



## ***ADOLESCENTS' VIEWS ON DIABETES***

Report of the Teen Conference, Croke Park, Dublin February 2009



# Acknowledgements

The Diabetes Federation of Ireland wish to acknowledge and thank the following people:

the adolescents who travelled from all parts of the country and gave so freely of their time and views.

the guest speakers who shared personal stories of their diabetes for the benefit of the adolescents.

the professionals who supported and facilitated the day.

the administration staff who organised the day.

## Foreword

Being an adolescent can be an especially difficult time as young people move from dependence on their parents to independence. Having type 1 diabetes can make that transition more difficult. During this transition period adolescents with type 1 diabetes have the added issue of managing their condition as well as having to cope with daily adolescent emotional, physical and social issues.

In the summer of 2008, the Diabetes Federation of Ireland's Cork Teen Group asked if they could meet adolescents from other parts of Ireland to discuss and compare living with diabetes in Ireland.

In February 2009, the Diabetes Federation of Ireland in conjunction with a range of hospital based healthcare professionals hosted a national conference for 70 adolescents between 13-18 years of age in Croke Park.

The conference covered a range of issues of concern to adolescents and provided an opportunity for them to share their views on managing their condition. Topics covered ranged from identifying optimal diabetes services for adolescents to fostering stronger relationships between adolescents with diabetes, their parents, siblings and friends.

This report sets out the findings of the various group discussions which will inform diabetes healthcare professionals on how to effectively organise their clinics to optimise their service to this age cohort and remove potential barriers to clinical support and help foster stronger relationships between adolescents with diabetes, their parents, siblings and friends.



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Chairperson

Diabetes Federation of Ireland

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# **Chapter 1**

## **Background**

One in every 600 children/adolescents in Ireland have type 1 diabetes. The incidence of type 1 diabetes is rising, and most especially in the under five age group, resulting in an increasing number of younger children needing diabetes care. To cope with the increased demand on paediatric diabetes services, there is a tendency to move older adolescents into adult diabetes services.

The paediatric diabetes service is characterised by a family centred, socially orientated, informal mode of medical care. The adult diabetes service is disease orientated with an emphasis on formal individualised responsibility for health outcomes. The transition from one service to another can be viewed as a passage between two distinct cultures that must be navigated. The health care provider has a role in insuring the passage is smooth which can only be provided by listening to the views of those making that passage and responding proactively.

Self-management of diabetes in adolescents must be understood in relation to their maturity and the healthcare system which dictates their medical care. The Irish healthcare system demands that adolescents transfer to adult diabetes services around the chronological age of 16-18 years. This age is considered to be the age when adolescents reach maturity, become increasingly autonomous and progress towards consolidating their personal identities. However, when asked, young people with diabetes reported that the most appropriate age for transfer to be 17-25 years<sup>1</sup>.

The transfer of young people from paediatric diabetes services to adult diabetes services often occurs at a sensitive time for the individual concerned, both personally and from the point of view of their diabetes. The differences in paediatric and adult diabetes services can hinder adolescents integrating into the new system and may result in unmet psychological and social needs. Many find the culture change unacceptable and non-attendance rates at adult diabetes clinics are often higher in young adults. Care can also become disjointed and young people can feel unsupported. This may be exacerbated when young people leave home and adopt more mobile lifestyles. Adolescents are

entitled to give their views on how this transition to adult services should be accomplished for best medical and psychological benefits.

### ***Literature Review***

In type 1 diabetes, the pancreas produces less than 80% of required insulin due to destruction of the pancreatic beta cells leading to abnormalities in carbohydrate, protein and fat metabolism. The goal of diabetes treatment is to keep blood glucose levels within normal range because hypoglycaemia (low blood sugar) affects quality of life and hyperglycaemia (high blood sugar) increases the progression of diabetes complications.

Adolescence can be an especially difficult time for those with type 1 diabetes<sup>ii</sup>. Type 1 diabetes mellitus is a chronic condition that may have an impact on adolescent's psychosocial adjustment<sup>iii</sup> which may result in poorer metabolic control independently of other risk factors<sup>iv</sup>. Adolescents with type 1 diabetes face a daunting task: control their blood glucose levels on a daily basis by monitoring and regulating diet, exercise and insulin dosage. Coping with the demands of diabetes self-management in adolescence can be a formidable task<sup>v</sup>. Studies extending over periods of time have shown adolescents with diabetes seem to be extraordinarily burdened by illness specific stressors such as hospital appointments, injections, dietary considerations etc, and in addition normal teenage stressors<sup>vi</sup>.

In modern western cultures, adolescence is an extended period as young people move from dependence on their parents to independence in meeting their own emotional, physical, social and financial needs. Psychological conflict and crises are a normal part of this process as a balance between freedom and responsibility is negotiated<sup>vii</sup>. For young people with diabetes, the renegotiation of roles and responsibilities in diabetes management must begin earlier because the child is away from direct parental supervision for much of the day. During school hours, the teenager must make decisions regarding insulin dosages, monitoring, diet and exercise which without parental support can be distressing for both parties.

It is well established that diabetes self-management adherence during adolescent years diminishes<sup>viii,ix</sup>. Adolescents have a need for autonomy which for diabetes management



may conflict with the parent's concerns over their child's well being and health. Adolescents focus on the short term effects of their diabetes, whereas parents are more concerned with long term health<sup>x</sup>. There is evidence that adolescents with a high degree of unresolved conflict are more at risk of recurrent diabetic ketoacidosis (DKA). Late adolescence is known to be a critical period in diabetes control due to hormonal changes and psychosocial conditions as the individual struggles for autonomy and independence<sup>xi</sup>.

Adolescents with diabetes may be more at risk of being 'bullied' than their healthy peers<sup>xii</sup> resulting in social anxiety and loneliness. Bullied adolescents may avoid interactions and be denied positive social experiences<sup>xiii</sup>. They may decide to 'hide' their diabetes or deny its existence. Many adolescents intentionally omit insulin regularly<sup>xiv</sup> and this may be related to denial, fear of social stigma, weight gain or fear of 'hypos'. Helping adolescents to recognise their internal conflicts would be beneficial to improving quality of life and achieving good diabetes control.

This difficult period for the adolescent with diabetes is confounded as it coincides with the transition of care from paediatric care to adult care services. During the transition, there is a higher risk of loss of follow-up with most adolescents experiencing the transition as traumatic<sup>xv</sup>. In Ireland, the transfer to adult services is generally at age 18 years or immediately post Leaving Certificate Examinations but some clinics set the transfer age to 16 years. Consequently, there are parallel transitions going on at the same time which may also be confounded by a transition from school to work/college.

In order to reduce the fear of the unknown adult services, the transition should be a coordinated process organised in partnership with the adolescent<sup>xvi</sup>. The transition should be a multi-faceted process whereby the medical, social and psychosocial needs of adolescents are met. However, there is much evidence that adolescents with chronic conditions experience negative feelings when transferring to adult services. Such feelings are expressed as "dumped", "thrown out" "abandoned"<sup>xvii</sup>. Involvement of adolescents in planning their care is essential as supportive communication patterns may result in better treatment adherence, metabolic control and a lower degree of conflict.

In order to engage the adolescent in the transitional process and to convey a sense of ownership of the process, their views on the optimal service should be sought. Although

adolescents' diabetes self-management care and health deviation behaviours are well researched and documented, a gap exists in the available literature relating to how adolescents perceive their diabetes care should be managed during the transition from paediatric to adult services and how they view the current diabetes service provision.

### ***Rationale for study***

Much previous research has emphasised the importance of addressing the psychological burden of diabetes and educational interventions to promote quality of life. However, there is limited appreciation of adolescents' perceptions of diabetes and their interaction within the Irish healthcare system. In addition, adolescents have not been formally asked to determine their optimal transition to adult diabetes clinics and when would be the most appropriate time for their departure from paediatric care.

There is general inconsistency in the choice of lower and upper age limits for defining adolescents<sup>xviii</sup>. The medical definition of adolescence alludes to the physiological changes as defining characteristics. The United Nations Convention for the Rights of the Child defines a child as below the age of 18 years. In England, the National Service Framework for Children covers children up to 19 years of age, although the English Specialist Paediatric Services definition describes children being ready to move to adult services by chronological age of 17 years depending on their condition. The European Union definition of paediatric services is to the age of 18 years. This inconsistency in the definition of adolescence limits the comparability of research findings and therefore, the defining age for inclusion in research studies is important. An appropriate age when young people are confident in their own views is proposed as 13 years of age. Therefore, adolescents in the present study are defined as persons between the chronological age of 13 years as of 01/01/09 and not more than 18 years on the 22/02/09.

### ***Aim and objectives of the study***

The aim of the current study is to give adolescents with diabetes a "voice" which could be included into health service policy decision making. The specific objectives are:

- To provide a forum for adolescents to meet each other and share their own experience of living with diabetes;
- To discuss and consider issues relevant to an adolescent's daily management of their condition making practical suggestions for consideration by others;

- To produce a reference document for Healthcare Professionals to help optimise delivery of service to adolescents;
- To foster stronger relationships between the adolescent with diabetes, their parents, siblings and friends through better understanding and support.

Initial discussion among adolescents and review of the available literature has resulted in identification of initial topics requiring exploration;

- The optimum diabetes clinic;
- Transition from paediatric to adult services – the difficulties;
- Telling my friends and school mates about diabetes – my fears;
- Relationships within my family;
- Taking responsibility for my own diabetes - my role/my family's role.

As this study is an initial explorative study of the perceptions of Irish adolescents about their diabetes care and peer interaction, a qualitative approach was deemed to be most appropriate.

## **Chapter 2**

### **Study outline**

Qualitative research is defined as the use of in-depth interviewing and observational techniques on small samples of target population groups to investigate attitudes, beliefs and social contexts associated with selected patterns of human behaviour. Focus group methods facilitate reaching a larger group of people than would be possible if using individual interviews. Focus groups also permit the participants being interviewed to stimulate the discussion and create a greater sense of involvement in the process of information generation.

Clear guidelines on the open ended questions to be asked at the focus group were defined during the planning stage so that the facilitators could not interject their own meaning onto comments and observations by participants.

To counteract any problems that might arise if the focus group brought together people who knew each other too well to partake openly in the discussion, the selection of participants was from all diabetes clinics providing diabetes care to adolescents. Diabetes teams were invited to nominate adolescents who the team considered vocal and confident enough to contribute actively to the discussion.

On acceptance of an invite to attend the focus group, the participant was informed of the purpose of the focus group, what their role in it would be, how the focus group would be managed and how the results would be analysed, verified and used. It was stressed that their participation was entirely voluntary but that once the focus group commenced, they were expected to stay in it and see the discussion through.

### **Discussion Groups**

Discussion groups usually vary between six to eight participants with six-eight considered to be the optimal number of participants. However, in order to allow for non attendance and the age of participants, it was appropriate to plan for ten-twelve participants for each discussion group.

Each discussion group was one hour long although those groups who requested additional time were accommodated. The format was a brief introduction by the facilitator, then an optional ice breaker followed by open discussion based on the semi-structured interview guide for that discussion group (see Appendix 1). The facilitator's main role was to initiate the discussion around the specific issue of that focus group and ensure that the discussion continued around those issues until all participants' views were voiced. Some of the groups used an ice breaker which broke the group into pairs based on the participant on the right of each person. Each pair were allowed a few minutes to determine their partners name, age, where they were from and one word they would use to describe their own diabetes. The purpose of the ice breaker was to relax the group and open up discussion about diabetes. However, in the event of the ice breaker not being successful, the facilitator had the option to read a scenario and ask questions around that scenario.

The questions to be asked in each discussion group were determined based on adolescents questions expressed during prior network meetings. Prior to the conference, all facilitators met up and reviewed the core questions for each discussion group.

### ***Ethical approval process***

#### ***Independent consent by adolescents***

In terms of current law, there is no provision setting out when children may provide their own independent consent to research. With regard to "non-therapeutic" research it may be that independent child consent is sufficient if they are "capable of understanding". Attendance at the day was considered consent to partake in the research.

#### ***Consent from parents***

Parents/Guardians were requested to give written consent, although — as is usual practice in "non-therapeutic" research — a non-response clause was used, ensuring the participation of children whose parents neither specifically opt out of the study nor return their consent form.

#### ***Ethical approval by the Diabetes Federation of Ireland***

Ethical approval was received from the Professional Services Committee of the Diabetes Federation of Ireland

### ***Data Analysis***

Each discussion group was recorded and a note taker took notes throughout the session for clarity and to pick up on non verbal communication. The recordings were transcribed to the extent permitted by the quality of the recordings. The data was categorised according to themes of “main repeating” points. The main points become the framework for the analysis and the statements that were made in relation to these points were summarised so that the “voice” of the teenager was apparent.

The main repeating points were categorised and two main themes were evident – diabetes /medical management, and diabetes/social relationships.

## **Chapter 3**

### ***Diabetes and Medical Management***

Prior to the day, 60 participants had pre-booked their place at the conference and they were allocated to a discussion group so that each group had a mixture of age, gender and good geographical spread with participants coming from different clinics and services. However, 72 adolescents attended on the day with the additional participants accommodated.

Each group was made up of 13 to 17 adolescents ranging in age from 13 years to 18 years. Most of the participants welcomed the opportunity to talk to the person beside them and were more comfortable describing that participant's perception of diabetes. There was no uniformity about using one word to describe having diabetes. In general, the majority described their diabetes in very negative terms such as "crap", "annoying", "hate" but there were some comments that reflected a less negative aspect "challenge", "ok". When asked to expand on what was meant by these comments, there was general agreement that diabetes interfered with the normal pattern of life.

*"Just having it is difficult, lunchtime is awkward in school, like having to go take your insulin at lunchtime and going low in class, teachers don't let you out and think I am trying to skip class"* (Female, age 17)

*"When you go out, you have to bring extra things with you"* (Male, age 16).

This need for bringing additional supplies and equipment was reiterated by other participants who perceived this as making them different.

### ***The Diabetes Clinic***

Discussion around the physical environment focused on how it looked. It was agreed that the environment contributed to the unhappiness of waiting times. *"It's all kids stuff in the*

*waiting area, there is nothing for us”* said a male, aged 16 who didn’t like the fact that the waiting area was set up for kids much younger and that there was nothing there for adolescents. Other participants nodded in agreement with this *“Maybe there could be a separate room for the small kids”* (Female, age 13).

There was general agreement that the clinic should be clean and bright and have items of interest to adolescents in an area preferably removed from the younger children area. When suggestions were made for improvements, the suggestions focused mainly on how to make the place look better and interesting to teens.

The group decided that the factors that might contribute to the physical environment were:

- use of bright colours (Female, age 15)
- a teen friendly décor (Male, age 14)
- a deli with healthy food (Male, age 17)
- a teen room separate from the younger age groups play areas (Male, age 13)
- TV with various channels (Male, age 15)
- background music or internet connection (Female, age 17).

The setting for when or where clinics were held did not appear to be an issue and that any efforts to make them more relaxed would be appreciated but would still be viewed as a hospital setting.

*“Even if they take off the white coat, it is still going into hospital”* (Female, age 16)

*“Does not make a difference what they wear, they are still doctors/nurses”*

(Male, age 13)

*“Staff wearing jeans and casual tops is a nice gesture but not going to make a difference to me”* (Female, age 15).



The general impression was that after school clinics were not acceptable to any of the adolescents and that they would not be liked.

*“That is sport time, can miss half day school but can’t miss sports”* (Male, age 15)

*“Have to come a long distance every three months and it would just not be on”*

(Female, age 17).

### **Summary of Findings**

**In summary, the setting for where the clinic was held did not appear to be important. Waiting areas should be more friendly and relaxed with brighter environment, comfortable seating and activities to facilitate teenage interaction. Action taken to achieve a more relaxed atmosphere such as casual clothing and music would be appreciated as nice gestures but could not replace the fact that this was a hospital clinic. After school clinics were not deemed an option.**

### ***Clinic Appointment***

The whole group was happy with the clinic they attended and two members in one group had contacted the clinic by phone (Male, age 17 and Male, age 13) and were happy with how their concerns were dealt with.

*“Help is there if needed and this is reassuring and eases concerns”* (Male, age 16).

There was agreement that the clinic could be run in a more efficient way with suggestions including seeing doctor and the nurse together, having appointments with the dietitian on the same day and having the opportunity to bring up topics for discussion during the consultation.

Some of the aspects that participants were less happy with were the waiting time in particular and the fact that the clinic time took so long.

*“A morning clinic is terrible, it takes so long and I miss school”* (Female, age 15).

Most agreed that the long waiting time resulted in missing a full day of school which was not liked. However, a positive aspect of the waiting was the opportunity to meet friends.

There was limited agreement of when was an appropriate age to attend for a clinic appointment on their own. Some of the participants had demanded attendance on their own which worked for them and advised others to suggest a solo appointment and see how it worked. Other participants attended the “nurse” on their own and then had a joint consultation with their parents and the doctor. However, for some this resulted in the doctor talking only to the parent and ignoring them resulting in negative repercussions after the consultation.

*“The doctor gives out to my mother all the time and then there is war outside afterwards with me” (Female, age 17).*

There was no agreement as to what age it might be appropriate to attend their clinic appointment on their own but most stated.

*“When it feels right” (Male, age 15)*

*“And that there has to be trust with your parents if you are going to do this”  
(Male, age 16).*

Parents attending a consultation without the teenager created a feeling of exclusion and could be detrimental to the relationship.

*“Hate when my parents go in without me” (Female, age 17).*

### **Summary of Findings**

**In summary, there was agreement that the current clinic appointments were not optimum with long waiting time. This could be addressed by attention to how appointments were scheduled. There was no agreement as to what age was appropriate to attend the clinic appointment without parents but there was a general consensus that this should happen when the teenager felt they were ready for it and there was trust from their parents in their ability to make that decision. In joint appointments, it is important that the adolescent is included in joint decision making with their parent and diabetes team as many adolescents felt excluded.**

### ***The Diabetes Team***

The other very clear area that significantly impacted on Adolescents' clinic experience was their relationship with the professional staff.

*“It is important to have friendly staff”* (Male, age 15)

*“It is good when the staff were helpful”* (Male, age 13).

Many of the other participants said that one of the things that was good about their clinic was that the staff were *'nice'* or *'friendly'* or that they liked their doctor. Any negativity appeared to have focussed mainly on doctors with the majority of participants commented on the friendly atmosphere and that staff were friendly and nice.

A particular concern expressed was the relationship with the doctor i.e. if the adolescent didn't like the doctor this resulted in a negative clinic experience. Many of the adolescents expressed dissatisfaction with meeting different doctors, student doctors observing and expressed a preference for having Irish doctors deliver their care. Further exploration of the preference for Irish doctors indicated that the teenager really wanted somebody that spoke good English and understood them. Seeing different doctors resulted in having to repeat a lot of information which the adolescent believed should be part of their medical notes.

*“Only see same doctor every 5 visits and you have to tell the story all over again”*

(Female, age 16).

The relationship with staff also influenced how adolescents feel about the actual clinic appointment with participants stating that what is important to them is that *“Everything is done properly”* and that *“the doctors care about us”*.

The adolescents view as to whether the clinic appointment was a success or failure was influenced by doctors ‘*giving out*’ about blood sugars and giving unrealistic advice about how to manage them.

A sixteen year old boy stated that when the doctors give out it doesn’t help, “*the doctors should give us advice on how to have better readings and not just give out, they should give realistic advice*”. Much of the group nodded in agreement with this.

The issue of discussion around alcohol and how to manage it was a cause for concern, particularly for some of the boys. They don’t like the fact that it is ignored as if it is not happening.

*“As if they think young people aren’t drinking”* (Male, age 16).

There was a general consensus that alcohol should be mentioned from the age of 16 with some discussion that maybe it should be brought up at a younger age so that they can know about it even before they start drinking. There was also a consensus that the clinic appointment should offer the opportunity to find out about new things e.g. pump therapy, inhaled insulin, career options and what they could and could not do in the future. Participants felt that the current set up did not allow time for this and some feel bad about asking questions as “*They are doing so much for us already*” (Male, age 15).

### **Summary of Findings**

**In summary, there was a good relationship with the diabetes team but occasionally this was marred by meeting different doctors. There was a general view that the clinic appointment should offer the opportunity of discussing new diabetes therapies and other areas important in the adolescents life which might influence their diabetes management.**

### ***Transition from paediatric to adult services***

The majority of the adolescents felt happy with their current service and appreciated *“Being with their own age group”* (Male, age 13) as opposed to *“To go with those people who are old and sick”* (Male, age 15).

Only two adolescents were attending a transition clinic (Letterkenny/Mullingar) and one had moved to an adult clinic (Waterford) with all of the others in the group including a female aged 18 years still attending paediatric services. Non communication indications were that they had only experience of the current service and did not appear to have given any thought to what it may be like in adult services.

Discussion around the age at which there should be a move towards adult services was lively with no agreement as to what age was *“best”*.

*“Person should be asked, some are ready sooner”* (Male, age 15).

Nevertheless, they appeared to all agree that the transition period should be over a few years. The youngest age proposed to move towards the adult service was 14 but the age of 21 got some agreement.

*“I think 21 is a good age, like you would be living away from home”* (Female, age 15)

*“I think you should finish growing first”* (Female, age 15)

*“I do not think you should move at 18 because you have college and there is no structure to your life”* (Female, age 16).

There appeared to be a general impression that college life was haphazard and that trying to move towards stricter diabetes control during this time would be difficult. All of the adolescents appeared to understand that there would be a greater emphasis on reaching stricter diabetes targets when they moved to adult services.

*“Adult doctors focus more on targets”* (Female, age 13)

*“like trying to drop from 8 to 5, going down that much in so short a time”* (Male, age 17)

*“They would want you to change the number of injections a day, like 2 now is easier than 4”* (Male, age 15).

Most adolescents wanted to have a longer transition period preferably through an actual transition clinic because they were aware that their current paediatric service was more friendly and relaxed than adult diabetes clinics.

*“Like the way there are small groups and you always see a face you know”*  
(Male, age 14)

*“Transition clinics would be good, treated like adults but with more freedom to adjust and encourage you to adjust”* (Female, age 14)

*“Important to get to know new doctors and nurses before moving to adult centre”*  
(Female, age 15)

*“Need a few years to adjust and maybe focus on just one target at a time”*  
(Male, age 17).

The expanded transition period would also allow additional time to move from the more relaxed targets used by paediatric to the more focused targets of adult clinics.

*“difficult to come down quickly, being 8 and their saying 5, that’s a lot whereas 7 to 6.5 wouldn’t be as big”* (Female, age 15).

### **Summary of Findings**

**It was decided by the group that there was a very necessary need for a transition period during which time adolescents could be encouraged to take control of their diabetes with a focus on one target at a time and getting to know the adult service providers. The age for transition would differ and should depend on the maturity of the person themselves, who then should be allowed to self-determine the age. Transition should start around 14 years and continue until such time as the adolescent felt ready to let go of the paediatric diabetes team. An age of 21 was proposed as being appropriate because growth would be finished, college life would be becoming more structured and people would most likely be living independently. For some, the transition may coincide with a move to college or leaving home.**



## Chapter 4

### **Diabetes and Social Relationships**

It was apparent during the discussion groups that adolescents viewed diabetes as impacting on their family and school life. There was a lot of discussion around who should know about their diabetes, how much responsibility the adolescent had to give diabetes information to other people and how supportive or disruptive imparting that knowledge was.

#### **Parents**

There was general agreement that parents were too controlling and most specifically the participants' mothers.

*“I have an overly controlling Mother. It changes, she wants to oversee, it’s so frustrating!”* (Female, age 16)

*“Mum can be annoying”* (Male, age 17).

However, some adolescents did relate that the parental need for control might be related to recent diagnosis.

*“At the start, my parents were controlling, but gradually left me off, cos our GP had a chat with them and encouraged them to trust me”* (Male, age 17)

*“My parents were very involved at the start, but they have left off now”* (Female, age 14).

Although there was a general agreement that “controlling parents” were not welcome, their support would be appreciated especially when diabetes was not controlled.

*“Diabetes is out of control for the past year, parents neither over or undercontrol. They check in with me now and then. It’s very frightening and worrying when it is out of control”* (Male, age 14)

*“HbA1c was 14, I don’t ever want to be that scared again. Manageable goals are very important”* (Female, age 15).

It was agreed that it was possible to strike a balance between supportive and controlling.

*“I want parents to check on things, maybe at the end of the day, not at every meal. (Expression of exasperation) Once a day would be good!”* (Female, age 16)

*“Sometimes parents get panicky if you are low, they keep on asking – are you OK? I don’t want to be babied, it’s very annoying. Parents worry too much”* (Male, age 13).

Most of the participants agreed that parents had a role to play in helping them to manage their diabetes,

*“Important that the parents buy the right foods so less temptation”* (Male, age 16).

but that this should not interfere with treats for the rest of the family.

*“Sweet foods should be bought so the rest of the family didn’t suffer”* (Female, age 14).

There was some agreement that mothers were generally more involved than fathers.

*“Dad ignores it”* (Female, age 15)

*“Mother a nurse and so more involved, dad has not got a clue”* (Male, age 17).

but there were exceptions.

*“Father more involved”* (Male, age 15)

*“Mother timid, father forceful, both helpful and you can choose what side you need to listen to”* (Male, age 16).

Having both parents involved offered opportunities for better understanding.

*“Dads more mellow, mother freaks out and always repeating same things so Dads easier to talk to”* (Male, age 17).

### **Summary of Findings**

**Participants felt that parents and especially mothers could be very controlling and overprotective about their diabetes. Adolescents felt that there should be a balance between being controlling and supportive. Support was especially needed during times of poor diabetes control.**

## **Siblings**

There appeared to be a lack of input from the other family members,

*“It’s mainly my mother that gets involved, the others in the family keep out of it”*  
(Female, age 15).

The lack of input did not mean that the other family members would not know what to do.

*“My brother would know what to do if high, my sister knows about it as well”*  
(Female, age 16).

However, there was some agreement that their support would be appreciated.

*“But I would kinda like their support”* (Male, age 17).

Even when other members of the family had diabetes this did not mean that the diabetes was shared.

*“My brother has diabetes as well, he got it first, but he does not interact with me about diabetes”* (Female, age 15).

Siblings were involved only to the extent that they understood about diabetes and were helpful when going low but there was also the feeling that the understanding was superficial.

*“Younger brothers and sisters tend to get jealous because you are getting more attention” (Female, age 14).*

#### **Summary of Findings**

**Adolescents viewed diabetes as altering their relationship with siblings and even when the sibling had diabetes, this did not result in a shared diabetes experience. Other members of the family were usually not involved except that they would know what to do in case of an emergency. Some felt that the person with diabetes was viewed as getting additional attention resulting in jealousy, whereas, many adolescents would welcome support from siblings in managing their diabetes.**

### ***Informing People and their reaction***

There was a general consensus that adolescents would only tell people about their diabetes *“as they need to know”* or in individual circumstances. Although, it was accepted that family and close friends should know about your diabetes.

*“I don’t really tell anybody, they just find it out as you go along”* (Male, age 17)

*“They need to know about your lows”* (Female, age 15)

*“I don’t think you particularly need to tell the people you baby-sit for”* (Female, age 15).

When socialising, it was agreed that there were ways to plan around your diabetes management.

*“We share the pizzas and eat small amounts so its fun and its ok”* (Female, age16)

*“I eat chewing gum so I don’t eat too much”* (Female, age 17).

There was also agreement that other peoples’ best intentions made a person with diabetes appear different.

*“Sometimes when you are drinking diet coke people ask you are you trying to lose weight. They just don’t understand”* (Female, age 15)

*“I am only allowed to stay over at my cousin’s house. Parents are anxious that your sugars might be high”* (Male, age 14).

The entire group were used to carrying lucozade, dextrose sweets or hypostop but only a few of the group carried their meter regularly.

*“I lost it once so now I don’t bring it with me”* (Male, age 15).

None of the adolescents brought their diabetes testing equipment with them on social outings.

*“I wouldn’t bother bringing it if I was going to the cinema with friends”*  
(Female, age 15).

### **Summary of Findings**

**It was generally agreed that adolescents told people when they believed that person should know because of an underlying concern that telling people would result in them being treated differently. For the majority, social outings were a cause for adaptation or for some resulted in limiting the social outings. Generally, the participants would take positive steps to manage their diabetes but while socialising would not carry monitoring equipment.**

### **School**

There was general agreement that “teachers and coaches” should have a better general understanding of what diabetes is prior to their initial contact with young people with diabetes, rather than asking the adolescent for general diabetes information.

Overall the group had mostly good experiences with regard to school but agreed that the teachers should be better informed. Some negative experiences were evident;

*“Some times they think you are looking for an excuse to miss class” (Female, age 15)*

*“When I was younger at Halloween all the children in school were given sweets but I got false nails. I felt really different. It was awful” (Female, age 16)*

*“The teachers sometimes give out even when I take a drink” (Female, age 14).*

but there were equally positive experiences.

*“My school is really good and they let my friends help me when I am hypo. They have a box with all the things I might need” (Female, age 16)*

*“They don’t really say anything but they know what to do” (Male, age 15)*

*“My friends in school are really interested; they look on and want to know more”(Female, age 13).*

The school experience was also mirrored in sporting activities with some participants reporting not telling their coach they had diabetes,

*“They may treat you differently if they think you have diabetes” (Male, age 16).*

or having informed the coach being targeted for different treatment on the playing pitch.



*“In the beginning I was left on the sideline, because the teacher didn’t understand”*

(Female, age 15)

*“I didn’t get to play the full match. I felt awful because I knew I was good. I know it was because of my diabetes”* (Female, age 17).

Others felt that having diabetes resulted in the constant fear of the onlookers that the teenager would go low to such an extent that it interfered with their sporting activities.

*“They are afraid to push you because they think you might go low”* (Female, age 14)

*“My coach does not want me to do long runs and my mother follows me around with sweets”* (Female, age 14)

*“I was dropped off the hurling team at the start, it was very annoying. I am back on it now. So, it’s OK now”* (Male, age 14).

Having diabetes impacted on all parts of their life.

*“Some people do not expect the same of you when you have diabetes. My teacher wants me to repeat the year just because I missed one week”* (Female, age 15).

### **Summary of Findings**

**It was generally agreed that teachers in general should have a better understanding and knowledge about diabetes. Physical Ed teachers and coaches**

**need to be more aware of the positive effects exercise has for diabetes management and not to restrict the adolescent's sports activity because of fear of low blood sugars.**

### ***Responsibility***

There was a lot of debate/exploration around when the teen should be independent with their diabetes self management with agreement that there was “*no specific appropriate age*” (Male, age 17) but “*Whenever they feel ready*” (Male, age 16) but that “*Less than 11 would be too young*” (Male, age 14).

There was some agreement that the age may be related to the length of time since diagnosis and should be related to self-administration of insulin and self-monitoring.

Some participants felt that their parents were overprotective,

*“Parents tended to ask the same questions every time the teen left home; have you got your insulin/strips, Coke etc?”* (Male, age 13).

with some participants reporting a very negative experience of parents lack of trust.

*“Parent needed to observe every injection administered”* (Male, age 14)

*“Checked the rubbish to count the test strips, there was no trust around diabetes”*  
(Female, age 15).

Others felt that trust had to be built on

*“That's normal for parents and trust needed to be built up gradually”* (Male, age 17).

and that trust was not just diabetes related.

*“Parents who trust the teen in other areas will trust them with their diabetes”* (Female, age 14) and vice versa (Male, age 13).

### **Summary of Findings**

**Adolescents considered that there was no specific age for self management of diabetes but the general consensus was when the person felt themselves to be ready and control was reasonable. Those that were diagnosed at an older age tended to have more independence. Adolescents perceived that the issue of parental trust about diabetes management was related to parental trust in other areas. Adolescents felt that the main role of parents should be to support them and that they felt listened to rather than nagged. This could be best achieved by discussing options and making joint decisions.**

### ***Other Themes***

During the course of discussion, it was apparent the participants were upset by the confusion “*out there*” between type 1 and type 2 diabetes. The media focus on poor lifestyle habits “in causing diabetes” is misleading as it is not related to getting type 1 diabetes.

It was generally accepted that having diabetes made “*you different*” and resulted in additional “*stresses*”

*“You have to mature much quicker than your friends; you always have to be prepared”*  
(Female, age 16)

*“Peers don’t have to worry, it’s really unfair”* (Male, age 15).

The additional stresses appear to be related to the additional equipment needed to carry around in order to manage diabetes.

*“I don’t mind the injections, but I hate carrying the stuff around”* (Male, age 17)

*“Have to carry everything around. Like when I go to the cinema with my friends, they only have to carry money”* (Female, age 16).

There was also a recognition that diabetes would continue to have a negative impact on some aspects of their life.

*“Insurance can be very high when you have diabetes, they don’t worry about heart disease”* (Female, age 16)

*“I was refused a jockey licence, I trained and my weight is fine”* (Male, age 14).

### **Summary of Findings**

**Adolescents were aware of the negative aspects of having diabetes which currently impacted on their social life and would continue to impact on their life as they grew older.**

## **Chapter 5**

### **Conclusion**

There was much overlap in the discussion groups with recurring themes echoed between the groups. Adolescents felt that having diabetes imposed additional strains on their life and had a negative impact on most areas of their life. Adolescents report a negative attitude to diabetes and consider that it interferes with the normal pattern of life.

The physical environment that adolescents attend for clinic appointment could be addressed and this would be appreciated and may lessen the disruption to daily life incurred by attendance at hospital regularly. Similarly, streamlining the appointments with hospital staff would be beneficial. The adolescent's relationship with hospital staff differed but generally there was a good relationship with the team and adolescents felt they could contact the clinic for support when needed. Negative views related around the waiting times and meeting different doctors at clinic appointments.

Adolescents wanted to be able to discuss with their diabetes teams what new and current options were available to them both in diabetes management and daily life. There was no ideal age for transition to adult services but there was agreement that there needed to be a longer transition period from paediatric to adult services so that individuals could move when other issues in their life either dictated a transfer or facilitated the move.

Having diabetes affected the relationship with parents and for some resulted in curtailment of certain activities. In general, having diabetes did not impact on peer relationships but had to be accommodated on social outings. Generally, adolescents did not bring their diabetes equipment with them when socializing. There was no appropriate time for assuming the responsibility for diabetes self-management but adolescents felt that they would know when and would assume responsibility when ready.

All of the adolescents expressed the view that telling people they had diabetes resulted in them being treated differently and for many had negative repercussions. They were also aware that diabetes would continue to have a negative effect on their career options and future life.

## **Chapter 6**

### **Recommendations**

1. Adolescents have concerns about the clinic they attend. They do not welcome sharing the waiting area with young children and feel that they should have designated areas where they could meet their peers and have some activities to minimise the hospital settings. The environment of clinics would be enhanced by more appropriate décor and whereas this would not improve the clinic visits, the gesture of improving décor would be appreciated.
2. Transition clinics should be set up between paediatric and adult services where the adolescent has the continuing support of the diabetes team they know while they get to know the “adult” team. The practice of seeing a different doctor for each visit results in repetition and wastage of professional time while contributing to a lack of trust in the healthcare system by the adolescent.
3. Adolescents would welcome the opportunity of having joint consultations with their nurse and doctor. Doctors should remember that when parents are part of the consultation, adolescents still should be included. It should be remembered that adolescents miss school for each hospital appointment and therefore all appointments should be on the same day. Out of hours clinics are not an option for adolescents because of their involvement in extra curricular activities which can not be missed without repercussions.
4. Diabetes impacts on all aspects of family life and families need professional support to manage this effectively for the normal development of the teenager.
5. Parental attempts to control their adolescents’ diabetes can reflect a lack of trust. Adolescents are aware that that trust can only be assumed gradually and that the trust is not just diabetes related.

6. The majority of families can accommodate the impact of diabetes successfully but there may be some families who have difficulties and they should have access to appropriate professional support.
7. Adolescents want to be joint decision makers with their parents and diabetes teams. The time at which they assume responsibility for their diabetes self-management should not be age related but dependant on ability to self-administrate insulin and self-monitor diabetes control.
8. Adolescents whose diabetes is not controlled welcome support from parents and siblings.
9. Adults, especially in a professional capacity, who know they will be in the company of young people with diabetes should have a reasonable knowledge of diabetes and its' management and should not rely solely on the teenager for information. The need for this is especially apparent among teachers and coaches.
10. There needs to be a better understanding from the general public that people with diabetes can live a full and normal life with diabetes and can take part in all sporting activities.
11. There needs to be increased focus on differentiating between type 1 and type 2 diabetes so that adolescents are not discriminated against due to lack of understanding of the difference between poor lifestyle habits contributing to the development of type 2 diabetes and the dietary and physical activity goals outlined in the management of type 1 diabetes.





## **Appendix 1**

### **Indicative questions for focus groups with young people**

For the purpose of these focus groups, the term “adolescent” should be taken to refer to people who are aged between 13 and 18 years.

The following questions were used to guide individual focus group discussions.

#### **1 The optimum diabetes clinic**

Each session began with a ice breaker to introduce each participant to each other and to the facilitator.

The participants broke into pairs and took a few minutes for each teen to introduce their partner’s details, i.e. name, age, where from, time diagnosed and one word to describe how they feel about diabetes.

Scenario (read by facilitator)

I have had Diabetes since I was 4 years old, I don’t remember a time when I did not have Diabetes, I have grown up with it and every three months I attend the OPD for review. More often that not, I meet with a different doctor and they ask me the same questions about my diabetes on a daily basis, they never ask about me! Sometimes they ask me questions and I know that the answers are written on the file – that is so annoying!! What is my Hba1c? Do I want to know, I am curious, but do I really want to know!! Mam always wants to know!!!

The following questions were addressed:

1. What makes a good diabetes clinic? .. characteristics, etc?
2. How/What would improve your experience attending a diabetes clinic? i.e. What would make attending your clinic better for you?
3. Which characteristics make your experience attending a diabetes clinic unpleasant?.....what do you not like in your current clinic?
4. At what age should you leave your mother outside and attend on your own? ..... individual consultations start?
5. Who should decide consultations are private to you alone (exclude parents)? .....is it you/ how can you tell your parents not to attend with you, the doctor,
6. What would an ideal diabetes clinic be? What is essential for an ideal clinic?

#### **2 Transition from Paediatric to Adult services – the Difficulties,**

Each session began with a ice breaker to introduce each participant to each other and to the facilitator.

The participants broke into pairs and took a few minutes for each teen to introduce their partner's details, i.e. name, age, where from, time diagnosed and one word to describe how they feel about diabetes.

Scenario (read by facilitator)

I turned 16 or 18 years recently and I have been transferred to the Adult OPD service for my three monthly review. I went to my first appointment and it was so different! My Mother was with me and we could not find the right place for ages. The first thing I noticed was all the old people in the waiting area, do all these people have Diabetes and some of them look sick! The nurses and doctors all look really under pressure and I don't see even one familiar face.

The following questions were addressed:

1. What do you like about the clinic you attend at present?
2. What about the surroundings/people are important to you?
3. Has anyone moved clinics? What is your experience?
4. How do you feel about the care you receive at present?
5. What age do you think you should move towards adult clinics?
6. What do you think is important for you and your doctor to discuss before you move?
7. Do you think you should be able to select which hospital/clinic to attend?
8. What factors are important in a transition clinic? Do uniforms make a difference? What about timings- would you like to attend an after school clinic?
9. What could the professionals be doing to help you?

### **3 Telling my friends and school mates about diabetes – my fears,**

Each session began with a ice breaker to introduce each participant to each other and to the facilitator.

The participants broke into pairs and took a few minutes for each teen to introduce their partner's details, i.e. name, age, where from, time diagnosed and one word to describe how they feel about diabetes.

Scenario (read by facilitator)

I was diagnosed with Type 1 Diabetes when I was eleven. I was in hospital and missed school for two weeks. I was nervous telling my friends but they had come to see me in hospital so I never really had to tell them straight out. My Mother went over the top and told the teachers and the principle, it was so embarrassing! I am going to secondary school in September and I am worried about the scene there, how will I tell, will I keep it to myself and just work it out for myself. I am afraid that people will call me a druggie if they see me with needles! One day somebody asked me if I had ate loads of sweets and is that why I have Diabetes???

The following questions were addressed:

1. Who do you think should know about your diabetes?
2. Recall a positive experience in telling someone about diabetes?
3. Recall a negative experience in telling someone about diabetes?
4. When should you tell someone?
5. Do you keep your diabetes a secret from anyone?

#### **4 Relationships within my family.**

Each session began with a ice breaker to introduce each participant to each other and to the facilitator.

The participants broke into pairs and took a few minutes for each teen to introduce their partner's details, i.e. name, age, where from, time diagnosed and one word to describe how they feel about diabetes.

The following questions were addressed

1. At what age do you think a person should be left to totally self-manage their own diabetes? i.e. blood test, adjust insulin attend clinics on their own.
2. How much responsibility do you have for your own diabetes?
3. How much responsibility for your diabetes do you feel you should have?
4. What do you think are the essential parts of looking after your own diabetes?
5. Do you think your mother is involved more that she should be? Is your mother overprotective?
6. Do you think your father is involved more that she should be? Is your father overprotective?
7. What about your brothers and sisters? Are they involved?
8. Role of school teachers?
9. Would you ever telephone the diabetes clinic about a diabetes issue you were concerned about?

#### **5 Taking responsibility for my own diabetes - my role/my family's role**

Each session began with a ice breaker to introduce each participant to each other and to the facilitator.

The participants broke into pairs and took a few minutes for each teen to introduce their partner's details, i.e. name, age, where from, time diagnosed and one word to describe how they feel about diabetes.

Scenario (read by facilitator)

My name is Michelle. I am a diabetic nurse specialist working in the HSE. I am currently working with a 15 year old girl, Claire who was diagnosed with diabetes 3 years ago. The last time we met her HbA1c was 14%. When Claire showed me her diary her bloods were all under 15. I think that she is making up the results in her diary.

Her mum tells me that Claire wants to manage her diabetes by herself and does n't want her mum to help her. Claire has told me that she thinks that she is old enough and responsible to manage her diabetes. Her mum on the other hand has told me that she never records her results in her diary and only does it the day before clinic appointments. She also tells me that Claire won't take her monitor with her when she is going out with her friends.

I want to give Claire the responsibility but I am also concerned about what her mum is telling me.

What should I do???

Here are some ideas.....

1. Leave mum with complete control of Claire's diabetes because realistically Claire won't be able to do it all and still needs her mum's help
2. Encourage Clare to do it all herself as she is 15 years old and will have to do it all herself soon anyway. She can learn from her mistakes.

The following questions were addressed:

1. At what age do you think a person should be left to totally self-manage their own diabetes? i.e. blood test, adjust insulin attend clinics on their own. How much responsibility do you have for your own diabetes?
2. How much responsibility for your diabetes do you feel you should have?
3. What do you think are the essential parts of looking after your own diabetes?
4. Do you think your mother is involved more that she should be? Is your mother overprotective?
5. Do you think your father is involved more that she should be? Is your father overprotective?
6. What about your brothers and sisters? Are they involved?
7. Role of school teachers?
8. Would you ever telephone the diabetes clinic about a diabetes issue you were concerned about?

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