

PARTNERSHIPS BETWEEN YOUNG PEOPLE AND THEIR PARENTS IN THE MANAGEMENT OF ASTHMA AND DIABETES

Thesis submitted in accordance with the requirements of the University of London
for the degree of Doctor of Philosophy by

Jennifer Newbould

Department of Practice and Policy
The School of Pharmacy
University of London

February 2005

ProQuest Number: 10104801

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 10104801

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

FOR MY MUM

For reading every word and so much more.

In memory of Rowan David Taylor

Abstract

The National Service Framework for Children, Young People and Maternity Services, standard three, highlighted the importance of a young person's family in their care. It was advocated that health care professionals approach young people and their parents as partners. The aim of this thesis was to describe the nature of partnerships between young people and their parents in the management of asthma or diabetes, from the perspective of young people and their parents.

Young people with asthma (aged 8 to 12 years) or diabetes (aged 8 to 15 years) were identified from GP surgery records and invited to participate in a home interview. Semi-structured interviews were conducted with parents and a topic guide used to interview young people. Quality of life (PedsQL) asthma or diabetes modules were completed by young people and their parents as proxy respondents.

Forty-three young people with asthma and their parents and twenty-six young people with diabetes and their parents participated in the research. Partnerships were generally harmonious and characterised by a joint approach to the management of the condition, sharing of tasks and discussion of the condition and its management. Young people and their parents, in both parts of the study, identified problems with condition management in schools. Young people's and parents' experiences of consultations with health care professionals were also reported. Measurement of the quality of life of young people with asthma and diabetes identified differences between quality of life as reported by young people compared to reported by parent proxy respondents. The findings of this thesis provide health care professionals with an insight into the management of asthma and diabetes within the context of partnerships between young people and their parents.

Table of Contents

List of tables	17
List of figures	20
List of abbreviations	21
Acknowledgements	22
Chapter 1 - Introduction	
1.1 Introduction	24
1.1.1 Overview of this thesis	24
1.1.2 Rationale for the research presented in this thesis	25
1.1.3 Definition of terms used throughout this thesis	26
1.1.3.1 Partnership	27
1.1.3.2 Young people	27
1.1.3.3 Parent	27
1.1.3.4 Management	27
1.1.3.5 Responsibility	27
1.2 Young people's experiences of a chronic condition	28
1.3 Parents' experiences of a young person's chronic condition	34
1.4 Research concerning young people's and parents' experiences of chronic conditions	41
1.5 Partnerships between spouses in the management of diabetes	50
1.6 The management of chronic conditions in schools	52
1.7 Young people's and parents' experiences of consultations with	56

1.8	Information needs and information used by young people and parents	64
1.9	Quality of life	69
1.9.1	The concept of quality of life and its measurement in young people	69
1.9.2	Health Related Quality of Life of young people with chronic conditions	72
1.10	Government policy	77
1.10.1	Government policy concerning health of children and young people	77
1.10.2	Government policy concerning health and schools	82
1.10.3	Government policy concerning chronic conditions	83
1.10.4	Government policy concerning asthma	84
1.10.5	Government policy concerning diabetes	86
1.11	Aims and objectives of the main study	87
	Summary of chapter one	89
 Chapter 2 - Methods		
2.1	Searching the literature	93
2.1.1	Use of language	93
2.1.2	Electronic searches	94
2.1.3	Reference lists from identified papers	94
2.1.4	Journals identified to be of specific interest	94
2.1.5	Excluded studies	95
2.2	Preliminary work	95
2.2.1	Aims and objectives of preliminary fieldwork	95

Contents

2.2.2	Preliminary work in relation to the asthma part of the study	96
2.2.2.1	Interview with an asthma nurse based in general practice	96
2.2.2.2	Contact with the National Asthma Campaign Help line	98
2.2.2.3	Review of written material designed for young people with asthma and their parents	99
2.2.2.4	Support groups for young people with asthma and their parents	100
2.2.3	Preliminary work in relation to the diabetes part of the study	101
2.2.3.1	Interview with a hospital based paediatric clinical nurse specialist in diabetes	102
2.2.3.2	Review of written material designed for young people with diabetes and their parents	103
2.2.3.3	Support groups for young people with diabetes and their parents	104
2.2.4	Impact of preliminary work on the development of the main study	109
2.3	Methodological issues in relation to research involving children	110
2.4	Pilot work	117
2.5	Methods for the main study	122
2.5.1	Selection of methodology	122
2.5.2	Recruitment of general practice surgeries	124
2.5.3	Inclusion/exclusion criteria	126
2.5.4	Recruitment of young people with asthma or diabetes and their parents	127
2.5.5	Written information designed for young people	129
2.5.6	Interview process	129
2.5.7	Quality of life instruments	131
2.5.8	Ethical approval	138

2.5.9	Data analysis of interview data	140
2.5.10	Data analysis of quality of life data	144

Chapter 3 - Sample characteristics and response rates

3.1	General practice surgeries for the recruitment of young people with asthma and their parents	147
3.1.1	Response rates of general practice surgeries	147
3.1.2	Non-participating general practice surgeries	149
3.2	Sample characteristics for the asthma part of the study	150
3.2.1	Recruitment of young people with asthma and their parents	150
3.2.2	Characteristics of young people with asthma and their parents	150
3.2.3	Non-participants	152
3.3	General practice surgeries for the recruitment of young people with diabetes and their parents	154
3.3.1	Response rates of general practice surgeries	154
3.3.2	Non-participating general practice surgeries	156
3.4	Sample characteristics for the diabetes part of the study	157
3.4.1	Recruitment of young people with diabetes and their parents	157
3.4.2	Characteristics of young people with diabetes and their parents	157
3.4.3	Non-participants	159

Chapter 4 - Experiences of young people with asthma and their parents

4.1	Introduction	162
4.2	Conduct of interviews	163
4.3	Roles of asthma management within the home	164

4.3.1	Ensuring continuous supplies of medication and collecting prescriptions from the pharmacy	168
4.3.2	Reminding/remembering to take medication	169
4.3.3	Administration of medication	171
4.3.4	Deciding on medication, according to need	174
4.3.5	Overall responsibility for asthma medication	175
4.4	Partnerships between young people and their parents in the management of asthma	177
4.4.1	Types of partnerships between young people and their parents in the management of asthma	177
4.4.2	Conflict in partnerships between young people and their parents	179
4.4.3	Partnerships in relation to the management of triggers of the young person's asthma	181
4.4.4	Restrictions on parents and young people due to the young persons' asthma	182
4.4.5	Partnerships of young people who lived in more than one family unit	183
4.5	Changes in partnerships	185
4.6	Management of asthma in schools	191
4.6.1	Young people who did not take asthma medication to school	191
4.6.2	Storage of medication and school policies relating to medication	191
4.6.3	Problems with the management of asthma in schools	193
4.7	The roles of health care professionals in the care for young people with asthma	196
4.7.1	Contact with health care professionals	197

4.7.2	The role of the asthma nurse in the care of young people with asthma	199
4.7.3	The roles of the general medical practitioner in the care of young people with asthma	203
4.7.4	The roles of the pharmacist in the care of young people with asthma	206
4.8	Information needs and information used by young people with asthma and their parents	206
4.8.1	Information needs and information used by parents	207
4.8.2	Information needs and information used by young people	209
	Summary of chapter four	211
 Chapter 5 - Experiences of young people with diabetes and their parents		
5.1	Introduction	215
5.2	Conduct of interviews	216
5.3	Roles of diabetes management within the home	218
5.3.1	Ensuring continuous supplies of medication and collecting prescriptions from the pharmacy	222
5.3.2	Remembering/reminding to monitor blood glucose levels	223
5.3.3	Monitoring of blood glucose levels	224
5.3.4	Remembering/reminding to administer injections of insulin	226
5.3.5	The administration of injections of insulin	228
5.3.6	Overall responsibility for diabetes medication	229
5.4	Partnerships between young people and their parents in the management of diabetes	231

Contents

5.4.1	Types of partnership between young people and their parents in the management of diabetes	231
5.4.2	Conflict in partnerships between young people and their parents	233
5.4.3	Partnerships in the management of the young person's diet	236
5.4.4	Restrictions on parents and young people due to the young person's diabetes	239
5.4.5	Young people who lived in more than one family unit	241
5.4.6	Information provision within partnerships regarding the serious nature of diabetes	243
5.5	Changes in partnerships	246
5.6	Management of diabetes in schools	250
5.6.1	Storage of items relating to diabetes and school policies regarding medication	250
5.6.2	Problems with the management of diabetes in schools	252
5.7	The roles of health care professionals in the care for young people with diabetes	255
5.7.1	Contact with health care professionals	256
5.7.2	The roles of the diabetes nurse in the care for young people with diabetes	257
5.7.3	The roles of the consultant in the care for young people with diabetes	261
5.7.4	The roles of the pharmacist in the care for young people with diabetes	264
5.7.5	Young people and parents who had changed hospital	264
5.8	Information needs and information used by young people with diabetes and their parents	265

5.8.1	Information needs and information used by parents	266
5.8.2	Information needs and information used by young people	267
	Summary of chapter five	269
Chapter 6 - Quality of life		
6.1	Administration of PedsQL asthma and diabetes modules	274
6.2	Validity of the PedsQL asthma and diabetes modules	275
6.3	Missing data from the PedsQL asthma and diabetes modules	276
6.4	Reliability of the PedsQL asthma and diabetes modules	283
6.5	Responses of young people to the PedsQL asthma module	285
6.6	Parent proxy responses to the PedsQL asthma module	289
6.7	Responses of young people to the PedsQL diabetes module	293
6.8	Parent proxy responses to the PedsQL diabetes module	297
6.9	Comparison of quality of life as reported by young people and parent proxy respondents	301
6.9.1	Quality of life of young people with asthma	302
6.9.2	Quality of life of young people with diabetes	307
	Summary of chapter six	312
	Summary of results chapters	313
Chapter 7 - Discussion		
7.1	Methodological issues related to the study	317
7.1.1	Recruitment through general practice surgeries	317
7.1.2	Sample characteristics of study participants	319

7.1.3	Characteristics of young people and parents who declined to take part in the research	321
7.1.4	Interviews	321
7.1.5	Young people as research participants	323
7.1.6	Contribution of this thesis to research involving young people	326
7.2	Discussion of research findings in relation to previous work	326
7.2.1	Roles of young people and their parents in the management of the young person's asthma or diabetes	327
7.2.1.1	The role of parents in the management of asthma and diabetes	327
7.2.1.2	The role of young people in the management of asthma and diabetes	328
7.2.2	Partnerships between young people and their parents	329
7.2.2.1	Shared responsibility of condition management	329
7.2.2.2	Conflict within partnerships	330
7.2.2.3	Parental strain of caring for young person with asthma or diabetes	330
7.2.2.4	Changes in partnerships between young people and their parents over time	332
7.2.2.5	Factors influencing transfer of control from parent to young person	334
7.2.2.6	Issues of condition management for young people who live in more than one family unit	337
7.2.3	Association between the age of the young person and length of time since diagnosis of asthma or diabetes and roles within the partnership	338
7.2.4	Management of asthma and diabetes in schools	340
7.2.4.1	Access to medication in school	340
7.2.4.2	School policies regarding medication	341

7.2.4.3	Parents' concerns regarding condition management in school	342
7.2.4.4	Young people's concerns regarding condition management in school	343
7.2.5	Health care professionals	344
7.2.5.1	Contact with health care professionals	344
7.2.5.2	The role of health care professionals	344
7.2.5.3	The role of young people in consultations with health care professionals	345
7.2.6	Information needed and used by young people with asthma and diabetes and their parents	348
7.2.7	The development of the use of PedsQL asthma and diabetes modules	349
7.2.8	Differences in research findings between the two conditions	355
7.3	Implications of research findings for health care professionals and the delivery of health care services	357
7.3.1	Health care professionals understanding partnerships between young people and parents in the management of asthma and diabetes	357
7.3.2	The need for health care professionals to engage young people in consultations	358
7.3.3	Health care professionals understanding the transfer of responsibility for asthma and diabetes from parents to young people	358
7.3.4	Health care professionals appropriately addressing the information needs of young people	358
7.3.5	Health care professionals providing support in relation to problems of young people whilst at school	359
7.3.6	Current policy in light of the findings of this thesis	359

Contents

7.4 Contribution to knowledge of the research presented in this thesis	361
References	364

List of Appendices

Appendix A	Letter sent to the National Asthma Campaign and British Lung Foundation requesting details of support groups	382
Appendix B	Letter sent to asthma support groups requesting their involvement in the preliminary work	383
Appendix C	Letter sent to Diabetes UK requesting details of support groups	384
Appendix D	Letter sent to diabetes support groups requesting their involvement in the preliminary work	385
Appendix E	Consent form for parents of young people with asthma	386
Appendix F	Consent form for young people with asthma	387
Appendix G	Consent form for parents of young people with diabetes	388
Appendix H	Consent form for young people with diabetes	389
Appendix I	Interview schedule for use with parents of young people with asthma	390
Appendix J	Interview schedule for use with parents of young people with diabetes	399
Appendix K	Topic guide for interview with young people with asthma	408
Appendix L	Topic guide for interview with young people with diabetes	411
Appendix M	PedsQL asthma module to be completed by parent proxy respondent	414
Appendix N	PedsQL diabetes module to be completed by parent proxy respondent	416
Appendix O	PedsQL asthma module to be completed by young person	418
Appendix P	PedsQL diabetes module to be completed by young person	420

Contents

Appendix Q	Letter of invitation to participate in the asthma part of the study sent to the Practice Manager or equivalent at the GP surgery	422
Appendix R	Letter of invitation to participate in the diabetes part of the study sent to the Practice Manager or equivalent at the GP surgery	423
Appendix S	Leaflet for young people with asthma	424
Appendix T	Leaflet for the parents of young people with asthma	426
Appendix U	Leaflet for young people with diabetes	428
Appendix V	Leaflet for the parents of young people with diabetes	430
Appendix W	Letter of invitation to participate in the asthma part of the study, with attached reply slip, sent to the parents of young people with asthma	432
Appendix X	Letter of invitation to participate in the diabetes part of the study, with attached reply slip, sent to the parents of young people with diabetes	434

List of Tables

List of Tables

Table 3.1	Response of general practice surgeries for the asthma part of the study	148
Table 3.2	Reasons from general practice surgeries for non-participation in the asthma part of the study	149
Table 3.3	Characteristics of young people with asthma interviewed	150
Table 3.4	Characteristics of parents interviewed, as reported by the parents of young people with asthma	151
Table 3.5	Medication used by young people with asthma, as reported by parents	152
Table 3.6	Reasons for non-participation identified by parents of young people with asthma	153
Table 3.7	Characteristics of young people with asthma who returned reply slips and declined to participate in the research	154
Table 3.8	Response of general practice surgeries for the diabetes part of the study	155
Table 3.9	Reasons from general practice surgeries for non-participation in the diabetes part of the study	156
Table 3.10	Characteristics of young people with diabetes interviewed	158
Table 3.11	Characteristics of parents interviewed, as reported by the parents of young people with diabetes	158
Table 3.12	Characteristics of young people with diabetes who returned reply slips and declined to participate in the research	159
Table 4.1	Roles of parents and young people in the management of asthma, as reported by parents	166
Table 4.2	Roles of young people and parents in the management of asthma, as reported by young people	167

List of Tables

Table 4.3	Overall responsibility for asthma medication, as reported by parents	175
Table 4.4	Conflict within partnerships between young people and their parents, as reported by parents	179
Table 4.5	Storage of asthma medication in schools as reported by young people	192
Table 4.6	Policies regarding medication in school as reported by parents	192
Table 4.7	Health care professionals most often seen by young people regarding their asthma, as reported by parents	198
Table 4.8	Length of time since young person saw a health care professional in relation to their asthma, as reported by parents	198
Table 5.1	Roles of parents and young people in the management of diabetes, as reported by parents	220
Table 5.2	Roles of parents and young people in the management of diabetes, as reported by young people	221
Table 5.3	Overall responsibility for diabetes medication, as reported by parents	229
Table 5.4	Conflict within partnerships between young people and their parents, as reported by parents	234
Table 5.5	Storage of items relating to diabetes in school, as reported by young people	251
Table 5.6	Policies regarding medication in school, as reported by parents	252
Table 5.7	Frequency of visits to the diabetes clinic by young people, as reported by parents	256

List of Tables

Table 6.1	Missing data on a per respondent basis from the asthma PedsQL module completed by young people and parent proxy respondents	276
Table 6.2	Missing data on a per respondent basis from the diabetes PedsQL module completed by young people and parent proxy respondents	277
Table 6.3	Missing data from the asthma PedsQL modules completed by young people and parents	278
Table 6.4	Missing data from the diabetes PedsQL modules completed by young people and parents	281
Table 6.5	Cronbach's alpha statistic for asthma PedsQL module	283
Table 6.6	Cronbach's alpha statistic for diabetes PedsQL module	284
Table 6.7	Responses of young people to the PedsQL asthma module	286
Table 6.8	Parent proxy responses to the PedsQL asthma module	290
Table 6.9	Responses of young people to the PedsQL diabetes module	294
Table 6.10	Parent proxy responses to the PedsQL diabetes module	298
Table 6.11	Mean scores from young person and parent proxy responses to the PedsQL asthma module	303
Table 6.12	Mean scores from young person and parent proxy responses to the PedsQL diabetes module	307

List of Figures

List of Figures

Figure 1.1	Theoretical model for parent-child transfer of asthma responsibility (Burford, 2004)	47
Figure 4.1	Roles of the asthma nurse in consultations, as reported by parents	200
Figure 4.2	Roles of the asthma nurse in consultations, as reported by young people	201
Figure 4.3	Roles of the general medical practitioner in consultations, as reported by parents	203
Figure 4.4	Roles of the general medical practitioner in consultations, as reported by young people	205
Figure 4.5	Issues identified by parents about which they would like more information	208
Figure 5.1	Roles of the diabetes nurse in consultations, as reported by parents	257
Figure 5.2	Roles of the diabetes nurse in consultations, as reported by young people	259
Figure 5.3	Roles of the consultant in the consultation, as reported by parents	261
Figure 5.4	Roles of the consultant in the consultation, as reported by young people	262
Figure 5.5	Information sources used by the parents of young people with diabetes	266
Figure 5.6	Issues identified by parents on which they would like more information	267
Figure 5.7	Information sources used by young people with diabetes	268
Figure 7.1	Adaptation of Burford's (2004) theoretical transfer model	333
Figure 7.2	Model to show factors influencing transfer of responsibility for asthma or diabetes from parent to the young person	335

List of Abbreviations

BTS - British Thoracic Society

CF - Cystic Fibrosis

CHQ-CF87 - Child Health Questionnaire

DFRQ - Diabetes Family Responsibility Questionnaire

DQOLY - Diabetes Quality of Life modified for Youths

GP - General medical practitioner

HR-QoL - Health-Related Quality of Life

ISAAC - International Study of Asthma Allergies in Childhood

NHS - National Health Service

NSF - National Service Framework

NUD*IST - Non-numerical Unstructured Data Indexing, Searching and Theory building

PAQOL - Pediatric Asthma Quality of Life

PedsQL - Pediatric Quality of Life

QoL - Quality of Life

SEIQoL-DW - Schedule for the Evaluation of Individual Quality of Life-Direct Weight

SPSS - Statistical Package for the Social Sciences

STD - Sexually Transmitted Disease

UPA - Underprivileged Area Score

USA - United States of America

Acknowledgements

Firstly I would like to thank my supervisors Dr Sally-Anne Francis and Dr Felicity Smith for their invaluable guidance and encouragement throughout this thesis.

I am thankful to the general practice surgeries who assisted with the recruitment of interviewees and to all those who participated in the preliminary and pilot work.

Enormous thanks must go to all one hundred and thirty-eight young people and parents who were interviewed, for welcoming me into their homes and speaking so openly about their experiences. Without them this thesis would not have been possible.

I am grateful to the School of Pharmacy, University of London and the Royal College of General Practitioners for funding this research.

Thanks go to all my friends for bearing with me and encouraging me throughout this thesis. Special thanks go to Claire Bateson for getting me through this and keeping me smiling on the way; to Nadeen Jibry for invaluable transatlantic support and advice; to Jenni Moss for her constant interest and concern for my well-being and to Katherine Newbould whose sisterly chats have kept me going.

My greatest thanks must go to the three incredibly special people without whom I simply could not have got this far; Brian Newbould, Janet Newbould and Ciaran Taylor. To my Mum and Dad, Janet and Brian, for their overwhelming emotional, practical and financial support over the last five years and most especially the last few months. Finally to Ciaran Taylor for being there for me every step of the way. For his consideration, patience, night walks and for putting life on hold while I completed this thesis. Our life together begins here ...

Chapter 1 - Introduction

Chapter 1 Introduction

The opening section of this chapter provides an introduction to the subject of this thesis and the definition of key terms used. The following sections of chapter one comprise a background literature review. Section 1.2 presents literature relating to young people's experiences of chronic conditions. Section 1.3 relates to research regarding parents' experiences of a young person's chronic condition. Section 1.4 examines literature related to both young people and their parents experiences of chronic conditions. Research relating to partnerships between spouses in the management of diabetes is outlined in section 1.5. Section 1.6 describes research regarding the management of chronic conditions in schools. In section 1.7 research concerning health care professionals, young people and parents is examined. Section 1.8 presents literature regarding information used and the desire for information by young people and their parents. Section 1.9 documents the measurement of quality of life in children with chronic conditions. Government policies in relation to children, asthma and diabetes are documented in section 1.10. The aims and objectives of the main study are documented in section 1.11. The chapter concludes with a summary.

1.1 Introduction

This thesis concerns partnerships between young people and their parents in the management of asthma and diabetes. Section 1.1 provides an overview of the study presented in this thesis, rationale for this research and definition of key terms.

1.1.1 Overview of this thesis

The thesis examines in depth the experiences of young people and their parents in the management of asthma and diabetes, from the perspective of both young people and their parents. The aims and objectives of this research evolved from a review of the current literature and Government policy related to young people and chronic

conditions. This review and the aims and objectives of the thesis are documented in chapter one of this thesis. Chapter two details the methods used in this research. A qualitative approach was taken and in depth interviews were conducted with young people and their parents. A quantitative research tool to measure the quality of life of young people with asthma and diabetes was also tested. Chapter three reports the sample characteristics and response rates of the study sample. The results of qualitative interviews with young people with asthma and their parents are described in chapter four. Chapter five documents the results of qualitative interviews with young people with diabetes and their parents. Chapter six presents the testing of the quality of life tool with both young people with asthma and diabetes, and their parents. The final chapter of this thesis, chapter seven discusses the implications of the findings of this research.

1.1.2 Rationale for the research presented in this thesis

Asthma and diabetes are common conditions amongst young people. It is estimated that in the UK one in eight children have asthma (National Asthma Campaign, 2001) and between one and two in every 1000 children have diabetes (Diabetes UK, 2002). Young people with these chronic conditions take frequent medication and are required to manage their condition on a daily basis; being aware of triggers to the condition and wheezing in the case of asthma and monitoring food intake and blood glucose levels if the young person has diabetes.

Although these young people visit health care professionals to monitor their condition little is known about their experience of managing their condition or the role of parents in the management of asthma or diabetes. For health care professionals to provide the necessary assistance and support to young people and their parents it is vital that they understand the day to day experience of living with these conditions. The National Service Framework for Children, Young People and Maternity Services (Department of Health, 2004) has also highlighted the importance of health care professionals

supporting a young person's family in their care. Health care professionals, who work with both young people and their parents, need to understand the role of each party in the management of a young person's asthma or diabetes, in order to appropriately provide help and support. This thesis focuses upon the nature of partnerships between young people and their parents in the management of these conditions and the shared responsibility between them. Also examined are how partnerships between young people and parents may change with the increasing age of the young person or number of years since diagnosis. In-depth interviews were used to gain an in-depth knowledge of the experiences of young people with asthma and diabetes and those of their parents.

With the time and resources available to health care professionals it is not always possible to gain an in-depth insight into a young person's condition from a single consultation. Therefore it is necessary to develop simple, effective tools which can determine the extent to which a young person's condition impacts upon their life. A frequent measurement of the impact of a disease on an individual's life is the measurement of quality of life (see section 1.9 for more detail regarding quality of life). Although used extensively with adults, as yet the measurement of quality of life in young people is in its infancy. This thesis aimed to validate the use of a quality of life measure for young people with asthma and diabetes.

The specific aims and objectives of this research were developed from a review of existing literature, Government policy and pilot work and are documented in the final section of this chapter (see section 1.11).

1.1.3 Definition of terms used throughout this thesis

Throughout this thesis a number of specific terms are referred to and section 1.1.3 defines each of these.

1.1.3.1 Partnership

The term partnership is used to describe different styles of cooperation, sharing of responsibilities and discussion regarding the management of the condition. The use of the term does not necessarily indicate harmony and might include young people and parents working together and experiencing conflict within the partnership.

1.1.3.2 Young people

The term young people has been used to describe those children, aged eight to fifteen years, interviewed in this research. Use of the term was selected as it was felt to be more respectful to participants than the terms 'child', 'teenager' or 'adolescent'.

1.1.3.3 Parent

Parents and guardians were invited to take part in this research, as all respondents were parents of young people the term parent has been used throughout this thesis.

1.1.3.4 Management

The term management has been used to describe all aspects of managing the condition, this encompasses the management of medication for the condition but also of lifestyle factors such as diet or exercise.

1.1.3.5 Responsibility

Responsibility refers to the person who is in charge of ensuring specific tasks of condition management are performed, for example ensuring continuous supplies of medication or administering injections of insulin. The following sections of this chapter review previous research relevant to the subject of this thesis.

1.2 Young people's experiences of a chronic condition

Section 1.2 concerns research which has focused exclusively upon the experiences of young people with chronic conditions and has not taken into account the views of parents.

Research by Gabe, Bury and Ramsay (2002) examined the social impact on a young person of managing a chronic condition. Young people aged 11 to 16 years with asthma were recruited from twelve GP surgeries. Screening of young people to monitor the severity of their asthma was conducted with the use of the International Study of Asthma Allergies in Childhood (ISAAC) questionnaire, sent to young people and parents with an invitation to participate in the research. In-depth interviews (n=55) were conducted with young people with moderate to severe asthma, as determined with use of the ISAAC questionnaire. Young people were interviewed regarding their experiences of living with asthma. They described how the symptoms of asthma affected their lives both at school and when at home. Within the school environment some young people experienced problems taking part in sports. Other young people felt that asthma was so common amongst peers that it was an accepted and normal part of school life. Within the home young people described their avoidance of triggers to the condition, how they managed the symptoms of their asthma and described their use of different types of medication. Young people frequently mentioned peers, parents and teachers as providing them with assistance in the management of the condition. Gabe, Bury and Ramsay (2002) noted the contrast between young people's descriptions of management of asthma at home, which appeared to give young people little anxiety, and their descriptions of asthma at school in which they reported anxiety and distress. The large sample of young people (n=55) interviewed and the in-depth approach are strengths of this research. The use of robust methodological and sampling procedures gives confidence in the reliability and generalizability of findings to other young people with moderate or severe asthma.

The experiences of young people with asthma have also been explored by Pradel, Hartzema and Bush (2001) who examined their knowledge, perceptions and autonomy in the management of asthma. Purposive sampling was used to recruit children (aged 7 or 12 years) from two asthma clinics in an American hospital. Pradel, Hartzema and Bush (2001) noted that subjects were selected as they were identified as 'information rich cases' which would best address the issues of relevance to the research. Inclusion criteria for children (n=32) were moderate or severe asthma defined as: children having daily symptoms of asthma, at least one symptom a week during nighttime and using daily medication. Interviews were conducted in children's homes, visited on two occasions and two types of interviews were conducted. At the first visit a drawing interview took place, this was an unstructured interview in which the child was asked to draw a picture of the last time he/she was sick. The child was not directed to focus on an asthma episode, if the child did not draw an episode associated with their asthma they were asked for a drawing of an asthma episode at the second visit. The researcher interviewed the child as they drew the picture with use of open questions, interviews were audio-recorded. If the child had drawn an asthma episode on the first visit, at the second visit they were asked to draw a picture of a non-asthma episode. The 'asthma figurative process' interview took place at the second visit of the researcher. Children were asked to describe to the researcher the process of an asthma attack, the symptoms they experienced and what was done before and during an asthma attack. To aid discussion the child was presented with a piece of paper on which was a horizontal line, a point on the line represented the time at which the child had an asthma attack. The researcher then discussed with the child going back from the asthma attack point in time to before the onset of symptoms, the researcher then went forward to ask the child to explain what action was taken when the child experienced symptoms and had an asthma attack.

Analysis of the drawing interview (n=31; 1 interview was not audio-recorded) was conducted from the interview recordings, transcribed verbatim. Content analysis of transcripts was conducted to extract pre-defined themes. Children's comments on a

specific theme were then compared by age group. The asthma figurative process interview (n=30; 2 respondents withdrew) was coded and the frequency of children's answers about symptoms and asthma management recorded and compared by age group. Triangulation was used and the findings of both interviews compared using a qualitative approach. From analysis of the drawing interview Pradel, Hartzema and Bush (2001) noted that the majority of children (55%) attributed the cause of an asthma attack as physical activity. Other triggers identified by children included outdoor temperature, changes in weather, pets, dust mites, pollens, dust, smoke and being unwell. Children did not appear familiar with the medication needed when they were having an asthma attack, only six children (n=31) specifically mentioned the medication which they needed to take when having an asthma attack. Only one child (aged 12 years) made a distinction between the use of preventer and reliever medication. Where children did refer to medication they tended to do so with slang terms (such as 'puffer') or with reference to the colour or shape of the medication. From the figurative process interview, younger children (aged 7 years) did not recognise early signs of deterioration of their condition, as older children (aged 12 years) did. Several (66%) older children expressed concern that their asthma medication did not always work. Results from both interview data indicated that most younger children (aged 7 years) reported their parents made the decision for them to use asthma medication during an asthma attack. Older children (aged 12 years) themselves often made the decision to use medication during an attack. The role of parents, particularly mothers, in the management of asthma was frequently reported by both age groups. Pradel, Hartzema and Bush (2001) concluded that the different age groups demonstrated different behaviours in response to an asthma episode and as children matured they became more active participants in the treatment of their asthma. A strength of this research is use of young people as respondents and the in-depth view obtained of the experiences of young people. A limitation of this study is the use of purposive sampling, findings cannot be generalized to other young people with asthma.

Research into young people with thalassaemia major (Atkin and Ahmad, 2000) provided an in-depth view of the management of a severe condition within the family unit. Semi-structured interviews were conducted with young people (n=25) aged 10 to 19 years. Young people were identified through health care professional records in six geographical areas. In five areas all known cases of thalassaemia were identified and in one area random sampling was used to establish the required number of young people. Young people were interviewed twice over a six-month period. This work provided an account of how chelation therapy, treatment for thalassaemia major, was managed by young people within the context of the family situation. Control of the condition was negotiated between carer and young person. The research identified reasons for non-compliance with chelation therapy amongst young people, despite their parents involvement in their treatment. Atkin and Ahmad (2000) demonstrated the importance of the role of the family unit in the management of the condition, in monitoring the health of the young person and assisting with the technological equipment needed to treat the condition while the young person was asleep. The in-depth nature of this work, use of two interviews and comprehensive sampling method provides confidence in the application of research findings beyond the study sample.

Kyngäs (2004) examined the support network of adolescents with a chronic disease. Adolescents (aged 13 to 17 years) with a chronic disease (asthma, epilepsy, juvenile rheumatoid arthritis or insulin-dependent diabetes) were identified from the Finnish Social Insurance register, randomly selected and sent a questionnaire about their condition and support from family, friends and health care professionals. The findings of the questionnaire are not reported in this paper, however it included an invitation for the adolescent to take part in a qualitative interview. Of the 1061 adolescents that returned the questionnaire 264 agreed to be interviewed, of whom 40 were randomly selected. The interviews explored the adolescents everyday life and experiences of a chronic disease and their support network. Data were analysed through the use of content analysis, from the interviews six main categories of support network were identified. As found in the work by Atkin and Ahmad (2000), family were reported by

adolescents as the most important part of their support network. Kyngäs (2004) noted that adolescents referred to parents in two distinct ways. The first group described open discussions with parents about their disease and other health issues and perceived their parents as having a natural interest in their well being and how they coped with daily life. In the second group adolescents described their parents as focussing on asking them questions about their condition and making sure that they had taken care of themselves. Adolescents in the second group perceived their parents were not interested in their disease and answered questions with what they thought their parents would want to hear, rather than the truth. This group of adolescents saw parents as nevertheless important members of their support network as they provided financial support and a home in which the adolescent lived. Other members of their support network identified by adolescents were peers, both those with or without the chronic disease, health care professionals, teachers, technology (such as chat rooms on the internet) and pets. Use of in-depth interviews with adolescents provides a comprehensive picture of their support networks. Use of a self-selecting sample limits the generalizability of research findings.

Much research which has relied solely on young people as participants has examined young people's compliance with medication. The literature reviewed frequently commented that health care professionals viewed adolescence as a time during which the management of chronic conditions was problematic. One reason for poor control of chronic conditions at this time has been attributed to young people's poor compliance with medication. Jonasson et al (1999) examined compliance in children (n=63) aged 7 to 16 years with mild asthma. Findings indicated that children aged younger than nine years demonstrated significantly better compliance with medication than those aged 10 to 16 years. Coutts, Gibson and Paton (1992) monitored compliance in children (n=14), aged 9 to 14 years, with use of a device attached to their inhaler, young people were unaware of being monitored. Under use of asthma medication was reported in 55% of study days. Poor compliance was linked with prescribed frequency of medication; children with a twice daily regimen achieved 71% compliance compared to 18% in children with a four times daily regimen. Studies of young people with diabetes

have also reported poor compliance. Morris et al (1997) assessed the association between prescribed insulin and the amount dispensed from pharmacies in participants (n=89) aged younger than 30 years (mean age 16 years). Sixty-four percent of participants had an adherence index suggestive of a missed dose of insulin and 28% of respondents obtained less insulin than their prescribed dose during the study period, indicating poor compliance. Research by Kyngäs (2000), conducted in Finland, explored compliance from the perspective of young people. Questionnaires were administered to adolescents (aged 13 to 17 years) with five chronic conditions, including asthma and diabetes. Sixty percent of adolescents placed themselves in the category of satisfactory compliance, 23% indicated that they fully complied with their health regimen and 17% reported poor compliance. Although studies have indicated poor compliance amongst young people, little research has explored in detail the management of chronic conditions by young people and their parents.

Although discussion of the concept of compliance was widely addressed in the literature in reference to young people, the concept of concordance was largely absent. Sanz (2003) highlighted considerations that need to be addressed in relation to concordance with young people; the involvement of the parent in the process, the extent to which young people should be involved in decisions about their care, whether health care professionals should focus on the provision of information for parents or young people, at what age should children be addressed directly about their illness and what should be done when parents' and young people's views do not coincide.

Within the study of adults with chronic conditions much attention has been paid to the affect of a chronic condition on a person's life and self-identity. Several models of chronic illness have been developed which have outlined how the experience of chronic illness disrupts the lives of adult sufferers. As a result of their chronic condition adults have to make adaptations to their lives to accommodate the limitations imposed by their chronic condition or its treatment. The onset of a chronic condition in adulthood has also been shown to impact not only on the physical well-being of the individual, but also

to affect their self-image and their sense of self-worth (Charmaz, 1983). Within the study of children with chronic conditions reference to models of chronic illness have been absent. There has been limited examination of the impact of a chronic condition on the self-identity of young people, although suggestions of a possible heightened awareness of self have led to concern of an increased prevalence of eating disorders amongst some young people.

Research by Jones et al (2000) explored the prevalence of eating disorders in adolescents with diabetes. Adolescents (n=356) aged 12 to 19 years were selected from diabetes clinics and schools in three cities in Canada. The sample included adolescent females with type 1 diabetes and those without. The response rate was 84% from the sample of adolescents with diabetes and 74% from other adolescents. Participants completed a self-report package, which included items to identify eating disorders. The study's findings identified that adolescents with diabetes were 2.4 times more likely than their peers to have an eating disorder. The author did not comment on the completion of the measures in different environments, diabetes clinic or school. However the large number of adolescents surveyed (n=356) and wide area from which respondents were recruited indicates generalizability of the findings.

In summary, section 1.2 has reviewed studies which have examined the experiences of chronic conditions from solely the perspective of young people. Research by Atkin and Ahmad (2000), Pradel, Hartzema and Bush (2001) and Kyngäs (2004) identified the important role of parents in their support of young people with a chronic condition. However, no research has examined the nature of this help and support.

1.3 Parents' experiences of a young person's chronic condition

Section 1.3 presents literature concerned with the role of parents in the management of their son's/daughter's chronic condition and considers research which has examined exclusively parents' views and not those of young people.

Much research with parents of young people with chronic conditions has reported the burden of caring for a young person with a chronic condition on the parent. Rydström et al (2004) examined the impact of caring for a young person with a chronic condition on the parent. Rydström et al's (2004) research, conducted in Sweden, examined the views of mothers (n=17) of children aged 6 to 16 years with moderate to severe asthma, two mothers were interviewed twice. Mothers were selected for participation in the research by an allergy nurse in a hospital. In depth interviews were conducted to examine the impact of dealing with a chronically ill child on the family and the well-being of family members. A constant comparative method (Strauss and Corbin, 1990) guided analysis. Mothers reported being accessible for the child with asthma, as the unpredictable nature of the condition meant they had to be constantly available. As a result the mother was less available for other family members, a factor which mothers felt other family members did not understand. In outlining the methodological approach to this research the author reported that two parents were interviewed twice but did not explain the reasons for this or how such data were dealt with. Lack of information regarding this point and the use of selective sampling limits the generalizability of the study findings.

Research conducted in Canada by Azar and Solomon (2001) examined the ways of coping adopted by parents (n=60) of children aged 8 to 11 years with diabetes. Parents were recruited through the Juvenile Diabetic Foundation and adverts in local newspapers and children's hospitals. During a home interview parents were administered with the Ways of Coping Questionnaire to assess the coping strategies of parents of young people with diabetes. The coping strategies of mothers (n=30) and fathers (n=30) were compared. Mothers were found to be more involved in the management of their child's diabetes, with fathers distancing themselves from the child and their condition. In this comprehensive study the large sample size (n=60) was a positive feature, yet the use of a self selecting sample indicates respondents had a particular interest in the condition, questioning the application of findings to a wider population.

Coping in mothers and fathers of children with diabetes in the UK has been examined by Eiser et al (1993). Questionnaires were sent to 107 parents (62 mothers and 45 fathers) to determine their confidence in coping with their child's diabetes. Parents were recruited through an advert in a newsletter of the British Diabetic Association, parents were requested to contact the researcher if they were willing to participate in the research. One hundred and eighty-four parents contacted the researcher and were sent questionnaires, 107 questionnaires were returned. Questionnaires obtained demographic data and contained four sections related to aspects of parental coping. The first set of questions focused on the parents confidence in managing their child and their illness (9 items rated on a five point scale, 1=not at all confident, 5=very confident indeed), the second section concerned parents perception of the extent to which the child's diabetes affected their school achievement, sports, ability to go out alone, age appropriate independence, relationships with friends and teachers and self care (rated on a five point scale 1=not at all, 5=very much indeed). The third section contained 33 items (adapted by the authors from McCubbin et al, 1983) to examine the extent to which parents found coping with an illness was helped by three factors; family, social support and medical care. The final scale contained 36 items from the parent behaviour inventory, created by the University of Iowa, to establish parent behaviours in relation to involvement, limit setting, responsiveness, reasoning guidance and intimacy. Children completed two measures, an adaptation of the diabetes self-efficacy scale (Grossman, Brink and Hauser, 1987) altered by the authors (22 items, responses on a 5 point scale, 1=I am very sure I cannot do that, 5= I am very sure I can do that') and the health locus of control measure, 30 items rated 'true', 'false' or 'don't know'. Children's measures were not analysed in relation to the child's experience of diabetes, but rather in relation to the parents measures of coping.

Parents who returned the questionnaire had children aged 9 to 15 years. For mothers, the longer time since diagnosis the less helpful they reported medical support to be. In fathers, the longer time since diagnosis the less confident they perceived themselves to be in managing their child's diabetes. Mothers who identified themselves as more

confident rated themselves as less warm and intimate towards their child, the converse was true with fathers. Those fathers who indicated more confidence in the questionnaire reported greater intimacy with their child. Differences in coping between mothers and fathers, who indicated from their questionnaire they were confident with managing their child and their diabetes were also identified. Confident mothers indicated that support from the family was important and coping by doing things (autonomy) or gaining medical knowledge was less helpful. In contrast to this, confident fathers rated medical knowledge as important but found support from other family members as less helpful. Eiser et al (1993) hypothesised that parents' confidence would be related to children's scores of efficacy in diabetes management and locus of control, as confident parents would provide good role models. Contrary to the expectations of the author, no association was found between parent's confidence and children's efficacy beliefs. In cases where parents responses indicated that they rated family coping as helpful the child had a lower self-efficacy score, the less they were able to perform diabetes tasks. Mothers who rated medical knowledge as more helpful had children with higher self-efficacy scores. Eiser et al (1993) concluded that parent's attitudes towards diabetes and coping abilities might affect their child's locus of control beliefs and diabetes efficacy. The large study sample is a strength of this research, as is the inclusion of measures completed by children to examine the influence of parental coping on the beliefs and behaviours of children. Limitations of this research include the self-selecting sample which limits the application of findings beyond the study sample.

Ganong, Doty and Gayer (2003) focused upon the experiences of coping with a child with cystic fibrosis (CF) by divorced mothers. In-depth interviews were conducted in America by registered nurses with expertise in CF. Mothers were recruited to take part in this research through a non randomised method with use of medical records and a telephone call made to them by the researcher. Divorced mothers (n=13), some of whom had remarried or were cohabiting at the time of interview, with a child with CF (aged 5 to 18 years) were interviewed within the clinic setting. Mothers reported a close bond with their child with CF and maintained constant vigilance in the treatment of their

child's condition. Despite enjoying this closeness, mothers also reported feeling overwhelmed by their sole responsibility for their child's condition, financial issues and managing the household without another adult. All mothers felt that their son's/daughter's diagnosis of CF had directly led to, or contributed to, the break up of their marriage. Ganong, Doty and Gayer (2003) noted that the breakdown in the parents' relationship further distanced the father from the child with CF and led to an even greater closeness between the mother and her child. This research also identified problems when fathers re-marry and a further family environment is formed. Mothers described going to great lengths to ensure their ex-spouse's new partner understood the severity of their child's condition. This research provided a comprehensive insight into the views of mothers who were divorced and their experience of having a son/daughter with CF. The length of interviews, two to two and a half hours, an in-depth approach to data collection, was a strength of this research. The use of three researchers and a constant comparison method in the analysis of data provided confidence in the management and analysis of data. The author does not comment on the nurse conducting the interviews, or state if the nurse was involved in the child's care. Use of a non-randomised method to sample parents suggests limits to the application of these findings to a wider group.

Other studies have focused upon parent's experiences of managing their son's/daughter's chronic condition. Research by Østergaard (1998) conducted in Denmark, involved qualitative interviews with parents (n=20) of thirty children with asthma aged 2 to 15 years, recruited from an outpatient asthma clinic. Data were collected with the use of semi-structured interviews which aimed to describe parent's perspectives of their child's asthma. The majority of parents reported being able to recognise patterns of asthma in their child and were alert to signs of worsening of their child's condition. Parents felt that they could understand and monitor their child's asthma better than the doctor. Interviews with parents enabled their views to be documented in detail. This study was conducted in Copenhagen where differences in family culture and health care provision suggest caution in generalizing findings to the

UK, although a lack of research conducted in the UK into the experiences of parents of the management of asthma, merits examination of this research in relation to the issues. A lack of sampling strategy information provided by the author was a weakness of this paper which reports parents were selected strategically but gives no further information regarding how this process was conducted.

Research by Peterson-Sweeney et al (2003), conducted in America, also concerned parents' perceptions of their child's asthma. Nurses conducted semi-structured face to face interviews, with use of open questions, with mothers (n=18) of children aged 2 to 18 years. Parents were recruited through the use of purposive sampling in the hospital setting. Eight themes emerged in relation to asthma management; the parent knowing the child best, trial and error in the management of asthma, partnerships with health care professionals, the need for more information, negotiating responsibility, hassles and worries, preferences with medication administration and the benefits of medication outweighing the side effects. Findings indicated that mothers controlled asthma management, the administration of medication, visits to health care professionals and communication with schools and day care centres. In most cases fathers were not involved in the management of the condition. Parents assumed the primary role of initiating or changing asthma medication and reported using trial and error as a way to gauge the correct medication for their son/daughter. A third of parents indicated distrust of the health care professionals involved in their child's care and six parents (n=18) commented that they disagreed with the health care professional regarding medication prescribed for their child. Parents described how the negotiation of responsibility for asthma occurred as children reached school aged years, before this time the parent was in sole control of the treatment regimen. Half of parents reported power struggles with adolescents regarding issues of responsibility. The extensive nature of in-depth interviews covering a broad range of issues gives strength to this research. However, the use of purposive sampling and the small sample size limits the application of these findings to other young people with asthma.

Parental involvement in the management of chronic conditions has been explored in the USA with adolescents with type 1 diabetes. Hanna and Guthrie (2003) recruited 31 parents of adolescents (aged 11 to 18 years) with type 1 diabetes from diabetes clinics. Parents completed four self-administered instruments while waiting for a clinic appointment, or were administered the items over the telephone. The Parental Involvement in Performance of Diabetes Management Checklist was formulated by the authors to include 34 items related to daily diabetes management (such as insulin administration) and non-daily role of diabetes management (such as obtaining supplies of medication). Answers were coded as 'parents involved' (either parent did item or both parent and adolescent did item) or 'not involved' (either adolescent did the role alone or nobody did the role). Items were summed for total diabetes management performance score. The second measure, the Parental Involvement in Decision Making for Diabetes Management Checklist contained the same 34 items as the previous instrument, this time parents were asked who made decisions about each item, rather than who performed the tasks. Again, responses were coded as 'parent involved' or 'not involved', items were summed. Parents also completed the Communication Amount for and Communication Agreement About Diabetes Management Checklist, this again contained the same 34 items, parents were asked to answer 'yes' or 'no' in relation to if they talked with the adolescent about each of the diabetes management tasks, they were then asked to indicate 'yes' or 'no' to whether they and their adolescent agreed about each of the tasks. Finally, parents completed the Parental Support for Diabetes Management Checklist containing the same 34 items. Parents were asked if they tried to help their adolescent with each of the management tasks and were asked to indicate 'yes' or 'no' for each statement, again items were summed. Results indicated that there was a high degree of parental involvement in performance, decision making, communication and support for diabetes management. The mean scores for parental involvement in performance of diabetes management tasks decreased from early to middle to late adolescence. Mean scores for parental involvement in communication, support and decision making in diabetes management decreased from early to mid adolescence and then increased from middle to late adolescence. Use of a Kruskal

Wallis test indicated no significant differences in parental involvement for different stages of adolescence. The research of Hanna and Guthrie (2003) provides an insight into the management of diabetes by parents and young people. The small study sample for a quantitative approach, is a weaknesses of the research.

In summary, section 1.3 has revealed a focus in the literature upon the impact of caring for a young person with a chronic condition on their parent. Few studies, Østergaard (1998) and Peterson-Sweeney et al (2003), have explored parent's views of the management of chronic conditions. Only the research of Hanna and Guthrie (2003) was identified which documented the involvement of parents in tasks associated with the management of their son's/daughter's chronic condition. Only the work of Eiser et al (1993) has examined the roles of parents in the UK.

1.4 Research concerning young people's and parents' experiences of chronic conditions

Section 1.4 examines literature identified from the search processes which referred to the roles of both young people and parents in management of a chronic condition.

Research by Williams (2000a, 2000b) has examined the gendered roles in the management of chronic conditions from the perspectives of both parents and young people. Williams' (2000a, 2000b) research involved interviewing twenty young people with asthma and twenty with diabetes, and their parents. Young people aged 15 to 18 years were included in the research. Participants were recruited through a number of methods hospitals, GP surgeries, snowball sampling and from an advert in a Diabetes UK publication. This review considers two papers from the work of Williams (2000a, 2000b).

Williams' (2000a) paper focused on how social constructions of masculinities and femininities affected how teenagers adapted to living with asthma or diabetes and drew

attention to different reactions to the use of medication and the management of chronic conditions between boys and girls. The interviews revealed a gendered approach to the management of chronic conditions. Girls appeared to show greater adaptation to their condition and were able to incorporate managing their condition and medication into their everyday lives and identities. In contrast to this, boys made efforts to reject their condition as part of their self-identity and attempted to not reveal their condition to others and conceal the presence of their asthma or diabetes.

A further paper by Williams (2000b) described gender differences between the roles mothers reported performing for sons compared to those mothers reported performing for daughters. The article focused on the involvement of mothers in their son's chronic condition and described the role of mothers in assisting sons to minimise the impact of their condition on their lives. This role was described by Williams (2000b) as that of an 'alert assistant', constantly alert to the needs of their sons and taking steps to assist them in minimising the impact of their condition on their lives. Williams (2000b) identified roles performed by mothers were muting the effects of the illness, absorbing emotions for their sons, mediating for their sons and liaising between the family world and outside worlds, such as with schools. Williams (2000b) noted that sons were often unaware of the work performed by their mothers in relation to assisting with how their condition was perceived by others and that this role was not present in the mothers of daughters with chronic conditions.

In-depth interviews in both these studies (Williams 2000a, 2000b) with a number of young people (n=40) and parents (n=40) provides a robust background for such in-depth research into the role of gender. The use of interviews with both parents and young people provides a detailed account of views from the perspectives of young people and their parents. The recruitment of some young people and parents through the use of snowball sampling and adverts in publications for those with diabetes suggests limitations of the study findings beyond the study sample.

Research into young people's and parents' beliefs about asthma by Callery et al (2003) involved in-depth interviews with twenty-five young people aged 9 to 16 years and their parents about asthma and its management. Young people and parents were recruited through hospitals and general practices. Those recruited through hospitals included those who had made unscheduled visits to accident and emergency and out patient clinics. The primary care sample was recruited from those who saw their GP without unplanned attendance at hospital during the same time period. A decision to recruit part of the sample through general practice surgeries was made during the study as interviews identified frequent references and emphasis on asthma attacks by respondents and the researchers wished to test the hypothesis that this would also occur when young people had not made a recent emergency visit to a hospital. Purposive sampling was used to recruit the majority of young people with moderate asthma, although the sample included participants with a range of asthma severity. Interviews with parents and young people, took the form of open-ended conversations about the experiences of living with asthma, interviews with young people also included the use of a role play exercise. In both participants recruited from accident and emergency and those from GP surgeries, there was much emphasis in accounts of experiences of acute asthma attacks. Parents tended to use the presence or absence of a recent attack as a measure of how well or poorly their child's asthma was controlled. Parents reported assessing and intervening in the child's management of asthma and responding to signs of worsening symptoms such as a wheeze and adjusting medication type and dosage accordingly. They described adapting health care professionals advice of their child's condition in the light of their own experiences of managing their child's asthma. Parents often sought to minimise the physical, psychological and social impact of the child's asthma and treatment on their lives, yet in doing so they accepted that the condition would mean a limiting of activities. Parents reported facing difficult choices about not wishing their child to be different from their peers, but also not wanting them to undertake activities which could worsen their asthma. Callery et al (2003) described how parents' descriptions of asthma management varied from those of young people. Young people tended to report a 'here and now' picture of asthma management and related to their condition in terms of 'good days' or 'bad days'. 'Good days' were those in which they

felt normal and could participate in activities, 'bad days' occurred when their asthma stopped them participating in activities and they were unable to hide their condition from others. Parents had a broader picture of asthma and related to a longer time frame. Use of young people's accounts of asthma management as well as those of their parents provided a strong position from which comparisons between accounts of parents and young people could be made. The use of purposive sampling is a limitation of the applications of the findings of this research beyond the study sample.

Prout, Hayes and Gelder (1999) have also reported the experiences of young people and their parents in the management of asthma. This qualitative study involved nine English families with at least one child between 7 and 12 years with a diagnosis of 'moderate' or 'severe' asthma. Participants were recruited through asthma clinics. Interviews were conducted separately with both parents and children. Interviews with children used a time line of events around the last asthma attack as a prompt for discussions with the child. Prout, Hayes and Gelder (1999) identified from their research that asthma in children was managed in the family through the construction of a sense of 'ordinariness'. The presence of asthma within the family was normalised and coped with, within the family unit. The in-depth approach taken by Prout, Hayes and Gelder (1999) is a strength of this work, enabling a detailed account of experiences of asthma within the family unit to be presented. Interviews conducted separately with young people and parents enabled independent pictures of management to be obtained from both parents and young people. Such a small sample size however (n=9) limits the application of the findings to a wider group. Recruitment of participants from asthma clinics also impacts upon the generalizability of findings to all families with asthma, as families who do not attend clinic appointments might have different patterns of, and attitudes towards, asthma management within the home.

Experiences of wellness within the context of a family with a child with diabetes were examined by Jutras et al (2003). Children with diabetes (aged 8 to 17 years) who had been diagnosed for at least one year and had a sibling aged 8 to 17 years were identified from a Canadian diabetic outpatient hospital. In cases where children with diabetes had

more than one sibling, one was chosen at random to participate in the research. Clinic staff assisted in the identification of participants and provided basic information about the study. Mothers (n=53), children with diabetes (n=53) and siblings (n=53) were interviewed separately in their own homes with use of a structured interview, interviews were audio-recorded. Content analysis was used to analyse transcribed data. Parents and their children were asked about the concept of 'wellness', mothers and children tended to refer to wellness in different ways. Mothers most frequently described wellness as a positive attitude such as: joy of life, sense of humour, good mood and optimism. Children with diabetes and their siblings tended to identify wellness as the absence of physical symptoms. Performance at school was rated highly by children (with diabetes and siblings) as a factor important to well-being, but was rarely mentioned by mothers. The absence of family conflict was a criterion for wellness rated highly by all participants, particularly by children with diabetes. Mothers and children with diabetes were asked about the concept of 'wellness of a diabetic child'. As before a greater number of mothers than children identified positive attitude and emotional factors to be of importance to the concept of wellness in a child with diabetes. Performance within the family and social settings were mentioned as often by mothers as diabetic children, yet school performance was mentioned significantly less often by mothers than by diabetic children. Emotional adjustment to diabetes was mentioned by a third of mothers, but none of the children with diabetes. Both children and mothers highlighted the limitations of diabetes to daily life, through the conditions physical and emotional repercussions. Jutras et al (2003) concluded that children (with diabetes and siblings) tended to focus more on wellness as the ability to perform physical tasks whereas mothers related more to emotional and psychological factors as creating a feeling of 'wellbeing'. The methodological in-depth nature of this research and large number of participants are strengths of this research, although recruitment from a hospital clinic limits the application of findings beyond the study sample.

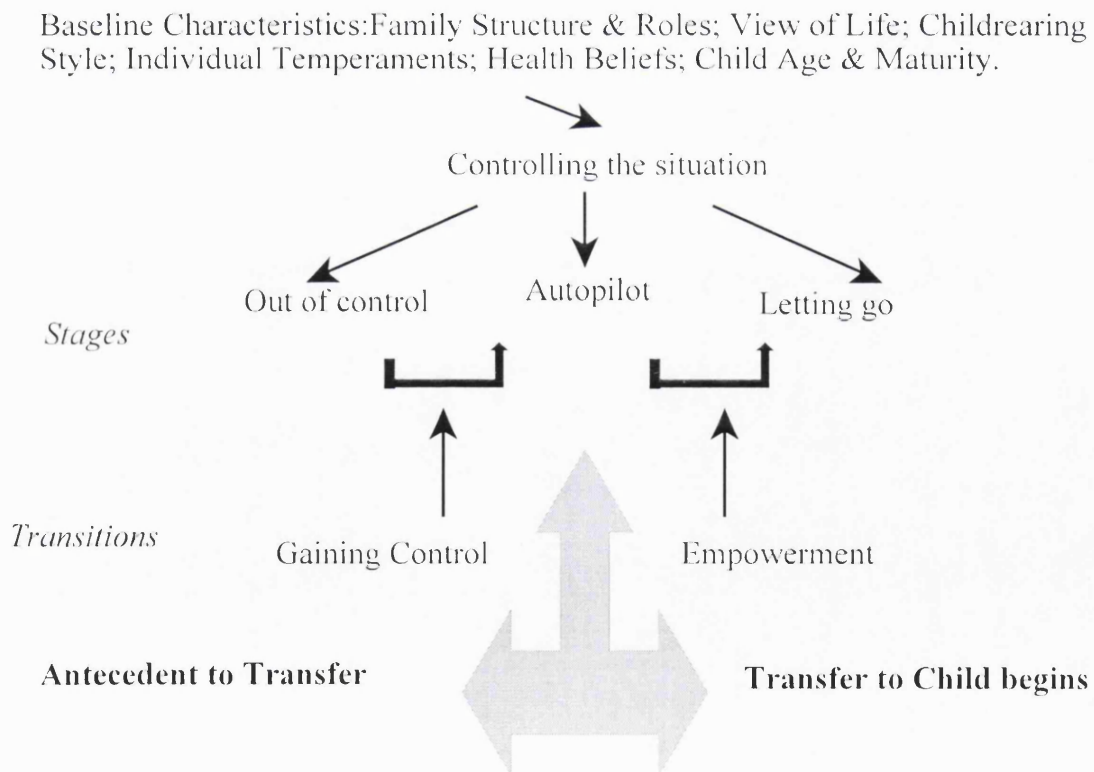
The sharing of diabetes responsibilities between mothers and children have been examined by Anderson et al (1990), through use of the Diabetes Family Responsibility Questionnaire (DFRQ). One hundred and twenty-one healthy children (aged 6 to 21

years) with type 1 diabetes were approached to participate in the research during an in-patient stay at an American hospital. Participants were healthy but were in-patients for the purposes of the collection of data for another research study. The DFRQ was a 17 item self-report questionnaire developed by the authors for the purposes of this study. The DFRQ consisted of 17 items in three sub-groups (general health maintenance, regimen tasks and social presentation of diabetes) that described diabetes or general health related situations or tasks. For each item the respondent had to indicate if the task was performed by a parent, shared by a parent and child or the responsibility of the child. Mothers and children independently completed the DFRQ. In addition to this, mothers and children were asked to rate the child's adherence to treatment on a three point scale (lower scores reflected higher levels of adherence). Children's metabolic control was recorded from clinic records in the form of an HbA_{1c} reading, an estimate of blood glucose control in the preceding six to eight week period. As part of the analysis for each item the extent to which mother and child agreed or disagreed were examined, where neither reported taking responsibility for a task this was also reported. Sixteen percent of the sample had no disagreement between responses of parent and child. A further 12.6% of mothers and children reported that nobody took responsibility for some items on the DFRQ. Age was strongly associated with scores of mothers and children on the total DFRQ. Older children assumed greater responsibility than younger children in all domains. Both mother and child's reports of adherence to medication were related to the child's age with older children associated with lower rates of adherence to treatment. Age was also related to HbA_{1c} levels with older children having poorer metabolic control than younger children. Children's report of overall adherence were related to their total DFRQ score, children who perceived they were taking more responsibility for their diabetes also reported better adherence to treatment. The large study sample included in this research (n=121) and involvement of both young people and parents provide comprehensive findings. Lack of information regarding the selection of study participants, limit generalizations of findings to a wider population.

Over time, roles associated with the management of a chronic condition might change from the responsibility of the parent to that of the child. Research by Burford (2004)

has examined parents' and children's perceptions of the transfer of responsibility for the management of asthma from parent to child. In this American research young people (n=14) aged 8 to 13 years and their carers (n=14) were interviewed separately with the use of an open ended interview guide regarding the transfer of responsibility for asthma. Purposive sampling was used, but the author does not describe the process by which young people and parents were recruited to the research, no response rate was given. The findings indicated that the transfer of control was a complex process occurring over several years but which involved identifiable stages and transitions. Burford (2004) developed a model of the transfer of responsibility in the families interviewed (see figure 1.1).

Figure 1.1 Theoretical model for parent-child transfer of asthma responsibility (Burford, 2004)



The model (see figure 1.1) consists of three discrete stages and two transitional stages. The discrete stages are 'Out of control', 'Autopilot' and 'Letting go'. The first 'Out of control' refers to an emotional response usually at first diagnosis where parents and children were unable to gain control of the condition or its management. 'Autopilot' occurred when families had incorporated the child's asthma care into their routine and management of asthma became automatic. The third discrete stage was that of 'Letting go' where children had independent self-management without assistance from their parents. The two transitional stages are referred to as 'Gaining control' and 'Empowerment'. 'Gaining control' related to families where control of the condition was more organised and in most cases there was rigid adherence to the regimen and 'Empowerment' described the stage at which the child realised the need to manage their own condition. With this stage came an awareness by parents that they would not always be there to manage their son's/daughter's condition. The use of both parent and young person accounts to develop the model of parent-child transfer is a strength of this research. However, the use of purposeful sampling and lack of information from the author regarding the recruitment process means that this model would need to be tested with a larger random sample to determine its generalization to a wider population.

The involvement of mothers in the management of diabetes and factors affecting transfer of responsibility has been examined in research conducted in America (Palmer et al, 2004). One hundred and twenty-seven children, aged 10 to 15 years, with type 1 diabetes and their mothers were recruited from a diabetes outpatient clinic or through a diabetes summer camp. Most participants were approached by a researcher at the clinic or summer camp and given survey packs to complete separately from one another in an allocated two hour period. Other participants were sent the questionnaire by mail, the author does not establish the number of participants who completed the surveys in each way. Mothers and children were given a number of instruments, both completed the Diabetes and Conflict Scale on which mothers and children rate who completes diabetes related tasks (such as giving insulin) and record responses on a scale from 1 (child does it alone) to 3 (mother and child share equally) to 5 (mother does it alone). Children completed the Psychosocial Maturity Inventory (Greenberger et al, 1974) to assess the

extent to which a child has a sense of control of their life without depending excessively on others. Participants rate statements from 1 (not at all) to 5 (very true). Mothers completed a measure created by the authors (Palmer et al, 2004) to explore mother's reasons for transferring responsibility to their children. This contained 13 items (such as finding it hard to help my child with his/her diabetes schedule) from which participants had to rate responses on a scale from 1 (not at all) to 5 (very much). Mothers also reported the pubertal status of their child, the extent to which their son/daughter displayed seven signs of puberty (gender specific) rated on a three point scale; 1=not at all, 2=just started, 3=a lot. Metabolic control, measured by HbA_{1c} values from medical records were also recorded, these reflect the average blood glucose control over the previous 6-8 week period.

Overall, children reported higher levels of responsibility for daily diabetes management tasks than reported by mothers. With increasing age children indicated that they completed diabetes management tasks more independently of their mothers. To explore transfer of responsibility principle-component factor analysis was conducted from the mean ratings from the questionnaire used to explore mother's reasons for transferring responsibility for diabetes management to their child (Palmer et al, 2004). Four factors were uncovered which accounted for 55.9% of variance, which indicated reasons for mothers transferring responsibility for diabetes tasks to their child. 'Hassles' was the first component identified and explained transferring responsibility due to the difficulties and hassles involved in diabetes management and conflict mothers had experienced with their child when trying to provide assistance with their diabetes. The second, 'promoting responsibility' was due to the parent wanting their child to be responsible for their own condition and a belief by parents that their child would learn better how to be responsible for their condition if they managed it alone. The third was 'child competence', the child being able to manage their condition alone or the time being right for a child to take on responsibility. The last was that of 'external pressure' from the child, friends, relatives or others. Palmer et al (2004) reported that data indicated mothers responded to their child's level of competence and also transferred responsibility to promote competence. Where children indicated greater autonomy they

indicated less maternal involvement in diabetes management tasks. Whereas from parent data pubertal status was a more important predictor of maternal involvement, parents used physical signs of maturity as a trigger to transfer responsibility to their child. The large sample size (n=125 pairs of data) is a strength of this research, the involvement of both children and mothers enabled both perspectives to be explored. The recruitment of participants largely through attendance at clinics limits the generalizability of findings beyond the study sample.

In summary, section 1.4 has described the views of parents and young people and their involvement in the management of a young person's condition. Studies reviewed in this section concerned with asthma have tended to focus on the management of the condition surrounding an asthma attack (Prout, Hayes and Gelder, 1999; Callery et al, 2003). Research that has explored the management of diabetes (Anderson et al, 1990) has used a quantitative approach to tasks performed by young people and parents. None of the research has identified the daily tasks of condition management performed by young people and their parents, or the extent to which they might work together in partnership in the management of the condition.

1.5 Partnerships between spouses in the management of diabetes

As outlined above no existing research has examined partnerships in the management of chronic conditions between young people and their parents. Research reviewed in this section concerns partnerships in condition management identified between adults with chronic conditions and their partners or spouses. Both articles identified from the literature concerned the management of diabetes.

Research by Rajaram (1997) conducted in the USA examined the nature of hypoglycemia as experienced from the perspectives of both adults with diabetes and their spouses. Adults (n=23) aged 24 to 50 years, with type 1 diabetes in a stable phase and their spouses were interviewed separately, open ended questions were used. Participants were recruited through three endocrinologists by letter and a subsequent

telephone call inviting them to participate in the research. Those with diabetes who were interviewed reported feeling vulnerable in relation to control of their diabetes and were aware of the constant threat that hypoglycemia could occur at any time, causing them embarrassment in social situations. The research revealed a conflict of views between the person with diabetes and their spouse. Whilst those with diabetes prioritised the ability to perform daily roles and maintain an image to those around them of not being 'ill', spouses were concerned about the health of their partner and the avoidance of the harmful effects of hypoglycaemia. The methodological approach taken in this study, with the use of open ended questions and separate interviews with people with diabetes and their spouses, provides confidence in the study findings. However extrapolation to a wider population is difficult due to the small number of participants, lack of non-response rates and the limited methodological detail regarding the process by which participants were identified.

The roles of partners in the management of diabetes have also been reported in research by Koch, Karlik and Taylor (2000) undertaken in Australia. Men with type 2 diabetes (n=6) volunteered to participate in four focus groups over a four week period, each with all men present. They revealed that the support of their partners was helpful in managing their condition, ensuring medication was taken and that they ate a healthy diet. Limitations of this research include the small sample size and that the participants were self selecting.

Research of Rajaram (1997) and Koch, Karlik and Taylor (2000) have documented the roles performed by partners and spouses in the management of diabetes in adults, such as an awareness of the signs of hypoglycemia, assistance with diet and reminding partners to administer medication. In the absence of literature regarding partnerships between young people and parents these studies reveal potential roles performed by parents in the management of their son's/daughter's chronic condition.

1.6 The management of chronic conditions in schools

Section 1.6 presents literature concerning the management of chronic conditions in schools. Much of the literature identified was that of personal opinion and recommendations of paediatricians, academics and charity organisations (such as Bannon and Ross, 1998, Watson, 1998 and American Diabetes Association, 2004) rather than that of original research. This section focuses on original research regarding the management of chronic conditions in schools.

Asthma, as the most common chronic condition amongst school children, has been the focus of a number of studies regarding medication in school. Pugh et al (1995) examined the storage of asthma medication. Questionnaires were sent to the head teachers of all primary and secondary schools (n=296) in County Durham, UK. The questionnaires covered aspects of medication policy and use of medication by young people in schools. Response rates were 76% in primary schools and 65% in secondary schools. Two-fifths of schools had a policy related to the care of children with asthma. Policies differed between primary and secondary schools, with three out of five primary schools allowing the child to look after their medication and all of the secondary schools. A school nurse was involved with 40% of primary schools and 70% of secondary schools. The broad coverage of this research, in terms of approaching all schools in the area, and high response rate are strengths of this research. However, generalizability to other geographical areas should be conducted with caution due to differences in education authority policies and provisions.

Fillmore, Jones and Blankson (1997) also conducted research concerning the management of asthma in schools. Questionnaires were sent to 216 head teachers of all schools in two areas of South Wales, they were completed and returned by 191 head teachers. The questionnaire related to issues such as facilities in the school to manage asthma, the head teacher's perception of the understanding of asthma management amongst school staff, the presence of written policies related to asthma and the head teacher's view on the need for further training for staff. All schools allowed asthma

medication to be taken to school. Seventy-six (40%) schools allowed children to be responsible for their own inhalers. Forty-eight (25%) schools had an asthma policy. One hundred and fifteen (60%) head teachers believed their staff were familiar with the management of asthma and 21 (11%) schools had a designated school nurse. The majority of head teachers (174, 91%) were interested in staff receiving further training in asthma management. The number of schools surveyed and high response rate is a strength of the research. As with the research of Pugh et al (1995), the generalizability of findings to other geographical areas cannot be assumed due to differences in educational authority policies.

The storage of all types of medication in primary schools within the London area were explored by Wong et al (2004). A list of primary schools was obtained from the Department for Education and Employment, a random number table was used to identify 172 schools whose the head teacher was sent a questionnaire. Topics covered included; knowledge of the policy document ‘supporting pupils with medical needs: a good practice guide’, issued by the Department of Education and Employment (1996) (see section 1.10.2), policies and procedures in place for medical treatments, staff involved in handling medication and medical needs, how information related to a child’s condition was documented and the nature of staff training. Sixty-five percent of head teachers returned the questionnaire. One third of head teachers were unaware of the document produced by the Department for Education and Employment related to the medical needs of children in school and less than half had read the document. Ninety-five percent of schools had a policy related to caring for the medical needs of children and 50% had individual care plans for children with asthma, diabetes or epilepsy. In relation to records surrounding medication, 16% of schools accepted verbal instructions and 24% did not keep written records of medication administered to pupils. Eighty-six percent of schools had arrangements in place for staff regarding medical training. Ninety-two percent of schools had a designated member of staff responsible for the medical needs of pupils, 79% of these were support staff. This research provides a comprehensive description of the management of medication in primary schools in

London, patterns of care might vary in different parts of the country or different education authorities.

The school experiences of children with cystic fibrosis (CF), as reported by teachers, were examined by Zoritch et al (1996). Fifty-three children with CF were approached at CF clinics in two areas in the UK and invited to take part in the study. Forty-one children (aged 7 to 17 years) consented to take part, all attended different schools. Children and parents indicated the class teacher best known to the child, who completed a questionnaire, in three cases the questionnaire was completed by the head teacher. The questionnaire was designed in two parts, to explore the practical, academic, attendance and coping in school of a child with CF, and to establish the teacher's knowledge of the condition. Teachers indicated that eleven children (26%) were restricted from school activities due to their CF, restrictions were most commonly imposed by parents. Outdoor games and day trips were the events most commonly restricted. Teachers indicated little absence from school, the mean number of days absent in the last month was 0 (range 0-15 days). Reasons for absence reported to the teacher were hospital appointments (27%), general illness (17%) or CF related illness (17%). The teachers of fifteen children (37%) reported the child experienced some practical difficulties related to school work mainly in relation to homework or continuous assessments. Children were perceived by teachers to be competent in their relationships with peers and had minimal behavioural problems. Children were generally described by teachers as resilient to the impact of managing CF on their school life.

Teachers were asked about their own knowledge of CF. Only 13 (32%) teachers felt well informed about the condition, yet these teachers did not score better than others in questions designed to test their knowledge of CF. Teachers answered a series of questions related to CF. Whilst 78% of teachers identified a cough as a sign the student might need to visit a CF clinic, only 17% identified abdominal pain and 17% weight loss as cause for concern in a child with CF. A minority of teachers knew about the

importance of exercise (17%) and a high fat diet (12%) for children with CF. Fifty percent of teachers expressed the need to have more information about the condition. The most common sources of information to teachers about CF were parents (75%), the child (49%), CF trust (49%) and the media (39%). Health care professionals provided limited information, the school nurse had given information to 37% of teachers and the hospital to 19%. A strength of this research is the information obtained regarding the knowledge of school teachers about CF, information was also largely obtained from class teachers rather than head teachers who might have more contact with the child. Although the authors (Zoritch et al, 1996) note the aim of this research was to document the school experiences of children with CF, as the data collected was from teachers a limitation of the study is that it relies on the teacher's perception of the experiences of a child with CF.

Research by Chadwick (1996) examined the management of asthma in schools from the perspective of students. Young people with asthma (n=32) aged 6 to 16 years were recruited through the use of surgery records from one GP surgery. Eight young people who met the inclusion criteria of the research declined to participate. The GP or practice nurse interviewed young people with the use of a semi-structured questionnaire. In relation to storage of medication thirteen out of fourteen primary schoolchildren reported restricted access to their inhalers. Thirteen out of fourteen secondary school children stated that exercise at school made their asthma worse. The involvement of young people as respondents in this research indicates a rigorous approach to obtaining their views. The author does not comment on the effect of a young person being interviewed by a doctor or nurse from the GP practice which they attended. Lack of comment on this issue and the use of sampling from one GP surgery has limitations for the application of these findings to a wider group of young people.

In summary, section 1.6 has reported original research regarding young people and the management of chronic conditions in school. The majority of previous research has focused upon school policies with regard to medication and the views of teachers. Only

the work of Chadwick (1996) has documented the management of chronic conditions in school from the perspective of young people. Whilst much research has focused upon asthma, no literature was identified which examined the management of diabetes in schools.

1.7 Young people's and parents' experiences of consultations with health care professionals

This section documents research into young people's and parent's experiences of health care professionals. A search of the literature identified limited papers which documented the experiences of young people with chronic conditions. Section 1.7 therefore reviews literature related to the experiences of consultations with health care professionals of young people with a range of conditions and those with no specific health problems.

Whilst much attention has been paid in the literature to the doctor-adult patient relationship, not discussed in this review, little research was identified from the search that related to communication between doctors and child patients. In consultations between young people and health care professionals the young person is commonly accompanied by their parent, leading to a three way interaction process during the consultation. Research by Aronsson and Ruderstrom (1988) explored this three way communication within the consultation. Consultations were audio recorded in an allergy outpatient clinic between children (n=32), parents (n=32) and doctors (n=6). Children aged 5 to 15 years were recruited through visits to allergy outpatient clinics, all children had experienced previous consultations with the doctor. The research investigated who controlled the child's contribution to the consultation from the quantitative analysis of verbal exchanges, using techniques of conversational analysis. The child made only eight percent of conversational contribution compared to 34% by the parent and 58% by the doctor. Aronsson and Ruderstrom (1988) noted the parent was most frequently responsible for excluding the child from involvement in the

consultation, parents intervened in 52% of the speech the doctor directed at the child. The methodological and sampling approaches taken in this study and number of consultations recorded (n=32) were strong features of the research. However the inclusion of six doctors, limitation of the setting to one allergy clinic and length of time since the research was conducted, sixteen years, does not permit the findings to be generalized to current consultations involving young people and parents.

A more recent study (Tates et al, 2002) analysed consultations between children, parents and doctors in terms of the presence of a 'supporting' versus 'non-supporting' approach to the child's participation in the consultation. Analysis was conducted on video recordings (n=105) of consultations between GPs, parents and children (aged 4 to 12 years) in the Netherlands. Consultations related to minor illnesses or temporary complaints. Videos of consultations were taken from an existing collection of recordings of consultations collected since 1975. Selection of consultations for analysis were made according to those which included children of the specified age group and which were of sufficient recording quality. Analysis focused upon non verbal and verbal interaction, with an examination of the child's display of involvement in the consultation on a scale ranging from 'active involvement' to 'no display of involvement'. Note was also made of cases in which children turned to their parents, verbally or physically, for support. As in the research by Aronsson and Ruderstrom (1988), Tates et al (2002) found the role of the parent in the consultation to be a factor in the participation of the child. Analysis revealed that the GP and parent predominantly assumed a non supportive role in the consultation, although GPs more frequently showed supportive behaviour towards children than parents. Research indicated that the age of the child was a factor, with both parents and GPs being more supportive of the role of the child when the child was of an older age. Children displayed most active involvement in the consultation when the GP adopted a supportive role in the consultation. Where parents asked a lot of questions or talked at length about their child's condition the GP's attention was on the parent rather than the child and this led the GP to take a non-supportive role of the involvement of the child. It was noted that

this shift in focus of the GP to the parent was irreversible and GPs rarely resumed supportive behaviour towards the child after discussions with parents. The number of consultations analysed for this research (n=105) and detailed analysis provides robust research findings. The author noted that consultations were taken from video recordings made since 1979 but does not indicate from which years the consultations analysed were taken. It is unknown if similar findings would be identified in a current UK setting.

Recent research has examined doctor-parent-child communication in an outpatient setting in the UK. Wassmer et al (2004) audio-recorded 51 medical paediatric clinic consultations, with 12 consultants. Questionnaires were also used to assess parents' and children's perceptions of the consultation. All paediatric consultants at Birmingham children's hospital were invited to participate in the research (n=65) of these 40 agreed to participate from which 12 were randomly selected. Quantitative methods were used to analyse communication in consultations. Doctors communication was categorised as three main behaviours; 'instrumental' (information giving and receiving by the doctor), 'affective' (the doctor displaying solidarity and empathy, reassures and encourages patient opinion and questions) and 'social' (general social conversation).

Communication of parents and children was categorised in three ways; 'giving information', 'seeking information' and 'social conversation'. Control of the conversation was analysed by conversational contribution and turn taking (the number of turns taken by each participant). Parents' and children's assessment of the doctor's communication skills were determined with use of a modified version of Streets questionnaire, with 14 statements. Response options for parents were on a 6 item scale from strongly agree to strongly disagree. Children responded to statements with 'yes', 'no', 'don't know' or 'don't understand the question'. Satisfaction with the consultation was assessed by parents on a scale of one to ten (1=very dissatisfied, 10= very satisfied), satisfaction of children was assessed by how much they 'liked' the doctor. Of the 51 consultations, 43 children (aged 4 weeks to 14 years) had been previously seen by the consultant.

Analysis of doctors behaviour revealed most (84%) was instrumental behaviour (information giving and receiving) and some (13%) affective behaviour (reassuring and encouraging the patient), there was minimal social conversation (3%). Parents' communication consisted of giving information (83%), seeking information (13%) and social conversation (4%). Children's conversation was giving information (78%), seeking information (3%) and social conversation (19%). The doctor contributed most to the conversation (61%) followed by the parent (25%) and the child (4%). The doctor asked most questions (85%) followed by parents (13%), children asked the least questions (2%). Analysis of interactions between participants identified that the longer the doctor spoke the less the parent spoke, and the more the parent spoke the less the child spoke. Questionnaires regarding satisfaction with the consultation were completed by all parents and 22 (43%) children. Ninety-five percent of children who completed the questionnaire indicated they were very satisfied with their doctor. Children identified their doctor as understanding (94%) and informative (91%). Sixty-six percent of parents were very satisfied with the doctors communication skills, only one parent was dissatisfied. The findings of Wassmer et al (2004) revealed in a UK population similar findings to previous work of Aronsson and Ruderstrom (1988) and Tates et al (2002), that young people had a limited role in consultations with health care professionals, and the role of parents can considerably affect the contribution made by the child in the consultation. The robust methodology and sampling procedures give confidence in the application of findings beyond the study sample. A limitation of this research is the focus on verbal interaction, non-verbal interaction and body language have not been documented.

Research by Kristensson-Hallström and Nilstun (1997) documented aspects of the three way doctor, parent, child relationship with the parents of paediatric in-patients. Twenty parents of children (aged 2 to 14 years) who were admitted to a Swedish hospital for surgery were interviewed. Interviews took place at the end of the child's hospital stay and were concerned with the parents's involvement in their child's care. Kristensson-Hallstrom and Nilstun (1997) identified three key situations that parents had

experienced whilst their child was in hospital. In the first, described as the ‘professional vs the parent’, the parent felt excluded from the care of their child and unable to influence elements of their care. In this model there emerged a conflict between the professional and the parent, in which the parent felt they had little autonomy. In the second situation, ‘the parent and the professional vs the child’, parents described occasions where they had co-operated with professionals against their child. Incidences of this included times when the child had not wanted treatment but parents and professionals had insisted. Although treatment was in the best interest of the child, parents described that they felt guilty that they had gone against the wishes of their child. In the third situation the professional was against the child and the parent, described as ‘the professional vs the child and the parent’. Parents were upset when professionals showed disregard for their child’s views and feelings. Due to the nature of the surgical ward in which this research was conducted, the study is concerned with the parents of boys who were operated on for a congenital malformation in which the urethra had not completely developed. The generalizability of the findings of this research to other in-patient populations and to the parents of girls is therefore unknown. This research by Kristensson-Hallstrom and Nilstun (1997) gave insights into the complex relationships that might occur between parents, children and health care professionals within a hospital setting. Due to differences in communication and health care environment it is unknown if similar findings would be identified in a UK setting.

A large study conducted in the UK explored teenagers’ views on their last consultation with a GP (Jacobson et al, 2000). Questionnaires were completed by 5152 teenagers (aged 15 to 16 years) in 38 schools, recruited as part of a larger sex education initiative. Questionnaires were completed by teenagers in a school lesson. The majority of teenagers (82%) indicated that it was easy to tell the doctor about their problem. Most (87%) were satisfied with the help or advice that they were given by the GP. Thirteen percent of the sample reported dissatisfaction with the consultation, the most common reasons for this were insufficient information provided by the GP and a lack of improvement in the condition following the consultation. Other reasons for

dissatisfaction were lack of care, embarrassment or a consultation with a male doctor (identified by girls only). A strength of this research is the large study sample. The authors (Jacobson et al, 2000) do not report the selection process by which schools were chosen for inclusion in the larger study from which this data were obtained. Lack of clarity on this point means it is not possible to comment on the application of the research findings outside of the study sample.

Children's and their parents' perceptions of the appearance of health care professionals were explored in research by Barrett and Booth (1994). A questionnaire survey was used with parents and children over five years of age (n=203) who attended an outpatient clinic over a three month period. Five photographs of a male or female doctor were shown to children and their parents. On the photographs doctors were dressed in different attire ranging from casual clothing to white coats. A researcher displayed all five photographs before the child and parent and participants were asked to assign positive and negative attributes to the photographs ranging from most competent to least competent. The results of the research indicated that children viewed formally dressed doctors as competent but not friendly, but those in casual dress as friendly but not competent. Children were shown in this study to be more conservative than their parents in their choice of clothing for doctors, with the majority of parents identifying doctors in casual clothing as 'competent'. This study suggested that the appearance of a doctor might affect how they are perceived by children. The large sample size with which this research was concerned (n=203) and use of both parents' and children's responses are positive aspects of this research. The author reported that parents were allowed to help their children with the photographs but not influence their choices, yet does not document if this process was monitored to assess parental influence on responses given by children. The author also does not allude to the comprehension of the concept of a competent doctor amongst children.

A young person's preference for health care professionals, in relation to their gender, has been examined in research conducted in America (Kappahn, Wilson and Klein,

1999). Data were obtained from adolescents who took part in the Commonwealth Fund 1997 Survey of the Health of Adolescent Girls. This large survey identified a nationally representative stratified sample of students from 267 schools and assessed access to health care, preventative health behaviours, health status, health risk activities and communication with health care professionals and parents. A total of 6748 students self-completed the survey, during school time. Data presented in the research paper reviewed here (Kapphahn, Wilson and Klein, 1999) were taken from 5067 students, school grades 5-12 (aged 10 to 18 years), who identified that they had received a health check up or physical examination within the last two years. The paper reported findings related to health care utilization and preferences. Fifty percent of girls indicated that they preferred to be seen by a female health care professional, while 48% reported that they had no preference. Younger girls (grades 5-8; aged 10 to 14 years) were most likely to prefer a female health care professional, older girls most frequently had no preference regarding the gender of the health professional. Most boys (65%) did not have a preference with regard to the gender of their health care professional.

Adolescents were asked their views on having the same physician as their parents, most girls and boys stated that it did not matter. Kapphahn, Wilson and Klein (1999) noted that age had a significant affect on preferences of adolescents to have a parent present during a medical examination. Most younger girls (grades 5-8; aged 10 to 14 years) preferred to have a parent present, whilst younger boys most frequently had no preference. Older age increased the likelihood that both girls and boys would prefer to be examined without a parent present. Sixty-two percent of adolescents reported that they could speak to a health care professional without a parent present, this rate was higher for boys (66%) than for girls (57%). Female health care professionals were more likely to provide girls with private consultation time, 68% of girls with female health providers had private time with health care professionals, compared with 53% of girls with male health care providers. There was little difference with boys seeing male (67%) or female (70%) health care professionals without a parent present. This research provides comprehensive findings of the preferences of adolescents in the USA regarding

the gender of health care professionals, the extent to which findings would be replicated in the UK is unknown due to differences in health care provision.

From the search of the literature one paper was identified which focused upon young people with chronic conditions and their experiences of health care professionals. Research by Beresford and Sloper (2003) concerned adolescents experiences (aged 10 to 12 years and 14 to 16 years) of communicating with doctors. Adolescents (n=63) with a chronic condition (cystic fibrosis, diabetes, epilepsy, juvenile chronic arthritis or Duchenne muscular dystrophy) that had been diagnosed for one year or more were identified from four hospitals in different areas of the UK. Participants were recruited through the use of a letter sent to them by hospital consultants, adolescents who wished to participate contacted the researcher. Adolescents were interviewed in their own homes and subsequently participated in two group discussion meetings. Data from both interviews and discussion groups were analysed to examine factors that hindered or promoted communication between young people with chronic conditions and doctors.

Where participants had contact with several health care professionals they preferred to raise issues with health care professionals known to them and liked to see familiar staff when attending clinic appointments. Also of importance to adolescents was the length of the consultation, with some feeling clinic appointments were rushed and did not enable them to engage with the doctor. Privacy of the consultation was valued by adolescents, some indicated that the presence of medical students inhibited communication. Participants also commented on the presence of parents in the consultation, some felt this inhibited the consultation and made it hard for them to participate. Other adolescents reported the role of parents as supportive and felt it gave them more confidence to interact with the doctor. Adolescents in younger age groups (aged 10 to 12 years) tended to ascribe the doctor high status and described difficulties in communicating with them. Adolescents in younger age groups were more likely to state that the doctor interacted mainly with their parents and that they felt excluded from consultations often by the complex language used by doctors. Those in older age groups

(aged 14 to 16 years) tended to be more concerned with issues of privacy in the consultation. In relation to asking doctors questions a number of participants acknowledged problems with their own communication skills and reported not knowing how to ask questions, particularly in relation to sensitive issues, such as the future nature of life threatening conditions. Some adolescents reported not asking questions as it would have meant revealing their engagement in forbidden or discouraged health behaviours, such as the consumption of alcohol. The relatively large number of adolescents (n=63) who participated in this in-depth research, the use of adolescents as respondents and the involvement of four geographical areas suggests that these results are applicable beyond the study sample.

In summary, section 1.7 has detailed literature concerned with young people's consultations with health care professionals. Papers reviewed have documented the experiences and preferences of young people with a range of conditions and young people with no identified health problems. Only the research of Beresford and Sloper (2003) had examined the experiences of young people with chronic conditions of consultations with health care professionals. Research to date has focused upon the role of the doctor in the consultation, no papers were found which related to consultations with other health care professionals.

1.8 Information needs and information used by young people and parents

Searching procedures revealed limited articles which explored the information needs or the information used by young people with chronic conditions and their parents. Papers that documented interventions which provided young people or parents with additional information about their condition were excluded from this review. Section 1.8 therefore reports the limited articles identified in the literature that concern the information needed and used by young people with chronic conditions and their parents and needed and used by parents and young people with other conditions and without specific health needs.

Research by Peterson-Sweeney et al (2003) previously described in detail in this chapter, conducted interviews with mothers (n=18) of children (aged 2 to 18 years) with asthma. Nearly half of the parents interviewed reported minimal or no education when their child was first diagnosed with asthma. Parents identified the need for additional education for themselves regarding the management of asthma and administration of medication. Parents identified themselves as having the primary role in educating their son/daughter about their condition and the use of their medication and therefore felt there was a need for them to be educated in order to pass on the correct information to their son/daughter. As previously outlined a strength of this research is the in-depth nature of the approach. Use of purposive sampling and a small sample size limits the application of research findings beyond the study sample.

Parents information needs when their child has Turner Syndrome have been examined by Starke and Möller (2002). Turner Syndrome is a sex chromosome disorder found in girls. Forty-four parents (33 mothers and 11 fathers) were approached when they attended their daughter's annual examination at a Swedish hospital, and were invited to participate in semi-structured interviews conducted by a social worker. Twenty three (52%) parents were dissatisfied by the information provided by the physician at the time of diagnosis of the condition and 21 (47%) were satisfied. Sixteen dissatisfied parents sought more information about Turner Syndrome as did ten satisfied parents. All satisfied parents did not report seeking specific additional information, but stated that they wanted to gain more knowledge about the condition. Dissatisfied mothers and fathers explained they wished to seek further information to learn more about the condition. Mothers often perceived that they were responsible for ensuring their daughters were given the right information about their condition from health care professionals and identified this as a reason to obtain further knowledge of the condition themselves. Mothers identified seeking further information as they wished to be able to answer questions from others about Turners Syndrome, especially from other mothers. Parents identified a variety of sources of additional information. Fathers tended to ask doctors or borrowed medical books from the library. Mothers also visited libraries to

obtain medical books, read articles in newspapers, asked questions to mothers of other children with Turner Syndrome, read booklets from the hospital or looked on the internet. Mothers who attended health care education classes sought information from course literature. More than half of parents were members of the Swedish Turner Association, 13 parents were not members and stated they did not wish to be, some parents commented that their child was 'normal' and therefore did not require contact with the association. Starke and Möller (2002) noted how motives for seeking information were to some extent related to parent's initial experiences in the consultation with the physician. Dissatisfied mothers used more and different strategies for obtaining information compared with fathers (both satisfied and dissatisfied) and satisfied mothers. The large study sample and in-depth nature of this work gives insight into the information sources used by Swedish parents of girls with Turner Syndrome. In the absence of literature related to parental information needs of children with chronic conditions these findings might provide insight into information sources used by parents in the UK.

Research concerning children suffering from acute illnesses has documented the information needs of parents when their child is acutely ill. Research by Kai (1996) used one to one and group interviews with the parents of children below school age and explored the information they required whilst their child was acutely ill. The one to one interviews were conducted with a purposive sample of 32 parents from a disadvantaged area, and a further 63 parents who took part in focus groups held at mother and toddler groups. The findings of the study revealed that parents often felt disempowered and found it difficult to make sense of their child's illness. Parents required more information from the doctor about their child's acute condition particularly in relation to the implication of the illness or treatment on the child, and the potential to prevent the illness in the future. Parents identified the media, magazines, television and publicity campaigns as the most common sources of specific information about illnesses. The most common suggestion from parents for how to present information in the future were an illustrated book with photographs or videos. The in-depth approach and relatively

large number of parents interviewed (n=95) were strengths of this research. The use of a purposive sample indicate findings are not applicable to all parents' experiences. The paper does not comment regarding whether respondents all had experiences of the same hospital staff, which would make generalizations to a wider group invalid.

American research (Ackard and Neumark-Sztainer, 2001) explored sources of health information used by adolescents in US classes grades 5-12 (aged 10 to 18 years). A nationally representative sample of adolescents (n=6728) who completed the Commonwealth Fund survey answered questions related to health care information. The survey was administered within the classroom and students completed the self-report survey anonymously. The survey contained four questions related to health care information; where the adolescent would go to find out more information on health care and who they would ask, what sources adolescents used to obtain information about health care, the identification of topics a doctor should talk about with someone their age, and if they had discussed such topics with their doctor, and the identification of topics the adolescent would feel uncomfortable or embarrassed discussing with a doctor. For each question there were a series of possible answers from which participants ticked the appropriate answer. Each question had a 'don't know' or 'other' option. The majority of adolescents identified their mother as the first person they would ask about health related issues, followed by a doctor and nurse and then friend. Parents were also identified by adolescents as the most common source used to obtain information about health care, other sources were health care professionals, health education classes in school or media such as magazines, television or newspapers. Gender differences were identified in relation to topics health care professionals should discuss with someone their age. Boys indicated drugs, smoking, STDs, alcohol and good diet whilst girls reported that health care professionals should discuss eating disorders, STDs, weight, good diet, smoking, preventing pregnancy, alcohol and exercise. Both boys and girls reported discussions of these issues had taken place with health care professionals less frequently than they would have liked. Boys and girls identified sexuality and body changes as topics they were too embarrassed, afraid or uncomfortable to discuss with

health care professionals. Girls also frequently identified menstruation as a topic in this category. The use of a nationally representative stratified sample of a large number of young people is a strength of this research. The extent to which findings would be replicated amongst young people in the UK is unknown.

With increased accessibility to the internet, recent research has focused upon the use of the internet for health information. Gray et al (2005) examined use of the internet by adolescents to seek health information. The study involved twenty-six single gender focus groups with 157 adolescents (aged 11 to 19 years) conducted in schools. Participants were a convenience sample of adolescents the United Kingdom (15 focus groups) and from the United States (11 focus groups). Group discussions centered upon perceptions of how the internet had changed participants work and leisure activities and adolescents experiences and perceptions of how the internet could be used to find health information. In 20 of the groups an internet exercise was undertaken with use of computers. Discussions were audio taped and transcribed verbatim. Several students had sought health information from the internet, the most likely to have done so were female students and older male students. The most common topics of information searched for were information in relation to diet and exercise. Adolescents identified advantages of use of the internet over face to face consultations as it reduced embarrassment and provided anonymity. Doctors were still seen by adolescents as a valuable and trusted source of information. One young person, who had acne, reported membership of an online community in which she was able to 'chat' to fellow sufferers about the condition. The in-depth nature of this work and large study sample provides detailed information regarding the use of the internet by young people in the UK and the USA, the use of a convenience sample is a limitation of this study with regard to the application of findings beyond the study sample.

Research by Tuffrey and Finlay (2002) examined use of the internet by parents of patients at paediatric outpatient clinics in the UK. Over a six week period, parents of children attending general paediatric outpatient clinics in eleven hospitals were asked to

complete a questionnaire survey. Of 577 questionnaires distributed 485 were returned, from parents of young people aged four weeks to 23 years. Parents were asked for which condition their child was attending the clinic, where possible conditions were categorised as 'acute disease', 'chronic disease' or 'symptoms only'. Thirty-two percent of parents had used the internet for health information in the past, parents of children with chronic diseases were more likely than other parents to have used the internet. Only 6% of parents had been directed by health care professionals to use the internet as a source of information. Eighty-eight percent of parents who completed the questionnaire felt that doctors should suggest internet sites suitable for parents. The findings from this comprehensive study, with a large sample size and high response rate provides confidence that findings are applicable to parents beyond the study sample.

In summary, section 1.8 has documented research which has explored the information needed and used by young people and parents. The search process revealed only the work of Peterson-Sweeney et al (2003) that had explored the information needs of young people with chronic conditions and their parents. Research identified in this section, in relation to young people with other conditions or healthy populations, suggests sources of information that might be used and information that might be required by young people with asthma or diabetes and their parents.

1.9 Quality of life

Section 1.9 consists of two sub-sections. Section 1.9.1 introduces the concept of quality of life and its measurement in young people. Section 1.9.2 reviews literature concerning the measurement of quality of life in young people with chronic conditions.

1.9.1 The concept of quality of life and its measurement in young people

Measurement of the quality of life (QoL) of a person refers to an individual's perception of their position in life in the context of the values of the society in which they live. The

QoL of a person is seen in relation to all aspects of their life such as housing, income and environment (Bowling, 1995).

From the measurement of QoL has emerged the development of the concept of Health Related Quality of Life (HR-QoL). HR-QoL describes the influence of a health state on the ability of an individual to live a fulfilling life. HR-QoL is defined as ‘optimum levels of mental, physical, role (e.g. worker, parent, carer) and social functioning, including relationships, perceptions of health, fitness, life satisfaction and well being’ (Bowling, 1995). HR-QoL is based on the World Health Organisation’s definition of health as ‘A state of complete, physical, mental and social well-being and not merely the absence of disease or infirmity’ (World Health Organisation, 1947). HR-QoL therefore provides a measurement of the psychological well-being of a person, their ability to perform daily activities and their perception of their well-being, in relation to their state of health.

Measurement of QoL can be through the use of an instrument that is self administered or administered by a researcher. Instruments might comprise a single item, scale or battery measure (Francis, 2001). The concepts measured by instruments vary dependent upon the design of the measure, but might encapsulate domains such as physical functioning and emotional well-being. QoL instruments might be scored, either as a single score summarising the measure as a whole, or separate scores for each dimension measured in the scale, for example physical functioning as distinct from social functioning. Scores from QoL instruments might be presented as raw scores, standardised or weighted. The weighting of scores reflects the priority of certain items used within the instrument (Francis, 2001).

Measurement of QoL can be through the use of generic or disease specific instruments. Disease specific HR-QoL measures have been developed across a range of conditions including; cancer, asthma, diabetes, mental health and cardiovascular conditions. Although numerous HR-QoL instruments have been developed for use in adults with a

variety of conditions, their development for use with children and young people has been much slower. Measurement of HR-QoL and QoL in children has often relied on the use of proxy measures, that is a parent's/guardian's perception of the health of the child. As Hart and Chesson (1998) noted, reporting by proxy can lead to measuring the impact of a child's illness on the proxy, rather than the impact of the illness on the child. Bowling (1995), in relation to the study of the HR-QoL of children with cancer, referred to questionable validity and reliability of the completion of QoL measures by proxy respondents. Juniper (1997) has stated that parents do not accurately perceive their child's HR-QoL and therefore it is necessary to obtain information directly from the child rather than their parent.

Recent attention has been focused on the development of instruments that can be administered directly to children, although the measurement of HR-QoL in young people is still in its 'developmental step' (Rajmil et al, 2004). Eiser and Morse (2001) noted the importance of the development of QoL instruments in paediatric medicine due to a move away from the management of infectious disease to the management of chronic conditions. The formulation of QoL measures for use with children has been slow to develop. This is potentially due to the additional consideration that has to be taken with the development of an instrument for use with children. Jenney and Campbell (1997) noted that the greatest difficulty in devising QoL measures for use with children was to achieve an accurate understanding of what dimensions of health are most important from the perspective of a child. In particular, how the child values his or her health or functional status and the ability of an instrument to accurately assess that (Jenney and Campbell, 1997). Connolly and Johnson (1999) have emphasised that extra care needs to be taken when designing HR-QoL instruments for use with children. For instruments to be accurate, it needs to be ensured that children fully understand the questions that they are being asked and have sufficient understanding of their own condition to enable questions to be answered in a relevant way.

1.9.2 Health Related Quality of Life of young people with chronic conditions

Section 1.9.2 presents research which has measured the QoL of young people with chronic conditions. Papers related to the development or testing of QoL instruments or the use of generic QoL instruments have been excluded from this review. A search of the literature revealed four papers that reported the findings of use of QoL instruments with young people with chronic conditions.

Research by Guyatt et al (1997) examined the QoL of children with asthma. Children aged 7 to 17 years (n=52) with a variety of asthma severity and their parents (n=52) were recruited to the study through routine visits to a Canadian asthma clinic. Parents and children were seen by researchers on their initial visit and then at four week intervals. At weeks 1, 5 and 9 the child completed the Paediatric Asthma Quality of Life (PAQOL) instrument (Juniper et al, 1996a). The PAQOL consists of a twenty-three item questionnaire relating to activity limitation (5 items), symptoms (10 items) and emotional functions (8 items). The measure was administered to young people by a trained interviewer. At 5 and 9 weeks parents and children completed the global rating of change questionnaire (Juniper et al, 1994), in which they were asked if they/their child had experienced a change in their asthma symptoms since their last clinic visit. Responses were scored on a 15 point scale (-7 = a great deal worse, 0 = no change, +7=a very great deal better). For one week prior to each visit participants recorded peak flow rates, symptoms and medication in a daily diary. At each clinic visit, weeks 1,2,5 and 9, airway caliber measures were taken. An asthma control score was calculated from diary information completed by children and parents to record physiological information about the condition (such as if the child woke at night with symptoms of asthma). The research examined changes in asthma over the study period, if the condition had stayed the same, improved or deteriorated. The results of the global rating of change questionnaire (Juniper et al, 1994) completed by parents and children were compared to the results from airway caliber measures, the asthma control score and the PAQOL (Juniper et al, 1996a) completed by children. Data were grouped to compare the

findings from children aged 7 to 10 years and those aged 11 to 17 years. In younger children (aged 7 to 10 years) the PAQOL scores and the asthma control score were more closely related to parents' rather than children's global rating of change questionnaire. The reverse was found in older children (aged 11 to 17 years); the correlations in global ratings of change in symptoms, the PAQOL scores and the asthma control score were higher in children than in adults. Guyatt et al (1997) concluded that in children aged 7 to 10 years clinicians cannot rely on parent report to provide information about QoL, although complementary information might be obtained from asking questions to both children and parents. In children over eleven years parents can provide little if any information beyond that obtained by questioning the child directly (Guyatt et al, 1997). The large study sample (n=52) and longitudinal nature of the study are strengths of this research.

The QoL of adolescents with type 1 diabetes was examined by Graue et al (2003) and involved comparison of the QoL of adolescents with diabetes and healthy controls. Participants with diabetes (aged 11 to 18 years; diagnosed aged 15 years or younger) were identified from patient records in an outpatient department of a Norwegian hospital. Adolescents were sent a letter prior to their outpatient visit and invited to participate in the study at their next clinic visit. Eighty-nine percent of those with diabetes agreed to participate (n=77). The control group (n=38) consisted of children aged 15 to 18 years, the author did not report the recruitment process of the control group. Both groups of adolescents completed the Child Health Questionnaire (CHQ-CF87), a generic measure related to functional health and well-being, which contained 87 items. In addition to this adolescents with diabetes completed the Diabetes Quality of Life modified for Youths (DQOLY) (Ingersoll and Marrero, 1991). The DQOLY contained three sub-scales, diabetes related burden, daily and future disease related worries and diabetes life-satisfaction. The measure was translated into Norwegian prior to use. When compared to the control group, adolescents with diabetes had overall lower rates of QoL, as defined with use of the CHQ-CF87 instrument. Amongst the adolescents with diabetes, age was considered a factor in reported QoL with use of the DQOLY (Ingersoll and Marrero, 1991). Older adolescents reported being more worried

about their diabetes and stated that diabetes had a greater impact on their daily life. Girls reported a greater impact of their diabetes on QoL than boys. A strength of this research are the large sample (n=115). The author does not comment on the use of different age groups in the control (aged 15 to 18 years) and diabetes (aged 11 to 18 years) groups, and potential impact of this difference in comparison of QoL between the two groups.

Wagner, Abbott and Lett (2004) examined the quality of life of youths with type 1 diabetes by use of a quality of life approach which enabled youths to nominate and evaluate their own quality of life domains, rather than through use of an instrument with standardised measures. Wagner, Abbott and Lett (2004) argued that by pre-selecting and limiting items to those included in a standardised measure, the researcher limits their understanding of a youth with diabetes. The measure devised by the authors (Wagner, Abbott and Lett, 2004) was based upon the Schedule for the Evaluation of Individual Quality of Life-Direct Weight (SEIQoL-DW) (Joyce et al, 2003). There were three stages to the administration of the SEIQoL-DW. In the first stage, participants nominated five life domains that they considered most important to their QoL. If participants are unable to nominate domains themselves examples are read to them from a list. To assess the child's understanding of the directions they were asked to 'retell' the directions to the researcher. If the child was unable to re-tell the instructions in simple terms they were excluded from the study. The second stage of administration consisted of a vertical visual analogue scale from 0-100 on which the two extremes were labelled 'best possible' and 'worst possible' health. For each domain participants were asked to rate it against the scale. In the third stage domains were weighted. Participants were given five centrally mounted interlocking laminated discs. Each disk was a different colour and labelled with the name of each domain. Disks could be rotated over each other to make a circle that formed a pie chart in which each domain represented a proportion of the chart to indicate the weight the participant attached to each QoL domain. The proportion of the chart that each sector represented can be scored on a 100 point scale, equivalent to the circumference of the pie chart. Total quality of life is

calculated by multiplying each domain importance rating (assessed in stage 2) with the domain rating (assessed in stage 3) and summing the products. Participants (n=80) were recruited from a diabetes summer camp in the USA, youths who were residents (aged 8 to 15 years) and young counsellors (age range not specified), who had attended the camp when they were younger. One week prior to the camp parents were sent a letter which explained the research and a consent form. Analysis indicated no difference between participants and non-participants in relation to age, gender, HbA_{1c} levels or duration of diabetes. The most frequently nominated domain was 'family', identified by 95% of respondents, this was followed by 'friends' (76%) and 'school' (58%). The nomination of 'diabetes' was also a common domain (61%), health was the fifth most common domain (38%). In total participants (n=80) identified 18 different domains. Total SEIQoL-DW scores ranged from 34.9-97.7. Wagner, Abbott and Lett (2004) noted that domains identified by youths shared many common characteristics. In comparison with the SEIQoL-DW used with adults, youths identified all the domains offered on the standardised list other than 'finances'. Youths chose some domains not typically nominated by adult participants such as 'approach to life or mental attitude' (12%) and 'treating others as you would like to be treated' (11%). Younger respondents (average age 12 years) were more likely to focus on diabetes and emphasise the importance of diabetes self-care behaviours. Older respondents (average age 15 years) were more likely to focus on general health and the need to live well despite having to manage diabetes. The large sample size is a strength of this research. Completion of the measures within a diabetes camp environment might have influenced the domains identified by youths, and might limit the application of findings beyond the study sample.

Research by Rätty, Larsson and Söderfeldt (2003) examined HR-QoL in young people (aged 13 to 22 years) with epilepsy in comparison with healthy peers. Measurement of the HR-QoL was conducted with the use of two measures the 'I think I am' instrument and the youth self-report competence scale. Self esteem was measured by the 'I think I am' instrument in the Swedish language which comprised 72 items; physical index

(14 items), skills (14 items), psychological well-being (16 items), relationship to family (14 items) and relationship to others (14 items). The four point response scale had response options: 'exactly like me', 'fairly like me', 'not exactly like me' and 'not at all like me'. Responses were scored on a scale from -2 to +2. A positive self-esteem corresponds to total scores between 1 and 144 points and a negative form -144 to 0. The Cronbach alpha was 0.80 for the scale as a whole and between 0.73 and 0.86 for the sub-scales. The youth self-report competence scale, devised by the University of Vermont, comprised of two parts. Part one consisted of a competency scale of 11 items in three domains; activities, social competence and school achievement. The competence scale was scored by summing the three sub-scales, an open ended item regarding illness and handicap was also included. In the second part of the scale behaviour/problems are measured with a 98 item instrument with nine sub-scales; withdrawn (7 items), somatic complaints (9 items), anxious/depressed (16 items), social problems (8 items), thought problems (7 items), attention problems (9 items), delinquent behaviour (11 items), aggressive behaviour (19 items) and self-destructive/identity problems (12 items). The 3 point response scale is scored; 0=not true, 1=sometimes true, 2=very true/often true. Cronbach alpha of the competency scale was 0.76 and 0.88 for the behaviour/problem scale.

Instruments were completed by young people with epilepsy (n=158) identified from medical records in four hospitals in Sweden and random controls (n=282) who lived in the same area, identified from the National Register of Swedish citizens. Instruments were sent to young people in the form of a questionnaire, additional information related to the condition was completed by the sample with epilepsy. Findings indicated that the age of a young person impacted upon their HR-QoL with older youths indicating poorer self esteem (as measured by the 'I think I am instrument') in both the epilepsy and control group. On comparing the epilepsy and control groups it emerged there was little difference in scores other than in relation to the youth self report competence scale, in which young people with epilepsy had lower scores. Girls, in both groups, had lower rates of HR-QoL, through use of the youth self report competence scale, than boys

(Räty, Larsson and Söderfeldt, 2003). The large sample size and length of QoL instruments (72 items) are potential strengths of this research, although a lack of information regarding the psychometric properties of the instruments makes comment on this issue difficult.

In summary, a review of the literature regarding the measurement of QoL in young people with chronic conditions identified the limited amount of previous research in this area. No research has been conducted within the UK relating to the QoL of young people with asthma or diabetes.

1.10 Government policy

Section 1.10 sets the research presented in this thesis in the context of United Kingdom government policy in relation to the health needs of young people with the chronic conditions of asthma and diabetes.

1.10.1 Government policy concerning the health of children and young people

‘Four or so years ago children were largely invisible in the policy direction of the Government in general, and particularly in the Department of Health’.
(Aynsley-Green, 2004, p.238)

As indicated by the above quote, the inclusion of children and young people in Government policy in relation to health is a recent development. Prior to 1997, and the publication of the House of Commons Health Committee report which addressed the health needs of children (House of Commons Health Committee, 1997), little attention had been paid in government policy to the health of young people. Parents were seen as in charge of making health choices for their children and were deemed to make decisions in the best interest of their child, without intervention from outside of the family unit. In recent years, this concept has been constantly challenged through media coverage of numerous court cases which have seen the views of parents being legally

challenged, with parties arguing that decisions being made by parents were not in the best interest of the child. These included parents wanting their child to have treatment staff perceived not to be of benefit to the child or parents refusing life-saving treatment for their child, for example organ donation (McCabe, 1996). A recent example of this was the High Court case between Portsmouth Hospitals NHS Trust and the parents of Charlotte Wyatt, who was born prematurely with severe heart and lung problems. Her parents believed the baby should be kept alive, but the hospital trust argued that her quality of life was so poor it would be in the best interest of the child that she be allowed to die. The court ruled in favour of the Portsmouth Hospitals NHS Trust (October, 2004). Not only in situations as severe as those which result in court cases, but throughout the health service it has been argued that the views of children need to be heard. Aynsley-Green et al (2000) argued that there was an urgent need for children and adolescents to be represented at all levels of health policy and that children and young people should not be treated as 'small adults', but as a group with specific health care needs.

The first Government document to specifically address the health needs of young people was published in 1997 in the form of a report by the House of Commons Health Committee, 'The Specific health needs of children and young people'. This document emphasised that a change in attitude was needed towards children and young people and stressed the importance of listening to their views on needs for health care provision (House of Commons Health Committee, 1997). This was followed five years later by the publication of the action plan 'Listening, hearing and responding' (Department of Health, 2002) which outlined an approach to address the care of young people, particularly those with long-term conditions. The action plan called for better information and choice for young people, better communication with children by health care professionals and parents to have full involvement in decisions made about their child's treatment and care.

In the same year the Royal College of General Practitioners and the Royal College of Nursing (2002) published a joint initiative, 'Getting it right for teenagers in your practice' designed to improve young people's use of GP surgeries for advice and support. The document outlined processes by which GP surgeries could review their current provision of services for young people and provided suggestions for improvements. In 2003 the Royal College of Paediatrics and Child Health published the report 'Bridging the gaps: Health care for adolescents' (Royal College of Paediatrics and Child Health, 2003). This report highlighted adolescence (aged 13 to 18 years) as a time when patterns of health behaviour and use of services were developed which tended to be continued during adult life. The need for good provision of services when transferring from child to adult services was emphasised. The report advocated that adolescents were given the opportunity for some consultation time without their parents present. It was also suggested that a routine consultation between GPs and adolescents should be introduced on or around their fifteenth birthday, to enable a more personal relationship to be formed between the adolescent and GP. Such a consultation would also enable the adolescent to decide if they wished their care to continue with their current GP or to change to another, perhaps not seen by their parents. Better training for doctors, at undergraduate and postgraduate level, in communicating and working with adolescents was also advocated in the report.

In 2003, the Government published the green paper, 'Every Child Matters' (Department for Education and Skills, 2003) followed in 2004 by the paper 'Every Child Matters - The Next Steps 2004' (Department for Education and Skills, 2004). These papers, which encompassed a range of areas from health to social issues, outlined five key outcomes; being healthy, staying safe, enjoying and achieving, making a positive contribution and securing economic well being. In 2004 the Government published their most extensive document related to children, the National Service Framework for Children, Young People and Maternity Services (NSF for children) (Department of Health, 2004). National Service Frameworks (NSFs) have been published in a number of health areas and populations, for example older people and mental health. They are

designed to effect rapid change to key services, improve standards of care and to reduce variations in access and quality of services throughout the country. Accompanying the main NSF for children document (Department of Health, 2004) a document of key issues for primary care (Department of Health, 2004) was also published, designed as a tool for health care professionals to implement the NSF.

The NSF for children, key issues for primary care document (Department of Health, 2004) advocated the role of the pharmacist in consultations with children and their parents. The important role of the family in the promotion and care of children's health was emphasised, health care professionals were encouraged to work with children together with their families. Although recommendations were also made that health care professionals assist young people in taking on increased responsibility for their own lives it was recommended that children spend part of the consultation without their parent present to enable discussion of lifestyle and psychological issues with a health care professional. The NSF for children (Department of Health, 2004) document, which defined children and young people as those aged nineteen years and younger, outlined 11 key standards.

Standard one of the NSF for children (Department of Health, 2004) was concerned with health promotion, reducing inequalities in health and promoting a healthy lifestyle. Standard two highlighted the importance of the family in care for a child and outlined the need for adequate education, information and support for parents when their child is ill. The importance of the role of the father was emphasised, as were issues faced by children whose parents were divorced or had started a second family. Standard three emphasised the importance of high standards of care for children and the provision of family centred services, with consideration given to the family situation. It was advocated that children, young people and parents work as partners in the care of young people. Attention was paid in this standard to health care professionals listening to the needs of children and ensuring that they are encouraged and supported to give their views regarding their care and condition. Standard four of the NSF for Children

(Department of Health, 2004) related to the age-appropriateness of services for children in relation to health promotion, such as pregnancy and STDs, and improved access to services. Of particular note to young people with chronic conditions is the emphasis on the transfer from child to adult health care services, and that services assist young people to take increased responsibility for their own lives. Standard five outlined the provision of services to protect children from harm and abuse.

Standard six related to children or young people who were ill. Particular reference is made in this standard to the needs of children with long term health conditions. It is recommended that children are given the chance to develop self-confidence and self-management skills with help and information provided by health care professionals. The importance of young people and parents receiving documentation and information about the child's care, including letters and reports is also stressed. The use of audio-recording of consultations with health care professionals was advocated, to enable children to listen to the consultation again. Standard seven focused on children and young people in hospital and the needs of parents for explanation, reassurance and information during this time. The treatment of children on designated wards, rather than in adult wards, was advocated. The need for children with long term conditions to be prepared for the transition to adult services is also reiterated in this standard. Standard eight set out guidelines for disabled children and those with complex health needs and standard nine documented the mental health issues related to the care of children. Standard ten was concerned with medicines for children and young people. Reference is made to the use of unlicensed and off-label medicines for children and the need for appropriate arrangements to be in place to monitor this. The concept of concordance is advocated with the use of shared decision making between parents, children and health care professionals. Regular medication reviews are advocated to establish inappropriate prescribing (too high or too low), side effects a child might have experienced and when a medication should be changed or stopped. This standard also advocated the provision of clear and understandable information for children and parents about the child's medication, available in formats suitable for the child's comprehension.

Standard eleven of the NSF for Children (Department of Health, 2004) concerned maternity services and the first three months of life and therefore will not be discussed here. Implementation of the full NSF is scheduled to take place over the next ten years. Further recognition of the needs of children and young people to be represented at Government level has been reflected in the creation of a new post, the Minister for Children, Young People and Families.

1.10.2 Government policy concerning health and schools

Government policy in relation to health and schools has often been in the form of joint initiatives between the Department of Health and the Department of Education and Employment. An association between these departments took place with the introduction of the Healthy School Standard (Department of Education and Employment, 1999) which advocated the promotion of health amongst pupils and education regarding health related behaviours, such as diet and exercise. The document also focused on school education and stated that it should address other health issues such as drug abuse and sexual health. This concept was further endorsed through standard one of the NSF for Children (Department of Health, 2004) which stressed the important role of the school curriculum in promoting healthy eating and physical activity in children. Standard three of the NSF for Children further merged the areas of education and health with the development of the concept of 'Extended schools', designed to improve access to health services for young people. Extended schools provide health services such as immunisations, healthy eating clubs, exercise opportunities and sexual health advice within the environment of the school. The Department for Education and Employment set out guidance to schools regarding the provision of support for young people with medical needs in the form of the guide 'Supporting pupils with medical needs: A good practice guide' (Department of Education and Employment, 1996). The document stated that it was the responsibility of the parent to provide the school with information regarding their son's/daughter's health and medical needs. Within the school head teachers were responsible for the

medical needs of children. In conjunction with the child's parents the head teacher should discuss and agree the medical needs of the child. The document touched on the legal position of teachers and emphasised that they were not legally required to administer medication, but might volunteer to do so if they wish. The implementation of school policies regarding medication were strongly recommended in the document and guidelines to assist schools in the formulation of a policy were laid out. For children with long term medical needs the document recommended the formulation of written individual health care plans, drawn up with the parents of the child, the head teacher and relevant health care professionals. It was suggested the plan be reviewed annually. One chapter of the document is concerned with asthma, epilepsy, diabetes and anaphylaxis. In relation to asthma the importance of not locking away asthma medication was highlighted and the need for young people to have access to their medication when on school trips or participating in physical activities. For young people with diabetes the document advocated that pupils have access to a private location in which to administer injections of insulin, that the timing of school meals accommodated a child's needs and that whilst participating in physical activities pupils with diabetes had access to a sugary drink. Most recently, the NSF for Children (Department of Health, 2004), standard ten, emphasised the need for schools to carefully consider arrangements made for the management of pupils' medication.

1.10.3 Government policy concerning chronic conditions

In 2001 the Department of Health launched a new approach to the management of chronic disease with the introduction of the 'Expert Patient' (Department of Health, 2001). The Expert Patient promoted a health care system in which the experiences of those with a chronic condition were valued. The aim of the scheme was that those with chronic conditions would become key decision makers in their treatment process, rather than merely recipients of health care services. The aim of the system is that it would enable patients to have greater control over their lives and an active role in their care. The document also set out the implementation of Expert Patient Programmes which aim

to develop confidence and motivation in those with chronic conditions to use of their own skills and knowledge to take effective control over their life and chronic condition. The aim of the initiative is not to withdraw those with chronic conditions from contact with health care professionals, but rather to empower patients and improve their self-confidence in consultations with health care professionals. The Government outlined that the Expert Patient scheme would be piloted from 2001 to 2004 and introduced throughout the NHS between 2004 to 2007. The Expert Patient document (Department of Health, 2001) is concerned solely with adults with chronic conditions. However, standard six of the NSF for Children (Department of Health, 2004) stated that children should have the opportunity to become 'expert patients', to develop confidence and to learn the necessary skills to manage their own condition. For the implementation of the Expert Patient programme for young people to be successful further provision for this patient group, such as specific Expert Patient Programs, will need to be considered.

1.10.4 Government policy concerning asthma

In recent years there has been little Government policy or guidance specifically in relation to asthma, other than the use of asthma as an exemplar model for the implementation of recommendations from the NSF for Children, Young People and Maternity Services (Department of Health, 2004). Lack of Government policy in relation to the condition might be due to the trend towards the policy of self management of asthma (British Thoracic Society/Scottish Intercollegiate Guidelines Network, 2003). In recent years the management of asthma has been led by the principle of guided self-management by the patient (British Thoracic Society et al, 1997). This is a process in which the person with asthma is provided with education from a health care professional regarding how to manage their asthma and then manage their asthma symptoms outside of the health care professional environment.

A study by Jones, Pill and Adams (2000) which explored the views held by GPs, practice nurses and patients to guided self management programmes in the treatment of

asthma was critical of their use. Focus groups were held separately with each of the three groups. Purposive sampling was used to select the focus group of professionals. Two groups of GPs were selected, half of whom had an interest in asthma care and half with no specific interest. Practice nurses were selected from a range of GP practices and were all trained in managing asthma. Patients were assessed as compliant or non-compliant with their medication and were allocated to different groups accordingly. In addition to two groups of adult patients one focus group consisted of young people with asthma aged 12 to 17 years. The results of the groups indicated that neither health professionals nor patients valued the use of self-management plans. Nurses believed that the need for patient education and monitoring was best achieved by regular attendance by patients at an asthma clinic, which they believed use of the self-management plan discouraged. GPs were also critical of the plans and stated that patients were unable to take on the appropriate amount of information regarding the management of their condition. Patients felt that self management plans might be of use to some patients, but no participant felt that they were of relevance to them personally. Adult patients reported that they were already self managing their condition by taking drugs and avoiding triggers of the condition. Teenage patients indicated that they would follow plans if given them, but felt they might lose them or would follow them only for a limited time. The care taken in selecting participants for the study should have ensured that the views of a variety of health care professionals and adult patients were represented in this research. Although this paper concluded that teenage patients showed the same view towards self management plans as adult patients, only seven teenage patients were included in the research compared to 25 adult patients. The teenagers also were not divided into compliant or non-compliant groups as adult respondents were, the author did not comment on the effect of the use of a mixed compliant and non-compliant focus group.

Little reference has been made at policy or guidance level of the application of asthma self-management plans for use with young people. Milnes and Callery (2003) surveyed self-management plans for use by school aged children from forty-seven medical centres in the UK. Asthma self-management plans for use with children were obtained and

their content reviewed. Thirty-one (66%) centres had adapted adult self-management plans for use with children, the remaining centres (34%) used the standardised National Asthma Campaign self-management plan, designed for use with adult patients. Of those centres who had adapted self-management plans for children there were considerable variations in the person to whom plans were addressed (parent or child), criteria for treatment and the stated objectives of self-management plans. It was also noted that there were few opportunities for an individualised approach to self-management, as has been encouraged with adult patients. Milnes and Callery (2003) concluded that whilst most centres agreed self-management plans needed adaptation for use with children, there was little consistency between centres with regard to the way plans had been altered.

1.10.5 Government policy concerning diabetes

Diabetes has in recent years become a topic of concern for the Government, in particular the increase in type 2 diabetes, as not only has the increase in cases been more dramatic than type 1 diabetes, but steps can be taken to delay onset of type 2 diabetes or even prevent it occurring. The Audit Commission published a report in 2000 which reviewed diabetes services in England and Wales (Audit Commission, 2000). It documented the increased prevalence of diabetes and estimated the total cost of diabetes care in the UK as two billion pounds a year. The report noted how the costs of care could be reduced if less people suffered complications of the condition and outlined how these could be prevented through better control of diabetes and improved screening. The report highlighted a variation in the standard of diabetes care in different areas of the country and in some areas insufficient access to medical care.

Following the report from the Audit Commission, the National Service Framework for Diabetes was published in two parts (Department of Health 2001, 2003). The first in 2001, the National Service Framework for diabetes: Standards, followed in 2003 by the National Service Framework for diabetes: Delivery Strategy. Although largely concerned with type 2 diabetes some of the recommendations made in the National

Service Framework (NSF) were applicable to those with type 1 diabetes. The NSF for diabetes: Standards (2001) set out twelve standards of care for those with diabetes. Four of these standards referred specifically to young people with diabetes, that of empowering people with diabetes and encouraging partnerships in decision making (standard three) and the rights of young people to receive a high quality of care with the involvement of family in day to day care of diabetes (standard five). Standard six stated that young people with diabetes should experience a smooth transition of care from paediatric to adult services and standard ten outlined how young people and adults with diabetes should receive regular surveillance for long-term complications of the condition. The NSF for diabetes: Delivery Strategy (2003) set targets for regular check ups for people with diabetes and systematic eye screening. It also listed plans for the organisation of services at a local level with the setting up of diabetes networks, including the involvement of people with diabetes, to determine local services.

Recent guidelines published by the National Institute for Clinical Excellence (NICE, 2004) have set out specific recommendations in relation to young people with type 1 diabetes. These included home-based services at first diagnosis and telephone support from paediatric diabetes care teams to parents of young people with diabetes. The guidelines also advocated parents and young people being provided with information regarding a target for long-term glycemic control and ongoing information about the condition, as well as involvement in decision making. Screening to prevent the long term complications of diabetes were also recommended.

1.11 Aims and objectives of the main study

The aims and objectives of the main study were devised from the review of previous literature and from Government policy documents. The overall aim of the research was to describe the nature of partnerships between young people and their parents in the management of asthma or diabetes, and for these findings to inform the development of services to support the needs of young people with asthma or diabetes and their parents.

There were six specific research objectives:

- to establish the roles of young people and their parents in the management of the young person's asthma or diabetes,
- to describe asthma and diabetes management in the context of shared responsibility between young people and their parents, from the perspectives of both young people and their parents,
- to establish if there is a relationship between the age of a young person or length of time since diagnosis and their roles within a partnership,
- to establish the implications of these patterns of shared responsibility for the advice and support provided by health professionals in the context of NHS provision,
- to validate use of the PedsQL measure of the quality of life of young people with asthma and diabetes from the perspective of young people and their parents,
- to inform better health care.

SUMMARY OF CHAPTER ONE

Chapter one has reviewed the literature relevant to the research presented in this thesis. As documented in this chapter few studies have explored the experiences of the management of chronic conditions solely from the perspective of young people. Much research has involved the parents of young people with chronic conditions and has focused upon the impact of caring for a young person with a chronic condition on their parent. Some studies (Østergaard, 1998; Peterson-Sweeney et al, 2003) have documented the parent's perspectives of the management of their child's condition. Studies have examined parents' and young people's views of the management of chronic conditions. In relation to the study of asthma, research has focused around management of the condition surrounding an asthma attack (Prout, Hayes and Gelder, 1999; Pradel, Hartzema and Bush, 2001; Callery et al, 2003). In relation to diabetes, studies have taken a quantitative approach to the roles of diabetes management performed by young people and their parents (Anderson et al, 1990; Hanna and Guthrie, 2003; Palmer et al, 2004). None of the research identified from the literature has taken an in-depth approach to the roles of condition management performed by young people and parents on a daily basis, or the extent to which they might work together in partnership in the management of the condition.

Research by Rajaram (1997) and Koch, Karlik and Taylor (2000) have documented the roles performed by partners and spouses in the management of diabetes in adults, in the absence of literature regarding partnerships between young people and parents these studies revealed potential roles that might be performed by parents in the management of their son's/daughter's chronic condition.

The majority of research identified in relation to the management of chronic conditions in school has focused upon the policies of schools and views of staff. The exception which documented the management of asthma in schools from the perspective of young people was that of Chadwick (1996). No research was identified which had examined the management of diabetes in schools.

Research concerning young people's and parents' experiences and views of health care professionals have been reviewed in this chapter. Only the work of Beresford and Sloper (2003) has examined the views of young people with chronic conditions of health care professionals. Research to date has tended to focus upon the relationships between young people and the doctor, rather than other health care professionals.

Limited work has concerned the information needed and used by young people with chronic conditions and their parents. For adequate support and advice to be provided to them it is vital that the information provided is that which they require and will use. The review of the literature identified few studies which have measured the QoL of young people with chronic conditions. The measurement of QoL of young people with asthma or diabetes has not been conducted in the UK.

In relation to the study of asthma, the influence of the age of a young person or length of time since diagnosis and roles of asthma management undertaken by young people have been largely absent from the literature. Studies of diabetes have documented the influence of age in relation to the role of parents in partnerships from a quantitative approach, although findings have been conflicting. Anderson et al (1990) and Palmer et al (2004) found that with increasing age children completed tasks of diabetes management more independently of parents, whereas Hanna and Guthrie (2003) found no significant differences in parental involvement in diabetes management at different stages of adolescence. No studies have explored the relationship between the number of years since diagnosis and roles of young people in diabetes management. Information regarding health behaviours in relation to the age of the young person, or length of time since diagnosis might inform health care professionals of the roles assumed by young people in the management of their condition.

The review of the literature informed the preliminary work and development of the main study protocol and the focus of this thesis; partnerships between young people and their parents in the management of asthma and diabetes. From gaps in the existing literature, the main study protocol was developed to encompass issues concerning the roles of

young people and parents in partnerships, the nature of partnerships between young people and their parents, the influence of age and number of years since diagnosis in relation to the management of chronic conditions, management of chronic conditions in school, young people's and parents' experiences of consultations with health care professionals and the information needs of young people and their parents. A measurement of the quality of life of young people with asthma and diabetes was incorporated into the main study design.

Chapter 2- Methods

Chapter 2 Methods

Chapter two describes the methods used in this research and the processes by which this methodological approach was developed. This chapter is divided into five sections. Section 2.1 outlines the search strategy adopted for identifying relevant literature. Section 2.2 reports the preliminary research conducted to inform the development of the main research study. The methodological issues concerning research involving children are examined in section 2.3. Section 2.4 reports the pilot work that was conducted and the implications of that work on the main study. The final section of this chapter, section 2.5, describes the methods used in the main study.

2.1 Searching the literature

Section 2.1 describes the search process undertaken to review the relevant current literature relating to this thesis research (see chapter 1). Given the broad topic areas of interest in this thesis several methods of literature searching were used. Searching was conducted throughout the research period from January 2000 to December 2004.

2.1.1 Use of language

The research presented in this thesis concerns young people with chronic conditions. In searching the literature these two key terms were sometimes used, but other similar terms were also found to be used in their place. To ensure articles of interest were not excluded, in all searches concerning the terms ‘young people’ or ‘chronic condition’, alternative words or phrases were also searched.

A number of terms were used in the literature to refer to those aged 8 to 16 years, the age range of concern in this research. In searches related to young people the terms ‘teens’, ‘teenagers’, ‘adolescents’ and ‘children’ were also used.

When searches were conducted related to a chronic condition the terms ‘chronic illness’ and ‘chronic disease’ were also searched.

2.1.2 Electronic searches

Electronic searches were used to identify research that had been undertaken on issues related to the thesis. The databases Medline, Sciencedirect, PubMed, BIDS and Psyclit were searched. Searches were conducted using databases from 1987- 2004.

Searches were conducted for articles using the keywords: ‘asthma’, ‘diabetes’, ‘young people’, ‘teens’, ‘teenagers’, ‘adolescents’, ‘children’, ‘chronic condition’, ‘chronic illness’, ‘chronic disease’, ‘doctor’, ‘nurse’, ‘school’, ‘parents’, ‘family’, ‘partnerships’ ‘knowledge’, ‘information’, ‘patient information’ and ‘quality of life’.

2.1.3 Reference lists from identified papers

Reference lists from identified papers were searched for further articles of interest. Where appropriate these were identified and reviewed. As with electronic searches papers prior to 1987 were excluded, other than where reference to a paper was made which was considered of particular significance to this research.

2.1.4 Journals identified to be of specific interest

Through the use of electronic searches certain journals were identified as of particular relevance to the research presented in this thesis. These journals were Archives of Disease in Childhood, BMJ, Diabetes Care, the Journal of Adolescent Health and Sociology of Health and Illness. Contents pages of each edition of these journals were hand searched throughout the research period (January 2000-December 2004).

2.1.5 Excluded studies

Research which explored the causes of asthma or diabetes, or technological developments in their treatment were not included in the review of literature. Whilst research concerned with chronic conditions was examined studies related to oncology patients were excluded, due to the unique nature of the condition, complexities of treatment and prognosis which were considered diverse in comparison to other chronic conditions. Studies that related solely to adult patients were also excluded as it was considered that the needs and experiences of adult patients would be diverse from those of young people.

2.2 Preliminary Work

Section 2.2 reports the preliminary work that was undertaken to inform the development of the main study. The section begins with a description of the aims and objectives of the preliminary fieldwork. Each method of preliminary work undertaken is reported, the findings summarised and implications for the development of the main study are outlined. The preliminary fieldwork for the asthma and diabetes parts of the study are described separately.

2.2.1 Aims and objectives of preliminary fieldwork

The preliminary fieldwork had two main aims. These were:

- to gain greater insight into the management of asthma and diabetes by young people and their parents,
- to establish issues that might be of importance to young people with asthma or diabetes and their parents for inclusion in the interview schedule in the main study.

2.2.2 Preliminary work in relation to the asthma part of the study

The preliminary fieldwork for the asthma part of the study consisted of three parts. These were an interview with an asthma nurse based in general practice, a telephone interview with a representative of the National Asthma Campaign help line and a review of written material designed for young people with asthma and their parents. Attempts to meet with young people with asthma and their parents at support groups are also described in this section.

2.2.2.1 Interview with an asthma nurse based in general practice

An interview was conducted with an asthma nurse who ran an asthma clinic for young people and was based in a general practice surgery. The aims of the interview were:

- to gain insight into the issues that surround the management of asthma in young people,
- to establish those issues a health care professional who works with young people with asthma considered would be of importance in this research.

General practice surgeries were randomly selected from health authority lists in the two areas with which the main study was concerned (Enfield and Haringey and North and East Hertfordshire). Surgeries were contacted by telephone by the researcher and asked if the surgery had an asthma nurse. If so, an interview with the asthma nurse was requested. Five GP surgeries were contacted. In three surgeries the asthma nurse declined to be interviewed as they did not feel they had the time to participate and one surgery did not have an asthma nurse. In one surgery the nurse who ran the asthma clinic consented to an interview.

The interview was informal and unstructured, although the researcher had a guide of topics to be addressed which related to the aims of the interview outlined above. The interview was audio recorded and subsequently transcribed. A qualitative approach was taken to the analysis of the transcript, data were coded in relation to addressing the aims of the preliminary work.

Analysis of the interview revealed that care for young people with asthma was usually concentrated within the GP surgery, but might be shared between GPs and nursing staff. Only severe asthma was managed by a hospital consultant. Young people with asthma were seen in the practice regularly by nursing staff and by GPs when unwell. The nurse identified her role as monitoring the growth of young people, showing inhaler technique, monitoring peak flow readings and providing support. Young people were seen with their parents in consultations usually up to the age of sixteen years and at times older. Young people from the age of six years were often able to use their own inhalers. The nurse identified that parents played an important role in assisting children with the self-management of asthma and helping them in aspects of their care such as altering dosage of medication or monitoring peak flow readings. The severity of asthma amongst young people varied, with some young people using only reliever medication and some preventer and reliever medication. Some young people used nebulisers. The nurse identified that some young people seen at the clinic had experienced problems with the management of their asthma whilst at school; gaining access to their medication, using medication without parental assistance and participating in sport. The nurse reported poor attendance at the clinic by young people.

Issues considered in relation to the main study from the interview with the asthma nurse were:

- 1 In relation to methods of recruitment there might be poor attendance at asthma clinics by some young people, suggesting recruitment by a researcher at an asthma clinic might result in poor response rates.
- 2 Management of asthma at school is an issue for some young people.
- 3 The different roles of health care professionals in the care of young people with asthma; the role of the GP focused on when the young person was ill and that of the nurse on regular check ups.
- 4 The role of parents in the management of a young person's asthma.

2.2.2.2 Contact with the National Asthma Campaign help line

Contact was made with the National Asthma Campaign help line. The aim of this part of the preliminary work was to establish the types of issues about which young people and their parents contacted the National Asthma Campaign. The National Asthma Campaign headquarters were contacted by telephone. The project was briefly explained and the researcher was referred to a member of the National Asthma Campaign help line staff. An informal telephone interview was conducted. No interview schedule was used, but the researcher's objective was to establish the range and types of queries received by the National Asthma Campaign help line from young people and parents. Notes were made by the researcher during the telephone interview and written up immediately afterwards. This account of the interview was analysed, issues of relevance to the aims of the preliminary work were identified and coded. This process was repeated to ensure all issues had been noted.

From the interview it emerged that young people rarely contacted the help line themselves for information. The majority of calls were from carers either of children or the elderly. Parents often contacted the help line in relation to problems with the management of asthma at school, seeking written information about asthma and its treatment that they could provide to school staff. Other common requests from parents were for information relating to medication, particularly the use of steroids. In the opinion of the employee interviewed, a move away from care in specialist asthma centres and into care in GP surgeries had led to less specialist care for young people with asthma, as practice nurses were sometimes not specifically trained to provide asthma care. The employee believed this had accounted for an increased number of calls to the help line.

Issues contemplated in relation to the main study from the interview with the National Asthma Campaign help line employee were:

- 1 Management of asthma at school as an issue of concern to parents.
- 2 Parents might have concerns related to the use of asthma medication, particularly the use of steroids.

2.2.2.3 Review of written material designed for young people with asthma and their parents

Literature designed for young people with asthma and their parents was reviewed. The aim was to establish the types of issues reported in written materials designed for young people with asthma and their parents. Information leaflets on asthma were acquired from asthma nurses, the National Asthma Campaign and GPs, a total of eight items were identified. Magazines designed for young people by the National Asthma Campaign (Xhale and Kids Zone) were also obtained. Sections of the website of the National Asthma Campaign (www.asthma.org.uk), visited on 21st July 2000, in relation to young people and parents were also examined.

Content analysis was used to examine the data. This method involved assessing the importance of a topic by means of:

the number of times it is mentioned, the number of column inches devoted to it, the square inches of photographs displayed, the number of times it appears in the index (Macdonald and Tipton, 1993, p.197).

The use of column inches was deemed inappropriate due to the nature of the written material. Therefore a simplified approach to content analysis was used in which the issue which was the focus of each article was identified and, if present more than once, the number of times it was mentioned noted. The focus of an article was identified as the topic with which the article was primarily concerned. Literature searches were conducted to establish methodological approaches to the analysis of website material but no information was found. The researcher therefore applied the principles of conventional content analysis (Macdonald and Tipton, 1993) to website material.

Written material was read systematically, themes or topics identified in the literature, such as school, were noted. Additional themes were identified as they arose, where issues were mentioned more than once the frequency of occurrence were recorded. Advertisements included in written information were excluded. Documents were re-read on a separate occasion and the process repeated. Analysis of the documents identified

the most common theme as medication (n=58) these included references to the use of medication, type of medication and inhaler devices. Articles were identified which related to triggers of asthma (n=28) these included references to pets and allergies. Sport was identified as a separate category (n=7). Reference to health care professionals (n=16) was identified from written information, as was information help lines or sources of support for young people with asthma or their parents (n=14). Other issues identified included charity events (n=4), school (n=3), smoking (n=1) and the effect of asthma on intimate relationships (n=1).

Issues taken forward for consideration in relation to the main study from the review of literature were:

- 1 The variety of different types of medication and inhaler devices that are used by young people with asthma.
- 2 Triggers to the condition and the impact of these on the social lives of young people with asthma.

2.2.2.4 Support groups for young people with asthma and their parents

Support groups for young people with asthma and their parents were contacted and invited to participate in discussions with the researcher regarding their experiences of the condition.

The aims of interviewing members of support groups for young people with asthma and their parents were:

- to gain greater insight into the experiences of young people with asthma and their parents,
- to find out about the experiences of young people with asthma and their families of health care services currently available to them.

The National Asthma Campaign and the British Lung Foundation were contacted by letter (appendix A) in September 2000 and asked for the contact details of support groups or organisations in London and the area near to the researcher's home.

A reply was received from the National Asthma Campaign in October 2000, listing three local groups. Each of these were contacted by letter (appendix B) in October 2000. One month later a follow up letter was sent to each of these groups. For two groups no response was received. The secretary of the remaining group contacted the researcher to report that their group was for adults and they did not believe it would be of help for them to participate in discussions.

The British Lung Foundation did not reply to the initial letter. A follow up letter was sent in October 2000 and an e-mail enquiry in November 2000, but no response was received. A telephone call to the British Lung Foundation in January 2001 revealed that the British Lung Foundation would contact the organisers of support groups on the researcher's behalf passing on the researcher's contact details. No further correspondence was received.

In summary, the preliminary work identified a number of issues of importance to the asthma part of the main study. These included the variety of inhaler types and medication available, that young people attended consultations with parents and that parents were often involved in their care. School was noted as a potential location for problems with the management of asthma. Parental concerns related to medication, particularly the use of steroids, were also identified. Triggers to asthma and the impact of these on the lives of young people were highlighted. Preliminary work identified poor attendance rates by young people at asthma clinics.

2.2.3 Preliminary work in relation to the diabetes part of the study

Section 2.2.3 outlines the preliminary work undertaken for the diabetes part of the study. The preliminary work comprised three parts, an interview with a hospital based paediatric clinical nurse specialist in diabetes, a review of written material designed for young people with diabetes and their parents and focus groups with members of support groups for young people with diabetes and their parents.

2.2.3.1 Interview with a hospital based paediatric clinical nurse specialist in diabetes

A hospital local to the researcher was contacted by telephone and a hospital based paediatric clinical nurse specialist in diabetes identified and invited to participate in an informal interview. The aims of the interview with the hospital based nurse specialist in diabetes were:

- to gain insight into the issues that surround the management of diabetes in young people,
- to investigate what issues a professional who works with young people with diabetes thought would be of importance in this research.

The interview was informal and unstructured although the researcher had a list of topic areas which acted as a guide for the interview. The participant requested the interview not be tape recorded. Therefore the researcher made notes during the interview process which were written up fully immediately after the interview. Notes from the interview were analysed and issues relating to the objectives of the preliminary work were coded. The interview account was re-read to ensure all issues had been noted.

Analysis of the interview with the hospital based paediatric clinical nurse specialist revealed care for young people with diabetes was managed within the hospital setting. In the hospital, within which the nurse was based, the diabetes clinic team was made up of consultants, specialist diabetes nurses, dieticians and psychologists. The children's clinic was run separately from adult clinics and was for young people from birth to the age of 16 years. From 16-18 years young people attended an adolescent clinic, designed as a transition of care from child to adult clinics. The nurse stated that, in her experience, obtaining good diabetic control in young people was a challenge to health care professionals, young people and their parents. The nurse identified parents as participants in the consultation and as having an important role in the management of the condition at home. She noted it could be difficult for health care professionals to ensure young people comprehend the long-term complications to their health of poor diabetic control. The nurse reported that young people often did not monitor their blood

glucose levels regularly and experienced problems with the over-use of injection sites, which can lead to poor absorption of insulin. Maintaining a healthy diet might be difficult for young people. The nurse expressed concern that young people might omit doses of insulin to cause weight loss, particularly young women, and that the number of eating disorders amongst young people with diabetes in the clinic was increasing. The nurse reported that conflict between young people and parents over issues related to their diabetes occurred frequently. Parents who attended clinics were often distressed by their son's/daughter's poor management of the condition.

Issues identified in relation to the main study from the interview with the hospital based paediatric clinical nurse specialist in diabetes:

- 1 Maintaining good diabetic control can be a challenge to young people and their parents.
- 2 Young people might not monitor their blood glucose levels regularly.
- 3 Maintaining a healthy diet might be difficult for young people.
- 4 Conflict might occur between young people and their parents related to the young person's diabetes.

2.2.3.2 Review of written material designed for young people with diabetes and their parents

Written material designed for young people with diabetes and their parents was obtained from diabetes clinics and Diabetes UK. Thirteen leaflets, booklets and magazines were collected from these sources. These included the most recent editions of the magazines by Diabetes UK included 'Link Up' a magazine for parents, 'On the Level' a magazine designed for teenagers and the 'Tadpole Times' a magazine for children. Areas of the website of Diabetes UK (www.diabetes.org.uk) related to children and young people, visited on 24th July 2000, were also examined. The aim of this part of the preliminary work was to establish the types of issues reported in written materials designed for young people with diabetes and their parents. A simplified version of content analysis (Macdonald and Tipton, 1993) was conducted on the written material, as described in section 2.2.2.3.

The written material was read systematically and the focus of each article recorded. Where themes were identified more than once the frequency was recorded. Documents were re-read on a separate occasion. Advertisements were excluded from analysis. Analysis revealed that the most frequent topics were items related to insulin and injections (n=56); the use of insulin, storage, type and how and where to inject. Identification of hypoglycemia and action to take in the event were also identified (n=38). Blood glucose monitoring was a topic frequently noted (n=32) as were issues related to exercise (n=30) and diet (n=24). Long term complications of diabetes were also addressed (n=15). Other topics included social behaviours, such as smoking and alcohol (n=13), descriptions of diabetes (n=11), information related to health care professionals (n=11), what to do in the event of illness (n=10), school (n=9) and travel (n=5). The remaining issues were fundraising (n=4), personal relationships (n=2), pregnancy (n=1) and the effect of hormones on diabetic control (n=1).

Issues considered in relation to the main study from the analysis of written material were:

- 1 The importance of the management of diabetes; monitoring of blood glucose levels, injection of insulin and healthy diet.
- 2 Understanding of the adverse effects of hypoglycemia and the importance of managing blood glucose levels.
- 3 The long-term complications of diabetes and sensitivity of this issue with young people and parents.
- 4 The impact of diabetes on social activities; exercise, travel, smoking, drugs and drinking alcohol.

2.2.3.3 Support groups for young people with diabetes and their parents

A letter was sent to Diabetes UK (appendix C) on 14th June 2000 requesting the contact details of support groups for young people with diabetes and their parents in an area within reasonable travelling distance of the researcher. On 28th July 2000 a reply was received with the contact details of three support groups known to Diabetes UK. Each of these were sent a letter (appendix D) requesting that the researcher visit the group and

talk informally to the parents of young people with diabetes. Two support groups (group A and group B) replied and visits to pre-arranged meetings of each group were arranged. Details of a further support group (group C) were given to the researcher by the secretary of group B, which was subsequently contacted and a visit arranged.

The aims of meeting with members of support groups for the parents of young people with diabetes were:

- to gain greater insight into the experiences of young people with diabetes and their parents,
- to find out about the health care services currently experienced by these young people and their parents.

The researcher attended pre-arranged meetings of the support groups rather than arranging additional meetings which would have taken several months. Data collection varied in each group due to the nature of the group and the environment of the meeting. The researcher had a list of topics for discussion with support group members.

Group A met at a member's home in the evening. The group was for the parents of young people with diabetes who met to share their experiences. The researcher held a focus group at the meeting with the six parents who were present, covering a range of topics such as the process of diagnosis, experiences of health care professionals, daily management of diabetes and schools. The focus group was recorded and field notes were made during the process to note who was speaking. The recording was transcribed verbatim and analysed.

Data from each focus group were analysed using the same process. Transcripts or field notes were read and themes relevant to the aims of the preliminary work identified and noted. Upon completion of the analysis of all focus groups the findings were examined together in relation to the objectives of the preliminary work.

The meeting of group B was held in a community hall on a weekend afternoon and comprised approximately seventy young people and parents. Young people played

games and participated in activities whilst parents spoke to each other in small groups. The meeting operated on a 'drop in' basis with people arriving and leaving throughout the afternoon. Parents were therefore approached by the researcher where they were sitting and were interviewed either alone or in the groups in which they had been talking. Every effort was made to ask similar questions to each group of parents interviewed. Field notes were made during interviews as due to the size of venue and noise of young people tape recording was not appropriate. Field notes were fully written up immediately after the meeting and analysed as previously described.

Group C was held in a large community venue in the evening and consisted of approximately twelve members who were parents of young people with diabetes. The meeting began with a pre-arranged talk by a young woman who had diabetes. After this the researcher conducted a brief focus group with the parents. Participants requested the focus group not be audio recorded. Notes were made during the discussion and were fully written up immediately after the meeting and subsequently analysed.

The results of the analysis for each group will be reported separately, issues considered in relation to the main study will encompass findings from all three focus groups. Analysis of group A identified the diagnosis of a child with diabetes as an extremely traumatic experience. Parents expressed anxiety and worry about their son's/daughter's diabetes and the potential long and short term health problems associated with the condition. Daily tasks related to their son's/daughter's diabetes were identified by parents as; monitoring blood glucose levels, the injection of insulin and monitoring of the young person's diet. Problems of the routine of injections and meals in school holidays or at weekends were discussed, particularly when the young person wanted to wake up at a later time. One parent described great difficulties in persuading his son to follow a healthy diet. Parents described anxiety and nervousness in relation to school trips and their son/daughter staying overnight away from them. Parents reported a lack of information from hospitals regarding long term complications of the condition, one parent was unaware of the complications of diabetes until she had received this information from other support group members.

All of the group expressed concern regarding the management of diabetes in school, particularly lack of knowledge amongst staff of the complications of diabetes and issues surrounding its management. Five of the six parents had sons/daughters who attended the same hospital. Parents commented on the lack of paediatric diabetes consultants and therefore the lack of understanding from consultants in relation to the management of the condition in children. The hospital attended by the majority of parents had no diabetes nurse at the time of the focus group which was a situation much criticised by group members, who spoke of valuing such support when their son/daughter was first diagnosed with the condition. A lack of support outside of visits to the hospital was identified as a problem, one parent suggested the implementation of a help line which could be contacted in situations when no other help was available.

Members of group B identified the management of diabetes in school as the issue of most concern to them in relation to their son's/daughter's diabetes. Several parents reported discussions with their son's/daughter's school in relation to the management of the condition and need for staff to be aware of the physical signs that the young person's condition had deteriorated and needed medical attention. Parents were concerned about the lack of knowledge of school staff regarding the condition and possible implications of this on the health of their son/daughter. One parent believed her son was not treated seriously by staff when he had experienced hypoglycemia, low blood glucose levels, she felt that school staff had thought her son was pretending to be unwell. Another parent identified the attitude of potential schools to her son's diabetes as a factor in selecting the secondary school which he would attend. Parents also described their distress and trauma at the initial diagnosis of diabetes. Some parents described social limitations experienced by their son/daughter due to their diabetes. Three parents felt that diabetes affected their son/daughter staying overnight with friends or being invited to friends' houses and noted that other parents were wary of the responsibility of their child visiting them. One parent identified that not being able to eat sweets was the most difficult aspect of the condition for her daughter. Two parents described the extensive impact of their son's/daughter's diabetes on their social life and that of other family members. One parent identified her son wanting to go to sleep overs with friends as a trigger for him taking on the role of injecting insulin without assistance. Five of the six parents had

children under the care of the same hospital. Parents praised clinic staff but felt that consultations took place with too many health care professionals in the room, usually five people. Three parents identified a lack of support from health care professionals outside of clinic visits and believed they were left to manage the condition alone. One parent felt that six monthly visits were not frequent enough.

Analysis of focus group C identified the infrequency of blood glucose monitoring by young people as an issue of concern to parents. Parents were also worried about dimpling of the skin at injection sites and bruising to their son/daughter caused by the injection of insulin. The impact of hormones and emotional changes to the young person were also discussed by parents and the impact that these might have on diabetic control. Parents described the emotional difficulties they had experienced whilst they had adjusted to their son's/daughter's initial diagnosis of diabetes. Diet was identified as an issue, particularly young people not being able to eat sweets. Four parents expressed anxiety for the future management of their son's/daughter's diabetes, as they approached adolescence and also in relation to when they left home or attended university. Two parents mentioned Diabetes UK holiday camps as important in educating their son/daughter and themselves about aspects of diabetes. Parents noted that although hospital services were good the majority of the time they felt alone in the management of their son's/daughter's diabetes, one parent described the role of group C in providing additional support as essential.

Issues identified in relation to the main study from meeting with support group members:

- 1 The emotional difficulties experienced by parents in coping with their son's/daughter's condition, particularly when first diagnosed.
- 2 Management of diabetes at school as an area of concern to several parents.
- 3 The importance of the young person following a healthy diet and difficulties associated with this.
- 4 Parents perceived much of the time they were alone in the management of their son's/daughter's diabetes and had limited assistance from health care professionals.

In summary, section 2.2.3 has reported the preliminary work in relation to the diabetes part of the study. The interview with a hospital based paediatric clinical nurse specialist, review of written material and focus groups with support groups identified a number of issues for consideration in the formulation of the main study protocol. These included an awareness of the emotional impact of diabetes on parents and therefore the need for a sensitive approach to issues during data collection. School as an issue of concern to parents was also identified as was the importance of a young person with diabetes monitoring their condition through blood glucose tests, diet and exercise. The complications of hypoglycemia and how they were managed were highlighted. Parents feelings of isolation in the management of their son's/daughter's condition and the potential for conflict between young people and their parents in relation to the management of diabetes were also noted. The following section, 2.2.4, reports the impact of the preliminary work from both parts of the study, on the development of the main study protocol.

2.2.4 Impact of preliminary work on the development of the main study

Several methods were used in the preliminary work to research the areas of asthma and diabetes and to obtain information to inform the development of the main study. Some issues considered were condition specific. In the asthma part of the study the preliminary work identified the variety of inhaler types and medication available and parental concerns relating to medication, particularly the use of steroids. In the diabetes part of the study the emotional difficulties of parents were reported, the importance of a healthy diet, the complications of hypoglycemia, parents feelings of isolation in the management of their son's/daughter's condition and the potential for conflict between young people and their parents were identified. In both conditions the preliminary work identified management in school as an area of potential problems and reported issues related to the involvement of health care professionals in the care of young people.

In relation to the methodological approach to be used in the main study, the preliminary work suggested limitations to the recruitment of young people through attendance of asthma clinics due to reported poor attendance rates. The use of focus groups as a

method of data collection revealed it was difficult to build a detailed description of the nature of the management of asthma or diabetes between one parent and young person when the experiences of a number of parents were being obtained. The following section of this chapter, section 2.3, examines methodological issues related to research involving children.

2.3 Methodological issues in relation to research involving children

At the time of preparing the main study protocol consideration was given to the appropriate methodological approach to be taken to research involving children. At this time (August 2000) limited authors had addressed the issues related to research involving children. As Dixon-Woods, Young and Heney (1999) noted, the lack of research into children had led to little discussion of appropriate methodologies for use when conducting research with this group and little available advice on the approach to research that should be taken with them. Section 2.3 reports methodological approaches that have been used in the study of children and highlights differing opinion and debate amongst researchers regarding the approach taken to the study of children.

James, Jenks and Prout (1998) have advocated, in research involving children, the need to consider the way in which children relate to the world as distinct from the perspective of adults. They have drawn particular attention to the relationship between the adult researcher and child participant. Children's relationships with adults are often structured and adults have a defined role such as teacher, nanny or sports coach. A child might therefore be unsure how to relate to a researcher, they might be suspicious or cautious of their presence and the role they were there to perform (James, Jenks and Prout, 1998). Such considerations have led to the development and use of novel methods in research involving children, which attempt to overcome the differences between adult researcher and child participant which Keats (2000) called 'the wide gulfs of age and experience'.

An ethnographic approach was used by Corsaro (1997) in which he attended nursery schools and sat and played amongst the children. Corsaro (1997) attempted to be seen

as a child by the objects of his study to facilitate his research of their environment. Corsaro (1997) noted that in his research in the United States children accepted his presence in an environment usually solely for children and after a while began to ask him questions and involve him in play, despite his obvious adult nature and size difference from children. James, Jenks and Prout (1998) have been critical of attempts from a researcher to become 'friends' with children whom they were studying and state that such an approach could be unsuccessful as it might be viewed with uncertainty by children.

An approach of non-participant observer was used in research by Waksler (1991) who examined the use of punishment in school by sitting at the back of a classroom and recording behaviours. Waksler (1991) reported her presence was largely unnoticed by children and was accepted within the environment. Observational methods, in the form of video diaries, were used by Rich et al (2000). Video diaries were used to record day to day experiences of having asthma, in young people aged 8 to 25 years, to show clinicians the realities of managing the condition in everyday life from the perspective of children. Use of observational methods did not involve the researcher engaging directly with children and therefore overcame the issues of communication and different status between adult researcher and child participant. Although suitable for an observation of behaviours of children, such approaches do not enable the researcher to elicit the opinions or views of children.

Some researchers have used children's drawings in an attempt to break down barriers of communication between children and researchers. Use of children's drawing in research stemmed from the use of drawing in relation to child therapy, in which drawings were used to facilitate discussion of issues such as depression, child abuse, sexual abuse and traumatic life events (Malchiodi, 1998). Children's drawings within research have been treated as data. Banks (1990) requested children, aged 3 to 15 years to draw a picture of a germ. Pictures were analysed through the classification of drawings into seven categories (line scribbles, faces, human forms, monsters, cell I - closed shape no internal markings, cell II - closed shape with internal markings and cell III - closed shape containing definite nucleus). Banks (1990) concluded that children saw germs as a living

thing not in human form, but that attitudes to germs and illness changed as children grew older. Children younger than 12 years saw germs as a 'monster' or in human form whereas children aged twelve years and over were more likely to draw pictures of cells. Parish (1986) advocated the use of the drawing approach as it enables children to communicate in greater depth than through verbal communication alone. She notes, from use of drawing with young people in hospital, that drawing facilitates more open and direct communication of the views of the child. Children's enjoyment of drawing has also been considered an advantage of use of the technique as it engages the child. Christensen and James (2000) noted, from their research of the social experience of being ten years old, that when given the choice the majority of children preferred to convey their weekly activities through drawing rather than writing.

Oakley et al (1995) combined the use of the drawing with writing as a methodological technique to explore children's (n=100), aged 9 and 10 years, knowledge of health and cancer prevention. Children in primary schools were asked to write or draw 'anything you think keeps you healthy' and 'anything you think makes you unhealthy'. Drawings were scanned into a computer database for analysis. Themes were identified from drawings and classified as 'healthy' or 'unhealthy' behaviours. 'Healthy' behaviours were categorised as diet, exercise and sport, hygiene (such as cleaning of teeth), not smoking, sleep and a category containing miscellaneous items. 'Unhealthy' behaviours were smoking, diet, environment, violence, hygiene, alcohol, medicines and a miscellaneous category. Children were also asked to write or draw anything about cancer. Children expressed that people could die from cancer, that it could cause hair loss and that it was caused by smoking. Those children who chose to draw, often drew pictures of cells, fires in the body or unpleasant faces or monsters. Oakley et al (1995) believed the use of such a method enabled children to effectively communicate their beliefs regarding health and the prevention of cancer.

A study by Pridmore and Lansdown (1997) compared the use of the drawing method with the written method to gain insight into the health perceptions of children. Children aged 9 or 10 years were divided into groups of 'draw and write', 'label and write' and 'write only' methods. A total of 126 children took part in the study and were selected

from three different types of school in the London area. The researchers reported that each method yielded approximately the same number and type of categories of responses to the research topic. Children appeared to enjoy drawing and writing more than only writing. Writing as a sole activity produced less detailed information yet was the quickest in the identification of major categories of information. Pridmore and Lansdown (1997) concluded that no single method was best in all contexts.

Researchers such as O’Kane (2000) have advocated the use of participatory techniques to engage children in the research process by involving them in activities. Such techniques were used in research which explored the participation of children (aged 8 to 12 years), who were under the care of local authorities, in decision making. O’Kane (2000) used two participatory techniques to facilitate discussion with children; a decision making chart and a pots and beans activity. The researcher and the child made a decision making chart. The child was asked to note types of decisions made in their life (e.g; when I see my Mum) and to write these on the chart. Children were also asked to note down people who made decisions in their life (e.g social worker, foster parent). Once the chart had been created coloured stickers were used by the child to gauge how much of a say the child felt they had in different decisions and the extent to which others made decisions about their life. A ‘pots and beans’ activity was also used in this study to explore the child’s participation in their case review meeting. The child was handed a pot of beans and had six jars labelled with items related to the review meeting (e.g; how much you are listened to in the meeting, how much you speak in meeting). For each pot the child was given three beans and had to decide how many beans each pot deserved and explain to the researcher why they had used that number of beans. Conversation that took place during the process was audio-recorded and the child’s views regarding who made decisions in their life were gathered from the transcript of the conversation and their actions in the participatory techniques.

A study by Harden et al (2000a) involved the use of what the researchers termed as ‘task centred’ methods with children in their research regarding perceptions of safety. This included asking children (aged 9 to 15 years) to make lists of things they felt were risky, completing sentences such as ‘I feel scared...’ and the use of cards with statements on

which children had to categorise as 'risky' or 'not risky' behaviours. Vignettes were also used with scenarios on them for children to comment upon. Harden et al (2000a) believed such methods facilitated the interview process with children by enabling them to express their views in a variety of ways and not rely solely through verbal communication.

Despite the development of novel research methods to relate to children some researchers have favoured the use of more conventional approaches. Conversational interviews it has been argued, enable children to communicate in their own words their views and opinions to the researcher (James, Jenks and Prout, 1998). In the use of interviews with children particular attention has been paid to the way in which a child relates to a researcher. Dixon-Woods, Young and Heney (1999) highlighted potential bias in interviews conducted by health care professionals as the child might say what they think the professional wants to hear, rather than their own views on issues. Scott (2000) has also noted how this might occur with any adult research and children might give the response they think the researcher wants to hear, rather than express what they might want to say.

In communicating with children Mayall (2000) identified the need for an awareness of generational issues, that is the assumption inherent in society that adults are superior to children. Mayall (2000) argued that a researcher needed to rid himself of such a position. The way this was done was dependent upon the nature of the research and the preference of the researcher. In the case of the work of Corsaro (1997) in nursery schools, the researcher attempted to be less 'adult like' and to become more 'child like' in his behaviours. Keats (2000) advocated, when interviewing young people, that the researcher 'comes down' to the physical level of children and bends down or sits down with them.

In order to relate to children a researcher needs to consider the terms and words used to ensure language and concepts are not too advanced for the child. Keats (2000) recommended the use of clear and plain language to communicate with children. Alderson (2000) provided a note of caution regarding this in her belief that 'talking

down' to children and the use of over simplistic words or concepts might alienate the child as much as the use of over complicated language. Harden et al (2000b) commented that the appearance of the interviewer and type of clothing might also be a factor in the creation of rapport with children. From their own work they noted a preference for casual clothing when interviewing children, yet the need to establish credibility with parents in their form of dress.

The environment of research with children was also a matter for attention. Much research with children has been conducted within schools or within the child's own home. Scott (2000) noted that schools as a place for data collection were advantageous in accessing a number of children at the same time. Yet participants might be influenced by views and behaviours of their peers. Interviews within the home might be more effective with children although the role of the parent as gatekeeper might have to be addressed (Scott 2000). Adaptations might also need to be made to the conventional approach to interviewing, used with adult participants. The researcher might need to give more leeway than with adult participants, for example when children are unsure of what a question means the researcher might need to paraphrase the question rather than to give the standard response used in adult research 'answer by what it means to you' (Scott, 2000). The length of time required for an interview might be a matter for the attention of the researcher. Keats (2000), in her guidance to interviewers, stated that a ten minute interview could be a long period of time for a child.

Attention within the study of children has focused on aspects of research beyond the collection of data. Particular attention has been given to ethical issues related to research involving children. Children are a vulnerable population and are relatively powerless in society (Scott 2000) and as such might be particularly susceptible to harm. Particular care must be taken in relation to issues of consent to participate in research with this population. Davis, Watson and Cunningham-Burley (2000) reported from their research how adults, such as teachers and parents, might believe consent from children was not necessary and that their own agreement was sufficient. Some studies, such as Oakley et al (1995) have not sought consent from children but from adults. For some researchers this was ethically unacceptable and consent from children was obtained.

McIntosh (2004) commented that although legally it is parents that are required by law to consent, children with sufficient understanding should be involved in consenting to participation in research. However the process of seeking consent from children might warrant review with regard to the child's comprehension of the consent process.

Roberts (2000) noted that particular care had to be taken to ensure that children understood that refusal to participate or withdrawal from research would not be held against them.

Consideration must also be given to the effect of the adult researcher on the analytical processes of data. Woodhead and Faulkner (2000) noted how the interpretation of data from children by an adult researcher meant that data were defined in terms of adult discourses rather than children's. Although this cannot be eliminated during analysis some methodological approaches might be more susceptible to the imposition of the adult researchers interpretation of data. For example, James, Jenks and Prout (1998) have been cautious of the use of drawing methods as the analysis process presupposes the ability of the adult researcher to interpret a child's drawings. Harden et al (2000b) commented that this problem is not exclusive to the study of children and point out that research involving adults inevitably does not involve participants in the analysis stage.

As in all research, reliability of responses is an issue for consideration. Scott (2000) noted that there was a perception of children as less reliable than adult respondents and there had been an inherent reluctance to take children's responses at face value. Yet as Roberts (2000) commented children have been shown to give reliable accounts particularly in areas of life in which they themselves are experts, such as at school.

The methodological issues outlined in section 2.4 informed the development of the study protocol. Consideration was given to the selection of a methodological approach that would enable children to communicate with the researcher and express their views. In communicating with children the study protocol encompassed issues relating to the use of language with children, the length of interviews and the environment in which data were to be generated. The researcher also paid attention to her appearance and dressed in a manner smart to parents yet still informal to children. The main study

protocol was formulated to ensure consent for participation was obtained from both the young person and parent and that the nature of the research and freedom to withdraw at any point were made clear to young people. The following section of this chapter describes the pilot work for the study which led to the development of the methodological approach used in the main study.

2.4 Pilot work

Section 2.4 describes the pilot work conducted prior to the main study. This was conducted upon receipt of ethical approval for the research and therefore enabled the researcher to conduct interviews with young people. The term young people has been used throughout this research to refer to those aged 8 to 15 years who participated. This term, rather than that of child or adolescent was selected as it was considered more respectful. The term parent rather than parent/guardian has also been used as, although guardians were eligible for inclusion in the study, all participants were parents.

Aims of the pilot work were to generate data that would be able to meet the following objectives:

- to ensure sampling and recruitment procedures through GP surgeries were workable,
- to develop a methodological approach suitable for research with young people,
- to ensure the method of data collection was acceptable for use with parents,
- to establish the roles of young people and their parents in the management of the young person's asthma or diabetes,
- to describe asthma and diabetes management in the context of shared responsibility between young people and their parents, from the perspectives of both young people and their parents,
- to establish whether there is a relationship between the age of a young person or length of time since diagnosis and their roles within a partnership,
- to establish the implications of these patterns of shared responsibility for the advice and support provided by health professionals in the context of National Health Service (NHS) provision,

-
- to measure the quality of life of young people with asthma and diabetes from the perspective of young people and their parents.

The pilot work consisted of six interviews with young people and their parents, three with asthma and three with diabetes, conducted between 9th March and 3rd July 2001. One young person with diabetes was recruited for inclusion in the pilot work through the participation of his mother in preliminary work with support groups for young people with diabetes and their parents (see section 2.2.3.3). The remaining five young people and their parents were recruited through general practice surgeries by the method used in the main study, as outlined in section 2.4.3 of this chapter. Pilot work indicated that such a method of recruitment for the diabetes part of the study was successful and this method was therefore adopted for use in the main study.

The recruitment procedure for the asthma part of the study involved surgery staff establishing the severity of the young person's asthma by use of guidelines from the British Thoracic society guidelines (British Thoracic society et al, 1997). Young people prescribed medication according to stages 2 and 3 of the British Thoracic Society (BTS) guidelines or those prescribed medication according to stage 4 of the BTS guidelines, but who had not stayed in hospital during the last year, were eligible to be invited to participate in the research. Such a process was adopted so that young people with very mild asthma (stage 1) such as seasonal asthma would not be interviewed as they might not regularly use medication. Those with severe asthma (stage 4) were excluded if they had spent prolonged periods in hospital as in such cases the management of medicines might be influenced more by health care professionals than by the young person or their parent. During the pilot work it emerged that it was not possible to use the BTS guidelines to define inclusion criteria for the study as staff at the surgeries could not spare the extra time to investigate the nature of the condition and it was often not clear from computer records at which BTS stage a patient was currently being managed. In the main study therefore GP surgeries identified all those taking medication for asthma and invited them to participate in the research. During the interview process in the main study data on medication were obtained.

Young people interviewed for the pilot work were aged 6 to 15 years, all parents interviewed were mothers. All interviews were conducted in respondent's own home. Consent was obtained from young people and parents (appendices E, F, G, H) prior to the commencement of the interview. From identification of issues from the relevant literature and the preliminary work disease specific semi-structured interview schedules for use with the parents of young people with asthma and diabetes were compiled. Similar semi-structured interview schedules were devised for young people covering the same topics but with the use of less complicated language. The complexity of language was assessed through the use of Flesch reading scores (Flesch,1997; see section 2.4.6) which indicate the simplicity of a document. Interviews were recorded and field notes were made immediately after the interview was completed. Recordings were listened to and field notes used to assess the success of the interview process in meeting the research study objectives.

The use of semi-structured interview schedules (appendices I,J) with parents were successful. Parents were able to talk at length on the topics addressed and the data collected met the study research objectives. Piloting revealed the use of semi-structured interview schedules with young people were not successful. Young people interviewed were of a range of ages and abilities and varied in their confidence in communicating with the researcher. The researcher found it difficult to adapt the semi-structured approach for young people with such diverse characteristics. Some young people did not understand the terms used and appeared awkward with the formal approach to questions. Young people tended to give short and formal answers to questions, often with a 'yes' or 'no' response. During use of the semi-structured interview young people became distracted from the interviewer when they consulted the schedule, or tried to look at the schedule with the researcher. The use of the interview schedule interrupted the flow of conversation between the young person and the interviewer. The length of the structured interview, approximately thirty minutes, also appeared too long for some young people who became tired and lacked concentration towards the end. Upon completion of three interviews the piloting of a more unstructured approach to the conduct of interviews with young people was adopted.

The researcher had a topic guide of issues to be covered (appendices K,L). Questions were phrased according to the language that the young person used, for example if the young person referred to an inhaler as a ‘puffer’ the researcher also did so. The unstructured approach to the interview was more informal and young people responded by answering questions at greater length and with more detail than the ‘yes’ and ‘no’ responses the semi-structured approach had elicited. Use of the topic guide also enabled the researcher to maintain eye contact with the young person being interviewed. Use of the topic guides enabled greater flexibility regarding the length of the interview, young people who talked at length on topics were prompted accordingly by the researcher and those who preferred to speak less could be accommodated. Young people were more relaxed during the interview process and conversation flowed with greater ease. These factors lead to the adoption of the unstructured approach to interviewing young people in the main study with the use of topic guides rather than semi-structured interview schedules.

Upon completion of the qualitative interview young people and their parents completed quality of life measures (see section 2.5.7), PedsQL asthma or diabetes modules (Varni, 1998). Parents completed the condition specific parent proxy measures (appendices M,N) with apparent ease and asked the researcher few questions. Young people were requested to complete the modules (appendices O,P) themselves. Whilst the young people completed this task the researcher sat quietly beside them. Young people in the pilot work tried to gain the attention of the researcher and procure her involvement in the task. Three young people became distracted and left the module without completing it until the researcher sat with them and noted their responses. The researcher therefore, in accordance with the administration guidelines of the module, sat with the young person whilst they completed the module and read each statement aloud to them. The young person then circled the number on the Likert scale to indicate their response to each statement. As this method was more successful its use was incorporated into the main study.

The pilot work informed the age limits imposed on the main study inclusion criteria. A search of the literature revealed limited guidance concerning the age range suitable for

involvement in qualitative research. James, Jenks and Prout (1998) have argued that the ascribed age of a young person might not indicate their ability to participate in research, and attention instead should be given to the ability and developmental skills of each individual child. The research topic and measures used are also factors which determine the age group suitable for participation (Scott, 2000). Due to this lack of guidance the age limits imposed in the main study inclusion criteria were devised solely from the experience of the researcher during the pilot work. A young person aged six years was interviewed as part of the pilot work. It was extremely difficult to conduct the interview as the young person did not wish to sit still and became distracted from the interview process and walked off to play a game. This age was too young to conduct a formal interview regarding issues with which this research was concerned. The youngest age of eight years was selected for the main study inclusion criteria. This age was in accordance with the researchers experience of interviewing two eight year olds during the pilot work who were able to participate in the interview, had a role in the management of their condition and appeared to comprehend the consent process.

The pilot work informed the main study with respect to the following issues:

- Use of BTS guidelines (British Thoracic society et al, 1997) by surgery staff as part of the inclusion criteria for young people with asthma were not workable. Therefore this process was removed from the main study protocol and all young people with asthma were invited to participate in the research.
- Sampling and recruitment procedures for the diabetes part of the study were successful.
- Home interviews with young people and parents were acceptable.
- Procedures of obtaining consent and audio-recording interviews were successful.
- The use of the semi-structured interview schedule with the parents of young people was agreeable.
- A semi-structured interview approach to interviewing young people was not workable. Data collection using an unstructured approach with young people was suitable for a range of abilities and could be adapted to varied use of language and confidence in communicating with the researcher.

-
- Young people needed to have the attention of the researcher during the interview process.
 - Interviews with young people needed to be shorter than those with parents.
 - Six years of age was too young to comprehend the interview process.
 - Young people were able to express their views and opinions on their condition through the interview process.
 - Use of the PedsQL asthma and diabetes modules were more successful with young people when statements were read aloud by the interviewer than when young people completed the module alone. The study protocol therefore encompassed the researcher asking the young person if they would prefer to complete the module alone or with the researcher.
 - PedsQL asthma and diabetes modules were self-completed by parents with apparent ease.

2.5 Methods for the main study

This section describes the methods used in the main study. Section 2.5 outlines the procedures for the recruitment of general practice surgeries and young people with asthma or diabetes and their parents. The interview process is described and data analysis procedures were documented.

2.5.1 Selection of methodology

In order to meet the research objectives an in-depth approach was required to ensure detailed accounts could be collected regarding partnerships in asthma and diabetes management between young people and their parents. Four possible methods were reviewed; focus groups, diaries, observational methods and interviews.

Focus groups with young people with asthma or diabetes and their parents would enable a group discussion concerning the nature of partnerships and a large number of views to be obtained. Discussion within the group might have enabled an in-depth discussion of issues. Hood, Kelley and Mayall (1996) have advocated the use of interviews with a

number of children at a time as an approach which lessens the social hierarchy that can exist between an adult researcher and child interviewee. A disadvantage of this method was identified in the preliminary work where difficulties in building a detailed description of the nature of a single partnership were found when the experiences of a variety of people were being obtained. O’Kane (2000) noted that bringing together a group of young people who do not know each other in the use of a focus group demands consideration of group dynamics. These issues might be complex in the case of young people as noted by Scott (2000) who recommended that focus groups with children should be organised in relation to age and gender. Such measures should minimise the effect of younger participants feeling intimidated by older participants or differences in communication styles of boys and girls causing communication problems within the group. Scott (2000) also reported the necessity for the use of small focus groups with young people, with no more than eight members, to ensure all young people express their views in an ordered way.

The use of diary data were considered for use in the main study, in which young people and parents would note tasks related to the management of the young person’s asthma or diabetes and record who performed tasks and when. This method would have enabled the experiences of a large number of young people and parents to have been elicited. Elliott (1997) commented that the use of diaries might be beneficial with children who might be unable to articulate their views effectively. The use of joint or separate parent and child diaries were considered. The use of joint diaries might not have involved the young person fully in the data collection process and would not have allowed for conflicting views of tasks performed within the partnership. Scott (2000) noted the use of diaries by child respondents necessitated care in the design of the diary so that it was sufficiently simple for young people to be able to complete them effectively, yet data were detailed enough to enable analysis to take place. Diaries have not been used widely as a method of data collection with young people, other than the presentation of their findings from use in the Family Expenditure Survey (Department of Work and Pensions, 2004), in which children aged 7 to 15 years reported their spending behaviours over a two week period. Comment on the success of this methodological approach has

not been made. A disadvantage of the use of diaries with adults has been the accuracy of self-reported behaviours (Stone et al, 2004).

An alternative method of data collection considered was the observation of young people and parents in asthma and diabetes management tasks. Observation could have occurred in the home, as the most likely place for asthma or diabetes management within this group. This could be by the researcher's presence or through the use of video recording equipment. The researcher's presence in the environment might have affected the behaviours being observed and might be impractical with data collection from a large number of young people and parents. The use of video recording equipment, as used by Rich et al (2000), to observe the behaviours of people with asthma might be expensive. Such a method also relies on participants to record such behaviours.

The final method considered was that of interviews. The use of interviews would enable detailed accounts of an individual parent's and young person's pattern of asthma or diabetes management to be explored in detail and separately from one another. The method would allow data to be collected on current partnerships, past behaviours and the views of young people and parents on the predicted future nature of partnerships. A disadvantage of this method is the time and resources needed to obtain the views of a large number of young people and parents.

After consideration of each of these methods the use of interviews to collect data was selected. Interviews were considered the best method to obtain the views of both young people and parents and to meet the objectives of the study.

2.5.2 Recruitment of General Practice surgeries

Two health authority areas were selected from which young people with asthma or diabetes and their parents were recruited. The health authority areas were selected using Under Privileged Area scores (UPA) (Jarman, 1983). Health authority areas were selected with varied UPA scores and within an acceptable travelling distance for the researcher.

The UPA score (Jarman,1983) is an indication of the social deprivation of an area based on eight variables which note the proportion of the resident population who are: elderly people living alone, one parent families, households with children under five years, unskilled manual workers, unemployed people, overcrowded households, residents who have changed address in the previous year and head of household born in the new commonwealth. An area with a higher UPA score is more deprived than one with a lower score, scores might be negative. The UPA score for North and East Hertfordshire health authority is -19.91, that of Enfield and Haringey health authority is 17.42 (National Digital Archive of Datasets, 1996).

Random number tables were used to randomly select GP surgeries from local health authority lists and to allocate selected surgeries either to participate in the asthma or diabetes part of the study. A single disease state was allocated to individual practices to avoid confusion in the recruitment process and to minimise the workload of staff in each practice. Initially equal numbers of GP surgeries were contacted for each condition, although to recruit the required number of young people with diabetes a greater number of GP surgeries were contacted.

Once identified, surgeries were initially contacted by telephone and the name of the Practice Manager was obtained. A letter inviting the surgery to take part in either the asthma (appendix Q) or diabetes (appendix R) part of the study and a condition specific information leaflet (appendices S,T,U,V) were then sent to the surgery addressed to the Practice Manager. In practices without a Practice Manager the researcher asked the receptionist to advise as to whom such information should be addressed.

The letter (appendices Q,R) emphasised that the researcher would undertake all the research herself, but that the surgeries assistance was required to recruit the sample. This was achieved by each GP practice conducting a search of the surgery computer database for young people eligible to take part in the research and addressing a pack of information, prepared by the researcher, to be sent to the parents of young people with asthma or diabetes. In the case of the asthma part of the study, each GP surgery were asked to send between twenty and twenty-five packs of information. Where the number

of young people eligible for inclusion in the study exceeded this number, GP surgeries were asked to randomly allocate young people from the computer records to be sent an information pack. For the diabetes part of the study, packs were sent to all young people identified from the computer search as eligible for participation in the research. These procedures were followed to ensure patient confidentiality was maintained and the researcher had no details of the participants until they had consented to take part in the research. Follow up telephone calls were made to the GP surgeries after one week to answer any questions they might have had about the study and to discuss their participation in the project. In all cases the researcher offered to visit the practice to discuss the project further. In total five visits to GP surgeries were requested by GPs and made.

2.5.3 Inclusion/exclusion criteria

The inclusion criteria for each condition will be outlined separately, including an explanation regarding reasons for choosing each criterion.

The inclusion criteria for young people with asthma were:

- those aged eight to twelve years,
- those who had been diagnosed with asthma for a minimum of one year.

Young people were chosen within the age range of 8 to 12 years. This was as a result of pilot work which indicated younger age groups were unable to participate in the interview process as effectively as those eight years and over. The preliminary and pilot work also indicated that young people aged eight and over assumed a role in asthma management. The upper age limit of 12 years was set so as to include a range of age groups and to examine patterns of partnership with young people of different ages. Young people who had been diagnosed for a minimum of one year were selected so as to ensure that time had been available for partnerships to have become established and the young person and parent to have had a period to adjust to the diagnosis.

The inclusion criteria for young people with diabetes were:

- those aged eight to fifteen years,
- those who had been diagnosed with type 1 (insulin dependent) diabetes for a minimum of one year.

The lower age limit of eight years was selected, as in the asthma sample, due to the ability of young people of this age to participate in the interview process, from experience of the pilot work. The upper age limit of fifteen years was chosen to be slightly higher than that of young people with asthma. This was to reflect the lower prevalence of diabetes amongst young people and to explore issues in an older age group. Young people were included if they had been diagnosed for a minimum of one year to enable patterns of partnerships to be established and the young person and parent to have had time to come to terms with the diagnosis of diabetes.

The exclusion criteria were the same for both the young people with asthma and those with diabetes and were as follows:

- young people who were in institutional care,
- young people and parents not fluent in English language.

Young people who were resident in institutional care, identified through the contact address from the reply slip, were excluded from participation as they were likely to have multiple carers and distinct needs not addressed in this study, which focused on parent and young person partnerships. Young people and parents not fluent in English language were also excluded as they would be unable to participate in the interview. This would be identified during the initial telephone call made by the researcher when arrangements were made for a home interview.

2.5.4 Recruitment of young people with asthma or diabetes and their parents

GP surgeries searched their computer records to find young people with asthma or diabetes who met the inclusion criteria for the project (see section 2.5.3). To protect patient confidentiality, staff at surgeries addressed condition specific information packs,

prepared by the researcher, and sent them to the parents of young people. These packs contained a letter inviting them to take part in the study, which included a reply slip on which to indicate whether they wished to participate in the research or not and a Freepost envelope with the address of the researcher. Two condition specific information leaflets were also included (appendices S,T,U,V), one for young people and one for parents. This was to involve both young people and parents in the decision to participate in the research and to inform them of the nature of the study. The letter (appendices W,X) explained how the young person and their parent had been selected for inclusion in the study and reassured them that their details had not been passed to the researcher. It was also made clear that the research was being conducted independently from their GP surgery. The reply slip contained in the letter had place for the parent to fill out their contact details if they wished to take part in the research and a space to detail reasons for not taking part in the research if they wished to decline participation.

In the early stage of the research an individual pack was prepared for the young person with their own letter and reply slip, so that young people would feel invited personally to take part in the research. In practice however this process appeared not to work, in all cases the parent either filled out both acceptance forms, or only one form was returned to the researcher. The researcher was concerned that the inclusion of additional paperwork in the recruitment pack might alienate participants and that the process for agreeing to participate was too complex. Due to this, after completion of five interviews, the recruitment pack was changed and only one letter and one reply slip were sent to the parents of young people with asthma or diabetes. Young people were addressed through their own information leaflet.

On receipt of a reply indicating that the young person and their parent wished to take part in the study the researcher contacted the parent by telephone, answered any questions that they might have had and arranged an appropriate time and location for an interview. From reply slips that indicated decline to take part in the study, the age and gender of the young person, number of years since diagnosis of the condition and reasons for non-participation, were recorded and collated at the end of the study. It was initially aimed that the sample size would include interviews with thirty young people

with asthma and their parents and thirty young people with diabetes and their parents. These numbers were selected so as to include a range of experiences and views of several types of partnerships.

2.5.5 Written information designed for young people

In the design of information leaflets for young people (see appendices S,U) care was taken to ensure that the presentation of documents would appeal to and be understood by the age-group for whom they were designed. A less formal type face was used to convey a more relaxed approach to the study and the leaflets were printed on coloured paper. Attention was also paid to the language used in such documents to ensure that it could be easily understood by young people. A Flesch reading score (Flesch, 1997) was used, which grades the readability of the document on an 100 point scale, the higher the score the easier it is to understand the document. A score of 90-100 is very easy to read, 80-90 easy, 70-80 fairly easy, 60-70 plain English, 50-60 fairly difficult, 20-50 difficult and less than 20 very difficult (Flesch, 1997). The information leaflet for young people with asthma had a Flesch reading score of 67 and the information leaflet for young people with diabetes a Flesch reading score of 66, indicating the document should be relatively easily understood.

2.5.6 Interview process

Parents were contacted by telephone and asked if they wished the interview to be conducted in their own home or at an alternative location. Where two parents wished to participate in the research they were interviewed jointly, questions were addressed to both parents and answered by either respondent. Where possible, young people and their parents were interviewed separately, so as to ensure free and open discussion.

Efforts were made by the researcher in her appearance to relax the young person. Informal clothing was worn in bright colours to put young people at ease and to emphasise the researcher was not a formal figure. A qualitative approach was chosen for the main study to enable the views of young people and their parents to be expressed

fully and in their own words. Informal, face to face interviews with use of a topic guide by the researcher were used, to help young people feel at ease and to speak openly about their views. Prior to the commencement of the interview, young people and parents were asked to sign consent forms (appendices E,F,G,H) and were reminded again of the nature of the research and that they were free to withdraw at any time. Consent to audio-record the interview was also invited at this point.

The interview schedules for use with the parents of young people (see appendices I,J) were devised from themes that had emerged from the review of the literature (see chapter 1), preliminary (see section 2.1) and pilot work (see section 2.3). The parent interview began with the interviewer noting the medication the young person was using at the time of the interview. Structured questions were then asked about tasks of asthma and diabetes management performed within the home followed by more open questions regarding the nature of partnerships. The experiences of young people at school and during consultations with health care professionals were also investigated during the interview. The topic guide for use with young people (see appendices K,L) was formulated as a result of the pilot interviews (see section 2.3). An unstructured interview approach was taken to enable the researcher to word questions in a way relevant to the young person's comprehension and language style. Topic guides for young people were created to cover equivalent topics to those of the parents, management within the home, at school and contact with health care professionals. The topic guide indicated topics to be covered with each respondent. After the qualitative interview quality of life measures were completed by young people and their parents.

Field notes were made by the researcher upon completion of the interview and once the house had been left. These included details of conversations that had gone on after the tape recorder had been turned off. Two thank you letters were sent, one to the young person and one to their parent.

2.5.7 Quality of life instruments

Upon completion of the qualitative interview condition specific quality of life (QoL) instruments were completed by young people and their parents. Section 2.5.7 outlines the selection and administration of the QoL instruments used in this study.

At the time of the development of the study protocol (August 2000), a review of the literature (see chapter 1) revealed that a limited number of instruments had been developed and tested for use to measure the QoL of young people with asthma and diabetes. As the focus of this research concerns the views of young people, instruments that relied solely upon the parent's perception of the QoL of their son/daughter were not considered. This resulted in consideration of two instruments that had been developed for the measurement of QoL in young people with asthma from the perspective of young people themselves, the Pediatric Asthma Quality of Life (PAQOL) instrument (Juniper et al, 1996a) and the Pediatric Quality of Life (PedsQL) asthma module (Varni, 1998). Two instruments for the measurement of QoL of young people with diabetes were identified from the literature, the PedsQL diabetes module (Varni, 1998) and the Diabetes Quality of Life modified for Youths (DQOLY) (Ingersoll and Marrero, 1991). The DQOLY (Ingersoll and Marrero, 1991) is an adaptation of the QoL instrument used in adults in the Diabetes Control and Complications Trial (Diabetes Control and Complications Trial, 1988). Use of the DQOLY was not considered in this research as the instrument is for young people aged eleven years and over and therefore would not have been suitable for use with all young people in this study sample. In considering the use of the PAQOL (Juniper et al, 1996a) the psychometric properties of the instrument were considered.

In Canada, Juniper et al (1996a) developed the Pediatric Asthma Quality of Life (PAQOL) instrument for use with young people aged 7 to 17 years. The team also developed the Paediatric Caregiver's Quality of Life (PACQLQ) instrument (Juniper et al, 1996b) to measure the QoL of parents of a young person with asthma. The PACQLQ is not discussed here as the aim of this research was to measure the QoL of young people with asthma, not that of their parents. The development of the PAQOL (Juniper et al,

1996a) instrument was from work with health care professionals, parents and young people with asthma. A list was compiled, from discussions with these groups, of 77 items which were thought to impact upon the QoL of a young person with asthma. A sample of young people with asthma (n=100) were asked to record which items they had experienced from the list and to rate each item on a scale from 1-5 in relation to how much the issue bothered them (1=does not bother me much, 5= bothers me very, very much). Items identified most frequently and which scored the highest were formulated into the PAQOL (Juniper et al, 1996a). The process by which the PAQOL instrument was constructed was reported as an indication of the content validity of the instrument (Juniper et al, 1996a).

The PAQOL instrument consists of a 23 item instrument with three sub-scales, activity limitation (5 items), symptoms (10 items) and emotional functioning (8 items). A seven point response scale is used for each item in which 1 indicates maximum impairment and 7 no impairment. Values are calculated as the mean score per item (1-7) for each scale; an overall score of QoL might also be calculated in this way. Scores are not weighted. The instrument included a personalised element in the activity sub-scale in which young people are asked to record three activities that are limited by their asthma and then asked the extent to which, as measured on the scale, these activities are impaired by their asthma. The inclusion of a personalised measure is reported to be a further indication of the validity of the instrument (Juniper et al, 1996a). These personalised elements are recorded and used if the instrument is repeated with the same respondent over a period of time. In order to facilitate the use of instruments with young people Juniper et al (1996a) devised the use of coloured response cards with which young people indicate their response to statements on the scale. On average the PAQOL takes ten to fifteen minutes to complete initially and five to ten minutes if use of the instrument is repeated with the same respondent. The instrument is administered by a trained interviewer.

The reliability and responsiveness of the PAQOL instrument has been assessed by Juniper et al (1996a). Young people aged 7 to 17 years (n=52) were recruited through visits to a Canadian asthma clinic. Young people were administered the PAQOL

instrument three times over a nine week study period, at week one, five and nine. In order to evaluate the use of the PAQOL participants also completed additional instruments. For one week prior to each clinic visit participants completed a diary. The diary, completed each morning and night, recorded morning peak flow readings, medication use, symptoms of asthma and limitations to the young person's daily activities due to their asthma. At each clinic in weeks one, five and nine the parent was asked if there had been a change to the young person's condition since the last clinic visit. If the parent identified change this was rated on a fifteen point scale from -7 to 7 (-7=a very great deal worse, 0=no change, +7=a very great deal better). Young people were asked at each clinic visit to rate their generic QoL by use of the 'feeling thermometer', a measure used to indicate how a respondent feels about their own overall health. The scale is a line with 0-100 in which 0 is the least preferred health state and 100 the most desired health state. Young people and parents also completed the global rating of change questionnaire (Juniper et al, 1994) about changes in QoL since the last clinic visit. Responses to the global rating of change questionnaire are scored on a 15-point scale from -7 (a very great deal worse) to 0 (no change) to +7 (a very great deal better). For the purposes of testing the instrument participants were divided into two study groups those whose condition had stayed the same (group A) and those whose condition had changed (group B). Division of subjects into these group was defined by scores from the global symptom rating of change questionnaire (Juniper et al, 1994), the caregiver's score of change in condition and clinical data collected at clinic visits. Responsiveness of the PAQOL was assessed through its ability to detect changes in the QoL of subjects over the nine week period in participant group B and its ability to distinguish between group A and group B participants. The mean change in overall QoL score during a four week period was 0.98. The change in group B (condition changed) was shown to be significantly different from the change in group A (stable). Juniper et al (1996a) concluded the PAQOL measure was successful in establishing relatively minor changes in the young person's condition, improvements or deterioration, and in the identification of young people whose condition had remained the same. Reliability of the measure was calculated with the use of an intraclass correlation coefficient to examine the ratio of between-subject variance and total subject variance. The overall QoL intraclass correlation coefficient was 0.95 and was similar across all domains.

Reliability was measured in young people who were stable (group A, n=37) throughout the study, and was deemed to indicate a high level of reliability of the instrument in stable patients (Juniper et al, 1996a). Juniper et al (1996a) reported young people had little difficulty understanding the completion of the PAQOL other than participants in younger age groups who experienced difficulties relating to the time frame of events that had occurred 'within the last week'. The author did not comment on response rates or missing data.

The Pediatric Quality of Life (PedsQL) asthma and diabetes modules were also considered for use in the main study. The PedsQL asthma and diabetes modules, formulated in the USA, were available in formats to be completed by young people themselves (aged 5 to 18 years) and by parents in the form of proxy respondents (parents of children aged 2 to 18 years). Parents reported the extent to which they perceived factors have affected their son's/daughter's QoL. The PedsQL asthma and diabetes modules were derived from over fifteen years of QoL work from Varni (for example; Varni et al, 1988; Varni et al, 1998; Varni et al, 2004) which led to the formulation of numerous measures of PedsQL for use in acutely ill and chronically ill populations. Varni, Seid and Kurtin (2001) have also formulated a generic PedsQL module for use in healthy populations or young people with existing health conditions, aged 5 to 18 years and for parent proxy respondents of young people aged 2 to 18 years. The generic PedsQL module could be administered in conjunction with disease specific modules to enable comparisons between those with a condition and healthy populations. The formulation of the asthma and diabetes PedsQL measures had been through the clinical experiences of the authors, collaboration with disease specific specialists, review of literature, parent focus groups and individual interviews, pre-tested and subsequent field tested with the target population (Varni and Burwinkle, 2004).

The asthma and diabetes PedsQL (parent proxy and child report) modules each consisted of twenty-eight items. The module was self-completed by parents and might be interviewer administered or self-completed by young people. The average completion time of each PedsQL module was reported to be less than four minutes. Young people were asked in the last month how much of a problem each item had been for them,

parents were asked how much of a problem their child had experienced in the last month with each of the statements. Parent proxy measures for each condition have been constructed directly in parallel to those of the young person's module. For each statement a five point Likert scale was used to indicate a response (0=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, 4=almost always a problem). Young people and parents were asked the same question, phrased accordingly in first or third person tense, an example of which is shown below.

Statement from PedsQL asthma module to be completed by the young person:

In the past ONE month, how much of a problem has this been for you

About my asthma	Never	Almost never	Sometimes	Often	Almost always
My chest hurts or feels tight	0	1	2	3	4

Statement from PedsQL asthma module to be completed by parent proxy respondent:

In the past ONE month, how much of a problem has your child had with

About my son's/ daughter's asthma	Never	Almost never	Sometimes	Often	Almost always
Pain or tightness in his or her chest	0	1	2	3	4

Each PedsQL module comprised sub-sections. For the asthma module there were four sub-scales; asthma symptoms (11 items), treatment problems (11 items), worry (3 items) and communication (3 items). The diabetes module consisted of five sub-scales; diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence

(7 items), worry (3 items) and communication (3 items). The asthma and diabetes PedsQL modules were scored in the same way, items from the Likert scale (0–4) were reverse scored to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Scores were not weighted. The mean score was calculated as the sum of the items over the number of items answered (therefore allowing for missing data). If more than 50% of items in the scale were missing, the score was not calculated (Varni and Burwinkle, 2004). The PedsQL asthma and diabetes modules enabled the calculation of a score for each subscale, an overall QoL score was not calculated. Higher scores indicated better QoL, fewer symptoms and fewer problems.

Selection of a QoL measure for use in research is usually based on the psychometric properties of the instrument (Francis, 2001). However, at the time of the selection of the QoL instrument to be used in the main study no published information was available regarding the psychometric properties of the PedsQL asthma or diabetes modules. Consideration was given for use within the asthma sample of the PAQOL (Juniper et al, 1996a) or the PedsQL asthma module (Varni, 1998), neither of which were designed for use within a UK population. Through personal communication with the author of the PedsQL asthma and diabetes modules, Dr James Varni, it was found that the modules had been adapted for use within an English population by Professor Chris Eiser at the University of Sheffield and were currently undergoing testing. The PedsQL asthma and diabetes modules were therefore selected for use in the main study. This enabled use of the modules designed for a UK population and the findings from this research to contribute to wider testing of the modules within the UK, also taking place at the University of Sheffield and University of Cardiff.

In the main study the selected PedsQL asthma modules (appendices M,O) and diabetes modules (appendices N,P) were completed by young people and parents at the end of the qualitative interview. The module was self-completed by parents after instructions from the researcher. Young people were given the option to complete the measure alone or with the researcher. In cases where the researcher was involved each statement was read aloud to the young person who circled their response on the Likert scale. Parents and young people completed the modules independently of each other. In accordance with

the PedsQL administration guidelines if a parent or young person asked the researcher a question in relation to what a statement meant or how it should be answered, the researcher did not interpret the question. The researcher asked the respondent to answer the question in relation to what they thought it meant and if they were unable to do this to leave the question blank.

After use of the PedsQL asthma and diabetes modules in this research, papers reporting the psychometric properties of the PedsQL asthma and diabetes modules, used in a US population, have been published. Research by Varni et al (2004) has examined the reliability and validity of the PedsQL asthma module. Young people with asthma and their parents were recruited through three methods; a State Children's Health Insurance Program, University research study and a summer camp sponsored by the American Lung Association. The PedsQL asthma module was completed by young people aged 5 to 16 years (n=404) and parent proxy respondents (of children aged 2 to 16 years) (n=526). The process of the administration of the PedsQL asthma module varied, the modules were either mailed to young people and parents for completion at home, or completed in the presence of a researcher. Young people with asthma were also administered the PAQOL (Juniper et al, 1996a) described previously in this section. Construct validity of the PedsQL asthma module was determined through a multitrait-multimethod matrix intercorrelation to compare findings from the PAQOL sub-scales and those from the PedsQL asthma module sub-scales. Effect sizes were designated as small (0.10), medium (0.30) and large (0.50). As hypothesised by the authors (Varni et al, 2004), the PedsQL asthma symptoms correlated positively with the PAQOL symptoms scale with large effect size (0.695), the PedsQL treatment scale correlated with the PAQOL symptoms scale with large effect (0.576) and the PedsQL worry sub-scale correlated with the PAQOL emotions scale with large effect 0.602). Such correlations were taken by the author to indicate validity of the PedsQL asthma module in measuring QoL in young people with asthma. Internal consistency and reliability of the PedsQL asthma modules were calculated with the use of Cronbach's alpha. For parent proxy and young person modules (aged 8 to 12 years) all sub-scales other than the child self-report 'Treatment Problems' met the minimum standard of reliability identified by the author as 0.70. The 'Treatment Problems' sub-scale had internal

reliability of 0.58. Varni et al (2004) indicated that until further testing was completed the sub-scale should only be used for descriptive or exploratory analysis. The percentage of missing item responses with use of the asthma PedsQL module was 0.8% for child self-report and 1.5% for parent proxy-report.

Since use of the modules in this research use of the PedsQL diabetes module has also been published (Varni et al, 2003). Young people with type 1 diabetes (n=300) aged 5 to 18 years and parent proxy respondents of young people aged 2 to 18 years (n=237) were recruited. Participants were identified when they presented to a clinic visit or through their physician in the USA. Administration of the PedsQL diabetes module either took place at the clinic when young people presented for appointment or by telephone where questions were read out verbatim to young people and parent proxy respondents. Internal reliability of the diabetes PedsQL module was calculated with use of Cronbach's alpha. A value greater than 0.70 was deemed by the author to indicate good reliability. This was achieved in two of the five sub-scales in the child self-report modules and four of the five sub-scales in the parent proxy respondent scales. Varni et al (2003) indicated that poor reliability in these four sub-scales necessitated that until further testing has been conducted the scales that did not achieve the standard of 0.70 (child report: 'treatment barriers', 'treatment adherence', and 'worry'; parent proxy report: 'treatment barriers') should be used for descriptive or exploratory purposes only. Missing data from the PedsQL diabetes module were reported as 1.4% of child self-report data and 3.6% of parent proxy respondents.

Chapter 7 of this thesis will discuss the contribution of the research presented in this thesis to the development and testing of the PedsQL asthma and diabetes modules in the UK.

2.5.8 Ethical approval

Before the commencement of any research, ethical approval was obtained from the two health authority areas. Approval was sought from the Enfield and Haringey health authority, where the researcher attended a meeting of the ethics committee. At the

meeting the researcher answered some general questions about the project from the ethics committee panel.

The questions and responses are outlined below:

- Why have these age ranges been chosen for each condition?

This was to ensure representation by a range of age groups and to enable details of partnerships at different stages of a young people's experiences to be explored.

- Why include a reply slip with a decline option when respondents rarely return them?

Although it is recognised that few respondents complete decline slips the researcher believed it to be important to include them as even if a small number of slips were returned it could indicate reasons for non-participation. For example, it could establish if there were methodological reasons or other factors that were associated with non participation. In this research this was particularly important as no other non-respondent data would be available to the researcher, due to reasons of patient confidentiality.

Ethical approval was applied for from the Enfield and Haringey ethics committee in August 2000 and obtained in October 2000.

Ethical approval was applied for from the East and North Hertfordshire health authority in August 2000. A reply was received to the application for ethical approval in October 2000, requesting an amendment to be made to the information leaflet for young people.

The request was for an additional phrase to be added to the statement regarding patient confidentiality so that the section read:

Nothing you say or write will be passed onto anyone else except if you mention that someone is harming you in some way. In such a case what you said will be passed to child health experts working on your behalf and concerned for your health and happiness.

A reply was sent to the ethics committee stating that as the researcher was not a health care professional nor trained to identify child harm the research team believed that the researcher was not in a position to intervene regarding health needs. The research team did set out a new procedure for the researcher to follow if the young person described any health worries to them, which was to suggest to the young person that they discuss the issue with a member of the asthma or diabetes health care professional team with whom they were familiar. Full ethical approval was granted from the East and North Hertfordshire health authority in February 2001, at a meeting attended by a member of the research team. The time taken to achieve ethical approval was five months after the initial application had been made.

On the merger of the North and East Hertfordshire and West Hertfordshire health authority areas an application was made to extend the research to include West Hertfordshire, approval was obtained in July 2001. On the merger of Barnet with the Enfield and Haringey health authority an extension was applied for to extend the research to the Barnet area and approval was obtained in November 2001. The UPA scores (Jarman, 1983) for West Hertfordshire was -18.98 and for Barnet -2.08 (National Digital Archive of Datasets, 1996).

2.5.9 Data Analysis of interview data

The gender, age and number of years since diagnosis of respondent and non-respondent data were compared with use of Chi squared and Mann Whitney U tests. A value of $p \leq 0.05$ was considered as an association between the two variables (Bryman and Cramer, 1997). Tape recorded interview data were transcribed verbatim. Where interviews were not audio-recorded notes of the interview were typed up immediately after the interview so as to be as accurate as possible. Field notes were also typed up directly after completion of the interview. Transcripts were given an identifying number which related to the order of interviews. Parent data were given the letter 'a' after the number and young person interviews the letter 'b'. This process enabled data from parent and young person interviews to be analysed separately, but comparisons between

parent and young person data to be made by reference to the corresponding interview number.

As noted by Mason (1996) the use of computer programmes can provide assistance to a researcher in the analysis of data. Due to the large volume of qualitative data (138 transcripts) the computer package Non-numerical Unstructured Data Indexing, Searching and Theory building (NUD*IST) was used to assist with data management. Two databases were formulated, one for asthma and one for diabetes. Before being entered into NUD*IST each transcript was re-read and checked to ensure it was correct with the tape recording of the interview. This process ensured the accuracy of data entered for analysis from the original source. Factors identifying the respondent, such as names of individuals or hospitals were made anonymous. Interview accounts which were not audio-recorded were entered into NUD*IST and a note made in the data that the interview was not a verbatim account.

As noted by Robson (1993) there are no clear and accepted conventions for the analysis of qualitative data, as there is for quantitative data. Yet procedures used in the analysis of data must be systematic (Robson 1993). The analysis of data in this research involved the coding of data, that is the application of labels to parts of the data relating to the same theme. Thirteen codes were developed and applied to the asthma data and twelve codes to the diabetes data. The origin of codes varied. Eleven codes were applied to both asthma and diabetes sets of data. The code of 'parent/young person' indicated a parent or young person transcript and the code 'medication' the type and frequency of medication used by the young person. The code of 'school' emerged from preliminary work and from the literature review particularly the work of Fillmore, Jones and Blankson (1997), Chadwick (1996) and Pugh et al (1995). The code 'health care professionals' was formed from the preliminary work and from research identified in the literature by Tates et al (2002). The category of 'information sources' emerged from preliminary work and the work of Kai (1996). These three categories were also topic areas explored within the interview schedule. The code of 'conflict' emerged from preliminary work. The codes of 'roles in partnerships' and 'changes in partnerships' were formed from the aims and objectives of the main study. The code of 'exercise'

was also applied to both sets of data and was devised from preliminary work. Three further codes used in only the asthma data were ‘triggers’, ‘steroids’ and ‘peak flow’ and stemmed from the nature of the condition. Codes used with the diabetes data were ‘diet’ and ‘disclosure of long-term effects’. The analysis of data in this research were guided from the review of previous work which helped frame the research questions asked and through them the design of the study (Robson, 1993).

Data were then considered and these codes applied to the data within NUD*IST as nodes. Within these nodes additional sub categories were identified and coded, for example within the node of ‘school’ a secondary node of ‘storage of medication’ was created. During the coding of data additional nodes were identified and created which emerged from the data, such as young people who lived in more than one family unit. On the formation of a new node or secondary node all transcripts were searched and the new node applied systematically to all data. Within NUD*IST the facility of text searching was used to ensure, in addition to the coding procedures followed by the researcher, all mention of a particular term or concept had been coded.

Once all data had been entered into NUD*IST summary tables were created by the researcher. Four separate tables were created for young people with asthma, their parents, young people with diabetes and their parents. A summary of issues were then entered onto the tables and the information re-checked with the transcripts within NUD*IST. These summary tables enabled the researcher to see with ease an overview of the data in each of the four sub-groups and to see a outline of particular issues, for example the number of young people who injected insulin without assistance. For the analysis of these concepts the data were revisited in NUD*IST in its original form.

In order to examine the relationship between roles within partnerships and the age of a young person or length of time since diagnosis, statistical tests were performed. From the transcripts of qualitative interviews data related to who performed tasks of condition management were identified. Data were then coded according to whether the young person was involved in a task (either alone or with their parent) or if the parent solely performed a task. This information was then entered into four databases (young people

asthma, parent asthma, young people diabetes and parent diabetes) into the computer package Statistics for the Social Sciences (SPSS). The age of the young person and length of time since diagnosis with asthma or diabetes was also entered in the database. Due to the type of data non-parametric unrelated tests were considered. Mann Whitney U tests were used. A value of $p \leq 0.05$ was considered as an association between the two variables (Bryman and Cramer, 1997).

Attention was paid in the analysis process to issues of reliability and validity. Validity has been termed as ‘the extent to which (data) are an accurate reflection of the phenomena that are the subject of the research’ (Smith, 2002). Within the use of qualitative methods data might be seen as possessing inherent content validity as data are the responses of the interviewee rather than the agenda of the researcher (Smith, 2002). Steps were taken in the analysis of data to ensure the validity of findings. The researcher searched data for cases which contradicted the main findings from the data, this has been termed argumentative validation (Smith, 2002). For example, the data indicated that young people and parents had harmonious partnerships, the researcher then searched the data for cases where this was not so and conflict in partnerships was identified.

The use of NUD*IST assisted in the validation processes by ensuring all references to a particular topic were identified and coded. Topics and key-words were searched for across the data enabling a check of the mention of a topic throughout all transcripts. A further process of validation, that of cumulative validation (Smith, 2002) was conducted in which the findings of this research were examined in relation to the findings of previous work and consistencies in findings were noted. In addition to this the presentation of numerical data in the research findings was included to demonstrate the responses from all respondents to each question. Incidences of missing data were also reported to ensure responses from all respondents were accounted for.

As Mason (1996) noted conventional measures of reliability are more comfortably associated with quantitative rather than qualitative research and as such statistical tests for reliability cannot be performed. Robson (1993) has identified the need for

confirmability in qualitative research. That is the process by which an outsider to the research can judge the findings. Robson (1993) advocated conducting research in a way that a researcher collects and maintains the ‘trail’ of data, to enable an outside person to follow the processes of analysis of data and justify the findings and conclusions drawn by a researcher in relation to the ‘trail of data’. In this research the explanation of the formation of codes used in the analysis and the processes by which conclusions were drawn has illustrated the ‘trail of data’ from which findings have been made.

2.5.10 Data analysis of Quality of Life data

Data from the PedsQL asthma and diabetes modules were coded and entered in the computer package Statistics for the Social Sciences (SPSS) in four databases (young people asthma, parent proxy asthma, young people diabetes and parent proxy diabetes). For each statement the mean score was calculated, SPSS excludes missing data from such calculations. This was repeated in each of the four databases. In order to calculate the mean of a sub-scale total it was necessary to create a new database (one asthma, one diabetes) with paired parent proxy and young person responses. For each sub-scale cases with missing data, from either respondent, were excluded. The sum of each sub-scale was then calculated separately for young person and parent proxy data. The mean and standard deviation of each sub-scale was calculated, for young person and parent proxy respondent data.

To examine the statistical difference between responses from proxy parent and young person a Wilcoxon signed ranks test was used on each statement and each sub-scale. A Wilcoxon signed ranks test was selected for use as the data were related. A value of $p \leq 0.05$ was considered significant (Bryman and Cramer, 1997). Internal consistency of each sub-scale and the overall measure, in each of the four modules, was calculated using Cronbach’s alpha. A value of 0.8 or over was deemed to indicate good internal reliability of the scale (Bryman and Cramer, 1997). The percentage of missing data were calculated on a per respondent and per module basis.

To calculate the percentage of missing data per respondent the following calculation was used:

$$\frac{\text{Total number of missing items per respondent}}{\text{Total number of items}} \times 100$$

To calculate the percentage of missing data per module the following calculation was used:

$$\frac{\text{Total number of missing items for all respondents}}{(\text{number of respondents}) \times (\text{number of statements})} \times 100$$

Mann Whitney U tests were performed to examine the relationship between the age of the young person and the presence of missing data from the PedsQL asthma or diabetes modules. As before, a value of $p \leq 0.05$ was considered as an association between the two variables (Bryman and Cramer, 1997).

Chapter two has described the methods used in the main study. The following chapter, chapter three, reports the response rates of recruitment participants and sample characteristics of young people and their parents.

Chapter 3 - Sample characteristics and response rates

Chapter 3 Sample characteristics and response rates

Chapter three describes the characteristics of the sample and reports the response rates separately for each condition. Section 3.1 describes the sample characteristics and response rates of the general practice surgeries approached to recruit young people with asthma and their parents. Section 3.2 reports the response rates and sample characteristics of young people with asthma and their parents who participated in the research. Where possible, the characteristics of non-participants are also reported. Section 3.3 details general practice response rates and characteristics of the surgeries related to the diabetes part of the study. Section 3.4 describes the characteristics of young people with diabetes and their parents who participated in the research and, where possible, those of non-participants. The characteristics of the study sample are discussed in relation to the research findings in chapter seven of this thesis.

3.1 General practice surgeries for the recruitment of young people with asthma and their parents

General practice (GP) surgeries identified young people with asthma eligible to be invited to participate in the research. Section 3.1 outlines response rates from GP surgeries and the characteristics of participating and non-participating GP surgeries.

3.1.1 Response rates of general practice surgeries

Table 3.1 reports the response of GP surgeries invited to participate in the research in relation to the asthma part of the study. Eighteen (24%) of the surgeries in which contact was pursued (n=74) agreed to participate. Of these eighteen, fifteen had three to ten partners and three surgeries were single handed practices. Contact for the purposes of recruitment was made in twelve (67%) surgeries with the Practice Manager, three (16%) with practice nurses and three (16%) with GPs.

Table 3.1 Response of general practice surgeries for the asthma part of the study

Response category	Health Authority Area		Total (n=92)
	Enfield and Haringey (n=48)	East and North Hertfordshire (n=44)	
Accepted	6	12	18
Declined	15	14	29
No response*	23	4	27
Not pursued**	4	14	18

* no response: Despite repeated telephone calls no firm response was obtained

**not pursued: GP surgery had been approached but agreement to participate was not pursued as the target number of interviews had been exceeded

3.1.2 Non-participating general practice surgeries

In this section non-participating surgeries are defined as those who declined to take part in the research (n=29) and those from whom no response was obtained despite repeated telephone calls (n=27). The total number of non-participating surgeries was therefore 56.

Those surgeries which declined (n=29) to take part were requested to specify the reason for their non-participation, these are reported in table 3.2. Eight GP surgeries did not report a reason.

Table 3.2 Reasons from general practice surgeries for non-participation in the asthma part of the study (n=21)

Reason given	Number of surgeries (n=21)
Already involved in research	7
GP not willing to participate	5
Lack of time	4
Workload	3
Staff shortages	1
Notes not computerised	1

Fifty-four (96%) surgeries which did not participate (n=56) had between three and nine partners and the remaining two (4%) surgeries were single handed practices. In surgeries which declined to take part, contact for the purposes of recruitment was made with the Practice Manager in forty-three (77%) cases, with the GP in twelve (21%) and in one (2%) surgery with the practice nurse.

3.2 Sample characteristics for the asthma part of the study

Section 3.2 reports the sample characteristics and response rates of young people with asthma and their parents who participated in the research. Rates and reasons for non-participation are also documented in this section.

3.2.1 Recruitment of young people with asthma and their parents

Four hundred and five packs were sent to young people with asthma and their parents inviting them to participate in the research. Forty-three (11%) returned the reply slips and were interviewed. No participants were excluded because of insufficient English language or the young person being resident in institutional care.

3.2.2 Characteristics of young people with asthma and their parents

Table 3.3 reports the characteristics of young people with asthma and their parents who participated in the research.

Table 3.3 Characteristics of young people with asthma interviewed (n=43)

Gender:	Male	27
	Female	16
Age:	Range	8-12 years
	Mean	10.5 years
	Median	10 years
Years diagnosed:	Range	1 - 11 years
	Mean	6.2 years
	Median	6 years

Table 3.4 describes the characteristics of the sample as reported by the parents of young people with asthma.

Table 3.4 Characteristics of parents interviewed, as reported by the parents of young people with asthma (n=43)

Parent/s interviewed:	
Mother	38
Mother and father (jointly)	4
Father	1
Ethnic group:	
White (White British and White - Other)	40
Mixed - white and Black Caribbean	1
Mixed - white and Asian	1
Asian or Asian British - Indian	1
Home ownership:	
Owned by parents	37
Owned by local authority	6

Table 3.5 shows the type of medication used by young people who participated in the research, as reported by parents of young people.

Table 3.5 Medication used by young people with asthma, as reported by parents (n=43)

Type of Medication	Number of young people (n=43)
Reliever inhaled medication	7
Preventer and reliever inhaled medication	33
Preventer and reliever inhaled medication and use of a nebuliser	2
Preventer and reliever inhaled medication, preventer medication in oral form and use of a nebuliser	1

3.2.3 Non-participants

Due to reasons of patient confidentiality the only information available to the researcher regarding non-participants was from reply slips enclosed in the original recruitment letter. In total 27 (7%:n=362) reply slips were returned to the researcher in relation to the asthma part of the study. Data taken from reply slips was treated with caution as the majority of those who declined to participate did not complete reply slips. Reasons for non-participation as indicated on reply slips are shown in table 3.6. Two parents did not specify reasons for non-participation.

Table 3.6 Reasons for non-participation of young people with asthma, identified by parents (n=25)

Reason for non-participation	Number of parents (n=25)
Young person not eligible*	18
Too busy	2
Family difficulties	2
Moving house	1
Parent did not wish researcher in home	1
Young person refused	1

* parent deemed young person not eligible as rarely had asthma or no longer had asthma

Table 3.7 reports the characteristics of young people with asthma who returned reply slips. There was no significant difference between participants and non-participants who returned reply slips in terms of the gender (Chi-squared test), age of the young person or number of years diagnosed with asthma (Mann Whitney U tests).

Table 3.7 Characteristics of young people with asthma who returned reply slips and declined to participate in the research (n=27)

Gender:	Male	17
	Female	10
Age:	Range	8-13 years*
	Mean	9.4 years
	Median	10 years
Years diagnosed:	Range	1 - 11 years**
	Mean	5.7 years
	Median	5 years

* Data missing from three reply slips

**Data missing from four reply slips

3.3 General practice surgeries for the recruitment of young people with diabetes and their parents

Section 3.3 describes the sample characteristics and response rates of GP surgeries approached to identify young people with diabetes eligible to participate in the research.

3.3.1 Response rates of general practice surgeries

Table 3.8 reports the response rates of GP surgeries. Forty-five (23%) GP surgeries agreed to participate, of which forty-one (91%) had two or more partners and four (9%) were single handed practices. The person with whom contact was made for the purposes of recruitment was the Practice Manager in 35 (78%) cases, five (11%) GPs and five (11%) practice nurses.

Table 3.8 Response of general practice surgeries for the diabetes part of the study

Response category	Health Authority Area		Total (n=196)
	Barnet, Enfield and Haringey (n=108)	East, North and West Hertfordshire (n=88)	
Accepted	12	33	45
Declined	25	21	46
No response*	56	27	83
No eligible patients**	15	7	22

* no response: Despite repeated telephone calls, no firm response was obtained

**no eligible patients: GP surgery agreed to participate but after searching their records found no patients that fulfilled the study inclusion criteria

3.3.2 Non-participating general practice surgeries

Section 3.3.2 describes GP surgeries that did not participate in the research.

Non-participating GP surgeries are defined in this section as those who declined to take part in the research (n=46) and those from whom, despite repeated telephone calls, no response was obtained (n=83). The total number of non-participating surgeries was 129.

The forty-six surgeries that declined to take part in this research were requested to specify the reason for their non-participation, these are reported in table 3.9. Nine GP surgeries did not report a reason for non-participation.

Table 3.9 Reasons from general practice surgeries for non-participation in the diabetes part of the study (n=37)

Reason given	Number of surgeries (n=37)
GP not willing to participate	12
Workload	10
Staff shortages	4
Notes not computerised	2
Already involved in research	2
GP felt diabetes was a hospital issue	2
Practice does not participate in research	1
GP retiring	1
New Practice Manager unable to cope with workload	1
Lack of time	1
Practice moving to new premises	1

One hundred and sixteen GP surgeries (90%) had between two and nine partners and thirteen (10%) were single handed practices. Contact for the purposes of recruitment was made with the Practice Manager in one hundred and four (81%) cases, with twenty-four (19%) GPs and one (1%) practice nurse.

3.4 Sample characteristics for the diabetes part of the study

Section 3.4 describes the characteristics of young people with diabetes and their parents who participated in this research. The characteristics of non-participants are also recorded in this section.

3.4.1 Recruitment of young people with diabetes and their parents

Eighty-seven young people with diabetes were identified from GP records and invited to participate in the research. Twenty-six (30%) young people with diabetes and their parents returned reply slips that indicated they wished to participate and were interviewed. No participants were excluded because of insufficient English language or the young person being resident in institutional care.

3.4.2 Characteristics of young people with diabetes and their parents

Table 3.10 reports the characteristics of young people with diabetes who participated in the research.

Table 3.10 Characteristics of young people with diabetes interviewed (n=26)

Gender:	Male	12
	Female	14
Age:	Range	8-15 years
	Mean	11.7 years
	Median	11.5 years
Years diagnosed:	Range	4 months -13 years
	Mean	4.8 years
	Median	3.5 years

Table 3.11 shows the characteristics of the sample as reported by the parents of young people with diabetes.

Table 3.11 Characteristics of parents interviewed, as reported by the parents of young people with diabetes (n=26)

Parent/s interviewed:	
Mother	17
Mother and father (jointly)	5
Father	3
Adoptive mother	1
Ethnic group:	
White (White British and White - Other)	26
Home ownership:	
Owned by parents	21
Owned by local authority	3
Rented from private landlord	2

Seventeen young people injected insulin twice a day and nine young people three times a day.

3.4.3 Non-participants

The only information available to the researcher regarding non-participants was from young people and parents who returned the reply slip enclosed with the original letter and indicated they did not wish to participate in the research. Only five parents (8%: n=61) returned the reply slip, discussion of non-participants is therefore limited to these young people. Four parents indicated that their son/daughter did not like to speak about their diabetes with anybody and had not wished to participate. One parent identified non-participation as both parents were not comfortable with the interview process.

Table 3.12 describes the characteristics of young people with diabetes who returned reply slips. Due to the limited data on non-participants it is not possible to establish differences between participants and non-participants in terms of gender, age or number of years since diagnosis (numbers too small to enable meaningful statistical analysis).

Table 3.12 Characteristics of young people with diabetes who returned reply slips and declined to participate in the research (n=5)

Gender:	Male	4
	Female	1
Age:	Range	11-14 years
	Mean	12.4 years
	Median	12 years
Years diagnosed:	Range	1 - 9 years
	Mean	4.2 years
	Median	3 years

Chapter three has described the sample characteristics and response rates of GP surgeries, young people and parents who participated in this research. Information on non-participants who returned the reply slip have also been reported.

Chapter 4 - Experiences of young people with asthma and their parents

Chapter 4 Experiences of young people with asthma and their parents

Chapter four describes the experiences of young people and their parents in the management of asthma. Section 4.1 provides an introduction to the presentation of data and terms in this chapter. Section 4.2 reports the conduct of interviews. Section 4.3 details the roles of asthma management within the home as performed by young people and their parents. Section 4.4 describes the types of partnerships between young people and their parents, conflict in partnerships, partnerships in relation to the management of triggers of the condition, restrictions experienced by young people and their parents and partnerships of young people who lived in more than one family unit. Section 4.5 recounts changes in partnerships over time and young people's and parents' views of the anticipated future nature of partnerships. Issues regarding the management of the young person's asthma within school are reported in section 4.6. Section 4.7 documents the role of health care professionals in the management of asthma. Section 4.8 reports information needs and information used by young people and their parents. The chapter concludes with a summary.

4.1 Introduction

Section 4.1 outlines the approach taken in the presentation of data and details the concepts and terms used throughout this chapter. The results presented are taken from both interviews with young people with asthma and with their parents. Data from parent and young person interviews were analysed and have been reported independently of each other so as to document young people's and parents' views of the management of asthma. Reference has been made in this chapter to cases in which young people and parents provided different accounts of behaviours, the identification of reasons for variations was not an objective of this research. Where possible findings in this chapter are presented from both interviews, so as to describe the experiences of the management of asthma from the perspective of both young people and their parents. For some issues results are taken solely from either parent or young person interviews. Due to the length

of interviews with young people (see chapter 2) some questions were only asked to parents. Throughout the chapter reference is made in italics to the data, from parents or young people, being presented. The names of young people have been changed. The term partnership is used to describe different styles of cooperation, sharing of responsibilities and discussion regarding the management of asthma. The use of the term does not necessarily indicate harmony and might include young people and parents working together and experiencing conflict within the partnership.

The age of the young person and length of time since they were diagnosed with asthma have been considered in relation to issues explored in this chapter. Mann Whitney U tests were used to explore associations between issues and the age of the young person or length of time since diagnosis with asthma. In this research young people with asthma were aged 8 to 13 years and had been diagnosed with asthma from 1 to 11 years, for more details of the personal characteristics of participants see section 3.2.2.

4.2 Conduct of interviews

Chapter four presents the findings from interviews with forty-three young people with asthma and their parents. Where two parents were interviewed together questions were addressed to both parents and answered by either respondent. All but one parent interviewed identified themselves as the primary carer of the young person. All interviews were conducted in respondents' own homes. In all cases the researcher requested that each young person and parent were interviewed alone. Fifteen (35%) interviews were conducted separately. Twenty-eight interviews were conducted with young people with their parent in the room, in 22 of these parents (51%) and young people were interviewed whilst the other party was in the room and six (14%) young people were interviewed with their parent present but the parent was interviewed alone. This issue is discussed in relation to the research findings in chapter 7.

In cases where more than one person was in the room the researcher reminded the young person and parent of the importance of responses being from the person who was being interviewed. Where the other party gave responses the researcher directed all questions to the person being interviewed and at times reiterated the importance of individual answers to questions. As interviews were conducted within the home they were sometimes interrupted by telephone calls or the young person or their siblings requiring the parent's attention. Siblings were frequently in the room in which interviews took place, but were often entertained with an activity and interruptions to the interview were minimal.

Parents were interviewed with the use of a structured interview schedule (appendix I). Young people were interviewed with the use of a semi-structured interview schedule (appendix K). Although questions on all topics were asked in each interview, some young people chose not to respond to questions or replied they 'did not know'. In these cases further prompting was used by the researcher, where no response was elicited the number of missing cases have been reported. Where young people responded to questions with a non verbal response, for example a shake of the head or 'thumbs up', the researcher asked for further clarification regarding their response to the question. Issues related to interviewing young people are discussed in chapter 2 of this thesis and in relation to this research in chapter 7. The length of parent interviews ranged from 19 to 72 minutes, mean length 28.7 minutes. Interviews with young people ranged from 11 to 32 minutes, mean length 17.4 minutes.

4.3 Roles of asthma management within the home

Section 4.3 describes the roles of young people and their parents regarding the management of asthma within the home. Parents were asked about their roles concerning five activities of asthma management, ensuring continuous supplies of medication, collecting prescriptions from the pharmacy, reminding the young person to take medication, assisting with the administration of medication and deciding on

medication according to need. As shown in table 4.1 parents reported that these tasks were performed solely by them, shared by them and their son/daughter or performed solely by the young person. Young people were asked to report their role and that of their parents in remembering/reminding to take medication and assisting with the administration of medication. Table 4.2 presents these tasks as identified by young people. The remainder of section 4.3 examines each of these tasks in detail.

Table 4.1 Roles of parents and young people in the management of asthma, as reported by parents (n=43)

Role	Solely performed by parent	Task shared by parent and young person	Solely performed by young person	Not applicable
Ensuring continuous supplies of medication	38	1	2	2*
Collecting prescriptions	43	0	0	0
Remembering/reminding to take medication	40	0	3	0
Assisting with the administration of medication	1	0	42	0
Deciding on medication according to need **	25	0	5	13***

* Two young people had seasonal asthma and therefore required only one supply of medication per year

**Medication prescribed for use 'when required'

***Thirteen parents reported that the young person's medication was not altered other than by health care professionals

Table 4.2 Roles of young people and parents in the management of asthma, as reported by young people (n=43)

Role	Solely performed by parent	Task shared by parent and young person	Solely performed by young person	Not applicable
Remembering/reminding to take medication	37	0	6	0
Assisting with the administration of medication	1	0	42	0

4.3.1 Ensuring continuous supplies of medication and collecting prescriptions from the pharmacy

Data from parents

The majority of parents (n=38) identified themselves as responsible for ensuring continuous supplies of medication. Twenty of these parents commented, as in the following quote, that they performed this role as they felt if left to their son/daughter supplies of medication would run out :

I'd have to keep an eye on it, he'd probably wait and say 'this is empty mum!'

Mother of Paul, aged 8
Iv no. 12a, lines 85-89

Two parents reported that their son/daughter (aged 10 years, diagnosed 2 years; aged 11 years, diagnosed 5 years) were responsible for ensuring continuous supplies of medication. The parents of both these young people reported their son/daughter used a turbo inhaler which indicated the number of doses and therefore showed when medication was running out:

Well his one has the numbers on it, so he will say to me when it is on like a ten and then I will put the form in for another one.

Mother of Steven, aged 11 years
Iv no. 44a, lines 178-180

The use of an inhaler that indicates the number of remaining doses might encourage a young person to take on responsibility for ensuring continuous supplies of medication. However, the parents of four other young people who used turbo inhalers stated that they were responsible for ensuring continuous supplies of medication.

One parent felt that ensuring supplies of medication was a role shared between herself and her daughter:

I: And does Susan keep an eye on it (medication) running out or is that something that you would do?

M: Generally half and half.

Mother of Susan, aged 11

Iv no. 47a, lines 456-7

This young person (aged 11 years, diagnosed 7 years) did not use an inhaler which indicated when dosage was low but on occasion used a nebuliser. The serious nature of the young person's asthma might have influenced her taking on the role of ensuring continuous supplies of medication. Analysis of the data from interviews with two other young people who used a nebuliser indicated that in each of these cases the parent was responsible for ensuring continuous supplies of medication.

In summary, the role of ensuring continuous supplies of medication was most commonly performed by parents. The use of an inhaler that indicates the number of remaining doses or the young person having severe asthma might have encouraged young people to take on a role in ensuring continuous supplies of medication. All parents (n=43) reported they were solely responsible for collecting prescriptions from the pharmacy.

4.3.2 Reminding/remembering to take medication

Data from parents

Forty parents reported that they were responsible for reminding their son/daughter to take their medication. The parents of three young people (aged 12 years, diagnosed 11 years; aged 10 years, diagnosed 8 years; aged 11 years, diagnosed 5 years) indicated that the young person was responsible for remembering to take their medication. The parents of each of these young people gave explanations for not reminding their son/daughter, two parents reported how their son/daughter was able to assess for themselves when their medication needed to be administered:

Well we don't need to remind him as he can feel for himself when he needs to use it, better than either of us could tell.

Mother of Louis, aged 10
Iv no. 28a, lines 438-439

The third parent described how she did not remind her son to take his medication as he had a routine of taking it after he had cleaned his teeth and therefore did not forget.

These three young people all used preventer and reliever medication.

Thirty parents gave further details, 19 identified their role in reminding the young person as most frequently in relation to the use of preventer rather than reliever medication, eleven of these parents indicated that their son/daughter often forgot to take preventer medication:

The blue is fine she does not have a problem with that but the brown, you know I think it's because she don't hear her breathing change or anything like that, if I didn't say to her to take it in the mornings and at night then I don't think she would remember.

Father of Elizabeth, aged 11
Iv no. 19a, lines 375-378

However, the parents of all young people who used only reliever medication (n=8) reported reminding their son/daughter to take it, five parents indicated that they would remind their son/daughter in response to hearing difficulties with their breathing:

Like the other night I was cooking and I could hear him in here (living room) coughing away and I said 'go up and take your blue bubble' (reliever medication with use of a spacer device).

Mother of Ollie, aged 9
Iv no. 42a, lines 143-145

Three parents reported reminding their son/daughter to use reliever medication when the young person was preparing to undertake an activity which was known to exacerbate their asthma, such as participating in exercise or visiting friends who owned a pet.

Data from young people

Thirty-seven young people indicated that their parents reminded them to take their medication, young people often commented that being reminded prevented them from forgetting to take their medication:

Well my mum will say when I go to bed at night 'don't forget the brown'. If she didn't say it I would probably forget! (Laughs)

David, aged 8

Iv no. 43b, lines 123-124

Six young people stated that they were not reminded to take their medication and remembered without assistance.

Eight young people gave responses that differed from those of their parents. Six young people, whose parents had reported reminding them, indicated that they remembered without assistance to take their medication. In two cases young people reported that they were reminded to take their medication and their parents stated that they did not remind the young person.

In summary, the majority of young people and parents indicated that parents had a predominant role in reminding the young person to take medication. Parents who reported their son/daughter remembered to use medication without assistance noted confidence in their son's/daughter's ability to remember to do so. Data suggested that a parental role in reminding the young person to take their medication occurred across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted).

4.3.3 Administration of medication

Data from parents

Forty-two parents reported that they did not give their son/daughter assistance with the

administration of medication and stated that the young person was able to administer medication without assistance. Of these, two parents reported that although they did not assist in the administration of medication they supervised the process:

- M: I supervise her while she uses it, I wouldn't want her to be taking medicine in her bedroom without me knowing about it.
- I: So talk through with me what happens when she takes it, and how you supervise?
- M: Well really I just sit next to her and watch that she does the two puffs and uses the right colour puffer.

Mother of Gail, aged 8
Iv no. 14a, lines 267-269

One parent reported that she assisted her daughter (aged 10 years, diagnosed 8 years) with the administration of medication. The parent of this young person described how her daughter suffered from asthma attacks particularly at night and often woke with trouble breathing. On such occasions the young person suffered from panic attacks and had to be calmed down by her mother and assisted in the use of medication:

I have to at night like, at three in the morning on Monday night, she gets in such a state her hands like are (moves hands to indicate shaking) and she can't even hold the thing let alone push the button down so I have to help her with that and I have to say to her 'calm down take the deep breaths'.

Mother of Hilary, aged 10 years
Iv no. 2a, lines 176-178

The parent reported such incidences occurred regularly, on average four times a week, and recalled how she had on several occasions telephoned for an ambulance to obtain further assistance in the administration of her daughter's medication.

Parent data were searched for occasions when parents reported providing assistance to their son/daughter in the use of medication. Six parents indicated that although they did not usually assist with the administration of medication, they did do so in cases where the young person was unwell or in incidences where their asthma had been severe:

When Peter has to use the puffing dragon (nebuliser) I help him then, as he is usually in a bit of a state when we get to needing that, well we are in a bit of a state when we get to needing that to be honest! He knows how to put in the nebuliser if he had to, but I would do it and probably put the tv on for him as a distraction and then sit with him, see if it worked.

Mother of Peter, aged 10
Iv no. 17a, lines 167-169

All parents that indicated their son/daughter had used a nebuliser (n=3) reported having provided assistance with its use. No account was found in the data of young people experiencing difficulties with their asthma and parents not providing assistance with the use of medication.

Data from young people

Forty-two young people reported that they had no assistance with the use of medication. One young person reported assistance with administration of medication when unwell during the night, also stated by her parent. Five young people reported that although they did not usually need assistance with their medication there were occasions on which their parents had helped:

Usually I would do it but sometimes, like if we are coming home in the car and I fall asleep my mum will wake me up and sort of do the puffer for me while I am still sort of asleep, sometimes I don't even open my eyes!

Lee, aged 9
Iv no. 38b, lines 105-107

Other situations in which young people reported they had received assistance with the use of medication were when they were unwell, had asthma attacks or used a nebuliser.

In summary, parents and young people reported the role of administering medication as a task usually performed by the young person without assistance. The severity of the condition, use of a nebuliser and when a young person was unwell were situations which led to the involvement of parents in the administration of medication. Both young person and parent data suggest the young person using medication without assistance

occurred across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted).

4.3.4 Deciding on medication according to need

Data from parents

Parents were asked about their roles in deciding on the dosage of medication for their son/daughter according to need, medicine had been prescribed for use ‘as required’. Thirteen parents reported that the dosage of medication was not altered other than by health care professionals. Parents that indicated they decided on dosage according to need (n=30) reported changes to dosage involved changing the frequency with which the young person used their medication (n=24) or changing from one type of medication to another (n=6), for example one inhaler of preventer medication to a preventer inhaler of a higher dosage. Twenty-five parents reported that they were solely responsible for deciding on the dosage of their son’s/daughter’s medication, according to need. Parents reported factors which led them to change the dosage of medication, such as the young person was unwell, had participated in a lot of sport or had been in contact with triggers to their condition. One parent described altering the dosage of medication prior to her daughter having contact with a trigger of her asthma:

If we are going to stay with my in-laws, who have the cats, then I’ll start her on the Piritons a couple a weeks before and I will up the brown and the blue inhalers a couple of weeks before too, to sort of build her lungs up, prepare them for what is coming.

Mother of Abby, aged 11
Iv no. 49a, lines 134-146

Five parents reported their son/daughter was solely responsible for deciding on the dosage of medication according to need, three of these parents mentioned that their son/daughter would tell them if they had altered the dosage:

Oh she does that if she feels bad or has a cold coming on, then she will up the puffs on her own and usually just say to me that she has done it.

Mother of Olivia, aged 12

Iv no. 63a, lines 768-770

All five young people who were responsible for deciding on dose, according to need, used both preventer and reliever medication, one young person switched between the use of two forms of preventer medication depending upon the severity of her condition. In summary, deciding on medication according to need was a role most frequently performed by parents, it was not possible to explore the relationship between the age of young people and number of years since diagnosis and their role in this task (numbers too small to enable meaningful statistical tests to be conducted).

4.3.5 Overall responsibility for asthma medication

Data from parents

The parents of young people with asthma were asked to identify who had overall responsibility for their son's/daughter's asthma medication, as shown in table 4.3.

Table 4.3 Overall responsibility for asthma medication, as reported by parents (n=43)

Person with overall responsibility	Number of parents
Parent	33
Young person	6
Responsibility shared between young person and parent	4

Several parents (n=25) noted that although their son/daughter had a considerable role in the use of their medication, they felt that the overall responsibility was that of the parent:

Well it's hard to say because she does a lot of it on her own, but, er, I think at the end of the day the buck stops with us. As a parent, it is my overall responsibility.

Mother of Poppy, aged 9
Iv no. 4a, lines 347-348

Parents' views of the role of the young person in the overall responsibility for the management of asthma was associated with the age of the young person (Mann Whitney U test, n=43, p=0.025). The mean rank age of young people was higher where parents reported that the young person had overall responsibility for asthma medication, or responsibility for medication was shared between the young person and parent, compared to those parents who reported that it was the parents' overall responsibility. There was no association between the length of time since diagnosis and the role of the young person in the overall responsibility for their asthma medication (Mann Whitney U test).

In summary, section 4.3 has outlined partnerships between young people and their parents in the management of asthma tasks from the perspective of both young people and their parents. Data suggest that the sharing of tasks has been reported throughout the age range and number of years since diagnosis. Most frequently parents ensured continuous supplies of medication and all collected prescriptions from the pharmacy. Parents had a significant role in reminding young people to use their medication and in deciding on medication according to need. Most young people administered their medication without assistance from their parents. The age of the young person was associated with parents reporting that the young person had a role in the overall responsibility for their asthma medication.

4.4 Partnerships between young people and their parents in the management of asthma

Section 4.4 examines partnerships between young people with asthma and their parents. Section 4.4.1 describes the nature of partnerships between young people and their parents and section 4.4.2 conflict in partnerships between young people and their parents. Section 4.4.3 documents partnerships in relation to triggers to the young person's asthma. Section 4.4.4 outlines restrictions described by young people and parents due to the young person's asthma. Partnerships in the management of asthma described by young people who lived in more than one family unit are documented in section 4.4.5.

4.4.1 Types of partnerships between young people and their parents in the management of asthma

Data from parents and young people

Transcripts of parent and young person interviews were analysed for details of types of partnerships that existed between young people and their parents. Parents and young people often emphasised during interviews the ways in which they worked together in the management of the young person's asthma. The extent to which parents and young people worked together varied, in some partnerships it involved the sharing of tasks or division of tasks between both parties. Other parents and young people described conversations and discussions about the young person's condition and its management. Parents tended to describe working together as a joint approach to the management of asthma, the following quote is typical of comments made by parents:

It's teamwork really, we do it together, I do some things she does others, we are always talking about how she is feeling, how wheezy she is sounding and making decisions together about things really.

Mother of Emma, aged 10
Iv no. 45a, lines 867-869

Young people often referred to working with their parent in the context of receiving 'help' with tasks:

I try to remember to do it (use inhaler) but without help from my mum I probably would forget.

Simon, aged 10
Iv no. 36b, lines 189-190

Examples were also identified of situations in which parents took a dominant role in the partnership; made decisions about the management of the condition, told the young person off if they had not taken their medication or instructed the young person to take their medication. At times young people appeared indifferent to the management of their asthma, and did as they were told:

I: So do you ever alter the number of puffs you have of your inhaler?

Y: Yeah

I: And how do you know when to do that?

Y: When my mum tells me to do more, I do more.

Sally, aged 12
Iv no. 21b, lines 111-115

On other occasions however young people were dominant in the partnership and made decisions about the management of their asthma which parents accepted:

I thought she should stick with using the bell (spacer device) and I told Gail it was much better for her, I'm sure she gets more of the medicine that way but she wouldn't use it, she said it was babyish, so now we just use the inhalers normally.

Mother of Gail, aged 8
Iv no. 14a, lines 615-617

No one parent and young person partnership fell exclusively into one of these categories. Rather, within each interview young people and their parents tended to move between these three types of partnership, often dependent upon the topic being discussed. For example, the parent might have had a dominant role in relation to when

health care professionals should be seen, and young people a dominant role with regard when medication should be used.

4.4.2 Conflict in partnerships between young people and their parents

Data from parents

The preliminary work of this thesis (see chapter 2) identified conflict between young people and their parents in relation to the management of chronic conditions. Data from interviews with young people and parents were searched for evidence of conflict. Conflict in partnerships was identified as disagreements, or differing views or perspectives regarding issues related to the young person's asthma. In the majority of parent interviews (n=37) no evidence of conflict within partnerships were found. As identified in the previous section, 4.4.1, parents and young people often described working together in the management of the young person's asthma. The majority of young people appeared to accept the roles of their parents in the management of their condition, such as their parent reminding them to take their medication and this was not revealed in interviews to be an issue of conflict between them. In six cases incidences of conflict were identified from parent interviews (see table 4.4).

Table 4.4 Conflict within partnerships between young people and their parents, as reported by parents (n=6)

Issue of conflict, identified by parent	Number of respondents
Parent reminding young person to take medication	3
Young person being prevented from participating in an activity	2
Parent reminding young person to carry medication	1

Parents described conflict as most often in relation to the young person being reminded by their parent in relation to their asthma, or the young person being prevented from taking part in a specific activity:

Oh the fights we have every morning before she goes to school I will ask her if she has taken her inhaler and she will say no and I'll make her go back and use (it) and oh we have the big stomp us the stairs and the sulk and everything!

Mother of Briony, aged 11

Iv no. 9a, lines 1067-1071

Data from young people

In the majority of interviews with young people (n=43) no evidence of conflict in partnerships were found. One young person (aged 12 years, diagnosed 7 years) reported disagreements regarding her parent reminding her to take medication.

Data from parents and young people

The influence of conflict on partnerships between young people and parents were considered. Interviews with parents in which conflict was identified (n=6) and the corresponding interviews with young people were analysed. In five cases in which conflict was noted in the parent interview it was not referred to in relation to other aspects of the partnership. On the contrary, young people and parents reported working together in tasks and conflict appeared confined to a specific issue.

In one case however, the young person and parent both reported arguments which had resulted in the young person refusing to perform tasks of asthma management. The views of this young person are described in the following quote:

If she (mother) says go and take the brown (inhaler), I will deliberately not go upstairs coz it annoys me that she goes on about it and I don't see why I should have to use my inhaler if I don't want to.

Steven, aged 11

Iv no. 44b, lines 89-91

In summary, partnerships between young people and parents were generally harmonious. In one case conflict within a partnership might have had implications for the management of the young person's asthma. Health care professionals might be well placed to identify conflict within partnerships and intervene to reduce the implications of this on the management of the young person's condition.

4.4.3 Partnerships in relation to the management of triggers of the young person's asthma

All parents and most young people identified triggers or situations which exacerbated the young person's asthma, several identified a number of factors. Triggers identified were; exercise, cold weather, allergies, hay fever, stress, upset, nervousness, tiredness, dust, dirt and in relation to eating certain types of artificial flavourings.

Data from parents

Seventeen parents described taking steps to ensure that their child avoided triggers to their condition. These included avoidance of visiting friends who had pets, writing letters to ensure that their child did not participate in sport at school and cleaning the house regularly and thoroughly. Three of these parents reported making changes to the home environment, such as purchasing special sorts of bedding. One of these parents described extensive changes that had been made to the family home:

As you can see we have completely got rid of the carpet all down here and next year I am going to do her room and just have like a little rug in there for her to put her feet on when she gets out of bed that I will wash regular. I don't let her have loads of cuddly toys on her bed, just the one and I put him (cuddly toy) in the freezer every couple of weeks.

Mother of Hilary, aged 10
Iv 2a, lines 665-672

Eight parents reported that they had discussed with their son/daughter ways to manage factors that triggered their condition, such as withdrawing from sport at school, taking

medication when staying with friends who had pets and not participating in sports when the weather was cold.

Data from young people

Eight young people identified ways in which their parents helped them to avoid situations or triggers which exacerbated their asthma, these included helping them to avoid houses in which there were pets, writing letters to excuse them from PE at school and regularly cleaning to reduce dust. One young person described how his mother had helped him to manage his asthma more effectively during sports at school:

I used to have loads of trouble with cross country, as running sets me off and I couldn't carry my inhaler so my mum she like sewed a loop on my sports shorts so that now I can carry my inhaler with me when I have to do the running and can use it at anytime.

Mark, aged 12
Iv no. 37b, lines 132-133

4.4.4 Restrictions on parents and young people due to the young person's asthma

Data from parents

The majority of parents reported that their son's/daughter's condition caused them few limitations. Several parents indicated that the mild nature of the young person's asthma was a reason for this. Five parents indicated that their child's asthma caused few difficulties compared to other conditions or situations in their lives such as allergies to peanuts (n=3) or a cleft pallet. One of these parents, whose son had autism and was separated from her partner stated:

Well considering what we have to deal with on a daily basis the asthma is just nothing, I certainly don't loose any sleep over that!

Mother of Louis, aged 10
Iv no. 28a, lines 1078-1080

Three parents indicated that the young person's asthma did cause some restrictions and difficulties in their lives. Two parents reported that due to the young person's asthma the family were unable to have a dog. One parent stated that asthma at night impacted upon her ability to get her daughter to school on time in the morning.

Data from young people

As with parents, most young people (n=37) stated that their asthma did not place limitations on their lives. Six young people identified restrictions caused by their asthma. Four young people reported that their ability to participate in sports was affected by their condition:

If it's like really cold outside and sort of frosty, you know when you can see your breath? When it's like that I find it hard to take big breaths when I am playing football.

Simon, aged 10

Iv no. 36b, lines 1238-1240

One young person stated that he wanted to be a fireman when he was older and could not because of this asthma and another young person was not allowed to take part in a Quazer laser game at a friend's party because of his asthma.

4.4.5 Partnerships of young people who lived in more than one family unit

Section 4.4.5 documents the experiences of young people who lived in more than one family unit. Interviews with young people and parents were analysed and issues related to another family unit, for example visiting a parent in a different home, were identified. Young people and parents described the home in which the interview was conducted as where the young person lived most of the time, referred to in this section as the young person's primary family unit. The visiting of another parent is referred to as the secondary family unit. The parent in the second family unit was not interviewed as part of this research and as such findings presented in this section rely on the reports of the

parent in the primary family unit, which might be of questionable reliability and completeness. Demographic data collected during the interview indicated that the parents of four young people were separated. Young people and parents were not asked during the interview about a secondary family unit, yet in two cases young people and their parents reported that the young person visited their father at weekends. This section is therefore concerned with those young people and parents who indicated in the interview that the young person lived in more than one family unit (n=2).

Data from parents

Both parents who identified their sons stayed with their fathers, noted that their sons had more responsibility for the management of their asthma in the secondary family unit, and indicated that the other parent was not involved in the management of the young person's asthma:

He's fairly responsible for it... he goes to his dad's and his dad doesn't deal with it, he does.

Mother of Gavin, aged 10
Iv no. 25a, lines 114-117

In addition to managing his asthma alone in the secondary family unit, the mother of one young person noted her son experienced an opposing view of asthma medication in the secondary family unit:

His dad is asthmatic ... his dad don't (use an inhaler), he has these views that if you start on it then you are on it for life so if you can deal without it then deal without it. That's how he is ... But Matthew, I got a bollocking because they (asthma nurse) said he should have one and he should use it regular and all this. I said well his dad reckons he shouldn't he should only use it when he really needs it.

Mother of Sam, aged 9
Iv no. 35a, lines 155-157

Data from young people

The two young people whose parents identified issues, also reported differences in the management of asthma between their primary and secondary family units. Both young people described how their parent in the secondary unit knew little about their asthma. Roles usually undertaken by the parent in the primary family unit were not performed in the secondary family unit:

- I: So does anyone ever remind you to take your medication?
Y: Yeah my mum, unless I am at Dad's then nobody does, I usually forget then. It is not easy to remember when mum is not there.

Ollie, aged 9

Iv no. 42b, lines 312-313

The small number (n=2) of young people in this research that identified themselves as living in more than one family unit means further analysis of the data was not possible. The accounts of these two young people and their parents suggested that young people who lived in more than one family unit might experience different roles in the management of asthma within their primary and secondary family unit. An awareness of these possible issues for these young people, including potential difficulties, might enable health care professionals to provide help and support to them.

4.5 Changes in partnerships

The first two sections in this chapter have focused upon the current roles of young people and their parents in the management of asthma. Section 4.5 reports how these partnerships have changed over time, potential triggers to changes in partnerships and young people's and parents' views of anticipated future changes to partnerships.

Data from parents

Changes were identified by parents that had occurred since their son/daughter had been diagnosed with asthma. Fourteen parents indicated that no changes had occurred to

roles of asthma management in this time. Of those parents who identified changes (n=29) 21 parents identified assistance with the use of medication as a role that had changed over time, with young people now able to administer their medication without assistance:

When he first had it I would put together the space thingy (spacer device) for him and he would hold it while I pushed the button on the puffer for him. Now he does it all on his own.

Mother of Richard, aged 12
Iv no. 56a, lines 1056-1059

Other changes included young people deciding on medication according to need (n=5) and remembering to take their medication (n=3) without assistance. Parents were seldom able to recall the exact age at which young people had taken on new roles of asthma management, but often identified situations or life events as triggers for a young person to take on more responsibility.

Data from young people

Twenty-five young people identified changes in partnerships since they were first diagnosed with asthma. Twelve young people stated that they now required less assistance from their parents in the management of their asthma, eleven young people specified no longer needing assistance with the administration of medication. Other changes identified by young people were remembering to take medication without being reminded and taking responsibility for ensuring continuous supplies of medication.

Data from parents

Of those parents who identified that changes to partnerships had occurred (n=29), 27 parents reported that changes to partnerships had occurred without planning, 15 parents commented that it was part of the natural process of the young person growing up and wishing to become independent:

- I: So what led him to start taking his medication without assistance from you?
- M: I think it was just part of the process of growing up really, wanting to do things for himself without us interfering.
Mother of Paul, aged 8
Iv no. 12a, lines 204-207

Fifteen parents identified specific events which had led their son/daughter to take on more responsibility for the management of their asthma. Eight parents noted that school trips, often reported as the first time the young person had stayed away from home without a parent, had led the young person to take on more responsibility for their asthma. Parents described how prior to the young person staying away they had encouraged the young person to manage their medication without assistance:

Well we have known about this trip (school trip) for a while now so we have been gradually, you know, making sure that she really knows when to take it and how to take it and what to do when she feels bad.
Mother of Lara, aged 8
Iv no. 60a, lines 124-127

Other situations which parents reported had led to the young person taking on more responsibility for their asthma included the young person wishing to stay the night with friends (n=4), changing from primary to secondary school (n=3) and the young person attending a residential Brownie camp (n=1).

Two parents described adopting a planned approach to their son/daughter taking on a greater role in the management of their asthma. Both parents explained how they had encouraged their son/daughter to take on additional roles and to take more responsibility for their condition:

-
- I: So have you made any plans for Stuart to take on more responsibility for his condition?
- F: Oh God she (mother) has!
- M: Well I think you have to be prepared, it is no good me still doing things for him when he is twenty for Christ's sake! I want him to grow up and be independent and to be able to manage his asthma on his own. I've encouraged him from the start. When he was five I got him to assemble his own spacer and then push the pusher down on his own. Now I try not to remind him as much as I used to, I want him to realise himself he needs to do it.

Mother and Father of Stuart, aged 10
Iv no. 24a, lines 978-987

Data suggested parents took an unplanned approach to changes in partnerships across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted). Parents were asked if they had ever spoken to a health care professional regarding their son/daughter taking on more responsibility for their asthma. Twelve parents reported that they were unable to remember. Twenty-seven parents reported they had never spoken to a health care professional regarding this issue. One parent felt that health care professionals did not wish to become involved:

I think there is an assumption that as a parent *you* have to be responsible for these things.

Mother of Nicola, aged 12
Iv no. 3a, lines 867-868

Four parents had spoken to a health care professional about their son/daughter assuming greater responsibility for the management of their asthma, in all cases this was a nurse. Two of these parents stated that they had told the asthma nurse that they were encouraging their son/daughter to take their medication without assistance and the nurse had encouraged them to continue this, but offered no additional advice. Another parent reported that the asthma nurse had recommended her son learnt to use his medication without her assistance by gradually teaching him how the inhaler worked and how to use it on his own. One of these parents reported that the asthma nurse had been of little help

when asked for advice about her daughter taking on more responsibility for the management of her asthma:

She (asthma nurse) wasn't much help to be honest with you. I sort of said to her 'do you think that Kate is doing enough for herself?' and she said 'are you happy?', and I said 'well we are ok but I want to know if she is doing enough for herself'. She didn't really give us any advice or help I didn't come away feeling very reassured, I mean I want Kate to be independent but I don't want to give her more responsibility than she can handle.

Mother of Kate, aged 10

Iv no. 13a, lines 156-162

Young people and parents were asked for their thoughts regarding the future nature of partnerships. Twenty-seven parents reported that they had not thought about future changes to the partnership, but assumed responsibility for the management of asthma would naturally become that of the young person as they grew older:

I don't really think about it, as he grows up he'll do more for himself, I won't be going to the pharmacy for his inhalers when he's forty!

Mother of Mark, aged 12

Iv no. 37a, lines 176-177

Four parents reported that they had not thought about the future nature of their son's/daughter's condition as they believed that the young person would grow out of their asthma and not have it when they were older. A further three parents stated they had not thought about the future and identified specific reasons for this. Two of these parents reported that they had not done so as they were presently concentrating on managing the young person's current condition and considered the young person (aged 8 years and 10 years) too young to think about the future of their condition. One parent, whose son regularly used a nebuliser, felt that the condition was too unstable to consider the future:

He's just so unpredictable at the moment, it's impossible to think about how he will be tomorrow, let alone how he is going to be in a year or several years time.

Mother of Lee, aged 9

Iv no. 38a, lines 345-347

Nine parents reported anticipating future changes to partnerships between themselves and their son/daughter and identified tasks the young person would adopt over time to assume sole responsibility for their condition:

Obviously as time goes on the things we do for him now, which in all honesty isn't that much, but like reminding him to use his inhalers, as time goes on we won't do that as much and he will remember on his own.

Mother of James, aged 11

Iv no. 51a, lines 412-415

Data from young people

Most young people had not considered future changes to partnerships in the management of asthma (n=18) or were unable to answer the question (n=22). Three young people stated they would be responsible for their asthma when they grew up:

Well when I think about the future I think of say when I am at University then I won't need Mum to book appointments to see the doctor, I will go myself.

Peter, aged 10

Iv no. 17b, lines 121-123

In summary, most parents identified changes that had occurred to roles of asthma management within partnerships over time, with young people taking on more responsibility for their condition. Changes occurred with little specific planning and frequently without the involvement of health care professionals. Most parents were aware changes to partnerships would occur in the future, but had given little consideration to them. Health care professionals need to acknowledge the changing nature of partnerships between young people and parents over time and provide guidance and support where needed as young people take on more responsibility for the management of their asthma.

4.6 Management of asthma in schools

Section 4.6 reports the management of asthma by young people in schools. Section 4.6.1 details young people who did not take asthma medication to school. Section 4.6.2 documents the place of storage of asthma medication in school and whether schools had a medication policy. Section 4.6.3 documents problems in relation to the management of asthma in school, as reported by young people and their parents.

4.6.1 Young people who did not take asthma medication to school

Data from parents and young people

Five young people and their parents (n=43) reported that the young person did not take asthma medication to school. In four of these cases both young person and parent stated the young person did not use asthma medication during school hours and therefore did not take medication to school. One young person reported that his parent did not allow him to take medication to school. His parent described the reason why:

If he needs it before he goes to school then I will allow him to use it. No way is he taking it to school because I know he would abuse it.

Mother of Sam, aged 9
Iv no. 35a, lines 564-567

4.6.2 Storage of medication and school policies relating to medication

Data from young people

Thirty-eight young people took asthma medication to school, they were asked where in school their medication was stored, their responses are reported in table 4.5. Young people whose medication was stored in a room away from the classroom or with a member of staff reported that they had to seek permission before the use of medication in school. Young people who carried their own medication used it when they wished without seeking permission.

Table 4.5 Storage of asthma medication in schools as reported by young people (n=38*)

Place medication is stored	Number of young people
With young person	22
Room in school away from classroom	8
With teacher or welfare staff	8

* Five young people did not take their asthma medication to school

There was no association between the age of the young person and whether medication was stored with them or elsewhere (Mann Whitney U test).

Data from parents

Parents were asked if their son's/daughter's school had a policy related to the storage and use of medication, their responses are presented in table 4.6.

Table 4.6 Policies regarding medication in school, as reported by parents (n=43)

Does your son's/daughter's school have a policy regarding medicines?	Number of respondents
Yes	19
No	11
Don't know	13

There was no association between the age of the young person and whether the school had a policy regarding medication (Mann Whitney U test).

4.6.3 Problems with the management of asthma in schools

Data from parents

Problems with the management of asthma in schools described by young people and parents were identified from interview data. Twelve parents reported their son/daughter had experienced problems. Nine of these parents described problems in relation to their son/daughter having access to their medication, this included policies that restricted the access to medication and it not being available to the young person when on a school trip:

M: I mean it was ridiculous she (head teacher) was saying that if they need the preventer inhaler they are too ill to come to school, I mean!

I: And is this still a problem?

M: No eventually Mrs Simms (teacher) who has asthma herself sort of stepped in and told the head that she was being stupid and now he is allowed to use the brown (preventer medication) at school.

Mother of Liam, aged 12

Iv no. 11a, lines 233-237

Two of these parents (n=9) had encouraged their son/daughter to break school rules regarding the storage of medication to enable them to have access to their medication whilst at school:

The rule is that I should hand in her inhaler to the secretary and it gets locked in her room. But that's no blimin' use if she's down in her classroom having an asthma attack and the secretary has gone to the loo or something! So I said to Kylie we will hand one in like we are meant to but sneak this other one into your pencil case and if you need it just use and if anyone tells you off tell them to speak to your Mummy.

Mother of Kylie, aged 9

Iv no. 27a, lines 617-621

The remaining three parents described problems with the school's attitude towards their son's/daughter's condition and expressed concern about the potential consequences of

their lack of understanding of the severity of the condition. This point was made emotionally by one of these parents:

And I have to say that is one area of concern, because I don't know who (at the school) knows whether he's got asthma or not. Now if he had a blinder of an attack like he did in 1999 I don't know whether they would be quick enough off the mark to realise what was happening.

Mother of Luke, aged 12
Iv no. 53a, lines 734-739

One parent described how her concern regarding the school's attitude to her daughter's asthma led her to keep her daughter at home when her condition was bad. Another parent reported that the school was unsympathetic when her daughter was late because she had been up at night due to problems with her asthma. Of those parents who identified problems with the management of the young person's asthma (n=12) six indicated that the school had a policy in relation to medicines, four parents that the school had no policy and two that they did not know. There was no association between the age of the young person or number of years since diagnosis and parental reports of problems with asthma at school (Mann Whitney U tests).

Twenty-five parents (n=43) indicated that they had spoken to a teacher about their son's/daughter's asthma or filled out a medical form indicating that their child had the condition. The remaining parents (n=18) were unaware whether the school knew that their son/daughter had asthma.

Data from young people

Six young people (n=43) reported problems related to their asthma in school, two of whose parents had also identified problems. Three young people expressed problems with being teased or bullied at school because of their asthma:

There was a friend that um, I had who had asthma and there were these two boys that always picked on us that we um, some people that were always frightening us. And it was a bit stupid, but everyone liked me and they didn't like these two other boys so and um, they would tell them to leave us alone.

Peter, aged 10

Iv no.17b, lines 401-407

Two young people reported the impact of their asthma on participating in physical activities at school:

At school sports days I find that I can't run as fast as the other children. When we play games in the playground like It and things like that I'm the first to get It and when we play Bulldog I'm always the first to get nominated.

Stuart, aged 10

Iv no. 24b, lines 331-334

One young person described difficulties on a school trip during which staff were unable to locate his medication. Of young people who identified problems in school (n=6) two parents indicated that the school had a policy in relation to medication, three that there was no policy and one parent that they did not know. Data from young person interviews suggests problems across the age range and number of years since diagnosis of asthma (numbers too small to enable meaningful statistical tests to be conducted).

Interviews in which young people had not identified problems with school were further analysed (n=37). Of these, seven young people noted that asthma was a common condition within the school and therefore did not present them with a problem. The following quote is a typical example of such a response:

I: How do you feel about using your inhaler in school?

Y: Well lots of people do it so it doesn't bother me.

Emma, aged 10

Iv no. 45b, lines 587-589

Further analysis was not able to establish why some young people experienced problems in school and others did not. Problems related to the young person's asthma in school,

such as bullying, might be related to other issues at school, not associated with the young person's asthma, this information was not available from the interview data.

In summary, young people of all ages and their parents reported dissatisfaction or difficulties in relation to school, some of which did and did not have policies regarding medication and in cases where the young person carried their own medication or where it was stored elsewhere. Parents tended to describe problems with school in relation to medication and the condition whereas young people's problems related to the social impact of their asthma. Problems within schools in which a policy relating to medication was in place, suggests that school policies might not be adequate in resolving problems surrounding medication and the management of asthma. Health care professionals might be well placed to assist in the formulation of school policies and in informing staff of the nature of the condition and its treatment. An awareness of the social impact of asthma on young people by school staff, parents and health care professionals might enable them to better provide support to young people in managing their condition effectively whilst at school. Findings suggest some schools might be unaware which pupils have asthma.

4.7 The roles of health care professionals in the care for young people with asthma

Section 4.7 documents the roles of health care professionals in the care of young people with asthma. Section 4.7.1 records the health care professionals that young people saw in relation to their asthma. Section 4.7.2 reports the role of the asthma nurse from the perspectives of both parents and young people. Section 4.7.3 recounts the role of the GP in the management of the young person's asthma as reported by young people and their parents. All young people and parents reported attending appointments with health care professionals together.

From field notes made immediately after the interview and the researcher's own reflections young people did not seem as engaged when talking about consultations with health care professionals (nurses or GPs) as they did when talking about management at home or at school. Several young people appeared bored by discussions of consultations and gave shorter answers to questions and, even with the use of prompts, appeared to have little to say. Although such observations are not generalizable, they might suggest a lack of interest amongst young people in consultations with health care professionals.

4.7.1 Contact with health care professionals

Section 4.7.1 provides a brief description of health care professionals seen by young people regarding their asthma and the frequency of visits. Data concerning visits to health care professionals were taken from interviews with parents as these generally included a fuller description of contact.

Data from parents

All parents (n=43) reported that the care of their son's/daughter's asthma took place at the GP surgery. In addition to this, two young people saw a hospital consultant in relation to their asthma, both of these young people suffered from medical problems in addition to asthma. As visits to the hospital were due to additional health problems the role of the hospital consultant will not be explored in this chapter.

Table 4.7 reports the health care professionals most often seen by young people regarding their asthma, as reported by parents.

Table 4.7 Health care professionals most often seen by young people regarding their asthma, as reported by parents (n=43)

Health care professional seen	Number of young people
Nurse	27
General practitioner	14
Hospital consultant	2

Most parents (n=38) reported their son/daughter had seen a GP at least once in relation to their asthma. The parents of ten young people reported never having seen an asthma nurse in relation to their son's/daughter's condition.

Parents were asked when their son/daughter last saw a health care professional in relation to their asthma, as reported in table 4.8.

Table 4.8 Length of time since young person saw a health care professional in relation to their asthma, as reported by parents (n=43)

Length of time since health care professional was last seen	Number of parents (n=43)
Six months or less	16
Seven months - one year	19
Greater than one year, up to three years	3
More than three years	5

The majority of parents (n=37) reported infrequent contact with health care professionals, but were satisfied with the care received:

It's fine, I mean we don't see anyone very often, most of the time we are on our own, but they (GP surgery staff) are there if you need them.

Father of Elizabeth, aged 11

Iv no. 19a, lines 867-868

Six parents indicated dissatisfaction with the frequency of contact with health care professionals:

I mean it must be about four years since we actually saw anyone up there (GP surgery) they just keep dishing out the repeats (prescriptions) but it makes me a bit nervous, how do they know he still needs it or if he maybe needs more medicines?

Mother of Neil, aged 11

Iv no.1a, lines 756-759

4.7.2 The role of the asthma nurse in the care of young people with asthma

Section 4.7.2 reports the role of the asthma nurse in the care of young people with asthma, as reported by young people and their parents.

Data from parents

Thirty-three parents reported their son/daughter had seen an asthma nurse on at least one occasion. Of these 18 parents reported their son/daughter had regular consultations with the asthma nurse, eight parents stated that they had previously had regular consultations with the asthma nurse but no longer did so and seven parents reported that their son/daughter had only had one consultation with an asthma nurse. Figure 4.1 reports the role of the asthma nurse in consultations as identified by parents, some parents identified more than one role of the asthma nurse.

Figure 4.1 Roles of the asthma nurse in consultations, as reported by parents (n=33)

Talking about asthma (n=18)
 Altering the dosage of the young person's medication (n=12)
 Demonstrating inhaler technique (n=9)
 Providing the young person with new inhalers (n=8)

Twenty-nine parents who had seen an asthma nurse (n=33) elaborated on their views of consultations. Most parents (n=24) commented on positive aspects of consultations with the asthma nurse such as the friendliness of the nurse, information about asthma that they provided, support provided by them and the frequency of contact. Five parents indicated negative aspects of consultations with the asthma nurse such as long waiting times, infrequent contact and disagreements with the nurse regarding medication.

Twenty-eight parents reported that they had asked an asthma nurse questions relating to their son's/daughter's condition, several parents indicated that they often asked questions:

Oh I am always asking her (asthma nurse) questions, I am Mrs Curious - I want to know about *everything!*

Mother of Poppy, aged 9
Iv no. 4a, line 345

Parents recalled having asked the asthma nurse questions regarding medication, the young person's growth, hayfever, peak flow monitoring and exercise. Three parents described disagreements with the asthma nurse, all in relation to their son's/daughter's medication. One parent wished the amount of medication her son was taking to be reduced and one parent requested that the nurse increase the amount of medication her son used. As described in the following quote, one parent had strong views about the use of asthma medication and this had led to disagreements between her and the asthma nurse:

- M: I don't want him to rely on it. I am not one of those people who say you have to have it in the morning and you have to have it before you go to bed, to me it's wrong. But then I get told that I am wrong because it keeps the tubes open.
- I: Has it caused friction do you think between you and the asthma nurse?
- M: Yes it does, you can see that she is not impressed, she says 'you are not the person who is suffering with it' which is true and I say that his dad suffers with asthma and he is even saying 'I don't want him relying on it'. I don't think he (her son) has seen the nurse since or a doctor to be honest. I have not taken him up there (GP surgery) because he's not really that severe with it.

Mother of Sam, aged 9
Iv no. 35a, lines 67-78

Twenty-three parents (n=43) reported that their son/daughter had asked the asthma nurse questions. Questions were related to medication, height, peak flow readings, nebulisers and medication at school.

Data from young people

Young people were asked to describe consultations with the asthma nurse. The role of the asthma nurse, as reported by young people, is shown in figure 4.2.

Figure 4.2 Roles of the asthma nurse in consultations, as reported by young people (n=33)

Talking about asthma (n=11)
Providing new inhalers (n=10)
Weighing and measuring young people (n=6)
Measuring peak flow (n=5)
Discussing problems with asthma (n=5)
Administering flu jab (n=2)
Showing inhaler technique (n=2)

Twenty young people were able to recall consultations with an asthma nurse, 13 of whom commented on positive aspects. Five young people referred to the asthma nurse by name and described a close relationship, with two referring to the asthma nurse as

their friend. Three of these young people described consultations with the asthma nurse as informative or beneficial to them. An articulate expression of this is shown in the following quote:

I like the fact that they (asthma nurse) keep track. I like it that there is someone professional who can help. It makes me feel more comfortable. It's just good to know that someone is there. If I have any problems I can just ask the nurse at my next appointment.

Sarah, aged 11
Iv no. 34b, lines 776-778

Five young people expressed dislike of consultations with the asthma nurse and identified reasons for this as long waiting times, boredom during consultations and the young person preferring to spend their time doing something else:

I: So what are the good things about going to see the asthma nurse?
Y: Nothing really.
I: Can you think of anything good about it?
Y: Not really, I would rather spend my time playing with my computer than listen to the nurse.

Billy, aged 11
Iv no. 62b, lines 178-182

Young people were asked if they had ever asked an asthma nurse questions regarding their asthma, 13 young people reported that they had done so. Five young people were able to recall areas regarding which they had asked questions these included height, weight, how to use medication, when to use medication, what different coloured inhalers did and if they would grow out of asthma. Eight young people were unable to recall the nature of the questions they had asked:

- I: Do you ever ask the asthma nurse any questions?
 Y: Yeah, sometimes.
 I: What sorts of things do you ask her about?
 Y: Stuff about asthma.
 I: Anything in particular, any topics you can remember asking her about?
 Y: Not really

Hilary, aged 10
 Iv no. 2b, lines 123-128

In summary, the majority of young people had seen an asthma nurse on at least one occasion, although the frequency of contact varied. Parents frequently asked asthma nurses questions relating to their son's/daughter's condition. Some young people felt consultations with an asthma nurse were informative, whilst other young people did not value the experience. Thirteen young people (n=43) reported that they had asked an asthma nurse a question.

4.7.3 The roles of the general medical practitioner in the care of young people with asthma

Data from parents

Five parents and young people reported they had never seen a GP in relation to the young person's asthma. Parents whose son/daughter had seen a GP (n=38) were asked to describe the role of the GP in consultations, as shown in figure 4.3.

Figure 4.3 Roles of the general medical practitioner in consultations, as reported by parents (n=38)

Treating illnesses related to asthma (n=14) Diagnosing asthma (n= 12) Prescribing medication (n=9) Overall management of young person's asthma (n=2) General care (n=1)

Thirty two parents reported that their son/daughter had consultations with the GP when they were unwell with a condition that exacerbated their asthma. Six parents stated their son/daughter had consultations with the GP in relation to asthma on a regular basis. Eighteen parents expressed their views regarding the GP, nine parents commented on positive aspects of consultations with the GP, usually in relation to the treatment of conditions that exacerbated the young person's asthma:

He's (the GP) very good, when he gets the chest infections he has a listen a straight away he says oh yes it'll be the infection again and writes out the prescription ..he's usually sorted in a couple of days.

Mother of Simon, aged 10
Iv no. 36a, lines 1067-1069

Other positive comments included being telephoned by the GP and being able to get medication from the GP with use of a repeat prescription. Nine parents expressed negative comments in the relation to the GP. These were; feeling rushed in the consultation, not being given enough information about the condition, several visits to the GP before a diagnosis of asthma was made and a mother whose GP had told her she was over-anxious. Seventeen parents had asked the GP questions relating to their sons/daughters asthma, most often in relation to illnesses which exacerbated it:

Well um, when we see him it's usually because of something that needs tablets so I usually ask the doctor how many she needs to take and for how long.

Mother of Nicola, aged 12
Iv no. 3a, lines 1026-1028

Parents also recalled asking questions related to use of inhalers, availability of nebulisers, flu jabs, allergies and triggers to the young person's asthma.

Three parents reported that their son/daughter had asked the GP a question about their asthma, one parent stated the question related to medication for a condition which had exacerbated her son's asthma, the two remaining parents were unable to recall the topic of questions. Eleven parents who indicated that their son/daughter had not asked the GP

questions indicated the young person preferred not to talk during consultations or was shy or nervous:

She doesn't really say much, I think she's a bit nervous of him really, she tends to let me do the talking and chatter away. She answers questions he (GP) asks her but like she'll just say yes or no, I have to give the details.

Mother of Hayley, aged 10
Iv no. 48a, lines 1276-1279

Data from young people

Figure 4.4 outlines the roles of the GP in the care of young people with asthma, as identified by young people, 12 young people who had seen a GP in relation to their asthma (n=38) were unable to recall the consultation.

Figure 4.4 Roles of the general medical practitioner in the care of young people with asthma, as identified by young people (n=26)

Providing medication (n=12) Providing care for illnesses (n=10) Examining young person (n=4)
--

Six young people commented on their view of the GP. Four young people indicated positive aspects of consultations with the GP and stated that consultations with the GP enabled them to learn about their condition and to obtain medication when they were ill. Two young people commented on negative aspects; one young person said that the GP was scary and the other that they did not like to be examined.

Young people who had seen a GP (n=38) were asked if they had ever asked a GP questions regarding their asthma, 18 young people stated they did not know and 20 young people that they had never asked a GP questions about their asthma.

4.7.4 The roles of the pharmacist in the care of young people with asthma

Data from parents

Sixteen parents (n=43) reported that they had spoken to a pharmacist regarding the young person's asthma, most often to receive instructions about the use of inhaler medication. Three parents had spoken to a pharmacist about the young person's hay-fever, which exacerbated their asthma, and one about the purchase of a nebuliser. Two parents stated that the pharmacist was a major source of information and support to them:

Oh he (pharmacist) is just great, it was him really who first said to go to the doctors as the cough might be asthma. He is great, I go to him before the doctors if I have a problem with Mark.

Mother of Mark, aged 12
Iv no. 37a, lines 278-280

In summary, section 4.7 has documented the roles of the asthma nurse and GP in the care of young people with asthma. Asthma nurses were identified as the health care professional most commonly seen in relation to asthma. Few parents and no young people were able to recall the young person asking the GP questions in relation to their asthma. Parents identified limited contact with pharmacists in relation to the young person's asthma. This section has also identified the lack of contact of some young people with health care professionals, with the parents of eight young people stating that their son/daughter had not seen a health care professional in relation to asthma for two years or more.

4.8 Information needs and information used by young people with asthma and their parents

Section 4.8 details the information needs and information used by young people with asthma and their parents. Section 4.8.1 reports the information sources previously used

by parents and issues for which they require more information. Section 4.8.2 identifies information sources used by young people and the additional information that they need.

4.8.1 Information needs and information used by parents

Twenty-four parents reported that they had obtained information about asthma primarily from consultations with health care professionals seen with their son/daughter, particularly asthma nurses (n=17). Some parents (n=18) had obtained their knowledge of asthma solely from health care professionals. However, the majority of parents (n=25) identified their information regarding asthma had been obtained from more than one source:

I've learnt about asthma from tons of places I suppose, the nurse obviously but I like to read about it in newspapers, books, I watch stuff on TV anything really, I've sort of got an ear out for anything about it and I'll be into it.

Mother of Abby, aged 11
Iv no. 49a, lines 675-677

Sixteen parents had read information leaflets about asthma from the GP surgery and five parents had read written information obtained from the National Asthma Campaign. Three parents were trained nurses and identified their knowledge as having been obtained through their professional training. Other sources of information about asthma identified by parents were books (n=2), the pharmacist (n=2) and a friend who was a doctor (n=1). Parents were asked if they would like more information regarding their son's/daughter's asthma and if so to identify issues about which they required more information. Twenty-five parents required more information about their son's/daughter's asthma, as shown in figure 4.5.

Figure 4.5 Issues identified by parents about which they would like more information (n=25)

Causes of asthma (n=5)
A cure for asthma (n= 4)
Triggers to asthma (n=3)
Pets as triggers to asthma (n=2)
Future prognosis of young person's condition (n=2)
Information about steroids (n=2)
New types of inhalers (n=2)
The use of alternative medicines in the treatment of asthma (n=2)
Reducing the amount of medication their son/daughter needed to take (n=1)
Stopping medication altogether (n=1)
What to do if their son/daughter had an asthma attack (n=1)
How asthma medication works (n=1)
Information on allergies (n=1)
Technological developments in the treatment of asthma (n=1)
Obtaining a nebuliser (n=1)
Information on lung function assessment (n=1)

Parents were asked in what format they would like additional information. Sixteen parents reported a preference for information to be given orally by a health care professional and nine parents requested information in a written format:

I like to have it written down as then you can take it away with you and it's always there for you to refer back to.

Mother of Steven, aged 11
Iv no. 44a, lines 389-392

There was no association between the parent requiring additional information and the age of the young person or number of years since diagnosis (Mann Whitney U tests).

In summary, parents identified health care professionals as their main source of information regarding their son's/daughter's asthma. However, they also identified numerous issues on which they would like more information.

4.8.2 Information needs and information used by young people

Young people were asked to establish the sources from which they had obtained information about asthma. The majority of young people (n=39) were unable to establish where they had obtained information regarding asthma. Those young people who were able to respond to the question (n=4) indicated they had obtained information about asthma from health care professionals (n=2), their mother (n=1) and books (n=1).

Eighteen young people were prompted and asked if they had ever read leaflets about asthma. In response, seven young people reported that they had done so. Four of these reported that they were satisfied with the content of the leaflets and two stated that the content had not interested them. One young person reported being frightened by a leaflet she had read at the GP surgery as it had explained how people could die from asthma attacks. Eleven young people, in response to the prompt from the researcher, indicated that they did not read leaflets about asthma as they found the content uninteresting to them:

- Y: She (asthma nurse) has given me stuff (leaflets) but I ain't that bothered about reading them.
I: Why is that?
Y: Coz I'm not really bothered.

Kate, aged 10
Iv no. 13b, lines 245-247

Young people were asked to identify issues on which they would like more information. Data were missing from 16 young people who were unable to answer the question and twenty-five young people who stated that they did not want any more information. Two young people required additional information, both regarding why they had asthma:

I think the only thing I'd like to know, the thing that I do wonder about is why have I got it, I mean why do I have asthma and not Howard (brother)?

Lee, aged 9
Iv no. 38b, lines 267-269

From data from young people, it was not possible to explore the association between the age of the young person or number of years since diagnosis and the desire for additional information (numbers too small to enable meaningful statistical analysis).

In summary, the majority of young people were unable to establish the sources from which they had obtained information about asthma and few young people identified issues on which they required more information.

SUMMARY OF CHAPTER FOUR

Chapter four has outlined tasks of asthma management performed by young people and their parents. The role of ensuring continuous supplies of medication was most commonly performed by parents. The use of an inhaler that indicates the number of remaining doses or the young person having severe asthma might encourage the young person to take on the role of ensuring continuous supplies of medication. All parents reported that they were solely responsible for collecting prescriptions from the pharmacy.

The majority of young people and parents reported that parents had a predominant role in reminding the young person to take their medication. Parents who reported their son/daughter remembered to use their medication without assistance indicated confidence in their son's/daughter's ability to remember this task. Parents and young people reported that the administration of medication was usually performed by the young person without assistance. The severity of the condition, use of a nebuliser and when a young person was unwell were situations which might lead to the involvement of parents in this task. Where medication was altered other than by health care professionals, the majority of parents were responsible for deciding on medication, according to need.

Data from parents' and young people's interviews suggest the sharing of tasks of asthma management across the age range, for the majority of tasks numbers were too small to enable meaningful statistical tests to be conducted. The parents' view of the role of the young person in the overall responsibility for asthma medication was associated with the age of the young person (Mann Whitney U test, $n=43$, $p=0.025$). The mean rank age of young people was higher where parents reported that the young person had overall responsibility for asthma medication, or responsibility for medication was shared between the young person and parent, compared to those parents who reported that it was the parents' overall responsibility.

The analysis of data did not reveal particular types of partnerships which related exclusively to pairs of parents and young people. Rather descriptions of partnerships suggested young people and parents worked together in the management of asthma, with situations determining different people taking the dominant role. Partnerships between young people and parents were generally harmonious. An account from one young person suggested that conflict within a partnership might have implications for the management of the young persons asthma.

Partnerships between young people and their parents were identified in relation to managing factors which exacerbated the young person's asthma. The majority of young people and parents did not report restrictions to their lives due to the young person's asthma. The findings presented in this thesis suggest that young people who lived in more than one family unit might experience different roles in a second family unit, including potential difficulties, in the management of asthma. An awareness of these potential issues for young people who lived in more than one family unit, might enable health care professionals to provide help and support to these young people and to address their specific needs.

Most parents and young people recalled changes that had occurred to partnerships in asthma management as the young person had grown older, with young people taking on more responsibility for their condition as time progressed. Changes occurred with little specific planning and often without the involvement of health care professionals. Most parents were aware changes to partnerships would occur in the future, but had given little consideration to them. Health care professionals should acknowledge the changing nature of partnerships over time and provide guidance and support to parents and young people as young people take on more responsibility for the management of their asthma.

Dissatisfaction or difficulties in relation to medication at school were reported by young people across the age range and their parents, in schools which did and did not have policies regarding medication and in cases where the young person carried their own

medication or when it was stored elsewhere. Problems within schools in which a policy relating to medication was in place, suggests that school policies might not be adequate in supporting young people to manage asthma. Health care professionals might be well placed to assist in the formulation of school policies and in informing staff of the nature of the condition and its treatment.

This chapter has documented the roles of the asthma nurse and GP in the care of young people with asthma. Asthma nurses were identified as the health care professional most commonly seen in relation to asthma, more young people had asked an asthma nurse questions than had asked a GP. Eight young people had not seen a health care professional in relation to their asthma for two years or more.

Parents reported the use of a variety of sources of information to find out more about their son's/daughter's asthma, with health care professionals as the main source of their information. Parents identified numerous issues on which they would like more information. The majority of young people were unable to establish from where they had obtained information about asthma and few young people identified issues on which they required more information.

Chapter 5 - Experiences of young people with diabetes and their parents

Chapter 5 Experiences of young people with diabetes and their parents

Chapter five describes the experiences of young people and their parents in the management of diabetes. Section 5.1 provides an introduction to the presentation of data and terms used. Section 5.2 details the conduct of interviews. Section 5.3 reports the roles of diabetes management within the home performed by young people and their parents. Section 5.4 describes types of partnerships, conflict in partnerships, partnerships in relation to the young person's diet, restrictions on young people and their parents due to the young person's diabetes and the experiences of young people who lived in more than one family unit. Changes in partnerships over time and young people's and parents' views of the anticipated future nature of partnerships are documented in section 5.5. Section 5.6 considers diabetes management in schools. Section 5.7 reports the role of health care professionals in the management of young people's diabetes. Section 5.8 documents the information sources used and information needed by young people and their parents. A summary is provided at the end of the chapter.

5.1 Introduction

The results presented in this chapter are from interviews with both young people and their parents. Data from parent and young person interviews were analysed independently and are presented separately so to document young people's and parents' views of the management of diabetes. Reference has been made to cases in which young people and parents provided contradictory accounts of behaviours. The identification of reasons for such variations has not been an objective of this research. Where possible findings have been documented from both interviews, so as to describe the experiences from the perspective of both young people and their parents. Due to the length of interviews with young people (see chapter 2) some questions were only asked to parents. Throughout the chapter reference is made in italics to the data, parents or

young people, being presented. The names of young people have been changed. As in the previous chapter, the term partnership is used in chapter five to describe different styles of cooperation, sharing of responsibilities and discussion regarding the management of diabetes. Use of the term does not necessarily indicate harmony and might include young people and parents working together and experiencing conflict within the partnership. Issues discussed in this chapter have been explored in relation to the age of the young person and the length of time since diagnosis of diabetes. Mann Whitney U tests were used to explore associations between issues and the age of the young person or length of time since diagnosis with diabetes. In this research, young people with diabetes were aged 8 to 15 years and had been diagnosed with diabetes from four months to eleven years, for more details of the personal characteristics of participants see section 3.4.2.

5.2 Conduct of interviews

Chapter five reports the findings from interviews with twenty-six young people with diabetes and their parents. All interviews were conducted in respondent's own homes. Prior to and on arrival at each interview the researcher requested that each young person and parent(s) were interviewed alone. Ten (38%) young people and parents were interviewed in a room alone with the researcher. Twelve young people and parents (46%) were interviewed whilst the other party was in the room, the remaining four (15%) young people were interviewed with their parent present but the parent was interviewed alone. This issue is discussed in relation to the research findings in chapter 7.

Where two parents were interviewed together questions were addressed to both parents and answered by either respondent. Twenty-five parents (n=26) identified themselves as the young person's primary carer. When young people and parents were both present in the room during an interview the researcher reminded both parties of the importance of responses being given by the person who was being interviewed. Where the other party

gave responses the researcher directed all questions to the person being interviewed and at times reiterated the importance of questions being answered by the respondent being interviewed. During the conduct of home interviews there were sometimes interruptions to the flow of the interview, such as telephone calls or the young person or their siblings requiring the parent's attention. Siblings were often in the room in which interviews took place but interruptions from them to the interview were minimal.

Interviews with parents were conducted with the use of a structured interview schedule (appendix J). Young people were interviewed with the use of a topic guide (appendix L). Questions relating to all topics were asked to each young person. However, some young people chose not to respond to questions or replied they 'did not know'. In these situations further prompting was used by the researcher, where no response was obtained the number of missing cases has been reported. Where young people responded to questions with a non verbal response, for example a shake of the head or 'thumbs up', the researcher asked for further clarification regarding their response to the question.

In the conduct of two interviews the researcher experienced difficulties initially engaging with the young person. At the beginning of the interview process each young person gave no verbal responses to questions asked by the researcher, both young people were interviewed alone. The researcher approached one of these young people (male, aged 10 years, diagnosed 3 years), who appeared shy and focused upon the interview schedule held by the researcher, by asking him if he would prefer to complete the quality of life module first. The young person agreed and after completion of the quality of life module with the researcher, for which he gave verbal responses, answered questions in the qualitative interview. The second young person (male, aged 11 years, diagnosed 10 years) gave non-verbal responses to questions. The young person sat with his head down and did not make eye contact with the researcher. Prompts were used and further questions asked but no verbal response was elicited from the young person. The researcher asked the young person if they would like to terminate the interview, the

young person responded that they did not want to do this. The researcher then explained to the young person that fuller responses were needed in order to explore his experiences of diabetes and to enable his views to be analysed together with those of other young people. The interview was resumed and the young person gave verbal responses to questions. The researcher was later informed that the young person had experienced a number of personal difficulties earlier in life and had been fostered a number of times before being adopted. The young person's adoptive mother felt that such experiences might have made the young person wary of the presence of the researcher. Issues relating to the interviewing of young people are discussed in chapter 2 of this thesis and in relation to this research in chapter 7.

The duration of interviews with parents ranged from 25 to 97 minutes, mean length 46 minutes. Interviews with young people ranged from 10 to 42 minutes, mean length 19 minutes.

5.3 Roles of diabetes management within the home

Section 5.3 describes the roles of young people and parents in the management of diabetes within the home. Parents were asked about their roles concerning six activities of diabetes management; ensuring continuous supplies of medication, collecting prescriptions, remembering/reminding to monitor blood glucose levels, the act of monitoring blood glucose levels, remembering/reminding to administer insulin injections and the administration of insulin. Table 5.1 summarises the roles of young people and parents in these tasks, as reported by parents. Young people were asked to report their role and that of their parents in four tasks; remembering/reminding to monitor blood glucose levels, the act of monitoring blood glucose levels, remembering/reminding to administer insulin injections and the administration of insulin injections. Table 5.2 summarises who performed such tasks, as reported by young people with diabetes. Parents and young people identified tasks as being performed solely by parents, solely by the young person or as shared between the young

person and parent. The remainder of section 5.3 examines each of these tasks in detail, from the perspective of both young people and their parents.

Table 5.1 Roles of parents and young people in the management of diabetes, as reported by parents (n=26)

Role	Solely performed by parent	Task shared by parent and young person	Solely performed by young person
Ensuring continuous supplies of medication	23	1	2
Collecting prescriptions	25	1	0
Remembering/reminding to monitor blood glucose levels	15	3	8
Monitoring of blood glucose levels	2	4	20
Remembering/reminding to administer insulin injections	13	4	9
Administration of insulin injections	5	11	10

Table 5.2 Role of parents and young people in the management of diabetes, as reported by young people (n=26)

Role	Solely performed by parent	Task shared by parent and young person	Solely performed by young person
Remembering/reminding to monitor blood glucose levels*	13	2	4
Monitoring of blood glucose levels**	1	4	20
Remembering/reminding to administer insulin injections***	13	4	5
Administration of insulin injections**	4	9	12

*Data missing from 7 young people

** Data missing from 1 young person

***Data missing from 4 young people

5.3.1 Ensuring continuous supplies of medication and collecting prescriptions from the pharmacy

Data from parents

The majority of parents (n=23) reported sole responsibility for ensuring continuous supplies of medication. Several parents commented that they performed this role due to the importance of not running out of medication:

Oh I do that, it's not something I would be happy letting her do because can you imagine if she forgot and we ran out!

Father of Sandra, aged 14
Iv no. 68a, lines 57-58

Two parents reported their son/daughter (aged 15 years, diagnosed four months; aged 10 years, diagnosed 3 years) had sole responsibility for ensuring continuous supplies of medication. Both these young people administered their own insulin injections and alerted their parents when supplies of medication were low, their parent then ordered the repeat medication. One parent reported that both she and her son (aged 14 years, diagnosed 9 months) were jointly responsible for ensuring continuous supplies of medication.

Most parents (n=25) reported sole responsibility for collecting prescriptions from the pharmacy. One parent reported that both she and her daughter (aged 15 years, diagnosed 4 months) shared the task, as shown in the following quote:

I: So who would collect her prescriptions from the pharmacy?

M: Um, it all depends really sometimes she would do it, sometimes me and sometimes my older daughter does, it depends who is around at the time.

Mother of Jemima, aged 15
Iv no. 20a, lines 330-332

In summary, the majority of parents were responsible for ensuring continuous supplies of medication and collected prescriptions from the pharmacy, data suggests this occurred

across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted).

5.3.2 Remembering/reminding to monitor blood glucose levels

Data from parents

Fifteen parents reported they were solely responsible for reminding their son/daughter to monitor blood glucose levels. Nine of these parents indicated that they reminded their son/daughter as it was a role the young person often forgot to perform or would deliberately not carry out:

Yeah I will tell him to do it because if I didn't I don't think he would ever do one ... part of it is the erm, the hassle of it but they also do hurt him still.

Mother of Jeremy, aged 10

Iv no. 66a, lines 97-98

Eight parents reported their son/daughter had sole responsibility for remembering to monitor blood glucose levels and three parents stated this was a role shared between themselves and their son/daughter (aged 13 years, diagnosed 9 years; aged 12 years, diagnosed 4 years; aged 13 years, diagnosed 9 years). There was no association between the role of remembering/reminding to monitor blood glucose levels as performed solely by parents, or by young people either alone or with their parents, and the age of the young person or number of years since diagnosis of diabetes (Mann Whitney U tests).

Data from young people

Thirteen young people stated that their parents reminded them to monitor their blood glucose levels, four young people reported remembering to monitor blood glucose levels without being prompted. Two young people (aged 11 years, diagnosed 10 years; aged 13 years, diagnosed 1 year) reported the role to be shared between themselves and their parent:

Well it's a bit hard to say because sometimes I remember and will do my blood sugars but at other times my Dad tells me and I have forgot.

Caroline, aged 13

Iv no. 22b, lines 35-37

Data were missing from seven young people. Data indicated that a parental role in reminding the young person to monitor blood glucose levels occurred across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted).

Three young people gave different responses to this question from those given by their parents, two young people stated that their parents reminded them to monitor blood glucose levels and their parents reported the young person remembered. One parent stated she was solely responsible for reminding the young person to monitor his blood glucose levels and her son indicated it was a joint responsibility.

In summary, the majority of young people and parents indicated that parents had a significant role in reminding their son/daughter to monitor their blood glucose levels. From parent data, there was no association between the role of remembering/reminding to monitor blood glucose levels as performed solely by parents or with young people's involvement (either solely the young person or shared by young people and their parents) in the task, and the age of the young person or number of years since diagnosis of diabetes (Mann Whitney U tests).

5.3.3 Monitoring of blood glucose levels

Data from parents

Twenty parents reported that their son/daughter monitored their blood glucose levels without their assistance. Fifteen of these commented that although they were not involved in the physical process of monitoring the blood glucose levels they would discuss the level with their son/daughter and on occasion help them make choices about

the food they should eat and, for some young people, the amount of insulin that they should inject:

He does it (monitors blood glucose levels) but he'll come to me after and say like what it is. If it's high or low we'll have a talk about it, think about what has caused it and how we can get him right again.

Mother of Tim, aged 12
Iv no. 50a, lines 314-315

Four parents described the role of monitoring blood glucose levels as shared between themselves and their son/daughter. They reported that the young person often monitored their blood glucose levels alone but that they provided assistance in certain situations such as if the young person was tired, unwell or hypoglycaemic. Two parents described themselves as performing the process of monitoring their son's/daughter's (aged 13 years, diagnosed 9 years; aged 9 years, diagnosed 7 years) blood glucose levels. One parent had diabetes himself and monitored his daughter's blood glucose levels at the same time as his own. The other parent reported she monitored her daughter's blood glucose level at the request of her daughter:

Well she wants me to do it for her still, I think it's laziness really it's easier for her just sit there while it do it rather than her having to do it for herself.

Mother of Millie, aged 9
Iv no. 23a, lines 432-434

Data from young people

Twenty young people reported monitoring their blood glucose levels without assistance, several young people commented on the ease of the task:

Oh I can do that on my own it's easy peasey all you have to do it like a quick click like that (demonstrates action on finger) then you get the number on the read out and that's it - done! Do you want me to show you?

Tom, aged 8
Iv no. 65b, lines 56-59

Four young people shared this task with their parents and one young person reported her parent monitored her blood glucose levels. Data were missing from one interview.

Three young people and parents gave conflicting responses, one young person and parent both indicated they were solely responsible for monitoring blood glucose levels, one young person reported the role was shared and her parent stated that the young person was responsible and one young person indicated sole responsibility and his parent indicated that the task was shared.

In summary, the majority of young people monitored their blood glucose levels without assistance from their parents. The young person being tired, unwell or hypoglycaemic were situations which led parents to assist in the monitoring of blood glucose levels. Data from both young people and parents, suggested that young people monitored their blood glucose levels without assistance across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted).

5.3.4 Remembering/reminding to administer injections of insulin

Data from parents

Thirteen parents reported reminding their son/daughter to administer insulin injections, ten parents commented that they reminded the young person as otherwise their son/daughter would forget:

I know it sounds stupid because it's a daily thing and er, it's really important, but it really is frightening how easy it is to forget it.

Mother of Jane, aged 15
Iv no. 32a, lines 541-543

Other reasons for reminding young people were in relation to the timing of food (n=4) or when the young person had changed regimen and therefore had to be reminded of an additional insulin injection (n=2).

Nine parents reported their son/daughter was solely responsible for remembering to administer insulin injections. The parents of four young people indicated the responsibility was shared between themselves and their son/daughter. There was no association between the role of remembering/reminding to administer injections of insulin, as performed solely by parents or with young people involved in the task, and the age of the young person or number of years since diagnosis of diabetes (Mann Whitney U tests).

Data from young people

Several young people (n=13) reported that their parents reminded them to administer injections of insulin. Four young people identified that the task was shared between themselves and their parent and five young people indicated that they were solely responsible for remembering to administer insulin injections. Data were missing from four interviews. There was no association between the age of the young person or number of years since diagnosis and the role solely performed by parents or with young people involved in the task (Mann Whitney U tests).

Five young people and parents gave different responses. Three young people stated their parent reminded them to administer insulin injections while their parents reported that the young person remembered. One young person felt her parent reminded her but her parent indicated it was a joint responsibility. The other young person stated the role was shared and his parent that the young person remembered to administer insulin injections.

In summary, young people and parents reported that parents often had a role in reminding the young person to administer insulin injections. There was no association between the age of the young person or number of years since diagnosis and the role of parents in reminding (Mann Whitney U tests). The most common reason identified by parents for reminding their son/daughter to administer insulin injections, was concern that the young person would forget.

5.3.5 The administration of injections of insulin

Data from parents

Eleven parents reported that the administration of insulin injections was a task shared between themselves and their son/daughter. All of these parents reported assisting for practical reasons such as to enable injections in sites which were not accessible to the young person, such as in their arm or bottom. Parents also commented that their assistance enabled the young person to rotate the sites of their injections and prevent the overuse of sites. Of the remaining parents, ten stated their son/daughter was solely responsible for the administration of insulin injections and five parents that they were solely responsible:

Oh I do her jecks (injections) for India still, she might say it's time to do it or bring the stuff to me, but she still won't do the actual jeck herself, we've tried but she won't do it.

Mother of India, aged 10
Iv no. 5a, lines 156-157

Data from young people

Twelve young people reported that they were solely responsible for the administration of insulin injections and four young people that their parent had sole responsibility, data were missing from one interview. The remaining nine young people stated that the role was shared between themselves and their parent, eight of these young people identified the use of hard to reach injection sites as the reason for assistance from their parents. One young person had previously been solely responsible for the administration of insulin injections, but due to poor absorption now required parental assistance to enable her to rotate and use different injection sites:

Yeah I have, I have been doing them for a whole year (on my own) but now my stomach, I am running out of places to do it (the injection) and it is going really hard so I normally get people to do it in my arm for me.

Claire, aged 12
Iv no. 7b, line 260-263

Four young people indicated different responses from those of their parents, with two young people indicating they had sole responsibility for the administration of insulin injections and their parents reporting the task to be shared. One young person and parent each reported they had sole responsibility and another young person indicated joint responsibility while her parent stated that the young person had sole responsibility.

In summary, the administration of insulin injections was a task often completed by the young person alone or shared with their parent. Parental assistance in the administration of insulin injections was frequently with injections in sites the young person was not able to reach themselves (numbers too small to enable meaningful statistical tests to be conducted in relation to age of young person or number of years since diagnosis, and parental role in the administration of insulin injections).

5.3.6 Overall responsibility for diabetes medication

Data from parents

The parents of young people with diabetes were asked to indicate who they felt had overall responsibility for their son's/daughter's diabetes medication, as shown in table 5.3.

Table 5.3 Overall responsibility for diabetes medication, as reported by parents (n=26)

Person with overall responsibility	Number of parents
Parent	18
Responsibility shared between young person and parent	3
Young person	5

The majority of parents (n=18) indicated that they had overall responsibility for the management of diabetes, ten of these parents noted the severity of the condition led them to feel this way:

I think that overall, even given the things that does for himself, the overall responsibility is mine and his dad's. I mean it's such a serious thing, I don't think it would be fair to say he was overall in charge of medicines at his age.

Mother of Finlay, aged 14

Iv no. 61a, lines 323-326

Three parents felt that the overall responsibility for the management of the young person's diabetes was shared between themselves and the young person. One of these parents, who himself had diabetes, described his reasons for this response. Prior to the interview the young person's mother had left the family home and as a result the young person and parent described monitoring each other's condition, such as being aware of signs of high or low blood glucose levels in each other. The following quote from the father demonstrates their joint approach to diabetes management:

We tend to, we are two of a kind really. We tend to do them (blood glucose tests) in spurts like we'll do an awful lot for a week and then we won't do any for a month.

Father of Caroline, aged 13

Iv no. 22a, lines 154-155

One other young person and parent were interviewed who both had diabetes. In this case the mother felt she had overall responsibility for the management of her son's diabetes. There was no association between the parent reporting overall responsibility for diabetes medication and the age of the young person or number of years since diagnosis (Mann Whitney U tests).

In summary, section 5.3 has outlined partnerships between young people and their parents in the management of diabetes within the home from the perspective of both young people and their parents. The majority of parents were responsible for ensuring continuous supplies of medication and collecting prescriptions from the pharmacy.

Parents had a significant role in reminding young people to monitor blood glucose levels and administer injections of insulin. Most young people monitored their blood glucose levels without assistance from their parents. Parents often helped young people with the administration of insulin injections, or young people undertook this role alone. Most parents identified themselves as having overall responsibility for the young person's diabetes medication.

5.4 Partnerships between young people and their parents in the management of diabetes

Section 5.4 describes partnerships between young people and their parents in the management of diabetes. Section 5.4.1 outlines types of partnerships between young people and their parents. Section 5.4.2 concerns conflict in partnerships between young people and their parents. Section 5.4.3 reports partnerships in the management of the young person's diet. Section 5.4.4 details restrictions on parents and young people due to the young person's diabetes. The experiences of young people who lived in more than one family unit are reported in section 5.4.5. Section 5.4.6 documents the role of parents in terms of educating their son/daughter regarding the serious nature of diabetes.

5.4.1 Types of partnerships between young people and their parents in the management of diabetes

Data from parents and young people

Transcripts of interviews with parents and young people were analysed for information regarding the types of partnership that existed between young people and their parents. Young people and parents frequently referred to a shared approach to the management of the young person's diabetes and often mentioned team work and working together. Parents also emphasised their role in supporting their son/daughter:

It's kind of a shared thing you know, we share decisions about what she should do and how we should manage it. I'm there as extra support for her, someone to share the decisions with.

Mother of Claire, aged 12
Iv no. 7a, lines 124-126

Examples were also identified from transcripts of situations in which parents had adopted a dominant role in the partnership and had made decisions about the young person's diabetes or medication:

If she had her way she would never do them (monitor blood glucose levels) so I have to make her, I tell her she must do them or I am taking her to Mr Fortnam (consultant) and telling *him* that she is not doing them!

Mother of Louise, aged 12
Iv no. 69a, lines 1245-1246

In some situations young people had taken a dominant role in the partnership and made decisions regarding the condition or medication contrary to the wishes of their parents:

He (consultant) and my mum they both want me to go onto three jabs (injections of insulin) a day but I won't do it, I've told them I won't, I refuse to have to do one while I am at school, whatever they say.

Charlie, aged 10
Iv no. 59b, lines 456-458

The majority of parent and young person partnerships (n=25) did not fall exclusively into one of these categories. Within each interview descriptions by young people and parents tended to move between the three types of partnership, dependent upon the topic being discussed. There was one exception to this, in the partnership between one young person (female, aged 15 years, diagnosed 4 months) and her parents. The young person had a dominant role in the partnership as she performed all tasks of diabetes management herself, other than the collection of prescriptions from the pharmacy which she shared with her mother. The parent's role in this partnership, from the perspective of both the young person and her parents, was that of providing support to the young person:

Well they (parents) are kind of back up I guess, but I'm fine doing it on my own I don't really need no help ... I guess I just sort of know they are there if I need them.

Jemima, aged 15
Iv no. 20b, lines 159-162

This young person was one of the oldest interviewed, all other young people who were aged fifteen (n=3) had partnerships which did not fall exclusively into one category.

5.4.2 Conflict in partnerships between young people and their parents

Section 5.4.2 documents conflict in partnerships between young people and their parents in relation to diabetes. Conflict between young people and parents in the management of chronic conditions was identified in the preliminary work of this thesis (see chapter 2). Conflict was identified as disagreements, or differing views or perspectives regarding issues related to the young person's diabetes.

Data from parents

In the majority of parent interviews (n=18) no reports of conflict were found. As reported in section 5.4.1, the majority of parents and young people described a shared approach to the management of the young person's diabetes. Conflict was identified in eight interviews, areas of conflict varied as shown in table 5.4.

Table 5.4 Conflict within partnerships between young people and their parents, as reported by parents (n=8)

Area of conflict as identified by parent	Number of respondents
Parent limiting young person's social activities due to their diabetes	4
Reminding young person regarding blood glucose monitoring or the administration of insulin injections	2
The young person's diet	1
Hospital visits	1

The most common area of conflict identified by parents was that of social limitations they had placed on the young person. Parents described examples of such situations which had led to disagreements such as them wanting to know where their son/daughter was going, insisting the young person ate at home and not letting their son/daughter stay overnight with friends. One parent reported how arguments with her daughter had become worse since a recent occasion in which her daughter had been hospitalised after getting drunk with some friends:

I mean it's hard you know because I want her to have a normal life and not be seen like as an ill person, but at the same time if you don't take care of them and they go out and get drunk and do silly things then it's going to have a big effect on them, much more than other people.

Mother of Stacey, aged 11
Iv no. 54a, lines 178-182

Seven disagreements were verbal arguments, one parent reported conflict of a physical nature in relation to ensuring her son treated his hypoglycaemia:

Not often touch wood, but when he is bad ... I mean it's a fight, a physical fight at times when you know he is high, to get Lucozade into him. You know he has got to have it, but he will *not* have it.

Mother of Gordon, aged 11
Iv no. 46a, lines 865-869

There was no association between the age of the young person or length of time since diagnosis and parental reports of conflict in the partnership (Mann Whitney U tests).

Data from parents and young people

Interviews with parents in which conflict was identified (n=8) and the corresponding interviews with their son/daughter were further analysed to examine the impact of conflict on the management of a young person's diabetes. In five cases young people and parents described sharing tasks of diabetes management, such as the administration of insulin injections, and made no further reference to conflict. In the other three interviews parents alluded to issues of conflict impacting on the management of the young person's diabetes; the young person eating sweets, refusing to monitor their blood glucose level and not wishing to attend the diabetes clinic.

Data from young people

Conflict was identified in three interviews with young people, conflict had been identified in an interview with one of their parents. Two young people (aged 11 years, diagnosed 6 years; aged 8 years, diagnosed 2 years) identified their parents 'nagging' them to monitor their blood glucose levels as an issue of disagreement. One young person (aged 9 years, diagnosed 2 years) reported arguing with her mother in relation to diet when eating in restaurants:

Like the other night we went to the Blue Bike (restaurant) at the end of the road and when it came to pudding I wanted to have the Pancake Surprise like Sebastian (brother) but Mum said 'oh no you can't because it will have too much sugar and chocolate' and we had a big fight about it and I was in tears.

Ellen, aged 9
Iv no. 67b, lines 254-257

Data from interviews with young people suggested conflict occurred across the age range and number of years since diagnosis (numbers too small to enable meaningful statistical tests to be conducted).

In summary, the majority of partnerships between young people and parents were harmonious. Conflict in some instances impacted upon the management of the young person's condition. Health care professionals should be aware of potential disagreements between young people and their parents and the impact these might have on the management of a young person's condition.

5.4.3 Partnerships in the management of the young person's diet

Data from parents

Section 5.4.3 reports partnerships described by young people and their parents in relation to the management of the young person's diet. All parents (n=26) reported discussing diet with their son/daughter on at least one occasion, the majority of parents (n=22) identified diet as a frequent topic of discussion. Eleven of these parents identified particular situations as triggers to discussions about diet with their son/daughter, these were in relation to the young person's blood glucose reading (n=3), eating in a restaurant (n=3), the young person undertaking exercise (n=3) or if the young person was eating away from their parent, for example at a birthday party (n=2).

Twelve parents reported that their son/daughter followed a healthy diet with relatively few problems. Ten parents reported their son/daughter had experienced difficulties in following an appropriate diet and of these seven indicated that difficulties were in relation to social situations:

At home he tends to be ok, I dish up the food and Jeremy will eat it, and he's alright with snacking at home too, he sticks to what he should have to be honest with you. *But*, when it comes to going to a birthday party or going out with mates for the day it's a different story, he just can't seem to not give into temptation, I think he likes to forget about diabetes and do what other kids do, but I keep telling him he just can't afford to do that.

Mother of Jeremy, aged 10
Iv no.66a, lines 239-243

Two parents reported problems experienced by their son/daughter (aged 12, diagnosed 10 years; aged 8, diagnosed 2 years) in relation to the content and timing of meals at school, as shown in the following quote:

Um, the diet, the school diet, is absolutely awful. It doesn't cater for healthy needs. It's more there's so much sweet stuff about and at breaks when diabetic people need a snack they have only got biscuits and high fat foods.

Mother of Claire, aged 12
Iv no. 7a, lines 865-868

One parent reported that her son (aged 11 years, diagnosed 3 years) had experienced, since diagnosis, extensive problems in adapting to the restrictions placed upon his diet. There was no association between the age of the young person or number of years since diagnosis and parents identifying problems in relation to the young person's diet (Mann Whitney U tests).

Further analysis of interviews with parents of young people who had not reported problems in relation to the young person's diet suggested that the personal tastes of the young person and family diet prior to diagnosis might be a factor in young people not experiencing problems. Of those parents who reported the young person had not had problems adapting their diet (n=12) seven parents gave explanations for this as their son/daughter did not like unhealthy foods (n=8), such as chocolate, or had a healthy diet prior to diagnosis (n=4).

Seventeen parents described having adapted the family diet to accommodate their son's/daughter's diabetes. These parents described changes they had made to the way they cooked family meals, as shown in the following quote:

...I use 'Sugarease' the sugar substitute and we all have that now so as not to distinguish. But we eat a variety of things anyway we eat, you know, we eat Japanese food and Mexican food and we just have to improvise. But we're more conscious of it obviously...

Mother of Louise, aged 12
Iv no. 69a, lines 1442-6

Four parents reported not allowing siblings of the young person with diabetes to eat sweets or chocolate to make this easier for the young person with diabetes. Nineteen parents recalled that their son/daughter had seen a dietician on at least one occasion. Thirteen parents felt that consultations with dieticians were too infrequent and therefore of limited assistance:

I mean the time we did see her (dietician) was when he was first diagnosed and to be honest, you are just *so* up in the air at that point erm, er, it just goes in one ear and out the other. We saw one another time, which was good but you know, twice in ten years isn't really much use now is it?

Mother of Gordon, aged 11
Iv no. 46a, lines 1227-1230

Data from young people

Eleven young people indicated that following a healthy diet was 'ok' and did not elaborate further. Eight young people reported no difficulties in relation to following a healthy diet. Two of these young people mentioned enjoying a healthy diet and two that they did not like sweet foods so did not miss eating them:

Well I think it is fine really because it's nice to eat fresh things and things that you know are healthy rather than eating chocolate and sweets all the time.

Jane, aged 15
Iv no. 32b, lines 125-126

Seven young people reported difficulties in relation to their diet, all parent and young person responses were in agreement. Of these seven young people, five identified specific areas of difficulty in relation to parties (n=2), eating in restaurants (n=2) and eating chocolate (n=1). The remaining two young people expressed particular difficulties in social situations:

When I'm at a party then it is very unfair because my friends all like chocolate and they all go 'mmm chocolate' and I am like 'yes shut up!'

Christina, aged 15

Iv no. 64b, lines 879-981

There was no association between the age of the young person or number of years since diagnosis and the young person identifying problems in relation to their diet (Mann Whitney U tests).

In summary, some young people had experienced difficulties in adapting to a healthy diet. Eating in social situations, such as at school or at parties, were areas of particular difficulty. Within the home parents took steps to aid young people in following a healthy diet. From the difficulties reported some young people and their parents might benefit from further support and advice from dieticians, particularly in relation to eating outside the home.

5.4.4 Restrictions on parents and young people due to the young person's diabetes

Data from parents

All parents (n=26) reported that the young person's diabetes impacted upon their lives, the life of the young person and that of the family as a whole. Eleven parents commented on the difficulties of accommodating the monitoring and management of the young person's diabetes when outside of the home; visiting friends, on holiday or going out for the day with the family:

I think it's just not being able to do anything spontaneous, it's rather like when you have a new born baby. We can't just say 'let's go out for the day' and leave the house, we have to think about what we are going to eat, where we are going to eat, pack the snacks, the blood monitor all that. You can't do anything without planning it all in advance.

Mother of Grace, aged 13
Iv no. 41a, lines 998-1001

Ten parents identified the young person's diet as an issue which placed restrictions upon the young person and parents (see section 5.4.3). Three parents reported that their son's/daughter's diabetes impacted upon their own ability to socialise:

I mean you can't just say we are going out to the cinema tonight we'll get a babysitter. For a start you don't want to leave them with someone that doesn't know what to do and secondly people don't want the responsibility of looking after her anyway as they are terrified of what to do. It's only really when the in-laws come to stay that we can go out, and that's not often as they live in Devon.

Mother of Ellen, aged 9
Iv no. 67a, lines 386-391

The remaining two parents identified restrictions to their lives due to the stress of the emotional impact of their son having the condition and the strain of being constantly alert to their child's needs.

Data from young people

Ten young people stated that having diabetes had placed restrictions on their lives. Six young people reported that their diabetes meant they were unable to eat the foods that they wished:

Well it means I can't eat sweets and doughnuts, which I would do if I didn't have diabetes.

Jaspar, aged 13
Iv no. 58b, lines 145-146

Other restrictions reported by young people (n=4) were not being able to go out without telling their parents where they were, not being able to join the army when they were

older, feeling ill when participating in sports and having to attend appointments at the diabetes clinic.

5.4.5 Young people who lived in more than one family unit

Section 5.4.5 documents the experiences of young people who lived in more than one family unit. References to another family unit, staying with a parent in another home or visiting a parent were identified from interviews with young people and parents. All young people and parents identified the home in which the interview was conducted as where the young person lived for the majority of the time, referred to in this section as the young person's primary family unit. The visiting of another parent has been termed the young person's secondary family unit. This research did not interview the parent in the secondary family unit and as such this section relies on the accounts of the parent in the primary family unit, which is of unknown reliability and completeness.

Data from parents

The parents of four young people reported their son/daughter visited a secondary family unit, all identified problems in the management of the young person's diabetes when they were there. All parents commented that their son's/daughter's control of their diabetes was precarious in the secondary family unit, as shown in the following quote:

He goes to his Dad's every other weekend um ... and his blood sugars are not very good, he doesn't do his blood sugars and I think he eats different food, and he comes back on a Sunday night and he's not very well... He's had crunchie McFlurrys when he's with his Dad that is normal, and I have to speak to him (Ethan's father) and say you know Ethan is not to eat these things, it's very important that he doesn't. Um, but it's very difficult because I am not there to enforce it.

Mother of Ethan, aged 11
Iv no. 6a, lines 130-132

All parents (n=4) described difficulties in communicating issues of diabetes management to the parent in the secondary family unit and in two cases their new

partner. Three parents expressed anxiety regarding the management of their son's/daughter's diabetes in the secondary family unit, one parent was particularly concerned that the parent in the secondary family unit would be unable to identify the signs of hypoglycemia.

Data from young people

Three young people reported an occasion when they visited or stayed in a secondary family unit. Young people identified differences in the management of their diabetes there. Within the primary family unit, all young people reported parental assistance with the administration of insulin injections, monitoring of diet and discussion of blood glucose levels. In the secondary family unit all young people described managing such tasks without assistance. Two young people referred to their parent in the second family unit as having limited involvement in the management of diabetes and limited knowledge of the condition:

- I: So tell me about what happens with your injections and diabetes when you are at your Dad's?
Y: Well at home like I said it is Mum that helps me with that. When I am at my Dad's I do it on my own as Dad doesn't know about that stuff so I do my jecks (injections) just in my tummy.
I: Do you do your blood sugars at your Dads?
Y: I don't really bother with them there.'

Jay, aged 10
Iv no.10b, lines 675-683

The other young person described her father asking her what her blood glucose reading was but stated he did not understand the process or significance of the reading. All three young people described difficulties with the management of their diabetes in the secondary family unit in relation to diet, the administration of insulin injections and management of the condition without support from the parent in the primary family unit:

-
- Y: Well when Dad is there doing it with me, the pricks (injections) and stuff then it is ok but when I am with Mum I think it is hard on my own to remember.
- I: It's hard to remember to do pricks?
- Y: Well not really then as if I forget I start to feel funny so I know, more like to do stuff like my sugars (blood glucose readings).
- Sandra, aged 14
Iv no. 68b, lines 134-139

In summary, the small number of young people identified in this research (n=4) as living in more than one family unit means findings are not generalizable. They indicate however that such young people might experience different roles in the management of diabetes in the secondary family unit and might encounter difficulties in the management of their condition. Health care professionals who work with young people with diabetes should be aware of these potential problems for young people who live in more than one family unit and provide help and support accordingly.

5.4.6 Information provision within partnerships regarding the serious nature of diabetes

Data from parents

Section 5.4.6 reports the role of parents within partnerships of informing young people regarding the serious nature of diabetes. The condition of diabetes can have potentially serious complications (see section 1.2.5). Parents were not asked a specific question concerning the serious nature of the condition. During the interview some parents expressed their concerns regarding possible health problems and long-term complications of diabetes and their uncertainty regarding the extent to which they should inform their son/daughter of these issues. References to these were identified from parent data and are presented in this section.

Thirteen parents referred to the serious nature of their son's/daughter's condition in the interview. Two parents commented on this at the beginning of the interview when describing the young person's initial diagnosis of diabetes. These parents (n=2)

described a traumatic, almost grief like process of coming to terms with the diagnosis and the serious nature of the condition, as described in the following quote:

I think it's accepting a life, er, coming to terms with the life threatening illness basically. And coming to terms with the fact that you know your kid's life expectancy is, has been considerably reduced.

Mother of Freddie, aged 10
Iv no. 18a, lines 646-647

Four parents commented on the serious nature of the condition in relation to health problems their son/daughter had experienced. These were a diabetic coma (n=2), amputation of a toe (n=1) and blurred vision (n=1):

I mean after the experience of er, erm, of her being hospitalised the other year (due to diabetic coma) erm, (coughs) it's obviously something, the er, erm, complications, it's something er, we are all too acutely aware of.

Father of Caroline, aged 13
Iv no. 22a, lines 967-969

Each of these parents were distressed when describing the health problems experienced by their son/daughter and did not comment on discussion of these issues between themselves and their son/daughter.

All parents (n=13) went on to comment on the serious nature of the condition in relation to the provision of information to young people and their parents. Six parents commented on the serious nature of diabetes in the context of the amount and type of information they should provide for their son/daughter. Five parents described uncertainty regarding the information they should give their son/daughter. These parents stated that whilst wanting to encourage good diabetic control and the avoidance of complications, they did not wish to concern or frighten their son/daughter. The dilemma of one parent is described in the following quote:

The concern is I will frighten him and I mean there will come a stage when he'll probably, no doubt, read up on it himself. I mean I just I try to be subtle with him and say... But, you know, when your eight year old looks round at you and says, 'I'm not going to die am I?' and it's like you don't want to say to an eight year old, 'well you could get terrible problems'. So it's very hard.

Mother of Tom, aged 8
Iv no. 65a, lines 797-808

At the time of some interviews a series of television programmes were being shown about diabetes, one episode of which followed the life of a young person who was blind as a result of poorly controlled diabetes. Two parents who were uncertain of what information to provide reported that they had not let their son/daughter watch the programme:

Did you see that programme on channel four the other night, the one about the blind girl? He wanted to watch it but I recorded it so I could have a look at it myself first and I have to say I don't think it's the sort of thing that is suitable for him. I've told him he can't watch it.

Mother of Finlay, aged 14
Iv no. 61a, lines 782-785

Four parents reported discussing the health implications and possible complications of diabetes with their son/daughter. These parents commented taking such an approach as they believed it to be in the best interest of their son's/daughter's health:

I think honesty is the best policy when it comes to telling her about the complications. I think she should have all the facts so that if she doesn't manage her diabetes right she knows what she is letting herself in for later on.

Mother of Stacey, aged 11
Iv no. 54a, lines 587-589

Three parents stated that they had decided not to tell their son/daughter of the long-term complications at the current time.

In summary, several parents raised the issue of the serious nature of the condition in the interview, particularly with reference to the information they should provide to their

son/daughter. Despite the joint approach to the management of the young person's diabetes identified in the majority of partnerships (see section 5.4.1) in relation to the serious nature of diabetes several parents indicated anxiety in relation to the extent to which this information should be shared between themselves and their son/daughter. Health care professionals should be aware of the sensitive nature of the disclosure of the complications of diabetes, associated health problems and the difficulties experienced by parents. A consultation with a health care professional without the young person present might enable parents to seek advice and support regarding this issue.

5.5 Changes in partnerships

The previous sections of this chapter have described current partnerships between young people and their parents in the management of diabetes. Section 5.5 reports changes in partnerships of diabetes management as recognised by respondents, potential triggers to changes and young people's and parents' views of the anticipated future nature of partnerships.

Data from parents

Nine parents reported that there had been no changes to roles in diabetes management since the young person had been diagnosed. Seventeen parents reported that changes to roles had occurred with the young person taking on more responsibility for the management of their condition by completing roles previous performed by the parent:

Well everything has changed really, when I think back to the beginning we did everything for him his blood sugars the lot. These days he does that on his own, some of his injections, he just takes a lot more responsibility for things now you know.

Mother of Gary, aged 13
Iv no. 57a, lines 432-435

Specific tasks identified by parents, for which the person responsible had changed, were the administration of insulin injections, responsibility for diet, monitoring of blood glucose levels and ensuring continuous supplies of medication.

Data from young people

Ten young people reported there had been no changes to the partnership since their diagnosis. Data were missing from four interviews. Twelve young people identified changes that had occurred within partnerships and identified tasks of diabetes management they now completed alone, but with which they had previously required assistance. These included the administration of insulin injections, monitoring of blood glucose levels and remembering to conduct these tasks without being reminded by parents. Parents and young people were frequently unable to recall the age at which young people had assumed responsibilities and often referred to changes as having occurred in the context of life or social events.

Data from parents

Ten parents who identified changes in partnerships (n=17) stated that this had occurred naturally and had happened without planning, as part of the natural process of growing up. Seven of these parents identified social situations or events that had led their son/daughter to take on more responsibility for their condition, for example young people attending residential school trips, changing from primary to secondary school or wishing to go socialise with friends:

I think really it was him wanting to go sleep overs with his friends you know a few times we'd drive to the house like at 6pm and do his jab (injection of insulin) and then go back in the morning at 8am to do his morning jab, but it got a bit much especially as some of his chums live a way from here. So in the end I sort of said to him it would be much easier if he learnt to do the jabs for himself.

Mother of Tim, aged 12

Iv no. 50a, lines 786-790

Three parents indicated more acceptable technology and equipment had led their son/daughter to take on greater responsibility for the management of their diabetes. These parents identified improved machinery for the monitoring of blood glucose levels as enabling their son/daughter to monitor these alone (n=2) and the use of injection pens, rather than needles, meant the young person could administer insulin injections alone (n=1).

Seven parents described a planned approach to changes in partnerships and had taken steps to encourage their son/daughter to take on more responsibility for the management of their diabetes. Parents described the ways in which they had done this, as shown in the following quote:

Well um yeah, I mean it was totally managed by me at the beginning. Um, to a certain extent my wife but yeah I took primary responsibility. Um, but we have encouraged Caroline from very early on to sort of start injecting herself and to take on tasks like that so I would say she has taken responsibility for it now.

Father of Caroline, aged 13
Iv no. 22a, lines 775-779

There was no association between the age of the young person or number of years since diagnosis and parents adopting a planned approach to changes in roles within partnerships (Mann Whitney U tests). No parents (n=26) had discussed the young person taking on more responsibility for their condition with a health care professional. Two parents indicated that they believed health care professionals were not interested in this:

I tried to mention it to her (diabetes nurse) once but she just sort of said 'oh you can work it out at home'. They are very nice and all that, but I think they are more concerned with the results, you know the HbA_{1c} rather than who does what.

Mother of Anna, aged 12
Iv no. 40a, lines 543-545

Young people and parents were asked their thoughts regarding the anticipated future nature of partnerships. The majority of parents (n=17) reported not having thought about how partnerships might change in the future and had not made plans. Six parents had considered the future nature of partnerships and planned for the young person to take more control of their diabetes and the ways in which this would happen, as shown in the following quote:

Yes we have (thought about it) a lot haven't we? We are always telling her that she has to take responsibility for herself... I also told her that when she gets older she can inject herself in the stomach, but she's not too keen on that at the moment.

Mother of Debbie, aged 11
Iv no. 15a, line 767-71

Three mothers reported worrying about who would look after their son's diabetes when they were no longer there and both expressed the hope that their sons would marry a partner who would take over that role from them.

Data from young people

The majority of young people (n=19) stated that they had not thought about the future nature of partnerships or did not know what would happen:

I: So when you think of the future, what it will be like when you are older with your diabetes, what sort of thing do you think about?

Y: I don't really think about diabetes much, when I'm older I think I am going to be a lawyer.

Millie, aged 9
Iv no. 23b, lines 101-103

Four young people commented that they would take on more responsibility for their condition as they grew older. Three young people stated that when they considered the future they hoped there would be a cure for diabetes and that they would not have to manage the condition.

In summary, parents and young people identified changes that had occurred to roles within partnerships over time. Factors associated with young people taking on a greater responsibility for their condition included the young person wishing to participate in social events, improvements in blood glucose monitoring and better insulin injection technology. Some parents identified changes had occurred without planning, but other parents described a planned approach to the transfer of responsibility for the management of diabetes. No parents had spoken to a health care professional about changes to partnerships. Most young people and parents had not considered the future nature of partnerships. Health care professionals should be aware of different parental approaches to the transfer of responsibility for the management of diabetes and that this is not associated with the age of the young person or the time since the young person was diagnosed with diabetes (Mann Whitney U tests). Particularly when a planned approach is taken, health care professionals might be able to provide help and support to young people and parents where needed.

5.6 Management of diabetes in schools

Section 5.6 reports the experiences of young people with the management of diabetes in schools. Section 5.6.1 outlines the storage of items related to diabetes within the school and whether the school had a policy regarding medication. Section 5.6.2 reports problems in relation to the management of diabetes in schools, as reported by young people and their parents.

5.6.1 Storage of items relating to diabetes and school policies regarding medication

Data from young people

Twenty-four young people (n=26) reported taking items related to their diabetes to school. These young people were asked where in school they stored items relating to their diabetes. Items taken to school by young people (n=24) included a pot of sugar,

food items, blood glucose monitoring equipment, insulin injections, blood testing strips, fizzy drinks, glucose tablets and Hypo-stop (a product that can be rubbed into the lips of someone who is suffering from hypoglycemia). Table 5.5 reports the place of storage of items related to the young person's diabetes in school.

Table 5.5 Storage of items related to diabetes in school, as reported by young people (n=24*)

Place items stored	Number of young people
Classroom	10
With young person	9
Medical room or nurse	4
School office	1

* Two young people did not take items relating to their diabetes to school

There was no association between the age of the young person and whether items relating to their diabetes were stored with the young person or elsewhere (Mann Whitney U test).

Data from parents

Parents were asked if their son's/daughter's school had a policy related to the storage and use of medication, their responses are shown in table 5.6.

Table 5.6 Policies regarding medication in school, as reported by parents (n=26)

Does your son's/daughter's school have a policy regarding medication?	Number of respondents
Yes	8
No	5
Don't know	13

There was no association between the age of the young person and whether the school had a policy regarding medication (Mann Whitney U test).

5.6.2 Problems with the management of diabetes in schools

Data from parents

Nine parents reported problems in relation to the young person's management of their diabetes in school. Five parents expressed concern that behaviours and practices encouraged within the home to ensure good diabetic control, such as snacking regularly and monitoring blood glucose levels throughout the day, could not be continued within the school environment due to school rules and policies. These parents (n=5) described incidences of their son/daughter being forbidden to engage in such behaviours:

It's just complete madness to me that they (the school) don't want her to be doing her blood sugars whilst at school, it's all to do with AIDS and that and them not wanting bodily fluids around, but for Christ's sake it's a pin prick of blood it's not vat fulls of the stuff lying around! I went up there (to the school) and I said to the Head (head teacher) what would you rather have her safely testing their blood, or her being rushed to hospital in a coma because she can't tell what her blood sugar is?

Mother of Stacey, aged 11
Iv no. 54a, lines1029-1034

A further two parents (young people aged 11 years, diagnosed 10 years; aged 12 years, diagnosed 10 years) described problems conveying to school staff the serious nature of the condition and the importance of their son/daughter adhering to their diabetic regimen:

The thing we come up against is the unwillingness of the staff to help and really he needs someone looking out for him. Yeah, most of the time he can do it himself but when he's going low he is sometimes so sick he goes beyond the point he can spot it.

Mother of Jeffrey, aged 9
Iv no. 39a, lines 367-9

Other issues reported by parents were problems with access to items relating to the management of diabetes on a school trip (n=1) and lack of a place within the school in which the young person could administer insulin injections (n=1). Of the parents who identified problems three reported the school as having a policy, two as not having a school policy and four parents stated they did not know. Five young people carried their own items relating to their diabetes and four young people stored such items in the classroom. There was an association between the age of the young person and the parent reporting a problem at school (Mann Whitney U test, n=26, p=0.019).

The mean rank age of the young people was lower where parents reported the young person had experienced problems in relation to their diabetes at school. There was no association between parents reports of problems at school and the length of time since diagnosis (Mann Whitney U test).

Twenty-five parents (n=26) indicated that they had spoken in person to a teacher about their son's/daughter's diabetes. One parent had sent a letter to the teacher explaining the young person's diabetes, but had not spoken to staff.

Data from young people

Eight young people reported problems in association with the management of diabetes in school. Three young people (aged 13, diagnosed 9 years; aged 12, diagnosed 10

years; aged 11, diagnosed 10 years), who administered insulin injections during the day, reported problems with the lack of a private location within the school where they could administer injections. These young people reported administering injections in the toilet but described this as cramped and unsatisfactory. The following quote is typical of how young people described the problem:

There isn't really much of a place you can do it (administer insulin injections). There is one place, the first aid room, but there's all windows about where the playground is, so there is no place you could do it without people seeing you.

Grace, aged 13

Iv no. 41b, lines 754-756

Two young people described situations in which their blood glucose levels had been unstable at school, they had become ill and had needed medical attention. Both young people described how staff had not been aware of what action to take:

I started to feel really weird and like I was shaking and getting sweaty and I felt a bit strange so I couldn't really tell Mr Simms and speak and he kind of just looked at me weird and asked if I was ok, but luckily Harvey (a school friend) knew what was wrong and he went to my box and got the Lucozade and gave it to me and it was ok my friends said Mr Simms was just sort of staring and he didn't move.

Finlay, aged 14

Iv no. 61b, lines 127-132

Two young people reported problems in relation to food, being forbidden from eating snacks (n=1) and the timing of school lunches making it difficult to control blood glucose levels (n=1). One young person reported that he was teased by other young people about his diabetes. Young people who identified problems attended schools with and without medication policies, carried items relating to their diabetes with them or had items stored in the classroom. From interviews with young people there was no association between the age of the young person or number of years since diagnosis of diabetes and problems in school (Mann Whitney U tests).

In summary, several young people and parents identified problems associated with the management of diabetes in school. Problems were identified in relation to the lack of a private location for young people to administer insulin injections, difficulties in adhering to diabetes regimens within school and difficulties communicating the serious nature of the condition to staff. Problems were identified in schools with and without school policies and in cases where young people carried items relating to diabetes and where items were stored elsewhere. From parent data, there was an association between the age of the young person and problems in school (Mann Whitney U test, $p=0.019$), the mean rank age of the young people was lower where parents reported the young person had experienced problems in relation to their diabetes at school. Problems within schools in which a medication policy was in place suggests such policies might be inefficient in resolving problems for young people with diabetes. Health care professionals might be well placed to assist in the formulation of school policies and in informing school staff of the serious nature of the condition. The identification of school policies, which in some cases hindered young people in the efficient management of their diabetes, might be a concern for the long term health of these young people, an issue health care professionals could address with school staff.

5.7 The roles of health care professionals in the care for young people with diabetes

Section 5.7 describes the roles of health care professionals in the care of young people with diabetes, as reported by young people and their parents. Section 5.7.1 provides an introduction to the chapter and documents the contact of young people with health care professionals. Section 5.7.2 describes the role of the diabetes nurse in the care for young people with diabetes. Section 5.7.3 documents the role of the consultant in their care. All young people and parents reported attending appointments at the diabetes clinic together. Section 5.7.4 reports the roles of the pharmacist in the care of young people.

5.7.1 Contact with health care professionals

Data from parents

Section 5.7.1 provides an introduction to this section and documents the health care professionals seen by young people in relation to their diabetes and the frequency of visits. Accounts concerning visits to health care professionals were taken from interviews with parents as these generally provided a fuller description of contact.

All parents (n=26) identified care for their son's/daughter's diabetes as taking place within a diabetes out patient clinic based at a hospital. Table 5.7 reports frequency of visits to the diabetes clinic, as reported by parents.

Table 5.7 Frequency of visits to the diabetes clinic by young people, as reported by parents (n=26)

Frequency of visits	Number of young people
Every 2 months	2
Every 3 months	13
Every 3-4 months	4
Every 3-6 months	1
Every 4 months	2
Every 6 months	4

All parents (n=26) indicated that they were satisfied with the frequency of contact with health care professionals regarding their son's/daughter's diabetes. In addition to their usual appointments, the parents of thirteen young people reported that their son/daughter attended a yearly assessment at which their HbA_{1c} level was measured and eyes and feet were examined.

The parents of all young people reported seeing a diabetes nurse (n=26) and consultant (n=26) when at the diabetes clinic. Additional members of the care team were identified as dieticians (n=19), nursing staff who weighed and measured young people (n=15) and psychologists (n=2). The following two sections of this chapter focus upon the role of the diabetes nurse and consultant in the care of young people with diabetes.

5.7.2 The roles of the diabetes nurse in the care for young people with diabetes

Data from parents

When parents (n=26) were asked to establish the role of the diabetes nurse in the care of the young person, some parents indicated more than one role, as shown in figure 5.1.

Figure 5.1 Roles of the diabetes nurse in consultations, as reported by parents (n=26)

Providing support and advice (n=17)
Talking about diabetes (n=14)
Advising about diabetes management (n=12)
Providing information about diabetes (n=12)
Discussing problems associated with the young person's diabetes (n=7)
Discussing blood glucose levels (n=5)
Providing information about developments in diabetes research and treatment (n=2)

All parents (n=26) expressed satisfaction with consultations with the diabetes nurse and frequently highlighted the importance of their role in providing information about the condition and discussing their son's/daughter's diabetes. Several parents (n=19) praised the role of the diabetes nurse when their son/daughter was first diagnosed with the condition. All of these parents (n=19) commented that this service provided them with invaluable support and information. The following quote is typical of the views expressed by these parents:

She (diabetes nurse) came every day for I think the first five days, and then every other day for another week and they sort of slowly ween you off of them and you don't realise it at the time but you are doing it by yourself. But without that (pause), if I had just been left here on my own (pause), I don't know what I would have done (pause) I just wouldn't have been able to do it.

Mother of Christina, aged 15

Iv no. 64a, lines 187-191

Although satisfied with current support, nineteen parents indicated that additional support from the nurse outside of visits to the diabetes clinic was needed. Seven parents reported having been given the telephone number of the diabetes nurse and having telephoned them when problems arose. Twelve parents identified a lack of support outside of visits to the diabetes clinic and a lack of resources in the event of a problem:

She had this stomach bug and she was just vomiting all over the place and having diarrhoea all the time and we couldn't keep anything down her and we were just so worried, it was like a Sunday and we tried the consultant but of course he wasn't there. We'd been given the number of Oak (children's) ward up at the hospital and we rang there but I mean it was useless they didn't know what to suggest, we ended up having to call out the GP but he didn't really know what to suggest so we had to trawl her out of bed and up to A and E and they weren't very knowledgeable. They called the Endocrinologist on call or something to sort us out. I mean you don't need all that when she is ill, not to mention the time it all takes, *anything* could happen in that time.

Mother of Ellen, aged 9

Iv no. 67a, lines 552-564

Five parents noted staff shortages meant there was no longer provision for support from a diabetes nurse other than at diabetes clinic appointments and one parent suggested the implementation of a telephone support service for parents staffed by nurses.

All parents (n=26) stated that they had asked the diabetes nurse questions regarding their son's/daughter's condition, most parents indicated that they had asked questions on numerous topics:

Oh yes I ask her lots of questions, I always have, there is just so much about it (diabetes) that I want to know there are always things that crop up, like new blood monitors and things like that I want to ask her (diabetes nurse) about.

Mother of Debbie, aged 11

Iv no. 15a, line 1093-1095

Specific topics about which parents had asked questions were in relation to different types and frequency of insulin injections, blood monitoring equipment, exercise and action to take in the event of hypoglycemia. Twenty-two parents reported that their son/daughter had asked the diabetes nurse questions about their condition. Questions were related to types of insulin, method of injecting, monitoring of blood glucose levels, foods they should not eat and their weight.

Data from young people

Young people were asked to identify the role of the diabetes nurse in consultations, as shown in figure 5.2. Data were missing from four interviews.

Figure 5.2 Roles of the diabetes nurse in the consultation, as reported by young people (n=22)*

<p>Giving information about diabetes (n=7) Talking about diabetes (n=5) Weighing and measuring young people (n=3) Discussing blood glucose levels (n=3) Discussing injections (n=2) Helping with injections (n=1) Making sure young person is healthy (n=1)</p>

*Data missing in 4 cases

Eleven young people did not elaborate on their views of the diabetes nurse. Eight young people indicated negative aspects of appointments with the diabetes nurse that it was boring (n=3), there were long waiting times (n=2), they did not learn anything (n=1), the nurse told them off (n=1) and they did not like having blood samples taken (n=1).

Seven young people expressed positive views of consultations with the diabetes nurse, as in the following quote:

Oh it's good, I think it's nice to see how I am getting on and like if I have grown and if my blood sugars are better and things like that.

Jane, aged 15

Iv no. 32b, lines 217-219

Young people were asked if they had ever asked the diabetes nurse any questions regarding their diabetes. Fifteen young people reported that they had asked the diabetes nurse questions, twelve reported they had asked questions on numerous issues:

Oh I've asked her quite a lot really, like about my jabs (injections), my sugars (blood glucose readings), erm, the food I eat, er, just loads of stuff really.

Louise, aged 12

Iv no. 69b, lines 1222-1223

Young people also identified injections, blood glucose metres and exercise as topics regarding which they had asked the diabetes nurse questions. Eight young people indicated that they had not asked questions and three young people that they were unable to recall.

In summary, parents identified the role of the diabetes nurse as discussing the condition and providing support. Several parents emphasised the importance of the role of the diabetes nurse when their son/daughter was first diagnosed. A number of parents reported the need for further support from the diabetes nurse outside of visits to the diabetes clinic when problems arose. Most young people had asked the diabetes nurse questions about their condition.

5.7.3 The roles of the consultant in the care for young people with diabetes

Data from parents

Parents (n=26) were asked to identify the roles of the consultant in the consultation, some parents identified more than one role, responses are shown in figure 5.3.

Figure 5.3 Roles of the consultant in the consultation, as reported by parents (n=26)

Discussing diabetes (n=16)
Altering type or frequency of insulin injections (n=14)
Managing overall care for the condition (n=8)
Discussing blood glucose levels (n=6)
Discussing test results (n=5)
Assisting in the management of diabetes (n=1)

Twenty-two parents noted positive aspects of consultations with consultants, most frequently in relation to changes made to medication or information obtained from the consultant about the young person's condition:

Well it's from him (consultant) that we get the HbA_{1c} results so from that, and once we have talked it over with him we kind of know if we are on the right track or not.

Mother of Charlie, aged 10
Iv no. 59a, lines 654-655

Four parents reported that consultations with the consultant were rushed and that there was often a long waiting time:

It's kind of woosh! You are in and out, you don't get the chance really to think about things and ask things then when you shut the door and leave the room your head is full of things you wish you'd asked.

Mother of Freddie, aged 10
Iv no. 18a, lines 1965-1967

All parents (n=26) reported that they had asked the consultant questions about their son's/daughter's condition, subjects included types of injections, frequency of injections, monitoring of blood glucose levels, HbA_{1c} results and foot checks. Two parents reported that their son/daughter had asked a consultant a question about their condition, but both were unable to recall the nature of the question asked. Twelve parents commented that their son/daughter did not speak much in consultations with the consultant, some parents indicated that the young person was shy or nervous of the consultant.

Data from young people

Young people were asked to identify the role of the consultant in consultations, as shown in figure 5.4. Data were missing from six interviews.

Figure 5.4 Roles of the consultant in the consultation, as reported by young people (n=20)*

Talking about diabetes (n=12) Discussing blood glucose levels (n=6) Adjusting insulin type or frequency (n=5) Telling off young person for poor control (n=1)
--

* Data missing in 6 cases

Twelve young people did not elaborate on their view of the consultant. Eight young people were dissatisfied with consultations with the consultant. Of these, five young people were intimidated or nervous of the consultant, two young people reported waiting times were too long and one young person stated that he would rather be doing another activity than visiting the consultant:

-
- Y: He's (consultant) kind of scary.
I: How do you mean?
Y: Well he's important and he has an office on his own and like a big chair and you don't get to see him for very long.
Stacey, aged 11
Iv no. 54b, lines 127-130

Six young people indicated that consultations with the consultant were beneficial to them, three young people reported that they learnt about their diabetes from the consultant, two that they found out about their HbA_{1c} tests and one young person that he got praised for better control of his diabetes.

Young people were asked if they had ever asked the consultant any questions regarding their diabetes, data were missing from 8 interviews. Two young people (aged 8 years, diagnosed 3 years; aged 15 years, diagnosed 4 months) stated that they had asked the consultant questions, regarding injections and the management of diabetes at school. Sixteen young people stated that they had not asked the consultant any questions. Ten of these gave reasons, six indicated that they were shy and four young people stated that they preferred their parent to talk to the consultant, as in the following quote:

- I: Have you ever asked the doctor any questions about your diabetes?
Y: I prefer to let dad do that

Jeremy, aged 10
Iv no. 66b, lines 1563-5

In summary, parents described asking consultants questions about their son's/daughter's condition but the majority of young people described having never asked the consultant questions, with some young people indicating they preferred to let their parent speak to the consultant. Health care professionals should be aware of the possible reluctance of young people to communicate in consultations and should attempt to involve them in the consultation process.

5.7.4 The roles of the pharmacist in the care for young people with diabetes

Data from parents

Twenty-three parents reported that they had never spoken to a pharmacist in relation to the young person's diabetes, four parents perceived that the pharmacist did not have sufficient knowledge of the condition:

No I don't talk to the pharmacist and I wouldn't I mean it's not a common condition they wouldn't have sufficient knowledge of it to give advice.

Father of Sandra, aged 14
Iv no. 68a, lines 800-802

Two parents who had not spoken to a pharmacist, indicated that they would have liked to have done:

I don't really talk to him (pharmacist), other than 'thank you' and 'bye', it's sad really because I have to go in there so often it would be nice if I could speak to him a bit about her diabetes.

Mother of India, aged 10
Iv no. 5a, lines 769-772

Three parents reported talking to the pharmacist about the young person's diabetes on a regular basis and seeking advice in certain situations, such as if the young person was unwell.

5.7.5 Young people and parents who had changed hospital

Data from parents

During the interviews seven parents reported that they had changed the hospital where the young person's diabetes was managed. Two parents had changed hospital due to moving house. Five parents had changed the hospital due to disagreements with the consultant (n=3), so that care for the parent's and young person's diabetes were at the

same hospital (n=1) or due to dissatisfaction with the technology at the local hospital (n=1):

You know the people were lovely there (first hospital) and everything but at the end of the day I want him to be able to have every check and monitoring that there is for his health long-term and when I found out that by switching to the X (second hospital) we could get that, a fifty minute car journey was a small price to pay.

Mother of Ethan, aged 11
Iv no. 6a, lines 1457-1459

The three parents that had moved care due to disagreements with the consultant identified differences related to the consultant blaming the young person for poor diabetic control (n=1), the treatment of diabetes (n=1) and personality differences between themselves and the consultant (n=1).

In summary, section 5.7 has documented the roles of the diabetes nurse and consultant in the care of young people with diabetes. These health care professionals were seen frequently by young people and their parents and might therefore be well placed to support partnerships between young people and their parents in the management of diabetes. In general, parents valued the support from the diabetes clinic but a small number of parents had changed the hospital where their son's/daughter's diabetes was managed.

5.8 Information needs and information used by young people with diabetes and their parents

Section 5.8 documents the information needs and information used by young people with diabetes and their parents. Section 5.8.1 reports the information sources previously used by parents and identifies issues about which they required more information. Section 5.8.2 details the information sources used by young people and their requirements for additional information.

5.8.1 Information needs and information used by parents

Data from parents

Parents were asked where they had obtained information regarding their son's/daughter's diabetes, their responses are shown in figure 5.5, some parents identified the use of more than one source of information.

Figure 5.5 Information sources used by the parents of young people with diabetes (n=26)

Health care professionals (n=9)
Diabetes UK (n=5)
Books (n=5)
Leaflets (n=4)
Support group (n=2)
Diabetes UK educational weekends (n=2)
Internet (n=2)
Articles in magazines (n=2)
Television (n=1)
From the management of own diabetes (n=1)

Health care professionals were the most common source of information for parents.

Two parents indicated that they had obtained information about diabetes from a support group, five parents who were interviewed (n=26) reported that they were members of a diabetes support group.

Parents were asked if they required more information regarding their son's/daughter's diabetes. The majority of parents (n=18) stated they did not require any additional information and were content with their knowledge of diabetes:

No there is nothing that I want to know more about, I've read a lot and as I get curious about something I'll go and find out about it then and there.

Mother of Claire, aged 12
Iv no. 7a, lines 972-973

Eight parents stated that they required more information and were asked to identify topics regarding which they would like more information. Responses to this question are presented in figure 5.6.

Figure 5.6 Issues identified by parents on which they would like more information (n=8)

Long-term effects of diabetes (n=2)
 Alternatives to injections (n=1)
 Causes of diabetes (n=1)
 Cure for diabetes (n=1)
 Information relating to diet (n=1)
 New equipment and products for the monitoring of diabetes (n=1)
 Information regarding diabetes which is easier to understand (n=1)

There was an association between the age of a young person and a parent identifying the need for more information about diabetes (Mann Whitney U test, n=26, p=0.043).

The mean rank age of the young people was higher where parents reported the need for additional information about diabetes. There was no association between the length of time since diagnosis and a parent requesting additional information (Mann Whitney U test).

In summary, parents identified the use of a number of sources of information regarding diabetes. The majority of parents did not require additional information. There was an association between the age of the young person and parents requests for more information. Health care professionals should be alert to parents need for information when young people are in older age groups.

5.8.2 Information needs and information used by young people

Data from young people

Fifteen young people identified sources of information from which they had obtained

information regarding diabetes, data were missing from eleven respondents who were unable to recall from where they had obtained such information. Figure 5.7 presents the information sources used by young people with diabetes, some young people identified the use of a number of sources.

Figure 5.7 Information sources used by young people with diabetes (n=15)

Leaflets from diabetes clinic (n=7)
Diabetes UK magazines (n=5)
Diabetes UK holidays (n=4)
Parents (n=3)
Health care professionals (n=3)
Internet (n=1)
Computer programme about diabetes (n=1)

Young people were asked to identify issues on which they would like more information. Eighteen young people did not require any more information about their diabetes, data were missing from seven interviews. The remaining young person required more information regarding diet.

In summary, the majority of young people had obtained information about diabetes from printed sources in addition to health care professionals and parents. Most young people identified that they did not require any additional information regarding their condition. There are implications from these findings for health care professionals who work with young people with diabetes.

SUMMARY OF CHAPTER FIVE

Chapter five has described the experiences of young people and their parents in the management of diabetes. Within the home, the majority of parents were responsible for ensuring continuous supplies of medication and collecting prescriptions from the pharmacy. Young people and parents indicated that parents had a significant role in reminding their son/daughter to monitor blood glucose levels, yet the majority of young people monitored their blood glucose level without assistance from their parents. The young person being tired, unwell or hypoglycaemic were situations which led parents to assist young people in this task.

Young people and parents reported that parents often had a role in reminding the young person to administer insulin injections, the most common reason identified by parents for reminding their son/daughter was concern that the young person would forget. The administration of insulin injections was most frequently conducted by the young person alone or shared with their parent. Parental assistance in this task was associated with administering injections in sites the young person was unable to reach or the young person requiring the rotation of injection sites. Most parents felt that they had overall responsibility for the management of their son's/daughter's diabetes, many parents stating that the severity of the condition led them to feel this way.

Most partnerships between young people and parents did not fall exclusively into one type of partnership, descriptions of partnerships suggested young people and parents worked together in the management of the condition. Partnerships between young people and their parents were generally harmonious. Some young people had experienced difficulties in adapting to a healthy diet. Eating in social situations, such as at school or at parties, were areas of particular difficulty. Problems associated with adhering to a healthy diet suggest that some young people and their parents might benefit from further support and advice from dieticians, particularly in relation to eating outside of the home.

Restrictions on the lives of young people and their parents due to the young person's diabetes were highlighted, such as limitations on social events and family activities. Problems were identified that were experienced by young people who lived in more than one family unit. The small number of these young people in this research means findings concerning this group are not generalizable. However, they suggest that young people who lived in more than one family unit might experience different roles in the management of diabetes in the secondary family unit and might experience potential difficulties with the management of their condition. Health care professionals who work with young people with diabetes should be aware of possible problems for this group of young people and provide help and support accordingly.

Several parents raised the issue of the serious nature of the condition in the interview, particularly with reference to the degree of information that they should provide to their son/daughter. Health care professionals should be aware of the sensitive nature of the disclosure of complications to young people. A consultation with a health care professional without the young person present might enable parents to seek advice and support on this issue.

Parents and young people identified changes that had occurred to roles within partnerships over time. Factors associated with young people taking on greater responsibility for their condition included the young person wishing to participate in social events and improvements in blood glucose monitoring and insulin injection technology. Some parents identified changes had occurred without planning, but other parents described a planned approach to the transfer of responsibility. Most young people and parents had not considered the future nature of partnerships. Health care professionals should be aware of different parental approaches to the transfer of responsibility for the management of diabetes and, particularly where a planned approach is taken, might be able to provide help and support to young people and parents.

Young people and parents identified problems associated with the management of diabetes in school. From interviews with parents, there was an association between the age of the young person and problems in school (Mann Whitney U test, $n=26$, $p=0.019$), the mean rank age of the young people was lower where parents reported the young person had experienced problems in relation to their diabetes at school. Problems within schools in which a medication policy was in place suggested that such policies might be inefficient in resolving problems for young people with diabetes. Health care professionals might be well placed to assist in the formulation of school policies and in informing school staff of the serious nature of the condition. The identification of school policies in some cases hampering young people in the management of their diabetes might be a concern for the long term health of these young people, an issue which health care professionals might also address.

In relation to health care professionals involved in the care of young people with diabetes, parents identified the roles of the diabetes nurse in terms of discussing the condition and providing support. Several parents noted the role of the diabetes nurse when their son/daughter was first diagnosed with diabetes as being of particular importance. A number of parents identified the need for further support from the diabetes nurse outside visits to the diabetes clinic. Most young people had asked the diabetes nurse questions about their condition. Parents described asking consultants questions about their son's/daughter's condition but the majority of young people reported that they had never asked questions to the consultant, with some young people indicating that they preferred to let their parent speak to the consultant. Health care professionals should be aware of the possible reluctance of young people to communicate in consultations and should attempt to involve them in the consultation process.

There was an association between the age of a young person and a parent identifying the need for more information about diabetes (Mann Whitney U test, $n=26$, $p=0.043$).

The mean rank age of the young people was higher where parents reported the need for

additional information about diabetes. Health care professionals should be alert to the need for parents of young people in older age groups to have additional information about the condition. The majority of young people had obtained information about diabetes from written sources, health care professionals and parents. Most young people identified that they did not require any additional information regarding their condition.

Chapter 6 - Quality of Life

Chapter 6 Quality of life

Previous sections of this thesis have described the concept of Quality of Life (QoL) and its measurement (see chapter 1) and the Paediatric Quality of Life (PedsQL) asthma and diabetes modules (Varni, 1998) used in this research (chapter 2). Measurement of the QoL of young people with asthma and diabetes enables health care professionals to access the impact of a young person's condition on their life.

Chapter 6 reports the findings of use of the PedsQL asthma and diabetes modules, as reported by young people and their parents, in the form of parent proxy measures. Section 6.1 documents the process of the administration of the PedsQL asthma and diabetes modules. Section 6.2 examines the validity of the PedsQL asthma and diabetes modules in this research. Section 6.3 documents missing data. Section 6.4 reports the reliability of the PedsQL asthma and diabetes modules. Section 6.5 presents the results in Likert scale format from the PedsQL asthma module completed by young people. Section 6.6 documents the Likert responses from the PedsQL asthma module completed by parent proxy respondents. Section 6.7 reports the PedsQL responses on the Likert scale of young people with diabetes. Section 6.8 outlines the parent proxy respondents PedsQL diabetes module responses. Section 6.9 draws comparisons between the findings from the young person and parent proxy respondents PedsQL asthma and diabetes modules. A final summary is provided at the end of the chapter, followed by a summary of the three results sections of this thesis.

6.1 Administration of PedsQL asthma and diabetes modules

Parents and young people completed the PedsQL asthma (appendices M,O) or diabetes modules (appendices N,P) at the end of the qualitative interview, with the exception of one participant who completed the diabetes module early in the interview as a means of assisting the researcher in communicating with him (see section 5.2). Young people were asked whether they wished to complete the PedsQL asthma or diabetes modules

alone or with the researcher. Most young people (n=66) completed the module with the researcher reading the statement aloud and the young person circling the response on the Likert scale. Young people who chose to self-complete the module (n=3) were aged 14 and 15 years. The majority of parents (n=69) self-completed the module, other than one parent who identified themselves as illiterate. The researcher administered the PedsQL diabetes module to the parent with use of the same procedure as used with young people. Parents and young people completed the PedsQL modules separately and without discussion, in 44 cases modules were completed in the room at the same time. In accordance with the PedsQL administration guidelines if a parent or young person asked the researcher a question in relation to what a statement meant or how it should be answered the researcher did not interpret the question. The researcher asked the respondent to answer the question in relation to what they thought it meant and if they were unable to do this to leave the question blank. This led to missing data, discussed in section 6.3 of this chapter.

6.2 Validity of the PedsQL asthma and diabetes modules

The validity of an instrument relates to how far it really measures the concept it purports to measure (Bryman and Cramer, 1997), in this research the extent to which the instrument measured the QoL of young people with asthma and diabetes. Examination of the validity of the measure was confined to the face validity of modules. The purpose of qualitative interviews in this research was not to examine the content of the PedsQL modules. However, many items included in the PedsQL asthma and diabetes modules were raised by respondents in the qualitative interview. The absence of questions relating to school, identified in qualitative interviews, suggests this to be an area which might impact upon the QoL of young people that is currently omitted from the PedsQL asthma and diabetes modules. In terms of ease of completion of the measures all young people and parents finished the modules within two to ten minutes and did not seem fatigued by its use. In terms of understanding the wording of the module young people and parents appeared to comprehend statements apart from three young people who

completed the asthma PedsQL module and indicated to the researcher that they did not understand the term ‘side-effects’ (aged 8 years, 9 years and 12 years).

6.3 Missing data from the PedsQL asthma and diabetes modules

A large amount of missing data might be an indication of poor validity of an item for use within the research sample. The amount of missing data from the PedsQL asthma and diabetes modules were calculated, on a per respondent basis and the total amount of missing data per module.

Table 6.1 reports missing data on a per respondent basis from the asthma PedsQL module.

Table 6.1 Missing data on a per respondent basis from the asthma PedsQL module completed by young people and parent proxy respondents (n=43)

Number of respondents with:	Parent proxy respondents	Young people
No missing responses	29	11
1 missing response	9	9
2 missing responses	3	7
3 missing responses	0	14
4 missing responses	2	2
Mean	0.53	1.70
Median	0	2

Table 6.2 reports missing data on a per respondent basis from the diabetes PedsQL module.

Table 6.2 Missing data on a per respondent basis from the diabetes PedsQL module completed by young people and parent proxy respondents (n=26)

Number of respondents with:	Parent proxy respondents	Young people
No missing responses	17	18
1 missing response	7	5
2 missing responses	1	3
3 missing responses	1	0
4 missing responses	0	0
Mean	0.46	0.42
Median	0	0

In relation to missing data from each module, the asthma PedsQL as completed by parent proxy respondents were 1.91%. Missing data from the asthma PedsQL completed by young people were 6.06%. The high rate of missing data in the PedsQL asthma module, completed by young people, indicated poor validity of some statements in the module in this study sample. Table 6.3 reports statements containing missing data and the number of participants whose responses were missing. Statements in table 6.3 do not use the exact wording as on the modules for example, the statement in the table shown as 'young person getting anxious about going to the hospital' would have been worded in the young person module as 'I get scared when I have to go to the hospital' and in the parent proxy module as 'getting anxious about going to the hospital'.

Table 6.3 Missing data from the asthma PedsQL modules completed by young people and parents (n=43)

Statement from PedsQL module	Parent proxy respondents Number of missing responses (n=43)	Young people Number of missing responses (n=43)
Young person getting anxious about going to the hospital	7	23
Young person getting scared during asthma attacks	4	23
Young person having asthma attacks	2	15
Young person worrying about the side effects from medical treatments	0	3
Young person coughing	0	2
Young person disliking carrying their inhaler	1	2
Young person getting out of breath	2	1
Young person playing with pets	1	1
Young person forgetting to take medication	0	1

Table 6.3 (cont...) Missing data from the asthma PedsQL modules completed by young people and parents (n=43)

Statement from PedsQL module	Parent proxy respondents Number of missing responses (n=43)	Young people Number of missing responses (n=43)
Young person getting anxious when they had to have medical treatments	1	1
Young person finding it hard to explain their illness to other people	0	1
Young person feeling wheezy	1	0
Young person taking a big breath	1	0
Young person waking at night with trouble breathing	1	0
Young person being responsible for their medicines	1	0
Young person's control of their asthma	1	0

As indicated in table 6.3 the majority of missing data from the PedsQL asthma module completed by young people and parent proxy respondents were from the statements related to asthma attacks and visits to the hospital. The qualitative interview identified few young people as having had an asthma attack or having been seen at a hospital in relation to their asthma, which indicates a possible explanation as to why data were missing. This indicates that the PedsQL asthma module might be more applicable for use with young people with more severe asthma, i.e those who suffer from asthma attacks or require visits to hospital in relation to their asthma. The author (Varni, 1998) does not specify use of the module in relation to the degree of severity of the condition. From the parent proxy PedsQL asthma module far fewer cases (see table 6.3) had missing data in the three statements which leads to confusion in relation to the validity of the module in the study sample.

Further details of information regarding the validity of statements was available. The interviewer who completed the PedsQL asthma module with young people coded missing responses as 'missing', the young person unable to give an answer, or 'not applicable', the young person verbalised that the statement did not apply to them. From the 73 missing responses from the asthma PedsQL module completed by young people 44 (60%) were coded as 'not applicable' and 29 (40%) as 'missing'. This information was not available for the asthma PedsQL module completed by parent proxy respondents. This finding further suggests a lack of validity of the PedsQL asthma module for young people with asthma in this sample. There was no association between missing responses and the age of the young person (Mann Whitney U test).

Missing data from the diabetes PedsQL, completed by parent proxy respondents were 1.65% and from young people 1.51%. The validity of the PedsQL diabetes modules within this sample is supported by the low level of missing data. Table 6.4 reports missing data from the PedsQL diabetes module, completed by young people and parent proxy respondents, as before the wording of statements has been altered.

Table 6.4 Missing data from the diabetes PedsQL modules completed by young people and parents (n=26)

Statement from PedsQL module	Parent proxy respondents Number of missing responses (n=26)	Young people Number of missing responses (n=26)
Young person finds it hard to wear and id bracelet/necklace or carry a card	4	7
Young person having stomach-aches	1	1
Young person finding it hard to eat snacks between meals when they should	1	1
Young person going 'low' or 'hypo'	0	1
Young person finding it hard to carry a fast acting carbohydrate	0	1
Young person getting shaky	1	0
Young person getting sweaty	1	0

Table 6.4 (cont...) Missing data from the diabetes PedsQL modules completed by young people and parents (n=26)

Statement from PedsQL module	Parent proxy respondents Number of missing responses (n=26)	Young people Number of missing responses (n=26)
Young person having trouble sleeping at night	1	0
Injections/blood tests causing young person pain	1	0
Young person finding it hard to inject insulin	1	0
Young person asking the doctors and nurses questions	1	0

As described previously, the researcher coded responses from young people as ‘missing’ (unable to answer) or ‘not applicable’ (young person verbalised the statement was not applicable to them). Of the 11 missing items from the module completed by young people eight (73%) were coded as not applicable and three (27%) as missing. This information was not available for the diabetes PedsQL module completed by parent proxy respondents. All young people who did not give an answer for the item that generated the most missing data, related to the young person wearing identification that they had diabetes, indicated that the statement was not applicable to them. Three parent proxy respondents also verbalised to the researcher that the statement was not applicable to their son/daughter as they did not wear items that identified them as having diabetes. This suggests that this statement was not valid for use within this study sample. There was no association between missing responses and the age of the young person (Mann Whitney U test).

6.4 Reliability of the PedsQL asthma and diabetes modules

Module reliability was examined through the use of Cronbach’s alpha and calculated for each sub scale and the module as a whole, in each of the four data sets. Table 6.5 reports the Cronbach’s alpha for the PedsQL asthma module.

Table 6.5 Cronbach’s alpha statistic for asthma PedsQL module (n=11-43)

Scale	Young person module (Cronbach’s alpha)	Parent proxy module (Cronbach’s alpha)
Asthma symptoms	0.852 (n=18)	0.873 (n=35)
Treatment	0.722 (n=18)	0.848 (n=35)
Worry	0.297 (n=40)	0.822 (n=43)
Communication	0.790 (n=42)	0.872 (n=43)
Overall measure	0.904 (n=11)	0.935 (n=29)

A Cronbach's alpha equal to or greater than 0.8 has been considered to indicate good reliability of a measure (Bryman and Cramer, 1997). The reliability of the overall measure for both the young person and parent proxy modules were high, indicating good internal consistency. For all parent proxy sub-scales internal consistency was also good (≥ 0.8). The young person module indicated poor internal consistency in three of the sub-scales; Treatment, Worry and Communication. The amount of missing data in the young person module compromised the calculation of the Cronbach's alpha to measure the reliability of the instrument, particularly that of the overall measure. However, given the exploratory nature of this work it was considered pertinent to calculate the Cronbach's alpha to give an indication of the reliability of the module, although the limitations of its use with the young person module data set are acknowledged.

Table 6.6 reports the Cronbach's alpha for the diabetes PedsQL module.

Table 6.6 Cronbach's alpha statistic for diabetes PedsQL module (n=17-26)

Scale	Young person module (Cronbach's alpha)	Parent proxy module (Cronbach's alpha)
Diabetes symptoms	0.559 (n=24)	0.888 (n=24)
Treatment barriers	0.439 (n=26)	0.534 (n=25)
Treatment adherence	0.613 (n=18)	0.725 (n=21)
Worry	0.669 (n=26)	0.862 (n=26)
Communication	0.723 (n=26)	0.871 (n=25)
Overall measure	0.836 (n=18)	0.912 (n=17)

The reliability of the overall measure for both the young person and parent proxy module indicated good internal consistency ($p \geq 0.8$). Cronbach's alpha indicated poor reliability ($p \leq 0.8$) of all sub-scales in the young person module and two sub-scales of the parent proxy module (treatment barriers and treatment adherence).

In summary, for both the asthma and diabetes PedsQL modules, completed by young people and their parent proxy, Cronbach's alpha indicated the overall measures to be reliable but some sub-scales were reported to lack internal consistency. In both conditions, rates of reliability were higher in the parent proxy measures than in those completed by young people. In the asthma PedsQL module the amount of missing data from the young people compromised the examination of reliability using the Cronbach's alpha statistic.

Given the exploratory nature of the use of the PedsQL asthma and diabetes modules in this research the use of factor analysis was considered as a means of identifying the main domains of the quality of life modules and their ability to explain the variance observed within the sample measurements. This would have enabled the exploration of the underlying factors within each sub-scale in each of the four samples. The reliability of factors revealed through the use of factor analysis are dependent upon the size of the sample (Bryman and Cramer, 1997; Kline, 1994). As indicated by Kline (1994) correlations found by use of factor analysis become acceptably reliable in a sample of one hundred or more respondents. Given the sample size of the PedsQL asthma young person (n=43), parent proxy (n=43), diabetes PedsQL young person (n=26) and parent proxy (n=26) modules, the use of factor analysis in this research was considered inappropriate. In small samples one single respondent can greatly affect the correlations (Kline, 1994). Furthermore, to be reliable factor analysis should only be undertaken where the number of respondents exceeds the number of variables (Bryman and Cramer, 1997), thus its use was not suitable with the diabetes PedsQL module in this study.

6.5 Responses of young people to the PedsQL asthma module

The responses of young people with asthma to the PedsQL module, as indicated on the Likert scale, are reported in table 6.7.

Table 6.7 Responses of young people to the PedsQL asthma module (n=43)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
ASTHMA SYMPTOMS (problems with ...)						
My chest hurts or feels tight	43	12	11	18	2	0
I feel wheezy	43	6	10	18	4	5
I have asthma attacks*	28	20	3	4	1	0
I get scared when I have asthma attacks*	20	11	4	2	1	2
I get out of breath*	42	3	12	12	10	5
I cough*	41	0	5	12	16	8
It is hard to take a big breath	43	13	14	10	4	2
I have a stuffy or runny nose	43	4	11	13	8	7
I wake up at night with trouble breathing	43	22	10	10	0	1
It is hard for me to play with pets*	42	27	4	6	5	0
It is hard for me to play outside	43	26	10	2	4	1
TREATMENT (problems with ...)						
My medicines make me feel ill	43	32	7	3	0	1
I have trouble sleeping because of my medicines	43	40	2	1	0	0

*Indicates missing data

Table 6.7 (cont...) Responses of young people to the PedsQL asthma module (n=43)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
I have trouble using my inhaler	43	35	5	1	1	1
I don't like to carry my inhaler*	41	24	7	1	4	5
It is hard for me to be responsible for my medicines	43	18	4	9	2	10
It is hard to control my asthma	43	19	11	7	3	3
I refuse to take my medicines	43	38	3	1	0	1
I forget to take my medicines*	42	11	10	13	3	5
I get scared when I have to have medical treatments*	42	25	6	6	2	3
I get scared when I have to go to the doctor	43	37	2	3	0	1
I get scared when I have to go to the hospital*	20	11	2	4	2	1
WORRY (problems with ...) I worry about the side effects from medical treatments*	40	32	7	1	0	0

*Indicates missing data

Table 6.7 (cont...) Responses of young people to the PedsQL asthma module (n=43)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
I worry about whether or not my medical treatments are working	43	26	9	5	3	0
I worry about my asthma	43	19	11	9	0	4
COMMUNICATION (problems with ...)						
It is hard for me to tell doctors and nurses how I feel	43	22	3	9	3	6
It is hard for me to ask the doctors and nurses questions	43	20	9	8	3	3
It is hard for me to explain my illness to other people*	42	19	7	8	4	4

*Indicates missing data

PedsQL asthma modules were completed by forty-three young people. As indicated in table 6.7 in eleven statements data were missing from some respondents. In the PedsQL asthma module young people reported relatively few problems in relation to the symptoms of asthma other than cough which 24 (56%) young people experienced often or almost always. Twenty-one young people (49%) indicated that they sometimes, often or almost always found it hard to be responsible for their medication and 13 young people (30%) stated that they sometimes, often or almost always found it hard to control their asthma. The findings from the PedsQL asthma module indicated most young people took their medication frequently, 8 (18%) young people indicated they often or almost always forgot to take medication. Most young people stated that they were not scared by medical treatments, 25 (58%) reported they were never scared when they had to have medical treatment.

6.6 Parent proxy responses to the PedsQL asthma module

Table 6.8 indicates the parent proxy responses to the PedsQL asthma module, reported in the Likert scale.

Table 6.8 Parent proxy responses to the PedsQL asthma module (n=43)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
ASTHMA SYMPTOMS (problems with ...)						
Pain or tightness is his or her chest	43	14	11	16	2	0
Feeling wheezy*	42	8	10	17	6	1
Having asthma attacks*	41	24	10	4	2	1
Getting scared whilst having asthma attacks*	39	26	9	2	1	1
Getting out of breath*	41	7	10	16	8	0
Coughing	43	2	8	17	11	5
Taking a big breath*	42	12	16	10	2	2
Having a stuffy or runny nose	43	5	7	15	12	4
Waking up at night with trouble breathing*	42	14	11	13	2	2
Playing with pets*	42	19	10	8	2	3
Playing outside	43	14	13	9	5	2
TREATMENT (problems with ...)						
Medicines making him or her feel ill	43	35	5	3	0	0

*Indicates missing data

Table 6.8 (cont...) Parent proxy responses to the PedsQL asthma module (n=43)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
Trouble sleeping because of medicines	43	33	7	3	0	0
Trouble using his or her inhaler	43	32	4	7	0	0
Disliking carrying his or her inhaler*	42	29	5	7	1	0
Being responsible for his or her medicines*	42	17	9	12	1	3
Controlling his or her asthma*	42	20	12	8	1	1
Refusing to take medicines	43	31	9	3	0	0
Forgetting to take medicines	43	13	11	15	3	1
Getting anxious when he or she has to have medical treatments*	42	24	12	6	0	0
Getting anxious about going to the doctor	43	27	9	6	1	0
Getting anxious about going to the hospital*	36	26	5	3	0	2

*Indicates missing data

Table 6.8 (cont...) Parent proxy responses to the PedsQL asthma module (n=43)

WORRY (problems with ...)						
Worrying about side effects from medical treatments	43	29	7	4	2	1
Worrying about whether or not medical treatments are working	43	27	7	7	2	0
Worrying about his or her asthma	43	16	10	11	6	0
COMMUNICATION (problems with ...)						
Telling the doctors and nurses how he or she feels	43	26	9	5	3	0
Asking the doctors or nurses questions	43	23	11	5	4	0
Explaining his or her illness to other people	43	22	7	13	0	1

*Indicates missing data

Forty-three parents completed the parent proxy PedsQL asthma module. As reported in table 6.8 there were missing data in relation to 12 statements. Parent proxy respondents reported few problems regarding asthma symptoms other than in relation to coughing, stated as a problem often or almost always by 16 (37%) parents. The young person having a stuffy or runny nose was also noted as a problem often and almost always by 16 (27%) parent proxy respondents. The majority of parents indicated medication never made the young person feel ill (n=35; 81%) and the young person never had trouble sleeping because of their medicines (n=33; 77%). It was reported that the majority of young people did not worry about their condition, 29 (67%) parent proxy respondents stated that their son/daughter never worried about the side effects of medical treatments and 27 (63%) reported that young people never worried about whether or not medical treatments were working. The majority of parent proxy respondents noted young people never worried about telling doctors or nurses how they felt (n=26; 60%) or asking doctors and nurses questions (n=23; 53%). Parent proxy respondents and young person scores of statements are compared in section 6.9.1 of this chapter.

6.7 Responses of young people to the PedsQL diabetes module

Table 6.9 reports the responses on the Likert scale of young people to the statements in the PedsQL diabetes module.

Table 6.9 Responses of young people to the PedsQL diabetes module (n=26)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
DIABETES SYMPTOMS (problems with ...)						
I feel hungry	26	3	4	15	4	0
I feel thirsty	26	3	6	8	9	0
I have to go to the toilet too often	26	7	10	8	1	0
I have stomach-aches*	25	9	12	4	0	0
I have headaches	26	5	7	11	3	0
I go 'low' or 'hypo'*	25	1	7	12	4	1
I feel tired	26	7	7	8	3	1
I get shaky	26	6	10	9	0	1
I get sweaty	26	10	8	6	2	0
I have trouble sleeping at night	26	12	6	6	2	0
I get grumpy or annoyed	26	4	6	9	5	2

*Indicates missing data

Table 6.9 (conti...) Responses of young people to the PedsQL diabetes module (n=26)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
TREATMENT - BARRIER (problems with ...)						
It hurts to prick my finger or give myself insulin injections	26	5	10	8	2	1
I am embarrassed about having diabetes	26	17	8	1	0	0
My parents and I argue about my diabetes care	26	19	2	3	2	0
It is hard for me to stick to my diabetes routine	26	7	9	8	2	0
TREATMENT - ADHERENCE (problems with ...)						
It is hard for me to do blood glucose tests	26	15	6	4	1	0
It is hard for me to give myself insulin shots	26	12	6	7	0	1
It is hard for me to exercise	26	14	9	1	2	0
It is hard for me to follow a healthy diet	26	7	11	7	0	1
It is hard for me to wear my id bracelet/necklace or carry a card*	19	11	3	2	1	2
It is hard for me to carry a fast-acting carbohydrate*	25	8	11	4	2	0

*Indicates missing data

Table 6.9 (cont...) Responses of young people to the PedsQL diabetes module (n=26)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
It is hard for me to eat snacks between meals when I should*	25	9	10	5	1	0
WORRY (problems with ...)						
I worry about 'going low' or 'hypo'	26	9	6	8	3	0
I worry about whether or not my medical treatments are working	26	11	6	9	0	0
I worry about the long-term problems from diabetes	26	12	10	3	1	0
COMMUNICATION (problems with ...)						
It is hard for me to tell the doctors and nurses how I feel	26	9	4	11	1	1
It is hard for me to ask the doctors and nurses questions	26	12	4	7	1	2
It is hard for me to explain my illness to other people	26	7	8	8	2	1

*Indicates missing data

Twenty-six young people completed the PedsQL diabetes module. Data were missing from five statements. Most young people indicated few problems associated with the symptoms of diabetes, the majority of young people reported symptoms were a problem never, almost never or sometimes. Problems were also most frequently identified as occurring never, almost never or sometimes in relation to the treatment of diabetes.

Twenty-five (96%) young people indicated that they were never or almost never embarrassed about having diabetes and twenty-one (81%) young people never or almost never argued with parents about their diabetes. The majority of young people indicated ease with measuring blood glucose levels, 21 (80%) young people reported it to be a problem never or almost never and 18 (69%) young people stated administering insulin injections to be a problem never or almost never. Most young people (n=22; 85%) indicated never or almost never worrying about the long-term complications of diabetes. Young people reported few problems in asking doctors and nurses questions only 3 (12%) young people stated it was often or almost always hard to ask doctors and nurses questions.

6.8 Parent proxy responses to the PedsQL diabetes module

Table 6.10 reports the parent proxy Likert scale responses to the PedsQL diabetes module.

Table 6.10 Parent proxy responses to the PedsQL diabetes module (n=26)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
DIABETES SYMPTOMS (problems with ...)						
Feeling hungry	26	0	4	10	9	3
Feeling thirsty	26	2	6	12	5	1
Having to go to the toilet too often	26	8	9	6	2	1
Having stomach-aches*	25	6	9	7	3	0
Having headaches	26	6	6	8	5	1
Going 'low' or 'hypo'	26	0	8	15	3	0
Feeling tired	26	4	8	11	3	0
Getting shaky*	25	8	5	11	1	0
Getting sweaty*	25	9	9	6	1	0
Having trouble sleeping at night*	25	9	8	7	0	1
Getting grumpy or annoyed	26	1	4	13	6	2

*Indicates missing data

Table 6.10 (cont...) Parent proxy responses to the PedsQL diabetes module (n=26)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
TREATMENT - BARRIERS (problems with ...)						
Injections/blood tests causing him/her pain*	25	2	5	12	5	1
Getting embarrassed about having diabetes	26	14	5	5	2	0
Arguing with me or my partner about diabetes	26	11	8	4	2	1
Sticking to his/her diabetes routine	26	5	6	4	5	6
TREATMENT-ADHERENCE (problems with ...)						
It is hard for my child to do blood glucose tests	26	12	6	1	4	3
It is hard for my child to give himself insulin injections*	25	9	6	5	4	1
It is hard for my child to exercise	26	15	6	2	3	0
It is hard for my child to follow a healthy diet	26	9	10	5	2	0
It is hard for my child to wear his/her id bracelet/necklace or carry a card*	22	17	1	0	2	2
It is hard for my child to carry a fast-acting carbohydrate	26	11	9	5	1	0

*Indicates missing data

Table 6.10 (cont...) Parent proxy responses to the PedsQL diabetes module statements (n=26)

Statement	Number of responses	Never	Almost never	Sometimes	Often	Almost always
It is hard for my child to eat snacks between meals as they should*	25	11	8	5	1	0
WORRY (problems with ...)						
Worrying about 'going low' or 'hypo'	26	9	4	9	3	1
Worrying about whether or not medical treatments are working	26	13	5	5	1	2
Worrying about long-term problems of diabetes	26	12	4	6	2	2
COMMUNICATION (problems with ...)						
Telling the doctors and nurses how he/she feels	26	7	7	6	2	4
Asking the doctors or nurses questions*	25	11	2	6	3	3
Explaining his/her illness to other people	26	15	3	4	3	1

*Indicates missing data

Twenty-six parents completed the parent proxy PedsQL diabetes module. Missing data were identified in 9 statements, 8 of which had only one response missing. Parent proxy respondents indicated few symptoms of diabetes to be a problem for their son/daughter other than 12 (46%) respondents who indicated feeling hungry to be a problem often or almost always. As with young people, the majority of parent proxy respondents indicated that the young person never got embarrassed about having diabetes (n=14; 54%). Most parents also reported that the young person never or almost never argued with them in relation to their diabetes (n=19; 73%). Parent proxy respondents reported low levels of worry in young people regarding their condition, 18 (69%) indicated the young person never or almost never worried if medical treatments were working. The majority of parent proxy respondents indicated that the young person had few problems explaining their illness to other people 17 (65%) parent proxy respondents reported this was never or almost never a problem.

6.9 Comparison of quality of life as reported by young people and by parent proxy respondents

Section 6.9 compares the quality of life of young people with asthma and diabetes as reported by young people and parent proxy respondents. Items from the Likert scale (0–4) were reverse scored and adjusted to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). The mean score was calculated for each statement from young person and parent proxy modules, as the sum of the items over the number of items answered (therefore accounting for missing data). If more than 50% of items in the scale were missing, the mean score was not calculated (Varni and Burwinkle, 2004). The statistical significance of the difference between the young person and parent proxy scores for each statement was calculated with use of a Wilcoxon signed ranks test (see 2.4.11). The sub-scale totals were calculated for each respondent. The mean and standard deviation of sub-scale scores were calculated for young person and parent proxy respondents separately. The statistical significance of the difference between mean

scores was calculated with use of a Wilcoxon signed ranks test, in cases where neither participant had missing data. Section 6.9.1 reports the mean scores from the PedsQL asthma modules and section 6.9.2 those from the PedsQL diabetes module.

6.9.1 Quality of life of young people with asthma

Section 6.9.1 reports the mean core scores from the young person and parent proxy respondents asthma PedsQL asthma module and discusses the quality of life of young people with asthma as reported by young people and parent proxy respondents. Table 6.11 presents the mean scores for each statement in the PedsQL asthma module from the young person and parent proxy instruments. The statistical significance of the difference between the scores is reported according to Wilcoxon signed ranks test. Sub-scale mean scores and the standard deviation were also calculated and the statistical significance of the difference between the mean scores is reported according to Wilcoxon signed ranks test. A value of $p \leq 0.05$ was considered significant (Bryman and Cramer, 1997). Statements shown in table 6.11 do not use the exact wording as on the modules, for example the statement in the table shown as ‘pain or tightness in young person’s chest’ would have been worded in the young person module as ‘my chest hurts and feels tight’ and in the parent proxy module ‘pain or tightness in his or her chest’. For the exact wording of statements please refer to the PedsQL modules (appendices M,O).

Table 6.11 Mean scores from young person and parent proxy responses to the PedsQL asthma module (n=27-43)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test**
ASTHMA SYMPTOMS (problems with ...)			
Pain or tightness in young person's chest	69.2 (n=43)	71.5 (n=43)	n.s (n=43)
Young person feeling wheezy	54.7 (n=43)	60.7 (n=42)	p=0.023 (n=42)
Young person having asthma attacks	87.5 (n=28)	82.9 (n=41)	n.s (n=27)
Young person getting scared during asthma attacks	Not valid*	87.2 (n=39)	N/A
Young person getting out of breath	48.8 (n=42)	59.8 (n=41)	p=0.026 (n=40)
Young person coughing	33.5 (n=41)	44.8 (n=43)	p=0.009 (n=41)
Young person taking a big breath	68.6 (n=43)	70.2 (n=42)	n.s (n=42)
Young person having a stuffy or runny nose	48.3 (n=43)	48.3 (n=43)	n.s (n=43)
Young person waking at night with trouble breathing	80.2 (n=43)	69.6 (n=42)	p=0.030 (n=42)
Young person playing with pets	81.6 (n=42)	73.8 (n=42)	n.s (n=41)
Young person playing outside	82.6 (n=43)	68.6 (n=43)	p=0.012 (n=43)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test**
TREATMENT (problems with ...)			
Medicines making young person feel ill	90.1 (n=43)	93.6 (n=43)	n.s (n=43)
Young person having trouble sleeping because of medicines	97.7 (n=43)	92.4 (n=43)	n.s (n=43)
Young person having trouble using their inhaler	91.9 (n=43)	89.5 (n=43)	n.s (n=43)
Young person disliking carrying their inhaler	75.0 (n=41)	86.9 (n=42)	p=0.027 (n=40)
Young person being responsible for their medicines	60.5 (n=43)	71.4 (n=42)	n.s (n=42)
Young person's control of their asthma	73.3 (n=43)	79.2 (n=42)	n.s (n=42)
Young person refusing to take medication	94.8 (n=43)	91.3 (n=43)	n.s (n=43)
Young person forgetting to take medication	61.3 (n=42)	68.6 (n=43)	n.s (n=42)
Young person getting anxious when they had to have medical treatments	78.6 (n=42)	85.7 (n=42)	n.s (n=41)
Young person getting anxious about going to the doctor	93.0 (n=43)	86.1 (n=43)	n.s (n=43)
Young person getting anxious about going to the hospital	Not valid*	86.8 (n=36)	N/A
WORRY (problems with ...)			
Young person worrying about the side effects from medical treatment	94.4 (n=40)	85.5 (n=43)	p=0.025 (n=40)
Young person worrying about whether or not medical treatments are working	83.7 (n=43)	84.3 (n=43)	n.s (n=43)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test**
Young person worrying about their asthma	73.8 (n=43)	70.9 (n=43)	n.s (n=43)
COMMUNICATION (problems with ...)			
Young person telling the doctors and nurses how they feel	68.6 (n=43)	83.7 (n=43)	p=0.021 (n=43)
Young person asking the doctors and nurses questions	73.3 (n=43)	80.8 (n=43)	n.s (n=43)
Young person explaining his or her illness to other people	68.5 (n=42)	78.5 (n=43)	n.s (n=42)
	Mean score and standard deviation of young person module	Mean score and standard deviation of parent proxy module	Statistical significance of the difference between mean scores, according to Wilcoxon signed ranks test**
Mean of sub-scale total for asthma symptoms	Not valid*	Not valid*	N/A
Mean of sub-scale total for treatment	Not valid*	Not valid*	N/A
Mean of sub-scale total for worry	Mean 257.5 S.D 41.7 (n=40)	Mean 241.3 S.D 66.2 (n=40)	n.s (n=40)
Mean of sub-scale total for communication	Mean 213.7 S.D 85.0 (n=42)	Mean 241.7 S.D 66.2 (n=42)	n.s (n=42)

* Calculation of statement mean score was not valid as less than fifty per-cent of respondents answered the question (Varni and Burwinkle, 2004)

**n.s - Wilcoxon signed ranks test showed no significance

In the sub-scale 'Asthma symptoms' five statements had a statistical significance, according to Wilcoxon signed ranks test, between the responses of young people and those of parent proxy respondents. Parent proxy respondents indicated higher mean scores, and therefore better QoL, than young people in relation to the young person feeling wheezy ($p=0.023$), getting out of breath ($p=0.026$) and coughing ($p=0.009$). Parent proxy respondents reported these symptoms to be more of a problem to young people than perceived by young people themselves. In two statements, in which there was a statistical significance between young person and parent proxy responses, young people reported a higher mean score. These were in relation to the young person waking at night with trouble breathing ($p=0.030$) and the young person playing outside ($p=0.012$). Parent proxy respondents indicated these were a greater problem to young people than reported by young people themselves. In the 'Treatment' sub-scale there was statistical significance in relation to the young person disliking carrying their inhaler ($p=0.027$). Parent proxy respondents reported higher mean QoL in this statement, this response would indicate that parent proxy respondents believed young people have less of a problem with this task than reported by young people.

In relation to the 'Worry' sub-scale there was statistical significance between the responses of young people and parent proxy respondents in relation to worry about the side effects of medical treatments ($p=0.025$). Young people indicated higher mean QoL than their parents, indicating better QoL. Young people find less of a problem worrying about side effects than reported by parent proxy respondents. In the 'Communication' scale parent proxy respondents indicated a higher mean score in relation to the young person having problems telling the doctor and nurse how they feel. There was a statistical significance between respondents ($p=0.021$), young people had greater difficulties communicating with doctor and nurses than perceived by proxy parent respondents.

Eight statements in the asthma PedsQL module reported a statistical significance, with use of Wilcoxon signed ranks test, between the score of proxy parent respondents and

those of young people. In five of these statements proxy parent respondents indicated higher scores, better QoL, than that reported by young people. In cases in which the difference between parent proxy and young person scores were significant, parent proxy respondents tended to underestimate the impact of asthma on the young person's QoL.

6.9.2 Quality of life of young people with diabetes

Table 6.12 presents the mean scores for each statement and the statistical significance is reported according to Wilcoxon signed ranks test. Sub-scale mean scores and the standard deviation were also calculated and the statistical significance of the difference between the mean scores is reported according to Wilcoxon signed ranks test. A value of $p \leq 0.05$ was considered significant (Bryman and Cramer, 1997).

Table 6.12 Mean scores from young person and parent proxy responses to the PedsQL diabetes module (n=16-26)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test*
DIABETES SYMPTOMS (problems with ...)			
Young person feeling hungry	55.8 (n=26)	39.4 (n=26)	p=0.005 (n=26)
Young person feeling thirsty	52.9 (n=26)	52.9 (n=26)	n.s (n=26)
Young person having to go to the toilet too often	72.1 (n=26)	70.2 (n=26)	n.s (n=26)
Young person having stomach-aches	80.0 (n=25)	68.0 (n=25)	p=0.003 (n=25)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test*
Young person having headaches	63.5 (n=26)	60.6 (n=26)	n.s (n=26)
Young person going 'low' or 'hypo'	53.0 (n=25)	54.8 (n=26)	n.s (n=25)
Young person feeling tired	65.4 (n=26)	62.5 (n=26)	n.s (n=26)
Young person getting shaky	69.2 (n=26)	70.0 (n=25)	n.s (n=25)
Young person getting sweaty	75.0 (n=26)	76.0 (n=25)	n.s (n=25)
Young person having trouble sleeping at night	76.9 (n=26)	74.0 (n=25)	n.s (n=25)
Young person getting grumpy or annoyed	54.8 (n=26)	46.2 (n=26)	n.s (n=26)
TREATMENT - BARRIERS (problems with ...)			
Injections/blood tests causing young person pain	65.4 (n=26)	52.0 (n=25)	p=0.030 (n=25)
Young person getting embarrassed about having diabetes	90.4 (n=26)	79.8 (n=26)	n.s (n=26)
Young person arguing with parent/guardian about diabetes	86.5 (n=26)	75.0 (n=26)	n.s (n=26)
Young person sticking to diabetes routine	70.2 (n=26)	49.0 (n=26)	p=0.020 (n=26)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test*
TREATMENT - ADHERENCE (problems with ...)			
Young person finding it hard to do blood glucose tests	83.7 (n=26)	69.2 (n=26)	p=0.018 (n=26)
Young person finding it hard to inject insulin	76.9 (n=26)	68.0 (n=25)	n.s (n=25)
Young person finding it hard to exercise	83.7 (n=26)	81.7 (n=26)	n.s (n=26)
Young person finding it hard to follow a healthy diet	72.1 (n=26)	75.0 (n=26)	n.s (n=26)
Young person finding it hard to wear an id bracelet/necklace or carry a card	76.3 (n=19)	83.0 (n=22)	n.s (n=17)
Young person finding it hard to carry a fast-acting carbohydrate	75.0 (n=25)	78.9 (n=26)	n.s (n=25)
Young person finding it hard to eat snacks between meals when they should	77.0 (n=25)	79.0 (n=25)	n.s (n=25)
WORRY (problems with ...)			
Young person worrying about going 'low' or 'hypo'	70.2 (n=26)	66.4 (n=26)	n.s (n=26)
Young person worrying if medical treatments are working	76.9 (n=26)	75.0 (n=26)	n.s (n=26)
Young person worrying about the long-term problems of diabetes	81.7 (n=26)	71.2 (n=26)	n.s (n=26)
COMMUNICATION (problems with ...)			
Young person telling the doctors and nurses how they feel	68.3 (n=26)	60.6 (n=26)	n.s (n=26)

Statement	Mean score young person module	Mean score parent proxy module	Statistical significance of the difference between scores, according to Wilcoxon signed ranks test*
Young person asking the doctors and nurses questions	72.1 (n=26)	65.0 (n=25)	n.s (n=25)
Young person explaining his or her illness to other people	67.3 (n=26)	76.9 (n=26)	n.s (n=26)
	Mean score and standard deviation of young person module	Mean score and standard deviation of parent proxy module	Statistical significance of the difference between mean scores, according to Wilcoxon signed ranks test*
Mean of sub-scale total for diabetes symptoms	Mean 721.7 S.D 114.4 (n=23)	Mean 677.2 S.D 185.9 (n=23)	n.s (n=23)
Mean of sub-scale total for treatment barriers	Mean 311.0 S.D 55.5 (n=25)	Mean 258.0 S.D 74.9 (n=25)	p=0.007 (n=25)
Mean of sub-scale total for treatment adherence	Mean 565.6 S.D 77.9 (n=16)	Mean 546.9 S.D 105.2 (n=16)	n.s (n=16)
Mean of sub-scale total for worry	Mean 228.9 S.D 54.2 (n=26)	Mean 212.5 S.D 83.7 (n=26)	n.s (n=26)
Mean of sub-scale total for communication	Mean 211.0 S.D 69.3 (n=25)	Mean 205.0 S.D 89.8 (n=25)	n.s (n=25)

*n.s - Wilcoxon signed ranks test showed no significance.

In the 'Symptoms' sub-scale there was statistical significance, with use of Wilcoxon signed ranks test, between the reports of parent proxy respondents and young people in relation to two statements. The young person feeling hungry ($p=0.005$) and the young person having stomach-aches ($p=0.003$), young people reported higher mean QoL scores than parent proxy respondents. This indicates that young people had less of a problem with these two issues than indicated by parent proxy respondents. In the 'Treatment-Barriers' sub-scale there was a statistical significance in relation to two of the four statements, injections/blood tests causing the young person pain ($p=0.030$) and the young person having problems sticking to their diabetes routine ($p=0.020$). In each of these statements, and in relation to the mean of the sub-scale total ($p=0.007$), young people reported higher mean QoL scores, better QoL, than that indicated by parent proxy respondents. Young people had less of a problem with these issues than perceived by parent proxy respondents.

There was statistical significance in relation to one statement in the 'Treatment-adherence' sub-scale. In the statement the young person found it hard to do blood glucose tests ($p=0.018$) young people reported higher mean QoL score, better QoL than indicated by parent proxy respondents. Young people found it less difficult to do blood glucose tests than indicated by parent proxy respondents. In the sub-scales 'worry' and 'communication' no statement showed statistical significance between young person and parent proxy responses.

Six statements indicated statistical significance, with use of Wilcoxon signed ranks test, between the responses of young people and parent proxy respondents. In all cases young people reported higher mean scores, better QoL, than those indicated by parent proxy respondents. Parents perceived the impact of the young person's diabetes on their QoL was greater than that reported by young people themselves.

SUMMARY OF CHAPTER SIX

Chapter six has documented the use of PedsQL asthma and diabetes modules administered to young people and parent proxy respondents in this research. The validity of the modules in this research has been commented upon, the amount of missing data from the young person PedsQL asthma module indicated the module might not be valid for use in this sample, most of whom reported relatively mild asthma in the qualitative interview. The reliability of the modules were documented with use of the Cronbach's alpha statistic which indicated good internal consistency of all four PedsQL asthma and diabetes modules, although a lack of reliability in relation to some sub-scales, particularly those completed by young people. The findings from the four PedsQL asthma and diabetes modules have been presented in the form of Likert responses and the mean scores for each statement and sub-scale calculated. Comparison of mean scores from the young person and parent proxy respondent PedsQL asthma and diabetes modules, indicated differences in reported quality of life between young people and that determined by their parents. Where differences in responses had statistical significance, with use of a Wilcoxon signed ranks test, in the PedsQL asthma module parent proxy respondents tended to have higher mean scores, better quality of life, compared to that reported by young people themselves. Parent proxy respondents in the PedsQL diabetes module reported lower mean scores, worse quality of life, than that reported by young people.

SUMMARY OF RESULTS CHAPTERS

Chapters 4,5 and 6 of this thesis have presented the results of the asthma and diabetes parts of the research. In both conditions the majority of parents were responsible for ensuring continuous supplies of medication and collecting prescriptions from the pharmacy. Parents frequently reminded the young person to take asthma medication, monitor blood glucose levels or administer injections of insulin. Most young people with asthma administered their medication without assistance from their parents other than when their condition was severe or when a nebuliser was used. Young people with diabetes usually monitored their blood glucose level without assistance from their parents. The administration of insulin injections was most often performed by the young person alone or with their parents. Young people and parents described discussions related to the management of the condition. In the asthma part of the study discussions related to the management of triggers to the condition and deciding on medication, according to need. Discussion in the diabetes part of the study was associated with the young person's diet or physical activity. The majority of parents, in both parts of the study, identified themselves as having overall responsibility for the management of the young person's condition. Partnerships between young people with asthma or diabetes and their parents were generally harmonious.

It was an objective of this research to examine roles within partnerships in relation to the age of the young person and number of years since diagnosis of the condition. In relation to some tasks, in both parts of the study, numbers were too small to enable meaningful statistical tests to be conducted. Where statistical tests were possible, there was no association between roles within partnerships and the age of the young person or length of time since diagnosis. An exception to this in the asthma part of the study was that, from parents' perspective, overall responsibility for the medication was associated with a significantly higher mean rank age of the young person (Mann Whitney U test, $p=0.025$).

Young people with asthma and diabetes who lived in more than one family unit, and their parents, identified problems with the management of their condition whilst in the secondary family unit. The small number of young people within this group who were interviewed means such findings are not generalizable. Changes were identified by young people and parents that had occurred within partnerships over time, with young people having taken on more responsibility for their condition as time had passed. In the asthma part of the study changes often occurred without specific planning and were triggered by events such as social occasions or school trips. In the diabetes part of the study, whilst the majority of parents noted changes had occurred without planning, other parents reported a planned approach to changes in roles within partnerships.

Young people with both conditions, and parents often reported not having considered the future nature of partnerships and the handover of responsibility for the condition and its management.

In both parts of the study young people and parents identified problems with condition management at school. Dissatisfaction or difficulties were identified with young people of all ages in schools which did or did not have medication policies and in situations where the young person carried their own medication or when it was stored elsewhere. Parents of young people with asthma and diabetes noted similar types of problems at school. Problems were related to the young person not having adequate access to medication or equipment related to their condition and staff not understanding the nature of the condition. Young people with asthma reported problems with the impact of the condition on life at school such as being bullied or teased about their asthma or their condition limiting their participation in physical activities such as sport. Young people with diabetes noted difficulties due to a lack of a suitable location to administer injections of insulin whilst at school and staff being unaware of the nature of diabetes and associated behaviours, such as the eating of snacks.

Most young people with asthma and their parents reported having seen an asthma nurse and a GP regarding the young person's asthma. All those with diabetes attended a

diabetes clinic and saw a diabetes nurse and consultant. Young people in both parts of the study reported rarely asking health care professionals questions regarding their condition. In relation to the needs for additional information relating to the young person's condition, twenty-five parents of those with asthma identified issues regarding which they would like to receive more information and eight parents of young people with diabetes. Young people in both the asthma and diabetes parts of the study reported using few additional sources of information about their condition and the majority did not request additional information.

Measurement of the QoL of young people with asthma and diabetes, was conducted with use of the PedsQL asthma and diabetes modules (Varni, 1998). Use of the modules was acceptable to respondents, although use of the diabetes module was more successful in terms of the amount of missing data. This may be due to greater homogeneity of the sample in the diabetes part of the study compared to the asthma sample. Significant differences between the mean scores of proxy parent respondents and those of young people were identified with use of a Wilcoxon signed ranks test. In the asthma PedsQL parent proxy respondents tended to report higher scores (better QoL) compared to reports from young people. In the diabetes PedsQL module proxy parent respondents most frequently recorded lower scores (worse QoL) than that reported by young people.

Chapter 7 - Discussion

Chapter 7 Discussion

Chapter seven consists of three sections. The first section considers methodological issues associated with the research presented in this thesis and the potential effect of these on the research findings. Section 7.2 discusses the study findings in relation to previous research. Section 7.3 discusses the implications of the findings for the advice and support provided by health care professionals in the context of current health care policy. The final section, section 7.4, outlines the contribution to knowledge from the research presented in this thesis.

7.1 Methodological issues related to the study

Section 7.1 considers the methodological issues related to the study design and examines the implications of these issues on the research findings. This section considers the advantages and disadvantages of five methodological issues.

7.1.1 Recruitment through general practice surgeries

Young people and parents were identified for interview through GP surgeries. The recruitment of GP surgeries to take part in the research was a time consuming method. It involved numerous telephone calls and letters from the researcher and persistent contact with GP surgeries. A further complication of the use of this method to recruit young people with diabetes, was the low numbers of young people in each surgery which met the study inclusion criteria. In some cases considerable time was spent recruiting a GP surgery which then did not have any patients eligible to take part.

Reasons for non participation given by GPs and surgery staff were primarily related to issues of time and resources at the surgery. Reasons for non-participation included workload issues related to National Health Service directives, policies and audits. In particular, surgeries in which a member of staff was on long-term sick leave expressed

workload difficulties. For reasons of patient confidentiality surgery staff searched patient records to find young people with asthma or diabetes eligible to take part in the research, following detailed written instructions from the researcher. It is unknown whether surgery staff correctly followed the recruitment procedures or inclusion/exclusion criteria nor the extent to which eligible patients were invited to participate in the research. In the asthma part of the study surgery staff were required to randomise young people to be invited to participate, the extent to which these procedures were followed is also not known. It was originally intended that recruitment of young people with asthma would be through the use of British Thoracic Society (BTS) guidelines (see section 2.4). However, such an approach was not possible as surgery staff were unable to select participants in this way. Use of such a method would have enabled the selection of a more homogenous sample of young people with asthma, which might have been of particular benefit in relation to the measurement of QoL with use of the PedsQL asthma modules.

The use of surgery staff's time to assist in finding participants was one of the most common reasons given by GP surgeries for declining to take part in the research. Five GPs who declined to participate and one GP who participated requested that the surgery receive remuneration. However, due to ethical constraints alternative approaches to recruitment were not permitted and participants had to be selected by surgery staff, such detailed procedures were time consuming for them. It is possible that the payment of remuneration might have increased the rate of participation from GP surgeries. This should be considered in future research funding strategies in studies which use similar methods.

An alternative approach might have been the recruitment of young people through asthma and diabetes support groups or through recruitment of young people at asthma clinics or diabetes clinics. The representativeness of young people and parents recruited through support groups would have been unknown. Recruitment through asthma clinics or diabetes clinics would have limited the sample to those young people with care from

the same health care professionals and those who attended appointments with health care professionals. This study's method of recruiting the sample enabled the recruitment of a representative sample in which young people were spread across age ranges, from different geographical locations and of varied times since diagnosis of the condition. The use of GP surgeries enabled a number of young people and their parents to be identified and interviewed (n=138). It meant inclusion in the research of young people who had not seen a health care professional for a number of years and that young people who were interviewed had experienced care under a number of health care professionals. In relation to the asthma sample those interviewed were under the care of eighteen different GP surgeries. In the diabetes sample young people attended eleven hospitals, this method of recruitment also enabled the identification of parents who had moved their son's/daughter's care to another hospital in another health authority area and the opportunity to explore reasons for their action. Recruitment of participants through GP surgeries enabled the invitation of a random sample of young people and their parents to be involved in the study and therefore greater generalizability of research findings.

7.1.2 Sample characteristics of study participants

Efforts were made in the study design to recruit young people across the eight to fifteen year age range and of a variety of social class (house ownership) and ethnic groups. Section 7.1.2 examines the sample characteristics of study participants in relation to age, social class and ethnic group. Characteristics of the study sample are presented in relation to previous research into social class and ethnic differences in the prevalence of the conditions and the characteristics of the populations in the geographical areas in which the research was conducted.

It was an objective of this research to examine the relationship between the age of a young person and their roles within the partnership. Recruitment procedures enabled the recruitment of young people across the age range with which the research was concerned (asthma, aged 8 to 12 years; diabetes, aged 8 to 15 years). In the asthma part of the

study each age was represented by a minimum of four young people, in the diabetes part of the study each age included at least one young person.

In relation to the social class of participants, previous research in relation to asthma suggested higher rates of asthma amongst lower socio-economic groups (Basagaña et al, 2004). In the asthma part of the study 86% of parents reported that they owned their own homes. Studies of children with diabetes have identified no association between the social class of children and the prevalence of type 1 diabetes (Baumer, Hunt and Shield, 1998). In the diabetes part of the study 80% of parents indicated that they owned their own homes. Information from the 2001 census indicated the percentage of home ownership in the areas in which the research was conducted were; East Hertfordshire 76.8%, Enfield 70.6%, North Hertfordshire 68.4%, Barnet 66.6% and Haringey 45.8%.

In relation to ethnic group, previous research by the National Asthma Campaign (2001) reported the highest rates of asthma were amongst children of Black Caribbean ethnic group, followed by children of White ethnic group. In the asthma part of the study 93% of participants identified themselves as 'White', 2% 'mixed White and Black Caribbean', 2% 'mixed White and Asian' and 2% 'mixed Asian or Asian British - Indian'. Previous research in young people with type 1 diabetes indicated 92% of children with the condition were White (Diabetes UK, 2002). In the diabetes part of the study all parents (100%) identified themselves as White. Information from the 2001 census indicated the percentage of respondents reported as White in the areas in which the research was conducted were; East Hertfordshire 97%, North Hertfordshire 93.2%, Enfield 77.1%, Barnet 74% and Haringey 66.6%. The percentage of the population identified as Black Caribbean from census data, reported as the ethnic group with the highest prevalence of asthma in children (National Asthma Campaign, 2001) were; Haringey 9.5%, Enfield 5.33%, Barnet 1.3%, North Hertfordshire 1.01% and East Hertfordshire 0.14%. A low representation of young people and parents from non-white groups might be due to spoken English being a requirement of participation in the research.

7.1.3 Characteristics of young people and parents who declined to take part in the research

Recruitment procedures and need for ethical consideration and patient confidentiality, did not enable detailed investigation of non-respondents in this research. Returned reply slips that indicated decline to participate provided the only information available in terms of the characteristics of young people who chose not to participate in the research. These can provide only an indication of possible reasons for non-participation and implications for the study sample. Reply slips requested information regarding the age and gender of the young person, the number of years since diagnosis of asthma or diabetes and space for reporting a reason for non participation (appendices W, X). Although only tentative conclusions might be drawn from the limited data available regarding non-participants, the decline slips returned to the researcher from the asthma part of the study indicated that those young people who declined to take part in the research did not differ significantly in terms of gender (Chi-squared test), age or number of years since diagnosis (Mann Whitney U tests) from young people who did participate in the research. In the diabetes part of the study, due to the small number of reply slips returned to the researcher, statistical comparison of respondents and non-respondents were not possible.

7.1.4 Interviews

The location of interviews might have had implications for the research findings. The conduct of interviews within the young person's own home enabled young people to be relaxed during the interview process and be easily entertained when they were not being interviewed. Siblings of the young person were also entertained during the interview process. The environment was also conducive to the use of audio-recording equipment which enabled interviews to be fully transcribed for the purposes of analysis. The location of the interview outside of a medical setting distanced the researcher from

identification with GP surgeries or hospitals and might have enabled young people and their parents to express more openly their opinions of health care professionals.

Although the objectives of the research would be best served by independent interviews there were ethical and practical problems related to this. The researcher was aware of parents' possible concerns regarding leaving their son/daughter with a stranger. Two parents and one young person were not happy for the young person to be interviewed alone and agreed this prior to consenting to participate in the research. Although methodological texts have highlighted the issue of parents as gatekeepers in research (Scott, 2000) little published research has commented on the issue of interviewing young people alone, other than Gabe, Bury and Ramsay (2002) who noted similar difficulties in interviewing young people without their parent present. There were also practical difficulties associated with interviewing young people alone. Several of the homes in which interviews were conducted had one main living area and a kitchen. The lack of available space outside of the main living area, often in which other family members such as siblings were present, was an added difficulty of conducting independent interviews.

On some occasions parents answered questions directed at the young person, or young people referred to their parent for answers. After intervention by the researcher on such occasions in most instances young people answered questions alone. The effect of the presence of a parent on the responses of young people in this research is unknown, as is the effect of the presence of a young person on the responses of their parent. However, although not generalizable, field notes and the researcher's own reflections indicated the presence of the parent did not inhibit the young person's participation in the interview. At the beginning of interviews it was common for young people to turn physically to their parent or to ask them for reassurance or for confirmation of their answers to questions. This occurred particularly in relation to factual questions such as the age at which the young person was diagnosed with the condition. After encouragement from the researcher, that she was interested in the young person's opinions and that their

parent would have the chance to give their views, young people became more confident and consulted parents less as the interview progressed. The majority of young people maintained eye contact with the researcher during the interview and body language indicated their engagement with the researcher. An examination of quotes from young people and of field notes did not establish evidence of young people feeling discomfort with the presence of their parent in the interview. It was the researcher's reflection that the presence of a parent at times gave the young person greater confidence in communicating with the researcher. Two interviews in which the researcher experienced difficulties in communicating with the young person (see section 5.2) were cases where the young person was interviewed alone.

In total (from both parts of the study) half (50.7%) of the parents interviewed were interviewed alone. Where parents were interviewed in the presence of their son/daughter field notes and the researcher's own reflections suggested that parents were not inhibited by the presence of the young person. Exceptions to this were two interviews conducted with the parents of young people with diabetes. At one point in each of these interviews the parent appeared uncomfortable with the presence of their son/daughter. One mother, whose son had experienced poor care when first diagnosed with the condition, stated she did not want to talk about these events while her son was present. He had no memory of the situation and she did not wish him to know what had occurred, as a result the young person left the room. One parent became upset when recalling his daughter's diabetic coma and stated he did not want to talk any more about it. It is unknown if this comment was due to the presence of his daughter in the room, or if he would have felt the same had he and the researcher been alone.

7.1.5 Young people as research participants

Upon commencement of the research consideration was given to the methodological approach to be taken with young people (see section 2.2). Section 7.1.5 uses field notes and the researcher's reflections to comment upon the methodological issues raised in

this study with respect to the involvement of young people in the research and the impact of these issues on research findings.

From the pilot work (see section 2.3) it emerged that the use of semi-structured interviews with young people was unsuccessful, young people did not talk at length and appeared awkward with the formal approach to questions. Use of a topic guide enabled the interview to be adapted by the researcher to the abilities of the young person and their use of language and this encouraged young people to talk more openly about their views and experiences. A disadvantage of the use of topic guides was that it did not enable the same questions to be asked in the same way to all respondents and therefore in some cases compromised the completeness of data. As this research was concerned with partnerships between young people and their parents ideally young people and parents would have been asked the same questions. However, piloting revealed young people were better suited to shorter interviews and as a result they were not asked all questions that were asked to their parents. This approach did not enable the views of young people to be explored in relation to some areas, such as who had overall responsibility for medication. Use of the methodological approach taken in this research, whilst essential in engaging young people, might have implications for the reliability and validity of research findings.

The researcher observed differences in young people's responses to interview questions, compared to responses given by adult participants. Young people sometimes used non verbal replies such as nodding or shaking of the head, shrugging shoulders or using 'thumbs up'. To be sure the researcher knew what the young person meant by such responses the young person was asked to clarify what they mean by such actions. Where young people gave non-verbal responses to questions they were often unable to elaborate on answers in detail. Young people at times replied to questions by stating 'don't know', which did not occur in interviews with parents. Despite the use of prompts young people often were not able to elaborate on this response to questions. Such responses were more evident in relation to certain topics in the interview, such as information

needs or consultations with health care professionals, and rarely occurred when young people were talking about management at school. Responses given by young people as 'don't know' have been reported in this thesis as 'young person was unable to give an answer', but treated as missing data. Findings in some areas of this research, such as information needs of young people, are therefore limited due to the large number of young people who were unable to answer the question. For most of the interview however, young people were able to talk at length and gave full answers to questions.

Much attention has been focused on the reliability of data obtained when young people participate in research (Scott, 2000). Although it was not an objective of this thesis to explore differences in accounts from parents and young people, there was little variation in young people's and parents' descriptions of roles and tasks performed within the partnership. In relation to the management of the condition outside of the home, such as school, young people's accounts were often more complete than those from parents.

The researcher obtained consent from young people prior to the commencement of the interview, the consent process was explained to the young person and that they were free to withdraw from the research at any time. Although young people appeared to comprehend this several were surprised with having to complete paperwork which indicated their consent to participate in the research. A number of young people commented that they did not have a signature with which to sign the form. Many young people appeared excited at completing the form, some commented that they felt 'grown up'. Although all young people in this study appeared comfortable completing the form, it is worthy of note that the completion of paperwork was a concept unfamiliar to young people and, in future research, might be intimidating to young people or make them nervous.

7.1.6 Contribution of this thesis to research involving young people

As documented earlier in this thesis (see section 2.3) research involving young people is still in its infancy. At the time of preparation of the main study protocol limited methodological texts concerned research with young people. Such research had been perceived as problematic in relation to ethical, communication and practical difficulties. The research presented in this thesis has shown the involvement of young people in research to be successful. With consideration of the methods and approach used in this research, young people were able to participate fully in the research process and spoke at length about their experiences of asthma and diabetes. For health care professionals to work together with young people, as advocated in the National Service Framework for Children (Department of Health, 2004), it is vital that they obtain greater insight into the view and experiences of young people in managing their conditions. Further research involving young people is essential to achieve this aim, this thesis has shown how research with young people can be workable and successful.

7.2 Discussion of research findings in relation to previous work

Section 7.2 discusses the research findings presented in this thesis in relation to previous research. Section 7.2.1 documents the roles of young people and their parents in the management of the young person's asthma or diabetes. Section 7.2.2 describes the management of asthma and diabetes as a shared responsibility between young people and their parents. Section 7.2.3 discusses the association between the age of the young person and length of time since diagnosis of asthma or diabetes and roles within partnerships. Section 7.2.4 examines issues related to the management of asthma and diabetes in schools. Section 7.2.5 reports contact with health care professionals in relation to asthma and diabetes. Section 7.2.6 details the information needs and information used by young people with asthma and diabetes and their parents. Section 7.2.7 reports the development of the PedsQL asthma and diabetes modules. The final

section, 7.2.8, documents the differences in the research findings between the two conditions.

7.2.1 Roles of young people and their parents in the management of the young person's asthma or diabetes

7.2.1.1 The role of parents in the management of asthma and diabetes

The research presented in this thesis has contributed to knowledge regarding the roles of young people and parents in the management of asthma and diabetes from the perspective of both young people and parents. Previous research which involved young people with asthma had commented on the roles performed by parents in the management of the condition. This research has confirmed the findings of previous work which identified the role of parents in monitoring their son's/daughter's asthma, particularly in maintaining an awareness of the worsening of asthma symptoms (Callery et al, 2003; Prout, Hayes and Gelder, 1999; Østergaard, 1998). The research presented in this thesis included young people aged eight years or over, whereas in previous research the youngest age group represented was nine years (Callery et al, 2003). Prout, Hayes and Gelder's (1999) work which identified the parental role in monitoring the young person's condition, was based on a small sample of nine young people and their parents. The research presented in this thesis, conducted on a larger sample (n=43) shows that this role is widely adopted amongst the parents of young people with asthma.

In both parts of the study parents were most frequently responsible for ensuring continuous supplies of medication and collecting prescriptions from the pharmacy. This research has also identified the considerable role of parents in the asthma part of the study in; reminding young people to take their medication and deciding on medication according to need. In the diabetes part of the study; parents reminded young people to monitor blood glucose levels or administer injections of insulin.

7.2.1.2 Role of young people in the management of asthma and diabetes

Findings of the research presented in this thesis identified that both young people with asthma and those with diabetes had comprehensive knowledge of their medication and regimen. Young people with asthma described in detail their use of different types of medication, both preventer and reliever, and some young people the use of more complex technology such as nebulisers. These findings differ from those of Pradel, Hartzema and Bush (2001) who reported that children (aged 7 or 12 years) were not familiar with the medication they required when having an asthma attack. In their research only one child (n=32) made a distinction between the use of preventer and reliever medication. Differences between these findings and those presented in this thesis might be due to the different methods of data collection. Pradel, Hartzema and Bush (2001) used a drawing and asthma figurative process interview and centered discussions on an asthma attack. The research presented in this thesis used an interview approach and focused on the daily management of asthma. Variations in findings might also be accounted for by a different age range of participants, Pradel, Hartzema and Bush (2001) included some young people aged seven years. Differences in findings may also be due to variations in the severity of the condition, Pradel, Hartzema and Bush (2001) focused on young people with moderate or severe asthma and this research predominantly those with mild to moderate asthma. No previous work was identified which had explored the knowledge and use of medication in young people with diabetes, this research indicated comprehensive knowledge of the condition, blood glucose monitoring and diet.

Young people with asthma and their parents reported that young people most frequently administered asthma medication without parental assistance, in agreement with the small scale work of Prout, Hayes and Gelder (1999). This finding in the UK is in line with American research (Peterson-Sweeney et al, 2003) which noted the role of parents in providing assistance with the use of nebuliser medication. In the diabetes part of the study young people with diabetes most frequently monitored blood glucose levels

without assistance from their parents, the administration of injections of insulin was a role often performed by young people alone or with assistance from parents. Parental assistance with more complex aspects of medical regimens concords with the findings of Atkin and Ahmad (2000) who noted the considerable role of parents in assisting young people with thalassaemia major with the complex technological equipment used in chelation therapy. In the asthma part of the study parental assistance was more common with the use of more complex technology, such as use of a nebuliser.

Previous research in relation to the management of diabetes (Anderson et al, 1990; Hanna and Guthrie, 2003; Palmer et al, 2004) had focused on the transition of tasks from parents to young people, but none had identified the specific roles of young people with diabetes and their parents in the management of the condition.

7.2.2 Partnerships between young people and their parents

7.2.2.1 Shared responsibility of condition management

In both parts of the study, young people and parents frequently referred to working together in the management of asthma or diabetes. With the exception of one partnership in the diabetes part of the study, all young people and parents identified aspects of a joint approach to the management of the condition. This sharing of responsibility encompassed the division of practical tasks of condition management and the discussion of the management of asthma or diabetes. Discussions in the asthma part of the study between young people and parents were related to triggers of the condition and dosage of medication; in the diabetes part of the study discussions focused on blood glucose readings and the young person's diet.

The identification of a shared responsibility for the management of asthma and diabetes, with both young people and parents noting their roles in condition management, adds to the observations made by Gabe, Bury and Ramsay (2002). They noted from interviews

with young people a shared sense of responsibility associated with the management of asthma. By the involvement of parents as well as young people in the research presented in this thesis the shared responsibility for asthma and diabetes management has been documented from both the perspective of young people and their parents and enabled the nature of partnerships to be explored.

7.2.2.2 Conflict within partnerships

Partnerships between young people and their parents, in both parts of the study, were generally harmonious. This finding is in contrast to the research of Peterson-Sweeney et al (2003) in which half of parents interviewed reported power struggles with adolescents in relation to responsibility for the young person's asthma. In the research presented in this thesis young people identified and accepted the roles of parents in the management of their asthma or diabetes. Research by Kyngäs (2004) identified the role of parents in supporting young people with chronic conditions, but also noted how some adolescents (aged 13 to 17 years) felt their parents focused on asking them questions and were not really interested in their condition. In the research presented in this thesis no young person identified a lack of parental support.

7.2.2.3 Parental strain of caring for young person with asthma or diabetes

Parents of young people with asthma reported few difficulties with the management of their son's/daughter's condition and in caring for the young person and their needs. This finding differs from the Swedish research of Rydström et al (2004) which noted, from interviews with mothers, the disruption caused to family life by the care for the young person and their needs. Mothers reported difficulties in being constantly available for the young person with asthma and the impact of this on the well-being and attention given to other family members. Differences in the findings between this and the research presented in this thesis could be due to cultural differences between Sweden and the UK. The research of Rydström et al (2004) involved young people aged 6 to 16

years, the inclusion of those in the younger age groups might mean a greater onus on parents for their care. The inclusion of young people with severe as well as moderate asthma might also lead to differences in findings, as the research presented in this thesis concerned young people with mild to moderate asthma. The involvement of young people in the research presented in this thesis and the focus in the interview on partnerships might also account for different findings.

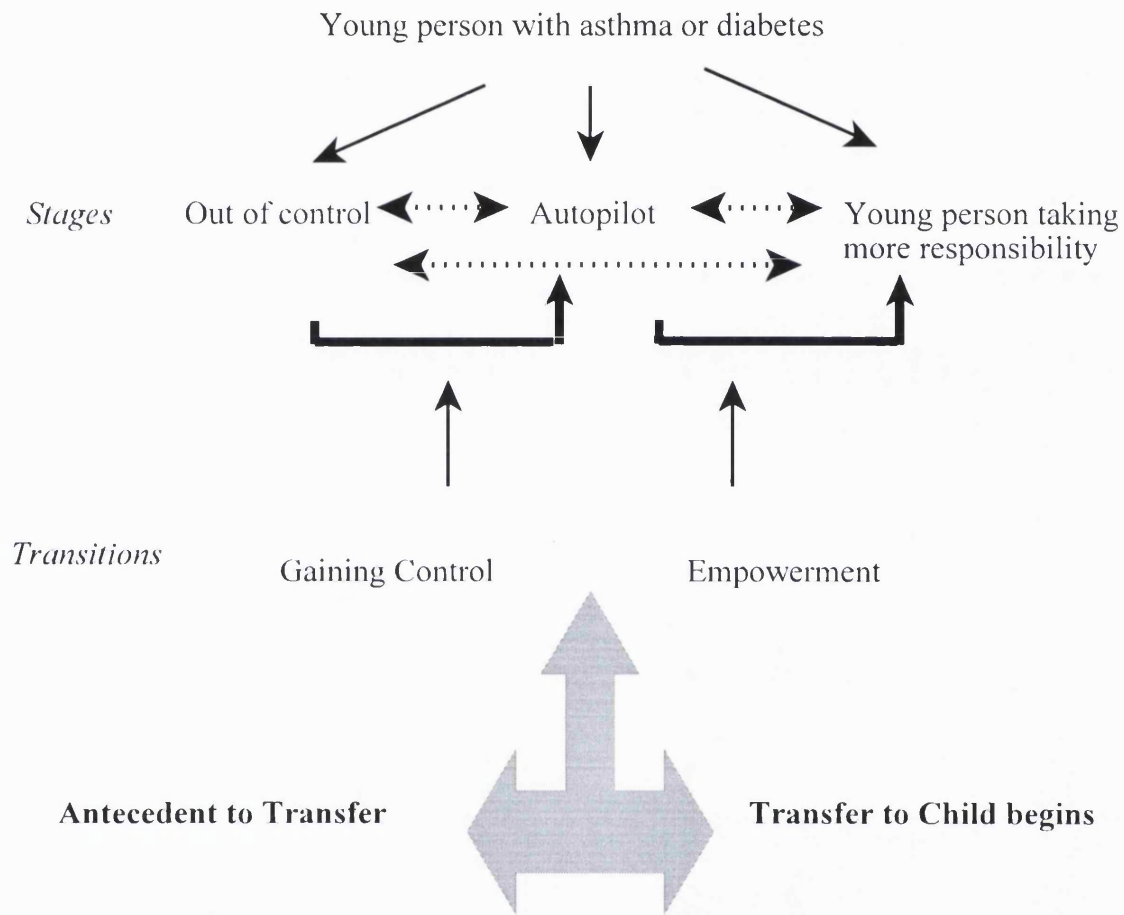
Parents in the diabetes part of the study reported little inconvenience or problems associated with assisting the young person in the management of their condition, often viewing such roles as an accepted part of daily life. Although some parents did describe restrictions on their lives due to the young person's diabetes, they did not comment upon the strain of managing their son's/daughter's condition on a daily basis. This finding contradicts that of Azar and Solomon (2001) who identified, from interviews with the parents of young people with diabetes different coping styles. Mothers and fathers identified different approaches to managing the strain associated with their son's/daughter's condition, with fathers distancing themselves from the situation and mothers using a planned approach to manage the condition. Differences in the findings of Azar and Solomon (2001) and the research presented in this thesis might be due to the focus in this research on the practical roles of diabetes management rather than the emotional coping strategies of parents. The research presented in this thesis also involved young people, whereas that of Azar and Solomon (2001) interviewed parents alone. There were also differences in sampling, the research presented in this thesis used random sampling, and that of Azar and Solomon (2001) advertisements in newspapers, charity publications and hospitals.

The management of asthma and diabetes in this thesis was reported as being incorporated into the daily family routine, rather than as a disruption to family life or strain on parents, as identified in previous research (Rydström et al, 2004; Azar and Solomon, 2001). This is in line with research of Prout, Hayes and Gelder (1999) which documented the experience of asthma within the context of the family unit through the

construction of a sense of ‘ordinariness’. This was when management of the condition within the home was seen as part of ordinary life and caused little anxiety to young people and parents. In this thesis the management of diabetes was also incorporated into the routine of family life, such as the modification of the family diet to accommodate a young person with diabetes. Responsibility for the condition in this context was not seen as the sole responsibility of the parent, but as a shared responsibility which involved both young people and parents, each having responsibility for certain aspects of the management of the condition. There was little variation in accounts from young people and parents regarding the roles of each in the management of asthma or diabetes, indicating respondents’ awareness of the other party’s role in the management of the condition.

7.2.2.4 Changes in partnerships between young people and their parents over time

Young people and parents, in both parts of the study, revealed the ways in which responsibilities for asthma and diabetes management within the partnership had changed over time. The transfer of responsibility from parent to young person in both conditions, as outlined in this thesis, furthers the understanding of the transition of responsibility for the management of asthma presented in the theoretical model of Burford (2004). Burford’s (2004) model (see figure 1.1) outlines stages through which control for the management of asthma transfers from the responsibility of the parent to that of the young person. The discrete states of ‘Out of control’, in which the parent has full responsibility at first diagnosis and ‘Autopilot’ in which families incorporate asthma care into routines, were evident in the accounts of young people and parents in this thesis, in both parts of the study. In agreement with the work of Burford (2004) the research presented in this thesis identified the process of transfer of responsibility for the management of asthma or diabetes as taking place over a number of years, with the gradual transfer of specific tasks of asthma management from parents to young people. The application of the findings of this thesis are shown in the adaptation of Burford’s (2004) theoretical model of transition shown in figure 7.1.

Figure 7.1. Adaptation of Burford's (2004) theoretical transfer model

The final stage in Burford's (2004) model, 'Letting go', in which young people adopted independent self-management without assistance from their parents, was not evident in the findings of the research presented in this thesis. In this adapted model (see figure 7.1) the stage 'letting go' has been replaced with 'young person taking on more responsibility'. In this study all parents had involvement in the management of the young person's condition, none had 'let go'.

Also absent from the modified model (figure 7.1) are the seven baseline characteristics, identified by Burford (2004), which impacted upon the transfer of responsibility. In the

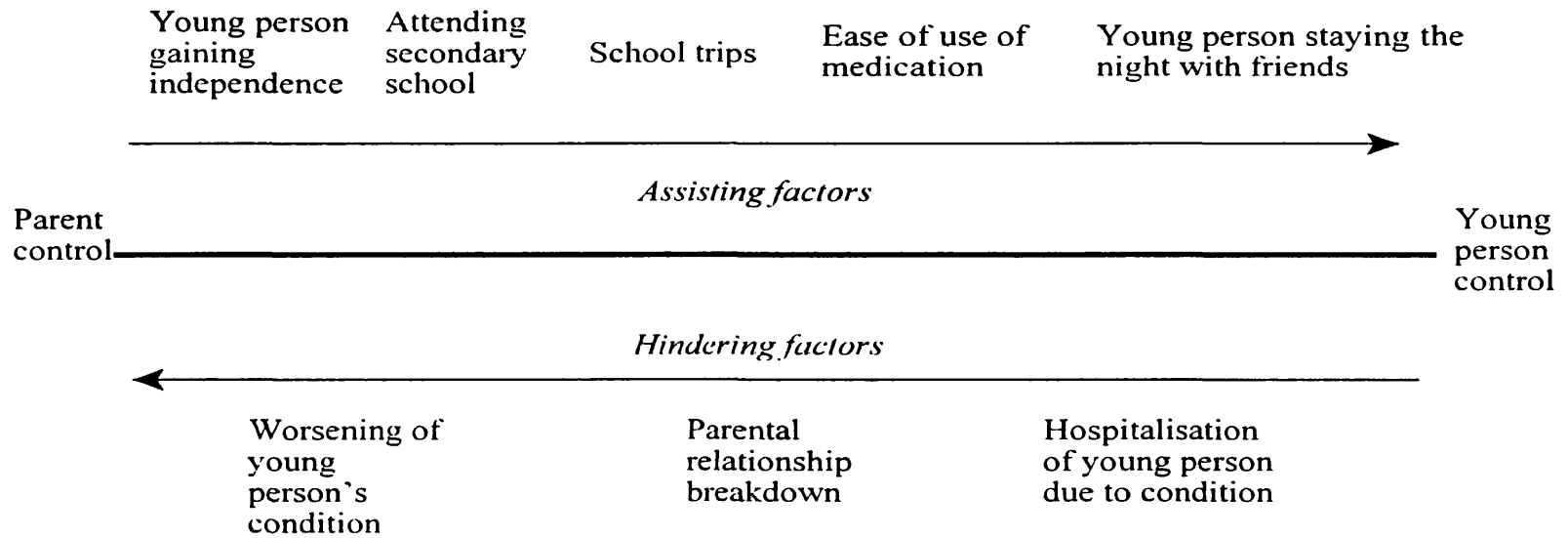
research presented in this thesis the two factors explored, age of the young person and number of years since diagnosis, did not influence transfer of responsibility from the parent to young person. Figure 7.1 also encompasses a further amendment to Burford's (2004) original model. Burford (2004) noted distinct stages of progression from 'out of control' to 'autopilot' to 'letting go'. Whilst the modified model (figure 7.1) shows this as the most common route it also signifies, with a dotted line, that it is possible for young people to revert backwards through stages. For example in the research presented in this thesis a young person reached the stage of 'taking on more responsibility' for their diabetes but then was hospitalised due to their diabetes and care returned to the 'autopilot' stage.

The research presented in this thesis furthers the work of Burford (2004) by the application of the model to both young people with asthma and those with diabetes. The adapted theoretical transfer model (figure 7.1) is based on interviews with sixty-eight pairs of young people and their parents, Burford's (2004) original model (figure 1.1) was based on interviews with fourteen young people and fourteen carers.

7.2.2.5 Factors influencing transfer of control from parent to young person

The research presented in this thesis identified the transfer of responsibility for asthma and diabetes management as a process which occurs with little prior planning and often as part of the young person growing up. Findings also indicated a number of factors which may assist or hinder the transfer or control from the parent to the young person. This has led to the development of the model to show factors influencing transfer of responsibility for asthma or diabetes from parent to the young person. As shown in the model (figure 7.2) a number of factors were shown in the research presented in this thesis to assist in the transfer of responsibility from parent to young person.

Figure 7.2 Model to show factors influencing transfer of responsibility for asthma or diabetes from parent to the young person



Factors were also identified as hindering transfer. The understanding of such a model may assist health care professionals in identifying factors in a young person's life which may assist or hinder the transfer of responsibility for asthma or diabetes from parent to young person and enable them to provide help and support accordingly.

The model (see figure 7.2) adds to previous research regarding factors which influence transfer of control in that it documents in detail factors which hinder transfer of responsibility and those which assist such transfer. Previous research in relation to asthma (Burford, 2004) and diabetes (Palmer et al, 2004) have noted a small number of factors as affecting the transfer of responsibility, few of which were practical issues.

Burford (2004) identified young people realising that their parents would not always be present was a factor in them taking greater responsibility for their asthma. Palmer et al (2004) attributed parents behaviours as key to the transfer of responsibility to the young person and noted four factors that led to transfer; hassles and difficulties with the parent managing the condition, promoting the young person's responsibility for their condition, parents' belief in their child's competence to manage the condition and pressure from others for the young person to take on responsibility for diabetes management tasks.

This research suggests practical issues and life events to impact on the transfer of responsibility rather than parental (Palmer et al, 2004) or young people's (Burford, 2004) beliefs.

7.2.2.6 Issues of condition management for young people who live in more than one family unit

All young people with asthma and diabetes and their parents identified within their primary home a shared responsibility for the management of the young person's condition. A small number of young people who lived in more than one family home, in both the asthma and diabetes parts of the study, identified difficulties with the management of their condition in their secondary family unit. They often reported the parent in the secondary family unit as taking a lesser role in the management of the condition and lesser responsibility for the condition. Parents in the primary family home also highlighted difficulties with the management of the young person's condition when at the secondary family home and difficulties in communicating with their former partner on issues relating to the young person's condition. Similar findings were indicated in research by Ganong, Doty and Gayer (2003), with mothers of young people with cystic fibrosis, who identified difficulties in communicating the severity of the condition and management issues with fathers and their new families. The research presented in this thesis has identified issues related to the management of a chronic condition from the perspective of young people themselves, whereas the research of Ganong, Doty and Gayer (2003) reported the views of mothers. It had not been anticipated that the topic of the management of asthma or diabetes within the secondary family unit would be an issue for young people and as such questions were not asked in relation to this topic in the interview. Data were therefore limited to young people and parents who raised this issue in the interview and as a consequence findings were limited. Only a small number of young people were identified as living in more than one family unit. This research focuses on the view of only the parent in the primary family unit. However findings suggest that there might be issues for young people who live in more than one family unit that should be addressed in further research. An awareness of the potential difficulties experienced by this group should also be reflected by the inclusion of a question related to family formation in future research involving young people.

7.2.3 Association between the age of the young person and length of time since diagnosis of asthma or diabetes and roles within the partnership

It was an objective of this thesis to examine roles within partnerships in relation to the age of the young person and number of years since diagnosis of the condition. This section begins by reporting associations from the data between the age of the young person and roles within partnerships. There was no association between roles in partnerships and the number of years since diagnosis of the condition. Limitations in the fulfilment of this research objective are also discussed in this section.

In the asthma part of the study there was an association between the age of the young person and the parents view that they had overall responsibility for the condition (Mann Whitney U test, $n=43$, $p=0.025$). Young people whose parent reported the parent had overall responsibility for asthma medication had a lower mean rank age than those whose parents identified overall responsibility to be shared or the sole responsibility of the young person. In the diabetes part of the study, there was an association between the age of the young person and parental reports of problems in school (Mann Whitney U test, $n=26$, $p=0.019$). Young people whose parent reported the young person had experienced problems in school had a lower mean rank age than those whose parents did not report problems. There was an association between the parent specifying the need for more information about diabetes and the age of the young person (Mann Whitney U test, $n=26$, $p=0.043$). Young people whose parent reported needing additional information had a higher mean rank age than those whose parents did not express a need for more information.

A further six Mann Whitney U tests were conducted in the asthma part of the study and nine Mann Whitney U tests in the diabetes part of the study, but these identified no association between the age of the young person or number of years since diagnosis of the condition, and roles within partnerships. In relation to six roles in the asthma part of the study and nine in the diabetes part of the study numbers were

too small to enable meaningful statistical tests to be conducted, data were grouped with a large number of young people or parents indicating one response. Findings therefore indicated trends in relation to tasks most frequently performed by parents, such as collecting prescriptions from the pharmacy, and those most commonly performed by young people, such as the monitoring of blood glucose levels. Such patterns in partnerships, across the study sample, might inform health care professionals with regard to the roles most likely to be performed by young people and parents and enable them to give advice and support accordingly.

In relation to the asthma part of the study previous research had not examined the age of the young person or length of time since diagnosis in relation to roles of young people and parents in partnerships. The research presented in this thesis indicated that there was no association between the age of the young person and roles within partnerships, other than in relation to overall responsibility for medication. The length of time since diagnosis of the condition was not related to roles in partnerships. Previous research in relation to diabetes has examined roles performed by young people in relation to the young person's age. Studies by Palmer et al (2004) and Anderson et al (1990) had reported, through the use of quantitative methods, that young people in older age groups assumed greater responsibility for tasks of diabetes management. The research presented in this thesis contradicts these findings and suggests little association between the age of a young person and roles within partnerships. This finding is in line with the work of Hanna and Guthrie (2003), which also used quantitative methods to establish no significant difference in parental involvement with diabetes management at different stages of adolescence. No previous research had examined the relationship between the number of years since diagnosis of diabetes and roles within partnership, the research presented in this thesis indicated no association between these factors.

7.2.4 Management of asthma and diabetes at school

Exploration of the issues of the management of asthma and diabetes in schools were not an objective of this research, but interviews with young people and parents highlighted relevant issues in this setting. The management of asthma or diabetes in schools necessitated that the young person managed their condition alone. This led both young people and parents to indicate difficulties and anxiety within the school environment.

7.2.4.1 Access to medication in school

Parents of young people with asthma identified their son's/daughter's access to asthma medication as an issue of concern. In the research presented in this thesis the majority of young people with asthma kept medication with them whilst at school for use when required. Previous studies which have examined access to asthma medication have indicated variations in findings (Fillmore, Jones and Blankson, 1997; Chadwick, 1996; Pugh et al, 1995). Questionnaires relating to the management of asthma in schools in research (Fillmore, Jones and Blankson, 1997) were sent to head teachers in two areas of South Wales. This research identified forty percent of young people as being responsible for their own inhalers. The analysis of questionnaires administered to head teachers in County Durham (Pugh et al, 1995) reported that all secondary schools and two-fifths of primary schools allowed young people to manage their own asthma medication. From interviews with young people with asthma, Chadwick (1996) noted limited access to asthma medication at school with 13 out of 14 young people reporting restricted use of medication. Differences in findings from these three studies and the research presented in this thesis might reflect geographical variations in the policies of educational authorities or particular schools in relation to the storage of medication. Reports from head teachers and young people themselves on access to medication might account for variations in findings, with possible differences between written policies and what actually

happens. In the diabetes part of the study the majority of young people stored equipment related to their diabetes in a classroom. Due to the nature of the condition young people with diabetes and their parents were not as concerned as those with asthma that medication be stored with young people. This suggests the need for school policies to consider the different needs of specific conditions.

7.2.4.2 School policies regarding medication

The parents of young people with asthma and diabetes reported on the presence of policies related to medication in school. In the asthma part of the study 44% of parents and in the diabetes part of the study 31% of parents stated that the schools with which they were associated had a medication policy. In both parts of the study parents identified a higher number of schools as having a policy regarding medication than the research of Fillmore, Jones and Blankson (1997), which identified twenty-five percent of schools as having a medication policy. However, findings in the research presented in this thesis identified a lower percentage of schools with school policies compared to the research of Wong et al (2004) in primary schools in the London area, in which 95% of schools had policies. Differences in these findings might be due to geographical differences in educational authority areas or greater sample size of respondents to the questionnaire (Fillmore, Jones and Blankson (1997) n=216; Wong et al (2004) n=172) compared to those who were interviewed (n=138). Variations might also be due to head teachers as respondents rather than parents or because the research in this thesis is more recent and medication policies might have become more widespread in response to Department of Education and Employment recommendations.

In the research presented in this thesis several parents were concerned regarding provision within the school for advice as to what action would be taken if the young person was unwell. The Department for Education and Employment have advocated the formulation of individualised care plans in schools for children with asthma,

diabetes, epilepsy or anaphylaxis (Department for Education and Employment, 1996). Research by Wong et al (2004) indicated the presence of individualised care plans in 50% of primary schools. Although in the research presented in this thesis, respondents were not specifically asked about this issue, none (n=138) identified that care plans were in place for the young person.

Whilst the focus of much Department of Education and Employment policy has been upon the formulation of school policies in relation to medication and ensuring young people have access to their medication whilst at school, the research presented in this thesis identified that young people in schools both with and without school policies and their parents both identified problems associated with the management of asthma and diabetes. This suggests that the presence of school policies does not necessarily eliminate difficulties for young people in the management of their condition whilst at school, or address all issues which are of concern to young people and parents.

7.2.4.3 Parents' concerns regarding condition management in school

The parents of both young people with asthma and those with diabetes identified anxiety in relation to staff's attitude to the management of the young person's condition. Parents reported that staff were unsympathetic to the needs of the condition. Parents of young people with diabetes were particularly concerned at the lack of provision for monitoring the condition whilst the young person was at school and noted difficulties in conveying the serious nature of the condition to school staff. Some young people reported difficulties with staff related to the staff's lack of knowledge regarding what action should be taken if the young person felt unwell. Zoritch et al (1996) identified concerns of teachers who had a child with CF in their class, regarding their lack of information about CF.

7.2.4.4 Young people's concerns regarding condition management in school

Previous research has identified the restriction of physical activity and participation in sport to be a particular difficulty for young people with asthma in school. Difficulties were identified by two young people with asthma in the research presented in this thesis. This is far fewer young people than had been identified in previous research. Chadwick (1996) indicated thirteen out of fourteen respondents had difficulties with participation in sport at school and Gabe, Bury and Ramsay (2002) reported it to be a common problem for young people. Differences in the findings of this research with previous studies might be due to the mild to moderate nature of asthma suffered by young people in this research, whereas other studies have focused on young people with moderate to severe asthma (Gabe, Bury and Ramsay, 2002; Chadwick, 1996).

Young people with diabetes, and more particularly with asthma, reported being bullied or teased by peers about their condition. This finding was not identified from interviews with parents which might suggest that parents were unaware of the extent of these problems experienced by young people. Young people with diabetes also identified difficulties with the administration of injections of insulin when at school and noted there was a lack of a private location in school where they could perform this task. This research has reported difficulties experienced by young people and parents not identified in previous research. Young people and parents identified different problems. Parents tended to focus on issues related to medication and ensuring staff were aware of the severity of the condition whilst young people reported problems related to the social impact of the condition at school, such as being bullied or teased, and practical issues such as a location in which to administer injections of insulin. Differences in problems reported by young people and parents demonstrates the importance of obtaining the views of both parents and young people themselves in relation to issues at school and the consideration of both groups' views by schools. Whilst some issues were identified as problems for both conditions,

some issues were specific to each condition, this suggests that schools need to be sensitive to the specific needs of each condition. The involvement of young people in this research has identified issues regarding the management of conditions in schools, not found in previous research which has focused on the views of teachers.

7.2.5 Health care professionals

7.2.5.1 Contact with health care professionals

The parents of young people with asthma identified limited contact with health care professionals, with eight young people having not seen a health care professional in relation to their asthma for two years or more. This finding is in keeping with previous research which also noted limited contact with health care professionals in young people with asthma (Gabe, Bury and Ramsay, 2002; Prout, Hayes and Gelder, 1999). Young people with diabetes reported frequent contact with health care professionals with young people visiting diabetes clinics every two to six months.

7.2.5.2 The role of health care professionals

Young people and parents in the asthma part of the study identified distinct roles performed by asthma nurses and GPs in relation to their care. Whilst asthma nurses were involved in routine appointments and discussions relating to the condition and medication, young people and parents often identified consultations with GPs as occurring when the young person was unwell and symptoms of asthma were worse. Parents of both young people with asthma and diabetes reported asking health care professionals questions about their son's/daughter's care. Parents of young people with diabetes particularly praised the roles of diabetes nurses when young people were first diagnosed and support was received in the young person's own home. Some parents described disagreements between themselves and health care professionals regarding their son's/daughter's care. In the asthma part of the study

this had taken the form of disagreements between three parents and asthma nurses regarding the type of medication the young person was prescribed. Parents of young people with diabetes had in four cases changed the hospital under which the young person received care, due to dissatisfaction with staff or facilities. These findings demonstrate the strong nature of parents' views towards the care provided by health care professionals and willingness to change care if they are not satisfied.

7.2.5.3 The role of young people in consultations with health care professionals

Young people with asthma and diabetes reported asking health care professionals few questions in consultations. Where young people did ask questions they more frequently asked nurses rather than GPs or hospital consultants. Several young people with asthma described particularly close relationships with asthma nurses and commented on the ease with which they could ask them questions. Although it was not an objective of the research presented in this thesis to compare findings from the qualitative research with those of the PedsQL modules, it was noted that in the qualitative interview young people reported that they did not ask health care professionals many questions. Yet in the PedsQL modules only 14% of those with asthma and 12% of young people with diabetes stated that it was often or almost always hard to ask doctors and nurse questions. Although these findings appears contradictory it is not necessarily so, young people might report little difficulty asking questions to health care professionals because they do not ask them.

The reluctance of young people asking questions to doctors was also identified by Beresford and Sloper (2003), who examined communication between health care professionals and young people with chronic conditions. Their research found that young people did not ask questions as they did not know what to ask or had concerns regarding their skills of communication with health care professionals or did not wish to disclose 'frowned upon' behaviours to health care professionals such as drinking alcohol (Beresford and Sloper, 2003). In common with those findings young people

in the research presented in this thesis often noted not having any questions they wanted to ask health care professionals. These findings contradict those of Jacobson et al (2000) who indicated that 82% of teenagers found it easy to tell the GP about their health problems. Differences in findings might be due to Jacobson et al's (2000) focus on young people with short term health problems, whereas young people in the research presented in this thesis and that of Beresford and Sloper (2003) had chronic conditions.

Young people, in both parts of the study, elaborated on their views of health care professionals and conveyed a range of views. In the asthma part of the study most young people who gave their view of asthma nurses expressed positive opinions, few young people expressed opinions of GPs. In the diabetes part of the study young people gave mixed views about diabetes nurse and diabetes consultants. This mixture of views differs from the findings of Wassmer et al (2004) in which 95% of children reported satisfaction with consultations with a consultant. Differences may be due to different methods of data collection, questionnaires rather than interviews; or due to differences in the age groups with which the studies were concerned. Wassmer et al (2004) included participants aged 4 weeks to 14 years, the research presented in this thesis involved young people aged 8 to 15 years.

Analysis of audio and video recorded consultations identified the role of parents within consultations attended by young people, health care professionals and parents. Aronsson and Ruderstrom (1988) analysed audio recorded consultations between young people, parents and doctors in an allergy out-patient clinic. Analysis of transcripts of conversations indicated that the parent excluded the young person from involvement in the consultation by intervening in speech directed at the child. The analysis of video recordings of consultations between young people with minor illnesses, parents and doctors (Tates et al, 2002) also noted the role of parents in excluding young people from participating in consultations and dominating the consultation. Recent research by Wassmer et al (2004) indicated that the doctor

contributed the most to the conversation in the consultation, followed by the parent and then the young person. The findings of this thesis are in agreement with the work Aronsson and Ruderstrom (1988), Bates et al (2002) and Wassmer et al (2004) in that young people and parents in this research described parents as asking health care professionals more questions during consultations. However, this finding suggested that parents adopted a dominant role within consultations, rather than interrupting consultations as identified by Aronsson and Ruderstrom (1988) and Bates et al (2002). Young people did not raise their parents role in the consultation as a problem.

Whilst other studies have focused upon the doctor, parent and young person relationship the research presented in this thesis also considered the role of the nurse. In the management of both asthma and diabetes the nurse was a health care professional often seen by young people and parents, in the asthma part of the study they were the health care professional most commonly seen. Accounts particularly from young people in this research suggested that different styles and types of communication occurred with nurses compared with GPs and hospital consultants. Particularly in the asthma part of the study, data suggested close and intense relationships between young people and asthma nurses. The research presented in this thesis would suggest consultations with nurses are of a different type than takes place with a GP or consultant. In view of these different types of relationship, further research should focus on the parent-young person-nurse consultation, and this triad of care.

The use of accounts provided by young people and parents identified limited involvement of young people in the consultation. A weakness of this study included asking respondents to recall previous consultations, young people in particular were often unable to recall details. Young people and parents were asked to reflect in the interview on whether they had asked health care professionals questions regarding the condition, as an indication of communication between the parent, young person and

health care professional. However, attitudes of young people towards needing additional information about their condition might suggest that young people did not want to know more about their condition and therefore did not ask questions, rather than a reluctance in communicating with health care professionals. Audio or video recordings of consultations might provide a greater insight into the communication of health care professionals with young people and parents in a consultation.

Limitations of this approach however are that the opinions of participants in the consultation would be observed by an external researcher and might not be viewed in the context of the partnership between the young person and their parent. Further research, perhaps involving observations of consultations and interviews with participants, is needed to explore three way consultations further with young people who have chronic conditions.

7.2.6 Information needed and used by young people with asthma and diabetes and their parents

No previous research had examined the information needs and information used by young people with asthma and diabetes and their parents. The research presented in this thesis indicated that parents of young people with asthma obtained information about their condition from a variety of sources, frequently from health care professionals. Parents identified numerous issues regarding which they required more information, particularly in relation to the causes of asthma, triggers to the condition and cures. Most young people with asthma were unable to recall from where they had obtained knowledge of the condition, only two young people required additional information. In the diabetes part of the study parents had obtained information from several sources, most frequently health care professionals or written information, some parents identified issues regarding which they would like more information. Young people with diabetes identified written sources, health care professionals and parents as the most common sources of information about diabetes. Only one young person required more information about their condition.

In relation to previous research regarding the internet, the findings of this thesis indicated little use of the internet by either young people (Gray et al, 2005) or their parents (Tuffrey and Finlay, 2002). There were parallels between the information sources used by parents with asthma and diabetes and those identified by Starke and Möller (2002), used by the parents of girls with Turner Syndrome such as books, leaflets, articles in newspapers and magazines and support groups. Although the information needs and information used by young people with asthma and diabetes and their parents were only briefly commented upon in the interview, due to a lack of existing research on this subject findings might provide health care professionals with an indication of the information used and type of information required by young people with asthma or diabetes and their parents. This finding is discussed in more detail in relation to current policy in section 7.3 of this chapter.

7.2.7 The development of the use of PedsQL asthma and diabetes modules

This research has reported the measurement of the Quality of Life (QoL) of young people with asthma and diabetes with use of the PedsQL asthma and diabetes modules (Varni, 1998) as reported by young people themselves and through proxy reports by parent respondents. A search of the literature revealed no previously published measurement of the QoL of young people with asthma and diabetes in the UK. Section 7.2.7 will discuss the use of the PedsQL asthma and diabetes modules in relation to their psychometric properties and the findings of the PedsQL modules used in this study.

The PedsQL asthma and diabetes modules appeared acceptable to young people and parents with all one hundred and thirty-eight respondents completing the modules. Both young people and parents completed the modules with ease and within a short time frame, less than ten minutes. Young people were usually read the statements aloud by the researcher and proxy parent respondents self-completed the modules. Respondents did not appear fatigued by completion of the modules even through their

use came after the qualitative interview. Respondents identified little difficulties in comprehension of the language, other than three young people that completed the PedsQL asthma module and informed the researcher they did not understand the term 'side effects'. These findings indicate the acceptability of the modules for use in the UK sample in this research.

The validity of the PedsQL asthma module for use with this research sample was questionable due to the large amount of missing data. Missing data from the PedsQL asthma module completed by parent proxy respondents were 1.91% and by young people 6.06%. This compares with published findings of use of the module with an American sample which reported missing data from 1.5% of parent proxy respondents and 0.8% in the module completed by young people (Varni et al, 2004). Rates of missing data were particularly high in relation to questions regarding asthma attacks and young people's views of visiting hospital. In the qualitative interview it was revealed that few young people had experienced asthma attacks or visited hospital due to their asthma. Missing data might therefore have been due to the mild nature of asthma experienced by young people in this study and suggests that future use of the asthma PedsQL module should be restricted to young people with more severe asthma, who had experienced asthma attacks and visits to hospital due to their condition. In relation to missing data from the asthma PedsQL module used with young people, 60% of missing data were coded as 'not applicable'. This further indicated a lack of validity of the module for use with young people with asthma in this sample. Varni et al (2004) did not report from which statements missing data were found, nor the severity of asthma within the study sample. Although there were missing data from proxy parent respondents in the asthma PedsQL module, rates were much lower than in the modules completed by young people.

Within this research use of the PedsQL diabetes module appeared more valid within the study sample with lower rates of missing data compared to the asthma part of the study. The diabetes PedsQL in this study had 1.65% missing data from parent proxy

respondents and 1.51% from young people as respondents, this compared with published use of the modules in America which reported missing data as 3.6% for parent proxy respondents and 1.4% from young people as respondents (Varni et al, 2003). One particular statement had higher levels of missing data than others in both the young person and proxy parent responses, which concerned the wearing of an id bracelet. This suggests that within the sample many young people did not wear items indicating they had diabetes and this particular statement was not valid in the study sample. Varni et al (2003) did not indicate from which statements missing data were found.

Internal consistency of the PedsQL asthma and diabetes modules were considered through calculation of the Cronbach's alpha statistic. The author Varni (1998) used a Cronbach's alpha of ≥ 0.7 to indicate reliability of the module. This was used to compare the internal consistency of the modules used in this research with published use of the modules (Varni et al, 2004). The PedsQL asthma module completed by parent proxy respondents indicated good internal reliability for all sub-scales. Reliability of the young person data however was poorer with Cronbach's alpha of < 0.7 in one of the four sub-scales ('worry', 0.297). Use of the Cronbach's alpha statistic to assess reliability was also compromised with young person data due to the amount of missing data, however due to the exploratory nature of the work it was used to give an indication of reliability. Recent publication of use of the asthma PedsQL worded in English-American (Varni et al, 2004) reported the Cronbach's alpha statistic in young people and proxy parent PedsQL asthma modules. In line with the findings of this research, overall lower rates of reliability were identified in the young person module compared to good reliability in the parent proxy module. Varni et al (2004) noted poor reliability in the 'treatment' sub-scale (Cronbach's alpha of 0.58) in the young person self-report data. The research presented in this thesis found a low Cronbach's alpha in the sub-scale of 'worry' about treatments, but a reliability rating of 0.734 (Cronbach's alpha) in the 'treatment' sub-scale. Differences in the areas of poor reliability might be due to the different wording of

the scales in the American English and the English versions of the asthma PedsQL modules. Different methods of administration of the modules were also used, Varni et al (2004) administered some modules in the presence of the researcher and some were sent by mail to respondents. The recruitment of participants through different methods might also lead to differences in responses with Varni et al (2004) recruiting participants through State insurance programmes, asthma summer camps and medical centres. Variations in sample size from the work of Varni et al (2004) (n=529) as compared to this sample (n=86), might also account for such differences. Although Cronbach's alpha indicated poor reliability in some sub-scales in the young person module, the overall reliability of both the asthma and diabetes modules were good in both young person and proxy parent responses.

With use of the diabetes PedsQL in this thesis poor internal reliability (≤ 0.7) was indicated in one of the five sub-scales on the module completed by proxy parent respondents ('treatment barriers', 0.53) and in four of the five sub-scales on the module completed by young people (all sub-scales except 'communication'). These findings are comparable with published use of the modules (Varni et al, 2003) in an American sample which indicated poor reliability in one of the five sub-scales in the parent proxy module ('treatment barriers', 0.68) and three of the five sub-scales in the module completed by young people (all except 'diabetes symptoms' and 'communication'). Differences in the measure of internal consistency of the scale might be due to differences in sample sizes, in this research (n=52) compared to research of Varni et al (2003) (n=300), or different methods of recruitment of participants. Respondents were recruited in the research presented in this thesis through the use of random sampling, participants in Varni et al's (2003) research were identified from visits to a clinician.

The findings presented in this thesis have furthered the development of the PedsQL asthma and diabetes modules through additional findings related to the internal reliability of the scales. In relation to the asthma PedsQL module, findings have

shown poor internal reliability of the 'worry' sub-scale in the module completed by young people, compared with poor internal reliability in the 'treatment' sub-scale in the research of Varni et al (2004). In the diabetes PedsQL module, findings from both studies (the research presented in this thesis and Varni et al, 2003) indicated poor reliability of the 'treatment - barriers' sub-scale in the module completed by proxy parent respondents. The PedsQL diabetes module completed by young people, had poor internal consistency in all sub-scales apart from 'communication' and the research of Varni et al (2003) reported poor internal consistency in all sub-scales apart from 'diabetes symptoms' and 'communication'. The findings of the research presented in this thesis confirm those of Varni et al (2003) and Varni et al (2004), that use of the PedsQL asthma and diabetes modules should be treated with caution, until further testing of the reliability of the sub-scale measures has been conducted.

Differences in reliability rates in both the asthma and diabetes PedsQL modules between the responses of young people and those of proxy parent respondents also need to be addressed. Lower completion rates by young people and poorer reliability of the asthma and diabetes PedsQL modules might indicate difficulties with completion of the modules by young people. The administration of the modules in a larger sample would enable the reliability of modules to be assessed more fully, possibly with use of a technique such as factor analysis.

Within this sample the validity of the asthma PedsQL module was limited due to the amount of missing data, particularly from the young person module. Validity of the asthma PedsQL module might be improved by restricting its use to young people with more severe asthma. Further research would clarify whether missing data were due to lack of validity in this study rather than other issues, such as a lack of understanding of questions. The greater validity achieved with the diabetes PedsQL module is perhaps due to a more homogeneous population, the more definite nature and severity of the condition and narrower variation in symptoms, compared to asthma.

The exploratory nature of this work has identified issues of poor reliability in the asthma and diabetes PedsQL modules completed by young people in some sub-scales and poor validity of the asthma PedsQL in the sample with which this research was concerned. The research presented in this thesis has identified the acceptability of modules to young people (with both asthma and diabetes) and parents and the ease with which they were administered after a qualitative interview. Use of the PedsQL asthma and diabetes modules has enabled comparisons to be made between the views of proxy parent respondents and young people themselves regarding the young person's QoL, and enabled the measurement of the QoL of young people with asthma and diabetes in a UK sample. The PedsQL asthma and diabetes modules extend the scope for the measurement of QoL in young people, which has previously involved the measurement of the QoL of young people with asthma as reported by young people themselves (Guyatt et al, 1997), measurement of the QoL of parents of young people who have asthma (Juniper et al, 1996b) and comparisons between the QoL of young people with diabetes and healthy controls (Graue et al, 2003).

Findings of the use of the PedsQL asthma and diabetes modules identified different perceptions of the QoL of young people with asthma and diabetes by young people themselves as compared to the responses of proxy parent respondents. Comparisons of the mean scores from young person and parent proxy responses to each statement on the PedsQL asthma and diabetes modules were used to identify differences in young person and parent perceptions of the QoL of young people with asthma or diabetes. Findings identified statistically significant differences (with use of a Wilcoxon signed ranks test) between the mean scores of young people and those of parent proxy respondents. In the asthma PedsQL module proxy parent respondents tended to report statistically significant higher scores of the young person's QoL than that reported by young people. In the diabetes PedsQL parents reported statistically significant lower QoL scores than reported by young people. These statistically significant differences identified different perceptions of the QoL of a young person, as reported by the young person themselves or by a proxy parent respondent. In the

asthma part of the study parents tended to overestimate the young person's QoL and in the diabetes part of the study parents underestimated the young person's QoL. Such differences illustrate the importance of the involvement of young people themselves in the measurement of QoL and limitations on the reliance of parent proxy responses. Findings also question the value of the use of parent proxy respondents in the measurement of the QoL of a young person, particularly as QoL as a concept can only really be determined by the individual. Findings from the research presented in this thesis suggest that, within this study sample, in which all young people were able to complete modules themselves, reports from proxy parent respondents were of limited use in the measurement of a young person's QoL. Future use of the modules might be suitable in a non-clinical setting, for example by psychologists to compare parental perceptions of QoL with those of young people themselves. Differences in findings in the measurement of QoL between parents and young people, suggest possible implications in consultations with health care professionals. If parents views in the consultation are dominant, health care professionals might be presented with a perception of the condition which differs from the young person's own experience.

7.2.8 Differences in research findings between the two conditions

This thesis has examined partnerships between young people with two conditions, asthma and diabetes. Although the majority of findings were similar across both sections of the study, as shown in section 7.2, there were some differences between the two conditions. These are reported in section 7.2.8.

Responsibilities were shared between young people and their parents in both parts of the study, with similar patterns across the two conditions. For example, both parents of young people with asthma and of those with diabetes most often ensured continuous supplies of medication. However, partnerships between young people with diabetes and their parents were more intense and described in greater depth by

participants. This might be due to greater homogeneity amongst the diabetes sample and the predominantly mild nature of asthma suffered by young people in this research. Young people with asthma and their parents frequently reported few restrictions on their lives due to the young person's condition, the converse was true for parents and young people with diabetes. The management of diabetes was seen in this research to be an on-going partnership which encompassed not just the management of medication but the monitoring of food, exercise, blood glucose levels and participation in social activities. Partnerships in relation to the management of asthma were less in-depth, possibly also due to the fact that during exacerbations of asthma parents were sometimes not with the young person, particularly when asthma was induced by exercise.

Differences in parental needs for information were noted between the two conditions. Whilst many (58%) parents of young people with asthma identified issues about which they would like more information, fewer parents (30%) of young people with diabetes indicated such issues. This difference possibly reflects the more serious nature of diabetes and therefore more information parents had already sought about the condition.

Measurement of the QoL of young people with the two conditions was the area in which differences were most evident. Although disease specific measures were used it was evident from responses that diabetes had a greater impact on the QoL of young people, with more 'often' or 'almost always' answers given than by respondents with asthma. One section of questions, related to communication with health care professionals, were identically asked to young people with asthma and those with diabetes. Respondents with asthma indicated greater difficulty communicating with health care professionals, indicating it 'often' or 'almost always' to be a problem more frequently than young people with diabetes. The greatest difference was in relation to the young person finding it hard to tell doctors and nurses how they felt. Twenty-one percent of respondents with asthma indicated this to 'often' or 'almost

always' be a problem, compared to eight per-cent of young people with diabetes. Greater difficulty communicating with health care professionals for young people with asthma may be due to the limited contact several young people in this research had with health care professionals, in contrast to young people with diabetes who all regularly attended clinics.

7.3 Implications of research findings for health care professionals and the delivery of health care services

Section 7.3 examines the implications of the research findings presented in this thesis for the advice and support provided by health care professionals and the delivery of health care services.

7.3.1 Health care professionals understanding partnerships between young people and parents in the management of asthma or diabetes

The research presented in this thesis has provided health care professionals with a greater insight into the management of asthma and diabetes within the home, particularly the extent of the responsibility held by young people themselves. Such findings will assist health care professionals in working more closely with families, as advocated in the NSF for Children (Department of Health, 2004), and to direct information to young people as well as parents. This research also identified particular problems young people may experience, such as management of the condition at school or when parental relationships breakdown, and enables health care professionals to be more alert to young people's specific needs and factors which may affect condition management.

7.3.2 The need for health care professionals to engage young people in consultations

Despite the roles of young people in the management of their condition at home and at school, young people and their parents often reported a limited role of the young person in consultations with health care professionals. Few young people asked questions to health care professionals and several stated they preferred their parent to speak during the consultation than to talk themselves. This findings indicates a need for health care professionals to engage effectively with young people during the consultation and encourage them to speak directly to young people.

7.3.3 Health care professionals understanding the transfer of responsibility for asthma and diabetes from parents to young people

This research has shown the transfer of responsibility for asthma and diabetes to be an often unplanned process, with little relation to the age of the young person or number of years since diagnosis of the condition. Transfer of responsibility is often viewed by young people and parents as part of the growing up process and often assisted or hindered by social and practical factors, as shown in the model of transfer of responsibility (figure 7.2). An understanding of this model may enable health care professionals to comprehend the process of transfer and provide help and support accordingly, particularly when young people experience factors which may hinder the transfer of responsibility.

7.3.4 Health care professionals appropriately addressing the information needs of young people

The NSF for Children (Department of Health, 2004) has emphasised the importance of health care professionals providing information to young people and has suggested numerous ways in which this should be done. However the research presented in this

thesis reported that young people had little interest in obtaining further information about their asthma or diabetes. Only one young person (n=69) has used the internet to find out more about their condition and few had taken steps to seek more information. This finding has implications for health care professionals and the delivery of health care services in that there is little point in providing a greater amount of information if it is neither required nor of interest to young people. The NSF for Children (Department of Health, 2004) has also advocated the use of Pharmacists to provide information to young people about their condition. This research suggests limitations to this approach as few young people with asthma or diabetes visited the pharmacy, with parents most commonly collecting prescriptions.

7.3.5 Health care professionals providing support in relation to problems of young people whilst at school

Both young people with asthma and diabetes, and their parents, reported problems with the management of their condition whilst at school. In some instances there were concerns regarding proper management of the young person's condition when they were at school. Health care professionals are well placed to provide support and advice to young people in relation to the management of the condition at school. Health care professionals should also work in partnership with schools to ensure provision for and understanding of chronic conditions amongst school staff.

7.3.6 Current policy in light of the findings of this thesis

Section 7.3.6 examines the findings of this thesis in light of current Government policy. The findings of this thesis indicate that health care professionals need to involve young people more in consultations and encourage them to express their views and ask questions. Previous documents such as 'Bridging the gaps: health care for adolescents' (Royal College of Paediatrics and Child Health, 2003) and 'listening hearing and responding' (Department of Health, 2002) have outlined ways for health

care professionals to improve communication with young people. However this research suggests young people remain passive in consultations with parents taking a more dominant role. Encouraging young people to attend consultations, or part of a consultation, without a parent present (as advocated in 'Bridging the gaps: health care for adolescents', Royal College of Paediatrics and Child Health, 2003) may assist in improving communication between young people and health care professionals. It is also possible that a radically different approach is needed towards consultations with young people, such as the use of games or health education in a group environment.

The views of young people and parents reported in this research establish the need for better support for young people with asthma and diabetes in schools. At present Government policy in relation to medication in school is directed by the Department of Education, with the NSF for Children (Department of Health, 2004) only concerned with health promotion in schools. The results of this thesis indicates a joint approach is needed between the Department of Health and the Department of Education to fully address the issues of condition management for young people whilst at school. It is possible that health care professionals could work together with school staff to ensure the safe management of chronic conditions.

As already outlined in this section (section 7.3.4) this thesis suggests recommendations in the NSF for Children (Department of Health, 2004) in relation to the provision of more information for young people may not be required or used by young people. The findings of this thesis also suggest that the provision of copies of medical records to young people, advocated in the NSF for Children (Department of Health, 2004) may also be of little interest to young people.

7.4 Contribution to knowledge of the research presented in this thesis

Section 7.4 summarises the contribution to knowledge of the research presented in this thesis:

- Contribution to the methodology of interviewing young people and the successful involvement of young people (aged 8 to 15 years) in research
- Identification of the considerable role of young people in the management of asthma or diabetes within the home, which does not appear to be reflected in their involvement in consultations with health care professionals
- Young people and parents taking shared responsibility for condition management, with little conflict in partnerships
- The transfer of responsibility for the management of asthma and diabetes most frequently occurs without prior planning and as part of 'growing up'. However, it was possible to establish factors which may assist or hinder the transfer of responsibility, as shown in the model of factors influencing transfer of responsibility for asthma or diabetes from parent to the young person (figure 7.2)
- The nature of partnerships, and roles performed by young people and their parents, did not appear to be related to either the age of the young person nor the number of years since diagnosis of the condition
- This research suggests that young people who live in more than one family unit may experience particular difficulties in the management of asthma and diabetes
- Young people showed little interest in receiving information about their condition, this has implications for future health care provision
- The age of a young person, or number of years since diagnosis of the condition did not appear related to roles within partnerships

- Despite differences in the nature of asthma and diabetes, there were parallels between the experiences of young people with each condition, such findings suggest there may be implication of the findings of this thesis for young people with other chronic conditions
- Measurement of the quality of life of young people with asthma and diabetes with use of the PedsQL asthma and diabetes modules is workable
- Parents reports of the QoL of the young person may differ from those reported by the young person themself

This thesis has described the nature of partnerships between young people and their parents in the management of asthma and diabetes. It has highlighted the challenges that face young people with asthma and diabetes, and their parents, and provides health care professionals with an insight into the daily experience for young people managing a chronic condition. A greater understanding of partnerships between young people and parents should better enable health care professionals to provide help and advice to young people and their parents.

References

References

Ackard, D.M. and Neumark-Sztainer, D. (2001) Health care information sources for adolescents: age and gender differences on use, concerns and needs. *Journal of Adolescent Health*, 29, pp.170-176.

Alderson, P. (2000) Children as researchers the effects of participation rights on research methodology. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.241-257.

American Diabetes Association (2004) Diabetes care in the school and day care setting. *Diabetes Care*, 27, pp.s122-s128.

Anderson, B.J., Auslander, W.F., Jung, J., Miller, P. and Santiago, J.V. (1990) Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology*, 15, 4, pp.477-492.

Aronson, K. and Rudström, B. (1988) Child discourse and parental control in paediatric consultations. *Text*, 8, pp.159-184.

Atkin, K. and Ahmad, W.I.U. (2000) Pumping iron: compliance with chelation therapy among young people who have thalassaemia major. *Sociology of Health and Illness*, 22, 4, pp.500-524.

Audit Commission (2000) *Testing times a review of diabetes services in England and Wales*. London, Audit Commission.

Aynsley-Green, A. (2000) Who is speaking for children and adolescents and for their health at policy level? *BMJ*, 321, pp.229-232.

References

- Aynsley-Green, A. (2004) Is all well with children and childhood and the health-related services provided for them in contemporary society?: Exploiting the opportunities for change. *Current Paediatrics*, 14, pp.237-245.
- Azar, R. and Solomon, C. R. (2001) Coping strategies of parents facing child diabetes mellitus. *Journal of Pediatric Nursing*, 16, 6, pp.418-427.
- Banks, E. (1990) Concepts of health and sickness of pre-school and school-aged children. *CHC*, 19, pp.43-48.
- Bannon, M.J. and Ross, E.M. (1998) Administration of medicines in school: who is responsible? *BMJ*, 316, pp.1591-1593.
- Barrett, T.G. and Booth, I.W. (1994) Sartorial eloquence: does it exist in the paediatrician-patient relationship? *BMJ*, 309, pp.1710-1712.
- Baumer, J.J., Hunt, L.P. and Shield, J.P.H. (1998) Social disadvantage, family composition, and diabetes mellitus: prevalence and outcome. *Archives of Disease in Childhood*, 79, pp.427-430.
- Basagaña, X., Sunyer, J., Kogevinas, M., Zock, J-P., Duran-Tauleria, E., Jarvis, D., Burney, P. and Anto, J.A. (2004) Socioeconomic status and asthma prevalence in young adults. *American Journal of Epidemiology*, 160, 2, pp.178-188.
- Beresford, B.A. and Sloper, P. (2003) Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *Journal of Adolescent Health*, 33, pp.172-179.
- Bowling, A. (1995) *Measuring disease*. 4th edition. Buckingham, Open University Press.

References

British Thoracic Society, National Asthma Campaign, the Royal College of Physicians of London, the General Practitioner in Asthma Group, British Association of Accident and Emergency Medicine, British Paediatric Respiratory Society and Royal College of Paediatrics and Child Health (1997) British Guidelines on Asthma Management: 1995 review and position statement. *Thorax*, 52, pp.s1-s21.

Bryman, A. and Cramer, D. (1997) *Quantitative data analysis with SPSS for windows*. London, Routledge.

Burford, T.A. (2004) Transfer of asthma management responsibility from parents to their school-age children. *Journal of Pediatric Nursing*, 19, 1, pp.3-12.

Callery, P., Milnes, L., Verduyn, C. and Couriel, J. (2003) Qualitative study of young people's and parents' beliefs about childhood asthma. *British Journal of General Practice*, 53, pp.185-190.

Chadwick, S. (1996) The impact of asthma in an inner city general practice. *Child: Care, health and development*, 22, 3, pp.175-186.

Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, pp.168-195.

Christensen, P. and James, A. (2000) Childhood diversity and commonality. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.160-178.

Connolly, M.A. and Johnson, J.A. (1999) Measuring quality of life in paediatric patients. *Pharmacoeconomics*, 16, 6, pp.605-625.

Corsaro, W.A. (1997) *The sociology of childhood*. London, Pine Forge Press.

References

Coutts, J.A., Gibson, N.A. and Paton, J.Y. (1992) Measuring compliance with inhaled medication in asthma. *Archives of Disease in Childhood*, 67, pp.332-333.

Davis, J., Watson, N. and Cunningham-Burley, S. (2000) Learning the lives of disabled children: developing a reflexive approach. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.201-224.

Department of Education and Employment (1996) *Supporting pupils with medical needs: a good practice guide*. London, DfEE Publications.

Department of Education and Employment (1999) *National Healthy School Standard: Guidance*. Nottingham, DfEE Publications.

Department of Health (2001) *National Service Framework for diabetes: Standards*. London, Department of Health.

Department of Health (2001) *The Expert Patient: A new approach to chronic disease management for the 21st century*. London, Department of Health.

Department of Health (2002) *Listening, hearing and responding, Department of Health action plan: core principles for the involvement of children and young people*. London, Department of Health.

Department of Health (2002) *National Service Framework for diabetes: Delivery Strategy*. London, Department of Health.

Department of Health (2004) *Getting the right start - the National Service Framework for children, young people and maternity services*. London, Department of Health.

References

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: Key issues for primary care*. London, Department of Health.

Department for Education and Skills (2003) *Every Child Matters*. London, The Stationery Office.

Department for Education and Skills (2004) *Every Child Matters: the next steps 2004*. London, The Stationery Office.

Department of Work and Pensions (2004) *Financial expenditure survey* [online] Available from: < www.dwp.gov.uk/asd/frs > [accessed 2nd February 2004].

Diabetes Control and Complications Trial (DCCT) research group (1988) Reliability and validity of a diabetes quality of life measure for the diabetes control and complications trial (DCCT). *Diabetes Care*, 11, pp.725-732.

Diabetes UK (2002) *The National Paediatric Diabetes Audit, results from the audit year 2002*. London, Diabetes UK.

Diabetes UK website [online] Available from : <www.diabetes.org> [accessed 12th July 2002].

Dixon-Woods, M., Young, B. and Heney, D. (1999) Partnerships with children *BMJ*, 319, pp.778-780.

Eiser, C., Havermans, T., Kirby, R., Eiser, J.R. and Pancer, M. (1993) Coping and confidence among parents of children with diabetes. *Disability and Rehabilitation*, 15, 1, pp.10-18.

References

- Eiser, C. and Morse, R. (2001) A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood*, 84, pp.205-211.
- Elliott, H. (1997) The use of diaries in sociological research on health experience. *Sociological Research Online* [online] Available from:
<<http://www.socresonline.org.uk/5/2/harden.html>> [accessed 18th February 2000].
- Fillmore, E.J., Jones, N. and Blankson, J.M. (1997) Achieving treatment goals for schoolchildren with asthma. *Archives of Disease in Childhood*, 77, pp.420-422.
- Flesch, R. (1997) *How to write plain English* [online] Available from:
<<http://www.mang.canterbury.ac.nz/courseinfo/AcademicWriting/Flesch.htm>>
[accessed 23rd November 2004].
- Francis, S-A. (2001) Measurements of health and illness. In: Taylor, K. and Harding, G. (Eds) *Pharmacy Practice*. London, Taylor and Francis, pp.411-431.
- Gabe, J., Bury, M. and Ramsay, R. (2002) Living with asthma: the experiences of young people at home and at school. *Social Science and Medicine*, 55, pp.1619-1633.
- Ganong, L., Doty, M.E. and Gayer, D. (2003) Mothers in postdivorce families caring for a child with cystic fibrosis. *Journal of Pediatric Nursing*, 18, 5, pp.332-343.
- Graue, M., Wentzel-Larsen, T., Hanestad, B.R., Båtsvik, B. and Søvik, O. (2003) Measuring self-reported, health related, quality of life in adolescents with type 1 diabetes using both generic and disease-specific instruments. *Acta Paediatrica*, 92, pp.1190-1196.

References

Gray, N.J., Klein, J.D., Noyce, P.R., Sesselberg, T.S. and Cantrill, J.A. (2005) Health information seeking behaviour in adolescence: the place of the internet. *Social Science and Medicine*, 60, pp.1467-1478.

Greenberger, E., Josselson, R., Knerr, C. and Knerr, B. (1974) The measurement and structure of psychosocial maturity. *Journal of Youth and Adolescence*, 4, pp.127-143.

Grossman, H.Y., Brink, S. and Hauser, S.T. (1987) Self efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care*, 10, pp.324-329.

Guyatt, G.H., Juniper, E.F., Griffith, L.E., Feeny, D.H. and Ferrie, P.J. (1997) Children and adult perceptions of childhood asthma. *Paediatrics*, 99, 2, pp.165-168.

Hanna, K.M. and Guthrie, D.W. (2003) Parental involvement in adolescents' diabetes management. *Diabetes Spectrum*, 16, 3, pp.184-187.

Harden, J., Backett-Milburn, K., Scott, S. and Jackson, S. (2000a) Scary faces, scary places: children's perceptions of risk and safety. *Health Education Journal*, 59, pp.12-22.

Harden, J., Backett-Milburn, K., Scott, S. and Jackson, S. (2000b) Can't talk, won't talk?: Methodological issues in researching children. *Sociological Research Online* [online] 5, 2 Available from <<http://www.socresonline.org.uk/5/2/harden.html>> [accessed 12th February 2001].

Hart, C. and Chesson, R. (1998) Children as consumers. *BMJ*, 316, pp.1600-1603.

Hood, S., Kelley, P. and Mayall, B. (1996) Children as research subjects: A risky enterprise. *Children and Society*, 10, 2, pp.117-129.

References

House of Commons Health Committee (1997) *The specific health needs of children and young people*. London, Stationery Office.

Ingersoll, G.M. and Marrero, D.G. (1991) A modified quality-of-life measure for youths: Psychometric properties. *Diabetes Educator*, 17, pp.114-118.

Jacobson, L.D., Mellanby, A.R., Donovan, C., Taylor, B., Tripp, J.H. and members of the adolescent working group, RCGP (2000) Teenagers' views on general practice consultations and other medical advice. *Family Practice*, 17, pp.156-158.

James, A., Jenks, C. and Prout, A. (1998) *Theorizing childhood*. Cambridge, Polity Press.

Jarman, B. (1983) Identification of underprivileged areas. *BMJ*, 286, pp.1705-1709.

Jenney, M.E.M. and Campbell, S. (1997) Measuring quality of life. *Archives of Disease in Childhood*, 77, pp.347-354.

Jonasson, G., Carlsen, K.H., Sodal, A., Jonasson, C. and Mowinckel, P. (1999) Patient compliance in a clinical trial with inhaled budesonide in children with mild asthma. *European Respiratory Journal*, 14, pp.150-154.

Jones, J.M., Lawson, M.L., Daneman, D., Olmsted, M.P. and Rodin, G. (2000) Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study. *BMJ*, 320, pp.1563-1566.

Jones, A., Pill, R. and Adams, S. (2000) Qualitative study of views of health professionals and patients on guided self management plans for asthma. *BMJ*, 321, pp.1507-1510.

References

- Joyce, C.R.B., Hickey, A., McGee, H.M. and O'Boyle, C.A. (2003) A theory-based method for the evaluation of individual quality of life; The SEIQoL. *Quality Life Research*, 12, pp.275-280.
- Juniper, E.F. (1997) How important is quality of life in pediatric asthma? *Pediatric Pulmonology*, 15, pp.s17-s21.
- Juniper, E.F., Guyatt, G.H., Fenny, D.H., Ferrie, P.J., Griffith, L.E. and Townsend, M. (1996a) Measuring quality of life in children with asthma. *Quality of Life Research*, 5, pp.35-46.
- Juniper, E.F., Guyatt, G.H., Fenny, D.H., Ferrie, P.J., Griffith, L.E. and Townsend, M. (1996b) Measuring quality of life in the parents of children with asthma. *Quality of Life Research*, 5, pp.27-33.
- Juniper, E.F., Guyatt, G.H., Willan, A. and Griffith, L.E. (1994) Determining a minimal important change in a disease-specific quality of life instrument. *Journal of Clinical Epidemiology*, 47, pp.81-87.
- Jutrus, S., Morin, P., Proulx, R., Vinay, M.C., Roy, E. and Routhier, L. (2003) Conception of wellness in families with a diabetic child. *Journal of Health Psychology*, 8, 5, pp.573-586.
- Kai, J. (1996) Parents' difficulties and information needs in coping with acute illness in preschool children: a qualitative study. *BMJ*, 313, pp.987-990.
- Kapphahn, C.J., Wilson, K.M. and Klein, J.D. (1999) Adolescent girls' and boys' preferences for provider gender and confidentiality in their health care. *Journal of Adolescent Health*, 25, pp.131-142.

References

- Keats, D.M. (2000) *Interviewing a practical guide for students and professionals*. Buckingham, Open University Press.
- Kline, P. (1994) *An easy guide to factor analysis*. 2nd edition. London, Routledge.
- Koch, T., Karlik, D. and Taylor, J. (2000) Men living with diabetes: minimizing the intrusiveness of the disease. *Journal of Clinical Nursing*, 9, pp.247-254.
- Kristensson-Hallström, I. and Nilstun, T. (1997) The parent between the child and the professional - some ethical implications. *Child: Care, health and development*, 23, 6, pp.447-455.
- Kyngäs, H. (2000) Compliance of adolescents with chronic disease. *Journal of Clinical Nursing*, 9, pp.549-556.
- Kyngäs, H. (2004) Support network of adolescents with chronic disease: Adolescents' perspective. *Nursing and Health Sciences*, 6, pp.287-293.
- McCabe, M.A. (1996) Involving children and adolescents in medical decision making: developmental and clinical considerations. *Journal of Pediatric Psychology*, 21, 4, pp.505-516.
- McCubbin, H.I., McCubbin, M.A., Patterson, J.M., Cauble, A.E., Wilson, L.R. and Warwick, W. (1983) CHIP - Coping Health Inventory for Parents: an assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and the Family*, 45, pp.359-376.
- Macdonald, K. and Tipton, C. (1993) Using documents. In: Gilbert, N. (Ed) *Researching social life*. London, Sage publications, pp.187-200.

References

- McIntosh, N. (2004) Ethical principles of research with children. *Current Paediatrics*, 14, pp.489-494.
- Malchiodi, C.A. (1998) *Understanding children's drawings*. New York, The Guildford Press.
- Mason, J. (1996) *Qualitative Researching*. 3rd edition. London, Sage publications.
- Mayall, B. (2000) Conversations with children: Working with generational issues. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.120-135.
- Milnes, L.J. and Callery, P. (2003) The adaptation of written self-management plans for children with asthma. *Journal of Advanced Nursing*, 41, 4, pp.444-453.
- Morris, A.D., Boyle, D.I.R., McMahon, A.D., Greene, S.A., MacDonald, T.M., Newton, R.W. and the DARTS/MEMO collaboration (1997) Adherence to insulin treatment, glycaemic control, and ketoacidosis in insulin-dependent diabetes mellitus. *The Lancet*, 320, pp.1505-1510.
- National Asthma Campaign Asthma Audit (2001) Out in the open - A true picture of asthma in the United Kingdom today. *The Asthma Journal*, 6, 3, pp.s1-s14.
- National Asthma Campaign website [online] Available from: <www.asthma.org> [accessed 12th July 2002].
- National Digital Archive of Datasets (1996) *Data for health authorities (Boundaries at April 1996) Underprivileged area scores (Jarman scores)*. [online] Available from: <<http://ndad.ulcc.ac.uk/CRDA/24/DS/1996/4/3/display.html>> [accessed 19th January 2005].

References

National Institute for Clinical Excellence (NICE) (2004) *Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults - NICE Guidelines*. London, NICE.

Oakley, A., Benedelow, G., Barnes, J., Buchanan, M. and Nasseem Husain, O.A. (1995) Health and cancer prevention: Knowledge and beliefs of children and young people. *BMJ*, 310, pp.1029-1033.

O’Kane, C. (2000) Development of participatory techniques. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.136-159.

Østergaard, M.S. (1998) Childhood asthma: a parents’ perspective - a qualitative interview study. *Family Practice*, 15, 2, pp.153-157.

Palmer, D.L., Berg, C.A., Wiebe, D.J., Beveridge, R.M., Korbel, C.D., Upchurch, R., Swinyard, M.T., Lindsay, R. and Donaldson, D.L. (2004) The role of autonomy and pubertal status in understanding age differences in maternal involvement in diabetes responsibility across adolescence. *Journal of Pediatric Psychology*, 29, 1, pp.35-46.

Parish, L. (1986) Communicating with hospitalized children. *Canadian Nurse*, 82, pp.21-24.

Peterson-Sweeney, K., McMullen, A., Yoos, L. and Kitzman, H. (2003) Parental perceptions of their child’s asthma: Management and medication use. *Journal of Pediatric Health Care*, 17, pp.118-125.

Pradel, F.G., Hartzema, A.G. and Bush, P.J. (2001) Asthma self-management: the perspective of children. *Patient Education and Counseling*, 45, pp.199-209.

References

- Pridmore, P.J. and Lansdown, R.G. (1997) Exploring children's perceptions of health: does drawing really break down barriers? *Health Education Journal*, 56, pp.219-230.
- Prout, A., Hayes, L. and Gelder, L. (1999) Medicines and the management of ordinariness in the household management of childhood asthma. *Sociology of Health and Illness*, 21, 2, pp.137-162.
- Pugh, E., Mansfield, K., Clague, H. and Mattinson, P. (1995) Children with asthma in schools: an opportunity for 'healthy alliances' between health and education authorities. *Health Trends*, 27, 4, pp.127-129.
- Rajaram, S.S. (1997) Experience of hypoglycemia among insulin dependent diabetics and its impact on the family. *Sociology of Health and Illness*, 19, 3, pp. 281-296.
- Rajmil, L., Herdman, M., Fernandez De Sanmamed, M-J., Detmar, S., Bruil, J., Ravens-Sieberer, U., Bullinger, M., Simeoni, M-C., Auquier, P. and the Kidscreen group (2004) Generic Health-Related Quality of Life instruments in children and adolescents: A qualitative analysis of content. *Journal of Adolescent Health*, 34, pp.37-45.
- Räty, L.K.A., Larsson, B.M.W. and Söderfeldt, B.A. (2003) Health-Related Quality of Life in comparison between adolescents and young adults with uncomplicated epilepsy and health controls. *Journal of Adolescent Health*, 33, pp.252-258.
- Rich, M., Lamola, S., Amory, S. and Schneider, L. (2000) Asthma in life context: Video intervention/prevention assessment. *Paediatrics*, 105, 1, pp.469-77.
- Roberts, H. (2000) Listening to children: and hearing them. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.225-240.

References

Robson, C. (1993) *Real world research*. Oxford, Blackwell Publishers.

Royal College of General Practitioners and the Royal College of Nursing (2002) *Getting it right for teenagers in your practice*. London, Royal College of General Practitioners.

Royal College of Paediatrics and Child Health (2003) *Bridging the gaps: Health care for adolescents*. London, Royal College of Paediatrics and Child Health.

Rydström, I., Dalheim-Englund, A-C., Segesten, K. and Rasmussen, B.H. (2004) Relations governed by uncertainty: Part of life of families of a child with asthma. *Journal of Pediatric Nursing*, 19, 2, pp.85-94.

Sanz, E.J. (2003) Concordance and children's use of medicines. *BMJ*, 327, pp.858-860.

Scott, J. (2000) Children as respondents: the challenge for quantitative methods. In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.98-119.

Smith, F. (2002) *Research Methods in Pharmacy Practice*. London, Pharmaceutical Press.

Starke, M. and Möller, A. (2002) Parents' needs for medical knowledge concerning the medical diagnosis of their child. *Journal of Child Health Care*, 6, 4, pp.245-257.

Stone, A.A., Shiffman, S., Schwartz, J.E., Broderick, J.E. and Hufford, M.R. (2004) Patient non-compliance with paper diaries. *BMJ*, 324, pp.1193-1194.

Strauss, A. and Corbin, S. (1990) *Basics of qualitative research. Grounded theory procedures and techniques*. California, SAGE publications.

References

- Tates, K., Elbers, E., Meeuwesen, L. and Bensing, J. (2002) Doctor-parent-child relationships: a 'pas de trios'. *Patient Education and Counseling*, 48, pp.5-14.
- Tuffrey, C. and Finlay, F. (2002) Use of the internet by parents of paediatric outpatients. *Achieves of Disease in Childhood*, 87, pp.534-536.
- Varni, J.W. (1998) PedsQL asthma and diabetes modules. San Diego, J.W. Varni.
- Varni, J.W. and Burwinkle, T.M. (2004) The PedsQL™ disease and condition specific modules: An update and status report. *Quality of Life Newsletter*, 33, pp.3-5.
- Varni, J.W., Burwinkle, T.M., Jacobs, J.R., Gottschalk, M., Kaufman, F. and Jones, K.L. (2003) The PedsQL™ in type 1 and type 2 diabetes - reliability and validity of the Pediatric Quality of Life Inventory™ Generic Core Scales and Type 1 Diabetes Module. *Diabetes Care*, 26, 3, pp.631-637.
- Varni, J.W., Burwinkle, T.M., Rapoff, M.A., Kamps, J.L. and Olson, N. (2004) The PedsQL™ in paediatric asthma: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales and Asthma Module. *Journal of Behavioral Medicine*, 27, 3, pp.297-318.
- Varni, J.W., Katz, E.R., Seid, M., Quiggins, D.J.L. and Friedman-Bender, A. (1998) The Pediatric Cancer Quality of Life Inventory-32 (PCQL-32): Reliability and validity. *Cancer*, 82, pp.1184-1196.
- Varni, J.W., Seid, M. and Kurtin, P.S. (2001) The PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ version 4.0 Generic Core Scales in healthy and patient populations. *Medical Care*, 39, pp.800-812.

References

Varni, J.W., Wilcox, K.T., Hanson, V. and Brik, R. (1988) Chronic musculoskeletal pain functional status in juvenile rheumatoid arthritis: An empirical model. *Pain*, 32, pp.1-7.

Wagner, J.A., Abbott, G. and Lett, S. (2004) Age related differences in individual quality of life domains in youth with type 1 diabetes. *Health and Quality of Life Outcomes*, 2, 59, pp.54-62.

Waksler, F.C. (1991) Dancing when the music is over. In: Waksler, F.C. (Ed) *Studying the social worlds of children: sociological readings*. London, The Falmer Press.

Wassmer, E., Minnaar, G., Abdek Aal, N., Atkinson, M., Gupta, E., Yuen, S. and Rylance, G. (2004) How do paediatricians communicate with children and parents? *Acta Paediatrica*, 93, pp.1501-1506.

Watson, M. (1998) Supporting pupils with diabetes. *Health Education*, 4, pp.148-153.

Williams, C. (2000a) Doing health, doing gender: teenagers, diabetes and asthma. *Social Science and Medicine*, 50, pp.387-396.

Williams, C. (2000b) Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health and Illness*, 22, 2, pp.254-272.

Willis, C.J., Scott, A., Swift, P.G.F., Davies, M.J., Mackie, D.R. and Manseell, P. (2003) Retrospective review of care and outcomes in young adults with type 1 diabetes. *BMJ*, 327, pp.260-261.

Wong, I.C.K., Awolowo, T., Gordon, K. and Mo, Y.W. (2004) Survey of administration of medicines to pupils in primary schools within the London area. *Archives of Disease in Childhood*, 89, pp.998-1001.

References

Woodhead, M. and Faulkner, D. (2000) Subjects, objects or participants? In: Christensen, P. and James, A. (Eds) *Research with children, perspectives and practices*. London, Falmer Press, pp.9-35.

World Health Organisation (1947) *Constitution of the World Health Organization*. Geneva, WHO.

Zoritch, B., Eiser, C., Hiller, E.J. and Taylor, C. (1996) Cystic fibrosis and school: the teachers' viewpoint. *Ambulatory Child Health*, 1, pp.302-310.

Appendices

**Appendix A - Letter sent to the National Asthma Campaign and
British Lung Foundation requesting details of support groups**

THE SCHOOL OF PHARMACY

UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifer.newbould@ulsop.ac.uk

22 September 2000

Dear Sir/Madam

Re: Research project concerning children with asthma and their parents

I am a PhD student at the School of Pharmacy, University of London. My PhD is looking at children with asthma, how they manage their condition and medication with their parents, and how they feel about current service provision for young people with asthma. I am also looking at how services for young people with asthma, and their parents, could be improved in the future.

I was wondering if you would be able to give me the contact details of the leaders of any local asthma voluntary support groups that I may be able to contact to talk to about their experiences? Any group near to London where I work (address above) or near to where I live (Hitchin, Hertfordshire) would be suitable.

Please do not hesitate to contact me if you need any further information. Thank you in advance for your assistance in this matter.

Yours faithfully

Jenny Newbould (Miss)
PhD research student

Appendix B - Letter sent to asthma support groups requesting their involvement in the preliminary work

THE SCHOOL OF PHARMACY

UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifer.newbould@ulsop.ac.uk

DATE

Dear (insert name),

I hope you will not mind me contacting you by letter. I was given your contact details by (name of contact) at (name of organisation), and I understand you run the group (insert name of support group).

I am a PhD student at the School of Pharmacy, University of London. My PhD is investigating the experiences of young people with asthma and their parents. I wish to look at how young people and their parents manage the condition, medication for asthma and how they feel about the current services available to them. I am also looking at how services for young people with asthma and their parents could be improved in the future. At this stage of the research I am interested in finding out more about the issues that are of importance to young people with asthma and their parents and I wondered if it would be possible to come to one of your meetings and talk to people about their views and experiences?

If you think this would be possible and would like to discuss it further, or if you have any questions, then please contact me on the phone number above.

I look forward to hearing from you.

Yours sincerely

Jenny Newbould (Miss)
PhD research student

Appendix C - Letter sent to Diabetes UK requesting details of support groups

THE SCHOOL OF PHARMACY

UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifer.newbould@ulsop.ac.uk

14th June 2000

Dear Sir/Madam

Re: Research project concerning children with diabetes and their parents

I am a PhD student at the School of Pharmacy, University of London. My PhD is looking at children with diabetes, how they manage their condition and medication with their parents, and how they feel about current service provision for young people with diabetes. I am also looking at how services for young people with diabetes, and their parents, could be improved in the future.

I was wondering if you would be able to give me the contact details of the leaders of any local diabetes voluntary support groups that I may be able to contact to talk to about their experiences? Any group near to London where I work (address above) or near to where I live (Hitchin, Hertfordshire) would be suitable.

Please do not hesitate to contact me if you need any further information. Thank you in advance for your assistance in this matter.

Yours faithfully

Jenny Newbould (Miss)
PhD research student

**Appendix D - Letter sent to diabetes support groups requesting their involvement
in the preliminary work**

THE SCHOOL OF PHARMACY

UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifer.newbould@ulsop.ac.uk

DATE

Dear (insert name),

I hope you will not mind me contacting you by letter. I was given your contact details by Chris James at Diabetes UK, and I understand you run the group (insert name of support group).

I am a PhD student at the School of Pharmacy, University of London. My PhD is investigating the experiences of young people with diabetes and their parents. I wish to look at how young people and their parents manage the condition, medication for diabetes and how they feel about the current services available to them. I am also looking at how services for young people with diabetes and their parents could be improved in the future. At this stage of the research I am interested in finding out more about the issues that are of importance to young people with diabetes and their parents and I wondered if it would be possible to come to one of your meetings and talk to people about their views and experiences?

If you think this would be possible and would like to discuss it further, or if you have any questions, then please contact me on the phone number above.

I look forward to hearing from you.

Yours sincerely

Jenny Newbould (Miss)
PhD research student

Appendix E - Consent form for parents of young people with asthma

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH ASTHMA: THE VIEWS OF
YOUNG PEOPLE AND THEIR PARENTS

Participant number: _____

CONSENT FORM FOR PARENTS/GUARDIANS OF YOUNG PEOPLE

Please initial box

1.	I confirm that I have read and understood the information sheets for parents/guardians and the information sheet for young people for the above study, and have had the opportunity to ask questions.	
2.	I understand that my child will be invited to take part in the above study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care, pharmacy services or legal rights being affected.	
4.	I understand that a request to record the interview will be made. I understand that some things I say may be used to illustrate the results of the study but that I will not be identified.	
5.	I agree to take part in the above study.	

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

Appendix F - Consent form for young people with asthma

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH ASTHMA: THE VIEWS OF
YOUNG PEOPLE AND THEIR PARENTS

Participant number _____

CONSENT FORM FOR YOUNG PEOPLE

Please tick box

1.	I have read and understood the information sheet for the above study and have been able to ask questions.	
2.	I understand that I can choose if I take part in the study or not and that I can stop at anytime without having to give a reason.	
3.	I understand that I will be asked if the interview can be tape recorded.	
4.	I understand that no one other than the research team will know what I have said during the interview, and that I will not be recognised in any of the data.	
5.	I agree to take part in the study.	

Name of participant Date Age Signature

Name of person taking consent Date Signature

Appendix G - Consent form for parents of young people with diabetes

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH DIABETES: THE VIEWS OF
YOUNG PEOPLE AND THEIR PARENTS

Participant number: _____

CONSENT FORM FOR PARENTS/GUARDIANS OF YOUNG PEOPLE

Please initial box

1.	I confirm that I have read and understood the information sheets for parents/guardians and the information sheet for young people for the above study, and have had the opportunity to ask questions.	
2.	I understand that my child will be invited to take part in the above study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care, pharmacy services or legal rights being affected.	
4.	I understand that a request to record the interview will be made. I understand that some things I say may be used to illustrate the results of the study but that I will not be identified.	
5.	I agree to take part in the above study.	

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

Appendix H - Consent form for young people with diabetes

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH DIABETES: THE VIEWS
OF YOUNG PEOPLE AND THEIR PARENTS

Participant number _____

CONSENT FORM FOR YOUNG PEOPLE

Please tick box

1.	I have read and understood the information sheet for the above study and have been able to ask questions.	
2.	I understand that I can choose if I take part in the study or not and that I can stop at anytime without having to give a reason.	
3.	I understand that I will be asked if the interview can be tape recorded.	
4.	I understand that no one other than the research team will know what I have said during the interview, and that I will not be recognised in any of the data.	
5.	I agree to take part in the study.	

Name of participant Date Age Signature

Name of person taking consent Date Signature

Appendix I - Interview schedule for use with parents of young people with asthma

INTERVIEW WITH PARENT/GUARDIAN OF YOUNG PERSON WITH ASTHMA

Participant no: _____

Date: _____

Before we start the interview, I'll just remind you briefly what the study is about.

We are interested in finding out more about the use of medication by young people with asthma and their views of the health services that are available to them. We appreciate that in the case of young people, the role of parent/guardians in managing the condition and medication may well be important. This is why it is important to get your views and opinions in this interview.

Ensure respondent has read BOTH information leaflets.

Ensure consent form is completed.

Obtain consent to audio-record interview.

Prompts are in italics

Appendices

1. Could I see all the medicines that takes for his/her asthma?

List medicines and dosage

Drug name	Form	Dose	Frequency

Prompts: reliever?

preventer?

other medicines?

spacer device?

2. When was (name of child) first diagnosed with asthma?

3. How old was he/she then?

4. Can you tell me about when was first diagnosed with asthma?

What were your initial thoughts/ feelings?

5. Do you notice any changes at different times of the year with 's asthma?

Any changes in medication he/she takes?

6. Has ever been in hospital due to his/her asthma?

If yes: When was that?

Can you tell me what happened?

What was it like in the hospital?

7. Has ... ever had an asthma attack?

If yes: When was that?

Can you tell me what happened?

8. Are there any particular triggers of 's asthma?

Food?

Activities?

Appendices

9. Would you say you are the main carer of?

If not, who is?

10. Thinking back, could you describe to me any help you have given with their medication or condition in the past week?

I want to ask you now about the particular ways in which you may help your son/daughter to manage their condition and medication. Some things you may do and others you might not.

11. Do you order, collect or take’s prescriptions to the pharmacy?

If no: who does?

How do you know medication is running out?

Do you have the medication on repeat prescription?

12. Do you ever remind to take their medication?

If yes: Are their specific times when you do this?

Does this ever cause problems?

13. Do you ever assist in taking his/her medication?

If yes: In what ways do you assist?

Does this ever cause problems?

Does the assistance you give them ever vary?

14. Do you help by deciding how much medicine he/she should take and how often?

If yes: Are their specific times when you do this?

Does this ever cause problems?

15. Are there any other problems that you have, or have had in the past, with.....’s medication?

16. Can you describe to me any worries or concerns that you have, or have had in the past, about’s medication?

Appendices

17. Has your son/daughter ever been asked to measure their peak flow?
- How often?*
- At home?*
- What happened with that info?*
- Was the dose to be altered as a result of this?*
18. Do you ever give information about their medicines?
- Have you ever given information about the possible side effects of his/her medication?*
19. Who would you say currently has overall responsibility or is in charge of’s medicines?
20. Has the way that you and manage his/her medication changed at all since they first started needing medication for asthma?
- In what ways has it changed?*
- Were there triggers that led to the changes?*
- At what age did these changes occur?*
- Can you describe your feelings and emotions about these changes?*
21. What happens regarding medicines when you and go out?
- Who carries the medicines?*
- Who is responsible for making sure that you have them with you?*
22. What happens regarding medicines when he/she goes on holiday?
- Who packs the medication?*
- Who ensures there are enough supplies?*
- I want to ask you a now about what happens with’s medicines when he/she is at school.**
23. Where are’s medicines kept at school?
24. What happens when he/she needs them?
25. Have you spoken to anyone at’s school about his/her medication or condition?
- What happened?*
- Were you asked to visit or did you arrange the meeting?*

Appendices

26. Do you know if the school has a specific policy about medicines in school?
27. Has ever missed a day of school because of their asthma?
If yes: how many days in the last year?
28. I want you to think now of what, to you, is your worst experience of's asthma. Can you tell me what happened?
What was the outcome?
Did the way you manage 's condition/medicine change as a result?

I want to ask you now a bit about the health care professionals that are involved in treating 's asthma. Thinking back to the last time you saw a healthcare professional about 's asthma.

29. Who did you see?
30. Who went into the consulting room?
31. Can you describe what happened?

Thinking now just in general about when you go to see health care professionals.

32. Who do you usually see about 's asthma?
Nurse?
Doctor?
33. When was the last time that saw a health care professional about his/her asthma?
Who was that then?
34. Does go to an asthma clinic? **(If not mentioned above)**
If yes: can you tell me what happens there?
If no: has anyone ever suggested that he/she attend an asthma clinic?
35. **(If sees an asthma nurse)** Can you tell me what happens when you go and see the asthma nurse?
What does s/he do?
36. **(If sees an asthma nurse)** Does ever ask any questions to the nurse?
37. **(If sees a GP)** Can you tell me what happens when you go and see the GP?
What does s/he do?

Appendices

38. **(If sees a GP)** Does ever ask any questions to the GP?
39. Are there any particular consultations with healthcare professionals that you remember especially, for good or bad reasons?
40. Do you feel that you know much about’s asthma?
41. The knowledge you do have about asthma, where do you think this has come from?
42. Would you like to know more about asthma?
In which ways would you like to find out more?
What would you like to know more about?
43. If you had a question about’s asthma, who would you ask?
44. Have you ever spoken to the pharmacist about ...’s medicines?
If yes: what happened?
45. What do you think are the best features of the current services that you and your son/daughter receive?
46. What do you think are the worst things about the current services that you and your son/daughter receive?
47. Is there anything you think could be done to improve services for young people with asthma?
48. Do you feel that there have been family adjustments due to’s asthma?
49. Do you feel that is ever treated differently because he/she has asthma?
If yes: By who?
In what ways?

Thinking now towards the future:

50. Have you thought about how the responsibilities for your son/daughters medication may change in the future?
51. Have any healthcare professionals ever helped or advised you about taking greater or lesser control of their medication or condition?
52. Do you have any thoughts about’s asthma in the future?

Ok, that is all my questions. Is there anything else about’s asthma that we have not talked about that you would like to mention?

I’d now like to just ask you some general questions

53. Do you have asthma?
54. Does any other member of your family have asthma?
If yes: Who?

I now just want to ask you some questions about yourself.

55. *Note sex of respondent*
56. Who do you live with?
57. Can you please tell me whether your home is:
- Owned by you/your household
 - Rented privately
 - Rented from the local authority
 - Other
58. a) Which of the following best describes your current employment status?

full time = more than 30 hours per week
 part time = one or more hours per week

Employed	Unemployed
<input type="checkbox"/> Working for an employer full time <input type="checkbox"/> Working for an employer part time <input type="checkbox"/> Self-employed, employing other people <input type="checkbox"/> Self-employed, not employing others <input type="checkbox"/> On a Government employment or training scheme <input type="checkbox"/> Waiting to start a job that s/he has accepted	<input type="checkbox"/> Looking for a job <input type="checkbox"/> Full time education <input type="checkbox"/> Unable to work because of long term illness or disability <input type="checkbox"/> Retired from paid work <input type="checkbox"/> Looking after the home or family

If employed go to question 59

- b) When were you last in paid employment?

Appendices

- c) Have you had a paid job within the last week?
- Yes go to question 58
 - No
- d) Have you had a paid job within the last 10 years?
- Yes
 - No
59. a) How many hours per week do you/ did you officially work in your main job?
- | | |
|------------------------------------|-----------------------|
| <input type="checkbox"/> Full time | No of hours per week: |
| <input type="checkbox"/> Part time | No of hours per week: |
- b) Can you tell me the full name of your job with your rank or grade?
60. Can you describe to me the main things you do/ did in your job?
61. To which ethnic group of the following do you consider you belong?
- White** British
 Irish
 Other
- Mixed** White and Black Caribbean
 White and Black African
 White and Asian
 Other
- Asian or Asian British** Indian
 Pakistani
 Bangladeshi
 Other
- Black or Black British** Caribbean
 African
 Other
62. **Just to finish off I would like to ask you to fill out this short questionnaire** (explain and let parent self-administer PedsQL module (appendix M).

Thank you very much for your help

Appendices

Completion Form (to be completed by interviewer)

Total Interview time =

Parent interview -

Young person interview -

Was anyone else present at this interview?

Parent interview -

Young person interview -

Please make some comments regarding their participation in this interview.

Was the interview taped? Yes / No

Colour of MD:

If no, state reason:

Any other comments about the interview:-

Appendix J - Interview schedule for use with parents of young people with diabetes

INTERVIEW WITH PARENT/GUARDIAN OF YOUNG PERSON WITH DIABETES

Participant no: _____

Date: _____

Before we start the interview, I'll just remind you briefly what the study is about.

We are interested in finding out more about the use of medication by young people with diabetes and their views of the health services that are available to them. We appreciate that in the case of young people, the role of parent/guardians in managing the condition and medication may well be important. This is why it is important to get your views and opinions in this interview.

Ensure respondent has read BOTH information leaflets.

Ensure consent form is completed.

Obtain consent to audio-record interview.

Prompts are in italics

Appendices

1. Could I see all the medicines that has for his/her diabetes?

List medicines and dosage

Drug name	Form	Dose	Frequency

2. When was (name of child) first diagnosed with diabetes?

3. How old was he/she then?

4. Can you tell me about when was first diagnosed with diabetes?

What were your initial thoughts are feelings?

5. Would you say you are the primary carer of?

- if not, who is?

6. Has ever been in hospital overnight due to his/her diabetes?

7. Has suffered recently from any hypos?

- can you tell me what happened?

- where was he/she at the time?

- does this happen often?

- symptoms - mood changes?

8. Has suffered recently from any lows?

- can you tell me what happened?

- where was he/she at the time?

- does this happen often?

- symptoms - mood changes?

9. Thinking back, could you describe to me the help you have given your son/daughter with their medication or condition in the previous week?

Appendices

I want to ask you now about the particular ways in which you may help your son/daughter to manage their condition and medication. Some things you may do and others you might not.

10. Do you order, collect or take’s prescriptions to the pharmacy?

If no - who does?

How do you know medication is running out?

Do you have medication on repeat prescription?

11. Do you ever remind to monitor his/her blood sugars?

If yes - Are their specific times when you do this?

Does this ever cause problems?

12. Do you ever remind to do their injections?

If yes - Are their specific times when you do this?

Does this ever cause problems?

13. Do you ever assist in doing his/her blood sugars?

If yes - In what ways do you assist?

Does this ever cause problems?

14. Do you ever assist in doing their injections?

If yes - In what ways do you assist?

Does this ever cause problems?

15. Do you ever assist ... in altering the dose of insulin?

If yes - In what ways do you assist?

16. Have you ever given any advice about his/her diet?

Does this ever cause problems?

Does have difficulties with their diet?

17. Does find it easy to exercise?

18. Do you ever give information about his/her medicines or condition?

19. Who would you say is overall currently responsible or in charge of medicines?

Appendices

20. Has the way that you and manage his/her medication changed at all since he/she was first diagnosed with diabetes?

In what ways has it changed?

Were there triggers that led to the change?

Can you describe your feelings or emotions about these changes?

21. Are there any problems that you have, or have had in the past with's medication?

22. What happens regarding medication when you and go out?

Who carries the medication?

Who is responsible for making sure that you have them with you?

23. What happens regarding medicines when he/she goes on holiday?

Who packs the medication?

Who ensures there are enough supplies?

I want to ask you a now about what happens with 's medicines when he/she is at school.

24. Does keep anything at school to do with his diabetes?

What is kept there?

Where are these things kept?

What happens when he/she needs them?

25. Have you spoken to anyone at 's school about his/her medication or condition?

What happened?

Were you asked to visit or did you arrange the meeting?

26. Do you know if the school has a specific policy about medicines in school?

27. Has ever missed a day of school due to his/her diabetes?

How many days in the last year do you think?

28. I want you to think now of what, to you, is your worst experience of's diabetes. Can you tell me what happened?

What was the outcome?

Did this change the way you manage 's condition/medication as a result?

I want to ask you now a bit about the health care professionals that are involved in treating your’s diabetes.

- 29. Which hospital do you go to for ...’s diabetic care?
- 30. How often do you attend the diabetic clinic?

Thinking back to the last time you saw a healthcare professional about’s diabetes.

- 31. Can you describe what happened?
- 32. Do you go into the consulting room with your son/daughter?

Thinking now just in general about when you go to see health care professionals.

- 33. Who do you usually see about’s diabetes?

Nurse?

Doctor?

- 34. **(If sees an diabetes nurse)** Can you tell me what happens when you go and see the diabetes nurse?

What does s/he do?

- 35. **(If sees an diabetes nurse)** Does ever ask any questions to the nurse?

- 36. **(If sees a consultant)** Can you tell me what happens when you go and see the consultant?

What does s/he do?

- 37. **(If sees a consultant)** Does ever ask any questions to the Consultant?

- 38. Are there any particular consultations with healthcare professionals that you remember especially, for good or bad reasons?

- 39. Do you feel that you know much about’s diabetes?

- 40. The knowledge you do have about diabetes, where do you think this has come from?

- 41. Would you like to know more about diabetes?

In which ways would you like to find out more?

What would you like to know more about?

- 42. If you had a question about’s diabetes, who would you ask?

- 43. Have you ever joined, or been invited to join a support group about diabetes?

Appendices

44. Have you ever spoken to the pharmacist about ...'s medicines?
If yes: what happened?
45. What do you think are the best features of the current services that you and your son/daughter receive?
46. What do you think are the worst things about the current services that you and your son/daughter receive?
47. Is there anything you think could be done to improve services for young people with diabetes?
48. Do you feel that there have been family adjustments due to 's diabetes?
49. Do you feel that is ever treated differently because he/she has diabetes?
If yes: By who?
In what ways?

Thinking now towards the future:

50. Have you thought about how the responsibilities for your son/daughters medication may change in the future?
51. Have any healthcare professionals ever helped or advised you about taking greater or lesser control of their medication or condition?
52. Do you have any thoughts about 's diabetes in the future?

Ok, that is all my questions. Is there anything else about 's diabetes that we have not talked about that you would like to mention?

I'd now like to just ask you some general questions.

53. Do you have diabetes?
54. Does any other member of your family have diabetes?

If yes: Who?

I now just want to ask you some questions about yourself.

55. **Note sex of respondent**
56. Who do you live with?

Appendices

57. Can you please tell me whether your home is:

- Owned by you/your household
- Rented privately
- Rented from the local authority
- Other

58. a) Which of the following best describes your current employment status?

full time = more than 30 hours per week

part time = one or more hours per week

Employed	Unemployed
<input type="checkbox"/> Working for an employer full time <input type="checkbox"/> Working for an employer part time <input type="checkbox"/> Self-employed, employing other people <input type="checkbox"/> Self-employed, not employing others <input type="checkbox"/> On a Government employment or training scheme <input type="checkbox"/> Waiting to start a job that s/he has accepted	<input type="checkbox"/> Looking for a job <input type="checkbox"/> Full time education <input type="checkbox"/> Unable to work because of long term illness or disability <input type="checkbox"/> Retired from paid work <input type="checkbox"/> Looking after the home or family

If employed go to question 59.

b) When were you last in paid employment?

c) Have you had a paid job within the last week?

- Yes go to question 49
- No

d) Have you had a paid job within the last 10 years?

- Yes
- No

59. a) How many hours per week do you/ did you officially work in your main job?

- Full time No of hours per week:
- Part time No of hours per week:

b) Can you tell me the full name of your job with your rank or grade?

Appendices

60. Can you describe to me the main things you do/ did in your job?

61. To which ethnic group of the following do you consider you belong?

White British

Irish

Other

Mixed White and Black Caribbean

White and Black African

White and Asian

Other

Asian or Asian British Indian

Pakistani

Bangladeshi

Other

Black or Black British Caribbean

African

Other

61. **Just to finish off I would like to ask you to fill out this short questionnaire** (explain and let parent self-administer PedsQL module (appendix N).

Thank you very much for your help

Appendices

Completion Form

Total Interview time =

Parent interview -

Young person interview -

Was anyone else present at this interview?

Parent interview -

Young person interview -

Please make some comments regarding their participation in this interview.

Was the interview taped? Yes / No

Colour of MD:

If no, state reason:

Any other comments about the interview:-

Appendix K - Topic guide for interview with young people with asthma

INTERVIEW WITH YOUNG PERSON WITH ASTHMA

Participant no: _____

Date: _____

Before we start the interview, I just want to read through this information leaflet with you. You might have already read it, but it is important that we read through it together. If you have any questions about anything as we go along just ask me, ok?

(Read information leaflet out loud to young person, ask if they have any questions.)

Consent Form

Now before we start we have to fill out this form, we will read through it together. It says that you are happy to talk to me today, but that at anytime if you don't want to continue talking to me then you just have to say so and we will stop the interview and I will go home. You are completely free to say that you want to stop at anytime. Have you got any questions? Are you happy to sign the form?

Consent to audio record interview

This part of the form asks if you mind if I tape record what you say to me today. I am the only person that is going to listen to what you have said. I just ask if you mind me recording what you say as it means that I can concentrate on listening to you, instead of having to try and write everything down very quickly as you say it. Are you happy for me to record what you say?

Ok is there anything else that you would like to ask me before we start?

As I said before there are no wrong or right answers. I am interested to hear from you what it is like for you to have asthma.

Appendices

NOTE - Topic guide is a list of topics to be covered during the interview and some suggestions of prompts, exact wording used depends upon nature of child respondent.

1. 1st diagnosed - *what do you remember?*
- *feelings/emotions?*
2. Medication - *what sort do you use?*
3. Daily routine of medication
- *before school*
- *whilst at school*
- *when get home from school*
- *before bed*
4. Do you have to carry your inhaler with you?
- *how do you feel about carrying your inhaler?*
- *is it hard to remember to take your inhaler with you?*
5. Have you ever had an asthma attack?
- *can you tell me what happened?*
- *how did you feel?*
6. Peak flow?
7. Are there any particular things that make your asthma bad?
- *allergies?*
- *playing outside?*
- *exercise?*
8. Reminding to take medicines - *what help?*
9. Assistance in using medicines - *what help?*
10. How much of medicine to use - *what help?*
11. Changes in amount of help with medication since first diagnosed?
- *what is different now?*
12. What happens with medication on holiday?
13. What happens with medication in school?
- *where are they kept?*
- *what happens if you want to use them?*
14. What happens when you do PE at school?
15. Have you ever missed a day of school because of your asthma?
16. How feel about asthma in front of friends?
- *is it hard to explain to other people what it is?*
17. Are you ever treated differently because of asthma?

Appendices

18. Have you ever seen an asthma nurse?
If yes - what happens when see him/her?
- have you ever asked any questions?
19. Have you ever seen a GP in connection with your asthma?
If yes - what happens when see him/her?
- have you ever asked any questions?
20. What are the best things about the services available to you?
21. What are the worst things about the services available to you?
22. Has having asthma ever stopped you from doing something that you have wanted to do?
23. Thoughts about control of medication in the future
24. Anything I have not asked you about your asthma that you would like to talk about?
25. **Just to finish off I would like to ask you to fill out this short questionnaire** (explain and administer PedsQL module (appendix 0)).

Thank you very much for your time

Appendix L - Topic guide for interview with young people with diabetes

INTERVIEW WITH YOUNG PERSON WITH DIABETES

Participant no: _____

Date: _____

Before we start the interview, I just want to read through this information leaflet with you. You might have already read it, but it is important that we read through it together. If you have any questions about anything as we go along just ask me, ok?

(Read information leaflet out loud to young person, ask if they have any questions.)

Consent Form

Now before we start we have to fill out this form, we will read through it together. It says that you are happy to talk to me today, but that at anytime if you don't want to continue talking to me then you just have to say so and we will stop the interview and I will go home. You are completely free to say that you want to stop at anytime. Have you got any questions? Are you happy to sign the form?

Consent to audio record interview

This part of the form asks if you mind if I tape record what you say to me today. I am the only person that is going to listen to what you have said. I just ask if you mind me recording what you say as it means that I can concentrate on listening to you, instead of having to try and write everything down very quickly as you say it. Are you happy for me to record what you say?

Ok is there anything else that you would like to ask me before we start?

As I said before there are no wrong or right answers. I am interested to hear from you what it is like for you to have diabetes.

Appendices

NOTE - Topic guide is a list of topics to be covered during the interview and some suggestions of prompts, exact wording used depends upon nature of child respondent.

1. 1st diagnosed - *what do you remember?*
- *feelings/emotions?*
2. Blood sugars - *describe how you do them?*
- *any help?*
- *how often?*
3. Injections - *describe how you do them?*
- *any help with?*
- *how often?*
4. Changes in amount of help with medication since first diagnosed
5. Reminding to do blood sugars - *what help?*
6. Reminding to do injections - *what help?*
7. Diet - *what help?*
8. Have you ever been in hospital because of your diabetes?
- *tell me what happened then?*
- *what was it like?*
9. What happens with medication on holiday?
10. Do you take anything to school to do with your diabetes?
- *where is it kept?*
11. Do you have to take snacks to school?
12. Does PE at school, ever make you high or low?
13. Have you ever missed a day of school because of your diabetes?
14. How feel about diabetes in front of friends?
- *is it hard to explain to other people what it is?*
15. Are you ever treated differently because of diabetes?

Appendices

16. Tell me now about what it's like when you go to the hospital clinic about your diabetes?
- who do you see there?
17. Have you ever seen an diabetes nurse?
If yes - what happens when see him/her?
- have you ever asked any questions?
18. Have you ever seen Consultant?
If yes - what happens when see him/her?
- have you ever asked any questions?
19. What are the best things about the services available to you?
20. What are the worst things about the services available to you?
21. Has having diabetes ever stopped you from doing something that you have wanted to do?
22. Thoughts about control of medication in the future
23. Anything I have not asked you about your asthma that you would like to talk about?
24. **Just to finish off I would like to ask you to fill out this short questionnaire** (explain and administer PedsQL module (appendix P).

Thank you very much for your time

Appendix M - PedsQL asthma module to be completed by parent proxy respondent

PedsQL Asthma module Parent report for children (8-12 years)

DIRECTIONS

Children with asthma sometimes have special problems. Below is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no wrong or right answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with

ASTHMA (problems with ...)	Never	Almost Never	Some-times	Often	Almost Always
Pain or tightness in his or her chest	0	1	2	3	4
Feeling wheezy	0	1	2	3	4
Having asthma attacks	0	1	2	3	4
Getting scared whilst having asthma attacks	0	1	2	3	4
Getting out of breath	0	1	2	3	4
Coughing	0	1	2	3	4
Taking a big breath	0	1	2	3	4
Having a stuffy or runny nose	0	1	2	3	4
Waking up at night with trouble breathing	0	1	2	3	4
Playing with pets	0	1	2	3	4
Playing outside	0	1	2	3	4
TREATMENT (problems with ...)	Never	Almost Never	Some-times	Often	Almost Always
Medicines making him or her feel ill	0	1	2	3	4
Trouble sleeping because of medicines	0	1	2	3	4

Appendices

	Never	Almost Never	Some- times	Often	Almost Always
Trouble using his or her inhaler	0	1	2	3	4
Disliking carrying his or her inhaler	0	1	2	3	4
Being responsible for his or her medicines	0	1	2	3	4
Controlling his or her asthma	0	1	2	3	4
Refusing to take medicines	0	1	2	3	4
Forgetting to take medicines	0	1	2	3	4
Getting anxious when he or she has to have medical treatments	0	1	2	3	4
Getting anxious about going to the doctor	0	1	2	3	4
Getting anxious about going to the hospital	0	1	2	3	4
WORRY (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
Worrying about side effects from medical treatments	0	1	2	3	4
Worrying about whether or not medical treatments are working	0	1	2	3	4
Worrying about his or her asthma	0	1	2	3	4
COMMUNICATION (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
Telling the doctors and nurses how he or she feels	0	1	2	3	4
Asking the doctors or nurses questions	0	1	2	3	4
Explaining his or her illness to other people	0	1	2	3	4

Appendix N - PedsQL diabetes module to be completed by parent proxy respondent

PedsQL Diabetes module Parent report for children (8-12 years) and teenagers (aged 13-18 years)*

* Below is child module, for teenage module the word 'child' is changed to 'teenager'

<p>DIRECTIONS</p> <p>Children with diabetes sometimes have special problems. Below is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling:</p> <p style="text-align: center;"> 0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem 3 if it is often a problem 4 if it is almost always a problem </p> <p>There are no wrong or right answers. If you do not understand a question, please ask for help.</p>
--

In the past **ONE month**, how much of a **problem** has your child had with

DIABETES (problems with ...)	Never	Almost Never	Some-times	Often	Almost Always
Feeling hungry	0	1	2	3	4
Feeling thirsty	0	1	2	3	4
Having to go to the toilet too often	0	1	2	3	4
Having stomachaches	0	1	2	3	4
Having headaches	0	1	2	3	4
Going 'low' or 'hypo'	0	1	2	3	4
Feeling tired	0	1	2	3	4
Getting shaky	0	1	2	3	4
Getting sweaty	0	1	2	3	4
Having trouble sleeping at night	0	1	2	3	4
Getting grumpy or annoyed	0	1	2	3	4
TREATMENT - I (problems with ...)	Never	Almost Never	Some-times	Often	Almost Always
Injections/blood tests causing him/her pain	0	1	2	3	4

Appendices

	Never	Almost Never	Some- times	Often	Almost Always
Getting embarrassed about having diabetes	0	1	2	3	4
Arguing with me or my partner about diabetes	0	1	2	3	4
Sticking to his/her diabetes routine	0	1	2	3	4
TREATMENT II (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
It is hard for my child to do blood glucose tests	0	1	2	3	4
It is hard for my child to give himself insulin injections	0	1	2	3	4
It is hard for my child to exercise	0	1	2	3	4
It is hard for my child to follow a healthy diet	0	1	2	3	4
It is hard for my child to wear his/her id bracelet/necklace or carry a card	0	1	2	3	4
It is hard for my child to carry a fast-acting carbohydrate	0	1	2	3	4
It is hard for my child to eat snacks between meals when they should	0	1	2	3	4
WORRY (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
Worrying about 'going low' or 'hypo'	0	1	2	3	4
Worrying about whether or not medical treatments are working	0	1	2	3	4
Worrying about long-term problems of diabetes	0	1	2	3	4
COMMUNICATION (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
Telling the doctors and nurses how he/she feels	0	1	2	3	4
Asking the doctors or nurses questions	0	1	2	3	4
Explaining his/her illness to other people	0	1	2	3	4

Appendix O - PedsQL asthma module to be completed by young person

PedsQL Asthma module child report (8-12 years)

<p>DIRECTIONS</p> <p>Children with asthma sometimes have special problems. Please tell us how much of a problem each one has been for you during the past ONE month by circling:</p> <p style="text-align: center;">0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem 3 if it is often a problem 4 if it is almost always a problem</p> <p>There are no wrong or right answers. If you do not understand a question, please ask for help.</p>
--

In the past **ONE month**, how much of a **problem** has this been for you

ABOUT MY ASTHMA (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
My chest hurts or feels tight	0	1	2	3	4
I feel wheezy	0	1	2	3	4
I have asthma attacks	0	1	2	3	4
I get scared when I have asthma attacks	0	1	2	3	4
I get out of breath	0	1	2	3	4
I cough	0	1	2	3	4
It is hard to take a big breath	0	1	2	3	4
I have a stuffy or runny nose	0	1	2	3	4
I wake up at night with trouble breathing	0	1	2	3	4
It is hard for me to play with pets	0	1	2	3	4
It is hard for me to play outside	0	1	2	3	4
TREATMENT (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
My medicines make me feel ill	0	1	2	3	4
I have trouble sleeping because of my medicines	0	1	2	3	4
I have trouble using my inhaler	0	1	2	3	4

Appendices

	Never	Almost Never	Some- times	Often	Almost Always
I don't like to carry my inhaler	0	1	2	3	4
It is hard for me to be responsible for my medicines	0	1	2	3	4
It is hard to control my asthma	0	1	2	3	4
I refuse to take my medicines	0	1	2	3	4
I forget to take my medicines	0	1	2	3	4
I get scared when I have to have medical treatments	0	1	2	3	4
I get scared when I have to go to the doctor	0	1	2	3	4
I get scared when I have to go to the hospital	0	1	2	3	4
WORRY (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
I worry about the side effects from medical treatments	0	1	2	3	4
I worry about whether or not my medical treatments are working	0	1	2	3	4
I worry about my asthma	0	1	2	3	4
COMMUNICATION (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4
It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
It is hard for me to explain my illness to other people	0	1	2	3	4

Appendix P - PedsQL diabetes module to be completed by young person

**PedsQL Diabetes module child report(8-12 years) and
teenager report (aged 13-18 years)***

* Below is child module, for teenage module the word 'child' is changed to 'teenager'

<p>DIRECTIONS</p> <p>Children with diabetes sometimes have special problems. Please tell us how much of a problem each one has been for you during the past ONE month by circling:</p> <p style="text-align: center;">0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem 3 if it is often a problem 4 if it is almost always a problem</p> <p>There are no wrong or right answers. If you do not understand a question, please ask for help.</p>
--

In the past **ONE month**, how much of a **problem** has this been for you....

DIABETES (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
I feel hungry	0	1	2	3	4
I feel thirsty	0	1	2	3	4
I have to go to the toilet too often	0	1	2	3	4
I have stomachaches	0	1	2	3	4
I have headaches	0	1	2	3	4
I go 'low' or 'hypo'	0	1	2	3	4
I feel tired	0	1	2	3	4
I get shaky	0	1	2	3	4
I get sweaty	0	1	2	3	4
I have trouble sleeping at night	0	1	2	3	4
I get grumpy or annoyed	0	1	2	3	4
TREATMENT - I (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
It hurts to prick my finger or give myself insulin injections	0	1	2	3	4

Appendices

	Never	Almost Never	Some- times	Often	Almost Always
I am embarrassed about having diabetes	0	1	2	3	4
My parents and I argue about my diabetes care	0	1	2	3	4
It is hard for me to stick to my diabetes routine	0	1	2	3	4
TREATMENT II (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
It is hard for me to do blood glucose tests	0	1	2	3	4
It is hard for me to give myself insulin shots	0	1	2	3	4
It is hard for me to exercise	0	1	2	3	4
It is hard for me to follow a healthy diet	0	1	2	3	4
It is hard for me to wear my id bracelet/necklace or carry a card	0	1	2	3	4
It is hard for me to carry a fast-acting carbohydrate	0	1	2	3	4
It is hard for me to eat snacks between meals when I should	0	1	2	3	4
WORRY (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
I worry about 'going low' or 'hypo'	0	1	2	3	4
I worry about whether or not my medical treatments are working	0	1	2	3	4
I worry about the long-term problems from diabetes	0	1	2	3	4
COMMUNICATION (problems with ...)	Never	Almost Never	Some- times	Often	Almost Always
It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
It is hard for me to explain my illness to other people	0	1	2	3	4

**Appendix Q - Letter of invitation to participate in the asthma part of the study
sent to the Practice Manager or equivalent at the GP surgery**

THE SCHOOL OF PHARMACY

UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifer.newbould@ulsop.ac.uk

DATE

Dear (insert name),

**Re: Young people with asthma and their parents: developing health services to support
partnerships in asthma management**

We are conducting a research study funded by the Royal College of General Practitioners that is investigating the processes and outcomes of shared management of medication between young people with asthma and their parents. It is expected that the findings will inform the development of health services for young people with asthma. A copy of the full study protocol is available on request.

General practice surgeries in the (insert health authority area) health authority area have been randomly selected for invitation to participate in this research project. All data collection and processing will be undertaken by the research team, however, we would be grateful for your assistance in the recruitment of the sample. This only requires that each surgery identifies 20-25 young people with asthma, aged 8-12 years, from their computer database and sends a ready prepared pack of information to the parents of the young people on my behalf. All postage costs will be covered by the University.

The pack of information includes a letter inviting them to take part in the research and two information leaflets. Please find enclosed a copy of the information leaflets that will be sent to young people (peach) and their parents (yellow). The research has been approved by the (insert health authority area) health authority local research ethics committee (insert reference number of ethics committee approval).

We will contact you by telephone in a few days time to discuss this further. In the meantime if you have any questions please do not hesitate to contact Jenny Newbould on **020 7753 5962**, or at the above address.

Many thanks for your help.

Yours sincerely,

Jenny Newbould
Research Assistant

Dr Felicity Smith
Reader

Dr Sally-Anne Francis
Lecturer

**Appendix R - Letter of invitation to participate in the diabetes part of the study
sent to the Practice Manager or equivalent at the GP surgery**

THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifer.newbould@ulsop.ac.uk

DATE

Dear (insert name),

**Re: Young people with diabetes and their parents: developing health services to support
partnerships in diabetes management**

We are conducting a research study funded by the Royal College of General Practitioners that is investigating the processes and outcomes of shared management of medication between young people with diabetes and their parents. It is expected that the findings will inform the development of health services for young people with diabetes. A copy of the full study protocol is available on request.

General practice surgeries in the (insert health authority area) health authority area have been randomly selected for invitation to participate in this research project. All data collection and processing will be undertaken by the research team, however, we would be grateful for your assistance in the recruitment of the sample. This only requires that each surgery identifies young people with diabetes, aged 8-15 years, from their computer database and sends a ready prepared pack of information to the parents of the young people on my behalf. All postage costs will be covered by the University.

The pack of information includes a letter inviting them to take part in the research and two information leaflets. Please find enclosed a copy of the information leaflets that will be sent to young people (blue) and their parents (green). The research has been approved by the (insert health authority area) health authority local research ethics committee (insert reference number of ethics committee approval).

We will contact you by telephone in a few days time to discuss this further. In the meantime if you have any questions please do not hesitate to contact Jenny Newbould on **020 7753 5962**, or at the above address.

Many thanks for your help.

Yours sincerely,

Jenny Newbould
Research Assistant

Dr Felicity Smith
Reader

Dr Sally-Anne Francis
Lecturer

Appendix S - Leaflet for young people with asthma

Contact for further information

If you would like to talk to me about any aspect of the study, then please do not hesitate to contact me.

Jenny Newbould
Centre for Practice and Policy
School of Pharmacy
University of London
Brunswick Square
London WC1N 1AX

Tel: 020 7753 5962

THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH ASTHMA: THE VIEWS OF YOUNG PEOPLE

You and your parent, or the person who looks after you, are being invited to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your parents, friends, relatives and your doctor if you want. Please contact us if there is anything that is not clear or if you would like

THANK YOU FOR TAKING THE TIME TO READ THIS

[REDACTED]

What is the study about?

We would like to find out more about the experiences of young people with asthma. Adults often talk about what are the best services for young people with asthma, I am interested in what you think.

Why have I been chosen?

Young people with asthma attending surgeries in the area will be invited to take part in the study.

What will happen if I take part?

At a pre-arranged time a researcher will visit you at home to talk to you. She will talk to you about your asthma and ask you some questions. She would like to know about the medicines you take for your asthma, how you feel having asthma affects your daily life and how doctors and other professionals help you with your asthma. She may also ask for your suggestions of how services could be improved for young people with asthma. We expect the interview to take about 30 minutes.

[REDACTED]

[REDACTED]

Will My Parents Be Told What I Say?

No. No one except the research team will have access to the data. All names will be removed from the data, so that you cannot be recognised from it.

Who is organising this study?

The research is being carried out by the School of Pharmacy, University of London. We are involved in education and research on health and medicines, we are not a money-making organisation.

Do I Have To Take Part?

No, it is up to you to decide if you want to take part or not in the study, but we hope you will be happy to take part and to tell us about your experiences.

We believe that the study will give us important information about the needs of young people with asthma and may help us to better plan future services for young people with asthma and their families.

Thank you for taking the time to read this. Please contact us if you would like any more information.

[REDACTED]

Appendix T - Leaflet for parents of young people with asthma




Contact for further information

If you would like to talk to me about any aspect of the study, or require any further information, then please do not hesitate to contact me.

Jenny Newbould
Centre for Practice and Policy
School of Pharmacy
University of London
Brunswick Square
London WC1N 1AX

Tel: 020 7753 5962
E.Mail: jennifer.newbould@ulsop.ac.uk



THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH ASTHMA

You and your son/daughter are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son/daughter, friends, relatives and your GP if you wish. Please contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

THANK YOU FOR TAKING THE TIME TO READ THIS



[REDACTED]

What is the purpose of this study?

We would like to find out more about the views and experiences of young people with asthma and their parents/guardians. Very little information about this is currently available from the perspectives of young people. This study aims to inform the future development of health services for young people with asthma and their parents/guardians.

Why have I been chosen?

Young people with asthma attending randomly selected surgeries, and their parents will be invited to take part in the study.

What will happen if I take part?

At your convenience a researcher will visit you at home on one occasion to interview you and your son/daughter. The researcher will first discuss your child's asthma with you and ask you a series of questions about how you and your child manage their medication and condition in general. You will also be asked about your experiences of current services and how services for young people with asthma and their families could be improved.

Your son/daughter will then be interviewed and asked about their medication, how asthma affects their daily life, how they feel about meeting health care professionals, their experiences of current services and suggestions of how services could be improved for young people with asthma in the future.

We expect each interview to take about 30 minutes.

[REDACTED]

[REDACTED]

Is the study confidential?

Yes. All information collected will be kept strictly confidential and will be made anonymous so that you cannot be recognised from it.

Who is organising this study?

The research is being carried out by the School of Pharmacy, University of London. We are an independent establishment involved in education and research, we are not a commercial organisation.

The study has been independently approved by the (insert local ethics research committee)local research ethics committee (insert reference number of ethics committee approval).

Do I Have To Take Part?

No, but we hope that you will be happy to take part. Your participation is entirely voluntary and you are free to withdraw from the study at anytime without your medical care, or that of your child being affected.

We believe that the study will give us important information about the needs of young people with asthma and may help us to better plan future services for them and their families.

Thank you for taking the time to read this. Please contact us if you would like any more information.

[REDACTED]

Appendix U - Leaflet for young people with diabetes

Contact for further information

If you would like to talk to me about any aspect of the study, then please do not hesitate to contact me.

Jenny Newbould
Centre for Practice and Policy
School of Pharmacy
University of London
Brunswick Square
London WC1N 1AX

Tel: 020 7753 5962


E.Mail: jennifer.newbould@ulsop.ac.uk

THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH DIABETES: THE VIEWS OF YOUNG PEOPLE

You and your parent, or the person who looks after you, are being invited to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your parents, friends, relatives and your doctor if you want. Please contact us if there is anything that is not clear or if you would like more information.

THANK YOU FOR TAKING THE TIME TO READ THIS



What is the study about?



We would like to find out more about the experiences of young people with diabetes. Adults often talk about what are the best services for young people with diabetes, I am interested in what you think.

Why have I been chosen?

Young people with diabetes attending surgeries in the area will be invited to take part in the study.

What will happen if I take part?

At a pre-arranged time a researcher will visit you at home to talk to you. She will talk to you about your diabetes and ask you some questions. She would like to know about the injections you have for your diabetes, how you feel having diabetes affects your daily life and how doctors and nurses help you with your diabetes. She may also ask for your suggestions of how services could be improved for young people with diabetes. We expect the interview to take about 30 minutes.



Will My Parents Be Told What I Say?

No. No one except the research team will have access to the data. All names will be removed from the data, so that you cannot be recognised from it.

Who is organising this study?


The research is being carried out by the School of Pharmacy, University of London. We are involved in education and research on health and medicines, we are not a money-making organisation.

Do I Have To Take Part?

No, it is up to you to decide if you want to take part or not in the study, but we hope you will be happy to take part and to tell us about your experiences.

We believe that the study will give us important information about the needs of young people with diabetes and may help us to better plan future services for young people with diabetes and their families.

Thank you for taking the time to read this. Please contact us if you would like any more information.



Appendix V - Leaflet for parents of young people with diabetes

Contact for further information

If you would like to talk to me about any aspect of the study, or require any further information, then please do not hesitate to contact me.

Jenny Newbould
Centre for Practice and Policy
School of Pharmacy
University of London
Brunswick Square
London WC1N 1AX

Tel: 020 7753 5962
E.Mail: jennifer.newbould@ulsop.ac.uk

THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

DEVELOPING SERVICES FOR YOUNG PEOPLE WITH DIABETES: THE VIEWS OF YOUNG PEOPLE AND THEIR PARENTS

You and your son/daughter are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son/daughter, friends, relatives and your GP if you wish. Please contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

THANK YOU FOR TAKING THE TIME TO READ THIS

[REDACTED]

What is the purpose of this study?

We would like to find out more about the views and experiences of young people with diabetes and their parents/guardians. Very little information about this is currently available from the perspectives of young people. This study aims to inform the future development of health services for young people with diabetes and their parents/guardians.

Why have I been chosen?

Young people with diabetes attending randomly selected surgeries, and their parents will be invited to take part in the study.

What will happen if I take part?

At your convenience a researcher will visit you at home on one occasion to interview you and your son/daughter. The researcher will first discuss your child's diabetes with you and ask you a series of questions about how you and your child manage the medication and their condition in general. You will also be asked about your experiences of current services and how services for young people with diabetes and their families could be improved.

Your son/daughter will then be interviewed and asked about their medication, how diabetes affects their daily life, how they feel about meeting health care professionals, their experiences of current services and suggestions of how services could be improved for young people with diabetes in the future.

We expect each interview to take about 30 minutes.

[REDACTED]

[REDACTED]

Is the study confidential?

Yes. All information collected will be kept strictly confidential and will be made anonymous so that you cannot be recognised from it.

Who is organising this study?

The research is being carried out by the School of Pharmacy, University of London. We are an independent establishment involved in education and research, we are not a commercial organisation.

The study has been independently approved by the (insert local ethics research committee) local research ethics committee (insert reference number of ethics committee approval).

Do I Have To Take Part?

No, but we hope that you will be happy to take part. Your participation is entirely voluntary and you are free to withdraw from the study at anytime without your medical care, or that of your child being affected.

We believe that the study will give us important information about the needs of young people with diabetes and may help us to better plan future services for them and their families.

Thank you for taking the time to read this. Please contact us if you would like any more information.

[REDACTED]

**Appendix W - Letter of invitation to participate in the asthma part of the study,
with attached reply slip, sent to the parents of young people
with asthma**

THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
Jennifer.newbould@ulsop.ac.uk

Dear Sir/Madam

**DEVELOPING SERVICES FOR YOUNG PEOPLE WITH ASTHMA: THE VIEWS OF YOUNG
PEOPLE AND THEIR PARENTS**

We are carrying out research to inform the development of health services for young people with asthma. This project seeks to find out the views and experiences of young people and their parents about asthma, medicines and the services that they receive.

This project is being run independently from your GP surgery, but they have sent this information to you on my behalf. I am a researcher from the University of London. This research is funded by the Royal College of General Practitioners.

I would like to invite you and your son/daughter to be part of this research. Taking part in this research involves one short interview with you and another with your son/daughter. The interviews will be arranged at a time and place convenient for you.

Enclosed with this letter you will find two information leaflets. The yellow leaflet tells you a bit more about the study. The peach leaflet is for your son/daughter, you may want to read it with them and decide together if you would like to participate in this research. All information will be kept strictly confidential.

Whether you are prepared to take part, or feel unable to do so, I would be grateful if you would complete the reply slip attached to this letter and return it to me in the pre-paid envelope provided.

If you would like to discuss taking part in the research further before you complete the slip, then please feel free to contact me by telephone on **020 77535962**.

I look forward to hearing from you.

Yours faithfully

Jenny Newbould (Ms)
Research Assistant

Appendices

REPLY SLIP

Name of parent/guardian (please print).....

Name of young person (please print)

Age of young person with asthma

Sex of young person (please tick): Male [] Female []

Number of years since young person was diagnosed with asthma

I am willing/am not willing* to take part in the research study 'developing services for young people with asthma: the views of young people and their parents'.

* - please delete as appropriate

If you **are not willing** to take part in the research it would very much help us if you could tell us your reasons for not wishing to take part

.....
.....
.....

If you **are willing** to take part in the research please complete the following section so that I can contact you to arrange suitable times for the interviews and answer any questions you may have.

Your tel. no

Your address.....

.....
.....
.....

Please return this slip in the pre-paid envelope provided (no stamp required)

Thank you very much for your time.

Office ref no.

**Appendix X - Letter of invitation to participate in the diabetes part of the study,
with attached reply slip, sent to the parents of young people
with diabetes**

THE SCHOOL OF PHARMACY
UNIVERSITY OF LONDON

Centre for Practice & Policy
Department of Pharmaceutics
Jennifer Newbould BSc

29/39 Brunswick Square
London, WC1N 1AX
Direct Line: 0207 7753 5962
Facsimile: 0207 7753 5920
jennifcr.newbould@ulsop.ac.uk

Dear Sir/Madam

**DEVELOPING SERVICES FOR YOUNG PEOPLE WITH DIABETES: THE VIEWS OF
YOUNG PEOPLE AND THEIR PARENTS**

We are carrying out research to inform the development of health services for young people with diabetes. This project seeks to find out the views and experiences of young people and their parents about diabetes, medication and the services that they receive.

This project is being run independently from your GP surgery, but they have sent this information to you on my behalf. I am a researcher from the University of London. This research is funded by the Royal College of General Practitioners.

I would like to invite you and your son/daughter to be part of this research. Taking part in this research involves one short interview with you and another with your son/daughter. The interviews will be arranged at a time and place convenient for you.

Enclosed with this letter you will find two information leaflets. The green leaflet tells you a bit more about the study. The blue leaflet is for your son/daughter, you may want to read it with them and decide together if you would like to participate in this research. All information will be kept strictly confidential.

Whether you are prepared to take part, or feel unable to do so, I would be grateful if you would complete the reply slip attached to this letter and return it to me in the pre-paid envelope provided.

If you would like to discuss taking part in the research further before you complete the slip, then please feel free to contact me by telephone on **020 77535962**.

I look forward to hearing from you.

Yours faithfully

Jenny Newbould (Ms)
Research Assistant

Appendices

REPLY SLIP

Name of parent/guardian (please print).....

Name of young person (please print)

Age of young person with diabetes

Sex of young person (please tick): Male [] Female []

Number of years since young person was diagnosed with diabetes

I **am willing/am not willing*** to take part in the research study 'developing services for young people with diabetes: the views of young people and their parents'.

* - please delete as appropriate

If you **are not willing** to take part in the research it would very much help us if you could tell us your reasons for not wishing to take part

.....
.....
.....

If you **are willing** to take part in the research please complete the following section so that I can contact you to arrange suitable times for the interviews and answer any questions you may have.

Your tel. no

Your address.....

.....
.....
.....

Please return this slip in the pre-paid envelope provided (no stamp required)

Thank you very much for your time.

Office ref no.