



**SCALING UP HEALTH
SERVICES FOR TYPE 1
DIABETES IN INDIA**

**TOWARDS A STRATEGY
TO TRANSITION TO
SUSTAINABILITY OF
PROGRAMMES
SUPPORTED BY CDIC IN
INDIA**

PREPARED BY
HEALTH SYSTEMS INNOVATION LAB
AT HARVARD UNIVERSITY



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About the report

This report, “Scaling up Health Services for Type 1 Diabetes in India: Towards a strategy to transition to sustainability of programmes supported by CDIC in India”, was developed under the guidance of Professor Rifat Atun, Professor of Global Health Systems at Harvard University and Director of the Health Systems Innovation Lab, and implemented by a team consisting of Dr Che L. Reddy, Associate Director *Health Systems Innovation Lab, Harvard University*, Zia Shakir, Research Scholar at *Health Systems Innovation Lab, Harvard University*, and Meghna Raman, Research Scholar at *Health Systems Innovation Lab, Harvard University*, and Anne Sofie Olsen who provided valuable comments. The analytical framework used in this report is drawn from earlier research and engagement with major global health initiatives led by Professor Rifat Atun at the Health System Innovation Lab.

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Executive Summary

In 2021, health systems missed an estimated one-half of the approximately 355,900 new cases of Type 1 diabetes (T1D) worldwide. As the number of incident cases is projected to increase to 476,700 by 2050, countries like India must invest in health systems to scale up high-value health services¹ for children and adolescents with T1D to prevent avertable deaths and improve care outcomes.

Since its inception in India in 2011, Changing Diabetes in Children (CDIC) has contributed towards expanding access to equitable health services for T1D, helping to reach 5951 children, the most in number of any CDIC collaborating country. There is a major opportunity to build on the existing CDIC platform to scale up access to high-value health services for T1D and contribute to advancing the goal of Universal Health Coverage (UHC) in India's transition to a high-value health system model by achieving the quadruple objectives of equity, efficiency, effectiveness, and responsiveness at the population level.

Conventional approaches to transition management overly focus on financial aspects to the detriment of sustainability in health systems. This report aims to inform a structured and evidenced-based process to scale up CDIC programmes in India, using a framework that is anchored in health systems, and contribute to existing policies, programmes, and initiatives to strengthen India's health system. We apply an analytical framework developed by the Health Systems Innovation Lab at Harvard University (HSIL) for CDIC to assess readiness to transition, inform strategic transition management, and achieve its sustainability objectives.

The report uses a mixed-method approach to generate and triangulate data from three sources: (I) surveys, (II) interviews of key opinion leaders, and (III) desk research. The adapted survey tool comprised 47 questions (33 integration and 14 receptivity questions). Interviews were conducted with key stakeholders, and a review of relevant studies and literature was undertaken to explain differences in data or opinion emanating from the survey and interviews or to examine emerging entanglements in more depth.

¹ A high value health service refers to both individual (medical care) and population level services (public health interventions) delivered by a health system effectively, efficiently, equitably and responsibly to improve health outcomes, user satisfaction and financial protection in relation to T1D.

The readiness to transition analysis revealed both low integration and low receptivity of the CDIC programme in India, indicating that efforts to promote receptivity and integration are required to accelerate the transition of programs supported by CDIC to sustainability in India. In terms of integration, the CDIC programme was well integrated with the health system for service delivery and monitoring and evaluation, moderately well integrated for resource management and financing, but not integrated to any significant extent in terms of governance and planning. The receptiveness assessment revealed a receptive health system context to transition CDIC to sustainability, but the adoption system was not sufficiently receptive to promote integration and transition to sustainability. Concerning the CDIC problem-solution fit, there were substantial opportunities to align health services for T1D (that benefit from CDIC support) optimally to the problem of T1D, as articulated by key stakeholders involved in CDIC.

Three approaches—(I) enhance integration; (II) promote receptivity; (III) expand integration and promote receptivity—could be pursued as part of a transition management strategy to advance the sustainability of CDIC-India within the health system and to align with Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PM-JAY) in India. We discuss these three approaches and outline a five-step strategy that could be implemented within CDIC to ensure sound transition management and broader sustainability in line with the expectations of critical stakeholders, beneficiaries, and health system demands. Finally, we model the additional budgetary room required to expand access to a benefits package within PM-JAY for T1D under three scenarios of scale and scope, which indicate a need for additional funding ranging from 0.2% (essential package) to 1.3% (comprehensive package) of the current national health budget.

Section 1: Introduction

1.1 Background and Overview

In 2021, an estimated one-half of the 355,900 new cases of Type 1 Diabetes (T1D) in children and adolescents were not diagnosed in health systems globally.¹ In Southeast Asian countries such as India, estimates suggest that health systems miss more than 65% of new cases of T1D.¹ As the number of incident cases is projected to increase to 476,700 by 2050, it is imperative that countries like India invest in health systems to scale-up health services for T1D to improve outcomes.¹

Since its inception in India in 2011, the Changing Diabetes in Children (CDIC) initiative has made a major contribution to expanding access to equitable health services for children and adolescents with T1D, helping to reach 5951 children, the most in number among the CDIC collaborating countries. There is a major opportunity to build on the existing CDIC platform—and develop a clear process for transition management throughout the Global Collaborative for Changing Diabetes in Children (GC-CDIC)²—to scale up access to high-value health services for T1D³ and contribute meaningfully towards the introduction of Universal Health Coverage (UHC) in India.^{4,5}

This report presents a systematic analysis of transition of the CDIC programme in India. Using a five-step process, we apply an analytical framework developed by the Health Systems Innovation Lab at Harvard University (HSIL) for CDIC to assess readiness to transition and to inform transition management and scale-up of services for T1D in India and other CDIC collaborating countries.^{2,6}

This report is organised into four sections. In section one, we discuss the importance of sustainability in the context of T1D healthcare in India, introduce the HSIL analytical framework and discuss the study methodology. Section two discusses the salient study findings and summarises the empirical evidence concerning each sustainability component. In section three, we analyse the results of the transition readiness assessment in CDIC supported and non-CDIC supported centres and explore Kerala state's Mittayi initiative as a case study to inform transition management in other states in India or other CDIC collaborating countries. In section four, we discuss pathways that CDIC could use to develop a transition management strategy, promote the

sustainability of programmes supported by CDIC in India, and contribute towards the country's progress towards achieving its health system objectives within PM-JAY.

1.2 Defining Sustainability

Sustainability of health programmes that benefit from external support is often presented as an aspiration. Sustainability is widely used as a catchphrase in global health systems, along with 'transition' and 'graduation' from external support.

Conventional approaches to transition management tend to emphasise the financial dimension of sustainability where countries reaching a certain level of per capita income (typically from a low-income and low-middle-income to upper-middle-income country category) are considered 'ready to transition' or 'to graduate' from international support or Overseas Development Assistance for health. This approach is too narrow as it does not consider readiness of the programme to continue to operate without support and the extent to which the programme is integrated with the health system to ensure continuity of care.

We adopt a more holistic view and define sustainability broadly as the degree to which a health programme that benefits from external support (e.g., CDIC) gradually integrated with the health system to provide high-value health services. In the context of T1D, high-value health services equate to the provision of health services (at the population and individual level) delivered effectively, equitably, efficiently, and responsively to meet population-level needs at scale.

A sound transition management process must build and strengthen the requisite health system capabilities, functions, structures, and processes to achieve the overarching sustainability goal. However, sustainability must also reflect the priorities of actors in the health system, particularly those involved in the delivery of health services; other vital groups include, among others, patients, policymakers, funders, and regulators. As part of developing the report, several consultative discussions were held with collaborators involved with CDIC India and leading clinicians who actively manage a major share of the children and adolescents with T1D in India to understand their sustainability objectives and jointly develop the study methodology.

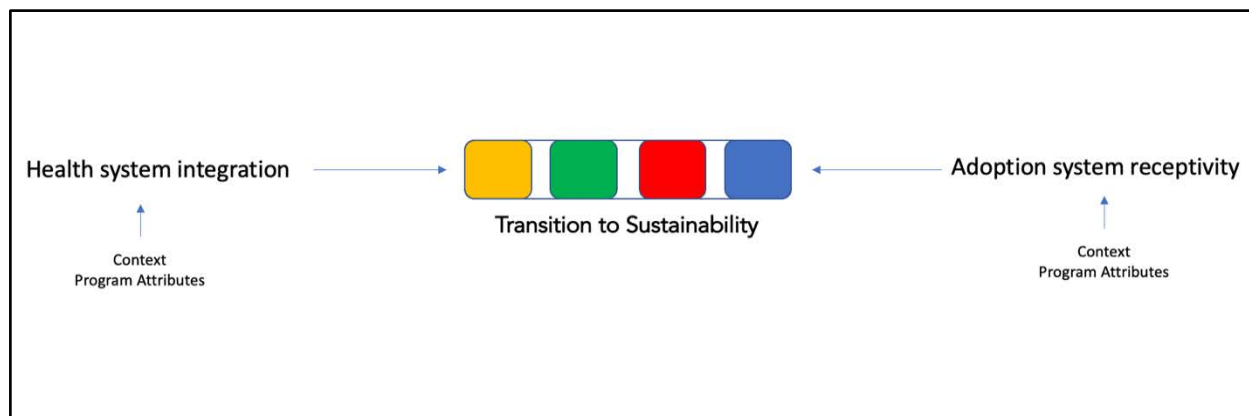
1.3 HSIL Analytic Framework for Assessing Transition Readiness

The HSIL sustainability framework provides an empirically grounded approach,⁶ informed by theory in comparative health systems and integration of innovations into health systems,^{4,7,8} to ascertain the sustainability of programmes benefitting from external support. The framework consists of two analytic components (Figure 1) and is implemented through a five-step process (Figure 26; discussed in detail and applied in section three):

- (I) Integration: the nature of interaction and extent of integration of the CDIC programme with the health system;
- (II) Receptivity: the degree of receptivity of the dominant actors in the adoption system of the health system to the CDIC programme;
- (III) Context and CDIC programme attributes: the degree to which relevant contextual factors and complexity of the CDIC programme influence integration and receptivity.

We analysed these components to ascertain the readiness of CDIC supported programmes in India to transition to sustainability, inform a health systems approach to CDIC’s sustainability, and align CDIC with broader efforts to strengthen India’s health system and to achieve UHC.

Figure 1: Conceptual Framework to Analyse the Transition to Sustainability



Source: Reddy CL, Atun R. Rethinking Transition to Sustainability: A Health Systems Approach. Health Systems Innovation Lab, Harvard University, MA. 2022

1.4 Study Methodology

This mixed-methods study was conducted in three stages: 1) study co-design; 2) study implementation, and; 3) study analysis and reporting. The study used a survey, interviews, and desk research to support data triangulation and to understand concepts and empirical data from multiple perspectives.

1.4.1 Study Co-design

Co-design of the study consisted of consultative meetings between the HSIL and the CDIC-India team. These consultative meetings served two primary purposes. First, the discussions permitted time and space to refine the purpose of the study and how the process could be used to define what sustainability constituted in the Indian context. Second, once there was consensus that this process would be beneficial in advancing the defined sustainability objectives, the meetings enabled the team to revisit the HSIL framework and discuss how it could be tailored to the Indian context and the design of CDIC supported programmes in India.

These discussions informed a structured process of framework and tool adaptation. Adaptation entailed testing the survey tool with several clinicians, using their feedback to revise specific questions concerning each component, and including additional questions to complement the original indicators. Each question and response were discussed considering its utility to inform our understanding of the sustainability of CDIC in the context of India and how health services for T1D are delivered. The adapted survey tool consisted of 47 questions, with 33 questions related to integration and 14 for receptivity (Appendix A).

1.4.2 Study Implementation

The HSIL sustainability tool ascertains transition readiness along the two overarching forces influencing sustainability by completing a survey on integration and receptivity. The survey was delivered through Harvard Qualtrics© and shared by CDIC India with all CDIC facilities and

within the CDIC clinician network to other non-CDIC supported centres that provide health services for T1D.

During the consultation meetings, it became evident that it would be prudent to understand how non-CDIC supported centres deliver health services for T1D to inform a more holistic account of CDIC sustainability in the health system context. While the survey was administered, HSIL team interviewed CDIC-affiliated clinicians to understand the barriers and enablers to CDIC sustainability. The HSIL team was guided on whom to interview by the CDIC India team. Six Interviews were conducted in Kannada, Tamil and Telegu and recorded using Zoom Cloud© provided by Harvard University.

1.4.3 Study Analysis and Reporting

All survey data were collected and pooled in Qualtrics©. Data from 70 purposively sampled respondents to the survey were analysed using Microsoft Excel version 16.67. The data for each question was cleaned and presented visually. The HSIL team then discussed the data for each question, the optimal way to present the data, and the critical data to include in the report (Appendix B).

All data gathered from multiple sources were used to calculate and generate a readiness to transition score for integration and receptivity. The integration and receptivity scores were then used to map CDIC-India in terms of its readiness to transition using spider diagrams to reveal integration and receptivity strengths and vulnerabilities. The HSIL team discussed the analysis to identify pathways that CDIC could use to promote the transition to sustainability. Desk research was conducted by the HSIL team in consultation with the CDIC India team (who engaged relevant stakeholders directly involved in healthcare service provision for T1D) when data was unavailable from the survey, to supplement data, or to elaborate on key insights that emerged from the interviews. All findings were discussed, reviewed, and synthesised into this report, which should be used to inform a transition management plan.

Section 2: The Transition to Sustainability Readiness Assessment

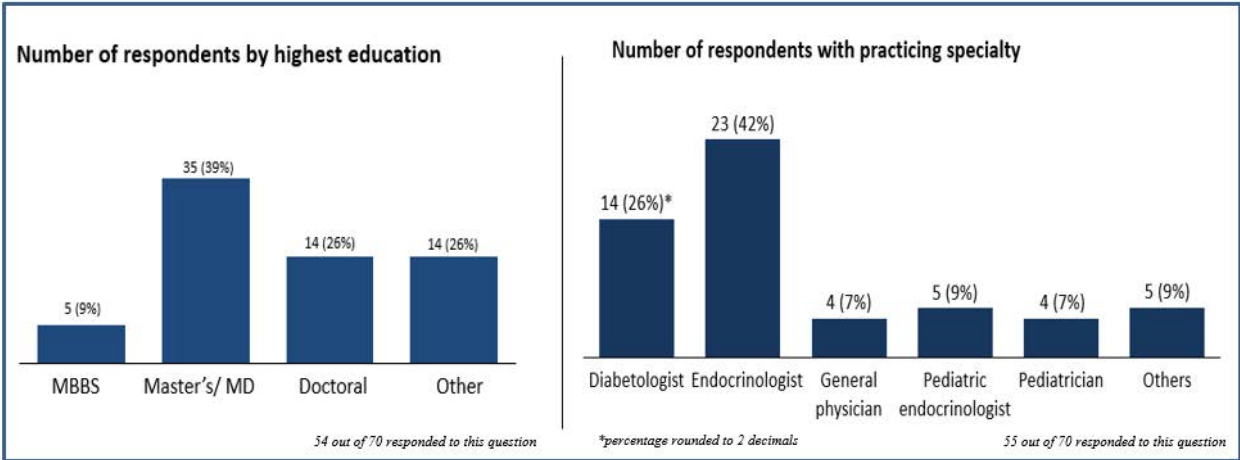
This section discusses the salient findings from the transition to sustainability readiness assessment. First, we focus on the characteristics of survey participants regarding the individuals who contributed to the survey and the facilities in which they work. The second part of this section provides an overview of CDIC integration into the health system, focusing on financing, governance, monitoring and evaluation, and service delivery. Finally, the third part focuses on receptivity findings emphasising the problem-solution fit, adoption system and context.

2.1 Characteristics of Respondents and Centres

2.1.1 Respondent Characteristics

The survey was primarily completed by clinicians with advanced medical degrees, with a total of 70 purposively sampled respondents (Appendix C). Most participants reported having a Medical Degree or a Master’s level qualification, followed by those with a PhD degree and non-specialised medical doctors (Figure 2). In terms of area of specialisation, most of the respondents were endocrinologists, followed by diabetologists, paediatric endocrinologists, paediatricians, General Practitioners (GP), and other.

Figure 2: Education and Specialty Training of Respondents

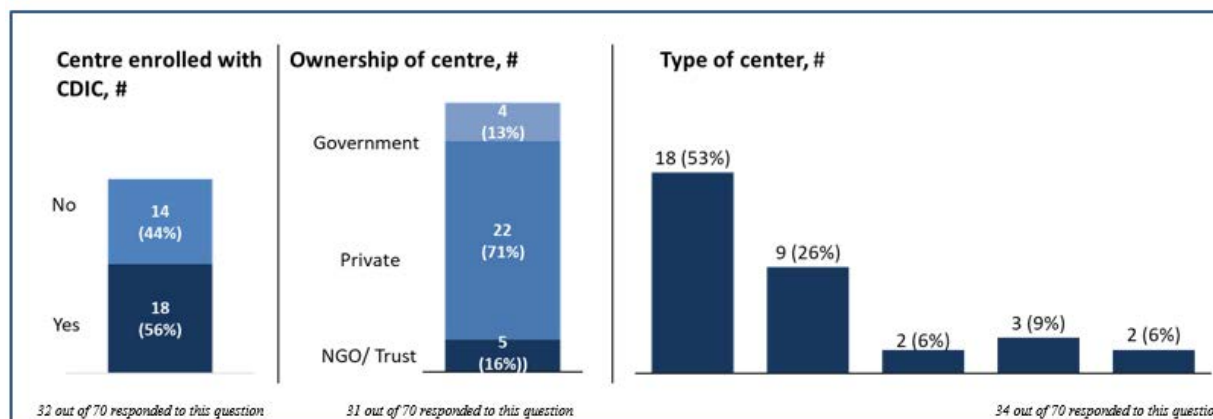


Source: Authors

2.1.1 Centre characteristics

Survey participants consisted of providers of health services for T1D; of these providers there was a comparable mix of CDIC-enrolled centres (44%, n=18) and non-CDIC-enrolled centres (56%, n=14) (Figure 3). In terms of ownership, most facilities were privately owned (71%, n=22), followed by facilities owned by a Non-Governmental Organization (NGO) or Trust (16%, n=5), and public government facilities (13%, n=4). Regarding the type of centre, most centres were private clinics (53%, n=18), followed by private hospitals (26%, n=9), government hospitals (9%, n=3), nursing homes (6%, n=2), and community clinics (6%, n=2) (Figure 3). The heterogeneity of respondents and facilities allowed us to gather insights minimising bias and ensuring we present a holistic assessment of T1D care currently provided for in India, across both CDIC supported centres and non-CDIC supported centres (Appendix C).

Figure 3: Enrolment, Ownership and Type of Centre



Source: Authors

2.2 Integration

2.2.1 Financing

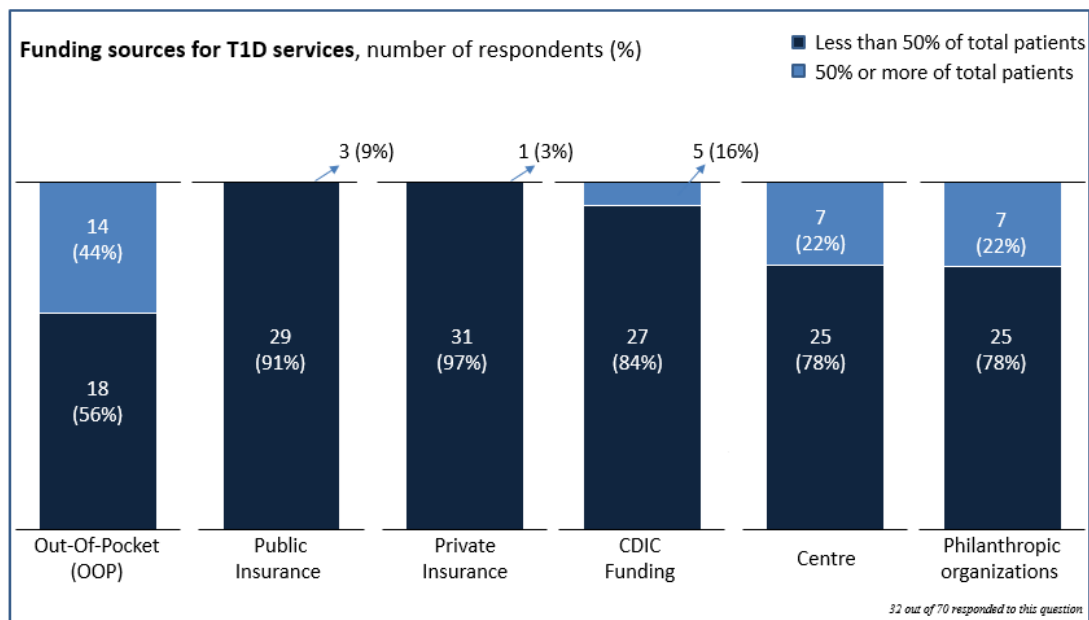
Financing is a critical dimension of sustainability and is principally concerned with how funding is mobilised, pooled, channelled, allocated, and ultimately used to pay for health services for T1D. In this first component of integration, we focus on the following questions as it pertains to the financing of health services for T1D among the participating centres:

- What are the sources of financing healthcare services for T1D?
- Are any healthcare services for T1D (screening, diagnosis, treatment) provided as part of the Government’s Universal Health Coverage policy, (PM-JAY)?

Resource Mobilization

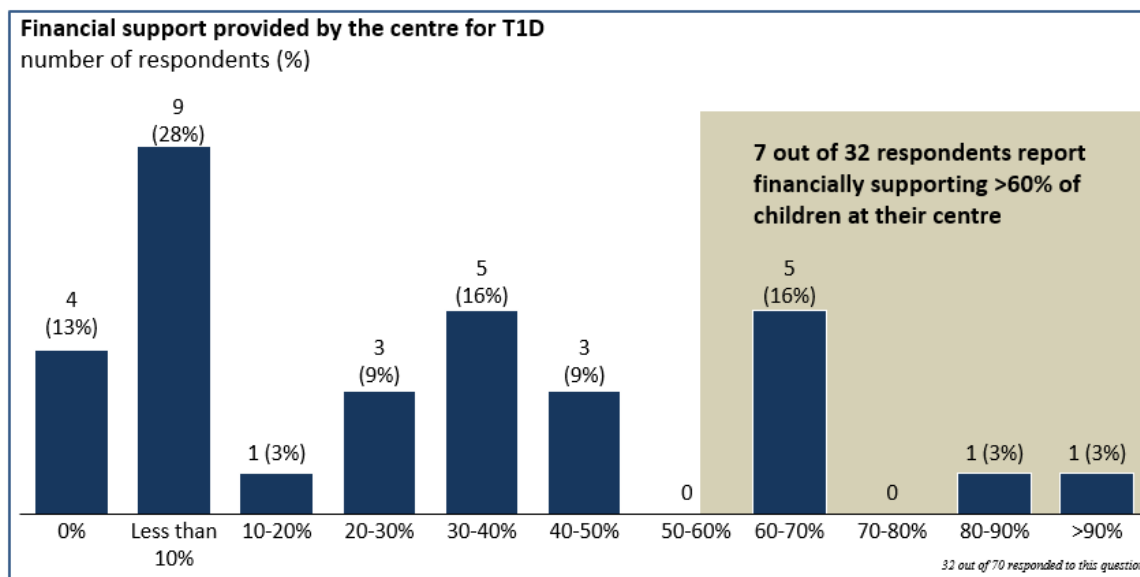
Among survey respondents, the majority (56%, n=18) reported that more than half of all T1D patients seen at their respective centres pay Out-of-Pocket (OOP) to fund healthcare services for T1D. Only a few (9%, n=3) respondents reported that more than half of all T1D patients receive funding from public insurance. Similarly, only one respondent (3%, n=1) reported that more than half of all T1D patients have private insurance, and a few (16%, n=5) reported that more than half of all T1D patients are funded through CDIC. Almost a quarter of the total respondents (22%, n=7) reported that more than half of all T1D patients seen at their facility are supported by the centre or through philanthropic entities. (Figure 4). Among all respondents, seven centres contribute funding of 60% or more towards delivering T1D healthcare services to patients that could not access care due to financial constraints. (Figure 5).

Figure 4: Sources of Funding for Healthcare Services for T1D



Source: Authors

Figure 5: Financial Support Provided by the Centre for T1D Management



Source: Authors

Insights from Key T1D Stakeholders: Scaling management of T1D needs dedicated funding

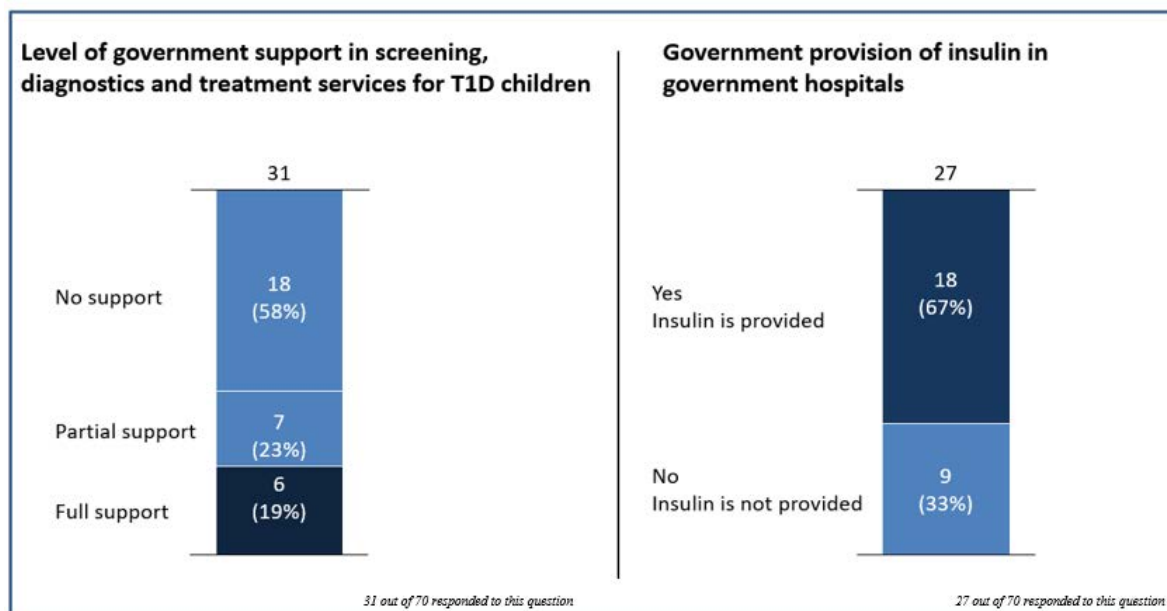
“The number one issue with scaling management of T1D is funding.”

“T1D does not fall under any public insurance to be covered. Only when the patient comes in with complications, they are treated for free.”

Universal Health Coverage

Most respondents (81%, n=25) reported that the government provides partial or no support for screening, diagnostics, and treatment services for children and adolescents with T1D. In comparison, almost one-fifth (19%, n=6) reported gaining full support from the government (Figure 6). Concerning the provision of insulin, there were mixed views. Most respondents (67%, n=18) reported that insulin was provided by the government when patients sought care in government hospitals. A minority (33%, n=9) of respondents noted that government did not provide insulin at state-operated and financed hospitals (Figure 6).

Figure 6: Government Role in Screening, Diagnosing, and Managing T1D



Source: Authors

Insights from Key T1D Stakeholders: T1DM needs to be explicitly prioritised

“If the government classifies T1D as a “special” category, it will aid in providing economic relief and financial benefits to patients who cannot afford out-of-pocket expenses.”

“Essential health benefits packages in Government currently include heart, kidney, brain, cancer, and accidents. Including T1D services in the ‘essential benefits package’ certainly helps.”

2.2.2 Governance

Governance in this analysis is concerned with the role of the Ministry of Health (at Union or State level) and how its various functions—policymaking, planning, stewardship, extent of decentralisation and degree of regulation and competition, among others—influence the delivery of health services for T1D. In this second component of integration, we focus on the following questions as it pertains to the governance of healthcare services for T1D delivered at the centres participating in this study:

- What policies and programmes exist to deliver high-value health services for T1D?

- What planning activities are practised, and which entities are responsible for conducting baseline assessments?
- Do regulation, accreditation, and certification processes exist for providers that deliver health services for T1D, and are these adopted throughout the health system?
- To what extent do providers adopt practices that align with national T1D guidelines and best practice management?

Policymaking

India does not have a national policy or programme for T1D. However, there are policies and state-level programmes that have contributed to the expanded access of health services that address Non-Communicable Diseases (NCDs) in India. For instance, the Government of India launched the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Strokes (NPCDCS) in 2008.⁹ This programme focuses on adult noncommunicable diseases (NCDs), but no initiatives target NCDs in children or adolescents. Other programmes focus on tobacco use, unhealthy food, and mental health.¹⁰ In addition, there are the Anganwadi centres, a long-standing programme initiated in 1975 that focuses on expanding access to child health services and, more recently, maternal health services.¹¹

In the absence of national-level policies to address T1D, a recent demonstration project under the National Health Mission, a central government programme, was implemented in certain districts of West Bengal where existing NCD clinics were upgraded to provide health services for T1D once a week.¹² The upgrades included training staff on comprehensive health services for T1D. Each district hospital was linked with a medical college to expand human resources and support training opportunities.

A comprehensive package of health services for T1D was provided, including anthropometry and child wellness interventions, free provision of insulin, glucose measuring devices and strips, laboratory investigations for T1D, monthly follow-up care management services, emergency care services, and timely referral to a tertiary healthcare facility for T1D complications such as Diabetic Ketoacidosis (DKA).¹³ In Kerala, another state in India, the Mittayi programme,¹⁴ a strategic

partnership led by the government, has helped to leverage existing NCD programmes to scale up health services for T1D within the state (see the Kerala Mittayi case study in Section 3).

Insights from Key T1D Stakeholders: Policymakers should explicitly include T1D within existing NCD policies and embed within UHC

“T1D has not been given its due credit, and no government programme exists, right from diagnosis to management, compared to T2D.”

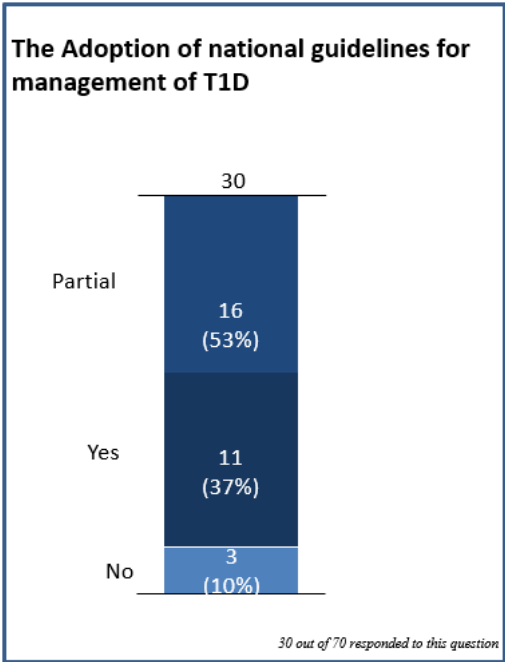
“Government concern is about NCDs, and diabetes is part of it, but not type 1 diabetes.”

Regulation

India has numerous institutional processes for the accreditation and certification of providers involved in delivering health services for T1D. Providers of healthcare services for T1D must be certified by the Medical Council of India,¹⁵ currently the National Medical Commission, a statutory body affiliated with the Ministry of Health and Family Welfare. Clinicians that provide T1D healthcare services in India are typically GP’s or specialists in Internal Medicine, Paediatrics, or Endocrinology. GP’s and specialists may only be certified following the completion and successful passing of examinations administered by the National Board of Examinations,¹⁶ an autonomous organisation under the Ministry of Health and Family Welfare.

In terms of process management and standardisation of health service delivery for T1D, the majority (53%, n=16) of respondents noted partial adoption of guidelines for management of T1D, followed by the number of respondents (37%, n=11) indicating full adoption of guidelines, while a minority (10%, n=3) reported not adopting any care guidelines for management of T1D (Figure 7).

Figure 7: The Adoption of National Guidelines for Management of T1D



Source: Authors

2.2.3 Planning

Planning

There is no national-level entity that is responsible for planning health service provision for T1D in India. Planning activities should typically entail reviewing the evidence and conducting baseline assessments of gaps in the provision of health services for T1D to inform and enhance resource allocation, financing, and delivery of services. While these activities may occur at the state level in one or two regions (e.g., Kerala), there is no evidence that states conduct rigorous planning activities in relation to T1D. The Registry of People with Diabetes with Young Age at Onset (YDR) was established in 2006 by the Indian Council of Medical Research (ICMR) to address the scarcity of information about youth-onset diabetes in India.¹⁷ While there have been numerous studies conducted to estimate the incidence and prevalence of children and adolescents with T1D in India, few studies have examined health system performance in relation to T1D¹—and there is no evidence to suggest that this information is adequately leveraged to inform decisions to deliver

more targeted, higher value health services for T1D. From our study, planning for T1D emerged as one of the weakest aspects of integration with the health system.

Demand Generation

No dedicated team or unit exists to deliver T1D Information Education and Communication (IEC), and such activities appear to be intermittent, covering less than 50% of the population of children and adolescents living with T1D in India.

While there are digital technologies that exist and that could be leveraged to deliver targeted IEC activities to children and adolescents with T1D to improve management of diabetes throughout the care cycle, to date such technologies have not been adequately adopted within CDIC or within the health system more broadly to ensure large-scale impact and population benefit. As one stakeholder remarked, there is also great synergy to underpin digital technologies with actual services. For example, using multi-disciplinary health teams consisting of clinical health associates, diabetic educators, dieticians, and social workers was emphasised by the stakeholders to visit schools and integrate screening for T1D within existing child wellness services using digital health technologies. The current level of support remains unpredictable due to heavy dependence on volunteers, no dedicated workforce, and suboptimal resource allocation to deliver IEC services.

Insights from Key T1D Stakeholders: T1D is a multi-disciplinary team effort

“We should set up a team with a dedicated doctor, diabetic educator, dietician, and social worker.”

“Even if we get equipment and strips for free, we do not have enough admin staff to use it; currently, all work is done by volunteers.”

2.2.4 Service Delivery

Service delivery is concerned with how health services for T1D are delivered in terms of effectiveness, efficiency, equity, and responsiveness. In this fourth component of integration, we

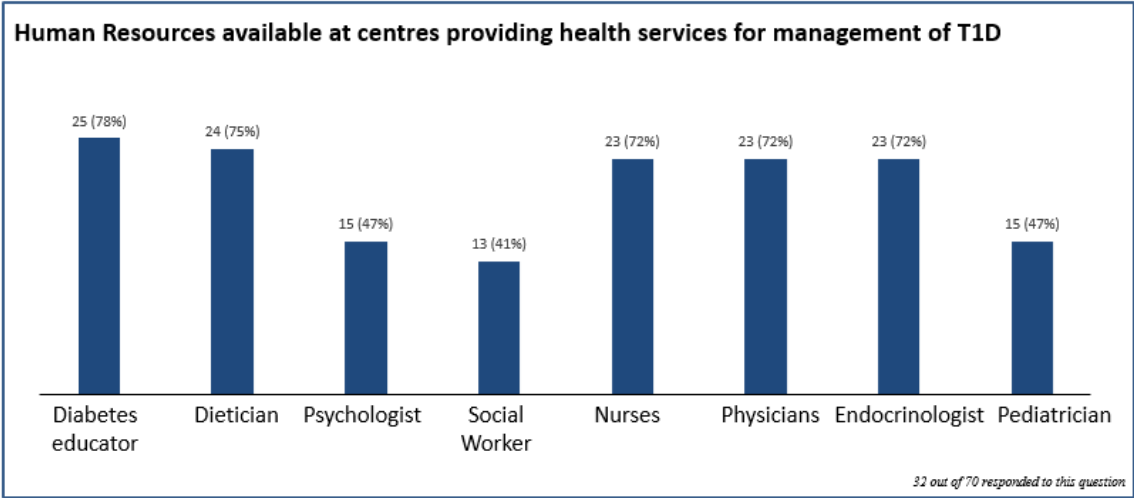
focus on the following questions, as it pertains to the delivery of health services for T1D at the centres participating in this study:

- What health services for T1D are provided at participating centres?
- Who provides health services for T1D?
- To what extent are health services for T1D delivered effectively, efficiently, equitably, and responsively?

Human Resources

Among the skilled health professionals available at the centre to support the delivery of health services for T1D, a majority of them (78%, n=25) reported having a diabetes educator, followed by those that have a dietician (75%, n=24), and those that have nurse, physician, or endocrinologist each (72%, n=23). Close to half of the total respondents (47%, n=15) reported having a psychologist or paediatrician each, and lastly, a sizeable number of respondents (41%, n=13), reported having a social worker at the centre (Figure 8).

Figure 8: Human Resource Availability at Centres Providing Health Services for Management of T1D



Source: Authors

An insight reinforced among stakeholders interviewed emphasises the importance of novel approaches to leveraging existing human resources in community health. For example, educating teachers in school about the signs and symptoms of T1D for prompt referral to a medical provider. Or, leveraging Community Health Workers (CHW) who have established and trusted relationships with patients and families, particularly using Anganwadi workers, could help to provide follow-up management of patients with T1D and promote wellness and behaviour change among patients and their families. Though CHWs are an important group of human resources, insights from the interviews also suggested the possible limitations of leveraging them for T1D, which should be carefully considered to guide development and introduction and support CDIC sustainability.

Insights from Key T1D Stakeholders: Non-physicians should be leveraged to improve equity and effectiveness of health services for T1D

“We should be able to improve paramedical personnel. It does not require high management or [necessarily] involve acute cases. It is only about increasing and decreasing insulin.”

“We don’t need more doctors; we need insulin adjustors.”

“We talked to teachers in Vellore about T1D, and they were so interested to learn and very grateful.”

“CHWs are bombarded with everything – family planning, malaria, TB, etc... There might be a million CWH employed in India and screening and caring for T1D is the least of their priority.”

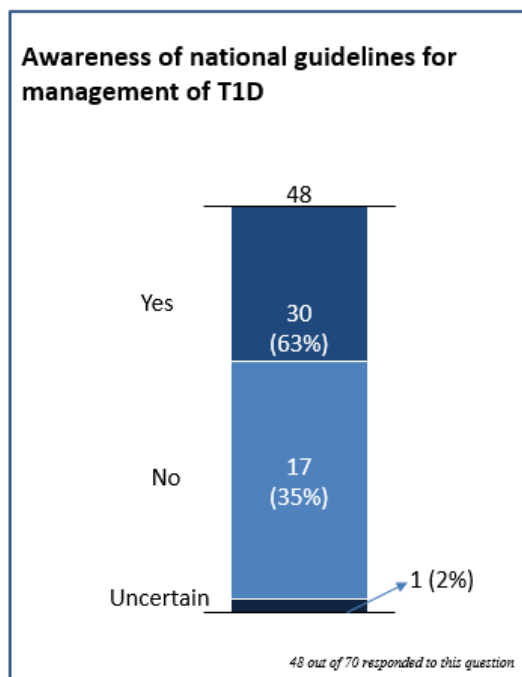
While strengthening clinical human resources will remain crucial for integration of health services for T1D, efficient task-shifting of other human resources in the health system—be it nurses, Anganwadi workers, Accredited Social Health Activist (ASHA) workers, educators, among others—towards enhanced health services for T1D will be critical in improving last mile delivery of insulin, and ongoing management of children with T1D, and thereby improve the effectiveness, equity, and responsiveness elements of health services for T1D in India.

Performance Management

Using evidence-based practices to inform healthcare delivery for T1D is an important aspect of ensuring effectiveness in the management of T1D. Among all respondents, the majority (63%,

n=30) were aware that there were national guidelines to inform management of T1D, compared to those who were not aware of the existence of guidelines (35%, n=17), and only one respondent (2%, n=1) reported being unsure whether there were guidelines or not (Figure 9).

Figure 9: Awareness of National Guidelines for the Management of T1D



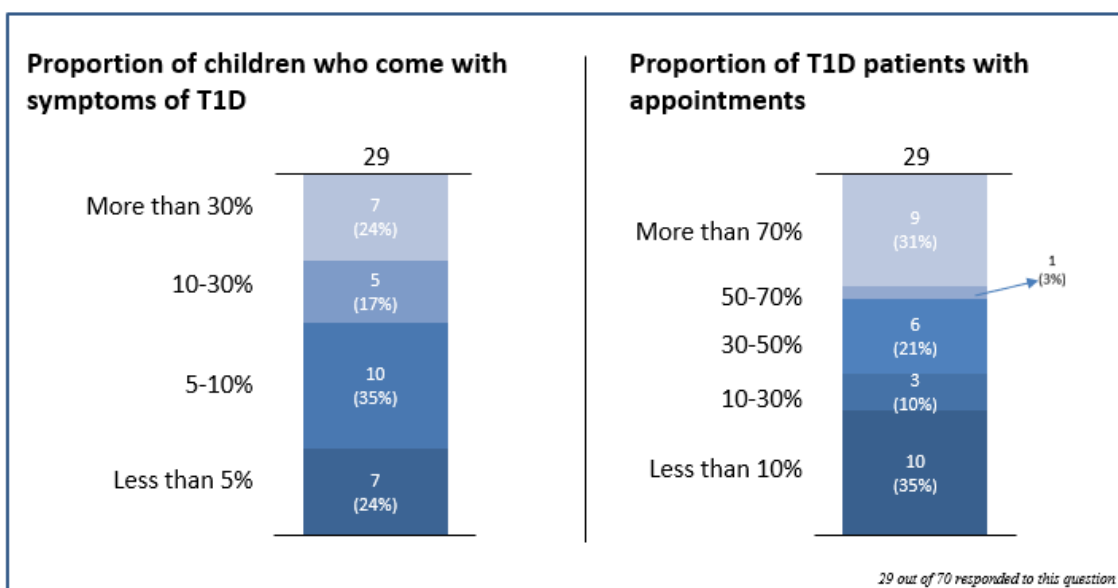
Source: Authors

Since there are major variations in the burden of disease regionally and variation in health system performance in relation to management of T1D,^{1,18} it is important to understand the extent to which patients present to T1D providers with symptoms. Among the respondents, the majority (59%, n=17) reported that a tenth or fewer children present with symptoms, while almost a quarter of the total respondents (24%, n=7) noted that a third or more of children presented with symptoms. A sizeable number of respondents (17%, n=5) fell in between, noting that children presenting with symptoms were roughly between 1 in 10 and 3 in 10 of all children with T1D attending their centre (Figure 10).

In terms of care organisation and efficiency in delivery, there was substantial variation in the proportion of children with T1D that attended a facility with a prior appointment. Many

respondents (35%, n=10) reported that less than 10% of all children with T1D had appointments, similar (34%, n=10) to those who noted that half or more children attended the facility with an appointment. The remaining proportion of respondents (31%, n=9) reported moderate use of appointments, reporting anywhere between a tenth and a quarter of children with T1D having an appointment (Figure 10). The organisation of T1D care in India remains sporadic and enabling access to diagnosis and care earlier in the T1D continuum forms a crucial element of integrating health services for T1D within India’s health system.

Figure 10: Children Presenting at Centres with Symptoms of T1D or an Appointment

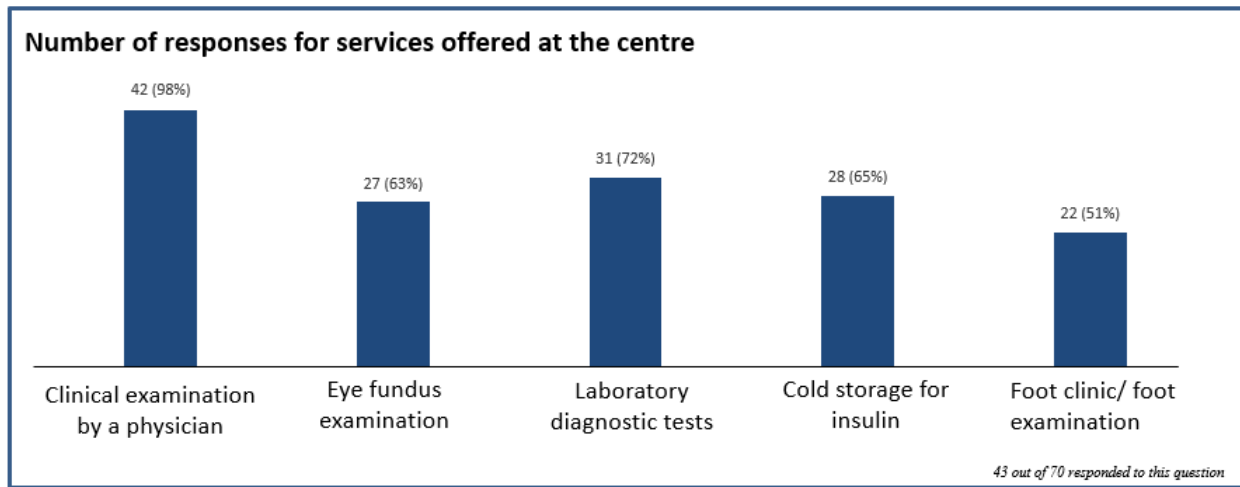


Source: Authors

Service Coverage

Among the services provided to diagnose and manage T1D, a majority (98%, n=42) conducted a clinical examination by a physician, followed by those who provided laboratory diagnostic tests (72%, n=31), had the adequate infrastructure to enable cold storage of insulin (65%, n=28), conducted an eye fundus examination (63%, n=27), and conducted an examination of the foot (51%, n=22) (Figure 11).

Figure 11: Health Services for T1D Provided at Centre



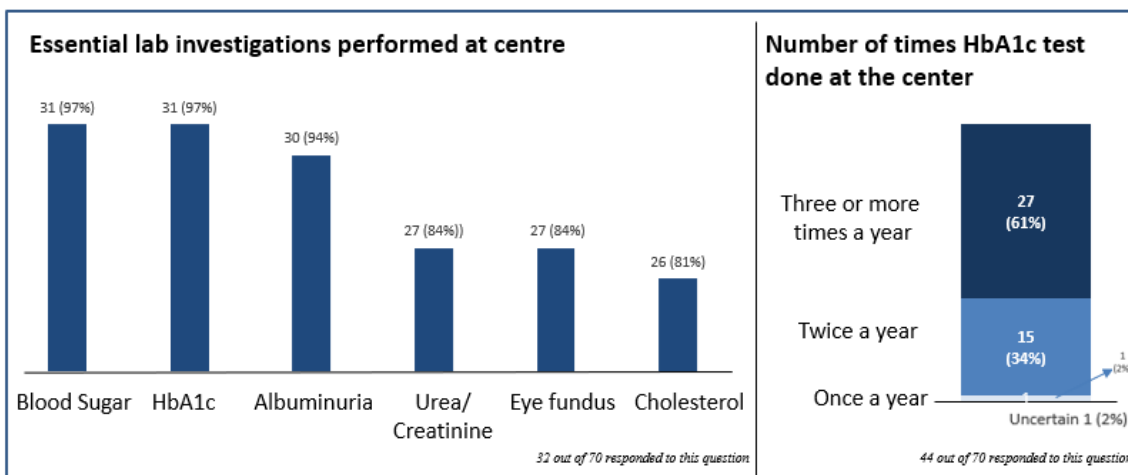
Source: Authors

The services offered at each centre present many opportunities to enhance diagnosis and management of T1D across India, given that the majority of centres surveyed were not offering and/or conducting what is considered the ‘essential benefits package’ in other health systems among India’s peer nations. More efforts are needed to enable a universal understanding amongst providers about the minimum investigations needed for a successful T1D diagnosis and make these services available across all centres managing children with T1D.

The types of lab investigations performed at each centre varied, with the majority (97%, n=31) responding that blood glucose and HbA1c testing was available at the centre, respectively, and a majority (94%, n=30) responded that they could conduct a urine albuminuria test using a Dipstick. Similarly, most centres (84%, n=27) could conduct a blood Urea/Creatinine and eye funduscopy, and offered (81%, n=26) blood cholesterol testing.

Concerning the frequency of HbA1c testing, most centres (61%, n=27) reported that testing is performed three or more times a year, while more than one-third (34%, n=15) responded twice a year, and only one respondent each (2%, n=1) reported annual testing or being uncertain (Figure 12). These findings suggest significant opportunities to standardise services investigations offered across all centres and regularise the frequency of T1D investigations based on national guidelines.

Figure 12: Lab Investigations and Frequency of HbA1c Testing



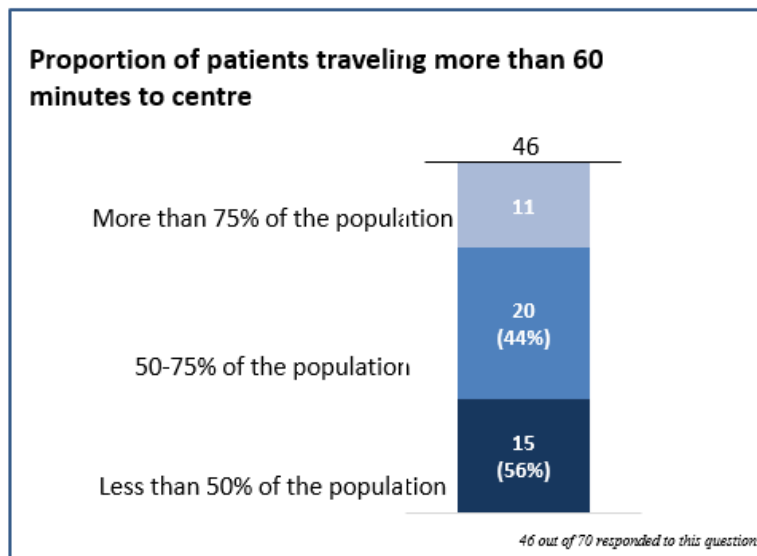
Source: Authors

2.2.5 Resource Management

Supply Chain Management

With respect to the physical accessibility of centres providing T1D healthcare services, most respondents (76%, n=31) reported that more than half of children attending their facility for management of T1D had to travel more than one hour to reach the centre. A minority of respondents (24%, n=15) reported that it took children less than 60 minutes to travel to their centre to attend their consultation (Figure 13). Ensuring shorter travel times with centres near the patients' residences, or leveraging health technologies to engage patients, particularly for ongoing monitoring, will be critical in ensuring that the children with T1D receive regular supplies of insulin and can actively manage their condition. While the initial diagnosis may continue to need travelling to larger urban cities, efforts are needed to decentralise insulin tracking and ongoing management of children down to the last mile, especially in rural areas across India.

Figure 13: Patients Travelling More than 60 Minutes to Reach a Centre



Source: Authors

Insights from Key T1D Stakeholders: Centres providing healthcare services for T1D are not accessible for most patients; new delivery models are urgently required

“People cannot keep coming to Mumbai once a month to receive insulin.”

“We need to [empower district hospitals] to create similar models that can be used by physicians to manage [T1D at the local level].”

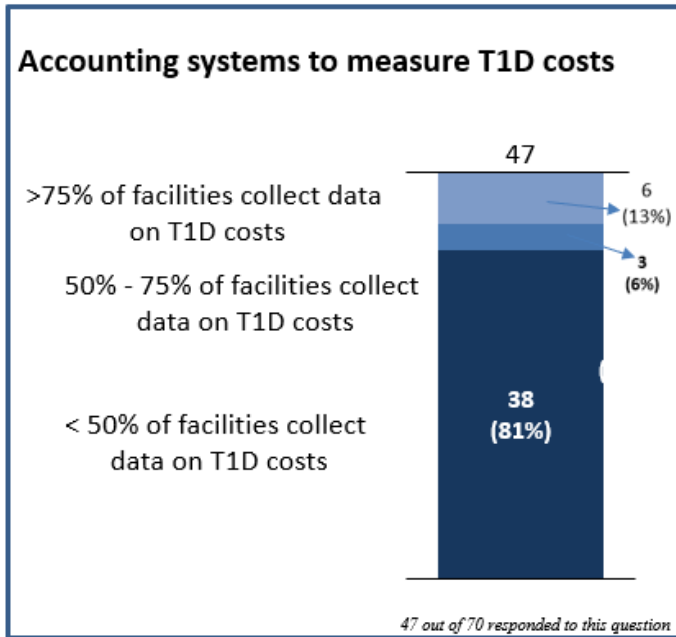
Cost Data

In terms of the ability to measure costs across the T1D care continuum, the majority of respondents (81%, n=38) reported that centres did not collect data pertaining to cost (<50% of facilities had measures in place to collect such data). In comparison, only a minority (19%, n=9) reported that facilities routinely collected cost data pertaining to the delivery of health services for T1D (Figure 14).

Increasing usage of digital applications across the country may allow India to adopt low-cost digital solutions to collect, track and manage data related to the cost of services for T1D. However,

such accounting practices only occur in select centres and are not well integrated with existing practices to measure and report cost in the health system using digital platforms.

Figure 14: Maintenance of Accounting Systems to Measure Costs of Health Services for T1D



Source: Authors

2.2.6 Monitoring & Evaluation

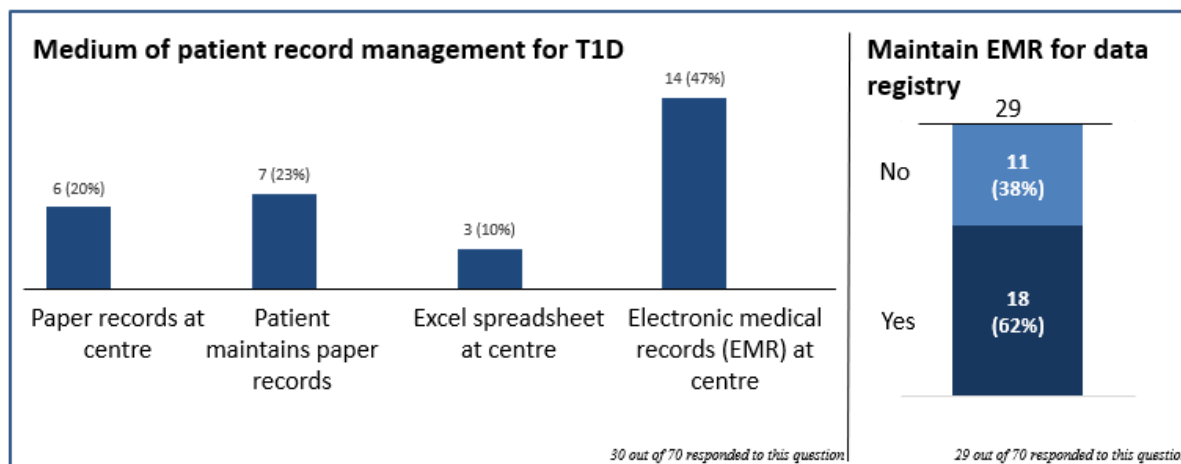
Monitoring and Evaluation is concerned with generating, organising, analysing, and ultimately using information and data to improve the efficiency, effectiveness, equity, and responsiveness of health services for T1D. In this fifth component of integration, we focus on the following broad questions as it pertains to the delivery of health services for T1D among those centres supported by CDIC:

- How is clinical information recorded, analysed, and used to inform decisions and interventions to enhance health services for T1D?
- Are clinicians and patients able to communicate with one another outside of consultations?

Clinical Data Collection & Analysis

In relation to capturing clinical data, many respondents (47%, n=14) reported that they use electronic medical records (EMR), followed by paper records managed by the patient (23%, n=7), paper records managed at the centre (20%, n=6), and excel spreadsheets at the centre (10%, n=3) (Figure 15). Similarly, a majority of respondents (62%, n=18) reported maintaining EMR as a data registry, and the rest (38%, n=11) did not maintain EMR as a data registry. There is no unified data system that enables providers to share a patient's entire medical record when patients are referred, and no comprehensive mechanism to extract relevant data from EMRs into registries that could enable enhanced planning, resource allocation and investment in T1D policies and programmes.

Figure 15: The Maintenance of Data Registry and the Medium of Patient Record Management for T1D



Source: Authors

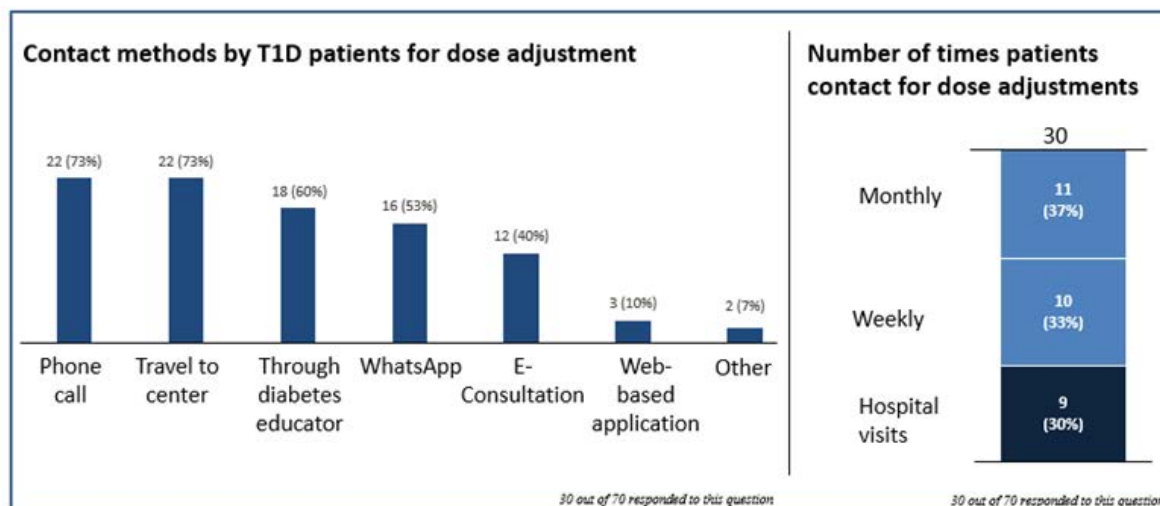
The accelerated adoption of digital technologies in patient medical record tracking has certainly had a positive impact on the management of T1D data processes in India. However, many centres continue to rely on the patient to maintain their paper records, especially since a patient may see multiple clinicians in their lifetime. This practice (prevalent across the management of many NCDs in India) is particularly risky for T1D as different individuals are involved in leading the management of the condition: initially by the patients' parents and then by the patient during

adolescence and adulthood. Effective mechanisms to ensure electronic data capture and interoperability between these systems are needed to ensure that each child’s management is tracked and managed from childhood to adolescence and insulin dose adjustments are tracked and understood across clinicians.

Information Technology Infrastructure

Patients have various methods of contacting the centre for dose adjustments. The common methods of communication include contacting by phone or physically visiting a T1D centre (73%, n=22), followed by engaging a diabetes educator (60%, n=18), an online messaging application such as WhatsApp (53%, n=16), E-consultation (40%, n=12), a web-based application (10%, n=3), and other methods (7%, n=2) (Figure 16). In this context, an ‘E-consultation’ refers to an aspect of telemedicine that enables communication between patients and specialists in a remote setting, whereas a ‘web-based application’ refers to a medium where an EMR is accessible by patients and enables communication via an online portal.

Figure 16: Contact Methods for Dose Adjustments



Source: Authors

A major challenge to self-management of T1D among children and adolescents is a lack of resources, leading to excessive contact of providers for insulin dose adjustment. The majority of

centres (70%, n=22) reported that patients contacted them weekly or monthly for insulin dose adjustment, and the rest (30%, n=9) reported that patients had their doses adjusted in the hospital setting (Figure 16). For the latter group, the reason for visiting the hospital was not ascertained and could be for a complication due to T1D (e.g., Diabetic Ketoacidosis) or another reason altogether, providing an opportunity for specialist clinicians to optimise medication in the hospital setting.

2.3 Receptivity

2.3.1 Context

Political

While there is no explicit policy that is focused on the expansion of access to health services for T1D in India, the broad political environment is favourable for such an expansion.

India has introduced policies and programmes at both the federal and state level that relate to NCDs, children's health, and UHC. Most crucially, India has demonstrated considerable support for advancing UHC through the Ayushman Bharat National Health Protection Scheme (PM-JAY). The National Health Authority was established in 2019 as the apex Government entity at the federal level with the overall responsibility for designing the implementation strategy of PM-JAY, and interacting with State Health Agencies to drive implementation at the state level.¹⁹

Kerala is the only state in India that provides free health services for T1D as part of its standard benefits package to which all children and adolescents with T1D are entitled. India is a significant player in several global political cooperation bodies and fora, including, the Group of 20 countries (G20), five leading emerging economies of Brazil, Russia, India, China, and South Africa (BRICS), South Asian Association for Regional Cooperation (SAARC) and the Shanghai Cooperation Organisation (SCO). As the holders of the G20 Presidency in 2023, India is well positioned to harness G20 meetings of health ministers, finance ministers and the G20 Heads of State to create opportunities to advance its health policy agenda.

Economic

Fiscal space for increased investment in health systems and for the introduction of a benefits package accompanied by an expansion of health services for T1D is favourable in India. The economy of India has demonstrated considerable resilience to the COVID-19 pandemic and the global economic crisis that followed, responding swiftly following the shock of the pandemic in 2020. After the worldwide economic slump when most countries experienced a contraction in their Gross Domestic Product (GDP) in 2020, India demonstrated stronger economic growth than its peers, with a GDP growth of 8.7% in 2021 and 6.8% in 2022.²⁰ A recent report by the World Bank noted: “while a 1 percentage point decline in growth in the US is associated with a 0.4 percentage point decline in India’s growth, the effect is around 1.5 times larger for other emerging economies”.²¹ This comparatively strong performance among peer nations may enable India to weather the storm expected from rising inflation and increases in global commodities, a threat to economic performance in other nations. A positive outlook of India’s GDP is projected for 2023 of 6.6% growth. A robust domestic market, favourable balance of payments, healthy foreign currency reserves, and prudent monetary policy are several reasons cited to explain the resilience of India’s economy.

However, India invests less in its health sector as a proportion of its GDP compared to peer nations. In 2019, India spent approximately 3.1% of its GDP on health compared to 5.3% in China, and 9.5% in Brazil.²² Expenditures on health from government sources as a proportion of Total Health Expenditure (THE) was 33%, less than China (56%) and Brazil (41%). Out-of-pocket expenses on health are high (55%) of THE in 2019, compared to 35% and 25% in China and Brazil, respectively, and there is considerable private sector activity in health compared to peer nations and a very large informal sector.²³ Although the central government has a political commitment to generate revenue through various fiscal policy reforms, there is less empirical evidence and precedent of harnessing India’s economic growth to expand fiscal space for health investment.²⁴

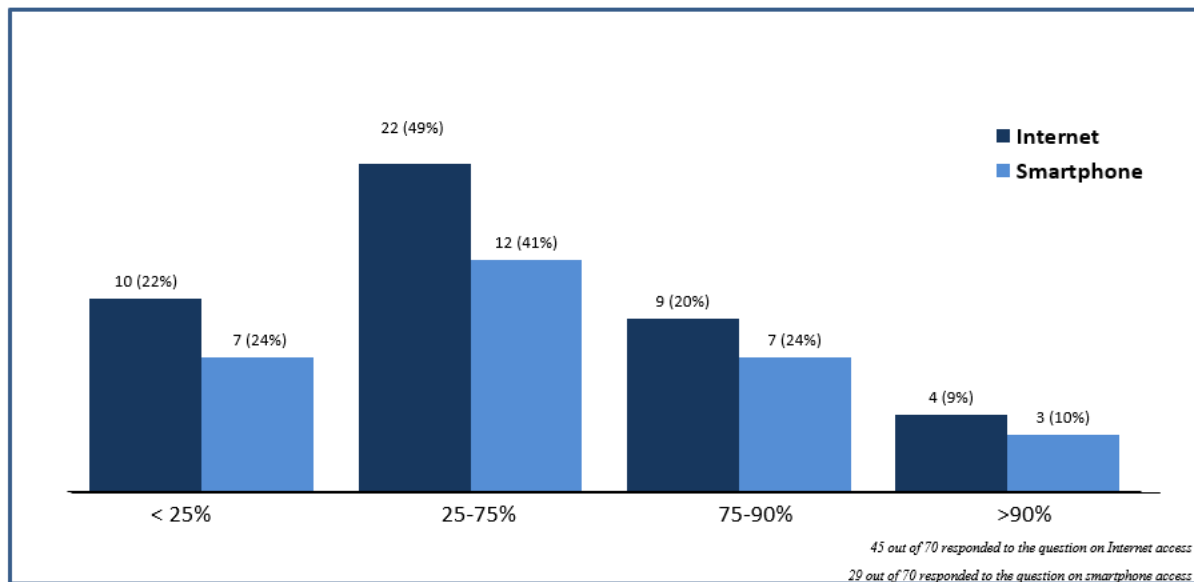
Technological

India has a robust technological ecosystem to leverage for expanded access to high-value health services for T1D. A major priority for the Government of India is the Ayushman Bharat Digital

Mission (ABDM), which aims to invest in integrated digital health infrastructure to enable interoperability and exchange of information between providers, payers and patients involved in the PM-JAY. India already has a favourable technological infrastructural backbone to leverage. With a population of nearly 1.4 billion individuals, 43% of Indians have access to the internet, with 84 out of every 100 people in India having a cellular subscription service.^{25,26}

The centres participating in this study, a few (9%, n=4) responded that 90% of the children have access to Internet, while one-fifth (20%, n=9) responded that 75-90% of the children have access to internet, close to half (49%, n=22) of them responded that 25-75% of the children have access to the internet, and the rest (22%, n=10) responded that only one in four children have access to internet (Figure 17). The use of smartphones followed a similar distribution to that of Internet availability. A few (10%, n=3) responded that more than 90% of the children at the centre have access to a smartphone, close to quarter (24%, n=7) responded that between 75-90% of the children at the centre, or less than 25% of the children have access to smartphone each, while less than half of them (41%, n=12) responded that 25-75% of the children at the centre have access to a smartphone.

Figure 17: Patient Accessibility to the Internet and Smartphone



Source: Authors

Insights from Key T1D Stakeholders: India’s robust technological ecosystem presents a major opportunity to improve delivery models and enhance healthcare services for T1D

“Technology should not be a problem. Due to COVID-19 online connectedness has improved vastly, and reaching the patients [digitally] is not an issue.”

“Technical infrastructure to provide services exists, but the problem is that it might not be free of charge. So, people who really need it will not have accessibility.”

Interviewees emphasised the ubiquity of smartphone usage and Internet access, which could be utilised more effectively in the context of T1D. It is estimated that Internet access and smartphone usage will reach one billion users by 2026.²⁷

Epidemiological

India is undergoing an epidemiological transition and is experiencing a rapid rise in NCDs, such as diabetes, cardiovascular disease, and cancer. The incidence of T1D in India for 2022 was approximately 8 per 100,000 people and is projected to increase to 12 per 100,000 people by 2050.²⁸ Currently, approximately one-quarter of all new-onset T1D cases present with Diabetic Ketoacidosis, a life-threatening complication due to elevated blood glucose. In Southeast Asian countries such as India, recent study from Harvard University has estimated more than 65% of cases are missed by health systems.¹

Legal

While the Constitution of India does not explicitly guarantee the right to health, there have been recent demands to declare the right to health a fundamental right in India. In 2019, the High-Level Group on the health sector constituted under the 15th Finance Commission recommended that the right to health be declared a fundamental right. Commentators on the subject note that while there is no explicit mention of health in the Constitution of India, these are inferable from the right to life, which is explicitly mentioned. India signed and ratified the International Covenant on

Economic, Social and Cultural Rights, in which health—the highest attainable standard of physical and mental health—is expressly a feature in Article 12.²⁹ It could be argued, therefore, that India according to international human rights law India should ensure the provision of equitable access to health services for T1D, and to ensure access and affordability to insulin, a World Health Organization essential medicine crucial for its management.

2.3.2 Adoption System

The adoption system comprises the critical stakeholders that influence the delivery of health services for management of T1D. These stakeholders include, among others, those that provide, receive, pay, or regulate health services for T1D. It is important to understand how each of these stakeholders perceives T1D and to what extent it is a priority for them—to analyse receptivity to expanded access and investment in T1D. While the major stakeholders include clinicians, patients, policymakers, and private and public funders, this study reports the perceptions among survey respondents (mostly clinicians) about how each of the major stakeholders perceives T1D in terms of urgency. We find that clinicians present the strongest support towards believing that T1D needs immediate action and efforts to strengthen care, followed by citizens, private funders, and public funders (Figure 18).

Operating under a scarcity of resources with competing priorities often necessitates adopting a robust priority-setting process and making critical trade-offs. We interviewed respondents to assess how they prioritise different investment areas in relation to health services for T1D. The objective here was two-fold – (1) to uncover the largest gaps or investment needs across the care continuum for T1D services and (2) to identify misalignments (if any) between different stakeholder groups, particularly clinicians and political decision makers in relation to T1D.

Clinicians

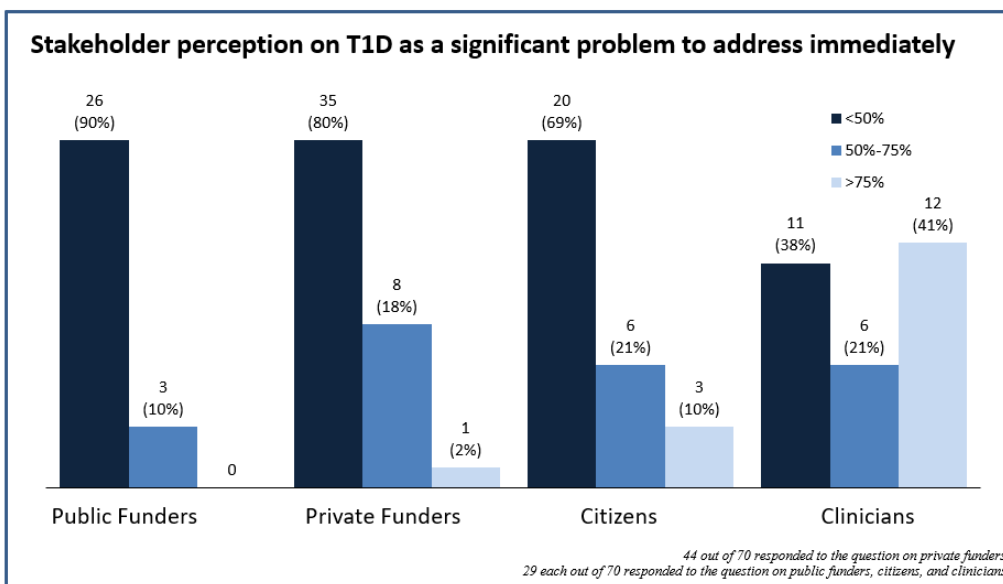
There was a diverse set of responses among clinicians who voiced their opinion on T1D being a problem that needs to be addressed with a sense of urgency. More than one-third (38%, n=11) respondents were of the opinion that less than half of the clinicians see T1D as a significant

problem, over one-fifth (21%, n=6) perceived that only 50-75% of the clinicians see T1D as a significant problem, and less than half of the respondents (41%, n=12) perceived that more than 75% of the clinicians viewed T1D as a significant problem (Figure 18).

When assessed on prioritisation, clinicians voiced the imperative for expanded investment in T1D from enhanced public sector resource allocation and financing in a way that both optimises the use of limited resources while increasing responsiveness at the field level.

Insights from clinicians helped reveal four key areas that need to be strengthened in current the management of T1D. First, there is a need to integrate health services for T1D as part of a comprehensive care package for all citizens with T1D. Second, care delivery needs to be underpinned by a robust data system. This data system should be designed to improve care delivery at a facility level, but also inform resource management and investment at the state and federal levels. As one clinician noted, existing data from the Youth Onset Diabetes (YDR) registry could be used to convey the magnitude of the T1D problem to policymakers. Third, referral between primary and secondary levels must be strengthened. The health services for T1D delivered at both primary and secondary levels should be defined better to optimise the allocation of resources, for example, for expanded access to insulin and glucometers.

Figure 18: Stakeholder Perspectives on the Urgency of T1D



Source: Authors

Citizens

There were diverse responses among clinicians on how citizens, their patients and families, viewed T1D. A majority of the respondents (69%, n=20) were of the opinion that less than 50% of the citizens viewed T1D as a significant problem, over one-fifth (21%, n=6) were of the opinion that only 50-75% of citizens view T1D as a significant problem, and the rest (10%, n=3) of them were of the opinion that more than 75% of the citizens viewed T1D as a significant problem (Figure 18).

When interviewed, clinicians expressed the following perspectives about how citizens, their patients, perceived T1D. First, for patients and families that are directly affected by T1D, T1D is a major problem; for families and citizens that are unaffected, T1D is not a significant problem, and many would not be aware of differences between T1D and Type 2 Diabetes Mellitus. Second, families with children or adolescents that have T1D, face a major financial burden to access effective health services for T1D, including paying for Insulin and glucometers. Third, families often struggle with implementing and sustaining lifestyle changes, and parents are often more prone to developing depression leading to suboptimal well-being both for the parent and the child.³⁰ These findings support the need to strengthen education both for the parent and the child, undertake targeted efforts to improve access to insulin supplies and increase awareness around the diagnosis and ongoing management of T1D.

Insights from Key T1D Stakeholders: No one wants to take responsibility

“People are afraid of T1D, and no one wants to take the responsibility.”

“There are social, cultural, and educational issues with T1D. Once a child is diagnosed with T1D, it is a gloomy picture for the entire family. Nobody wants to take responsibility for the patient.”

Private Funders

Respondents’ opinion on how private funders viewed T1D was similar to that for public funders. A majority of the respondents (80%, n=35) believed less than half of the private funders viewed T1D as a significant problem, while a sizeable number of respondents (18%, n=8) thought that 50-75% of the private funders considered T1D to be a significant problem, and only one respondent

(2%, n=1) perceived that more than 75% of the private funders view T1D as a significant problem (Figure 18).

When interviewed, clinicians expressed the following perspectives about how private funders perceived T1D. First, that private funders were primarily concerned with the financial dimensions associated with T1D and operating a private practice. Second, since there are larger problems, and medical conditions that affect more people, private funders are more interested in providing these services that address these conditions. Third, while some excellent initiatives like CDIC, and others, these programmes are small and should expand and integrate more effectively with government initiatives to expand access and create a sustainable impact.

Insights from key T1D stakeholders: The social determinants of T1D must be identified and prioritised as part of a holistic approach to T1D in India

“By documenting the trouble that families go through, we will get donors who are willing to help. Show them the benefits of treatment versus untreated as examples.”

“We know people with T1D who are bright, hardworking, and living a healthy life. We must raise some children to be models and advocate for T1D.”

Public Funders

Respondents believed that public funders did not perceive T1D as a significant problem. Most participants (90%, n=26) responded that less than 50% of the public funders view T1D as a significant problem, and one-tenth (10%, n=3) responded that 50-75% of the public funders viewed T1D as a significant problem. No respondents (0%, n=0) believed 75% or more of public funders viewed T1D as a significant problem (Figure 18).

When interviewed, clinicians expressed the following perspectives about how public funders perceived T1D. First, public funders are not likely to view T1D as a major priority because they have not been well engaged. Second, diabetic, paediatric and endocrinology professional associations could work with universities to develop a more persuasive case to include basic set of health services for T1D to be covered by the Ayushman Bharat National Health Protection

Scheme. Third, public-private partnerships that focus on expanding access to T1D would assist in gaining traction and could be used to support public investment in T1D.

Insights from Key T1D Stakeholders: Framing T1D to promote awareness, prioritisation and sustainable funding

“If we conceived the CDIC as a research project instead of philanthropy, we might have made more progress.”

“At Vellore’s Christian Medical College, it was suggested that if we join hands, collaborate and work together, we can do fundraisers and benefit shows which will raise awareness of T1D.”

Policymakers

Through our surveys and interviews, we uncovered that there might be a perception that policymakers do not understand the magnitude of T1D and, as a result, do not consider T1D as a major health issue.

Insights from Key T1D Stakeholders: CDIC as a model for management of T1D and the imperative for a collaborative approach

“Government is supposed to learn from the model that was set up by CDIC. Of late the government is showing interest and is willing to develop two centres of excellence.”

“CDIC has taught us structured T1D care (diagnostics and therapeutics) along with the importance and feasibility of follow-up with T1D children at regular and more frequent intervals.”

“Policymakers should involve the citizens when designing policy changes. These policies for T1D should be a separate entity and not clubbed into NCDs.”

“We are in a stage where the government wants to have a medical college in every district. Maybe that is a place where we can utilise T1D patients.”

Interviewees specifically noted that improving the affordability of care, enhancing data systems, improving parent and child education on management of T1D, and building capability at the health centres delivering T1D care as the primary issues that policymakers should be made aware of. In addition, policy and regulatory changes that promote partnerships between government, industry, and NGOs could help reduce barriers to cross-sectoral collaborative initiatives.³¹ Stakeholders emphasised that policymakers should involve citizens when reviewing and designing policies related to T1D. One stakeholder stated: “there is no collective enterprise” when addressing T1D from a systems perspective, emphasising the lack of an organised movement to engage policymakers and inform programmes, initiatives, and resource allocation decisions at the systems level.

2.3.3 Problem-Solution Fit

Problem-Solution Alignment

Health services for T1D that benefit from the support of CDIC are moderately aligned with the problem of T1D.

Insights from Key T1D Stakeholders: management of T1D is complex, must focus on children, adolescents and adults, and requires a system approach

“The change must be brought at society level, school level, district level, national level.”

“Public service awareness should exist for T1D on symptoms, awareness, detection and prevent complications.”

“We need to support the children at least till 18 years of age. With all possible monitoring, pumps, CGM, and insulin post-18, they can fund their survival and take care of themselves.”

“People are aware of T1D. It is not like 1 or 2 injections and eradicating it. There must be a team which should handhold the child till adulthood.”

Health services for T1D encompass interventions delivered at the individual level (medical services) and interventions delivered to populations (health promotion, prevention, and protective services). Across CDIC facilities, there is great variation in the comprehensiveness of health services for T1D and the extent to which they are delivered effectively, efficiently, responsively, and equitably.

Degree of complexity

Health services for T1D are complex interventions, as they require multiple interventions over one's lifetime involving multiple stakeholders, different levels of care and behaviour change, which are more difficult to integrate into health systems compared to simpler interventions such as a one-time vaccination. Adoption and diffusion of complex interventions in health systems is more difficult compared to simpler interventions.

The nature of T1D and disease progression also lends to a higher degree of complexity. It is often difficult for children to adopt the practices needed for proper management as suggested by current best practices. Children and adolescents with T1D must make substantial changes in behaviour and develop a daily routine around their condition.

The perceived inconvenience of taking insulin interferes with eating, exercise, and daily routines, along with anxiety associated with hypoglycaemia, injection pain, time required to administer, and unique challenges of transitions into adolescents and adulthood.³² In addition, diabetic patients may be stigmatised in India and must deal with substantial emotional burden, due both to disease-specific requirements and social demands.³³

Section 3: Analysis of the Transition Readiness Assessment

3.1 Analysing Transition Readiness and Mapping of Readiness

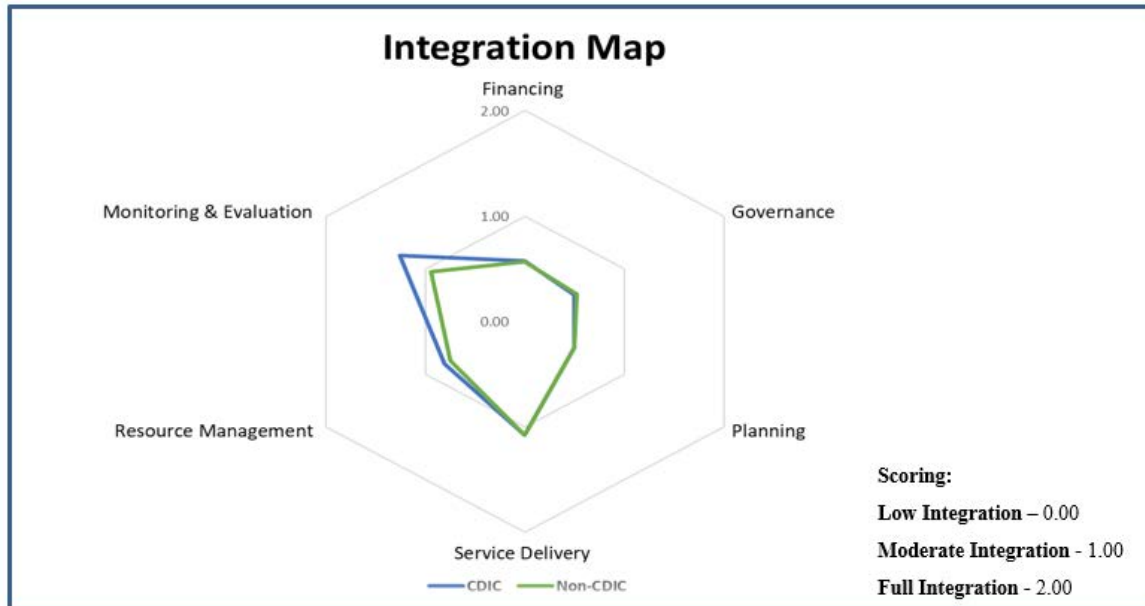
The integration analysis aims to ascertain how well the CDIC programme interacts and integrates with the Indian health system in critical health system functions. The receptivity analysis aims to understand how favourable the Indian context and adoption system is to enable transition and scale-up of the CDIC programme. Integration and receptivity were analysed and used to generate a score for integration and receptivity (Appendix D) and mapped separately on a spider diagram to understand strengths and vulnerabilities along each of the dimensions critical for integration and receptivity (Figure 19 & Figure 20). Finally, the overall readiness to transition score (comprising both integration and receptivity) was mapped on a transition readiness decision tree (Figure 22).

The readiness to transition to sustainability assessment revealed the following key findings, which could inform a transition management strategy for CDIC India. In terms of integration (Figure 19), the CDIC programme was well integrated with the health system in terms of service delivery and monitoring and evaluation, moderately well for resource management and financing, but not integrated to any significant extent in governance and planning. The receptivity assessment (Figure 20) revealed a receptive health system context to transition CDIC to sustainability, but the adoption system was not sufficiently receptive to promote integration and transition to sustainability. Concerning CDIC problem-solution fit, there were substantial opportunities to design and deliver health services for T1D that are better targeted to addressing T1D as experienced by providers and patients in India.

Five components comprise the health system context. While the context was moderately favourable to promote T1D investment and resource allocation, a closer look at each component reveals that the technology and economic components are strongly aligned and receptive; however, the political and epidemiological components were moderately receptive, and the legal component was not receptive to any significant extent (Figure 21).

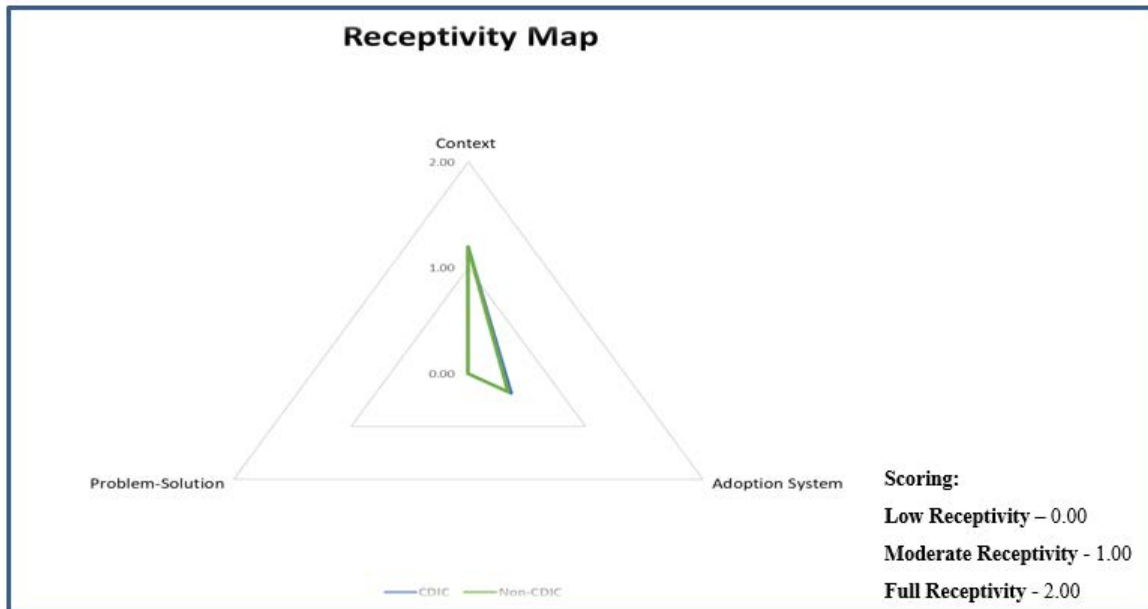
Finally, the readiness to transition analysis and mapping (Figure 22) revealed both low integration and low receptivity scores, indicating that efforts to promote both receptivity and integration are required to accelerate the transition to sustainability of the CDIC programme in India.

Figure 19: Integration Analysis for CDIC India



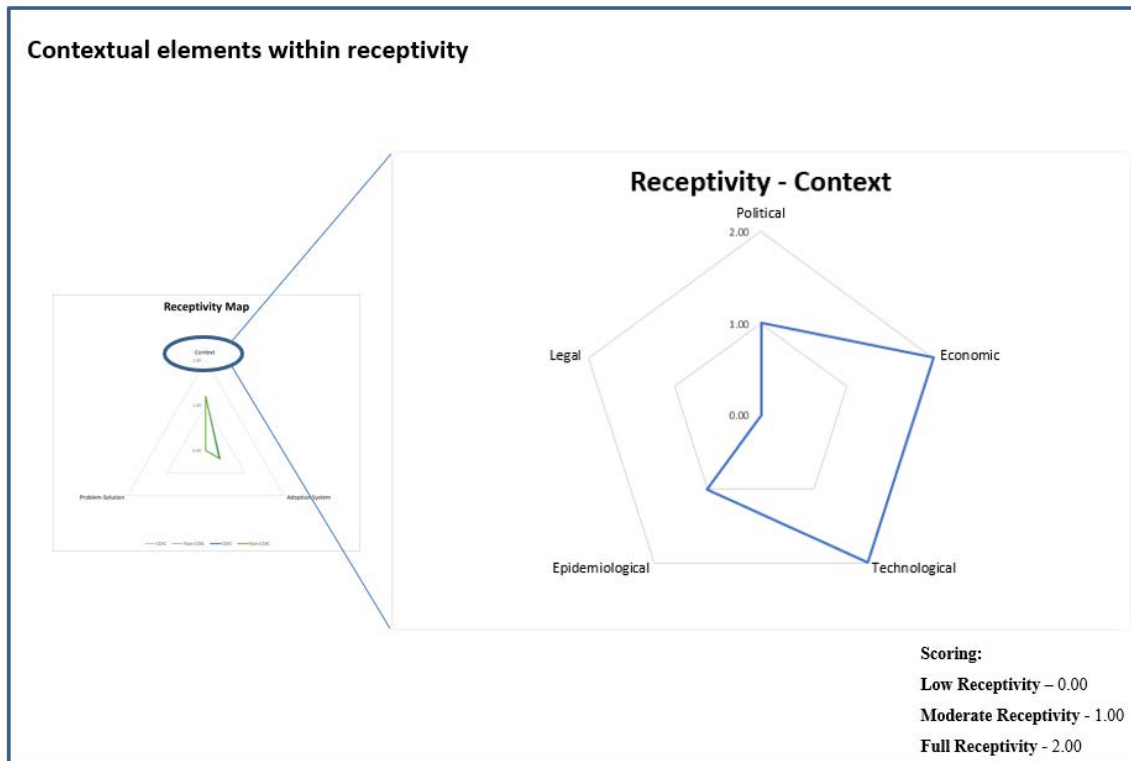
Source: Authors

Figure 20: Receptivity Analysis for CDIC India



Source: Authors

Figure 21: Breakdown of Contextual Factors Influencing Receptivity



Source: Authors

3.2 Comparative Analysis of CDIC Supported and Non-CDIC Supported Centres

A comparative sub-analysis of the integration and receptivity was done between CDIC supported centres and non-CDIC supported centres to understand variability and major differences regarding integration and receptivity components and their respective sub-components (Figures 19, Figure 20, Appendix E for scores).

While the overall score for the various components that comprise integration did not differ significantly, there were meaningful differences among certain sub-components (Figure 19). For example, while the overall score for the financing component was similar for CDIC supported centres (0.58) and non-CDIC supported centres (0.57) centres, there were important differences for resource mobilisation, a sub-component of financing. Regarding resource mobilisation, CDIC supported centres were more integrated (0.93) than non-CDIC supported centres (0.72), as fewer children paid for healthcare services out of pocket. Furthermore, a more significant proportion of

children received healthcare services for T1D due to direct support provided by CDIC supported centres (0.79) compared to non-CDIC supported centres (0.33).

Monitoring and evaluation was better integrated among CDIC supported centres (1.26) compared to non-CDIC supported centres (0.95). This difference is largely due to CDIC supported centres making better use of information technology so that patients have more ways to contact the centre compared to non-CDIC supported centres. These communication channels also enabled patients to contact the centres for dose adjustments more frequently. In addition, data collection and analysis among CDIC supported centres scored better (1.32) than non-CDIC supported centres (1.04). More CDIC supported centres have an EMR compared to non-CDIC supported centres. In addition, better tracking of patients exists at CDIC supported centres compared to non-CDIC supported centres, using various mediums such as EMRs, web-based applications, and excel spreadsheets. Supply chain management within resource management was higher among CDIC supported centres (1.31) than non-CDIC supported centres (1.00). This difference was largely due to T1D patients having to travel long distances to access care at non-CDIC supported centres than CDIC supported centres and the greater availability of cold storage facilities for Insulin in CDIC supported centres. While service delivery was similar across CDIC supported centres and non-CDIC supported centres, there was greater availability of human resources on-site among CDIC supported centres (1.29) compared to non-CDIC supported centres (1.17). These skilled health professionals included endocrinologists, physicians and diabetes educators.

Scores for the different components and sub-components within receptivity remained almost the same and overlapped between CDIC supported centres and non-CDIC supported centres (Figure 20). But not surprisingly, clinicians within CDIC supported centres voiced more favourable responses to consider T1D as a major national health problem that needs addressing urgently, compared to non-CDIC supported centres.

3.3 Sustainability Case Study: Six Crucial Imperatives from the ‘Mittayi’ T1D Programme in Kerala

Mittayi (“Confectionary”) is a programme launched in 2018 by the Kerala state government to improve the health of children and adolescents with T1D by providing free and comprehensive

treatment. We reviewed this programme to determine the major lessons from this programme and examine how its design, implementation and scale-up in Kerala could inform the scale-up of health services and programmes for T1D supported by CDIC in other states.

Imperative 1: Establish political will and commitment to providing comprehensive T1D care

Mittayi’s T1D programme was initiated and championed by the Kerala state government and it includes providing services for T1D at healthcare facilities, follow-up care at home, and the treatment of complications such as Diabetic Ketoacidosis (DKA). While India does not have an explicit focus on T1D, through strong political will and commitment of the state government leadership, Mittayi has been able to garner the initial support for a successful start and is poised to scale up throughout the state, confirming that addressing the political component within the context is indispensable.

Imperative 2: Harness the power of a multi-disciplinary, evidence-based approach to improve demand generation

The programme provides public health services for T1D at the population level, focusing on health promotion activities and creating awareness among relevant stakeholders, including, among others, teachers, parents, and social workers to enhance early detection and management. Mittayi also leverages academic institutions and medical schools in Kerala to strengthen research efforts and generate evidence that could improve T1D care and control. Although there is a lack of a national registry for T1D, estimates indicate that there are more than 5000 patients in the state of Kerala with T1D; 1700 are registered with the “Mittayi” programme. Including different stakeholders to create awareness and educating them to become knowledgeable about T1D, the Mittayi programme has aided and influenced not only the perception but also the priority of T1D. Furthermore, by taking an evidence-based approach and improving early detection and management, the programme enhances the ability to obtain better estimates of prevalence and incidence and use research findings to inform Mittayi focus and expansion.

Imperative 3: Lessen the financial burden for families with T1D

Since administering insulin is costly (insulin and glucose strips cost approximately INR5,000-10,000, equivalent to US\$60-120 per month) and more than 75% of children with T1D in Kerala

are from low-income families, the government of Kerala came to view T1D as a social mission. By re-framing management of T1D as a social mission through alleviating the financial burden, Mittayi has gained traction in addressing management of T1D for the most vulnerable population segments. Financing being one of the most critical elements of integration, Mittayi has successfully mobilised resources to expand access to health services for T1D. Nevertheless, setting up regulatory mechanisms, instilling governance, along with standardising and implementing guidelines for T1D care across all districts needs to be seen.

Imperative 4: Focus on delivering high-value health services for T1D throughout the T1D journey

Children are required to register with the Mittayi Programme online and are subsequently provided with a date to visit a centre for their initial consultation, which includes a full assessment of patient's history, clinical examination, and T1D testing. Patients are then provided with free insulin therapy and a continuous glucose monitoring device. T1D education and training are also provided to patients, their families, and teachers on wellness, managing the condition, follow-up, and recognising complications. Each patient is assigned a doctor to coordinate care and who is responsible for managing the patient journey and experience. Establishing an online platform, charting the course of action, follow-ups, training, and aligning resources has improved adherence among the T1D patients Mittayi serves. Through enhancing service coverage, strengthening supply chain management, leveraging existing service delivery channels, and developing a tracking system, Mittayi appears to have strategically integrated Mittayi with the Keralan health system in a manner that understands and values the patient experience.

Imperative 5: Enhance service delivery through a partnership model

Mittayi partnered with district hospitals and government medical colleges to introduce and iterate the programme at five facilities and was incrementally scaled to all fourteen districts in Kerala. The partnership model vastly enhanced service delivery and accelerated scale-up. Collaborating with government medical colleges provided opportunities for research, medical training, and student advocacy groups. Furthermore, each patient is assigned to a doctor to coordinate comprehensive services for and ensure responsiveness and continuity of treatment. Through the strategic partnership with existing institutions, leveraging existing infrastructure, and continuity of

treatment through assigned resources, the programme has been able to iterate and build on its initial success to support scale-up. Developing and deploying systems to systematically measure the efficiency, effectiveness, responsiveness and equity of health services for T1D would provide valuable lessons to leverage the full capabilities of the partnership model and expand actors participating in it.

Imperative 6: Build a collective enterprise with a shared vision that harnesses the capabilities of all partners

Mittayi programme is an example of a strategic partnership between various entities including the Kerala Social Security Mission, Health and Family Welfare Department, physicians, hospitals, and medical colleges, along with the political will, high level leadership, and institutional capability to be successful. Understanding the barriers and enablers to the design, implementation and scale-up of Mittayi in the Kerala health system and wider context could provide important insights for CDIC sustainability and replicability in other states in India. By improving affordability, educating stakeholders, and building capacity, Mittayi has been favourable in terms of adoption. Bringing together multiple entities as one cohesive force, essentially forming a collective enterprise, Mittayi provides insights into sustainability and replicability of such a programme in other states in India.

Section 4: A strategy to Transition CDIC India to Sustainability

4.1 Pathways of Transition to Sustainability and to Inform Transition Management

Three approaches could be pursued as part of a transition management strategy to promote the sustainability of CDIC India within the Indian health system and to align with PM-JAY to expand access to health services for T1D as part of the UHC policy agenda.

4.1.1 Enhance Integration (Pathway One)

The first approach, Pathway one, involves measures to enhance the integration of CDIC programmes within existing health system functions. As illustrated in Figure 19, while CDIC has demonstrated substantial integration in terms of monitoring and evaluation and enhancing service delivery, there are major opportunities to develop specific activities that promote integration of CDIC with existing health system functions in relation to financing, governance, planning, and resource management. CDIC continues to operate largely as a parallel program, especially in terms of financing and governance and planning, thereby not being able to leverage synergies through strong public-private partnerships, nor able to achieve the desired scale and reach. Pathway one focuses on opportunities to co-develop sustainability activities that strengthen integration along these functional areas.

4.1.2 Promote Receptivity (Pathway Two)

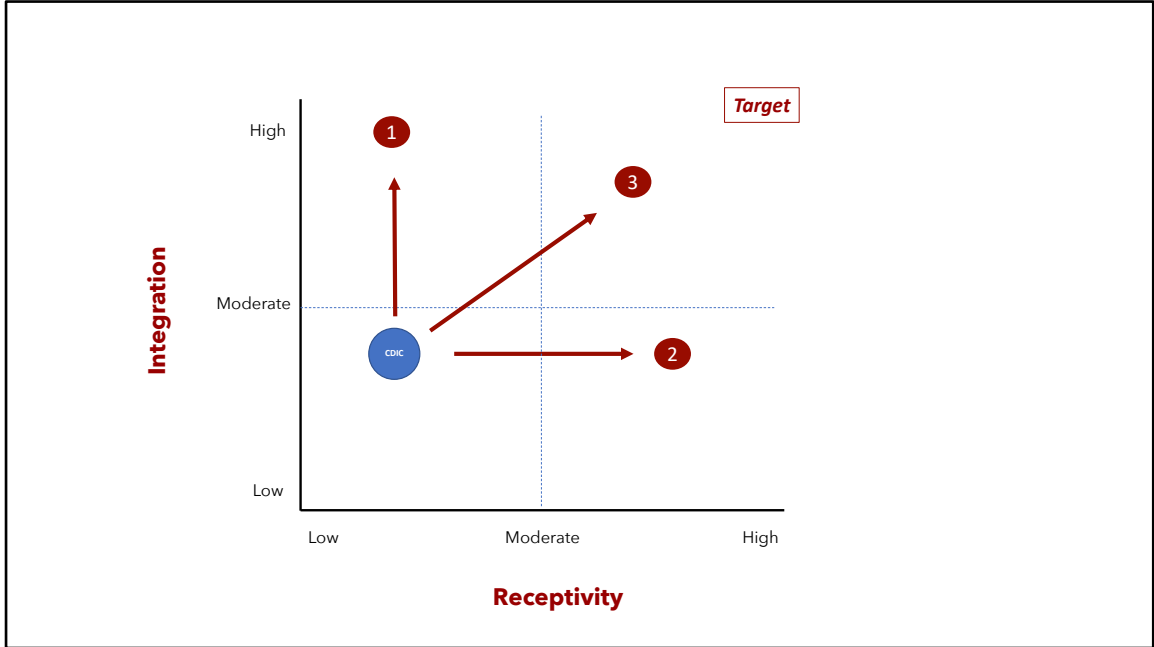
Pathway two involves focusing on efforts that promote receptivity for CDIC among the major stakeholders and within the broader context that shapes the Indian health system, within which CDIC is situated. In relation to the broad context, the economic and technological dimensions were favourable, while the political and epidemiological dimensions were moderately favourable for CDIC adoption. Specific activities targeted to harness these contextual windows could be developed within CDIC and implemented. For example, an investment case and accompanying fiscal space analysis could be developed to integrate a set of health services for T1D within the PM-JAY. This investment case should leverage data from CDIC and research emanating from GC-CDIC India to recommend specific services, the projected cost, and health system benefits with

spill over effects into other development sectors. Another opportunity lies specifically with harnessing existing technological platforms within CDIC-India and pursuing an explicit approach to integrate with and support PM-JAY Digital Mission and the UHC policy agenda. Finally, CDIC may lead efforts to educate stakeholders, including clinicians, institutions, political bodies, and citizens, to bring much-needed attention to T1D as a health priority for India. Most stakeholders are not actively engaging with the health system for enhanced health services for T1D and most private sector efforts are fragmented solutions or parallel efforts, which have not achieved the desired scale and reach. Opportunities exist for CDIC to demonstrate critical leadership by aligning interests, promote cohesion among interested partners and strategically engage policymakers to elevate the priority of T1D in India.

4.1.3 Enhance Integration and Promote Receptivity (Pathway Three)

The third pathway encompasses activities that blend pathways one and two. This pathway should analyse the proposed integration and receptivity activities to select and implement those activities that are most feasible, and most likely to lead to desirable sustainability outcomes and impact.

Figure 22: Readiness to Transition Mapping and Pathways to Sustainability



Source: Authors

4.2 Developing a Sustainability Strategy for CDIC India in Five Steps

Sustainability is arguably the most crucial aspect to the GC-CDIC. Substantial progress has been made to expand access to T1D healthcare services in India, but there is now a critical opportunity to leverage the existing platform, for system-wide impact and population-level benefit. Though CDIC is not well integrated into the Indian health system and there is progress to be made in terms of receptivity, there are clear pathways to sustainability, which need to be explored as a matter of urgency to ensure sustainability of CDIC and support of current priorities to improve health system performance in India through PM-JAY, India’s chosen path to achieve UHC. While this report provides an initial assessment of the readiness of CDIC India to transition to sustainability, subsequent sustainability efforts in CDIC India should follow the proposed five-step sustainability process (Figure 25).

Figure 23: Five Steps to Developing a Strategy for CDIC sustainability



Source: Health Systems Innovation Lab, Resources on Transitioning to Sustainability, 2021

- (I) Define the sustainability objectives: The findings of this report should provide an important starting point to begin a formal process of transition management of

CDIC India, informed by each of the five steps. The process of co-developing this study enabled important conversations around what sustainability means in the context of CDIC India. These initial discussions should be built upon to establish and elaborate on the sustainability objectives of CDIC India by engaging a more stakeholders that are involved in the program, and are impacted by it.

- (II) Develop a sustainability-focused transition continuum: once there is consensus about the sustainability objectives, a transition continuum should be developed to clearly establish the stages and milestones that will constitute the transition management process. This step should also discuss and develop approaches to create incentives that enable implementing partners to balance risk and reward and collaborate inclusively on the sustainability program. Bringing in support from multiple actors at this point, and defining incentive mechanisms for each, would be critical for the success of CDIC India.
- (III) Conducting a transition-to-sustainability readiness assessment: this transition readiness assessment could be complemented by convening a sustainability workshop to present findings to all stakeholders, engagement of government to explore PM-JAY alignment, and co-design an evidenced-based and inclusive transition management plan.
- (IV) Analysing transition readiness to inform a transition management plan: CDIC should use the transition assessment to develop a detailed transition management plan. This plan should clearly outline the pathway that will underpin the transition management strategy, prioritised activities that will enable progression along the transition continuum, timelines, risk and mitigation strategies, governance arrangements, and cost for programmatic support of transition activities. Existing activities that do not advance transition management should be discussed and decision taken to continue, abandon, or adapt.
- (V) Creating an enabling environment for sustained transition management: the three crucial and non-negotiable assets to sound transition management should be fostered: (I) strategic vision, partnership, and leadership; (II) data and technology; and (III) integration and alignment of exiting CDIC activities with those that are

sustainability-focused such that sustainability becomes an ingrained and virtually indistinguishable component of CDIC implementation and scale up.

4.3 Integrating T1D Services into Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PM-JAY)

In evaluating the pathways to sustainability, it is crucial to understand how an essential T1D benefits package could be delivered as part of the PM-JAY, India's policy to achieve Universal Health Coverage. While there is a lack of publicly accessible and comparable data on the costs of T1D healthcare services in India, there is evidence that the direct costs of delivering health services for T1D are high in relation to household income, with home blood glucose monitoring and insulin being the largest driver of expenditure, and the cost of treatment within the private sector being four times higher than the public sector.³⁴ Given the major financial burden placed on families, integrating T1D services as part of PM-JAY could help promote more equitable and responsive delivery of health services for T1D in India.

4.3.1 Designing and financing a benefits package for T1D

Three broad considerations require clarity when designing and implementing a T1D benefits package within PM-JAY:

Consideration 1: What health services for T1D should the benefits package include?

Health services for T1D include screening, diagnostic, and therapeutic interventions to detect and manage patients with T1D. Hence identifying a set of services for T1D that will be delivered as part of PM-JAY's must be established. Various criteria and economic evaluations could assist in making this determination, for example cost-effectiveness analysis to establish an appropriate mix of services by measuring costs and effects (e.g., improved clinical measures or quality of life) of various interventions for T1D, and taking into account economic and political considerations, as well as capacity of providers to deliver such services.

Consideration 2: How will benefits package be expanded and scaled to ensure universal coverage?

There are three pathways to the expansion of healthcare services for T1D:

- Expanding the scope of services for priority populations before expanding the coverage for all children. This would include focusing on providing a comprehensive set of healthcare services for T1D for a priority population first (for instance, those children and adolescents from low-SES households) before expanding the package to other population segments (i.e., those who can obtain private insurance).
- Expanding service coverage to include all children, before expanding the services offered. For example, such an approach could include the provision of a limited set of healthcare services for T1D to the entire population. Such an example could include the delivery of diagnostic and management services, but limited follow-up and hospital coverage for emergencies to all children and adolescents with T1D.
- Expanding the coverage and the scope of services. Service coverage would include pursuing both expansions of scope and scale simultaneously.

Consideration 3: Who will pay for the T1D benefits package, and how?

Once the T1D benefits package and the mode of expansion are established, it is important to evaluate the cost of the T1D package, determine the range of funding available, and identify potential funding sources.

4.3.2 Potential sources of funding

A formal fiscal space analysis could help identify the fiscal envelope to fund the T1D benefits package. Fiscal space refers broadly to the budgetary room to expand government expenditures, including for health, without compromising fiscal sustainability.³⁴

Fiscal space is influenced by; (i) macroeconomic conditions; (ii) government budget allocation to the health sector; (iii) allocation of health sector-specific resources to priorities and interventions; (iv) improved health system efficiency that will lead to savings in the budget (for example more

efficient procurement or supply chain management); (v) funding from external sources, and; (vi) innovative financing (Table 1).³⁵ Our preliminary analysis reveals favourable fiscal space for increased investment in health in India, and specifically, that sufficient funding could be mobilised to expand access for a T1D benefits package from increased macroeconomic growth alone – without any increased budgetary allocation to the health sector, efficiency-enhancing measures, innovative financing mechanisms. As discussed in a prior section, recent analyses by the IMF, emphasise the resilience of India’s economy in bouncing back after COVID-19, a comparative advantage over peer nations in weathering the inflation storm, and a robust domestic market – crucial factors for continued macroeconomic growth and healthcare investment.^{20,21}

4.3.3 Costing Model for health services for Type 1 Diabetes (T1D)

To estimate the cost of a T1D benefits package, it is important to understand the value chain of T1D care and grasp the cost of each health service for T1D, for each year and at the individual patient level. Additionally, to arrive at the share of the health budget that needs to be allocated to fund the services for T1D, the year-over-year (YoY) growth and inflation in costs should be considered, along with the burden on the economy if health services for T1D were to be reimbursed under PM-JAY.

The cost projection model (Appendix F) included multiple parameters (Table 1), such as medical devices, testing supplies, insulin and other medications, lab investigations, doctor consultation fees, disease severity where a specialist or expert consultation is needed, in-patient department on complications, associated transport and food and beverage, and remote monitoring costs. Within each of these parameters, reasonable assumptions were made, and the instruments were identified to either be included or not included in the benefits package. The range of costs was estimated, and the frequency of use of each instrument was included as input parameters. The cost for each instrument and the total cost for each parameter was estimated for both government and private sectors with reasonable discount for testing supplies (25%) gained from private entities (Appendix F).

The unit cost was extrapolated to arrive at an estimation of the total cost of including the prioritised services for T1D under PM-JAY given population growth, prevalence, expected increases in T1D

cases, and current percentage of population covered within PM-JAY. Similarly, the cost burden on the economy was based on the GDP growth rate, India’s fiscal budget, the health budget, and total health expenditures. The cost burden of including T1D under PM-JAY and the burden on the economy to reimburse for healthcare services for T1D were calculated for three scenarios and estimated from years 2023 to 2028 (Table 2):

- Scenario I: All T1D services for all children
- Scenario II: All T1D services for children under PM-JAY
- Scenario III: Only insulin for children under PM-JAY

Table 1: Input parameters for unit cost per patient year

	Input parameters considered	Instruments modelled
1	Medical Devices	Insulin Pen, Glucometer (optional: Insulin pump, Insulin patch, CGM)
2	Testing Supplies	Glucose Strips, Lancets
3	Medicine supplies	Basal insulin, Bolus insulin, other medicines
4	Lab Test	HbA1C, Creatinine, Hb, TSH, Albuminuria
5	Doctor consultation fees	Endocrinologist, Paediatrician, Diabetes educator, Ophthalmologist
6	Severity	Reference to Higher Consultations (e.g., due to Diabetic Ketoacidosis)
7	Hospitalization	In-patient hospitalization costs
8	Transport, F&B	Transportation, food and beverage
9	App/Remote Monitoring	Tele-consult and monitoring applications

Source: Authors

Table 2: Estimated additional health budget required for including healthcare services for Type 1 Diabetes (T1D) as a proportion of the current government health budget

Health budget estimation for health services for T1D (for 2023)	Total estimated cost (low end)			Total estimated cost (high end)		
	in crore, INR	in billion, USD	as % of health budget	in crore, INR	in billion, USD	as % of health budget
Scenario 1: All T1D services covered for All children	912	0.11	0.9%	1274	0.15	1.3%
Scenario 2: All T1D services covered for All children eligible under PM-JAY	365	0.04	0.4%	509	0.06	0.5%
Scenario 3: Only insulin provision covered for All children under PM-JAY	159	0.02	0.2%	212	0.03	0.2%

Source: Authors

Extending coverage for all children under PM-JAY and provide all health services for T1D (scenario 2), including insulin, glucose monitoring, consultation, and managing complications in certain cases, would require an additional fiscal envelope between 365-509 Crore INR (0.04-0.06 B USD), reflecting between 0.4-0.5% of India's 2023 health budget. Assuming a nominal growth in India's GDP at 6% YoY, the additional government health budget created due to GDP growth alone, would be ~5-6k INR, without any increase in allocations to health.

The required fiscal envelope to cover T1D services (~365-509 Crore INR) would be 6-9% of this additional budget expected. Based on the cost model estimations, India should be able to support health services for T1D at a relatively small incremental cost, which could be met from the expansion of the government fiscal space with GDP growth alone, even if the proportion of the health budget allocated from the Union budget remains the same. We see strong government impetus to increase allocations to health aided by robust economic growth such that funding health services for T1D for all may require an even smaller outlay of the health budget in the coming years.

References

- 1 Ward ZJ, Yeh JM, Reddy CL, *et al.* Estimating the total incidence of type 1 diabetes in children and adolescents aged 0–19 years from 1990 to 2050: a global simulation-based analysis. *The Lancet Diabetes & Endocrinology* 2022; **10**: 848–58.
- 2 Reddy CL, Atun R. Program of Work for the Global Collaborative for Changing Diabetes in Children (Unpublished Internal Document). 2021.
- 3 Reddy CL, Garcia JR, Atun R. Rethinking the Design of Health Systems: Transitioning to the High Value Health System Model (Position Paper). 2022.
- 4 Atun R, Moore G. Building a High-Value Health System. New York: Oxford University Press, 2021 DOI:10.1093/oso/9780197528549.001.0001.
- 5 Atun R. Transition to High Value Health Systems: A Primer. Boston, MA: Health Systems Innovation Lab. Harvard University, 2022.
- 6 Reddy CL, Atun R. Rethinking Transition to Sustainability: A Health Systems Approach. Position Paper. *Health Systems Innovation Lab, Harvard University* 2021.
- 7 Atun R, De Jongh T, Secci F, Ohiri K, Adeyi O. Integration of targeted health interventions into health systems: A conceptual framework for analysis. *Health Policy and Planning* 2010; **25**: 104–11.
- 8 Atun R, de Jongh T, Secci F, Ohiri K, Adeyi O. A systematic review of the evidence on integration of targeted health interventions into health systems. *Health Policy and Planning* 2010; **25**: 1–14.
- 9 National Programme for prevention & Control of Cancer, Diabetes, Cardiovascular Diseases & stroke (NPCDCS) :: National Health Mission. <https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=1048&lid=604> (accessed Dec 16, 2022).
- 10 Bhargava B, Paul VK. Informing NCD control efforts in India on the eve of Ayushman Bharat. *The Lancet (British edition)* 2022; **399**: e17–9.
- 11 Anganwadi Services | Ministry of Women & Child Development. <https://wcd.nic.in/schemes/anganwadi-services> (accessed Dec 16, 2022).
- 12 West Bengal govt to launch clinics for diabetic kids in 5 districts. The Times of India. 2022; published online March 26. <https://timesofindia.indiatimes.com/city/kolkata/govt-to-launch-clinics-for-diabetic-kids-in-5-dists/articleshow/90450928.cms> (accessed Dec 17, 2022).
- 13 Yasmin M, Mukhopadhyay P, Ghosh S. Model of care for Type 1 diabetes in India: Integrated approach for its incorporation in future national health care policy. *The Lancet Regional Health - Southeast Asia* 2022; **3**. DOI:10.1016/j.lansea.2022.05.003.
- 14 Mittayi. <https://www.mittayi.org/> (accessed Dec 16, 2022).
- 15 Website of Medical Council of India| National Portal of India. <https://www.india.gov.in/official-website-medical-council-india> (accessed Dec 16, 2022).

- 16 एनबीईएमएस NBEMS. <https://www.natboard.edu.in/> (accessed Dec 16, 2022).
- 17 Praveen PA, Madhu SV, Mohan V, *et al.* Registry of Youth Onset Diabetes in India (YDR). *J Diabetes Sci Technol* 2016; **10**: 1034–41.
- 18 Gomber A, Ward ZJ, Ross C, *et al.* Variation in the incidence of type 1 diabetes mellitus in children and adolescents by world region and country income group: A scoping review. *PLOS Global Public Health* 2022; **2**: e0001099.
- 19 National Health Authority | GOI. <https://nha.gov.in/> (accessed Dec 17, 2022).
- 20 India and the IMF. IMF. <https://www.imf.org/en/Countries/IND> (accessed Dec 16, 2022).
- 21 India Better Positioned to Navigate Global Headwinds Than Other Major Emerging Economies: New World Bank Report. World Bank. <https://www.worldbank.org/en/news/press-release/2022/12/05/india-better-positioned-to-navigate-global-headwinds-than-other-major-emerging-economies-new-world-bank-report> (accessed Dec 16, 2022).
- 22 GDP (current US\$) | Data. <https://data.worldbank.org/indicator/NY.GDP.MKTP.CD> (accessed Feb 14, 2022).
- 23 Out-of-pocket expenditure (% of current health expenditure) - India, China, Brazil, South Africa | Data. <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS?locations=IN-CN-BR-ZA> (accessed Dec 16, 2022).
- 24 Behera DK, Dash U, Sahu SK. Exploring the possible sources of fiscal space for health in India: insights from political regimes. *Health Res Policy Syst* 2022; **20**: 32.
- 25 Individuals using the Internet (% of population) - India | Data. <https://data.worldbank.org/indicator/IT.NET.USER.ZS?locations=IN> (accessed Dec 17, 2022).
- 26 Mobile cellular subscriptions (per 100 people) - India | Data. <https://data.worldbank.org/indicator/IT.CEL.SETS.P2?locations=IN> (accessed Dec 17, 2022).
- 27 India To Have 1 Billion Smartphone Users By 2026, As Rural India Comes Online. IndiaTimes. 2022; published online Feb 23. <https://www.indiatimes.com/technology/news/india-1-billion-smartphone-users-by-2026-562762.html> (accessed Dec 21, 2022).
- 28 Ward ZJ, Yeh JM, Reddy CL, *et al.* Estimating the total incidence of type 1 diabetes in children and adolescents aged 0–19 years from 1990 to 2050: a global simulation-based analysis (Supplementary Appendix). *The Lancet Diabetes & Endocrinology* 2022; **10**: 848–58.
- 29 International Covenant on Economic, Social and Cultural Rights. OHCHR. <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights> (accessed Dec 16, 2022).
- 30 Capistrant BD, Friedemann-Sánchez G, Novak LK, Zuijdwijk C, Ogle GD, Pendsey S. Mental health and well-being among type 1 diabetes caregivers in India: Evidence from the IDREAM study. *Diabetes Res Clin Pract* 2017; **134**: 168–77.

- 31 Swaminathan K, Mukhekar V, Cohen O. Breaking Socioeconomic Barriers in Diabetes Technologies: Outcomes of a Pilot Insulin Pump Programme for the Underprivileged in Rural India. *Indian J Endocrinol Metab* 2019; **23**: 242–5.
- 32 Wangnoo S, Maji D, Das A, *et al.* Barriers and solutions to diabetes management: An Indian perspective. *Indian journal of endocrinology and metabolism* 2013; **17**: 594–601.
- 33 Kesavadev J, Sadikot SM, Saboo B, *et al.* Challenges in Type 1 diabetes management in South East Asia: Descriptive situational assessment. *Indian J Endocrinol Metab* 2014; **18**: 600–7.
- 34 Ajay Tandon, Cheryl Cashin. Assessing public expenditure on health from a fiscal space perspective. Washington, DC: World Bank, 2010
<http://documents.worldbank.org/curated/en/333671468330890417/Assessing-public-expenditure-on-health-from-a-fiscal-space-perspective>.
- 35 Reddy CL, Vervoort D, Meara JG, Atun R. Surgery and universal health coverage: Designing an essential package for surgical care expansion and scale-up. *Journal of Global Health* 2020;

Appendix:

Appendix A: Survey questions, scoring, and data sources (Integration and Receptivity)

Integration component

No	Analytic component	Interview question	Score - 0 (Low integration)	Score - 1 (Moderate integration)	Score - 2 (Full integration)	Data Source (Interviews, Survey, Desk Review)
1	Financing					
1.1	Resource Mobilization	Who pays for the healthcare services provided for Type 1 Diabetes (T1D) in children and adolescents?	CDIC provides > 25% of funding for T1D healthcare services	regional/national funding (75-95%)	year budget cover >95% of total for T1D services	Interviews
1.1.1		What % of children (1-25 years) with T1D at your centre pay completely out of pocket?	>70%	30% - 70%	<30%	Survey
1.1.2		What % of children (1-25 years) at your centre are supported through public insurance and/or Government funds?	<30%	30% - 70%	>71%	Survey
1.1.3		What % of children (1-25 years) at your centre are supported through private insurance?	<30%	31% - 70%	>71%	Survey
1.1.4		What % of children (1-25 years) at your centre are supported through CDIC?	<30%	31% - 70%	>71%	Survey
1.1.5		What % of children (1-25 years) at your centre are supported financially by your centre?	<30%	31% - 70%	>71%	Survey
1.1.6		What % of children (1-25 years) at your centre are supported through patient support groups/philanthropic organizations?	<30%	31% - 70%	>71%	Survey
1.2	Universal Health Coverage	What proportion of T1D healthcare services (screening, diagnostics, treatment) for children and adolescents are included in the essential benefits package?	essential benefits services	essential benefits services and deployed widely at scale	essential benefits services and are universal, provided at	Interviews
1.2.1		Does your country government support screening, diagnostics, treatment services for children (1-25 years) with T1D?	No	Partial support	Yes	Survey
1.2.2		In your state, does the government provide insulin in government hospitals?	No		Yes	Survey
2	Governance					
2.1	Polymaking	Do the national health policies include plans for improving and expanding financing and healthcare services for T1D for children and adolescents?	policies related to T1D for children and diabetes	mentioned in some health policies, but there is no national program for T1D nor plans to	included in national health plans with dedicated funding and a national program	Interviews, Desk Review
2.2	Regulation	Who accredits, licenses and certifies providers and practitioners involved in the care of children and adolescents with T1D?	No entity exists	regulates providers that deliver T1D healthcare	regulating general healthcare providers and practitioners and undertake licencing	Desk Review
2.2.1		Are you aware of the national guidelines published for the management of T1D children?	No		Yes	Survey
2.2.2		Does your centre adopt and follow these national guidelines for management of T1D?	No - stakeholders are not aware of the guidelines	Partial - most stakeholders are aware of the guidelines but adoption is partial	Yes - all stakeholders in the centre universally adopt all guidelines	Survey
3	Planning					
3.1	Planning	Is there a dedicated institution that conducts baseline assessments and surveys for T1D, determines priorities and allocates resources for healthcare services related to ?	formal system or process exists for regular baseline assessment and	involved in baseline assessments and surveys for T1D to determine priorities and allocate	and stakeholders to ensure regular and effectively coordinated baseline	Interviews
3.2	Demand Generation	Who is responsible for and who funds the development of information, education and communication (IEC) of health promotion activities for T1D?	activities are intermittent and cover less than 50% of population	the activities are not coordinated and cover less than 75% of population	organizations involved in T1D to ensure provision of IEC of health services for T1D	Interviews, Desk Review
4	Service Delivery					
4.1	Human Resources	Who is responsible for providing T1D healthcare services?	CDIC staff	Shared between general health workers and CDIC staff	General health workers	Interviews, Desk Review
4.1.1		Please indicate which of the below resources are available at your centre for children (1-25 years) with T1D? (select all that apply)	No physician or endocrinologist available	Either a physician or an endocrinologist available	Physicians and endocrinologist available	Survey
4.2	Performance Management	Are there national guidelines for the management of T1D?	No guidelines exist	Multiple guidelines exist, but their use id patch (less than 50% of practitioners)	National guidelines exist and are widely used	Interviews
4.2.1		What % of children (1-25 years) with T1D who come to your centre have an appointment?	<30%	31% - 70%	>71%	Survey
4.2.2		What % of total children (1-25 years) seen at your centre come with symptoms of T1D? (of all children who come for any treatment at your centre)	<5%	6%-30%	>31%	Survey
4.3	Service Coverage	Geographically, is there adequate provision of effective T1D services?	Few Primary Health Care facilities provide T1D services; <50% of demand is met	Many Primary Health Care facilities provide T1D services; 50% - 75% of demand is met	Most Primary Health Care facilities provide T1D services; >75% of demand is met	Desk Review
4.3.1		Please indicate which of the below services are provided at your centre for children (1-25 years) with T1D?	No clinical examination, or lab tests or eye fundus available	No clinical examination, but lab tests or foot exam available	Clinician examination, lab and/or eye fundus examination available	Survey
4.3.2		How frequently do your T1D patients get HbA1c test done?	Once	Twice	Three or more	Survey
4.3.3		Which essential lab investigations are performed at your centre for a child with T1D (1-25 years) select all that apply	No HbA1c or blood sugar tests available	Either HbA1c or a blood sugar test available	HbA1c and blood sugar tests available	Survey
5	Resource Management					
5.1	Supply Chain Management	What proportion of children (1-25 years) with T1D travel more than 60 minutes to reach your centre?	> 76% of the population	51% - 75% of the population	< 50% of the population	Survey
5.2	National Health Accounts	Do accounting systems exist to collect relevant data to measure the cost of healthcare services for T1D?	< 50% of facilities collect data on T1D costs	50% - 75% of facilities collect data on T1D costs	>75% of facilities collect data on T1D costs	Survey
6	Monitoring & Evaluation					
6.1	Information Technology Infrastructure	How do children (1-25 years) with T1D contact you for dose adjustments? (select all that apply) - Selected Choice	Less than 3 methods available	3-5 methods contact methods are available	5 or more contact methods are available	Survey
6.1.1		How often do children (1-25 years) with T1D contact your centre for dose adjustments?	Only during hospital visit	Monthly	Weekly	Survey
6.2	Data Collection and Analysis	Is there a digital registry for T1D?	No digital registry for T1D exists	Registries for T1DM exist, but not core data set used to inform M&E processes	Registries exist with an agreed core data set used to inform M&E processes	Interviews
6.2.1		Does your centre maintain electronic medical records for a digital data registry for all children (1-25 years) with T1D?	No		Yes	Survey
6.2.2		How do you currently track progress for T1D children enrolled at your centre?	asked to maintain paper records at their end	sheet maintained at our centre, Web-based application used for data capture	Electronic medical records maintained at our centre	Survey
7	Comments					
7.1	Miscellaneous	Please provide additional comments that could help clarify your answers provided				

Receptivity component

No	Analytic component	Interview question	Score - 0 (Low receptivity)	Score - 1 (Moderate receptivity)	Score - 2 (Full receptivity)	Data Source (Interviews, Survey, Desk Review)
1 Context						
1.1	Political	Does the government prioritize healthcare and adequately finance the health system?	< 50% of total current health expenditure is from government sources	51-75% of total current health expenditure is from government sources	> 75% of total current health expenditure is from government sources	Desk Review
1.1.1		Does a political environment and commitment exist to improve UHC?	There is no conducive environment or commitment to improve UHC	Political environment and commitment exist, but no implementation plan in place	Political environment and commitment exist, with implementation plan in place	Interviews, Desk Review
1.2	Economic	How favourable is the fiscal envelope for health?	< 1%	1.1-4.9%	> 5%	Desk Review
1.3	Technological	What % of children (1-25 years) at your centre with T1D have access to the internet?	< 25%	26-75%	> 76%	Survey, Interviews, Desk Review
1.3.1		What % of children (1-25 years) at your centre with T1D have access to a smartphone?	< 25%	26-75%	> 76%	Survey, Interviews, Desk Review
1.4	Epidemiological	Does T1D constitute a significant burden of disease in children and adolescents compared to other health conditions?	< 5% of the total disease burden in children and adolescents	5.1%-9.9% of the total disease burden in children and adolescents	> 10% of the total disease burden in children and adolescents	Interviews, Desk Review
1.5	Legal	Do citizens have a legal right that entitles them to receive healthcare services or entitlement to universal health coverage for essential health services?	No legal right exists	Some entitlements exist in sub-national regions by state constitutions, acts or articles	National constitutional right exists for all citizens	Interviews, Desk Review
2 Adoption System						
2.1	Clinicians	Do clinicians consider T1D as a major national health problem that needs addressing urgently?	<50% clinicians consider T1DM as a major national health problem	51-75% clinicians consider T1DM as a major national health problem	> 76% clinicians consider T1DM as a major national health problem	Survey
2.2	Policy makers	Do policy makers consider T1D as a major problem to address urgently?	<50% policy makers consider T1DM as a major national health problem	T1DM as a major national health problem	> 76% policy makers consider T1DM as a major national health problem	Interviews
2.3	Citizens	Do citizens consider T1D as a major national health problem to address urgently?	<50% of citizens consider T1DM as a major national health problem	51-75% of citizens consider T1DM as a major national health problem	> 76% of citizens are engaged in decision making process for T1D	Survey
2.4	Public Funders	Do public funders view T1D as a major health problem to address urgently?	<50% public funders see T1D as a problem	51-75% public funders see T1D as a problem	> 76% public funders see T1D as a problem	Survey
2.5	Private Funders	Do private funders view T1D as a major health problem to address urgently?	<50% private funders see T1D as a problem	51-75% private funders see T1D as a problem	> 76% private funders see T1D as a problem	Survey
3 Problem-Solution						
3.1	Problem - Solution Alignment	How comprehensive are the healthcare services for T1D?	provided at PHC level but not in all parts of the country	are provided at primary health care level at 50-75% of the country	provided at primary health care and hospital levels throughout the country	Interviews
3.2	Degree of Complexity	How complex are the healthcare services for T1D?	Highly complex health services are required for T1D	Moderate level of healthcare services are required for T1D	Simple healthcare services are sufficient for T1D	Interviews
4 Comments						
4.1	Miscellaneous	Please provide additional comments that could help clarify your answers provided				

Appendix B: Overview of survey methodology analysis

- The initial survey was designed with input from key opinion leaders and tested. The survey was further refined based on feedback from select audience.
- The finalized survey was sent to clinicians who focused on management of T1D, and included those who were affiliated with CDIC and those who were not.
- A total of 70 responses were received through Harvard Qualtrics.
- All survey responses received through Qualtrics were cleaned and analysed using Microsoft Excel.
- Each question was mapped to specific analytic components within integration or receptivity.
- Responses for each question were coded appropriately as low, medium, or high, for both integration and receptivity, and aligned to the rubric in the transition tool.
- Questions were grouped for each of the analytical components and score was averaged.
- Where applicable, the survey response was augmented and verified through the interviews and desk review.

Appendix C: Survey respondents and location characteristics

Total number of responses	70
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Highest Educational Qualifications	#
Doctoral / PhD	14
If Other, please mention as text below	14
Masters / equivalent degree	21
MBBS / equivalent degree	5
Not Specified	16

Practicing Speciality	#
Diabetologist	14
Endocrinologist	23
General physician	4
Paediatric endocrinologist	5
Paediatrician	4
Others	5
Not Specified	15

Urban/Rural	#
Rural	3
Urban	50
Not sure	1
Not Specified	16

Centre located in major city	#
No	26
Yes	26
Not Specified	18

Location Ownership	#
Government owned and operated	4
NGO/trust owned and operated	5
Privately owned and operated	22
Not Specified	39

Location Category	#
Community clinic (ASHA, social)	2
Government hospital	3
Nursing home	2
Private clinic (only consultation services)	18
Private/Corporate hospital	9
Not Specified	36

CDIC Center	#
No	18
Yes	14
Not Specified	38

Appendix D: CDIC Integration and Receptivity Scores

Integration		
No	Analytic component	CDIC
1	Financing	
1.10	Resource Mobilization	0.58
1.20	Universal Health Coverage	0.60
	Financing	0.59
2.00	Governance	
2.10	Polymaking	0.00
2.20	Regulation	1.00
	Governance	0.50
3.00	Planning	
3.10	Planning	1.00
3.20	Demand Generation	0.00
	Planning	0.50
4.00	Service Delivery	
4.10	Human Resources	1.29
4.20	Performance Management	0.56
4.30	Service Coverage	1.39
	Service Delivery	1.08
5.00	Resource Management	
5.10	Supply Chain Management	1.31
5.20	National Health Accounts	0.31
	Resource Management	0.81
6.00	Monitoring & Evaluation	
6.10	Information Technology Infrastructure	1.20
6.20	Data Collection and Analysis	1.32
	Monitoring & Evaluation	1.26

Receptivity		
No	Analytic component	CDIC
1	Context	
1.1	Political	1.00
1.2	Economic	2.00
1.3	Technological	2.00
1.4	Epidemiological	1.00
1.5	Legal	0.00
	Context	1.20
2	Adoption System	
2.1	Clinicians	1.15
2.2	Policymakers	0.00
2.3	Citizens	0.38
2.4	Public Funders	0.08
2.5	Private Funders	0.23
	Adoption System	0.37
3	Problem-Solution	
3.1	Problem - Solution Alignment	0.00
3.2	Degree of Complexity	0.00
	Problem-Solution	0.00

Appendix E: Comparison between CDIC Supported Centres and Non-CDIC Supported Centres

Integration			
No	Analytic component	CDIC	Non-CDIC
1	Financing		
1.10	Resource Mobilization	0.55	0.45
1.20	Universal Health Coverage	0.60	0.69
	Financing	0.58	0.57
2.00	Governance		
2.10	Polymaking	0.00	0.00
2.20	Regulation	1.00	1.04
	Governance	0.50	0.52
3.00	Planning		
3.10	Planning	1.00	1.00
3.20	Demand Generation	0.00	0.00
	Planning	0.50	0.50
4.00	Service Delivery		
4.10	Human Resources	1.29	1.17
4.20	Performance Management	0.56	0.67
4.30	Service Coverage	1.39	1.40
	Service Delivery	1.08	1.08
5.00	Resource Management		
5.10	Supply Chain Management	1.31	1.00
5.20	National Health Accounts	0.31	0.50
	Resource Management	0.81	0.75
6.00	Monitoring & Evaluation		
6.10	Information Technology Infrastructure	1.20	0.85
6.20	Data Collection and Analysis	1.32	1.04
	Monitoring & Evaluation	1.26	0.95
	Overall Integration Average	0.79	0.73

Receptivity			
No	Analytic component	CDIC	Non-CDIC
1	Context		
1.1	Political	1.00	1.00
1.2	Economic	2.00	2.00
1.3	Technological	2.00	2.00
1.4	Epidemiological	1.00	1.00
1.5	Legal	0.00	0.00
	Context	1.20	1.20
2	Adoption System		
2.1	Clinicians	1.15	0.94
2.2	Polymakers	0.00	0.00
2.3	Citizens	0.38	0.44
2.4	Public Funders	0.08	0.13
2.5	Private Funders	0.23	0.20
	Adoption System	0.37	0.34
3	Problem-Solution		
3.1	Problem - Solution Alignment	0.00	0.00
3.2	Degree of Complexity	0.00	0.00
	Problem-Solution	0.00	0.00
	Overall Receptivity Average	0.52	0.51

Appendix F: Cost estimation model of health services for Type 1 Diabetes (T1D)

Parameters Considered:

Model - T1DM	
1 Objectives	
1	Arrive at Cost / Patient / Year broken down for each T1D service <i>Look at Value Chain of T1DM care</i>
2	Estimate cost burden for all patients with T1D <i>Look at total cost accounting for # of children with T1D, expected YoY growth, inflation in costs</i>
3	Estimate burden on economy if T1D services were to be reimbursed under PM-JAY <i>Look at share of health budget allocation to fund T1D care</i>
2 Arrive at Cost / Patient / Year	
Cost Parameters	
1	Medical Devices : Insulin Pump, Glucose monitoring, Insulin patch, CGM
2	Testing Supplies : Glucose Strips, Lancets, Glucose Control Solution)
3	Medicine supplies : Basal insulin, analogue insulin, other medicines
4	Lab Test : HbA1C, Creatinine, Hb, TSH, tTG
5	Doctor consultation fees (suite of specialities)
6	Severity : Reference to Higher Consultations (due to DKA)
7	Hospitalization : In-patient costs
8	Transport, F&B : Transportation and meals
9	App / Remote Monitoring : Tele-consult and monitoring applications
Frequency	
1	Types of Frequency (Daily/Weekly/Monthly/Yearly)
Reimbursement	
1	Share reimbursed by Government
3 Population Extrapolation and Burden on Economy	
1	Populated covered under PM-JAY
2	Provision of T1D care : private vs govt
3	Prevalence of T1D cases
4	Expected YoY growth in T1D cases
5	GDP growth rate
6	Inflation rate
7	India union budget
8	% allocation of budget to health
4 Additional parameters (not considered)	
Timing / Schedule of Insurance	
1	Covering Period missed due to Late Diagnosis
2	Overlap of PMJAY with state run insurance schemes

