

BEYOND ACCESS TO INSULIN: A HEALTH SYSTEMS APPROACH TO MANAGING TYPE 1 DIABETES

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Acronyms

ACCISS	Addressing the Challenge and Constraints of Insulin Sources and Supply
ADA	American Diabetes Association
BGM	Blood Glucose Meter
CCM	Chronic Care Model
CHW	Community Health Worker
HNT1D	Hierarchy of Needs for Type 1 Diabetes
ICCCF	Innovative Care for Chronic Conditions Framework
LMIC	Low- and middle-income country
NCD	Non-communicable disease
PHC	Primary Health Care
RAP	Rapid Assessment
SDG	Sustainable Development Goal
UHC	Universal Health Coverage
WHO	World Health Organization

Executive Summary

Previous work by the Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS) Study highlighted the poor availability and affordability of insulin. While insulin for type 1 diabetes is a rare example of an absolute need for a given medicine, insulin alone is not enough to ensure the proper management of diabetes. A variety of health system factors, from well-trained health care professionals to access to diagnostics, education and support, are all necessary in order to ensure that care is provided in a comprehensive way.

The World Health Organization (WHO) defines a health system as all activities which focus on promoting, improving and maintaining health. Specifically, for chronic conditions (including diabetes), the WHO developed the Innovative Care for Chronic Conditions Framework, which presents the different components necessary for a health system to be appropriately organised to deliver care. This framework places significant importance on the policy environment and community at large.

To manage type 1 diabetes, beyond health system components, an emphasis must be placed on the individual and how the health system responds to their specific needs. The Hierarchy of Needs for Type 1 Diabetes (HNT1D) framework prioritises interventions to improve type 1 diabetes management. This approach highlights more urgent needs and ensures that countries, especially those with low resources, focus on a series of specific interventions that allow for the foundations of diabetes services to be developed.

The HNT1D was developed following a comprehensive review of the literature and in-depth interviews with 101 individuals with type 1 diabetes in 13 countries. This framework focuses on different groups of needs: Survival, Safety, Belonging, Self-Esteem, and Self-Actualisation Needs.

To apply the HNT1D to the health system, it is required that the factors that guarantee survival of the individual with type 1 diabetes are addressed. This includes: policies; organisation of the health system; insulin; delivery of insulin and glucose control (e.g., blood or urine glucose); healthcare workers; and information and education. For example, overall policies for type 1 diabetes should focus on ensuring that care and medicines are provided at the lowest possible cost possible, if not free. To do this, a comprehensive idea of what is already available for diabetes care at each level of the health system is needed. Recommendations to improve the health system must include a clear definition of the role of each level of the health system for type 1 diabetes care (such as specialised clinics and referrals)

Heavily based on the Hierarchy of Need, and building on other conceptual and theoretical frameworks, the model in this guide presents an overall approach for countries developing their diabetes services within their health system. This step-by-step approach aims to assist countries on where to begin and highlights the different elements they should address to build a positive environment for the type 1 diabetes management. It is also recommended that, before addressing the specific challenges of diabetes management in a given country, a baseline analysis of issues that might hamper access to diabetes medicines and care is undertaken. One proposed approach is using a standardised Rapid Assessment Protocol (RAP) that has been used in different settings for diabetes. Although most of the literature on

the delivery of services for type 1 diabetes focuses on children, this report aims to provide an overall framework for the management of type 1 diabetes in all ages.

The proposed model to develop health systems for type 1 diabetes uses a hub and spoke approach. This is suited to type 1 diabetes given the need for specialised services and the low number of beneficiaries. The hub offers a comprehensive list of services with spokes providing fewer services, but being linked to the hub. The overall configuration should be governed by specific guidelines. At each level, there is also a strong link to the community at large to address the wide-ranging issues, such as support and education activities. Overarching health policies need to facilitate this development of the system in addition to wider policies outside the realm of health. Type 1 diabetes can be viewed as a useful tracer within chronic conditions and, therefore, the material presented in this report can have wider ramifications for health systems.

This report relies heavily on previous material developed by David Beran.^{1,2}

Background

Previous work by the Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS) Study highlighted the poor availability and affordability of insulin.^{3,4} The factors leading to this included a variety of barriers at global and national level. Little is known about why the price of insulin has remained consistently high over time. It is thought, however, to be the result of market domination by three multi-national companies, Eli Lilly, Novo Nordisk and Sanofi.⁵ This domination has also meant that individuals with diabetes have had to change types of insulin as these companies have the ability to withdraw formulations from the market.^{6,7}

Insulin for type 1 diabetes is a rare example within chronic conditions where there is an absolute need for a given medicine. Although global disease burden data is lacking, it is estimated that about one million individuals aged 19 and under are living with type 1 diabetes.⁸ Further, it is estimated that for 63 million people living with type 2 diabetes, insulin⁸ is required for better control and management of decompensation. Its use is dependent on capabilities existing within different health systems.

That said, insulin alone is not enough for the proper management of diabetes. A variety of health system factors are necessary to ensure that comprehensive care is provided. A non-extensive list includes trained health professionals, access to diagnostics, referrals in case of complications, and education tools for individuals and their families. As with any health-related issue, the larger socio-economic situation of the country and individuals must be considered. Poverty is, in many instances, a primary barrier to access to appropriate health. However, the focus here is to build on different conceptual and theoretical frameworks to provide countries an overall approach to developing their diabetes services within their health systems. The model presented details different elements countries should address to build a positive environment for the management of type 1 diabetes through a step-by-step approach.

1. Addressing Chronic Conditions: A Health Systems Perspective

1.1. The World Health Organization’s health system building blocks and Innovative Care for Chronic Conditions Framework

The World Health Organization (WHO) states that a health system includes all ‘activities whose primary purpose is to promote, restore and maintain health’⁹ and have as their objectives to:⁹

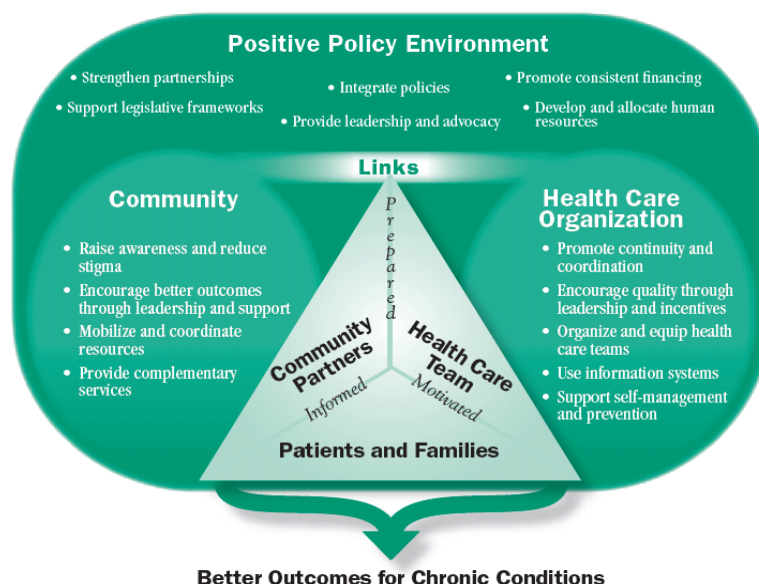
1. improve the health of the populations they serve
2. respond to the populations’ expectations
3. provide financial protection against ill-health

In trying to achieve these aims, health systems need to provide six key elements:¹⁰

1. Service delivery: how services are organised and delivered through the presence of safe and quality healthcare provision, facilities and infrastructure
2. Healthcare workforce: human resource availability and training
3. Information: Research, surveillance systems, among others
4. Medical products, vaccines and technologies
5. Financing
6. Leadership and governance: Sometimes called “Stewardship”, is the role the government plays in engaging other national actors that impact health ^{9,11}

To specifically address the issue of chronic health condition management within health systems, Wagner et al.¹² developed the Chronic Care Model (CCM). To adapt this model to low- and middle-income country (LMIC) contexts, WHO further expanded this model into the Innovative Care for Chronic Conditions Framework (ICCCF) (Figure 1).¹³ In comparison to the CCM, the ICCCF places more importance on the policy environment and community.

Figure 1. WHO Innovative Care for Chronic Conditions Framework, copied from WHO 2002¹³



The ICCCF presents the different components necessary for a health system to be appropriately organised to deliver care for chronic conditions.¹⁴ One element that is highlighted by this model is the emphasis put on the role of the individual and their family in the daily management of chronic conditions.

1.2. Using Type 1 Diabetes as a Tracer Condition

Kessner et al.¹⁵ were the first to use the concept of tracers with regards to health systems. The concept was based on radioactive tracers that were used by healthcare workers to see how different organs work. They then applied this idea to health systems—using certain conditions as tracers to show how a health system worked. These tracer conditions needed to be distinct and identifiable health problems that demonstrated how particular parts of the health system worked together to provide healthcare. They established six criteria for tracers. These are (in order of importance):

1. The condition used as a tracer should have a measurable impact on the patient and treatment of this condition should also influence outcomes
2. A tracer condition should be well defined and easily diagnosed
3. The prevalence of the conditions should be significant enough to allow for adequate data collection
4. The progression of the condition should vary with varying use of the health system
5. Medical/Clinical management of the condition should be well defined in at least one of the following areas: prevention, diagnosis, treatment or rehabilitation
6. Non-medical aspects of the condition should be known, as well as the epidemiology

The suitability of type 1 diabetes with regards to these six criteria is detailed in Table 1.

Table 1. The suitability of type 1 diabetes as a “tracer” condition¹⁶

Criteria for “tracer” condition based on Kessner et al. ¹⁵	Factor related to type 1 diabetes
Condition should have a measurable impact on the patient	Type 1 diabetes has a clear impact on the individual
Treatment of this condition should also influence outcomes	Without insulin the person will die
Well defined and easily diagnosed condition	Type 1 diabetes is clearly defined clinically with specific diagnostic criteria
Prevalence of the condition should be significant enough to allow for adequate data collection	This is the case in some populations, but not all. However, each population, no matter where, will have at least some people with type 1 diabetes
Progression of the condition should vary with varying use of the health system	Progression and development of complications is directly linked to use of health system
Medical/Clinical management of the condition should be well defined in at least	Type 1 diabetes qualifies in the following areas:

Criteria for “tracer” condition based on Kessner et al. ¹⁵	Factor related to type 1 diabetes
one of the following areas: <ul style="list-style-type: none"> • Prevention • Diagnosis • Treatment • Rehabilitation 	<ul style="list-style-type: none"> • Diagnosis • Treatment
Non-medical aspects of the condition should be known as well as the epidemiology	These are known and clearly described in the literature. Epidemiology in most settings is known. In others where it is unknown, predictions exist as type 1 diabetes is present to varying degrees in all populations.

Nolte et al.¹⁷, in applying this concept, developed a mortality to incidence ratio for 29 industrialised countries using related published data. They used the mortality/incidence ratio as a crude indicator of “case fatality” and thus the overall quality of healthcare. This measure was used to identify differences in the performance of health systems. A wide variation was found across countries highlighting differences in the provision of care for people with diabetes.

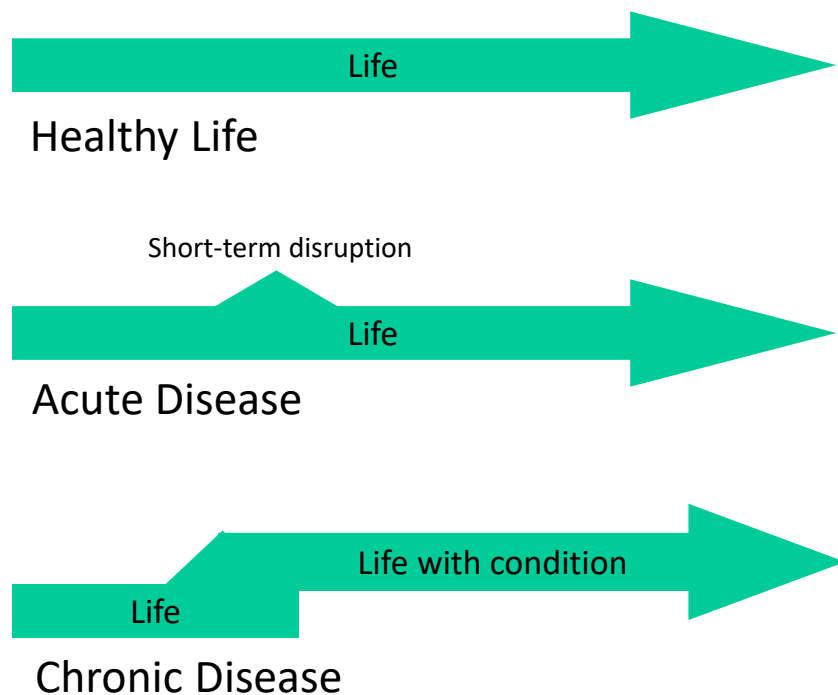
Diabetes is argued to be a good “tracer”, as the tools needed in the health system to provide management are similar to those of other chronic conditions.

1.3. Focusing on the Individual with Type 1 Diabetes

Changes at a health system level need to consider the individual. The diagnosis of a chronic condition such as type 1 diabetes can lead to the immediate change in all aspects of the individual’s life: adoption of new self-management skills (e.g., daily use of insulin and testing blood glucose, changes to diet and exercise); the need for family or peer involvement and support; and the development of coping mechanisms.^{12,18,19} Bury²⁰ describes chronic conditions as a “biographical disruption” where the life of the person and things that they normally take for granted change. Chronic conditions impact all areas of work and home life, from their costs on time, to the socioeconomic and emotional toll.²⁰ This change in “biography” is described in

Figure 2. With an acute condition, the change in routine is for a few days, weeks or even months, but once recovered, the individual returns to “normal”. With a chronic condition the definition of “normal” changes as the person needs to adapt their entire life, to a “new normal”. In addition, the person may face a certain amount of stigma because of their condition.²¹

Figure 2. Chronic Conditions as a “biographical disruption” adapted from Bury²⁰



With this in mind, Asadi-Lari et al.²² argue that, to improve health, health systems must to be designed to meet people’s needs. As argued by McKee²³, those managing health systems should identify these needs and find a way to prioritise these. This report will use the Hierarchy of Needs for Type 1 Diabetes (HNT1D) as a framework for proposing a stepwise approach for health systems to address the different needs of people with type 1 diabetes.

2. The Hierarchy of Needs for Type 1 Diabetes

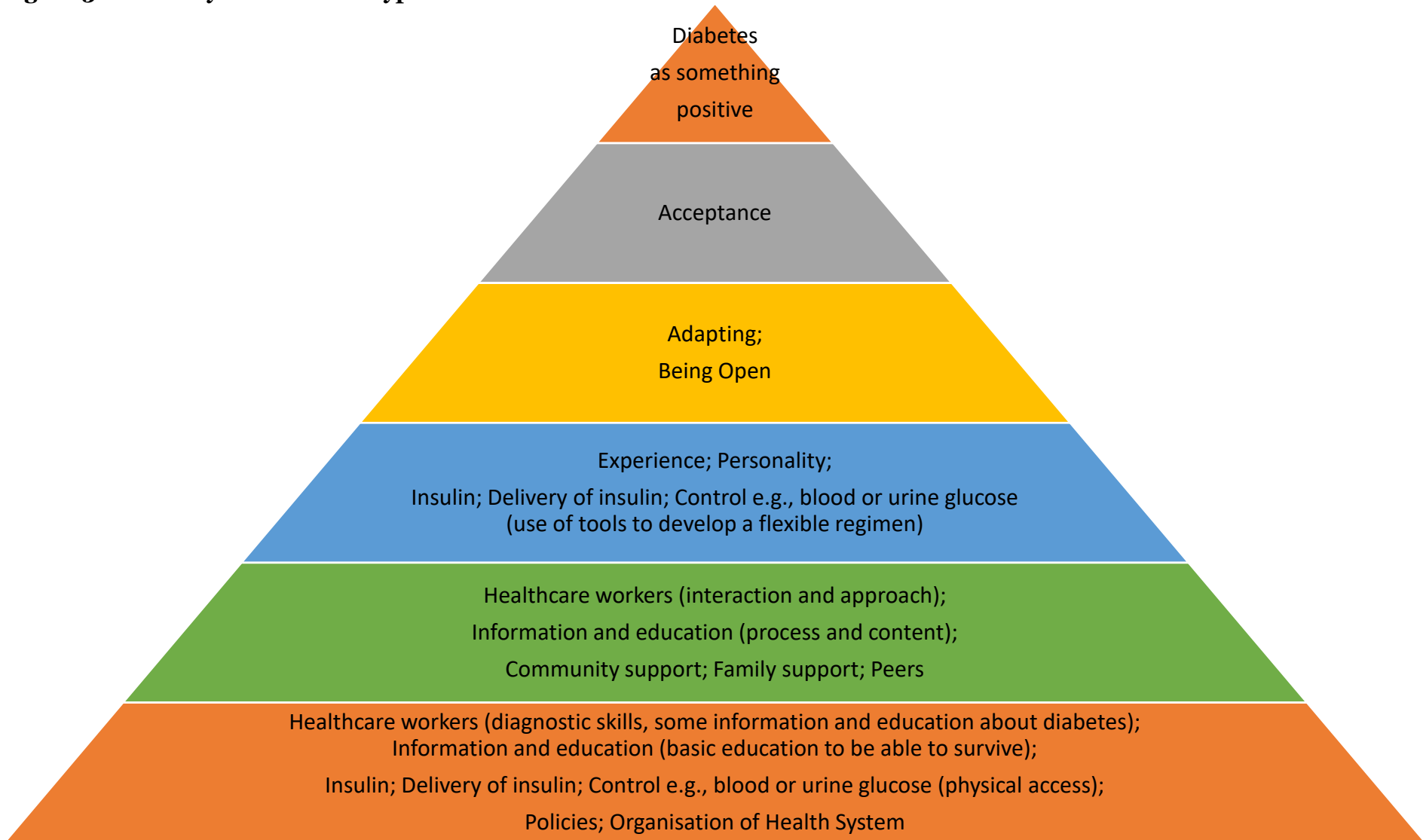
The HNT1D was developed following a comprehensive review of the literature and in-depth interviews with 101 people in 13 countries living with type 1 diabetes.²⁴ For the purpose of this report, the HNT1D is divided into six levels as presented in Table 2. The overall HNT1D is presented in Figure 3.

Table 2. The six levels of the HNT1D

Level ^{a25}	Elements
Level 1 – Survival Needs	Healthcare workers and Information and Education Insulin, Delivery of insulin and Control (e.g., blood or urine glucose) Policies and Organisation of Health System
Level 2 – Safety Needs	Healthcare workers and Information and education Community support, Family support and Peers
Level 3/4 – Belonging Needs	Experience and Personality Adoption of insulin regime into lifestyle (delivery of insulin and control, e.g., blood or urine glucose) Adapting Being Open
Level 5 – Self-Esteem Needs	Acceptance
Level 6 – Self-Actualisation Needs	Diabetes as something positive

^a These levels are inspired by Maslow's Hierarchy of Needs

Figure 3. Hierarchy of Needs for Type 1 Diabetes



The model outlined in this guide will use Table 2 and Figure 3 as a framework to highlight interventions to improve diabetes management. This approach aims to prioritise more urgent needs and ensure that countries, especially those with low resources, can focus their attention on a series of specific interventions that will allow for the foundations of diabetes services to be developed.

2.1. Rapid Assessment Protocol

Before addressing the specific challenges of diabetes management in a given country, it is useful to have a baseline of the different issues that might hamper access to diabetes medicines and care. In various LMIC contexts, a standardised Rapid Assessment Protocol (RAP) has been implemented to assess the overall health system and diabetes care. Using purposive samples, RAPs have been used extensively to assess services for communicable conditions, including malaria, tuberculosis and sexually transmitted diseases, for the purpose of developing interventions.²⁶⁻³² The main principles of RAPs are: speed in data collection for the decision making process; use of multiple data sources; pragmatism, with validity and reliability being achieved by triangulation among different sources of information; and cost-effectiveness. RAPs collect data from existing sources, as well as interviews with stakeholders from health officials to individuals, with a target condition using structured data collection tools.³³⁻³⁴

Within the context of diabetes, a RAP for Insulin Access (RAPIA)³⁴ has been successfully implemented in Kyrgyzstan, Mali, Mozambique, Nicaragua, the Philippines, Vietnam and Zambia.³⁵⁻⁴² The RAPIA focuses on a variety of health system factors, such as availability of medicines and diagnostics, delivery of care, human resources, and organisation of data collection. In addition, for each element, this approach looks both at the “meso” view of the health system—focusing on the policy context—and the actual implementation (or not) of the policy in practice; and the “micro” view—or the actual experience of receiving (or not) appropriate care by the individual.

The RAPIA experiences led to the development of the manual [*How to investigate access to care for chronic non-communicable diseases \(NCD\) in low- and middle-income countries*](#), supported by the WHO, which has been field-tested in Lima, Peru, looking at diabetes and hypertension.⁴³ This manual describes operational and practical aspects of how to investigate access to care for NCDs.⁴³ The approach uses mixed-methods data collection techniques, collecting secondary information from local literature and secondary data from national statistics, as well as primary data from observations and interviews. The assessment is carried out at four levels: national, intermediate, local, and individual; and describes 11 themes for the selected conditions: general information; healthcare structure; financial issues; health insurance; policies, programmes, and activities; supply/procurement systems; resource allocation/availability of care; price/affordability of care; condition management and treatment issues; referral issues; and patient issues. Patient issues include aspects such as challenges at the time of diagnosis, access to care and medicines, use of traditional medicine.

Table 3 demonstrates how the HNT1D framework can be applied and populated using RAPIA results, within six countries where the approach was implemented.

Table 3. Linking health system assessments with the HNT1D

Level and elements	Mozambique (2003 and 2009)	Zambia (2003)	Mali (2004)	Nicaragua (2007)	Vietnam (2008)	Kyrgyzstan (2009)
<p>Level 1—Survival Needs</p> <p>1. Healthcare workers and information and education</p> <p>2. Insulin, delivery of insulin and control (e.g., blood or urine glucose)</p> <p>3. Policies and Organisation of health system</p>	<p>1. Limited to central hospital in capital city</p> <p>2. Issues with access and cost of syringes and diagnostic tools. Insulin subsidised.</p> <p>3. Health care for diabetes focused on hospitals, for type 1 diabetes mainly at central hospital in capital city. Care not decentralised. 2003—Chronic disease law (80% subsidy on insulin); 2009—prescription</p>	<p>1. Limited to university hospital in capital city</p> <p>2. Issues with access and cost of syringes and diagnostic tools. Insulin subsidised.</p> <p>3. Health care for diabetes focused on hospitals, for type 1 diabetes mainly at university hospital in capital city. Care not decentralised. Most elements of care provided for free; issues of access to appropriate care for type 1</p>	<p>1. Limited to two hospitals and diabetes association clinic in capital city</p> <p>2. Issues with access and cost of syringes and diagnostic tools. Insulin unaffordable to most—US\$12 per vial.</p> <p>3. Health care for diabetes focused on hospitals, for type 1 diabetes mainly in capital city. Care not decentralised. No policies positively impacting people with</p>	<p>1. Limited to national paediatric hospital in capital city</p> <p>2. Issues with access to syringes and diagnostic tools. Insulin provided for free.</p> <p>3. Health care for diabetes focused on hospitals, for type 1 diabetes mainly at national paediatric hospital. Some care decentralised with “diabetes focal” points at regional level. All elements of care provided</p>	<p>1. Limited to paediatric hospitals in large cities</p> <p>2. Issues with cost of all aspects of diabetes care.</p> <p>3. Health care for diabetes focused on hospitals, for type 1 diabetes mainly at paediatric hospitals in large cities. Care not decentralised. Depending whether people have insurance or not, the cost of diabetes is either out of pocket or covered by their</p>	<p>1. Limited to national paediatric hospital in capital city</p> <p>2. Issues with access to syringes and diagnostic tools. Insulin provided for free.</p> <p>3. Health care for diabetes focused on hospitals, for type 1 diabetes mainly at national paediatric hospital. Only insulin is provided for free NCDs and diabetes on government agenda. Also, existence of</p>

Level and elements	Mozambique (2003 and 2009)	Zambia (2003)	Mali (2004)	Nicaragua (2007)	Vietnam (2008)	Kyrgyzstan (2009)
	fee of US\$ 0.20. Most elements of care provided for free; issues of access to appropriate care for type 1 diabetes. Diabetes included in NCD policy, but not implemented.	diabetes. No NCD policy.	diabetes. Mali operates on a system of cost recovery. Draft NCD policy exists and diabetes included.	for free, but some issues with availability of syringes. Blood glucose meters (BGM) provided via the diabetes association. NCDs and diabetes on government agenda.	insurance. Push for insurance coverage in Vietnam. NCDs and diabetes on government agenda.	Diabetes Law.
Level 2—Safety Needs 4. Healthcare workers and information and education 5. Community support, family support and peers	4. Very little training, except for specialists. 5. Existence of diabetes associations, but mainly in capital city and more focused on type 2 diabetes. Very little in the way of support for families and interaction	4. Very little training except for specialists. 5. Existence of diabetes associations, but only in capital city. Specific focus on type 1 diabetes with support for families and interactions between peers.	4. Very little training except for specialists. 5. Existence of diabetes associations, but mainly in capital city and more focused on type 2 diabetes. Very little in the way of support for families and interaction	4. Very little training except for specialists. Some training at Regional level, but insufficient. 5. Existence of diabetes association specifically for type 1 diabetes. Very active throughout country offering	4. Very little training except for specialists. 5. No diabetes association, but some support groups being developed with external funding at two paediatric hospitals.	4. Very little training except for specialists. Some training at regional level, but insufficient. 5. Existence of diabetes association specifically for type 1 diabetes. Offers support to families and education activities.

Level and elements	Mozambique (2003 and 2009)	Zambia (2003)	Mali (2004)	Nicaragua (2007)	Vietnam (2008)	Kyrgyzstan (2009)
	between peers.		between peers.	strong support to families and organisation of activities for peer interactions.		Located within the national paediatric hospital.
Level 3/4 – Belonging Needs 6. Experience and personality 7. Insulin, delivery of insulin and control (e.g., blood or urine glucose)	6. Nothing 7. Nothing—access to blood glucose monitoring extremely poor.	6. Nothing 7. Nothing—access to blood glucose monitoring extremely poor.	6. Nothing 7. Nothing—access to blood glucose monitoring extremely poor.	6. Some activities through association address this. For some individuals, health professionals invest time and energy for this. 7. Association tries to provide BGM for children.	6. Nothing 7. Nothing—access to blood glucose monitoring extremely poor.	6. Nothing 7. Association tries to provide BGM for children.
Level 5–Self-Esteem Needs 8. Adapting 9. Being open 10. Acceptance	8. Nothing 9. Nothing 10. Nothing	8. Nothing 9. Nothing 10. Nothing	8. Nothing 9. Nothing 10. Nothing	8. Some individuals able to do this based on duration of having diabetes and	8. Nothing 9. Nothing 10. Nothing	8. Some individuals able to do this based on duration of having diabetes and

Level and elements	Mozambique (2003 and 2009)	Zambia (2003)	Mali (2004)	Nicaragua (2007)	Vietnam (2008)	Kyrgyzstan (2009)
				<p>support from health professionals.</p> <p>9. Role of association in fostering this</p> <p>10. Role of association in fostering this</p>		<p>support from health professionals.</p> <p>9. Nothing—might be hampered by view of diabetes as a disability and individuals being able to get additional government subsidies due to this</p> <p>10. Nothing—same as above</p>
<p>Level 6—Self-Actualisation Needs</p> <p>11. Diabetes as something positive</p>	11. Nothing	11. Nothing	11. Nothing	11. Some individuals in their involvement with the diabetes association have achieved this	11. Nothing	11. Nothing

According to Table 3, Mozambique, Zambia, Mali and Vietnam are still addressing issues in **Level 1—Survival Needs**, with access to insulin being particularly unreliable in these settings. This element, as experience in Rwanda shows, can dramatically increase the chance of survival in people with type 1 diabetes.⁴⁴ Across all of the example countries, there are also challenges of poor access to health facilities and, therefore, barriers to diagnosis, lack of diagnostic tools and poor healthcare worker training.

Nicaragua and Kyrgyzstan have started addressing **Level 2—Safety Needs**, mainly via an active diabetes association that is focused on type 1 diabetes. In both cases, these associations are run by parents of children living with type 1 diabetes. Through the strong role of the association, and their activities, they enable some of those they serve to achieve higher levels on the HNT1D.

This approach of having a clear assessment of the health system, and an understanding of how this relates to the needs of people with type 1 diabetes and the HNT1D, allows for a prioritisation of activities to address existing gaps and builds on strengths within the existing system.

3. Applying the HNT1D to Improve Health Systems for People Living with Type 1 Diabetes

Within this section, approaches to addressing the needs presented using the HNT1D framework are detailed. They take a stepwise approach—focusing first and foremost on **Survival Needs**—to develop a targeted response to managing type 1 diabetes. Although most of the literature on the delivery of services for type 1 diabetes focuses on children, this report aims to provide an overall framework for the management of type 1 diabetes in all ages.

3.1. Survival Needs

In order to ensure the survival of a person living with type 1 diabetes, the following are required:

- Targeted national policies addressing a range of issues which may impact people with type 1 diabetes, for example, provision of free or affordable insulin
- Efficient organisation of the health system for the management of type 1 diabetes
- Physical access to insulin; insulin delivery devices; and blood glucose testing materials (e.g., blood or urine glucose)
- Healthcare workers' knowledge of diabetes and related diagnostics
- Basic information and education for those with diabetes

'Policies' and 'Organisation of Health System' are necessary as they will determine the environment in which the person with diabetes will be diagnosed and then cared for.

3.1.1. Policies

For an effective health system that can manage type 1 diabetes to be put into place, a suitable policy environment must exist. Policies within the health system mainly impact the financial

burden on the individual for their care, including insulin and diagnostic devices, and range from policies on medicine procurement to the coverage of the population for healthcare related costs. Other policies are aimed at improving national standards on NCDs and/or diabetes management and care, and are wider than just type 1 diabetes. They include purchase of medicines, organisation of the health system, as well as others that fall outside of the remit of the Ministry of Health, for example, improving and/or strengthening the social structure. Overall policies for type 1 diabetes need to focus on ensuring that care and medicines are provided at the lowest possible cost, if not free, and that people living with type 1 diabetes have equal opportunities to education and employment, reducing stigma and discrimination.

Given the increased focus on NCDs following the 2011 United Nations High Level Meeting, countries have also started developing specific NCD policies that may or may not include diabetes. According to the WHO's 2016 Global Report on Diabetes, many LMICs have adopted national diabetes policies, guidelines or standards for diabetes management.⁴⁵ For instance, the report claims that about 70 percent of all low-income countries, roughly 60 percent of lower middle-income countries and approximately 75 percent of middle-income countries had a national diabetes policy. Similarly, between 30 and 60 percent of LMICs have begun to adopt operational diabetes guidelines. Furthermore, most countries have adopted policies regarding risk factors for NCDs (e.g., unhealthy diet, physical inactivity) and many have established an operational NCD department or unit within their Ministry of Health.⁴⁶ However, not all these policies are adequately funded or operational, which is an important shortcoming.⁴⁷ There is also the issue that much of the global policy guidance on NCDs and diabetes focuses on prevention versus care.

Beyond diabetes specific policies, there is also a current focus on achieving universal health coverage (UHC). UHC is a key policy issue and is a target included in the Sustainable Development Goals (SDG) (under SDG 3), which aims at better health outcomes. The aim of UHC is to ensure that people have access to the health services they need without exposing them to financial hardship when they pay for these services. UHC includes 'financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all'.⁴⁸ Countries should aim towards achieving UHC, which includes rethinking, reorganising and strengthening health systems.⁴⁹

WHO guidance at a policy level focuses on empowerment of people with chronic conditions by stating that policies need to address a wide range of services, such as health education; should include sharing of clinical decisions between individuals, their families, caregivers and healthcare providers; promote self-management; and focus on strengthening human resources.⁵⁰

3.1.2. Organisation of the Health System

Overall, there are three main challenges that exist in addressing type 1 diabetes within health systems. First, health systems in LMICs need to move from acute to chronic care and adapt to new challenges, as the NCD burden is rising quickly in these countries.⁵¹⁻⁵³ This is challenging because managing chronic conditions is different from managing acute conditions. People living with diabetes need, among other things, long-term care, continuity of treatments, continuous access to medicines and diagnostic devices, the possibility to acquire self-management skills.⁵⁴⁻⁵⁵ Furthermore, reorganising health systems is challenging because

health systems in LMICs face many challenges, such as lacking physical infrastructure, equipment and human resources, inadequate drug supplies.^{56,57} These barriers have important implications on the lives of people living with diabetes. A major problem is that people are often only diagnosed with diabetes when they come to a clinic with a complication, either acute or chronic, or when they are overtly symptomatic, but not through a regular use of the health system.⁵⁸

The next challenge is the actual number of people with type 1 diabetes. Although lack of services has a significant impact on the well-being of individuals with type 1 diabetes, the limited number of people in a given region or district may not justify specific resources being allocated, especially in LMICs where human resources are already in short supply. There is also the need to provide paediatric and adult services for type 1 diabetes, including transition services and coordination between paediatric and adult services, which usually operate as separate/parallel health systems.^{59,60}

Finally, diabetes, and type 1 diabetes in particular, remains a condition managed by doctors in hospitals in large urban areas.⁶¹⁻⁶³ To respond to the need to decentralise NCD care to Primary Health Care (PHC), the WHO has proposed the WHO Package of Essential NCD (PEN) interventions for primary health care in low-resource settings. This is ‘a prioritised set of cost-effective interventions that can be delivered to an acceptable quality of care, even in resource-poor settings’. Its implementation aims to reinforce health systems by strengthening its building blocks. Countries should take steps to implement it to ensure that people living with type 1 diabetes receive care, no matter where they live in a country.⁶⁴ However, the challenge in most LMICs is the capacity of PHC to manage a complex condition such as type 1 diabetes, and the need to have secondary levels of care for supervision and referral.

3.1.3. Insulin, Delivery of Insulin and Control

The truly tangible needs for type 1 diabetes are insulin, insulin delivery devices, and blood glucose diagnostic and monitoring tools. *Insulin, Delivery of Insulin and Control* (e.g., blood or urine glucose). Medicines play a fundamental part in the provision of healthcare, and insulin in type 1 diabetes is a unique example of this. Insulin is needed for survival for anyone living with type 1 diabetes, making it a key requirement and top priority. Unfortunately, insulin is a medicine that is high-priced both for the system (when these are subsidised or paid for) and for the individual (when they need to pay out of pocket). Ineffective procurement practices are a barrier to affordability of insulin. Further, not only the issue of affordability needs to be addressed, but also insulin availability.

Availability can be affected by poor quantification and distribution. For example, in 2003 in Mozambique, 77 percent of the total insulin ordered was supplied to institutions in the capital city.⁵⁴ Several reasons can explain this situation, including mismanagement and inefficient national distribution logistics. In Kenya, stocking issues, miscommunication between medical centres and local depositories, as well as problems with the supply chain, were frequently reported in 2013 and often lead to unavailability of insulin in many locations.⁶⁵

These issues are not only relevant for medicines and insulin, but also for insulin delivery devices (e.g., syringes) and diagnostic tests (e.g., HbA1c tests, home glucometers and test

strips). Countries must take steps to make them available.⁴⁷ Without access to diagnostic testing tools, the actual diagnosis of diabetes can be difficult. Laboratory equipment and tests are required to measure HbA_{1c} and other biological factors. The American Diabetes Association (ADA) recommends that diagnostic tools need to be present within the health system. Further, each person living with type 1 diabetes should have access to their own blood-BGM and test strips. The ADA recommends people living with type 1 diabetes should test themselves at least four times per day using a BGM.⁶⁶ These measurements are used to assess hypoglycaemia and hyperglycaemia, and often to determine insulin dosage. Although a staple of diabetes management in many settings, the prices of BGMs and their test strips for individuals can be prohibitive in LMICs. Additional tools and diagnostic measures are needed to treat the complications of diabetes, such as test to measure ketone levels. Other clinical tools are needed as well, for example, it is recommended that, at each visit, blood pressure should be measured.^{66,67}

3.1.4. Healthcare Workers

The healthcare workforce plays an essential role in diabetes management, with trained and skilled healthcare workers having a role in prevention, health promotion and empowerment of people living with diabetes.⁵⁴ Given that in most contexts type 1 diabetes will be a relatively rare condition, the challenge is identifying which health professionals will be available in the given setting to manage this condition. In some contexts, this is a paediatrician (in cases of children) with either a specialisation in diabetes and/or endocrinology, or a diabetes/endocrinology specialist who also takes care of children. Given this most type 1 diabetes care might be provided in specialised settings versus at PHC level.

Adequate diabetes care requires a number of different health professionals working together as a team. There is not only a need for a team approach to care, but coordination of treatment between health professionals and the integration of the person living with diabetes as a member of the care team are important.⁵⁴ A non-exhaustive list of health professionals was provided by the WHO Global Report on Diabetes, including:⁴⁷ Doctors; Dieticians; Nurses; Ophthalmologists; Obstetricians; Vascular surgeons; Physiotherapists; and Podiatrists.

There is a clear lack of knowledge when it comes to the diagnosis of type 1 diabetes in some settings.^{62,68} Bassili et al.⁶⁹ found that, in Egypt, adult diabetologists were the main healthcare providers in 60 percent of the cases studied. In sub-Saharan Africa and Latin America very few specialists exist and, if they are present, they are located in the capital city.^{36,70} A study in England found that 21.2 percent of children with type 1 diabetes in a particular hospital faced delayed diagnosis by more than 24 hours.⁶⁸ The main cause of this was misdiagnosis at the local hospital or by a General Practitioner (GP).

3.1.5. Information and Education

Health education has been defined by WHO as ‘any combination of learning experiences designed to help individuals and communities improve their health, by increasing their knowledge and influencing their attitudes’.⁵⁰ Health education messages (e.g., diet and physical education) should be adapted to the socio-economic, cultural and educational levels of targeted people living with diabetes (e.g., issues with illiteracy).⁷¹ Specifically for type 1 diabetes, there is also the need for these to be age appropriate.⁷² Education needs to include understanding of the body and understanding how it works in relation to the condition in question.⁷³

As described by Assal⁷⁴, education directed at people living with diabetes plays a key role in diabetes care. This education does not necessarily have as its aim to make the individual more knowledgeable about diabetes, but aims to enable and support the management of their diabetes in their everyday setting.⁷⁵ For proper diabetes management, goals should be set and lifestyle adaptations should be made to ensure that the various medical and psychological aspects of a person's diabetes can be handled on a daily basis.⁷⁵

People living with diabetes must receive adequate health education, not only to ensure they are aware of what they need to do to take their medicine and avoid complications, but also to empower them to self-manage their condition every day. Empowerment of people living with a chronic condition is defined by WHO as the process of enabling people to increase control over and to improve their health.⁷⁶ The active participation of people living with diabetes and their families in the care and management of their condition is fundamental for achieving better health outcomes. Empowerment is also about the relationship that develops between the person living with diabetes and the clinical and non-clinical healthcare providers, which should be equal and reciprocal,⁵⁰ and should rely on a partnership between the two parties.^{64,77} (See Section 3.1.4) Family members should also be engaged so they can positively support the person living with diabetes.⁵⁰ (See Section 3.3.2)

Education can take many delivery forms: oral, written guidelines, booklets, other media, using group teaching sessions, role playing, use of audiovisual materials, as well as peer groups, diabetes association meetings, online communities and diabetes camps (for children and adolescents). The WHO Expert Committee on Diabetes Mellitus highlighted the following factors related to patient education:⁷⁸

- Basic knowledge of diabetes
- Technical skills (e.g., injection techniques, blood glucose monitoring)
- Psychological factors linked to attitudes towards diabetes
- Continuous education
- Ability to assess dangerous situations and ability to deal with them or seek appropriate advice

3.2. Recommendations for Survival Needs

In Italy, the “Italian Diabetes Law” provides a policy framework for the organisation of the health system.⁷⁹ Despite some flaws, lack of services in some areas of Italy, and not all areas implementing this national law, Italy has organised its health system for the provision of diabetes care as follows:

- Primary level: paediatrician or GP
- Secondary level: specialist paediatric diabetes units within paediatric units
- Tertiary level: regional units for paediatric diabetes care

Policies and practices around the purchase of insulin, its distribution, who can prescribe it and where in the health system it should be present also need to be addressed. In addition, pricing issues need to be tackled with both price transparency throughout the supply chain, as well as providing insulin at the lowest price possible, or for free to individuals. For

example, addressing the removal of any taxes on tools used by people with insulin-requiring diabetes.⁷⁰ The same is true for diagnostic tools, for example, the places where blood glucose testing is available, the prices and also if BGMs are provided for free. Price transparency should also be included in all policies enabling people to know the actual price of their diabetes supplies.

Other policies should be made to help ensure that people living with diabetes not only survive, but thrive. An example of this is a policy that created in the Netherlands after it was found that some jobs were unavailable to people with diabetes and some people reported problems in their work setting.⁸⁰ Others might be linked to education and empowerment. In Australia, a law was established that provided the right for people living with type 1 diabetes to be fully integrated into education.⁸¹ The United States (US) also prevents discrimination of people with type 1 diabetes, including in the school setting.⁸² It could be argued that these policies are not necessary for survival and are more linked to 'Being Open' and 'Acceptance', included in Level 5 of the HNT1D.

Countries should include diabetes within their UHC benefits.⁶¹ UHC is not only crucial for diabetes because it aims at enabling access to quality care, but also because this condition has often important economic impacts on people living with diabetes and their families.

A clear plan of what is available for diabetes care at each level of the health system is needed. This may entail new rules being put into place that enable nurses to perform certain roles, for example, prescribing medicines. Data is also essential. The RAP approach to provide barriers and facilitators to care is described previously (see Section 2.1) and studies, such as those by Marshall et al.⁴⁴, allow for documenting type 1 diabetes and providing information to help define policy responses, as well as monitor any progress.³⁸

An important element to integrate in the health system component of addressing type 1 diabetes is data. Data plays a key role in the management of diabetes and chronic conditions. This data can be used for planning, policy implementation and monitoring and evaluation.⁸³ Routine data, such as attendance records, patient files and registers at different levels of the system (national, regional, sub-regional and facility based), are suggested. ADA guidelines highlight the need for the healthcare workers to keep a medical history for each person.⁶⁶ This collection of data should be standardised, either through paper or electronic registers, and used for different clinical (care for an individual) and management (planning and ordering of medicines and supplies), as well as monitoring and evaluation activities.

Insulin and other medicines for diabetes care should be accessible at the proper public facilities. It should be clear to people in need where they are able to get their medication and other supplies (such as syringes). In addition, sustainable financing systems need to be in place to ensure that price is not a barrier to care. The health system must have an adequate budget allocated to the purchase of insulin. Adequate buying and quantification procedures should be in place to ensure efficient procurement and efficient distribution of the medicines and insulin throughout the country. This is at a system level. Insulin specific recommendations are detailed in other work by the ACCISS Study.

Each level of the health system needs to have the means of diagnosing and testing for urine/blood glucose. The tools available need to be the appropriate tools for resources

available, both at the overall health system level, as well as at the right level within the health system. Additional tools and diagnostic measures are needed to diagnose and treat the complications of diabetes. Within the health system, the means to measure urine or blood glucose and ketones need to be present. Laboratory equipment and tests are required to measure HbA1c and other biological factors. Other clinical tools that are needed (such as blood pressure monitoring) should also be considered. There is also the need for intensive care units as hospitalisation is often required at diagnosis, as well as when and if a person is poorly controlled.⁶⁶ The WHO PEN guideline⁶⁴ and others⁸⁴ provide indications as to what tools and medicines should be available at PHC, but can be adapted for other levels of the health system.

For BGMs and test strips for personal use, this is a decision that needs to be made by the government, whether or not these are provided by the health system. Given limited resources, insulin and syringes need to be prioritised before BGMs and test strips. In addition, it is not only the provision of the BGMs and test strips, but also the education and information that should be provided in order for individuals to effectively use this tool. (See Section 3.5.3)

Ideally, people with type 1 diabetes need to be managed by a diabetes team comprising a paediatric endocrinologist, a nurse educator, a dietician and mental health professional at the time of diagnosis.⁶⁶ The ADA guidelines state the importance of having healthcare workers who have diabetes specific knowledge as well as being familiar with child development. Alongside doctors, the ADA suggests that children should have access to mental health professionals, diabetes educators and dieticians. It is suggested that telephone links be established between the person living with diabetes and their health professionals. This is the gold standard and may not be feasible in many settings, but a multi-disciplinary approach is something for which to strive. In parallel to this formal care, the ADA guidelines highlight the need to involve the school nurse and provide any necessary training in order to manage diabetes or any complications that may occur in the school setting. The presence of school nurses is lacking in many contexts, but, at a minimum, teachers need to be aware of diabetes in general, and hypoglycaemia and how to manage this.

The WHO Expert Committee on Diabetes Mellitus⁷⁸ highlights the importance of educating healthcare workers in not only the medical and technical skills, but also adequate skills to train and educate people with diabetes. Hambly et al.⁸⁵ found that addressing psychosocial issues during the consultation was more important than medical issues, but doctors felt that they were not properly trained to address this. As described by Clark⁸⁶, in caring for people with chronic conditions, healthcare workers need to address three aspects. First, they must tailor their message, care and treatment to the individual. Second, they must be able to communicate with the individual in order to develop a partnership to manage the condition effectively. Lastly, the healthcare worker must ensure that the individual understands the different elements of their condition so that they can act accordingly in their self-management.⁸⁷

Nurses play an important role in the management of type 1 diabetes. Carvallho and Saylor⁸⁸ describe a model programme in which 56 participants were managed by a nurse case manager, a multidisciplinary clinic team, and educational and counselling interventions in order to empower families to improve self-management of their child's diabetes. This study

showed improvements with regards to self-management and a statistically significant improvement in self efficacy beliefs of parents. Nurses have also been used in providing home care for children with diabetes to provide support to families and avoid readmission to hospital.^{89,90}

Proposals to address the issue of healthcare workers focus on three components: training; use of existing resources; and the need for guidelines.

Type 1 diabetes management needs to be integrated into all curricula for health professionals. As discussed earlier, type 1 diabetes can serve as a tracer condition and, as a pedagogical approach, the management of type 1 diabetes requires many elements that are useful for other chronic conditions where it is not only the professional's clinical skills that are important, but also "soft" skills, such as communication, teamwork and patient education. Therefore, these elements need to be integrated in training at medical faculties, at postgraduate level as well as in continuing education programmes. For continuing education programmes, these should be based on a training of trainers cascade model focusing on practical aspects, especially around patient education. In addition, a team approach to diabetes care must be developed with different specialisations working together, and nurses and other ancillary staff playing an important role in care. This will require new roles to be developed (e.g., diabetes specialist nurses and diabetes educators) in settings where these do not exist.

Health systems in many countries are faced with staff shortages. Certain roles in diabetes care may therefore need to be passed on to different staff, for example nurses and clinical officers. In some instances, roles may even be devolved to the community. Steps should be taken to train and integrate health workers and nurses, as well as other actors (e.g., non-medically trained health workers, community health workers, family caregivers) to help deliver diabetes care whenever possible. There should be a distinction between treatment initiation—requiring a specialist or doctor—and treatment continuation, which can be carried out by a non-specialist or nurses. However, this may also require changes in policies, for example, with regards to which health professionals can prescribe insulin.

Community health workers (CHWs) have been shown to have a positive role regarding chronic condition management. Different studies have shown that, with training, CHWs can play a role in diabetes management.⁹¹⁻⁹³ In some contexts there is also the need to include traditional healers.⁹⁴ Another player in the care of people with diabetes is the pharmacist. The pharmacist can play an additional role of explaining the treatment course and reiterating and supporting information the patient has been given by doctors or nurses.

Health professionals also need clinical protocols, and these may need to be developed and approved locally. A useful international resource is the International Society for Paediatric and Adolescent Diabetes Clinical Practice Consensus Guidelines.⁹⁵ These guidelines also include material about education and information.

Survival Needs with regards to education at the time of diagnosis should focus on "survival skills", with a key element of this being insulin dosage and administration. The aim of management of the first few weeks is to minimise trauma, provide initial prompt and safe treatment, offer support for person being diagnosed and their family, and guide them

through the learning process of diabetes.⁹⁶ The language used should be simple and should not give too much information.⁷⁸ The use of images and individualised education is recommended. Family members need to be included in this education and understand the daily implications of diabetes, including administering insulin and changes to the diet.

Education around the psychosocial aspects and impacts that diabetes might have on the child or adolescent should also be included. This education needs to be ongoing and combined with the ability to contact a healthcare worker by telephone, when necessary.⁶⁶ Parent and healthcare workers play an active role in transitioning the child to manage their diabetes by themselves with the aim, as stated by the ADA, to have the child self-manage their diabetes in the period during middle and high school.^{66,67} Specific skills, such as learning about foot care, are also part of the overall education of the person with diabetes.

Previous work has identified three components of education, namely what is delivered, how it is delivered and healthcare worker specific factors.⁹⁷ At the time of diagnosis, diabetes education should focus on survival skills and include:^{72,96}

- Explanation of diabetes and how it was diagnosed
- Simple explanation of the uncertain cause of diabetes and that there is nothing and no one to blame
- The need for insulin and its role
- Blood glucose levels and normal ranges
- Practical skills, such as insulin injections, blood and/or urine self-monitoring and the importance of monitoring
- Dietary guidance
- What hypoglycaemia is and the need to always have a source of sugar
- Management of diabetes when sick
- Management of diabetes at home, school and during exercise
- Need to carry an identity card or wear a necklace or bracelet
- Joining a diabetes association and other support groups
- Help psychologically to adjust to the diagnosis
- Provision of emergency contact information

Educational materials beyond traditional written information should be explored (e.g., drama or oral explanation might provide educational messages to illiterate people).⁵⁴ A study conducted in South Africa showed that Diabetes Self-Management Education educational materials were lacking cultural adaptation and the incorporation of the perspective of people living with diabetes.⁹⁸

New technologies can be instrumental in the development of innovative care models and, when used adequately, can facilitate patient empowerment and education (e.g., mHealth and shared electronic medical records).⁵⁰ For instance, the use of web-based educational tools proved to have a positive impact on diabetes outcomes and improved the communication between health providers and people living with diabetes.⁶⁴

How this education is delivered should address: the quantity of information that is delivered; education for parents and children; specific programme of education; different healthcare

workers; use of parent volunteers; diabetes associations; small group sessions; parallel activities. Who provides the education also needs to be thought of, with a possible role for diabetes associations and peers (See Section 3.3.2). Following this initial education needed for survival, there is ongoing education, detailed in Section 3.3.1.

3.3. Safety Needs

Healthcare Workers and Information and Education are also in the second level of the HNT1D, but here the support from healthcare workers and the information and education provided go beyond what is needed for survival. In this case, they are no longer something tangible and are linked more to a process of how the interaction between the healthcare worker and their person living with diabetes takes place, as well as how the information and education is delivered.

3.3.1. Healthcare Workers

The ADA guidelines state that care should be provided during a diabetes specific consultation by a diabetes team.^{66,67} The consultation should offer education, diagnostic tests for monitoring and diagnosis, as well diagnosis of complications.^{66,67} For this aspect, the literature focused on the need for multi-disciplinary teams.^{81,99-103} Daneman and Frank¹⁰² state that care provided by this multidisciplinary team needs to be “family centred”, with the focus of the team being the individual with type 1 diabetes and their family. In Thailand, the use of this team approach included paediatric endocrinologists, a dietician, a psychologist, nurses and volunteers in a specialist centre was found to impact HbA1c, length of stay in hospital and readmission rates.¹⁰⁰

3.3.2. Community Support, Family Support and Peers

The health system may provide the majority of aspects that a person with type 1 diabetes requires, however the burden of care falls on the individual and their family as the majority of the time spent managing a chronic condition is done outside of the health system.¹⁰⁴ Issues around education and empowerment need to be addressed.^{12,105,106} People living with type 1 diabetes and, when applicable, their families, need to be informed and take an active role in their care so that the interactions with healthcare workers are more productive.¹⁰⁶

An important component of the chronic care model is to ‘mobilise community resources to meet the needs of patients, for example, by encouraging patients to participate in effective community programs’.⁵⁴ Local beliefs need to be addressed within the community.⁵⁴ The WHO¹⁰⁷ defines community involvement as ‘including the provision of access to emotional support, to community funds for destitute people, as well as reducing the family’s burden and stigma’.⁵⁴ The WHO PEN recommends community interventions to complement primary health care and to offer structured training to community workers so that they can contribute to detecting and managing non-communicable conditions.¹⁰⁸

Diabetes care and management should be community-based because diabetes not only affects the person living with the condition, but also his/her family and the community at large. Families and the local community need to be educated about diabetes symptoms and care, and not only be involved in diabetes management, but also to address stigma and misunderstandings about diabetes in general. Families, and communities, from schools to workplaces, can both provide support to a person managing their diabetes on a daily basis.

In addition, peers can provide support and further offer a unique opportunity to share experiences.

3.3.3. Information and Education

Information and education provided needs to be adapted based on the context and the individual. For example, some insulin regimes may require a person to adhere to a strict mealtime routine, while others may provide the user with some flexibility with specific guidelines. These different treatment approaches will also require the availability of a BGM and test strips, and the education provided on how to use this tool effectively. Information and education as a safety need should enable the individual with diabetes to be able to manage any circumstance they are presented with in their daily life. This requires both a different approach from health professionals (See Section 3.3.1), as well as an active role of the community, family and peers (See Section 3.3.2).

This information and education needs to focus on nutrition and physical activity combined with the management of insulin. This is especially important in LMICs, where fixed dose combinations are used, meaning that it is essential to have regular meals and little possibility of insulin adjustment to physical activity. Self-management is an important aspect of diabetes care and includes the need to have an individualised care plan, goal setting by both the healthcare worker and individual, development of skills, continued follow-up and support, link to community resources, and continuous access to quality care.¹⁰⁹ Self-management puts the onus of condition management with the individual, but it is challenging and requires motivation on the part of the individual.¹¹⁰ One key element is problem solving that can be supported by the community and healthcare workers.

Kyngas¹¹¹ defines adherence as an ‘active, intentional and responsible process’ that needs to be a collaboration between the individual and their healthcare worker to ensure proper outcomes. Adherence is linked closely to the following factors:

- Motivation
- Normality
- A clear understanding of what actions lead to what results
- Energy and willpower
- Parental support
- Support from healthcare workers
- Positive attitude towards the condition and its treatment
- No threat to social, emotional and physical well-being

Self-efficacy² is key to diabetes management, even in young children.¹¹² The first aspects of self-efficacy in diabetes management for young children are to learn about self-care tasks, such as measuring their blood glucose, carbohydrate counting and dosing of insulin. In young children, the onus of self-efficacy is placed on the parents. As the child matures, self-efficacy should focus on implementing diabetes knowledge into the child’s everyday life.

Education becomes empowerment when knowledge is applied for positive change. Empowerment is giving the person with diabetes the capacity to affect change to their own

² Being capable of carrying out certain tasks that lead to success in certain situations

health.¹¹³ From the perspective of the person living with diabetes, it is stated as the most important factor in their management of the condition.¹¹⁴ To be empowered, people need sufficient knowledge, control and resources, and sufficient experience. In this context, the role of the healthcare workers is to ensure that people with diabetes have the necessary knowledge and skills to overcome the challenges that diabetes may impose on them. This allows for a transition from diabetes management based on following healthcare workers instructions, or what was learnt from information materials, to a level of knowledge and understanding that enables the person with diabetes to make their own decisions. The core element to this approach is that people will only change what they understand and see as having a positive impact.

3.4. Recommendations for Safety Needs

Diabetes care health professionals must provide adequate education and information to people with diabetes. This information needs to be tailored to the individual, as well as to the stage of their diabetes, with different information and approaches needed at the time of diagnosis versus ongoing care.⁹⁷ The healthcare worker's approach becomes just as important as their clinical skills and knowledge. This is a transition in the role of healthcare workers in managing chronic conditions from being an expert, instructing and deciding for their patient, to being a guide in supporting, advising and helping manage the condition for the person living with diabetes. In addition, other specialties are needed to address the variety of factors involved in managing type 1 diabetes.

The main element requiring careful consideration here is how to move from general education to individualised and tailored education, adapting to the specific reality of the individual. This requires time, organisation of consultations and follow-up, as well as the development of a team approach to education. As discussed in Section 1.4, this will also require training in “soft skills” for various health professionals, and a link with families and communities. In some settings, this role might be taken by peers and diabetes associations.

The WHO Expert Committee on Diabetes Mellitus⁷⁸ mentions the following factors with regards to the management of diabetes and describes the individual's home as a “health unit” for this very specific reason. Managing in a family with a person living with type 1 diabetes can be extremely challenging and places a great deal of stress on the family. Therefore, the family needs education, development of proper attitudes towards the individual with diabetes, knowledge of how to manage diabetes and how to help with compliance and dietary factors.

Diabetes organisations—which can take on many forms, including national diabetes associations, specific type 1 diabetes organisations, or youth or adult centred non-profit or for profit organisations—provide an opportunity for people with diabetes to interact and learn about diabetes from their peers.¹¹⁵ It was found that membership of a diabetes association had a positive impact on HbA1c levels, but that those who join diabetes groups are more likely to want to take responsibility for their condition management may also be a factor in this.¹¹⁶ Mali, Mozambique and Zambia have diabetes associations of different sizes and differing tasks, but all aim to improve the life of people with diabetes and their families.^{38,117,118} The roles taken on by diabetes associations depends on the needs of people living with diabetes in the country, as well as the capabilities of the associations.³⁸

In some settings, traditional healers still play an important role in providing care and can be the first point of reference for people seeking care. Especially where there is a shortage of healthcare workers (e.g., in rural areas), traditional healers should be integrated into community-based health programmes and receive adequate training, whenever possible.^{119,120} Training should include knowledge about appropriate referrals and cooperation with other actors from the healthcare system.⁵⁴

The community plays a key role in chronic condition management. The community and families of people with diabetes need to be educated on how to care and support for people with diabetes. Parents, siblings, teachers and school nurses all form part of the community that must help with the management of the child's diabetes.⁶⁶ Diabetes organisations are present in many countries and their roles can evolve as the needs of people with diabetes evolve in their country. As a source of information, peers should be seen as a key resource to be used. Diabetes care should not only focus on the condition, but also concentrate on the child with diabetes, their parents and the family unit as a whole.¹²¹ In addition, the impact of the condition varies from different people depending on their role in society, such as where they live, their age or gender.⁷³ Therefore, the family as a whole needs to be involved.

New methods and technologies have also been used to increase education for diabetes, for example, the internet,^{122,123} or specific management of different patient factors using telemedicine,¹²⁴⁻¹²⁶ the use of text messages,¹²⁷⁻¹³¹ use of telephone calls to provide support and assistance,¹³² use of applications on mobile phones,¹³³ web based simulations,¹³⁴ web-based/"virtual" clinic¹³⁵ and online discussion forums¹³⁶. In an analysis of the use of online discussion forums by young people with diabetes, the use of these forums was used for social support, gaining information, seeking advice and also sharing experiences.¹³⁶

The main recommendation to enable this tailored educational approach to happen is to focus on the organisation and resources available and information for the individual adapted to their circumstances.

Many LMICs have implemented diabetes-related empowerment and education programmes. China has a structured diabetes education programme called The Patient Empowerment Programme^{137,138}, consisting of two components: 'generic self-efficacy enhancement and lifestyle modification' and; condition-specific knowledge and skills. In this programme, sessions covered healthy diets, regular exercise habits, goal setting, problem solving skills, responsibility of self-care management, medication in diabetes control and so on. Two studies have shown that enrolment in the programme was associated with lower all-cause mortality for people living with type 2 diabetes. In a similar manner, a study conducted in Brazil to assess the effectiveness of an empowerment programme consisting of support 'for psychosocial, behavioural, and clinical aspects of diabetes' found a positive impact of the empowerment programme on HbA1c, other metabolic indicators and other secondary outcomes.¹³⁹

Several randomised-controlled trials have also shown that short-term education initiatives can have positive impact on the lifestyle and health of people living with diabetes. For instance, in Costa Rica, a randomised controlled trial relying on community-based nutrition and an exercise programme separated people living with diabetes into two groups. One of

them received basic diabetes education, while the other received eleven weekly nutrition classes and participated in walking groups three times a week. After three months, ‘improvements in weight, fasting glucose levels, and HbA1c were all significantly greater in the intervention group than in the control group’. In a similar manner, an integrated prevention programme in China, in which one group only received basic diabetes education and the other in-depth diabetes education (i.e., meal plans and nutrition counselling, blood glucose monitoring, weekly progress meetings) showed that in-depth education was positively affecting diabetes management.¹⁴⁰

Evidence from South Korea has shown that structured and intensive patient education programmes are efficient for people living with diabetes, but need to be accompanied with ‘regular and sustained reinforcement with encouragements’ to achieve the best health outcomes possible.¹⁴¹ More research on implementing such programmes in LMICs is needed.

Diabetes camps provide a safe environment for the experience of managing diabetes away from home, sharing experiences with peers, sometimes for the first time, and learning new skills.^{66,67} Some diabetes organisations also organise camps and other continuous education/training programmes for people with diabetes. Their aim is to both provide a camp experience in a safe environment and the opportunity to meet and share experiences with peers. Camps have been shown to have a positive impact on diabetes management and HbA1c in Thailand and Turkey.^{142,143} Tumini et al.¹⁴⁴ describe how camps, besides providing skills and diabetes specific knowledge, also help develop friendships and a feeling of community where children with diabetes are “normal” as they are interacting with others who also have diabetes. Camps also aim to make children take more responsibility for their diabetes management by integrating opportunities for education provided by medical and camp staff.¹⁴⁵ The following have been described as benefits of camps for children with type 1 diabetes:^{72,146}

- Experience of sharing with other people with diabetes
- Seeing that other people also have type 1 diabetes and that the child is not alone
- Getting away from the family setting
- Opportunity for children to have fun in a safe environment
- Learning new skills
- Increase self-confidence and independence of diabetes management
- A break for parents from the stress of managing a child with diabetes.

3.5. Belonging Needs

At this level of need, the role of the health system becomes less and less important and the wider community and environment in which the individual is living gains in significance.

3.5.1. Insulin, Delivery of Insulin and Control

This level of the HNT1D again includes *Insulin, Delivery of Insulin and Control* (e.g., blood or urine glucose). At this level, it is how individuals use these tools, not only for their survival, but as tools that enable them to function within their daily lives without diabetes being an impediment.

3.5.2. Experience and Personality

Experience and Personality are also important at this level of the HNT1D as they both help shape the individual and the way they manage their diabetes. This and the next two levels can be considered to be intangible needs. This is both due to the variety of other needs that are required to be met, but also the increasing importance of the individual with very little other than support that can be provided by the health system.

3.5.3. Adapting

Adapting includes both the adjustment to daily use of insulin and other treatment aspects of diabetes, but also the change in perspective the person has as they now have a chronic condition and all the biographical changes this means. For example, in type 1 diabetes, eating goes from being a mundane activity to one that involves a whole thought process about what is being eaten and its interaction with insulin.¹⁴⁷ Every time a person with type 1 diabetes eats something, they must know about nutritional values (i.e., carbohydrate content) and portion and match this with their blood glucose level and insulin, as well as considering timing of their insulin dose to when they eat. Often adapting to the daily ups and down of diabetes management and sticking with tight control, outside of taking insulin, especially for adolescents and young adults, can be difficult. It has been reported that adolescents find blood glucose monitoring the most inconvenient, disruptive, and least favourite aspect of managing their diabetes. This can lead to testing their blood sugar less often than recommended.^{148,149} This was the case in the UK and Finland, where diet and blood glucose monitoring were adhered to less well than aspects that could be viewed as more medical, such as injections.^{111,150} Palardy et al.¹⁵¹ argue that in order to improve adherence in adolescents, healthcare workers should focus on the benefits of adhering to treatment, rather than the negative aspects of not adhering to treatment.

3.5.4. Being Open

Nassau and Drotar¹⁵² identify three areas that may limit the full participation of an individual with a chronic condition in peer activities. These are actual barriers due to the illness, imposed barriers by parents, and the individual's actual perception of their condition and its perceived limiting nature. Parents play an important role in ensuring full participation of their children in sports and activities. In doing, so this impacts the perception their children have of being the same as peers who do not have a chronic condition.¹⁵³ In describing their experience with children with type 1 diabetes, parents related that they felt their children actually hid the fact they had type 1 diabetes—mainly not to appear different to their peers.¹⁵⁴ However, some parents noted that by being open about their condition, their children actually got support from their peers and others.

By fully participating in “normal” life and activities, other individuals (e.g., teachers and colleagues) must be made aware that the individual has type 1 diabetes and, therefore, *Being Open* is necessary. In an ideal setting, if all the factors for proper management of type 1 diabetes are present, but children are not allowed to test their blood glucose or inject in schools in front of their peers, this will lead to poor diabetes management.¹⁴⁸ This highlights that chronic condition management goes beyond the clinical setting and includes the home, schools and workplace.⁸⁶ For example, schools need adequate information to assist child in managing their diabetes.¹⁵⁵ The school needs to be aware and assist with the child's medical and psychosocial needs. Davis¹⁵⁶ provides an example of this being told by a teacher not to eat bread as it would make her fat, when in fact she was doing this to prevent hypoglycaemia.

Davis¹⁵⁶ states the reason for this comment as being lack of knowledge about diabetes. This lack of knowledge was also highlighted by a study by Rasmussen et al.¹⁵⁷, where it was found that the general public is unaware of the differences between type 1 and type 2 diabetes. Having people living with both type 1 and type 2 diabetes who are open to discuss their conditions and publicly visible can help communities to understand more fully both conditions and reduce stigma. In addition, it was found that stigma and discrimination in the workplace still exist and need to be addressed. This study also shows the importance of social networks and knowing other people with diabetes is important and that this role is sometimes played by diabetes camps.

3.6. Recommendations for Belonging Needs

Greater flexibility is provided by multiple daily insulin injections in combination with counting of carbohydrates.^{66,158} In this form of treatment, the dose of insulin is determined by three factors: blood glucose level before the meal, the amount of carbohydrate in the meal, and the expected level of physical activity.

This requires a clear understanding of the individual from the perspective of the healthcare worker, as well as a comprehension of diabetes by the individual and their family. Again, the components of education and information, healthcare workers, community and family support all play an essential role.

One important element for **Belonging Needs** is having a health professional who can use the experience of the individual, as well as adapting to them as an individual in terms of how their diabetes is managed.

In order to adapt, the way in which *Insulin*, *Delivery of Insulin* and *Control* are used is important. To use these tools more effectively and move from a fixed to a more flexible regimen, information and education from healthcare workers and the community at large (including family, diabetes organisations and peers) needs to be present. In addition, the information and education needs to be adapted and delivered in a way that is appropriate to the individual.

Children faced more challenges at school, mainly due to the lack of knowledge about diabetes among teachers, coaches and administrators.¹⁵⁴ There is a lack of understanding about type 1 diabetes, and the difference between type 1 and type 2 diabetes, in the community as a whole. A better understanding of diabetes in the community will impact the acceptance into society of the person with diabetes. This may also impact the provision of healthcare services for people with diabetes.⁷⁸ To address this, the community again plays an important role and there is the need for the health system to find ways of linking with other institutions, for example, schools and workplaces, as well as providing the individual tools to be able to do this.

3.7. Self-Esteem and Self-Actualisation Needs

Acceptance (i.e., coming to terms with having diabetes) requires *Adapting*, *Being Open* and *Personality*. These factors show that, on one hand, practical aspects of diabetes management

(*Adapting*) are needed, and on the other hand, social aspects of the individual (*Being Open* and *Personality*) need to be present in order for the person to accept their diabetes.

The highest level of the HNT1D is *Diabetes as Something Positive*. Viewing a chronic condition, such as diabetes, as something positive in an individual's life has an impact not only for the individual concerned, but also for others.

3.8. Recommendations for Self-Esteem and Self-Actualisation Needs

To achieve these needs, the previous elements must be provided by the health system, diabetes associations and the wider environment in which the individual with type 1 diabetes operates. Diabetes associations can play a strong role to promote this. As seen in previous work, many people who had activities in the area of self-actualisation had somehow linked these to diabetes, whether in terms of their choice of profession, providing support to others with diabetes or turning their diabetes into something positive.¹⁵⁹

Key recommendations from each of these elements are presented in Table 4

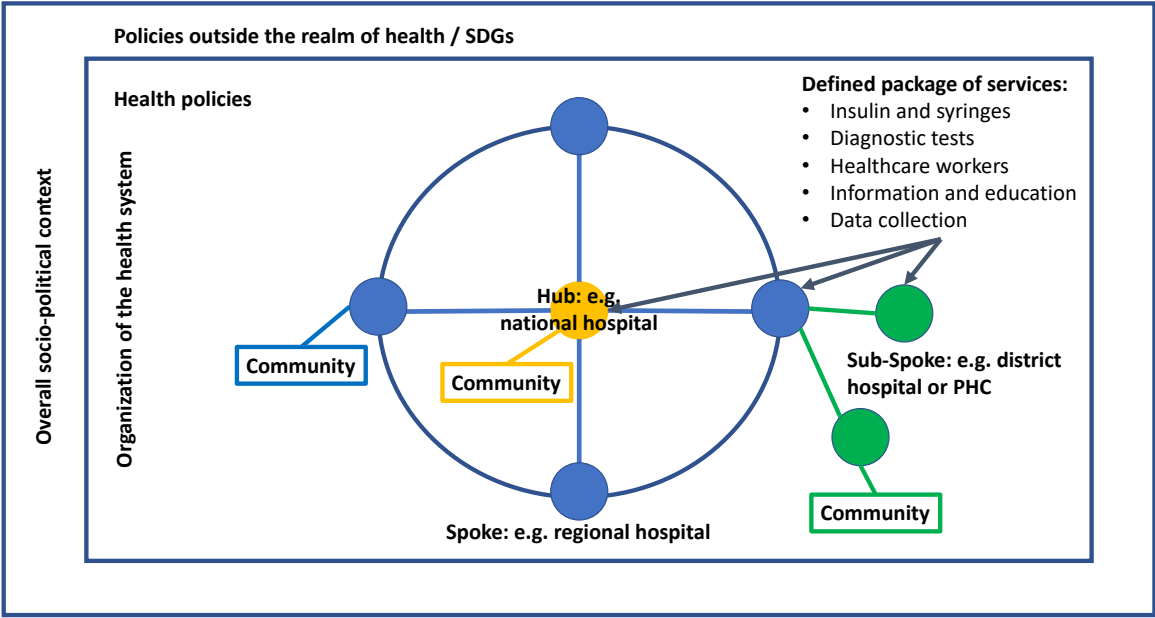
Table 4. Key Recommendations

Level	Elements
Survival Needs	<ul style="list-style-type: none"> • Universal Health Coverage to include diabetes. • Type 1 diabetes specific policies focusing on ensuring that care, testing and medicines are provided at the lowest possible cost possible, if not free. • Other policies, e.g., purchase of medicines and organisation of the health system. • Policies beyond the remit of the Ministry of Health. • National guidance of what is available for diabetes care at each level of the health system. • Data. • Medicines for diabetes care should be accessible at the proper public facilities. • It should be clear to patients where they are able to get their medication and other supplies. • Adequate budget allocated to the purchase of insulin, syringes and diagnostic devices. • Adequate buying and quantification procedures need to be in place to ensure efficient procurement and efficient distribution of the medicines and insulin throughout the country. • Each level of the health system must have the means of diagnosing and testing for urine/blood glucose in order to diagnose and monitor people with diabetes. • Diabetes training included in all components of medical education. • Training and integration of health workers, nurses, as well as other actors, to help deliver diabetes care whenever possible. • Clinical protocols adapted to LMIC using essential medicines and human insulin need to be developed. • Education to focus on survival skills, with a key element of this being insulin dosage and administration • How and who provides this education needs to be adapted to the specific context. • <i>Insulin specific recommendations are detailed in other work by the ACCISS Study.</i>
Safety Needs	<ul style="list-style-type: none"> • Individualised and tailored education adapting to the specific reality of the individual. • Role of the community. <ul style="list-style-type: none"> ◦ Parents, siblings, teachers, school nurses, traditional healers, etc. all form part of the community that need to help with the management.
Belonging Needs	<ul style="list-style-type: none"> • Clear understanding of the individual from the perspective of the healthcare worker as well as a comprehension of diabetes by the individual and their family. • Having a health professional who can use the experience the individual has, as well as adapting to them as an individual in terms of how their diabetes is managed. • Community again plays an important role and there is the need for the health system to find ways of linking with other institutions (e.g., schools and workplaces), as well as providing the individual tools to be able to do this.
Self-Esteem Needs	<ul style="list-style-type: none"> • Practical aspects of diabetes management ('Adapting') are needed and, on the other hand, social aspects of the individual ('Being Open' and 'Personality') need to be present in order for the person to accept their diabetes.
Self-Actualisation Needs	<ul style="list-style-type: none"> • Important role of diabetes organisations.

4. Proposed Approach

A model that has been used by Changing Diabetes® in Children is the hub and spoke approach.¹⁶⁰ Given the need for specialised services and the low number of beneficiaries, the hub and spoke approach is suited to type 1 diabetes. This model has a hub that offers a comprehensive list of services, with spokes providing fewer services, but linked to the hub.¹⁶¹ This approach may enable the integration of lower levels of the health system, including PHC, with specific roles in follow-up of people with type 1 diabetes, and a clear referral and counter-referral pathway between the hub and spoke(s). This distinction could be linked to the hub and spoke model, with treatment initiation at the hub and continuation at the spoke. Beyond each spoke, there can be another level (Sub-Spokes), but this should be developed only once the hub and key spokes have been sufficiently strengthened. This overall configuration should be governed by specific guidelines. Continuing education programmes should be based on a training of trainers cascade model, following the hub and spoke model—experts from the hub train people at each spoke, who subsequently train other at their level (and at sub-spokes).. Each spoke could also have a focal point to ensure continued follow-up of people with type 1 diabetes in their specific area. A national focal point could be located at the hub, for example, at the national hospital of paediatrics and/or national referral centre for diabetes. At each level there is also a strong link to the community at large to address the wide-ranging issues, such as support and education activities described above. Overarching health policies need to facilitate this development of the system in addition to wider policies outside the realm of health. As described in the ICCCF, a “positive policy environment”¹³ is needed. This model is described in Figure 4.

Figure 4. Proposed hub and spoke approach for managing type 1 diabetes



5. Discussion

A variety of elements must be provided to ensure that an individual with type 1 diabetes can survive and thrive. Some of these elements can be provided by the health system and are tangible (e.g., insulin, health professionals and education). Once these needs are met, these elements must be delivered in a specific way and processes become more important. For example, it is not only diabetes education, but, more importantly, how and at what frequency this education is delivered. Finally, **Belonging, Self-Esteem and Self Actualisation Needs** cannot be delivered by the health system, but should be seen more as the result of the success of the tangible elements that the health system has been able to deliver in a specific way, with clear links and roles to communities and families.

The WHO defines health as ‘total social, psychological and physical well-being’.¹⁶² In order to achieve health for the populations they serve, health systems need to adapt their role to meet the needs of their populations. For type 1 diabetes this care goes beyond that of the formal health system as an individual will need to manage their diabetes at home, school, work, community without the continuous assistance of a health professional. As described by Bury²⁰, chronic conditions are a “biographical disruption”, meaning the health system is required to respond to the individual’s needs. Many of these needs are not traditionally seen as the remit of the health system, but should be integrated, as the individual will be managing their health mainly outside the confines of the formal health system. Throughout an individual’s diagnosis, treatment and follow-up the care provided should be tailored to their needs and these needs integrated into management. For example, a child with newly diagnosed type 1 diabetes will have a very different set of needs to an adolescent who has had type 1 diabetes for five years or a 50-year-old who has had diabetes since they were five years of age. One could argue that the elements that the health system is expected provide are the same, but different in terms of their content and priority for given individuals at given times.

The prioritisation presented in the HNT1D and the overall contents of this report, although specifically developed for type 1 diabetes, can be relevant for all NCDs. By using the HNT1D and providing different ways of addressing the needs presented in this framework, this document hopes to serve as a guide for those working in this area. As mentioned, an overall understanding of the health system is needed before embarking on such an exercise. This is needed in order to identify current challenges and prioritise these, with content from this report aiding in tackling some of these issues and the hub and spoke model providing the architecture on which to build on.

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