

The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances?

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Glossary of terms/abbreviations

Abbreviations

ADSN – Adult Diabetes Specialist Nurse

CCN – Children’s Community Nurse

CONA – Adult Consultant

CONP – Paediatric Consultant

DCCS - Diabetes Continuity of Care Scale

DCCT - Diabetes Control and Complications Trial

DMSES - Diabetes Management Self-Efficacy Scale

DNA - Did not attend scheduled clinic appointment

DSN – Diabetes Specialist Nurse

DQoLY - Diabetes Quality of Life measure for Youth

GP – General Practitioner

GPwSI – General Practitioner with a specialist interest

HbA1c - Glycosylated haemoglobin

HCCQ - Health Care Climate Questionnaire

IQR – Inter quartile range

NIHR - National Institute for Health Research

NSF - National Service Framework

NURSCON – Consultant Nurse

PCDS - Perceived Competence for Diabetes Scale

PDSN – Paediatric Diabetes Specialist Nurse

PEI - Patient Enablement Instrument

SNP – Staff Nurse Paediatrics

SPR – Specialist Registrar

Glossary

Glycosylated haemoglobin - the amount of glycosylated haemoglobin in blood is related to the concentration of blood glucose over an approximately two to three month period. This can be measured by taking a blood sample and analysing the red blood cells. The measurement is known as an HbA1c level and has been shown to be related to the risk of diabetes-related complications in the future.

Hyperglycaemia – blood glucose concentrations above the normal range.

Hypoglycaemia – blood glucose concentrations below the normal range.

Ketoacidosis – an acute metabolic complication associated with inadequate circulating concentrations of insulin within the body in which there is a progressive accumulation of acid within the blood (acidosis), usually associated with hyperglycaemia. When severe, this may be life-threatening.

Macro-vascular complications – a long-term complication of (usually poorly-controlled) diabetes in which abnormalities develop in the major blood vessels, threatening the blood supply, for example, to the legs (peripheral vascular disease).

Nephropathy – a long-term complication of (usually poorly-controlled) diabetes which leads initially to excess protein in the urine and ultimately kidney failure.

Neuropathy - a long-term complication of (usually poorly-controlled) diabetes which leads to impaired sensation often in the limbs or abnormal function of internal organs such as the gastro-intestinal tract.

Peripheral vascular disease – see macro-vascular complications.

Polydipsia – excessive thirst which is often a symptom of hyperglycaemia.

Polyuria - excessive urine production which is often a symptom of hyperglycaemia.

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Executive Summary

Background

The importance of getting the transition from paediatric to adult diabetes services right for young people is increasingly acknowledged but research evidence to inform the design of services is weak.

Aims

This study aimed to:

- identify, map, categorise and enumerate the range of diabetes transition models in use in England,
 - develop a conceptual framework of models, building on National Institute for Health Research Service Delivery and Organisation programme research on continuity of care,
 - undertake in-depth evaluation of a purposive sample of models to develop an understanding of users'/carers'/providers' experiences of, and preferences for, transition services, the processes and organisational challenges involved and assess costs,
 - make recommendations about what works best to promote 'a smooth transition', for whom and in what circumstances,
 - contribute to understanding of pathways through transition and develop further theories of continuity of care.
-

Methods

The study was informed by the seven dimensions of continuity identified by Forbes *et al.* in their review of transition service arrangements: experienced continuity (smooth progression of care from the service users' point of view); continuity of information (excellent information transfer); cross-boundary continuity (effective communication between professionals and services); flexible continuity (adjustment to the needs of an individual over time); longitudinal continuity (care from as few professionals as possible); relational or personal continuity (a therapeutic relationship with a named health professional) and developmental continuity (care which grows with the changing demands of the client group and works to facilitate that change). These concepts were refined through an iterative data generation and analysis process.

Stage 1: Service Mapping

A survey instrument was developed in order to map transition services in England. It was predicated on the assumption that smooth transition depends on achieving different kinds of continuity and that there were different ways of achieving these effects reflecting local service constraints. It included questions about context, structure, mechanisms for transfer and organisational practices associated with the continuities of care identified as contributing to smooth transition. The survey was administered to a 20% random sample of services drawn from the Directory of Diabetes Care. Sampling continued until no new service arrangements were identified. A typology of transition models was developed reflecting the range of transition services.

Stage 2: Realistic Evaluation of Transition Models

The typology was used to select a sample of five transition models for in-depth exploration informed by the principles of realistic evaluation. Each model represented an identifiable configuration of service components designed to manage the transition pathway between paediatric and adult services. Observations, the analysis of organisational documents and interviews with health professionals were used to build up model descriptions. Case studies were undertaken with young people and their carers (n=46). Each participated in separate qualitative interviews on three occasions over 12-18 months. The interviews generated data on their experiences of, and preferences for, transition. Medical record review was combined with clinical interviews with health professionals to build up an understanding of each case. Individual case studies were treated as 'outcomes' and informed the model evaluations. They were also taken into account during the analysis of users'/carers' experiences to ensure that their views were interpreted in the context in which they were expressed. The quality of life domains nominated by young people were described and their stability or change over time assessed.

For each model, parallel surveys of young people with type 1 diabetes, approaching, undergoing or less than 12 months post transition and their carer were administered. The questionnaires included instruments that measured satisfaction (including perceived continuity), healthcare climate and quality of life, selected following a systematic review and appraisal of instruments. Analysis takes the form of summary statistics and regression models.

The study also included a costs and consequences analysis.

Results

Stage 1: Service Mapping

All services included elements of practice designed to promote cross-boundary and informational continuity, and most included elements to promote relational and longitudinal continuity. The features that discriminated between services were the extent to which they included interventions designed to ensure developmental and flexible continuity and the number of stages in the transition process. The survey revealed a strong trend towards sequential transition. By combining the structural characteristics (one, two or three stages) with the process characteristics (the proportion of continuity interventions) we created a typology of transition models.

Stage 2: Realistic Evaluation of Transition Models

What works?

Data synthesis across the sample of models revealed that seven types of continuity contribute to users'/carers' experiences of smooth transition: relational, longitudinal, informational, management, cultural, developmental and flexible. These continuity concepts are a modification of Forbes *et al.*'s original framework.

Relational and longitudinal continuity are central to transition because they facilitate other kinds of continuity: flexible and management continuity (continuity of diabetes management through a common purpose and plan). They also provide a sense of safety at times of change, obviating the need for formal informational continuity interventions. Flexible and cultural continuity also emerge as important.

Cultural continuity is a new concept developed for the purposes of this study. The literature on transition focuses on the differences between child and adult service cultures and the need to support young people in adjusting to this. While some models fitted this portrayal, in others paediatric and adult services were culturally continuous. Young people and their families in models exhibiting high levels of cultural continuity experience better outcomes on a range of measures.

There are challenges involved in achieving a balance between developmental and flexible continuity interventions. Young people and their families experience better outcomes in those models where support is responsive to individual need (flexible continuity) than in those with more proactive approaches (developmental continuity).

Across models a range of service components are deployed to achieve the continuities that contribute to smooth transition. The relative effectiveness of individual service components was assessed as well as the combined costs and consequences of the interventions comprising each model.

For whom?

Overall there were high levels of agreement between young people and carers about the mechanisms central to smooth transition.

There was, however, one area where what works for young people does not work for carers. Mothers are an important source of continuity for young people, but this is not formally recognised in policies in this field. Whilst the progression to lone consulting and/or transfer to adult services is a key developmental milestone for young people, many mothers become cut off from the process and can no longer access the advice needed to support their child. They also have their own needs for support which is lost when they are no longer routinely interacting with service providers.

Young people who were poor clinic attenders and/or who had strained relationships with carers were not represented in the user/carer case studies. We do not know to what extent the study findings can be extended to this group.

In what circumstances?

Models with high levels of relational, flexible and cultural continuity achieve smooth transition with relatively informal, low cost informational and management continuity mechanisms.

Models with more complex divisions of labour and low levels of relational and longitudinal continuity need to invest in more formal interventions to facilitate management, flexible and informational continuity to ensure smooth transition is not compromised.

Conclusions

Whilst the language of 'models' has been used to describe the phenomena of interest for the purposes of this report, the real world of practice is infinitely more complex. In a given locale, the configuration of service components necessary to ensure smooth transition will depend on local organisational context and related model components, and services may experience on-going modifications in response to wider organisational exigencies. Accordingly, the aim of this study was not to compare models for the purpose of identifying the best model in an absolute sense; but rather to consider in-depth a sample of models reflecting the range of existing service provision in order to identify and understand the generative mechanisms central to smooth transition, their inter-relations and the service components through which these can be achieved in a given organisational context.

There are questions we believe warrant further research. These are:

- Research to address young people's singular support needs at this stage of the life-course and their implications for service delivery and organisation.
- Research to address young people's needs for, and access to, information and their preferences for information format.
- Longitudinal research to examine how far self-care practices in adolescence and young adulthood are predictive of adult health behaviours.
- Research which examines the costs and benefits of strict and relaxed approaches to diabetes management at this stage of the life-course.
- Research to develop and evaluate different interventions to support the management continuity needs of carers.
- Research to develop and evaluate different interventions to address carers' support needs.
- Research to address mechanisms for promoting cultural continuity across services.
- Research to address young people's needs and preferences in relation to dietary advice.
- Research to address the relationship between continuity mechanisms and clinical outcomes.
- Research to address the relationship between continuity mechanisms and clinical outcomes on large populations using quasi-experimental methods.
- Development and evaluation of a 'Rolls-Royce' model of transition through a randomised controlled trial.

The Report

1 Background

Type 1 diabetes is a long-term condition requiring continuous self-management. During adolescence many experience deterioration in the control of their condition. They are particularly vulnerable as care is transferred from child to adult services. The importance of getting transition right is increasingly acknowledged across international healthcare arena. All too often transition has been perceived as a single event and there has been a lack of appreciation of the need for developmentally appropriate services⁽¹⁾. Since transition first became a health policy concern over twenty years ago, a strong professional consensus has emerged on best practice in this domain and numerous guidelines now exist⁽²⁻⁴⁾. Research to inform the design of services is weak⁽⁵⁾ however, and prevailing views about 'the problem of transition' are based on assumptions about adolescence, adulthood and the management of long-term conditions which have been accepted uncritically⁽⁶⁾. The aim of this study was to begin to address these gaps in understanding.

1.1 What is diabetes?

Diabetes is a major health problem, accounting for approximately 9% of acute National Health Service (NHS) expenditure⁽²⁾. Type 1 diabetes results from the gradual destruction of pancreatic beta (insulin-producing) cells. A lack or relative insufficiency of insulin causes hyperglycaemia, which leads to polyuria, polydipsia, lethargy and weight loss. If untreated, ketoacidosis occurs, causing vomiting, coma and, eventually death. Complications associated with diabetes include retinopathy, which can result in blindness; nephropathy, which can result in kidney failure; neuropathy, which can result in lower limb amputation; macro-vascular complications, which can result in heart disease and strokes; peripheral vascular disease and infections⁽⁷⁻⁸⁾. In industrialised countries the long-term prognosis is worse in early onset diabetes, with a higher risk of kidney damage and increased relative mortality⁽⁹⁻¹⁰⁾. For children and young people with type 1 diabetes, the target for long-term glycaemic control is an HbA1c of 7.5% without frequent hypoglycaemia. In the UK, fewer than 20 percent of children and young adults achieve this target. Indeed, 48 percent are unable to achieve an HbA1c of 9.0%, a threshold above which the risk of long-term complications rises steeply⁽¹⁰⁾. The risk of dying of any cause for children diagnosed with type 1 diabetes is double that expected in the general population⁽¹¹⁾. People who develop diabetes in childhood can have their life-span

reduced by as much as 20 years and many develop long-term complications before middle-age⁽¹²⁾.

1.2 Living a life with diabetes

Management of diabetes is aimed at maintaining optimal blood glucose control. It depends on the individual performing insulin injections several times daily or making regular adjustments to the continuous rate of insulin infusion through a pump-delivery system, monitoring blood glucose levels and attending closely to diet and exercise. Insulin and diet must be modified according to activity and blood glucose levels. The complex nature of diabetes self-care makes it difficult to manage well. According to sufferers, diet and exercise are the most challenging aspects of treatment⁽¹³⁻¹⁴⁾ and 75 percent of diabetic patients report deviating significantly from recommended dietary guidelines at least weekly⁽¹⁵⁾.

“Coping with diabetes is a full-time job, 7 days per week, 52 weeks per year. One cannot take a vacation from diabetes without risking at least temporary health impairment.”

(16: 559)

1.3 Young people and diabetes

During adolescence there is a marked deterioration in metabolic control⁽¹⁷⁻¹⁹⁾. This appears secondary to several factors. Physiological changes in glucose metabolism during adolescence increases insulin ‘resistance’ and, coupled with increased growth hormone concentration in association with the pubertal growth spurt⁽²⁰⁾, augments insulin requirements which may need to be adjusted regularly⁽²¹⁾. Adolescence and young adulthood is a period of multiple social changes which can magnify the challenges of self-management⁽²²⁻²⁴⁾. Even subtle changes in the routines of everyday life can have important consequences⁽²⁵⁻²⁶⁾. ‘Non-compliance’ with recommended medical regimen is a particular concern at this stage in the life-course⁽²⁷⁻²⁸⁾.

1.4 Empirical studies of transition

Research on diabetes transition services in the UK is limited. Eiser *et al.*⁽²⁹⁾ report on a survey of users’ (n=69) perceptions of a diabetes clinic for under 25s and their experiences of transferring from paediatric clinic. The study identified that paediatric and adult staff had different orientations to service provision. Paediatric staff placed greater emphasis on school progress and family relations, whereas adult providers emphasised the importance of exercise and blood glucose levels. In general respondents recalled little difficulty in transferring clinic, but considered that it would be helpful if they could visit the under 25 clinic before transfer, if there was improved

coordination between paediatricians and adult physicians and if a nurse from the under 25 clinic could visit the paediatric team. The authors conclude that, at least in retrospect, young people do not report any difficulties associated with the transfer to adult services. This is despite the fact that they do report differences in clinic culture.

Kipps *et al.*⁽³⁰⁾ report on a regional survey of transfer from paediatric to adult services. They identified a marked decline in clinic attendance around the time of transition. Clinic attendance rates two years post-transfer were higher among those who moved away to attend university but retained their diabetes care within region, compared with those who did not move away to university. Age at transfer was not related to transfer outcome. The authors observe high rates of dissatisfaction among young people who transferred directly from a paediatric to an adult clinic. But even among those who transferred to a young adult clinic there were still differences in perception. The authors conclude that the mode of transfer is more important than the age at which it occurs. Transfer to a young adult clinic is preferable to direct transfer but this does not resolve all the problems. Prior contact with the consultant from the adult clinic seems to be an important determinant of outcome.

Jones *et al.*⁽²²⁾ report on an interview study of eight young people before and after transfer to adult services. In contrast to other research in this area, all respondents found the process of transition difficult and in particular breaking away from established relationships in the paediatric service. Adult consultations were described as impersonal and predominantly focused on medical rather than social issues. Relationships with nurses were highly valued and young people particularly valued being able to contact the nurse in between clinic appointments. All young people claimed that they required more support in young adulthood than they had as children and access to advice from a known health professional was considered important.

Datta⁽²¹⁾ examined six transition models. While not inclusive of all types of transition arrangements, the models ranged across a diverse geographical area, served different communities and had varying caseloads. According to Datta, they provide insight into the differing experiences of young people making use of these services. The model descriptions offered in the report concentrate on service structures, relatively little information is provided on service processes.

The perspectives of young people are examined using qualitative interviews and a quality of life questionnaire. Overall, young people expressed satisfaction with services. The majority did not know when or where the adult clinic was held or how often their appointments would be and most were ignorant of the doctor or nurse they would be seeing in the adult clinic and more than half had

not met adult staff. Interviews with service providers indicate attempts to organise education programmes but these were not popular with young people. Despite the fact that they had not been well prepared for transfer, most seemed ready for the move and were not worried about it. According to Datta, relationships with staff were more important for young people than structural arrangements for managing transition. A majority stressed the importance of a non-judgemental approach, with many appreciating the informality and friendliness of diabetes nurses and the time diabetes nurses had to care for them.

The findings from this study furnish useful insights into young people's experiences of transition, however, no attempt is made to draw comparisons between models and the study design did not permit identification of the relative effectiveness of individual service components.

1.5 Dominant constructions of transition¹

In this section we describe how 'the problem of transition' has been defined in the professional and UK policy literature and examine the assumptions that underpin it. This is not intended to present an exhaustive review; our aim is to identify the main characteristics of the dominant discourse which has shaped thinking in this field. The notion of discourse is taken from the social sciences and refers to ways of organising knowledge through which problems come to be defined in particular ways and through which particular solutions are privileged.

1.5.1 The value and vulnerability of young people

Literature on transition is informed by a commitment to the value of young people coupled with a concern for their vulnerability. Although young people are one of the healthiest groups in the population judged by mortality and health service use, there are other aspects of their health which have become the focus for adult attention. For example, the easy availability of cigarettes, alcohol and 'recreational' drugs, combined with changes in sexual mores, presents young people in developed societies today with a whole new range of risks⁽³¹⁾. Moreover, adolescence and young adulthood is widely assumed to be the stage in the life-course during which life-long health care behaviours are established^(24, 32) and therefore represents a window of opportunity to promote health behaviour and influence the health burden of tomorrow's adults⁽³³⁻³⁴⁾. 'Non-compliance' with recommended medical regimen is a particular concern, with

¹ This section draws substantially on 6. Allen D, Gregory JW. The transition from children's to adult diabetes services: understanding the 'problem'. *Diabetic Medicine*. 2009;26(2):162-6. (2008).

adolescence portrayed as a time of emotional turmoil and risk-taking which can threaten health.

1.5.2 Psychosocial barriers

Psychosocial barriers to transfer are believed to contribute to the challenges of transition. These include a reluctance on the part of both users and providers to let go of a relationship which has developed over many years in the paediatric context⁽³⁵⁻³⁷⁾, carer fear of the long-term complications of the condition that transfer signifies⁽³⁸⁾ and resistance to the philosophy of independence that underpins adult services which might leave them feeling excluded⁽³⁹⁾. Such concerns have led to an emphasis on early preparation for transition so that it is 'accepted, expected, and recognised as the norm' and perceived as a positive event⁽⁴⁰⁾ and the importance of ensuring there is an opportunity to establish relationships with adult providers before transfer.

1.5.3 Clinic attendance

Ensuring that young people do not lose contact with the service is another central concern. This reflects a prevailing view that a relationship exists between clinic attendance and diabetes management. Less frequent contact with a hospital clinic has been linked to poorer prognosis⁽⁴¹⁾, poorer blood glucose control⁽⁴²⁾ and an increased prevalence of complications⁽⁴³⁾. High rates of non-attendance by young people at clinic appointments have been reported after transition into the adult service⁽⁴⁴⁾. The response to these concerns has been the emergence of age-stratified clinics, outreach and attention to clinic environments.

1.5.4 Service cultures

The challenge of building bridges between paediatric and adult service cultures has also received considerable attention. Paediatric care is portrayed as family-centred and developmentally-focused, whereas the ethos of adult services is believed to emphasise independence, self-management and direct communication with users⁽³³⁾. An additional concern is that in the adult service young people will be brought into contact with older people who have experienced serious complications such as blindness or amputations⁽⁴⁵⁾. Adult clinics are portrayed as busier than children's services⁽⁴⁴⁾. In the paediatric service, systems for following up individuals who do not attend clinics are often rigorous, whereas in adult services if an appointment is missed the onus is on the service user to make alternative arrangements⁽⁴⁶⁾.

One response to these concerns has been the emergence of age-stratified clinics. A national survey of paediatricians found that 52 percent of respondents had organised age-stratified clinics and

nearly all of these were either adolescent or young adult clinics⁽⁴⁷⁾, although as Dovey-Pearce *et al.* note, this does not guarantee appropriate specialist care⁽⁴⁸⁾. In parallel, there has also been a focus on the need to develop strategies to ensure that young people are equipped to function in the adult service. A consensus is emerging that timing of transfer should be based on the 'readiness' of the young person rather than age, and that there is a need for interventions to support independent self-management. As yet, however, there is insufficient evidence to recommend adoption of a particular educational programme and no programme has been proven effective in randomised studies for those with poor glycaemic control⁽⁴⁹⁾.

1.5.5 Organisation

Cultural differences between services are believed to be compounded by organisational factors which militate against seamless transfer. The absence of formal systems to support handover and communications are identified as a common system weakness⁽⁴⁴⁾. Casual agreements between doctors, while easy to set up, are prone to failure and vulnerable to staff departures⁽²⁾. Increasingly there is recognition of the need to ensure that the necessary administrative arrangements, policies and protocols are in place to support transition⁽⁴⁹⁾ and roles and responsibilities clearly defined.

1.6 Understanding the 'problem' of transition

While a consensus appears to be emerging in relation to best practice in this field, the evidence base is relatively weak^(2, 5). Furthermore, understanding of the problem of transition has been informed by a set of assumptions which have been accepted uncritically. In the following section we will draw on the social sciences literature to examine the ideas through which transition has come to be understood and consider alternative interpretations of the 'problem'.

1.6.1 The myth of independence

Models of transition are strongly influenced by developmental psychology and based on the belief that a central goal of adolescence is to establish independence from carers. This is considered a prerequisite for transfer to adult services. Dependence is presented as 'childish' and carers as 'over protective'⁽⁵⁰⁻⁵¹⁾. Yet weakened social ties are not an inevitable feature of recent social history⁽⁵²⁾. Changes to higher education and youth labour markets have meant that many young people are dependent on carers into early adulthood with an increasing number living in the family home⁽⁵³⁾. Empirical evidence indicates that young people and their carers often retain close relationships and some studies suggest that the need for carer support can actually increase in young adulthood^(52, 54-55) and that there are

dangers associated with the withdrawal of support under the misguided expectation that young adults should be independent. As Ribben⁽⁵⁶⁾ notes, valuing independence implies a future orientation; the development of independence may necessitate training and effort from carers. Research has repeatedly demonstrated the role of significant others in supporting chronic disease management⁽²⁵⁾ and in the context of diabetes care, there is evidence that young people have an increased need for support as they are becoming independent⁽²²⁾ and interventions to improve outcomes are most effective with continued carer involvement⁽⁵⁷⁾. Holdsworth and Morgan⁽⁵³⁾ maintain that just because an individual has the capacity to act independently they may not choose to do so and, although we may chastise someone for being not able to think for themselves, we also recognise the necessity of being able to care for others as the basis of intimacy and personal relations. These authors suggest that the concept of inter-dependencies is more meaningful in understanding young people's lives.

1.6.2 Compliance, self-management and risk

A further feature of the way the 'problem of transition' has been constructed is the emphasis that is placed on supporting young people in developing adult-like health behaviours. These are taken to be rational and compliant with medical advice and are privileged over the purported irrational and risk-taking behaviours of children and young people⁽⁵⁸⁾. These assumptions are problematic for several reasons.

First, dominant perspectives of adolescence are based on a 'storm and stress' model⁽⁵⁹⁾ in which adolescence is portrayed as a distressing time characterised by emotional turmoil⁽⁶⁰⁾. In recent years, however, an accumulative body of work has revealed the conventionality and conformity of contemporary youth⁽⁶¹⁾. Gillies *et al.*⁽⁵²⁾ studied 'ordinary' young people and their carers living in a range of circumstances. In contrast to the problem-focused content of previous research they found respondents described their family relationships in positive terms and few carers identified with the common public representations of the teenage years as particularly difficult.

Second, implicit in constructions of the problem of transition is the assumption that adult behaviour is compliant with medical advice. There is a wealth of evidence which demonstrates that adults do not comply with medical regimens, albeit for rational reasons⁽⁶²⁻⁶⁷⁾. In his study of people who suffered with epilepsy, Conrad⁽⁶⁵⁾ found that nearly half the respondents altered their prescribed medications and engaged in some kind of self-regulation. Modifying medication practice as a vehicle for asserting control over illness has been shown to be generalisable^(64, 67-69) and what has emerged is a recognition

that far from being deviant behaviour, 'non-compliance' reflects reasoned decision-making processes^(62-63, 69) and that knowledge does not predict compliance with medically determined treatment plans⁽⁷⁰⁾.

The assumption that patients ought to be following medical orders and that non-compliance is deviant and irrational has recently been questioned, with the terms 'compliance' and 'adherence' giving way to that of 'concordance' in order to signify the importance of partnership between health professionals and users. However, as Thorn⁽⁶³⁾ points out, despite this change in terminology, much of the medical literature is based on the ideology that non-compliance is deviant behaviour with considerable activity being devoted to the development of different interventions to promote behaviours to support self-management consistent with medically-determined treatment plans.

One consequence of these linked assumptions about adolescence, adulthood and transition, to paraphrase Skelton⁽⁷¹⁾, is that it opens up the possibility for transition failures which can reinforce negative representations of young people. For people with a chronic illness, there is a perceived obligation to show they are doing their best to control and manage it. Yet whilst diabetes carries high levels of responsibility in terms of self-management, ultimate power and control are maintained by health professionals through surveillance and this appears to be informed by a culture of distrust⁽²⁴⁾. Like others with chronic conditions, the basic strategy of young people for managing their diabetes is 'normalisation'⁽⁶⁴⁾; 'non-compliance' is an unavoidable by-product of collisions between the clinical world and other competing worlds of work, play, friendship and family life⁽⁷²⁾. Setting unrealistic or unattainable treatment goals or adopting a punitive approach will often trigger a sense of failure and drive the young person into a state of denial and disengagement⁽²⁴⁾. Moreover, the overarching notion that adolescence is a problematic time means that other factors and constraints which might impact on management are overlooked. Rather than being accused of non-compliance, young people need to be helped to find creative solutions to the conflict between self-management regimen and other aspects of their lives. Peyrot *et al.*⁽⁶⁴⁾ introduce the concept of 'relaxed control' in order to avoid the implication that people with diabetes who do not share the target level of glucose control determined by health professionals are necessarily unconcerned about control. Most want to achieve some level of control but disagree with health professionals about somewhat higher than recommended glucose levels.

1.6.3 Clinic attendance and metabolic control

Clinics are accorded a central role in monitoring glucose control and the literature indicates concern with high rates of non-attendance by young people. This arises from the belief that good metabolic control

results in improved outcomes⁽⁷³⁾ and that a relationship exists between the former and clinic attendance. However, the evidence underpinning both these assumptions is equivocal. Whilst the Diabetes Control and Complications Trial (DCCT) has shown that intensive therapy can improve glycaemic control and reduce complications, Murphy *et al.* ⁽¹⁰⁾ report that

“...even in the setting up of the rigorously conducted Diabetes Control and Complications Trial, achieving optimal glycaemic control in adolescents proved difficult. Management of the younger cohort is reported to have taken up a disproportionate amount of staff time and yet the mean glycosylated haemoglobin (HbA1c) values of adolescents were still approximately 1% higher than the adults.”

(10: 935)

This intensive intervention also included a threefold risk of increased severe hypoglycaemic episodes. Moreover, whilst clinical experience demonstrates repeatedly that young people who attend an adult service only after a problem has arisen could have averted it with proper knowledge and self-care, there is little evidence that demonstrates that those who stop attending diabetes centres have poorer metabolic control^(2, 10). These issues question whether clinic attendance is necessarily the best approach to supporting young people with diabetes management.

1.7 The ‘problem of transition’: are we focusing on the right issue?

Despite growing recognition that young people with diabetes should be looked after by specialist teams into adulthood^(3, 74), dominant constructions of the problem have produced a focus on the goal of adulthood and the requirements of the adult service, rather than the needs and experiences of young people and their carers. Attention has concentrated on the fact that young people fall outside the principal focus of paediatric and adult medicine and the primary concern has been to ensure a smooth transfer of care between services whilst maintaining metabolic control and good clinic attendance. This is reflected in the frequently quoted^(34, 38, 75-76) America Society for Adolescent Medicine definition of medical transition as: ‘the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions, *from child-centred to adult-oriented health care systems*’ (our emphasis). The solutions to this challenge, as reflected in the recommendations for practice, are: communication between services, ensuring readiness for independent self-management, creating opportunities to build relationships with new service providers, providing information so that young people and carers understand the new arrangements for care and encouraging regular clinic attendance through age-stratified, young-person friendly clinic environments and

effective outreach (Appendix 1). In the absence of any stronger evidence and resources to develop dedicated services for young adults, this is sound guidance. However, the overwhelming emphasis is on supporting young people to fit into the healthcare system rather than attending to their experiences and needs at this stage of the life-course. Where attention has been directed at the needs of young people this has tended to focus on so-called risk factors, rather than the breadth of young people's lives.

For over twenty years professionals and policy makers have focused on the question of how best to manage transition and there is evidence of considerable effort on the part of local clinicians in developing their services to address this 'problem', often with little wider organisational support. However, a review of progress two years after the introduction of the UK National Service Framework for Diabetes, explicitly acknowledges that the challenge of transitional services remains⁽⁷⁷⁾. Perhaps the time has come to start thinking about this issue differently and consider alternative formulations of the 'problem'. Rather than asking how transition should be managed, we might ask how best to meet the needs of young people with diabetes at this stage of the life-course. This requires understanding of the experiences of young people and families, the social networks in which they are embedded and consideration of how self-management might be supported by the healthcare system.

1.8 Methods and methodology

1.8.1 Research question

The Department of Health National Service Framework (NSF) for Diabetes states that: 'all young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult services'⁽²⁾. The central concern of this project was to generate evidence on the most effective approaches to achieving this standard. As such it was framed within the dominant construction of the problem of transition as reflected in the practice and policy literature. However, our aim was to ensure that the questions driving data generation allowed space for alternative formulations. Accordingly, a secondary concern was to examine the experiences of young people and their carers to identify whether alternative approaches are called for. Young people tend to accept the arrangements for their care without reflecting on how they could be different⁽²¹⁾.

1.8.2 Research aims

1. Identify, map, categorise and enumerate the range of diabetes transitional models in use in England.

2. Develop a conceptual framework of models building on SDO commissioned work.
3. Undertake in-depth evaluation of a purposive sample of models to examine:
 - a) stakeholders' definitions of 'a smooth transition', their experiences and preferences
 - b) structures, mechanisms and processes involved in achieving 'smooth transition'
 - c) the relative effectiveness of transition models in achieving 'smooth transition'.
4. Use these data to develop an understanding of users'/carers'/providers' experiences of, and preferences for, transitional services, the processes and organisational challenges involved and assess costs.
5. Make recommendations about what works best to promote 'a smooth transition', for whom and in what circumstances.
6. Use these data to contribute to our understanding of transitional care trajectories and develop further theories of continuity of care.
7. Use these data to generate hypotheses and research questions for future exploration.
8. Involve service users as appropriate throughout the research process and evaluate this process.

1.9 Theoretical framework

In addition to the critical analysis of dominant constructions of transition, the study design was influenced by three main literatures: system theories of healthcare work, previous National Institute for Health Research (NIHR) Service Delivery and Organisation (SDO) programme commissioned research on continuity of care and realistic evaluation methodology.

1.9.1 Systems thinking

The research was framed within a systems approach to service delivery. Grounded in interactionist theories of the division of labour, this perspective recognises the interdependence of system components in shaping trajectories of care, including how the social worlds and life-course of users/carers interact with the service⁽⁷⁸⁾. Here the concern is with how people, structures, processes and technology interact to produce service outcomes.

Strauss *et al.*'s concept of an illness trajectory provided a useful sensitising concept. It refers to the physiological unfolding of a disease *and* the total organisation of work done over its course^{(25, 79-}

⁸⁰⁾. The notion of a trajectory brings into view the active role that people play in shaping the course of an illness and directs attention to the interplay of 'workers' (including young people and carers), and the non-medical features of management along with relevant medical ones. The concept enables an analytic focus on the social context for illness management and the social relationships that affect it.

1.9.2 Continuity of care

While our aim was to understand 'smooth transition' from the perspective of stakeholders, Forbes *et al.*'s work on continuity of care in transitional service arrangements was used as an orientating framework⁽⁵⁾. Forbes *et al.*, building on Freeman *et al.*'s⁽⁸¹⁾ study, identify seven dimensions which they consider to be relevant to an understanding of this area of service provision: experienced continuity (the experience of a coordinated and smooth progression of care from the service users' point of view); continuity of information (excellent information transfer following the service user); cross-boundary and team continuity (effective communication between professionals and services with service users); flexible continuity (flexibility and adjustment to the needs of an individual over time); longitudinal continuity (care from as few professionals as possible, consistent with needs); relational or personal continuity (one or more named individual professionals with whom the service user can establish and maintain a therapeutic relationship) and developmental continuity (care which not only grows with the changing demands of the client group but also works to facilitate that change). These concepts were modified and refined as a result of an iterative data generation and analysis process.

As we were carrying out this research Parker *et al.*⁽⁸²⁾ were engaged in a review of previously commissioned NIHR-SDO studies on continuity of care. This entailed critical interpretive synthesis of how continuity of care was defined by the research studies; narrative synthesis of evidence on what influenced continuity of care and the outcomes it led to and descriptive synthesis of continuity of care measures and their psychometric properties. The findings of the review were published as we were finalising the report for this study. We consider how far our findings concur with those of the review authors in the synthesis of the study findings.

1.9.3 Realistic evaluation

The study design followed the principles of realistic evaluation methodology⁽⁸³⁾ in which interventions are conceptualised as social systems - comprising the interplay of agency and structure, human and non-human actors and micro and macro processes – which always work though the action of mechanisms. Underpinned by a generative theory of causation, the aim is not to identify variables

which associate with one another, but to explain how the association itself came about.

Realistic evaluation studies typically start with a theory of what makes an intervention work and the circumstances in which it is likely to be efficacious. Pawson and Tilley express this in the simple formula: context + mechanism = outcomes (C+M=O), in which 'mechanisms' reside in the black box of interventions and 'context' describes the conditions that are relevant to the activation/deactivation of mechanisms. The relationship between mechanisms and their effects is contingent; all social programmes are embedded in a wider set of social relationships and a crucial task is to examine how far structures enable or disable the intended mechanisms. It is possible to have the same intervention activating different mechanisms in different contexts. The primary concern in realistic evaluation is with identifying mechanisms or what it is that produces a particular effect. Following this framework leads us to ask the following questions: What works? How? For whom does it work and in what circumstances? Realistic evaluation focuses on outcome footprints; it does not produce a pass or fail verdict. The underlying rationale for this approach is that if we know and understand how different interventions produce varying impacts in different circumstances, we are better able to decide what policies/services to implement in what conditions.

2 A survey of diabetes transition models in England

A survey of diabetes providers was undertaken to map the range of transition services in England. The primary objective was to identify those features which discriminated between different approaches to managing transition in order to develop a typology of models which could be used to sample the spectrum of service provision for in-depth evaluation in Stage 2 of the study.

2.1 Method

2.1.1 Questionnaire development

A survey instrument was developed informed by previous work on continuity of care^(5, 81) and the wider literature on transition. Building on the work of Forbes *et al.*⁽⁸¹⁾, the survey instrument was predicated on the assumption (theory) that smooth transition (experienced continuity) depended on achieving different kinds of continuity of care and that there were different constellations of service components in use to achieve these effects reflecting local histories and constraints. Two versions of the questionnaire were developed; one designed for use with paediatric services, the other for adult services. It included general questions about the service, details of the service structure, information on mechanisms for transfer and organisational practices. Questions were also asked to establish why the service had evolved in the way that it had. The instrument was designed to enable responses to be categorised at the time of the interview. It was important to capture practices not identified in the literature; therefore an 'other' category was included in the coding scheme and space for free-text description. The questionnaire was piloted with local service providers (dietitians, nurses and consultants) from both paediatric and adult services.

2.1.2 Sampling

Diabetes services were sampled from the Directory of Diabetes Care⁽⁸⁴⁾. The Directory contains the details of 260 services in England, divided into four regions: London, South, Mid & East and North. Although this is a relatively comprehensive list, paediatric services are often unavailable. Invitations to participate were addressed to the health professionals listed in the Directory as a first point of contact who were asked to pass the information to the person able to comment on transition within their service. Interviews were undertaken with both paediatric and adult services

unless individual respondents had a detailed knowledge of the corresponding service.

Services were sampled via a list of computer generated random numbers. The first 20% of services within each region were selected for interview (52 services in total) and contacted in writing. Services which did not reply were contacted by telephone three weeks later and then on a further two occasions at two weekly intervals. In total, 26 interviews were conducted with service providers from the first sample. As follow-up was not successful in 50% of services contacted, a second sample of 20% was created and service providers were contacted and followed up in the same way. A further nine interviews were conducted from the second sample.

Data were generated and analysed concurrently. Interviews were conducted until no new service components or structures were identified which changed the emerging typology. The typology was verified by an opportunistic sample of 40 diabetes service providers attending the 2007 Diabetes UK Annual Conference. Theoretical saturation was achieved with approximately a 20% sample of service providers.

In total, 35 interviews were conducted. 32 participants were nurses, 3 were doctors. 41% were based within paediatric diabetes services and 59% were based in adult diabetes services.

Table 1. Number of respondents by region

Region	Respondents
London	2
South	11
Mid & East	9
North	14
Total	35

2.1.3 Data generation

The survey was administered via a telephone interview, exploring the context, structures and components of transition services. Questions were open-ended to allow full exploration of responses. Answers were only coded following respondent confirmation that interpretation of the information provided was correct. All interviews were audio-recorded for quality control purposes.

2.1.4 Ethics

The service mapping was determined to be pre-research activity and did not require formal NHS ethics or research governance approval.

2.1.5 Data analysis

Data were entered into a Microsoft Access database and plotted onto a grid based on the categories from the survey instrument. Any practices that were coded under an 'other' category were assigned a new category. The number of stages in the transfer process, the main criteria for transfer from each clinic and the staff involved were also plotted on the grid. Similarities and differences between services were noted. This led to a process of data reduction and the creation of broader categories based on the features discriminating between services. Service components were categorised according to the primary continuity of care mechanism they were designed to effect. This process revealed overlap between the continuity of care concepts identified by Forbes *et al.* which made it difficult to assign service components to a single continuity of care mechanism. Therefore we simplified their original framework and based the analysis on three paired continuity mechanisms: relational and longitudinal, informational and cross-boundary and developmental and flexible continuity.

A key challenge in analysing these data is mapping individual responses from service providers onto discrete transition models. Whilst the language of 'models' has been used to describe the phenomena of interest for the purposes of this report, the real world of practice is infinitely more complex. Transition is a process; models of transition in so far as they exist in an identifiable sense, are a constellation of structures and components designed to manage the interface between at least two services (and in some cases different organisations) whilst meeting the needs of young people at this stage of the life-course. Paediatric services may transfer into multiple adult services with each transition pathway (model) varying according to the arrangements in place in the receiving service. Aggregating multiple responses across a single transition model is also challenging as the continuity mechanisms may vary on each side of the service. For example, paediatric services may have a complex division of labour necessitating formal interventions to support inter-professional communications, whereas the receiving adult service may have a simpler form. In consideration of these difficulties and given that the primary purpose of the survey was to develop a typology of models in order to sample the full range of service provision for Stage 2 of the study, data were analysed per the 35 provider responses. Given that we had roughly equal representation from paediatric and adult services, we considered this to be a more reliable form of analysis than attempting to map provider responses onto discrete models which

would have introduced an additional interpretative element into the process.

2.2 Results

2.2.1 Transition model histories

All respondents gave a brief account of the development of their service arrangements. Four major influences were identified.

Guidelines

In approximately one third of interviews providers pointed to the influence of guidelines, with NICE guidelines and the National Service Framework for Diabetes being the most frequently cited. Several expressed the view that these were research based.

"I guess it's because of standard 8 in the NSF which basically says that you've got to have a transition clinic."

"I presume it would be to do with the Children's Act and...the NICE guidelines and the various research studies that have gone on over the years."

Clinic attendance

Improving clinic attendance was identified as another service driver with this being offered as a reason for transition models in approximately one third of all responses.

"We'd lose a lot of people from the paediatrics to the young adults and we're trying to hopefully reduce the amount of people we lose. That's why the transitional clinic has come about really, to improve the service."

"There's a big difference isn't there between paediatrics and adult with how often they get reviewed, and you know, you get a bigger DNA rate don't you once they've left paed to adult so whether maybe that's why [things have developed this way]."

Leadership

Approximately one sixth of service providers attributed the development of transition services to specific staff members.

"He's immensely interested in young people and teenagers and [his commitment to these patients] has a significant impact."

Service user need

Approximately one third of respondents suggested that their service had been developed to reflect the fact that young people have different needs to adult patients with diabetes.

“They have different needs to the rest of the adult population really.”

“It’s so many different issues...you can’t just sit and tell them...what they should be doing. You have to sort of work around their needs.”

2.2.2 Service structure

Stages of transfer

The survey identified examples of direct transition (i.e. direct transfer from paediatric to adult services) and indirect transition (i.e. transfer via an interim clinic or clinics). The number of stages in the transfer process refers to the number of interfaces it is necessary for young people to cross as they move from the paediatric service through to the adult service. For example, direct transfer from paediatric to adult services would be a one stage model. 8.7% (n=3) of services used a one stage transfer process, 54.2% (n=19) used a two stage process, and 37.2% (n=13) used a three stage process.

Age-banded clinics

91.4% (n=32) of services included an interim age-banded clinic for older children and/or younger adults. Most stated that there was flexibility on the age of transfer between the interim clinics and the adult clinic. The median age for entry into an interim clinic was 16 years (range 12 – 17 years), and the median age for exit from an interim clinic was 25 years (range 19 to 30 years). Interim clinics for older children/younger teenagers lasted for a median of 48 months (range 12 to 198 months). Interim clinics for older teenagers/young adults lasted for a median of 78 months (range 24 to 114 months).

2.2.3 Service components

A range of service components were identified through the survey. These were categorised according to the primary pair of continuity of care mechanisms they were designed to generate.

Relational and longitudinal continuity

Three service components were identified designed to effect relational/longitudinal continuity, with one arising inductively through open questioning.

Joint clinics

85.7% (n=30) of services operated a joint clinic attended by paediatric and adult service providers. The intention is that young people will either become familiar with the clinicians they will see when they transfer to adult services, or be more comfortable meeting a new service provider with a familiar clinician from paediatric services present. In some cases clinicians from both services undertook joint consultations and in others clinicians consulted separately but were both in attendance at the clinic.

Handover meetings

Handover meetings are conducted before or immediately after transfer to the adult service, and allow a formal introduction to the new diabetes team. These are single events. 17.1% (n=6) of services provided a handover meeting.

Boundary workers

Several services had employed workers specifically to span the paediatric-adult interface. In some instances individuals were based in both the paediatric and adult services, and in others, individuals provided outreach. 37.1% (n=13) of services employed a professional who was a boundary spanner or an outreach worker for the purposes of transition. Another approach was to appoint an individual to liaise between the two services or for a member of a team to assume this role. 8.6% (n=3) of service providers did this.

As well as generating relational/longitudinal continuity, the elements of practice described above also appeared to have the potential to generate informational and cross-boundary continuity.

Table 2. Relational and longitudinal continuity service components

Service component	% of services
Joint clinics	85.7 (n=30)
Handover meetings	17.1 (n=6)
Boundary Workers	37.1 (n=13)

Informational and cross-boundary continuity

A further five service components were identified which were designed to effect informational and cross-boundary continuity. All five were identified deductively.

Transfer of notes

Most service providers stated that they transferred a complete copy of the medical notes from the paediatric to the adult diabetes service, with 91.4% (n=32) reporting that this occurs within their service.

Information provision

91.4% (n=32) of providers stated that they prepared young people for transition by providing them with practical information about what to expect from the adult service. Within this 21.9% (n=7) provided written information as part of this process. In most cases, guidance was provided verbally, as part of routine care.

Protocols

Service protocols for transition are formally written procedures that state how the transition from paediatric to adult diabetes services should be managed. 57.1% (n=20) of services reported that they had local service protocols relating to transition.

Guidelines

77.1% (n=27) of providers stated that they followed specific guidelines for transition. Guidelines differ from protocols, in that they do not prescribe transition procedures. However, they do promote a common standard to which service providers should orient.

Team planning meetings

Several services reported holding team meetings in order to plan the transition process for individuals or small groups of patients. 31.4% (n=11) of services reported that team meetings assisted them in providing continuity of care for patients going through transition.

Table 3. Informational and cross-boundary continuity service components

Service component	% of services
Transfer of medical notes	91.4 (n=32)
Information provision about new service (verbal)	91.4 (n=32)
Information provision about new service (written)	21.9 (n=7)
Formal written protocols	57.1 (n=20)
Guidelines	77.1 (n=27)
Team transition planning meetings	31.4 (n=11)

Developmental and flexible continuity

Our survey also identified measures designed to effect developmental and flexible continuity. Developmental/flexible continuity interventions included policies of encouraging the patient to become more active in their diabetes management, learning to manage diabetes in line with other life-course transitions, and adjusting to changes in their clinical consultations. Several respondents referred to modifications of approach, but because this lacked specificity, we did not categorise this as a specific developmental/flexible continuity intervention for the purposes of the survey. Five main elements of practice relating to developmental/flexible continuity were identified, two of which (gradual lone attendance and preparation for 'culture shock') were generated inductively.

Gradual lone attendance

48.6% (n=17) of services encouraged lone consulting by the young person as a gradual, phased process.

Supporting independent diabetes management

28.6% (n=10) of services said that they specifically provided education/advice on self-care to promote independent diabetes management. In most cases, this was done individually and was built into routine care, although 5.7% (n=2) of services provided group education/teaching sessions.

Carer support

Some services provided support for carers in adjusting to changes in their role in managing their child's diabetes and in enabling their child to gain independence. 60% (n=20) of services said that they provided carer support through the transition process, although this appeared to be via the care of the young person.

Preparation for 'culture shock'

One of the challenges of transition are the cultural and organisational differences between paediatric and adult diabetes services and the initial experience of the adult diabetes service can often be shocking for young people. 45.7% (n=16) of services attempted to adjust users' expectations of the diabetes services by preparing them for a different approach to their care prior to transfer. This was usually achieved by through discussion.

Life-course support worker

14.3% (n=5) of services employed a dedicated staff member to work specifically with young people to encourage effective diabetes self-management, and/or other areas of their health and lifestyle, around the transition period. Health professionals in this role included a liaison psychologist, a youth worker, a sexual health liaison worker and nurses.

Table 4. Developmental and flexible continuity service components

Service component	% of services
Gradual lone attendance	48.6 (n=17)
Supporting independent diabetes management	34.4 (n=12)
Carer support	60 (n=21)
Preparation for culture shock	45.7 (n=16)
Life-course coaches	14.3 (n=5)

2.3 Typology of transition models

The objective of Stage 1 was to map service provision in order to develop a typology from which to sample different models for in-depth evaluation. The purpose of a typology is to enable the observer to see order in a complex universe; they are created by noting homogenous attributes in heterogeneous phenomena. Winch⁽⁸⁵⁾ distinguishes between 'heuristic' and 'empirical' typologies. Heuristic typologies are derived primarily from theory and empirical typologies are derived primarily from data. Hybrid typologies are empirically grounded but theoretically informed. The typology developed in this study is an example of this latter approach. It is based on empirical data generated by the survey, but assembled according to our theoretical focus on continuity of care. Its purpose was to generate categories of transition model which spanned the full range of existing service provision in order to identify the generative mechanisms central to smooth transition and the service components through which these can be achieved in a given organisational context. It is possible therefore that our data, could be categorised in alternative ways for different purposes.

All services included service components designed to promote informational/cross-boundary continuity, and most included elements to promote relational/longitudinal continuity. The features that discriminated between services were the extent of developmental/flexible continuity practices (a service was defined as using a greater degree of developmental and flexible continuity practices if it incorporated at least three of these elements of practice) and the stages in the transition process. By combining the structural characteristics (one, two or three stages) with the process characteristics (the proportion of continuity service components) we created a typology of six transition models (Table5).

The proportion of services in each category are enumerated in the table below; however, in interpreting these figures it is important to recognise (a) the singular purposes for which the typology was developed and (b) that the results are based on provider responses to the survey and do not necessarily map directly onto a discrete real life transition model.

Table 5. Typology of transition models and percentage of services categorised by each model type

No. of stages in transition model	Informational/cross-boundary & relational/longitudinal continuity	Informational/cross-boundary, relational/longitudinal & developmental/flexible continuity
1	5.7% (n=2)	2.9% (n=1)
2	37.1% (n=13)	17.1% (n=6)
3	20.1% (n=7)	17.1% (n=6)

2.4 Discussion

Six models were identified from the survey. Service components appeared to centre on either informational/cross-boundary continuity and relational/longitudinal continuity or developmental/flexible continuity. This resonates with the findings of Forbes *et al.* who found that '[i]n some initiatives the focus was on getting the young person from child to adult services as safely and efficiently as possible; in others, a more developmental model to continuity was established by equipping the young person with the resources necessary not only to weather the transition but to take on a new role in relation to their condition or disability' (p.69)⁽⁵⁾. Given the number of services across England, there were surprising similarities between them, despite functioning within different contexts. The results demonstrate a movement towards sequential models of transition; few services operated via a direct transition process. Two of the three examples of direct transition we identified were planning service change within the next 12 months, and the one case in which no changes were planned had a very small number of young people transferring into adult care.

Our survey indicates that diabetes transitional services display a high degree of 'institutional isomorphism'⁽⁸⁶⁾. DiMaggio and Powell use this term to refer to the processes that force one organisation in a given field to resemble others which face the same set of environmental conditions. DiMaggio and Powell develop a theory which enables them to account for the processes through which organisations become more similar even if they do not necessarily become more efficient. They argue that early adopters of innovations are commonly driven by the desire to improve performance. Over time, however, new practices become 'infused with value beyond the technical requirements of the task at hand' (p.17)⁽⁸⁷⁾. As an innovation spreads, a threshold is reached beyond

which adoption provides legitimacy rather than improves performance.

DiMaggio and Powell identify three sources through which isomorphic change occurs. Coercive isomorphism arises from pressures exerted on organisations by other organisations on which they are dependent and the cultural expectations of the societies in which they function. Of particular relevance for current purposes is the role of the state and its rules and systems of legitimation which provide an orienting framework within which organisations structure their activities. Mimetic isomorphic processes are the result of uncertainty which encourages organisations to model themselves on other organisations. A third source of organisational isomorphic change is normative pressures. According to DiMaggio and Powell this stems primarily from the growth of professions, which they argue are subject to the same kinds of coercive and mimetic pressures as organisations. Professions within a field are subject to similar kinds of socialisation processes and professional networks allow new models to diffuse rapidly.

DiMaggio and Powell argue that it should be possible to predict empirically which organisational fields will be most homogeneous in structure, process and behaviour (pp.155-156).

Hypothesis 1: 'The greater the extent to which an organizational field is dependent upon a single (or several similar) sources of support for vital resources, the higher the level of isomorphism.'

Centralisation of resources causes homogenisation by placing organisations under similar pressures from resource suppliers. In the case of the NHS this is the state, or local commissioners of services.

Hypothesis 2: 'The greater the extent to which the organizations in a field transact with agencies of the state, the greater the extent of isomorphism in the field as a whole.'

Governments routinely designate industry standards for a whole field which require adoption by competing firms. In the diabetes context in recent years we have seen the emergence of a range of Department of Health sanctioned national service frameworks delineating 'best practice' in this area. Almost a quarter of all services surveyed indicated that guidelines had been highly influential in the development of their transition services and many mistakenly believed these to be evidence-based.

Hypothesis 3: 'The fewer the number of visible alternative organizational models in a field, the faster the rate of isomorphism in that field.'

Our survey suggests that there is relatively little variation in approaches to managing the problem of ensuring a smooth

transition, and thus, following DiMaggio and Powell we might predict an acceleration of isomorphic processes in the future.

Hypothesis 4: 'The greater the extent to which technologies are uncertain or goals are ambiguous within a field, the greater the rate of isomorphic change.'

While a consensus appears to be emerging in relation to best practice in managing diabetes transitional services, the evidence base underpinning these recommendations is relatively weak^(2, 5,88).

Hypothesis 5: 'The greater the extent of professionalization in a field, the greater the amount of institutional isomorphic change.'

Transitional care is a highly professionalised field. In addition to guidelines, the second most important determinant of organisational forms according to our survey was the special interests of particular members of staff – either consultants or specialist nurses.

Hypothesis 6: 'The greater the extent of structuration of a field, the greater the degree of isomorphics.'

DiMaggio and Powell suggest that 'fields that have stable and broadly acknowledged centres, peripheries, and status orders will be more homogeneous both because the diffusion structure for new models and norms is more routine and because the level of interaction among organizations in the field is higher.' The highly professionalised nature of diabetes transitional services in a state funded health service, suggests that diabetes transitional care is a strong candidate for institutional isomorphism.

There is a clear fit between the organisation of diabetes transition services and each of the hypotheses DiMaggio and Powell argue are predictive of a tendency towards homogeneity of structure. Considered within this framework, the relatively uniform organisational forms to be found in the field of diabetes care can be understood. We consider the implications of these findings in the synthesis and overall study conclusions.

2.5 Conclusion

Six different models were identified by the survey. There appears to be considerable similarity in the underlying structure of services. Theories of institutional isomorphism relate to institutional forms and it is well understood that these may not necessarily translate into homogeneity of practice and organisational processes. Whilst the survey instrument aided the development of a typology of models for the purpose of selecting a sample for Stage 2 of the study, it has several limitations: (a) it is based on provider responses to the survey which, given the complexity of transition services, do not necessarily map directly onto discrete models (b) it draws on public accounts and as such reflects provider intention rather than actual practices, (c) it only identifies formal structures and processes;

informal processes, organisational culture and taken-for-granted practices are not captured (d)the typology focuses on the primary generative mechanisms an intervention is designed to effect, whereas in practice an intervention may generate more than one mechanism and the same intervention can generate different mechanisms in different contexts. The aim of Stage 2 is to examine in greater detail transition model components, the mechanisms generated by different organisational forms and the extent to which they produce a smooth transition from the perspective of service users and carers. Comparison of the effects of different service components in different models will also allow the relationship *between* generative mechanisms to be examined.

3 Transition model evaluation methods

3.1 Methods

3.1.1 Transition model sample

The typology was used to select a purposive sample of transition models for in-depth evaluation. Services of less than 12 months duration or where significant changes were planned were excluded. The original study design proposed a sample of eight models. The sample size was chosen to enable in-depth investigation of all theoretically relevant transition models within available resources. Owing to the institutional isomorphism revealed by the service mapping, a sample of six models was considered sufficient to ensure adequate representation of the spectrum of provision.

The sample included two 2-stage models and two 3-stage models with predominantly relational/longitudinal and informational/cross-boundary continuity interventions, or a combination of relational/longitudinal, informational/cross-boundary and developmental/flexible continuity interventions (Table 6). We included another two 3-stage models which had additional interesting features. One was selected because transition arrangements necessitated the management of an organisational interface between a children's hospital and an adult hospital and had a strong community orientation. Another was selected because it provided an integrated service for adults up to 40 years in a dedicated diabetes centre. Unfortunately, owing to service pressures, this latter model withdrew from the study at a stage when substitution was not feasible. Moreover, whilst the direct transfer model of transition is a theoretical possibility within our typology, in practice there were few services which had caseloads large enough for inclusion and those which did were moving towards an indirect model. No examples of direct transition models are therefore included in the study. However, we remained alert to the possibility that within our sample there may be individuals who do not follow the primary model of transition within a service and who, for a variety of reasons, elect to transfer directly to adult services or to the care of their general practitioner. We identified several such cases and these are considered within the individual model evaluations.

Table 6. Transition model sample

No. of stages in transition	Informational/cross-boundary & relational/longitudinal continuity	Informational/cross-boundary, relational/longitudinal continuity & developmental/flexible continuity
2	Model 3	Model 5
3	Model 4	Model 2 Model 1 Model 6 (withdrew)

3.1.2 Ethical considerations

NHS Research and Development Office and Research Ethics Committee approvals were received.

Informed consent

All participants were provided with information about the aims and purpose of the study. A suitably placed service manager provided signed consent for the service to participate and within this all individual service providers and users/carers gave written permissions. Return of the survey instrument was taken as evidence of consent from this study population. All participants were informed that they could withdraw from the study at anytime without offering a reason. Users/carers were reassured that their care would be unaffected by such a decision. Once they had agreed to participate in the study, their GP was informed.

Data presentation

All research participants were assigned a code in order to anonymise the qualitative and quantitative data. Information linking anonymised materials and personal information was kept in a locked filing cabinet and on password protected computers. All qualitative data has been anonymised and edited to remove identifying materials. In presenting data generated from service providers role designations have not been provided to ensure anonymity. Young people have been assigned pseudonyms selected by the research team. Data relating to young people is prefixed with 'YP' and data relating to carers is prefixed with 'C'.

3.1.3 Data generation

Each transition model was evaluated drawing on a range of qualitative and quantitative data.

Organisational ethnography

In order to develop a rich description of each model data were generated through: documentary analysis, interviews and selected observations. Relevant organisational documents were collated to build up a picture of the model. Semi-structured interviews were undertaken with service providers/managers in order to generate information on model antecedents and history of implementation, service components relating to young people, service components relating to carers, service components relating to providers, local division of labour and working relationships, service components relating to continuity of care, provider experiences and preferences for transitional services and resource costs of the model. Interviews were audio-recorded or transcribed as contemporaneous fieldnotes. Selected observations were undertaken in each in order to provide contextual information. Data were recorded as low-inference, near verbatim fieldnotes and later transcribed.

Individual case studies

In each transition model we carried out case studies of users identified by staff as undergoing or about to undergo transition. Our target sample was 12 per model stratified by gender. For the purposes of the study the 'case' was defined as the user, their main carer and their surrounding network of diabetes care. Potential cases were identified by appropriately placed health professionals and a purposive sample selected by the researchers. As far as possible, cases were sampled across the full transition period within each model. However recruitment proved challenging and despite our best efforts and the support of service providers we did not achieve the desired sample size (Table 7) and were not able to sample cases across the full transitional period in all models. It was also our intention to conduct case studies of users/carers identified by staff as poor attenders but this was not possible. Datta⁽²¹⁾ reports similar challenges in accessing a meaningful sample of this particular group and suggests that access through service providers may not be the most appropriate method. Alternative sampling strategies need to be developed and this is an area for further research. Only two cases dropped out of the study.

Table 7. Case study sample by model

Transition Model	Females	Males	Carers	Total
Model 1	1	4	5	10
Model 2	2	5	6	13
Model 3	5	4	7	16
Model 4	8	3	10	21
Model 5	7	7	11	25
Total	23	23	39	85

Each case was studied over 12-18 months. Retrospective and contemporaneous data were generated from multiple sources.

(a) Clinical records were reviewed in order to provide background information and explore patterns of service provision. A pro-forma was developed to support extraction of qualitative and quantitative data which could then be depicted diagrammatically.

(b) Interviews were undertaken with users/carers and relevant providers. Interviews with users/carers were semi-structured and designed to gain an in-depth understanding of their engagement with the service, life context and social world, and experiences of transition and preferences for service provision. Users and carers were interviewed at baseline and then at approximately 6 monthly intervals. The content of interview schedules at each stage was modified to reflect the emerging analysis, with the final interviews specifically designed to test empirically the emerging context-mechanism-outcome hypotheses for each model and for the study as a whole. Young people and carers were also asked questions designed to ascertain the user-borne costs of the service.

In most cases, three interviews were undertaken with each young person and their carer. The first was carried out face-to-face and lasted approximately an hour, the second by telephone lasting approximately 30 minutes and the third face-to-face lasting approximately an hour. Face-to-face interviews were carried out mainly in the young person's home, with a minority undertaken in alternative venues such as cafes. The majority of user and carer interviews were carried out separately and in private; although in a small number of cases at the request of the family the young person or carer was present at the time of the other party's interview. We recognised that this may constrain the content of interviews, but given the challenges of recruitment to the study, we were eager to avoid attrition and therefore made the necessary compromise in order to respect families' wishes.

Interviews with service providers were designed to ascertain significant contributory factors that had shaped service outcomes in each case. While some interviews were undertaken with individual

service providers, for practical reasons most were conducted in groups in order to minimise the pressures on clinical teams. Interviews were audio-recorded.

Table 8. Interviews per transition model

Transition Model	Young people	Carer	Individual health professional*	Total
Model 1	15	16	4	35
Model 2	21	15	6	42
Model 3	24	21	6	51
Model 4	35	36	9	80
Model 5	43	30	13	86
Total	138	118	38	294

*In order to reduce the demands on clinicians, in some models, health professionals were interviewed in groups; these data are in addition to the individual interviews listed here.

(c) Users/carers were provided with diaries in which to record diabetes related events, their experiences, thoughts and reflections on transition. Diaries were relatively unstructured and it was not a requirement to make an entry every day. Nineteen completed diaries were returned (11 carers; 8 young people) and the quality of entries varied considerably. Some young people used them purely as a record of their diet and insulin requirements, whereas others recorded their feelings and thoughts on key events in which diabetes had been consequential. In some cases, the uniformity of handwriting strongly indicated that multiple entries had been made at the same time. The diaries yielded little additional data than that generated by the interviews and, given the small number returned, their value was limited to that of cross-checking with findings arising elsewhere.

(d) We had intended to record service delivery processes in our cases, but for practical reasons this proved very difficult. It was challenging to schedule fieldwork visits to coincide with times when our cases were attending clinic. To overcome this, we secured ethical permission to record some examples of consultations with additional service users but the volume of data generated was variable across models and of limited value for current purposes, although it may have future potential in relation to the questions about consultation style raised by the wider study.

(d) Psycho social outcome measures – young people were asked to complete SEIQOL on two occasions (Appendix 2).

User/carer survey

Parallel surveys of young people with type 1 diabetes, approaching, undergoing or under 12 months post transition (as defined in the study sites), and their principal carer were administered between October 2008 and June 2009.

The questionnaires included instruments that measured satisfaction (including perceived continuity), healthcare climate and quality of life. The questionnaire for young people included the Healthcare Climate Questionnaire (HCCQ), the Diabetes Continuity of Care Scale (DCCS), the Patient Enablement Instrument (PEI), the Diabetes Management Self-Efficacy Scale (DMSES) and the Diabetes Quality of Life measure for Youth (DQoLY). These scales were chosen following a systematic review of the literature (Appendix 3). The questionnaire for carers also includes the HCCQ and DCCS and the Perceived Competence for Diabetes Scale (PCDS) and the Short Form 36 (SF36). Both questionnaires contained supplementary questions aimed at measuring how young people and their carers felt about their health professionals and attending clinics, along with the clinic a patient was currently attending and which health professional was considered to be most important to them in providing their diabetes care. See Appendix 4 for a summary of the number of items in the scales used and their range of possible values.

3.1.4 Analysis

Qualitative

All data were transcribed and entered into computer-assisted qualitative data analysis software to facilitate data retrieval and analysis. Data from different sources were triangulated in order to build up a comprehensive picture of each transition model and comprised analysis of:

- organisational arrangements
- service users'/carers'/providers' perspectives
- user/carer case studies.

Organisational arrangements

Following the first phase of fieldwork and interviews with health professionals and managers, ethnographic descriptions of each transition model were developed and verified with service providers. For each model, hypotheses were identified about model components and their generative mechanisms. These were derived from a combination of induction, the literature and analysis of interviews. Some were model specific, others common to all five models. They

guided subsequent data generation and were revised and reframed in line with the on-going analysis.

Users'/carers' perspectives

A thematic analysis was undertaken of users'/carers' experiences of living a life with diabetes and the transition process. This generated themes which were common to all models (Appendix 5) as well as insights on individual models and their constituent components. We found a high level of agreement between young people and carers' on the services received and so their views are reported together. In those instances in which services impacted differently on young people and carers their experiences are analysed separately.

Case studies

Data from clinical record review, interviews and observations were synthesised to build up a profile of each individual case and care pathway. Care pathways were verified by young people and their carers. The method allows examination of the whole system of care as it is experienced by both recipients and providers in a given social and organisational context and facilitates the identification of hypotheses about enhancers and facilitators of transition. Case study pictograms were assembled derived primarily from information extracted from clinical records. In addition, for each case, a short narrative summary of the pathway through the service was produced derived from the interview data. Individual case studies were treated as 'outcomes' and informed the individual model evaluations. They were also taken into account during the analysis of users'/carers' experiences of and preferences for the service, to ensure that views were interpreted in the context in which they were expressed. A further aim was to describe the quality of life domains nominated by young people and assess stability or change over time (Appendix 2).

Quantitative

Survey

While the survey was administered at two different time points to the same sample, the number responding to both was very small (82/739 (11%)). Both time points were therefore combined. For those who had responded twice, one of their questionnaires was randomly selected. Results for specific models were split by completer (either young person or carer) and by the type of clinic the young person was attending. With respect to this latter item the questionnaire gave the options: children's diabetes clinic, young person's/teenage diabetes clinic, adult diabetes clinic, GP surgery or other. The three stage models included in the evaluation have two interim clinics which could be categorised as young person's/teenage clinic and this has to be taken into account in interpreting the outcomes of the survey. Model 1 is one of four possible models

through which transition from the children's service is managed. The sample for the survey was based on young people meeting our inclusion criteria who were registered with the children's hospital only, as the adult hospital did not have electronic records and could not access this information. Therefore, the survey results in model 1 refer to all young people attending the children's hospital including those who transferred to the three other adult hospitals.

Regression analysis was performed for the DQoLY and HCCQ scales for young people. Explanatory variables include age (of the young person when the first questionnaire was administered); gender; the clinic a young person was attending (with children's clinic as the reference category) and descriptors, specific to certain models, which were developed from the qualitative analysis (the presence of high levels of relational, developmental, flexible and cultural continuity). Not all qualitative descriptors were included in the model due to redundancy (Appendix 6).

Regression analysis was performed on three of the SF36 scales (general health, vitality and mental health) for carers. Explanatory variables include those that were used in the young person regression models (described above) as well as whether or not a carer attended consultations with their child.

The results of the regression models are presented in a summary table with arrows pointing up indicating a significantly (at the 5% level) higher score with the corresponding factor present, and arrows pointing down indicating a significantly lower score with the corresponding factor present. The models are also presented in more detail, with coefficients, 95% confidence intervals and p-values, in Appendix 7. A selection of young person scales were correlated with carer scales to measure the strength of association between responses. Correlation coefficients were checked for HCCQ scores (for both completers), for DQoLY: satisfaction (young person) against SF36: general health (carer) and for DMSES (young person) against PCDS (carer).

Cost and consequences of transition models

The economics component of the study adopts the form of a costs and consequences analysis rather than a more formal cost effectiveness or cost benefit evaluation. This is because the aim of the study was to identify which components of transition models work best in various circumstances rather than identifying any model as being unambiguously superior in terms of a single clinical outcome. A cost effectiveness analysis could not be undertaken due to the multiple outcomes of the study⁽⁸⁹⁾. A cost utility analysis was not attempted because of the unlikelihood of differences in transition models leading to significant differences in health utilities.

The costs and consequences framework used here cannot produce an economic conclusion but will identify both the direct costs of the

different models and provide an indication of the costs borne by patients and their carers as well as their use of other NHS resources. These will be discussed in relation to the outcomes which can be affected by different forms of transition service.

Direct costs

The costing exercise involved estimating the resources devoted to transition. In many cases this was made difficult by the fact that, transition did not involve a free standing service with dedicated staff and facilities. Staff often had to disentangle time spent on activities judged to be 'transition' from those considered to be a normal part of paediatric or adult care. Difficulties in identifying other resources such as equipment or facilities led to the estimation of direct costs focusing solely on costs of staff.

Service providers were asked to identify the full range of relevant activities for each transition model - for example, adolescent/young adult clinics, team briefings, home visits, transfer visits, etc. - and for each activity to report the number and grade of staff involved and the hours per week devoted by each to each activity. Where relevant this included time spent travelling.

Unit costs for staff (hourly rates) were derived from Curtis⁽⁹⁰⁾ based on costs by professional roles and include salary on-costs (employers' National Insurance contributions, superannuation, etc) as well as ongoing training and qualifications, indirect and capital overheads (see Appendix 8). Unit costs are reported by activity e.g. per consultation and/or per hour. Unit costs are often separated into 'client contact' and 'non-client contact' hours. Time inputs were valued by the appropriate unit cost e.g. travel time was valued as 'non-client contact' time. The cost of providing any service is influenced by the number of transition patients cared for. Total costs were converted to per patient costs using the number of patients registered with the service at the beginning of the study as a proxy for the number of patients seen per month.

Indirect costs

Indirect costs include patient/carer borne and other NHS costs incurred during the study period. Travel and parking costs incurred during hospital visits were recorded, as well as any carer time away from their normal work that was required when accompanying children to appointments. Of those sampled from each of the models, the primary carers were invariably the mothers of the young person with diabetes. Other NHS costs include visits to the hospital for medical care other than that received in transition.

Data on user/carer borne costs were obtained during the interviews with the user/carer case studies for each model. This required information on any expenses incurred in connection with clinic visits or additional health care requirements due to managing diabetes and its complications. Respondents also reported time off school for

diabetes problems and time off work by carers in order to deal with the patient's diabetes e.g. accompanying them to clinics.

Interviews took place at three points over the course of the 18-month study period – March 2008 and October 2009. On each occasion, the questions related to what had occurred during the previous 3 months. This provided data for a total of 9-months and is reported as an average cost per month per patient.

The sample size for each model ranged from 5 to 14 patients. As this represents only a small proportion of the patients receiving care in each model, this analysis can only provide an indication of the additional costs incurred by patients, carers and the NHS.

Travel costs were calculated according to information provided as to the mode of travel, distance to the clinic, and any parking costs incurred per visit. Bus fares were quoted as they were incurred and car travel expenses were calculated according to the standard mileage charge (40p/mile) provided by the HMRC (see: <http://www.hmrc.gov.uk/RATES/travel.htm>). When the duration (mins) of the travel to a clinic appointment was provided with no details of mileage, an average mileage of 30mph was employed to calculate the cost of travel.

Any additional time away from work required by carers (usually a parent) was calculated according to the Office of National Statistics (ONS), Annual Survey of Hours and Earnings (ASHE, 2009 – See online resource: <http://www.statistics.gov.uk/pdfdir/ashe1108.pdf>). ASHE report median weekly earnings of £489, which translates into a daily rate of £97.80 (employing a 5-day week).

Use of other NHS services included contacts with the GP, practice nurse, school nurse, specialist diabetic nurse, optician, audiologist and dentist as well as any hospital admissions or accident and emergency episodes and any calls made to NHS Direct. Unit costs and sources for each of these services are listed in Appendix 9.

3.1.5 Data synthesis and cross model comparison

For each transition model multiple sources of data have been synthesised to examine how contexts and mechanisms interact at individual and aggregate levels to produce outcomes (Appendix 10) these materials form the substance of the main report. In addition, discrete reports are presented as appendices for the review of instruments (Appendix 3) and individualised quality of life (Appendix 2). The study was informed by a service user reference group – this process is described and evaluated in Appendix 11 and the findings were shared with key stakeholders in order to consider their implications for policy and practice (Appendix 12).

4 Results of the individual transition model evaluations

4.1 Conceptual framework

The evaluation of transition models was guided by Forbes *et al.*'s framework of continuity of care in transition services^(5, 81). As these authors acknowledge, however, this is limited by the quality of the literature from which it was derived which privileged formal processes over human elements of care and by the lack of research focusing on the young person's perspective⁽⁹¹⁾. One of the aims of the study was to consider the usefulness of this framework for understanding transitional models and take into account the meaning of 'smooth transition' from the perspective of users. Through an iterative process of data generation and analysis we modified Forbes *et al.*'s original concepts and identified eight inter-related continuities of care which have been used to analyse the transition models.

4.1.1 Experienced continuity

For the purposes of the study we have retained the original definition of 'experienced continuity' as the experience of a coordinated and smooth progression of care from the service users' point of view or, in other words, 'smooth transition'. Here then 'smooth transition' is an overall service outcome.

We identified seven additional dimensions of continuity of care. For the purposes of this study these are conceptualised as the mechanisms which, in different configurations in different contexts, generate smooth transition.

4.1.2 Relational continuity

Relational continuity refers to an ongoing therapeutic relationship between the patient and one or more providers⁽⁹²⁾. Young people and carers valued highly personalised relations with health professionals who knew them individually and understood the fabric of their everyday lives.

4.1.3 Longitudinal continuity

Closely related to relational continuity is longitudinal continuity. This refers to uninterrupted relationships with service providers over time consistent with need⁽⁸¹⁾. It is possible to have longitudinal continuity with a limited number of service providers with whom one also enjoys relational continuity or longitudinal continuity of service

provider in which individual relationships are less personalised. A small number of cases preferred a more detached relationship with health professionals but nevertheless appreciated familiarity of service provider.

4.1.4 Management continuity

Management continuity refers to continuity of diabetes management consistent with needs through a common purpose and plan⁽⁹²⁾. There are clear links with Forbes *et al's* cross-boundary and team continuity concept which refers to the centrality of effective communication between service providers and their continuity of information concept which refers to excellent information transfer following the service user⁽⁵⁾. Both are interventions to generate management continuity, but are not the only means through which this may be achieved. A central feature of this concept for our purposes is that young people and carers are considered to be members of the health team, with their own management continuity requirements.

4.1.5 Cultural continuity

Cultural continuity refers to a seamless progression from a child to adult service culture across service interfaces. It is a new continuity of care concept derived from the data and specific to transition models. A key theme in the literature concerns the challenges of transferring young people from the family-oriented ethos of the children's service to the individual-oriented ethos of the adult service⁽²⁹⁾. Moreover, children's services are better resourced than are main adult services where the onus is on young people to sustain contact with the service. As we have argued, orthodox assumptions about the problem of transition centre on how best to prepare young people to cope with adult service cultures. In models in which child and adult services cultures are disparate, there is a requirement for developmental and informational continuity interventions (see below) to prepare the young person for transfer. This includes age-banded clinics and equipping young people with the knowledge and skills to function in the adult service. However, in models in which there is cultural continuity between service elements and a preparedness to tailor provision flexibly to the needs of young people (flexible continuity), such interventions become less necessary.

4.1.6 Flexible continuity

Forbes *et al.* define flexible continuity as flexibility and adjustment to the needs of an individual over time⁽⁶⁾. In the context of this study we take this to refer to care which is responsive to the needs of young people and their families and takes into account the reality of their everyday lives; it does not simply refer to the perceived risk factors of young adulthood. In the context of transition, this includes flexibility about the timing of transfer to accommodate individual

need and other life-course transitions and a preparedness to engage in the challenges of diabetes management at this stage of the life-course. Central to this is the extent to which decisions about day-to-day management are underpinned by a model of compliance or concordance.

4.1.7 Developmental continuity

Forbes *et al.* define developmental continuity 'as care which not only grows with the changing demands of the client group but also works to facilitate that change'⁽⁵⁾. For current purposes we limit our definition of developmental continuity to care that is intended to proactively facilitate the transition to adulthood and/or adult services and provide specific support to help young people develop physically, psychologically and socially.

4.1.8 Informational continuity

For the purposes of this study, informational continuity is taken to refer to the provision of information in order that young people and their families are prepared for transition and understand the new arrangements for their care. It does not refer to information exchange between service providers, this is categorised as a component of management continuity.

4.2 Summary

These concepts constitute key elements of smooth transition. The five models each comprised of a different configuration of structures and components designed to accomplish this end. Each had singular features which produced different tradeoffs and given the inherent complexity of this topic, it is cautioned that examining outcomes from model components in isolation from the context of the programme as a whole may be flawed. As Freeman *et al.* observe, continuity is a complex process and whilst it is possible to identify different elements of continuity of care in an abstract sense, in real life practice '[c]ontinuity of care is seldom an isolated or one dimensional virtue which can be enhanced without some corresponding and even conflicting event' (p.6)⁽⁸¹⁾. Accordingly, the aim of this study was not to compare models for the purposes of identifying the best model in an absolute sense; but to consider in-depth a sample of models representing the spectrum of services identified by the survey in order to identify the generative mechanisms central to smooth transition, their inter-relations and the service components through which these can be achieved in a given organisational context.

4.3 Transition model evaluation

In this section we present the evaluation of transition models. A summary of each model structure and resource usage is given, followed by a description and evaluation of the service components and generative mechanisms relating to smooth transition. For ease of exposition relational and longitudinal continuity, flexible and developmental continuity and management and cultural continuity are considered together. For each model we have produced a diagram and summary of key features. We recommend that these are considered alongside the evaluation below. There is more that could be written about each model, but descriptions are always produced for particular purposes. The descriptions below are crafted to bring out salient features in relation to the aims of the study.

4.4 Common quantitative outcomes

Descriptive quantitative outcomes are presented for each model. However, certain quantitative outcomes were common. A total of 230 young people with diabetes, from 739 that were approached across all five models, responded to the survey (a response rate of 32%).

All models reported, on average, a positive relationship (an overall median score of 4 out of 5, with an Interquartile range (IQR) between 3.9 and 4.5) between respondents and their service providers through the HCCQ. There was also evidence to suggest that respondents were satisfied with continuity of care (median scores of 4 out of 5, IQR between 4 and 5, through the DCCS scales). This maps on to our management continuity concept. Young people and their carers were also asked to rate (on a 5 point Likert scale, 1 – strongly disagree, 5 – strongly agree) how they felt about their health professionals (whether they felt frustrated, supported, informed about their diabetes or abandoned), how they felt about attending their clinics (whether they felt frightened, comfortable, guilty or worried) and whether they felt involved in the care they receive. Young people from all models reported positive levels of satisfaction with their health professionals. Median scores were high (median 4 out of 5, IQR between 3 and 5) for the positive statements (feeling supported and informed by their health professionals) and low (median 2 out of 5, IQR between 1 and 3) for the negative statements (feeling frustrated and abandoned by their healthcare professionals). This pattern was evident for both completers (young people and carer). Respondents from all models reported positive levels of satisfaction about attending clinics, again, with median scores high (median 4 out of 5, IQR between 3 and 5) for positive statements and low (median 2 out of 5, IQR between 1 and 3) for negative statements. This was also echoed across both completers. Participants from all models, on average, agreed or

strongly agreed that they felt involved in the care that they (or their child) received (median 4 out of 5, IQR between 4 and 4).

4.5 Model 1

Model 1 has 3 stages (paediatric- adolescent-young adult-adult clinic) and is operated by a regional children's hospital and a foundation hospital trust. The children's hospital transfers young people into four adult services, here we focus on the transition model in relation to one adult provider.

4.5.1 Cases

Five cases were recruited: four males and one female between 14-17 years and their main carer. Two had recently entered adolescent clinic from children's clinic and one made this transition during the study; one transferred from adolescent clinic to young adult clinic and two were planning to make this transition at the close of the research (Appendix 13). No cases transferred to main adult services.

4.5.2 Model structure

The children's service comprises four consultants (CONPs) and their junior medical staff, five paediatric diabetes specialist nurses (PDSNs) and two paediatric dietitians (SRDPs). It provides services to 320 patients. The team runs a paediatric and an adolescent clinic. There is a highly valued 24-hour on-call service and a strong emphasis on home visits and work with schools by nurses and dietitians. There is also a Saturday 'drop-in' service in the city centre popular with young people and their families.

"I mean it is just fantastic, it really does put your mind at rest that you know if there's anything at all you're worried about you've got that on a Saturday that you can just go along to." [1-C154]

Aged 19 young people transfer to the young adult service, run by an adult consultant (CONA), CONP (from the children's hospital), specialist registrar (SPR) and adult diabetes specialist nurse (ADSN). Funded by a pharmaceutical company, the ADSN functioned to provide a 'bridge' between services in response to concerns about clinic non-attendance after transfer. Consultations are longer and more frequent than in main adult services and there is a higher level of nursing support, including supplementary nurse-led clinics and access to the transition nurse's mobile phone number. Although the service is hospital rather than community focused, the aim is to provide a similar level of support to that provided by the children's service. Young people remain in the service until age 21-22.

Main adult services are provided by six CONAs, 11 ADSNs, dietitians and podiatrists. They have a caseload of 8000 and run a range of general and specialist clinics. Nurses are accessed by referral only.

The children’s hospital team has regular meetings, but there are no whole transition model meetings. **See Appendix 14 for model diagram and Appendix 15 for summary of key features.**

4.5.3 Resource allocation

Table 9. Model 1: Hours per month for health professionals

	hours per month				total
	Consultant	DSN (Band 7)	SPR	SRD (Band 7)	
transition stage (registered patients, n = 89)					
Children’s Hospital Adolescent Clinic	7.61	27.90	7.61	8.88	52.00
Children’s Hospital Drop-In Centre		12.69			12.69
Children’s Hospital Home Visits & Community Work		17.57		14.64	32.21
Young Adult Clinic	8.00	4.00	4.00		16.00
Nurse-Led Young Person’s Clinic		10.00			10.00
Ongoing Contacts		10.83			10.83
total hours	15.61	82.99	11.61	23.52	133.73
(% of total staff time)	(0.12)	(0.62)	(0.09)	(0.18)	(1.00)

4.5.4 Relational and longitudinal continuity

In children’s services there is limited relational continuity. The home care team is the primary relationship and underpinned by an explicit policy of the engagement of all members with the young person and their family. Most of our cases had built up relationships with the team and valued being able to contact any member (longitudinal continuity) but few described close relationships with a single health professional.

“I think it’s great because you don’t get to rely on that one person, you ring up ‘Is Bernadette (PDSN5/5) there? Oh no, oh, oh well when will she be in then, oh I’ll ring back tomorrow then’. You knew that you could talk to any of them.” [1-C137]

Clinic consultations are multidisciplinary but there is limited continuity of medical provider; young people see any of four consultants and/or additional junior medical staff. Relational and longitudinal discontinuity of doctor was not identified as particularly

problematic because the presence of home care team members at consultations ensured longitudinal continuity.

"[Y]ou see the registrars most of the time and sometimes we are seeing the consultant, I wouldn't say it makes any difference really because the contacts are the nurses and the healthcare workers [...] it doesn't feel as if we should have a constant person." [1-C179]

However, several of our cases indicated that they found the multidisciplinary consultation format intimidating and expressed a preference for one-to-one consultations.

"It's like a bit like being ganged up on sometimes if they're saying you're doing something wrong you feel a bit like. [...] I think that has the adverse effect to what they want it to be like, they want it to be like of a team that's there for you but instead it feels like that a team of them and you." [1-YP154]

"I think maybe if there was a lot of people in the room especially people I don't know it's kind of a bit more awkward, you feel a bit more pressured." [1-YP180]

Whilst the same team runs paediatric and adolescent clinics, on transfer to adult services, young people change hospitals and healthcare providers. Service users regarded the change as highly significant.

"(Moving from children's to adolescent clinic) was just a continuation of care; the time that it altered was when he went from them to the adult clinic. That was the transition." [1-C137F]

Young adult clinic is run by CONA, one of two CONPs, SPR and the transition ADSN. Longitudinal continuity is provided by CONPs and ADSN who attends the adolescent clinic at the children's hospital. In the young adult service young people enjoy relational and longitudinal continuity with the ADSN and longitudinal continuity with CONA and SPR. One case transferred to young adult clinic and two were about to make this move. Two positively evaluated having the opportunity to meet ADSN and Ben, who had made the transfer, appreciated having the paediatric consultant attend his initial consultation.

"It was good because you get to know the adult doctor but also with the doctor that you're familiar with as well, so it kind of eases it a little." [1-YP137]

"But it's quite nice that they do have staff from (the children's hospital) go to the Children's so [...] they won't be complete strangers to him." [1-C154]

In addition to positively evaluating the opportunity to develop a prior relationship with ADSN, Ben also valued having a single point of contact and one-to-one consultations during this period of change.

“I think the only person I do actually know fairly well is ADSN and I feel like she’s the only one that kind of, because when I see ADSN it’s only me and ADSN so we do just talk so I think it’s more personal whereas when you see, I haven’t seen the same doctor twice.” [1-YP137]

There is very little relational continuity in main adult services and contact with the nursing service is by referral only. Care is taken to ensure that transfer does not take place until the young person is capable of coping with this changed culture. None of our cases had made this transition and so we are unable to assess their experiences of the service.

4.5.5 Informational continuity

The paediatric service attends very closely to informational continuity and has in place a range of formal mechanisms. However, the approach adopted is shaped by their need to manage four organisational interfaces, representing different models of transition.

There is a proactive attempt to communicate to young people and their families the underlying rationale for the adolescent clinic. Young people are given an information sheet explaining its purpose which includes raising awareness of transfer to adult services. Three cases transferred from paediatric to adolescent clinic and had received this information and could recall its content.

On transfer to young adult services young people receive a letter and a leaflet – designed by the children’s team - explaining what to expect from adult care. The leaflet is intended for use by all service users, irrespective of their intended adult care destination and provides general information about adult services including GP care. All three cases who moved into or were anticipating moving into adult care recalled receiving this information. Preparation for transfer is also woven into clinic appointments, and can be discussed at home visits and the Drop-in Centre. Young people are specifically coached on how to get the best out of adult services (see developmental continuity). A further information continuity mechanism is the transition nurse’s participation in adolescent clinic owing to her familiarity with the specific details of the service into which young people will transfer.

Ben was the only case to have made this transfer. He was well informed about the differences between children’s and adult services and very comfortable about the process.

“I had loads (of preparation) because ADSN come and sit in with me for a good three, two or three clinics so no they’ve prepped me loads and told me how it was going to work, what was going to happen, how different it was going to be, so no I was quite prepared for it.” [1-YP137]

Whilst Ben described a well informed and smooth transition to young adult services in line with the intention of the model, others were more critical.

"I just think the lack of information regarding what will happen when he goes to adult care, there's just nothing and it's just shocking in a way that you're not given any information at all. [...] it's just a case of oh right okay, they've moved on from children's clinic, they've now gone into adolescent clinic, the next step is adults and it's just boom, boom, boom and they're expected to just get on with it and move along and that's it. They're not looking at them as individuals and families, it's very business-like, it strikes me as for a caring profession there's not a lot of care sometimes. [...] I really don't know what to expect for him and that's what worries me, I don't know what support he will get, how often he'll have to have his check-ups and so I really, really don't know what to expect and that concerns me." [1-C154]

Having had their awareness of the imminence of transfer to adult services raised, several mothers expressed uncertainty and concern about follow on arrangements. Indeed anxiety about adult services was more pronounced in this than in the other models, which is surprising given the systematic approach to informational continuity. One possible explanation is that because transfer is to another hospital and unknown care providers, it assumes a higher level of significance and creates greater fear. Many carers believed that the hitherto high levels of support and involvement they had enjoyed would cease and the adult hospital had a poor local reputation which fed into these concerns. There is also some evidence to suggest that in their efforts to ensure young people are fully equipped to function in the adult service, the informational continuity interventions are founded on worst-case scenario perceptions of adult service culture which serve to raise anxiety and were at odds with service realities. Indeed provider accounts indicate that the appointment of the ADSN had resulted in an improved understanding between services and had prompted the children's team to reassess the information provided. There was in actuality greater cultural integration across the service than was appreciated by paediatric staff. Thus, whilst there were several interventions in place to prepare families for transition, these raised families' awareness of the imminence of transfer and with it their anxiety about the future, but did not provide them with the answers to the specific questions they had in relation to the services they would be transferring to.

4.5.6 Management and cultural continuity

Within the paediatric service, the children's and adolescent clinic are run by the same team and as such, there are no specific management continuity challenges at this interface. However, within this model there are ever-present management continuity challenges

in the paediatric service arising from its complex division of labour. Within the home care team, management continuity is promoted by the co-location of nurses and a culture of on-going handover between nursing and dietetics staff. This is facilitated by a central report book in which all recent contacts with young people are recorded. Detailed nursing notes serve as record for ensuring continuity of care and key issues that may have a major impact on a young person's diabetes management are highlighted on a sheet designed for this purpose. Notes include both medical and social care details. The evidence indicates that these measures were very effective.

Additional challenges arise from the relational and longitudinal discontinuity of medical care. Although the team recognised the importance of relational and longitudinal continuity with a single consultant, in practice the young person could see any one of four paediatric consultants. In order to address this risk a multi-disciplinary meeting is held prior to paediatric and adolescent clinics. Led by the nursing team manager, the meeting is a vehicle through which clinical and social information is shared with the whole team – 'to put them into a person context rather than just a set of notes of a child who's coming through the clinic door'. In particular it aimed to ensure doctors were informed fully about any psychosocial issues which may have had a bearing on how they approached a particular individual's care. However, doctors did not always attend the full meeting, compromising its effectiveness. An additional management continuity mechanism was the presence of home care team members in the consultation.

A mixed picture emerged with respect to the effectiveness of these measures. Our cases reported largely consistent care and indicated that nurses were an important source of management continuity during consultations.

"[T]he nurses know Maria better than the doctor so the nurses will have a big input into the discussion or you know, sometimes say more than the doctor." [1-C148]

Nevertheless, several of our cases reported negative experiences of seeing an unfamiliar consultant. Matt, Rob and Maria all described consultations which left them feeling judged.

"Rob had put weight on and she handled it in a most insensitive way that you could possibly think of. [...] he'd gone up about 7 or 8 kilos and she just kept drumming into him that if it carried on he was going to be obese. [...] I sat there and I was just absolutely horrified and poor Rob, I mean you could see he was getting more and more upset by this." [1-C154]

In this model nurses were an important management continuity mechanism in circumstances in which the consultant was less familiar with the details of an individual case – both prior to and during

consultations. However, our data indicate that consultants are not always well-briefed and in the event of a consultant getting it wrong nurses did not always intervene. In Rob's case this experience resulted in the family becoming disenchanted with the service and made Rob nervous about asserting himself at consultation.

On transfer to the young adult service a letter is sent to the adult consultant summarising the young person's care. Young people have already established a relationship with the ADSN who undertakes to brief the consultant on the singular features of new cases. However, the ultimate aim is to enable young people to become accustomed to the adult service culture which encouraged stricter blood glucose control than the paediatric service. Adult service providers seek to empower young people and work with them to identify optimal management regimes rather than simply telling them what to do.

When young people first enter the young adult clinic, the consultant uses the initial consultations as an opportunity for relationship building, once relationships are established the approach becomes 'tougher' and is aimed at improving diabetes control. Only Ben had transferred to young adult services during the life time of the study and he concurred with the service provider's views of the differences in the adult services culture.

"[T]hey're kind of going on about effects and stuff and about if I don't do this and this is going to happen and they do a lot of that so it's like okay, you're a bit doom and gloom lately, so I need to do that a bit more. They're a lot more if you don't do this, this is going to be the effect now go away and do it kind of approach. [...] It's not my condition, it's yours kind of, arms length." [1-YP137]

Since the ADSN had started attending adolescent clinic, she had introduced the children's team to more 'aggressive' approaches to diabetes management, creating scope for their introduction prior to transfer, making the transition a smoother process.

When young people transfer to main adult services, they may see any one of six consultants and have no clinic contact with nurses. There are risks to management continuity here, but this is off-set by deferring transfer until the young person has developed the skills to proactively manage their own condition.

4.5.7 Developmental and flexible continuity

The children's hospital had a systematic approach to developmental continuity which was reinforced by management continuity mechanisms designed to ensure all young people were prepared for adult services, had moved towards greater independence in self-management and had had an opportunity to discuss all developmentally relevant issues. Developmental continuity was proactively addressed at particular stages in the transition pathway and included attention to individualised needs as well as risk factors.

Whilst there is some flexibility about the timing of transfer to adult services there is limited scope for deferring transfer until the young person is ready to make this move.

When young people transfer to secondary school, formal study days are provided in order to prepare them for independent diabetes management. This is in recognition of the fact that prior to this, it is parents who are primarily responsible for their care. Hereafter developmental continuity is supported through home visits, on-going contact and consultations in the Drop-in Centre. Risk factors are addressed at about 16 and there is strong evidence to indicate that this did indeed happen.

“They’ve started talking about smoking, drinking, all that type of stuff more, the growing up side of things.” [1-YP137]

Compared to clinic consultations, home visits and the Drop-in Centre were regarded as affording relaxed contexts in which to discuss sensitive topics. Staff indicated that they would encourage young people to come to the Drop-in Centre if they believed there were such issues to be discussed which were not being raised in clinic.

“I think Rob (YP154M/Patient) probably feels more comfortable in just that little Drop-in Centre that they’ve got as opposed to a clinic situation; I think he probably feels more comfortable as well.” [1-C154]

“You can just relax and talk about it in your own time, you’re not rushed because they’ve got to see someone else.” [YP137]

Prior to transfer, the home care team undertake a transfer home visit and as part of this process, they ensure that all risk factors have been discussed. The pro forma on which the details of home visits or home care team contacts are documented, includes a section for recording information about alcohol and smoking. Staff indicated that sometimes young people can be very embarrassed by such conversations and ‘not hear it’ and as such, part of the rationale for carefully recording these contacts is to provide some evidence that the paediatric service has broached these issues before transfer.

A lot of the preparation for transfer is aimed at equipping young people with the skills necessary to access the support needed from the adult services as well as supporting them to become independent managers of their condition. On transfer to adolescent clinic, staff modify their approach in the consultation to encourage greater responsibility for diabetes management.

“[M]ostly the doctor talks to me or the dietitian would talk to me and my mum is just there and my dad’s just there. [...] I guess it’s been more that way since I moved to the over fourteen clinic and it’s not so much that they’re talking to my parents or giving the advice to my parents as it is me.” [1-YP179]

“I think moving from the child to the adolescent it gave me more, it gave me more like independence and more like, they respected you more and they treated you more like an adult rather than a child and it gave you more confidence to speak to the dietitians and the nurses and the doctors.” [1-YP148]

Carers took their cues from staff and took a more peripheral role as service providers engaged more directly with the young person. Staff also made a point of dealing more directly with young people during home visits and by telephone rather than through carers.

In response to emerging research evidence that carer involvement can be supportive of the transition process, the team leaves the decision about carer involvement in consultation to the family. In four of our cases, mothers continued to attend the consultation, and although they had gradually taken a more peripheral role, most felt that they were involved in the caring process, benefited from it personally and could also be available to support their child if necessary.

“They make him feel valued as an individual [...] and that I never feel left out as a parent.” [1-C179]

Ben was the only case to move to lone consulting in adolescent clinic and he transferred to young adult clinic during the study. Ben felt fully prepared for transfer and appeared to be coping with the challenges of building new relationships with the adult team but his mother wished to be better informed and missed the on-going support of the home care team.

Within young adult services, health professionals are willing for carers to participate in the consultation, although many mothers appeared to treat transfer as a trigger for lone consultation. For many of our cases, transfer to the young adult service was a significant developmental milestone, signalling the progression towards adulthood.

“(Transferring to adult services is a big deal) because it’s kind of they’re more like saying that I’m trusted enough to deal with it more on my own.” [1-YP180]

Whereas there is a strong ethos in the children’s service of ensuring young people are fully prepared for transfer when they enter adult services, the ADSN does not consider transfer to be the end of transition. She regarded her role to be to continue with the process of supporting young people to manage their condition and function in the main adult service. In collaboration with the dietitian, she offers individualised life-course specific education on topics such as: weight management, eating away from home, eating at university.

Only Ben had transferred to young adult services, but he described having quickly developed relational continuity with ADSN and

receiving intensive on-going care and support in order to improve his diabetes management.

"I need to do four blood sugars a day, eight blood sugars a day, I need to do one before a meal and then one two hours after, so they want me to do eight a day. [...] And they want me to phone them every week. (ADSN) has me like every two weeks or so, I mean I saw her today, I was there today, so I've seen her today. [...] She's lovely, I think she's great, she's really helpful, so it just makes things easier. [...] If I've got a problem with something she will help me with it and she'll come up with different ways to help me like control it and stuff. She really does help, she's really helpful."
[1-YP137]

Whilst the transition nurse meets carers in adolescent clinic and considers this to be an important relationship, few attend young adult clinic. This is interesting, as many of our carers expressed concerns that at the point of transition the support they had enjoyed in children's service would no longer be available. For example, while Ben had successfully transferred to young adult services, his mother had not found the process as easy.

"I don't know what's expected of me anymore and I don't know what to expect from them. Is there still a hotline or not, he's an adult and they keep saying that, you know he's an adult he has to go to the adult clinic etc you know, but for me he's still my son and he's still got diabetes and he still needs help and guidance. He still needs reminding to do a blood sugar even though he doesn't do it but if I remind him he'll do it, do you know what I mean." [1-C137]

Two other carers anticipating transfer to adult services expressed similar concerns despite the fact that in both cases their children felt ready to make the move. Whilst it might be true that there is a reduced level of support, the intent of the ADSN is to have a continuing relationship with carers if they desire it. Here then is clear evidence of the need for better informational continuity to ensure that carers do not become unduly anxious and seek support from the service when it is available.

4.5.8 Quantitative outcomes

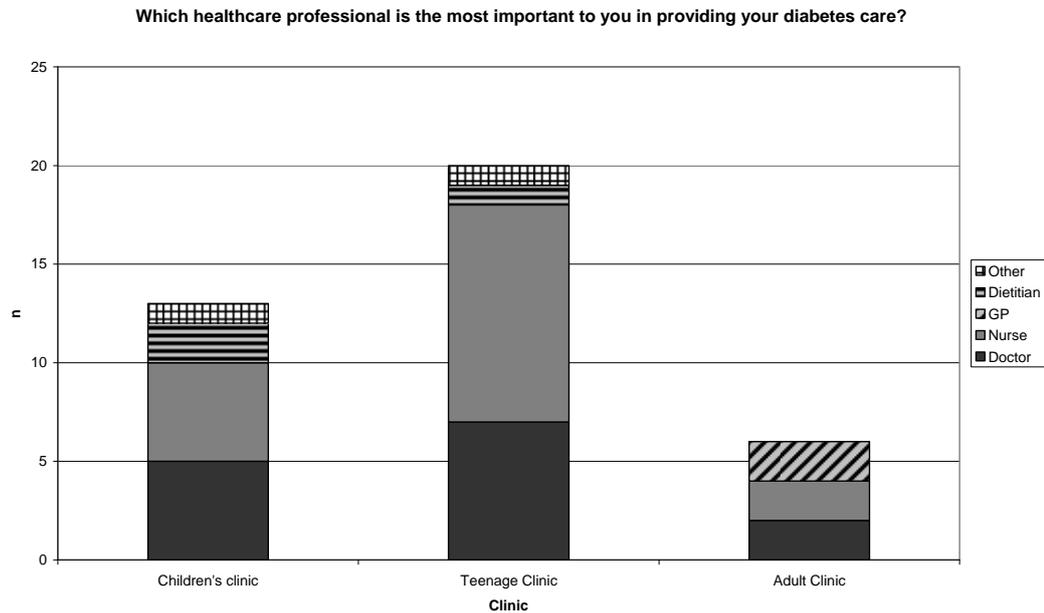
A total of 127 young people were approached in model 1. The sample for the survey was based on young people meeting our inclusion criteria who were registered with the children's hospital only. The adult hospital in this model did not have electronic records and could not access this information. Furthermore, as noted in chapter 3, young people attending the children's hospital transferred into one of four adult services, all representing slightly different transition models. The response rate was 33% (n = 42). 36% attended a children's clinic, 48% attended a teenage/young person's clinic and 17% attended an adult clinic. Lone consulting was

reasonably low in each clinic. Carers stated they currently sat in on 83% of consultations for young people attending a children's clinic, 71% for those attending the teenage clinic and 86% for those attending the adult clinic. Lone consulting was not proactively encouraged in this model and the multidisciplinary consultation format possibly acted to discourage young people from initiating lone consulting.

The average age for young people in model 1 was just over 17. Unlike the other models, there was not a distinct age gradient between clinics. Young people attending the children's clinic had an average age of just over 17, those attending a teenage/young person's clinic had an average age of exactly 17 and those in an adult clinic had an average of just over 18. These findings may be a methodological artefact and reflect the sample used for model 1. Furthermore, the fact that young people in this sample were attending a children's hospital and were anticipating transfer to a new adult hospital may have influenced how they interpreted the clinic descriptions in the survey instrument. As described in chapter 3, the survey instrument contained only three clinic categories: child, teenage/young adult, adult; whereas model 1 had two interim clinics. Overall, just under half of young people in model 1 were male. This differed slightly between clinics, with 60% of young people attending a children's clinic being male, 40% in a young person's/teenage clinic and 43% in an adult clinic.

For those attending a children's clinic, 39% considered a doctor to be the most important health professional. This percentage was the same for the nurse. Two responders (15%) attending the children's clinic considered a dietitian to be most important. In the teenage clinic, the nurse was considered the most important health professional (55%), with 35% for the doctor. 5% of young people in the teenage clinic considered the dietitian to be the most important. In the adult clinic, responses were split equally between doctor, nurse and dietitian (Figure 1). While carers considered the doctor most important when it came to providing their child with diabetes care in the children's clinic, the nurse was considered most important in the teenage and adult clinics.

Figure 1. Most important health professional for young people in model 1



Young people reported diabetes management self-efficacy which got higher across the different clinics. Participants in the children's clinic had a median score of 65 (Interquartile Range (IQR): 52 – 79), those in the teenage clinic had a score of 72 (IQR: 63 – 84) and those in the adult clinic had a median score of 79 (IQR: 60 – 88). Similarly for the DQoLY satisfaction scale, responders reported life and treatment satisfaction scores which increased across the clinics. Although the difference between children and teenage clinics is marginal (median of 61 in children clinic compared to 62 in teenage clinic), the median satisfaction score for the adult clinic is 70 (Table 10).

Table 10. Model 1: Young person outcome measures

Young person outcome measures	Children's clinic	Young person's/ teenage clinic	Adult clinic
PEI	23.0 (18.0, 26.0)	20.0 (18.0, 23.0)	20.0 (17.0, 28.0)
DMSES	65.0 (52.0, 79.0)	72.0 (63.0, 84.4)	79.0 (60.0, 88.0)
DQoLY: Impact of Treatment	8.0 (6.0, 11.0)	7.0 (6.0, 9.0)	8.0 (5.0, 9.0)
DQoLY: Symptom Impact	7.0 (6.0, 8.0)	8.0 (6.0, 9.0)	7.0 (6.0, 10.0)
DQoLY: Impact on Activities	10.0 (7.0, 12.0)	9.0 (7.0, 11.0)	9.0 (5.0, 15.0)
DQoLY: Parental Control	8.0 (7.0, 10.0)	9.0 (7.0, 9.5)	6.0 (4.0, 10.0)
DQoLY: Satisfaction	61.0 (53.0, 69.0)	62.0 (57.0, 67.0)	70.0 (56.0, 81.0)

Median (lower quartile, upper quartile)

PEI – Patient Enablement Instrument

DMSES – Diabetes Management Self-Efficacy Scale

DQoLY – Diabetes Quality of Life for Youth

Carers of responders in the teenage and adult clinics reported higher SF36 general health scores than those in the child clinics (medians of 77 in teenage and adult clinic compared to median of 67 in child clinic). There was a similar pattern with the SF36 social functioning (for children, teenage and adult, medians of 81, 100 and 88 respectively) and role emotional (medians of 67, 100 and 92 respectively) scales (Table 11).

Table 11. Model 1: Carer outcome measures

Carer outcome measures	Children's clinic	Young person's/ teenage clinic	Adult clinic
PCDS	3.5 (2.5, 4.8)	4.0 (3.0, 4.4)	4.0 (2.8, 4.4)
SF36: General health	67.0 (49.0, 78.6)	77.0 (48.5, 82.9)	77.0 (47.0, 92.0)
SF36: Reported health transition	2.0 (1.0, 4.0)	1.0 (1.0, 3.0)	1.0 (1.0, 1.0)
SF36: Physical functioning	95.0 (87.5, 100.0)	95.0 (86.3, 100.0)	100.0 (75.0, 100.0)
SF36: Role physical	93.8 (65.6, 100.0)	100.0 (87.5, 100.0)	100.0 (71.9, 100.0)
SF36: Role emotional	66.7 (47.9, 100.0)	100.0 (83.3, 100.0)	91.7 (62.5, 100.0)
SF36: Social functioning	81.3 (56.3, 100.0)	100.0 (93.8, 100.0)	87.5 (37.5, 100.0)
SF36: Bodily pain	44.0 (41.8, 50.3)	44.0 (32.0, 50.0)	50.0 (41.8, 50.0)
SF36: Vitality	47.5 (40.0, 55.0)	45.0 (26.3, 55.0)	45.0 (22.5, 57.5)
SF36: Mental Health	52.0 (40.0, 69.0)	60.0 (42.0, 68.0)	60.0 (28.0, 65.0)

Median (lower quartile, upper quartile)

PCDS – Perceived Competence for Diabetes Scale

SF36: Reported Health Transition: 1 – Much better now than one year ago; 2 – Somewhat better now than one year ago; 3 – About the same as one year ago; 4 – Somewhat worse now than one year ago; 5 – Much worse now than one year ago

4.5.9 Summary

Model 1 entails management of transition across an organisational interface. The process is systematic and proactively managed with a strong emphasis on developmental continuity. There is limited relational continuity in the paediatric service and a range of interventions in place to militate the management continuity challenges this presents. There is mixed evidence of their effectiveness in this regard. Moreover, although enjoying longitudinal continuity with the home care team, given a choice, young people would prefer relational continuity with a smaller number of service providers. On transfer to young adult services there is relational continuity with a single nurse and a smaller medical team and this is reflected in the quantitative outcomes on preferred health professional.

Transfer from children's to adult services is underpinned by boundary spanning activity to provide relational and management continuity. Young adult clinics provide an enhanced service in recognition of the support needs of young people at this stage of the life-course. As with children's services, developmental continuity is proactively

driven by service providers. The transition nurse had only been in post 12 months and in some respects the model was still adjusting to this new initiative. For example, some of the inadequacies of the informational continuity mechanisms were becoming evident to the team as a result of their interaction with the ADSN who afforded the opportunity for greater cultural integration. Both sides of the service expressed the view that since her appointment understanding between the two services had improved and there was a growing flexibility at the interface between the two organisations.

The model is characterised by a strong emphasis on developmental continuity for young people and on-going support and involvement of carers as appropriate. Young people and their families valued highly the home care team in the paediatric hospital and the level of service and support provided. Transfer to adult services is a highly symbolic event. Not only did it involve moving to a new hospital and new service providers, it was also a marker of their child's passage into adulthood. Many believed – erroneously – that once their child entered adult services they would cease to have involvement in their medical care. Furthermore, whilst mothers anticipated having a continuing role in supporting their child's diabetes management and envisaged that they would be encountering new situations at this stage of the life-course, they were uncertain where to go for support and advice. The children's hospital values informational continuity highly, but has real challenges in preparing young people for entry into four different adult services and had different kinds of relationships with the four providers with which they interacted. As a consequence, whilst they went to considerable effort to inform families of the process, much of the information was at too high a level of generality to be helpful and given its symbolic significance, once their awareness of the transition process was raised made carers anxious about transfer who felt they had not been well prepared.

4.6 Model 2

Model 2 has 3 stages (paediatric-adolescent-young adult-adult clinic) and is provided by a large city-based trust.

4.6.1 Cases

The sample comprised two females and five males aged 13-21 spanning the full transition process (Appendix 16). Four cases were dyads of young people and their mothers. All were living with parents, although one had lived independently and moved out of the family home during the study. All cases except one had excellent clinic attendance; one case did not attend two scheduled appointments.

4.6.2 Model structure

The paediatric diabetes team comprises 3 PDSNs, 1 CONP, SPR, and SRDP. They have a caseload of 300. Nurses undertake home visits and outreach work with schools. The service provides four aged-banded clinics including an adolescent clinic. The service is a combination of consultant and nurse-led clinics; families typically see professionals individually. In between clinic appointments nurses can be contacted 24-hours by telephone. Dietary advice is offered responsively up to 16 years.

Transfer to adult services is at age 17 and managed through a handover clinic. Attended by a PDSN, ADSN and SRDP, each appointment is scheduled for 45 minutes and the aim is to introduce the young person to the ADSN, explain what to expect in the young adult clinic and to ensure that all the relevant education and information sharing has taken place.

The adult service comprises five CONAs, two ADSNs and an adult dietitian (SRDA). They have a caseload of 5000 patients. A young adult service is run by a CONA with special interest in this field, an SPR and SRDA. The resources in adult service were widely regarded as overstretched. There are insufficient resources for on-going nursing support and no 24-hour contact.

There are regular meetings of the whole transition service.

See Appendix 17 for model diagram and Appendix 18 for summary of key features.

4.6.3 Resource allocation

Table 12. Model 2: Hours per month for health professionals

transition stage (n = 154)	hours per month				total
	Consultant	DSN (Band 7)	SpR	SRD (Band 7)	
Adolescent Clinic	4.00	8.00	4.00	4.00	20.00
Handover Clinic		6.00		2.50	8.50
Home Visits & Community Work		50.00			50.00
Young Adult Clinic	3.00		3.00	3.00	9.00
Ongoing Contacts	13.17	16.25			29.42
total hours	20.17	80.25	7.00	9.50	116.92
(% of total staff time)	(0.17)	(0.69)	(0.06)	(0.08)	(1.00)

4.6.4 Relational and longitudinal continuity

There is considerable relational and longitudinal continuity in each half of this service model, but relational and longitudinal discontinuity at the children's-adult services interface. Relational and longitudinal continuity was highly valued by service providers and service users. Their accounts indicate that these acted as a mechanism to generate flexible and management continuity.

"I think it's nice to have a specific person because they get to know him and [...] a little bit about his personality [...] the dietitian [...] knows a lot about John and about his eating patterns and about how much he exercises." [2-C64]

A named-nurse scheme operated in the children's service based on geographic location, but despite this, only Helen reported a strong relationship with a single nurse. Most families knew all the nurses and several reported changes to their named-nurse. Although at any one time families might have a closer relationship with one nurse than others, those who had developed relationships with all the nursing team were happy to contact anyone and believed that whoever they spoke to was well-informed. One mother expressed a preference for discussing issues with the doctor with whom families enjoyed high levels of relational and longitudinal continuity.

Knowing that relational continuity of all service providers would be maintained on transfer to adolescent clinic made this a relatively smooth process free from anxiety. However, a major fault line occurs at the interface between adolescent and young adult clinics which involves a complete change of service providers. Several mechanisms are intended to manage the risks associated with this.

Adolescent and young adult clinics are held at the same time in order that young people will become familiar with adult service providers and this appeared to be effective.

"I met CONA a couple of times before I actually went, I think that were enough really." [2-YP181]

"No I mean I knew CONA because I'd seen him." [2-YP26]

In addition, handover clinic is intended to facilitate introduction to the adult service, but given that young people have little on-going contact with the adult nurses and that the SRDA and CONA are not in attendance, this service feature has limited value as a relational continuity mechanism.

Relational continuity is supported in individual cases by informal boundary blurring at the children's/adult service interface. Doctors consult jointly after transfer to young adult services - an arrangement facilitated by the concurrent running of adolescent and young adult clinic - and PDSNs have continuing involvement in some cases. Richard reported on-going support (which service providers said assisted with the marked improvement in his blood glucose

control in young adult services) and Helen's mother anticipated continuing contact with her named nurse when she first entered young adult services.

"[Y]ou always rely on PDSN1 from the children's side, I still talk to PDSN1 every so often because I've known PDSN1 for so long and it's easy to speak to PDSN1 [...] the other nurse who took over was ADSN1 and I haven't really had much dealing with her." [2-YP181]

"[S]he said she might have a time with PDSN2 or PDSN1 just to come in and have a chat, but she said they are there." [2-C26]

The primary relationship in young adult clinic is with CONA. As in model 1, when young people first transfer to his care, the young adult consultant spends time getting to know them and building up trust. Young people alternate between seeing CONA and SPR in clinic and in between CONA provides ongoing support. Three of our cases had had an opportunity to develop relationships with CONA. Richard and Jake evaluated this relationship positively; James was unconcerned with relational continuity.

"[I]t's easy to speak to CONA because CONA knows what kind of situation I'm in [...] CONA understands me a lot more than what any other doctor would who's down there because he's dealt with me since I moved down to that clinic." [2-YP181]

For the dietitian, relationship building could be difficult because contact is through referral appointments only. She has attempted to put in place arrangements to support on-going contact – such as a contact card - but this has proved challenging. None of our cases who had entered young adult services reported seeing the dietitian regularly and the requirement to make a separate appointment appeared to act as a disincentive to seek advice.

"[I]f I had gone to the hospital and the dietitian was there I might have gone up to her and said have you got a minute but other than that not really. I wouldn't have got in contact specially." [2-YP185]

Similarly, there was limited nursing support and although young people were introduced to the ADSN at transition clinic, relationship building was difficult when there was little on-going contact. Whilst all of our cases valued relational continuity highly and acknowledged that changing service provider was a significant event and that building new relationships would take time, none of those who had made this transition reported any major difficulties arising from relational discontinuity on entry to young adult services. The relative ease of the transfer appears to reflect the fact that they had a degree of familiarity with CONA, enjoyed high levels of relational continuity on entry to the service and continued to see PDSNs as necessary after transfer.

On transfer to the main adult service, they remain under the care of the same consultant and thus enjoy considerable relational continuity

at this interface. At the close of the study Richard was alternating seamlessly between young adult and main adult clinics depending on the availability of appointments. James was anticipating moving to main adult clinic and did not perceive this to be a major change.

4.6.5 Informational continuity

Preparation for transfer to adolescent clinic is undertaken in consultations and families receive a letter confirming these new arrangements. Our cases indicated that they had had limited preparation for transfer, but all were informed that their care providers remained the same and that clinics would take place at a different time and location. Some were also aware that there would be more of an emphasis on teenage issues and lone consultation would be encouraged. None of the young people expressed concerns about transfer; most did not consider it to be a significant change. Mothers, on the hand expressed a desire for more information.

“No we’ve just sort of been told it will happen but we haven’t had anything to read or any meetings to go to or. (We would like to know) what’s going to happen in the next one, two, four years or whatever.” [2-C66]

In fact all of this information was available on the service’s website, but none of our cases made reference to having accessed this information source.

Adolescent clinic is held in a Diabetes Centre at the same time as a young adult clinic to enable young people to get used to an adult environment. Young people who had made this transfer expressed shock at the difference between clinic environments and a sense of feeling unprepared for this change.

“[I]n this one it’s all like older ones, I know there’s one who’s about nineteen and he had tattoos everywhere and I was just like yeah I don’t feel comfortable like this.” [2-YP66]

“I will admit I was nervous the first time because it’s a new place and you just see all these people and it’s just like oh god, you know, you’re an adult now.” [2-YP26]

Preparation for transfer to young adult services takes place in adolescent clinic and is reinforced by letter about the planned transfer. Families are also provided with an information booklet, produced by paediatric and adult nurses, describing young adult service arrangements and explicitly outlining how these differ from the children’s service.

Information about clinic is also available on the hospital website, including the expectation that young people will be moving towards independent management and attend without their parents. The handover transition clinic is also used as an opportunity for staff to explain to the young person the new arrangements for care and the

differences between clinics. Helen, the only case to transfer to young adult services, could recall having plenty of advance preparation and having participated in a transition clinic but did not make reference to having received the information leaflet. Both Helen and her mother described the transfer as well-timed and smooth.

4.6.6 Management and cultural continuity

Young people enjoy relational and longitudinal continuity with a single consultant in the children's service. All evaluated this highly and did not enjoy consulting with unfamiliar doctors – such as an SPR - because of their lack of understanding about their individual history. A named-nurse system was also a feature of this service. The underlying rationale is that this promotes relational continuity which in turn acts as a management continuity mechanism. The trade-off with these arrangements is that management discontinuity can arise in the event of staff absences. However, most families knew all team members and were happy to speak with any of them if their individual nurse was unavailable, although sometimes the nurse concerned would not necessarily have a detailed understanding of an individual's care. Adolescent clinic is a combination of consultant and nurse-led clinics. The whole team meets afterwards for management continuity purposes.

Each patient in the paediatric and adolescent service is provided with an A5 ring-binder folder and after clinic they are sent a summary of what was discussed and agreed. Many mothers found the summary useful and Paul's mother found it particularly helpful when she had been unable to attend clinics.

"I find it more useful now I'm not going to clinic with him because as I say Dad's getting the information but he doesn't always remember the details [...] I keep it so that I can refer to it, so yes I do feel that's very important, very useful [...] if you sort of forget what's been discussed it's written down, the odd time we've forgotten it's actually written down for you to refer to it before you come back next time." [2-C58]

Young people also offered positive evaluations and believed that as well as providing important information about HbA1c, it served as a useful reminder for self-management purposes and thus functioned as a developmental continuity mechanism.

"Yes I do quite a lot just seeing what my HbA1c is and what I need to change. [...] I look back on it and see what am I doing and what I'm meant to be doing if they've changed what I've, if I'm meant to change or not. [...] Sometimes there's stuff in there like what I was doing last time and what I need to do because when I went this time we discussed what to do if I'm ill so that's on the card now, so

if I'm ever ill again I'll just look back at that and say right I need to that then." [2-YP58]

Older young people indicated that the summary was less important and did not miss this service when they transferred to young adult services.

The primary mechanisms for ensuring management continuity at the children's-adult interface are a detailed transfer letter and 'quick chat' between consultants. In addition, in some cases, consultants see young people jointly for their initial appointments. When young people first transfer to his service the CONA does not change care. Two of our cases could recall the process of transfer and neither reported abrupt discontinuities of approach.

There is little on-going nursing support available in adult services. Of the three cases who received care in young adult clinic, one claimed he had never met the adult nurse and the other two described minimal on-going support. However, none of these cases identified this as particularly problematic. This may in part reflect their satisfaction with the high levels of support offered by CONA and the fact that they still felt able to contact the PDSNs albeit informally.

"I still talk to PDSN1 every so often because I've known PDSN1 for so long and it's easy to speak to PDSN1 or it's easy to speak to CONA because CONA knows what kind of situation I'm in which kind of cuts out the nurse in the adolescent and adult one [...] I haven't really had much dealings with her." [2-YP181]

Following transfer CONA informs the children's team about initial progress by letter and continues to do so in those cases in which PDSNs have continuing contact. He also liaises with PDSNs if there are management queries with individual cases. This system seems to work well, provided young people with higher levels of on-going support with a health professional who knew them, and did not seem to present any problems with management continuity. Following young adult clinic CONA and SPR hold a meeting which functions as a management continuity mechanism.

Young people continue to see CONA in main adult services. Management continuity is therefore maintained.

Despite their very different resource levels, overall this model is characterised by high levels of cultural continuity and joint working between paediatric and adult services. There is a commitment on both sides of the service to relational continuity as the foundations for high quality care and a strong emphasis on working with young people in partnership and engaging with the reality of their lives. At the time of the study both sides were involved in a range of activities designed to improve services for young people. None of our cases reported experiencing major discontinuities in approach on transfer to adult services.

This relatively seamless transfer of diabetes management, in part reflects the high levels of relational continuity in this model and the close working relationship between paediatric and adult services so that when young people transfer to adult services they are not confronted with a markedly different culture and ethos, despite the resource constraints of the adult service.

4.6.7 Developmental and flexible continuity

Transfer through each service component is determined by age. There is a strong emphasis on developmental continuity and at each stage of the service there are subtly different developmental expectations which are delineated on the website. Within this, however, the approach is patient-centred, with high levels of relational continuity providing the foundations for individualised care (flexible continuity).

“It is tailored to individual need, I think this is what I really like and I think it needs to be individual for every patient, every child, because children they are still growing up aren't they into adults and they need to know things.” [2-C26]

As they progress through the service young people are encouraged to gradually take more responsibility. This includes encouragement to attend consultations alone and take a more active role. Many of our cases who had progressed through children's clinic observed these subtle changes in care and welcomed them. Lone consultation is proactively encouraged on entry to adolescent clinic but an effort is made to keep carers engaged by consulting with the young person alone and inviting carers back in afterwards. Carers will also be seen separately by nurses if required in order to support the transition to independence. Our observations of adolescent clinic indicated that some young people attended consultations alone and some with their carers. However, our sample, all attended consultations with their carer and so we are unable to evaluate the success of this approach. In addition, within children's services, the post consultation summary represents an important mechanism through which to ensure the engagement of carers. We do not have any examples within our cases where this occurred, but it is a logical possibility within this model.

Although life-course education and developmentally appropriate approaches are tailored to the needs of individuals, during the time they are seen in the adolescent clinic, staff systematically address developmentally relevant issues including risk factors and begin planning for transfer to the adult service. This overall approach is underpinned by an adolescent teaching plan which functions as a management continuity mechanism to ensure that education for all developmentally appropriate issues are covered prior to transfer. Based on a proforma, the plan includes injection technique, rotation of injection sites, blood glucose monitoring, exercise, managing

illness, adjusting insulin, alcohol, smoking, drugs, clubbing/late nights, sexual health, preconception advice, driving, career advice, eye care, foot care, leaving home, holidays and travel, dental hygiene. However, when asked, none of our cases were aware of their plan of care. This appears to be a missed opportunity to engage young people and their families more proactively in addressing their developmental continuity needs.

Group education sessions are available but only one case referred to participating in such activity, and it would seem that whilst there are economies of scale in providing developmental continuity support in groups, there are risks that the topics discussed are not appropriate for all participants.

“[T]here have been days when they’ve taken a few aside and talked about growing up and things like that and drink but I mean I don’t think that she really appreciated that because I think she was a bit too young.” [2-C66]

Materials are also provided on the website covering: sex and contraception, drugs, alcohol, smoking, driving, careers, exercise and general information on diabetes. Young people and their families are encouraged to access these, however, our data suggests that they were not widely used and those who had consulted them did not find them particularly helpful.

“I’ve had a quick look on the website but I haven’t really talked to her about alcohol and tattoos and she’s not having one. [...] Well it was just a bit factual and there was just information, it didn’t really do much.” [2-C66]

“I don’t often go, the first thing I wouldn’t think of is to look on the website for information, I don’t know why I just, I don’t ever, not the first thing I think of really. We get a Balance magazine through which we get a bit of information from and things like that.” [2-C64]

Staff had also produced a range of leaflets on specific topics aimed at young people: managing drink, tattoos, piercing. Young people appeared to be aware that they could access this information but few of them appeared to have done so.

“[I]f you need stuff like that then you can get it, if I was to go up to PDSN2 and say I’m drinking, I’m staying out late what do I do, she would explain to me and then give me some leaflet about it, stuff like that.” [2-YP26]

“I’ve seen leaflets but I haven’t really checked through or what, but I generally know the concerns and how to be careful and stuff like that.” [2-YP64]

This may reflect the fact that the information leaflets were not systematically organised in clinics. Our field observations indicated that the waiting room created a sense of information overload.

Although formal education was not seen to be part of the handover clinic, the dietitian underlined the importance of meeting with young people before leaving the paediatric service to ensure they had the requisite information before entering adult services. This in part reflected the fact that she only sees families in relation to specific problems; she does not routinely see them to provide general dietary advice. Only one of our cases transferred to young adult clinic during the study. Having been heavily dependent on her mother for her diabetes management, on entry to young adult clinic Helen considered she had learnt a lot. As Helen had hitherto not consulted on her own, the PDSN also used the transition meeting as an opportunity to coach her on how to get the best out of a consultation.

“I’m learning quite a lot at the moment like do you know because I’m growing up and yeah they’re teaching me a lot more about things for people my age and keep your life as normal and as simple as possible really.” [2-YP26]

In young adult services there is a stronger emphasis on flexible continuity. Service providers indicated that at this stage in the life-course young people are experiencing so much change they need more rather than less support. The consultant emphasises informality of approach and all of those receiving care referred to him by his first name and not by title. The emphasis is very much on understanding the everyday lives of young people and offering support for diabetes management within this context. The aim is to allow young people to set the agenda and work with them in a shared decision-making process. Because young people in this service do not have on-going support from adult nurses, the adult consultant maintains contact in between clinic appointments by email. The underlying approach is one in which high levels of access is provided initially and then greater independent decision making is encouraged. The consultant works closely with the dietitian copying her into email communications as necessary and providing scope for additional dietetics support. Richard had made extensive use of this system and valued it highly.

“I mean I can get in touch with him if I need to and stuff like that, if I find out something is going wrong, if I think I’m not responding to my insulin or something I can send him an email and he’ll arrange to get me an earlier appointment so I can come and see him and sort it out and then he’ll probably get back to me or if there are any problems or any questions then I can get in touch with him when I need to. It’s a good help to be able to speak to someone like that. [...] since I’ve been working with CONA as well it’s made me a bit more like that because I’ve started making more, shall we say, adult decisions on things like decisions to make like with the pump and stuff like that, it was like my decision that I wanted to go onto it because I felt it would help.” [2-YP181]

Although James had never used the email system, he indicated that he too considered it to be a helpful way of supporting self-management if clinic consultations were less frequent. Similarly while Jake had not had call to use the email support system, he found it reassuring to know that this ongoing support was available should he need it. When asked, other young people in this model expressed positive views about the system of email support.

Dietetics support is by referral only, however, both dietitians expressed a life-course sensitive approach which took into account the reality of children's and young people's lives and their dietary preferences. Dietary advice was offered in response to specific problems.

There is no formal age at which young people transfer to main adult services. Decisions are usually based on an assessment of an individual's readiness to make this move. This is defined in terms of their independent diabetes management and their on-going support needs. The consultant has continued to see people up until the age of 30 if they do not want to move on.

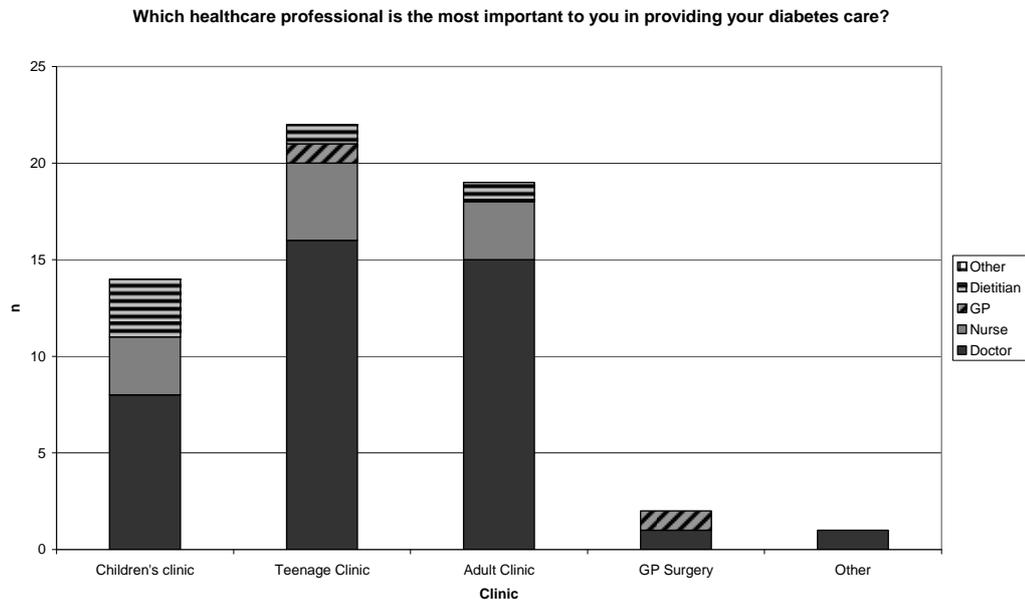
4.6.8 Quantitative outcomes

153 young people were approached in model 2. The response rate was 42% (65). 25% attended a children's clinic, 37% attended a teenage/young adult clinic and 34% attended an adult clinic. Two cases attended a GP surgery for their diabetes care and one case stated that they attended a 'diabetic unit at a local general infirmary', with no indication of whether this unit was aimed at children, teenagers or adults. Differences in lone consulting were more evident in this model. Carers stated that they attended clinics for all who attended the children's clinic, for just under two thirds (65%) of those attending the teenage clinic and for a quarter of those attending the adult clinic.

The average age for respondents was just over 18. There was a distinct age difference between clinics, with young people who attended a children's clinic having an average age of 14, those in a young person's/teenage clinic with an average of 16, and those in an adult clinic with an average age of just over 23. Overall, 49% of young people were male. 63% of young people attending a children's clinic are male, 42% attending a teenage clinic are male and 50% attend an adult clinic are male.

As shown in Figure 2, the doctor was the most important health professional in providing diabetes care to young people across all clinics, reflecting the significant role played by CONA in young adult clinic. This result was similar among carers. For between 16% and 20% of patients, the nurse was considered the most important healthcare professional.

Figure 2. Most important health professional for young people in model 2



Young people reported a decrease in the level of parental control, in terms of their diabetes care, across the different clinics. Median scores of the DQoLY parental control scale ranged from 9 (IQR: 5, 12) in the children's clinic, to 8 (IQR: 5, 11) in the teenage clinic, to 7 (IQR: 5, 11) in the adult clinic (Table 13).

Table 13. Model 2: Young person outcome measures

Young person outcome measures	Children's clinic	Young person's /teenage clinic	Adult clinic	GP
PEI	19.0 (18.0, 21.0)	22.0 (18.0, 25.0)	22.5 (18.3, 24.9)	22.0 (18.0,)
DMSES	77.0 (62.0, 81.3)	75.0 (68.0, 84.0)	79.5 (68.8, 87.5)	76.8 (76.2,)
DQoLY: Impact of Treatment	7.0 (5.0, 8.0)	7.0 (4.0, 8.3)	7.0 (6.0, 9.0)	7.5 (6.0,)
DQoLY: Symptom Impact	7.0 (5.0, 9.0)	6.0 (5.0, 8.0)	7.0 (5.3, 9.8)	
DQoLY: Parental Control	9.0 (5.0, 12.0)	8.0 (5.0, 11.0)	7.0 (5.3, 11.0)	7.5 (8.0,)
DQoLY: Impact on Activities	8.0 (6.0, 12.0)	7.0 (5.0, 11.0)	8.5 (5.3, 11.0)	11.5 (8.0,)
DQoLY: Satisfaction	64.5 (55.5, 68.0)	68.0 (60.3, 73.8)	61.0 (48.0, 67.5)	59.7 (55.0,)

Median (lower quartile, upper quartile)

PEI – Patient Enablement Instrument

DMSES – Diabetes Management Self-Efficacy Scale

DQoLY – Diabetes Quality of Life for Youth

Comparing the teenage and adult clinics to the children's clinic, there is a marginal improvement in PCDS score, which indicates that carers of young people in teenage and adult clinics felt that their child was more capable of managing their diabetes compared to those in the child clinics. Carers with participants in an adult clinic had much lower general health scores (median: 59), compared to those with participants attending the teenage and child clinics (medians 75 and 80 respectively) (Table 14).

Table 14. Model 2: Carer outcome measures

Carer outcome measures	Children's clinic	Young person's/ teenage clinic	Adult clinic
PCDS	3.1 (2.8, 4.0)	4.1 (3.6, 4.8)	4.0 (3.5, 5.0)
SF36: General health	79.5 (32.8, 88.8)	74.5 (63.3, 86.5)	58.5 (50.0, 80.8)
SF36: Reported health transition	1.0 (1.0, 3.0)	1.0 (1.0, 2.5)	1.0 (1.0, 1.0)
SF36: Physical functioning	100.0 (83.8, 100.0)	100.0 (91.9, 100.0)	95.0 (86.3, 100.0)
SF36: Role physical	100.0 (81.3, 100.0)	100.0 (87.5, 100.0)	100.0 (87.5, 100.0)
SF36: Role emotional	95.8 (85.4, 100.0)	100.0 (77.1, 100.0)	100.0 (75.0, 100.0)
SF36: Social functioning	100.0 (62.5, 100.0)	100.0 (62.5, 100.0)	100.0 (75.0, 100.0)
SF36: Bodily pain	43.0 (41.0, 50.0)	50.0 (43.0, 50.0)	44.0 (42.0, 50.0)
SF36: Vitality	42.5 (35.0, 60.0)	50.0 (41.3, 58.8)	40.0 (30.0, 50.0)
SF36: Mental Health	58.0 (53.0, 64.0)	64.0 (55.5, 72.0)	62.0 (45.0, 68.0)

Median (lower quartile, upper quartile)

PCDS – Perceived Competence for Diabetes Scale

SF36: Reported Health Transition: 1 – Much better now than one year ago; 2 – Somewhat better now than one year ago; 3 – About the same as one year ago; 4 – Somewhat worse now than one year ago; 5 – Much worse now than one year ago

4.6.9 Summary

Model 2 is a divided transition service characterised by high levels of cultural continuity and a belief in the importance of relational continuity as key to meeting the needs of young people. At all stages of the transition process young people are encouraged to develop relationships with a single service provider. There are high levels of relational and longitudinal continuity in paediatric and adult services and successful formal and informal systems in place to manage relational discontinuity at the interface between services. In children's services developmental continuity is proactively addressed but individually tailored. The model includes a range of written information sources which appear to be under-utilised. Young adult

service providers recognise the higher need for support at this stage in the life-course and have endeavoured to address this despite resource constraints. In the absence of a nursing service, CONA is an important source of on-going support and this is reflected in the quantitative outcomes on users' perceptions of most important health professional. The young adult service team display a clear orientation to the life world of the population they serve and a preparedness to modify their approach to ensure engagement with the service. The handover clinic functioned as an effective information continuity mechanism, but with great involvement of adult service providers it has the potential to function as a relational and management continuity mechanism. Moreover, the organisation of adult dietetics services leaves few opportunities for young people to establish this relationship of trust, potentially making them less-inclined to make contact despite efforts to ensure they have access to the services.

4.7 Model 3

Model 3 has 2stages (child-young-person-adult clinic) and is delivered by a small integrated team located in a medium sized trust.

4.7.1 Cases

The sample comprised 5 females and 4 males aged 15-21 and spanned the transition service (Appendix 19). Seven were dyads of young people and mothers. All young people lived with parents; but three had previously lived independently and one left home during the study. With the exception of one case, clinic attendance was good.

4.7.2 Model structure

The paediatric service comprises CONP, PDSN/ADSN and SRDA; they have a caseload of 52 patients. Families are seen in clinic and PDSN/ADSN undertakes home visits and works in schools as required. The diabetes nurses can be contacted between 9.30am and 9.30pm after which families are directed to the ward. Informally, PDSN/ADSN allows contact outside normal working hours.

The adult service (CONA, ADSN1, PDSN/ADSN and SRDA) runs a young person's clinic for 16-21 years, led alternately by CONA and ADSN1. ADSN1 undertakes home visits and outreach in workplaces, schools or colleges, although at the time of the study this service had been recently curtailed. Diabetes nurses can be contacted between 9.30am until 9.30pm. Outside these hours contact is via the adult diabetes ward or Accident and Emergency. However, informally ADSN1 allows contact outside normal working hours.

Transfer to main adult clinic takes place aged 21 but there is flexibility depending on the readiness of the young person. The adult service is provided by CONA, SPR, PDSN/ADSN, ADSN2 and SRD. Service users are seen at least annually and young adults will be seen more frequently – 4-6 monthly. There are no home visits; young people can make an appointment to see the nurses and dietitian at the hospital. PDSN/ADSN encourages young people to contact her in between clinics if necessary; this facility is not open to all adult patients.

In clinics nurses undertake pre-clinical activities and will consult with young people separately from the doctor if required.

There are regular meetings of the whole transition service.

See Appendix 20 for model diagram and Appendix 21 for summary of key features.

4.7.3 Resource allocation

Table 15. Model 3: Hours per month for health professionals

transition stage (n = 84)	hours per month			total
	Consultant	DSN (Band 8a)	DSN (Band 7)	
Young Person's Clinic	4.50	4.50	4.50	13.50
Home Visits		2.90	1.45	4.35
Ongoing Contacts		2.04	3.05	5.09
total hours	4.50	9.44	9.00	22.94
(% of total staff time)	(0.20)	(0.41)	(0.39)	(1.00)

4.7.4 Relational and longitudinal continuity

Model 3 is provided by a small integrated team and there is considerable relational and longitudinal continuity across children's and adult services. There is relational continuity with a single consultant within each transition stage and longitudinal continuity of consultant across young person's and main adult clinic. A single dietitian serves both paediatric and adult services and at each stage of the process young people are assigned a nurse who functions as their key worker. Although each nurse carries their own caseload and develops close bonds with young people and their families, they

make a point of knowing all cases in order to cover for absences. Our cases indicated that they were happy to consult with all the diabetes nurses. In addition PDSN/ADSN spans children's and adult services.

Many of our cases had developed an especially close relationship with PDSN/ADSN with some referring to her as a family friend. In the majority of cases this was a positive feature and helped to account for the relatively smooth transition young people experienced as they moved through the different segments of the service.

"I think PDSN/ADSN is the [...] person I've talked to all the time because she looked after me when I was a kid and then through the transition into the adult clinic and then stayed as my nurse sort of thing." [3-YP121]

However, this sense of friendship led Catherine to assume that discussions with the nurse would remain confidential, which had created some difficulties in the past, and Megan's mother also suggested that PDSN/ADSN was reluctant to take a firmer approach with her daughter, highlighting the risk that relations can become so close that professional detachment cannot be sustained.

On entry to young person's clinic, four cases transferred from the care of PDSN/ADSN to ADSN1 and whilst they acknowledged that time was needed to build relationships with their new nurse, all made this transfer smoothly. Furthermore, all three cases who continued in PDSN/ADSN's care in adult clinic had met ADSN2 and were happy to be cared for by her if necessary. Thus whilst PDSN/ADSN was a key healthcare provider for all our cases, this did not appear to produce problematic dependency.

A major fault line in this model occurs when young people transfer to young person's clinic and change consultant and nurse. Because it is held at the same time as the paediatric clinic, PDSN/ADSN can span the boundary at this service interface, providing a familiar face. At the first appointment PDSN/ADSN introduces the patient to ADSN1 and CONA and can also be involved in a joint consultation. In addition, there is relational continuity of dietitian.

Four cases transferred to young person's clinic. Although they knew they would be experiencing some relational discontinuity, the transfer was made smoother by the knowledge that PDSN/ADSN would be present at clinic and it was also recognised that she was a potential source of management continuity.

"I think it's nice to see like a face that you know and [...] to be able to speak to her again and I think it's important as well because she knows about a lot of the background stuff." [3-YP82]

"But I think it is nice, like when she was in the other clinic and now she's changed over, you know PDSN/ADSN, know SRD, you sort of know who they all are and I think it's easier as well for Catherine.

[...] I think she feels that she can talk to them if she needs to." [3-C86]

Another relational continuity mechanism at this interface is the boundary spanning practice of CONA who attends paediatric clinics periodically, so that when young people enter the adult service they are familiar with him.

"CONA used to come and sit in sometimes. [...] I think I would be a bit nervous but I've met him before and I know he's a really nice like man [...] he didn't used to just sit there you know, he did like talk to me." [3-YP82]

Four of our cases transferred to young adult services and did so with relative ease.

"[W]e knew PDSN/ADSN was there and all the other nurses are fantastic as well and it's the same staff practically you know. Familiar faces do help." [3-C79]

Nevertheless, transfer did necessitate investment in new relationships and whilst adult service providers were familiar to them they did not necessarily have a detailed knowledge of the young person's daily lives.

"You can have a chat with her about anything if you know, she's like PDSN/ADSN but because PDSN/ADSN has been there longer with me I'd rather chat to PDSN/ADSN than ADSN1 but I'd still quite happily sit there babbling on with her." [3-YP86]

"PDSN/ADSN has been to the house and seen her in hospital and all that sort of thing, she's seen her dancing videos and so she knows her really very well. And this new nurse, ADSN2 has only been a few times really to clinic so I mean she's probably getting to know what sort of personality she is but she doesn't know her." [3-C82]

On transfer to main adult services young people re-engage with PDSN/ADSN. Unfortunately no cases made this transition so we cannot evaluate this process. However, three transferred directly to main adult from paediatric services and there is strong evidence that our cases valued this on-going relationship. Indeed, it may have been precisely because of this relational and longitudinal continuity that young people were happy to make a direct transfer.

"I think it is good to keep the same kind of people involved with it. [...] just small things like PDSN/ADSN knows my life, well not like on a personal level but she knows about my football, she knows about my driving, my college and it feels comfortable when I go." [3-YP116]

4.7.5 Informational continuity

There are no written or formal informational continuity mechanisms in this model. Preparation for transfer to young adult clinic is woven

into clinic consultations. Service users are informed that they will be moving to the young adult services and are given information about health professionals into whose care they will transfer. It is explained that there will be differences in the content of clinic consultations and that consideration will be given to the challenges of this stage of the life-course. Four of our cases made this transfer and in only one case was there any suggestion that preparation for transfer could have been improved. Hayley made the transfer to young adult services with ease, but her mother had stopped attending consultations. Although she had received a letter on the content of clinic consultations, this did not include information on transfer. She was therefore dependent on Hayley to provide information and this was not forthcoming.

Young people transfer to main adult services once they are able to make their own decisions about diabetes management. The timing is flexible and there is no formal procedure. Main adult clinic is very busy and nurses prepare young people for the different clinic environment. None of our cases made this move although three had gone directly from child to adult services. They portray a picture of a gradual introduction to the idea of transfer and of staff emphasising the continuities as well as the differences between service components. For Sam and Michael this was adequate preparation for transfer, however Naomi was more critical. Naomi described being unconcerned about transfer to adult services and having been forewarned by the nurses that clinics involved longer waiting times, but being shocked by the clinic milieu when she encountered it.

“Before I actually got there I thought it would be alright because I’d been going to the clinic on my own anyway and because I was a bit older because they’d waited until I was nineteen but when I got there it was just full of old people [...] I would have preferred it if there were a few more people my own age.” [3-YP121]

A particular issue was the long waiting times in adult clinics which made it difficult for Naomi to accommodate clinics in between studying and work. Naomi’s younger brother also had diabetes and had transferred to young person’s clinic. The reason for Naomi’s direct transfer into adult services remains opaque but on reflection, both Naomi and her mother considered that it would have been preferable for her to have followed the same pathway as her brother. Michael’s mother also believed he was misplaced in main adult clinic. Overall, however, despite the absence of formal informational continuity mechanisms few young people and their parents expressed concern or anxiety about transition through the different elements of the service and appear satisfied with their preparation for transfer.

4.7.6 Management and cultural continuity

This model is characterised by high levels of cultural continuity. There is a common ethos and no major discontinuities of approach as young people make the transition to the adult service. Cultural integration is facilitated by the stability and small size and co-location of the whole team and the cross boundary working of CONA, SRD and PDSN/ADSN which ensures that all team members develop an understanding of both services and develop skills which transcend service boundaries. The whole team also meets regularly to discuss latest developments and consider overall strategy and the adult consultant, as part of his commitment to a life-course approach to diabetes, attends an annual meeting of paediatricians working with children with diabetes. There was strong evidence in support of this common ethos.

"[Y]ou can tell that they've worked together for a long time [...] they all sing from the same hymn sheet really." [3-C82]

"Obviously you know in terms of meeting a new consultant you know, he's got the same, you know he's got the same kind of structure behind what he wants from me in terms of diabetes." [3-YP116]

Four cases transferred their care from paediatric to young adult services and changed key worker. Although they clearly experienced some relational discontinuity and recognised that it would take time to develop the understanding they had enjoyed with PDSN/ADSN, they all noted a common approach.

"Well she's just like, she's very nice but I used to have PDSN/ADSN but she's just, it's just the same really, I can't really tell the difference if you know what I mean." [3-YP82]

In addition to the common ethos, the PDSN/ADSN boundary spanning role was an important source of management continuity. As we have seen PDSN/ADSN fosters close relationships with young people and their families and, having supported them through diagnosis, had an intimate understanding of their lives. On transfer to young adult clinic, young people and their families experience a complete change of nurse and doctor. However, because this clinic is run concurrently with paediatric clinic, PDSN/ADSN functions as an important management continuity mechanism, speaking to ADSN1 and the doctor about the young person prior to the clinic and attending consultations if required. In addition, she consults with ADSN1 and the doctor before, during or after clinic to share knowledge and ideas if patients are a particular concern. In the absence of this role, there would be a requirement for joint clinics in order to ensure a smooth transfer between these components of the service.

While a common ethos and the integrating role of the PDSN/ADSN function to ensure management continuity throughout the service,

within each component, relational and longitudinal continuity is the primary management continuity intervention. Potential challenges arise within and between each element.

In all stages of this model young people and their families usually see the nurse and consultant separately at clinic and may also have contact with nurses in between clinics, which carries the risk of inter-professional management discontinuity. In between clinic appointments these risks are off-set through on-going discussions about patients (facilitated through co-location), email communication or through a review of cases prior to clinics. Within clinic staff described an informal process of movement between consulting rooms to maintain lines of communication and in a minority of cases, nurse and doctor may consult jointly. These interventions appear to have been effective; there was strong evidence of management continuity within each component of the service and communications between the team were perceived to be strong.

“CONA when he sees her he knows everything that’s on her file, what she’s been doing, what’s happened, you know and he will say PDSN/ADSN has said this or ADSN1 has said that.” [3-C89]

Although the nurses each carry their individual caseload, they are familiar with all patients. This helps to ensure management continuity as young people move through the different service components and when there is a need for cross-cover. There are formal handovers of individual patients in order to cope with planned absences and when a young person transfers from one part of the service to another. Our cases provided evidence that these strategies were effective.

“They seem to know everything really, so they do communicate and I don’t know whether they write it down in a file or whatever but they go oh yeah we do know. [...] I don’t have a clue how they remember everyone, I really don’t.” [3-YP107]

When young people transfer to the care of a different doctor on entry to young person’s clinic, an additional management continuity mechanism is the transfer letter, giving details of current issues (personal and diabetes related), what has recently been discussed with the patient, and a brief history. The diabetes nurses are an important additional source of management continuity.

“I’m confident the diabetes nurses know Catherine [...] CONA probably doesn’t know her but that doesn’t bother me because I know that the diabetes nurse will relay everything and they know her, they know her history, they know everything.” [3-C86]

There was little evidence of management discontinuity in this model. Mark, who attended clinic erratically and tended to drop in and see PDSN/ADSN as he felt like it, recounted a rare example of a consultation with CONA in which there was a breakdown in understanding.

4.7.7 Developmental and flexible continuity

Model 3 is characterised by high levels of flexible continuity across the life-course. There is little formal educational provision and no check-list of issues to be addressed at different stages of the process. The emphasis is on assisting young people to live their life with diabetes without judgement, rather than proactively preparing for transfer to the adult service. Transfer at all interfaces is flexible in response to the needs of the young person and young people are encouraged to set the agenda for consultations. Our cases provided strong evidence that health care providers understood young people's lives and sought to assist them in accommodating their diabetes management within this.

"They just have more of a general chit chat, with a diabetes twist to it. [...] It's about general things that's going on in my life really and how it's affecting me." [3-YP94]

"You always get that feeling from them that you know nothing surprises them, you know, it's not like if (patient name) said, oh I went out on Saturday and I had a bender and you know, and had a hypo, they were like oh god, shock horror kind of thing you know." [3-C116]

"[T]hey give you suggestions, but then if you don't agree with them then they'll change it to work around you rather than just say look this is what you're doing." [3-YP86]

This model is also characterised by high levels of on-going access to advice in between clinic appointments across the full range of the service. The aim is to support the young person in becoming increasingly confident in making their own decisions in relation to their diabetes care.

"Megan has not had very good control [...] ADSN1, she's taken Megan on now and at one point she was seeing her once a week [...] we have had a tough time." [3-C89]

"PDSN/ADSN says just ring me at home if you're struggling with something don't sit there [...] I can just ring her at home. [...] You know which is brilliant." [3-C116]

Moreover, there is an emphasis on contact with the service and the team works flexibly to keep in touch with young people even when they are not attending clinic. Mark had poor control and his attendance at clinic was erratic. Health care professionals found time to see him whenever he chose to appear and made considerable effort to keep him engaged with the service.

"I think they do care quite a lot because like I say I always get text messages off PDSN/ADSN, how are you, don't so much get them off ADSN1, ADSN2 sends me one every now and again and then." [3-YP107]

Whilst the predominant ethos was that of flexible continuity, the service was not simply reactive. Care is also taken to prepare young people for anticipated challenges to diabetes management at this stage of the life-course, such as changes in routine and risk factors (developmental continuity). There is strong evidence to indicate that health care providers were proactive in anticipating these issues in our cases.

“They knew that a student or a young person is going to go out till all hours drinking and missing meals, eating the wrong things, they knew that that’s going to happen.” [3-C94]

“They just seem to know what’s coming next and they know what she’s up to.” [3-C89]

“[T]hey expect certain things as well when you get to a certain age. Like when you start going out with your mates more and you start getting boyfriends and you start doing this and start doing that, and you start college and all that so I think it is good because you know what to expect sort of thing, well the nurses know what to expect.” [3-YP82]

In all elements of the service there was a flexible approach to carer involvement. When young people enter young person’s clinic staff encourage young people to see the doctor alone, but carers are kept involved and are invited into the consultation after the young person has been seen. Efforts were made to prepare and support carers in assisting their child to become more independent, whilst recognising their continuing role in care.

“PDSN/ADSN prepared me a bit, she used to say oh you won’t be quite as involved now you know, you won’t be told everything and don’t think we’re excluding you it’s not purposeful it’s just as they’re getting older and they have to manage it themselves that they will take a bigger part in it.” [3-C121]

Moreover, in those cases still in receipt of care in children’s services in which the young person had started to consult alone, written information is provided to carers providing management continuity.

In only one case in our sample was there continuous carer involvement in the consultation, however in two cases the mother attended some consultations and not others and/or part of the consultation. Young people valued the continuing involvement of their carer. Moreover, carers in this model who had moved to lone consultation felt engaged with the service and able to access the support of the diabetes nurses if required.

“I mean he’s nineteen now, he’s an adult and if he doesn’t want me there, that’s fair enough. [...] [I]f I had any worries PDSN/ADSN would be there to ring anyway.” [3-C93]

“[I]f you have concerns it’s not like oh no parents if you know what I mean. [...] I think it’s important that even, she’s seventeen now

[...] I know I could still phone ADSN/PDSN and I can just ask her."
[3-C86]

It is possible that in this model the relational continuity offered by PDSN/ADSN gave carers confidence that they could remain in contact with the service, whereas in other models the progression to lone consulting coincided with a change in providers.

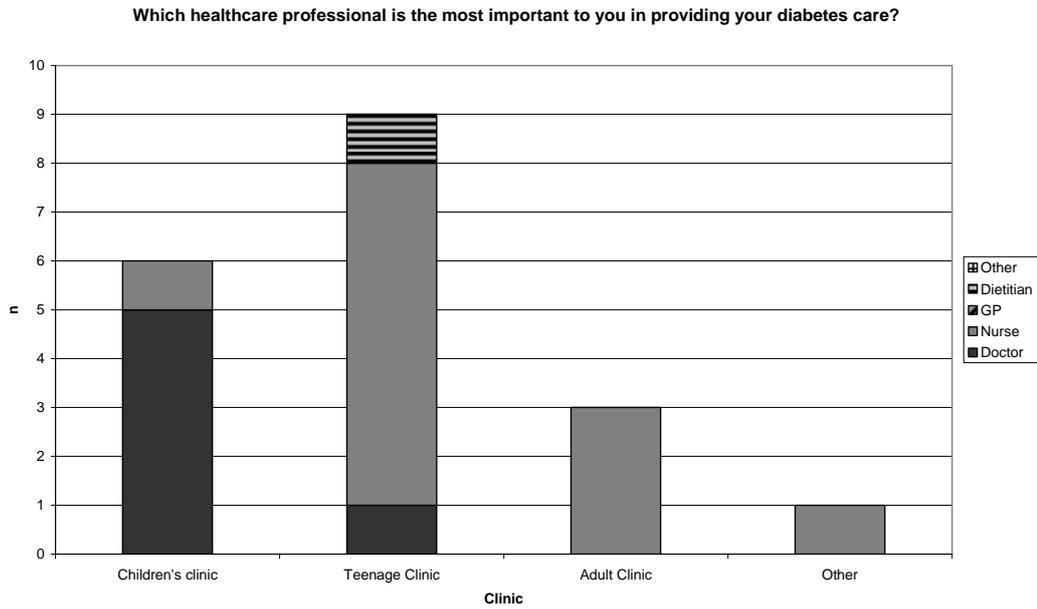
4.7.8 Quantitative outcomes

Of the 84 young people approached, a total of 22 questionnaire responses were received from model 3 (response rate = 26%). 27% attended a children's clinic, 41% attended a teenage/young adult clinic and 27% attended an adult clinic. One case stated that they were currently awaiting a GP referral to a clinic, but were not attending a clinic at the time of responding. Lone consulting followed a similar pattern to that in model 2. 88% of carers sat in on consultations for those attending children clinics, 75% for those attending teenage clinics and 25% for those attending adult clinics.

The average age of respondents was just under 19. There was a distinct age gradient between clinics. Respondents attending a children's clinic had an average age of just under 16, with those attending a teenage clinic having an average of just under 18 and those in an adult clinic just under 23. Overall, 59% of respondents were male. While the split was 50/50 in the children and adult clinics, 78% of those who attended a teenage/young person's clinic were male.

There is a marked shift between clinics when it came to selecting their most important health professional. While the doctor was the most important in the children's clinic, the nurse was the most important to patients in the teenage and adult clinics (Figure 3).

Figure 3. Most important health professional for young people in model 3



Young people attending a teenage clinic felt, on average, much more capable of managing their diabetes (median: 90) than patients in the children or adult clinics (medians: 79 and 68 respectively) (Table 16).

Table 16. Model 3: Young person outcome measures

Young person outcome measures	Children's clinic	Young person's/teenage clinic	Adult clinic
PEI	22.0 (21.0, 25.5)	20.0 (19.5, 26.0)	18.0 (17.8, 21.0)
DMSES	78.6 (67.0, 81.3)	90.0 (60.1, 92.5)	67.5 (62.5, 78.0)
DQoLY: Impact of Treatment	7.5 (5.8, 8.5)	9.0 (4.5, 10.0)	8.0 (5.8, 10.5)
DQoLY: Symptom Impact	6.0 (5.8, 7.5)	8.0 (4.0, 10.5)	5.0 (5.0, 7.5)
DQoLY: Parental Control	9.0 (8.0, 9.3)	9.0 (7.5, 12.5)	9.0 (5.0, 12.0)
DQoLY: Impact on Activities	8.5 (5.0, 12.0)	9.0 (6.0, 12.5)	9.5 (8.0, 10.3)
DQoLY: Satisfaction	68.0 (59.1, 73.7)	66.0 (48.0, 82.5)	63.0 (60.5, 67.8)

Median (lower quartile, upper quartile)

PEI – Patient Enablement Instrument

DMSES – Diabetes Management Self-Efficacy Scale

DQoLY – Diabetes Quality of Life for Youth

Carers for participants attending the adult clinics reported worse SF36 scores than those with participants attending child or teenage clinics (Table 17).

Table 17. Model 3: Carer outcome measures

Carer outcome measures	Children's clinic	Young person's/teenage clinic	Adult clinic
PCDS	4.0 (3.5, 4.8)	4.0 (3.8,)	4.1 (2.9, 4.8)
SF36: General health	77.0 (60.0, 92.0)	67.0 (55.5, 92.0)	59.5 (23.0, 72.0)
SF36: Reported health transition			2.5 (1.0, 4.0)
SF36: Physical functioning	95.0 (91.3, 100.0)	95.0 (75.0, 100.0)	75.0 (31.3, 92.5)
SF36: Role physical	96.9 (75.0, 100.0)	96.9 (84.4, 100.0)	53.1 (17.2, 93.8)
SF36: Role emotional	100.0 (77.1, 100.0)	87.5 (62.5, 100.0)	75.0 (43.8, 100.0)
SF36: Social functioning	100.0 (81.3, 100.0)	100.0 (50.0,)	81.3 (46.9, 96.9)
SF36: Bodily pain	47.0 (41.8, 50.0)	50.0 (43.3, 50.0)	46.0 (34.3, 51.0)
SF36: Vitality	57.5 (41.3, 63.8)	47.5 (32.5, 58.8)	22.5 (12.5, 40.0)
SF36: Mental Health	62.0 (53.0, 67.0)	56.0 (41.0, 71.0)	42.0 (40.0, 56.0)

Median (lower quartile, upper quartile)

PCDS – Perceived Competence for Diabetes Scale

SF36: Reported Health Transition: 1 – Much better now than one year ago; 2 – Somewhat better now than one year ago; 3 – About the same as one year ago; 4 – Somewhat worse now than one year ago; 5 – Much worse now than one year ago

4.7.9 Summary

Model 3 can be characterised as an integrated life-course model. It is united by a common approach to supporting people to live a life unconstrained by diabetes underpinned by high levels of relational continuity. Grounded in a realistic and non-judgemental ethos, the emphasis is on keeping young people engaged and supporting their transition into adulthood, rather than their transfer to adult services. A key feature of this model is the PDSN/ADSN role which acts as a relational, management and cultural continuity mechanism. Lone consultation is encouraged but there is continuing engagement with carers once this has taken place.

Key to the model's success is the strong leadership exhibited by the adult consultant and PDSN/ADSN. A number of staff identified the common ethos and observed that this was possible because the team was relatively small. However, whilst one of the model's strengths, it also contains several risks. There is only one nurse with a specialist paediatric diabetes qualification and in her absence young people do not have access to this level of specialist expertise. Similarly the dietitian is only adult trained and whilst our interviews generated little data through which to evaluate the effectiveness of the service,

a small number of participants indicated that on occasion the dietary advice offered did not appear realistic given the dietary practices of normal teenagers. A fundamental component of the model is the unique joint PDSN/ADSN. The role incumbent has specialist expertise in both paediatric and adult services. If the current incumbent were to leave, it is not certain that they would find easily a suitably qualified applicant.

4.8 Model 4

Model 4 has 3 stages: (paediatric- adolescent-young adult-adult clinic) and is provided by a foundation trust. There is a twenty year history of joint working and children's and adult services sit within a single directorate. Identical services are run in two sites to facilitate access in the context of poor local transport infrastructure.

4.8.1 Cases

The sample comprised 3 males and 8 females between 13-18 years spanning paediatric to young adult services in the main hospital site (Appendix 22). No cases transferred to main adult services. Ten were dyads of young people and mothers. Four cases were referred to the clinical psychologist and two did not attend appointments on two occasions. With one exception, all lived with parents.

4.8.2 Model structure

The paediatric team comprises CONP, PDSN, SRDP and a health care assistant (HCA). It has a caseload of 160 and runs two age-banded clinics. CONP and PDSN consult together. SRDP sees families by appointment. PDSN undertakes home visits for children up until the age of 16. She encourages carers and young people to telephone or text her if they need advice.

Young people transfer to adolescent clinic at 12/13 years. The service is run jointly by the paediatric and adult service.

A young adult service is provided by a CONA1, NURSCON and SRDA. This comprises 12 monthly clinic appointments with CONA1 and appointments with NURSCON and SRDA at least 6 monthly. Young adults up to the age of 40 will be seen. The aim is to provide a higher level of support than that available in main adult services, including intensive one-to-one teaching sessions.

The adult service is provided by three CONAs, two SPRs, NURSCON, two ADSNs, SRDA and HCA. There is no formal process of discharge from the young adult service. Transfer is negotiated on an individual basis.

The whole team meets monthly.

See Appendix 23 for model diagram and Appendix 24 for summary of key features.

4.8.3 Resource allocation

Table 18. Model 4: Hours per month for health professionals

transition stage (n = 158)	hours per month					Total
	Consultant	DSN (Band 6)	Nursing Cons.	SRD (Band 8b)	HCA	
Adolescent Clinic	6.67	3.42	3.42	3.42	3.00	19.93
Home Visits & Community Work - Main Site		2.75				2.75
Ongoing Contacts - Main Site		1.30				1.30
Young Adult Clinic - Main Site	3.75		2.50	2.50		8.75
total hours	10.42	7.47	5.92	5.92	3.00	32.73
(% of total staff time)	(0.32)	(0.23)	(0.18)	(0.18)	(0.09)	(1.00)

4.8.4 Relational and longitudinal continuity

A key feature of this model is the joint adolescent clinic. In paediatrics there is relational and longitudinal continuity with a single consultant, nurse and dietitian and it was clear that many of our cases had formed strong bonds with this team, particularly the PDSN. When young people attend the adolescent clinic they continue to see the paediatric team and are introduced to CONA1 and NURSCON. The data suggest that the model was effective in allowing relationships with the adult team to develop, but this process could take time. In addition, adult service providers were perceived to have markedly different consultation styles for which families were unprepared. Several made comparisons between the warm and personalised approach they had enjoyed in paediatric services and the more direct clinical focus of the adult team.

“With PDSN [...] we had more of a relationship, she knows you more [...] whereas with the adult clinic it’s more any problems, no, yes do this, do that and you’re gone.” [4-C94]

“[T]he first time [...] it was a bit scary. Stephanie and I both came out and we said, oh no we don’t want to see them again. [...] it was a completely different, it was a much more clinical appointment whereas with CONP [...] it’s much more oh come in and we’ll have a chat and just make sure you’re happy with everything and we’ll check the figures while we’re at it.” [4-C50]

Although designed to support longitudinal and relational continuity with the adult team, the organisation of adolescent clinic also produced relational discontinuity with paediatric providers. The team aimed for young people to see a doctor at least once a year, but they could consult with either the CONP (with CONA1) or the PDSN and SRDP (with NURSCON) and at other times might see only the doctors or only the nurses for successive clinics. If they had a close relationship with a particular service provider then they could experience relational discontinuity.

Indeed, the PDSN was identified as a key relationship by nine cases and widely regarded as the person with whom they felt most able to discuss emotional issues and practical concerns. While some adjusted to less contact with the PDSN with relative ease, several young people experienced this negatively with important implications for management and developmental continuity (see below). For example, on transfer to adolescent clinic two young women always saw the doctors; both were reluctant to discuss certain issues with them. Another expressed frustration at attending clinic and wishing to speak with a nurse, but having seen a doctor and, unlike in other services where nurses had contact with all young people as a result of undertaking pre-clinic activities such as checking weight and height, in this model this was undertaken by an HCA. In theory, young people and their families were able to contact the PDSN outside of clinics, but in practice, it appears they were reluctant to do so for non-urgent issues.

Despite many of our cases expressing initial reservations about the adult service providers and some experiencing periods of relational discontinuity, most indicated that over time they were able to adjust to a different approach and that the process of this gradual introduction to adult service providers in the adolescent clinic was a factor which facilitated transition.

"[S]he was very anti, she was saying well I don't like NURSCON as much as PDSN, I mean she's okay but I don't like her as much but this time she actually said oh she's really nice, I'm happy with her so yes." [4-C52]

"[B]ecause I've had conversations with CONA1 and NURSCON [...] has made it more relaxing for me to then go on to the adult clinic with him." [4-YP69]

One of our cases (69) transferred to young adult services and by the point of transfer was perfectly comfortable in the relationships she had established with the adult service providers. When young people move to main adult clinics they continue to see the NURSCON, but there is less relational continuity of consultant. None of our cases transferred to main adult services so we cannot assess users' experiences of transferring across this interface.

4.8.5 Informational continuity

Like model 3, informational continuity was relatively unstructured at all service interfaces, with preparation for transfer woven into clinic consultations. There is strong evidence that families were not well prepared for entry to adolescent services in this model. Few could recall explicit processes of preparation and many were uncertain of the identities of adult team members and the rationale for clinic arrangements. Three cases did not realise they were attending an adolescent clinic and thought they were in paediatrics. Furthermore, because, owing to other commitments, not all health professionals attended clinics at all times, it was possible for young people and their families to meet only paediatric or adult service providers. In the absence of explicit information about the underlying rationale for the service, they were prompted into sense-making to understand the pattern of their clinic consultations. Consultation with the adult team prompted three families to surmise that they had been transferred to adult services without being told about it, and a return to consultation with paediatric staff having consulted adult service providers prompted another two to interpret this as evidence that transition had been postponed.

"I didn't know that I was going to see that man [CONA1], I thought it was still going to be like the same as before [...] I would like to know that that man was going to be there [...] I don't even know him and I'm discussing all my life with him." [4-YP94]

"I think we have been transferred but nobody has said anything, but we haven't seen CONP probably the last, definitely twice and maybe even three, so I think we've sort of been transferred now anyway." [4-C91]

There was also uncertainty about the arrangements for transfer from adolescent to young adult services and several were prompted to seek more information as a result of participating in this study. Three cases moved or were poised to move into young adult services. Although the service rationale appears to become more apparent with imminent transfer, all cases indicated they found transfer to be abrupt.

"I think it would have been nice to have been given more notice about when I was going to move to the adult whereas I went to the last appointment and they said [...] we'll make the next appointment at the adult clinic. I would have liked to have been given more notice, I mean I only saw PDSN and NURSCON, I didn't get a chance to see CONP which I think if it was going to be my last appointment it would have been nice to have seen her as well." [4-YP69]

4.8.6 Management and cultural continuity

Management continuity in paediatric clinic is assured by the relatively small team, the continuity of the PDSN - who maintains ongoing contact with young people and their families in between clinics - and the fact that CONP and PDSN consultant together. Our cases indicate that they had developed strong relationships with the paediatric team – particularly the PDSN - and believed that they had a deep understanding of their lives.

Management continuity at the paediatric/adolescent clinic interface is supported by longitudinal continuity of the paediatric team. The aim is to provide management continuity whilst enabling adult service providers an opportunity to develop an understanding of the young people and their diabetes management. Our cases provide strong evidence that young people and their families valued this continuity, however, because the consultation styles of the adult team were quite distinct from paediatric service providers it could be difficult for young people and their families when they first encountered it (cultural discontinuity). Furthermore, if the division of labour in clinic led to a young person losing contact with a valued member of the paediatric team, this could result in a loss of management continuity if the young person felt uncomfortable talking to other team members. For example, Leanne had established a close relationship with the PDSN but during the study only consulted with the doctors. Because she did not feel comfortable talking to them, she believed her care was compromised.

Several of our cases recounted incidents in which they had consulted with the adult providers and had found the more direct approach challenging, uncomfortable and some of the advice inconsistent with that received in the past. A common complaint was that adult health professionals expected stricter blood glucose control and that they took a more permissive approach to general health behaviours (see developmental continuity).

“[H]er readings were very good and CONA1 [...] instead of (saying) well done you’re doing really well, he said they’re very good but they could be better. I didn’t like that because I thought well you know, that’s not giving her the encouragement to stay well controlled, that’s making her think well I’ve just done all this, I’ve just eaten all this, I can’t have this, don’t do that and now you’re saying I could still do better.” [4-C52]

“[H]is blood level had gone up [...] such a little bit that I thought it didn’t really warrant the telling off [...] I think we were led to believe, especially in adolescence, they can’t always keep it under seven so CONP said try and keep it under nine and it was under nine but I think perhaps because he’s an adult consultant he was like oh it’s above seven and that’s not good.” [4-C91]

For others, however, the clinic arrangement gave them access to a range of views which was considered a positive service feature.

Adolescent clinic caseload was shared between a medical and a nurse consulting team presenting risks to management continuity if young people and their families did not see the same team on successive clinic visits or if they consulted with the doctors but received care from the PDSN in between clinic appointments. In order to counter these risks the team hold meetings before and after adolescent clinic, although it was not unusual for individuals to miss these meetings because of other commitments. The PDSN acts as an additional management continuity mechanism. Co-located with the adult diabetes team, she worked closely with CONP who had a separate office and in between clinic appointments acted as an important source of management continuity between the adult consultant and paediatric consultant and also the paediatric dietitian. There are no formal mechanisms.

Our cases reveal a mixed picture of the effectiveness of these arrangements. When asked, several observed that the team appeared to communicate well and that the general level of care offered was consistent.

“CONP was explaining to the other consultant about Tom’s regime and everything.” [4-C12]

“[W]e’d never met this particular dietitian before but PDSN had obviously told her about Emily.” [4-C49]

“I think they, they all seem to know, even people that haven’t been there in certain things.” [4-YP69]

On the other hand, others offered specific incidents in which management continuity was compromised and had been a source of dissatisfaction. Heath’s mother expressed surprise that an insulin regime change which was supported in between clinics by the PDSN was not passed on to the other team members and Kate went for a year without a consultation as a result of a failure of the service to arrange an appointment.

When young people move into young adult service the intention is that they will be familiar with health professionals who will have knowledge of their care. Unfortunately, because relatively few of our cases made this transfer, and the two who did made the move at the end of the data generation period, we do not have data through which to assess management continuity at this interface. However, we do know that these cases had developed a relationship with NURSCON and CONA1 and it is reasonable to infer that this would provide a mechanism for securing management continuity.

4.8.7 Developmental and flexible continuity

There is little formal education and no check-list of issues to be addressed at different stages of the process. However, transfer to adolescent clinic at 12-13 years is a key event. Young people are introduced to the adult service culture and a change in consultation style. Young people describe being addressed more directly and carers being prompted to take a more peripheral role. This new approach was not specified as a developmental continuity intervention in staff accounts but from the perspective of young people and their mothers this was a significant and perceptible change.

“Well I think the fact that they direct the questions to her shows her that they want her to be in control of her own situation.” [4-C52]

“[T]hey treat me as an adult, they talk to me more than they talk to my mum and dad now and I think that’s kind of like helped because I know when I go up into the adult clinic that’s the way it’s going to be.” [4-YP69]

In the case of Fiona, who was reluctant to talk at consultations, her mother ventured the opinion that this changed approach was a step too far for her daughter at this time. Similar views were expressed by Leanne’s and Stephanie’s mothers.

“[S]he is still a child whereas they treated her more like an adult which I know that’s what she’s got to get used to but I don’t think just yet.” [4-C94]

“I think their approach is they’re speaking to an adult whereas she’s not an adult yet [...] there’s not a merge between the two [...] it’s a big jump to the adult level.” [4-C50]

Young people in this model encounter adult service culture at a relatively young age. Rather than adopting the same consultation style for all cases and expecting young people to adapt, our findings indicate the need for greater account to be taken of the singular needs of individual young people.

Staff from both sides of the service described a flexible approach to carer involvement in the consultation, with the decision to move to lone consulting left to the young person. Young people and their families positively evaluated this flexibility.

Whilst transfer from paediatric to adolescent clinic takes place between 12-13 years, transfer between adolescent and young adult clinic is more flexible. Young people remain in adolescent clinic until they are ready to transfer to adult services. The aim is to accommodate individual need, rather than proactively managing the process.

"I would say it's an individual thing [...] seeing how the land lies isn't it and yes, because we don't treat everyone by protocol, you can't can you, not when it's emotive."

Our cases reveal mixed evidence as to whether this aim was realised in practice. When asked, many of our cases indicated that staff were responsive to their changing needs and in some instances suggested regime change to accommodate anticipated needs.

"I think they do well at treating them individually." [4-C91]

"They've given me sort of advice and tips on how to cope with like sport and obviously when I do a lot sport all day, when it's intense, they sort of give me pointers to help make sure that I'm sort of the best I can be whilst I'm doing the sport in terms of my sugar levels being fine and having the right amount of energy and stuff like that." [4-YP45]

"They changed my insulin when I was about thirteen to fit in so that it was more sociable because the insulin I was on when I was younger I was restricted to times that I could eat." [4-YP69]

Other offered a less positive appraisal, with many contrasting the disease-focused approach of adult providers with the individualised care received in the paediatrics.

"I don't think they have any idea [...] how we live and how I feel and you know they have never asked any of these questions." [4-C54]

"I mean we're only in there about ten minutes [...] I explained about that she was running high and he just kind of went oh we'll try it at a different time of day and that was it [...] it's not so personal as it was before. [...] I don't think they really see her as a separate person." [4-C94]

Educational needs were also met on an individual basis in clinic and, if necessary, through a home visit with the PDSN or appointment with the dietitian. Staff also issued information leaflets as required when young people attended clinic. A mixed picture emerges of the effectiveness of these strategies. Emily's mother was highly satisfied with her daughter's care. Emily had moved to an insulin pump and had received high levels of support from PDSN and SRDA.

"I think they (educational needs) have been met and I suppose in some ways perhaps at a high level because she's had the education on a personal basis you know." [4-C49]

Others were more critical.

"[A]nything Kate (YP45/Patient) learns she learns from belonging to Diabetes UK and getting their magazine once a month." [4-C45]

"[T]here's no education, there's no, it's like checking the pulse and making sure you're still alive and coming out again." [4-C54]

Moreover, although the team did not negatively judge teenage behaviours, there is evidence of a failure to proactively address sensitive issues. One mother suggested that the team appeared to avoid difficult issues and several young people said that they felt that the onus was on them to broach the subject rather than this being introduced by service providers. Some indicated that clinic organisation was not facilitative of such conversations. Young people who had experienced relational discontinuity on transfer to adolescent clinic did not feel able to raise certain topics and some indicated that carer participation in consultations discouraged discussion of such issues. Overall it would appear that the complex division of labour in adolescent clinic and the shortcomings in management continuity, also impinged on the success of the model in achieving developmental flexible continuity. There is clear evidence of the need for more robust systems of record keeping and communication in this regard.

The aim of the nurse-led young adult services is to provide one-to-one support for patients. Service providers' accounts indicate that the emphasis is primarily on medical rather than social issues. Unfortunately we do not have data with which to assess this service.

4.8.8 Quantitative outcomes

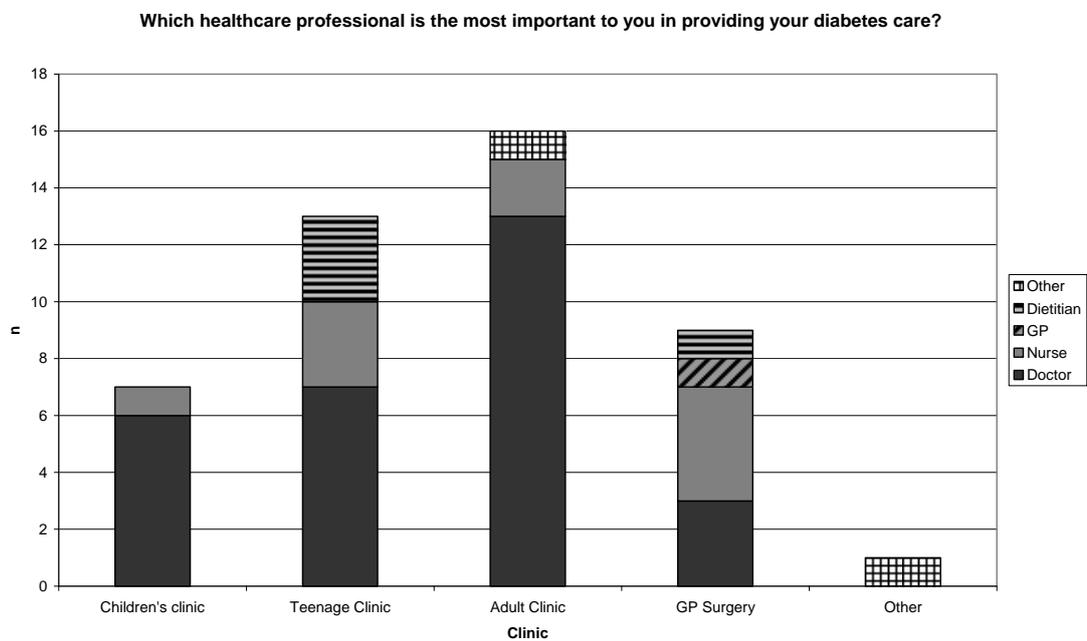
In total, 51 responses were received from the 217 young people approached in model 4 (response rate = 24%). 14% were attending a children's clinic, 61% attended a teenage clinic and 35% attended an adult clinic. A total of nine cases (18%) attended a GP surgery for their diabetes care. One case had not attended any clinics or surgeries for their diabetes care. Differences in lone consulting were still evident in this model, but the direction was not as clear as it was in models 2 and 3 where lone consulting was proactively encouraged. Carers reported that they attended consultations with their children for two thirds of those attending children's clinics, for 92% of patients attending teenage clinics and 36% of patients attending adult clinics. Only one carer reported that they attended the GP surgery with their child for their diabetes care.

The average age for respondents was just under 18. Respondents attending a children's clinic had an average age of just under 15, those in a teenage/young person's clinic just over 15 and those in an adult clinic just under 21. The older than predicated average age of those attending children's clinic, may reflect the confusion expressed by the case study subjects regarding the status of the teenage clinic in this model. The nine cases who mainly attend a GP surgery for their diabetes care had an average age of just under 21. Overall, 43% of respondents in model 4 are male. While this overall percentage was similar for respondents in a children's (43% male) or teenage clinic (44% male), 39% of respondents in an adult clinic

were male and 56% of respondents attending a GP surgery were male.

In model 4, the doctor is generally viewed as the most important healthcare professional and this remains constant across all clinics. This seems to concur with the qualitative findings about the dominance of the adult service culture in this model. In the GP surgery it is a lot more equal between the doctor and nurse, however (Figure 4). While this view is similar for the carers of young people in the adult clinics, for carers with respondents attending child or teenage clinics, the split is even.

Figure 4. Most important health professional for young people in model 4



Respondents attending an adult clinic felt, on average, more confident in their ability to manage their diabetes, and felt less controlled by their carers, compared to those attending teenage or child clinics (Table 19).

Table 19. Model 4: Young person outcome measures

Young person outcome measures	Children's clinic	Young person's/teenage clinic	Adult clinic	GP
PEI	19.0 (18.0, 24.0)	21.0 (18.3, 22.8)	22.0 (19.0, 24.0)	19.0 (17.0, 24.0)
DMSES	65.3 (52.8, 89.0)	77.0 (69.0, 87.0)	81.0 (69.5, 85.0)	69.0 (50.5, 75.0)
DQoLY: Impact of Treatment	8.0 (7.0, 11.0)	6.0 (6.0, 8.0)	7.5 (5.0, 10.0)	7.0 (5.5, 10.0)
DQoLY: Symptom Impact	8.5 (6.8, 9.3)	8.0 (6.0, 9.0)	8.0 (5.0, 10.0)	8.0 (6.0, 11.5)
DQoLY: Parental Control	7.0 (4.0, 9.0)	7.0 (6.3, 12.0)	6.0 (3.5, 8.0)	9.0 (5.5, 10.5)
DQoLY: Impact on Activities	11.0 (7.3, 13.3)	9.5 (6.3, 12.8)	10.0 (5.0, 12.3)	9.0 (7.5, 11.5)
DQoLY: Satisfaction	61.0 (56.5, 68.6)	65.5 (61.5, 70.8)	64.0 (57.9, 69.5)	58.4 (39.3, 67.5)

Median (lower quartile, upper quartile)

PEI – Patient Enablement Instrument

DMSES – Diabetes Management Self-Efficacy Scale

DQoLY – Diabetes Quality of Life for Youth

Carers for those attending adult clinics reported worse role physical scores than those with respondents attending the teenage and child clinics. While carers for those attending teenage clinics reported better social functioning scores, they also reported worse vitality scores, compared with those with respondents attending children or adult clinics (Table 20).

Table 20. Model 4: Carer outcome measures

Carer outcome measures	Children's clinic	Young person's/teenage clinic	Adult clinic	GP
PCDS	4.0 (2.3, 4.5)	4.0 (3.3, 4.4)	4.0 (3.8, 4.9)	4.0 (2.0, 4.3)
SF36: General health	77.0 (59.5, 81.8)	69.5 (45.5, 90.8)	68.5 (32.8, 80.8)	64.5 (49.0, 78.3)
SF36: Reported health transition	1.0 (1.0, 1.5)	1.0 (1.0, 2.5)	1.0 (1.0, 4.0)	1.0 (1.0, 3.0)
SF36: Physical functioning	100.0 (91.7, 100.0)	92.5 (73.8, 98.8)	95.0 (56.3, 100.0)	80.0 (35.0, 95.0)
SF36: Role physical	100.0 (68.8, 100.0)	100.0 (93.8, 100.0)	87.5 (50.0, 100.0)	93.8 (43.8, 100.0)
SF36: Role emotional	100.0 (47.9, 100.0)	91.7 (47.9, 100.0)	95.8 (77.1, 100.0)	66.7 (41.7, 83.3)
SF36: Social functioning	68.8 (46.9, 100.0)	81.3 (56.3, 100.0)	68.8 (37.5, 100.0)	62.5 (62.5, 75.0)
SF36: Bodily pain	50.0 (48.5, 50.0)	50.0 (34.3, 50.0)	50.0 (42.5, 50.0)	42.0 (41.0, 54.0)
SF36: Vitality	47.5 (31.3, 56.3)	30.0 (12.5, 50.0)	40.0 (31.3, 57.5)	40.0 (35.0, 60.0)
SF36: Mental Health	48.0 (31.0, 59.0)	52.0 (36.0, 66.0)	54.0 (39.0, 70.0)	48.0 (40.0, 60.0)

Median (lower quartile, upper quartile)

PCDS – Perceived Competence for Diabetes Scale

SF36: Reported Health Transition: 1 – Much better now than one year ago; 2 – Somewhat better now than one year ago; 3 – About the same as one year ago; 4 – Somewhat worse now than one year ago; 5 – Much worse now than one year ago

4.8.9 Summary

Model 4 has a long history of joint working and comprises many features designed to support integrated working: co-location of the diabetes team, a single funding source and a jointly run adolescent clinic. Although this model was highly integrated at the level of service structures, there was limited cultural continuity with marked contrasts between paediatric and adult services. The adult service was the predominant culture in adolescent clinic, and many young people and carers felt uncomfortable with this when they first encountered it. The service was also poorly understood, with many cases unprepared for the abrupt change in service culture transfer heralded.

Although facilitating longitudinal continuity with adult providers, joint adolescent clinic also resulted in relational and longitudinal discontinuity of paediatric provider – with potential threats to both management and developmental continuity. The service had relatively few developmental continuity mechanisms. Rather the

emphasis was on being flexible and providing the necessary support until individuals were ready to enter adult services. The service was designed to accommodate this diversity of need by allowing young people to remain in the adolescent service for a long-time, rather than proactively managing the transition process. Our cases indicated a mixed picture in relation to overall educational provision and suggest a disinclination to address teenage issues. All of our cases valued the opportunity adolescent clinic afforded them for getting to know the adult service providers and most felt comfortable about the transfer to adult clinic when this occurred. However, the dominance of adult culture, the loss of relational continuity with the PDSN and the aspects of clinic organisation all presented risks to management and developmental continuity and as such indicate a need for more structured processes and written information sources.

4.9 Model 5

Model 5 has two stages (paediatric - teenage/young adult (T/YA) – adult clinic) and is provided by district general hospital. Identical parallel services are run in two sites to facilitate access in the context of a poor transport infrastructure.

4.9.1 Cases

The sample comprised 7 males and 7 females aged 14-21 spanning the full transition process (Appendix 25). Ten cases were dyads of young people and mothers. One case transferred to her GP following a period of shared care when she went to university. All but one young person lived with parents, although two had experienced independent living.

4.9.2 Model structure

The paediatric team comprises two CONPs (1/2), two children's community nurses (CCNs) - one with a specialist qualification in paediatric diabetes - a staff nurse (SNP) and two paediatric dietitians (SRDP1/2). The nursing team provides diabetes care as part of a generic community caseload. Children up to 14 years attend paediatric clinic run by CONP2, two CCNs (working interchangeably) and one dietitian (SRDP1). Consultations are typically serial, young people see the nurses, CONP2 and SRDP1 on request. Nurses provide support via home visits and school outreach and can be contacted by telephone. Outside working hours formal contact is via the ward but informally nurses make themselves available to families experiencing difficulties.

T/YA clinic is run jointly by paediatric and adult services. Young people begin consulting with CONP1 and move onto CONA1. Typically consultations are only with the doctor unless there are particular issues which require the involvement of the whole team.

Nurses undertake pre-clinic activities. There was some disagreement as to whether this was an appropriate use of qualified nursing time, but the nurses themselves saw this as an opportunity to engage the young person in a conversation about their diabetes management and there is strong evidence that this was valued by families.

“Sometimes I think the nurses are more important [...] you’re so very quickly with the consultant and the nurses just do everything else.” [5-C41]

“[T]he consultant deals with the actual medical side and then the nurses have a much more practical outlook.” [5-YP22]

Dietitians see families on the basis of need. Transfer to adult services is flexible, although typically occurs at aged 21.

The paediatric team meets regularly but there are no whole transition service meetings.

Adult services comprise two CONAs (1/2), two SPRs, two GP clinical assistants, two ADSNs (1/2) and a SRDA. Adult services are a combination of general and specialist diabetes clinics, run jointly by the consultants and ADSNs and nurse-led clinics.

See Appendix 26 for model diagram and Appendix 27 for summary of key features.

4.9.3 Resource allocation

Table 21. Model 5: Hours per month for health professionals

transition stage (n = 158)	hours per month							total
	Consultant	DSN (7)	CCN (7)	CCN (6)	SRD (6)	Staff Nurse (5)	HCA	
Teenage & Young Adult Clinic - Main Site	7.00	3.50	3.50	2.00	3.50	3.50		23.00
Home Visits & Community Work			10.00	5.75		0.88		16.63
Ongoing Contacts		3.00	6.00	6.00		2.00		17.00
Teenage & Young Adult Clinic - Satellite Site	3.17	1.59	1.58		1.58		1.25	9.17
total hours	10.17	8.09	21.08	13.75	5.08	6.38	1.25	65.80
(% of total staff time)	(0.15)	(0.12)	(0.32)	(0.21)	(0.08)	(0.10)	(0.02)	(1.00)

4.9.4 Relational and longitudinal continuity

According to the model there is relational and longitudinal continuity of consultant in paediatric clinic, although six cases reported changing consultant when the service was organised into its current form. The children's community nursing service is managed along team lines in order to ensure adequate cover for annual leave and other absences. Most families were happy to receive care from any of the nurses, but some had developed close relationships with particular team members, which could often be traced back to the point of diagnosis.

On transfer to the T/YA clinic young people shift to the care of a new paediatric consultant (CONP1) and CONA1 but remain with the same nursing team. For historical reasons, some knew CONP1, but others did not and found establishing new relationships challenging.

"[T]he consultants have changed so you have to kind of get to know new people and it's quite hard for them probably and me as well getting to know someone." [5-YP42]

The intention of the model is that young people initially consult with CONP1 and gradually transfer to CONA1. In practice, because of the busyness of clinics, the processes through which young people are allocated to a consultant were somewhat ad hoc. Some elected to see whoever was free to minimise time at clinic; others waited to see their preferred consultant. Whilst the fluidity of arrangements affords service users choice, it does leave to chance whether the model functions in the way it is intended. In practice these risks seem to be off-set by the extended period of time young people spend in T/YA clinic and longitudinal continuity of nursing care.

"I think the continuity of the nursing staff is a really positive thing, there has to be some kind of continuity or you feel you're starting all over again and the hardest thing has been leaving the paediatric consultant behind and beginning to establish a relationship with somebody different." [5-YP42]

"I think even though the doctors were different, having the same nurses in both clinics was invaluable." [5-YP22]

It is expected that whilst attending T/YA young people will become familiar with the ADSN1 who then provides relational and longitudinal continuity on transfer to adult services.

Young people described a gradual transfer of care from paediatric to adult services which they understood as preparation for transfer.

"In the child bit I met some of the nurses that are in the teenage bit, in the teenage bit you met some of the nurses and doctors from the adult bit, from the adult bit you got all the ones you know haven't you." [5-YP34]

"I've changed doctors, well because I used to have CONP1 and now I've gone into CONA since I've been in adolescents. [...] So they're sort of getting me ready for it." [5-YP54]

4.9.5 Informational continuity

Preparation for transfer at both service interfaces is woven into consultations and supplemented by information leaflets developed jointly by adult and paediatric nurses. Cases were able to recall the information provided and were generally satisfied with the process.

"I remember CCN1 or CCN2 saying this is the next stage, this is what happens, CONP1 is there and an adult person [...] and explaining it's to try and get you a little bit more used to being a bit more grown up." [5-C45]

"[T]hey've explained a lot more, handed out leaflets and that sort of thing saying what's going to happen and mainly a list of who's at both so that I haven't got to go, if I was worried about new doctors that sort of thing, they've told me that the same sort of people that would be there. So for instance CONA does both and I think some of the nurses do both." [YP-51]

However, despite this, several respondents expressed uncertainty as to the identities of health professionals in T/YA clinic. In more than one case when a young person had seen the CONA they believed they had seen a locum doctor. Moreover, on entry to T/YA clinic many were unclear about the rationale for having both adult and paediatric staff running the service and perceived clinic to be disorganised.

"[S]ometimes it all seems a bit haphazard." [5-C42]

"[T]hings are a bit disorganised at the clinic and they need to sort of organise themselves a bit more. I mean I don't feel I need to see CONP2 anymore because obviously moving towards the adult I generally see CONA1 more so, sometimes that will change sometimes I will have to see CONP2 I'm not too sure why." [5-YP18]

Part of the difficulty in evaluating this element of the service, is that preparation was most evident in the 6-9 month period immediately prior to transfer and many cases had not reached this stage in the transition when we were inviting comments. Moreover, where young people were lone consulting, parents were dependent on them for information which was not always forthcoming; so parents were less than certain in their responses. What is clear is that despite these uncertainties about the process, most indicated that they were ready for transfer when it occurred and most claimed the transition was relatively smooth. Families seemed largely unperturbed by the lack of information, interpreting this as evidence that no changes in their

care were imminent and were confident they would have control over the process.

“I’d imagine they would do something a bit similar to what they did (before), maybe just say you’re approaching the age now where you can move up to the next stage, you’re seventeen or eighteen or sixteen and you could go to the adult clinic if you wanted to.” [5-YP45]

One advantage of this model is that families do not consider transfer to be a major issue. When people feel comfortable with the service and believe they will have control over the timing of transfer – and most of our cases appeared to – then they seemed to have confidence in the process despite limited information. This may also reflect the high levels of relational and longitudinal continuity afforded by the model and trust in the service. All four cases who transferred their care to adult services felt ready to make the move.

4.9.6 Management and cultural continuity

In the paediatric clinic relational continuity with a single paediatric consultant is one mechanism for ensuring management continuity. The paediatric nurses have a team approach and work interchangeably, continuously updating each other, so as to ensure consistency of approach. Management continuity is also supported by a post-clinic multidisciplinary debrief meeting. These processes appeared to work well.

In T/YA clinic care is transferred to two new consultants. The medical notes are transferred but there is no formal handover, however, the longitudinal continuity of paediatric nurses helps to safeguard management continuity at this interface, particularly in relation to the psychosocial details of a young person’s care. The team aim to provide a joint CONP1/nursing appointment when young people first attend this clinic, although this did not always happen in practice.

“Well I have to say I think, in a way I think it’s more important that the nurses are the thread, I think really because they’re the ones you ask the daft questions to.” [5-C45]

“I think it has been and the fact that the nurses are the constant helps in the handover of information.” [5-C42]

Few cases reported major management discontinuities on transfer to T/YA clinic. Only one was very critical and this was in the context of a period of strained relations with health professionals. However, some commented on the more relaxed approach of CONP1 which led to some management discontinuity.

“CONP1 made an unfortunate comment to Ewan at his first clinic, he was surprised that Ewan was still doing as many checks, he says carte blanche to just not. So the last time his average wasn’t as

good, it wasn't disastrous by any manner of means but it wasn't as good and I'd had a little trouble through the summer sort of persuading him that he needed to be doing more because whatever CONP1 had said Ewan had interpreted that as he really didn't need to. [...] So Ewan got a little, we got a little wake-up call in November and as a result he's been doing more checks. So I think that consultants have to be very mindful of what they are saying especially to adolescents who are at the stage where they want to be the same as everybody else." [5-C42]

Within T/YA clinic health professionals consult separately and young people may see different consultants on successive clinic visits. In order to ensure management continuity, the team regularly held a post clinic meeting. These were systematic events which, however late the clinic finished, would be adhered to by staff, and were designed to mitigate the potential service discontinuities that might arise from the division of labour in clinics. When asked, most of our cases expressed the view that communication between the team was good and that they did not have to repeat information when they consulted with different people. The majority considered that their care was consistent with no major management discontinuities, but acknowledged that the two consultants had different interpersonal styles.

"[S]he's been well supported all the way through and there's been no sudden big changes in her care." [5-C16]

"[E]ven though CONP1 and CONP2's approaches are different the care I receive is still the same in the end, it's just the way they go about giving it to you is different." [5-YP22]

Service providers also remarked on the short-comings of a joint clinic in which consultants did not consult jointly and so there was no prospect for a merging of child and adult perspectives; or in other words, greater cultural continuity.

On transfer to main adult services management continuity is ensured through longitudinal continuity of ADSN and CONA1. Only two of our cases had transferred to adult clinic by the cessation of the study, none expressed concerns with management discontinuity, but given that their care was provided by the same health professionals this is to be expected.

4.9.7 Developmental and flexible continuity

Young people transfer from paediatric clinic at around 14 years and spend up to eight years attending T/YA clinic. The expectation is that during this time they will receive high levels of support to become independent so that they are able to function in the adult service. This seems to be achieved by a combination of developmental and flexible continuity interventions. There is no formal education.

Staff accounts describe a process through which young people gradually move from care provided by the paediatric team to greater adult services input, which is considered to be more developmentally appropriate. Until the age of 16-18 the majority of the support continues to be provided by the paediatric team. Then this is a gradual shift to the adult team, which will address slightly different developmentally appropriate issues. However, as we have seen the ad hoc processes in clinic had the potential to disrupt the logic of this model (see below).

On entry to T/YA clinic young people are expected to start attending consultations on their own. All of our cases moved to lone consulting in T/YA clinic and many described how it had acted as catalyst for taking greater responsibility for the management of their diabetes.

"I think it's had a good effect, she's definitely more sensible about it [...] she will listen to them but if I'm in there she'll just take it that they're talking to me and switch off." [5-C63]

"[I]t's certainly made me be more independent whereas at the paediatric clinic it was often the advice was given to my mum rather than to me." [5-YP22]

With the exception of one case, in which a young man had encountered an unfamiliar consultant the first time he consulted on his own, none of the young people in the study described lone consulting negatively and for many it represented an important developmental milestone. However, carers could find this change challenging. Several referred to feeling cut off from the process which was difficult after being deeply involved in their child's care since diagnosis.

"I do think it's very important that you have feedback on it because ultimately he's still under my care and although we do want him to start doing more for himself he's still not completing his diary and things like this so I kind of need to know what's what." [5-C41]

"In some ways I'd quite like them to give you some sort of feedback.[...] I mean they're still your child, they're still your responsibility [...] Even if they just sent you a quick letter saying everything was fine, we just did this or you know." [5-C22]

In many cases the young people in question were sixteen and as such there was a limit to what could be discussed about a young person's case without their permission. However, in all but one of our cases, young people still lived in the family home and mothers still had an impact on their diabetes management, and young people's diabetes management had an impact on mothers. One mother was very stressed about her son's poor diabetes management and was taking anti-depressants. Another was regularly dealing with her daughter's nocturnal hypoglycaemia to the detriment of her own well-being. There was no facility for carers to continue to interact routinely with the service and respondents

indicated that the onus was on them to seek out nursing support in T/YA clinic, rather than this being proactively offered.

There were few other developmental continuity interventions in this model; rather the emphasis was on flexible continuity with support offered responsively to address individual need. There was no tick box of topics to be covered or a structured record. In the main respondents indicated that at least some health providers (usually the nurses) had an understanding of their lives and commented positively on the sensitivity of the service to their changing needs.

"[T]hey explained that if a lecture over ran or something into lunchtime, on the two injections a day there's a chance that I would end up having a hypo during the lecture whereas if they moved it to four I haven't got to stick to 12 o'clock lunch or whatever and I was happy enough to do that so it worked better for me." [5-YP51]

"[T]he nurses would always try and have a little chat with you [...]. At the last one they broached the subject of teenage parties and alcohol and he came with a leaflet or two about alcohol [...] it's been done informally and I feel, I'm really pleased about the way the information has been fed to us because it's been bit by bit, too much at once would probably have scared us rigid and depressed us." [5-C42]

As this last extract indicates, information was directed at individual needs and woven into the clinic encounter. For many of our cases, this approach worked very effectively, but in others, young people acknowledged that, with hindsight, there had been gaps in the information they had been provided and some argued that health professionals had made inaccurate assumptions about their level of understanding.

"[T]hey didn't really offer me advice that aided me in my social life at university." [5-YP18]

"I have definitely noticed a difference in my blood sugars when I drink alcohol which I have had to adjust to [...] which I wasn't necessarily expecting a couple of times [...] they haven't really mentioned it in so many words but they have told me the risks about drinking alcohol [...] in a more scientific way." [5-YP22]

The dietetics service received particular criticism from our cases.

"The dietitians they just don't seem to grasp normal life. I mean you tell them what you eat on a normal day and they will try and tell you what you should eat and it's like well okay I'm not seeing you for food advice, in real life you can't always eat the right things [...] they don't understand okay well what if you're out on the motorway and you want something to eat, there's only MacDonald's around you know, you can't get two slices of brown bread with nothing on it. They don't seem to understand that, the dietitian is

no good at all, the consultant, like CONP1 and CONP2 tend to focus more on your sort of day to day life." [5-YP18]

Service providers reported a troubled history in providing dietetics services and for a period of time support in T/YA clinic was provided by a newly qualified junior dietician who, by her own admission, was out of her depth and found it very difficult to engage teenagers.

A key feature of this transition model is the extended period young people can remain in T/YA clinic. There is strong evidence that this was positively evaluated by our cases, enabling young people to achieve independent management at their own pace and in relation to key life-course events and, as we have indicated, may help to account for the relatively relaxed attitude to transfer expressed by the cases in this model. However, non-medical staff indicated that the service was dominated by a medical model and they aspired to have an increased focus on social concerns.

Overall those cases in our sample that transferred to adult services or were anticipating transfer, seemed confident in their preparedness for this move and the majority considered that the service had offered an individualised approach. However, some education issues could be overlooked because responsibility was dispersed and there are no formal recording keeping systems.

Satellite services

Four cases attended clinics at the satellite sites. All underlined the importance of ease of access and indicated that if they had to attend clinics at the main hospital attendance would be more difficult. Ease of access was also important in facilitating independence for some young people as they were not reliant on carers to transport them to clinic.

4.9.8 Quantitative outcomes

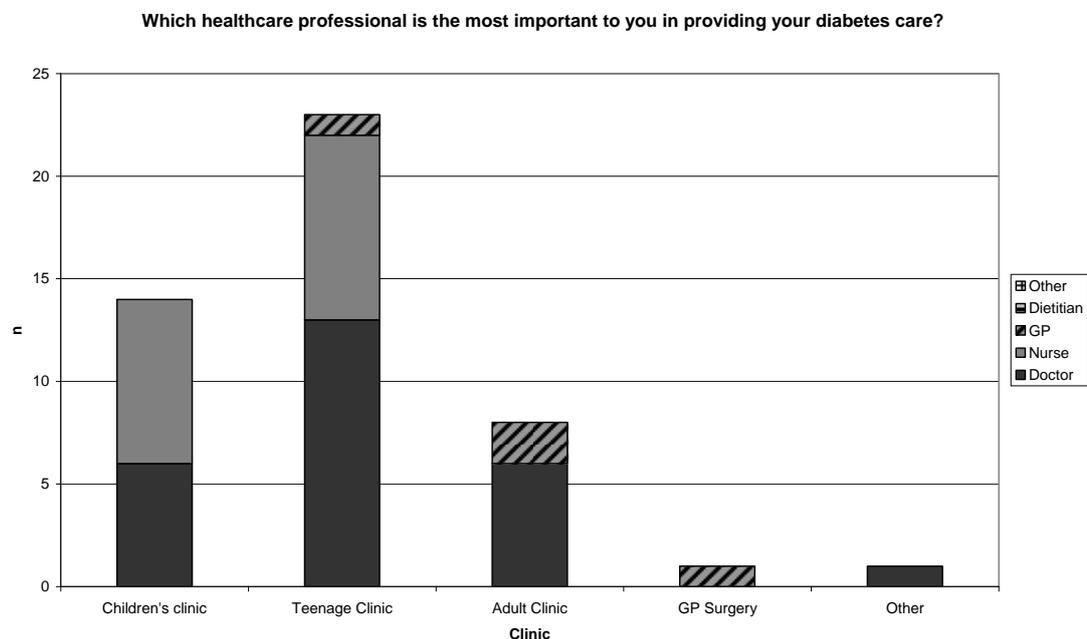
A total of 158 young people were approached from model 5. The response rate was 32% (50). Of the 50 young people that responded to the questionnaire, 28% attended a children's clinic, 46% attended a young person's/teenage clinic and 22% attended an adult clinic. One respondent attended a GP surgery. One stated that they mainly attend a private naturopath. There is a similar pattern of lone consulting to models 2 and 3 in which lone consulting is encouraged. All carers of respondents attending child clinics attend consultations, just under half (47%) of carers attend appointments for young people attending teenage clinics and one in four carers attend appointments for those attending adult clinics.

Overall, the average age of young people in model 5 was just under 18. This varied, as expected, between clinics, with respondents in a children's clinic having an average age of just under 14, those in a teenage clinic with an average age of 18 and those in an adult clinic

with an average age of 21. Taken as a whole, 60% of respondents were male. Of respondents in the children's clinic, half were male, of those in a teenage clinic just under 70% were male and of those in an adult clinic, just under 55% were male.

For those attending child clinics, nurses are considered (marginally) more important to their diabetes care than doctors. This shifts in the opposite direction for those attending teenage clinics (again, marginally). For those attending adult clinics, the doctor is considered to be the most important health professional among the majority (Figure 5), possibly reflecting the low level of nursing service available in this component of the model.

Figure 5. Most important health professional for young people in model 5



Those attending child clinics felt, on average, less confident in their ability to manage their diabetes (DMSES median: 74), compared to those attending teenage or adult clinics (medians: 81 and 80 respectively). The impact of parental control on quality of life shifts noticeably between clinics. While those attending child clinics have a median of 7, this increases for those in teenage clinics to 9, decreasing to a median of 5 in the adult clinics (Table 22). This could be due to the fact that teenagers tend to perceive carer involvement in their life more negatively than children would (whether or not there has been any *actual* change in the level of involvement or not).

Table 22. Model 5: Young person outcome measures

Young person outcome measures	Children's clinic	Young person's/ teenage clinic	Adult clinic
PEI	20.0 (18.8, 24.0)	21.0 (18.0, 24.0)	24.0 (18.0, 29.0)
DMSES	73.5 (63.9, 85.9)	81.3 (75.0, 89.0)	80.0 (69.0, 91.0)
DQoLY: Impact of Treatment	8.0 (5.0, 9.0)	6.0 (5.0, 8.5)	6.0 (5.0, 9.0)
DQoLY: Symptom Impact	6.5 (6.0, 8.0)	6.0 (5.0, 7.0)	6.0 (5.0, 7.0)
DQoLY: Parental Control	7.0 (5.0, 7.8)	9.0 (5.0, 7.0)	5.0 (3.0, 11.0)
DQoLY: Impact on Activities	10.0 (6.5, 11.4)	8.4 (7.0, 10.3)	10.0 (8.0, 13.0)
DQoLY: Satisfaction	64.5 (61.3, 67.5)	68.0 (60.0, 78.0)	63.0 (57.0, 71.6)

Median (lower quartile, upper quartile)

PEI – Patient Enablement Instrument

DMSES – Diabetes Management Self-Efficacy Scale

DQoLY – Diabetes Quality of Life for Youth

Carers for young people attending the adult clinics reported better general health scores than those attending the teenage or child clinics (median of 86, compared to 72 and 62 respectively). Role physical, role emotional, vitality and social functioning scores were also lower for carers with respondents attending child clinics (Table 23).

Table 23. Model 5: Carer outcome measures

Carer outcome measures	Children's clinic	Young person's/teenage clinic	Adult clinic
PCDS	4.0 (3.1, 4.0)	4.0 (3.7, 4.8)	5.0 (4.8, 5.0)
SF36: General health	62.0 (41.0, 91.0)	72.0 (62.0, 87.0)	86.0 (82.0, 93.8)
SF36: Reported health transition	1.0 (1.0, 3.0)	1.0 (1.0, 3.0)	1.0 (1.0, 2.5)
SF36: Physical functioning	100.0 (92.5, 100.0)	95.0 (95.0, 100.0)	100.0 (95.0, 100.0)
SF36: Role physical	87.5 (75.0, 100.0)	100.0 (81.3, 100.0)	100.0 (93.8, 100.0)
SF36: Role emotional	75.0 (66.7, 100.0)	95.8 (81.3, 100.0)	100.0 (100.0, 100.0)
SF36: Social functioning	75.0 (62.5, 100.0)	100.0 (62.5, 100.0)	100.0 (100.0, 100.0)
SF36: Bodily pain	50.0 (42.0, 52.0)	44.0 (42.0, 50.0)	50.0 (44.0, 50.0)
SF36: Vitality	35.0 (25.0, 50.0)	42.5 (35.0, 55.0)	60.0 (46.3, 63.8)
SF36: Mental Health	48.0 (40.0, 66.0)	58.0 (52.0, 65.0)	62.0 (60.0, 70.0)

Median (lower quartile, upper quartile)

PCDS – Perceived Competence for Diabetes Scale

SF36: Reported Health Transition: 1 – Much better now than one year ago; 2 – Somewhat better now than one year ago; 3 – About the same as one year ago; 4 – Somewhat worse now than one year ago; 5 – Much worse now than one year ago

4.9.9 Summary

In model 5 young people progress from paediatric through an extended joint T/YA clinic on to adult services. Our findings indicate some informational continuity shortcomings which appear to have been offset by longitudinal continuity of nursing care and users' sense of control over the process. The challenges to a smooth transition are most acute at the interface between paediatric and T/YA clinic; however, our evidence suggests that any negative effects of relational discontinuity of consultant are mitigated by the longitudinal continuity of nursing care. Lone consulting is actively encouraged and whilst young people evaluated it positively, carers experienced management and informational discontinuity.

The central feature of this model is the extended time young people are cared for in the T/YA clinic. These arrangements are intended to foster a gradual developmental process in which the young person moves from the family-centred ethos of the paediatric service to the individual ethos of the adult service having gained a familiarity with adult service providers. Each side of the service was seen as having a distinct culture and approach, and this was considered to be entirely appropriate. The aim of the service was to support the young person in adjusting to such differences and affect a transfer of

care at a time that met individual needs. The service intends that young people begin by consulting with CONP1 and then move on to CONA1. Despite the rather ad hoc patient allocation processes, our cases received consistent care. One possible explanation for this finding is that medical care in this model tends to be narrowly technical, with nurses concentrating on the practical and psychosocial dimensions. Moreover, attendance at post clinic briefing meetings is strictly adhered to.

There is little formal education which is addressed on an individual basis, but the lack of a formal transition plan and the fluid clinic arrangements creates risks that young people do not receive all the information they need. In addition, dietary advice was considered inappropriate.

The mechanism in this model most consequential for ensuring a smooth transition was flexible continuity. Allowing young people to remain in the service and tailoring provision to meet individual needs was positively evaluated by our cases. Adult services are significantly less well resourced than paediatrics and the paediatric nursing team had a very strong maternal commitment to young people and was reluctant to move them on until they were ready. However, there was evidence that this created workload tensions for the paediatric service which calls into question the model's sustainability.

5 Transition model evaluation synthesis

5.1 *Achieving smooth transition*

The aim of this study was to evaluate a range of transition models to identify what works to ensure a smooth transition, for whom and in what circumstances. For each model we have drawn together the ethnographic descriptions, qualitative case studies, health professional resource allocations and quantitative data to examine their effectiveness in achieving the continuities central to smooth transition. Each model comprises a unique combination of structures and service components and as such they create singular challenges in relation to the different dimensions of experienced continuity. Models created to ensure continuity of one kind can have a deleterious impact on continuity of another kind and the particular combination of interventions necessary to ensure smooth transition depends on the context.

In this chapter we draw together the findings emerging across all five transition models to consider (a) the contribution of the different continuities to young people and carers' experiences of smooth transition; (b) the effectiveness of different service components in achieving these continuities as reflected in the case studies and revealed by the organisational ethnography; (c) the relationship of service continuities to psychosocial outcomes as measured by the survey instruments; and (d) the costs and consequences of each service model. In interpreting these findings we also draw on young people's and carer's experiences of living a life with diabetes (Appendix 5).

5.1.1 Relational and longitudinal continuity

The case study data indicates that the mechanisms central to smooth transition are relational and longitudinal continuity. When asked, most young people and carers expressed a preference for a relationship with a technically competent health professional who knew them personally over someone who was technically brilliant but did not know them as an individual. Relational and longitudinal continuity were believed to provide the foundations for the development of trust.

"[I]t's good to have someone that's continuous I think. [...] because you kind of just learn to trust them and I think it would be really hard if you just got kind of dumped onto people that you'd hardly ever spoken to before and then they're turning round and

saying oh yes just change your insulin to this and do that and you don't know them." [3-YP121]

Relational and longitudinal continuity also foster a non-judgemental approach. The treatment of illness inevitably takes place within a moral framework. There is a perceived obligation for young people with diabetes and their families to show they are doing their best to control and manage it. Yet whilst diabetes carries high levels of responsibility in terms of self-management, ultimate power is maintained by health professionals through surveillance⁽⁹³⁾. The aim of most young people and their families is for 'normalisation' and on occasion less than optimal blood glucose control can arise from the collisions between diabetes management and the other competing worlds of work, play, friendship and family life. Adolescence and young adulthood are a time of profound social change, which can make diabetes management challenging. Many of the young people in our study had experienced periods in which their control had deteriorated. Where they enjoyed relational continuity of provider, these 'blips' could be understood in the wider context of their lives and individual illness trajectory, rather than being narrowly defined as 'non-compliance'.

"I kind of feel they might be a bit more understanding if you're not doing quite so well as you could be because they know what's happened before and they know if you've having like a bad few months that it's not to standard it's just a bad few months." [1-YP180]

These findings resonate strongly with the observations of Parker *et al.*⁽⁸²⁾ in their conceptual review of continuity of care about patients' desire to be dealt with in a wider context that acknowledges their life situation.

A non-judgemental approach in turn fosters honesty, which is valued by service providers so that they can offer advice based on an understanding of actual self-management practices rather than trying to second guess accounts shaped by the desire of young people to manage identity and culpability in the clinical encounter.

Not only do relational and longitudinal continuity bridge past to current care, they also connect to the future and provide a sense of predictability⁽⁹²⁾. There is strong evidence that young people and their families are able to move across service interfaces and cope with other changes with relative ease if relational and/or longitudinal continuity are sustained. In models with high levels of relational and/or longitudinal continuity in which there were limited informational continuity mechanisms at key service interfaces families were still relatively relaxed about transfer (models 3, 5) but in those which entailed a complete change of care provider, families had high needs for information (models 1, 2). Relational and/or longitudinal continuity with trusted health professionals appears to provide safety at times of change and there is strong evidence that

high levels of relational continuity in adult services is positively valued by young people in models requiring a complete change of provider on transfer (models 1, 2). We have suggested that in model 3 the willingness of cases to transfer directly to adult services was in part a reflection of the fact that they were to continue in the care of PDSN/ADSN.

Not only are relational and longitudinal continuity valued intrinsically, they also promote management continuity. In models or service components in which there were high levels of relational/longitudinal continuity, management continuity was achieved with relative ease (see below). Moreover, relational continuity facilitates the provision of flexible continuity as an understanding of young people and their carer's lives facilitates individualised care.

Paediatric nurses were key sources of relational and longitudinal continuity. Many young people and their families had developed a close therapeutic relationship with key individuals (models 3, 4) and/or whole nursing teams (models 1, 2, 5). In all models families had high levels of access to the support and advice of children's nurses and in the main, it was nurses who were generally regarded as having an understanding of the fabric of young people's daily lives and with whom families elected to discuss the practicalities of diabetes management. The young adult consultant in model 2 developed a similar role in the absence of on-going nursing support. While families were happy to have access to a nursing *team*, there is clear evidence that in clinic young people prefer a simple consultation format. In model 1 children's services clinic consultations involved all multidisciplinary team members and although these arrangements functioned in part as a management continuity intervention, young people indicated that they felt intimidated by such a large consulting team. In model 4 the team had changed from a multidisciplinary consultation format for this reason. In addition, in some models, as young people progressed through the service, the organisational arrangements resulted in a reduction in the opportunities available to have a one-to-one conversation with a nurse, causing relational discontinuity which was negatively evaluated (model 4) (see below).

We have examined a range of service arrangements designed to support relational and longitudinal continuity. The clearest example is the joint PDSN/ADSN post in model 3 which spanned paediatric and adult diabetes services and was positively evaluated. We also identified effective examples of formal (model 1) and informal (model 2) boundary blurring at key service interfaces which enabled new relationships to be built prior to transfer or established relationships to be sustained whilst new ones developed. In addition some models included arrangements which enabled young people to familiarise themselves with new service providers before being formally transferred to their care. These included simultaneously running adolescent and young adult clinics (model 2) and doctors attending each other's consultations as observer (model 3).

Two models in this study had joint clinics. We hypothesised that joint clinics would promote relational and longitudinal continuity, but our findings indicate that this is not necessarily the case. Model 4 provided clear evidence that unless careful attention is given to the division of labour and families' opportunities for accessing service providers, joint clinics can result in discontinuities of care provider with deleterious consequences for management, flexible and developmental continuity. Interestingly, we learnt from service providers that historically, clinic organisation did ensure relational continuity as the whole team consulted together but these arrangements were changed with the appointment of the PDSN and, as we have seen, young people in this study expressed a preference for a simple consultation format. We identified other examples in which models had undergone minor alterations which had impacted on relational and longitudinal continuity. This highlights the importance of attending to internal processes as well as external structure when implementing service improvements/modifications.

As we have argued, continuity of care is a complex concept and relational and longitudinal continuity are not without some risks. In model 3 in which there were high levels of relational continuity with the PDSN/ADSN there was some evidence that relationships became too close. Moreover, there are challenges in covering for staff absences and departures. Indeed, it was precisely to cover such eventualities that some services operated team-based systems of longitudinal continuity (models 1, 2, 5). Furthermore, in small teams if the young person and their family fail to build a satisfactory relationship with the health professional then no alternative is open to them. We identified a handful of cases in which relationships with health professionals became strained and transfer to new service providers was positively welcomed. In addition, relational continuity needs to be balanced with considerations of expertise. In model 5 in which paediatric service providers continued to care for families into young adulthood, concerns were expressed about professional competence.

Table 24. Effectiveness of service components designed to support relational and longitudinal continuity

Service component	Effectiveness	Risks
One to one consultation format	Not formally evaluated; but large multidisciplinary team consultation format experienced negatively by young people	One to one consultation format in models with low levels of relational/longitudinal continuity may lead to management discontinuity
Joint PDSN/ADSN role	Very effective	Relationships may become too close; arrangements are required to accommodate departures and absences; at present this is not a formally recognised role, therefore replacing the post incumbent may prove challenging; a service may become too dependent on a single individual
Named/team nursing	Very effective	Arrangements required to cover for staff absences/departures in named-nursing systems
Formal boundary blurring	Very effective and can promote cultural continuity	Resource implications
Informal boundary blurring after transfer to adult services	Very effective and can be undertaken on a selective basis	Vulnerable due to informal nature; can stretch the competence of healthcare providers.
Clinic attendance as observer	Promotes longitudinal but not relational continuity; can promote cultural continuity	Resource implications
Simultaneously running adolescent and young adult clinics	Early introduction to adult service providers promotes longitudinal continuity	Early encounter with young adult services can present a culture shock; there is a temptation to batch process educational interventions for young people from each clinic which may not be appropriate to individual need
Joint clinics	Promoted in the literature as good practice	Depending on their organisation, joint clinics can create relational discontinuity and can also lead to a diffusion of responsibility which, without robust communication systems, can create management discontinuity

5.1.2 Management and cultural continuity

In models with small co-located teams with high levels of relational and longitudinal continuity, management continuity can be sustained by relatively informal low cost communication systems (model 3). In teams with a more complex division of labour and lower levels of relational continuity additional management continuity mechanisms are required and this has resource implications. There is evidence that these are not always given priority however. We saw in models 1 and 4 that service providers did not always attend formal meetings before and after clinic with negative implications for management continuity; whereas in model 5 this was religiously adhered to with evidence of more positive outcomes. Models with team-based systems of nursing had in place effective management continuity interventions in order to ensure good communications and a consistent approach (models 1, 5) and in several models, longitudinal continuity of nursing team mitigated the negative effects of discontinuity of medical care (models 1, 5). Nevertheless, several cases in all models identified management discontinuities arising from relational discontinuities caused by complex medical teams, some with long-lasting negative effects. Whereas nursing teams appeared to operate in a consistent fashion and work interchangeably if necessary, team-based approaches in medical care seemed more difficult to achieve although this was more problematic in some models than others. This appears to be partly because of the need to accommodate transient team members such as trainee doctors or locum staff and partly because of the strong ethos of professional autonomy in medicine. In several of our services we noted marked differences in approach and ethos between permanent paediatric and adult consultants (models 4, 5) but we also identified such differences *within* the paediatric team (model 5). There were also discontinuities of advice between nursing and medical teams and the dietitian (model 5).

Formal written communication was a key management continuity mechanism in those models in which young people transferred to the exclusive care of a new consultant (models 1, 2, 3). The content of transfer letters tends to be narrowly technical however and our evidence suggests that experienced continuity is deeply embedded in psychosocial understanding. This is why relational and longitudinal continuity promote management continuity. In models 1 and 2 in which the transition service was clearly divided between adult and paediatric services, boundary blurring at this interface was in place to off-set these risks. In addition, in both models adult providers prioritised relational continuity and relationship building on entry to the service, before reviewing diabetes management. This contrasts with the experiences of young people entering joint clinics (models 4, 5) who immediately encountered management discontinuity on meeting new consultants. Health professionals attributed these differences in approach to 'personalities' and seemed to imply that

this was inevitable. Such views point to the privileging of medical autonomy and the expectation that young people will fit into the system.

Mothers are key contributors to management continuity, but this has not been formally recognised in policy guidance in this field. Mothers undertook considerable work in supporting their child's diabetes management, even as they were becoming progressively independent (Appendix 5). All of the models provided high levels of support for families in children's services and there was strong evidence that this was highly valued and enabled carers to access information in order to make decisions about their child's diabetes management. Several of our cases indicated that because they had access to advice and support, they had been able to manage diabetes related events obviating the need for admission to hospital.

"I know at the end of the day they'll be there if I need them, 24 hours a day and I think because when you're going through a situation it's quite frightening. I mean when things happen and you think oh 'what shall I do?' [...] I can always ring them and ask for advice or they say ring me up." [1-C148]

As young people undergo transition, carers are often less able to access this level of advice and yet remain engaged with their child's diabetes management, albeit in a different capacity. Only in model 3 did mothers feel able to contact the service after their child moved into adult services. One possible explanation for this is the high level of relational and longitudinal continuity in this model which meant carers had established relations with the PDSN/ADSN. A team member also proffered the view that because PDSN/ADSN knew families she was well-placed to support carers to 'cut the umbilical cord'. In model 1, the transition nurse in young adult clinic expressed a willingness to work with carers, however, in practice when young people moved into the service carers did not engage, assuming erroneously that they would not be welcome.

Eventually young people progress towards attending consultations alone. For young people this acted as an important developmental continuity mechanism but for mothers it could be a source of management discontinuity.

"I didn't actually get to see anyone [...] but there's only so much she's allowed to tell me now because of his age [...] you go from one extreme to another. [...] it gives him somewhere that he can talk freely then I'm all for that but [...] while they're still living at home and you've got that transition period going on I think we need to just be kept in the loop. [...] [W]hether they feel there are any issues that I need to be looking out for." [4-C16]

In some models a written report of the consultation was provided to carers for young people who had moved to lone consulting but were under the age of 16 and provision made for carers to attend some of

the consultation while the child attended part on their own (models 2, 3). While we have limited evidence with which to evaluate directly the effectiveness of these service components, given the challenges at this interface they stand out as an example of good practice. Beyond the age of 16 there are clearly issues of confidentiality which prohibit carers having access to the content of private consultations between their child and care providers. Nevertheless, it would still be possible for them to have access to practical advice and support without betraying patient confidentiality. It would be unacceptable for other 'workers' in the healthcare division of labour to operate in such an information vacuum and it is difficult to justify why carers should be expected to do so.

Related to management continuity is cultural continuity. Certain of our models were more culturally continuous than others. Where there was a common approach across paediatric and adult services (models 2, 3), transition was relatively seamless and there was little need for explicit informational continuity or developmental continuity mechanisms aimed at preparing young people for the changes they would encounter in adult services. In model 1 the children's hospital also had to manage transfer into three other adult services. They went to great lengths to prepare young people and their families, but this was based on a stereotype of adult care rather than a detailed understanding of specific service arrangements. In the model examined for the purposes of this study there was greater cultural continuity between services than paediatric staff recognised and the introduction of a transition nurse role had acted as a mechanism for greater understanding and cultural continuity across the paediatric adult service interface. Health professionals in other models also pointed to the importance of routine contact between services as a mechanism which facilitated cultural continuity.

The findings from this model draw attention to the importance of creating opportunities for paediatric and adult staff to interact in order to negotiate greater cultural continuity across service interfaces. This could entail the introduction of adult diabetes management regimes at the upper end of paediatric services and a more family friendly focus in adult services. In many models, staff reported having enjoyed higher levels of team building activities in the past – such as whole team meetings, seminars and away days - but when services are under pressure these become difficult to sustain. Nevertheless, although creating opportunities for paediatric and adult staff to interact should be valued, routine contact between service providers does not guarantee cultural continuity. In model 4 there was a long history of joint working and high levels of structural integration between services including an adolescent clinic in which paediatric and adult service providers consulted together. Despite this, there were clear cultural differences between paediatric and adult services and little preparation for young people entering into adolescent clinic. Young people encountered the adult service

culture at a relatively young age and many found it uncomfortable initially. Staff accounts indicated that there were also cultural differences between adult and paediatric providers in model 5, but the extended length of stay in teenage/young adult clinic and the fluidity of consulting arrangements, afforded young people and their families considerable choice as to which consultant they saw in clinic and the relational and longitudinal continuity of community children's nurses smoothed this transition.

On reflection, clinical leadership appeared to be the additional active ingredient in those models exhibiting highest levels of cultural continuity. In model 3, which was the most culturally continuous of all services, the adult consultant regularly engaged with the paediatric community, attended clinic in an observational capacity and attended paediatric conferences. In addition, the nursing team was led by an individual with a joint PDSN/ADSN role. In model 2 the children's nursing team manager although not working in a dual role, had done so in the past and also operated with a strong social model of health having previously worked as a health visitor. The adult consultant also had a special interest in young adults and was highly committed to addressing their singular needs. In model 4, on the other hand, despite the structural integration of the service, staff accounts indicate that the impetus behind the model was the desire to bring diabetes expertise into the paediatric service, rather than a commitment to adolescent health *per se*. The adult services culture was dominant in adolescent/young adult clinic and there was little evidence of a preparedness to adopt a more blended approach.

Table 25. Effectiveness of service components to support management and cultural continuity

Service component	Effectiveness	Risks
Formal meetings – pre and post clinic	Effective in supporting management continuity	Meetings may not be prioritised by all members
Formal written communication	Effective in communicating clinical information	Important psychosocial and contextual information omitted
Multidisciplinary consultation format	Moderately effective in promoting management continuity	Young people find format intimidating; power imbalances can result in nurses being reluctant to intervene.
Engagement with mothers	Very effective in promoting management continuity	Management discontinuity can arise as young people progress to lone consulting and/or transfer to adult services
Written summary of consultation provided for carers of young people under the age of 16 who are lone consulting	Very effective	Increased administrative costs
Provision for mothers to attend part of the consultation when young people progress to lone consulting	Limited evidence generated in the study to assess effectiveness, but common sense indicates likely value.	Increased clinic appointment times
Routine contact between paediatric and adult service providers	Some evidence to suggest this can promote cultural continuity, but not guaranteed if clinical leadership is not committed to a more blended approach	Costs of building in time for health professionals to meet to agree services

5.1.3 Informational continuity

Each model had different requirements for informational continuity. In those models with high levels of relational, longitudinal and cultural continuity across service interfaces, young people and their families seemed able to make a smooth transition even in the absence of informational continuity (model 3). However, in models in which there was a complete change of service provider at the child-adult interface then informational continuity was more important (models 1, 2). Our findings indicate the value of child and adult service providers working collaboratively in such circumstances to develop information leaflets about service differences and for this to include precise information about the new arrangements for care. In model 1 paediatric staff paid considerable attention to informational continuity, however, this was not based on specific and accurate information about adult services and may have contributed to the high levels of anxiety carers expressed in the qualitative interviews about the transfer to adult services. In model 2 paediatric and adult staff jointly produced a leaflet explaining the differences between children's and adult services. This appears to be the sort of information users require but unfortunately we have no data on which to evaluate its effectiveness.

Our findings also point to the need to explain the rationale for joint clinics and the staff involved in these prior to transfer. In models 4 and 5, although the relational and longitudinal continuity of paediatric staff appeared to give families a degree of confidence about transfer, there was considerable uncertainty about clinic arrangements and what they signified and this led to the perception of clinics being disorganised which undermined families' sense of safety in the system. There is clearly a balance to be struck between making transfer between stages a normal and natural process – or seamless – and ensuring families have sufficient information. It is a well known challenge of health provision that users' confidence in service providers is derived from the knowledge that they have expertise and experience in a given field. However, this can lead health professionals to forget that what is normal business for them, is a singular event for young people and their families⁽⁹⁴⁾.

None of the models studied had a transition protocol or care pathway, which is surprising given the large number of services which made this claim in the service mapping study. It is possible that this over-estimates the extent to which services are protocol-based and responses reflect the widespread belief that service configurations had taken the form they had because of best practice guidance and service frameworks. This is a rather looser interpretation of protocol-based care than that adopted here. We asked service users about the potential of care pathways as an information continuity mechanism; our findings indicate mixed views. Many felt it would be helpful to clarify pathways through the service, but several expressed concern that this could result in a loss in the

flexibility in service processes which were highly valued. This indicates an area for further research.

Table 26. Effectiveness of service components to promote informational continuity

Service component	Effectiveness	Risks
Jointly produced information resources	Given the wider study findings there is value in jointly produced information sources – unfortunately we do not have evidence to evaluate this definitively	Resource implications, particularly for paediatric providers transferring into multiple adult services; challenging for services which are frequently modified
Generic information resource produced by children’s services	Not very effective	Risk stereotyping adult services and providing insufficient information on adult service arrangements and how these differ from children’s services
Verbal information	Effective in small teams with high levels of relational and longitudinal continuity	May be forgotten by users/carers; not effective in large teams with low levels of relational and longitudinal continuity

5.1.4 Flexible and developmental continuity

The models had subtly different combinations of developmental and flexible continuity. In those in which there was less flexibility of transfer and a complete handover of care to adult providers there was greater emphasis on developmental continuity (models 1, 2). In both examples, developmental continuity was systematically addressed according to a check-list of topics and interventions were in place to ensure all issues had been dealt with before transfer. There was evidence to suggest that such a systematic approach does go some way to ensuring all educational needs have been met, particularly in transition models with low levels of relational continuity. In other models where there was a simple division of labour and high levels of relational continuity it was possible to address developmental and flexible continuity needs without structured systems (model 3); but in services without structured approaches and where the division of labour was more complex and

presented management continuity challenges then there was evidence that educational needs were missed (models 4, 5). There is also evidence that large clinic teams can produce a diffusion of responsibility which can lead to developmental and flexible discontinuities in the absence of a protocols or systematic recording methods.

The emphasis on developmental continuity which characterised models 1 and 2 was driven in part by a (mis)perception of adult services as poorly resourced and offering little on-going support compared to children's services. Whilst providing certain assurances about the preparedness of young people to leave children's services, it clearly leaves less scope for young people to set the pace of their own development. Moreover, there is also evidence to indicate that systematically recording developmental continuity interventions was used as much to benefit staff, providing security that all necessary issues had been addressed prior to transfer, as it was service providers. For example, staff in model 1 indicated that they used a check-list to record that issues had been discussed to cover themselves when young people were disinclined to raise them and in model 2, where a teaching plan was in operation no cases were aware of it.

Health professionals differed slightly in the approach they took to supporting young people. Although blurred at the boundaries, in practice it is possible to detect two different approaches: the relaxed and the intensive. In certain models, adult providers explicitly adopted a policy of *relaxed* control and a light touch approach to general health behaviours – such as diet, alcohol and smoking. Such an approach acknowledges the experiences of young people at this stage of the life-course and the normalising impulse which shapes self-care practices which can make strict blood glucose control challenging. By adopting a more relaxed approach the aim is to ensure young people maintain contact with the service and many believe that this is difficult to achieve if young people believe health providers are judging their life style choices and/or imposing tight blood glucose management. This description best fits models 3 and 5. Those who adopted an *intensive* approach expected stricter blood glucose control and put in place high levels of one-to-one support to achieve this (models 1, 2, 4) and encourage healthy behaviours.

The DCCT⁽⁷³⁾ demonstrated that lowering blood glucose concentration slows or prevents the development of complications and the DCCT cohort has also demonstrated that after the end of the intervention when HbA1c values became comparable between the two arms of the trial, persisting longer term benefits occurred for patients in the arm that had received intensive therapy with a relative improvement in relation to the development of several complications⁽⁹⁵⁻⁹⁸⁾. However, this has to be balanced with the need to keep young people engaged with the service and part of the impetus behind the attention to

transition in recent years is the large number of young people who are lost to the service following transfer⁽³⁰⁾.

Dominant discourses in this field present transition as a linear process. However, as Valentine⁽⁹⁹⁾ observes, and as our cases illustrate, many people do not move neatly from a state of dependence to independence. They might start work and then lose their job, leave home, move into rented accommodation for a while and then move back home. Or they might simultaneously be child-like and adult-like, for example by living at home and being financially dependent on their carers while also having an autonomous sexual relationship and becoming carers themselves. Transitions from childhood to adulthood can therefore be complex and fluid. Dovey-Pearce *et al.*⁽¹⁰⁰⁾ draw on the concept of 'emerging adulthood'⁽¹⁰¹⁾ which is conceptualised as a distinct phase between 18-25 in Western industrialised societies, where socio-cultural factors, such as more time in education and later marriages, extend the period before settling into adult roles and responsibilities. During this time young people are refining their attitudes and views and continuing to explore roles and opportunities. Dovey-Pearce *et al.*⁽⁴⁸⁾ argue that 'bringing together a young person with a chronic condition, who is still experimenting, exploring and keeping some of their options open, with a health care system that expects engagement, partnership and adherence that will last a lifetime is an unlikely marriage.' Much of the writing on transition assumes that adolescence is a time when life-long health behaviours are laid down, but it has never been established if poor self-management of particular aspects of treatment has a variable course over time or if poor self-management is relatively consistent across long periods of time⁽¹⁰²⁾. It is beyond the scope of this study to assess the implications of these different approaches in this age group but this indicates an area where further research is indicated.

In models in which adult providers explicitly adopted a relaxed approach to health behaviours, this could create tensions with mothers who, having attended to their child's health throughout childhood looked to service providers for support in reinforcing healthy behaviours as they became more autonomous in their healthcare choices. These findings point to the need for improved management continuity mechanisms and partnership working so that in supporting young people, carers and health professionals are not pulling in different directions.

In all models, service providers modified their approach to young people in order to encourage greater independence. This entailed engaging with young people directly, rather than through carers, both in and in between clinic appointments. Eventually young people begin to consult with healthcare providers alone. In some models this was proactively encouraged (models 2, 3, 5) in others, staff left the decision to young people and their families (models 1, 4). The survey indicates that lone consultation was more pronounced in

models where it was proactively encouraged. This suggests that health professionals tend to encourage a shift to lone consultation sooner than young people and their parents do when left to set the pace of their own development. However, it may also be significant that in these models the consultation format was also one-to-one rather than multidisciplinary and therefore potentially less intimidating.

Overall, young people positively evaluated the continuing involvement of carers in their care and the research evidence indicates that young people have better outcomes with continued carer support⁽¹⁰³⁻¹⁰⁵⁾. In most cases young people remained in the family home and, as a consequence, mothers still had an impact on their diabetes management, and young people's diabetes management had an impact on mothers. Mothers were an important source of continuity for young people. As we have seen, in some models when young people moved to lone consultation carers felt cut off from the process and experienced management discontinuity. However, it is also the case that mothers also lose a crucial form of personal support when they are no longer routinely interacting with service providers.

Only in model 3 did carers still feel able to contact the service on transfer to adult care; this highlights a gap in service provision. In the literature carers' resistance to the philosophy of independence which characterises adult services is often presented as a barrier to transition⁽³⁹⁾. However, this fails to acknowledge that the individualised approaches of adult services do not sit well with the realities of many young people's lives which are characterised by inter-dependencies. Moreover, as teenagers increasingly move away from childhood dependency, carers can find themselves facing developmental challenges of their own as roles and relationships must be negotiated in the shift towards a different kind of family existence⁽¹⁰⁶⁾. Our findings echo Parker *et al.*'s⁽⁸²⁾ observations on the ambiguous status of carers in policy and practice and their desire to have their contribution recognised and the importance of having their own support needs met.

There was little formal education for young people in any of our models, although staff in four (models 1, 2, 4, 5) aspired to develop further this component of the service. However, whilst mothers tended to view formal education favourably, there was rather less enthusiasm for this on the part of young people. Many were reluctant to attend events over and above routine clinic appointments, and few expressed enthusiasm for peer-based support by young people with diabetes. This concurs with Datta's findings⁽²¹⁾. Model 2 had well-developed information sources to support developmental continuity, but websites were not well used and several cases indicated that the information provided did not meet needs. We have also identified the importance of an individualised approach; in models where adolescent and young adult clinics were

run concurrently and staff targeted education at groups of young people the information was not always appropriate. How to meet the educational and information needs of young people with diabetes at this stage of the life-course is clearly an important policy concern and an area where further research is indicated.

Best practice guidance on transition points to the benefits of age appropriate clinics. However, our findings indicate this does not automatically guarantee appropriate specialised care. In some models, adolescent and young adult clinics were run concurrently and there were clear benefits in terms of facilitating longitudinal continuity with future care providers. However, several of our cases reported being unprepared for the adult clinic milieu. Moreover, in model 4 joint adolescent/young adult clinic brought young people into contact with adult service culture at a relatively young age and with few concessions made to individual need, many found this difficult. Again this points to the importance of attention to processes as well as service structures and highlights the importance of professional education and training to foster age-appropriate consultation styles. Consultation style and interpersonal skills were clearly consequential for the experiences of young people and their families and should not be dismissed as unchangeable on the basis of 'personality'.

In all models there was recognition that young adults required higher levels of on-going support and access than that routinely available in main adult services. There was a diversity of arrangements in place designed to meet this perceived need. In model 5 this was achieved primarily through the extended length of stay in teenage/young adult clinic, in which young people remained under the joint care of children's and adult services until they were ready to transfer. Yet, here there was evidence of resource tensions with paediatric services apparently subsidising adult services and concerns expressed on the part of paediatric providers about their competence to care for young adults. In many ways a compensatory model, the paediatric nurse manager described the nursing service as "being run on guilt" and raised questions as to its sustainability. Nevertheless, this was a factor which facilitated the provision of high levels of flexible continuity in this model. In models 1 and 4 the appointment of a nurse-led young adult facility was intended to offer a similar level of support to that provided in children's service. In model 2, despite the low levels of nursing resource, the adult consultant designed a system of email support to provide the advice and encouragement necessary to support independent management. This system was highly valued by those who had experienced it and positively evaluated in principle by those cases with whom the idea was shared. In this model, advice was offered by the consultant and there were concerns about the capacity of this individual to meet demand. However, this service component could equally well be provided by a nurse and potentially offer a cost-effective means of

supporting young people at this stage of the life-course. There is a need for a fuller evaluation than that which was possible in this study. In other models nurses informally gave their mobile phone numbers to young people and families and permitted contact for on-going support. Clearly this is an example of individual health providers supplementing the service, but there was no evidence that this was abused.

Our findings indicate the importance of creating private spaces in which young people feel able to discuss potentially sensitive topics with a trusted member of staff. In model 1 there is evidence that the multidisciplinary consultation format was not conducive to such conversations, but this was offset by the high level of home visits undertaken and the availability of the Saturday Drop-in Centre. On the whole it was with nurses that these conversations took place and so ensuring that clinic organisation or wider service arrangements permit young people to have this contact is very important. For example, in model 5, nurses' involvement in routine clinic observations, created a space in which young people could discuss any concerns. Seeing the nurse jointly with the doctor, may not be suitable as there is evidence that young people and their families do not consider it appropriate to discuss the minutiae of everyday management with doctors. Similarly, whilst young people valued their carers' involvement in consultations, this could circumscribe what could be discussed by either young person or carer, pointing to the need to build in opportunities for young people and/or carers to have a proportion of the consultation in private.

Although in most models dietitians were members of health teams, they figure relatively little in our cases' accounts. Often access to dietary advice was by referral only – particularly once young people had moved to adult services – and the absence of a pre-existing relationship and the requirement to make a separate appointment made young people disinclined to seek dietary advice. Of all health providers, dietitians were more likely to be criticised by service users; this was true of all models except model 2. Our evidence suggests that dietary advice is not considered helpful when it insists on rigid adherence to perfectly healthy behaviours and that a more permissive – and arguably realistic - approach may be more appropriate, with the aim being to find a good enough diet to facilitate diabetes management (the approach adopted in model 2). Our evidence suggests that dietary advice in response to specific issues – such as sport – is more highly valued than generic advice on diet. There may also be value in dietitians working more closely with nursing staff in order to update themselves on the psychosocial dimensions of a case and ensure management and cultural continuity across the whole diabetes team. This is an area where further research is indicated.

A key concern in the literature on transition is the number of young people who drop out of the service following transfer. Adult services

typically do not have in place the resources to follow up defaulters. In all of our models, healthcare providers recognised this risk and endeavoured to ensure young people remain engaged with the service. They tackled this in different ways. For example, in model 1, paediatric staff followed-up young people who had transferred to adult services to ensure that they had received and attended their first appointment and in model 2, the CONA bent the trust rules about removal from the service following non-attendance in order to keep contact with young people. Model 3 is distinctive in so far as health professionals did not equate attendance at clinic with engagement with the service; they went to great lengths to maintain contact with young people even if they did not attend clinics. We do not have the data to evaluate the effectiveness of these different approaches, however. On the whole, when asked, young people indicated that they were satisfied with the frequency of clinic appointments which in most cases was 3-4 monthly. When asked about alternative models, few expressed enthusiasm for GP-based care, primarily on the grounds that GPs were not perceived to have expertise in this field. Some indicated that more virtual systems of on-going support would be attractive, but that they would wish for this to be provided by a known and trusted health professional. The extent to which clinic attendance is the most effective mechanism to support diabetes management at this stage of the life-course is uncertain. This is an area where further research is indicated.

Table 27. Effectiveness of service components to promote developmental and flexible continuity.

Service component	Effectiveness	Risks
Systematic approaches to developmental continuity – using check lists	Very effective in ensuring developmental issues addressed	Can limit the scope for young people to set the pace of their own development and result in inappropriate care; can end up serving the interests of health professionals rather than the needs of young people
Relaxed approaches to diabetes control and a light touch approach to healthcare behaviours	Uncertain – this was beyond the scope of this study	Can create tensions with carers if this is a management change from approaches experienced in children’s services; risks to long-term health unknown
Intensive approach to diabetes control and health care behaviours	Uncertain – this was beyond the scope of this study	Young people may drop out of the service
Lone consulting	Very effective in promoting independence in young people	In the absence of compensatory mechanisms this can create management discontinuity for mothers
Age appropriate clinics	Not guaranteed	Early introduction to adult service cultures can cause a culture shock for young people; temptation for education to be batched but this may not be appropriate to individual need
Continuing involvement of carers	Positively evaluated by young people and carers	Creates challenges in relation to patient confidentiality
Opportunities for one to one consultation with a known nurse	Positively evaluated by young people	Resource implications

5.1.5 Discussion

In this section we have drawn on the case study and ethnographic data to examine the contribution of different kinds of continuities to

young people and their carers' experience of smooth transition and the effectiveness of the different service arrangements for achieving these. The continuities that emerge as most important are relational, longitudinal, flexible and cultural continuity. Relational and longitudinal continuity are valued in their own terms but also because they are also mechanisms to ensure other kinds of continuity: informational, management and flexible. In addition, where there was cultural continuity across child and adult services, transition was relatively seamless, young people experienced management continuity and there was little need for information or developmental continuity interventions to manage transfer. Models employed different combinations of developmental and flexible continuity interventions. Young people and carers positively evaluated flexible approaches. Our findings suggest that young people and carers' value the ability of health professionals to anticipate future needs, but that their preference is for this to be individually determined. Models which emphasise developmental continuity interventions actively foster young people's progression towards independent management but leave less scope for them to set the pace of their own development with risks that care may not be appropriate to individual need.

Service providers face different local constraints which shaped the model of transition in operation. Common to all models were resource constraints. The number of young people diagnosed with type 1 diabetes is rising and new forms of treatment – such as pump systems – necessitate more intensive levels of support. Respondents referred to activity-based diabetes events which were routinely organised in the past having been curtailed in the face of service pressures and in many models, staff had been advised to limit home visits to save money. Several models were supported by considerable additional work undertaken informally by health professionals and concerns were expressed about the capacity of individuals to sustain the level of input being provided (models 2, 3, 5). Some of the transition specific posts had been funded originally by non-recurrent funds and in model 2 a transition nurse post was lost when the trust could not continue to support it once the original funding source was withdrawn. As service providers pointed out, this makes planning extremely difficult and is arguably precisely the kind of exigency which results in the modification of models with disruptive consequences for continuity of care. Space was also an issue for several services and constrained the number and timing of clinics. None of our models held clinics in teenage-friendly environments. While this was an aspiration for many staff and is widely regarded as best practice⁽²⁾, it did not appear to be a primary consideration for young people and their families, although our findings indicate that premature exposure to main adult services should be avoided. In some models the requirement to provide training opportunities for medical and nursing staff made the division of labour complex, with implications for relational, longitudinal,

flexible, cultural and management continuity. Models also varied in their staff turnover which impinges on service culture. Paediatric services transferring into multiple adult services face singular challenges.

5.2 Regression analysis

In order to assess whether continuity of care was associated with psychosocial outcomes we categorised transition models according to whether they scored highly on those service continuity interventions that the qualitative data indicated were most important in terms of achieving smooth transition.

Table 28. Models categorised by continuity type

	Levels of continuity by type			
	High relational/ longitudinal continuity	High develop- mental continuity	High flexible continuity	High cultural continuity
Model no		✓		
2		✓		✓
3	✓		✓	✓
4				
5			✓	

Regression analysis was performed for Diabetes Quality of Life (DQoLY), Health Care Climate (HCCQ) and Diabetes Management and Self Efficacy (DMSES) for young people. Included in the models were age (of the young person when the first questionnaire was administered); gender; the clinic a young person was attending (with children's clinic as the reference category) and descriptors, specific to certain models, which were developed from the qualitative analysis (the presence of high levels of relational, developmental, flexible and cultural continuity) (Appendix 6). These were all fitted as binary variables (high vs low or moderate level of continuity) and model categorisation is given in Table 28.

Similar analysis was also performed for carers on general health, vitality and mental health (SF-36 subscales) and confidence in their child's management of their diabetes (PCDS scale). Explanatory variables include those that were used in the young person regression models (described above) as well as whether or not a carer attends consultations with their child.

The aim of these analyses was to look for patterns across continuities which may indicate positive or negative associations with important psychosocial outcomes for young people and their carers.

The results of the regression models are presented in summary tables (Tables 29 and 30) with arrows pointing up indicating a significantly (at the 5% level) higher score with the corresponding factor present, and arrows pointing down indicating a significantly lower score with the corresponding factor present. The individual models are presented in more detail, with coefficients, 95% confidence intervals and p-values, in Appendix 7.

5.2.1 Relational/longitudinal continuity

Because they are so closely related, for the purposes the regression model relational and longitudinal continuity were combined. Young people with diabetes, consulting in models with high levels of relational/longitudinal continuity, reported significantly higher impact of treatment, symptom impact and parental control quality of life scores. This indicates that, on average, young people in models with high levels of relational/longitudinal continuity considered their diabetes treatment, diabetes symptoms and the control that their carers had over them to have a significantly higher impact on their quality of life. Participants also reported significantly lower life and treatment satisfaction scores (indicating that they were less satisfied with their life and diabetes treatment) and lower self-efficacy scores (indicating that they did not feel as confident managing their diabetes as those consulting in models without high levels of relational continuity). Healthcare climate scores were significantly higher in models with high levels of relational/longitudinal continuity. Carers of children consulting in models with high levels of relational continuity reported significantly lower general health, vitality and mental health scores (as measured by the SF36). While the higher health care climate scores appear to support the qualitative findings, the other outcomes associated with high relational/longitudinal continuity are more difficult to interpret and in many respects are counter-intuitive given the strength of the qualitative findings. One possible explanation is that closer patient-professional relationship stimulates a greater self-awareness of diabetes and its management. In addition, only model 3 was categorised as having high relational/longitudinal continuity for regression modelling purposes, and it is possible that there are other factors which account for these outcomes, such as the clinical challenges facing survey respondents. Qualitative interviews with health professionals indicated that at the time of the study their caseload was proving particularly problematic.

“[W]e’ve got a worrying batch at the moment.”

5.2.2 Developmental continuity

Respondents consulting in models with high levels of developmental continuity reported significantly higher parental control scores, lower impact on activities scores and lower life and treatment satisfaction scores. Satisfaction with the service provided by health professionals, along with self-efficacy scores, was also significantly lower in young people consulting in models with high levels of developmental continuity. Carers of children consulting in models with high levels of developmental continuity reported significantly lower general health scores and higher vitality and mental health scores.

5.2.3 Flexible continuity

Respondents consulting in models with high levels of flexible continuity reported significantly lower symptom impact and impact on activities scores, with significantly higher life and treatment satisfaction scores. Healthcare climate and diabetes management self-efficacy scores were also higher in participants consulting in models with high levels of flexible continuity. Carers with children consulting in models with high levels of flexible continuity reported significantly higher general health, vitality and mental health scores. These findings suggest that models with high levels of flexible continuity have more positive outcomes than those with a predominantly proactive approach (developmental continuity).

5.2.4 Cultural continuity

Respondents consulting in models with high levels of cultural continuity reported significantly lower impact of treatment, symptom impact and impact on activities quality of life scores. Life and treatment satisfaction, healthcare climate and self-efficacy scores were higher in young people who consulted in models with high levels of cultural continuity. Carers of young people consulting in models with high levels of cultural continuity reported higher vitality and mental health scores.

Table 29. Regression analysis for young person scales

	DQoLY Scores					Healthcare Climate	Diabetes Management Self-Efficacy
	Impact of Treatment	Symptom Impact	Impact on Activities	Parental Control	Life and Treatment Satisfaction		
Teenage/young person's clinic*	↓		↓	↑	↑	↓	↑
Adult clinic*			↓		↑		↑
Age			↑	↓	↓	↓	↑
Female	↑	↑	↑	↓	↓	↓	↓
High relational/longitudinal continuity	↑	↑		↑	↓	↑	↓
High developmental continuity			↓	↑	↓	↓	↓
High flexible continuity		↓	↓		↑	↑	↑
High cultural continuity	↓	↓	↓		↑	↑	↑

* Compared to children's clinic

Table 30. Regression analysis for carer scales

	SF36			Perceived Competence for Diabetes Scale
	General Health	Vitality	Mental Health	
Teenage/young person's clinic*	↑	↓	↑	
Adult clinic*	↑	↓	↓	
Age	↑	↑	↑	
Female	↓	↑		
High relational/longitudinal continuity	↓	↓	↓	
High developmental continuity	↓	↑	↑	
High flexible continuity	↑	↑	↑	
High cultural continuity		↑	↑	
Does not attend diabetes consultations with child	↑	↑	↑	

* Compared to children's clinic

5.2.5 Correlation between young person and carer scales

Significant positive correlation ($p \leq 0.01$) was observed for all comparisons. The HCCQ scales and the DMSES against the PCDS were both correlated moderately (coefficients = 0.503 and 0.542 respectively), with weak correlation between the satisfaction and general health scales (coefficient = 0.226) (Table 31).

Table 31. Correlation coefficients for young person and carer scales

Young person scale	Carer scale	Correlation coefficient	p-value
HCCQ	HCCQ	0.503	≤ 0.01
DQoLY: Satisfaction	SF36: General Health	0.226	≤ 0.01
DMSES	PCDS	0.542	≤ 0.01

5.2.6 Discussion

There are strong resonances with our findings and those of Nakhia *et al.* ⁽¹⁰⁷⁾ published after the completion of our analysis. These authors undertook a retrospective cohort study which tracked 1507 young people in Ontario Canada with type 1 diabetes up to the age of 20 over a four year period. Rates of hospital admission before and after transfer to adult diabetes care were compared and the effect of five different models of transition were assessed: transfer to a new physician and a new team, transfer to a new physician but the same team, transfer to a new team but the same physician or transfer to a physician who had no team. In the 2 years after transfer to adult care the rate of diabetes related admissions increased from 7.6 to 9.5 per 100 cases (P=0.03). After controlling for confounding factors, young adults were 77% less likely to be hospitalised after the transition period if their physician had not changed compared with those who had been transferred to a new physician (relative risk, 0.23; 95% confidence interval, 0.05-0.79). As Matyka ⁽¹⁰⁸⁾ observes, the study design does not provide any explanation for this relationship. She argues that, it is not clear whether continuity is in itself beneficial or whether the different clinical styles of paediatricians compared to adult physicians is important. Our findings suggest that continuity of physician is likely to provide relational/longitudinal, cultural and flexible continuity and as such points to the generative mechanisms responsible for the study findings.

5.3 Health economics

5.3.1 Direct costs

Tables showing the absolute and relative inputs of health professionals to each model were presented in chapter 4. Administration costs were not included in those tables as the intention was to show the contributions of the professionals whose

input impacts on young people and carers. Table 32 below shows the administration time reported for each model.

Table 32. Administration hours by activity

Model no.	Activity	Band 3	Band 4	Band 5
1	Children's hospital Adolescent Clinic	3.81		19.03
	Young Adult Clinic	4.00		
2	Adolescent Clinic	4.00	7.50	
	Young Adult Clinic		7.50	
3	Young Person's Clinic		2.17	
4	Adolescent Clinic		32.50	
	Adolescent Clinic Main Site	30.33		
5	Teenage & Young Adult Clinic – Main Site	31.33		
	Teenage & Young Adult Clinic – Satellite Site	1.00		

Total monthly staff costs per model including administration are shown in Table 33 below.

Table 33. Summary of monthly staff costs and levels of continuity by type

Model no	Patients per model (n)	Monthly staff costs (£)	
		per site	per patient
	89	12391.34	139.23
2	154	11493.62	74.63
3	84	2574.37	30.65
4	158	5344.57	33.82
5	158	6210.68	39.31
mean	128.60	7602.92	63.53
sd	38.51	4194.98	45.84
range	84-158	2574.37-12391.34	30.65-139.23

The cost per month per patient varied considerably from £30.65 to £139.23 with a mean (SD) of £63.53 (£45.84).

5.3.2 Indirect costs

Indirect costs include those costs borne by patients and carers (Table 34) and those borne by other parts of the NHS whilst patients are in transition (Appendix 9).

Table 34. Summary monthly patient/carer borne costs per model (£)

Model	1	2	3	4	5	mean	sd	range
sample (n)	5	7	8	12	14	9.20	3.70	5-14
travel/ parking per patient	5.77	4.84	1.10	3.58	3.29	3.72	1.77	1.10-5.77
parent/carer time- off per patient	10.39	11.39	0.71	5.89	0.78	5.83	5.08	0.71-11.39
total cost per patient (£)	16.16	16.23	1.81	9.47	4.07	9.55	6.68	1.81-16.23

Patients reported an average of 4 to 5 clinic visits per year (0.4 visits per month). The average monthly cost of travel and parking ranged from £1.10 (model 3) to £5.77 (model 1) with an average monthly cost per patient of £3.72 (sd 1.77). The monthly cost of time-off work by parents/carers ranged from £0.71 (model 3) to £11.39 (model 2) (mean=£5.837, sd=5.08). These figures are low due to the fact that most respondents did not report a requirement for time away from work. Total patient/carer borne costs range from £1.81 per month (model 3) to £16.23 per month (model 2) (mean=£9.55, sd=6.68).

Table 35 provides a summary of the patients' use of other NHS resources over the course of an average month whilst in transition.

Table 35. Summary monthly NHS costs (£)

model	1	2	3	4	5	Mean	sd	range
participants (n)	5	7	8	12	14	9.20	3.70	5-14
A&E attendance	-	-	111.00	222.00	111.00	88.80	92.87	0-222.00
Audiologist	33.00	-	-	-	-	6.60	14.76	0-33.00
Clinical Psych	-	-	-	82.00	-	16.40	36.67	0-82.00
Dentist	-	-	162.00	-	54.00	43.20	70.41	0-162.00
Diabetic Nurse	20.93	-	-	20.93	41.86	16.74	17.51	0-41.86
GP	36.00	108.00	288.00	324.00	468.00	244.80	173.40	36.00-468.00
Hosp Admission	-	-	538.00	269.00	-	161.40	240.60	0-538.00
Nephrologist	-	61.00	-	-	-	12.20	27.28	0-61.00
Optician	150.00	25.00	-	25.00	200.00	80.00	89.09	0-200.00
Paramedic	344.00	-	-	-	344.00	137.60	188.42	0-344.00
Practice Nurse	-	-	11.00	44.00	77.00	26.40	33.55	0-77.00
School Nurse	-	55.00	-	22.00	11.00	17.60	22.81	0-55.00
total cost (£)	64.88	27.67	123.33	112.10	145.21	94.64	47.58	27.67-145.21
average cost per patient (£)	12.98	3.95	15.42	9.34	10.37	10.41	4.32	3.95-15.42

The average monthly cost per patient of NHS services ranged from £3.95 (model 2) to £15.42 (model 3) (mean=£10.41, sd=4.32). The samples were too small to attempt any statistical analyses of possible difference in indirect costs between models.

5.3.3 Costs consequences analysis

Monthly per patient staff costs are repeated in Table 36 below together with a summary of survey results in terms of the different types of continuity.

Table 36. Summary of monthly staff costs (direct costs) and levels of continuity by type

	Monthly staff costs per patient (£)	Levels of continuity by type			
		High relational/longitudinal continuity	High developmental continuity	High flexible continuity	High cultural continuity
Model no	139.23		✓		
2	74.63		✓		✓
3	30.65	✓		✓	✓
4	33.82				
5	39.31			✓	

Model 1

Model 1 was characterised by a complex division of labour necessitating robust formal mechanisms to ensure management continuity and had high levels of developmental continuity, driven in part by a misperception of adult services provision. There is a strong emphasis on community outreach. It has a relatively high monthly staff cost (£12,391) and per patient cost (£139) which is largely due to the high input by DSNs of 83 hours/month. The relative contribution of DSNs to this model is also high at 62% of total professional staff input.

Model 2

Model 2 is similar to model 1 in that it has high levels of developmental continuity but is also cultural continuous. It has relatively high monthly staff costs (£11,494) although with a larger number of patients the monthly cost per patient is lower at £75. Again, this is due to a high input by DSNs (80 hours/month) with a high relative share of professional staff input (69%). This model also has relatively high input from CONA, who is substituting for adult nursing support in young adult services committing an additional 13 hours/month over clinic time for ongoing contacts by phone or email.

Model 3

Model 3 is characterised by high levels of relational, longitudinal, flexible and cultural continuity. It has the lowest reported monthly staff cost (£2574) and the lowest cost per patient (£31). As with models 1 and 2 the relative contribution of DSNs is high (80%) although the total hours is considerably less (18 hours/month). The relatively low cost of this model does not appear to impact on its achieving high levels of continuity suggesting smooth transition can be achieved in models exhibiting these features without the need for

formal and more costly informational, management or developmental continuity interventions.

Model 4

Model 4 was not categorised as achieving high levels in any of the continuities. It had the lowest total professional input at 33 hours/month and differs in terms of the range of health professionals involved, including a nursing consultant and a health care assistant. Total monthly cost of staff time is £5345 with a cost per patient of £34.

Model 5

Model 5 was categorised as exhibiting high levels of flexible continuity. It had a different combination of health professionals to the other four models including community children's nurses (CCN)s, a staff nurse and with a small input by a health care assistant. The CCNs contribute just over half of the total professional input to this service (53%) lending evidence to the perception that the children's service was subsidising adult service provision. Total monthly staff cost was £6211 and the cost per patient was £39.

5.3.4 Discussion

The analysis of direct staff costs showed substantial differences between models. However, as previously stated, some of these differences may be due to the exclusion of some activities that are carried out in child or adult diabetes services, but are not seen as relating exclusively to transition. Indeed, a major difficulty associated with this exercise has been the fact that transition is a 'process' and, consequently, transition models/services rarely have well defined boundaries.

Moreover, different service configurations mean that some staff costs were additional to those already accounted for in child or adult services, while others reflected substitution. It was beyond the scope of this study to estimate by how much child and adult services costs were reduced as a result of the transition model in place. Therefore, differences in direct staff costs between models do not necessarily reflect differences in the quality of the service received by patients. Future research into direct staff costs of transition models may focus on the costs of the entire diabetes service function and the distribution of costs between child, adult and transition activities.

Services have to organise transition models in different ways because of wider constraints. In some, smooth transition could be accomplished with relatively informal low cost options. In others, more complex mechanisms are required and these come at a cost.

The results suggest that the costs borne by users of the services are minimal. Moreover there was no suggestion of a relationship between the direct costs of transition services and patients' use of

other NHS resources although the samples were too small to show significant differences had they occurred.

6 Conclusions and implications for policy/practice and research

The aim of this study was to identify which components of a sample of transition models work best to promote smooth transition, for whom and in which circumstances. We conducted a survey to identify the range of services in England and developed a typology of six models based on the number of stages in the transition process and the relative balance of continuity interventions. We identified a trend towards sequential models of transition. The primary purpose of the survey was to select a sample of models for detailed evaluation in Stage 2 of the study.

Six models were selected for in-depth analysis but one dropped out of the study, leaving five models in the final sample. Our approach was informed by systems thinking, realistic evaluation methodology and previous SDO programme research on continuity of care. Service users were involved at critical points in the research process and the study findings were shared with key stakeholders at a dissemination event and consideration given to their implications for policy and practice (Appendix 11).

6.1.1 Continuity of care and smooth transition

Young people and their carers identified relational and longitudinal continuity as most important to the experience of smooth transition. Relational and longitudinal continuity were valued for their intrinsic qualities, but also because they contributed towards management and flexible continuity. The regression modelling revealed that models categorised as having high levels of relational and longitudinal continuity had significantly improved scores on healthcare climate, although other associated psychosocial outcomes were more difficult to interpret. Flexible and cultural continuity also emerge as important. Our findings suggest that young people and carers value the ability of health professionals to anticipate future needs, but that their preference is for this to be individually determined. Young people and carers in receipt of care in models categorised as having high levels of flexible continuity had significantly better outcomes on a range of psychosocial measures and young people and carers in receipt of care in models as having high levels of developmental continuity had significantly worse outcomes on a range of measures. Young people and carers consulting in models with high levels of cultural continuity also reported significantly better psychosocial outcomes.

6.1.2 Achieving smooth transition

Small integrated teams appear to find it easier to establish relational and longitudinal continuity than those with more complex divisions of labour. This seems to resonate with the findings of Baker *et al.* in relation to primary care practices⁽¹⁰⁹⁾. Small teams with high levels of relational and longitudinal continuity also enable smooth transition to be accomplished without the need for costly information and management continuity interventions, but carry risks relating to staff absences and departures. Larger teams with more complex divisions of labour and transient staff require more systematic approaches to ensure management continuity, but are better able to provide cross-cover and access without requiring staff to work beyond their formal contractual obligations. In models in which there is a complete transfer of care at the child-adult interface, boundary-blurring to facilitate an early introduction to adult care providers and/or sustained input from paediatric staff whilst new relationships are built up, helps mitigate the negative effects arising from relational/longitudinal discontinuity. High levels of relational continuity in adult services also appear to facilitate transfer. There is evidence of the need for services to work closely together to produce accurate information about the new arrangements for care; families' information needs are greatest when they are moving into the care of unfamiliar service providers. We have highlighted the central role of carers in supporting young people at this stage of the life-course and the need for interventions which ensure they receive support and are able to provide management continuity once their child is interacting independently with service providers. These are important gaps in provision identified in the models considered in this study.

The service mapping provided evidence of institutional isomorphism in the diabetes field in so far as there was a clear trend towards staged transition services with age-banded clinics. But this theory relates to organisational *form*. Our findings point to the importance of *processes* in shaping young people and their families' experiences of smooth transition and should act as a cautionary tale for those considering modifying service structures to bring them in line with notions of best practice in this field. For example, joint clinics provide a mechanism for enabling relationships to be established with adult service providers, but consideration should be given to their internal operation to ensure that clinic organisation does not result in relational discontinuity. Moreover, there is evidence that joint clinics can be confusing for young people and their families and thus informational continuity interventions are required in order that their operation and underlying rationale is understood. Similarly, age banded clinics are recommended as an example of good practice, but they are no guarantee of appropriate care.

Cultural continuity is a new concept developed for the purposes of this study. Much of the literature on transition focuses on the

differences in child and adult service cultures and the need to support young people in adjusting to this. While some models fitted the portrayal of adult and paediatric services in the literature (models 4, 5), others had high levels of cultural integration (models 2, 3). As young people moved through the service they did not experience major discontinuities of ethos but a seamless blending of the two in adolescent and young adult services. As we have argued, opportunities for contact between children and adult service providers help to promote greater cultural continuity but cannot guarantee it. Our findings point to the importance of clinical leadership and the potential of dual or specialist qualifications and/or training in this field and this was endorsed by participants at the stakeholder workshop (Appendix 11). Stakeholders also pointed to the value of jointly developed care pathways as a mechanism for promoting cultural continuity, but noted the challenges of securing professional engagement across the whole transition process and the importance of ensuring these had inbuilt flexibilities. This is an area where further research is indicated.

Of all the concepts in our conceptual framework, developmental and flexible continuity are the least well developed and the most difficult to map on to specific service components. Best practice guidelines point to the desirability of a shared structured approach to the provision of education focused on providing young people with the knowledge and skills they need to maintain their metabolic control^(2, 49). Given the breadth and variety of young people's lives there are clear challenges involved in achieving a balance between proactive developmental continuity interventions and responsive flexible continuity interventions. In models in which there is less flexibility about timing of transfer and a total handover of care to adult service providers, there is a tendency for paediatric staff to cover all risk issues, but this may not be appropriate to individual need.

In models with complex divisions of labour and no systematic process for recording flexible and developmental continuity interventions, there was evidence of gaps in young people's knowledge. Our findings point to the value of a personal education plan as an intervention for ensuring an individually tailored and negotiated programme which is systematically recorded and which can transcend service boundaries if required, rather than a check-list of work to be done. Staff in many models aspired to provide more formal education for young people, but young people themselves expressed little enthusiasm for this and written information in those models in which it was provided was poorly utilised. Adult service providers in different models also had different expectations for blood glucose control but the relationship between these, engagement with the service, and long-term health and complications remains unclear. We identified some innovative approaches for providing support – such as the email systems – which were positively received, but would benefit from more systematic evaluation.

As we have argued, the trend towards sequential models of transition identified by the service mapping is understandable in terms of DiMaggio and Powell's theory, but raises important questions about future service development in so far as it potentially constraints alternative approaches. We suggested in our critical review of the literature that the problem of transition has been constructed through a particular set of discourses which privilege an associated set of solutions. This has resulted in an approach which seeks to find ways to fit young people into pre-existing service structures. Given this construction of the problem, in this study we have examined which service components work best to ensure a smooth transition, for whom and in what circumstances. Alternative formulations, however, might begin with the question of how best to meet the needs of young people at this stage of the life-course. Several health professionals in our study pointed to the value of dedicated adolescent/young adult services and our findings would lend support to this view.

In the stakeholder workshops, one group was asked to consider the study findings in relation to the different kinds of continuities and, starting with a blank canvas, consider how they would construct a new clinical service to promote smooth transition. Prioritising relational, longitudinal, flexible and cultural continuity as the mechanisms essential for smooth transition, the group concluded that these were most likely to be realised in a transition model that was distinct from child or adult services. They proposed a young adult transition service with its own singular identity, and which was person-centred in its approach and focussed on the specific needs of adolescents. The group suggested that the service be based on the model of the 'teenage cancer trust', i.e. a service where young adult patients are not expected to be dealt with in the same way as smaller children or older people and where the relevant paediatric and adult expertise is available. The service would function as a one stop shop with young people and families deciding which of the available health professionals they wished to consult, according to need. There was also a general consensus on the need for more training of both adult and child diabetes specialists in dealing with adolescent-specific concerns. This represents an ideal model which reflects the logic of the study findings about the most significant continuity mechanisms and might usefully inform service commissioning. However, we have shown, most models reflect the singular local constraints in which they have developed and, given these challenges, this study has demonstrated the effectiveness of a range of service components in achieving smooth transition in diverse contexts.

6.2 Reflections on the research process and study limitations

The study was guided by a clear analytic framework in which transition models were evaluated using continuity of care as a conceptual lens. We used Forbes *et al.*'s⁽⁵⁾ concepts as an initial orienting framework, but found it necessary to modify and add to these for our purposes. The advantages of the approach were that it ensured consistency in the analysis and description of individual transition models and facilitated comparisons in relation to their relative effectiveness in promoting smooth transition even when the service arrangements in place for achieving these aims were diverse. Focusing on generative mechanisms rather than service structures also conferred advantages in so far as it produces insights which permit approaches to service design which are responsive to locally operating constraints rather than one size fits all recommendations. This leaves open the possibility of innovative approaches to supporting continuity of care which are not represented in the models evaluated here, such as the idealised model proposed by our stakeholders. The framework also ensured that the analytic focus remained on processes rather than service structures, revealing instances in which underlying structural arrangements were not functioning in ways which might have been predicted from the literature. We have also been able to show the inter-relationships between different kinds of continuity, the trade-offs inherent in particular models and their resource implications. Feedback from participants provided strong evidence of the face validity of the findings and indicated that viewing transition models through the dual prism of realistic evaluation and continuity of care mechanisms was a different way of thinking about services but very useful.

Notwithstanding the advantages of such an approach, it was not without its challenges. A major difficulty with the framework is that there is rarely a direct relationship between a continuity mechanism and a given service component. Service components typically affect more than one continuity and, as we have seen, some continuity of care mechanisms may contribute to other kinds of continuity. It was for this reason that we used a simplified framework for the survey. For the purposes of the in-depth evaluation a more detailed framework was necessary to capture the subtle differences between transition models and the relationship between continuities, but this did present challenges in crafting the model descriptions because certain service components contributed to multiple service continuities. In our report we grouped closely related continuity concepts together for ease of exposition and to avoid excessive repetition and/or cross-referencing. Nevertheless, we are conscious that the individual transition model descriptions are rather laborious and there is a degree of repetition in chapter 4. Nevertheless, we consider that this is a necessary step in the process of identifying what works, for whom and in what circumstances and stands as a

transparent account of the analytic steps we have taken in reaching our conclusions. It was also an essential part of the process necessary for categorising service models for the purposes of the regression modelling. We were also conscious of the interest of the health professionals in participating models in learning from the study findings. So our aim was that each transition model evaluation could be free-standing.

The other challenge with the analytic framework, as Parker *et al.* ⁽⁸²⁾ point out, is that it is not always clear whether continuity of care is an outcome or a process ⁽¹¹⁰⁻¹¹¹⁾. For our purposes, experienced continuity has been conceptualised as an outcome and the other continuity of care mechanisms conceptualised as processes or generative mechanisms which interact depending on the singular features of a given model to produce that outcome, or not as the case may be. However, each continuity mechanism is itself an outcome of a service component or components. Accordingly, in addressing the 'what works?' question, we are actually confronted with two dimensions: which continuities are most important in achieving smooth transition and which service arrangements in which contexts are most effective in achieving the respective service continuities.

This was an ambitious project and we were more successful in achieving some aims than others. We have referred to these shortcomings as they arise throughout the report. These are summarised here in order that our conclusions are understood in the context of the study's limitations.

The first challenge has been that of identifying and isolating transition models for evaluation purposes. The problem of transition as it is currently constructed is fundamentally the problem of managing the interface between paediatric and adult diabetes services, whilst simultaneously attending to the singular needs of young people. In many diabetes services it is possible to identify multiple models of transition depending on the service components that characterise the contributing paediatric and adult services. Paediatric services may transfer into multiple adult services and similarly, adult services may receive young people from a wide range of paediatric services, particularly those located in cities with universities. Whilst it was possible to isolate transition models for the purposes of the qualitative components of the study; this was more difficult in other elements of the research. Thus, the service mapping relates to service respondents rather than directly to models, although given that we spoke to even numbers of paediatric and adult providers and validated our typology with 40 respondents at the Diabetes UK conference, we have confidence that findings are sufficiently robust for our purposes. Similar observations hold true in relation to the survey of models.

Estimation of the costs of transition was complicated by the fact that no transition services had well defined boundaries. The absence of dedicated staff meant that time spent on transition activities had to be disentangled from time devoted to normal paediatric or adult care. The absence of dedicated resources such as facilities and equipment meant that the costing exercise had to be restricted to staff costs alone.

Recruitment to our case studies proved more challenging in some models than others and we did not succeed in recruiting cases which spanned the full transition period in all models. Accordingly, in some models there are service components which we did not have sufficient data to evaluate. In addition, we were unable to recruit young people identified by health professionals as poor clinic attenders. With hindsight this was an overly ambitious aspiration given the complexity of the project design. The majority of young people in our sample attended clinic regularly and had positive relationships with their carers. Although interviews were conducted separately, there were high levels of agreement about those elements of the service that worked to promote smooth transition. However, they are not necessarily representative of the experiences of all young people. We do not know, for example, whether young people and carers who are experiencing strained relationships may have a different view about which service elements work best for them and there is much to be learnt from the experiences of those who attend clinics rarely. Accessing such hard to reach groups is resource intensive, however, and alternative approaches to recruitment are required. This is an area where further research is indicated; firstly to develop and test methodologies for accessing hard to reach groups and secondly, to examine their reasons for non-attendance and their needs from the service.

Similar challenges were faced in trying to get responses to the survey. This was conducted in two rounds and measures were implemented in the second round to improve response (e.g. providing opportunities for electronic completion), but with little effect. The resulting small numbers per model have meant that the transition model based data is presented purely descriptively as an adjunct to the qualitative data. The sample size for the regression analysis across models is adequate for the number of explanatory variables, however, some caution is needed in terms of generalisability due to potential biases in who responded.

It was our intention to use diaries completed by young people and carers to supplement the case study data. In practice, very few were returned, and those that were received added little to the data generated through the interviews.

6.3 Conclusions

The aim of this study was to identify which components of a sample of transition models work best to promote smooth transition, how, for whom and in which circumstances.

6.3.1 What works?

Seven types of continuity contribute to users' experiences of smooth transition: relational, longitudinal, informational, management, cultural, developmental and flexible. Relational and longitudinal continuity were identified as the continuity mechanisms central to transition because they facilitate other kinds of continuity: management and flexible continuity. They also provide a sense of safety at times of change, obviating the need for formal informational continuity interventions. Flexible and cultural continuity also emerge as important. Across models a range of interventions are deployed to this effect, depending on the structural characteristics of individual services and the local contexts within which they operate. We have evaluated the effectiveness of different service components in achieving continuity mechanisms and their resource implications in particular contexts.

6.3.2 For whom?

Overall there were high levels of agreement between young people and their carers across all models about the mechanisms central to smooth transition and within models about the relative success of service components in achieving smooth transition. Mothers are an important source of continuity for young people whose lives are characterised by interdependencies, but this is not formally recognised in policies in this field. This is the primary area where what works for young people, does not work for carers. Whilst the progression to lone consulting was a key developmental milestone for young people, many mothers felt cut off from the process and could no longer access the advice they needed to support their child. Mothers also have their own needs for support which is lost when they are no longer routinely interacting with service providers.

Young people who were poor clinic attenders and/or who had strained relationships with carers were not included in the study. We therefore do not know to what extent the study findings can be extended to this group.

6.3.3 In what circumstances?

Models with high levels of relational, flexible and cultural continuity are able to achieve smooth transition with relatively informal, low cost informational and management continuity mechanisms.

Models with more complex divisions of labour and low levels of relational and longitudinal continuity need to invest in more formal interventions to facilitate management, flexible and informational continuity to ensure smooth transition is not compromised.

6.4 Implications for policy/practice

We have referred throughout the conclusions to the implications of our findings for policy and practice. Summarised these are:

Relational and longitudinal continuity

- Models with high levels of relational and longitudinal continuity are valued highly by young people and carers
- Models with high levels of relational and longitudinal continuity foster trusting and non-judgemental relationships
- Models with high levels of relational and longitudinal continuity support management continuity
- Most young people find large multidisciplinary consulting formats intimidating
- Young people and their carers value opportunities for one-to-one discussions with a known-nurse on the day-to-day aspects of diabetes management
- Roles which span child and adult services fulfil a valuable integrating function
- Joint clinics are no guarantee of relational continuity if the division of labour is not carefully attended to
- Relational continuity is highly valued by young people on transfer to adult services

Management continuity

- In models with small co-located teams with high levels of relational and longitudinal continuity, management continuity can be sustained by relatively low cost informal mechanisms.
- In models with more complex divisions of labour and lower levels of relational continuity, additional management continuity mechanisms are required
- Psychosocial understanding is an important component of management continuity as experienced by young people and their carers
- Boundary blurring at the child-adult interface can be an effective means for supporting management continuity
- Mothers are an important source of management continuity and can experience discontinuities when their child moves to lone consulting/adult services

- There is a need for greater attention to the information needs of mothers when their child moves to lone consultation, whilst respecting the young person's right to confidentiality
- There is a need for greater attention to the support needs of mothers when their child moves to lone consulting/adult services

Cultural continuity

- In services in which there is a common approach across paediatric and adult services transition can be relatively seamless and there is little need for interventions to support transfer
- In services in which paediatric and adult services are culturally distinct then interventions are necessary to minimise culture-shock
- Routine contact between paediatric and adult service providers may foster more culturally continuous services
- Paediatric and adult consultants have a central role in supporting management and cultural continuity
- Our findings point to the importance of clinical leadership and the potential of dual or specialist qualifications and/or training in this field

Informational continuity

- In models in which there is a complete handover of care on transfer to adult services young people and carers have high needs for information
- There are benefits in paediatric and adult services working collaboratively to develop information resources to support transfer
- Joint clinics can be confusing for young people and their carers and therefore information resources explaining their rationale and operation are indicated

Flexible and developmental continuity

- Systematically recording developmental continuity mechanisms should be encouraged
- Young people express little enthusiasm for formal education
- Young people are reluctant to attend clinics over and above routine clinic appointments – this suggests that 'one-stop shops' are most likely to ensure they have access to support and advice
- Consultation style and interpersonal skills are highly consequential for the experiences of young people and their

families and point to the need for professional education and training

- Consultations should be organised to enable young people to be seen on their own as well as with carers
- Service funding arrangements should take into account young adults' needs for higher levels of on-going support
- Our findings point to the value of a personal education plan as an intervention for ensuring an individually tailored and negotiated programme which is systematically recorded and which can transcend service boundaries if required, rather than a check-list of work to be done

Transition model implications

- Models with high levels of relational, flexible and cultural continuity are able to achieve smooth transition with relatively informal, low cost informational and management continuity mechanisms
- Models with more complex divisions of labour and low levels of relational and longitudinal continuity need to invest in more formal interventions to facilitate management, flexible and informational continuity to ensure smooth transition is not compromised
- Minor modifications to transition models can have significant impacts on continuity mechanisms; there is a need for service providers to consider the implications for continuity of care of changes to transition models

6.5 Implications for research

We have referred throughout the conclusions to questions we believe warrant further research. Summarised these are:

- research to address young people's singular support needs at this stage of the life-course and their implications for service delivery and organisation
- research to address young people's needs for and access to information and their preferences for information format
- longitudinal research to examine how far self-care practices in adolescence and young adulthood are predictive of adult health behaviours
- research which examines the costs and benefits of strict and relaxed approaches to diabetes management at this stage of the life-course
- research to develop and evaluate different interventions to support the management continuity needs of carers

- research to develop and evaluate different interventions to address carers' support needs
- research to address mechanisms for promoting cultural continuity across services
- research to address young people's needs and preferences in relation to dietary advice
- research to address the relationship between continuity mechanisms and clinical outcomes on large populations using quasi-experimental methods
- the development and evaluation of a 'Rolls Royce' model of transition through a randomised controlled trial

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Appendix 1: Recommendations for practice in managing the transition from children's to adult diabetes services in the UK.

- Flexibility in relation to the time of transfer based on the developmental readiness of the young person⁽¹⁻³⁾.
- Shared structured approach to the provision of education focused on providing young people with the knowledge and skills they need to maintain their metabolic control⁽²⁻³⁾.
- The importance of each young person understanding the arrangements for their care⁽¹⁻²⁾.
- The need for paediatric and adult teams liaising closely during the period leading up to and following transfer⁽²⁾.
- Records should be problem oriented, copies of key letters and summaries to be given to the young person to keep and GPs kept fully informed⁽³⁾.
- Support for joint consultation or arrangements which provide an opportunity for the young person to be introduced to the new team⁽²⁾.
- Care should be appropriate to needs and in an environment appropriate to this age group, for example clinics arranged to fit around the demands of School/college (Department of Health, 2001); age-banded clinics are recommended⁽⁴⁾.
- Following transfer of care there should be effective outreach to ensure that young adults do not lose contact with the service⁽²⁻³⁾.

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Appendix 2: Measuring individualised quality of life in young people with diabetes experiencing transition care

Introduction

The predominant nomothetic measurement model of quality of life assumes a consistent approach by respondents to measurement scales with scores being comparable across time and populations⁽¹⁻³⁾. Within this model individual variation in cognitive appraisal processes are regarded as sources of error. In contrast, an individualised approach regards such variation as integral to quality of life assessment and seeks to embrace individual differences.

Standard approaches to quality of life assessment in young people have sought to identify and measure set sub-domains within each scale, but which will vary from instrument to instrument. Hence the DQOLY-SF includes six sub-scales which measures constructs such as impact of treatment, symptom impact and satisfaction⁽⁴⁾. In contrast the ADDQOL-Teen claims to reflect a more individualised approach to assessment by asking respondents to rate how much they are bothered by the impact of their diabetes on different aspects of their life⁽⁵⁾. However, this may not necessarily reflect the value that the respondent places upon that domain and may rather measure the degree to which that aspect of life is troublesome. Nevertheless, other generic measures (e.g. Patient Generated Index, Schedule for the Evaluation of Individualised Quality of Life) may more clearly represent an individualised assessment of quality of life⁽⁶⁻⁷⁾.

Longitudinal assessment of quality of life may seek to determine change (improvement or deterioration) in state over time. Such assessment assumes constancy in the measurement tool over time but for self-reported outcomes that measurement tool includes the individual who must formulate a response according to their own internal criteria and metric for response. If the internal metric used by an individual changes over time, caution is required to interpret scores at different time points. Such changes in internal metric have been labelled re-calibration response shift, and two other forms of response shift have also been identified: re-prioritisation (change in the value attached to components of quality of life) and re-conceptualisation (change in what constitutes quality of life for an individual⁽⁸⁾). Response shift may confound the ability to determine the contribution of therapeutic interventions if it is not assessed and

controlled for, and may lead to underestimate and over-estimation of clinical effect⁽⁹⁾.

Response shift has most usually been considered as a phenomenon that occurs due to a change in clinical state (e.g. that a deterioration in health may lead to a process of adaptation resulting in re-calibration). However, it is possible that change may also result from other factors such as maturation. It is quite possible that for individuals progressing through adolescence there may be important changes in focus, over quite short periods of time. If this leads to a response shift, assessment of clinical interventions may be confounded if these effects are not accounted for.

The aims of the current study were to firstly describe the nature of quality of life domains nominated by this group of young people with diabetes. This utilises the data generated by completion of the Schedule for the Evaluation of Individual Quality of Life (SEIQoL-DW). This would then enable an assessment of stability or change over time in domain content (i.e. re-conceptualisation response shift). The extent to which this is apparent is evidenced through the use of individual case scenarios. Response shift may also be demonstrated by changes in the value placed by respondents upon otherwise stable quality of life domains. This is an example of re-prioritisation response shift.

Methods

Case study interviews

An individualised assessment using the direct weighting method of SEIQoL-DW was included at two time-points between (12 and 18 months apart)⁽¹⁰⁻¹¹⁾. These formed part of the individual case study interviews with young people across the five sites, specifically the first and last interview. In both cases SEIQoL-DW administration was to precede the remainder of the interview. Although this initial section of the interview was not being recorded, the interviewer was asked to make notes regarding the description of the quality of life domains ('cues') elicited in the interview. In the second interview the interviewer additionally probed the respondent if there were apparent changes to the cues that they had previously nominated at baseline. These probes were asked only after cues had been nominated a second time in the follow-up interview. This allowed an assessment of whether the respondent would verify any apparent change to factors contributing to their individual quality of life.

The Schedule for Evaluating Individual Quality of Life (SEIQoL-DW)

SEIQoL-DW assesses quality of life from the perspective of the individual respondent, and application involves three stages. Firstly, five important areas of life (referred to as 'cues') are nominated by the respondent. Secondly, each nominated area is scored according

to its current level (using a 10cm vertical scale anchored by descriptors of 'worst possible' and 'best possible' at either end). Thirdly, the respondent assigns a weight to each area according to its relative importance. The latter step of 'direct weighting' involves a 'dynamic pie chart'^(7, 11) which enables much quicker completion than the approach (judgement analysis) used in the original SEIQoL measure. Completion time may be between five and 10 minutes. SEIQoL has been used in more than a dozen countries and over 200 studies, is considered suitable for use in any clinical population and is one of ten quality of life methods listed by WHO (and the only one for individualised quality of life⁽⁷⁾).

SEIQoL-DW is administered by a trained interviewer and is guided by an instrument manual⁽¹⁰⁾. If respondents fail to nominate five cues a standard list of prompts is provided. When eliciting the cues, the interviewer records both the label used to describe the content area as well as a brief description. This is important when the respondent is to be subsequently re-assessed to determine if the same cues are being described. An 'index' quality of life score may also be obtained for the purpose of group comparison and is calculated by multiplying each cue level with corresponding weight and aggregating the resulting values⁽¹⁰⁾.

Using SEIQoL-DW to explore quality of life

SEIQoL cue labels and associated cue descriptions will be used to develop a categorisation of quality of life domain. Although frameworks have been constructed using this approach previously, construction of the framework will be driven by the emergent data. Further data on reasons for apparent change in cue labels or content may also help to clarify emerging categories.

Using SEIQoL-DW to assess response shift

When Schwartz and Sprangers reviewed approaches for assessing response shift within the context of quality of life research they distinguished between six broad approaches⁽¹²⁾. Their categorisation featured qualitative methods and included generic strategies which may be adapted to assess response shift (Table 1). Individualised methods, such as the Patient Generated Index and the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) are included specifically to explore re-prioritisation and re-calibration.

Table 1 Methods for assessing response shift in quality of life

Method	Example
Individualised	<i>Repertory Grid Technique, SEIQoL</i>
Preference-based	<i>Extended Q-TWIST, Preference mapping</i>
Successive comparison approaches	<i>Pairwise comparison, card sorting</i>
Design	<i>Thentest, ideal scale approach</i>
Statistical	<i>Covariance/factor analysis</i>
Qualitative	<i>Ideographic assessment of personal goals</i>

A simple comparison of cue labels at baseline and follow-up may indicate response shift. Consistently nominated cues at both time-points would suggest stability. Differently weighted cues would suggest re-prioritisation response shift. Different cue labels would suggest re-conceptualisation response shift⁽¹³⁾. However, further information about each cue would provide stronger evidence of stability or change⁽¹⁴⁾. The cue definition provided and probed by the interviewer allows a better understanding of what the respondent considers the cue label to represent. This allows the construction of the quality of life domain framework described above. As a simple cue label can mask complexity (for example, 'family' may refer either to a relationship with specific individual or to broader feelings about the emotional support provided by a family) it is important to go beyond such labels. The derived quality of life framework facilitates an assessment of whether there are important shifts within or across domains. Directly probed, respondent verification of stability will provide additional evidence in the assessment. Descriptive case studies will be used to review evidence of (i) stability, (ii) re-prioritisation response shift and (iii) re-conceptualisation response shift. Finally, quantitative assessment of quality of life change will use SEIQoL-DW summary scores. The influence of available demographic characteristics (gender, age and study site) gender will be assessed.

Results

Interviews and sample description

Assessments were completed on 47 young people at baseline and 41 at follow-up across the five study sites (Table 2). The SEIQoL-DW assessments generated 228 cues at baseline and 208 at follow (436 in total) as in eleven completed interviews only four (n=8 interviews), three (n=2) or two (n=1) cues were nominated. The

mean age of respondents at baseline was 16.4 years with the youngest being 13 and the oldest 22.

Summary individualised quality of life scores were calculated with an average score at baseline of 71.9 (SD 13.2) and at follow-up of 77.6 (SD 9.3) for the 41 respondents (21 male, 20 female) with data at both assessment points. This difference was statistically significant ($t=2.43$, $p=0.02$) in a paired comparison. Whilst female respondents had higher mean SEIQoL-DW scores at follow-up compared to males (80.3 and 75.1 respectively), neither gender nor age at baseline were significantly associated with follow-up SEIQoL-DW score.

Table 2 Number of SEIQoL-DW assessments completed and cues elicited

Site	Baseline: Assessments completed (total cues provided)	Follow-up: Assessments completed (total cues provided)
1	5 (24)	5 (25)
2	7 (35)	6 (30)
3	9 (43)	8 (40)
4	12 (59)	10 (54)
5	14 (67)	12 (59)
Total:	47 (228)	41 (208)

Constructing quality of life

All cues at both baseline and follow-up were considered in this analysis and were constructed into a framework of quality of life domains with twelve main headings (Table 3). Within each a number of key sub-themes were further clarified. For the most part individual nominated cue labels were consistent with either the main or sub-theme descriptor (i.e. if 'family' had been provided by the respondent, the cue was included under this general or a specific sub-theme). However, for some nominated cue labels the name of the main or sub-theme it was categorised under may have been different. This was likely to be the case for example, if the original label was vague, but further clarified in the interview. The twelve main headers vary in the frequency of cues coded within them and the degree of differentiation described within them. Frequently nominated domain areas such as 'family' allowed a greater degree of exploration of sub-themes compared to those which encompassed relatively few cues (such as 'finance').

The constituency of each main domain is described below:

Family

The most commonly nominated cue related to the family and descriptions related to different aspects of family life that were considered to be important. Families as a source of support was a strong theme and this further expansion upon this theme referred to families providing love, care, understanding and guidance as well as happiness. Support could also include material and financial support. Another theme elicited referred to the constancy of family relationships and often their unconditional nature. Families as recipients of love and care were mentioned by some young people, and some cues related to the dynamic ('ups and downs') of family life. Families represent shared time, interests and activities; the importance of maintaining relationships with family members was also mentioned. Descriptions were mostly generic in nature – not distinguishing between specific family members, but a few respondents mentioned either specific family members, or referred to members of the extended family.

Friends

Another very frequently elicited cue was 'friends'. Several respondents noted how friends represented an active choice and compared that to their family relationship. Whilst like families, friends provide a supportive and accessible framework, some respondents noted how friends were simply on the same wavelength as themselves and were an outlet for when they had family concerns. Friendships meant companionship, shared interests and activities and a means of having fun and exploring interests. A few young people described specific friends ('best friend', long-established friendship) but mostly friends were referred to in general terms. Similarly, a few respondents described intimate relationships either in the absence of any reference to friends in general or alongside a description of friends. One respondent indicated dissatisfaction with this aspect of life but most references to partners suggested the support and understanding provided within that relationship, including in helping with their diabetes. A small number of respondents either referred to socialising as a cue or provided a description which equated to this. Although this was sometimes in addition to a separate cue for 'friends', friends were nevertheless implied – hence the inclusion of socialising within this main domain header. Mostly this referred to having fun (e.g. 'doing cool stuff').

Leisure & social life

Although some content included within this domain necessarily implied shared activities with friends, the focus of the nominated cue

was upon activity even if that in some cases was a means to an end (e.g. to make friends). A good example of that was a commonly mentioned interest in the internet, computers or mobile phones for developing, maintaining and coordinating social life. The value of the internet for maintaining awareness of the outside world was also described, and hence was seen as educational. Whilst a few young people described a list of activities when prompted following their cue nomination, most respondents restricted themselves to one or two activities. After information technology and mobile communications, music was the most frequently nominated cue within this broad domain and could include both listening to recorded and live music, as well as playing music. Other examples included television, reading and shopping. Of particular note considering the clinical group sampled was the expressed enjoyment of eating, including specific foods (e.g. chocolates, ID541). Finally, although usually nominated as a separate cue, the importance of animals is represented as a sub-theme here. Descriptions include long-standing interest and relationships with pets, and pets as a source of companionship.

Education

As may be expected, education was a frequently nominated cue and also varied in the particular focus expressed by respondents. The importance and satisfaction of educational achievement as an end in itself was described by several young people, as well as the importance of education for enabling progression to either higher education or future work. Learning itself (i.e. in its own right) was mentioned, and interest in particular subjects or topics was described by a few young people. That education took time, effort and could entail anxiety and burden was described by some. Several respondents described how education could include the school as a social environment - as a means of developing or conducting friendships. Educational establishments and education as a process could provide structure and with it familiarity and security. A few respondents also described their place of education as an active choice.

Work

The importance of work and the income it provided to enable other activities was mentioned by several young people. Another sub-theme described was interest in the specific job engaged in or the importance of a future career. Few other aspects of work were described but included socialising, learning and being able to make a social contribution.

Finance

Similar to the domain of work above, the enabling function of money was the most commonly expressed component of this domain. One respondent mentioned financial concerns.

Sport and exercise

Similar to descriptions provided under the 'leisure and pastimes' domain, this domain included some general statements of the importance and value of sport or exercise and some lists of activities participated in by individuals. The value of such activities when expressed included enjoyment and health benefits. Occasionally this was also related to diabetes, but only in a small number of cases. A few young people nominated specific sports or activities (e.g. swimming, darts). The social benefits of sport were also mentioned by a few respondents. A small number of respondents related sport and exercise to more abstract concepts such as status, achievement, challenge and career aspirations.

Health

Several cues related to health either directly or in-directly. Many of these represented an aspiration to feel, be or remain well and the importance of remaining healthy to avoid future difficulties. This was not always expressed in relation to diabetes, although for a few respondents this was explicitly stated. One respondent (ID266, a 14-year old girl) noted the influence of others in this domain area (i.e. other's worrying about her health). The role of professional carers and health technology in general was mentioned by two respondents.

Diabetes

Although diabetes was implied or referred to in the context of other domain areas, only three respondents used the term in their nominated cue label. Controlling diabetes to avoid future problems, coping and responsibility were three areas described under this domain.

Holidays and travel

A few young people described cues relating to the importance of travelling or holidays. This could enable social life (including with family), as well as promote self-benefits such as relaxation. Five respondents described the importance of driving and the benefits to independence that this brought.

Personal environment

An affective appraisal of the home environment was described by a few respondents – the value of the home as a source of refuge, security, comfort, familiarity. Four respondents described the value they placed upon the broader environment (e.g. being in a rural or coastal setting).

Psychological constructs

A small number of elicited cues related to abstract psychological constructs and have been collated under this main domain heading. They include independence, self-expression, aspiration and social awareness. Self-expression included a description by two respondents about the importance of fashion and image in their lives (ID37, ID494) and of being creative. The sub-theme of aspiration refers to the value of personal goals and a future-orientation. Social awareness includes firstly an interest in understanding the social world, as well as an altruistic intent to help others.

Table 3 Categorisation of quality of life domains

Quality of Life Domain	Key sub-themes
Family	<ul style="list-style-type: none"> • As a supportive relationship (caring, loving, guiding, understanding) • Constant & unconditional • Family as recipients of love and care • Specific and extended family members
Friends(hip)	<ul style="list-style-type: none"> • Friendships as active choice, compared to families • Support, companionship, fun • Specific friendships • Intimate partners • Socialising
Leisure and social life	<ul style="list-style-type: none"> • General statement combining several activities • Specific activities: e.g. information and communication technology; music (listening, playing); television, reading • Food • Pets and other animals: interest, companionship
Sport & exercise	<ul style="list-style-type: none"> • General statement combining several activities or non-specific activities • Health benefits, including for diabetes • Enjoyment, challenge, career aspiration • Social benefits • Specific sports / activities
Education	<ul style="list-style-type: none"> • The value of learning • The value of achievement • Education as an enabler for further study, career • Interest in specific subjects • Organisational setting as social environment • Organisational setting as structure and security
Work	<ul style="list-style-type: none"> • Work as a provider of income • Interest in specific work • Longer-term career aims • Learning, socialising, social contribution
Finance	<ul style="list-style-type: none"> • Money as an enabler for other activities • Worries about money
Health	<ul style="list-style-type: none"> • Feeling, being & staying well • The avoidance of future problems • Looking after diabetes • Professional carers • Health technology / therapeutics
Diabetes	<ul style="list-style-type: none"> • The avoidance of future problems • Coping • Responsibility
Holiday and travel	<ul style="list-style-type: none"> • To support social and family life • Benefits including relaxation • Car driving and independence
Personal environment	<ul style="list-style-type: none"> • Affective appraisal of home – e.g. refuge, security, comfort, familiarity • Value of the broader domestic environment
Psychological constructs	<ul style="list-style-type: none"> • Independence • Self-expression • Aspiration • Social awareness

Response shift case studies

There was only one example of observed stability in cue label across the 41 participants. The remainder represented at least a change in cue label at follow-up, although the content described may have been similar to baseline. Most cases therefore represented some change in presentation of cue label, content or weighting. Three cases have been selected to illustrate the nature of apparent and actual change found in the data.

Case study 264

This male participant was 14 years old at baseline and reported the following cues 'family', 'school', 'sports', 'friends' and 'entertainment' (Figure 1). He nominated the same cues at follow-up. At both time points his description of the family cue consistently referred to the supportive component of family life (e.g. 'look after you', 'support'). Similarly, both at baseline and follow-up his cue description for entertainment provided a generic description encompassing several activities. In both cases this indicates stability in what he values within these domains. For the 'school' cue, at both time points the value of achievement is suggested, although at follow-up this has an additional focus upon the importance of getting qualifications for future work prospects. Both descriptions of his fourth cue, 'sports', includes references to enjoyment and the benefit for overall fitness, with at follow-up additional comment about social aspects and a particular sport. Finally, both descriptions of the cue 'friends' refer to spending time with, and having fun with friends with at baseline the additional notion of friends as people that you can relate to.

For this respondent, reported quality of life drops considerably between assessments. This is a reflection of a fall in cue level in all but one domain ('entertainment'). Levels have dropped in three domains in particular, 'family', 'sports' and 'friends' (drop of 20, 27 and 43 points respectively). The respondent reported at follow-up that his reduced score for 'sports' was accounted for by him stopping playing a particular sport and a consequent reduction in fitness. His family life was scored worse because of some difficulties in diabetes self-management and he also reported how some disagreements amongst his friends had led him to rate that cue lower at follow-up.

That his overall quality of life score is not even worse is accounted for by an increased valuation (weighting) for one of the higher rated cues ('family') and by a decreased valuation for one of the now lower rated cues ('friends'). The respondent commented upon his increased valuation of family by saying he was more aware of how much they do for him and that he appreciated this more. In contrast he reflected on how his friends were being dispersed in different classes in school, suggesting perhaps a more transient set of relationships.

In summary, the broad areas of life that contribute to this young man's quality of life remained stable between assessments. Even within each individual domain the focus is consistent across time. There were some real changes in circumstances that had caused him to lower his rating for individual domain areas reflected in a much lower overall quality of life rating. However, this overall rating at follow-up may have been even lower if he had placed the same value on constituent domains as he had done at baseline. Therefore, this would represent an example of stable quality of life conceptualisation but some re-prioritisation response shift.

Case study 154

At baseline this male participant was 15 years old and reported the following domain areas: 'family', 'friends', 'school', 'socialising' and 'health' (Figure 2). At follow-up his cue labels were similar, with 'health' now modified to 'healthy' and instead of 'school' he nominated 'new school'. Whilst at baseline he nominated 'socialising', at follow-up this had been replaced by a new cue 'future'. His baseline description of the family cue included the supportive nature of family life whilst at follow-up he also described the need to get on with family. Interestingly, whilst at baseline he described both 'friends' (enjoyment of good friends) and 'socialising' (e.g. going out, having fun) at follow-up the latter appeared to have been subsumed within the description of friends. Thus he appeared to have provided an expanded definition of friends the second time around, with greater coverage.

At follow-up, he described how he was moving on to a new school, hence the modified cue label. At both assessments, his description of health related mostly to his diabetes. The newly elicited cue at follow-up ('future') reflected his anticipation of future work and university experiences.

Unlike the previous case study, this young man showed a big increase in his quality of life across assessments. This is mostly accounted for by an increased rating for 'school' and by a high rating for 'future'. An additional contributor to the raised level of quality of life was the high weighting he attached to the 'future' cue (26) and to the decreased weighting attached to 'health/y' (from 22 at baseline to 9 at follow-up). The respondent described how his focus upon the (new cue) 'future' was a reflection of where he was in his schooling career. Similarly he described how socialising is less important now that he has passed on from his GCSEs and he is more serious about the future. He was also about to start a new school and reported recently attending an induction. In relation to his health, he noted that he was now more used to his diabetes at follow-up (consistent with his rating of 'health/y') and also that he didn't want his diabetes to dictate his life (maybe in contrast to how he felt previously).

In summary, there is some stability in quality of life domains for this young person, but also some changes in cues which appear consistent with his life-course development. In some cases what he is reporting as included within individual domain areas is also expanding over time. There is a change in the importance that he reports attaching to certain areas of life over time. Again this is consistent with his accommodation to diabetes and to his progression through the secondary education system and anticipation of future life prospects. His profile is consistent with some re-conceptualisation response shift and also some re-prioritisation response shift. In both cases these changes appear to contribute substantially to an improved quality of life appraisal.

Case study 281

At baseline this young man was 21 years old and described 'family', 'money', 'work', 'health' and 'travelling' as contributing to his quality of life (figure 3). 'Family', 'money' and 'work' also featured at follow-up. His consistent description of family emphasised their supportive value to him. Similarly, in both assessments work as a provider of income was the key focus of that domain area. At baseline, the relationship between what one can earn and what one can afford was highlighted in the 'money' domain, although at follow-up there seemed to have been a shift in focus as he commented upon the stress associated with a lower wage and increased outgoings. At baseline, he nominated 'health' as a cue which he at least in part related to his diabetes. At follow-up, the cue label elicited was 'diabetes' and included a description of coping with the ups and downs of managing the condition. In figure 3 therefore, the health and diabetes cues have been represented by the same patterning to reflect the shared focus of the two labels. 'Travelling', relating to the freedom to visit people associated with driving was nominated only at baseline. The respondent noted that he was less able to travel due to financial restrictions at follow-up. In contrast, 'girlfriend' (as a supportive influence) was only elicited as follow-up.

This young man's recorded quality of life improved between assessments. Contributing to this was an improvement in level for work. However, he noted how work was less stressful and that therefore it was less important to him now. This reduced the overall contribution of work to his quality of life, but the combined effect (of level and weight) still represented a big improvement for him. Mostly importantly though was the new emphasis upon his intimate relationship at follow-up which was rated highly and also accorded a large weighting. He commented that he had previously underestimated the support that he received from her and suggested that their relationship had increased in importance with duration. Similarly, he also commented upon how managing his diabetes was easier for him and therefore, he was inclined to place less importance

upon this. This actually decreased his quality of life score at follow-up. When prompted he reported that his lower rating of cue level for diabetes was a reflection of the lower importance he now attached to it. If this is the case, he has inadvertently conflated the level and weighting for this cue when supposed to consider only cue level. The effect is to reduce the overall reported quality of life score.

In summary, there is some stability in labelled quality of life domain and content across assessments. There is also some actual stability in cue content despite a change in cue labelling (diabetes and health). This can give the appearance of change when in fact there is relative stability. There is though also some re-conceptualisation of content domain. As the young man was in a relationship at both assessment time points but only explicitly nominated his partner at follow-up, it is possible to attribute the change to a revision in her apparent importance to him. That is, this apparent re-conceptualisation is due to re-prioritisation.

Figure 1 Case study example of stable quality of life conceptualisation, some re-prioritisation response shift

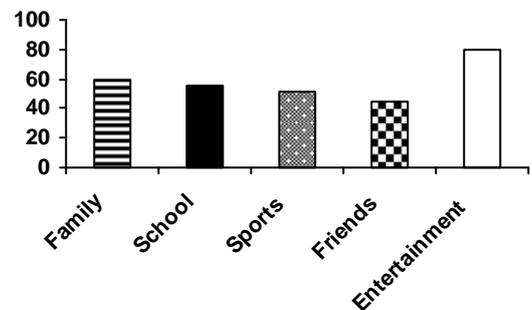
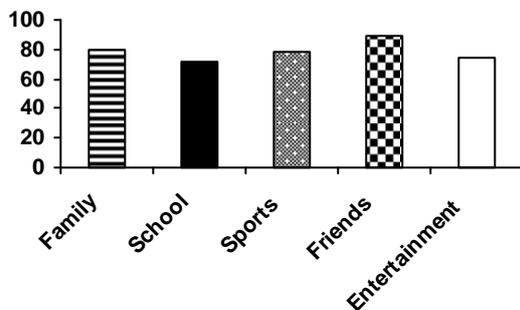
ID264	Age:	14	Baseline SEIQoL-DW score:	78.4
	Gender:	Male	Follow-up SEIQoL-DW score:	57.7

SEIQoL cues, levels and weights

Baseline

Follow-up

Levels



Weights

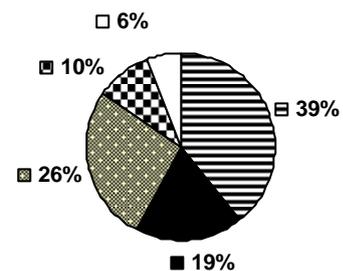
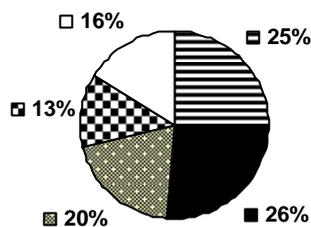


Figure 2 Case study example of partial re-conceptualisation and some re-prioritisation

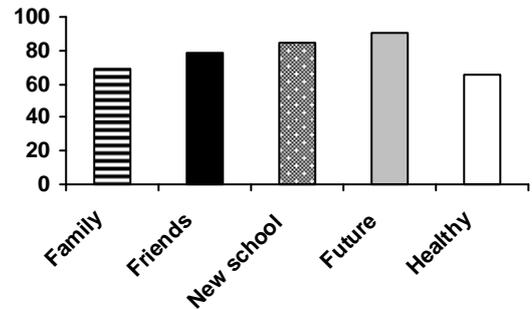
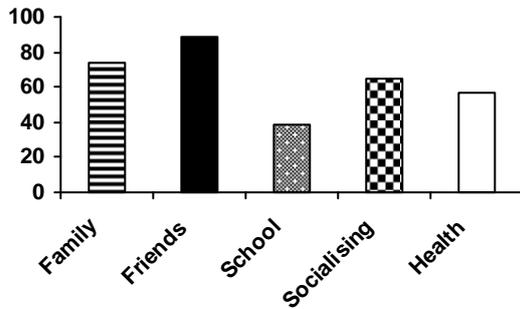
ID154	Age:	15	Baseline SEIQoL-DW score:	64.41
	Gender:	Male	Follow-up SEIQoL-DW score:	80.58

SEIQoL cues, levels and weights

Baseline

Follow-up

Levels



Weights

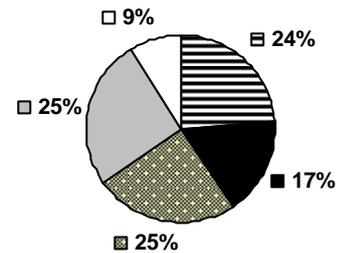
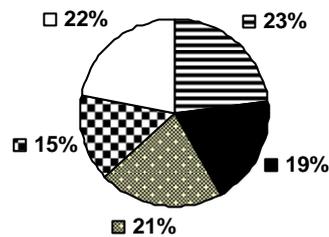


Figure 3 Case study example of partial re-conceptualisation, some re-prioritisation, and re-labelling of consistent cue content.

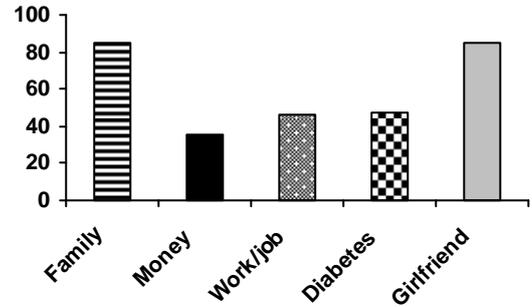
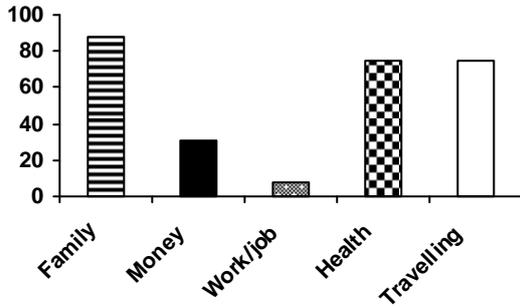
ID281	Age:	21	Baseline SEIQoL-DW score:	59.5
	Gender:	Male	Follow-up SEIQoL-DW score:	73.1

SEIQoL cues, levels and weights

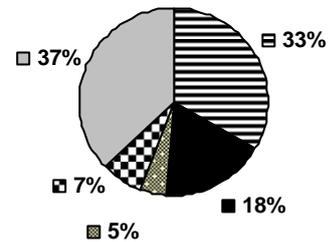
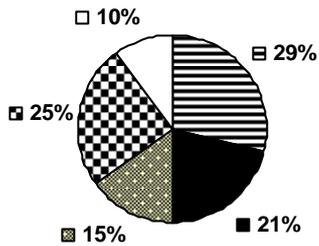
Baseline

Follow-up

Levels



Weights



Discussion

This assessment of individualised quality of life has been integrated within a broader case study of teenagers and young people experiencing transitional care for diabetes at five English study sites. A descriptive framework has been derived which demonstrates both the breadth of content that young people consider to be important to their quality of life and also its complexity. The dynamic nature of quality of life content for individual participants has been represented through the use of case studies. Interview data provided descriptions which support observed changes in quality of life level between assessments. Some apparent change in quality of life content over time may be explained by simply a re-labelling of the content by the respondent, or by subtle changes in focus. There also appear to be clearer changes in the importance attached to certain quality of life domains, either attracting increased or decreased priority over time. Broader changes in quality of life conceptualisation also appeared evident, and may be consistent with normal psychosocial developmental changes at this dynamic stage of life.

The formal assessment of quality of life in teenagers with diabetes has mostly addressed health-related quality of life (e.g. DQOLY-SF, ADDQOL-Teen)^(4, 5). However, individualised approaches have been used- including SEIQoL-DW - and found to be acceptable in children as young as 12⁽¹⁵⁾. Wagner reported that the five most commonly reported domains by 67 young people with type 1 diabetes aged 8-17 were 'family', 'friends', 'diabetes', 'school' and 'hobbies'. Further work by the same author emphasised the multidimensionality of quality of life for young people with diabetes, and that any focus upon diabetes may modify with age⁽¹⁶⁾. This study has explored the diversity of quality of life content within a comparable UK sample of young people with diabetes. Although diabetes was described in relation to several areas of life, only a small number of respondents particularly focused upon the condition. This may reflect the slightly older sample compared to that in the US study and also the context of data collection (the US study was conducted during a diabetes summer camp). It is also worth noting that finance was not nominated as a domain in the study by Wagner and colleagues and there was a greater emphasis upon 'work' in the current study. Both these observations probably reflect lifespan differences between the two study groups.

The purpose of developing a classification framework in this study was not to quantify frequency of cue nomination, although this could be formally addressed in secondary analysis. However, there is a risk of reducing descriptions of content to labels which fail to capture the quality of what is important to young people. The strength of the derived framework is that it better represents the complexity of such quality of life domains and its dynamic quality.

Wagner reported a re-calibration response shift in a group of US children with type 1 diabetes using the Problem Areas in Diabetes questionnaire (PAID)⁽¹⁷⁾. Interestingly, Wagner found some evidence that this was linked to glycaemic control. The current study has provided evidence of what may be referred to as re-conceptualisation and re-prioritisation response shift. Although cue label change was observed for most respondents, it was also clear that for some, this did not actually represent change at all – simply the use of a different descriptor (an example of re-labelling change)⁽¹⁴⁾. The content of some cues changed over time – either with their focus being expanded or contracted at follow-up. These have both been referred to as *cue re-formulation* changes. There were also many examples of cues simply being replaced over time with different cues.

An approach that is driven by individual appraisal mechanisms (such as SEIQoL-DW) would appear to provide an assessment with high face validity, and which measures what is important to those being assessed⁽¹⁸⁾. It provides a relatively brief means of capturing the life world of young people with diabetes and the way that it may change over a relatively short period of time. As such it may be more responsive than standardised measures of quality of life. The change in quality of life detected by the summary score may be seen as evidence of that. However, that is only the case if there has been a real improvement in life quality – and in this study there has been no formal intervention between assessments. Nevertheless, the changes to quality of life content and valuation described in this study seem credible and not artefacts, and related to real lifespan developments. Thus, the response shift re-prioritisation and re-conceptualisation described above are not simply sources of measurement error, but important developmental outcomes.

The standard application of SEIQoL-DW includes some probing within the interview to clarify the meaning of the nominated cue for the respondent. On the whole this did provide some insight into the nature of the cue elicited and facilitated a more detailed representation of individualised quality of life. However, audio-recorded interviews with expanded probing may have provided further detail about factors affecting quality of life and some insight into the robustness of individual cues as contributors to an individual's quality of life. Secondary analysis of the current data set is limited by the brevity of descriptions provided, but could seek to formally quantify the frequency of quality of life domains described by respondents. A limiting factor here though is that single cues are likely to be legitimately represented by more than one domain area – (i.e. that any one description may be double-coded).

In summary, this analysis has provided a detailed description of what is important to the quality of life of young people with diabetes who are at a transitional stage in their diabetes care. Neither diabetes, nor more broadly, health, are dominant influences, although the

condition does have an impact that permeates a number of areas of personal importance. Real changes in how young people appraise their own quality of life were found which may be described as response shift. Although, response shift can be considered a source of measurement error, within an approach that emphasises individual appraisal as part of the measure, this better represents the lifespan progression being experienced by the current sample.

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Appendix 3: Survey instrument review of the literature

Introduction

In order to inform the development of the survey instrument, a detailed literature review was undertaken. The purpose of the review was to identify suitable age-specific, diabetes-specific or generic, instruments that measure relevant outcomes in young people with type 1 diabetes and their carers. Evaluative criteria used to assess identified measures included reliability, validity and sensitivity to clinically important change (responsiveness). The results of the review would inform the selection of scales for use in the Transitions Study. The review involved the development of a systematic search strategy to identify candidate instruments. Study populations considered relevant were young people with type 1 diabetes aged between 13 and 25 years and their carers. Populations of potential relevance were children and/or adolescents with type 2 diabetes and adults with type 1 diabetes. Outcome domains of relevance included diabetes-specific quality of life, self-efficacy (and related measures including self-management/care), relationship to service providers (including therapeutic alliance) and other outcomes relevant to transition (for example, service satisfaction, continuity of care).

Papers were retrieved if they reported scales relevant to the domains of interest and which included a full version of the actual instrument in question; updated a relevant instrument or otherwise provided evidence of an instrument's validity, reliability or responsiveness. Data extraction on relevant retrieved scales was guided by the use of an extraction template and evaluation directed by a priori criteria (e.g. validity, reliability). Of the small number of scales retained in the review process, all had evidence of validity and reliability, but little evidence of responsiveness was reported. Most scales reviewed had been validated in relevant UK clinical populations and the quality of life measures were similar in length and presentational format. Therefore, the selection of measures for use was predominantly guided by preference for scale sub-domains and overall fit within an integrated survey schedule.

Method

Search strategy

A three-stage strategy was designed to locate literature relevant to the review.

Stage 1

An initial search was conducted of Medline; PsycInfo and Embase using the natural language terms of the topic to identify relevant key words and MeSH terms.

Stage 2

The text words contained in the title and abstract of all relevant articles along with the controlled language index terms used to describe the paper were analysed and used to develop a comprehensive and sensitive subject search to ensure that all relevant material was captured. Two broad search strategies were developed:

- Quality of Life Search Strategy
- 'Other instruments of interest' Search Strategy

Both of these strategies searched for published materials electronically within the databases: Medline; PsycInfo and Embase and each search strategy was modified according to the database searched.

Quality of life search strategy (QoLSS)

This strategy focused on instruments measuring quality of life. An initial strategy was designed and subsequently refined to ensure maximal capture. The initial QoL searches (Step1) of Medline, between 1966-June week 1 2006; Embase, between 1980-2006 Week 24 and PsycInfo, between 1806-June Week 2 2006, in combination yielded 199 papers. The second refined searches (Step2), of Medline, PsycInfo and Embase, covering the same timeframes, used modified search terms, i.e. truncated search terms, to broaden/extend capture. This search resulted in 300 papers once duplications and papers focusing on patients over the age of 60 had been removed.

'Other instruments of interest' search strategy

The second and broader search strategy sought to identify a range of measured domains: self-efficacy, self-management/care, therapeutic alliance, personal satisfaction, service satisfaction and continuity of care. The databases searched for published material included: Medline; PsycInfo and Embase within the same time frame as QoLSS. This resulted in 517 papers once duplicates and papers focusing on patients over the age of 60 years had been removed.

Stage 3

Stage 3 involved a variety of hand-searching approaches. Key journals and books, producing a high yield of relevant material were hand-searched as were potentially relevant websites. Throughout the review contact was maintained with other researchers who were also studying outcome measures for young people with diabetes. Reference lists and bibliographies from all of the retrieved articles meeting the inclusion criteria of the review were searched for additional references (i.e. snowballing). Books which reviewed the development of outcome measures were also considered. In total Stage 3 added 16 additional papers: 7 extra QoL and 9 'Other Measures', as well as 18 reviews: 8 QoL reviews and 10 'Other Measures' reviews.

Filtering process

Quality of Life - Strategy 1

Our search strategies identified a total of 510 QoL articles. Papers were screened for relevance based on the title alone (filter 1), resulting in 87 papers. All remaining 87 articles were screened by abstract (filter 2) resulting in 22 articles - including eight reviews, which were retained for reference. Following consideration of the full text of 22 articles (filter 3), seven QoL papers, which looked at the development of three instruments, were retained for instrument consideration and inclusion in the survey instrument (Table 1). Of the eight reviews, six were retained for reference; the book chapters were discarded.

Other measures - Strategy 2

Our search strategies resulted in a total of 533 'other measures' articles. Papers were reviewed for relevance based on the title alone, resulting in 74 papers. Remaining articles were reviewed by abstract resulting in 16 papers and ten reviews, two of which were retained for reference; the book chapters were discarded. The full texts of remaining 26 papers were reviewed and non-relevant articles excluded, yielding seven papers, which looked at the development of five instruments, for consideration and potential inclusion in the survey instrument (Table 1).

Table 1: Potential Measures for use in Development of TCADS Survey Instrument

Search Strategy	Domain Measured	Instrument number and name	Year	Paper Number
1	1. QoL (Quality of Life)	1 Audit of Diabetes Dependent Quality of Life (ADDQoL)	1999	1
		Audit of Diabetes Dependent Quality of Life – Teen (ADDQoL-Teen)	2004	2
		Diabetes Quality of Life Measure (DQoL)	1988	3
		2 Diabetes Quality of Life Measure Youth (DQoLY)	1991	4
		Diabetes Quality of Life Measure Youth – Short Form (DQoLY-SF)	2006	5
		3 Paediatric QoL Inventory™ 4.0 + 3.0 – generic core scales + condition specific module (US original version)	2003	6
		PedsQL™ 4.0 (UK version)	2005	7
2	2. Self-efficacy	4 Diabetes Management Self-Efficacy Scale for Adolescents with Type 1 Diabetes (DMSES)	2001	8
		Patient Enablement Instrument (PEI)	1998	9
		5 Patient Enablement Instrument – modified for chronic disease management (PEI modified)	2007	10
		6 Perceived Competence for Diabetes Scale (PCDS)	1998	11
	3. Continuity of care	7 Diabetes Continuity of Care Scale (DCCS)	2004	12
	4. Relationship to service provider	8 Heath Care Climate Questionnaire (HCCQ)	1998	11
			1999	13

Assessment of instruments

Search strategies 1 and 2 identified eight instruments (from 14 papers) relevant to the study (Table 1). These were split into four groups according to which domain they measured. Group 1 consists of the *Quality of Life* measures ADDQoL and its variant ADDQoL-Teen, DQoL and measures derived from it (DQoLY and DQoLY-SF) and PedsQL™ (versions 3.0 and 4.0). Groups 2, 3 and 4 represent the results of search strategy 2, which had sought ‘other measures’. Group 2 consists of self-efficacy measures, including DMSES, PEI and PEI modified. Group 3 includes DCCS, a measure of continuity of care. Group 4 includes HCCQ, a measurement of the relationship to the service provider/therapeutic alliance.

The eight identified instruments were assessed for their suitability for use in the study according to established criteria.

Evaluative criteria

A template was used to extract relevant details for each of the eight candidate instruments. The variables which formed the criteria for assessment and selection of the eight instruments relate to three specific areas:

Characteristics of the population in which the instruments were developed - including:

Study setting, Sample description, Diabetes type, Duration of disease, Treatment type

Instrument description - including:

Number of scales and items, Response format, Response collection mode

Psychometric and other evaluative properties - including:

Validity:

Face validity: the extent to which the instrument appears to measure what it intends to.

Content validity: the extent to which the domain of interest is comprehensively sampled by the questions/items in the instrument.

Construct validity: the extent to which an instrument measures the hypothetical construct(s) it aims to represent. This is assessed in various ways. For example, item/scale analysis - where internal construct validity is tested via factor analytic methods and convergent and discriminant validity - where external construct validity is tested via correlation analysis.

Responsiveness: the extent to which an instrument is sensitive to changes over time that are important to respondents.

Reliability - testing:

Internal consistency: how well items within a scale measure a single underlying domain. This can be assessed using item-total correlation or Cronbach's α .

Reproducibility: whether, when respondents have not changed on the domain being measured, the instrument yields the same results on repeated application. This is assessed by checking test-retest correlation coefficients.

Acceptability - the impact upon the respondent, carers and family, including:

Time to complete

Item and Unit non-response

Feasibility - ease of instruments use for the researcher/clinician, including:

Administration time

Ease of process and analysing responses

Impact upon clinical care

Cumulatively, this empirically derived information would guide selection of instruments for use in the study.

Results

This section will present the various assessments detailed previously for each of the eight instruments.

Group 1 - QoL instruments

Audit of Diabetes Dependent Quality of Life (ADDQoL)

Description of instrument

The ADDQoL was developed in the UK in a National Study of Audit of Diabetes Care⁽¹⁾. This scale aims to access the *individual patient's view* of their own quality of life. Development was based on a review of existing instruments, discussions with health professionals and in-depth interviews with 12 patients with diabetes. The ADDQoL comprises a single scale and 13 domain specific items. Each item has two stems, in effect resulting in 26 questions (Table 2). The first stem assesses the *impact of diabetes* on each aspect of life for the individual respondent, i.e. within a particular domain (as identified by an item), e.g. 'If I did not have diabetes..... would be.....'. The second stem assesses the *importance of that same aspect/domain*, for the QoL of the individual respondent, e.g. 'very important' to 'not at all'. The second stem, the *importance rating*, was introduced so that scores could be assigned an individualised weighting. The double stems render it less straightforward to use, demanding a more complex cognitive task⁽¹⁾ than other more conventional instruments. In addition to the 13 life-domain items, there are also two global items which ask the respondents about (1) their present QoL and (2) what their QoL would be without having diabetes. Respondents of the ADDQoL are required to use a mixture of Likert-like scales: stem 1 has 7-point scale responses and stem 2 has 4-point scale responses; the two global items have 7-point scale responses.

Population in which instrument is evaluated

The ADDQoL was evaluated at two separate sites in the UK; in Bromley at a Diabetes open-education setting and in Cambridge at a hospital outpatient department (Table 3). The samples were approximately equal male/female percentages (males 54%) but the mean age of the patients, which was 62 and 52 years respectively, did not closely match the age criteria for which we were searching.

Despite the inappropriate age group, the details of this instrument are reported here because this instrument is the pre-cursor to the ADDQoL-Teen. It therefore plays an important part in the developmental process by providing preliminary evaluation of the instrument⁽¹⁾.

Instrument properties

Validity

Face Validity: The consensus about the ADDQOL measuring what it intends to measure was achieved between the BDA/RCP Working Group and four adults with diabetes; this indicates some face validity.

Content Validity: The degree to which the instrument comprehensively covers the domains of interest, is indicated by the type and the range of item sourcing. In this case, not only was there a literature review of previous QoL measurement but there was also consultation with health professionals and in-depth interviews, at routine diabetes clinics, with 12 adults with diabetes. The development of the ADDQOL was carried out across two sites; it was at the Bromley site, with the larger sample population where one of the health professionals, a dietitian who was involved in this instrument's development, suggested the addition of the thirteenth item – 'enjoyment of food'. Due to the late introduction of this extra item, the number of respondents with type 1 diabetes to evaluate the full ADDQOL, with 13 rather than 12 items, was restricted to the 45 type 1 diabetes Bromley respondents.

Construct Validity: Forced (1 factor) factor analysis on all 13 items resulted in all factors loading at least 0.4 (between 0.4 and > 0.5). 12 items loaded at least 0.5 (between 0.5 and > 0.8). Percentage of variance explained is not reported. The mean weighted ADDQoL score correlated with the variables: 'number of reported complications' (Spearman's $\rho = -0.2141$, $p < 0.005$), 'actual number of complications' ($\rho = -0.2289$, $p < 0.003$) and 'perceptions of hypoglycaemia' ($\rho = -0.3237$, $p < 0.001$).

Responsiveness: Reported by the Dose Adjustment for Normal Eating (DAFNE) study group, who found significant reduction in the impact of diabetes at six months and in the general quality of life, measured by the summary item at one year. However, this is not a formal measure of scale responsiveness.

Reliability

Internal Consistency: Cronbach's α for all 13 items was $\alpha = 0.8460$. For 12 items $\alpha = 0.8435$. Item-total correlation ranged from 0.37 to 0.67. The presence of reliability and validity for all QoL measures can be viewed in Table 4.

Acceptability

It has been estimated that it takes less than ten minutes to complete the ADDQOL⁽¹⁾ and the response rate is acceptable at 74%. Another *indirect measure*, which indicates the ADDQOL's acceptability is its sensitivity to positives and negatives both of diabetes and of treatment, e.g. increased enjoyment of food, greater physical fitness and motivation levels, plus less worry about future. *Direct measures* of acceptability include: respondent views and subsequent revisions of the instrument; for greater applicability the breadth of domains was increased with an extra added item and the wording was simplified e.g.: 'employment/career opportunities' changed to 'working life and work related opportunities'; 'family relationships' changed to 'family life'; 'sport' changed to 'leisure activities'. As a result of greater applicability the number of 'N/A' options was reduced and this further increased acceptability.

Feasibility

No evidence reported.

Table 2: Description of Instruments

Domain	Instrument	Scales & Items	Response Format	Time to complete	Self Complete (Y/N)	Parent Proxy (Y/N)
1	ADDQoL	Single index -impact of diabetes on patient (13 domain specific items) stem 1: relevance of domain/item stem 2: importance of domain/item -overview/global questions (2 items) present QoL diabetes dependent QoL	7pt Likert 4pt Likert 7pt Likert 7pt Likert	<10 mins	Y	N/A
	ADDQoL-Teen	2 scales - 25 items -impact self (10 items) stem 1: frequency of domain in their life stem 2: how much the domain bothers them -impact others (15 items) stem 1: frequency of domain in their life stem 2: how much the domain bothers them -overview/global questions (2 items) present QoL diabetes dependent QoL	4pt Likert 5pt Likert 4pt Likert 5pt Likert 5pt Likert 5pt Likert	10-15 mins	Y	N
	DQOL	4 scales – 46 core items + 16 auxiliary items (for adolescents) - Core items - treatment satisfaction (15); impact of treatment (20); worry: social/vocational (7); worry: diabetes related (4) - Auxiliary Items - school experience and family relationships (16)	5pt Likert 4pt Likert	15-20 mins	Y	N
	DQOLY	3 scales + general question - 51 + 1 items - Diabetes/Life Satisfaction (17); Disease Impact Scale (23); Disease Related Worries (11) - health perception (1)	5pt Likert 4pt Likert		Y	N
	DQOLY-SF	6 scales + general question - 39 items - impact of treatment (3); symptom impact (3); impact on activities (5); parental control (3); future worries (7); satisfaction (17) - health perception (1)	5pt Likert 4pt Likert		Y	N
	PedsQL™	4scales - 23 items - physical functioning (8); emotional functioning (5); social functioning (5); school functioning (5) 5scales - 28 items - diabetes symptoms (11); treatment barriers (4); treatment adherence (7); worry (3); communication (3)	5pt Likert 5pt Likert	5-10 mins	Y	Y
	DMSES 	Single index – 26 items	5pt Likert		Y	
	PEI	Single index – 6 items	3 anchors	Seconds	Y	N/A
	PEI Modified	Single index – 6 items	3 anchors	Seconds	Y	N/A
	PCDS	Single index – 4 items	7pt Likert		Y	
3	DCCS	5 scales - 47 items Care by Doctor (13); Care by Other HCPs (12); Access/Getting Care (10); Communication between HCPs (5); Self-care (7)	5pt Likert		Y	
4	HCCQ modified	Single index - 5 items (Paper1)	7pt Likert		Y	N/A
	HCCQ modified	Single index - 4 items (Paper14)	7pt Likert		Y	N/A

Table 3: Population in which instruments were evaluated

Instrument	Setting	n	Age (Mean)	Age Range	Males (%)	Condition /Treatment	%	Duration (years)
Audit of Diabetes Dependent Quality of Life (ADDQoL)	UK - education open-evening (Bromley)	102	62		54	IDDM	37	7
	UK - out-patients (Cambridge)	52	52		54		62	13
Audit of Diabetes Dependent Quality of Life – Teen (ADDQoL-Teen)	UK - 6 centres - Paeds + Adult Clinics - sub-set	152	16	10-24	47	IDDM	51	
		124	16	13-18				
Diabetes Quality of Life Measure (DQOL)	N. America, Europe + Asia; 18 countries – 21 Paeds centres - sub-set adults - sub-set adolescents	134	28	18-41	60	IDDM	100	9
		56	16	13-18	59			6
Diabetes Quality of Life Measure Youth (DQOLY)	USA - 1 Paeds centre	74	16	11-22	62	IDDM	100	6
Diabetes Quality of Life Measure Youth – Short Form (DQOLY-SF)	N. America, Europe + Asia; 18 countries – 21 UK Paeds centres	2101	14	10-18	52	IDDM	100	6
Paediatric QoL Inventory™ 4.0 + 3.0 original (PedsQL™ 4.0+3.0) generic core scales + condition specific module	USA - paed office + diabetes clinic + hospital in/out-patient - child report + parent proxy paired - child report only	328						
		279	13	2-18	45	IDDM	73	
		299	14	5-18	45			
Paediatric QoL Inventory™ 4.0 + 3.0 UK	UK - 23 UK, South Wales schools - parent proxy with healthy children - parent proxy with diabetic children - child self-report - healthy children - child self-report - diabetic children	665						
		103	12*			Mixed chronic and healthy		
		1034		8-18	47*			
		124	13**		49**			
Diabetes Management Self-Efficacy Scale for Adolescents with Type 1 Diabetes (DMSES)	Belgium + Holland - hospital patients	84	15	12-18	43	IDDM	100	6
Patient Enablement Instrument (PEI)	UK - General Practice	613				Mixed chronic and acute		
Patient Enablement Instrument Modified (PEI Modified)	UK - 72 GP/general practice surgeries	228	51	--	49	Asthma	100	91% >5yrs
Perceived Competence for Diabetes Scale (PCDS)	USA - Diabetes Centre – university affiliated community hospital	128	55	18-80	44	IDDM	37	14
Diabetes Continuity of Care Scale (DCCS)	Canada - Health Centre, Phase 1	46	59		46	IDDM	12	11
	Canada - Health Centre, Phase 2	60	61		57		12	11
Health Care Climate Questionnaire (HCCQ)	USA - Diabetes Centre – university affiliated community hospital	128	54.5	18-80	44	IDDM	37	14
Health Care Climate Questionnaire (HCCQ)	USA - Suburban High School, New York	300						

* Parent proxy value (across all health states)

** Self-reported value (across all health states)

Table 4: The Validity and Reliability of the Instruments from Group 1 (Quality of Life)

Group	Measure	Validity	Reliability
1	ADDQoL	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓ Responsiveness - ✓	Internal Consistency - ✓
	ADDQoL-Teen	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓
	DQoL	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓ Reproducibility - ✓
	DQoLY	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓
	DQoLY-SF	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓
	PedsQoL (US)	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓ Responsiveness - ✓	Internal Consistency - ✓
	PedsQoL (UK)	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓

Audit of Diabetes Dependent Quality of Life - Teen (ADDQoL-Teen)

The ADDQoL was amended for teenagers to derive the ADDQoL-Teen. The development of this instrument was based on interviews with 23 teenagers with diabetes, aged 13-16, about questionnaire items and response format choices. The ADDQoL-Teen aims to remove, or at least reduce, the abstract and age-inappropriate items often found in adult QoL instruments. Such adaptation of the original ADDQoL serves to develop its underlying philosophy, which is to focus on the individual. The ADDQoL-Teen differs specifically from other, simplified/modified, paediatric and adolescent instruments in the ways in which it seeks to identify, specifically, those aspects which matter personally to respondents; it adopts a particularly sensitive teenager-centred approach.

Description of instrument

The ADDQoL-Teen has two scales with a total of 25 items, almost twice as many as in the original ADDQoL (Table 2). In the development of this instrument items were generated by asking young people what they perceived to be important for their QoL with diabetes. Here, as with the original ADDQoL, each item in the ADDQoL-Teen has two stems; in this case, however, the stems are slightly different, they ask young people about: a) the *frequency* with which diabetes impacts on each particular aspect of life or domain (as identified by the item), e.g. 'Do you ever.....' and b) *how much that same aspect/domain bothers* the individual respondent e.g. 'Does it bother you when..... because of your diabetes'⁽²⁾. Again the ADDQoL-Teen includes two global items which measure the respondents' 1) *present QoL* and 2) what their *QoL would be without having diabetes*. This instrument's response format is more visual, and so possibly more accessible to young people than the original ADDQoL; it has, also, amended the response format so that stem a) has 4-point scale responses, stem b) and the two overview questions have 5-point scale responses. Despite its length and its double stems, this instrument takes only 10-15 minutes to complete.

Population in which instrument is evaluated

The ADDQoL-Teen was developed for a population aged 13-16, with a view to also using it with 17-18 year olds many of whom would still be attending school⁽²⁾. In the end, this instrument was evaluated with respondents within a broader age range (10-24 years), with a mean age 16.4 years. There were 152 respondents of whom 31 were aged between 17-18 years, 7 were younger than 13 years and 21 were older than 18 years (Table 3); this closely matched the criteria for which we were searching. This sample was recruited from six UK centres, six paediatric (n=113) and five adult (n=39) clinics; it is made up of 51% of patients with type 1 diabetes, 47% of which are male (Table 3).

Instrument properties

The ADDQoL-Teen is an evaluated instrument with very good psychometrics, improving on the original ADDQoL.

Validity

Face Validity: Group interviews were carried out with young people (n=23) aged 13-16 years, to ensure that the questionnaire items, response choices and format had face validity for that age group.

Content Validity: The ADDQOL-Teen builds on the original means of item sourcing not only carrying out a literature review and consulting with health professionals, but additionally increasing the level of patient input and observing clinic sessions with this age-group.

Construct Validity: A forced (2 factor) factor analysis resulted in 2 factors; Impact-Others, which loaded between 0.4 and > 0.7 on a sub-group of 13-18 year olds; and Impact-Self, which loaded between 0.5 and > 0.7 on a sub-group of 13-18 year olds. Percentage of variance explained for each of the factors is only reported for the full sample (which has very similar results to the sub-group) and is 21% and 17% respectively.

Reliability

Internal Consistency: Cronbach's α on the sub-group of 13-18 year olds for all 25 items in the instrument was $\alpha = 0.913$, indicating some redundancy. For the whole sample, the two factors had $\alpha = 0.883$ and $\alpha = 0.818$ respectively, with all item total correlations > 0.38.

Acceptability

Although response rate is an *Indirect Measure* of acceptability, the ADDQOL-Teen's excellent item completion rate of 98% suggests that during development of this particular, age-specific, version of the ADDQOL, the attention to face validity and the subsequent amendments to format and content have worked to overcome potential difficulties of double-stemmed items. Another indirect measure of the ADDQOL-Teen's acceptability to the 'transition' age group is its applicability across paediatric, adolescent, transition and adult clinics. This instrument was applied successfully to a much wider age range than originally intended, i.e. mean age for one centre was 19.

Feasibility

The ADDQOL-Teen's two stem questions and average weighting of items makes this more complex to administer, process and analyse and with some remaining 'N/A' questionnaire response options the psychometric analysis is still challenged.

Future work

Further work assessing reproducibility and responsiveness would make the evaluation more complete.

Diabetes Quality of Life Measure (DQoL)

The DQoL was developed in the USA, in the early 1980s, by Diabetes Control and Complication Trial (DCCT)⁽³⁻⁴⁾ to assess the patient-perceived burden on QoL of two different diabetes treatment regimens/strategies. It is designed to measure patient perception of impact and patient satisfaction with specific features of diabetes treatment. The initial item pool resulted from a review of the literature, expertise of health professionals who were knowledgeable about treatment of diabetes and experiences of patients with type 1 diabetes. Subsequent reviews, of the meaning, the relevance and the readability of the instrument involved: diabetes nurses, physicians, behavioural scientists and patients with type 1 diabetes who also participated in pre-testing. Although, following these reviews, the instrument had been culled of items with peripheral relevance, there was also a domain added, which had not, traditionally, been included in QoL measures. This additional 'Worry' domain is covered by two separate scales.

Description of instrument

There are four primary scales in the DQOL, with a total of 46 core-items which attempt to tap into four different diabetes related perspectives, i.e. respondent's satisfaction with self; impact of treatment; respondent's worry related directly to diabetes and worry about anticipated social/vocational effects (Table 2). In addition to these mostly diabetes-related items, there are 16 auxiliary items which assess general life experience/satisfaction, i.e. schooling experience and family relationships; these extra items are aimed at the adolescent age-group⁽³⁾. The response format of this self-complete instrument, with single stem questions, is largely a 5-point Likert scale, although for its auxiliary 16 items a 4-point Likert scale is used (Table 2).

Population in which instrument is evaluated

The DQOL was evaluated with a 100% type 1 diabetes population (Table 3). There were 21 paediatric centres, across 18 countries, within North America, Europe and Asia already participating in the Diabetes Control and Complications Trial (DCCT); these were asked to provide a list of 40 non-DCCT patients and then from these lists to select, randomly, 10 patients to participate in this DQOL study. The 192 who consented to complete the DQOL had a mean age of 28 years, with an age range 13-40 years. Of these, 60 % were male and the average duration of diabetes for these patients was 8 years. For the purposes of evaluation this sample was divided into 2 sub-sets: 136 adults between 18-41 years with a mean age

of 28 years and 56 adolescents between 13-17 years with a mean age of 16 years. Respectively, these sub-sets were 60% and 59% male and their average diabetes duration was 8.5 and 6.4 years (Table 3). For the all scales included in the DQOL, the higher the score the lower the patient's QoL.

Instrument properties

Validity

The total DQoL and the four primary scales have undergone extensive psychometric assessment, including a comprehensive testing of construct validity (Table 4).

Face Validity: During development of the DQOL; patients with type 1 diabetes, experienced diabetologists and diabetes nurses reviewed drafts of the instrument with regard to its meanings, relevance and readability.

Content Validity: A literature review was conducted to identify typical concerns of individuals with diabetes and the problems that impacted on their lives. Unlike other QoL measures, the DQOL includes 'worry' scales because concerns or worries have been described as an important way that diabetes can influence the patient and their family. Also taken into account was the clinical experience of health professionals' knowledge about the treatment of diabetes and the life or personal experience of patients who have type 1 diabetes. The initial item pool was culled to select items of most relevance to patients with type 1 diabetes undergoing treatments of different intensities.

Construct Validity: Three external assessment instruments: the Symptom Checklist 90-R (SCL); the Bradburn Affect Balance Scale (ABS); and the Psychosocial Adjustment of Illness Scale (PAIS) were compared to the DQoL total score, as well as the four sub-scales (satisfaction, impact, diabetes worry and social worry). For the adolescent sub-group significant correlation coefficients were found between the satisfaction, impact and total DQoL scores and the SCL, ABS and PAIS scores as expected. The worry scales were most strongly correlated with the measures of psychological distress, also as expected.

Reliability

The DQoL is a very reliable scale.

Internal Consistency: Cronbach's α for an adolescent sub-group was $\alpha = 0.92$ (full scale), $\alpha = 0.86$ (satisfaction sub-scale), $\alpha = 0.85$ (impact sub-scale), $\alpha = 0.66$ (diabetes worry sub-scale) and $\alpha = 0.87$ (social worry sub-scale).

Reproducibility: Test-retest correlation coefficients for an adolescent sub-group were $\rho = 0.92$ (full scale), $\rho = 0.86$ (satisfaction sub-scale), $\rho = 0.89$ (impact sub-scale), $\rho = 0.88$ (diabetes worry sub-scale) and $\rho = 0.88$ (social worry sub-scale).

Acceptability

The reported time to complete the DQOL (15-20 minutes) is longer than that estimated for later diabetes-specific instruments. However, 99% of respondents provided complete data, which is an extremely high completion rate and, in the absence of any direct measure, offers a very positive indirect indicator of its acceptability.

Feasibility

Although the DQOL's number of items is large (62 in total), the conventional formatting of the instrument makes it a convenient and reliable method of assessment and with relatively easy administration, processing and analysis, its feasibility is assured.

Future work

Outstanding evaluative work on the DQOL includes assessment: 1) with more heterogeneous patient samples, 2) of its responsiveness and 3) of its predictive validity.

Diabetes Quality of Life Measure modified for Youth (DQoLY)

The DQoLY is a modification of the original DQOL, adapted specifically for adolescent and older-child populations. A review by specialists in paediatric diabetes care: a diabetologist; nurse practitioner and social worker led to the removal of items of limited value to young people whilst items related to school-life and peers were added. Pilot testing with a small group of 11-18 year olds led to the simplification of wording and improved readability.

Description of instrument

The initial DQoLY has three scales rather than the four associated with the DQOL from which it is derived (Table 2). Following assessment of internal consistency, uncorrelated items were removed from the disease impact scale, reducing its 26 items to 23 and from the disease-related worries scale, with a reduction of 13 items to 11. For the Life Satisfaction scale all 17 items contributed to overall scale variance so no items were removed. In total the DQoLY has ten less items; it has 51 plus a single self-rated overall health item by comparison to the 62 items of the DQOL. The revised DQoLY clearly defines its total of 41 diabetes-related items from its 10 general life-satisfaction items and its single general self-rated health perception item. In the DQoLY, the scoring of the health-perception question is inverted to assist analysis, i.e. the higher the score the more positive rating of personal health⁽⁵⁾.

Population in which instrument is evaluated

The DQOLY was evaluated with a sample of 100% patients with type 1 diabetes, taken from a single paediatric centre in the USA. This was the only paediatric hospital in the state of Indiana and purports to serve a broad range of patients in terms of ethnic and social backgrounds. The 74 type 1 diabetes patients, of whom 62% were male, and whose average duration of diabetes was 5.6 years, had a mean age of 16 years, ranging between 10 and 21 (Table 3).

Instrument properties

Validity

The DQoLY is also a well validated instrument (Table 4).

Face Validity: The original DQOL items were reviewed by paediatric specialists.

Content Validity: Following interviews with healthcare professionals in paediatric diabetes care (paediatric diabetologists; nurse practitioners and social workers) a consensus was reached. This resulted in both the removal of items thought to be of limited value for children, e.g. 'How often do you worry about whether you will be denied insurance?' and the addition of items related to school life and peers. However, the opinions of teenagers themselves were not sought directly.

Construct Validity: The three sub-scales in DQoLY (satisfaction, impact and worries) were not found to be statistically independent. Inter-scale correlations were all highly significant ($p < 0.001$). All three scales were predictive of self-related health status in the direction expected (i.e. disease-related impact and disease-related worries were inversely related to health status and diabetes life satisfaction was positively related). The three scales in combination gave a multiple correlation of $r = 0.54$ and accounted for 29% of the variance in self-reported health status.

Reliability

Internal Consistency: Cronbach's α for satisfaction sub-scale was $\alpha = 0.85$, for the impact sub-scale $\alpha = 0.83$ and for the worries sub-scale $\alpha = 0.82$.

Acceptability

The instrument retains a 5-point Likert scale response format for all the 41 diabetes-related items. For all items in the revised satisfaction with life scale, where the DQoL had used a 7-point Likert scale, the DQoLY introduces the same 5-point Likert scale for simplicity. Furthermore, the DQoLY aligns negative responses throughout the instrument. Standardising the response format to a 5-point Likert scale throughout the DQoLY resulted from pilot testing the DQoL with a random sample of 15 youths (ages 11-18). An additional increase in acceptability, resultant from this pilot testing, via adjustment to the original DQoL, was the simplification of the instrument's wording of items to facilitate readability.

Feasibility

The DQoLY's reduced number of items and simpler structure and scoring facilitate administration, processing and analysis. By comparison to the original DQoL, the DQoLY has simpler language, simpler scoring and has ten less items.

Future work

Further validation is required with a much larger sample. The finding that, for this age group, HbA1c does not correlate with QoL is worthy of further exploration.

Diabetes Quality of Life Measure - Short Form (DQoLY-SF)

This revised short-form version of the DQoLY was evaluated within a DCCT sample population of 2077 young people with diabetes. Subsequent development of DQoLY-SF resulted in three new factor solutions or DQoLY models. The new six factor solution, which was the 'best-fit model', had better construct validity, than the previous DQoLY and two other new models. This revised short-form version of the DQoLY⁽⁶⁾ was developed in the UK in collaboration with Denmark.

Description of instrument

Although this short-form of the instrument has only 39 items, its number of scales (n=6) is greater than that of its two predecessors, the DQoL (n=4) and the DQoLY (n=3) (Table 2). The DQoLY-SF retains the largest scale, common to the DQoL and DQoLY; here the satisfaction scale still retains 17 items, but show the scale as being more accurately represented as a single rather than the dual scale. The worries scale, which becomes 'future worries' rather than 'diabetes-related', is reduced from 11 to 7 items and the total items of the impact scale is reduced from 23 to 14 items but separated into 3 short impact scales plus a 'parental control' scale. The latter scale has three items, as do the 'impact of treatment' and 'symptom impact' scales, with the 'impact on activities' scale having five items. The DQoLY-SF, like the DQoLY, has a single health perception item. This instrument also retains the 5-point and 4-point Likert scoring scales of the DQoLY.

Population in which instrument is evaluated

All three DQoL instruments had populations who were 100% type 1 diabetes and they all recruited via the DCCT. The DQoLY had the smallest sample size (n=74) recruiting from just one paediatric centre but the DQoL and DQoLY-SF, both recruited from paediatric centres across 18 countries within North America, Europe and Asia. Although the response rates for

both the DQoLY-SF and the DQoL were well above 90%, the actual number of respondents for the DQoLY-SF was far greater (n=2101) than that of the DQoL (n=192). The DQoLY-SF sample had a mean age of 14.3 years, with an age range 10-18 years. The sample was fairly even in terms of gender (52 % were male) and the average duration of diabetes for these patients was 5.8 years (Table 3). The findings of this large DQoLY-SF evaluation were not published until 2006, almost 15 years after those of the DQoLY and a couple of years after those of the ADDQoL-Teen. During the development of both of these diabetes-specific instruments, DQoLY and ADDQoL-Teen, it was acknowledged that adolescents were different to both children and adults (as they have different needs) and that they needed to be measured differently.

Instrument properties

Validity

The DQoLY-SF is a very well validated instrument (Table 4).

Face Validity: The DQoLY-SF relies largely on work done previously to the DQoL and DQoLY instruments.

Content Validity: See above

Construct Validity: Exploratory factor analysis produced three possible models of a revised questionnaire (two with four factors and one with six factors), with confirmatory factor analysis (using structural equation modelling) identifying the six factor model as the best fitting (the CFI, NFI and RMSEA indices all indicated a good fit). While the revised version of DQoLY is distinctly shorter than the original, the scales seem to correlate well. The future worries scale correlated 0.95 with the full worry scale from DQoLY. The modified impact scale correlated significantly with DQoLY's impact scale. Combining the three impact scales with the parental concerns scale, a correlation with the original DQoLY impact score of 0.92 was obtained.

Reliability

The DQoL-SF is a reliable instrument.

Internal Consistency: Cronbach's α for the three impact scales combined was $\alpha = 0.79$, for the parental control scale $\alpha = 0.78$ and for the future worries scale $\alpha = 0.83$.

Acceptability

The acceptability of the DQoLY-SF is indicated indirectly by an exceptional completion rate of 99% with 2,077 respondents out of 2,101 recruits returning completed data.

Feasibility

The DQoLY-SF has the same Likert scoring scales as the improved DQoLY. It is also shorter, with more distinct domains than its predecessors. It is easy to administer, process and analyse. It is suggested that even though it is shorter than DQoLY and DQoL, it could be shortened yet further by using only the treatment part of satisfaction scale and therefore keeping all items specific to diabetes.

Future work

The DQoLY-SF is shorter than DQoLY and DQoL, but it could be shortened further by using the treatment satisfaction scale only, therefore keeping all items specific to diabetes. Further shortening the DQoLY-SF would serve to increase the acceptability and feasibility of the instrument.

Here papers 6 and 7 are considered together.

Paediatric QoL Inventory™ (PedsQL™) Version 4.0 and 3.0

PedsQL™ 4.0 and 3.0 were designed, in the USA with the aim of integrating the merits of generic and disease-specific instruments⁽⁷⁾ measuring health-related quality of life (HRQoL). This two part instrument was the first multi-dimensional instrument for the age group of 2-18 years with both self-report and parent proxy-report. The first part of the instrument, the PedsQL™ 4.0, is the generic core measure designed for integration with a range of disease-specific modules. The second part, the PedsQL™ 3.0, is the add-on module for type 1 diabetes. Key characteristics of the PedsQL™ 4.0 are its brevity, its age-appropriate versions and its parent-proxy option.

Not long after the original US version was evaluated, a UK-English version of the PedsQL™ 4.0 was developed and evaluated⁽⁸⁾. The development of the UK-English version of the generic instrument involved three experienced psychologists who made preliminary changes to the original PedsQL™ 4.0. These were then reviewed and further modifications suggested by one of the designers of the original instrument, Professor Varni. Further changes were made after 13 parents and 22 children had completed the revised questionnaire and provided feedback about items and response ratings.

Description of instrument

The PedsQL™ 4.0 + 3.0 is a 2 part instrument. Its generic component, PedsQL™ 4.0, includes four scales with 23 items, whilst its diabetes module PedsQL™ 3.0, which is slightly longer, includes five scales with 28 items

(Table 2). Both scales use a 5-point Likert scale and despite the number of items it takes only 5-10 minutes to complete (Table 2). The UK-English version of the PedsQL™ 4.0 represents a modified version of the original generic instrument, the US PedsQL™ 4.0. Changes are restricted to the finer details (culturally specific) so that the number of items and scales and the response format are not changed (Table 2).

Population in which instrument is evaluated

The original US PedsQL™ 4.0 + 3.0 are evaluated with a child plus parent population, which in total included 328 respondents (Table 3). Respondents were recruited in the USA across two sites at a paediatric office, diabetes clinic and at hospital in-patients and out-patients. Of completed responses, 85% (n=279) were paired child/self-report and parent-proxy and 91% (n=299) of the total responses were child/self-report only. Of the total responses, 9% (n=29) were parent-proxy only. The mean age and age ranges for the paired child/parent and child only responses were 13, 2-18 years and 14, 5-18 years respectively. 73% of the total respondent-reports were for type 1 diabetes patients. Males represented 45% of respondents.

The UK-English version was evaluated with 1399 children (self report) and 970 of their parents (Table 3). Healthy respondents were recruited from 23 schools across South Wales in the UK. Children with chronic conditions were identified via patient records. Responses for children who were healthy included 1034 self-reports and 665 parent-proxies. For those with diabetes there were 124 completed self-reports and 103 proxy-reports. The combined total for other chronic conditions was 241 completed self-reports and 202 proxy-reports. All questionnaires were completed under the supervision of a researcher and both verbal and written information was provided. The self-report questionnaires were completed in classrooms at 23 schools and the parent proxy questionnaires were sent to parents, from school, for home or clinic completion. The child's mean age for self-report was 13 years and for parent proxy 12 years. For both these groups the age range was 8-18 years and the percentage of males was very similar for both self-report and parent-proxy, at 49% and 47% respectively.

Instrument properties

Validity

The PedsQL™ 4.0 + 3.0 is a well validated instrument (Table 4).

Face Validity: The US PedsQL™ 4.0 + 3.0 underwent both pre-testing and field-testing measurement development protocols. Early development of the UK-English version of the PedsQL™ 4.0 used professional input from experienced psychologists and feedback from one of the instruments designers, Dr Varni. Following administration of the revised version, cognitive interviews were used for feedback about patients' and parents'

interpretation and understanding of items. On the basis of this and of response rates, further changes were made.

Content Validity: The US PedsQL™ 4.0 + 3.0 employed a range of means to ensure content validity. Both used focus groups, pre-testing and field-testing measurement development protocols and cognitive feedback interviews. For the PedsQL™3.0, a literature review was also carried out.

Construct Validity: Construct validity was indicated for the US PedsQL™ 4.0 + 3.0 by convergent validity, where the generic part of the instrument was compared with diabetes specific module. This produced high inter-correlation results for self-report ($r=0.66$) and for proxy-report ($r=0.54$). Strength of association with other scales ranged between medium and large, with coefficients between 0.35 and 0.66. Construct validity was indicated for the UK-English version of the PedsQL™ 4.0 by discriminant validity, which compared HRQoL with gender and across chronic health conditions using multivariate analysis of variance. For self-report, there were significant differences in reported HRQoL between males and females ($p=0.003$) and across the chronic health conditions ($p<0.001$). For proxy-report, significant differences were reported across the chronic health conditions ($p<0.001$).

Responsiveness: Some evidence of sensitivity is reported but not quantified (de Witt). However, this is only for the US version.

Reliability

There is reasonable evidence to show that the PedsQL instrument is reliable.

Internal Consistency: Cronbach's α for the PedsQL generic core scale was $\alpha = 0.88$ for self-report and $\alpha = 0.89$ for proxy-report. For diabetes module scales the average α for self-report was 0.71, and for proxy-report was 0.77.

Acceptability

For both versions of PedsQL™ 4.0 and 3.0, direct measures of accessibility were made. In both cases, there was an assessment of respondent views via pre-testing and field testing with feedback and cognitive interviews. Indirect measures for the US integrated and UK generic are represented by short completion times (5-10 minutes and 5 minutes respectively), clear presentation format, clearly set-out administration guidelines and, as questionnaires are given face-to-face, there are also verbal instructions. Both versions also benefit from the options of administration face-to-face, by telephone or by post. This results in the minimisation of missing responses and maximisation of response rates. For the US integrated version, PedsQL™ 4.0 + 3.0, response rates were 94% for parents and 91% for children. For the UK-English PedsQL™ 4.0 version, where the sample population was far greater, the response rates were not as high. For parents the response rate was 56% and for children 80%. The larger response rate for children may be accounted for by some administration occurring at schools.

Feasibility

While it was proven in US and in UK that the instrument was easy to apply face-to-face, by telephone or by post, the latter is a less time consuming form of administration. This instrument shows that clinical and human function are relatively independent and so HRQoL tools such as this one are very important to inform clinical practice.

Future work

The instrument requires an evaluation of its reproducibility and responsiveness.

Group 2 - Self-Efficacy

There are three instruments from five papers which contribute to the self-efficacy component of the survey instrument. These instruments will now be considered in turn.

Diabetes Management Self-Efficacy Scale for Adolescents with Type 1 Diabetes (DMSES)

DMSES measures diabetes management self-efficacy in adolescents with type 1 diabetes. It was developed in Belgium and the Netherlands⁽⁹⁾. Initially, self-management items were derived from focus group interviews, informed by the literature, and the diabetes education programme of a Belgian hospital. The resultant 30-item instrument was sent to five Dutch experts involved in the wider project and five newly recruited experts. These ten experts were asked to rate the relevance of items on a 4-point scale (from 1=not relevant at all to 4=very relevant). All items rated as 3 or 4 by eight or more experts were retained. Experts were asked to make comments and suggestions on existing items and generate new ones for those aspects of self-management that they felt were missing.

Description of instrument

This single-index instrument has 26 items and uses a 5-point Likert response format. The instrument is easy to administer and easy to use so, although it is not reported, the completion time for this instrument should not be long (Table 2).

Population in which instrument is evaluated

This instrument was evaluated with a convenience sample of 130 adolescents with type 1 diabetes, who were being treated in five different hospitals in Belgium and the Netherlands. Although there was a response rate of 70% (n=90), six response forms were not usable leaving only 84 complete responses for evaluation (Table 3). The respondents were 43%

male, with a mean age of 14.6 years (range 12-18 years), and a mean duration of illness of 5.8 years.

Instrument properties

Validity

Details of the validity and reliability of measures from groups 2, 3 and 4 can be viewed in Table 5.

Face Validity: Focus group interviews with adolescents with type 1 diabetes, which used information from the literature and the diabetes education programme of a Belgian hospital, identified the most relevant tasks in diabetes management for adolescents, the complexity of these tasks and the challenges such tasks posed.

Content Validity: Based on the scoring of nine out of ten expert judges (one did not score) the content validity index (CVI) showed that six out the initial thirty instrument items were scored too low to be included. Four items were removed and two were amended according to the comments/suggestions made by the experts so that a total of 26 items remained.

Construct Validity: Factor Analysis showed a 2 factor solution which explained 33.3% of the variance in scores (factor 1 explained 24.5% and factor 2 explained 8.8%). The correlation between factors was $r = 0.34$. The two factors were interpreted as reflecting the two dimensions of the self-efficacy concept: strength and magnitude. Intra sub-scale correlations of Factor 1 ($r=0.34$) and Factor 2 ($r=0.33$) were not systematically higher than the inter-correlation between the two factors ($r=0.34$). This indicates that, although two factors have been explored here, there is not enough evidence to support the existence of two sub-scales (i.e. a single overall score was more favourable).

Reliability

Internal Consistency: Cronbach's α for the 26-item instrument was $\alpha = 0.86$. The mean inter-item correlation was 0.34. Both of these results indicate that the instrument is reliable as a single overall score.

Acceptability

Although acceptability is not reported directly, the complexity of the items in DMSES was addressed by focus groups at the outset of item generation. This simplification of items, in combination with the good response rate of 70%, implies its acceptability.

Feasibility

This is not reported, but the straightforward format and response scale suggest that in terms of administration, processing and analysis, this should be an easy instrument to utilise. This in turn should enhance clinical utility

via assessment of adolescents' educational needs and evaluation of the effectiveness of the diabetes education programmes.

Future work

Further evaluation is required with a larger sample population, specifically in relation to convergent/divergent validity, criterion validity and responsiveness.

Table 5: The Validity and Reliability of the Instruments from Groups 2 (Self-Efficacy), 3 (Continuity of Care) and 4 (Relationship to Service Provider)

Group	Measure	Validity	Reliability
2	DMSES	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓
	PEI	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓
	PEI Modified	Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓
	PCDS	Construct Validity - ✓	Internal Consistency - ✓
3	DCCS	Face Validity - ✓ Content Validity - ✓ Construct Validity - ✓	Internal Consistency - ✓ Reproducibility - ✓
4	HCCQ	Construct Validity - ✓	Internal Consistency - ✓

Here papers 9 and 10 are evaluated together.

Patient Enablement Instrument (PEI)/PEI Modified

The PEI was a new primary care outcome measure developed in the UK⁽¹⁰⁻¹¹⁾. The measure addresses two areas associated with consultations of particular importance to patients - a feeling of patient-centeredness and empowerment and an ability to understand and cope with illness/health. In combination these themes (termed 'enablement') are considered to be

complementary but quite different from satisfaction. During its development, the PEI was compared against two existing satisfaction scales to test whether 'enablement' and 'satisfaction' were related constructs and whether the PEI instrument's internal consistency could be enhanced by inclusion of satisfaction items⁽¹⁰⁾. The subsequent PEI modified⁽¹¹⁾, adapts the original scale with a minor change in the opening statement. This modified scale has been adapted for use with chronic-condition/asthmatic patients and has been evaluated with this population.

Description of instrument

The PEI is a self-complete single index instrument with six items and three Likert-type anchors, e.g. 'much better/much more'; 'better/more'; 'same or less' (Table 2). The response scale had been altered during early development work, from the more conventional symmetrical to asymmetrical, this was achieved by merging the two responses which were infrequently used: 'same or less' and creating the central response of 'better'. The addition of a fourth response option, 'not applicable', was later evaluated and it was shown that it was useful for 33% of respondents (n=31) who utilised it. The subsequent version of the PEI modified for use in asthma (Table 2) underwent a minor alteration to the introductory statement so that instead of 'As a result of your visit to the doctor today, do you feel you are....', the modified version begins 'As a result of the treatment that you have been on for your asthma, do you feel you are....'. The scoring system for both instruments is the same.

Population in which instrument is evaluated

Single questionnaire forms containing three instruments: Medical Interview Satisfaction Scale (MISS); Consultation Satisfaction Questionnaire (CSQ) and the new PEI, were given to 818 general practice patients who were attending routine surgery consultations in three different urban areas. There is no detail about this sample population other than it is of a varied socio-economic mix. It includes patients with both acute and chronic conditions (Table 3). There was a response rate of 74.9% and all of the 613 forms that were returned, including parent-proxy responses, were used to evaluate whether 'enablement' was an independent construct or whether it is related to 'satisfaction'. The PEI modified for chronic conditions was evaluated specifically with asthmatic patients taking part in a trial comparing patients on different treatment plans. This sample of 228 patients from across 72 general practice surgeries was 49% male and included respondents with a mean age of 51 years (Table 3).

Instrument properties

Validity

Face Validity: The themes which informed the identification of items were derived from conducting a literature review of patient satisfaction,

discussions with local patient-representative agencies and semi-structured interviews with patients. This is an attempt to identify what is important to patients rather than just/only to health professionals. However, for the modified PEI version there has been no direct enquiry as to the patients' views of what constitutes 'enablement' in the long-term management of asthma.

Content Validity: The six PEI items were taken from a larger instrument which measured satisfaction. The items were derived from a literature review on patients' well-being, enablement and empowerment. The PEI items were piloted in small studies in an Edinburgh GP surgery and patients were interviewed following their consultations to see if the instrument seemed to match-up with patients' experiences.

Construct Validity: Statistically significant correlations between the PEI and the two satisfaction scales (MISS and CSQ) were found. However, none of the correlations exceeded 0.53, suggesting that PEI measures a concept different from, but related to general satisfaction. The PEI modified, when compared with the Mini Asthma Quality of Life Questionnaire (Mini AQLQ), had a non-significant correlation of $\rho = 0.13$, indicating that PEI measures a different construct to that of a QoL measure.

Responsiveness: No reported evidence.

Reliability

Internal Consistency: Cronbach's α was 0.925, giving good justification for the representation of the PEI as a single index. For the PEI modified, Cronbach's α for the full scale was 0.92, indicating some redundancy.

Acceptability

There are a number of indirect measures which indicate the acceptability of both versions of the PEI. It is a very short instrument, only half a page in length; it has a simple response scale and clear response format. Cumulatively, these features facilitate its quick completion, taking only a few seconds to complete. Another indirect measure indicating acceptability of the PEI is the response/completion rate for the original PEI of 74.9%, ($n=613$). The modified PEI only reports the number of completed responses across 72 general practices, but not the actual number of people in the full-sample approached. Direct measures of acceptability include, for the original PEI, respondent views about the validity (i.e. the importance of the items to the respondents). Here, during piloting, patients were interviewed following their consultations to see if the instrument seemed to match-up with their experiences.

Feasibility

The instrument is very easy to administer, process and analyse despite the inclusion of the 'N/A' response. The 'N/A' response option can sometimes challenge psychometric analyses but, in this case, its early evaluation had established that this item had no negative effect and so the processing and analysis of this tool was straightforward.

Future work

Following evaluation of the PEI it was felt that more work needed to be done to identify the factors that contribute to some patients being 'enabled' but not 'satisfied' and vice versa.

Perceived Competence for Diabetes Scale (PCDS)

The PCDS is adapted from the generic Perceived Competence Scale (PCS), which utilises constructs closely related to self-efficacy⁽¹²⁾. The PCS is a short instrument designed to assess participants' feelings (or perceptions) of their own competence to engage in an activity (e.g. learning; interpersonal relations; healthy behaviour etc). The PCS is designed to be adapted to measure the specific behaviour under study (i.e. in the case of this study the PCDS, or Perceived Competence for Diabetes (Management), has been adapted to assess an individual's perceived competence/self-efficacy in the management of their diabetes).

Description of instrument

The PCDS slightly adapts the item stems of the generic PCS (Perceived Competence Scale): 'I feel confident in my ability to....' to 'I now feel capable of.....'; 'I am able to.....' to 'I feel able to meet the challenge of....'. The PCDS, whose completed items specifically assess the degree of confidence about being able to make (or maintain) a change to carry out a diabetes treatment regimen, retains four items in its adapted scales (Table 2). These self-complete instruments each use a 7-point Likert scoring scale, which is simple to process and analyse since an individual's score is simply the average of his or her responses on the four items (Table 2).

Population in which instrument is evaluated

The PCDS was evaluated in the USA with a sample of 128 patients with diabetes, of whom 37% had type 1 diabetes. These patients were recruited from a diabetes centre at a university-affiliated community hospital. Their mean age was 55 years (range 18-80), with a mean disease duration of 14 years. 44% of these patients were male (Table 3).

Instrument properties

Validity

Face Validity: Not reported directly.

Content Validity: As above.

Construct Validity: Perceived competence was significantly negatively related to HbA_{1c} at all three time points ($r = -0.35$, $p < 0.001$ at T1; -0.36 , $p < 0.001$ at T2; and -0.26 , $p < 0.01$ at T3). Using multiple regression analysis, it was found that an increase in perceived competence at time point 2 significantly decreased the HbA_{1c} score at time point 3 ($B = -0.31$, $p < 0.001$).

Reliability

Internal Consistency: Cronbach's α for three different time points were 0.85, 0.87 and 0.84 respectively.

Acceptability

Not reported but it is a very short scale with only four items. The 86% completion rate is an indirect indication of its acceptability.

Feasibility

Not reported, but the very short PCDS seems straightforward to administer, process and analyse with very little training required.

Future work

The PCDS was related to 'autonomous reasons' and HbA_{1c}. However, limitations of this study include 1) a sample that was self-selected and 2) a modest sample size for regression analysis ($n = 128$). There is no reported face or content validity.

Group 3 - Continuity of Care

Diabetes Continuity of Care Scale (DCCS)

The DCCS was developed in Canada to determine patients' perception of continuity of care⁽¹³⁾. Item generation began by holding focus groups with participants. Transcripts were coded by two research team members and potential items were categorised into groups. Three reviewers checked the items and removed duplicates; they also determined the instrument's domains. Five patients were asked to read and explain each item on the scale, two health educators also provided feedback on language and readability. Four diabetes experts checked for clinical sensibility. Finally, three reviewers determined further changes by consensus.

Description of instrument

The DCCS instrument has five scales and 47 items each using 5-point Likert scales⁽¹³⁾. These five scales and their items are: access to care ($n=10$); care by doctor ($n=13$); care by other healthcare professional ($n=12$); communication between healthcare professionals ($n=6$) and self-care ($n=7$) (Table 2).

Population in which instrument is evaluated

There was notable emphasis placed on face and content validity during phase 1 (item-generation development), with input from the patient sample (n=46) via seven focus groups far outweighing that of healthcare practitioners (n=18), who were involved in only two focus groups. The patients involved in phase 1 had a mean age of 59 years, 46% of whom were male (Table 3). Phase 2 was concerned with scale domains, reliability and validity testing and included a small Canadian population of 60 patients recruited at the Group Health Centre (GHC), Canada. These patients had a mean age of 61 years, 57% of whom were male. Their disease duration was 11.3 years and only 12% were people with type 1 diabetes (Table 3).

Instrument properties

Validity

The DCCS is a well validated instrument. Patients from the same population as those who attended focus groups completed five other questionnaires in order to test the validity of the DCCS. The other questionnaires were: (1) the Components of Primary Care Instrument (CPCI); (2) the Perceived Involvement in Care Scale (PICS); (3) the Quality of Care Scale (QOCS) and (5) a five-point general satisfaction question.

Face Validity: Face validity is tested by asking five patients to read and explain the meaning of each item on the scale. A Flesch-Kinkaid assessment of reading ease is used. Four experts compared items to a questionnaire on 'clinical sensibility' and made suggestions regarding the relevance of certain items.

Content Validity: Derived from focus groups with patients (n=46) and practitioners (n=18), the instrument was reduced into specific and homogeneous domains.

Construct Validity: Total DCCS scores were correlated moderately with the CPCI and satisfaction scales (0.56, $p < 0.01$ and 0.32 $p < 0.05$ respectively). Total DCCS scores did not correlate well with the PICS or QOCS scales (0.17 and 0.16 respectively). The DCCS was able to discriminate (in the directions anticipated) between the indicators from the Good Health Outcomes in Diabetes (GHOD) Index (i.e. low scores on the DCCS meant lower scores on the GHOD Index and vice versa). DCCS scores were significantly lower in patients who did not have an HbA1c test or foot exam done within 6 months. DCCS scores were also lower in those patients who did not have their albumin and proteinuria checked at one year.

Reliability

Internal Consistency: Cronbach's α for the 47 items is $\alpha = 0.89$

Reproducibility: Test-retest reliability for the total DCCS score after a two week interval was $\rho = 0.73$. All 5 domain scores were moderately or well

correlated between times 1 and 2 (correlation coefficients ranged from 0.59 to 0.73).

Acceptability

Although the DCCS has 47 items and its format is not very clear, with relatively small font size spread over one and half pages, it does have a simple 5-point Likert scale and its accessibility and acceptability has been indicated when, at time 2 in the test-retest, there were 95% completed responses.

Feasibility

Not reported specifically but the straightforward 5-point Likert scale suggests ease of processing and analysing.

Future work

The small sample size limits the claims of psychometric properties (i.e. reliability and validity). Additionally, there was no test of what constitutes a minimum clinically important difference in DCCS scores. Furthermore, despite heavy involvement of patients during item-generation, their lack of contribution to item-reduction leaves way for an over-influence of researcher perspective.

Group 4 - Relationship to Service Provider (Therapeutic Alliance)

Health Care Climate Questionnaire (HCCQ)

The HCCQ measures participants' perceptions of the degree of autonomy supportiveness of their service provider. The HCCQ is used to assess an individual health professional's interpersonal style, but where there are several health providers (e.g. a consultant, a nurse and a dietician) dealing with a particular problem, the whole team may be assessed.

For current purposes, we are interested in versions of the HCCQ which relate either to diabetes management or to the adolescent age-group. In this review we considered two papers, both testing the validity of relevantly adapted measures of 'autonomy supportiveness'. Of these papers, one has validated the HCCQ with the age-group of interest. Paper 11 uses a 5-item adaptation of the HCCQ⁽¹²⁾, with the target behaviour of 'diabetes management'. However, the sample population is much older than that specified for the study (Table 3). Paper 14 uses the HCCQ again within the 'health-care' domain. A modified, shorter version of the HCCQ (Table 2) is used, and although the target behaviour is not 'diabetes management', but smoking-cessation, since the 'autonomy support' climate is assessed within a healthcare climate and with older school-children (14-18 years, Table 3), this instrument is relevant to this study⁽¹⁴⁾.

Description of instrument

The modified HCCQ is presented potentially as a 6-item questionnaire but both 5-item and 4-item instruments have been used and tested. There is guidance as to the reconstitution of the original HCCQ, that is, which specific six items should be selected from the original 15 item instrument; these are items 1, 2, 4, 7, 10, and 14. Furthermore, when an assessment of the 'interpersonal climate' using the HCCQ is related to a group rather than to an individual service-provider, there is advice as to the appropriate substitute wording (e.g. the word 'providers' or 'practitioners' is substituted for 'physician' or 'doctor'). Scoring of the scale simply entails the averaging of items, with a higher score indicating a higher level of 'perceived autonomy'. In this review we look at two different versions of the HCCQ from papers 11 and 13 which use, respectively, five and four items (Table 2).

Population in which instrument is evaluated

Paper 11 utilised the 5-item HCCQ, evaluating it in the USA alongside the PCDS⁽¹²⁾ with a sample of 128 patients with diabetes, of whom 37% had type 1 diabetes. These patients were recruited from a diabetes centre at a university-affiliated community hospital. Their mean age was 55 years (range 18 - 80years) and the mean duration of diabetes was 14 years. Males accounted for 44% of participants (Table 3).

Paper 13 sampled 300 adolescents attending a suburban high school in a study of autonomy support for smoking cessation.

Instrument properties

Validity

Face Validity: Not directly reported by either paper.

Content Validity: As above.

Construct Validity: For paper 11, HCCQ (autonomy support) was significantly negatively related to HbA1c at T2 and T3 ($r = -0.40$, $p < 0.01$ and $r = -0.21$, $p < 0.05$ respectively). When a hierarchical multiple regression analysis was performed, HCCQ significantly predicted reductions in HbA1c over 12 months (coefficient = -0.13 , $p < 0.05$), accounting for 2% of the variance in the change of HbA1c value. For paper 13, it was found, after controlling for smoking status, that the 'choice' presentation was perceived to be more autonomy supportive than the 'demand' presentation (coefficient = 0.34 , $p < 0.001$). The perceptions of autonomy support did significantly predict a reduction in smoking (coefficient = -0.12 , $p = 0.04$).

Reliability

Internal Consistency: For paper 11, Cronbach's $\alpha = 0.80$. For paper 13, Cronbach's $\alpha = 0.72$, indicating the HCCQ is internally consistent.

Acceptability

The adapted shorter 4-6 item versions of the HCCQ, which retain the straightforward 7-point Likert scale of the original and very clear formatting, appear quick and easy to use. Reported response rates suggest that there have been no major acceptability problems.

The shorter versions of the HCCQ are sometimes an integral part of a larger instrument, and so sit alongside a number of other scales. This is the case for the 5-item and 4-item HCCQs which have been evaluated here.

Response rates for the instruments in which these modified HCCQs have been embedded are, respectively, 86%⁽¹²⁾ and 50-60%⁽¹⁴⁾. Each of these studies has been conducted over time and an attrition rate may be expected. However, the big discrepancy between response rates for the 5-item and 4-item modified versions of the HCCQ may be attributable to the perceived severity of the healthcare issue being examined, than to any difficulty in interpreting the questionnaire items.

There are no direct measures, i.e. feedback from patients or practitioners, about the instrument items reported in any of the papers considered here.

Feasibility

Very simple scoring system with minimal training required. Very short in length for 4 to 15 items with simple 7-point Likert scales, so extremely easy to process and analyse.

Discussion

Ideally, a patient reported outcome measure would be developed with direct input from the intended respondent population. The range of measures reported here varied considerably in the extent to which patients (or where appropriate, parents / carers) have been involved in development.

Measures solely reliant upon professional input may miss domain content which could decrease the validity of the final instrument.

Measures are validated relative to the population in which they are intended to be used. Thus, a measure developed within one culture or setting would require further validation to confirm its suitability for use in another setting. The measures reviewed include those that have been either developed or subsequently evaluated in a UK clinical context. Those that have undergone formal adaptation or assessment would still require some further evidence to confirm their suitable use in UK setting.

The measures reviewed mostly represent a nomothetic approach to assessment with only the ADDQoL introducing personal weightings. Quality of life assessment in the present study was supplemented by the use of the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) an idiographic approach which allows respondents to not only weight domains, but also nominate which domains ('cues') should be considered as relevant to quality of life.

Across all the measures there is much evidence provided about scale validity and reliability. However, there is very little evidence provided about scale responsiveness (which in this review has been summarized under validity, but equally could be presented under its own heading). The design of measures such as ADDQoL which adopt a partially individualised approach may increase sensitivity to change, but for the most part this has still to be demonstrated. Whilst some information is reported about changes over time on the measures, there are no examples of formal responsiveness statistics. Simply reporting that there was improvement or deterioration in scale score over time reveals little about the sensitivity of the scale to clinically important change. The accumulation of further evidence of responsiveness is an outstanding general requirement in this area.

Although a stepped adjectival (verbal) scale descriptor is common across the reviewed scales, different scale anchors and differences in the number of steps make a coordinated and consistent approach to questionnaire form construction more difficult to achieve. Modifications to response scale format can help with a consistent 'look and feel' to an integrated package of scales, and would ideally benefit from pilot work to evaluate the impact of such modifications.

Finally, although reported response (form) and completion (item) rates vary between scales, this is likely to be driven as much by the study design within which data were collected, as by the design of the scale.

Selection of scales for use in the Transitions Study

The selection of instruments for use in this study took into account the setting within which scale validity data were accrued. All of the quality of life scales had involved evaluation within populations of patients with diabetes. The Teen and Youth versions of the ADDQoL and the DQOLY respectively had been evaluated in a highly relevant age group (aged 10-22 years, including respondents to both original and short versions). The PedsQL had also been evaluated in younger children but not in respondents over 18 years old. The shortened versions of the DQOLY and the teen version of the ADDQoL and PedsQL had all been evaluated in UK samples. All scales considered consisted of a moderate number of items, involved self-completion and reported completion times ranged from under 10 minutes to 20 minutes. All scales had evidence for validity and reliability but not for responsiveness. The selected quality of life instrument, the DQOLY-SF, is brief has been developed and well validated in the UK, has an excellent completion rate and has undergone extended assessment of construct validity and differentiation into separate sub-scales.

The non-quality of life scales reviewed vary much more in terms of their relevance to the population of young people experiencing a transition in diabetes care. The DMSES, the PCDS, the DCCS and the HCCQ had not been evaluated in a UK population. The PEI had only been evaluated in a primary care setting, although it is also currently being used in an on-going

UK trial within a teenage diabetes population. Of the various scales, only the DMSES has been reportedly evaluated in an age-relevant group of respondents. The scales vary in the number of constituent items but that reflects the intended scope of the measures. All have supportive data on reliability and validity but little evidence regarding responsiveness. The one measure not chosen amongst the non-quality of life measures, the PCDS, has relatively little evidence for face and content validity and is not as brief as the Patient Enablement Inventory.

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Appendix 4: Summary of scales used in the survey instrument

Patient Scales	Number of items	Minimum Score	Maximum Score	Interpretation Note
HCCQ	8	1	5	Higher scores indicate that patients are more satisfied with the care they receive from their healthcare professional
PEI	6	6	30	Higher scores indicate that patients are more able to live with their diabetes
DMSES	19	19	95	Higher scores indicate that patients are more confident in managing their diabetes themselves
DQoLY: Impact of Treatment	3	3	15	Higher scores indicate that diabetes treatment impacts on quality of life more (negatively)
DQoLY: Symptom Impact	3	3	15	Higher scores indicate that diabetes symptoms impacts on quality of life more (negatively)
DQoLY: Parental Control	3	3	15	Higher scores indicate that parental control impacts on quality of life more (negatively)
DQoLY: Impact on Activities	5	5	25	Higher scores indicate that restriction of activities due to diabetes impacts on quality of life more (negatively)
DQoLY: Satisfaction	17	17	85	Higher scores indicate a higher satisfaction with patients lives and treatment.

Carer Scales	Number of items	Minimum Score	Maximum Score	Interpretation Note
HCCQ	8	1	5	Higher scores indicate that carers are more satisfied with the care their child receives from their healthcare professional
PCDS	4	1	5	Higher scores indicate that carers are more confident with their child's ability to manage their diabetes
SF36: General health	5	0	100	Higher scores indicate better general health
SF36: Physical functioning	10	0	100	Higher scores indicate better physical functioning
SF36: Role physical	4	0	100	Higher scores indicate better role-physical functioning
SF36: Role emotional	3	0	100	Higher scores indicate better role-emotional functioning
SF36: Social functioning	2	0	100	Higher scores indicate better social functioning
SF36: Bodily pain	2	0	100	Higher scores indicate lack of bodily pain
SF36: Vitality	4	0	100	Higher scores indicate better vitality
SF36: Mental Health	5	0	100	Higher scores indicate better mental health

Appendix 5: Living a life with diabetes: an ecology of diabetes care

interviews relating to young people and their carers' experiences of living a life with diabetes. These are presented as context for the specific model evaluations. Understanding the experiences of young people and their parents of living a life with diabetes helps us to understand their perceptions of and preferences for transition models.

Diagnosis

The diagnosis of a child with diabetes has a devastating effect on families. Parents' offered rich and detailed accounts of diagnosis and its impact. These typically included expressions of guilt for being responsible for the condition and/or for a failure to recognise the symptoms of the disease. Many also described initial shock at the requirements of living with the disease and being over-whelmed by the volume of information offered following diagnosis. The support of healthcare staff at this time is highly valued and families developed a singular relationship with the individuals involved.

Self, life and diabetes

In all five models there was a strong ethos of normalisation with families strongly encouraged to live a normal life. In contrast with the large body of social sciences literature on chronic illness which has focused on its stigmatising effects (1-3), the majority of young people maintained that having diabetes had not impacted negatively on their sense of self and their main concern was to live their lives whilst minimising its intrusions. This concurs with the findings of Adams *et al.* who argue that chronic illness only results in a diminished self if an individual is unable to reconcile their identities as a bearer of a chronic condition with other social identities (4). Only a small number of respondents described curtailing their activities on account of diabetes; more often, both young people and their carers offered examples of events in which they had participated in life unfettered by diabetes.

"[H]e went through cubs and scouts and he used to go off and do camps, overnight stays and things like that." [4-C16]

"[H]e was ill sort of the end of November, beginning of December and then in March he went skiing and we left him in ski school albeit my husband watched from afar but we were determined that he was going to do that and so I mean we've not let it stop him doing anything." [5-C41]

Alongside these stories of normalisation, there were also stories of constraint, but these were presented as the exception rather than the rule.

In all of these cases, constraints on living a normal life were portrayed as external to the young person and their family.

"[P]eople were a bit wary about having him round to stay obviously because they had concerns of their own about whether they could cope with a child with this type of condition and lots of myths around." [4-C16]

"[S]he was due to go on a school trip to Holland, and it's true to say that this was very early on, she'd only just been released from hospital, CONP and PDSN were very happy for her to go, the school weren't." [4-C52]

Normalisation did not entail denying their condition, but adopting strategies for management which incorporated diabetes into the rhythms and routines of normal life and kept diabetes in the background.

"[I]t's not like it controls my life [...] I know I can just be like normal and [...] it kind of takes a back seat and lets me get on with my life." [1-YP148]

"[Y]ou do have to think constantly about it but not loud thinking, just sort of quietly thinking about." [4-YP49]

Nevertheless, many respondents also pointed to the tedium of self-management and the need for planning to ensure diabetes did not prevent full participation in everyday life.

"[I]t hasn't really restricted me that much [...] but it can be like a pain sometimes when I have to go and do my injection." [1-YP179]

Furthermore, illness, stress and changes in routine can cause diabetes to surface and make its presence felt more acutely.

"Generally I don't mind it, most of the time it just seems like I've always had it but sometimes when I'm at sleepovers and things I just think oh I wish I didn't have to worry about that." [4-YP50]

"[Y]ou just notice that it's when you want to do something spontaneously." [4-C91]

Within this overall picture, several respondents pointed to episodes of frustration with the condition and pointed to the need to take some time off from diabetes. This has been acknowledged in the literature on adults with diabetes (5) and was acknowledged by some, but not all parents, as an acceptable strategy in order to enable their child to live a normal life.

"I manage it quite well but obviously I do have days when I'm like oh I can't be bothered, you know checking my sugar or yeah I'm going to eat chocolate." [3-YP79]

"I was on holiday [...] just sort of letting go and having fun and not, well not really thinking oh I need to eat now, I need to have my injection now, I need to do this now. [...] I want to have fun on holiday I don't want to be 24/7 thinking oh I need to do this, I need to do that." [5-YP40]

"[I]f he goes away for a couple of days on his Duke of Edinburgh or something then I think [...] I would rather he was running a bit too high

for the week he's away or two days or whatever because I think that's just less aggravation for all concerned. And I suppose I feel well if he's running at fifteen for three days it's not going to be the end of the world and that's that." [5-C63]

In childhood parents are deeply involved in their child's diabetes management and care is embedded in family life and domestic routines. With increasing independence, young people face the challenge of managing their condition as life becomes less routinised.

"Well just that they [friends] can go and eat what they want where they want and they can miss meals and things like that but then she's not used to doing that." [2-C66]

"Because like I have to, because I've left school now a lot of people my age like go to bed like five, six in the morning and wake up at two/three in the afternoons and stuff like that but I can't do that." [3-YP82]

Several respondents pointed to the increased flexibility afforded by a four injections a day regime and in all of our models young people were encouraged and supported to move to a regime of multiple injections as they got older.

What emerges from our data is a picture of young people and their families working hard to live unfettered by diabetes. Achieving 'normalisation' however, requires considerable effort. In studying illness trajectories, Corbin and Strauss (6) draw an analytic distinction between illness work, biographical work and every day work. Illness work refers to the activities entailed in managing the condition; every day work refers to normal everyday activities; and biographical work concerns the activity undertaken in defining and maintaining an identity. These different kinds of work have reciprocal impact; changes in one can have important implications for the management of other lines of work. Periods of stability in chronic disease management hinge on keeping these three kinds of work in a balanced and mutual relationship. Whilst this allows for a routinisation of various types of work, because these lines of work take place in the context of daily living, the management of routines are often disrupted by contingencies arising from that living. For most young people, diabetes could be incorporated into daily routines and rituals and whilst ever-present, remained in the background. Situations and events which were departures from the normal rhythm of life brought diabetes into the foreground and as such could be triggers for the expression of frustration and annoyance about the constraints of the condition, although for the most part these were episodic intrusions.

The ecology of diabetes care

Young people's diabetes management is shared between family and friends, who act as supportive agents (7). This division of labour and responsibility changed over time, but even in those cases in which young people had successfully made the transition to 'independent self-management' this was not an entirely individualised activity. Rather, living with diabetes entails

the negotiation and re-negotiation of ecologies of diabetes care across the life-course.

Mothers' role

On entry to the study most young people were responsible for managing injections and monitoring blood glucose levels, but many still had considerable support from parents, even in cases where the young person had left home. The division of parental responsibility for diabetes support was strongly gendered. In one case, an interview was undertaken with a husband and wife together; but in all other cases mothers were identified as the principal carer.

"Yes it's mainly me, well totally me, that works everything out and you know, I mean his Dad goes to clinics with him, but on the day to day management of it, it comes down to me and Tom." [1-C154]

"I think it's more me than my husband unfortunately, because to be honest I don't think my husband would know, because he's on two types of insulin one for evening and one during the day, I don't think my husband would know what was what." [4-C12]

Kevin my husband, he's aware of it but hasn't, aware of it that's the wrong word, he obviously knows all about it, he hasn't got any confidence to make the decisions but that's probably more because I've dealt with it and I was the one in the hospital with her and so that's not because he doesn't want to. He's aware of everything and I do talk to him about it but I think he's in his mind, like a typical man I think, oh somebody else will take the ultimate decision. So if it came down to a problem he would go, well I don't know, what do you think?" [4-C50]

"My husband is just, you know lovely chap, but very, doesn't tend generally to take responsibility for many things, he's just I don't know what it is, they seem to go to work and think oh done all that hard stuff I'll just come home and I won't be in charge of anything. I don't know, I don't feel that my husband has the same knowledge that I have." [5-C45]

For some women the requirement to assume primary responsibility for their child's condition had required personal sacrifices.

"I used to work in London, used to leave the house here at seven and I'd go to London and I'd drop the kids off at nursery when they were little and then come back in the evening so when she was diagnosed [...] that wasn't doable any more so then I got a job locally [...] It is a big difference, you go from a decent salary to, you know, earning thousands a month to earning six hundred pounds a month." [4-C41]

In one of the few qualitative studies into young people, mothers and chronic illness, Williams (2, 8) describes the work undertaken by mothers in supporting the management of their child's condition. According to Williams, there are gendered differences in how young people incorporate chronic illness into their self-identity and this has consequences for how diabetes is managed and the activities mothers undertake in supporting

their child. Williams argues that boys tend to conceal their condition from friends and this requires mothers to undertake considerable work designed to keep diabetes hidden. Our findings confirm that mothers do a great deal to assist their child to live a life with diabetes, but there is no evidence of gender differences. In the following section, we describe the categories of work undertaken by mothers in supporting their child's diabetes management. In so doing, we are following an approach common in sociological studies of work, which concentrates on the work necessary to accomplish a given activity (9). Such an approach facilitates examination of how this ecology of care evolves over time and the associated changes in the division of roles and responsibilities of 'workers'.

Organising

Living a life with diabetes requires high levels of planning and organisation. Mothers played an important role in ensuring that the young person had all the necessary equipment and materials necessary for day-to-day management.

"She carries a bag with the needles and a book and everything for school [...] I just check occasionally perhaps on a Monday that she's got enough stuff in there. [...] When she's going out just saying to her have you got some wine gums in your bag, have you got your insulin pen, you know, it's like things like that to support her." [1-C148]

Diet

Mothers also played a key role in supporting the young person to manage their diet. This entailed ensuring that healthy foods were available within the home and calculating the carbohydrate content of foods.

"When she first went on a new regime she would take packed lunch so I'd do her lunch and then on the foil I'd write three on the orange I'd write one on the little chocolate or something, I'd write two on the box of raisins I'd write one so just to help her." [1-C148]

Mothers' ability to influence their child's diet diminished as young people became more independent of parental control, and in some cases this resulted in tension and or parental anxiety which they often looked to health professionals to resolve.

Monitoring and prompting

Mothers described how they monitored their child's eating and diabetes management and offered prompts to encourage good self-management. Young people recognised the value of this role, although for some this support could slide into nagging.

"I do have to remind her to have snacks now and then, so you'll hear me mid morning, 'it's snack time', so just a little prompt like that. And she'll say to me can I have something for afters and I'll say 'what are your figures like today?' and if they're not too bad then she'll have an afters, if not she won't. So we discuss like that." [4-C50]

Decision-making

Mothers also played a key role in supporting decision-making, acting as a sounding board in situations in which the correct course of action was unclear. Often the young person had independently reached their own decision, but had found reassurance in discussing the proposed course of action with their parent.

"I would double check with my mum say if I had eaten a bowl of pasta or something I would say do I need four units and then she might say oh I'd give five but I would do all of the physical things of it." [4-YP41]

"I'm involved when something is out of the ordinary, if it's the ordinary she just gets on with it, if she thinks something is a bit different to what she's expecting then we'll discuss things with her." [4-C50]

Maintaining a safe environment

Parents played a key role in assisting the young person to maintain a safe environment. At diagnosis this entailed ensuring that members of the young person's key social networks had the information necessary to support their diabetes management and take the appropriate action in an emergency. As new situations were encountered this work was extended with the aim of ensuring that the young person was not prevented from living a normal life.

"Behind the scenes which he probably doesn't realise, there's been a lot of talking with the school, talking with people who've taken on a bit more extra care with the school but it hasn't stopped him doing anything." [5-C41]

"[T]he first times he's been with the orchestra and things like that, I've done a long list and this is what happens, this is what could happen, if this happens do this, if he starts talking absolute rubbish and you can't get him to, get him to a hospital, you know." [5-C22]

Normalisation

The work routinely undertaken by parents in supporting their child's diabetes management was designed to support good diabetic control and good health, but also to ensure that the young person could lead a normal life unencumbered by diabetes. Parents described a whole range of additional support work which was undertaken in order to ensure the life of the young person was unrestricted by their condition, even if this resulted in their own activities being curtailed.

"[S]he didn't like to do her jabs and we didn't make a meal of it thinking fine you know, when you're ready, then even if she went on camp [...] we used to drive, crack of dawn, drive there so she could still go but then we'd give her a jab and then we'd turn round again." [4-C41]

"I mean it wasn't particularly a problem but say for example on Saturday night, you know, Heath had gone to a friends on Saturday you don't really

think anything of it and he was coming back you know, so we didn't, he didn't take his insulin with him because he only has it morning and night and then just things, obviously that impacts on you just in that he phoned up and he said oh mum Meryl has said I can stay for tea, you know, and it's a nine mile drive and you don't want to say no, so I had to take his insulin round so that he could stay for tea, you know things like that." [4-YP91]

Negotiating 'independence'

Adolescence is a time during which young people are negotiating independence from parents, but also independence in relation to their diabetes management. The literature on the transition is founded on a parallel assumption about a transition from dependence to independent diabetes management. In this study, mothers regarded independence to be a positive social value, and acknowledged that achieving this should be an incremental process of a handing over of responsibility for self-care, although not necessarily a withdrawal of all sources of social support. Some parents described this as a conscious-process in which decisions about dependence/independence in relation to diabetes management were balanced with other developmental considerations.

"I mean he does often say to me oh what shall I give myself and I try very hard to say well let's try and work it out, what do we think, what's your blood, what have you got on your plate. So again, trying to get him to work it out and I know he can [...] I don't intend to have a twenty-two year old son who doesn't know how many units he needs when he has a pizza but equally I don't see the need to foist too much on him too early on.[...] So my view is you've just got to edge there and eventually they'll be doing it and I also think you should be a little bit led by them [...] they have to come to things in their own time rather than you sort of foisting it upon them." [5-C45]

Others described the path to independence as a seamless process which had occurred almost organically often in response to the actions of the young person and which was only discernible in retrospect.

"He's always done his own injections, it's just happened really, I used to do all the calculating of doses but that's just, I couldn't even tell you when that changed, I still make the odd suggestion or but he seems to know what his body needs and how much." [5-C42]

It was common for respondents to describe changes in parental involvement as a response to a trigger of some kind: a change from a fixed regime to multiple daily injections, encountering new social situations and transferring to a new clinic.

"Yes well I was too young to deal with it myself really when I was diagnosed so mum did most of the work and then I switched insulin regime as well so that was when I started to become more independent with it and work it out myself." [5-YP22]

"I'd say probably the first four months I did her injections but then she was in a pantomime and I couldn't be there and she let somebody else do it and then she went to do it herself." [3-C82]

Whilst most parents valued independence and believed that letting go was the right thing to do, many described this as a difficult process, particularly if they perceived that their child was not managing their condition as well as it had been when it was under greater parental control.

"I'd be lying if I didn't say I didn't have concerns because it probably bothers me more than it bothers Samuel at the moment because I don't feel that he's taking it seriously enough or maybe I'm just being an over anxious Mum. But at the moment I do feel a little bit as though it's out of my hands, out of my control and he is growing up and he needs to be able to manage his condition without me having to prompt him all the time and maybe he does better when I'm not around I don't know, but when he goes to stay with his Dad he's of a similar opinion, a little bit sloppy. He can be a bit blasé about the whole thing at the moment." [4-C16]

Whilst for some parents stepping back from their child's care was a relatively straight forward process, for others there was a need to adjust to their reduced role with the ecology of diabetes care and the re-alignment of responsibilities that this entailed.

"I suppose for me the difficulty with her being so in control is that I'm not in control at all and so sometimes that makes me feel a little bit nervous if she's not around." [4-C49]

"So at the moment he's, I'm feeling it's a bit out of my control because he's sort of taken over really. [...] I know he's going to have to deal with that himself, but at the moment because I've been so involved in it, you know, it's just a new thing to us in the last couple of months really." [2-C58]

"It's horrible, horrible not being, not that I was in full control before but you know, part of the growing away process which isn't nice anyway for a parent but this is like a more worrying part of it that you know, I don't know what his blood sugars are, I haven't got a clue so." [3-C93]

Friends

In all models it was clear that health professionals had encouraged young people to enrol their friends in their diabetes management. Friends undertook activities that mirrored certain of those undertaken by parents: maintaining a safe environment, monitoring and prompting and normalisation. In their interview accounts, some young people explicitly acknowledged that their friends acted as supportive agents when they moved beyond the surveillance of family. Many cases described strong social networks in which their friends knew what to do if a problem arose.

"If she's having a hypo or anything, oh come on Helen (C26F/Patient) you need a sugary drink and one of [...]((her friends)) will actually take her out and give her a sugary thing." [4-C26F]

"I mean he's got a really, really good group of friends as well [...] if he looked like he was dipping or anything it would be 'Tom come on get yourself sorted' and they'd really chivvy him round." [1-C154M]

Parents of young people who had the support of their friends were given more confidence in the ability of their child to manage their condition away from home. Parents who were uncertain about friends' capacity to provide support expressed concerns about their child's well-being when they were no longer under parental surveillance.

"It's frustrating for me and for my husband because it does worry me that, you know, he goes out and I don't know what he's doing really. Whether he has got something just in case he goes into a hypo and whether his friends even know that he's diabetic half the time. I mean I know his school friends do know, but you know, the mates he goes out with I don't know." [5-C54M]

"I don't think that they [friends] know as much as I'd like them to know. Because they haven't seen her have a bad hypo, they've had one bad case so I don't think, they say they know what to do, but I've never been, I wasn't there when she did have this hypo so I don't know." [2-C66F]

Life-course transitions which necessitate the negotiation of new social networks can disrupt a young person's diabetes support rendering them more vulnerable. This was a source of parental anxiety, particularly for those young people who were preparing to leave home.

"I think it will get harder, I do think ahead to when she goes to university [...] you think oh what about that, you know, when she goes away and that will be difficult I think. If she goes off to a new situation where she hasn't got her friendship group around her, you then worry about if something happens whether someone will know." [4-C49F]

Many of the parents included in the study continued to have high levels of on-going contact with their children even after they had left home and gone to university and several indicated that they were applying to universities near home so that parents could be available to offer support if required.

Summary

In this section of the report we have summarised the main themes arising from the baseline interviews which relate to young people and their parents' experiences of living a life with diabetes. What emerges is a strong normalisation narrative in which young people with diabetes are supported to live a life unfettered by their condition. However, normalisation requires considerable work on the part of the young person, their family and friends. This provides the context for understanding families' experiences of and preferences for transition in each of the five transition models.

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Appendix 6: Model categorisation for regression analysis purposes

	Model 1	Model 2	Model 3	Model 4	Model 5
High levels of Relational/Longitudinal Continuity			√		
High levels of Developmental Continuity	√	√			
High levels of Flexible Continuity			√		√
High levels of Cultural Continuity		√	√		

Appendix 7: Results of regression models

DQoLY: Impact of treatment (n=202)				
Variable	Coefficient	95% CI		P-value
		Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/ teenage clinic	-0.489	-0.834	-0.144	0.005
Adult clinic	-0.165	-0.658	0.329	0.513
Age of YP at baseline	-0.022	-0.071	0.028	0.388
Female (YP)	0.631	0.350	0.911	<0.001
High relational/longitudinal continuity	1.221	0.561	1.881	<0.001
High developmental continuity	0.156	-0.300	0.611	0.503
High flexible continuity	-0.329	-0.771	0.113	0.145
High cultural continuity	-0.602	-1.007	-0.196	0.004

DQoLY: Symptom impact				
(n=201)				
Variable	Coefficient	95% CI		P-value
		Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	0.169	-0.181	0.519	0.343
Adult clinic	-0.187	-0.683	0.309	0.459
Age of YP at baseline	0.024	-0.024	0.071	0.330
Female (YP)	0.308	0.027	0.589	0.032
High relational/longitudinal continuity	1.201	0.536	1.866	<0.001
High developmental continuity	-0.212	-0.672	0.249	0.368
High flexible continuity	-1.297	-1.742	-0.853	<0.001
High cultural continuity	-0.779	-1.186	-0.371	<0.001

DQoLY: Impact on activities				
(n=205)				
Variable	Coefficient	95% CI		P-value
		Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	-0.629	-0.975	-0.282	<0.001
Adult clinic	-0.546	-1.031	-0.062	0.027
Age of YP at baseline	0.132	0.085	0.179	<0.001
Female (YP)	0.326	0.048	0.605	0.022
High relational/longitudinal continuity	0.222	-0.434	0.879	0.507
High developmental continuity	-0.589	-1.042	-0.135	0.011
High flexible continuity	-0.393	-0.833	0.047	0.080
High cultural continuity	-0.750	-1.154	-0.347	<0.001

DQoLY: Parental control				
(n=204)				
Variable	Coefficient	95% CI		P-value
		Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	0.755	0.408	1.102	<0.001
Adult clinic	-0.446	-0.932	0.040	0.072
Age of YP at baseline	-0.090	-0.137	-0.043	<0.001
Female (YP)	-0.520	-0.798	-0.241	<0.001
High relational/longitudinal continuity	2.085	1.424	2.745	<0.001
High developmental continuity	0.619	0.165	1.074	0.008
High flexible continuity	-0.273	-0.707	0.162	0.219
High cultural continuity	-0.047	-0.457	0.363	0.823

DQoLY: Satisfaction		95% CI		P-value
(n=207)		Lower	Upper	
Variable	Coefficient			
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	2.250	1.905	2.594	<0.001
Adult clinic	2.211	1.728	2.694	<0.001
Age of YP at baseline	-0.496	-0.543	-0.450	<0.001
Female (YP)	-4.107	-4.384	-3.831	<0.001
High relational/longitudinal continuity	-1.020	-1.673	-0.367	0.002
High developmental continuity	-1.946	-2.403	-1.489	<0.001
High flexible continuity	1.071	0.631	1.511	<0.001
High cultural continuity	0.977	0.576	1.377	<0.001

HCCQ (cubed)		95% CI		P-value
(n=210)				
Variable	Coefficient	Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	-0.722	-1.064	-0.380	<0.001
Adult clinic	0.330	-0.151	0.812	0.179
Age of YP at baseline	-0.292	-0.339	-0.245	<0.001
Female (YP)	-3.815	-4.089	-3.541	<0.001
High relational/longitudinal continuity	2.598	1.945	3.250	<0.001
High developmental continuity	-1.093	-1.537	-0.648	<0.001
High flexible continuity	3.001	2.571	3.431	<0.001
High cultural continuity	6.455	6.056	6.854	<0.001

DMSES (cubed)		95% CI		P-value
(n=203)		Lower	Upper	
Variable	Coefficient			
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	49617	49616	49617	<0.001
Adult clinic	9876	9875	9876	<0.001
Age of YP at baseline	8264	8264	8264	<0.001
Female (YP)	-51248	-51249	-51248	<0.001
High relational/longitudinal continuity	-122848	- 12284 9	- 12284 8	<0.001
High developmental continuity	-65144	-65145	-65144	<0.001
High flexible continuity	34393	34393	34394	<0.001
High cultural continuity	58269	58269	58270	<0.001

SF36: General health				
(n=198)				
Variable	Coefficient	95% CI		P-value
		Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	4.598	4.248	4.948	<0.001
Adult clinic	5.018	4.527	5.510	<0.001
Age of YP at baseline	-0.500	-0.548	-0.452	<0.001
Female (YP)	-2.348	-2.664	-2.031	<0.001
High relational/longitudinal continuity	-2.410	-3.194	-1.625	<0.001
High developmental continuity	-0.708	-1.122	-0.293	0.001
High flexible continuity	3.716	3.254	4.179	<0.001
High cultural continuity	-0.124	-0.577	0.329	0.591
Does not attend diabetes consultations with child	0.827	0.486	1.167	<0.001

SF36: Vitality				
(n=188)				
Variable	Coefficient	95% CI		P-value
		Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	-2.086	-2.443	-1.730	<0.001
Adult clinic	-4.168	-4.676	-3.659	<0.001
Age of YP at baseline	0.288	0.239	0.337	<0.001
Female (YP)	1.009	0.687	1.331	<0.001
High relational/longitudinal continuity	-2.080	-2.869	-1.290	<0.001
High developmental continuity	3.190	2.763	3.618	<0.001
High flexible continuity	4.488	4.018	4.957	<0.001
High cultural continuity	1.020	0.551	1.490	<0.001
Does not attend diabetes consultations with child	1.565	1.213	1.918	<0.001

SF36: Mental health		95% CI		P-value
(n=198)		Lower	Upper	
Variable	Coefficient			
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	0.609	0.260	0.959	0.001
Adult clinic	-1.816	-2.308	-1.324	<0.001
Age of YP at baseline	0.125	0.077	0.173	<0.001
Female (YP)	-0.159	-0.474	0.156	0.323
High relational/longitudinal continuity	-6.859	-7.635	-6.083	<0.001
High developmental continuity	2.186	1.771	2.601	<0.001
High flexible continuity	5.321	4.855	5.787	<0.001
High cultural continuity	5.432	4.982	5.883	<0.001
Does not attend diabetes consultations with child	2.292	1.950	2.634	<0.001

PCDS (n=193)		95% CI		P- value
Variable	Coefficient	Lower	Upper	
Children's clinic	Reference category for "Where does your child mainly go for their diabetes care?"			
Young person's/teenage clinic	0.152	-0.203	0.507	0.402
Adult clinic	0.201	-0.302	0.704	0.433
Age of YP at baseline	0.046	-0.002	0.095	0.062
Female (YP)	0.002	-0.319	0.322	0.993
High relational/longitudinal continuity	-0.210	-1.012	0.592	0.607
High developmental continuity	-0.212	-0.634	0.209	0.323
High flexible continuity	0.152	-0.315	0.620	0.523
High cultural continuity	0.134	-0.325	0.593	0.567
Does not attend diabetes consultations with child	-0.093	-0.437	0.251	0.597

Appendix 8: Salary costs for NHS roles

role	*rate (£)	frequency
A&E Treatments	111.00 ^a	per treatment
Audiologist	33.00 ^b	per hour
Clinical Psychologist	41.00 ^a	per hour
Dentist	54.00 ^d	per hour
Diabetic Nurse	20.93 ^a	per 15.5min consultation (average length of consultation)
GP	36.00 ^a	per 11.7min surgery consultation
Hospital Admission	269.00 ^c	per inpatient day without surgery
Nephrologist	61.00 ^d	per hr of face-to-face patient contact
NHS Direct	29.00 ^e	per call
Optician	25.00 ^f	per consultation
Paramedic	344.00 ^a	average cost per patient journey for a Paramedic Unit
Physiotherapist	26.00 ^a	per hour
Practice Nurse	11.00 ^a	per 15.5min consultation (average length of consultation)
School Nurse	11.00 ^a	per 15.5min consultation (costed as per 'Practice Nurse')

* Inc. salary, salary oncosts, overheads, capital overheads (and qualifications)

NB: Unless the average length of a consultation is specified by the patient, or listed in the above references, it is assumed that an average encounter with a patient lasts one hour.

a. Curtis (2008) Unit costs of health and social care, published by Personal Social Services Research Unit (PSSRU), Kent.

b. <http://www.glanclwyd.demon.co.uk/audiology/jobs.htm> - Hourly rate from post of similar salary level, Curtis (2008)

c. Simon *et al.* (2008) - Ref NHS (2007) Annual financial returns of NHS trusts 2003-2004. Leeds: NHS, 2007. Note: inflated to 2005-6 prices from published costs using Department of Health's pay & price inflation indices.

d. <http://www.jobs.nhs.uk/cgi-bin/advsearch> - Hourly rate from post of similar salary level, Curtis (2008)

e. Snooks H (2006) NHS Direct Wales Evaluation Report, Centre for Health Improvement Research and Evaluation (CHIRAL) funded by the Welsh Assembly Government and NHSDW

f. Eccles M, Hawthorne G, Whitty P, Steen N, Vanoli A, Grimshaw J, Wood L, Speed C & McDowell D. (2006) A cluster RCT of a Diabetes Recall and Management system: the DREAM Trial

Appendix 9: Unit costs of transition service staff

staff roles	band	hourly rates*				source of unit cost data (Curtis, 2008. <i>Unit costs of health & social care, PSSRU.</i>)
		with client contact (£)	without client contact (£)	home visit rate (£)	in-clinic rate (£)	
Consultant		163.00	163.00			(p.159 Consultant - Medical) Patient-related hourly rate provided
DSN (Diabetes Specialist Nurse)	8a	110.65	43.72			(p.104 Specialist Nurse) Band 6 rate provided and proportionally adjusted for Band 7 and 8a (see p.168 Pay Bands*)
	7	94.18	37.21			
	6	81.00	32.00			
Nursing Consultant	8b	86.98	56.12			(p.107 Nurse Advanced, Senior Specialist) Band 7 rate provided and proportionally adjusted for Band 8b (see p.168 Pay Bands**)
SpR (Specialist Registrar)		54.00	54.00			(p.158 Specialist Registrar, Speciality Doctor)
CCN (Children's Community Nurse)	7	79.06	38.37	84.88	60.46	(p.101 Community Nurse) Band 6 rate provided and proportionally adjusted for Band 5 and 7 (see p.168 Pay Bands*)
	6	68.00	33.00	73.00	52.00	
	5	52.79	25.62	56.67	40.37	
SRD (Dietician)	8b	70.82	52.08			(p.138 Dietician) Band 5 rate provided and proportionally adjusted for Band 6, 7 and 8b (see p.168 Pay Bands*)
	7	50.93	37.45	86.87	47.93	
	6	43.35	31.88			
Staff Nurse	5	43.00	23.00	56.67		(p.147 Staff Nurse) Band 5 rate provided
Administrator (Receptionist, Secretary etc)	5		25.32			Salary for Band 3 (£16300) + salary oncosts (£3269), overheads (£2961), capital overheads (£3301) from p.141 = £25831 /1585hrs/annum = £16.30. Proportional adjustments made for Bands 4 and 5 (see p.168 Pay Bands*)
	4		19.95			
	3		16.30			
HCA (Health Care Assistant)	3	15.63	20.10	25.68		(p.149 Clinical Support Worker) Band 2 rate provided and proportionally adjusted for HCA - Band 3(see p.168 Pay Bands*)

* Hourly rates include salary, salary on-costs, overheads, capital overheads, qualifications)

** Curtis (2008)(Curtis 2008) p.168 provides an Agenda for Change Pay Bands. These have been used to guide adjustments to hourly rates, employing the median full-time equivalent basic salary.

Appendix 10: Data synthesis

		Organisational ethnography	Individual user/carer case studies			Survey
			User/carer interviews & diaries	Provider interviews	Case-notes	
CONTEXT	Transition model	X				
	Life worlds of users/carers		X		X	
MECHANISMS		X	X	X		
OUT	Experiences, preferences, satisfaction		X	X		X
	Quality of Life		X			X
	Clinical outcomes				X	X
	Costs	X	X	X	X	

Appendix 11: Stakeholder involvement

The study involved stakeholders throughout the research process. The project team included service providers (Gregory, Lowes, Channon, Owens, Harvey) who informed the study design and acted as an advisory group. Purposively selected service providers were also involved in piloting the service mapping instrument and validating the typology of diabetes models developed on the basis of the survey (Chapter 2). In addition, two service user reference groups (SURG) of young people with diabetes and parents of young people with diabetes participated in the study at critical junctures. One of the aims of the research was to evaluate this process. It was our intention to do this from both a service user and researcher perspective. A number of interviews were undertaken with SURG members about their engagement in the study, but these yielded poor quality data, primarily because individuals had limited recollection of the process. We have therefore restricted our evaluation to the researcher perspective. Our experience points to the need to evaluate service user involvement immediately after the event, rather than at the end of the study. Evaluation of service user engagement may also be more effective when undertaken with groups that are more longstanding⁽¹⁾.

Service User Involvement

SURG membership was recruited from Cardiff. Local recruitment conferred advantages in terms of convenience and costs of meeting attendance to SURG members and the research team. Seventeen young people with diabetes and 26 parents were identified by LL (paediatric diabetes specialist nurse) and invited to contribute. Potential members were selected on the basis of local knowledge of individuals' suitability to participate (e.g. they were not involved in other studies, were able to contribute significantly to the study). Potential SURG members were sent a letter of invitation and an information sheet explaining the research and the purpose and extent of their involvement. Thirteen young people and 15 parents subsequently consented to involvement in a SURG.

SURG members attended two meetings over the life time of the project and participated in telephone interviews. As recommended in the literature⁽²⁾, meetings were arranged in the early evening to accommodate work and school commitments and to take into account examination schedules. They were held at the hospital where the young people and their parents/carers attended diabetes clinic. They were familiar with this venue and there were no transport or access difficulties. Refreshments were supplied and travel costs were offered, although in practice no claims were made.

The SURGs contributed to key elements of the study: survey instrument development and the qualitative data generation strategy. They were also invited to contribute to a stakeholder dissemination workshop (Appendix 14), but none accepted the invitation.

Survey instrument development

SURGs informed the survey instrument content and the instrument design.

Survey instrument content

The survey questionnaire comprised several validated instruments selected through systematic review processes and additional questions designed by the research team to measure users' satisfaction with the service. SURG views were sought on the service satisfaction questions.

Draft survey questions on service satisfaction were sent to both SURGs before the meeting with a letter of explanation and instructions on issues for consideration. This allowed SURG members to examine the survey instruments before the meeting and formulate notes or comments to bring with them to aid discussion. Contact details of the research team were also included.

Both SURGs met simultaneously on 6 November 2007. Attendees comprised 3 young people and 7 parents/carers. LL who knew the SURG members greeted individuals on arrival and facilitated introductions to the research team: DA, CA, CL, SC. The meeting opened with a brief presentation of the study aims and an explanation of the contribution of the survey to the wider generation methods. SURG members were given an opportunity to ask questions about the study and seek clarification.

Parents and young people were then divided into two groups, each with a facilitator and scribe. Facilitators worked to an agreed plan and a series of pre-prepared prompts to aid discussion. The aim was to consider:

- whether the survey questions were understandable
- identify any questions which were not easy to understand and why
- establish what would make difficult questions more understandable
- identify which questions were easy to understand and why
- identify which questions were most relevant and why
- establish how any questions identified as irrelevant could be made more relevant
- identify whether there were any other areas regarding transition service provision that were not covered by our questions which SURG members felt were important.

Both groups had lively discussions which produced useful feedback on the survey questions.

Feedback from the parents' SURG

- the preamble to each section was too long
- several of the questions seemed to be asking the same thing
- questions seemed to be written from the perspective of health professionals and this could discourage respondents
- the questions did not appear to address issues which were important to them (access to advice; organisation of out-patient departments; support for parents; reduced support for young people in 'adulthood')
- concerns that the questionnaire was too constraining and a qualitative approach was preferable
- suggestions made about the inclusion of open questions in the survey instrument
- the use 'child' should not be used; 'young people' was preferred
- rather than asking specific questions about feelings, it was suggested that there was a list of words which respondents could be invited to circle to indicate feelings - 'abandoned' was a word used a lot to describe feelings by the group
- evidence that some questions required a filter as they were not always relevant
- suggested adding a question on how far professionals involved parents in their care
- 'continuity of care' – suggested that this be replaced with 'team's awareness of your child's previous care'
- suggested that questions were included which asked whether health professionals kept the GP informed
- suggestions that a question was included which indicated where respondents were in the transition process
- inclusion of a question which captured the issue of support for people in a crisis

Feedback from the young people's SURG

- questions seem too positive
- it is difficult to put feelings into a category
- repetition
- specific questions identified as too long

Instrument format

SURG feedback was used to inform the survey instrument on a second occasion. Here the aim was to seek SURG views on the survey format, design and layout. Separate instruments were designed for young people and parents. SURG members were sent a copy of the appropriate draft instrument and asked to complete it. This was followed by a telephone interview in which individuals were invited to comment on specific issues relating to the survey design, drawing on their experiences of survey completion. For this purpose a cognitive interview schedule was developed with specific questions relating to each of the two survey instruments. Six young people with diabetes and ten parents were sent the questionnaire, completed it at home and then participated in telephone interviews to elicit their views.

Individuals were thanked for taking the time to complete the questionnaire and it was explained that the purpose of the interview was to assist in finalising its design and to ensure that questions were asked in a way that was clear and understandable. It was emphasised that there were no right or wrong answers and that we were most interested in their experience of completing the questionnaire.

The interview began with general questions on their experiences of questionnaire completion: length of time for completion; usefulness of the instructions and whether it was laid out in a way that was clear to read and understand. This was followed by more specific questions directed at particular sections or questions. These were designed to ascertain whether questionnaire items had been interpreted as intended and whether items were relevant to their experience. The questionnaire included examples of different response formats and SURG members were asked whether they had a preference and, if so, the reasons for their preference. At the end of the interview, respondents were asked:

- Whether there were any aspects of diabetes care and living with diabetes that are important which are missed by this questionnaire.
- Whether anything could be done to make it easier to answer the questions.
- Whether there was anything about responding to the questionnaire that made them feel uncomfortable.
- Whether there was anything else they would like to tell us about the questionnaire.
- Although more resource intensive than the workshop, the cognitive telephone interviews were very useful in informing decisions on the final version of the survey instrument.

Qualitative data generation strategy

Qualitative data generation and analysis were undertaken concurrently, with data analysis informing data generation. Prior to the final interviews with research participants, SURG members were invited to attend a meeting in order that we could share the emergent study findings and seek their views on the qualitative data generation strategy for the final phase of the study.

The workshop was convened on January 6 2009. As with the first meeting, attendance did not reflect the number of invitations, i.e. 28 Service Users (13 young people, 15 parents) were invited; 6 had indicated they would attend, but only 3 (1 young person and 2 mothers) subsequently did. One young person was working, although her mother did attend, and another young person went to the wrong venue. One carer was unable to get back from a previous commitment in time and had indicated that this would be a possibility. There was no separation of young people and parents into different groups at this meeting.

The aim of this meeting was to:

- update on progress
- share emerging findings on
 - models of transition management
 - experiences of young people
 - experiences of carers
- gauge SURG members' reactions and responses
- contribute to the next stage of data generation.

As part of the presentation, each model was considered in turn and SURG members were asked to comment. The intention was to share some findings from the interviews with illustrative data extracts but there was extended discussion on the models and we ran out of time. The service users felt that common to all these models was that young people were expected to fit into an existing system, taking little account of the needs of the individual.

Overall, the group focused on the tasks set them, but they inevitably referred back to their own experiences in formulating their responses. Nevertheless, SURG members' comments about the models were adequate to inform the next round of data generation and confirmed the overall direction of the study, giving confidence that were we asking the right kinds of questions from a service user perspective.

Evaluation of service user involvement process

Despite many young people with diabetes and their parents agreeing to participate in the SURG, in practice attendance at meetings was relatively low. However, the difference between the number of service users

consenting to participate and the number who actually attended is not unusual in this population^(2,3). Furthermore, our previous experience of clinical and research initiatives involving young people with diabetes and their parents/carers led us to anticipate this drop in membership, which is why we over-recruited from the outset.

The first meeting held was designed to solicit initial views on the service satisfaction questions in the survey instrument. Despite yielding very useful feedback, the discussion posed real challenges for facilitators with many participants using the meetings as an opportunity to share their own dissatisfaction with the transition service, which at times made it difficult to sustain engagement with the focal concerns of the workshop. Given that the purpose of the meeting was to invite SURG comments on the survey questions relating to satisfaction and specifically whether the questions omitted any issues which were important from a service user perspective, it is inevitable that participants would draw on and share their own experiences and that this would shape the dynamics in the group. Moreover, SURG were a self-selected group and as such there was a high likelihood that members were motivated to contribute because they had strong views on transition derived from their singular experiences. LL's experience of actively involving parents of young people with diabetes in a number of studies suggests that this is not unusual, with such experiences believed to be part of the value of public engagement⁽⁴⁾. With hindsight, it was naïve of us not to anticipate this effect and, whilst we had provided clear instructions about the issues we wished members to consider, we could have specified more clearly the ground rules for the workshops at the outset, which may have assisted in sustaining the focus of the workshops. In addition, there may have been benefits in building in time for sharing individual experiences at the beginning of the meeting, with the explicit purpose of bracketing off this kind of discussion from the main business. The process may also have been assisted if we had been more directive about the issues we wished members to address in relation to specific questions rather than soliciting more general impressions. However, given that this was the first meeting, we were eager not to create the impression that the SURG's scope for influencing the study was constrained. Individual interviews by telephone may have facilitated a more tightly prescribed focus but whilst this overcomes the challenges of group facilitation, the benefits of the group dynamic are lost and the process is less cost-effective.

The telephone interviews provided us with more specific feedback than the group discussions; questioning was more focused because interviewers were able to adhere more closely to the interview schedule. This was appropriately structured at this stage of the survey development, since there was a limit to what could be changed.

For the purposes of informing the qualitative data generation, the workshops proved to be a very useful method of engaging SURG. For these purposes, there were distinct advantages in learning from the group discussion as emerging findings were presented. Overall our experiences point to the need for researchers to consider carefully the most appropriate

method and format for engaging service users depending on the task at hand and the stage of the research process. In particular, future researchers should consider carefully how far they wish to harness a group dynamic to positive effect in soliciting user engagement and to plan carefully how groups will be briefed and facilitated.

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Appendix 12: Report on the Stakeholders' Workshop, March 11th 2010 Aberdare Hall, Cardiff

Towards the conclusion of the study, a dissemination event was convened in order to share with key stakeholders the study findings, assess their face validity and consider their implications for policy and practice. This formed part of the study's wider strategy for engaging research and service users.

Stakeholders invited to attend included: all services participating in the study (up to five places per service), Service User Reference Group members and representatives from key constituencies:

- Diabetes UK
- Juvenile Diabetes Association
- British Society for Paediatric Endocrinology and Diabetes
- Royal College of Nursing
- Society for Endocrinology
- Royal College of Paediatrics and Child Health
- Royal College of Physicians

Attendees included:

- Model 1 (ADSN)
- Model 4 (NURSCON; SRDA)
- Model 5 (CCN, PDSN, acting service manager)
- Justin Warner (British Society for Paediatric Endocrinology and Diabetes)
- Marie Marshall (RCN Children and Young People's Interest Group)
- Natalie King (Diabetes UK)

Apologies received from:

- Model 2
- Model 3

The morning was devoted to sharing the study findings. Feedback from participants provided strong evidence of the face validity of the findings and indicated that viewing transition models through the dual prism of realistic evaluation and continuity of care mechanisms was a different way of

thinking about services but very useful. In the afternoon, participants were organised into three groups to consider the implications of the findings for practice. The questions for consideration in the workshops and notes from the discussion are summarised below. Participants had handouts of the model diagrams, summaries of models key features and definitions of the continuity of care concepts to refer to.

Workshop 1: What are the implications for practice of the study insights about relational and longitudinal continuity?

Relational and longitudinal continuity was generally regarded as important even in adult teams.

Attention was drawn to the challenges of covering for absences.

The group pointed to involvement with young people and their families at the point of diagnosis as highly consequential for laying the foundations for relational continuity and the challenges for those health professionals not involved at this stage, although increasing the length of contact helped relations develop over time. The group considered how to achieve this. It was suggested that all adult diabetes specialist nurses should be involved in transition but they needed to be motivated. This would also have resource implications. Staff would need to be individually flexible. Relational continuity was felt to be valuable in promoting patient independence from health providers. The issue would need prioritising within clinical services and would therefore need evidence to support arguments for increased resources to be devoted to it.

Barriers:

- increasing independence of the young person
- limited number of adult diabetes specialist nurses
- lack of staff interest.

Facilitators:

- joint adult-paediatric diabetes specialist nurses boundary blurring (i.e. flexibility between whether adult or paediatric diabetes specialist nurses dealt with the patient's problem though concern was expressed that managers would not like this model)
- involvement other health professionals, such as dietitians, or volunteers.

The group considered the most important aspects of service provision to change: two contributors identified the need for more joined-up working through paediatric and adult use of diabetes centres for education etc and

one participant, pointed to the need for the development of a young adult clinic for 18-30s.

Workshop 2: What are the implications for practice of the study insights about cultural continuity?

The workshop began with clarification of the cultural continuity concept and the interventions identified in promoting cultural continuity. There was a general discussion around the factors contributing to cultural discontinuity. These included:

- resources
- policies - paediatrics may, for example, 'chase up' DNAs, adults do not – the onus is on the patient to make contact
- anonymity of individuals when dealing with administrative staff in adult services rather than health professionals in paediatric services
- paternalistic approaches in paediatrics
- children's services are nurse-led and adult services are often doctor-led which can exaggerate cultural discontinuity
- individual personalities and consultation styles – but even if these were removed there are still other elements of cultural discontinuity between services
- paediatric services focus on family and not just the individual
- working practices different – 24 hour support in paediatrics and office hours in adult

The group discussed the relative merits of gradual transition versus clear transition points where approaches to care changed. Reflecting on their own practice, it was suggested by one member that that young people may need a sharper divide and paediatrics were holding them back.

There was a wider discussion about paediatric service culture covering:

- paternalistic vs partnership working
- expert patient/expert parent: need for less hands-on involvement by health professional
- parents feeling they're being judged in clinic
- young person finding it difficult to move to an unknown service
- paediatrics as a 'safety net' – people return to paediatrics if they are not getting on in adult services
- paternal approaches possibly reflect professional uncertainty and more experienced practitioners can feel more comfortable with a more hands-off approach

- young person moving on – parents not
- should paediatrics gradually be made more adult like by reducing the frequency of appointments (resource considerations influenced this suggestion)

Implications for practice:

- Individualised care plan for transition
 - plan content/focus of clinic appointments
 - shared goal-setting
 - evaluation
 - could be carried forward into adult service
 - links with management continuity
- Transitional care pathway
 - who should be involved in its development?
 - is having the protocol enough?
 - could this be linked into individualised care plan?
 - challenges of health professionals coming from different backgrounds and getting buy-in
- Dual qualification

Workshop 3: Consider the contribution of different forms of continuity to smooth transition. Starting with a blank canvas, how would you construct a new clinical service to promote smooth transition if resources were not your primary consideration?

The group was asked to review the different forms of continuity, and select which should receive the highest priority and why. The general consensus was that relational and longitudinal continuity were the most important for a number of reasons. A good relationship is:

- key to a participant's progress
- developed over time
- inclusive (involving the family)
- can overcome a lack of formal processes
- more person-focussed and less artificial
- can facilitate many other forms of continuity.

In developing a smooth transition from child to adult services, a patient's ideal situation would be to feel as though nothing has changed and that any

transition was a 'natural' process. However, it was acknowledged that, whatever the nature of the transition, a change was inevitable and the young person and carer would need to accept this and deal with a loss of some kind in their relationship with child services.

The teenage/young adult phase (approx. age 14 to 25) was seen as a particularly vulnerable life stage that requires a completely different level of understanding from children or adults. The cultural differences between child and adult services were discussed, in that children's services is much more support-focussed and considerate of a patient's situation (disposition, family, school/work life, etc.). In contrast, adult services are more clinically-focussed, relying on the independence of the patient in dealing with their condition and other life issues. The difference between cultures, however, was acknowledged as being more acute between child and adult consultants than between child and adult nurses. It was also recognised that training for adult consultants tended to focus on the elderly, and there was a lack of participation in training concerned with adolescents. Child consultants, on the other hand, noted the immense job satisfaction and motivation they received from dealing with adolescents.

The discussion moved on to what would be required in order to address these issues. It was suggested that a transition service was needed that was distinct from child or adult services. A young adult transition service was required that:

- had its own identity
- was person-centred in its approach
- focussed on the specific needs of adolescents
- was based on the model of the 'teenage cancer trust' i.e. a service in which young people are not expected to be dealt with in the same way as smaller children or older people and where the expertise is available to manage a variety of adolescent concerns – whether these concerned their difficulties in dealing with their diabetic condition, their personal relationships, sex, drugs, living at home, etc.

The group also recommended that families should be encouraged to organise their own 'triage', i.e. deciding for themselves whether they required the attention of a child or adult consultant, PDSN, ADSN or other health professional. The aim of this was to encourage independence on the part of the family and the patient in dealing with their condition and their relationship with diabetes services.

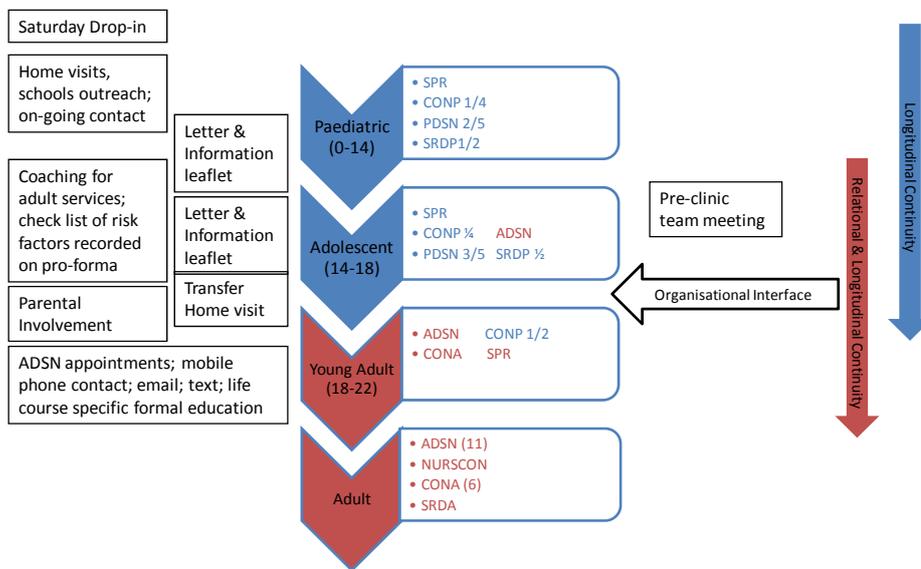
Finally, the group were asked to provide their wishes for the one aspect of the service they could change to promote smooth transition if resource were unlimited. The general consensus was for more training of both adult and child diabetes specialists in dealing with adolescent-specific concerns at this time of life.

Appendix 13: Model 1 case sample across the transition service

Case	Children's	Adolescent	Young Adult	Adult
180				
148; 154; 179				
137				

Appendix 14: Model 1 diagram

MODEL 1



Appendix 15: Model 1 key features

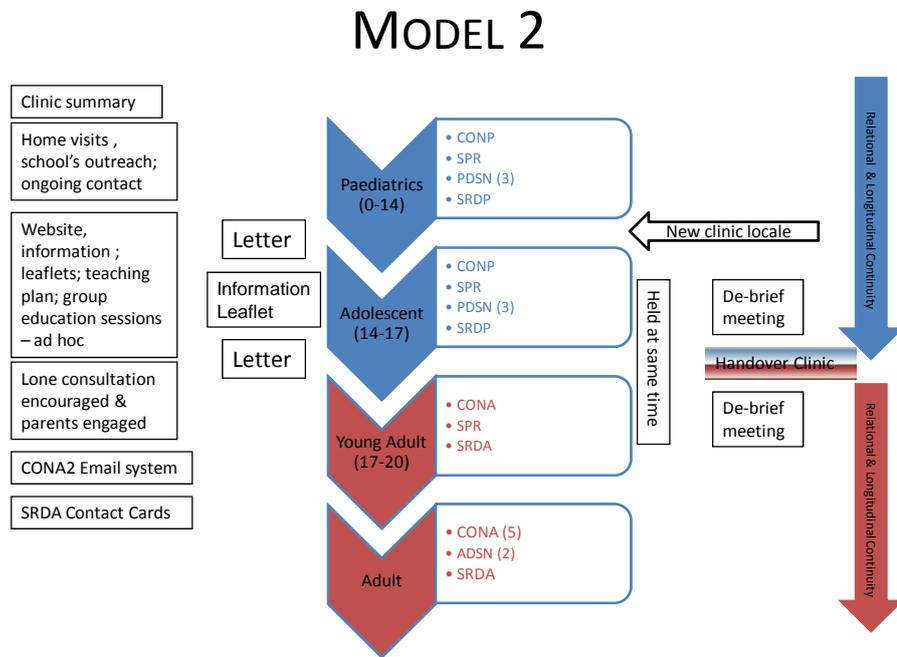
- 3 stages (child – adolescent-young adult-adult)
- Major relational discontinuity interface between paediatric and adult service
- Transfer across an organisational interface
- Relational and longitudinal continuity interventions
 - No relational continuity in paediatrics and multidisciplinary consultation format
 - Longitudinal continuity of paediatric *team* through children's and adolescent clinic
 - Relational continuity with ADSN and CONA in young adult services
 - Building in time for relationship building at transfer
 - ADSN transition nurse role spanning the boundary between child and adult services
 - Paediatric consultant participation in young adult clinic
- Informational continuity interventions
 - Preparation for transfer
 1. Letters
 2. Information leaflets
 - Rationale for adolescent clinic
 - What to expect in adult services
 3. Transfer home visit
 4. ADSN transition nurse attending adolescent clinic
- Management and cultural continuity interventions
 - Clinic pre-briefing meeting
 - On-going handover
 - Transition nurse working across service boundaries

- Transfer letter between consultants
- CONPs working across service boundaries
- Relational continuity in young adult services
- Cross boundary working by ADSN promoting greater understanding and cultural continuity between services
- Developmental and flexible continuity interventions:
 - Coaching to prepare for adult services (paediatrics)
 - Structured approach, milestones and risk factors to be addressed prior to transfer and formally recorded on a pro-forma
 - Intensive support in young adult services
 - Formal education in young adult services
 - Private spaces of Saturday Drop-in Centre and home visits
 - Continue to involve parents in care

Appendix 16: Model 2 case sample across the transition service

Cases	Children's	Adolescent	Young Adult	Adult
58; 64	Dark Grey	Light Blue	Light Blue	Light Blue
66	Dark Grey	Dark Grey	Light Blue	Light Blue
26	Light Blue	Dark Grey	Dark Grey	Light Blue
185; 186	Light Blue	Light Blue	Dark Grey	Light Blue
181	Light Blue	Light Blue	Dark Grey	Dark Grey

Appendix 17: Model 2 diagram



Appendix 18: Model 2 key features

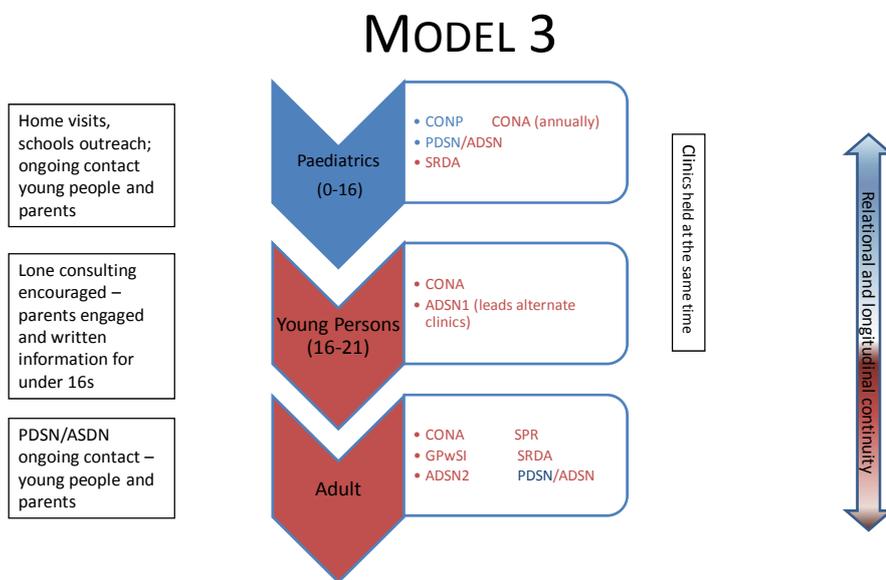
- 3 stages transition process (paediatric-adolescent-young adult-adult)
- Major relational discontinuity interface between paediatric and adult service
- Relational and longitudinal continuity interventions
 - Relational continuity of consultant throughout model
 - Named nurse scheme in children's service
 - Shared clinic environment and timing (adolescent and young adult clinics)
 - Relationship building at transfer
 - Informal PDSN boundary blurring at transfer
 - Joint consultations with doctors as required
- Informational continuity interventions
 - Preparation for transfer built into consultations
 - Website
 - Handover clinic
 - Letters
 - Information leaflets about young adult service and differences with children's service
- Management and cultural continuity interventions
 - Relational continuity
 - De-briefs
 - Clinic summary sent to family – up to age 16
 - Transfer letter between consultants
 - Joint consultations – as required
 - Shared clinic environment and timing (adolescent and young adult clinics)

- Shared ethos – relational continuity emphasis
- Written communication between CONA and PDSNs in the event of informal boundary blurring
- Developmental and flexible continuity interventions
 - Check-list of education coverage in paediatrics including risk factors
 - Clinic summary sent to family – up to age 16
 - Website
 - Leaflets
 - Ad hoc group education sessions
 - Shared clinic environment and timing (adolescent and young adult clinics)
 - Realistic, non-judgemental approach
 - Lone consultation encouraged
 - Email system – young adult consultant
 - Dietician contact cards

Appendix 19: Model 3 case sample across the transition service

	Children's	Young Person's	Adult
89; 86; 82; 79			
107; 94			
121; 116; 93			

Appendix 20: Model 3 diagram



Appendix 21: Model 3 key features 2-stage model (paediatric-young person's-adult)

Small integrated team

Joint PDSN/ADSN role providing relational and service continuity throughout

CONA engaged with paediatrics

- Relational and longitudinal continuity interventions
 - High levels of relational continuity at each stage of the process
 - Longitudinal continuity of CONA and PDSN/ADSN between all stages of the process
 - Key worker system within diabetes nursing team
 - Relational and longitudinal continuity of SRD throughout service
- Informational continuity interventions
 - Woven into clinic appointments
- Management and cultural continuity interventions
 - Relational continuity
 - Concurrent running of paediatric and young person's clinics
 - Formal handover to cover absences
 - Formal handover at key interfaces
 - PDSN/ADSN and CONA boundary spanners
 - Summary of clinic consultation for parents for young people who are lone consulting under aged 16
 - Joined up philosophy and common ethos and
 - CONA annual attendance at paediatric clinic
- Developmental and flexible continuity interventions
 - Patient centred and non-judgemental approach
 - High levels of on-going support in between clinic appointments at all stages of the service
 - Lone consultation encouraged but with continuing engagement with parents

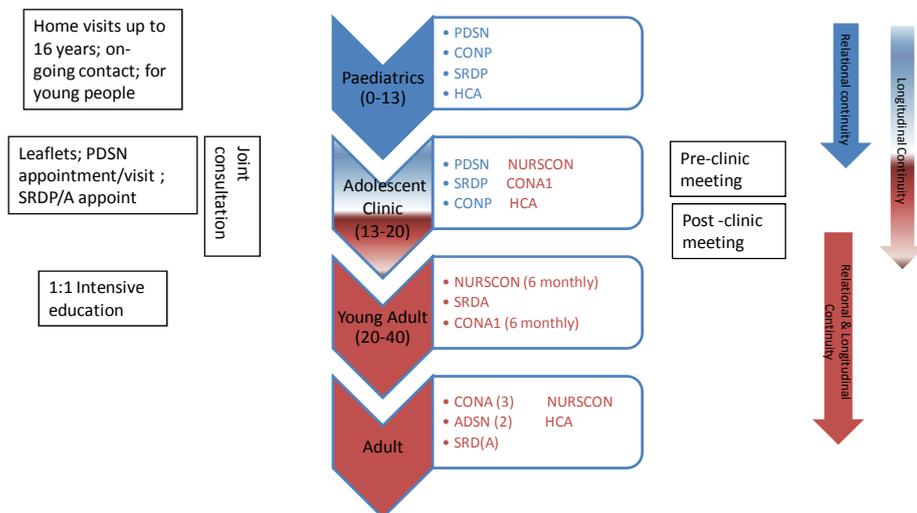
- Engagement rather than clinic attendance

Appendix 22: Model 4 case sample across the transition service

Cases	Children's	Adolescent	Young Adult	Adult
69				
12; 16; 45; 41; 50; 52; 94; 91; 54				
49				

Appendix 23: Model 4 diagram

MODEL 4



Appendix 24: Model 4 key features

- 3 stage process (paediatric-adolescent-young adult-adult)
- Joint adolescent clinic and nurse-led young adult clinic
- Integrated diabetes nursing team
- Single funding source
- Parallel services provided in two sites
- Relational and longitudinal continuity interventions
 - Strong relational and longitudinal continuity with the paediatric team
 - Joint adolescent clinic – designed to engender ‘familiarity and comfort’ with adult team
 - Nurse consultant – providing relational and longitudinal continuity at adolescent/young adult clinic
- Informational continuity interventions
 - Built into consultations
- Management and cultural continuity interventions
 - Supported by relational continuity in paediatrics
 - Supported by relational and longitudinal continuity at two key interfaces
 - Shared office accommodation
 - Pre-brief and de-brief meetings in adolescent clinic
 - Marked cultural discontinuity between paediatric and adult services – joint clinics intended to allow time for young people to adjust
- Developmental and flexible continuity interventions
 - Transfer to adolescent clinic – developmental milestone
 - Parents remain welcome in consultation
 - Nurse-led young adult service
 - Home visits and educational meetings with PDSN; NURSCON; SRDs

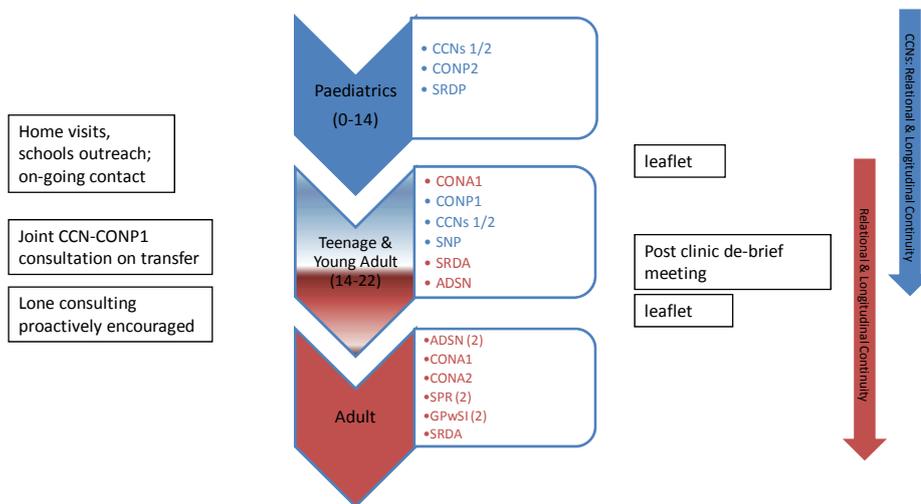
- Emphasis on choice and flexibility of service provision in response to maturity of young person
- Different approaches in two services, but seen as appropriate, adolescent clinic designed to act as gradually introduction

Appendix 25: Model 5 case sample across the transition service

Cases	Children's	Teenage/Young Adult	Adult	GP
63				
41; 45; 62				
63; 56; 40; 42; 54; 51;				
34; 22; 19				
16				

Appendix 26: Model 5 diagram

MODEL 5



Appendix 27: Model 5 key features

- 2 stage process (paediatric-teenage/young adult-adult)
- Parallel services provided at two sites
- Combined T/YA clinic
- Relational and longitudinal continuity interventions
 - Paediatric nursing team provides relational continuity from paediatrics through T/YA clinic
 - Relational discontinuity of consultant at paediatric-T/YA interface
 - Longitudinal and relational continuity of care with the paediatric nursing 'team'
 - ADSN and CONA provide relational and longitudinal continuity from T/YA adult clinic through to main adult services
 - No formal process of introduction with consultants
 - No formal process of introduction with dieticians
 - Extended period in T/YA clinic
- Informational continuity interventions
 - Leaflets developed for each interface of the service, but not considered that important by service users
 - Preparation for transfer commences 6-9 months before and information is woven into the consultation
- Management and cultural continuity interventions
 - Nursing team are an important source of service continuity between paediatrics and T/YA clinic
 - Joint nursing/CONP1 appointment on entry to T/YA clinic
 - Combined adolescent clinic – de-brief meetings
- Developmental and flexible continuity interventions
 - Onus is on flexibly supporting a process of development to independence

- Extended period in T/YA clinic – in order to receive on-going support from CCNs
 - When young people enter T/YA service the expectation is that they will see the consultant independently of their parents, but there is flexibility
 - Lone consulting acts as a catalyst for independent management
-

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The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.