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National paediatric diabetes audit feasibility study report

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National Office of Clinical Audit

NATIONAL PAEDIATRIC DIABETES AUDIT FEASIBILITY STUDY REPORT



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NATIONAL OFFICE OF CLINICAL AUDIT (NOCA)

The National Office of Clinical Audit (NOCA) was established in 2012 to create sustainable clinical audit programmes at national level. NOCA is funded by the Health Service Executive Office of the Chief Clinical Officer and operationally supported by the Royal College of Surgeons in Ireland.

The National Clinical Effectiveness Committee (NCEC) defines national clinical audit as "a cyclical process that aims to improve patient care and outcomes by systematic, structured review and evaluation of clinical care against explicit clinical standards on a national basis" (NCEC, 2015, p. 2).

NOCA supports hospitals to learn from their audit cycles.

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National Office of Clinical Audit

National Paediatric Diabetes Audit Feasibility Study Report

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25 March, 2022

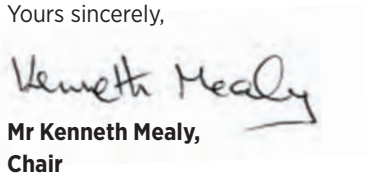
Dear Prof Murphy,

I wish to acknowledge receipt of the *National Paediatric Diabetes Audit Feasibility Study report.*

Following your presentation to the NOCA Governance Board on the 24th March 2022 and feedback garnered from our membership, we are delighted to endorse this report. I wish to congratulate you, NOCA Paediatric Programme Manager Cliona McGarvey and the Steering Committee in the development of this report.

Please accept this as formal endorsement from the NOCA Governance Board of the *National Paediatric Diabetes Audit Feasibility Study report* and we wish you every success in your ongoing commitment to the paediatric diabetes patients in Ireland.

Yours sincerely,



Mr Kenneth Mealy,
Chair
National Office of Clinical Audit Governance Board

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FOREWORD



The proposal to develop a National Paediatric Diabetes Audit in Ireland is to be welcomed as an important step in delivering a high-quality service to children and young people (CYP) and their families.

Experience from Germany, Sweden, the Netherlands and England and Wales shows clear benefits in terms of care improvement in many aspects of diabetes, not solely glycosylated haemoglobin as important as that is. Coupling the audit with measures of CYP and family satisfaction along with outcomes that matter to both CYP and families and health care professionals maximises the value that can be derived from such a proposal.

Measures in the audits to date have provided a stimulus to staff to think about care delivery, particularly in the areas of being patient centred, timely in interactions, efficient, safe and effective in therapy use, and above all equitable in who can access care and derive best health from the resources available.

The audit will also provide users with assurance on the care that they are receiving, and how it benchmarks within Ireland and internationally. Service commissioners will also be able to better focus resources to maximise improvements.

Audits such as the one proposed generate a spirit of improvement, collaboration, and cooperation amongst health care professionals and CYP and their families.

The proposed audit is an integral part of quality improvement in diabetes in Ireland. Congratulations on the proposal - now just deliver it!!!



Professor Peter Hindmarsh
Professor of Paediatric Endocrinology
London
United Kingdom

GLOSSARY OF TERMS AND DEFINITIONS

ACRONYM	FULL TERM
ANP	advanced nurse practitioner
CGM	continuous glucose monitor
CHI	Children's Health Ireland
CMO	context-mechanism-outcome
CNS	clinical nurse specialist
CSII	continuous subcutaneous insulin infusion
DCCT	Diabetes Control and Complications Trial
Decompensate/ decompensation	functional deterioration of system; inability to compensate for functional overload resulting from disease
DKA	diabetic ketoacidosis
DNA	did not attend
DNS	diabetes nurse specialist
DRS	Diabetic RetinaScreen
eHR	electronic healthcare record
Flash	Flash Glucose monitoring system – a way of measuring sugar levels
GDPR	General Data Protection Regulation
GP	general practitioner
HbA1c	glycated haemoglobin
HIPE	Hospital In-Patient Enquiry
HIQA	Heath Information and Quality Authority
HSE	Health Service Executive
ICDNR	Irish Childhood Diabetes National Register
ICT	information and communication technology
ICU	intensive care unit
IHI	Individual Health Identifier
ISPAD	International Society for Pediatric and Adolescent Diabetes
KPI	key performance indicator
LIMS	laboratory information management system
LTI	Long-Term Illness
MDT	multidisciplinary team
mmol/mol	millimoles per mole
MRN	medical record number
NHS	National Health Service

NOCA	National Office of Clinical Audit
NPDA	National Paediatric Diabetes Audit
NQAIS	National Quality Assurance and Improvement System
OPD	outpatients department
PCRS	Primary Care Reimbursement Service
POCT	point-of-care testing
RAMESES	Realist and Meta-Narrative Evidence Synthesis publication standards
RCPCH	Royal College of Paediatrics and Child Health
RCPI	Royal College of Physicians in Ireland
RCSI	Royal College of Surgeons in Ireland
T1DM	type 1 diabetes mellitus
Time in range	Percentage of time the blood glucose levels stay within a pre-determined range
UK	United Kingdom
VPN	virtual private network
WTE	whole time equivalent

EXECUTIVE SUMMARY

Ireland has a high incidence of type 1 diabetes mellitus (T1DM), a chronic condition that places huge demands on affected individuals, their families, and the health service. Continuous and integrated multidisciplinary patient support is required to empower patients and caregivers to maximise self-management skills in order to achieve optimal diabetes control, which has been definitively shown to reduce the risk of acute and long-term diabetes-related complications. Paediatric T1DM care requires prioritisation because of its high incidence and the significant long-term sequelae of suboptimal care. No national paediatric diabetes audit (NPDA) exists in Ireland, and available data originate from single-centre, stand-alone, or retrospective studies. The lack of reliable data precludes healthcare professionals from making informed decisions about how to improve services, and means that disparities in paediatric diabetes care are neither identified nor prospectively addressed. A national audit of paediatric T1DM will highlight areas of good practice, identify deficits, and promote improvement in the quality of care delivery and data-driven resource allocation. The need for an NPDA was specifically emphasised in the Model of Care for All Children and Young People with Type 1 Diabetes.

In this feasibility study, the steering committee (which had broad expertise and representation from patients and multidisciplinary professionals nationally), working with the National Office of Clinical Audit (NOCA), reviewed what is known about the impact of national audits on clinical outcomes, as well as the contextual factors that have influenced audit implementation and how these factors might translate in an Irish context. This report describes the configuration of paediatric diabetes services nationally and the patient journey from diabetes diagnosis through ambulatory care to the transition to young adult services. It also highlights areas of variability that might be amendable to audit and quality improvement. The multidisciplinary team resources available to children with diabetes nationally are reviewed and current practice across services for measurement and reporting of the key performance indicator (KPI) of glycated haemoglobin (HbA1c) described. Existing data sources potentially available for this audit are also explored. Learnings from international audits and registries highlight the need for resources for data collection, that the accuracy and efficiency of data collection is optimised by the use of electronic systems, integrated into healthcare and that data-driven decision-making and quality improvement are fostered by systematic data collection. The impact of these factors on the feasibility of a national audit was used to inform recommendations for a national paediatric audit of T1DM in Ireland.

A NATIONAL AUDIT OF PAEDIATRIC T1DM WILL HIGHLIGHT AREAS OF GOOD PRACTICE, IDENTIFY DEFICITS, AND PROMOTE IMPROVEMENT IN THE QUALITY OF CARE DELIVERY AND DATA-DRIVEN RESOURCE ALLOCATION. THE NEED FOR AN NPDA WAS HIGHLIGHTED IN THE MODEL OF CARE FOR ALL CHILDREN AND YOUNG PEOPLE WITH TYPE 1 DIABETES.

KEY FINDINGS

→	National clinical audits of paediatric T1DM have been shown to lead to improvements in quality of care and patient outcomes.
→	A national audit of paediatric T1DM is feasible in Ireland, and data collection, analysis and feedback have the potential to drive quality improvements.
→	Significant variation exists between centres in Ireland in terms of multidisciplinary team resourcing and expertise, availability of electronic systems for data collection and method of measurement of HbA1c levels.
→	There is currently no systematic capture of data that will permit the measurement of process and outcome metrics that can be benchmarked against international standards.
→	HbA1c is the key outcome KPI for paediatric diabetes care and accurate collation of HbA1c data is critical for the proposed NPDA. Data relating to many metrics of interest would only be accessible by manual extraction from patient notes.
→	Availability of the Individual Health Identifier (IHI) would permit linkage of existing Health Service Executive (HSE) data sources and this would greatly enhance the value of audit data by enabling linkage with available metrics such as technology use (through the Primary Care Reimbursement Service (PCRS)), appointment attendance (national patient administration systems), admissions (through the Hospital In-Patient Enquiry (HIPE) scheme/National Quality Assurance and Improvement System (NQAIS)) and diabetes retinal screening.
→	Accuracy and efficiency of data collection and analysis are optimised by using electronic systems integrated into routine clinical care, and this should be progressed for all centres delivering T1DM services. Current deficits and variation in information and communication technology (ICT) infrastructure and data management across centres increases the burden of audit data collection.

KEY RECOMMENDATIONS

1.	A national audit of T1DM care is feasible in Ireland and should be progressed under the governance of the National Office of Clinical Audit (NOCA). The recommended phases of implementation are: **Phase 1**: paediatric audit, including all patients with T1DM who are aged under 16 years attending all 19 paediatric centres nationally **Phase 2:** audit extended to include all patients with T1DM who are aged 16–25 years **Phase 3:** audit extended to include all patients with T1DM nationally.
2.	The IHI should be made available for the purpose of the national audit to permit complete, accurate and timely collection of data. This will facilitate linkage to existing data sources and reduce the burden of data collection on multidisciplinary teams delivering paediatric T1DM care. The preferred audit methodology is to collect data prospectively as part of clinical care using the electronic healthcare record (eHR).
3.	A minimum core dataset should be collected on all patients with T1DM. As audit is key to driving quality improvement, until an eHR is available for all patients with T1DM, identifiable information obtained with consent should be collected electronically for a national register of patients with T1DM.

CAPTURING PATIENT PERSPECTIVES



I was delighted to be asked to take part in the feasibility study for the proposed national paediatric diabetes audit.

Our daughter has had a very positive experience on her patient journey, from a reasonably quick diagnosis without diabetic ketoacidosis at the age of 11 years through to independently managing her diabetes with her diabetes pump at the age of 14 years, and we envisage a smooth transition to adult services on the horizon in a few years.

All children, regardless of which centre they attend in Ireland, deserve to have the highest level of care when diagnosed with type 1 diabetes mellitus (T1DM).

Being involved in this feasibility study has meant that I have been able to use our daughter's experience to be part of the process of improving care for the many children who will be diagnosed with T1DM in Ireland in the future.

From my perspective, the most valuable parts of the feasibility study were the outputs from the working groups. Mapping out the patient journey with the team helped to identify potential auditable data points or stages where there are variances in care along the patient pathway.

Even while working remotely, we were able to identify a three-part patient journey efficiently: from diagnosis to ambulatory outpatient care and through to the transition to adult care.

Use of technology has been hugely positive for our daughter and helped to improve her blood sugar control, time in range and glycated haemoglobin levels. If we did not receive education and support from professionals in using continuous glucose monitoring, changing insulin type, and moving from multiple daily injections to the pump, our daughter may not have such good control of her blood sugar levels today.

I would encourage all parents of children with T1DM to consent to sharing their data to allow improvements in the care of all children with type 1 diabetes in Ireland.

Emer Gunne
Public and Patient Interest Representative
Paediatric Diabetes Feasibility Study Steering Committee



Rachel Gunne

CHAPTER 1
INTRODUCTION



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CHAPTER 1: **INTRODUCTION**

1.1 PAEDIATRIC TYPE 1 DIABETES MELLITUS IN IRELAND

Type 1 diabetes mellitus (T1DM), the most common form of diabetes in children, is a chronic condition caused by immune-mediated destruction of the pancreatic beta cells, resulting in insulin deficiency and high blood glucose levels (or hyperglycaemia). The aetiology of T1DM is multifactorial and complex, and involves environmental triggers superimposed on an individual's genetic susceptibility (Mayer Davis *et al*., 2018). Left untreated, the child with diabetes will acutely decompensate and a life-threatening complication called diabetic ketoacidosis will occur. Chronic hyperglycaemia damages blood vessels and nerves which can result in diabetes-related complications, including retinopathy (which can be vision threatening), nephropathy (which causes renal failure and the need for dialysis) and cardiovascular disease (which can result in heart disease, stroke and amputations). Optimal diabetes control dramatically reduces the risk of both short- and long-term complications and increases quality of life for affected individuals and their families. The level of glycated haemoglobin (HbA1c) in the blood is an established key performance indicator (KPI) of long-term diabetes control which inversely correlates with adverse outcomes (DCCT, 1993; EDIC, 1999).

The incidence and prevalence of T1DM is rising globally, with the greatest increases evident among younger age groups and in countries experiencing rapid economic growth (Patterson *et al*., 2014). The incidence of T1DM among children and young people in Ireland is one of the highest in Europe, with diabetes incidence rates in the top 25% worldwide and with an increase in the incidence rate from 16.3 cases per 100,000 population <15yrs in 1997 to 27.3 per 100,000 in 2008 (Patterson *et al*., 2014; Roche *et al.*, 2014). The rate has now stabilised at 27.1 cases per 100,000 population (2018) (McKenna *et al.,* 2021).

As a lifelong condition, continuous and integrated multidisciplinary support is required for patients with T1DM, with the ultimate goal being the prevention of acute and chronic complications. Care should aim to empower patients and caregivers and maximise their self-management skills in order to achieve optimal diabetes control (Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland, HSE 2015). There is widespread consensus on what constitutes good practice in diabetes care delivery, and national and international guidelines and standards are available for measuring processes and outcomes of care e.g. guidelines of the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the criteria adopted for the UK Best Practise Tariff in paediatric diabetes (www.diabetes.org.uk).

1.2 PAEDIATRIC T1DM SERVICES IN IRELAND AND THE RATIONALE FOR DEVELOPING A NATIONAL PAEDIATRIC DIABETES AUDIT

Paediatric T1DM care requires prioritisation because of its high incidence and significant long-term sequelae (Patterson *et al*., 2009; The Diabetes Control and Complications Trial/ Epidemiology of Diabetes Interventions and Complications Research Group, 2000). Many Irish paediatric T1DM services are under-resourced and perform suboptimally across KPIs, such as the national mean HbA1c level and access to streamlined multidisciplinary care (O'Brien *et al*., 2014; Roche *et al*., 2002). Furthermore, the care provided by individual paediatric diabetes services varies unacceptably (Hawkes and Murphy, 2014; Savage *et al*., 2008).

Currently, no national paediatric diabetes audit (NPDA) exists in Ireland, and available data arise from single-centre, stand-alone, or retrospective studies. The lack of reliable data precludes healthcare professionals from making informed decisions about how to improve services and means that the extent of inequality in paediatric diabetes care is neither publicised nor prospectively monitored. The need for an NPDA was specifically emphasised in the *Model of Care for All Children and Young People with Type 1 Diabetes* (O'Riordan *et al.*, 2015).

To establish a rationale for implementing an NPDA, several factors need to be considered. First, the impact of national clinical audits on clinical outcomes needs to be reviewed. Second, factors that influenced the implementation processes of other, pre-existing national or comparative audits in their respective organisational contexts need to be identified. Third, how these factors would translate to an Irish context needs to be considered. The latter consideration requires a broad understanding of the landscape of Irish paediatric diabetes care, including stakeholder views, patient experiences, available resources, data infrastructure, and measurable process and outcome measures. Taken together, these data will allow us to consider the best options for designing a sustainable and feasible NPDA in the Republic of Ireland that measures the elements of care that matter most to children in Ireland living with T1DM and their families.

1.3 THE CONCEPT OF MULTICENTRE COMPARATIVE CLINICAL AUDITS

Multicentre clinical audits involve the collection of data from individual contributing centres and analysis of these data to provide an overall picture of care standards for a given health condition on a regional or national level. They facilitate national benchmarking and an informed approach to resource allocation and service design, with overarching goals of improving clinical outcomes and equitable care (McErlane *et al*., 2018; Dixon, 2013;). Audit on this large scale is not a new concept, and many national or multicentre audits are in operation (see Chapter 4). The United Kingdom's (UK's) National Clinical Audit and Patient Outcomes Programme, commissioned by the National Health Service (NHS), manages 30 national audits monitoring important health conditions. These include the UK National Paediatric Diabetes Audit, which audits paediatric diabetes care annually against best practice and which has resulted in improved outcomes for young people with diabetes (National Paediatric Diabetes Audit and Royal College of Paediatrics and Child Health, 2017).

1.4 THE BENEFIT OF MULTICENTRE COMPARATIVE CLINICAL AUDITS

1.4.1. National audits are associated with improvements in key clinical outcomes

The process of audit is embedded within healthcare and is used as a method of comparing the quality of care against best practice in order to identify areas for service improvement. As a process designed to drive quality, there are surprisingly few studies examining whether audit as an intervention can improve clinical outcomes. A systematic review of these studies revealed that audit only improves healthcare outcomes if done correctly (Ivers *et al*., 2012). However, audits included in this systematic review were single-centre and retrospective rather than national clinical audit approaches. Evidence that national clinical audits improve clinical outcomes is limited, but some studies showed promising results. A South African study investigated whether annual participation of 40 diabetes services in a multicentre, prospective clinical audit could lead to improvements across 9 KPIs for diabetes care (Govender *et al*., 2012). Over 5 years, pooled audit data demonstrated an improvement in seven of the nine outcomes. A study reporting on a similar national prospective audit of diabetes care in France found an improvement in mean HbA1c levels and adherence to recommended screening 1 year after implementation of a full audit cycle (Varroud-Vial *et al*., 2001). Further evidence for the impact of national clinical audits on patient care comes from a study reporting on the Scottish Hip Fracture Audit, an audit that was discontinued 6 years after its introduction due to funding issues before being reinstated the following year. The authors found that there was a steady improvement in key parameters relating to hip fracture care in the six 6 years following audit implementation, including a reduction in mortality and time to surgery. This improvement plateaued after audit discontinuation, but began to trend upwards again on audit reintroduction (Ferguson *et al*., 2016). Although none of these studies was designed to establish causality, it appears that national audits are associated with improvements in clinical care.

1.4.2. National audits detect interservice variability in care

A consistent finding in the literature was the ability of national comparative clinical audits to detect important interservice variations in the care provided. The UK's National Diabetes Foot Care Audit revealed an unacceptable national variation between services in the prevalence and care of diabetic ulcers. The resulting investigation attributed this variation to a lack of awareness in certain centres regarding minimum standards in podiatry services (Chaplin, 2018b). A report on the UK National Pregnancy in Diabetes Audit also revealed significant interservice variation, and prompted the discovery that regions performing poorly received less obstetric funding (Chaplin, 2018a). A report on the pilot New Zealand and Australia National Diabetes in Pregnancy Audit had remarkably similar findings (Simmons *et al.,* 2007). An analysis of data from the UK's National Lung Cancer Audit detected a dangerous interservice variation in clinical care that could not be explained by case mix, which prompted an NHS-funded investigation of underperforming centres (Beckett *et al.,* 2012). In all cases, the audit committees disseminated recommendations that highlighted the need for service development in the underperforming regions.

National audits also identify high-performing outliers: an interrogation of data from the UK's National Diabetes Audit elucidated factors associated with high-quality diabetes services, such as insulin pump use and blood glucose strip prescribing. While these findings are again associations rather than statements of causality, it is useful to know which factors are worth researching further in order to establish whether funding these resources could independently lead to improvements in care (Heald *et al.,* 2018). National audits are equipped to identify areas of suboptimal care, to spark investigations into discrepancies, to identify factors associated with high-quality care, and to redirect funding appropriately.

1.4.3. National audits detect information overlooked by single-centre audits

In addition to facilitating interservice comparisons, national audits may elucidate facts about health conditions that can be overlooked by single-centre audits. For example, researchers analysed data from the UK's National Audit of Cancer Diagnosis in Primary Care in order to investigate the timeliness of liver cancer diagnoses and found that the interval from presentation to onward referral was unacceptable. Liver cancer is a relatively rare diagnosis, and the low absolute number of cases per individual centre resulted in this fact being missed in multiple previous single-centre audits. However, when data were collated nationally, this new information was used to redesign the liver cancer referral pathway (Hughes *et al*., 2016). Similarly, an analysis of Australian National Stroke Audit data revealed that Indigenous patients with stroke received poorer care than non-Indigenous patients. Previous single-centre audits had too few Indigenous patient cases to allow comparison between ethnic groups. The national audit facilitated this comparison and identified a clear area of need that has since been incorporated into new stroke care pathways designed to equalise care standards (Pepper *et al*., 2006; Crowley and Hankey, 1995).

1.5. FACTORS THAT INFLUENCED THE IMPLEMENTATION OF EXISTING MULTICENTRE AUDITS

1.5.1. Stakeholder engagement

Most studies referenced the importance of engaging stakeholders in the audit design process, which was achieved in several ways. For example, the team behind Ireland's pilot Major Trauma Audit conducted a preparedness survey of key stakeholders in order to ascertain their views (Deasy *et al.,* 2016). A group promoting the participation of primary care practitioners in the UK's National Diabetes Audit nominated leaders – called audit champions – from all participating practices at all levels of responsibility (Gadsby *et al.,* 2016). Developers of France's pilot National Diabetes Audit 'DIABEST' initially struggled with designing an audit tool that participating centres agreed on. In order to overcome this, they invited all stakeholders to a consensus committee meeting to collaboratively design an audit tool (Varroud-Vial *et al.,* 2001). The UK's National Hip Fracture Database found that maintaining communication between the audit team and clinical data collectors was essential for maintaining project momentum; two dedicated project coordinators were employed to provide telephone support to troubleshoot teething problems, and these roles evolved into a formal NHS-mandated support hub and a full-time lead clinician (Boulton and Wakeman, 2016). All of these stakeholder engagement processes emphasise distributed leadership and collaborative design (Chreim and MacNaughton, 2016; Thompson *et al.,* 2010).

1.5.2. Good governance structure

A key point that emerged from the literature was the importance of establishing robust governance structures. For example, a paper outlining the implementation process behind Ireland's Major Trauma Audit describes the steps taken to ensure effective governance of the audit process. A Major Trauma Governance Group was established, which is responsible for ensuring the integrity and success of the audit process. Next, a national project coordinator and clinical lead were recruited. Finally, each participating hospital was requested to establish its own governance committee with local clinical leads (Deasy *et al*., 2016).

Data governance also emerged as a distinct priority. Ireland's pilot National Diabetes in Pregnancy Audit team encountered difficulties when analysing their data: their audit tool had omitted data fields capturing baseline demographic data, rendering some data challenging to interpret (Egan *et al*., 2020). Similarly, the initial implementation stages of the Irish Hip Fracture Database were hampered by data collection inconsistencies which threatened audit validity (Ellanti *et al*., 2014). A subsequent study found that the multiple errors in the Irish Hip Fracture Database stemmed from unclear documentation and an uncertainty about how to interpret certain data points. Clear governance structures for collecting data were designed and a data coordinator recruited for all participating centres (Hughes *et al*., 2019). Farther afield, the Australian National Diabetes Information Audit and Benchmarking Initiative has perfected its data governance structures since its inception in 1998. Data collection is now coordinated in a double-blind format: designated audit secretaries send coded data collection forms to participating sites, the forms are completed with the assistance of online pro formas, and the forms are then returned to the audit secretaries for validation (Lee *et al*., 2018). Implementing a national audit is a large-scale project, and it appears that robust governance structures help to streamline the process.

1.5.3. Clear feedback mechanisms

Feedback is a cornerstone of effective audit (Ivers *et al.,* 2012). All studies describing successful national audit implementation defined clear data feedback pathways. For example, the UK's National Hip Fracture Database initially provided annual feedback in tabular form. However, discussions with clinical service providers revealed that data were of little use in this form, and informatics support was transferred to a dedicated audit provider that enabled service providers to view data in real time on run charts (Boulton and Wakeman, 2016). Similarly, the UK's National Lung Cancer Audit data collection tool now permits users to generate real-time data reports benchmarked against the national average (Beckett *et al.,* 2012). Successful national audit implementation was specifically associated with open reporting of data that was fair and transparent, which avoided a disengagement with the audit process (Thompson *et al.,* 2010; Green and Wintfeld, 1995). Lastly, feedback on data needs to be accompanied by notes on case mix adjustment in order to avoid conferring an unfair culpability on services that are, in fact, performing well given their circumstances (Mella *et al.,* 1997; Hayes and Murray, 1995). This is essential in the context of outcomes-based commissioning, where remuneration depends on service-level performance (NPDA and RCPCH, 2017; Randall, 2012).

1.5.4. Time-consuming audit tools do not work

Several studies described an overzealous approach to data collection that often required rationalisation later in the implementation process due to stakeholder disengagement. A report on the pilot Australian National Diabetes in Pregnancy Audit described a contradictory desire among the audit implementation team to collect as much data as possible while also aiming for an easy-to-use audit tool. This resulted in a very lengthy tool featuring hundreds of items, which was, not surprisingly, unsustainable (Simmons *et al.,* 2007). The audit tool for the UK's National Hip Fracture Database initially had 150 data fields but was reduced over several iterations to a shorter web-based tool that was acceptable to audit participants (Boulton and Wakeman, 2016). Similarly, the UK's National Lung Cancer Audit described its initial cumbersome data collection process as a barrier to stakeholder engagement; again, a shorter online data collection tool was developed that facilitated easy data collection. In order to further support users, a telephone help desk was set up to troubleshoot problems (Beckett *et al.,* 2012). While arduous data collection processes were identified as clear barriers to national audit implementation, a feature of long-standing successful national audits was a simple data collection process that used data that were routinely generated by clinical work (NPDA and RCPCH, 2017; Gadsby *et al.,* 2016; Stewart *et al.,* 2016).

1.5.5. Challenges of combining paper and electronic medical records

A final consideration emerging from the literature was the challenges presented by heterogeneous healthcare record formats. An example of this is the Australian National Diabetes in Pregnancy Audit, where an initial concern regarding the validity of data was attributed to difficulty in comparing data generated from paper records with those generated from electronic records. An immediate nationwide introduction of an electronic healthcare record would not have been pragmatic; instead, the solution was to provide centres with paper-based records with predefined pro formas available online to use as 'stepping stones' to an electronic healthcare record (Simmons *et al.,* 2007). Similarly, Ireland's pilot National Diabetes in Pregnancy Audit attributed some of its initial issues with data validity to difficulty with reconciling information gleaned from very different healthcare record formats (Egan *et al.,* 2020).

1.6. NATIONAL CLINICAL AUDITS IN IRELAND

National comparative audits are becoming more commonplace in the Republic of Ireland: the National Office of Clinical Audit (NOCA), established in 2012, already provides operational support and robust governance structures for eight successfully implemented Irish national audits. One such example is the Irish Hip Fracture Database, a web-based audit that has collected data on the care and outcomes of patients with hip fractures across 16 acute trauma centres in Ireland since 2012 (NOCA, 2017). While this database is still maturing, it has been successful in rapidly establishing itself as a powerful resource: there are now more than 10,000 patient records on the database thanks to active participation by all of the intended centres. The successful implementation of audits such as the Irish Hip Fracture Database has prompted other services to work towards establishing additional national audits; however, there is currently no national paediatric or adult diabetes audit in place in Ireland.

1.7. THE CHALLENGES OF CONDUCTING AUDIT

Conducting audit in any form is not easy. Several studies have explored the challenges of conducting audit at local level, with facilitators of the process including electronic medical records and open dialogue between providers and consumers, and barriers including poor communication between stakeholders and lack of clear governance structures (Bowie *et al.,* 2012; Johnston *et al.,* 2000). The influence of these factors may be magnified when performing collaborative audit at a national level.

1.8. THE IMPORTANCE OF CONTEXT TO THE AUDIT PROCESS

The number of existing national clinical audits suggests that implementing large-scale audit is feasible. However, there are a number of multicentre or national clinical audits that were not successfully implemented or that disintegrated after a short duration (J. Bailie *et al.,* 2017; Ferguson *et al.,* 2016; López-Campos *et al.,* 2013; van Hamersveld et al., 2012; Hearnshaw et al., 2003). There is little published data to explain how and why national clinical audits are successfully implemented in the first instance. Interventions are implemented within social systems that are affected by contextual factors that include individuals, interpersonal relationships, institutional settings, and organisational infrastructure, and it cannot be assumed that factors that led to the successful implementation of national audits elsewhere will automatically do so within an Irish context (Pawson and Tilley, 1997).

AIM AND SCOPE OF THE FEASIBILITY STUDY FOR THE PROPOSED NPDA

The specific objectives of the feasibility study were as follows:

1. to review what is currently known about the incidence and prevalence of T1DM in the Irish paediatric population; to review how services are configured in 2022 and the vision for how they should be configured; and to review additional factors that influence the health and quality of care of paediatric patients with T1DM
2. to review how paediatric T1DM services are audited in other jurisdictions and what the proposed NPDA in Ireland can learn from international experience
3. to describe the patient journey from presentation with T1DM through follow-up (until transition to adult services) in order to identify quality-of-care parameters that are prone to variation and that are amenable to measurement and audit
4. to describe the current transition pathways from paediatric to adult services for patients with T1DM in Ireland and to identify parameters that are prone to variation and that are amenable to measurement and audit
5. to describe the current resources deployed in paediatric T1DM management in Ireland
6. to describe the current data sources relevant to paediatric T1DM care delivery
7. to consider what aspects of paediatric T1DM care have the greatest impact on the quality of care delivery
8. to consider the options for methodology and design and make evidence-based recommendations for the NPDA.

SCOPE

Phase 1 of the study will include the care of all children and adolescents with T1DM attending paediatric services in Ireland, with consideration of options for extension to include a cohort of young adults with T1DM aged up to 25 years (Phase 2) and, ultimately, all patients with T1DM (Phase 3).

WHO IS THIS REPORT AIMED AT?

This report is aimed at healthcare policy-makers, healthcare providers and service users, as well as the public at large. The report provides recommendations for implementation of a national audit of paediatric T1DM care delivery in Ireland, with planned phased expansion to include all individuals with T1DM. These recommendations provide the detail necessary for informing policy-makers and those involved in commissioning national clinical audit of both the need for a national audit and the feasibility of implementing such an audit in Ireland. For service providers and patients, it highlights the importance of continuous monitoring of care delivery in improving service delivery and the quality of care provided to patients.



CHAPTER 2
METHODOLOGY

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CHAPTER 2: **METHODOLOGY**

The methodology for this feasibility study draws on approaches used in previous national audit feasibility studies, including NOCA's *Deteriorating Patient Audit Feasibility Study* (2021) and the *National Asthma Audit Feasibility study* commissioned by the Healthcare Quality Improvement Partnership (HQIP) in the UK in 2017.

ESTABLISHMENT OF A STEERING COMMITTEE TO PROVIDE OVERSIGHT AND EXPERT ADVICE

A core group representing NOCA, the National Clinical Programme for Paediatrics and Neonatology, and Diabetes Ireland conducted a stakeholder mapping exercise in order to identify individuals who were likely to be interested in the T1DM audit objectives, either as providers/users of services or as quality improvement and audit methodology experts. Two public and patient interest representatives were invited to participate in the mapping exercise, bringing advocacy and personal experience to the steering committee. Smaller regional units were also represented on the committee (see Table 2.1). Information on the proposal for a national audit was circulated to potentially interested individuals, along with an invitation to become involved in the process or to nominate a representative. The mapping exercise led to the establishment of a steering committee that would oversee the planning and execution of the feasibility study and produce a report of the study findings. Clinical leadership for the steering committee was provided by Professor Nuala Murphy, Consultant Paediatric Endocrinologist at Children's Health Ireland (CHI) at Temple Street, and Dr Colin Hawkes, Consultant Paediatric Endocrinologist at Cork University Hospital, who were appointed at the first meeting in February 2021 as Chair and Deputy Chair of the committee, respectively. The complete membership of the steering committee is provided in Appendix ii. The committee met three times over the duration of the study with the following objectives:

MEETING 1: Agree and endorse the Terms of Reference and methodology for the feasibility study.

MEETING 2: Discuss the study findings and reach consensus on an appropriate methodological approach and recommendations for the national audit.

MEETING 3: Endorse the final report of the feasibility study for submission to the NOCA Governance Board and the Health Service Executive (HSE) Office of the Chief Clinical Officer.

TABLE 2.1: NATIONAL PAEDIATRIC DIABETES AUDIT FEASIBILITY STUDY STEERING COMMITTEE STAKEHOLDERS

HSE National Clinical Programme for Paediatrics and Neonatology
HSE National Clinical Programme for Diabetes
Consultant paediatric endocrinologists (regional and tertiary services)
Royal College of Physicians of Ireland (RCPI) Faculty of Paediatrics
Paediatric diabetes nurse specialists (regional and tertiary services)
Association of Clinical Biochemists in Ireland
Public Patient Representatives (advocacy and patient experience)
Diabetes Ireland
Irish Childhood Diabetes National Register (ICDNR)
Chief Information Officer at CHI
NOCA
Clinical Psychologist
Paediatric Dietitian
Non-consultant hospital doctors (national and international)
Pharmacist

The Terms of Reference document identified the tasks needed for an options appraisal for the development of a national clinical audit of paediatric T1DM (see Tasks 1 to 5).

A core project team consisting of NOCA staff, the Chair and Deputy Chair of the steering committee, and Paediatric Endocrinology Specialist Registrar Dr Sinead McGlacken-Byrne met regularly in order to progress and coordinate this work. Drawing from the expertise of the steering committee, a number of work strands identified for each task were assigned to separate working groups, which fed back to the core project team. The findings from all work strands were presented to the wider steering committee at the second meeting on 29 June 2021 (Figure 2.1). The work strands identified for each task are outlined, with further detail provided in the relevant chapters throughout this report.

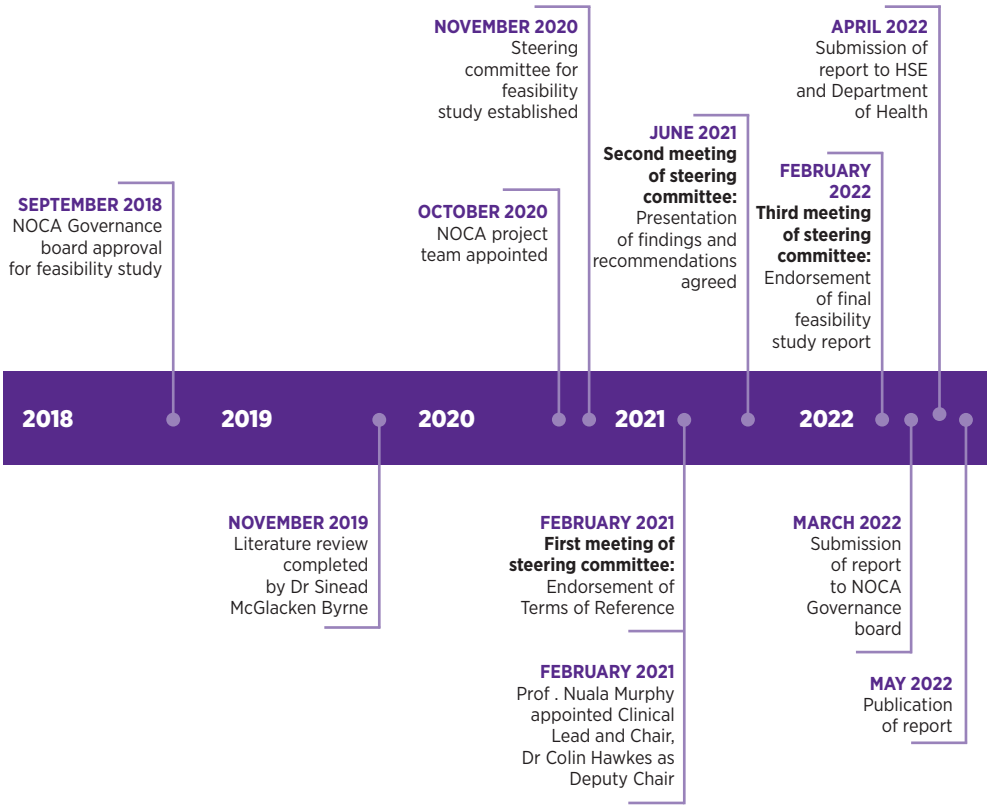


FIGURE 2.1: TIMELINE OF THE NATIONAL PAEDIATRIC T1DM FEASIBILITY STUDY

CHAPTER 2

TASK 1: REVIEW OF THE LITERATURE ON THE INCIDENCE AND MANAGEMENT OF T1DM AND CONTEXTUAL FACTORS IMPORTANT FOR AUDIT IMPLEMENTATION

A. Literature review

Dr Sinead McGlacken-Byrne undertook a literature review and realist synthesis to inform the feasibility study on audit design and methodological approaches, including lessons learned from international experience. Additional research work included a review of national and international guidelines for paediatric diabetes care in order to establish that standards were available for use in the audit. In addition, consultations were conducted with experts in national clinical audit and quality improvement, including Professor Edna Roche, lead for the ICDNR, and representatives of selected national clinical audits. A complete list of these consultations is provided in Appendix i. Due to COVID-19 restrictions, consultations were conducted online via Zoom or Microsoft Teams.

The literature review aimed to identify two main topics of interest:

1. Standards and criteria for inclusion in the audit: the processes and outcomes most important in paediatric diabetes care that are prone to inequality or variability but are amenable to improvement
2. Audit design: the factors influencing sustainable collection of relevant data at national level, what approaches worked well elsewhere, and how these approaches could work in Ireland.

B. Realist review using realist synthesis methodology to identify important contextual factors affecting audit implementation

A realist synthesis of existing literature was conducted to identify important contextual factors affecting audit implementation. Implementing a national comparative clinical audit is inherently challenging as it involves applying a large-scale project in multiple heterogeneous contexts. Realist synthesis has been frequently used in health policy research to help understand complicated, non-linear, and context-dependent interventions (Wong *et al.,* 2013;Kastner *et al.,*, 2011). Realist synthesis aims to extrapolate from empirical studies the contextual factors (C) that trigger the mechanisms (M) that generate an outcome (O) when an intervention is applied to a given context(s) (Pawson *et al.,* 2005). These 'context-mechanism-outcome' (CMO) configurations are the essential outputs of realist synthesis – how, why, for whom, and when an intervention works or fails to work (Ford *et al.,* 2016).

This study followed the five steps of a realist synthesis (Howard *et al.,* 2019). All processes were conducted in accordance with Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES). The review included two searches: the first broadly examined contextual factors affecting audit implementation, and the second focused on the concept of audit feedback (a factor overlooked in the first search). The full search strategy is outlined in Appendix iii.

Data were organised into categories pertaining to context, mechanism or outcome and analysed using framework analysis. Using contextual factors as index points, relationships between contexts, mechanisms and outcomes were identified and CMO relationships were elucidated. These outcome-derived CMO configurations are discussed in Chapter 3.

TASK 2: ENGAGEMENT WITH THE HEALTHCARE COMMUNITY AND DETERMINATION OF EXISTING DATA SOURCES RELEVANT TO THE NATIONAL AUDIT OF PAEDIATRIC T1DM IN IRELAND

A scoping review was conducted in order to establish existing and emerging datasets relevant to T1DM that could potentially contribute to the national audit. The feasibility of collection and linkage of datasets with potential audit data was also explored.

Formal engagement with the healthcare community included the following:

- RCPI Faculty of Paediatrics autumn meeting (21 October 2021)
- Saolta Paediatric Diabetes Group meeting (1 October 2021)
- All Ireland Paediatric Diabetes Webinar for Healthcare professionals (26 November 2021).

Direct correspondence with chief executives and clinical directors of hospitals during the organisational survey also formed part of the feasibility study and served to raise awareness of the proposed national audit.

TASK 3: DESCRIPTION OF THE PATIENT JOURNEY FROM PRESENTATION WITH T1DM THROUGH TO AMBULATORY CARE IN ORDER TO IDENTIFY PARAMETERS PRONE TO VARIATIONS IN QUALITY OF CARE THAT ARE AMENABLE TO MEASUREMENT, AND CHARACTERISATION OF THE CURRENT NATIONAL RESOURCES AVAILABLE FOR PAEDIATRIC T1DM

The following components of the feasibility study were aimed at establishing structures and processes f T1DM care delivery in Irish healthcare:

1. organisational survey of service providers
2. laboratory survey of HbA1c measurement methods and accessibility of results
3. mapping exercise to describe the patient journey from diagnosis, through ambulatory care, to transition from paediatric to adult care services
4. thematic analysis of paediatric T1DM care delivery in Ireland in order to identify topics and measures for audit
5. identification of the quality improvement potential of audit topics.

TASK 4: IDENTIFICATION OF THE TRANSITION PATHWAYS FROM PAEDIATRIC SERVICES TO ADULT SERVICES NATIONALLY IN ORDER TO IDENTIFY PARAMETERS PRONE TO VARIATIONS IN QUALITY OF CARE THAT ARE AMENABLE TO AUDIT

All Task 3 components were repeated for the transition process in Task 4. Each centre's policy on transition was included in the organisational survey.

TASK 5: CONSIDERATION OF VARIOUS NATIONAL CLINICAL AUDIT DESIGNS AND RECOMMENDATIONS

The outcomes of the various work strands were combined in order to inform the national audit strategy. The process of selecting what to include in the audit was based on a number of factors, including availability of standards for benchmarking, measurable metrics with which to monitor compliance, and the potential for improvement in quality of care. Ease of data capture and measurement, evidence of variability across the system, linkage to existing data sources, and consent were also important considerations.

The feasibility of available options for the national audit was outlined based on this work by the project team and presented to the steering committee for consideration. Consensus on the preferred approach was reached at the second committee meeting, when the recommendations for the national audit (which are outlined in Chapter 11 of this report) were formulated.

CHAPTER 3

ANALYSIS OF CONTEXTUAL FACTORS INFLUENCING THE IMPLEMENTATION OF A NATIONAL MULTICENTRE AUDIT



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CHAPTER 3: **ANALYSIS OF CONTEXTUAL FACTORS INFLUENCING THE IMPLEMENTATION OF A NATIONAL MULTICENTRE AUDIT**

This section has been modified from a stand-alone thesis submitted to Trinity College Dublin as part of a Health Services Management Master of Science degree, *A preimplementation analysis of contextual factors influencing implementation of a National Paediatric Diabetes Audit in Ireland* (McGlacken-Byrne,S.,2019).

Four key context-mechanism-outcome (CMO) configurations identified by the realist synthesis review are discussed in this chapter.

CMO 1: ENSURING TRUSTWORTHY DATA

Reliable data governance structures, quality assurance processes, and data security measures ensure that those participating in and overseeing a national audit are accountable for the data generated, which results in trustworthy data. Effective data security measures also reassure audit participants of the trustworthiness of the data. Defined data collection processes are clear and easy to follow, which facilitates data accuracy and completeness and therefore increases data trustworthiness. This effect is further enhanced if participant capability is maintained with ongoing operational support.

Quality assurance

The development of quality assurance processes was one factor that facilitated the generation of trustworthy data from national multicentre audits in many studies. Some were third-party verification processes, where data were sent externally for quality review (Beck *et al.,* 2018; Dixon, 2013). Other studies described the implementation of internal quality assurance procedures, such as two-person data entry systems where data were reviewed or double-checked by a second individual in order to ensure reliability (Hansen *et al.,* 2019; Ferguson *et al.,* 2016; Mian *et al.,* 2005; Khunti *et al.,* 1999). Another approach was the internal review of unusual or unexpected data prior to central submission, conducted manually by clinical staff (Dowding *et al.,* 2019; Deasy *et al.,* 2016) or semi-automatically using audit filters that flagged outlying results (Dente *et al.,* 2016; Gaies *et al.,* 2016). Another technique was the provision of an instant report, at the time of data submission, reporting on data completeness and quality (Warner, 2018). These quality assurance processes generated a visible accountability for the quality of audit data, which resulted in a trustworthy process that facilitated clinical change (Reszel *et al.,* 2019; Warner, 2018). Implementation processes that did not incorporate quality assurance structures reported a reduction in the actual and perceived trustworthiness of their audit data (Cameron *et al.,* 2007; Scott *et al.,*2006). This lack of accountability and loss of trust limited the use of data in service planning decisions (Egholm *et al.,* 2019; Taylor and Jones, 2006).

Data governance

Rigorously designed data governance structures were also identified as a factor that enhanced data trustworthiness via the mechanism of ensuring accountability. Often, data coordinators at local level were charged with the responsibility of overseeing the collection of reliable and complete data (Dowding *et al.,* 2019; Deasy *et al.,* 2016; Dixon, 2013). Mandatory training – sometimes with a requirement for interval re-accreditation – facilitated reliable data collection processes in some cases (Deasy *et al.,* 2016; Gaies *et al.,* 2016; Dixon, 2013).

Data security

Processes to maintain data security were not mentioned in every study. However, discussions on several successfully implemented audits referenced data security, particularly if the audit involved sharing or transferring patient information between centres. Some audit processes relied on encrypted data collection tools in order to enhance security (Mehta *et al.,* 2017; Dixon, 2013; López-Campos *et al.,* 2013). Others conferred an external data processing group with the responsibility of ensuring data security (Beck *et al.,* 2018). A further safety mechanism was the use of pseudonymised data when comparing results between centres (Deasy *et al.,* 2016; Mian *et al.,* 2005; Khunti *et al.,* 1999). Again, these measures gave rise to a visible accountability for the safety of audit data and a perception that audit results came from a trustworthy source. There was also a sense that paying attention to data security was a source of reassurance for patients and participants that their contributed data were being handled appropriately. This was overtly acknowledged during the implementation of an Irish national multicentre audit, when data security procedures were broadcast to patients in order to reassure them that their data were being used appropriately (Deasy *et al.,* 2016). It was also acknowledged in the design of a multicentre audit in primary care, where prospective participants were invited to workshops where data security processes were collaboratively designed (Khunti *et al.,* 1999). Interestingly, the majority of the audits discussed did not require signed consent from patients to collect their data, and audit was implicitly considered as part of routine clinical care; the one group that was required to obtain consent had very low participation rates, purportedly due to the excessive time it took to adhere to this degree of governance (McKinney *et al.,* 2005).

Defined data collection processes

Defined data collection processes were found to increase the capability of audit participants to collect trustworthy data. Intuitively designed audit tools and electronic interfaces were easy to use without the need for intensive training (Egholm *et al.,* 2019; Simmons *et al.,* 2007). Readily accessible handbooks, education on data handling, and data dictionaries guiding data collection facilitated the collection of reliable and complete data (Beck *et al.,* 2018; Deasy *et al.,* 2016; Bowie *et al.,* 2009). Defined data collection processes also provided clarity to data collection processes. For example, the use of mandatory data input for some or most audit fields can help ensure that core data are collected completely (Egholm *et al.,* 2019; McLain *et al.,* 2017; Gaies *et al.,* 2016). Importantly, defined data processes can impede rather than facilitate clarity if they contain vague or ambiguous definitions (Wagner *et al.,* 2019; Dente *et al.,* 2016). In these instances, participants became confused or frustrated by the data collection task and entered incomplete or erroneous data, which compromised the ability of the audit to generate improvement (Egholm *et al.,* 2019; Reszel *et al.,* 2019; Hearnshaw *et al.,* 2003; Balogh *et al.,* 1998).

Operational support

A further important factor increasing the capability of audit participants to collect trustworthy data was ensuring ongoing operational support that facilitated problem-solving and troubleshooting of issues encountered during data collection (Beck *et al.,* 2018; Gavalova and Fellows, 2018; Deasy *et al.,* 2016; Aggarwal *et al.,* 2014; Gardner *et al.,* 2010; Batty *et al.,* 2004). Mostly, this process consisted of virtual communication between audit participants and a clinical audit office via a monthly (Roos-Blom *et al.,* 2019), weekly (Gaies *et al.,* 2016), or as-needed teleconference (Beck *et al.,* 2018; Hartley *et al.,* 2017; Deasy *et al.,* 2016). Clinical audit offices were often the source of operational support, but an open communication conduit between the audit office and participants was not a given; one study cited a lack of this communication as a barrier to effective operational support (Egholm *et al.,* 2019).

CMO 2: ENCOURAGING AUDIT PARTICIPATION

Stakeholder motivation is a key driver of audit participation. Governance structures are a source of extrinsic motivation, while multidisciplinary collaboration and distributed leadership are sources of intrinsic motivation, and facilitate a sense of collective ownership that drives audit participation. Transparent data processes and placing healthcare professionals in leadership roles enhance the perceived fairness and legitimacy of the audit intervention. Resource-limited and heterogeneous healthcare contexts can give rise to perceived unfairness if these factors are not acknowledged in the audit design. Data collection processes that acknowledge and alleviate resource constraints increase stakeholder acceptance of the audit workload.

Extrinsic motivation

Multiple interdependent factors synergistically facilitated audit participation. Mandated governance procedures extrinsically motivated stakeholders to engage with the audit process. For example, mandatory participation was a feature of several audits, including 29 of the 70 national audits operating in the UK (Egholm *et al.,* 2019; Gitkind *et al.,* 2014; Dixon, 2013; Gardner *et al.,* 2010;). Financial incentivisation was another source of extrinsic motivation. Several audit processes, including the existing UK National Paediatric Diabetes Audit, incorporated outcomes-based commissioning based on audit results, which encouraged participation (Gavalova and Fellows, 2018). Notably, one multicentre audit reimbursed participants if they collected any data, rather than rewarding results. This audit did not see an increase in participation levels, suggesting that financial incentives need to be well-specified in order to be effective (Scholte *et al.,* 2016).

Intrinsic motivation - Distributed leadership

While top-down governance processes did facilitate participation, contextual factors that intrinsically motivated stakeholders also emerged as important. If an audit was perceived as being 'imposed', resistance to the process rose over time (Bowie *et al.,* 2012). Shared, fluid and collective leadership was an antidote to this – essentially, descriptions of distributed leadership emerged from several studies (Gardner *et al.,* 2010; Uhl-Bien, 2006; Spillane, 2005; Gronn, 2002). Local leaders were seen as 'change champions' and as key drivers of audit participation (Belizán *et al.,* 2011). These leadership roles were either assigned or filled by individuals naturally engaged in the audit process (Deasy *et al.,* 2016). By explaining to stakeholders how the audit would facilitate their roles at local level, a sense of a shared organisational vision (Wagner *et al.,* 2017) and collective ownership of the audit process developed (Gardner *et al.,* 2010). However, local leadership required complementary higher-level leadership in order to sustainably facilitate audit participation (Deasy *et al.,* 2016). Healthcare staff in visible clinical leadership roles were important here, as this enhanced the perceived legitimacy of the audit process and assured local participants that collective audit ownership extended to the national level (Cameron *et al.,* 2007).

Multidisciplinary collaboration

Acting synergistically with distributed leadership was multidisciplinary collaboration, which was a prominent feature of many successful audits. Meaningful collaboration with relevant stakeholders during audit design via workshops, focus groups, Delphi processes and local audit committee meetings further facilitated the intrinsic motivation of stakeholders to participate in the audit (R. Bailie *et al.,* 2017). Increased trust in the process (Ross *et al.,* 2017), perceived relevance (Egholm *et al.,* 2019), and autonomy (Scholte *et al.,* 2016) were cited as drivers of this motivation. Maintaining this collaboration throughout the audit implementation process

cultivated the sense of collective audit ownership that had been seeded by change champions (Batty *et al.,* 2004). This was achieved by regularly scheduled workshops to review data collection processes (Hartley *et al.,* 2017), feedback strategies (Khunti *et al.,* 1999), and general user experience of audit participation (Cooke *et al.,* 2018; Puszka *et al.,* 2015).

This sense of collective ownership resulted not only in increased audit participation, but also in a meaningful partnership that facilitated an interdisciplinary problem-solving approach to quality improvement (Laycock *et al.,* 2016). The importance of multidisciplinary collaboration was emphasised by implementation processes that failed to include it in their design: 'tick-box' involvement of staff, or lack of any staff involvement at all, resulted in poorer quality data and a lower commitment to audit participation (Dodd *et al.,* 2010). Despite the importance of patient empowerment to chronic disease management and to the generation of meaningful audit data (Warner, 2018), service users were particularly neglected in described collaborative design processes (Dodd *et al.,* 2010).

Resource-limited healthcare environments

The majority of studies reported some degree of resource limitation within the audit implementation environment – a lack of funding (Ayieko *et al.,* 2019), time (Egholm *et al.,* 2019), or both (Gude *et al.,* 2019b). If insufficient resources were provided to enable operational support for the audit, the newly increased workload was perceived as unfair and stakeholders disengaged from the process (Roberts *et al.,* 2010). However, efforts to redirect resources in order to ease the audit burden were viewed favourably by stakeholders and facilitated participation (Deasy *et al.,* 2016). In particular, data collection processes that acknowledged the challenge of working in a resource-constrained environment contributed to audit acceptability; successful audits often had a manageable, carefully prioritised data collection tools at the core of their design (McErlane *et al.,* 2018; López-Campos *et al.,* 2013).

Heterogeneous healthcare environments

The audit implementation environments were further complicated by their significant heterogeneity. Multicentre audits were implemented across healthcare contexts that offered different levels of care (Deasy *et al.,* 2016; Gardner *et al.,* 2010) that were geographically disparate (Hysong *et al.,* 2017) (López-Campos *et al.,* 2013), and that reported varying quality of clinical care (Khunti *et al.,* 1999; Balogh *et al.,* 1998). Interestingly, most audits were implemented across centres that had either paper or electronic records; combining the two types of records was infrequently reported and did not appear to be a significant factor influencing implementation success (Gavalova and Fellows, 2018; Balogh *et al.,* 1998). Indeed, most factors contributing to heterogeneity were not often cited as barriers to implementation. However, participating in an audit within these heterogeneous environments sometimes translated to an unequal workload burden across centres, which resulted in perceived unfairness and disengagement from the audit if resources were not available to equalise this burden (Gardner *et al.,* 2010; Mian *et al.,* 2005). Heterogeneity in clinical contexts was also relevant to feedback structures, as discussed in Section CMO 4.

CMO 3: DRIVING AUDIT SUSTAINABILITY

Audits that adapt to, and integrate with, healthcare contexts on an individual basis are more likely to result in a sustainable audit. Piloting of audit processes and efforts to incorporate existing organisational structures into audit design facilitate this. Ongoing operational and financial support translates to a responsive audit that is equipped to support its participants over multiple audit cycles.

Incorporation of existing structures into audit design

While factors influencing stakeholder engagement are important, so too are those that facilitate a sustainable audit that grows, endures several audit cycles, and ultimately becomes embedded into organisational culture. Adaptability and integration were identified as key generative mechanisms; a one-size-fits-all audit approach is unlikely to result in a sustainable process (Bailie *et al.,* 2008; Balogh *et al.,* 1998). A key factor driving these mechanisms was the incorporation of existing organisational structures into audit design. This was achieved by making use of 'off-the-shelf' audit tools that had previously worked in similar contexts (Deasy *et al.,* 2016), exploiting data that were already routinely collected (Dowding *et al.,* 2019; Aggarwal *et al.,* 2014), and availing of existing meeting times and communication conduits in order to connect with stakeholders (Gitkind *et al.,* 2014; Moore, 2008). Piloting enabled these potentially exploitable existing structures to be identified prior to audit implementation (Deasy *et al.,* 2016; Brooker *et al.,* 2005). Piloting was particularly effective if it resulted in iterative refinement of the audit process until it was appropriately tailored to the intended implementation environment (Puszka *et al.,* 2015; Dodd *et al.,* 2010). For example, one successfully implemented audit described how a pilot process identified two data items that were too laborious to collect in certain centres; these were therefore omitted from the data collection tool, prioritising adaptability over data completeness and facilitating audit sustainability in the process (Simmons *et al.,* 2007).

Provision of ongoing audit support

The availability of ongoing operational and financial support for audit processes was important for audit sustainability. The availability of ring-fenced, reliable funding streams was needed if an audit was to weather several audit cycles (Beck *et al.,* 2018; Deasy *et al.,* 2016). This facilitated the provision of meaningful, ongoing operational support from clinical audit offices, both virtual (Bailie *et al.,* 2008) and face-to-face (Deasy *et al.,* 2016). The absence of ongoing operational and financial support usually resulted in the disintegration of core audit processes and, ultimately, audit discontinuation (López-Campos *et al.,* 2013; van Hamersveld *et al.,* 2012).

CMO 4: FACILITATING AUDIT CYCLE COMPLETION

Audit cycle completion entails the implementation of change. Effective feedback is required in order to motivate participants to act on audit findings. Feedback transparency can generate accountability for making change; however, this needs to be balanced with the perceived fairness of feedback processes in order to avoid demotivating participants. Facilitated action planning translates to a responsive audit process capable of addressing identified deficits, and can instil in participants a sense of self-efficacy in their own capacity for change.

Feedback transparency

Trustworthy data, engaged participants and a sustainably embedded audit are little use if they do not result in the implementation of change, which is the final step of the audit cycle (Benjamin, 2008). Feedback on audit data was broadly seen as a key driver of change, but interestingly opinions on what constituted effective feedback varied. The role played by accountability and extrinsic motivation in encouraging audit participation was discussed earlier in this chapter. Some studies also identified transparent and public feedback processes that generated accountability as key facilitators of quality improvement; in these studies, audit data were fully transparent, identifiable and publicly available (Reszel *et al.,* 2019; Warner, 2018).

This approach was modified in some cases in order to enhance perceived fairness. Some audit feedback processes involved pseudonymisation of contributing hospitals, which facilitated benchmarking but prevented identification of individual centres (Khunti *et al.,* 1999). Others published audit data alongside service-level data that described the resources allocated to each participating centre, allowing for case mix adjustment and a fairer picture of clinical performance (Beck *et al.,* 2018; Gaies *et al.,* 2016; Bailie *et al.,* 2008). However, the design of other feedback processes reflected the view that any inter-centre comparison would introduce unhealthy competition between centres (Wagner *et al.,* 2017; Ghaderi *et al.,* 2013). In these instances, feedback was delivered to contributing centres privately and on an individualised basis, relying on local motivating processes to drive change (Gude *et al.,* 2019a; Hartley *et al.,* 2017). Standard feedback processes for NOCA audits are outlined in Appendix iv.

Formative feedback

All of these various feedback processes facilitated improvement in their given contexts, which precludes selection of a single method that is best equipped to facilitate audit cycle completion. However, regardless of decisions around feedback transparency, one factor was reproducibly linked to audits that resulted in clinical improvement: an emphasis on formative, rather than summative, feedback. Feedback processes that were overly critical created a culture of blame that resulted in disenchanted participants and an audit that was not capable of generating sustainable quality improvement (Payne and Hysong, 2016; Bowie *et al.,* 2012; Belizán *et al.,* 2011). Formative feedback that was non-punitive, helpful and task-specific facilitated the intrinsic motivation of stakeholders to improve care quality (Gaies *et al.,* 2016; Hysong *et al.,* 2006; Bours *et al.,* 2004).

Action planning

A second factor uniformly facilitating completion of the audit cycle was the incorporation of action planning into feedback processes (Gould *et al.,* 2018). Passive dissemination of feedback often resulted in limited actionability of audit findings (Trietsch *et al.,* 2017; Ivers *et al.,* 2013). Action planning involved providing participants with recommendations for action at the same time as audit feedback (Belizán *et al.,* 2011; Bowie *et al.,* 2009; Balogh *et al.,* 1998). This facilitated change by increasing participant self-efficacy in their ability to improve their practice (Bailie *et al.,* 2008) and by empowering participants to problem-solve solutions to identified issues (Reszel *et al.,* 2019). Action planning was particularly effective if conducted face-to-face within outreach workshops facilitated by those centrally overseeing the audit (Belizán *et al.,* 2011;Batty *et al.,* 2004). This type of organisational commitment to enabling improvement resulted in participants perceiving the audit as responsive to the needs of their healthcare environment, further motivating improvement efforts and inducing a positive cycle of change (Gaies *et al.,* 2016). An audit that simply fed back results with neither the provision of recommendations nor support of change was viewed as neither valuable nor responsive by participants and did not result in the implementation of meaningful change (Bowie *et al.,* 2012; van Hamersveld *et al.,* 2012).

CHAPTER 4

INTERNATIONAL EXPERIENCE WITH PAEDIATRIC DIABETES AUDIT



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CHAPTER 4: **INTERNATIONAL EXPERIENCE WITH PAEDIATRIC DIABETES AUDIT**

UK – *National Paediatric Diabetes Audit*

The National Paediatric Diabetes Audit has reported on the quality of care of children with diabetes in England and Wales since 2011. Routine clinical data are collated from Twinkle (a paediatric diabetes patient management system) and other hospital databases and are submitted by clinics to an online data capture system. Participation in the audit is mandatory for all hospitals in England as per the National Health Service (NHS) standard contract, and in Wales as per the *NHS Wales National Clinical Audit and Outcome Review Plan (2019)*. The best practice tariff, introduced in England in 2012 to enhance funding of paediatric diabetes services, is awarded for each patient for whom care is delivered in line with prescribed standards.

As its aims are considered to be in the public interest, the NPDA has section 251 approval (NHS Act 2006, GDPR Article 6 (1) (e), article 9(2) (i)) to collect patient-identifiable data without explicit patient consent in order to improve standards of paediatric diabetes care. In addition to producing annual national reports on care processes and outcomes, spotlight audit reports on topics such as diabetes technologies and the workforce delivering paediatric diabetes care are also produced. The spotlight audits seek to highlight variability in the structure and delivery of care for patients with paediatric diabetes in England and Wales. The audit also reports on hospital admissions related to diabetes by obtaining patient-identifiable information from the Hospital Episode Statisitics database and from the Patient Episode Database for Wales. These data are linked with audit data in order to ensure a complete representation of diabetes-related admissions. Patient Reported Experience Measures are collected via online anonymised surveys which patients and their parents or carers are invited to complete. The National Paediatric Diabetes Audit collaborates with the National Diabetes Audit (adult audit) to produce the National Diabetes Transition Audit.

The key finding from the most recent annual report (Royal College of Paediatrics and Child Health, 2021) was that the national median glycated haemoglobin (HbA1c) has remained constant at 61.5 millimoles per mole (mmol/mol) between 2018–2019 and 2019–2020 following several years of year-on-year decreases (improvement) in the national median. In 2011–2012, 17.4% of children and young people with diabetes in England and Wales achieved the National Institute for Health and Care Excellence recommended HbA1c target of <58 mmol/mol. In 2019–2020, 11% of children in England and Wales achieved the (tighter) HbA1c target of <48 mmol/mol, while 31% achieved the HbA1c target of <58 mmol/mol.

Scotland – *Scottish Diabetes Survey*

Scotland has an international reputation for excellence in diabetes data collection. Since 2002, Scottish Care Information – Diabetes Collaboration (SCI-DC) has demonstrated annual improvements in the quality of diabetes care. SCI-DC provides clinical information, support for diabetic screening services and data for national and local audit programmes.

SCI-DC delivers a single core product: SCI-Diabetes. SCI-Diabetes is a world-leading clinical management and information system and enables the tracking of the effects of health policy on the delivery of care and outcomes for people with diabetes in Scotland. It is a fully integrated shared electronic patient record to support the treatment of NHS Scotland patients with diabetes. It provides functionality for both primary and secondary care clinicians and includes specialty modules for paediatrics, podiatry, diabetes nurse specialists and dietetics (Scottish Care Information Diabetes Collaboration (n.d.)).

NHS Research Scotland maintains a diabetes research register. This is an electronic database of patients who have agreed to be contacted about research for which they are eligible. Consent allows the NHS Research Scotland Diabetes Network to securely access the electronic diabetes records held in SCI-Diabetes. The SCI-Diabetes record can be flagged to show that a patient has given consent to join the diabetes register.

Austria and Germany – *Diabetes Patient Progress Documentation*

In Germany and Austria, an electronic health record specific to paediatric diabetes has been developed and continuously updated since it was first launched in 1995. Diabetes Patient Progress Documentation (*Diabetes Patienten Verlaufsdokumentation*; DPV) initially focused on children and adolescents with diabetes and was extended to adult patients in 1997. Data are recorded once and are then available for numerous functions. Participation in DPV is voluntary and anonymised data are submitted to the DPV registry. External quality comparisons are sent to participating institutions twice annually. DPV is currently used by 426 centres, mainly from Germany and Austria, but also from Luxembourg and Switzerland (Hofer *et al*., 2016).

SWEET *(Better control in paediatric and adolescent diabeteS: Working to crEate cEnTers of reference)*

DPV is used for the SWEET project (SWEET (n.d.)). The SWEET-DPV documentation software allows centres to upload their data files to the server in the University of Ulm, in Germany. Twice a year, members receive the SWEET Benchmarking report. There are more than 30 certified centres of reference, and 3 Irish centres are included (Cork University Hospital, University Hospital Limerick, and CHI at Crumlin). Certification is based on clearly defined quality-of-care guidelines and requirements that must be met. The SWEET database uses standardised documentation and objective comparison of quality indicators.

The SWEET project was initiated with support from the European Union Public Health Program with a main aim of improving secondary prevention, diagnosis and control of type 1 and type 2 diabetes in children and adolescents by supporting the development of centres of reference for paediatric and adolescent diabetes services across the European Union.

Sweden *SWEDIABKIDS – Swedish national quality registry for diabetes in children and adolescents*

The Swedish National Diabetes Register (NDR) collects data on children and adolescents in Sweden who are aged under 18 years and provides detailed comprehensive annual reports on all aspects of care (incidence of diabetes, percentage in diabetic ketoacidosis (DKA) at diagnosis, care delivery, HbA1c, technology use, etc.). The NDR developed a tool for improving diabetes management, called 'Knappen', which is available on its website (www.ndr.nu) and can be used by healthcare professionals as well as by families. Since May 2018, the SWEDIABKIDS register (which was established in 2000) has been on the same platform as the NDR, which includes adults with diabetes. SWEDIABKIDS has been web-based since 2008 and allows each diabetes centre to follow its results and to benchmark them with those of other centres (Peterson *et al*., 2014). Outpatient attendance data are continuously submitted and can be followed continuously. The participation rate is almost 100%. The NDR displays results openly through an interactive web tool which allows the user to make their own searches quickly and easily. The NDR has a network of contacts at all paediatric diabetes clinics. This contact person is responsible for attending an annual meeting, informing local services about the NDR, encouraging reporting to the NDR and promoting the use of NDR findings for local quality improvement.

Denmark *– DanDiabKids- Danish registry of childhood and adolescent diabetes*

DanDiabKids is part of the shared Danish Diabetes Database (DDD) and has been collecting national data on children and adolescents with type 1 diabetes since 1996. Since 2006, children with all types of diabetes are included. DanDiabKids was extended in 2015 to include every child aged up to 18 years who is admitted to a paediatric centre (Svensson *et al*., 2016).

The unique Danish personal identification number allows linkage at the individual level of the DDD with other Danish registers, such as the National Patient Register. Once a year, all patients in the National Patient Register who are not found in DanDiabKids are validated in order to ensure that all children with diabetes are captured by DDD.

Once a year, over 90% of the participating centres send one HbA1c sample to a specialised laboratory in the Department of Paediatrics and Adolescent Medicine at Copenhagen University Hospital, where the determination of HbA1c is performed for all participating centres in Denmark according to the International Federation of Clinical Chemistry and Laboratory Medicine standard.

The variables in DanDiabKids are quality indicators, demographic variables, associated conditions, diabetes classification, family history of diabetes, growth parameters, self-care, and treatment variables. The quality indicators are selected based on international consensus of measures of good clinical practice. The indicators are metabolic control as assessed by HbA1c, blood pressure, albuminuria, retinopathy, neuropathy, number of severe hypoglycaemic events, and hospitalisation with ketoacidosis.

Norway – *Norwegian Childhood Diabetes Registry*

The Norwegian Childhood Diabetes Registry (NCDR) was established in 2006. Informed consent is obtained from each patient and/or parent before the patient is registered. The NCDR collects data prospectively, both incident cases and clinical data from yearly examinations of all children and adolescents with diabetes who were treated in paediatric departments in Norway (Hanberger *et al*., 2014). Data are collected via the eReg registry solution, which is built on a Microsoft relational database with a web-based user interface. Since 2008, all paediatric departments in Norway have reported to the NCDR and are anonymously benchmarked for quality indicators. HbA1c is determined for all participants by high-performance liquid chromatography at the same central standardised laboratory. The NCDR has a new supplementary interactive website where results can be viewed. The NCDR is a national prospective population-based study, which reports on incidence, prevalence, quality of care delivery, and complications, and provides national data for research and quality improvement initiatives.

United States of America – *T1D Exchange Diabetes Registry*

The T1D Exchange Registry (T1DX), established in 2010, collects data with informed consent from 81 paediatric and adult endocrinology practices in 35 states in the United States of America (USA). Thirty-eight of the centres primarily care for paediatric patients, 19 care for adults only, and 24 care for both paediatric and adult patients. Core data are updated annually from medical records (Miller *et al*., 2015). Individual consent for participation in T1DX is required for all patients, which can introduce selection bias to this multicentre study.

The T1DX consists of three complementary parts:

1. a network of adult and paediatric clinics that prospectively collects clinical data on a large population of patients with type 1 diabetes mellitus (T1DM)
2. a website called GLU that serves as an online community for patients to provide information that could be used for research while also learning, communicating, and motivating each other
3. a biobank to store biological human samples for use by researchers.

Australia – *National (insulin treated) Diabetes Register*
Australasian Paediatric Endocrine Group's state-based register

In 1999, a National Diabetes Register – administered by the Australian Institute of Health and Welfare (AIHW) – was established. A contract has been in place between the Australasian Paediatric Endocrine Group (APEG) and the AIHW since 1999 (Australian Institute of Health and Welfare (2021)). The purpose of the contract is for APEG state-based registers to provide secondary ascertainment data to the AIHW on all forms of paediatric insulin-treated diabetes (type 1, type 2, and other forms of diabetes) prospectively. The NDR also uses the National Diabetes Services Scheme database for case ascertainment.

Each Australian state maintains an APEG with ethical approval at all local sites. The purpose of the APEG register is to accurately determine the annual rates of all types of diabetes in young people throughout Australia. Consent for inclusion in the register is sought from all newly diagnosed young people in Australia. The register only applies to young people who live in Australia, whose diabetes was diagnosed in Australia or while on holiday overseas, and who were aged under 19 years at the time of diagnosis. Ascertainment is estimated to be 99%.

The APEG dataset contains information on young people with insulin-treated diabetes who were aged 0–14 years at the time of diagnosis. As insulin-treated type 2 diabetes is rare in children aged under 15 years, most of the children and adolescents listed on the APEG dataset have type 1 diabetes.

TABLE 4.1: SUMMARY OF INTERNATIONAL DATA COLLECTIONS

Country	UK	Scotland	Austria/Germany	Sweden
Name of data collection	NPDA	SCI-Diabetes	DPV	SWEDIABKIDS
Year commenced	2011	2002	1995	2000
Age range of patients	Up to 18 years Link to adult audit	Paediatric and adult	Paediatric and adult	Up to 18 years Link to adult register
Data collection method	Online submission	Electronic record	Electronic record	Knappen online tool
Type of diabetes	T1DM and type 2 diabetes	All	All	T1DM and type 2 diabetes
Participation	Mandatory	Integrated to routine care	Informed consent	Mandatory
Identifiable data included?	Yes	Yes	Yes – if consented	Unique personal identifier
Coverage (%)	>95%	99%	95%	98%
Funding source	NHS	NHS	Multiple sources*	SALAR^

Country	Denmark	Norway	USA	Australia
Name of data collection	DanDiabKids	NCDR	T1DX	NDR – APEG
Year commenced	1996	2006	2010	1999
Age range of patients	Up to 18 years Link to adult register	Paediatric and adult	Paediatric and adult	Paediatric and adult
Data collection method	Electronic database	e-Reg online tool	Online data platform	Electronic database
Type of diabetes	All	All	T1DM	All
Participation	Mandatory	Informed consent	Informed consent	Informed consent
Identifiable data included?	Unique personal identifier	Yes	Yes	Yes
Coverage (%)	100%	>95%	N/A	99%
Funding source	RKKP^^	Regional Health Authority	Charitable trust	AIHW

* The DPV initiative is financially supported by Germany's Federal Ministry of Health, the German Diabetes Foundation, the German Diabetes Association, the German Center for Diabetes Research (*Deutsches Zentrum für Diabetesforschung*; DZD, grant no. (*Förderung-skennzeichen*; FKZ): 82DZD01402), the Dr Bürger-Büsing Foundation, and the European Foundation for the Study of Diabetes.

^ The Swedish Association of Local Authorities and Regions (SALAR) represents the Decision group for National Quality Registers, Sweden's municipalities and regions.

^^ Danish Regions are administered by the Danish Clinical Registries (*Regionernes Kliniske Kvalitetsudviklings Program*; RKKP) that constitute the infrastructure of the national clinical quality databases in Denmark.

LESSONS FROM INTERNATIONAL EXPERIENCE

1. Resources (electronic and human) are required for data collection

The UK's NPDA reported that some of the perceived poor adherence to care processes in audit findings were not necessarily a true reflection of a failure to perform these processes in the clinics but may instead reflect inadequate information technology (IT) resources for data collection and submission to the NPDA. The NPDA also acknowledges that participation in the audit is a time-consuming process, particularly where there is a lack of resources and/or computer software to aid data collection. One of its recommendations in the latest annual report states: "Ensure Paediatric Diabetes Units have appropriate staffing levels in the paediatric multi-disciplinary teams (MDT) to provide excellent quality care to young patients with diabetes. This must include dedicated administrative support and IT support to record good quality data" (Royal College of Paediatrics and Child Health, 2021, p.14).

2. Efficiency and accuracy are optimised by integrated electronic data collection, and the analysis and dissemination of findings

International registries commonly use an electronic record that is integrated into routine clinical care. Scotland, with a population size similar to that of Ireland, has successfully implemented an electronic data management system for all patients with diabetes. This facilitates audit, benchmarking and transition from paediatric to adult care, and allows tracking of each individual across services. In the Irish context, where resources are limited, integration of audit into clinical care is essential to ensure that complete data are collected with minimal additional burden on the delivery of clinical care.

3. Registers and electronic systems foster quality improvement and data-driven decision-making, which can inform practice (e.g. resource allocation, investment in technology)

A cross-sectional analysis of HbA1c data from international audits and registries (Table 4.2) shows the value of audit in identifying how well services are performing (Charalampopoulos *et al.*, 2018). Sweden had the lowest mean HbA1c value and, together with the other Nordic countries, demonstrated that excellent glycaemic control can be achieved in childhood.

TABLE 4.2: INTERNATIONAL SOCIETY FOR PEDIATRIC AND ADOLESCENT DIABETES TARGET ACHIEVEMENT OF INTERNATIONAL AUDITS AND REGISTRIES

Country	Registry/audit	National coverage	International Society for Pediatric and Adolescent Diabetes target achievement (% of patients)
Sweden	SWEDIABKIDS	~98%	49
Germany	DPV	~95%	46
Austria	DPV	~80%	43
Denmark	DanDiabKids	~100%	38
Norway	NCDR	>95%	29
England	NPDA	>95%	20
Wales	NPDA	>95%	17
USA	T1DX	N/A	18

In the absence of a national paediatric diabetes audit, accurate Irish data are lacking in many areas. The incidence of T1DM in children in Ireland who are aged under 15 years is captured by the Irish Childhood Diabetes National Register (ICDNR), but outcome data are not captured or available to inform clinical care in Ireland.

CHAPTER 5
THE PATIENT JOURNEY



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CHAPTER 5: **THE PATIENT JOURNEY**

RATIONALE

Patient journey mapping helps provide a better understanding of how patients interact with the healthcare system. The mapping exercise in this chapter aims to outline all of the patient contacts during each stage of interaction in order to expose gaps in care and opportunities for quality improvement.

AIM

All points of patient interaction with paediatric diabetes care delivery, from diagnosis through ambulatory care to transition from paediatric services to adult diabetes services, were mapped in order to identify care processes that are subject to variability and are amenable to audit.

METHODOLOGY

A multidisciplinary subgroup of the steering committee – consisting of consultant paediatric endocrinologists, clinical nurse specialists in paediatric diabetes, a paediatric dietitian and a parent representative – was tasked with the mapping exercise, which was conducted over a series of Zoom calls during which a number of drafts were reviewed and refined. The three phases of the patient journey are as follows:

- **Phase 1:** Diagnosis: This phase begins at the time of first presentation with diabetes and continues through structured education and support to the first outpatient appointment.
- **Phase 2:** Ambulatory outpatient care: This phase follows Phase 1 and includes multidisciplinary clinic appointments, annual review appointments, additional education and technology initiation, psychological support, and retinopathy screening and comorbidity screening in line with national guidelines.
- **Phase 3:** Transition: Transition of care from the paediatric diabetes service to the young adult diabetes service.

Efforts were made to highlight points where there was possible variability between centres, including factors such as resources, format of data recording, etc. Another factor considered during the process was the capture of extraordinary events in the journey (e.g. hospital readmission with DKA or severe hypoglycaemia, diagnosis of comorbidities, or mental health issues, including eating disorders).

This mapping exercise was restricted to hospital-based care. Stages of the patient journey prior to the confirmed diagnosis of T1DM warrant attention, as delayed diagnosis is an important variable that may be amenable to audit and quality improvement. This phase in the patient journey was not included, as it is not currently captured systematically in hospital-based services.

Phase 1: Diagnosis of T1DM

The patient's medical journey during the diagnosis phase is outlined in Figure 5.1. Possible auditable metrics are highlighted in green, and decision points in the pathway are indicated by diamonds.

Classic osmotic symptoms of T1DM at diagnosis include polydipsia, polyuria, and weight loss, and same-day referral to the emergency department (ED) is the standard of care for children and adolescents with suspected T1DM. Symptom recognition is key to early diagnosis of T1DM prior to decompensation. Patients may present with these symptoms to their general practitioner (GP), an urgent care centre or an ED.

Where early symptoms are not recognised or where referral is delayed (e.g. sent by post), children and adolescents can decompensate and present with DKA. Approximately 30–40% of patients present after decompensation with DKA at diagnosis; one-fifth of these patients are severe (Finn *et al*., 2019; McKenna *et al.,* 2018; Oyarzabal Irigoyen *et al*., 2012; Rewers *et al*., 2008). Depending on the severity of the DKA at presentation, this complication may require care in a paediatric intensive care unit. While the outcomes of DKA are generally favourable, this condition carries a risk of cerebral oedema and death (Siafarikas and O'Connell, 2010; Glaser *et al*., 2001). Blood tests are required in order to confirm the diagnosis (glucose, ketones, electrolytes, blood gas, HbA1c, and autoantibodies). Testing for comorbidities (coeliac disease, thyroid dysfunction) is also performed at the time of diabetes diagnosis. The standard of care is that a member of the diabetes multidisciplinary team (MDT) should see all children who are diagnosed with T1DM within 24 hours of diagnosis on a weekday and within 48 hours of diagnosis on a weekend (Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015).

STRUCTURED EDUCATION

All children with T1DM and their families require structured education so that they can acquire the necessary skills for appropriate self-care to achieve optimal glycaemic control. Optimal diabetes control is associated with a marked reduction in the risk of developing diabetes-related complications (The Diabetes Control and Complications Trial Research Group, 1994; 1993). This education is provided by a trained MDT and should be delivered efficiently to allow safe discharge home and close follow-up in the days after diagnosis. A trained MDT (including a diabetes clinical nurse specialist (DNS) and dietitian) delivers structured education, and psychosocial team members provide further support to families. Following discharge, patients should have close contact with the paediatric diabetes CNS until competent in self-care, and should have access to skilled paediatric diabetes advice both during and outside of standard working hours. How structured education is delivered at diagnosis currently varies between services and children may be admitted to hospitals without a full, dedicated paediatric diabetes MDT.

Key audit metrics would include:

- completeness of diagnostic testing at diagnosis, in accordance with ISPAD international guidelines
- DKA management as per HSE national guidelines
- completion of required referrals
- assessment of skills and knowledge base prior to discharge (insulin administration and blood glucose monitoring, knowledge of blood glucose targets, management of hypoglycaemia and hyperglycaemia, basic carbohydrate counting)
- frequency of interactions with the diabetes MDT following discharge
- timing of follow-up appointments with the DNS, dietitian and diabetes clinic
- incidence of unscheduled readmission.

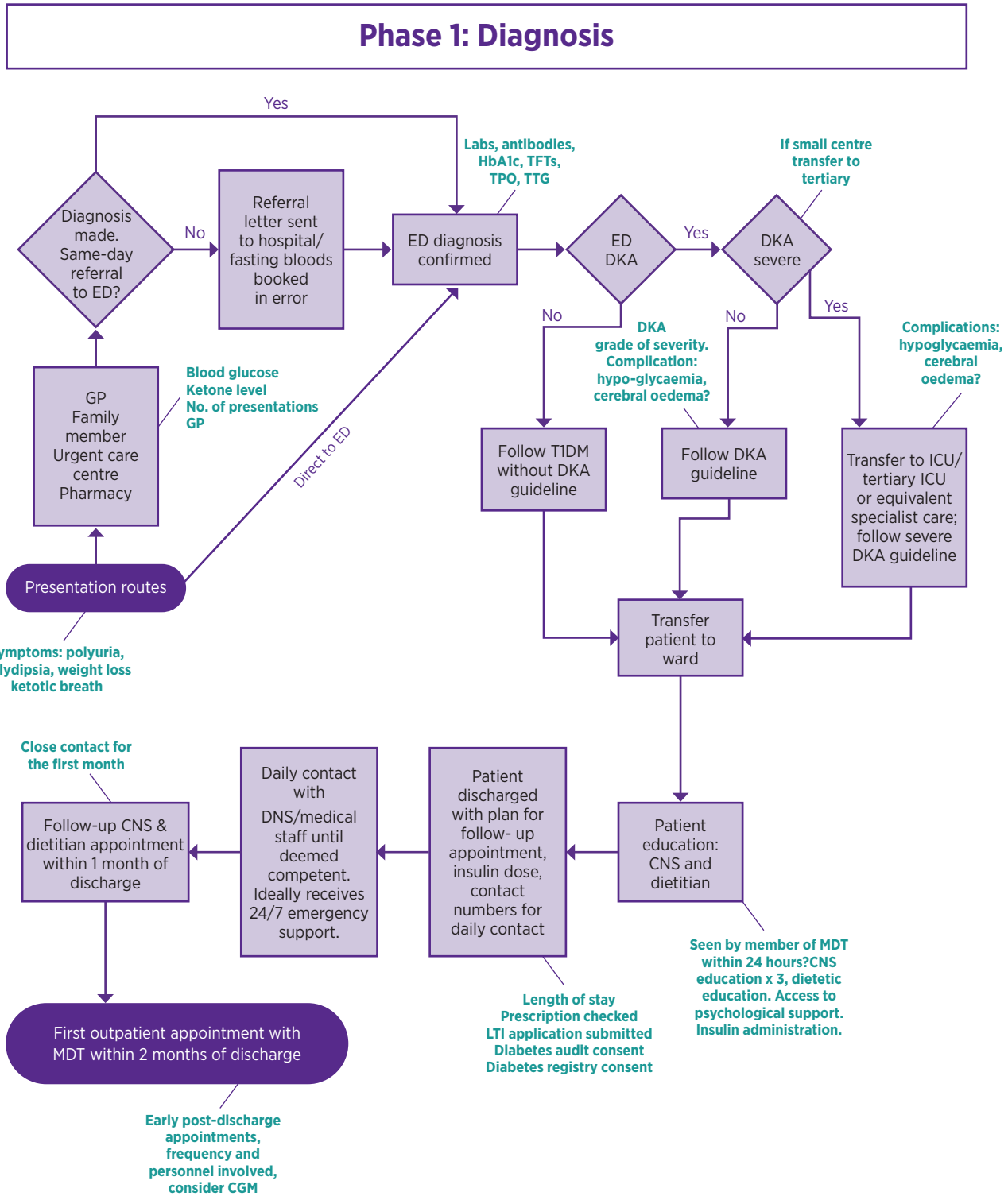


FIGURE 5.1: PHASE 1: DIAGNOSIS OF TYPE 1 DIABETES MELLITUS IN CHILDREN AND ADOLESCENTS

Phase 2: Ambulatory outpatient care

The patient's medical journey during the ambulatory outpatient phase is outlined in Figure 5.2. It is recommended that the first outpatient clinic appointment with the diabetes MDT should take place within 2 months of discharge from hospital after initial diagnosis admission, and that children should be offered MDT appointments every 3 months thereafter. Where the child is not brought to an appointment, the relevant national guideline should be followed (HSE National Clinical Guidelines, Clinical Strategy and Programme Office HSE, 2019).

The focus for children with T1DM and their families at this time is on optimising health, glycaemic control and quality of life. At each clinic visit, children with T1DM should have auxology measurements (height and weight) taken, injection sites reviewed, HbA1c measured, glycaemic data reviewed and tailored education provided as required (hypoglycaemia and sick day management, etc.). Where necessary, dose titration should be undertaken (Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015).

Every child should have access to a fully trained paediatric diabetes MDT and care should be tailored to each patient's needs. Where team resources are limited (in smaller centres with small patient cohorts), patients should be linked to their regional centre in order to ensure access to the full range of available services and technology. Early pump initiation (also termed continuous subcutaneous insulin infusion (CSII)) should be accessible for all preschoolers with T1DM. Patients should be assessed for pump therapy (CSII) suitability and readiness and, where appropriate, this therapy should be accessible in a timely manner.

Where glycaemic control is suboptimal, additional paediatric diabetes MDT education and support are required and should be offered in line with national guidelines.

Annual review and comorbidity screening should be provided as per the relevant national guideline. This includes referring patients aged over 12 years for retinopathy screening.

At each stage, appropriate guidelines for addressing suboptimal glycaemic control and non-attendance at clinic appointments should be followed. For patients whose HbA1c levels are elevated, additional phone and psychosocial support should be provided, as these patients are at increased risk of developing short- and long-term complications.

Appropriate measurable audit metrics include:

- the number of outpatient appointments offered and attended each year
- compliance with comorbidity screening
- time between decision to commence insulin pump therapy and pump initiation
- frequency of interactions with each discipline within the paediatric diabetes MDT
- glycaemic control as assessed by HbA1c levels.

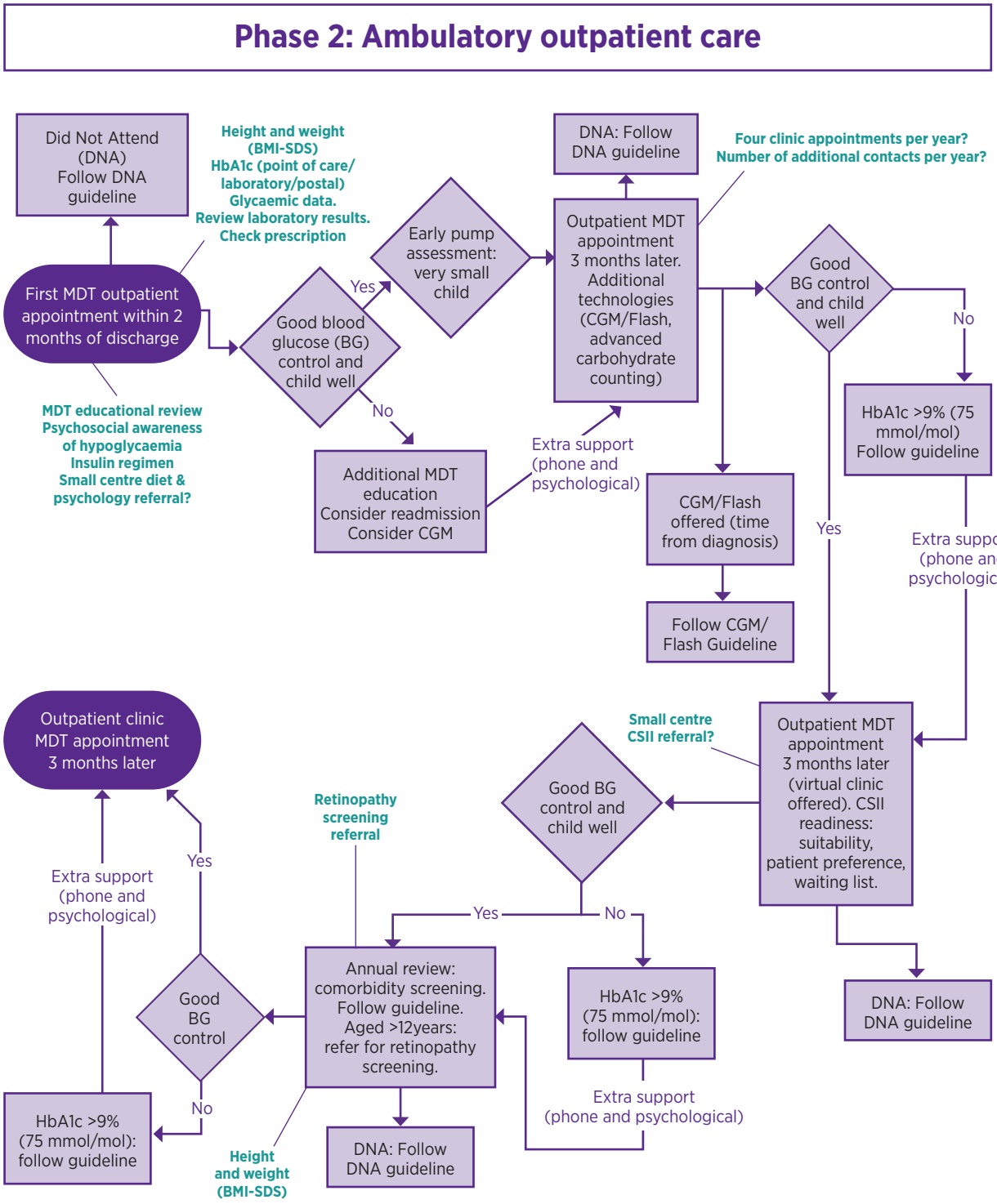


FIGURE 5.2: PHASE 2: AMBULATORY OUTPATIENT CARE OF PAEDIATRIC PATIENTS WITH TYPE 1 DIABETES MELLITUS

Phase 3: Transition of patients with T1DM from paediatric to adult diabetes services

A smooth transition from paediatric to adult diabetes services is essential for ensuring continued engagement with healthcare services and maintaining optimal glycaemic control. This is a vulnerable stage for young adults with T1DM and carries increased risk of suboptimal diabetes management and the resultant complications, especially as young adults assume more autonomy and independence.

The transition should be a structured process rather than a single time point when the patient reaches a certain age. Discussions on the process should be initiated early to ensure adequate preparation. Transition preparation education sessions are recommended for adolescents and their parents or carers. Policy on the best age for transitioning to adult services varies between centres, but generally adolescents move to adult services when they are aged between 16 and 18 years. All centres should have a local transition policy and an identified team member to coordinate and support this process. Ideally, joint clinics should take place between adult and paediatric teams to support successful transition, and ideally, teens aged 16 years and over should move to a dedicated young adult clinic within adult diabetes services. The paediatric team should prepare a transfer letter or summary for the receiving adult team. Education around issues pertinent to young adults (e.g. alcohol, smoking, recreational drug use, contraception and pregnancy, mental health, exams, sexual health, and self-advocacy) are important in the young adult clinic (Figure 5.3) and should be tailored and age-appropriate.

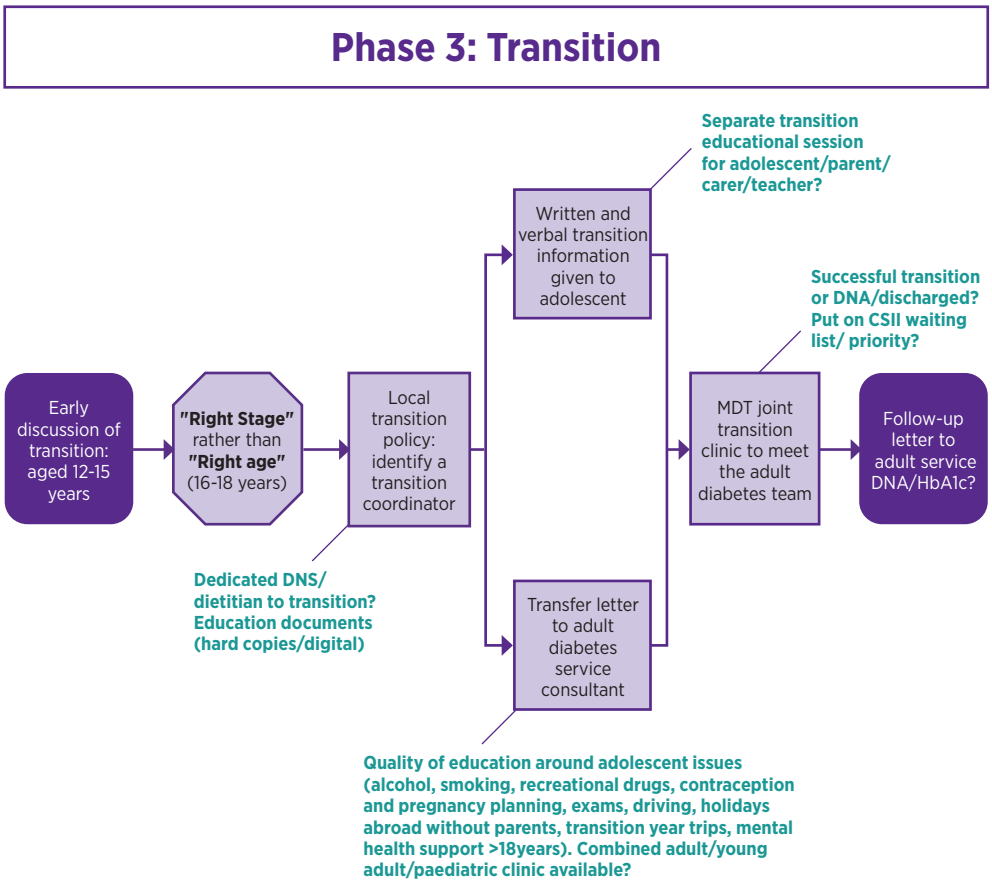


FIGURE 5.2: PHASE 3: TRANSITION FROM PAEDIATRIC TO ADULT SERVICES

SUMMARY OF PATIENT JOURNEY METRICS

The mapping exercise highlighted points in each stage of the care pathway where data are collected and areas where quality of care could potentially be measured in a national audit. A summary of these potential metrics is listed in Table 5.1. This information is incorporated into the thematic analysis of paediatric diabetes care delivery outlined in Chapter 9 of this report.

TABLE 5.1: SUMMARY OF POTENTIAL MEASURABLE METRICS BY STAGE OF PATIENT JOURNEY

MEASURABLE METRICS OF NATIONAL AUDIT OF PAEDIATRIC T1DM BY STAGE OF PATIENT JOURNEY		
Stage of patient journey	**Metric**	**Metric Type**
Stage 1: Diagnosis	Completion of appropriate blood testing at diagnosis	P
	DKA management as per guidelines, plan in place for location of DKA management and for transfer to PICU if needed	P
	Completion of relevant newly diagnosed paperwork	P
	Assessment of skills pre-discharge, assessment tool used, insulin administration and blood glucose monitoring, targets, management of hypoglycaemia and hyperglycaemia, basic carbohydrate counting	P
	Dietetic education at diagnosis and formal carbohydrate counting (tailored to famiy needs)	P
	Structured initiation of follow-up phone calls	P
	Availability of phone support (24hours, office hours, personnel)	S
	Referral for retinopathy screening if aged over 12 years	P
	Team access to electronic diabetes data platform	S
	Follow up appointments with diabetes nurse, dietician, outpatients clinic	P
	Percentage of patients with known T1DM admitted with DKA	O
Stage 2: Ambulatory Care	First outpatient appointment within 2 months of diagnosis	P
	Attends a diabetes MDT that includes a consultant with specific postgraduate training in paediatric diabetes; paediatric diabetes CNS; a dedicated paediatric diabetes psychologist; social worker; and a paediatric diabetes dietitian	P
	Frequency of interactions with CNS/dietitian: minimum of 4 outpatient department visits per yearGuidelines followed for non-attendance	P
	Adherence to international guidelines in comorbidity screening: tTG, TFTs, lipids, microalbuminuria, BP, BMI-SDS	P
	Access to CSII (criteria, waiting list time, etc.)	S
	Annual review and comorbidity screening	P
	Percentage of clinic cohort using CGM	O
	Percentage of clinic cohort using CSII	O
	HbA1c: annual average excluding HbA1c level at diagnosis (percentage achieving optimal glycaemic control)	O
	Number of readmissions with DKA/severe hypoglycaemia	O
	Annual review/health check completion rate	P
	Perentage of patients with DKA in preceding year	O
	Percentage of children using CGM who can interpret their own data	O
	Percentage of patients identified as requiring additional psychological support who see a paediatric psychologist within 1 month	O
Stage 3: Transition	Completion of Transition readiness check	P
	Percentage of patients aged over 16 years still attending paediatric diabetes MDT meetings	O
	Percentage of young adults attending adult clinic 1 year post-transition	O
	% change in HbA1c one year post transition	O

S = structural measures, P = process meaures, O= outcome measures

CHAPTER 6

ORGANISATIONAL SURVEY OF EXISTING PAEDIATRIC DIABETES SERVICES IN IRELAND



CONTENTS >

CHAPTER 6: **ORGANISATIONAL SURVEY OF EXISTING PAEDIATRIC DIABETES SERVICES IN IRELAND**

PAEDIATRIC DIABETES SERVICES IN IRELAND

Specialised MDTs with appropriate training and expertise in paediatric diabetes and use of diabetes technologies are required to deliver optimal care to children and adolescents with T1DM and their families (NICE, 2015; Pihoker *et al.*, 2009). Figure 6.1 shows the recommended MDT whole time equivalent (WTE) per 150 patients (Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015).

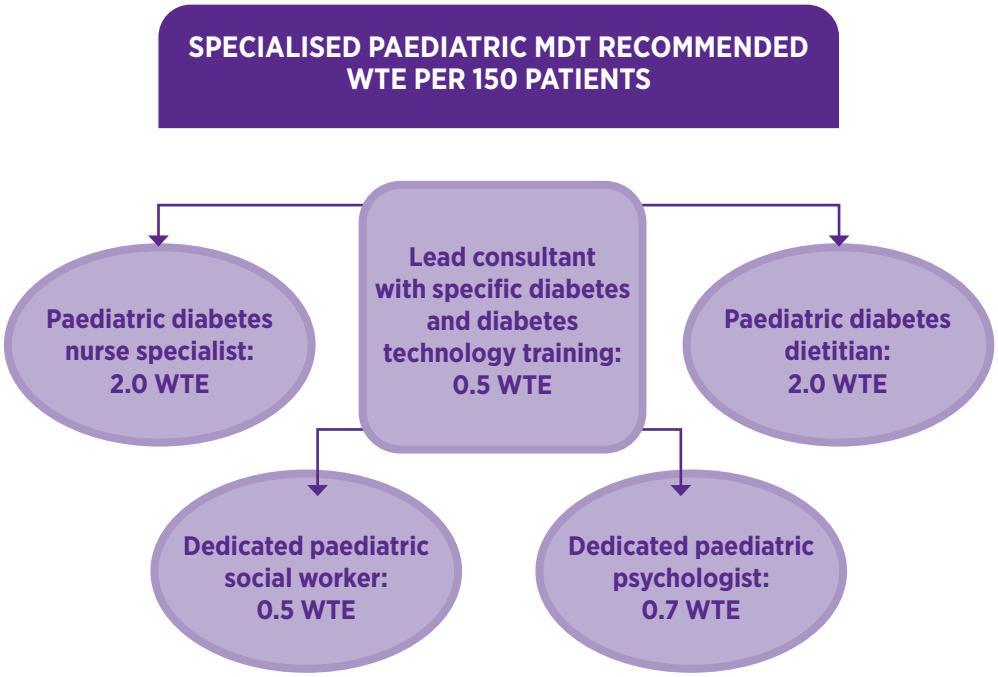


FIGURE 6.1: RECOMMENDED WHOLE TIME EQUIVALENT FOR A SPECIALISED PAEDIATRIC MULTIDISCIPLINARY TEAM

Paediatric diabetes services are currently provided in 19 hospitals across Ireland (Table 6.1). Specialist services are provided at three sites in Dublin at Children's Health Ireland (CHI) (Crumlin, Temple Street, and Tallaght), as well as in Cork University Hospital (with planned outreach to University Hospital Kerry and Tipperary University Hospital), Regional Hospital Mullingar, University Hospital Waterford, University Hospital Limerick, University Hospital Galway (with outreach to Portiuncula University Hospital and Mayo University Hospital), Sligo University Hospital (with outreach to Letterkenny University Hospital) and Our Lady of Lourdes Hospital Drogheda (with planned outreach to Cavan General Hospital). In addition, regional services are provided at Midland Regional Hospital Portlaoise, St. Luke's General Hospital Kilkenny and Wexford General Hospital.

TABLE 6.1: HEALTH SERVICE EXECUTIVE HOSPITALS PROVIDING PAEDIATRIC DIABETES SERVICES

Hospital Group	Hospital
Children's Health Ireland	CHI at Crumlin CHI at Temple Street CHI at Tallaght
Dublin Midlands Hospital Group	Midland Regional Hospital Portlaoise
RCSI Hospital Group	Our Lady of Lourdes Hospital Drogheda Cavan General Hospital
Ireland East Hospital Group	Wexford General Hospital Regional Hospital Mullingar St Luke's General Hospital, Carlow/Kilkenny
Saolta University Health Care Group	Letterkenny University Hospital University Hospital Galway Portiuncula University Hospital Mayo University Hospital Sligo University Hospital
University Limerick Hospitals Group	University Hospital Limerick
South/South West Hospital Group	Cork University Hospital Tipperary University Hospital University Hospital Kerry University Hospital Waterford

OBJECTIVES

The objectives of the organisational survey were as follows:

- to describe the current landscape of care delivery across Irish paediatric diabetes centres
- to characterise available MDT resources at each centre
- to identify current practice for transition from paediatric services to adult services in each centre
- to identify the methods employed for measurement of the KPI of HbA1c levels in each centre.

METHOD

An organisational survey was created in consultation with the Chair of the feasibility study steering committee and was sent to all 19 services delivering care to children and adolescents with T1DM in Ireland. Hospital chief executive officers and managers were informed of the survey. The questionnaire was piloted for ease of completion by a consultant paediatric endocrinologist and a paediatric diabetes CNS, and adjustments were made as necessary. The self-report questionnaire took approximately 15 minutes to complete and was sent via email (using SurveyMonkey) on 21 April 2021 with a deadline for completion of 12 May 2021.

The questionnaire consisted of 15 questions capturing information on:

- number of patients
- MDT resources providing diabetes care
- diabetes data management
- clinic practice for HbA1c measurement
- transition policy and process.

In addition, a free text box was provided to offer centres the opportunity to share additional information or to highlight issues they felt were pertinent to their service delivery (see Appendix v.)

RESULTS

The survey was completed by 17 of the 19 centres nationally, giving a response rate of almost 90%. A member of each centre's paediatric diabetes team completed the survey; in most cases, this was the lead consultant. After further contacts, patient numbers and MDT resources were obtained from all 19 centres, giving 100% completeness for these data items. Paediatric diabetes services accepted new patients up to the eve of their 16th birthday. The paediatric diabetes centres reported that care is provided nationally to 3,332 patients with T1DM, with 385 new patient attendances reported in 2020 (most were newly diagnosed, but some had already been diagnosed and had recently moved to Ireland). Shared care of patients between two centres may have resulted in a small number of patients being counted twice, and this figure included all attenders, meaning that some of this number were aged over 16 years and awaiting transition to adult services. The number of patients attending individual services was highly variable (ranging from 21 to 500 patients) and 41% (n=1262) of patients attend the Dublin-based CHI centres.

Consultant resources

All 17 participating centres reported that they provide a consultant-led paediatric diabetes clinic (Figure 6.2). In the majority (76%) of centres, care was led by a consultant with specialist training in paediatric diabetes: this was a consultant paediatric endocrinologist in 59% (n=10) of centres, and a consultant general paediatrician with a special interest in diabetes in 18% (n=3) of centres. In four additional centres (23%), care was led by a consultant general paediatrician who cares for patients with T1DM as part of their general paediatric role. Two of the consultant paediatric endocrinologists (University Hospital Galway and Sligo University Hospital) currently provide outreach to smaller centres (Portiuncula University Hospital, Mayo University Hospital and Letterkenny University Hospital). Consultant time allocated to paediatric diabetes care was not prescribed and was estimated to be between 0.10 and 0.28 WTE.

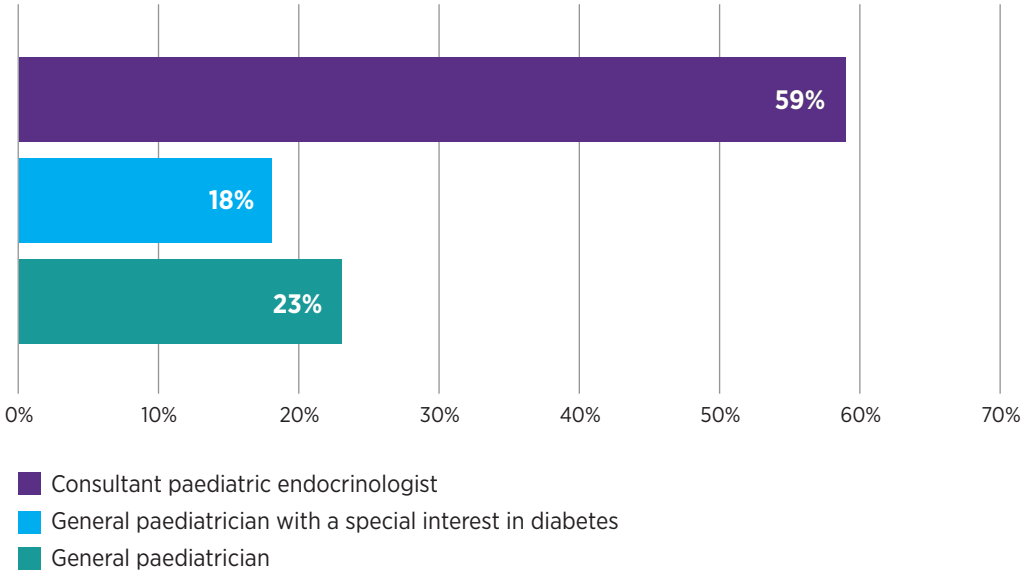


FIGURE 6.2: CLINIC CONSULTANT STAFFING

Specialist nursing resources

The breakdown of specialist nursing staff is shown in Figure 6.3. Most centres (n=14, 82%) had paediatric nurse specialists: 10 centres (59%) were staffed by CNSs, 1 (6%) was staffed by advanced nurse practitioners (ANPs) trained in paediatric diabetes, and 3 centres (18%) were staffed by both CNSs and ANPs. Three centres (18%) had no specialist paediatric diabetes nurses available and relied on CNS staff from the adult diabetes services to deliver care to children with diabetes. Specialist nursing resources allocated to paediatric diabetes care were variable and estimated at 0.05 WTE (where very limited cover was provided to the paediatric clinic by an adult diabetes CNS) to 4.20 WTEs.

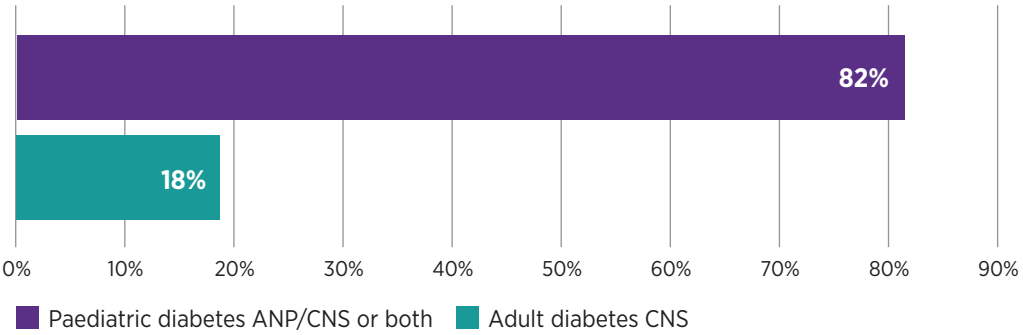


FIGURE 6.3: CLINIC SPECIALIST NURSE STAFFING

Health and social care professional resources

All participating centres indicated that patients with diabetes had access to a dietitian; the majority (71%) had a specialist dietitian dedicated to paediatric diabetes (Figure 6.4). The dietitian resourcing that was allocated varied by hospital, from 0.1 to 1.0 WTE. Dedicated paediatric diabetes psychosocial services were unavailable in most centres; only 18% of centres had dedicated access to a social worker for paediatric diabetes and less than one-quarter (24%) of centres had access to a psychologist dedicated to the paediatric diabetes team. The dedicated psychology WTE in the centres ranged from 0.2 to 0.5 WTE. Some centres had access to psychosocial services from general paediatrics (12% for psychology and 29% for social work), but access was limited and subject to waiting lists.

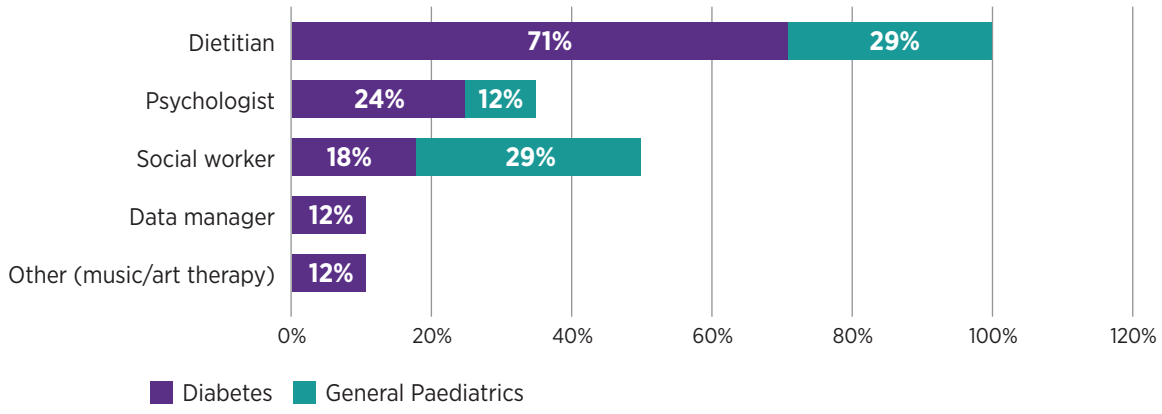


FIGURE 6.4: CLINIC HEALTH AND SOCIAL CARE PROFESSIONAL STAFFING RESOURCES

Multidisciplinary resource gaps

All participating centres were contacted again in November 2021 to reconfirm their patient numbers and MDT resources (Table 6.2) to conduct a gap analysis comparing the funded WTE resources with the recommended WTEs (Table 6.3). Very large gaps in MDT resources were identified in Children's Health Ireland and the South/South West Hospital Group across the full MDT. Services in University Hospital Limerick, Sligo University Hospital, Letterkenny University Hospital, Portiuncula University Hospital, Regional Hospital Mullingar and Midland Regional Hospital Portlaoise met the recommended standard for paediatric diabetes specialist nursing resources. Gaps in dedicated paediatric diabetes psychosocial care were identified across all Hospital Groups.

TABLE 6.2: PATIENT NUMBERS AND FUNDED MULTIDISCIPLINARY RESOURCES WHOLE TIME EQUIVALENTS, BY CENTRE

Hospital	Number of patients	Consultant WTE for diabetes	CNS/ANP WTE	Dietitian WTE	Psychologist WTE	Social worker WTE
CHI at Crumlin	500	1.5	4.2	1.5	0.5	0.5
Cork University Hospital	466	0.5	3.0	1.0	0	0
CHI at Temple Street	445	1	3.0	0.9	0.5	0.5
CHI at Tallaght	362	0.5	3.8	1.0	0.5	0.5
University Hospital Limerick	231	0.375	3.5	0.75	0.2	0
University Hospital Galway	198	0.25	1.0	0.5	0	0
Our Lady of Lourdes Hospital Drogheda	190	0.25	1.5	0.6	0	0.1
Regional Hospital Mullingar	130	0.25	2.0	0.5	0.5	~
University Hospital Waterford	120	0.25	1.0	0.8	0	~
Letterkenny University Hospital	113	0.3*	2.0	0.5	0	0
Mayo University Hospital	98	0.25*	1.0	0.05 (general paediatrics)	0	0
Sligo University Hospital	91	0.2	1.5	1.0	0	0
Midland Regional Hospital Portlaoise	86	0.2	1.0	0.5	0	0
Wexford General Hospital	80	0.25**	0.5	0.25	0	0
St Luke's General Hospital, Carlow/ Kilkenny	63	0.3**	0.3 (adult)	0.8	0	0
Portiuncula University Hospital	58	0.35*	0.75	0	0	~
University Hospital Kerry	46	0.25**	0.33 (adult)	0	0	~
Cavan General Hospital	34	0.1**	0.1	0.1	0	0
Tipperary University Hospital	21	0.1**	0.05 (adult)	0.05 general paediatrics)	0	~

* Figure includes general paediatrician WTE + 0.1 visiting consultant paediatric endocrinologist WTE
** This is provided by general paediatricians
~ Indicates general paediatrics cover for social workers

TABLE 6.3: DEFICIT IN MULTIDISCIPLINARY TEAM MEMBERS BY HEALTH SERVICE EXECUTIVE HOSPITAL GROUP VERSUS *A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND* RECOMMENDED MULTIDISCIPLINARY TEAM MEMBERS

Hospital	Consultant WTE for diabetes required	CNS/ ANP WTE required	Dietitian WTE required	Psychologist WTE required	Social worker WTE required
Children's Health Ireland	1.3	6.4	5.2	4.6	2.9
South/South West Hospital Group	1.6	4.7	2.4	3.1	2.3
Saolta University Health Care Group	1.1	1.9	2.1	2.6	1.9
RCSI Hospital Group	0.35	1.4	0.7	1.1	0.6
Ireland East Hospital Group	0.3	1.3	0.8	0.8	0.9
University Limerick Hospitals Group	0.4	None	0.8	0.9	0.8
Dublin Midlands Hospital Group	0.1	0.2	0.1	0.4	0.3

Source: Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015.

Transition from paediatric to adult diabetes services

A total of 233 patients were transitioned from paediatric to adult diabetes services during 2020. The timing of transition from paediatric to adult diabetes services varied and occurred when patients were aged between 16 and 19 years.

Most centres (n=10, 59%) indicated that the transition process was initiated by a referral letter to the adult diabetes service. Seven centres (41%) indicated that the process was initiated by a joint transition clinic with the adult and paediatric diabetes teams to handover care to the adult service.

Which adult service the patient transitions to depends on where they live and, in some cases, on where they are planning to attend third-level education. Smooth transition processes were in place in several centres, but many reported delayed access for patients transitioning to adult services and some reported that co-located adult diabetes services did not accept transition patients who were using diabetes technology. Table 6.4 shows the hospitals offering specialist transition clinics or young adult clinics and pump services in 2018.

TABLE 6.4: SPECIALTY DIABETES CLINICS (AS OF 2018)

Hospital	Type 1 transition clinic	Young adult clinic (18–25 years)	Insulin pump
Ireland East Hospital Group			
Mater Misericordiae University Hospital	✔	✔	✔
St Vincent's University Hospital		✔	
Regional Hospital Mullingar	✔	✔	
Wexford General Hospital	✔		
St Columcille's Hospital, Loughlinstown		✔	✔
St Michael's Hospital, Dun Laoghaire			✔
Dublin Midlands Hospital Group			
St James's Hospital		✔	✔
Tallaght University Hospital	✔	✔	✔
Naas General Hospital			✔
Midland Regional Hospital Portlaoise	✔	✔	
RCSI Hospital Group			
Beaumont Hospital	✔	✔	✔
Our Lady of Lourdes Hospital Drogheda and Louth County Hospital		✔	
Connolly Hospital	✔		✔
South/South West Hospital Group			
Tipperary University Hospital		✔	
Cork University Hospital	✔		✔
University Hospital Kerry		✔	
University Limerick Hospitals Group			
University Limerick Hospital	✔	✔	
Saolta University Health Care Group			
University Hospital Galway	✔	✔	✔
Mayo University Hospital	✔		
Sligo University Hospital		✔	✔
Letterkenny University Hospital	✔	✔	✔

✔ Indicates nurse-led

Source: (O'Donnell *et al*., 2018).

Measurement of HbA1c

HbA1c is a test used to monitor glycaemic control and is a KPI for diabetes care. Most centres use point-of-care testing (POCT) in their diabetes clinics (88%, n=15). Five centres (29%) use laboratory venous samples in addition to POCT, and two centres (12%) use three methods to measure HbA1c (laboratory venous testing, laboratory capillary testing and POCT). Two centres (12%) use laboratory venous samples only. The majority of centres (82%) stated that they currently audit their patients' HbA1c measurements annually.

Data management

The survey results demonstrate information and communication technology (ICT) infrastructure and data management deficits across centres, with only nine centres indicating that their data are managed using an electronic data management system. The data management systems used vary between centres (Table 6.5). Four centres indicated that records are paper-based and six centres reported that they maintain a Microsoft Excel spreadsheet of their clinic data. Only two centres have part-time data manager resources. Data management was reported as time-consuming, with services indicating that the processes should be integrated into routine clinical care.

TABLE 6.5: DATA MANAGEMENT IN PAEDIATRIC DIABETES CENTRES

Hospital Group	Data Management
Children's Health Ireland	Diamond – diabetes digital platform (CHI at Crumlin* and CHI at Tallaght) Orion database (CHI at Temple Street)
Dublin Midlands Hospital Group	Paper charts Microsoft Excel spreadsheet – POCT results
RCSI Hospital Group	Microsoft Excel spreadsheet – shared among MDTs Paper charts
Ireland East Hospital Group	Paper charts only Microsoft Excel spreadsheet Epi Info Cellma healthcare information system
Saolta University Health Care Group	Diamond – diabetes digital platform ProWellness Chronic Diseases Management System Paper charts only
University Limerick Hospitals Group*	Microsoft Excel spreadsheet Paper charts
South/South West Hospital Group*	Microsoft Excel spreadsheet Paper charts

* Submits data to the SWEET Initiative

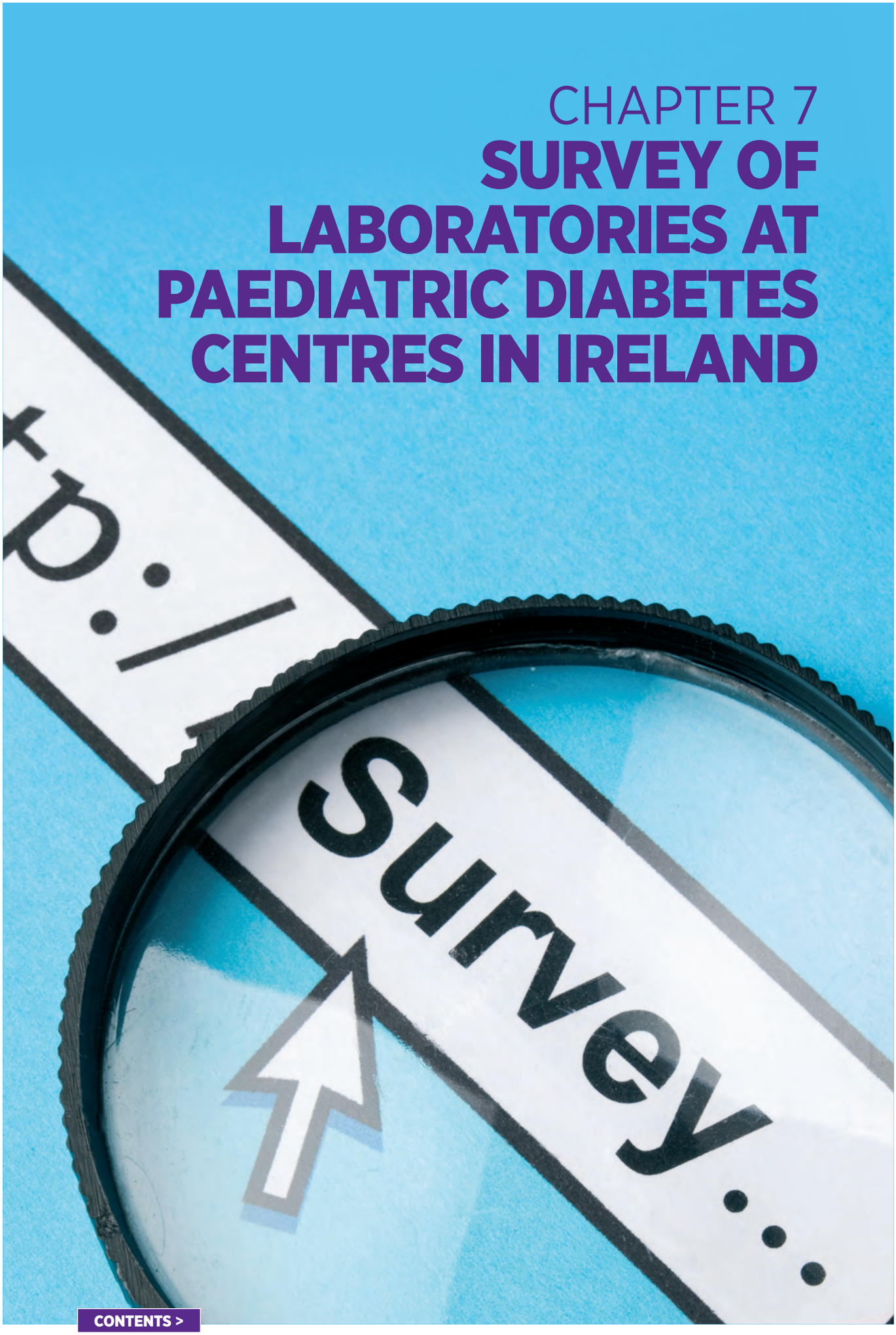
CHAPTER 6

SUMMARY AND IMPLICATIONS FOR THE FEASIBILITY OF THE AUDIT

Significant investment in regional paediatric diabetes MDTs has been made since the first audit in 2012 (Hawkes and Murphy, 2014). Psychosocial gaps remain in all services, although the burden of T1DM is known to be associated with significant psychosocial burden for patients and families. Large services (such as CHI in Dublin and Cork University Hospital) with the greatest number of patients have the largest resource gaps across the MDTs. Accessing young adult services is associated with waiting lists in several centres. Current deficits in ICT infrastructure and data management increase the burden of audit data collection, and methods to address this need to be carefully considered in audit development. A national electronic healthcare record with integrated data management and benchmarking capability is essential for facilitating this process. Data-driven decision-making is critical to rational resource allocation to drive quality improvement in paediatric diabetes services nationally.

CHAPTER 7

SURVEY OF LABORATORIES AT PAEDIATRIC DIABETES CENTRES IN IRELAND



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CHAPTER 7: **SURVEY OF LABORATORIES AT PAEDIATRIC DIABETES CENTRES IN IRELAND**

BACKGROUND

Optimal glycaemic control reduces the risk of developing microvascular complications in individuals with type 1 diabetes (International Society for Pediatric and Adolescent Diabetes, 2014; The Diabetes Control and Complications Trial Research Group, 1993). The HbA1c level reflects the mean blood glucose level over the previous 3 months and is a reliable long-term glycaemic control measure with robust outcome data (DiMeglio *et al*., 2018).

HbA1c measurements are useful both for assessing the risk of developing long-term complications and as a real-time tool that drives efforts to optimise glycaemic control. Facilities for the measurement of HbA1c levels should be available to all centres caring for paediatric patients with T1DM. Capillary blood collection is preferable as it is more acceptable for children (due to being less painful) and allows access to results at the time of the clinic visit, thus facilitating immediate therapy adjustments. POCT can measure HbA1c levels from a finger prick blood sample and provide results in 5 minutes. Observational studies have shown strong positive correlations in terms of accuracy between HbA1c POCT and laboratory measurement (EurA1c Trial Group, 2021; Health Quality Ontario, 2014). POCT should be carried out according to Ireland's *Guidelines for safe and effective near-patient testing (NPT)* (National Near-Patient Testing (NPT) Consultative Group, 2021).

The International Society for Pediatric and Adolescent Diabetes (ISPAD) recommends a target HbA1c level of <53 mmol/mol (<7.0%) (ISPAD, 2018), while the British Society for Paediatric Endocrinology and Diabetes recommends a lower target of <48 mmol/mol (<6.5%) (NICE, 2015). Both organisations recommend that HbA1c be measured at each clinic visit, scheduled every 3 months.

Annual review for comorbidities and complications

Along with measuring HbA1c levels at clinic visits, interval assessment for associated comorbidities and complications is required in children and adolescents with T1DM in line with agreed HSE national guidelines.

Testing includes:

- coeliac disease (screen with tissue transglutaminase (tTG))
- thyroid dysfunction (thyroid function tests (TFTs))
- lipid profiles
- urine testing for microalbuminuria (albumin/creatinine ratio (ACR)).

OBJECTIVES

The objectives of the laboratory survey were as follows:

1. Capture the method by which laboratories across the system are measuring HbA1c levels, and how and where results are stored.
2. Ascertain the accessibility of comorbidity laboratory data.

METHOD

An online laboratory survey was developed in consultation with the consultant clinical biochemist who is a member of the feasibility steering committee. All laboratories at centres providing paediatric diabetes clinics were contacted and the questionnaire was disseminated to the chief medical scientists or laboratory managers by email using SurveyMonkey on 1 April 2021, with a deadline for completion of 16 April 2021. Reminder emails were sent to follow up on any non-responders.

The survey consisted of 15 questions capturing information on methods used for measurement of HbA1c levels, the laboratory information management system (LIMS) used, the POCT device used and, where the laboratory had co-located adult and paediatric diabetes services, the feasibility of extraction of laboratory results for paediatric patients with type 1 diabetes (see Appendix vi.).

RESULTS

A total of 15 of the 19 laboratories completed the survey (79%). Partial data were obtained from the remaining four centres through follow-up phone calls. Table 7.1 shows how HbA1c levels are measured in each site along with the POCT device used.

TABLE 7.1: GLYCATED HAEMOGLOBIN DATA COLLECTION INFORMATION FOR PARTICIPATING HEALTH SERVICE EXECUTIVE HOSPITAL LABORATORIES

Hospital (listed according to size of patient population)	HbA1c testing method	POCT device (where stated)
CHI at Crumlin	Laboratory POCT	DCA Vantage Analyzer
Cork University Hospital	Laboratory	Not applicable (n/a)
CHI at Temple Street	Laboratory POCT	DCA Vantage Analyzer
CHI at Tallaght	Laboratory POCT	Roche cobas b 101
University Hospital Limerick	Laboratory POCT	DCA Vantage Analyzer
University Hospital Galway	Laboratory POCT	DCA Vantage Analyzer
Our Lady of Lourdes Hospital Drogheda	Laboratory POCT	unknown
Regional Hospital Mullingar	Laboratory	n/a
University Hospital Waterford	Laboratory POCT	unknown
Letterkenny University Hospital	Laboratory POCT	Roche cobas b 101
Mayo University Hospital	Laboratory POCT	unknown
Sligo University Hospital	Laboratory POCT	DCA Vantage Analyzer
Midland Regional Hospital Portlaoise	Laboratory POCT	unknown
Wexford General Hospital	POCT Laboratory	DCA Vantage Analyzer
St Luke's General Hospital, Carlow/Kilkenny	POCT Laboratory	DCA Vantage Analyzer
Portiuncula University Hospital	POCT Laboratory	DCA Vantage Analyzer
University Hospital Kerry	POCT	DCA Vantage Analyzer
Cavan General Hospital	Laboratory POCT	DCA Vantage Analyzer
Tipperary University Hospital	Laboratory	n/a

WHERE IS HbA1c MEASURED?

A total of 15 of the centres use both laboratory testing and POCT to measure HbA1c levels. Laboratory testing is routinely performed at T1DM diagnosis and for comorbidity testing. Not all laboratories measure HbA1c levels on-site; seven refer samples to another laboratory for testing. Where samples are sent out, the returned results may be scanned into the electronic healthcare record (eHR), manually entered, or scanned into the LIMS.

Where are POCT results stored?

Patient chart	All (19)
LIMS	2
Local database	4
eHR	2

ACCESSIBILITY OF RESULTS

Three main LIMS are in use nationally and two laboratories use customised software. While some laboratories answered that it was not possible to retrieve HbA1c results for paediatric patients from the LIMS, at least one user of each type of LIMS said that it is possible. This may depend on the version of software in use and the availability of the Cognos database search tool. Where customised software was used, one laboratory reported that it was not possible to extract paediatric data and a second reported that it would be extremely time-consuming (one of these sites does not use POCT). In some cases, retrieving HbA1c testing results is a manual process that is time-consuming. The estimated time required to capture 1 year of paediatric HbA1c data ranged widely, from 2 hours to 2–3 weeks. Nine laboratories answered that it was possible to extract other annual blood results with similar caveats.

While the majority of HbA1c levels checked in paediatric patients will be in children with T1DM, there are exceptions. Most patients with diabetes in Ireland who are in the paediatric age group have type 1 diabetes, but a small proportion have type 2 diabetes, and distinguishing between the two would be challenging at laboratory level. In addition, HbA1c levels are checked as part of clinical care in small numbers of children with hypoglycaemic disorders, such as congenital hyperinsulinism and metabolic disorders. Cross-checking with the diabetes centre will be required in order to ensure that the HbA1c results relate to the correct patient cohort.

SUMMARY

Most centres (84%) delivering paediatric diabetes care performed HbA1c POCT measurements at clinic visits with laboratory HbA1c samples checked only at the time of the T1DM diagnosis and when comorbidity laboratory testing was performed. Not all POCT machines are quality assured. POCT machine results are generally recorded manually in the patient notes and may be collated on local clinic databases. As this recording is manual, it is therefore subject to human error and collation of the data is labour intensive for overstretched clinical staff.

The challenges to collecting laboratory HbA1c data for a national paediatric diabetes audit include the following:

- multiple LIMS in use
- the lack of interfacing between POCT devices and existing LIMS in many centres, making data extraction challenging and dependent on local systems and ICT expertise
- the use of customised LIMS in some centres, limiting data extraction capability
- results usually being returned in paper format where venous samples are analysed in external laboratories; these may be entered manually or scanned into the LIMS, which impacts on the ability to extract results directly from the LIMS, and accessing the results may require manual collation from charts or paper reports
- gaps in expertise in spreadsheet manipulation at laboratory level in some services
- the lack of resources in the laboratory services to enable timely data extraction and collection.

IMPLICATIONS FOR THE FEASIBILITY OF THE AUDIT

HbA1c is the key outcome KPI for paediatric diabetes care, and accurate collation of HbA1c data is critical for the proposed national paediatric diabetes audit. HbA1c data (both POCT and laboratory testing values) at T1DM diagnosis, during the ambulatory care phase (when levels should be checked every 3 months) and at transition need to be collected prospectively and systematically. A national eHR would facilitate this process. In the absence of an eHR, supports will be needed for laboratories and diabetes units to collate and extract HbA1c data systematically, and data management and data analytics expertise will be needed in order to analyse and report on the data.

CHAPTER 8

REVIEW OF EXISTING AND EMERGING DATASETS RELEVANT TO AUDIT OF PAEDIATRIC TYPE 1 DIABETES



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CHAPTER 8: REVIEW OF EXISTING AND EMERGING DATASETS RELEVANT TO AUDIT OF PAEDIATRIC TYPE 1 DIABETES

INTRODUCTION

An important element of audit design is reviewing relevant existing and emerging data sources and determining how this information could potentially be harnessed to assist with the audit objectives. Where data collection structures are already in place, access to these data for secondary use is very cost-effective and may be useful for validation purposes. International best practice on the use of health information indicates that data should be collected once and used many times (Health Information and Quality Authority, 2018). The HSE Quality and Patient Safety Directorate's *A Practical Guide to Clinical Audit* recommends that:

Where possible, relevant, routinely collected raw data from existing sources should be used for the purposes of the clinical audit as this avoids duplication of information and work and allows for repeated data collection and re-audit with minimum effort. Examples of such sources are clinical information systems, service user records, [the Hospital In-Patient Enquiry] and observation of practice. Collection of data from several sources may overcome the problem of incomplete data sources. (HSE Quality and Patient Safety Directorate, QPSD-D-029-1 A practical guide to clinical audit, 2013 page 31.)

OBJECTIVE

The objective of this work was to identify and describe existing and emerging datasets which are relevant to paediatric T1DM, and to determine: (1) whether the information in these datasets can be extracted, and (2) if the data extracted would be relevant and useful for the proposed national paediatric diabetes audit.

METHOD

A list of data sources was derived from consultations with the steering committee members and individuals involved in data collection. The consultation group members are listed in Appendix i. of this report.

Three main queries were used to identify useful routine data (Bain *et al*., 1997):
1. What potentially useful data sources are available?
2. Which data elements are captured in the data sources?
3. Are there alternative and/or innovative ways of using the existing data sources?

Each data source identified was reviewed for adequacy using the following criteria:
- governance
- data source
- data quality, data elements, data characteristics (quantitative or qualitative)
- collection methods used
- accessibility
- potential metrics for use in a national audit of paediatric T1DM
- limitations.

RESULTS

A description of the identified datasets is provided below. For ease of comparison, a summarised account of all reviewed datasets is provided in Tables 8.1–8.5.

Hospital In-Patient Enquiry dataset

The Hospital In-Patient Enquiry (HIPE) dataset is a national health information system designed to collect demographic, clinical and administrative information on all discharges and deaths in acute hospitals in Ireland. The HSE's Healthcare Pricing Office (HPO) oversees all functions associated with the operation of the HIPE database, including development and support of the data collection and reporting software; training of coders; verification of data quality; and audit, analysis and reporting. Policymakers, clinical teams, finance, senior HSE management and researchers use the data. Each HIPE record represents one episode of care, and a single patient may have had more than one admission with the same or different diagnoses recorded in the HIPE database. In the absence of an individual patient identifier, the records can facilitate analyses of hospital activity related to managing a disorder rather than the incidence of that disorder. The data are used to assess activity levels, compare performance indicators, apply specialty costs, etc. (HPO, 2020).

The system collects a principal diagnosis for each discharge, together with up to 29 additional diagnosis codes. A principal diagnosis is defined as "the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care, or an attendance at the healthcare establishment, as represented by a code" (Australian Coding Standard ACS 0001, Independent Hospital Pricing Authority 2017). An additional diagnosis is defined as "a condition or complaint either co-existing with the principal diagnosis or arising during the episode of admitted patient care" and may be used as an indication of the level of comorbidity for conditions that impact this episode of care and meet certain criteria (Australian Coding Standard ACS 0002, Independent Healthcare Pricing Authority 2017). Procedures are coded using the Australian Classification of Health Interventions. HIPE also collects information on hospital-acquired diagnoses (HADx) – conditions that arise after admission and which may or may not be related to the quality of care. The data can be reported in many ways, for example by diagnosis-related group (DRG), by Hospital Group, or by whether the patient was attended by a consultant on a private or public basis. The DRG scheme enables the disaggregation of patients into homogeneous groups which undergo similar treatment processes and incur similar levels of resource use. In 2019, HIPE captured 99.5% of all care episodes eligible for inclusion in the database. Aggregate data are accessible via submission of requests using an online form. Access to identifiable data is not possible without obtaining adequate permissions.

There are limitations to the use of the data in a national audit; HIPE data only apply to inpatient care, while most care provided to paediatric patients with T1DM (apart from that provided at the time of initial diagnosis) is outpatient-based. HIPE data cannot differentiate between newly diagnosed patients with T1DM and those with known T1DM (pre-existing diagnoses). There is also the potential for double counting of patients who attend different hospitals for different episodes of care. Advantages of using HIPE include the complete capture of all inpatients and outpatients admitted nationally with a type 1 diabetes diagnostic code, and the timely availability of data. It is possible to select specific patients or patient groups based on information reported in their HIPE records (e.g. date of birth, sex, region, hospital, length of stay, etc.). Combinations of selections help to find the specific patient group of interest. Patient information is de-identified and full date of birth is not available at national level.

National Quality Assurance and Improvement System Clinical

The National Quality Assurance and Improvement System (NQAIS) Clinical is an online interactive application that analyses hospitals' own HIPE data in order to provide detailed feedback to clinicians and managers (Croke, 2017). The primary focus of NQAIS Clinical is to optimise the length of stay (LOS) for safe patient care in all publicly funded Irish hospitals. The NQAIS Clinical Steering Group oversees the application on behalf of the Royal College of Surgeons in Ireland (RCSI), the Royal College of Physicians of Ireland (RCPI), and the Acute Hospitals Division HSE, in partnership with HSE National Clinical Programmes. The application is hosted within the Health Atlas Ireland technical and security infrastructure, which is managed by the Health Intelligence Unit of the HSE. The overall aim of NQAIS Clinical is to provide interquartile comparisons of average LOS (AvLOS) for different teams providing similar care. Hospital or team performance can be compared to the top quartile teams nationally for AvLOS and day case rates. Training is provided to personnel who are authorised to access the system at hospital, Hospital Group or national level. The dataset is available for the period from January 2016 onwards and is reported monthly. NOCA has access to the NQAIS Clinical portal and data can be analysed as required by NOCA staff. Data can be stratified by region and age, allowing the areas of greatest need to be identified. A high incidence of complications, readmissions, etc. indicates scope for improvement. There is the potential to assess one element of care (average LOS for newly diagnosed paediatric patients with T1DM) and to highlight outliers to clinical teams, but there are often valid clinical reasons for prolonged LOS. It is also possible to identify admissions with complications from T1DM (e.g. severe hypoglycaemia or diabetic ketoacidosis). Each record has an encrypted medical record number (MRN) which permits the identification of multiple episodes of care relating to the same individual in the same hospital. However, it is not possible to identify admissions of a single individual attending different hospitals and, in the absence of an individual patient identifier; errors can arise with the same patient having duplicate MRNs on occasion.

Irish Childhood Diabetes National Register

The Irish Childhood Diabetes National Register (ICDNR) was established in 2008 to identify the incidence of T1DM in the paediatric population in Ireland and is a prospective national register of all patients diagnosed under the age of 15 years. The ICDNR provides robust anonymised data on the incidence of T1DM, which allows the HSE to plan for diabetes care delivery. Clinicians in all 19 centres collect data at the time of diagnosis of T1DM. The incidence rates and epidemiology of T1DM in patients aged under 15 years are published periodically in peer-reviewed journals. This is a detailed source of incidence data which are complete for the population; however, direct access to the data at present is limited by the consent requirements under the current General Data Protection Regulation (GDPR). Additionally, the ICDNR only includes children aged under 15 years and does not currently collect data after the initial diagnosis. Aggregate data from the register could provide accurate denominator data for a national audit of T1DM and assist with validation. The current enrolment consent for participation in the ICDNR could be explored for feasibility of amalgamation with a broader prospective national audit enrolment, if required.

Primary Care Reimbursement Service

All medications for type 1 diabetes are available to children and adolescents for free under the HSE's Primary Care Reimbursement Service (PCRS). The PCRS is therefore a rich data source. The data cover the main national health schemes throughout the country, including General Medical Services (GMS), the Drugs Payment Scheme (DPS), the Long-Term Illness (LTI) Scheme, the Primary Childhood Immunisations Scheme etc. The PCRS is the richest source of national prescription data. It is used for multiple purposes, such as monitoring diseases, organising services, informing policymaking, conducting research, and planning for future healthcare needs at both local and national level. Data are published annually in the PCRS report, available on the PCRS dedicated area of the HSE website.

The PCRS data contain information on the medicinal products that are prescribed and dispensed. Medications and technology for the treatment and management of diabetes are provided to patients under this service, and the data can be stratified by age; hence, the PCRS dataset can provide national data on paediatric patients with T1DM (Gajewska *et al*., 2020a). However, these data are not linked to other datasets and there may be difficulties distinguishing patients with type 2 diabetes or other forms of diabetes from those with T1DM. The biggest challenge to interrogating these data is the lack of an Individual Health Identifier. Newly diagnosed patients with T1DM could be identified by using new PCRS applications as a proxy. Previously, it has been possible to gain restricted access to the dataset via a virtual private network (VPN) (or to receive data cuts), but this process may take time given multiple demands on the PCRS data analytics team.

Diabetic RetinaScreen programme

Retinopathy screening for patients with diabetes is an internationally accepted standard of diabetes care. Diabetic RetinaScreen (DRS) – the National Diabetic Retinal Screening Programme initiated its national population-based diabetic retinopathy screening programme in February 2013. The primary objective of the screening programme is to reduce the risk of sight loss among people with diabetes through early detection and treatment of sight-threatening retinopathy. DRS receives referrals from general practitioners (GPs), endocrinologists, ophthalmologists and other health professionals with an MRN, as well as self-referrals from patients and families (National Screening Service, n.d.; HIQA, n.d.). DRS holds demographic data on eligible people diagnosed with type 1 or type 2 diabetes and arranges screening of registered patients, sets standards and carries out quality assurance audits (National Screening Service, 2019). This service is available to all persons with diabetes who are aged 12 years and over and who are entered on the DRS register. Data are published annually and access requests, when granted, are facilitated via a VPN. This is a complete and accurate dataset for patients referred for retinopathy screening, capturing data on the development and treatment of retinopathy in the population aged over 12 years. It can report on detection rates, percentage attendance at screening appointments, treatment and outcomes. If referral to DRS were completed for all children with T1DM attending all 19 centres (by the age of 12 years), the register would then be a very valuable data source for assessing transition success and for call or re call purposes where young adults drop out of young adult services. An individual patient identifier would be hugely valuable in this context for patients with T1DM.

Laboratory Information Management System

Patient HbA1c levels, a key metric for a national audit of paediatric T1DM, are measured in all centres nationally; however, only data from HbA1c levels that are measured in a laboratory are included in the LIMS. A detailed description of this data source is provided in Chapter 7.

SUMMARY OF RESULTS

This review outlines the currently available datasets that capture data relating to paediatric patients with T1DM in Ireland.

The existing ICDNR captures incidence data on all patients eligible for inclusion in a population-based audit, but it is restricted to patients aged under 15 years and does not collect prospective data past the point of diagnosis; hence, data on care delivery are lacking. Data on older children (aged 12 years and over) are captured by the DRS programme, which can provide aggregate data that are limited to retinopathy detection and progression rates and referrals for screening, but this register also does not capture data on other outcomes important to all paediatric patients with T1DM.

Other than the ICDNR, there is no data source that can identify newly diagnosed patients directly; however, new applications to the LTI Scheme on the PCRS database may be used as a proxy. The PCRS dataset captures data on patients of all ages and is complete for the population. This database can provide information on incidence and prevalence, as well as use of technology, and will be an important source for the validation of audit data. However, there are limitations to using this dataset, as previously discussed.

Information on patients hospitalised at diagnosis or with potentially preventable T1DM complications (e.g. severe hypoglycaemia or diabetic ketoacidosis) can be obtained from the HIPE dataset, which captures inpatient data on all admitted patients nationally. However, it is not possible to confirm from this information which patients are newly diagnosed, and there is the added complexity of potentially double counting a patient who is admitted to multiple different hospitals over a single reporting period. Hence, these data must be used with caution. NQAIS Clinical provides similar data as HIPE, but is anonymised and therefore more accessible than HIPE.

IMPLICATIONS FOR THE FEASIBILITY OF A NATIONAL PAEDIATRIC DIABETES AUDIT

Although a number of relevant data sources exist that capture population-based data, there is currently no single dataset that provides the systematic capture of data and/or detail required in order to conduct an adequate national audit of the complete cohort of patients with T1DM. The absence of an individual patient identifier limits the usefulness of and linkages between the various data sources. The assignment of an Individual Health Identifier to all children diagnosed with T1DM should be urgently considered because, with consent, this would facilitate these linkages and audit.

The greatest benefit of these datasets to the national paediatric diabetes audit currently is for validation purposes, providing accurate denominator data for specific age groups, patients hospitalised for complications of T1DM, and technology use. Informed consent is required to enable linkages between the data sources and key quality indicators. Other than data collected by clinicians for the ICDNR at the time of diagnosis, the existing data are insufficient to permit the measurement of process and outcome metrics that can be benchmarked against standards. There are also data quality concerns relating to difficulties in distinguishing multiple hospital episodes of care of individual patients and identifying newly diagnosed patients. The retrospective nature of the datasets is subject to problems with missing data and provides information on the care documented rather than on the care provided. In order to ensure optimal quality and completeness of the data included in the national audit, real-time data should be collected prospectively by clinical staff at the point of care in all centres nationally. This would be most adequately provided via the future eHR, but regardless of format will depend on standardised methods of extraction of quality-assured, relevant data in all centres providing care to paediatric patients with T1DM.

TABLE 8.1: HOSPITAL IN-PATIENT ENQUIRY SCHEME

Governance	Healthcare Pricing Office
Description	Demographic, clinical and administrative data relating to discharges from, and deaths in, acute public hospitals in Ireland. Includes data on patients in intensive care units (ICUs) and high dependency units, transferred patients, same-day admissions, and discharged patients.
Collection	Data are taken from medical charts and records and coded by trained clinical coders before being entered into the HIPE system.
Accessibility	Data are provided to a number of State agencies. Data requests can be submitted using an online request form and are subject to governance arrangements with the HPO.
Data Fields	Admission date and time, transfer, type, LOS, days in critical care bed, principal diagnosis, procedures and codes, age, sex, public/private status, case mix, primary and all secondary diagnoses, with specific codes for distinct complications. Multiple ways of reporting, e.g. by Hospital Group, DRG, public/private status and patient type, and Hospital Groups by DRG, etc.
Potential metrics	Number of discharges for specific complications, glycaemic outcomes, readmissions, LOS and ICU days.
Coverage	National, all acute public hospitals. Hospital inpatients only. 99.5% of discharges coded and included.
Limitations	HIPE cannot differentiate patients with newly diagnosed diabetes from patients with previously diagnosed diabetes. Without an IHI, it is not possible to analyse the number of hospital encounters per patient at national level.
Potential Information	Complete national data on patients admitted to hospital. High activity levels of admissions of patients with complications indicate areas for improvement. Data must include encrypted MRN in order to ensure that multiple admissions of the same patient are not identified as separate individuals. Individual patients admitted to different hospitals cannot be tracked across the system.

TABLE 8.2: NATIONAL QUALITY ASSURANCE AND IMPROVEMENT SYSTEM CLINICAL

Governance	HSE Health Intelligence Unit The NQAIS Clinical Steering Group oversees the application on behalf of the Acute Hospitals Division the RCSI and the RCPI.
Description	Pseudonymised HIPE data on an interactive application that provides analysis and detailed feedback on hospitals' own HIPE data. The primary focus is on optimising LOS for safe patient care. Encrypted MRN used to pseudonymise data.
Collection	User controls content of displays and reports. Results can be displayed by admission diagnosis, procedure or specialty. Patterns of interest can be easily explored.
Accessibility	Online, interactive. NOCA has access to the NQAIS portal. User must have authorisation to access the portal and must comply with HSE information policy.
Data Fields	As with HIPE, drives improvements in patient care by comparing AvLOS across different healthcare teams. It is possible to identify the same patient with multiple admissions via the encrypted MRN, if within the same hospital (MRN varies by hospital).
Potential metrics	Incidence of admissions for specific complications, glycaemic outcomes, readmissions, LOS, ICU days and transfer information. Identification of number of procedures performed and diagnoses made in a period of time.
Coverage	Hospital inpatients with 99.5% of care episodes captured. Would have to decide whether to capture primary diagnosis or all diagnoses for all episodes of care. Data elements relevant to patients with T1DM can be explored at hospital level, Hospital Group level and national level.
Limitations	As with HIPE, the data are only as good as what is documented at the time of coding – accuracy of coding and timeliness are important for the quality of the data.
Potential Information	Complete national data on patients admitted to hospital. High incidence of complications, readmissions, etc. indicate areas for improvement. Can be stratified by region and age. Areas of greatest need can be identified.

TABLE 8.3: IRISH CHILDHOOD DIABETES NATIONAL REGISTER

Governance	CHI at Tallaght and Trinity College Dublin Funded by National Children's Hospital Foundation.
Description	Prospective national register. Overall purpose is to develop and maintain an epidemiological register of children and young people aged under 15 years who develop T1DM in the Republic of Ireland.
Collection	Collected at point of care by local paediatric consultants or endocrinologists and diabetes nurse specialists. Data entered on pro forma data sheets and centrally entered into a register via a Microsoft Access database on the Tallaght University Hospital server.
Accessibility	Signed, informed consent required. Data sharing from register not permissible.
Data Fields	Paper form includes name and address. Database includes unique register identification; location (urban/rural); date of birth; sex; date of diagnosis; date of first insulin injection; hospital at which diagnosis was made; consultant responsible for care; symptoms (if any) and duration of symptoms (in days/weeks); blood results at diagnosis; height/weight at diagnosis (if available) and at first outpatient department appointment; number of brothers/sisters; birth order; birth history; birth weight, gestation (in weeks), mode of delivery; infant feeding method and duration; age at first solid feed (in months); Bacillus Calmette–Gu rin (BCG) vaccination (yes/no); history of type 1 or type 2 diabetes in immediate family (mother, father, brother, sister, twin); associated/autoimmune disease; medical card (yes/no); long-term illness card (yes/no); private health insurance (yes/no); parents' occupation; ethnic origin.
Potential metrics	Percentage of patients with diabetic ketoacidosis (DKA) at diagnosis; number of consented patients; bloods at diagnosis; antibodies at diagnosis (for checking other siblings); symptoms at presentation.
Coverage	All patients nationally diagnosed with T1DM aged under 15 years. 19 participating units nationally care for children with T1DM.
Limitations	No data sharing or linkage permitted. Data relate to point of diagnosis only and are restricted to children aged under 15 years.
Potential Information	Provides snapshot of incidence rates in population aged under 15 years and will be useful for validation purposes.

TABLE 8.4: PRIMARY CARE REIMBURSEMENT SERVICE

Governance	HSE national health schemes data
Description	Reimbursement service for primary care contractors for the provision of health services to members of the public. Primarily for administrative purposes. The PCRS is the richest source of national prescription data and the largest data source for measuring drug exposures in specific populations in Ireland.
Collection	Claims data processed and payments made by PCRS under schemes such as GMS, the DPS, the LTI Scheme, the Childhood Immunisation, and HSE-Community Ophthalmic Scheme. Data are collected continuously in real time and in batches from various health services, e.g. pharmacies.
Accessibility	Applications for data take time. Data linkage is not permitted and data are anonymised.
Data Fields	Basic demographic information, including age, sex, region of residence and details on monthly products prescribed and dispensed from the main community drug schemes, including the DPS and the LTI Scheme.
Potential metrics	Percentage of children using pumps/continuous glucose monitors (CGMs). Denominator data for validation of audit data.
Coverage	All patients diagnosed with diabetes in receipt of reimbursement via main national health schemes, e.g. the LTI Scheme, GMS, etc. LTI Scheme does not include means testing; hence, all patients nationally are entitled to this scheme, which provides free medications for 16 specified chronic illnesses including diabetes. Covers insulin, oral hypoglycaemic agents, glucometer test strips, needles, infusion sets, etc.
Limitations	New applications of relevant patients to the LTI Scheme will be used as a proxy for newly diagnosed patients. There is no confirmation of T1DM diagnosis, hence difficulties with distinguishing between patients with type 1 diabetes and type 2 diabetes.
Potential Information	Data cuts will provide information on prevalence and incidence of T1DM in the paediatric population. Important data for resources, planning and comparison with international data. Validation of audit data.

TABLE 8.5: DIABETIC RETINASCREEN PROGRAMME

Governance	HSE National Screening Service
Description	Screening for early detection and treatment of sight-threatening retinopathy. Programme has constructed a population register containing demographic data to identify eligible people aged 12 years and over. Clinical data also included for follow-up treatment and referral recommendations. Standards developed for service provision (National Screening Service, 2019).
Collection	Files imported from the PCRS and via facilitated self-registration, and via registration by health professionals with MRN from the HSE website *(www.diabeticretinascreen.ie)* GPs, ophthalmologists and endocrinologists can add data to the register with patients' consent.
Accessibility	Consent required for identifiable data. Requests to access anonymised dataset are facilitated via a VPN.
Data Fields	Demographic details, including name, address, personal public service number, date of birth, photographs/images from screened patient notes, medical history data, treatment, and outcomes.
Potential metrics	Percentage of children aged 12 years and over with T1DM on the register for screening. Timeliness of referrals and feedback to programme. Percentage of children attending for screening. Percentage and age of onset in the population of patients aged 12 years and over with T1DM. Percentage of patients attending for follow-up. Treatment and outcomes.
Coverage	National dataset. Offered free to all people with type 1 and type 2 diabetes aged 12 years and over. Acceptance of screening invite by patients aged 12–21 years is 92%.
Limitations	No data on children aged under 12 years. Because there is no integration of healthcare records, it is not possible to analyse referrals by type of diabetes, HbA1c concentration, body mass index (BMI), blood pressure or dyslipidaemia. Cannot easily distinguish patients with type 1 diabetes from patients with type 2 diabetes.
Potential Information	Aggregate data on patients aged 12 years and over. No linkage possible. Denominator data on the population of children aged 12 years and over.

CHAPTER 9

ANALYSIS OF FEASIBILITY FINDINGS BY THEME AND POTENTIAL FOR QUALITY IMPROVEMENT



CONTENTS >

CHAPTER 9: **ANALYSIS OF FEASIBILITY FINDINGS BY THEME AND POTENTIAL FOR QUALITY IMPROVEMENT**

BACKGROUND

Optimal management of paediatric T1DM is patient-centred and should be provided by a trained multidisciplinary team (MDT) led by a consultant paediatric endocrinologist and should include specialist paediatric diabetes-trained nursing, dietetics and psychological MDT. The goal of care is for individual patients and their families to acquire the necessary self-management skills that will allow them to maintain optimal diabetes control and prevent acute and long-term complications and live fulfilled lives. Care provision by a paediatric diabetes MDT has been shown to optimise self-care and improve glycaemic control, as evidenced by lower HbA1c levels, fewer days in hospital and lower readmission rates (Zgibor *et al*., 2002; Levetan *et al*., 1995). *A National Model of Care for Paediatric Healthcare Services in Ireland* (HSE, 2015), HSE *National Clinical Practice Guidelines* (2019) and *International Society for Pediatric and Adolescent Diabetes Guidelines* (ISPAD) provide standards to guide optimal care delivery.

As recommended by the Department of Health's National Clinical Effectiveness Committee, the selection of topics that should be included in the proposed national audit is based on factors such as the availability of standards for benchmarking, the availability of metrics with which to monitor compliance with standards, and the potential of these metrics to improve care quality. Ease of data capture and measurement and evidence of variability across the system are other important considerations.

OBJECTIVES

To identify appropriate care pathways and topics and for inclusion in a national audit the findings of the various work strands in the feasibility study were reviewed with the following objectives:

1. Explore processes of paediatric T1DM care delivery in order to identify themes.
2. Outline potential quality indicators and outcome measures within each theme, aligned with appropriate guidelines and standards, where relevant.
3. Align potential audit options with available data sources.

ORGANISATION OF CARE PROCESSES BY THEME

A modified version of the methodology used for previous national audit feasibility studies (e.g. Healthcare Quality Improvement Partnership's (HQIP's) National Asthma Audit Feasibility study, 2017 and NOCA's *Deteriorating Patient Audit Feasibility Study., 2021*) was adopted for exploring options for a national paediatric diabetes audit. The care of patients with T1DM is complex, and steering committee members familiar with care delivery contributed to the exercise. A subgroup of the steering committee, including the Chair, Deputy Chair and Dr Sinead McGlacken-Byrne, considered the various aspects of care delivery and grouped these by theme, based around available clinical guidelines. Themes were then reviewed with regard to potential variability in quality of care delivery, and potential metrics of success were identified along with structures and processes driving the outcomes. The key areas of care identified for analysis are shown in Figure 9.1.

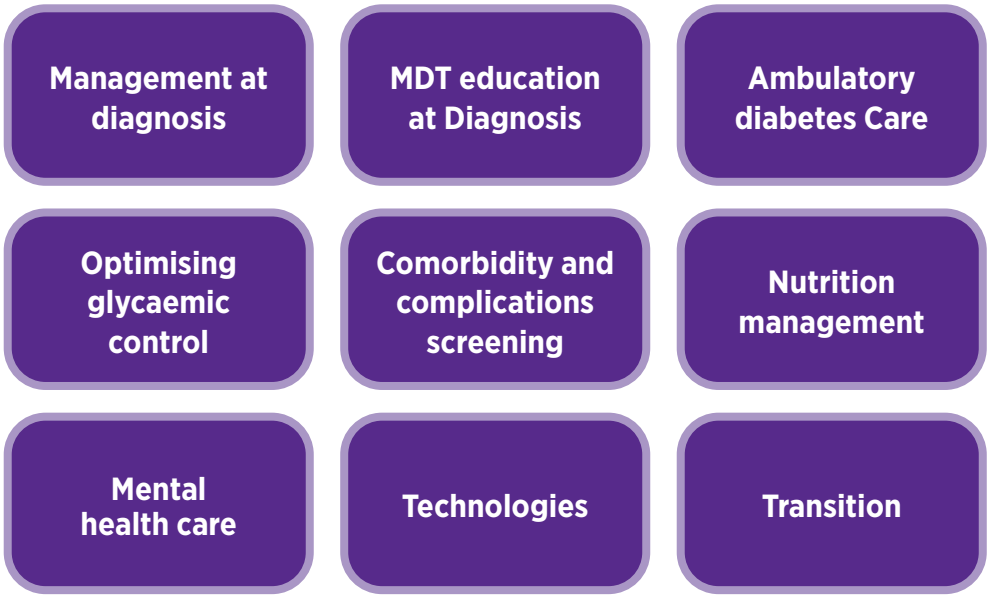


FIGURE 9.1: BROAD CARE PROCESSES OF PAEDIATRIC PATIENTS WITH TYPE 1 DIABETES MELLITUS

ALIGNMENT OF METRICS, GUIDELINES AND QUALITY IMPROVEMENT OBJECTIVES WITHIN CARE PROCESSES

Information on available datasets, standards and guidelines, and quality improvement potential was aligned within each theme in order to summarise the suitability of distinct care processes for audit. A summary of each care process is provided in Tables 9.1–9.9.

Management at diagnosis

Early evaluation and timely access to appropriate care is needed in order to improve outcomes for patients with T1DM. National clinical practice guidelines exist for care of children who are newly diagnosed with T1DM without DKA and for management of paediatric DKA (HSE Clinical Guidelines, 2021a, 2021b). Symptom recognition is key to early diagnosis and prevention of DKA. Effective tailored management from the time of diagnosis optimises glycaemic control, which reduces the risk of diabetes-related complications (The Diabetes Control and Complications Trial Research Group, 1994; 1993). Multiple research studies highlight the importance of good control from the time of diagnosis (Hofer *et al.*, 2014; Edge *et al.*, 2010).

Outcome measures for this theme include the management of patients presenting with DKA (Table 9.1). The proportion of patients referred early to hospital care depends on awareness and prompt recognition of the symptoms of T1DM in the community and the availability, awareness and knowledge of national guidelines among healthcare professionals. Knowledge and awareness of guidelines also influence subsequent care and outcomes. Best practice guidelines require that a member of a trained MDT see the newly diagnosed patient within 24 hours of diagnosis (or within 48 hours of a weekend diagnosis) and that appropriate first-line investigations are made, including checking for diabetes autoantibodies. The ICDNR currently collects data on all newly diagnosed patients aged under 15 years. Additional consent would be required for use of these data in a national audit. Data on admissions for DKA and insulin treatment for all hospitalised patients are available via HIPE and the NQAIS; however, a reliable method for identifying newly diagnosed patients will be required. This also applies to data on autoantibodies captured by laboratory datasets. Acquiring information on process measures requires new data collection from patient records.

TABLE 9.1: OPTIMAL MANAGEMENT AT DIAGNOSIS

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients with DKA managed according to best practice guidelines, including transfer to a paediatric intensive care unit if required** • **Percentage of patients with DKA experiencing complications** • **Percentage of patients seen by a member of the MDT within 24 hours of diagnosis (or within 48 hours of a weekend diagnosis)** • **Incidence of unscheduled readmission**	• Commenced DKA protocol if diagnosed with DKA/if indicated • Commenced subcutaneous insulin therapy if DKA protocol not indicated • Correct diagnosis established • Prompt referral from community to hospital care • Assessment of skills and knowledge base prior to discharge	• Seen by a member of the MDT within 24 hours of diagnosis (or within 48 hours of a weekend diagnosis) • Appropriate newly diagnosed laboratory and referrals sent (in line with national guidelines) • Availability and implementation of national guidelines • Awareness of symptoms of diabetes in community and healthcare settings.	• Admissions data in HIPE and NQAIS Clinical • Laboratory dataset • ICDNR • Diabetic RetinaScreen

RELEVANT GUIDELINES/STANDARDS

- *Care of the Child Newly Diagnosed with Type 1 Diabetes without DKA* (HSE, 2021a)
- *Management of Paediatric Diabetic Ketoacidosis* (HSE, 2021b)
- HSE Paediatric Type 1 Diabetes Resource Pack (RCPI Clinical Programmes, 2021c)
- ISPAD Clinical Practice Consensus Guidelines 2018, Chapter 1: Definition, epidemiology, and classification of diabetes in children and adolescents (Mayer-Davis et al., 2018)

MDT education at diagnosis

Diabetes management in children can be challenging, and young patients are reliant on parents and family for support with the demands of daily self-care. Early education is central to optimising diabetes management, self-management and well-being, and should commence at diagnosis with a family-focused education package (Paediatric Endocrinology and Diabetes Care. In: *A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015*). The national clinical guideline on care of the newly diagnosed patient recommends developing an education plan that is age-appropriate, developmentally appropriate, and tailored to the family's needs. This education plan provides the patient and their family with the knowledge and skills needed to optimise self-care, including management of high and low blood glucose readings, insulin dose adjustment, carbohydrate counting, advice on managing diabetes during exercise and school, and managing emergencies (Swift, 2009). Adolescents in particular require intensified resource-dependent MDT support. Access to a trained MDT that includes physicians trained in diabetes care, diabetes nurses, dietitians, social workers and psychologists is required in order to ensure that families are adequately informed and supported. Daily contact with the MDT and frequent early follow-up is required in the early stages following diagnosis. Metrics for this element of care include: access to a trained MDT; whether or not a patient is seen by a consultant with training in paediatric diabetes within 24 hours of diagnosis (or within 48 hours of a weekend diagnosis); provision of no fewer than three education sessions with a paediatric diabetes nurse, and two sessions with a paediatric diabetes dietitian at the time of diagnosis; and consultation with a member of the psychosocial team (psychologist or paediatric social worker) prior to discharge. Data on the care delivered to families are collated in patient notes. Potential outcome measures (Table 9.2) include the proportion of patients diagnosed with DKA or severe hypoglycaemia within 1 year of T1DM diagnosis and diabetes control metrics such as HbA1c levels. Potential sources of these data are the readmission data from HIPE, NQAIS Clinical, outpatient clinic notes and HSE workforce data.

Ambulatory diabetes care

Following initial diagnosis, care delivery transitions to outpatient ambulatory management that is aimed at optimising glycaemic control and quality of life. Close monitoring of patients at MDT clinics ensures timely screening for complications and comorbidities. It is recommended that children with T1DM attend the diabetes clinic and are seen by a consultant with training in paediatric diabetes and by a specialised MDT (including specialist diabetes nursing, dietitian, and mental health support) every 3 months, and that they have eight additional contacts with the MDT per year (*A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015*). Further additional appointments should be offered as required. In the United Kingdom (UK), these standards of care form the basis for a best practice diabetes tariff, which provides financial reimbursements to the service provider when 14 key standards are met (Randell 2019). Clinical practice guidelines are available for management of patients who do not attend clinical reviews or who have poor glycaemic control with HbA1c levels consistently above 75 mmol/mol (9%) (HSE National Clinical Guidelines, 2019b). Drivers of optimal ambulatory care are access to a trained MDT, adequate staffing levels of the trained MDT, structured checklists in use in the clinic, and patient and family engagement with appointments (Table 9.3). The percentage of patients diagnosed with DKA or severe hypoglycaemia in the preceding year are key outcome measures for audit. Additional metrics are listed in Table 9.3.

TABLE 9.2: OPTIMAL EDUCATION AT DIAGNOSIS

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients with DKA within 1 year of diagnosis** • **Percentage of patients developing severe hypoglycaemia within 1 year of diagnosis** • **Percentage of patients having completed structured education checklist**	• Patient seen and evaluated by consultant with specific endocrinology and diabetes training within 24 hours of diagnosis (or within 48 hours of a weekend diagnosis) • Patient seen by paediatric social worker before discharge • Three or more interactions with paediatric diabetes nurse specialist prior to discharge • Education session with paediatric diabetes dietitian no fewer than two times before discharge	• Access to a trained MDT • Clear guidelines/ structured education curriculum • Structured education checklist • Formative patient assessment checklist • Proactive follow-up (based on need) after discharge • Patient feedback on education assessment	• Readmissions data in HIPE and NQAIS Clinical • Patient records (electronic or paper-based) • HSE workforce data

RELEVANT GUIDELINES/STANDARDS

- *Care of the Child Newly Diagnosed with Type 1 Diabetes without DKA (HSE, 2021a)*
- *Management of Paediatric Diabetic Ketoacidosis (HSE, 2021b)*
- *National School Management resources. Meeting the Care Needs of Primary School Children with Type 1 Diabetes during School Hours. Clinical Design and Innovation HSE.ref CDI 001/2021*
- MDT resource requirements (*Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland*, HSE, 2015)
- HSE Paediatric Type 1 Diabetes Resource Pack (RCPI Clinical Programmes, 2021c)
- ISPAD Clinical Practice Consensus Guidelines 2018, Chapter 6: Diabetes education in children and adolescents (Phelan *et al.,* 2018)

TABLE 9.3: OPTIMAL AMBULATORY CARE OF PAEDIATRIC PATIENTS WITH TYPE 1 DIABETES MELLITUS

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients with DKA within previous year** • **Percentage of patients with severe hypoglycaemia within previous year** • **Percentage of patients achieving target HbA1c levels** • **Dedicated education session by paediatric diabetes nurse within previous year** • **Average number of outpatient diabetes appointments offered within previous year** • **Percentage of patients seen by paediatric diabetes dietitian within previous year** • **Percentage of patients with depression or mental health issues seen by mental health team member within previous year (psychologist, social worker)**	• Patient seen and evaluated by a consultant with training in paediatric endocrinology every 3 months • Access to specialist diabetes advice 24 hours per day, 7 days per week • Eight contacts with MDT team (in addition to review every 3 months by consultant) • Annual physical assessment • Annual education assessment • Patient offered two paediatric diabetes dietitian reviews in the year following diagnosis and annual reviews thereafter • Age-appropriate screening for comorbidities and complications • Psychosocial screening • Timely access to diabetes technology	• Access to trained MDT, including psychologist and out-of-hours services (in line with Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015). • Structured education curriculum • Proactive outreach (based on need) after discharge • Staffing numbers	• Readmissions data in HIPE and NQAIS Clinical • Appointment data (Patient Information Management System) • Annual review of laboratory results (LIMS) • Outpatient clinic notes • Retinopathy screening (for those aged over 12 years) DRS programme

RELEVANT GUIDELINES/STANDARDS

- *Management of Paediatric Type 1 Diabetes Patient who did not attend (DNA), were not brought or repeatedly cancels their appointments* (HSE, 2019a)
- *Management of Paediatric Type 1 Diabetes Patient with a HbA1c > 9% (75mmol/mol)* (HSE, 2019b)
- MDT resource requirements (Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015)
- HSE Paediatric Type 1 Diabetes Resource Pack (RCPI Clinical Programmes, 2021c)
- *ISPAD Clinical Practice Consensus Guidelines 2018*, Chapter 7: The delivery of ambulatory diabetes care to children and adolescents with diabetes (Pihoker *et al.,* 2018)

Optimising glycaemic control

One KPI of diabetes management is the patient's HbA1c level. ISPAD guidelines recommend a target HbA1c level of <53 mmol/mol (<7.0%) for children, adolescents and young people with diabetes (Acerini *et al.*, 2014). There is clear evidence from the Diabetes Control and Complications Trial (DCCT) that better glucose control, as evidenced by lower HbA1c levels and achieved through intensive management of type 1 diabetes, is associated with fewer, and later onset of, microvascular complications. Furthermore, the DCCT observational follow-up study demonstrated that achieving good glycaemic control for a period of time has a durable effect, with reduction in early-stage complications translating into substantial reductions in severe complications and cardiovascular disease (Nathan and DCCT/EDIC Research Group, 2014). Good control depends on patients having access to an MDT, education, out-of-hours support, and technology to aid insulin delivery and monitoring of glucose levels, as well as audit of care delivery in order to ensure adherence to standards and improvement in outcomes (Table 9.4). Even transient hyperglycaemia or hypoglycaemia can have long-lasting effects on the development and progression of diabetic complications (Thomas, 2014).

The *National Model of Care for Paediatric Healthcare Services in Ireland* (HSE, 2015) recommends regular national audit of the process of diabetes service delivery, including documentation of the proportion of patients with T1DM in each service who achieve the target HbA1c levels. Measurement of the proportion of patients who achieve this target, and accordingly the proportion of patients who have suboptimal or poor glycaemic control, can then be used for benchmarking. Patient HbA1c levels are monitored and recorded during clinic visits. Variation in practice and systems for measuring and recording between clinics is discussed in Chapters 6 and 7 of this report.

TABLE 9.4: OPTIMISING GLYCAEMIC CONTROL

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients with T1DM for more than 1 year with HbA1c <53 mmol/mol** • **Percentage of patients using CGMs with >70% time in range** • **Percentage of patients with DKA in previous year** • **Percentage of patients with severe hypoglycaemia in previous year**	• Education on hyperglycaemia avoidance strategies • Plan for daily blood glucose monitoring • Regular optimisation of insulin dosage • Patient and caregiver confidence	• Clear management protocols • Structured education checklist • Access to MDT support (including out of hours) • Access to diabetes technology • Diabetes team education • Regular attendance at diabetes ambulatory clinic • Audit of clinic HbA1c levels	• Laboratory dataset • Annual review of laboratory results (LIMS) • Outpatient clinic notes

RELEVANT GUIDELINES/STANDARDS

- *HSE National Clinical Guideline Annual review and comorbidity screening in Paediatric T1DM Clinical Designs and Innovation* (HSE, 2020a)
- *HSE National Clinical Guideline. Identification and Management of Hypoglycaemia in Children with Type 1 Diabetes (2019c)*
- *Management of Paediatric Type 1 Diabetes Patient with a HbA1c > 9% (75mmol/mol)* (HSE, 2019b)
- *Managing Children with Type 1 Diabetes who use Continuous Glucose Monitoring or Flash Glucose Monitoring (HSE 2020b)*
- HSE Paediatric Type 1 Diabetes Resource Pack (RCPI Clinical Programmes, 2021c)
- ISPAD Clinical Practice Consensus Guidelines 2018, Chapter 8: Glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes (DiMeglio *et al.,* 2018)

Comorbidity and complication screening

Hospitalisation with complications of T1DM constitutes a significant proportion of the healthcare costs of diabetes care delivery, accounting for 67% of the total estimated cost associated with diabetes care in Ireland (Friel *et al*., 2021; O'Neill *et al*., 2018). In children and adolescents with T1DM, the most common complications include hypoglycaemia, hyperglycaemia, DKA and psychiatric disorders. Long-term diabetes-related complications associated with hyperglycaemia include:

- macrovascular complications, where large blood vessels are damaged, resulting in heart disease, cerebrovascular disease and peripheral vascular disease
- microvascular complications, where small blood vessels are damaged, resulting in diabetic eye disease (retinopathy), kidney disease (nephropathy) and nerve disease (neuropathy).

Mortality among paediatric patients with diabetes is mainly as a result of metabolic disturbances, DKA and hypoglycaemia (Patterson *et al*., 2007). Optimal glycaemic control reduces the risk of complications but is most effective when implemented early on after the diagnosis of diabetes. Annual review and access to an MDT provide an opportunity for the clinician and child, and their parents or carers, to review all aspects of their diabetes care and these reviews should include screening for complications and comorbidities (coeliac disease, dyslipidaemia and thyroid dysfunction) at appropriate ages and intervals. Recommendations for the timing and intervals of screening are provided in national guidelines in order to facilitate standardisation and consistency of practice across units. Data on the proportion of patients who have completed all recommended reviews and screening at the required stages and intervals are recorded in outpatient clinic notes. These data are not likely to be of a standardised format and would have to be anonymised for use in a national audit. Data on hospital admissions for complications can be retrieved from the NQAIS and HIPE, with additional details on hyperlipidaemia recorded in the unit laboratory datasets. Ireland has the national Diabetic RetinaScreen programme available to all people aged over 12 years who are diagnosed with T1DM, and registered patients are invited at agreed intervals for screening. The proportion of patients aged over 12 years who are registered, who attend, and who have evidence of retinopathy are potentially auditable metrics (Table 9.5).

Nutrition management

Nutrition management is one of the cornerstones of diabetes care and education. A specialised paediatric dietitian with experience in childhood diabetes should be part of the MDT in order to provide education and support around dietary and lifestyle issues. Advice on diet and lifestyle should be initiated soon after diagnosis and adapted to individual needs: two sessions with the dietitian are recommended before discharge, with two more sessions recommended in the first year, and annual sessions recommended thereafter with additional sessions if required (Chapter 23: Paediatric Endocrinology and Diabetes Care. In: A National Model of Care for Paediatric Healthcare Services in Ireland. HSE, 2015; ISPAD, 2018). Nutrition management aims to achieve optimal glycaemic control, prevent acute complications, and reduce the risk of microvascular and macrovascular complications, while preserving quality of life and maintaining psychosocial well-being and family dynamics (Smart *et al*., 2009). Optimising nutrition management depends on the availability of clear management guidelines, access to a paediatric diabetes dietitian, access to technology and regular attendance at ambulatory care appointments. Metrics of success in nutrition management include the proportion of children who have been offered and have attended a dedicated appointment with a specialist paediatric diabetes dietitian during the previous year at the appropriate interval; the proportion of patients competent in carbohydrate counting and diet-related dose adjustment; and the proportion of patients with elevated cholesterol levels who are receiving focused nutritional support (Table 9.6). This information is currently only recorded in outpatient clinic notes and accessing these data for audit purposes would require consent if the data were not anonymised.

TABLE 9.5: APPROPRIATE SCREENING FOR LONG-TERM COMPLICATIONS AND COMORBIDITIES

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients who have completed all age-appropriate screening** • **Percentage of patients screened (if eligible) in previous year for each of the following:** - **Percentage of patients with hypothyroidism** - **Percentage of patients with mental health issues** - **Percentage of patients with neuropathy** - **Percentage of patients with hypertension** • **Percentage of patients with low-density lipoprotein (LDL) cholesterol above acceptable threshold who had a consultation with a dietitian within previous year** • **Percentage of patients aged over 12 years screened for retinopathy in previous year**	• Screening at appropriate intervals in line with national guidelines for: - hyperlipidaemia - hypothyroidism - mental health issues - neuropathy - hypertension - retinopathy (if aged over 12 years).	• Access to a trained MDT, including psychology and out-of-hours support (in line with Model of Care, 2015) • Annual review process • Clear screening protocols • Access to interdisciplinary care	• Outpatient notes – annual review • Admissions data in HIPE and NQAIS Clinical • Annual review of laboratory results (LIMS) (for hyperlipidaemia) • Retinopathy screening (for those aged over 12 years) DRS programme

RELEVANT GUIDELINES/STANDARDS

- *HSE National Clinical Guideline Annual review and co-morbidity screening in Paediatric Type 1 Diabetes* (HSE, 2020a)
- *Management of Paediatric Type 1 Diabetes Patient with a HbA1c > 9% (75mmol/mol)* (HSE, 2019b)
- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 18: Microvascular and macrovascular complications in children and adolescents (Donaghue *et al.,* 2018)
- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 19: Other complications and associated conditions in children and adolescents with type 1 diabetes (Mahmud *et al.,* 2018)
- *Clinical Practice Guidelines for Treatment Clinics.* (n.d.) Diabetic Retinascreen. 1st ed. National Diabetic Retinal Screening Programme HSE

TABLE 9.6: OPTIMAL NUTRITION MANAGEMENT

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients competent in carbohydrate counting** • **Percentage of patients screened for disordered eating in the past year** • **Percentage of patients with a dedicated nutrition visit in the first year after diagnosis** • **Percentage of patients with elevated LDL cholesterol seen by a nutritionist within the past year** • **Percentage of patients with elevated BMI seen by a nutritionist within the past year**	• Two sessions with paediatric dietitian before discharge, two more sessions in the first year after diagnosis, annual sessions thereafter and additional sessions if required • Children and adolescents competent in carbohydrate counting for insulin doses	• Clear management protocols • Access to paediatric dietitian with training in T1DM • Annual review process • Structured education checklist • Access to diabetes technology • Diabetes team education • Regular attendance at diabetes ambulatory care clinic	• Outpatient notes – annual review • iPIMS

RELEVANT GUIDELINES/STANDARDS

- *Care of the Child Newly Diagnosed with Type 1 Diabetes without DKA* (HSE, 2021a)
- *HSE National Clinical Guideline. Identification and Management of Hypoglycaemia in Children with Type 1 Diabetes (2019c)*
- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 10: Nutritional management in children and adolescents with diabetes (Smart *et al.,* 2018)

Mental health support/care

A diagnosis of T1DM presents many challenges for children and their families, and psychosocial care can facilitate patients adapting to their new regimen and lifestyle changes. Anxiety about future health, stress related to daily requirements of diabetes management, difficulties with peers, and social adjustment contribute to higher rates of depression, anxiety and eating disorders among children with T1DM than among the general population (Gallagher, 2017; Kovac *et al.*, 1997). The incidence of depressive symptoms among adolescents with T1DM is as high as 25% (Lawrence, 2006), and the American Diabetes Association recommends routine depression screening in this population (ADA 13 Children and Adolescents: Standards of Medical Care in Diabetes, 2019).

Medical management of diabetes in children with T1DM should include psychosocial assessment and follow-up as recommended by the *Model of Care for All Children and Young People with Type 1 Diabetes* (O'Riordan *et al.*, 2015), ISPAD, and the American Diabetes Association (Delamater *et al*., 2014; American Diabetes Association, 2014). The paediatric diabetes best practice tariff in the UK includes psychological assessment as 1 of 14 criteria: "each patient must have an annual assessment by their MDT as to whether input to their care by a clinical psychologist is needed, and access to psychological support, which should be integral to the team, as appropriate" (Randall, 2012). Many children and families in Ireland do not have this support. A risk assessment of children with T1DM in Ireland showed that almost one-third of children are at moderate or high psychosocial risk, an effect that was not reduced over time with routine care (Hennessy *et al.*, 2019). This study highlighted the need for trained clinical psychologists for children with T1DM. Optimising psychosocial care requires that a social worker see the patient during DKA admissions and that a psychologist review the patient within 1 year of diagnosis with T1DM (Table 9.7). Data for monitoring performance relating to provision of psychosocial care are only held in clinical notes.

TABLE 9.7: OPTIMAL MENTAL HEALTH CARE

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients aged over 12 years screened for depression** • **Percentage of patients aged over 12 years who screened positive for depression who were seen by a psychologist in the preceding year** • **Percentage of patients aged over 12 years seen by a diabetes psychologist within 1 year of diagnosis** • **Percentage of patients seen by a social worker in preceding 2 years** • **Percentage of children with HbA1c levels >70 mmol/mol seen by a diabetes psychologist in preceding year**	• Seen by social worker during DKA admissions • Annual assessment by an MDT as to whether input by a clinical psychologist is needed • Access to a dedicated psychologist as part of the MDT • Psychologist review within 1 year of diagnosis • If aged over 8 years, seen by a psychologist once yearly	• Access to a dedicated paediatric social worker as part of the diabetes MDT • Access to a dedicated paediatric clinical psychologist as part of the diabetes MDT	• Outpatient notes – annual review

RELEVANT GUIDELINES/STANDARDS

- *A National Model of Care for Paediatric Healthcare Services in Ireland,* Chapter 23: Paediatric Endocrinology and Diabetes Care (Health Service Executive, 2015)
- *Care of the Child Newly Diagnosed with Type 1 Diabetes without DKA* (HSE, 2021a)
- *ISPAD Clinical Practice Consensus Guidelines 2018, Chapter 16:* Psychological care of children and adolescents with type 1 diabetes (Delamater *et al.,* 2018)

Technologies

Diabetes technology is rapidly developing and expanding. Continuous subcutaneous insulin infusion (CSII), or pump therapy, provides increased lifestyle flexibility and has been shown to improve glycaemic control and enhance quality of life (Churchill *et al*., 2009; Shalitin and Phillip, 2008). Pump therapy is recommended by ISPAD as the preferred method of insulin administration for preschool children (Sundberg *et al*., 2017) Uptake in children and adolescents in Ireland (37% of patients with T1DM) is lower than the average across Europe (44% of patients with T1DM) and the USA (60% of patients with T1DM) (Gajewska *et al*., 2020b).

The use of continuous glucose monitoring (CGM) and flash glucose monitoring by children with T1DM has increased in recent years and it is expected that this number will rise as the technology becomes less expensive, easier to use, and more integrated with insulin delivery in automated complete or hybrid 'closed-loop' systems. Studies have demonstrated a positive impact of flash glucose monitoring and CGM on quality of life, and these devices should be offered to all children and adolescents with T1DM (Evans *et al.*, 2020; Murphy *et al*., 2019).

Pump therapy and CGM are funded for use in children with diabetes and should be offered to all appropriate patients. A trained specialist team (including an endocrinologist, a diabetes nurse specialist and a dietitian) should initiate use of pump therapy, and training in accurate carbohydrate counting, technical skills, and problem-solving should be provided to children and caregivers in order to ensure the effective use of these devices. Patients and their families must be competent in interpreting and uploading CGM data, and these skills depend on the availability of and access to the technology and to an MDT which can provide education supported by regular attendance and buy-in at the diabetes clinic. While technological devices are funded in Ireland, insufficient MDT staffing levels to provide the required education and support result in extensive waiting lists for children for whom this treatment would facilitate optimal medical care. Furthermore, children currently using these devices are not receiving the amount of support and education required for their optimal use.

Measurable outcomes of successful integration of diabetes technology with clinical care and the associated clinical guidelines are listed in Table 9.8. It is possible to extract anonymised data on the proportion of patients using technology from the Primary Care Reimbursement Service (PCRS) database. Details of HbA1c levels for patients using this technology are recorded in hospital laboratory systems and in outpatient notes. For patients using CGM, the data must be provided by the patients' families. An Individual Health Identifier would allow the linkage of these data sources (with caregiver consent).

Transition

The transition from paediatric to adult diabetes care services is a vulnerable stage in the T1DM patient journey, with enormous risks to the patient if they disengage with services or are lost to follow-up in the transition process. Clear policies and a structured transition are required for all young adults moving on to adult centres (Table 9.9). A framework document on the transition of patients from paediatric to adult care services is currently being drafted with the adult National Clinical Programme for Diabetes. Current data on success of transition are captured in patient notes only. If all patients aged over 12 years who have T1DM were registered for the Diabetic RetinaScreen programme, this information could be used as a resource to assess whether patients within this group are linked to services and to re-invite them to clinic if they have disengaged.

TABLE 9.8: OPTIMAL INTEGRATION OF DIABETES TECHNOLOGY WITH CLINICAL CARE

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of patients achieving optimal control (target HbA1c level and time in range)** • **Percentage of patients using an insulin pump** • **Percentage of children using CGM** • **Percentage of children using CGM who uploaded data at previous clinic visit** • **Percentage of children/families who can interpret their own data** • **Percentage of children who start an insulin pump and continue to use the device 1 year later** • **Percentage of children aged under 5 years using an insulin pump** • **Percentage of children on an insulin pump admitted with DKA in preceding year** • **Time between decision to start pump therapy and initiation**	• Timely access to pump therapy and CGM with support in initiating and maintaining technology when used • Diabetes team expertise in review and management of diabetes technology • Patient and family competent in administering and adjusting insulin dose using pump • Patient and family competent in interpreting and uploading CGM data	• Trained MDT availability for initiation of technology • Trained MDT availability to support optimal technology use (dose titration, data interpretation) • Funding for technology • Diabetes MDT education • Patient and caregiver confidence • Regular attendance at ambulatory care clinic	• The PCRS has data on the percentage of patients using pumps and CGM • Laboratory dataset • Outpatient notes

RELEVANT GUIDELINES/STANDARDS

- *Managing Children with Type 1 Diabetes who use Continuous Glucose Monitoring or Flash Glucose Monitoring*
- *Care of the Child Newly Diagnosed with Type 1 Diabetes without DKA* (HSE, 2021a)
- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 8: Glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes (DiMeglio *et al.,* 2018)
- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 21: Diabetes technologies (Sherr *et al.,* 2018)

TABLE 9.9: OPTIMAL TRANSITION TO ADULT CARE SERVICES

Identifiable metrics of success	Primary drivers	Secondary drivers	Data Source
• **Percentage of children aged over 16 years still attending paediatric diabetes services** • **Percentage of children aged over 18 years still attending paediatric diabetes services** • **Percentage change in HbA1c levels 1 year after transition** • **Percentage of young adults attending adult clinic 1 year post-transition**	• Planned organised transition of care from paediatric to adult services • Continuity of care between paediatric and adult services • Individualised, tailored approach to timing of transition • Transition readiness check	• Structured approach to supporting families in transitioning autonomy in an age-appropriate manner, culminating in formal transition to adult care • Continuity of care between paediatric and adult services • Transition coordinators/staff on MDT • Joint attendance of adult and paediatric team members at transition clinics or dedicated adolescent transition clinics	• Outpatient notes • Diabetic RetinaScreen dataset

RELEVANT GUIDELINES/STANDARDS

- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 17: Diabetes in adolescence (Cameron *et al.,* 2018)
- *ISPAD Clinical Practice Consensus Guidelines 2018,* Chapter 8: Glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes (DiMeglio *et al.,* 2018)

Identifying potential for quality improvement

Information from patient journey mapping, consensus guidelines and standards review, and international diabetes audit datasets was used to identify drivers of high-quality care within the previously discussed care domains, elucidating focus areas for future quality improvement interventions. The requirements for optimal care delivery for paediatric patients with T1DM, based on the information collated in Tables 9.1–9.9, are listed in Table 9.10.

A series of driver diagrams was constructed to visually represent the primary and secondary drivers of care delivery. Possible outcome measures were also considered.

TABLE 9.10: REQUIREMENTS FOR OPTIMAL CARE DELIVERY TO PAEDIATRIC PATIENTS WITH TYPE 1 DIABETES MELLITUS

Requirements of an optimal paediatric care delivery centre	
1	Lead consultant with specific diabetes and diabetes technology training
2	Availability of trained MDT members by discipline with specific diabetes and diabetes technology training
3	Defined location and process for DKA management
4	Patient seen or discussed by member of MDT within 24 hours of presentation (or 48 hours for weekend presentation)
5	Provision of structured education programme tailored to patient and family's needs at diagnosis and throughout attendance at clinics
6	24-hour access to advice and support for patients and families
7	Minimum of 4 outpatient clinic visits per year
8	HbA1c testing in diabetes clinic: minimum of 4 HbA1c measurements per year
9	Each patient is offered additional contact by the MDT for check-ups, telephone contacts, school visits, troubleshooting, advice, support, etc.; 8 contacts per year are recommended as a minimum
10	At least 1 additional appointment per year with a paediatric dietitian with training in diabetes
11	Age-appropriate annual review and comorbidity screening provided
12	Annual MDT assessment to determine need for clinical psychologist and access to psycological support as appropriate
13	Prospective data collection for quality assurance and improvement via electronic patient record integrated with national audit
14	Structured handover to adult services around transition

An overall representation of factors important to the required infrastructure for the delivery of optimal care to paediatric patients with T1DM is outlined in Figure 9.2.

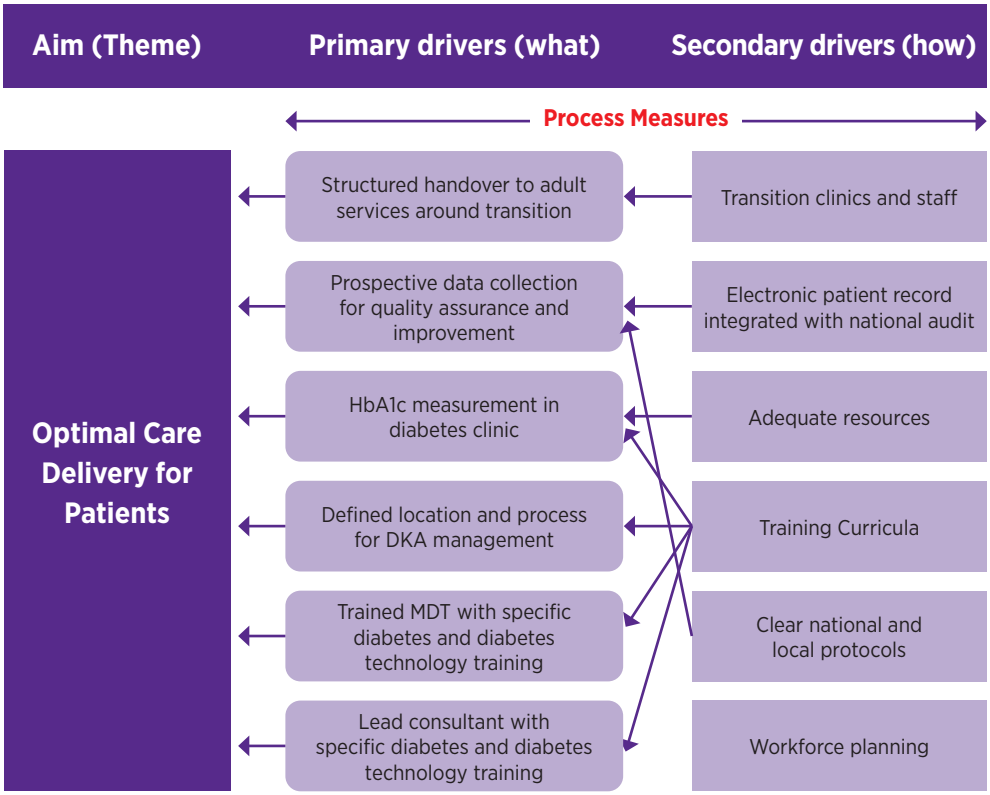


FIGURE 9.2: PRIMARY AND SECONDARY DRIVERS OF OPTIMAL INFRASTRUCTURE FOR DELIVERY OF CARE FOR PAEDIATRIC PATIENTS WITH TYPE 1 DIABETES MELLITUS

Similar detailed schema are provided in Appendix vii. for the following improvement objectives:

- optimising management at first presentation
- optimising education at diagnosis
- optimising ambulatory diabetes care
- optimising glycaemic control
- reducing long-term complications
- optimising nutrition management
- integrating diabetes technology with clinical care
- ensuring psychosocial care
- optimising transition and transfer of care.

CHAPTER 10

OPTIONS FOR IMPLEMENTATION OF A NATIONAL PAEDIATRIC DIABETES AUDIT IN IRELAND



CONTENTS >

CHAPTER 10: **OPTIONS FOR IMPLEMENTATION OF A NATIONAL PAEDIATRIC DIABETES AUDIT IN IRELAND**

The findings of the various components of the feasibility study were used to inform potential methodological models for conducting a national paediatric diabetes audit of paediatric diabetes in Ireland. As outlined in Chapter 8 of this report, no routinely collected dataset adequately fulfils the requirements of a national audit. Furthermore, as data relating to many metrics of interest are only available from patient notes, standardised and quality-assured data collection will be necessary. The options for the national audit that are outlined below were formulated based on the following parameters explored during the feasibility study:

- quality indicators most likely to guide quality improvement and quality assurance
- availability of standards of care for benchmarking
- data availability and accessibility and the legal basis for data processing
- burden of data collection on healthcare workers
- ability to incorporate existing data infrastructure into the audit design
- comparability with national paediatric T1DM audit in other jurisdictions.

All potential models were presented to the steering committee and consensus was then reached on the most viable and effective approach.

OPTION 1: AUDIT USING PSEUDONYMISED DATA COLLECTED WITHOUT CONSENT

Data are collected without consent in most existing NOCA national audits; patient-level data are pseudonymised at hospital level and submitted to NOCA for analysis and reporting. The data are collected via data-sharing arrangements between NOCA and participating units; NOCA is identified in HSE contracts with hospitals as an entity with which hospitals should work. The enabling conditions under article 9 of the current General Data Protection Regulation (GDPR) for the clinical audit data are: "9(2) (h) - processing is necessary for the purpose of preventative... medicine...the provision of health or social care or treatment or the management of health or social care systems and services" and "9(2) (i) necessary for ensuring high standards of quality and safety of care".

This is the gold standard approach for conducting a national audit, data can be collated from all relevant units with no risk of bias (e.g. if the clinician were to approach only certain patients to request consent) and a complete national picture can be provided that facilitates the universal application of system improvements. Families are informed of the audit and data usage via information leaflets and posters displayed in the units. Coordination of data input is conducted by audit coordinators within all units and facilitated by the development of an electronic tool for data submission.

Disadvantages to this approach include difficulties associated with double counting of some patients attending more than one unit (e.g. due to changing address, transferring to a second hospital, patients requiring medical attention while on holiday, etc.) and loss of potential future research opportunities where explicit consent is required. Furthermore, it will not be possible to 'follow the patient' and link data with other existing data sources, limiting the potential of the audit.

OPTION 2: AUDIT WITH REGISTER FUNCTIONALITY

The second potential approach is collection of a minimum core dataset for the purpose of audit using pseudonymised data as in option 1, and in addition seeking consent for patient information to be entered on a national register of paediatric T1DM patients. The advantage of this approach is that all patients are included in the audit phase of the process, which avoids drop-off because of the consent process. The establishment of a national register will ensure accurate information on patient numbers and outcomes, while the audit function provides buy-in from hospitals. A register without an audit function would require consent and would therefore not provide a complete national picture. Prospective data collection reduces errors resulting from inaccurate recording and missing data. Furthermore, because the register data are identifiable, it will be possible (with appropriate consent) to follow the patient and link their data with other relevant datasets. Use of the Individual Health Identifier (IHI) is the most efficient way to achieve linkages of KPIs from the audit with other process and structural metrics.

This model optimises the potential of the data collection by providing a framework for further quality improvement and research. It allows for a layered consent approach, which can be adapted to include additional consent requests for patients to be contacted later in relation to any future relevant research projects. This consent relates to contact only and does not constitute consent to any future research project. An additional advantage of a patient registry is the potential to contribute to patient education and communication by providing a platform for patients to receive online information, generate reminders, etc. A patient register will allow the impact of quality improvement measures and interventions to be tracked over time.

The greatest disadvantage of this approach is the significant effort that will be required to secure consent and ensure continued compliance with the GDPR. Patients will have to give consent again when they reach the age of 16 years.

Until systems are implemented that will facilitate the centralised collection of data, the basic core dataset will need to be extracted from routinely collected data (with consent). Audit coordinators will be required to upload the data into a web-based portal. Proposed data elements to be included in the minimum core dataset for the national audit are outlined in Table 10.1; they will be reviewed and refined during the audit development phase and will align with those collected in other jurisdictions (see Chapter 4). The data elements are included in a matrix with reference to the relevant standards and compared with the Hospital In-Patient Enquiry (HIPE), laboratory, and/or other datasets in order to aid data validation (see Chapter 9). The development phase of the audit will incorporate a gap analysis to ensure that relevant data can be collected across all sites. This ensures that the Irish national paediatric diabetes audit has a defined dataset that allows data sharing and cross-analysis comparison of processes and outcomes.

TABLE 10.1: PROPOSED MINIMUM CORE DATASET FOR THE NATIONAL PAEDIATRIC DIABETES AUDIT

Category	Variable
Demographics	Sex
	Ethnicity
	Date of birth
	Date of diagnosis/duration of diabetes
	County of residence; centre attended
Ambulatory care (calendar year)	Mean number of appointments per year Mean number of additional contacts per year
	Hospital emergency department visits for hypoglycaemia/ hyperglycaemia per year
	Hospital admissions for diabetes-related issue(s) per year
Treatment regimen	Pump/multiple daily insulin (MDI) (if pump device used, date of commencement)
	CGM/Flash Glucose Monitor usage (which device, date of commencing, linked to healthcare provider)
	Mean (median) annual HbA1c level (annual review)
Annual reviews	Comorbidity screening (coeliac screen, lipid profile, thyroid function tests (TFTs))
	Dietetic review
	Psychological assessment
	Structured education attendance
From the age of 12 years onwards	Diabetic RetinaScreen and retinopathy status
	Lipid profile check
	Blood pressure check
	Urinary albumin check

OPTION 3: NATIONAL AUDIT DATA COLLECTED VIA THE ELECTRONIC HEALTHCARE RECORD AND INTEGRATED INTO ROUTINE CLINICAL CARE

As delivery of healthcare services moves away from paper-based systems and towards digital systems, the optimal model for the national paediatric diabetes audit (NPDA) is that of collecting data via a national electronic healthcare record (eHR) integrated into routine patient care across centres. This is the most efficient and accurate method of data collection for this prospective audit.

An electronic data management system across all diabetes units would allow data collection at the source, reflecting real-time data that would be complete for the population and avoiding additional burden on already overstretched MDTs. Quicker access to complete, accurate information and streamlined processes can improve the quality of patient care and is recommended in the *National Model of Care for Paediatric Healthcare Services in Ireland* (HSE, 2015). The National eHR Programme aims to integrate patient data from operational systems across the entire continuum of care by relevant users, including the patients themselves, enabled by the IHI (eHealth Strategy for Ireland, DOH, 2013).

A key quality metric of the proposed NPDA is the patient's HbA1c level, and accurate collation of these data is critical for success. HbA1c data (point-of-care and laboratory values) at T1DM diagnosis, during the ambulatory care phase, and at transition need to be collected prospectively and systematically. A national eHR would facilitate this process most efficiently and enhance the value of the data by facilitating linkage of HbA1c data with other relevant information, including process metrics such as technology use, staffing, availability of the MDT, etc. This eliminates the need to seek permissions for linkage of KPIs to other external data sources. In the absence of an eHR, supports will be needed for laboratories and diabetes units to collate and extract HbA1c data systematically, and data management and data analytics expertise will be needed in order to analyse and report on the data.

The greatest drawback to this approach for the NPDA is the likely delayed implementation and rollout of a national eHR that is currently planned only in Children's Health Ireland (CHI). It is likely to be some time before this system is available for use in regional units outside of CHI. Using integrated modules would require hospitals' systems to develop the capability to interface with CHI systems.

An additional consideration is that use of a national eHR obviates initial contact with families and, as such, a process must be developed for contacting families with regard to consent for research purposes.

OPTION 4: AN 'OPT-OUT' VERSUS AN 'OPT-IN' REGISTER

This involves mandatory notification of patient data and requires legislation for exemption from the GDPR. The complexities and likely lengthy time frame involved in establishing the requirements for implementing the necessary legislation make this a difficult approach that is unlikely to be possible within the time frame of the eHR's national rollout.

CHAPTER 11
RECOMMENDATIONS OF THE NPDA FEASIBILITY STUDY STEERING COMMITTEE FOR THE NATIONAL AUDIT



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CHAPTER 11: **RECOMMENDATIONS OF THE NPDA FEASIBILITY STUDY STEERING COMMITTEE FOR THE NATIONAL AUDIT**

The purpose of the NPDA is to provide information that will improve care delivered to children with T1DM and their families. The audit will highlight areas of good practice, identify deficits, and promote improvement in the quality of care delivery and data-driven resource allocation.

Several potential models for audit methodology were reviewed in order to determine which would best satisfy these requirements. Options for the national audit (outlined in Chapter 10) were presented to the steering committee for consideration and consensus was reached on the most viable and appropriate model, after which recommendations for the national audit were agreed. It was the unanimous view of the committee that the NPDA would be facilitated using the IHI for all with T1DM and an electronic healthcare record for the purpose of data collection. Recognising the uncertainties relating to timelines and availability of the IHI the following recommendations were made with the caveat that the most appropriate option for the data collection would be scoped out further during the development phase of the audit.

The steering committee's recommendations for the NPDA are as follows:

1. A national audit of T1DM care is feasible in Ireland and should be implemented under the governance of NOCA. The recommended phases of implementation are:
   Phase 1: paediatric audit, including all patients with T1DM who are aged under 16 years attending all 19 paediatric centres nationally
   Phase 2: audit extended to include all patients with T1DM who are aged 16–25 years
   Phase 3: audit extended to include all patients with T1DM nationally.
2. The IHI should be made available for the purpose of the national audit in order to permit complete, accurate and timely collection of data. This will facilitate optimal use of existing data sources and reduce the burden on multidisciplinary teams delivering paediatric T1DM care. The preferred audit methodology is to collect data prospectively as part of clinical care using the electronic healthcare record (eHR).
3. A minimum core dataset should be collected on all patients with T1DM. As audit is key to quality improvement, until the eHR is available for all patients with T1DM, identifiable information (obtained with consent) should be collected electronically for a national register of patients with T1DM.

RECOMMENDATION 1

A national audit of paediatric T1DM is feasible in Ireland and should be implemented under the governance of the NOCA. The recommended phases of implementation are:

PHASE 1: paediatric audit including all patients with T1DM who are aged under 16 years attending all 19 paediatric centres nationally

PHASE 2: audit extended to include all patients with T1DM who are aged 16-25 years

PHASE 3: audit extended to include all patients with T1DM nationally

Rationale

- The incidence of T1DM among children and young people in Ireland is one of the highest in Europe (Gajewska *et al.,* 2020a; Roche et al., 2016).
- T1DM places a significant burden on healthcare systems with substantial economic impact resulting from hospitalisations for associated complications, which are a cause of considerable morbidity and mortality and negatively affect patients' quality of life.
- Optimal diabetes control markedly reduces the risk of diabetes-related complications, which are costly for the individual, the health service and society.
- In the *National Model of Care for Paediatric Healthcare Services in Ireland* (HSE, 2015) national management guidelines and KPIs are defined for T1DM.
- Data on the processes and outcomes of Irish paediatric T1DM care delivery, which are required for shaping quality improvement, are currently lacking. The development of an Irish national diabetes audit will characterise the care provided to children and adolescents living with T1DM at local, regional and national level and inform resource allocation and quality improvement initiatives.
- Rigorous governance structures are required in order to ensure sustainable national audit. NOCA provides the governance framework for a range of prioritised national clinical audits, standardised against national and international criteria, enabling the Irish healthcare system to continually improve its standards of care (NOCA, 2021).

What action should be taken?

- A national paediatric diabetes audit should be prioritised for funding and established under the governance framework of the National Office for Clinical Audit (NOCA).
- The development phase should include a scoping exercise to determine the most appropriate method of data collection, a pilot of the recommended data collection system, validation and reporting, stakeholder engagement, building and testing of IT solutions, management and governance, and development of policies and procedures to support the national audit.
- Implementation should include appointment of the audit team, communication with sites and the public and training of relevant personnel.

Who will benefit from this action?

- Young patients with T1DM, empowered by improvements in care and outcomes, will live healthier, productive independent lives with reduced risk of short- and long-term preventable diabetes related complications in line with Sláintecare objectives.
- Multidisciplinary teams will benefit from a national audit which will highlight areas of excellent practise, identify deficits in care delivery and make data driven recommendations for resource allocation and service provision. This will lead to improvements in quality of care and outcomes for paediatric patients with T1DM and reduce the workload associated with management of diabetes related complications.
- The health service will benefit from fewer costly hospital admissions and reduced burden of managing expensive preventable diabetes related complications (renal failure, cardiovascular disease, blindness, peripheral vascular disease, mental health burden).

Who is responsible for implementing this action?

- The National Steering Committee for Clinical Audit in the HSE OCCO is responsible for prioritising the commissioning and funding of the implementation of the national audit by NOCA.

When should this recommendation be implemented?

- Following publication of the Feasibility Study Report in 2022, the NPDA should move to the development phase without delay.

Evidence base for the recommendation

- *The A National Model of Care for Paediatric Healthcare Services in Ireland, Chapter 23 Paediatric Endocrinology and Diabetes Care* (HSE, 2015) details the requirements for providing optimal diabetes care based on availability of national and international standards and guidelines. Previous work has demonstrated variation in the delivery of care across centres in Ireland and suboptimal outcomes (Hawkes and Murphy 2014; Savage et al., 2008), and current gaps in resources for diabetes care delivery are outlined in this report (Chapter 6).
- Review of HbA1c data from international audits and registries showed the value of national audit in improving glycaemic control (Charalampopoulos *et al.,* 2018). Countries adopting a national audit of paediatric diabetes have demonstrated improvements in HbA1c levels which can lead to corresponding reductions in complications and hospital admissions (see Chapter 4 of this report).
- Population-based data provide information on the magnitude of public health problems and the effectiveness and equity of interventions. National data will facilitate the universal application of audit findings and comparison with international performance (Morrato *et al.,* 2007; Anderson *et al.,* 2005).

RECOMMENDATION 2

The IHI should be made available for the purpose of the national audit to permit complete, accurate and timely collection of data. This will facilitate optimal use of existing data sources and reduce the burden on multidisciplinary teams delivering paediatric T1DM care. The preferred audit methodology is to collect data prospectively using the electronic healthcare record (eHR).

Rationale

- Use of the IHI for patients with T1DM is the most efficient method of collating data from multiple sources and permits linkage of KPIs with other process and structural metrics, maximising the potential of the audit to identify areas for improvement.
- The optimal model for collection of data for a national clinical audit is through an eHR. This system is superior in terms of efficiency of collecting data, which are collected prospectively and are reliable, accurate and complete for the population. This has previously been implemented successfully for the care of patients with epilepsy via the epilepsy EPR (Fitzsimons et al., 2013)
- Use of an IHI and eHR for T1DM care delivery would align with the eHealth Strategy for Ireland, as recommended by a recent Health Information and Quality Authority (HIQA) report (HIQA, 2021) and with Sláintecare objectives.
- Chapter 4 of this report describes a number of international T1DM audit frameworks. Successful national audits of paediatric diabetes in other jurisdictions are based on electronic data collection that is either mandatory for the national diabetes audit or collected as part of routine clinical care.
- The eHR has the potential to expand in the future as the National eHR Programme ultimately aims to integrate patient data from operational systems across the entire continuum of care by relevant users, including the patients themselves, enabled by the IHI.

What action should be taken?

- A scoping exercise should be undertaken in the development phase of the audit to determine timelines on availability and accessibility of the IHI to facilitate the audit.
- Contingent on Recommendation 1, the Chair of the NPDA Governance Committee, Clinical Lead of the NPDA and NOCA should consult with the Access to Information & Health Identifiers Programme Division of the HSE's Office of the Chief Information Officer to determine the feasibility of using the IHI for the national audit.
- T1DM should be included on the eHR currently being planned for implementation in CHI, and subsequently in all units nationally. Until the eHR is extended to all units nationally, integrated standardised modules for incorporating T1DM data should be made available to all units providing care for patients with T1DM.

Who will benefit from this action?

- Patients with T1DM will benefit from improved patient safety promoted by use of a health identifier which permits accurate identification and linkage of patient information, reducing the risk of errors and facilitating quality improvement in care delivery.
- The diabetes multidisciplinary team will benefit from improved efficiency and accessibility of patient information. An efficient electronic data management system will facilitate day-to-day work and optimise potential for improving quality of patient care and outcomes.
- Audit coordinators and NOCA staff will benefit from the improved efficiency and accuracy of the dataset eliminating problems of double counting and allowing accurate linkage of data sources.

Who is responsible for implementing this action?

- The Office of the Chief Information Officer in the HSE has responsibility for the Health Identifiers Programme.
- The OCCO in the HSE is responsible for advocating for use of the IHI for the national audit.

When should this recommendation be implemented?

- The feasibility of using the IHI should be explored in the development phase of the audit, contingent on the implementation of Recommendation 1.

Evidence base for the recommendation

- The National Health Information Strategy 2004 and the report *Building a Culture of Patient Safety: Report of the Commission on Patient Safety and Quality Assurance* (Department of Health, 2008) recommend the introduction of a system for unique identification within the health sector in order to improve the quality and safety of patient care.
- A recent HIQA report (HIQA, 2021) outlined major deficiencies in the collection, use and sharing of health information, which is being managed on different electronic systems or using inefficient paper-based records, and the associated impact on patient safety. Lack of an operational IHI is highlighted as a fundamental shortcoming in the Irish healthcare system, and the role that the IHI played in COVID-19 and the rollout of the vaccination programme is proposed as an opportunity to build on that success.
- The national epilepsy electronic patient record (EPR) uses patient IHIs to link patient records and has demonstrated effectiveness in making performance management efficient and objective in addition to supporting clinical care (Ryan *et al.,* 2016; Fitzsimons *et al.,* 2013). The epilepsy EPR is currently used in 10 sites nationally and is continuously being enhanced, including the development of a patient portal, communication with general practitioners (GPs) via Healthlink, and data analytics visualisation. The Epilepsy Lighthouse Project, Providing Individualised Services and Care in Epilepsy (PISCES) (Epilepsy Ireland, n.d.), demonstrates how use of the eHR can help improve quality and safety in delivery of healthcare.
- The use of an IHI has been a key enabler of the success of national audits in other jurisdictions, such as Denmark (see Chapter 4 of this report).

RECOMMENDATION 3

A minimum core dataset should be collected on all patients with T1DM. As audit is key to driving quality improvement, until an eHR is available for all patients with T1DM, identifiable information obtained with consent should be collected electronically for a national register of patients with T1DM.

Rationale

- A minimum core dataset of information collected on all patients with T1DM will enable a complete national report on T1DM in Ireland. Data-sharing arrangements between NOCA and HSE hospitals permit the collection of pseudonymised data for the purpose of national audit. This enables the collection of population-based information on a minimum set of variables.
- In order to avoid problems of double counting and to permit linkage with other data sources, identifiable information is required. This will require consent but will support future research opportunities.
- A defined dataset aligned with data collected by audits in other jurisdictions would allow cross-analysis comparison of processes and outcomes. This will permit more detailed risk-stratified or intervention outcomes to be analysed and compared.
- To maximise the potential of the audit, the data collection should continue as patients transition to adult services. A national framework for transition of paediatric patients with T1DM to adult services is currently in development with the adult diabetes clinical programme. With consent, individuals recruited into phase 1 should continue on the register pending roll out of phase 2.

What action should be taken?

- The proposed minimum dataset will be defined in the audit development phase following further consultation with stakeholders.
- The development phase of the audit will incorporate a gap analysis in order to ensure that the relevant data can be collected across all sites and are comparable with international audits.
- Contingent on Recommendation 1, NOCA should engage with relevant sites to progress to the development stage of the NPDA, including piloting an online tool for data collection and establishing a process of obtaining consent for a national register.
- Following establishment of the audit in the paediatric units, and the availability of guidelines on transition, the audit should be extended to other units and age groups on a phased basis.
- To avoid duplication of data collection, NOCA should work with the ICDNR to align the goals, data collection and consent protocols of both registries. This work should be conducted as part of the development phase of the NPDA with a view to developing a system that will support the goals of both systems.

Who will benefit from this action?

- The use of routinely collected data will reduce the workload on audit coordinators.
- The completeness of the audit dataset for the population will permit universal application of audit findings.
- Patients aged over 16 years will benefit from extension of the scope of the audit to include patients who have transitioned to adult services.
- Patients who consent to their details being included in the national register may potentially benefit from additional services such as patient education initiatives and communication, and from reminders.

Who is responsible for implementing this action?

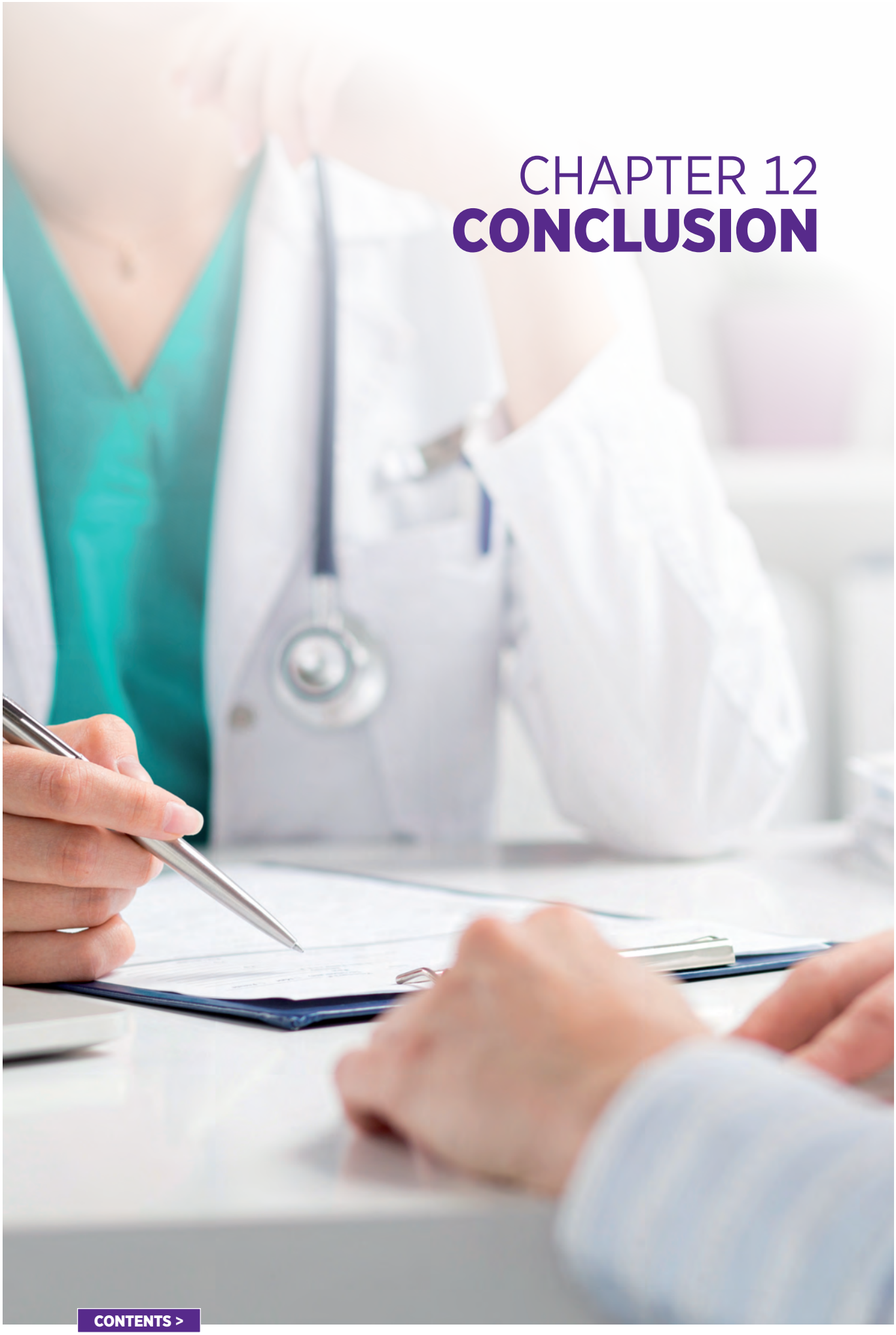
- The Governance Committee of the National Paediatric Diabetes Audit, together with NOCA are responsible for defining and implementing collection of the minimum core dataset for the national audit.

When should this recommendation be implemented?

- Piloting of the data collection for the national audit should be undertaken during the development phase of the audit as soon as possible after the audit is commissioned by the HSE. The minimum core dataset will be refined during the development phase prior to implementation.

Evidence base for the recommendation

- Routine population-based information is essential for informing policy decisions and evaluating their effectiveness, and aids generalisability of audit findings (Morrato *et al.,* 2007).
- HIQA's *Information management standards for national health and social care data collections* and *National Standards for Safer Better Healthcare* outline key principles for health information and seven dimensions contributing to data quality (HIQA, 2017; 2012). Complete, high-quality data are required to provide an accurate picture of care delivery, including identifying areas with high standards of care as well as providing opportunities for informing and implementing service improvements. Conversely, poor-quality data have a substantial impact on the safety of service users.
- Successful national audit of paediatric T1DM in other jurisdictions is based on the collection of identifiable information in order to achieve objectives.
- National registers have the added advantage of efficiently monitoring and reporting trends, identifying high-risk groups and enabling timely evaluation of interventions (Glicklich *et al.,* 2020).
- The eHR is currently being used successfully in Ireland for delivery of epilepsy care (*HSE Epilepsy Model of Care*, 2016)

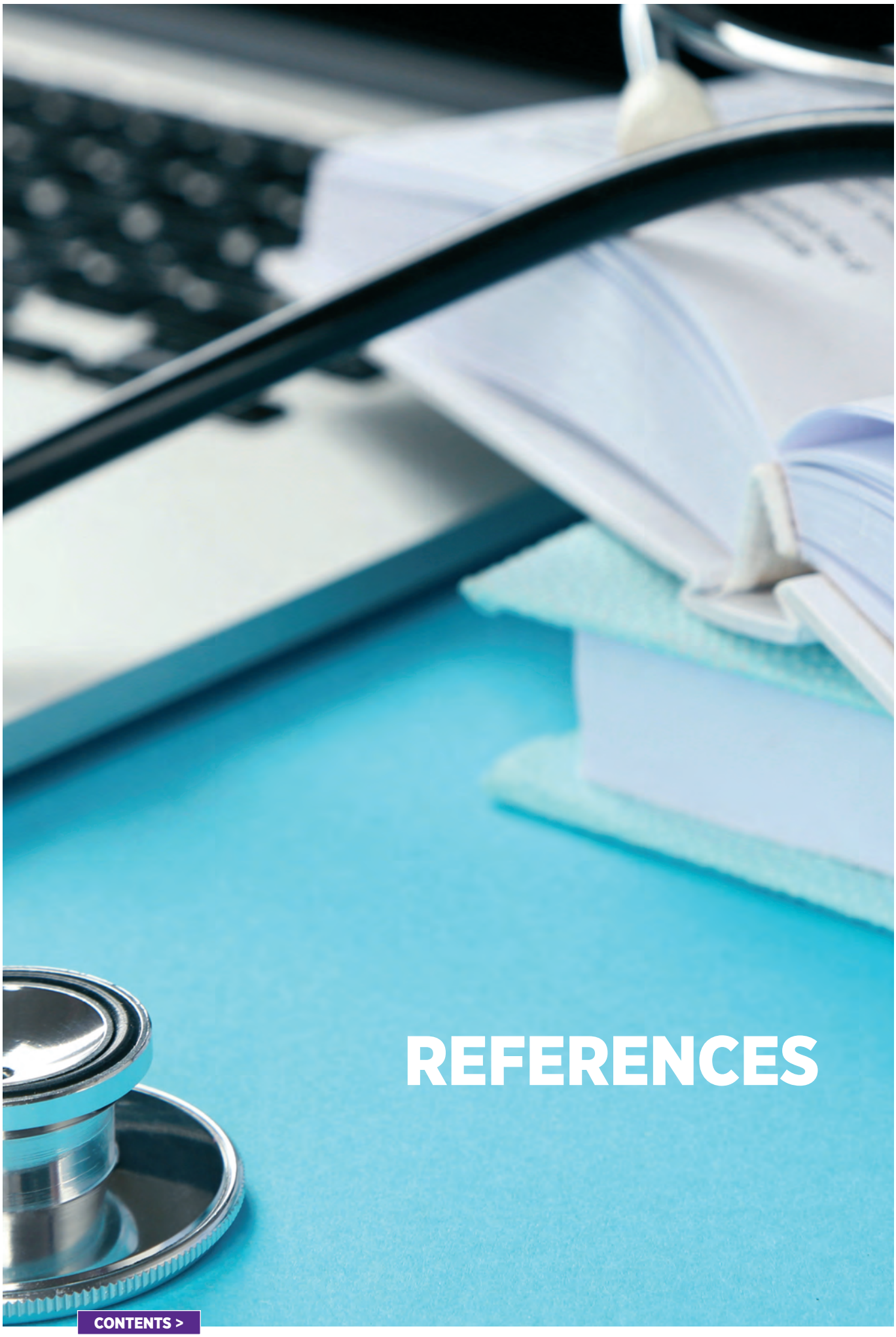


CHAPTER 12
CONCLUSION

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CHAPTER 12: **CONCLUSION**

This feasibility study demonstrates the value and urgent need for a national audit of paediatric diabetes care delivery in Ireland which is an outlier among European countries where national audit of paediatric T1DM is already well established. The report highlights variability in many aspects of care delivery nationally including multidisciplinary team resourcing and emphasises the need for continuous monitoring of outcomes to improve quality of care delivered to patients. The feasibility study group explored methodological options for the proposed national audit; the data elements required will be scoped out in the audit development phase and should incorporate information based on the patient and family experience (PREMS). The national audit should be embedded into clinical care with electronic data capture supported by a national IHI to facilitate linkage to relevant existing data sources. As audit is key to driving quality improvement, pending availability of the eHR for all patients with T1DM, a core dataset of identifiable information obtained with consent should be collected electronically for a national register.



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APPENDICES



CONTENTS >

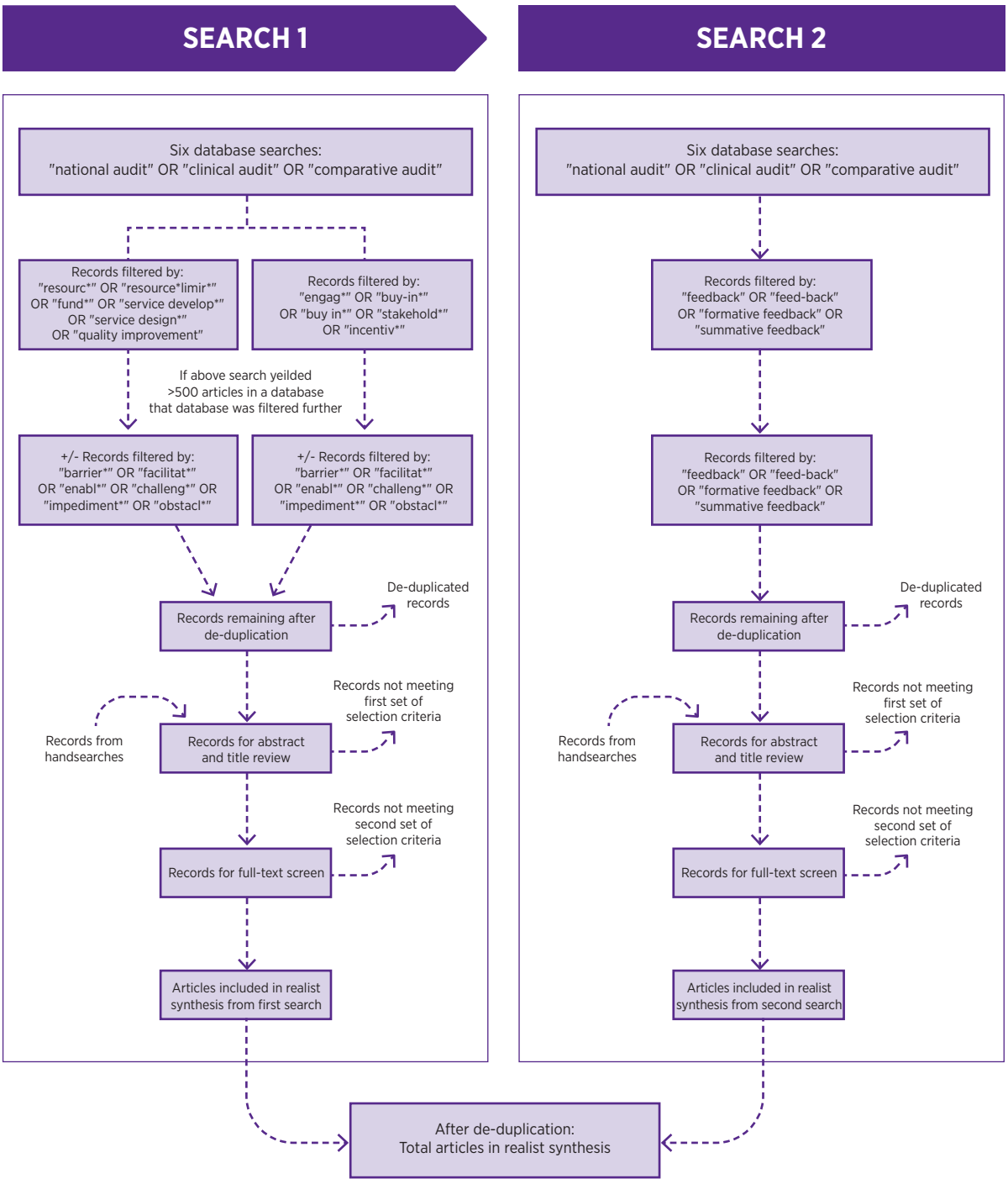
APPENDIX 1: LIST OF CONSULTATIONS

Consultation	Organisation	Objective	Date
Michael Sykes	National Diabetes Audit Quality Improvement Lead, Newcastle University	Quality improvement opportunities in a national audit of paediatric diabetes	20.11.2020
Prof. Justin Warner and Holly Robinson	National Paediatric Diabetes Audit (NPDA), United Kingdom (UK)	Discussion on experience of running the UK national audit and pitfalls experienced	10.12.2020
Aisling O'Leary and Catríona Ní Choitir	Hepatitis C Registry	Experience of using Primary Care Reimbursement Service (PCRS) data for the Hepatitis C Registry	08.03.2021
Prof. Edna Roche	Irish Childhood Diabetes National Register (ICDNR)	How the ICDNR will complement the NPDA and experience of using PCRS data for validation	09.03.2021, 21.05.2021
Neil O'Hare	Chief Information Officer, National Children's Hospital Group	Status of electronic healthcare record in Children's Health Ireland (CHI) and opportunities for audit	
Rita Brady	Hospital In-Patient Enquiry (HIPE) Manager, CHI at Temple Street	Possibilities of HIPE dataset for use in audit and coding admissions and procedures for patients with type 1 diabetes mellitus (T1DM)	15.03.2021
Jacqui Curley, Deirdre Murphy and Sinead O'Hara	Healthcare Pricing Office	Practicalities and limitations of HIPE data usage for the audit process	07.12.2021
Eilish Croke	National Quality Assurance and Improvement System (NQAIS) Programme Manager	Potential for use of NQAIS dataset for information on admissions and complications of patients with T1DM	13.05.2021
Brid Moran	National Office of Clinical Audit (NOCA) Information Governance Manager	Legal basis and obligations for collection of audit data	25.05.2021
Dr Maria Keogh and Marina Cronin	NOCA Deteriorating Patient Audit Feasibility Study	Approach and method of feasibility study, lessons learned	18.12.2020
Godfrey Fletcher and Laura Kirwan	Cystic Fibrosis Registry of Ireland	Securing consent of patients for a national register, factors influencing high coverage	20.04.2021
Dr Kate Mulvenna and Ger McClean	PCRS	Use of PCRS data for information on technology use by patients with T1DM, validation of audit data	24.06.2021

APPENDIX 2: NATIONAL PAEDIATRIC DIABETES AUDIT STEERING COMMITTEE MEMBERSHIP AND MEETING ATTENDANCE

Name	Organisation	Meeting 09.02.21	Meeting 29.06.21	Meeting 15.02.22
Prof. Nuala Murphy	Chair and National Clinical Lead for Paediatric Diabetes	✓	✓	✓
Dr Colin Hawkes	Consultant Paediatric Endocrinologist	✓	✓	✓
Dr Orla Neylon	Faculty of Paediatrics, Royal College of Physicians of Ireland	N/A	✗	✓
Prof. Neil O'Hare	Group Chief Information Officer at Children's Health Ireland	✗	✗	✓
Prof. Sean Dinneen	Clinical Lead for National Diabetes Clinical Programme	✗	✓	✓
Prof. Hilary Hoey	Diabetes Ireland, Public and Patient Interest – Advocacy	✓	✓	✓
Emer Gunne	Public and Patient Interest – Experience	✓	✓	✗
Prof. Edna Roche	Irish Childhood Diabetes National Register	✓	✓	✓
Donal Burke	Senior Pharmacist	N/A	✓	✓
Dr Jennifer Brady	Association of Clinical Biochemists in Ireland	✓	✓	✓
Dr Sinead McGlacken-Byrne	International Trainee Representative	✓	✓	✓
Dr Tracey Conlon	Education and Training Representative, Royal College of Physicians of Ireland	✓	✓	✓
Dr Niamh McGrath	Regional Diabetes Services Lead	✓	✓	✗
Aisling Egan	Clinical Nurse Specialist (CNS) in Paediatric Diabetes, Children's Health Ireland at Crumlin	✓	✓	✗
Conor Cronin/Laura Crowley	CNS in Paediatric Diabetes, Cork University Hospital	✓	✗	✓
Claire Maye	CNS regional diabetes unit	N/A	✗	✓
Dr Claire Crowe	Senior Clinical Psychologist	✓	✗	✗
Emer Dwyer	Paediatric Dietitian	N/A	✗	✗
Cliona McGarvey	National Office of Clinical Audit	✓	✓	✓
Karina Hamilton	National Office of Clinical Audit	✓	✓	✓
Jacqueline de Lacy	Programme Manager, National Clinical Programme for Paediatrics and Neonatology	✓	✓	✓
Cliodhna O'Mahony	Programme Manager, National Clinical Programme for Diabetes	✓	N/A	N/A

APPENDIX 3: REALIST SYNTHESIS SEARCH STRATEGY



APPENDIX 4: NOCA AUDIT FEEDBACK PROCESS

USER		DATA SOURCES	FORMAT
Service Providers	Hospital Units	Quarterly reports	Dashboards
	Hospital groups	Quarterly reports	Dashboards
	HSE	Annual national reports	Online/paper
	Department of Health	Annual national reports	Online/paper
Service Users	National Clinical Programmes	Annual national reports	Online/paper
	Patients and Families	Annual Summary reports	Online/paper
	General Public	Annual Summary reports	Online/paper
	Advocacy and PPI	Annual National and Summary reports	Online/paper

In addition to standard NOCA national annual reports, hospitals will receive quarterly reports on key quality indicators, identified during the audit development phase. With the implementation of the NOCA strategy 2021-2025, it is envisaged that individual hospitals will have access to interactive dashboards that will permit visualisation of this information when required. In addition to information on activity and KQIs for an individual hospital, the dashboards will also provide national data for comparison purposes. It may be possible to view data by hospital group in the future. Access to data on dashboards will be restricted to national data and the hospital's own data.

APPENDIX 5: ORGANISATIONAL SURVEY QUESTIONNAIRE

The National Office of Clinical Audit (NOCA) is carrying out a feasibility study for a national audit of paediatric diabetes (type 1 diabetes mellitus (T1DM) only). In order to ascertain the accessibility of data in each individual centre, we would appreciate if you could answer this questionnaire.

Q1. How many patients currently attend your service?

Q2. How many new patients did you have in 2020?

Q3. Do you have a dedicated consultant-led diabetes clinic? Yes/No

Q4. What consultant resources do you have involved in providing paediatric diabetes care? (Tick all that apply.)

- ☐ Consultant paediatric endocrinologist
- ☐ Consultant paediatrician with specific training in paediatric diabetes
- ☐ Consultant paediatrician who takes care of patients with diabetes as part of their role
- ☐ Consultant paediatricians who between them share the care of patients with diabetes as part of their roles

Q5. What resources do you have involved in providing paediatric diabetes care? (Tick all that apply.)

- ☐ Paediatric diabetes advanced nurse practitioner
- ☐ Paediatric diabetes clinical nurse specialist
- ☐ Adult diabetes clinical nurse specialist
- ☐ Paediatric diabetes dietitian
- ☐ Paediatric diabetes cover form, general paediatric service
- ☐ Paediatric diabetes social worker
- ☐ Paediatric social worker cover from general paediatric service
- ☐ Paediatric diabetes psychologist
- ☐ Paediatric psychologist
- ☐ Data manager
- ☐ Other (music therapy, art therapy)

Q6. Please specify whole time equivalent (WTE) for each available resource:

Consultant WTE

Specialist nursing WTE

Dietitian WTE

Social worker WTE

Psychologist WTE

Data manager WTE

Q7. How do you currently manage data? (Tick all that apply.)

- ☐ Diabetes information management system
- ☐ If yes, which one and which version
- ☐ Diamond (what version); Orion portal; SWEET; other
- ☐ Diabetes clinic database
- ☐ If yes, please specify (e.g. Microsoft Excel)
- ☐ Paper charts only
- ☐ Other (please specify)

Q8. Up to what age do you accept new referrals of patients with diabetes?

Q9. Where is glycated haemoglobin (HbA1c) measured at your hospital? (Tick all that apply.)

- ☐ Laboratory venous samples
- ☐ Laboratory capillary sample
- ☐ Point-of-care testing in diabetes unit
- ☐ If yes, is this report then available on the laboratory system?

  Other (please specify)

Q10. Do you currently audit HbA1c? Yes/No

If yes, please specify:

Q11. At what age (range) do you transition your patients with diabetes to adult services?

Q12. Where do you transition to? (List name(s) of hospital(s)/clinic(s).)

Q13. What is the transition process? (For the majority of patients, as it is understood that exceptions will arise.)

- ☐ Joint transition clinic
- ☐ If yes, clinics held jointly with adult and paediatrics before handover?
- ☐ Single handover joint clinic
- ☐ Referral by letter
- ☐ Other (please specify)

Q14. How many patients did you transition in 2020?

Q15. Is there any other issue/additional information that you wish to highlight in relation to your service

APPENDIX 6: LABORATORY SURVEY QUESTIONNAIRE

The National Office of Clinical Audit (NOCA) is carrying out a feasibility study for a national audit of paediatric diabetes. A key outcome metric is glycated haemoglobin (HbA1c) levels. In order to ascertain the accessibility of paediatric HbA1c and other annual review blood data (once consent has been obtained), we would appreciate if you could answer this questionnaire. It should take no more than 5 minutes.

Q1. Where is HbA1c measured at your hospital? (Tick all that apply.)

- ☐ Laboratory
- ☐ Point-of-care testing (POCT) in diabetes unit
- ☐ Both
- ☐ Other (please specify)

Q2. Please specify your laboratory HbA1c method:

Q3. For laboratory HbA1c testing, are results stored in the laboratory information management system (LIMS)?

- ☐ Yes
- ☐ No

Q4. What LIMS do you use, including version number?

Q5. Is it possible to search the LIMS to retrieve the following data specifically on patients with type 1 diabetes aged 0–18 years for a defined time period?

Name, date of birth, date of sample, HbA1c result in millimoles per mole (mmol/mol)

- ☐ Yes
- ☐ No

Q6. Please estimate the staff time that would be required to retrieve these data for a 1-year period.

Q7. Is it possible to search for and retrieve other annual bloods (tissue transglutaminase (TTG), lipids, albumin/creatinine ratio (ACR), thyroid function test (TFT)) or bloods at diagnosis (antibodies) on this same group of patients?

- ☐ Yes
- ☐ No

If yes, please comment on the complexity of doing this.

Q8. Can the data be exported to a Microsoft Excel spreadsheet?

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

Q9. Is any data manipulation required in order to make data readily usable?

- ☐ Yes
- ☐ No

If yes, please elaborate.

Q10. If you answered 'yes' to question 9, please estimate the staff time that would be required for data manipulation covering a 1-year period.

The following questions relate to HbA1c testing by point of care. Please leave blank if there is no paediatric HbA1c POCT at your site.

Q11. What is the name of the HbA1c POCT device?

Q12. When are point-of-care tests used?

- ☐ At every visit
- ☐ Interspersed with laboratory HbA1c
- ☐ Don't know

Q13. Are results of HbA1c POCT stored in your LIMS?

- ☐ Yes
- ☐ No

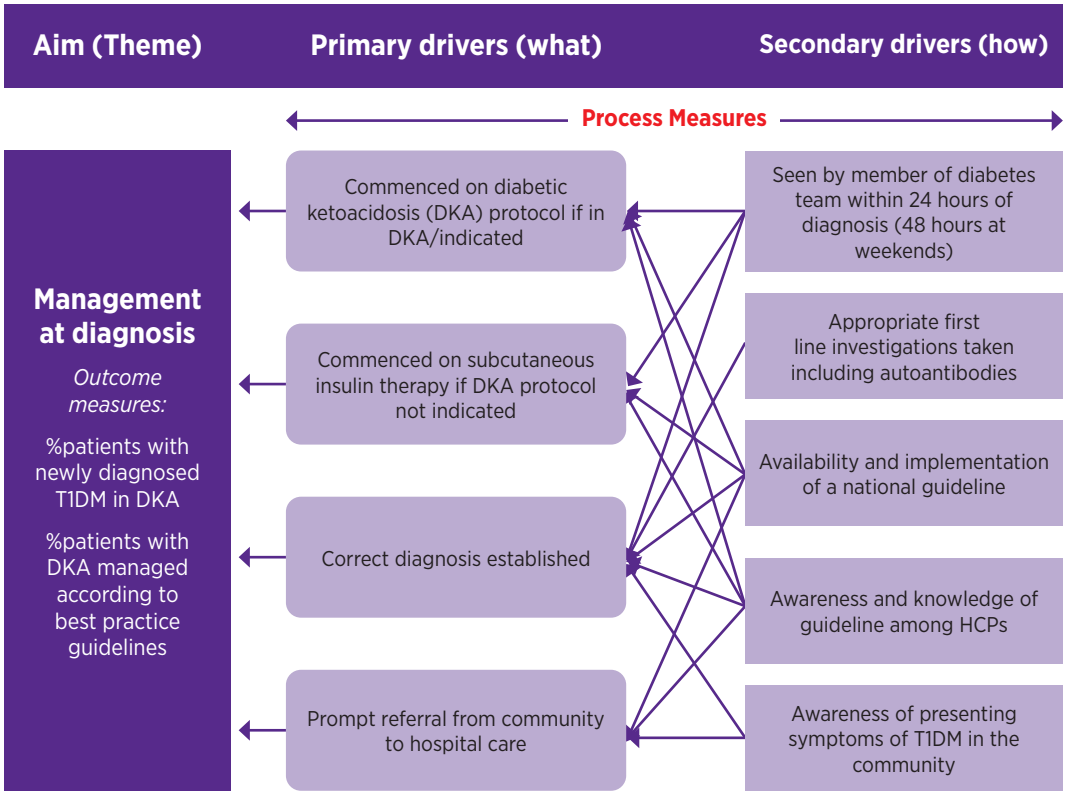
Q14. If you answered 'yes' to question 13, how are the results entered into the LIMS?

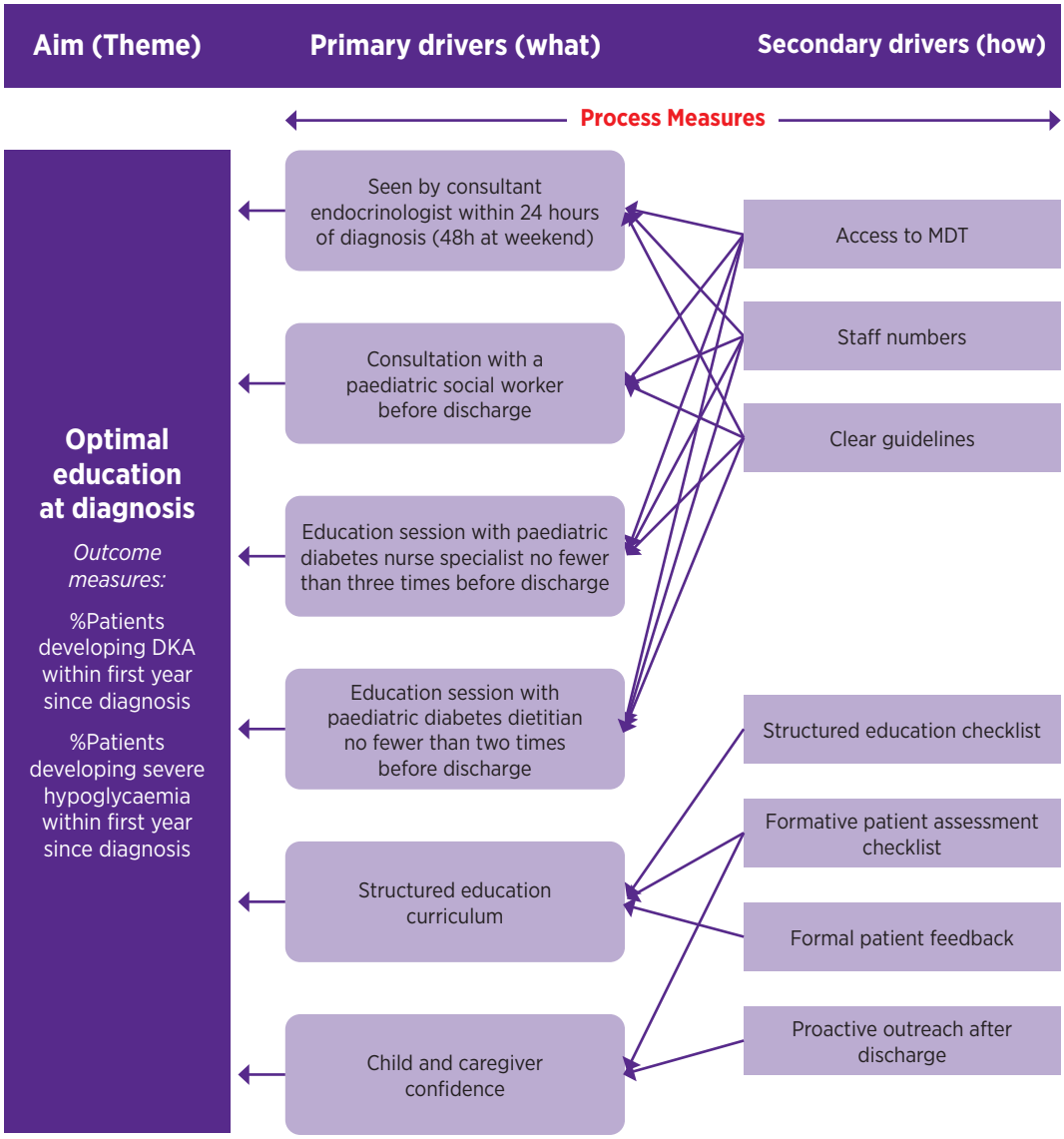
- ☐ Via an interface
- ☐ Manually

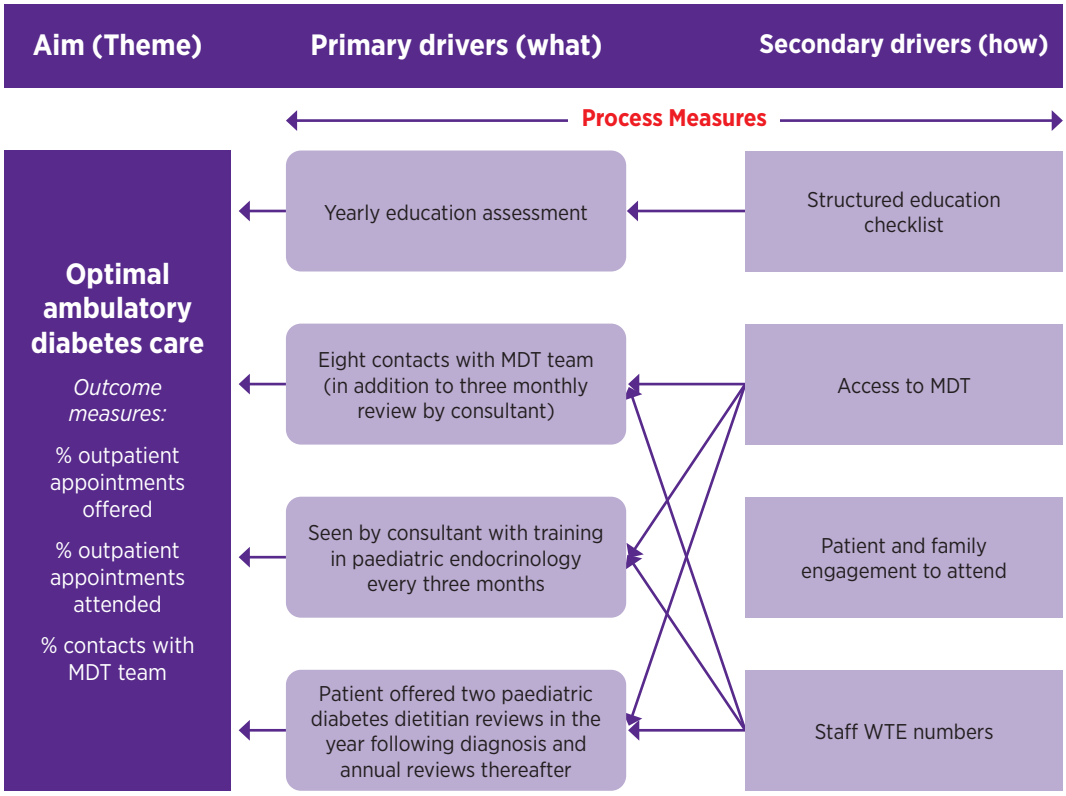
Q15. If you answered 'no' to question 13, where are POCT HbA1c results stored? (Tick all that apply.)

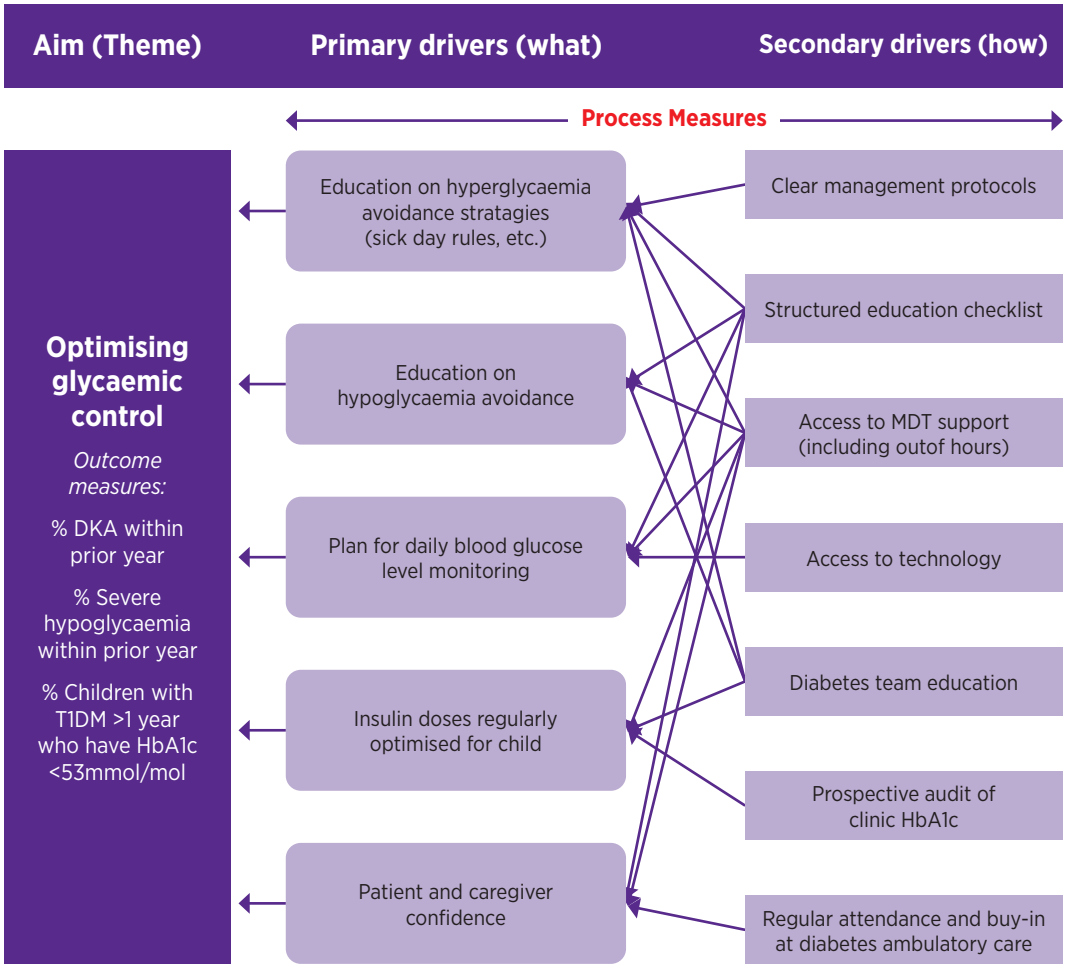
- ☐ In the patient chart
- ☐ On the POCT device (please specify time period of storage)
- ☐ In a local database (please specify who manages this database)
- ☐ Other (please specify)

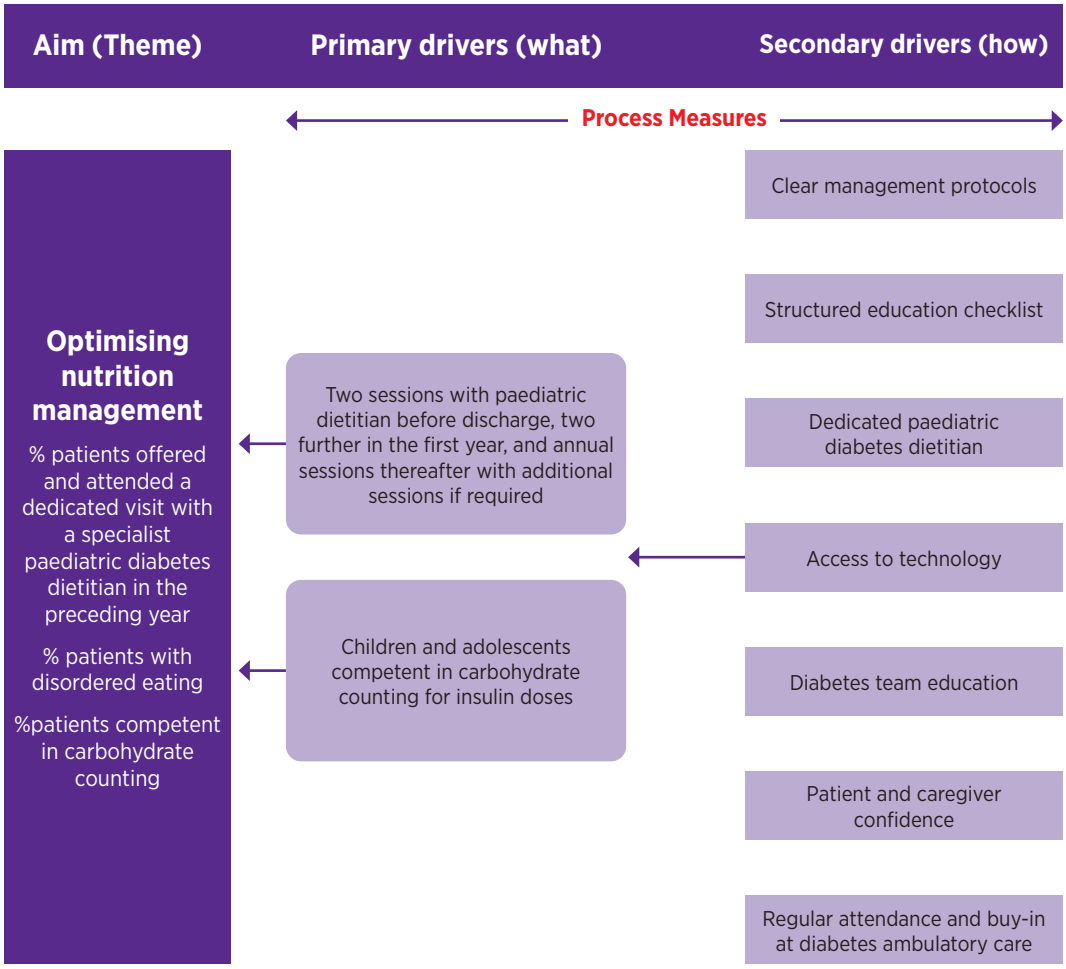
APPENDIX 7: DRIVER DIAGRAMS

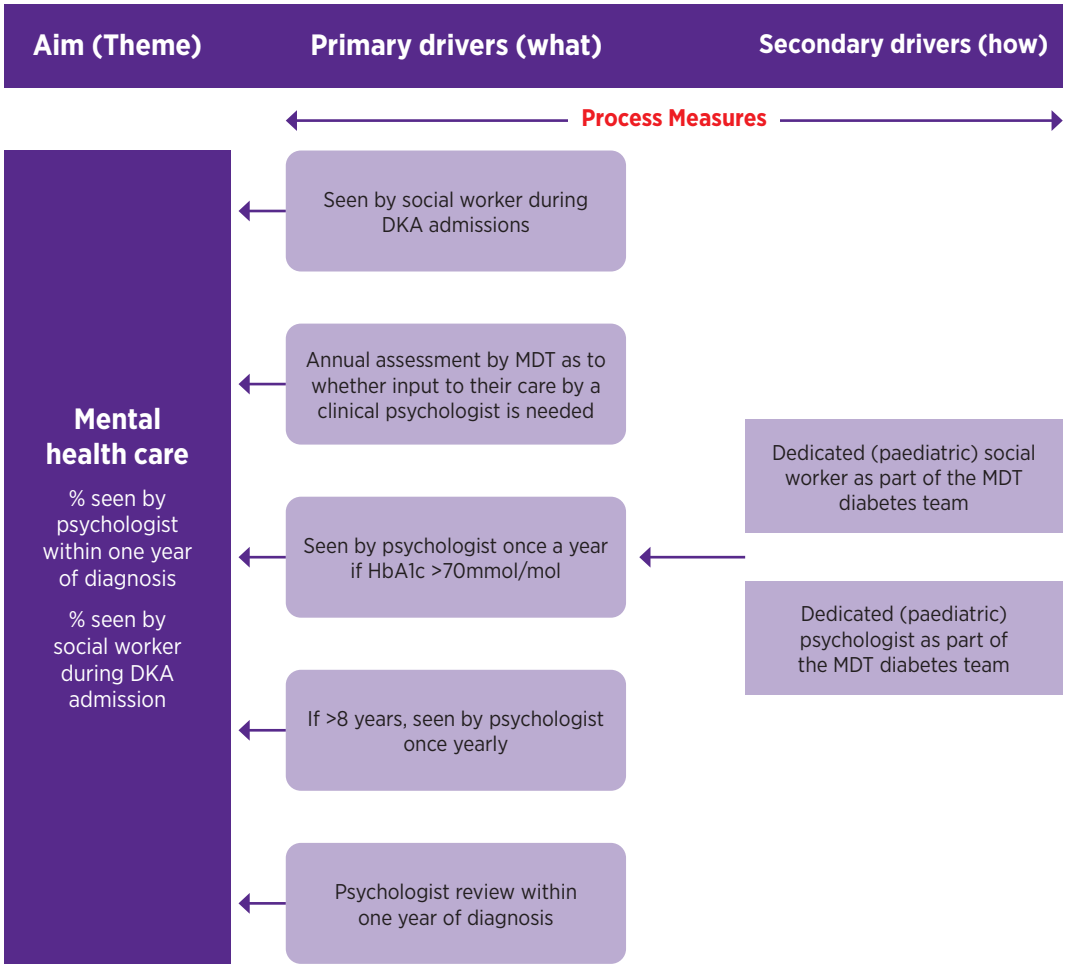


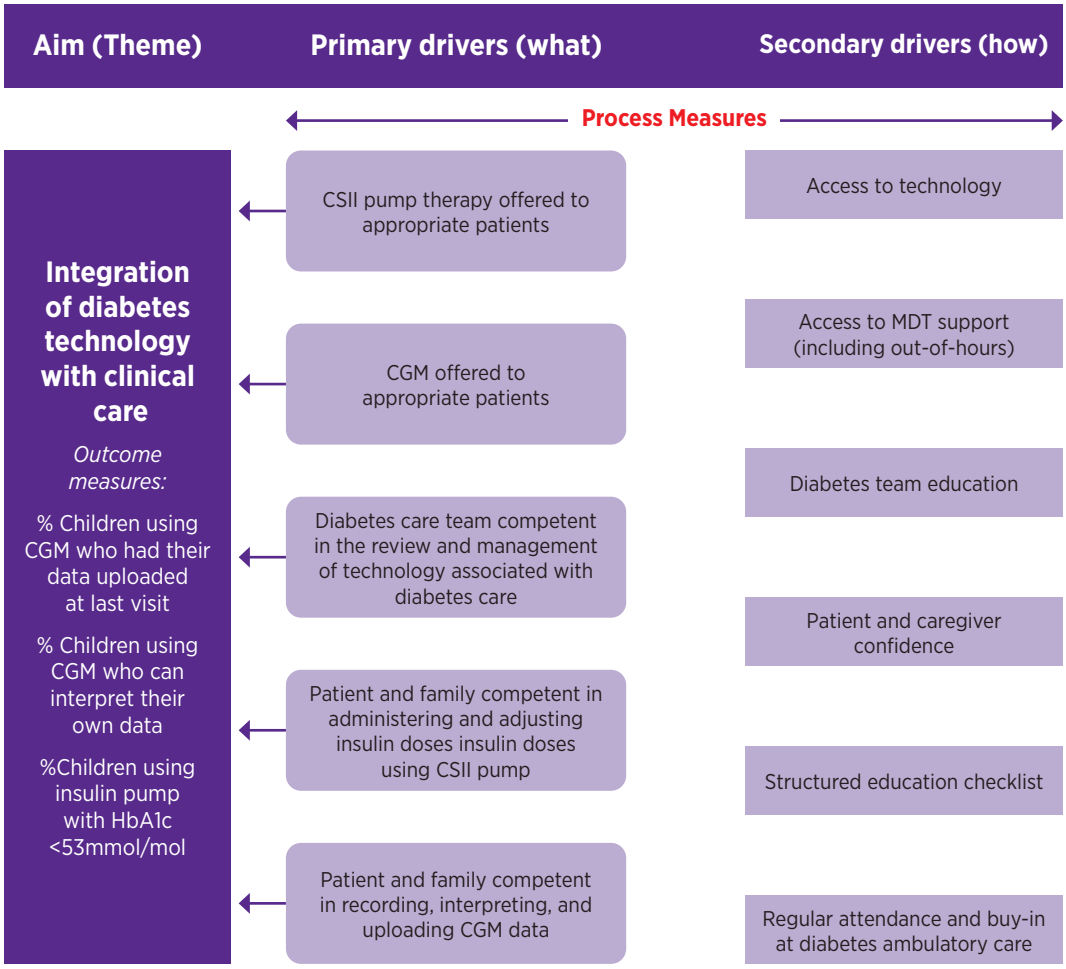

Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Optimal education at diagnosis
Outcome measures:
%Patients developing DKA within first year since diagnosis
%Patients developing severe hypoglycaemia within first year since diagnosis
Seen by consultant endocrinologist within 24 hours of diagnosis (48h at weekend)
Consultation with a paediatric social worker before discharge
Education session with paediatric diabetes nurse specialist no fewer than three times before discharge
Education session with paediatric diabetes dietitian no fewer than two times before discharge
Structured education curriculum
Child and caregiver confidence
Access to MDT
Staff numbers
Clear guidelines
Structured education checklist
Formative patient assessment checklist
Formal patient feedback
Proactive outreach after discharge

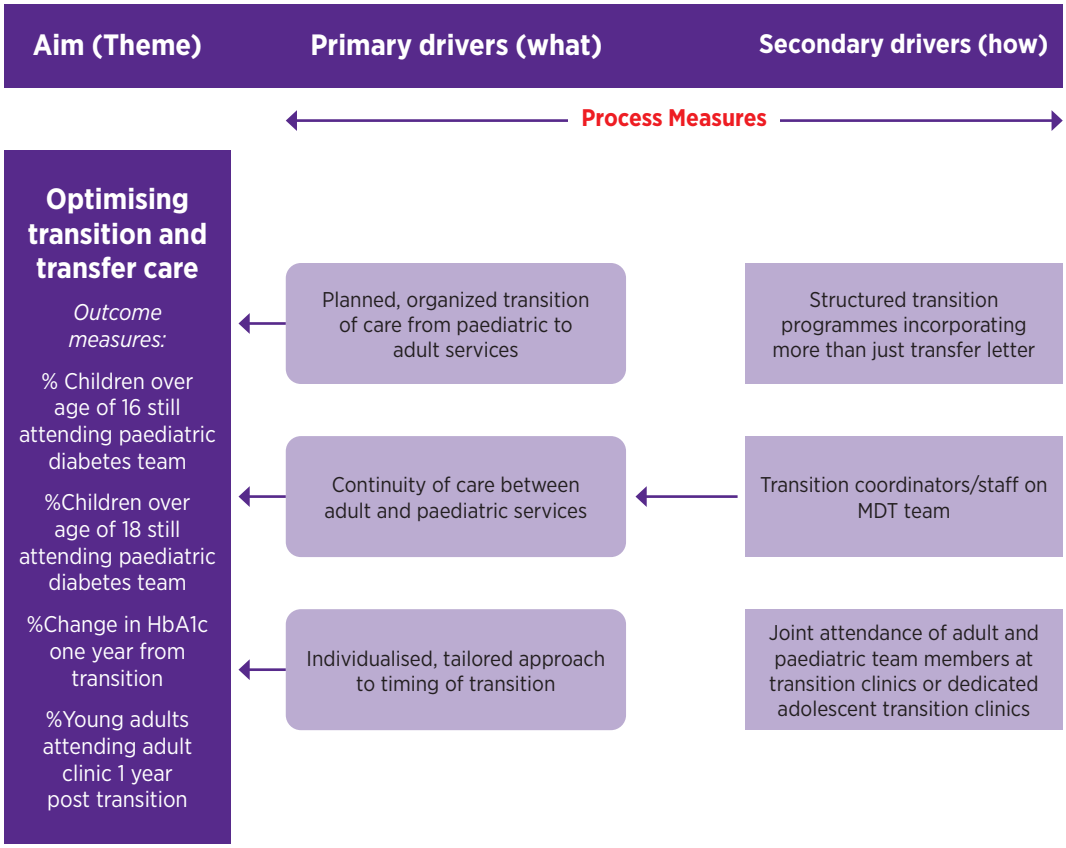

Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Optimal ambulatory diabetes care
Outcome measures:
% outpatient appointments offered
% outpatient appointments attended
% contacts with MDT team
Yearly education assessment
Eight contacts with MDT team (in addition to three monthly review by consultant)
Seen by consultant with training in paediatric endocrinology every three months
Patient offered two paediatric diabetes dietitian reviews in the year following diagnosis and annual reviews thereafter
Structured education checklist
Access to MDT
Patient and family engagement to attend
Staff WTE numbers

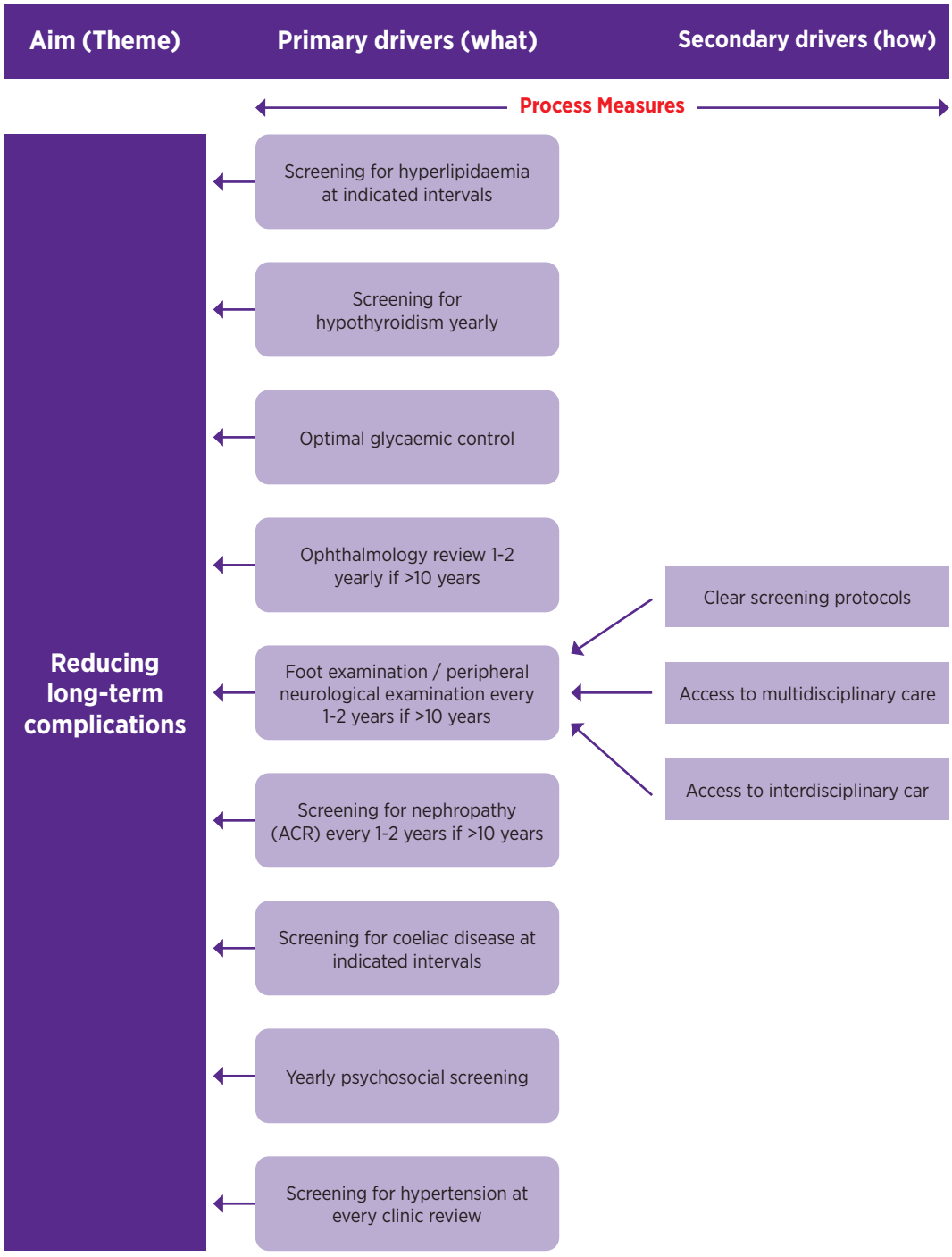

Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Optimising glycaemic control
Outcome measures:
% DKA within prior year
% Severe hypoglycaemia within prior year
% Children with T1DM >1 year who have HbA1c <53mmol/mol
Education on hyperglycaemia avoidance stratagies (sick day rules, etc.)
Education on hypoglycaemia avoidance
Plan for daily blood glucose level monitoring
Insulin doses regularly optimised for child
Patient and caregiver confidence
Clear management protocols
Structured education checklist
Access to MDT support (including outof hours)
Access to technology
Diabetes team education
Prospective audit of clinic HbA1c
Regular attendance and buy-in at diabetes ambulatory care


Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Optimising nutrition management
% patients offered and attended a dedicated visit with a specialist paediatric diabetes dietitian in the preceding year
% patients with disordered eating
%patients competent in carbohydrate counting
Two sessions with paediatric dietitian before discharge, two further in the first year, and annual sessions thereafter with additional sessions if required
Children and adolescents competent in carbohydrate counting for insulin doses
Clear management protocols
Structured education checklist
Dedicated paediatric diabetes dietitian
Access to technology
Diabetes team education
Patient and caregiver confidence
Regular attendance and buy-in at diabetes ambulatory care


Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Mental health care
% seen by psychologist within one year of diagnosis
% seen by social worker during DKA admission
Seen by social worker during DKA admissions
Annual assessment by MDT as to whether input to their care by a clinical psychologist is needed
Seen by psychologist once a year if HbA1c >70mmol/mol
If >8 years, seen by psychologist once yearly
Psychologist review within one year of diagnosis
Dedicated (paediatric) social worker as part of the MDT diabetes team
Dedicated (paediatric) psychologist as part of the MDT diabetes team


Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Integration of diabetes technology with clinical care
Outcome measures:
% Children using CGM who had their data uploaded at last visit
% Children using CGM who can interpret their own data
%Children using insulin pump with HbA1c <53mmol/mol
CSII pump therapy offered to appropriate patients
CGM offered to appropriate patients
Diabetes care team competent in the review and management of technology associated with diabetes care
Patient and family competent in administering and adjusting insulin doses insulin doses using CSII pump
Patient and family competent in recording, interpreting, and uploading CGM data
Access to technology
Access to MDT support (including out-of-hours)
Diabetes team education
Patient and caregiver confidence
Structured education checklist
Regular attendance and buy-in at diabetes ambulatory care


Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Optimising transition and transfer care
Outcome measures:
% Children over age of 16 still attending paediatric diabetes team
%Children over age of 18 still attending paediatric diabetes team
%Change in HbA1c one year from transition
%Young adults attending adult clinic 1 year post transition
Planned, organized transition of care from paediatric to adult services
Structured transition programmes incorporating more than just transfer letter
Continuity of care between adult and paediatric services
Transition coordinators/staff on MDT team
Individualised, tailored approach to timing of transition
Joint attendance of adult and paediatric team members at transition clinics or dedicated adolescent transition clinics


Aim (Theme)
Primary drivers (what)
Secondary drivers (how)
Process Measures
Reducing long-term complications
Screening for hyperlipidaemia at indicated intervals
Screening for hypothyroidism yearly
Optimal glycaemic control
Ophthalmology review 1-2 yearly if >10 years
Foot examination / peripheral neurological examination every 1-2 years if >10 years
Screening for nephropathy (ACR) every 1-2 years if >10 years
Screening for coeliac disease at indicated intervals
Yearly psychosocial screening
Screening for hypertension at every clinic review
Clear screening protocols
Access to multidisciplinary care
Access to interdisciplinary car

APPENDIX 9: COST ESTIMATE FOR DEVELOPMENT PHASE OF A NPDA WITHIN NOCA

Cost items	Detail	Estimated costs (€ per annum)
Human Resources	Audit manager (1 FTE)	€90 000.00
	Data analyst (1/5 WTE): Support dataset development; lead data cleansing and validation; analysis of findings, provision of health service provider reports, overall findings report	€15 000.00
	Technical analyst (1/5 WTE)	€19 000.00
Communications	Facilitate focus groups with patient groups	€10 000.00
	Lead public engagement on audit	
	Information leaflets	
	Audit pilot information pack for health service providers	
	Lead clinical engagement – conferences, meetings, etc.	
	Development of local reports – dashboard	
	Development of national report	
Total		**€134 000.00**

FTE: full-time equivalent
WTE: whole time equivalent

The costs of audit implementation will be established during the audit development phase. Costs will depend on data collection decisions and data management requirements as well as data processing and reporting. Clinical audit presents information on current practices, highlighting areas for improvement to improve patient outcomes. Optimising diabetes control has been definitively shown to reduce the incidence of short and long term preventable diabetes related complications, which result in large healthcare costs. Investing in audit to improve patient outcomes will therefore result in cost saving for the health service.

National Office of Clinical Audit

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