know, and when they wanted to know it. Differences in coping style, notably information-seeking versus avoidant coping behaviours, and the fact that, in some instances, not wanting information appears to be an adaptive coping strategy, will affect both what and how much a young person needs to know. The findings of other research support this argument (for example, Weitz, 1991; Phipps and Srivastava, 1997).

In addition, we identified a second factor which influenced type and level of information need. Our findings suggest that young people's exposure - directly or vicariously - to events or situations relevant to their condition was related to the need for new or different information. This was a stronger influence on information needs than factors such as age. Broadly speaking, this finding aligns itself with current thinking about the role of chronological age in understanding and predicting all aspects of development. It is now acknowledged that children do not follow a simple series of age-related stages during their development, instead social factors and personal experiences play a key role in a number of developmental processes (for example, Mandler, 1983; Nelson, 1986). This would suggest that while an awareness of the potential areas of information is important, it is impossible to be prescriptive about what a child or adolescent with a medical condition needs to know, and when.

5.3.4 Sources of information

A number of information sources were identified by the young people, and there were clear differences in what were perceived to be appropriate sources of medical information and psychosocial information. While health professionals - especially the young person's doctor - were viewed as a key source of medical information, their role in providing psychosocial information was seen as very limited, and specifically with respect to planning for the future. Parents and written information were the other main sources of medical information. In terms of meeting psychosocial information needs, the preferred sources of information were parents, friends and others with the same condition. However, for all the major information sources

identified by participants, difficulties existed with respect to accessing or using them.

Using health professionals as an information source
It could be argued that information needs that could be met by a health professional need never remain unmet. If there is open communication between a young person and his or her doctor, then information needs could be addressed as they arose. With this in mind, we spent a considerable amount of time exploring the participants' experiences of communicating with their doctors. The findings from this project suggest that for many young people, current patterns of communication are far from ideal and, as a result, information needs remain unmet. A number of factors which promote or hinder effective communication were identified.

Central to the process of communication was the rapport that existed between the young person and his/her doctor and the nature of their relationship. In essence the young people were calling for more equal status with their doctors. Issues such as a condition-focused, as opposed to young person-centred, approach; the use of overly medical or scientific language; and exclusion of the young person from interactions between the doctor and parent were all seen to contribute to devaluing a young person's status within a consultation.

Many of the factors identified by the young people in this project as forming barriers to effective communication with doctors have also been reported by research into parent/adult patient-doctor interactions (for example, Street, 1992; Shiminskimaher, 1993; Hall *et al*., 1994; Bernzweig *et al*., 1997). However, this issue is complicated for children and adolescents for a number of reasons. First, children's and young people's social status is still commonly perceived as being lower or inferior to adults (Beresford, 1997). Second, children's ability to understand information and express opinions is underrated (for example, Fine and Sandstrom, 1988; McGurk and Glachan, 1988), and their rights to information are often unacknowledged (for example, Alderson and Montgomery, 1996). Third, the presence of parents can interfere with the development of a rapport or relationship between a child and doctor.

In Chapter One we reported that very little was known about communication between doctors, young people and their parents, especially within the United Kingdom. Thus the findings presented in this report offer a useful insight to the issues and difficulties that exist. As with previous work, it appears that especially among children and young adolescents, interaction mainly occurs between the doctor and parent, leaving the child excluded (for example, Dulmen, 1998). In addition, as has been suggested by Dulmen (1998), this exclusion is caused both by doctors failing to address the child or adolescent directly, and parent's own needs to communicate with and put questions to the doctor. Our finding that some of the young people

in this project did not find their interactions with their doctor promoted a sense of equality and partnership is a real challenge to the philosophy of patient partnership expressed in recent government directives (for example, Department of Health, 1996b). We return to this issue in a later section.

The role of parents

The project found that parents occupied more than one role in relation to meeting the information needs of the young people. In line with other research, we found that many parents were a key source of medical information (for example, Olsen and Sutton, 1998). While previous research has tended to focus on the effect of increasing age on decreased reliance on parents as an information source (for example, LaGreca *et al.*, 1995), our findings suggest a more complex picture. We found that a number of other factors may also affect the degree to which young people use, or may be reliant on, their parents as an information source. These factors include age at diagnosis, duration of the condition, parental involvement in day-to-day care, and perceived levels of parental knowledge.

Parents also affected the extent to which the young person used health professionals as an information source. In some cases parents were seen as helping the young person to ask questions, while others - especially the older participants - said the presence of their parents during consultations with their doctor was inhibiting.

Written and audio-visual information

As we reported in Chapter One, very little seems to be known about children and adolescents' use of written information. The key message from this project is that booklets or leaflets are perceived as an important but limited information source, and that, similar to the findings of previous research, obtaining information through face-to-face contact is preferred (Ellis and Leventhal, 1993; Doorbar, 1996). The reason for this is that the information obtained in the latter way is qualitatively better since it can be tailored to specific, personal circumstances. Written information was seen as being particularly useful for providing pictures and diagrams which enabled a clearer understanding of the condition, and statistical information about prognosis and outcomes.

Other young people with the condition

Contact with other young people with the same condition was something that virtually all the participants wanted, yet only a minority experienced. While other information sources may be

interchangeable, others with the same condition were viewed as a unique source of medical and psychosocial information. Other research has also highlighted the value of support groups for children and adolescents with a chronic medical condition (for example, Lansdown and Goldman, 1998; Hockenberry-Eaton and Minick, 1994; Barlow and Harrison, 1996). However, the findings from this project suggest that alternative forms of contact need to be provided. Not all young people want to belong to a group - indeed the notion of a belonging to a support group was seen as negative and stigmatising to some of our participants. A more appealing means of bringing a group together would be to base meetings around social activities. Other ways of contacting young people with the same condition suggested by participants included pen-pal schemes, Internet chat rooms and either personal or telephone contact between just two individuals.

Other sources of information

Telephone help lines were not an information source that participants had used or would envisage using in the future, except in a crisis situation where no other support was available. This contrasts with the increasing use of help lines by adults with medical conditions (Broadstock and Borland, 1998; Clode, 1998) and raises questions as to whether this particular method of offering information is appropriate to young people whose experience of using of the telephone is likely to be limited to conversations with friends and family.

The Internet was identified by participants as having the potential to be a useful source of medical and psychosocial information. At the time of the project, very few had access to the Internet, though this will obviously change in the future.

Finally, in terms of meeting psychosocial information needs, participants were keen to stress the importance of their circle of friends. Being able to discuss with friends issues such as how to cope with over-protective parents or feeling low, was important to the great majority of participants. Other research has similarly highlighted significant role of peer support (for example, LaGreca, 1992; Lightfoot *et al.*, 1998). However, it also known that the onset of a chronic illness may disrupt previous friendships (Spirito *et al.*, 1991; LaGreca, 1992), and indeed this was the experience of a number of participants in our project who had been recently diagnosed. Finally, it is important to note that a small minority of the young people in our project had not told their friends about their condition.

5.4   UNDERSTANDING INFORMATION NEED: THE THEORETICAL CONTEXT
Stress and coping model
In Chapter One, we described the process model of stress and coping (for example, Lazarus and

Folkman, 1984). This theoretical model informed the whole of the research process and offered a framework for investigating and understanding the information needs of young people with a chronic medical condition. We have found the concepts offered by this model useful and relevant, and although this project did not set out to 'test' the model, our findings support its validity as a theoretical model.

The stress and coping model argues that having a chronic medical condition has wide-ranging repercussions which demand a holistic approach to understanding the impact of a condition on an individual's life (Cohen and Lazarus, 1979). Indeed we found that the information needs identified by this project extended far beyond medical facts, and included a wide range psychosocial issues. Knowing how to deal with or live with the consequences of their condition on a day to day basis was identified by many of the young people as being as important as knowing about and understanding their condition and its management. The types of information which could act as a coping resource when faced with condition-related stressors included: information about the condition; problem-solving skills; sources of practical and/or social support; ways of dealing with distressing emotions; and knowing how to manage stressors which cannot be managed or resolved, such as pain and uncertainty. As well as needing information to deal with current stressors, relevant information was also important in terms of thinking about and planning for the future, especially among older participants.

The stress and coping model also predicts differences in information need both between and within individuals. As reported in Chapter Three, this project found evidence of considerable differences between and within individuals in terms of how much information they wanted, especially medical information. These differences were related both to differences between young people in the way they perceived or appraised events and situations related to their condition, and differences in coping style and the perceived effectiveness of information-seeking in different circumstances.

Patient empowerment
Another concept discussed in Chapter One was the notion of patient empowerment. Again the importance of addressing the psychosocial aspects of living with a medical condition is emphasised, though within this concept the focus is on managing treatment demands within day-to-day life. The findings reported in Chapter Three - especially the sections on lifestyle factors and restrictions - clearly demonstrate the need to take account of the psychosocial issues that may threaten the management or treatment of a condition. The findings from this study suggest that in order to promote patient empowerment, individuals need to have access to a number of sources of information, not just health professionals. In particular, it would appear that others

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with the condition, of the same age or slightly older, can be an important source of information related to psychosocial issues.

A definition of information

Finally, the findings of the project support the idea put forward in the first chapter that information cannot be objectively defined or described, nor should it be restricted to certain types of knowledge. To repeat the definition offered by Dervin *et al.* (1980): information is *anything* that a person finds informing.

5.5   IMPLICATIONS FOR PRACTICE

The findings from this project have a number of implications for practice within health care settings. They can be divided into implications related to meeting the range of information needs that a young person with a chronic medical condition may have, and the more specific issue of promoting better and more effective communication between young people and health professionals.

5.5.1   Meeting information needs

- Health professionals need to adopt a holistic approach to understanding and responding to the information needs of children and adolescents with a chronic medical condition. This requires developing an appreciation of the wide range of psychosocial issues that a young person may face as a consequence of his or her condition. This increased awareness should in turn affect the nature and scope of consultations between a young person and his or her doctor.

- Health professionals should remember that young people have a *right* to information about the treatments they receive.

- Good quality, accurate and age-appropriate written information should be actively offered. Given the changing information needs of young people, relevant written information should be offered on a regular basis. Where possible, the provision of new information verbally should be accompanied by written information.

- As well as specific information about the condition, written information about relevant aspects of human biology should be provided.

- Details of other information sources such as Web Sites, help lines and voluntary organisations should be provided. Again, these details need to be offered on a regular

basis.

- Contact between young people with the same condition and of about the same age should be encouraged *and* facilitated. This can take a variety of forms and need not involve direct, face-to-face contact. Contact involving meeting others should be regular and informal, and not focused on the condition. Social or activity events which offer the opportunity to get to know others with the condition are preferable to a 'support group' type approach. A young person may not want contact with others when first offered the opportunity but may do so at a later stage. Thus, once again, it is important that the young people are made aware of opportunities for contact on more than one occasion.

- In terms of thinking and planning for the future, contact with young adults representing positive achievements or outcomes would be valued by those in middle and late adolescence.

5.5.2 Promoting effective communication between young people and health professionals

Recognition of the importance of effective doctor-patient communication has been slower in the case of young people than for adults. However, as noted in Chapter One, such recognition is growing, and in recent years professionals with a particular interest in this area have provided valuable advice and guidelines based on their clinical experience (Edwards and Davis, 1997). The ideas and experiences of the young people involved in this research project validate and add to these professional contributions. As we reported in Chapter Four, the participants involved in this project had a number of suggestions for improving communication between themselves and their doctor. These suggestions can be summarised as follows.

The children and adolescents wanted:
- choice about who else (for example, parents, student doctors) is present when they see their doctor.
- continuity of contact with one doctor.
- to feel that their doctor was interested in them and not just their condition.
- to be asked questions (as opposed to their parents answering questions).
- their doctor to talk to them, rather than their parents.
- the opportunity to ask questions.
- the language used to be understandable.
- to be treated with respect and in a way appropriate to their age.
- to made to feel comfortable and not rushed.
- finally, where possible to have a choice about whether they are seen by a male or female

doctor.

Communication skills for health professionals AND young people

•   Health professionals and young people may both need to acquire new skills in order to promote effective communication. Research which has evaluated the outcome of communication training skills programmes for health professionals suggest they have a limited effect (for example, Joos *et al*., 1996). One reason for this, it is argued, is because the intervention did not include patients as well. Others have argued that communication skills training will have a limited effect if attention is not also paid to health professionals' attitudes to doctor-patient communication, and their perceived self-efficacy in being able to communicate effectively (Parle *et al*., 1997).

Changing health professionals attitudes to communication

•   In addition to skills training, therefore, attention needs to be paid to attitude changes among professionals in order to promote sustained improvements in doctor-patient communication. Some recent studies (Parle *et al*., 1997; Fallowfield *et al*., 1998) provide evidence of positive preliminary findings for communication training that takes this broader approach, but further research is needed to identify the most effective approaches to improving doctor-patient communication.

Challenging beliefs and presumptions about young people

•   In order to achieve effective communication and promote partnerships between doctors and young people with chronic medical conditions, the attitudes towards and presumptions held by health professionals about childhood and adolescence need to be challenged and addressed (Alderson and Montgomery, 1996). However, it is important to note that intervention work already carried out in this area suggests this is likely to be a challenging and difficult task (Batenburg and Smal, 1997).

5.6   MEETING INFORMATION NEEDS: POLICY ISSUES

While this project was not driven by a particular policy issue, at the beginning of Chapter One we identified three areas of policy which were relevant to this project: health service policy, policy about children and international policy on children's rights.

In terms of health service policy, the findings from this project have implications in terms of the range of information needs that are perceived to be relevant. Provision of information to patients

is a key feature in current health service rhetoric. However, it is limited to information about the condition and service provision (Department of Health, 1996b) and the need to provide information is seen in terms of enabling patients to take part in decisions about their treatment and care.

However, the findings from this project show that management of daily treatment regimes and decisions about care form only one aspect of daily life with a chronic medical condition. The information needs caused by the various psychosocial situations and stresses associated with a chronic medical condition were, in the views of the participants of this project, as important as their medical information needs. The question then arises as to who is responsible for meeting these psychosocial information needs? The findings of this project would suggest that health professionals are not perceived as an ideal source of psychosocial information, though that it not to say they could not assume a role in ensuring that these information needs are addressed if a more holistic approach, for instance as recommended by Edwards and Davis (1997), is taken.

Responsibility for the welfare of young people with a chronic medical condition is unclear (Bolton, 1997). The 1989 Children Act does not identify children with a chronic medical condition as a specific group of 'children in need'. While some may fall into the disabled children group, others will not. Certainly the current resource climate within social services departments, and the dominance of child protection services, means that social work support services for disabled children may be limited to crisis interventions and/or the most severe cases (Social Services Inspectorate, 1994). A lack of distinct provision for the needs of young people is also apparent within the health service. A survey conducted a couple of years ago found that only one in ten health authorities had specific policies or service specifications for secondary or tertiary care for adolescents (Viner and Keane, 1998). Similarly, the House of Commons Health Committee recently noted that health services 'do not always focus on and are not always designed to meet the needs of children and young people' (House of Commons Health Committee, 1997: para 120). There therefore seems to be a 'policy gap' in terms of defining responsibility for meeting the wider psychosocial support and information needs that children and adolescents with a chronic medical condition may have.

Poor communication with patients and a lack of information have been identified as considerable problems within the health service. The findings from this project support this contention, and provide clear evidence of the difficulties children and adolescents face in terms of obtaining information from their doctors. The Government charter for health services for young people states that children and adolescents have a right to information about their treatment (Department

of Health, 1996d). The findings from this project suggest that, to a greater or lesser extent, this right is being withheld from young people. For example, one of the key areas of unmet information need among our sample concerned the side effects of medication. In addition, in some cases it appeared that parents were being informed about possible adverse side effects but these were not being divulged to the young person.

This specific finding highlights a more general issue about the role of parents as an information source and, consequently, the control they may exert over how much a young person knows about his or her condition. According to many of the participants in this project, especially those in the younger age group, their parents were a key source of medical information. We are not suggesting that parents wantonly withhold information, but for some conditions parents face an enormously difficult task of knowing 'when' and 'what' to tell their child. Reliance by health professionals on parents to be a child's main information source may not best serve the child's information needs and their right to information, as well as placing a considerable burden on parents. The independent rights of young people to information needs to be reasserted within health care policy and their legal rights to information clarified (Alderson and Montgomery, 1996); and within this the issue of the role of parents as information providers and gatekeepers needs to be addressed.

In support of previous research, this project has provided ample evidence that young people can experience significant difficulties communicating with their doctor. Doctors' attitudes - specifically the perceived importance of communicating directly with the young people - were identified by participants as a barrier to using health professionals as an information source. We would argue that this reflects a more general cultural issue within health services as to the rights, and the value of the opinions, of children and adolescents. The lack of direct involvement of children and adolescents in consultations about service planning and development, as noted by MacFarlane (1997), supports this argument. Thus, while the UN Convention on the Rights of the Child (and the 1989 Children Act) appears to be slowly resulting in greater consultation with young people within social service and other local government organisations (Willow, 1997), only a few examples of such consultation exist within health services (for example, McGuire, 1998). Policies directed specifically at addressing the needs of children and adolescents, and their rights to being informed, involved and consulted would serve to promote a change in culture.

5.7   SUGGESTIONS FOR FURTHER RESEARCH

Both the findings and limitations of the project described in this report highlight issues which need further research. Listed below are issues and questions which, as far as we know, have

either not been explored previously, or deserve further research attention.

1. Health professionals' attitudes towards communicating with children and adolescents with a chronic medical condition, and the perceived barriers to this process.

2. The role of health professionals other than doctors as sources of information.

3. The use telephone help/information lines by children and adolescents with chronic medical conditions.

4. The information needs of parents of young people with a chronic medical condition.

5. Within families with a child with a chronic medical condition, the process of information exchange between family members on matters relevant to the condition.

6. The views of young people with a life-limiting condition on the provision of information at the end stage of their condition.

7. The information needs, and ways of meeting those needs, of young people with learning disabilities.

8. The information needs, and ways of meeting those needs, of young people with from minority ethnic groups.

A number of these ideas would lend themselves to a project which included a development phase, in which the research findings could be used to inform some form of training or intervention. In terms of specific development work we would suggest the following is a particularly pressing issue:

9. Design and evaluation of interventions to promote better communication between health professionals and children and adolescents.

APPENDIX 1

SAMPLE OF LETTER USED FOR INITIAL CONTACT WITH FAMILIES

Dear [Parent's name]

I am writing to you about a research project which I think you might be interested in.

The 'What I Need to Know' project is looking into the sorts of information children with a medical condition need to have, and the best ways to provide that information. The project workers are very keen to include children with [condition] in the project and I have agreed to approach some of the families who come to my clinics.

Enclosed with this letter are information sheets about the project for yourself and your child. Please read them careful and discuss them with your child. If you and your child are interested in taking part and would like to find out more, please complete the enclosed form and return it to the researchers in the envelope provided. The researchers will then contact you.

Thank you.

With best wishes.

Yours sincerely

APPENDIX 2

**SAMPLES OF PROJECT INFORMATION LEAFLETS
FOR CHILDREN, ADOLESCENTS AND PARENTS**

About the 'What I Need To Know' project

This project wants to find out what children with a medical condition need to know. The only way to do this is to talk to the children themselves.

We can't talk to everyone, but we think it is important that some children with diabetes are included in the 'What I Need To Know' project.

About us

Our names are Bryony Beresford and Jennie Macdiarmid. We are the project workers.

Our job is to work with children like you on the project, and then to tell doctors and other people who look after children what we found out. We are based at the University of York.

Why me?

Dr   has told us it is OK to get in touch with some of the children who come to his clinics to see if they want to take part in the 'What I Need To Know' project. That is why we have written to you and your parents.

What would happen if I took part in the project?

First of all, one of us would come to see you at home. This is so you can ask more about the 'What I Need To Know' project, and we can find out a little about you.

Then we would like you to come along to two group meetings. There will be about eight other children with diabetes at the meetings, and they will all be about your age. You might know some of them from the clinic. We will be at the group meetings too. The first meeting will be in the autumn.

What will happen at the group meetings?

There will be lots of different activities to help you to think and talk about the things you feel children with diabetes want to know. We also want you to tell us the best ways of giving information to children.

Thank you tokens

We are sure that you will find taking part in the 'What I Need To Know' project interesting and fun. You will be given a £10 record, book or clothes token at the end of each meeting. You can choose which sort of token you would like.

It's private!

Everything you tell us is private. But, of course, you can tell your family and friends about the project. When we write the report about the project, we won't use your name.

What if I don't want to take part?

That's OK. We only want children to take part in the project if they really want to. Nobody will mind if you don't want to take part. If you do decide to take part and then change your mind, that's OK as well.

Yes, I'd like to be involved in the 'What I Need To Know' project

That's great! Ask your mum or dad to fill in the contact form, and send it back to us. When we've heard from you, we'll get in touch to arrange a visit.

Any questions?

If you would like to talk to us more about the project please telephone us. The project telephone number is: 01904-433608. Please ask to speak to Bryony.

You can also write to us at:

'What I Need To Know' Project
Social Policy Research Unit
University of York
York
YO1 5DD

What's it all about?
'What I Need To Know' is a national project working with children and young people with either arthritis, cystic fibrosis, diabetes, epilepsy or muscular dystrophy. The project wants to discover the sorts of information these children and young people need, and the best ways of providing that information.

Your chance to have a say...
The 'What I Need To Know' project gives you the chance to let doctors and other professionals know about the sorts of information children and young people need as they grow up with a medical condition, and the best ways of giving that information. At the end of the project we will write a report of the project for doctors and other professionals. We will also draw up a list of recommendations about the best way to meet the information needs of children and young people who have a medical condition.

Why me?
Dr   has told us it is OK to get in touch with some of the young people who come to his clinics to see if they want to take part in this project. This is why we have written to you and your parents.

What would I have to do?
If you are interested in joining the project we will visit you at home. This will give you a chance to meet one of the project workers and to ask about the project. It will also allow us to find out about you.

Taking part in the project involves attending two group meetings with other young people with diabetes. These meetings will be held in   . The first group meeting will be in the autumn, and the second meeting will take place in early 1998.

During these meetings we want to find out about and discuss with you the sorts of things children and young people with diabetes need to know, and the best ways to provide that information. At the second meeting we will work together to produce a list of recommendations about the best ways of making sure children and young people know what they need to know.

We value your opinions!
All the young people taking part in the project will receive a £15 book, clothes, or record voucher at the end of each group meeting. We will also pay any travel expenses.

It's private and confidential!
Everything said at the meetings will be totally confidential. We will not tell anyone else what you say. When we write the report about the project, we will make sure that the children and young people who took part in the project cannot be identified.

What if I don't want to take part?
That's OK. We only want young people to take part in the project if they really want to. Nobody will mind if you don't want to take part. If you do decide to take part and then change your mind, that's OK too.

Yes, I'd like to be involved in the 'What I Need To Know' project
That's great! You or your mum or dad need to fill in the contact form, and send it back to us. When we've heard from you, we'll get in touch to arrange to visit you.

About us
Our names are Bryony Beresford and Jennie Macdiarmid. We are based at the Social Policy Research Unit at the University of York. We are not doctors, but we are experienced in working with children and young people on projects like this one.

If you have any questions about the project please do not hesitate to telephone or write to us.

Bryony Beresford
'What I Need To Know' Project
Social Policy Research Unit
University of York
York. YO1 5DD

About the project
Having a medical condition inevitably raises questions in a child or young person's mind. These questions may range from details about the condition itself, to the impact it may have on their current and future life.

'What I Need To Know' is a national project working with children and young people to discover the sorts of information they need about issues in their everyday life, and the best ways of providing that information. The project will be working with children and young people with one of five conditions: arthritis, cystic fibrosis, diabetes, epilepsy or muscular dystrophy.

What the project involves
First of all, one of the project workers will visit you. This will give you a chance to meet one of us and to ask about the project. It will also allow us to find out a little about the children who will be coming to the group meetings.

Taking part in the project would involve your child attending two group meetings with others of a similar age and with the same condition. These meetings will be held in   . Using a range of activities, the project workers will encourage the children to think about the sorts of things they need to know, and the best ways to provide that information.

The first group meeting will be held in the autumn, and the second meeting will occur in early 1998. Children taking part in the project will receive a book, clothes, or record voucher. We will also cover any travel expenses.

What will come out the project?
A lot of professionals who work with children with a medical condition now realise that it is important to make sure that these children have the right sorts of information at the right time. They will find the results of this project very interesting and helpful.

We will write a report of the project for doctors and other professionals. We will also draw up a list of recommendations about the best way to meet the information needs of children and young people with a medical condition. Both the report and the recommendations will be distributed widely.

The project workers will also speak at conferences about the findings of the project.

Some questions parents may have...

Will you be giving detailed information to the children about their condition?

No. The purpose of the project is to discover the sorts of things children want to know, when they need to know it, and the best ways of giving that information. Naturally this will include information about the condition, but it also includes what children need to know about the impact of the condition on all aspects of their lives.

In a sense, we will be the ones asking the questions, and the children will be giving us the answers. There will be leaflets about diabetes produced by the British Diabetic Association available to parents and young people at the group meetings

What sort of help and support can you give a child who joins the project?

We have appointed five advisors to the project. One of these advisors has a lot of experience of working with children and young people with diabetes. She will attend the relevant group meetings for children and young people with diabetes, and will be able to provide confidential general advice and support. However, if a child raises particular questions about their condition, we will suggest they talk to Dr   at their next outpatient appointment.

The children and young people taking part in this project will be able to contact the project workers or the project advisor at any time during the project.

It is very important that the children involved in this project understand that this is a research project and not a support group. However, we do believe that the children taking part in the project will find it a positive and beneficial experience.

The project workers

Our names are Bryony Beresford and Jennie Macdiarmid. We are based at the Social Policy Research Unit at the University of York. We are not doctors, but we are experienced in working with children on projects like this one.

If you have any questions about the project please do not hesitate to telephone or write to us.

Bryony Beresford
'What I Need To Know' Project
Social Policy Research Unit
University of York
York. YO1 5DD   Telephone: 01904-433608

APPENDIX 3

CONTACT FORM

'WHAT I NEED TO KNOW...'

We are interested in the What I Need To Know project. We would like the researchers to contact us so we can find out more about the project.

Name..

Child's Name.. **Age**...............

Address...

....

....

....

Telephone number: ....

Please return this form to the researchers using the envelope provided. You do not need to use a stamp. Thank You.

Bryony Beresford and Tricia Sloper
Social Policy Research Unit
University of York
Heslington
York YO1 5DD
(01904-433608)

APPENDIX 4

CONSENT FORMS

'WHAT I NEED TO KNOW'

CONSENT FORM FOR CHILDREN
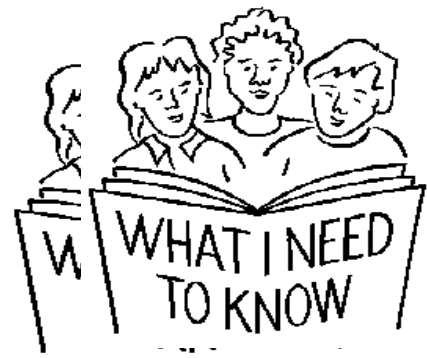
Have you read the children's information sheet about the 'What I Need To Know' project?   Yes/No

Have you talked to one of the project workers about the project? Yes/No

What is their name?

....

Do you feel you understand what taking part in the project involves?   Yes/No

Do you know that you can leave the project any time, and without giving a reason?   Yes/No

I would like to take part in the 'What I Need To Know' project:
Yes/No

Please sign your name here:

....

Please write your name here:

....

'WHAT I NEED TO KNOW'

CONSENT FORM FOR YOUNG PEOPLE

Have you read the young people's information sheet about the 'What I Need To Know' project?   Yes/No

Have you talked to one of the project workers about the project? Yes/No

What is their name?

....

Do you feel you understand what taking part in the project involves?   Yes/No

Do you know that you can leave the project any time, and without giving a reason?   Yes/No

I would like to take part in the 'What I Need To Know' project: Yes/No

Please sign your name here:

 ....

Please write your name here:

 ....
'WHAT I NEED TO KNOW'

CONSENT FORM FOR PARENTS

Have you read the parents' information sheet about the 'What I Need To Know' project? Yes/No

Have you talked to one of the project workers about the project? Yes/No

What is their name?

 ....

Do you feel you understand what taking part in the project involves?   Yes/No

Do you understand that your child is free to withdraw from the study at any time, and without giving a reason? Yes/No

Are you happy for your child to take part in the 'What I Need To Know' project? Yes/No

Signed: ....

Name:..

APPENDIX 5

**TOPIC GUIDE FOR
INDIVIDUAL INTERVIEWERS**

INTERVIEWER'S SCHEDULE FOR HOME VISIT

Joint session with parent and child

i)   **Introduce self** as project worker working with all children/young people with [condition]. Say that you're not a doctor, but are experienced with working with children and young people

ii)   **Explain purpose of visit** - i) so family can meet one of the project workers; ii) to answer queries; and iii) if happy to take part, to talk to the child - so have some background information before the group discussion meetings.

iii) **Answer questions** and **provide information** about the study.

iv)   **Confirm details about the group meetings**
      purpose; date; venue; time; meeting travel costs. Explain that you'll be sending through written information, maps etc. Check parent's travel needs.

v)   **Check about the child's needs for the group meeting**. Ask quite a general question..
      "Can I just check whether [child's name] has any particular needs which we will need to cater for, for instance, diet?"

      If child does have particular needs, reassure that we will make sure arrangements are in place.

      * Make a note of any needs in your fieldnotes, along with your observations about the child/young person's abilities in terms of: comprehension, reading, writing, speech and mobility.

vi)   **Check parent's preferences for group meeting**, eg. would they like the chance to meet other parents, to meet a rep. from a vol. organisation. *Check with BB/TS on proposed arrangements.*

vii) **Ascertain whether child and parent happy to take part** (if you feel it is appropriate, offer to leave room for a while to give them a chance to chat), and then go through the **consent form** with them. **Reiterate confidentiality**

viii) The **project advisor**: name her and explain her role.

ix)   **Interview** child/young person using topic guide.

INTERVIEW WITH CHILD/YOUNG PERSON

TOPIC GUIDE

BEFORE STARTING......

i) **Recheck consent**

ii) Remind that **it is OK to stop** interview at any time, or not to answer a particular question.

Rehearse with child various strategies (whatever seems appropriate)

        * using red and yellow cards (perhaps with something written on)
        * choose a phrase to use if want to stop
        * choose a phrase to use if don't want to answer a question
        * can use a silly word if don't want to answer a question

iii) Ask **permission to tape record**. Offer child chance to listen back. Or the chance to ask some questions (be the interviewer) later on.

If OK, switch tape machine on

1.   INTRODUCTION

i)   Thank you

Thank child for agreeing to take part and say that you are sure they will enjoy being part of the study and will get things out of it for themselves.

ii)   ...You are the expert

Say something along the lines of:

> *I think it's very important for you to know that I don't know as much about [condition] as you do. I am very interested to hear your views and experiences. I and the other workers on this project strongly believe that it is the children and young people taking part who are the experts.*

iii)   There are no right or wrong answers

Stress the study is about finding out about children and young people's views and experiences. There are no right or wrong answers. We are just interested in what you think and feel about things.

2. BACKGROUND QUESTIONS

[To be used as warm up questions, don't spend too long on this section]

i) School

Perhaps we can start off by you telling me about your school and the things you do there......

PROMPT:
  * name
  * whether changed/changing school recently,
  * how long been there
  * what subjects enjoy and what dislike

ii) Spare time

.....and what about when you're not at school or doing homework! What sorts of things do you so in your spare time?

PROMPT:
  * activities in and out of home
  * clubs
  * hobbies

3.   HOSPITAL(S) CHILD ATTENDS

[These questions are seeking background information as well as leading the interview towards more specific and personal views and information We should have given you details about the child's consultant and hospital]

i)   Attendance details

As you know it was Dr [   ] who wrote to you about this project. Who else do you see at [name of hospital]?

PROMPT FOR EACH PROFESSIONAL:
      *   How often AND why does child see them

[Suggest interviewer compiles a list of possible professionals child might be seeing to use for prompting.]

ii)   Views on hospitals/professionals
[Just getting a general opinion here, not too much detail, will return to this later.]

And do you like [name of hospital]? (Could do as an exercise: Can you tell me one good thing about [name of hospital], and one bad thing)

PROMPT:
      *   what like, and what dislike
      *   why like/dislike

What are the people like, are some nicer/better than others (again, could do as an exercise. Tell me one good thing about the people you see there, and one bad thing)

PROMPT
      *   why like/dislike; who's better/nicer

iii)   Other hospitals?
Check if child attends any other hospitals for their condition.....if so repeat questions.

4. TALKING ABOUT THE CONDITION

i) Language

I'd like to ask you some questions about your [name of condition] now. Some children/young people I have spoken to don't use the word [name of condition] when they talk about it. Do you have any special words or phrases you use?

(The child might have already been using words and phrases. If so, check what they mean, and check for others, eg. *I've noticed that [.....] is a word you use when you talk about [name of condition], and do you have any other words?*)

PROMPT:
* language used to name condition and to describe symptoms and treatment

* language used with different sorts of people (family vs others: careful here, friends may not know)

ii) Managing the condition

I know that children with [name of condition] may have to [list various treatment regimes]. Can you tell me what YOU have to do day by day?

PROMPT:
* all types of treatments (eg. drugs, physio, diet, monitoring..)

* does child/young person know what each treatment is for

5.   EFFECTS ON EVERYDAY LIFE

So far you've been telling me about your hospital, your doctor and the other people you see about your [name of condition], and the treatments you have.

What I'd like to talk about now is the way [name of condition] fits in with the rest of your life and what you do....... .   How do you find having [name of condition] affects your everyday life?

PROMPT:

   *   sense of health/energy levels

   *   what does in spare time

   *   what you eat/drink

   *   friendships

   *   school - work, taking part in activities

   *   the sorts of ideas and plans they have for the future (jobs, leaving, home, having a partner/family)

6.   ACCESSING INFORMATION

As you know, this project wants to find out about the sorts of information children and young people with a medical condition need.

i)   **Exercise:**
I'd like you to think about the last time you had a question or concern about [name of condition], or the way it affects what you do.

GIVE CHILD TIME TO THINK ABOUT THIS.

You don't have to tell me what it was, but can you tell me whether you got an answer to that question or concern?

IF child can't think of anything, ask them to imagine.

PROMPT
*   Who did they ask, talk to about it?
*   Was it easy to ask the question, or tell someone they were concerned?
*   Was the answer satisfactory
*   Is that the usual person the child goes to?
*   Is that person the child's ideal choice? Who would be?

ii)   Talking to the doctor/other health professionals
If they needed to, does child/young person feel able to put questions to hospital doctor

PROMPT
*   What makes that easy? OR What makes that difficult?
    (The following aren't really prompts, more to give you an idea the sorts of things that might emerge...
        - parents/other people in the room
        - not knowing how to ask questions
        - doctor's manner
        - only see doctor/other
        - knowing that won't understand doctor's answer)

iii)   **If relevant, repeat for another professional** (eg. if child sees physio. a lot)

iv)   **Written/other information**

Have you ever read any books or leaflets about [name of condition]

PROMPT:
* leaflets, books, videos, TV programmes)
* how did they get hold of it? (doctor, other professional, parents, voluntary organisation, book shop)
* have they been useful/satisfaction with.........

7. UNANSWERED QUESTIONS

i)   Exercise

I'd like you to imagine that someone you know (or someone you met somewhere) has just found out they have [name of condition]. What would you tell them? What would be important for them to know?

PROMPTS: (use carefully)
* cause
* treatment (reasons for and effects)
* outcome (very careful)
* ways the condition might make you change what you do now and in the future

ii)   Unmet information needs
Following on from the previous exercise.....
And are there things you would like to tell them, but you're not quite sure about yourself?

PROMPT: (use carefully)
* cause
* treatment (reasons for and effects)
* outcome (very careful)
* ways the condition might make you change what you do now and in the future

iii)   Future concerns
.....again following on.......
What about when you're older (leave ambiguous), do you think you might have different questions or concerns?

PROMPT:
* treatment (effects)
* outcome (very careful)
* ways the condition might effect what you do

8.   ISSUES FOR THE GROUP MEETING

Giving the child/young person a chance to suggest issues for the group meeting:

I think we've nearly finished now.

As I explained to you and your mum/dad, the most important part of the project will be the group meeting you'll be coming to in [state date]. We want to be sure that you and the other children/young people coming have the chance to talk about things that are important to them.

Is there anything that we haven't talked about today that you would like to talk about at the group meetings with the other children/young people?

Remind child/young person that they can write/phone you before the meeting if they think of something. Use the envelope in the help pack. DOESN'T MATTER IF THEY DON'T.

9.   CLOSE

i)   Does the child/young person have any questions
It feels like I've been asking you lots of questions. Is there anything you would like to ask me?

ii)   Help pack
Give the child/young person their help pack containing contact cards, and a reply paid envelope if they want to get in touch. Go through explaining what's on each card.

iii)   Remind re confidentiality

iv)   Tokens
Find out what sort of token child/young person would like. Show them the list

iv)   Thank you

APPENDIX 6

**DEALING WITH DISCLOSURE:
GUIDELINES**

DEALING WITH DISCLOSURE
- GUIDELINES -

These guidelines relate to the action that should be taken in the event of a child or young person disclosing something which concerns or worries a project worker or advisor, but does not relate to the condition they have or its management.

[The consultants involved in the project have asked where a child/young person voices specific concerns about his/her condition, that we recommend he/she talks to his/her consultant/doctor. It may be appropriate to discuss with the child/young person how they would go about doing that. More general queries about the condition can be dealt with by their project advisor.]

First of all, you MUST tell the child/young person that you are concerned by what they have told you, and ask if they would like help. What you do next depends on how the child/young person responds to this, and their age.

I   For children and young people under 16 years

*   If the child says they would like help, ask if it is alright to tell the parents about what the child has disclosed and that the child would like help.

*   Discuss disclosure with parents and possible routes of referral (eg. self-referral, going through a professional who already knows child/family). Inform and consult with child about course of action. If necessary support family as they contact and disclose to a professional.

*   If appropriate, give family a card with the Childline telephone number and address.

*   Maintain contact with family until referral is in place.

a)   If the child does not want to inform/involve his/her parents...
*   Tell the child/young person that you cannot refer them without parents permission, but help them to think about someone they know (eg. consultant, GP, teacher) who they could talk to and who might be able to take things further.

*   Help the child to think about how they might talk to this person (eg. talking about a good time/place to talk to them, thinking about some 'opening sentences').

*   Alternatively, and if appropriate, encourage the child to contact Childline and give them a card with the Childline phone number and address.

II   Young people 16 years and over

*   Young people who are 16 years or older do not need to have their parent's permission to be referred to services.

*   Discuss with the young person whether he/she would like you to approach an agency or whether they would like to talk to a professional (eg. teacher, consultant, GP) they already know. If they choose the latter approach, help them to think about how they might talk to this person (eg. when and where, and thinking about some 'opening sentences').

*   If the young person wants his/her parents to be involved then inform and discuss with them.

*   Keep the young person/family informed about any action you take, and follow up to ensure that services do make contact with the young person.

III   If child/young person or parent does not want to tell anyone else/does not want any help

There is very little we can do in these circumstances... It is work saying something like 'My experience is that when someone is talking in this way or experiencing that sort of thing that they would like to talk to someone about it...'.

By all means leave the Childline card with the child/young person, and remind them about the project 'contact cards'. Offer to stay in touch, and if appropriate arrange how you will do this.

a)   Exceptions

There are two instances where it may be necessary to break the confidentiality rule. First, if the child is threatening to commit suicide; and second, if the child clearly reveals they are being sexually abused. In these instances, the information you have learnt should be disclosed to an appropriate professional (eg. local social services, GP). You will need to talk to Bryony or Tricia about this.

It is very important that the child knows that you are going to have to tell someone else because you are so concerned about their welfare. Whether or not you inform the parents will depend on the situation.

IV   Make a written record

As soon as possible after the encounter make notes about what the child/young person said, your responses, the parent's responses and any action taken.

V   Don't forget yourself!

Finally, please contact Bryony or Tricia if you find yourself in this sort of situation, or are concerned in any way. You do not need to break confidentiality in doing so, and it's likely that you'll feel the need to talk to someone too.

APPENDIX 7

EVALUATION QUESTIONNAIRE
(Two versions)

WHAT I NEED TO KNOW PROJECT

This is a short questionnaire about what it has been like to take part in the **What I Need to Know** project. It would be very helpful if you could find time to fill it in. Please feel free to be honest with us! Your answers will be treated with total confidentiality. You do not need to use the form if you would find it easier to type your answers on a word processor or typewriter.

1. **Your name:**

2. **What was your *main reason* for taking part in the project?**

3. **Did you take part in the project because *you* wanted to, or did someone have to persuade you? Who was that?**

4. **Do you remember reading the project information sheet? Was it helpful?**

5. **What has been good about taking part in the project?**

6. **If you came to a group meeting(s), which activity did you enjoy most?**

7. **Are there any things that were *not* good about taking part in the project?**

8. **What could we have done to make sure that did not happen?**

9. **Please use this space for any other comments you may have.**

Staying involved

Last of all, if you would like to carry on helping with the project by either reading and commenting on our project report or by doing some illustration/artwork to put in the report please tick below. In both cases we would need your help in the autumn.

❑ I would like to read and comment on the project report.

❑ I would like to contribute some illustrations/artwork to be used in the project report

Thank you very much for filling in this form. Please return it to us using the reply paid envelope.

WHAT I NEED TO KNOW PROJECT

We would like to know what it has been like to take part in the **What I Need To Know Project.** It would be very helpful if you could find time to fill in this short questionnaire. For each question, you can just tick the boxes that best show what you think. Please feel free to be honest with us! We will not tell anyone else about your answers.

1. Your name:

....

Please tick your answers to the questions. You can tick more than one box for each question.

2. What was your *main reason* for taking part in the project?

To meet other people with muscular dystrophy ❏

To talk to other people with muscular dystrophy about what they think

❏

To find out more about muscular dystrophy ❏

The gift vouchers ❏

Don't know ❏

Other reason. Can you tell us what this was..

....

3. Did you take part in the project because *you* wanted to, or did someone else have to persuade you?

I wanted to ❏

My mum or dad persuaded me ❏

Someone from the hospital persuaded me ❏

4. Do you remember reading the project information sheet?

Yes ❏

No ❏

If you did read it, was it helpful?

Yes ❏

No ❏

5. What has been good about taking part in the project?

Meeting other people with muscular dystrophy ❏

Talking about our experiences ❏

Being asked what I thought ❏

The gift vouchers ❏

Something else. Can you tell us what this was...

....

Don't know ❏

Nothing ❏

6. Are there any things that were *not* good about taking part in the project?

Someone coming to talk to me at home ❏

Meeting other people at group meetings ❏

Feeling anxious at group meetings ❏

Not being able to come to group meetings ❏

The activities at group meetings ❏

Something else. Can you tell us what this was..

....

Don't know ❏

Nothing ❏

Please use this space for any other comments you have.

Staying involved
If you would like to carry on helping with the project by reading and commenting on the project report or by doing some drawings to put in the report please tick below.

I would like to read and comment on the report ❏

I would like to do some drawings to be used in the project report. ❏

Thank you very much for filling in this form. Please return it to us using the reply paid envelope.

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