

**Transition of care of
Adolescents/Young Adults with Type 1
Diabetes Mellitus from paediatric to
adult outpatient services:
A mixed methods study of adult
outpatient health care providers**

Final report on behalf of National Clinical Programme Diabetes

Written by

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GLOSSARY OF ACRONYMS

ANP	Advanced Nurse Practitioner
CGM	Continuous Glucose Monitoring
CNS	Clinical Nurse Specialist
CPD	Continuous Professional Development
CSII	Continuous Subcutaneous Injectable Insulin
FGM	Flash Glucose Monitoring
GP	General Practitioner
HbA1c	Glycosylated Haemoglobin A1c (measurement of glycaemia)
HSE	Health Service Executive
iCGM	Intermittently scanned Continuous Glucose Monitoring
MDI	Multiple daily injections (of insulin)
MDT	Multidisciplinary Team
MMUH	Mater Misericordiae University Hospital
RANP	Registered Advanced Nurse Practitioner
T1DM	Type 1 Diabetes Mellitus
WTE	Whole Time Equivalent

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Table of Contents

Executive Summary	1
Key Findings.....	1
Key Recommendations.....	2
Introduction	4
Methods	6
Online questionnaire.....	6
Online survey procedure.....	6
Follow up telephone interviews.....	7
Results	8
Response rate.....	8
Respondents.....	8
Non-responders.....	8
Source of referrals.....	9
Age at referrals.....	9
Transition clinics/service.....	10
Referral letter.....	11
Recall of adolescents/Young adults.....	13
Type of clinic adolescents/young adults attend in adult service.....	13
DNA policy.....	14
Transition of Care Coordinator.....	15
Accept referrals of adolescents/young adults on pumps.....	15
Adult Service Clinical Staff supporting insulin pump service.....	17
Training for staff to support pump service.....	18
Barriers and facilitators to delivering a pump service.....	19
Knowledge of transitioning YAs regarding pump technology.....	19
Adolescent/Young adult preferences.....	19
Discussion	22
References	26

Executive Summary

Background

This was a mixed methods study (online survey and follow up telephone interview) conducted in 2022 to assess current practices before, during and after the transfer of care from public paediatric to adult outpatient services from the perspectives of adult care providers. 62% (n = 18) of eligible outpatient services completed an online survey and 59% (n=17) provided numbers of adolescents/young adults transitioned in 2021.

Key Findings

- Referrals to adult diabetes outpatient services from the standalone children's hospitals usually happen at 16 years of age. Referrals from other paediatric outpatient services usually happen at the age of 17-18 years after the young person has completed their Leaving Certificate exam at the end of the secondary school system.
- Over half of adult services reported holding joint face-to-face paediatric-adult transition clinics prior to the transfer of care. Variations existed in which paediatric services they held transition clinics with, how often they met with the young adult prior to the transfer of care, which health care professionals attended the transition clinics and where transition clinics took place.
- Referral letters from paediatric services are usually unstructured with a written medical summary being the main type of information provided. A psychological summary and information on the young person's self-care skills, goals, transition readiness and preferences for parent/carer involvement in adult services were less likely to be included although some of this information is shared verbally in hospitals that hold joint paediatric-adult transition clinics.
- Many adult outpatient services are not meeting international guideline recommendations that the time between the last paediatric and first adult care appointment should be 3- 4 months.
- Many adult outpatient services are not meeting international guideline recommendations that young adults with T1D should be seen by a specialist diabetes team every 3 months at minimum.
- Over half of adult outpatient services reported seeing transitioning adolescents/young adults in a Young adult (YA) Clinic but differences exist across adult outpatient services in the upper age limit that attend the YA clinic and the size of the YA clinic.
- The percentage of transitioning adolescents/young adults on CGM/FGM ranged from 42% to 100%.
- The percentage of transitioning adolescents/young adults on insulin pumps ranged from 12 to 88% with higher proportions being reported by adult services who received most of their referrals from the standalone children's hospitals.

- Over half of adult services reported having a DNA protocol. Variations exist in terms of the number of sequential DNAs before the young adult was discharged back to their GP ranging from 1 to 4 DNAs. The majority of adult services perceived DNA rates in this group to be higher than in other age groups with estimated DNA rates ranging between 25 and 50%.
- Not all adult services accept transitioning adolescents/young adults using pump therapy from paediatric outpatient services. This was a particular issue where on-site paediatric services that provided a pump service could not transition these patients to their on-site adult service.
- Barriers to providing an insulin pump service included the time involved in providing a pump service, lack of dedicated nursing and/or dietetic time to support a pump service and lack of clinical staff's knowledge of pump technologies.

Key Recommendations

- A more structured systematic approach to transition of care and better collaboration and communication between paediatric and adult providers is required to improve the transition of care experience and outcomes of adolescents/young adults transitioning from paediatric to adult services in some centres.
- Each centre providing a paediatric service need to have a defined pathway to adult services that is written down and agreed and each paediatric centre should know approximately how many each year they need to transition to adult Diabetes services and location of same. There will need to be flexibility to accommodate the young person with Diabetes preferences given they may be moving away to commence college or employment. There are benefits to using a person-centred structured referral letter including other types of information including a psychological summary, self-care skills, goals, transition readiness and preferences for parent/carer involvement in adult services in addition to the standard medical summary provided.
- Considering the high level of DNA rates reported among this group, further exploration of alternative methods of engaging with this cohort of people with Diabetes to support Self-Management should be explored in addition to the traditional face to face clinic appointment.
- The Adult Diabetes centres receiving the care of the young adult need to identify what they need to ensure that they can meet the clinical needs of this cohort of young people with Diabetes. This may include a review of staffing levels in Diabetes centres and formulating business case for sufficient staffing for Diabetes and Technology clinics and young adult clinics. Medical clinicians, nursing, Dietitian, Psychology and dedicated administration resources should be available.

- There is a need to support national training and education for diabetes outpatient staff involved in initiating and supporting patients on insulin pump therapy as these technologies continue to evolve rapidly.
 - Importance of basic training in the functions and principles of insulin pump therapy and CGM is also important for non-specialist hospital staff who are likely to come in contact with people using these technologies when attending health services for other reasons other than their diabetes.
 - ‘Specialist’ hospital centres that are currently initiating and/or supporting people on insulin pump therapy on behalf of other hospitals that cannot currently provide this service need to be adequately resourced to provide this service.

Introduction

Transition of care from paediatric to adult services has been defined as the '*purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centred to adult-oriented health care systems.*'¹ Transition of care refers to an active process over a period of time that happens before, during and after the transfer of care from paediatric to adult services. A successful transition of care aims to provide young people with the required knowledge, skills and support to adapt to their new role of self-managing their condition in an adult health care setting and reduce the risk of young people 'dropping out' of the health care system and/or experiencing poorer health outcomes.

'Emerging' adults has been defined as a developmental period in between adolescence and adulthood spanning from about ages 18-29 years occurring mainly in Westernised cultures where young people are allowed a prolonged period of independent role exploration during the late teens and twenties.²

The transition from family-oriented paediatric health services to more autonomous adult services can be challenging for 'emerging' adults with type 1 diabetes (T1D), their families and the health care professionals that support them.³ Young adults often struggle to adjust to different styles of health service delivery in the adult service and the new levels of personal responsibility expected of them at a time that they are also becoming more independent and moving out of home to attend college or to join the workforce.⁴

The transition of care from paediatric to adult services for young adults with type 1 diabetes has been associated with a decline in outpatient hospital clinic attendance, poorer self-management, deterioration in glycaemic time in range and an increased risk of adverse outcomes and higher blood glucose levels compared to younger and older people with the condition.^{5,6}

Advances in technology have had a major impact on type 1 diabetes management. Meta-analyses have shown a significant reduction in HbA1c in patients using continuous glucose monitoring (CGM) compared to self-monitoring of blood glucose (SMBG) and in patients using insulin pump therapy (also known as continuous subcutaneous insulin infusion (CSII) therapy) compared to multiple daily injections.^{7,8}

CGM and insulin pump therapy are increasingly being used in children with type 1 diabetes as they have been shown to improve glycaemic control and quality of life.⁹ The Irish National Paediatric Clinical Programme's Model of Care (2012) recommends that insulin pump therapy should be provided to children under five, where appropriate.¹⁰ Although uptake of insulin pumps in people with type 1 diabetes in Ireland remains

low compared to other European countries, a study conducted in 2016 found that the uptake was five times higher in those aged under 18 years with 43% of those using insulin pumps being children and adolescents.¹¹

With the growing use of insulin pump therapy in Ireland, more and more young people with T1D will be using this therapy at the time of transition of care to adult outpatient services. A national audit of Irish paediatric services reported that a total of 233 adolescents/young adults aged 16-19 years were transitioned from paediatric to adult outpatient diabetes services in 2020. Although the number using insulin pump therapy was not reported, anecdotal evidence from the audit suggested some paediatric services were unable to transition adolescents/young adults on insulin pump therapy to co-located adult services as the adult service did not provide an insulin pump service.¹²

The National Clinical Programme for Diabetes (adult programme) was established in 2010 as a joint collaborative between the H.S.E. and the Royal College of Physicians. The primary aims of the programme were to provide clinical leadership to improve the quality and access to Diabetes services while also improving the efficient use of resources. The programme provides clinical leadership through the development of evidenced based best practice Models of Care and guidelines. In 2011, The National Clinical Programme for Paediatrics and Neonatology was established as a joint initiative between the HSE and Faculty of Paediatrics at RCPI. A Clinical Lead for Paediatric Diabetes was allocated. In 2021, the Clinical Lead with the adult Diabetes programme was requested to join a Transition working group to review the process and challenges for transition of care. The need for this mixed methods study was identified. The Adult Diabetes NCP had experience of completing a comprehensive study of diabetes care in Adult Services in 2017 using a similar methodology.

The objectives of this mixed methods study of adult outpatient health care providers on the transition of care of adolescents/young adults with type 1 diabetes from paediatric to adult outpatient services were to establish:

- 1) Adult outpatient services involvement in the transition of care process prior to the transfer of care to adult services
- 2) The clinical management of adolescents/young adults in the adult service following transfer of care
- 3) The proportion of adolescents/young adults using CGM/FGM at the time of transition
- 4) The proportion of adolescents/young adults using insulin pump therapy at the time of transition.

Methods

This was a mixed methods study using a sequential explanatory design where the researcher (MOD) collected and analysed quantitative online survey data first and then conducted telephone interviews with respondents to gather data to explain and elaborate on the quantitative findings from the survey data. The study was conducted between June and October 2022.

30 public outpatient services were approached via email by the National Diabetes Programme and asked to:

- i) complete an online questionnaire to measure existing transition of care services and adult outpatient care for this population following transition of care
- ii) take part in a follow up telephone interview to explore in greater detail responses to the completed online questionnaire.
- iii) provide numbers of adolescents/young adults transitioned to their adult outpatient service in 2021 and if using CGM/FGM and/or pump technologies.

One survey was completed on behalf of the following hospitals

- Cavan and Monaghan
- Our Lady of Lourdes Hospital Drogheda and Louth County Hospital
- University Hospital Limerick Group (UHL, St John's Hospital, Ennis, Nenagh)

Online questionnaire

The questionnaire was developed by members of the National Diabetes Programme and was informed by existing survey instruments reported in the research literature.¹³⁻¹⁵ The questionnaire was piloted in 1 adult service in the Saolta Hospital Group. Following feedback from the pilot, minor adjustments were made to the questionnaire.

Online survey procedure

An email invitation was sent to a named Consultant Endocrinologist or Physician involved in delivering outpatient adult diabetes care in each hospital. The Consultant was asked if they or another member of their team would be willing to complete the online survey on behalf of the hospital and to provide numbers of adolescents/young adults transitioned to their adult service in 2021. They were informed that on completion of the online survey they would also be asked to take part in a follow up telephone interview to clarify and/or seek further information on responses. Prompt reminder emails with request were sent.

Follow-up telephone interviews

Interviews were conducted by telephone by MOD following completion of the online survey. A semi-structured interview schedule informed by individual's responses to the online survey was used to guide the interviews. Quotes from interviewees presented in the results section are referenced using study ID numbers.

Results

Response rate

Online survey

18 of the 30 hospital outpatient services completed the online survey giving a response rate of 60% (18/30). Of these 18 services, 1 adult service did not accept referrals of YA with T1D to its adult service and was excluded from further analysis. Another hospital only provided qualitative feedback in the comments box of the online survey so only 16 hospital services were included in the quantitative analysis of the survey responses.

Follow up telephone interviews

12 survey participants took part in a follow up telephone interview covering 13 hospital services. Two of the 12 interviewees indicated that their responses were based on their own clinical practice and that their fellow consultant endocrinologist may have different responses based on their own practice.

Number of adolescent/young adult referrals

17 hospital outpatient services provided numbers of adolescents/young adults transitioned in 2021. One respondent only provided numbers for their onsite referrals and not referrals from other sites and 2 provided estimated numbers. Of these 17 hospitals, 14 had also completed an online survey and additional information on numbers was provided by 10 adult services in the follow up interview.

Respondents

Survey respondents included 9 Consultant Endocrinologists (covering 10 outpatient adult services), 2 Advanced Nurse Practitioners (ANP), 3 Diabetes Clinical Nurse Specialists (DNS) and 1 dietitian. The 12 interviewees included 7 Consultant Endocrinologists, 1ANP, 3 DNS and 1 dietitian.

Non-responders

No online survey was completed by the eight hospitals in the Ireland East hospital group but 3 of these 8 hospitals provided numbers of adolescents/young adults referred in 2021. One hospital in the Dublin Midlands group did not complete an online survey but provided numbers. Two hospitals from the Saolta Group, and 1 from the South-South West hospital group did not complete an online survey or provide numbers on adolescents/young adults transitioning in 2021.

Main source of referrals

Hospitals with on-site paediatric services

11 of the 16 hospital services have an on-site paediatric service. 10 of these hospital services participated in a follow up telephone interview. Of these:

- 6/10 indicated that the main source of their referrals was their on-site paediatric service.
- 3/10 received referrals from both on-site and other paediatric sites
- 1/10 described their paediatric service as an 'ad hoc' service. The majority of their referrals were from paediatric patients who had been referred to specialist centres and were now transitioning back to the adult service.

Hospitals with no on-site paediatric service

Of the 5 services with no on-site paediatric service, 3 took part in a follow up telephone interview. Of these 3 hospital services:

- 2 received referrals from more than one paediatric service
- 1 received referrals from one paediatric service

Age at referral

Fourteen of the 16 adult outpatient services reported that 16 was the earliest age their adult service accepted referrals from paediatric outpatient services. Two adult services reported that 18 was the earliest age their adult service accepted referrals.

Additional feedback from the 13 respondents who participated in the follow up telephone interview that most paediatric services kept young adults until they had completed their Leaving Certificate and that the usual age of referral would be 17 or 18 years old.

"In general they don't tend to transition them until Leaving Cert year (012)

Hospitals receiving referrals from the stand-alone paediatric services said that patients would be referred at the age of 16. Other hospital sites also described how some 16-year-olds would also be accepted into the adult service if they had been admitted to hospital for their diabetes.

"Yes, from the stand-alone paediatric hospitals it would be 16 years" (08)

"...if coming in frequently (to hospital) for DKA...so we (adult services) ...if we are seeing them as adults (as inpatients) we would take them over, we take them earlier...."(01)

1 interviewee who reported that 18 years was the earliest age they accepted referrals into the adult service described how “*young adults transfer from the paediatric service to the transition service at 16 years (apart from those on pumps who stay in paediatric service until 18) and when they reach age 18 they transfer to adult service.....but if vulnerable, we keep them until 19 or 20 (in transition service).* (04)

Transition clinics/service

10 of the 16 hospital services (63%) who completed the survey indicated that they always/usually held joint face to face transition clinics (with paediatric colleagues) where members of the adult team met with the transitioning young adult prior to the young adult attending the first adult service appointment.

Additional feedback from the follow up telephone interview for 7/10 of these hospital services highlighted the variation in transition services across hospitals in terms of:

- The number of paediatric services with which adult services held joint transition clinics
- how often they met with the young adult prior to transition of care ranging from 1 appointment to 3-4 appointments before attending adult service
- which HCPs from paediatric and adult service attend clinics and
- the location in which these clinics took place.

One interviewee commented that ‘*there is no clear evidence on what the approach should be*’ with transition clinics and that the most important thing was to make a connection with the transitioning YA before they attended the adult service for the first time.

Of the 4 hospital services that did not have a transition service, 2 provided additional information in a follow up telephone interview. One service had set up a transition clinic but could not sustain it due to staffing issues but their dietitian attended both the paediatric and adult service so was familiar with the adolescents/young adults transitioning to the adult service.

Another hospital service reported being unable to set up a transition service because of the demands on both the paediatric and adult services with no capacity to add a transition clinic to the existing service. This interviewee commented that adult specialist nurses try to link in with the paediatric nurses and the adult service has also held group evening meetings in the past where transitioning YAs can attend to meet the adult diabetes team.

Referral letters

Survey data on the types of information usually included in a referral letter from outpatient paediatric services to adult services is shown in Table 1.

Table 1 Types of information included in a referral letter from outpatient paediatric services (n = 16)

Type of information	Always/Usually N (%)	Sometimes N (%)	Rarely/Never N (%)
Medical summary	16 (100)	0 (0)	0 (0)
Psychosocial summary	5 (31)	0 (0)	11 (67)
YA goals	1 (6)	3 (19)	12 (75)
YA self-care skills	4 (25)	3 (19)	9 (56)
Transition readiness	4 (25)	1 (6)	11 (69)
Pending actions summary	7 (44)	1 (6)	8 (50)
YA preference for parent/carer involvement	4 (25)	0 (0)	12(75)

A written medical summary was always/usually provided in the transition of care referral letter from paediatric services. Less than a third (5/16) reported receiving a psychosocial summary in the referral letter. Only a quarter of respondents (4/16) reported receiving written information on the young person's self-care skills, transition readiness and the young person's preference for parent/carer involvement in adult services.

Qualitative data confirmed that the main type of information provided in a referral letter was a medical summary. Some interviewees whose adult service had a transition clinic/service with paediatric services commented that other types of information in addition to medical summary would often be shared during these transition clinics.

"We do a shared transition clinic with X paediatric service so when we meet the paediatric team a lot of this information is discussed between the adult and paediatric teams so we have a feel of what the YA is like but this may not be written down formally" (08)

"In the referral letter it is mainly medical information but in the transition service there would be additional information shared (verbally) between paediatric nurses and adult nurses and consultants" (04)

Another commented that since completing the online survey their adult service now received a detailed referral letter from their on-site paediatric service in addition to running the transition clinic.

Qualitative feedback from interviewees indicated that most written referrals are not structured and that the level of information will vary depending on the consultant/paediatric service referring. Only one interviewee indicated their service used a structured proforma for referrals from paediatric services to their adult diabetes service and that the information they received was quite detailed.

- Length of time before 1st appointment in adult service eight of 11 hospitals (73%) reported seeing adolescents/young adults referred from their on-site paediatric services within 6 months of their last paediatric appointment.
- Seven of 11 hospitals (64%) reported seeing adolescents/young adults referred from other paediatric outpatient services within 6 months following last paediatric appointment.
- 1 hospital reported a gap of over 7-9 months before adolescent/young adults were seen in adult service. The interviewee clarified in the follow up interview *“we don’t manage the waiting list for the adult service....when we are requesting appointments in adult service we ask for 4 monthly or 6 monthly but may be take longer”* (04)
- 1 hospital reported a current waiting time of 10-12 months. In the follow up interview the interviewee commented that she was relatively new in post and that she hoped this waiting time would be reduced over time.
- *“My waiting list, my clinic lists, takes up to a year. I am hoping this will change, just the way my clinics have been built, not much flexibility to add in a new clinic currently”* (03)
- 1 hospital reported a waiting time of over 12 months due to long waiting lists to access adult service

Two hospitals reported different waiting times to access service for on-site and other paediatric referrals in the online survey. One interviewee explained the difference in times in the follow up interview.

“From here (onsite paediatric service) all that happens is someone books them into young adult clinic, nurses ring over from paediatric service and they are booked into YA clinic....if it comes from other paediatric service (via referral letter), they have to be graded by one of the consultants and assigned to a YA clinic so may take a bit longer” (01)

Recall of adolescents/Young adults

Three of the 16 (19%) adult services reported a recall time of every 3 months and 7 out of 16 (44%) reported a recall time of every 6 months for adolescents/young adults attending their adult service. Of these hospitals, two interviewees provided additional information in the follow up interviews saying it would depend on the person's individual needs.

"they would usually be seen every six months, patients that are doing well, every 3 months if not doing well or needing more support" (07)

Type of clinic adolescents/young adults attend in adult service

Nine of the 16 adult services (56%) reported that adolescents/young adults were seen in a Young Adult clinic. Additional feedback from the follow up telephone interviews highlighted variation across the age group range attending YA clinics in different adult services. One hospital service reported an age range of 16-19 years.

" Our Young adult clinic is for people aged 16 to 19 years, after 19 years they go to the general diabetes clinic" (02)

The majority of other interviewees reported upper age limits of 23, 24, 25 and 30 years for their Young adult clinic.

"17 to 23 years of age. We used to do it to 25 years but numbers were getting too big...so had to adapt age" (07)

"When they hit 24, we move them to the adult type 1 service" (08)

"At the moment they attend Young adult clinic up until 25 and then attend adult clinic" (10)

"Age group for young adult clinic is 16 to 30 years" (012)

Variations in the size of the young adult clinics were also reported by interviewees ranging from 10 to 30 young adults attending a Young Adult clinic.

Qualitative data also highlighted differences in the type of clinic adolescents/young adults on pumps attended with one hospital describing how adolescents/young adults on pumps attended both the Young adult and pump clinic.

"We try to get young adults on pumps to go to one pump clinic once a year and the other appointments are in the Young Adult clinics. The reason for this is the pump team is very specialized....we talk about technology, it's focused on what their rates are, what pump they are on, the Young Adult clinic is more holistic" (01)

Two other interviewees indicated young adults on pumps either attended the Young adult clinic or attended the adult pump clinic (for all pump users) following transition of care.

"...they just attend the Young Adult clinic, when they transition at 24 they go to the pump clinic" (08)

"If on pumps they attend the adult pump clinic, if young adults not on pumps they attend the YA clinic (012)

DNA policy

Seven of the 16 adult services (44%) reported they had no DNA protocol for adolescents/young adults with type 1 diabetes attending their adult service and that they continued to offer them follow-up appointments.

Of the 9 survey respondents (56%) who reported they had a DNA protocol, variations existed across adult services in terms of the number of sequential DNAs before the young adult was discharged back to their GP ranging from 1 DNA to 4 DNAs.

All but one hospital service reported either in the online survey or in the follow up telephone interviews that young adults who missed appointments were usually followed up with a telephone call either on the day of the clinic or in the days after the clinic or both.

"I ring them after every (missed) appointment but they rarely answer, I ring them to see if there was any reason they didn't turn up" (01)

The majority of interviewees perceived DNA rates in this group to be higher than in other age groups with interviewees estimating DNA rates of between 25% and 50%. Interviewees also commented that DNA rates also varied depending on the time of year the clinic was being held.

One reason for high DNA rates reported by interviewees was that many young adults were unable to attend their local adult service because they were attending university or college elsewhere in the country at the time of the clinic appointment. A number of interviewees who delivered young adult clinics described how they tried to schedule these clinics to coincide with university/college holidays to address this.

"We have a high attrition rate...most young people when they go to college....many of them would go elsewhere, they are DNAing as they are actually away to be fair to them...." (011)

"...we try and coincide it (young adult clinic) with their college holidays" (02)

One interviewee whose adult service was currently receiving referrals of young adults on pumps to their service as the local adult service currently did not accept pump referrals from its own on-site paediatric service commented that these patients were also more likely to DNA.

“The patients (on pumps) referred to us from Hospital X don’t want to come to us, they would much prefer to continue to attend the hospital they have attended all their life....so frequently they ...don’t attend and we never develop a good relationship with them as their attendance and commitment is a bit ad-hoc” (08)

Transition of Care Coordinator

Survey respondents were asked if their adult service had a transition of care coordinator defined as ‘a dedicated member of staff who supports people transitioning from one health setting to another’.

Four of the 16 (31%) adult services said they had a transition of care coordinator. In these 4 hospitals the TOC co-ordinator was a clinical member of staff (2 ANP, 2 DNS) who were involved in orientating patients transferring to the adult service and participating in clinical care and education of young adults.

Qualitative data gathered from interviewees who said they did not have a transition of care coordinator would suggest that specialist nursing staff in the adult services were also engaged in orientating patients transferring to the adult service by participating in transition clinics, following up on patients who missed appointments and participating in the clinical care and education of young adults but these services did not perceive this as a ‘dedicated member of staff’ supporting this transition of care.

One interviewee also described how this transition of care role was primarily led by the paediatric service.

“No, they (paediatric service) are doing a lot, they take them out of their service well, they are the coordinators, they are preparing them for the TOC. Once they get to us (adult service), they don’t have a dedicated person” (01)

Accept referrals of adolescents/young adults on pumps

12 of 16 (75%) adult services said their adult service accepted referrals of adolescents/young adults on pumps. Of the 11 hospital sites with an on-site paediatric service, 8 (73%) accepted referrals of patients on pumps. Three hospitals with on-site paediatric services who did not complete an online survey also accept referrals of adolescents/young adults on pumps based on the numbers they provided on adolescents/young adults transitioning to their service in 2021.

Of the 8 adult services with on-site paediatric services who took part in a follow up interview, differences in the type of pump service provided were described.

- 5 hospital sites indicated that both their on-site paediatric service and adult service initiated pump therapy and provided support to those on pumps
- 1 adult service provided support to patients on pumps but their paediatric and adult service did not initiate pump therapy

“we don’t do pump start-ups in our paediatric service.... Or in our adult service, but we support those on pumps” (04)

- 1 adult service described their on-site paediatric service as ‘ad hoc’ with most paediatric patients attending other specialist paediatric centres. The adult service provided support to adolescents/young adults on pumps transitioning back to their adult service but did not initiate pump therapy in the adult service

“ We don’t do any pump start-ups here (paediatrics and adult service), it’s only if they come back from a specialist centre, we will accept them back on a pump but won’t do start-ups” (02)

Of the 4 hospitals who did not currently accept referrals of young adults on pumps, 3 had an on-site paediatric service. Qualitative data from follow-up interviews indicated that:

- Two adult services reported that their on-site paediatric service did initiate and support pump therapy and that these patients were referred to another hospital site when transitioning to adult care.
- One adult service said their on-site paediatric service did not initiate or support pump therapy and that patients wanting this service would be referred to another paediatric hospital service. Those transitioning from this other paediatric site would then have to be referred to another hospital adult service as the adult service did not accept referrals of adolescents/young adults on pumps

“There is no pump service in our paediatric service, if they wanted a pump they would usually be referred to Hospital X, and then as there is no adult pump service in Hospital X, those transitioning from paediatric services would be referred to either to Hospitals Y or Z” (05)

Two interviewees provided additional information on 3 adult outpatient services with on-site paediatric services that did not take part in the study reporting that currently these adult services did not accept transitioning adolescents/young adults on pumps from their on-site paediatric services.

Another interviewee that received referrals of young adults on pumps to their adult service from several other paediatric services commented that such referrals were concerning because if *they (young adults) run into trouble they are going to be admitted into their own local hospital inpatient service*” which may have little experience or knowledge of pump technology. (09)

Adult Service Clinical Staff supporting insulin pump service (n = 12)

Adult services who accepted referrals of adolescents/young adults on pumps from paediatric services were asked how many consultant endocrinologists, specialist nurse staff and dietitians were currently involved in the delivering the adult insulin pump service. The number of clinical staff supporting the insulin pump service is shown in Table 2

Table 2 Clinical Staff Supporting Insulin Pump service

	Consultant endocrinologist	ANP	DNS	Dietitian
Ireland East	No survey data provided			
Dublin Midlands				
Tallaght	1	0	3	1
Naas	1	0	2	0.2
Portlaoise	2	0	1	0
RCSI hospitals				
Beaumont	2	1	1	1
Connolly	1	1	1	1
UL Hospital Group	2	0	1	1
South/South West				
Tipperary	1	0	3	0.5
Cork*	0	0	0.25	0.5
SIVUH	1	2	0	0.2
Saolta				
UHG	4	1	1	0.5
Sligo	2	0	2	1
Letterkenny	1	0	2	0

*Nurse led pump clinic

Of the 12 adult services who reported accepting referrals of adolescents/young adults on pumps, 2 adult services said they had no dietitian supporting their insulin pump service. One of these hospitals provided additional information in the comments box of the questionnaire stating:

“Our adult insulin pump service is very limited due to no dietetic support. We currently accept young adults who are on insulin pump to our service but we are not able to start insulin pump at adult service due to lack of dietetic support” (016).

Qualitative data also highlighted the lack of dedicated psychological support for young adults on pumps and the young adult type 1 population in general with only one interviewee reporting they had dedicated psychological hours for their young adult type 1 population.

Training for staff to support pump service

The types of training clinical staff received to support their pump service was explored further in follow up interviews with the 12 hospitals providing a pump service. The training individuals reported receiving included:

- Training from pump companies
- Online training modules
- DAFNE pump training
- Received training in another country when working there
- Received training from other members of staff more experienced in delivering pump service

Only one hospital described a more formal training arrangement for their adult service where an experienced clinical team delivering a pump service in another country came and trained their adult diabetes team.

“We organized a pump training course with a centre in Denmark, they came over and delivered a course for all of the diabetes team.....it gave people more confidence that there had been formal training, a 3 day course, funded from a nursing education fund, it was a team from there and it was our whole team so it wasn’t done piecemeal so I think there was a big advantage to that.....” (012)

Interviewees who described how more experienced HCPs provided training to other HCPs commented that this was to provide NCHDs and nurses with a basic knowledge of pumps so they knew how to interpret pump readings and make adjustments as needed.

“We would organize one hour training for everyone so they can see the pump. ...All the medical staff need to know how to adjust the pump up or down. They don’t need to know how to put on the pump, they just need to know how to adjust it.....” (01).

Interviewees also highlighted that training in pump technology was an ongoing process due to the constant advances in pump technology and new devices being developed.

Barriers and facilitators to delivering a pump service

For those currently delivering a pump service, interviewees commented that the main barriers they currently have in delivering a pump service included:

- Time constraints especially when doing pump start-ups
- Lack of dedicated nursing and/or dietetic time to support the pump service
- Difficulty in recruiting experienced staff to the hospital diabetes service
- Experienced nursing staff leaving hospital setting to work in the community.

One interviewee who currently delivers a pump service commented that

“staff can be intimidated by technology as not familiar with it”. (07)

Another commented that the

“key motivator is if you have an interest (in delivering pump service) you get on and do it”. (08)

Of the 4 adult services that currently did not accept adolescents/young adults on pumps into their adult service the main reasons provided in the follow up interviews were

- lack of and difficulty recruiting specialist nursing staff
- lack of dietitian support, and/or
- a lack of experience in pump technology.

Knowledge of transitioning YAs regarding pump technology

A number of interviewees commented that the level of knowledge of pump technology varied in adolescents/young adults transitioning to the adult service

“...we do have some patients that come to us from paediatrics and it is clear to us that they know nothing about the pump and part of the transition process is to try and get them more confident in using the pump, understanding how the pump works, getting the parents to step away a bit more” (08)

Adolescent/Young adult preferences

Two interviewees providing additional comments on adolescents/young adults’ treatment preferences. One commented that some adolescents/young adults prefer not to use pumps with another describing how some adolescents/young adults might request to discontinue pump therapy when they enter the adult service.

“in the last 12 months, maybe 2 or 3, we have taken them off the pump because they have actually hated it but they were on it because I suppose their parents wanted them on itbut the kid had actually

hated itas they have got a bit older and have got to know us a bit more, they have transitioned to come off it” (08)

Number of adolescent/young adult T1 referrals in 2021 (n = 17)

Hospital group	On-site paed	Other paed	% on CGM/FGM	% on pumps
Ireland East				
St Lukes Kilkenny	9	N/A	100%	78%
Mullingar	8	3	55%	18%
Wexford	5	0	80%	0%
Dublin Midlands				
Tallaght & Naas	23	15	92%	88%
Portlaoise	6	20	42%	12%
Tullamore	N/A	0	0%	0%
RCSI Hospitals				
Beaumont	N/A	30	90%	83%
Drogheda and Louth	7	N/A	43%	0%
Cavan & Monaghan	6	0	100%	0%
Connolly	N/A	11	73%	27%
UHL Group	24 (est)	3 (est)	90% (est)	30% (est)
South/South West				
Cork*	0	0	0	0
South Tipperary	2	5	86%	14%
Bantry	N/A	20	80%	0%
Saolta				
UHG	13	Don't know	69%	23%
Sligo	20 (est)	N/A	80% (est)	50% (est)
Letterkenny	19	N/A	100%	26%

*Cork was not accepting new referrals from paediatrics to adult services due to staffing issues

The percentage of transitioning adolescents/young adults on CGM/FGM ranged from 42% to 100%. The percentage of adolescents/young adults using insulin pump therapy also varied ranging from 12% to 88%. Tallaght and Naas and Beaumont hospital reported that over four-fifths of adolescents/young adults transitioning to their adult service were on insulin pump therapy. The main sources of referrals to these adult

services were from the Children's Hospital Group (Tallaght, Crumlin and Temple Street) and from other adult services that currently did not provide an insulin pump service to transitioning adolescents/young adults. Other adult services reported smaller proportions of transitioning adolescents/young adults on insulin pumps indicating that the use of pump technologies also varies across paediatric outpatient services.

Qualitative data would suggest that for hospitals with a higher proportion of adolescents/young adults using pump technology there is an increase in the number of patients using CGM rather than FGM because of its compatibility with the pump the young adult is using. For hospitals where a higher proportion of adolescents/young adults were on multiple daily injections (MDI), the general perception was that "*people not using pumps mostly using Libre (FGM).....*"

Discussion

Findings from this mixed methods study highlight the variations that exist across public adult outpatient diabetes services in terms of involvement in the transition of care process prior to the transfer of care and subsequent clinical management of these adolescents/young adults in the adult service following the transfer of care which may impact on patient outcomes.

The response to the online survey was 60% which is reasonable considering the pressure and increased clinical workload on public hospital outpatient services following the impact of Covid 19 on waiting lists for clinic outpatient appointments. Information was collected from adult services across the 5 hospital groups including adult services with/without on-site paediatric services and services that currently did/did not deliver an insulin pump service. The mixed methodology (on-line survey and follow-up interview) is a strength of the study as it allowed a more in-depth exploration of the context of responses to the online survey.

The majority of participants indicated that transitions of care usually happened at the age of 17-18 years after the young person had completed their Leaving Certificate exam at the end of the secondary school system. Referrals from the stand-alone children's hospitals usually happened at 16 years of age. Recent international recommendations on transition of care from paediatric to adult services recommend that transition should be developmentally appropriate and informed by the young person's individual medical and psychosocial needs rather than being determined by arbitrary age limits.^{16,17} Qualitative feedback from participants in this study would also suggest that some paediatric services transition individuals based on their individual needs rather than at a specific age.

Over half of the participating adult services reported holding joint face-to-face paediatric-adult transition clinics prior to the transfer of care but variations existed in which paediatric services they held transition clinics with, how often they met with the young adult prior to the transfer of care, which health care professionals attended the transition clinics and where transition clinics took place. The main purpose of these transition clinics was to introduce the transitioning adolescent/young adult to members of the adult team before they attended the adult service for the first time. Previous research suggests that meeting members of the adult team can improve outcomes in young adults transitioning to adult services.¹⁸ Some hospital sites with onsite paediatric and adult services did not deliver transition clinics but had health and social care professionals working across both services which provided continuity of care for the transitioning adolescents/young adults.

All participants reported that the transition of care referral letter from paediatric services mainly contained a written medical summary. The referral letter was less likely to contain a psychosocial summary or written

information on the young person's self-care skills, goals, transition readiness and the young person's preferences for parent/carer involvement in adult services. Qualitative feedback from interviewees suggests that some of this information would be shared verbally in adult services that held transition clinics with paediatric services.

'Got Transition' a US-funded initiative describes a core set of six common components of quality transition care including a transition policy, transitioning youth registry, transition readiness, transition planning, transfer of care and ensuring transition completion. This initiative has also developed various transition care tools to help facilitate transition of care.¹⁹ Young people's preference for parental involvement, especially in the first year following transfer of care to adult services, is also important to establish as preferences may differ amongst adolescents/young adults.

International guidelines recommend that the time between the last paediatric and first adult care appointment should be 3-4 months.²⁰ Very few adult services reported a gap of less than 3 months with the majority reporting a gap of between 3 and 6 months. International guidelines also recommend that young adults with diabetes should be seen by a specialist diabetes team every 3 months at minimum.^{20,21} Half of the participating adult services in this study reported a recall time of between 3 and 4 months with the remainder reporting a recall time of 6 months or over. Qualitative feedback from some adult services would also suggest that recall times are also determined based on an individual's needs.

Emerging adults with gaps in care and infrequent clinic follow up are at risk of disengagement with health care services and at increased risk of acute and chronic diabetes related complications.^{5,6} Considering the level of DNA rates reported amongst this cohort of patients and the fact that many young adults are unable to attend local adult services frequently because they are attending college or university elsewhere, further exploration of alternative methods of engaging with this cohort of patients to support self-management should be explored in addition to the traditional face to face clinic appointment. The D1 Now pilot study conducted in a number of Irish adult outpatient services found that a support worker who is present at each young adult clinic appointment and communicates with the young adult between clinic appointments is useful to both young adults and staff.²²

Not all adult outpatient services currently provide an insulin pump service to transitioning adolescents/young adults using this technology from paediatric services. This was a particular issue where on-site paediatric

services provided a pump service but were unable to transition patients on insulin pump therapy to their on-site adult service. More collaborative working and sharing of knowledge between on-site paediatric and adult sites could help support the needs of adolescents/young adults on insulin pump therapy who want to transition to their local adult diabetes service.

In other hospitals, initiation of insulin pump services and/or support for insulin pump patients is currently not available in the paediatric or the adult outpatient service with these patients having to attend other 'specialist' centres for their care. It is important to ensure that those 'specialist' centres have the necessary specialist staff and ongoing training in pump technologies to support these patients.

Insulin pump therapy demands a high level of self-management with individuals requiring regular review and support by a diabetes specialist team. NICE guidelines (2008) recommends that this team should at a minimum, include a pump-trained consultant diabetologist, a diabetes specialist nurse and a dietician.²³ Barriers to providing an insulin pump service reported in this study included the time involved in providing a pump service, lack of nursing and/or dietetic staff and lack of experience in pump technologies. Similar findings have been reported in a previous survey conducted in 2017 in Ireland which reported that a lack of trained staff and the heavy workload involved were the main reasons for not initiating insulin pump therapy in adult diabetes services.¹⁵

Qualitative data from this study would suggest that the use of diabetes technologies including CGM and insulin pump therapy is often driven by parents and/or paediatric health care providers. Adolescents/young adults' preferences for diabetes management should be assessed as part of the transition process to ensure that the use of these diabetes technologies meet their current needs. It is also important to ensure they are given the necessary support to provide them with the understanding and skills to independently manage their diabetes using these technologies.

Insulin pump technology is rapidly evolving, with new technologies becoming available every year, highlighting the importance of ongoing training for diabetes outpatient staff involved in initiating and supporting patients who use these technologies. Basic training in the functions and principles of insulin pump therapy and CGM is also important for non-specialist hospital staff who are likely to come in contact people using these technologies when attending health services for other reasons other than their diabetes.

In this study we only obtained the experiences of adult service providers. Future work should explore the emerging adult's and paediatric care provider's experiences of transition care to help provide a more complete picture of current deficiencies in transition care delivery.

Conclusion: This study highlights the variation across adult services in current transition of care practices and provision of care for adolescents/young adults in the adult service following transfer of care from the perspectives of adult care providers. A more structured approach to transition of care and better collaboration and communication between paediatric and adult providers could improve the transition of care experience and outcomes of adolescents/young adults transitioning from paediatric to adult services.

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