

Our rights to health

Using Human Rights to advocate for universal access to diabetes care.





Contents

Acknowledgments: Frank Brennan originally conceived and wrote the first draft of the Toolkit. Emma Klatman provided significant edits to the Toolkit, with additional contributions made by Rachel Clayton, Graham Ogle (Life for a Child), Kate Armstrong (CLAN Child Health), Jehangir Sidhwa, Colin Hunter and Alicia Jenkins (Insulin for Life), Amy Eussen, and Mark Barone. We thank ADJ Diabetes Brasil and Fundación Diabetes Juvenil Ecuador (FDJE) for providing case studies.

“Health and Human Rights are inextricably linked.”¹”

Jonathan Mann

Introduction

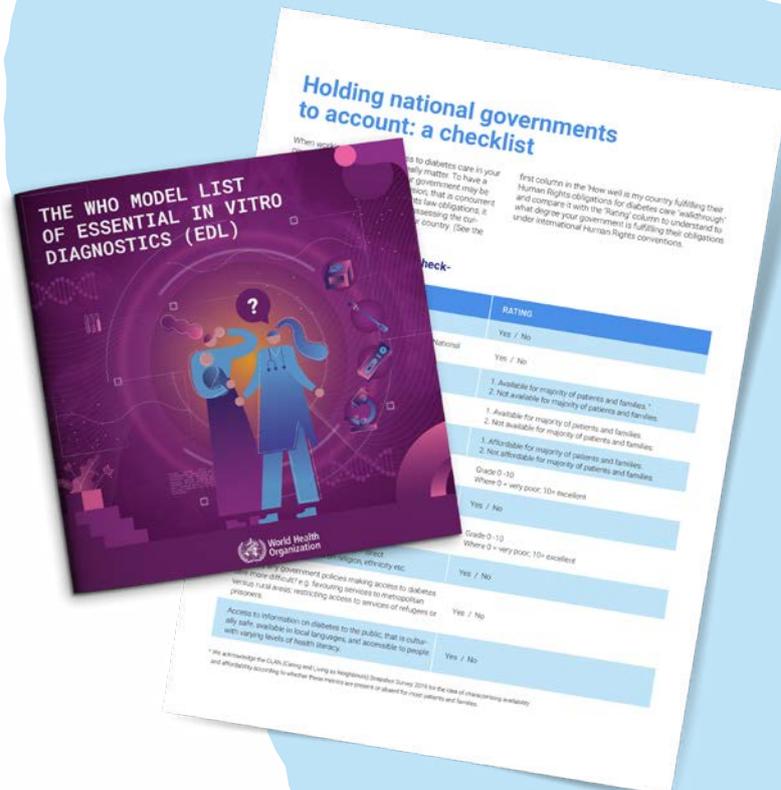
This Toolkit will introduce you to the concept of Human Rights and how they relate to diabetes care.

It will help you to create or strengthen an argument based on Human Rights. It will show you how this approach can strengthen advocacy for universal and equitable access to diabetes care.

The Toolkit has been developed for anyone concerned with increasing access to diabetes care, be they advocates living with diabetes, allies including health care professionals, policy makers, and lawyers. It can also be provided to Government officials as part of your advocacy work to improve access and accountability around diabetes care.

The Toolkit will set out appropriate resources you can use and point you to further resources on this topic.

Human Rights language can be very technical. It is therefore important to think about the language you use during advocacy depending on the audience you are targeting. This Toolkit uses plain language, avoids technical terms and uses graphics to convey our main points.





Manuel in Bolivia.

Manuel, a 12-year-old boy, has Type 1 diabetes mellitus. He lives in a country with poor access to insulin.

Nomkile, a 53-year-old woman has Type 2 diabetes mellitus. She has many other illnesses. She lives on the outskirts of a major city. Nomkile struggles getting access to information about her diabetes and its complications, basic medicines and trained medical and nursing support.



Diabetes – a global perspective

Insulin therapy became first available for use in 1922. A century later, many people around the world lack basic diabetes care and some die unnecessarily, because they cannot afford access to insulin and equipment they need.

There are key social and cultural determinants of health that impact on the lives of people living with diabetes. These include access to shelter, food, clean water and sanitation. Other important factors are access to education and employment and experiences of social isolation, stigma and racism.

Many people living with diabetes lack access to insulin, medications, clinical care, diabetes education and glucose and ketone monitoring (hereafter called “diabetes care”).

Globally, approximately 463 million people have diabetes, of whom approximately 79% live in disadvantaged regions.²

All people with Type 1 diabetes, and 15-20% with Type 2 diabetes and gestational diabetes, need insulin.

Children and adolescents with Type 1 diabetes are at great risk of dying without full access to insulin. People living with diabetes living in poverty and rural and remote regions are especially vulnerable.

Diabetes is a non-communicable disease (NCDs). NCDs are chronic (long-lasting) conditions that do not spread from person to person. Diabetes and high blood pressure are good examples. The UN has challenged the nations of the world to meet a series of Sustainable Development Goals (SDGs), including in relation to NCDs, by 2030.

Amongst the numerous responses to these inequalities, an argument has emerged that diabetes care should be seen as a human right. But, just what does this mean? How can this statement be justified? How could this argument be used by advocates?

537 million
people have diabetes, globally

81%
live in
disadvantaged
regions²



What are Human Rights?

Towards the end of World War II and following the atrocities that took place, the global community came together and formed the United Nations.

Member States of the United Nations (more commonly known as “countries”) agreed that governments have a responsibility to respect the dignity of all human persons, to permit basic freedoms, to protect people from harm and to provide people with the basic elements of living. These were termed **Human Rights**.

The obligations to fulfill these rights are set out in documents called International Human Rights covenants, conventions or instruments. There are a wide range of Human Rights. One example is the right to health. The main international Human Rights conventions are listed in the snapshot below. Extracts from several of these documents will appear in this Toolkit.

Over time, regions of the world created their own regional Human Rights charters. An example is the *African Charter on Human and Peoples’ Rights*. [Available to view here*](#).

* <https://www.achpr.org/legalinstruments/detail?id=49>

Finally, the constitutions of many countries contain a human right that is relevant to diabetes care, including a right to health care.

This Toolkit will refer to each of these sources of Human Rights.

Our Rights to Health in Africa: A Type 1 Diabetes Youth Advocacy Workshop



In 2021, Life for a Child, CLAN Child Health, and Insulin for Life convened a virtual workshop of Rights Based Advocacy in the African setting. Advocates shared lessons learned from their own experiences in implementing rights-based advocacy.

Snapshot

Existing international Human Rights conventions that support your rights

- *Universal Declaration of Human Rights*. Passed early in United Nations (UN) history and broadly sets out international Human Rights.
- *International Covenant on Civil and Political Rights*. Civil and political rights include the right to free assembly and to free and fair elections.
- *International Covenant on Economic, Social and Cultural Rights*. Includes the right to health.
- *Convention on the Rights of the Child* (children and adolescents up to the age of 18).
- *Convention on the Elimination of All Forms of Discrimination Against Women*
- *International Convention on the Elimination of All Forms of Racial Discrimination*
- *UN Declaration on the Rights of Indigenous Peoples’*
- *Convention on the Rights of Persons with Disabilities*

Human Rights terminology and concepts that can support your advocacy

Human Rights

Human Rights are rights for everyone. These universal rights are inherent to all humans, regardless of age, gender, religion, nationality, skin color, language or any other status. They range from the most fundamental – the right to life – to those that make life worth living such as the right to food, education, work, health and liberty.³

Human Rights Law and international Human Rights conventions. At the time of the formation of the United Nations, the Universal Declaration of Human Rights (UDHR) set out basic rights held by all human persons. This was followed by specific international conventions on civil and political rights (such as the right to free assembly) and economic, social and cultural rights (such as the right to health). Other conventions followed including, amongst others, the Convention on the Rights of the Child and [Convention on the Rights of Indigenous Persons](#).*

* <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>



Right to health

The right to health means the right to health care and services. It is broadly interpreted and includes an obligation on signatory nations to ensure other elements to the enjoyment of health – basic housing, adequate nutrition, fresh water and sanitation. The right to health is included in many UN Human Rights Conventions, regional human right charters and national constitutions. The content of this right shall be described in detail in later sections of this Toolkit.

Right to life

The right to life is read broadly. The UN Special Rapporteur on Health expressly linked the right to health and the right to life in the context of children and, relevant to Type 1 diabetes, stated *“The right to health is ... closely linked to the right to survive of young children.”*

Right to information

The right to the provision of health information is seen as part of the right to health and the right to education.

UN Special Rapporteur on the Right to Health

A Human Rights expert who is appointed by the UN to oversee the right to health and regularly report to the UN General Assembly and Human Rights Council on the extent of its fulfillment.

Dignity

A foundation principle for Human Rights. Essentially, the inner value held by all human beings. The main UN Human Rights Conventions commence with a statement that *“We, the undersigned nations, recognising the inherent dignity of all human persons...”*

Equality

The state of being equal in rights, status or opportunities. Equality is about ensuring that every individual has an equal opportunity to make the most of their lives and talents.⁴

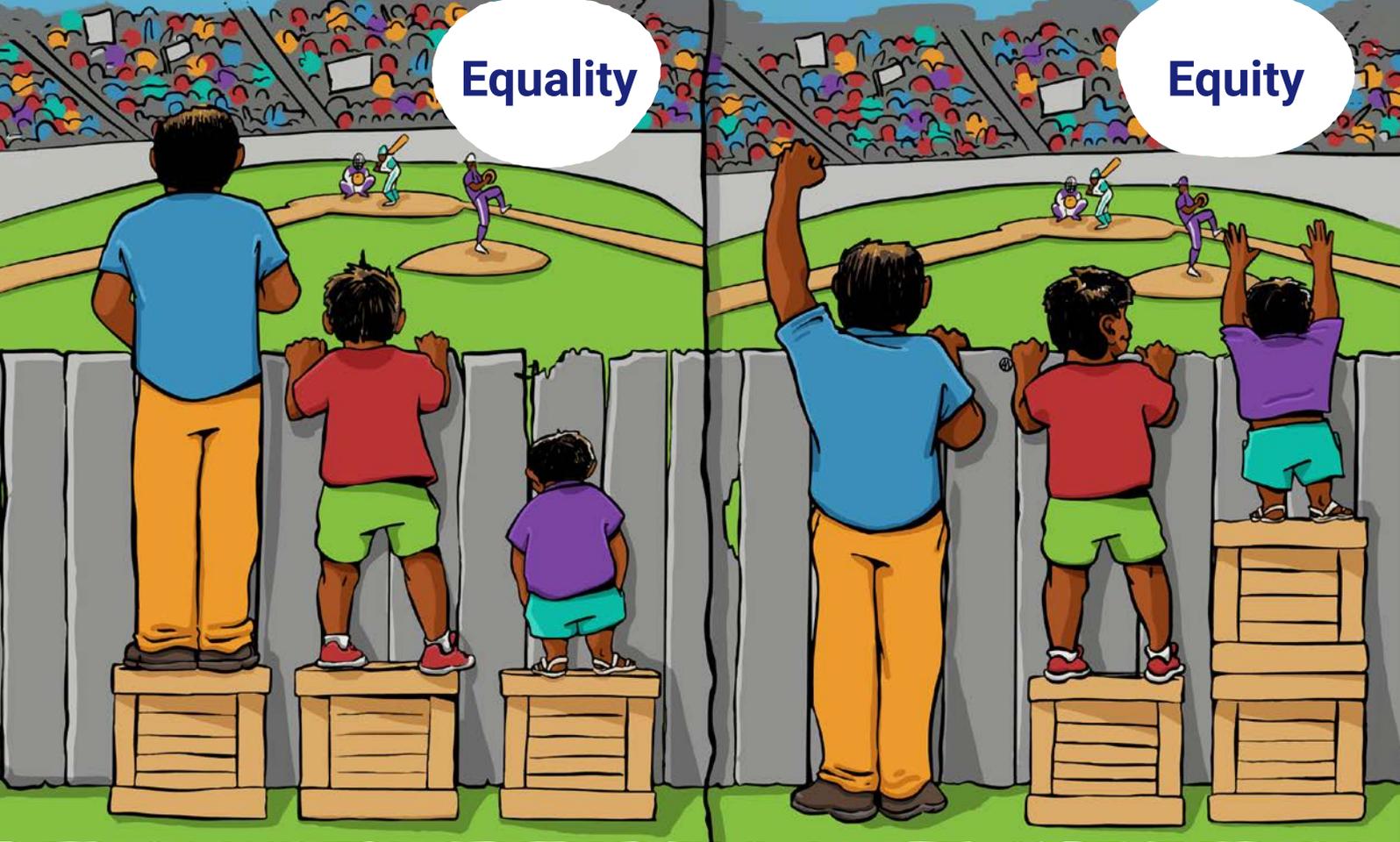


Image Reference: "Interaction Institute for Social Change | Artist: Angus Maguire."

Equity

The quality of being fair and impartial. Freedom from discrimination. An equitable society is one in which all can participate and prosper.

Human Rights Council

The main specialist body within the United Nations that promotes and oversees international Human Rights.

National Essential Medicine List (NEML)

Every nation develops its own list of medicines it considers essential, based on the WHO Essential Medicine List (EML) and Essential Medicine List for Children (EMLc). See below and next page.

World Health Assembly (WHA)

The forum of national Ministers of Health gathered to guide the work of the WHO.

World Health Organization (WHO)

The principal body directing international health policy within the United Nations system.

WHO Model List of Essential Medicines (WHO EMLs) and WHO Model List of Essential Medicines for Children (WHO EMLc)

A list of medicines considered essential to achieving health for a population by the WHO.

The WHO **Model List of Essential Medicines** is a list of medicines published that the WHO considers to be essential to the minimum needs of health care. Access to these medications should be universal. All nations are encouraged to provide these medicines. Visit WHO [here for more detail](#).*

There is also a list for children up to 12 years of age (**WHO Model Essential Medicine List for Children - EMLc**). You can visit WHO [here for more detail](#)**.

Insulin is a WHO Essential Medicine in both lists and has been so since their inception.

* <https://www.who.int/groups/expert-committee-on-selection-and-use-of-essential-medicines/essential-medicines-lists>

** <https://apps.who.int/iris/rest/bitstreams/1374783/retrieve>

A young man with diabetes attaching a blue circle pin to a minister in Tanzania.

In addition, there is also a **WHO Essential Diagnostics List (EDLs)**.⁵ This is a WHO priority list of medical tests that gives nations guidance on which tests to use, including in the context of diabetes care. [Read more here](#).^{*}

Each nation has their own National Essential Medicines List (NEML), guided by the above lists. [Visit here to check what is on your country's NEML](#).^{**}

* <https://www.who.int/publications/m/item/the-who-edl-brochure>
 ** <https://list.essentialmeds.org>

EXERCISE

Understanding the WHO Model Essential Medicine List

A good exercise is to look up the WHO Model Essential Medicine List⁶ and WHO Model Essential Medicine List for children⁷ and compare that to the National Essential Medicine List of your country. You can do this here:

<https://list.essentialmeds.org>

In addition to understanding human right terminology, it is also beneficial to understand Universal Health Coverage (UHC).

The aim of UHC is all about ensuring every person has access to the health care they need without being exposed to financial hardship.

The cornerstone of UHC is access to affordable, available, and quality health care.

The governments of the world have committed to Universal Health Coverage as part of the UN Sustainable Development Goals (SDGs) for 2030. With reference to insulin and blood glucose meters and test strips, many countries in Low- and middle-income countries (LMICs) struggle to provide both critical elements of diabetes care.

It has been noted that if these supplies are not available in a UHC program in a LMIC, then there is a risk that diabetes is not included in their SDG commitments.

Ref: Klatman EL, McKee M, Ogle GD. Documenting and visualising progress towards Universal Health Coverage of insulin and blood glucose tests strips for people with diabetes. *Diabetes Research and Clinical Practice* 2019; 157:107859.

Insulin coverage

	Population covered	Types covered	Costs covered
United Kingdom	100%	100%	100%
Guyana	100%	67%	100%
Ecuador	63%	33%	100%
Haiti	100%	0%	0%

Strips coverage

	Population covered	Daily amount	Costs covered
United Kingdom	100%	100%	100%
Guyana	100%	67%	100%
Ecuador	63%	33%	100%
Haiti	100%	0%	0%

High-income countries usually provide complete coverage of diabetes care, in accordance with the WHO Model Essential Medicine List. As country income levels decline, coverage of diabetes care provision tends to decrease, even when there is a public health system that theoretically covers the entire population.

Case Study

Maria is a 5-year-old girl living in Ecuador. When she was 3-years-old, she was diagnosed with Type 1 diabetes.

Recently, she was referred to a children's hospital, a long distance from her home. The paediatric endocrinologist was very frustrated at this public hospital as the kind of insulin Maria needed was not available there. Maria's parents do not have a permanent job so do not have the resources to buy insulin and supplies in the private sector and sustain long-term treatment.

In the past, this children's hospital was always reliable in having available insulin, glucose meters, test strips, glucagon and training booklets. But due to a drastic reduction in its budget, it can no longer deliver the same quality of these services.

Case study from Fundacion Diabetes Juvenil Ecuador



Is diabetes care a Human Rights issue?

Human Rights are founded on two points of basic and fundamental recognition:

- a. that all persons have an inherent dignity, and
- b. with that recognition of universal human dignity, comes an obligation on governments and all members of society to preserve, protect and fulfill some basic entitlements of all peoples.

Diabetes is a Human Rights issue because:

1. People living with diabetes may die due to inadequate access to diabetes care.
2. The inherent dignity of the person living with diabetes can be impaired where there is no diabetes care or inadequate diabetes care.

3. All stages of diagnosis and the management of diabetes requires adequate access to skilled health care and diabetes education, essential medicines such as insulin, monitoring and dispensing equipment and other general elements of health such as adequate nutrition, housing and safe, potable water. Each of these elements may be difficult or impossible to access in some countries.
4. People living with diabetes (and their carers) need information on the condition, its treatment and how to access care.

Policies can directly or indirectly impact people living with diabetes.

Knowing your rights

Since the establishment of the United Nations, a series of international Human Rights conventions have been agreed upon and implemented. Each contain several rights.

Of the international Human Rights, these are the most relevant to diabetes care:

-  **A. The right to health**
-  **B. The right to life**
-  **C. The right to information**
-  **D. The right to be treated without discrimination**

A. The right to health

The right to health is set out in a series of UN international Human Rights conventions and covenants:

1. The main statement is in the *International Covenant on Economic, Social and Cultural Rights (ICESCR)*.⁹ Article 12 (1) of that Covenant states:

The State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Importantly, the Covenant states that the rights in this Covenant (including the right to health) should be “progressively realized” according to the resources of the nation. Essentially, this means that governments should do all the realistically can to provide the right to health based on their economic situation. The progressive realization of rights also places a responsibility on developed nations to assist other nations who are unable to fulfill this right.

2. Convention on the Rights of The Child (CRC)¹⁰
3. Convention on the Elimination of All Discrimination Against Women (CEDAW)¹¹
4. International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)¹²
5. UN Declaration on the Rights of Indigenous Peoples (UNDRIP)¹³



EXERCISE

What obligations does your government have in fulfilling your right to health?

The expression “a right to health” is very broad. What does this mean in practical terms? In other words, what could you say to governments about what they are obliged to provide under the international right to health as it relates to diabetes care? The Committee that helps provide member states with Guidance on the ICESCR explained the governments core responsibilities regarding the right to health:¹⁴

1. The right to health has four “interrelated and essential elements” – availability, accessibility, acceptability and quality of health care goods and services. Authors of this Toolkit believe ‘affordability’ particularly underpins accessibility.
2. Governments have an obligation to respect, protect and fulfill the right to health.
3. That access to health should be “progressively realized”. In other words that the provision of health care should not go backwards.

4. The Covenant states that the provision of the rights listed, including health, should occur according “to the maximum of its available resources”.
5. Nevertheless, there are certain things that are “core obligations” that *should occur immediately, whatever the resources of the nation*. They include the obligation “*To adopt and implement a national public health policy.*”

To ensure access to Essential Medicines, as listed by the World Health Organization (WHO), To ensure equitable distribution of all health facilities, goods and services, and that health care is given to everyone without discrimination. There are two types of discrimination. Discrimination can occur directly - based on gender, sexuality, ethnicity, religion etc (deliberately not giving health care to a certain racial group) – or indirectly – an example here would be only allowing an essential medicine to be available in city hospitals but not in rural hospitals or clinics.

EXERCISE

Is there any responsibility on non-government bodies, such as pharmaceutical companies?

According to the Universal Declaration of Human Rights, responsibilities for Human Rights belong to “every organ of society”, including “the private business sector”.¹⁵

The UN has collaborated with business to draw up the *UN Global Compact*, with several thousand businesses affirming that business should take steps to protect international Human Rights.¹⁶

The UN Special Rapporteur on the Right to Health has published a description on the Human Rights responsibilities of industry in the *Human Rights Guidelines on the Responsibilities of Pharmaceutical Companies in Relation to Access to Medicines*.¹⁷ For a summary of these guidelines view the Snapshot on the following page.

Mireille, a girl living with type 1 diabetes in Rwanda



Snapshot

Extract from Guidelines made by the Special Rapporteur on the Right to Health to pharmaceutical companies in relation to access to medicines, including insulin.

The Special Rapporteur recommended that pharmaceutical companies:

1. **Integrate a Human Rights approach into company activities.** They should adhere to the essential elements of the right to health including accessibility, availability, acceptability and quality of goods and services. (Guideline 2)
2. **Create a clear public policy on access to medicines.** This includes setting and disclosing quantitative and accountable targets. Companies should ensure that medicines are affordable to as many people as possible, especially to disadvantaged populations including children, older persons and those living in poverty. The policy should consider the economic development of the country. (Guidelines 10, 12, 33, 34, 35)
3. **Ensure that discount and donation schemes** and their delivery channels are as simple and inclusive as possible. (Guideline 37)
4. **Disclose information on pricing and discounting arrangements,** the absolute quality and value of drug donations, the number of beneficiary patients treated annually, where possible, and the amount of tax benefit arising from these donations. (Guideline 38)
5. **Publicly adopt anti-corruption policies.** (Guideline 15)

HbA1c testing in Rwanda



B. The right to life

The right to life is contained in several international Human Rights instruments including the *International Convention on Civil and Political Rights (ICCPR)*, Article 6(1), the *Convention on the Rights of the Child (CRC)*, Article 6 and the *UN Declaration on the Rights of Indigenous Peoples*, Article 7.

The UN Human Rights Commission explained that the right to life “should not be interpreted narrowly” or “in a restrictive manner” and its protection “requires that States adopt positive measures...to increase life expectancy.”¹⁸

This broad interpretation aligns with diabetes care and is a strong starting point for advocacy. The lack of access to insulin in a person with Type 1 diabetes mellitus, can inevitably lead to death. Considering international Human Rights law, nations have a positive obligation to adopt positive measures to prevent the person dying prematurely.

This is especially relevant to children with Type 1 diabetes mellitus. The UN Special Rapporteur on Health expressly linked the right to health and the right to life to children: “The right to health is ... closely linked to the right to survive of young children.”¹⁹

C. The right to information

Under international Human Rights law, the right to information concerning health issues is critical to persons living with diabetes and their families and carers. This information includes medical information about diabetes and ways to prevent, monitor and manage it. The sources of that right are:

1. The Committee that oversees The International Covenant on Economic, Social and Cultural Rights that contains the main statement on the right to health.²⁰
2. The International Convention on Civil and Political Rights²¹
3. Convention on the Rights of the Child (CRC)²²
4. *UN Declaration on the Rights of Indigenous Peoples*.²³ This is relevant to ensure educational material on diabetes care is available in local languages and is culturally safe and appropriate.

D. The right to non-discrimination

International Human Rights law states that human beings should enjoy all rights without discrimination on any basis including race, religion, gender, language, skin colour, political or other opinion, national or social origin, property, birth or other status.²⁴

Specifically, in relation to the right to health, the Committee on ICESCR stated that one of the “core obligations” on signatory nations, irrespective of their resources, is:

To ensure the right of access to health facilities, goods and services on a non-discriminatory basis...²⁵

Discrimination may be direct or indirect (see page 21).



Kisima draws up his insulin dose in Mali



A diabetes education and activity day in Rwanda

Knowing your rights as a young person

Children and adolescents have:

- **The right to health**
- **The right to life**
- **Right to information**
- **Right to non-discrimination**

In addition, the *United Nations Convention on the Rights of the Child* (applying to all people up to 18 years of age) contains other rights relevant to diabetes care:

Children who have any kind of disability should receive special care and support so that they can live a full and decent life. (Article 23)

- Right to a standard of living adequate for the child's physical...development. (Article 27)
- Right to social security and insurance. (Article 26)

CLAN (Caring & Living As Neighbours) has created an excellent resource all about children living with diabetes and their rights. [Available here.](#)*

Download** The CLAN Child Friendly Rights Flyer for more information.



?

If you were trying to communicate the rights of young people living with diabetes to your government, where would you start and what would your approach be?

* <https://www.clanchildhealth.org/diabetes.html>

** [https://www.clanchildhealth.org/uploads/8/3/3/6/83366650/clan_child-friendly_diabetes_rights_flyer_-_english_\[e\].pdf](https://www.clanchildhealth.org/uploads/8/3/3/6/83366650/clan_child-friendly_diabetes_rights_flyer_-_english_[e].pdf)

When advocating for increased access to diabetes care, a Human Rights approach provides a strong platform. This organizational infographic helps sequentially visualize this.

Advocacy for access to diabetes care through a Human Rights law framework[^]

Access to...

- Insulin
- Diabetes management supplies
- Diabetes care
- Diabetes information



...Is reflected in international human rights laws including:

- The right to health
- The right to life
- The right to information
- The right to non-discrimination



...whereby

Governments are linked to their international obligations.

Pharma and device companies work to address international targets for diabetes.



...to ensure that

People with diabetes, and their communities, are able to live safe and healthy lives. Action is taken by governments, clinicians, and NGOs based on the principles of dignity, non-discrimination, and equity of access.



[^] Originally designed by Emma Klatman. Reproduced with acknowledgement from Brennan et al. A Human Rights approach to improve access to insulin and other aspects of diabetes care. Diabet Res and Clin Pract 2022

Real case studies

As you read the Case Studies below, think about how you might tackle a similar situation in your own country using a Human Rights approach.

Case Study: Mia

Mia is a 7-year-old girl in the rural area of a low-income country. Mia was recently diagnosed with Type 1 diabetes. Already, her parents are struggling to pay for her insulin and diabetes consumables. Her father works on a daily wage; her mother has a disability. They have received little information about diabetes. Supplies of insulin to her location are unreliable.

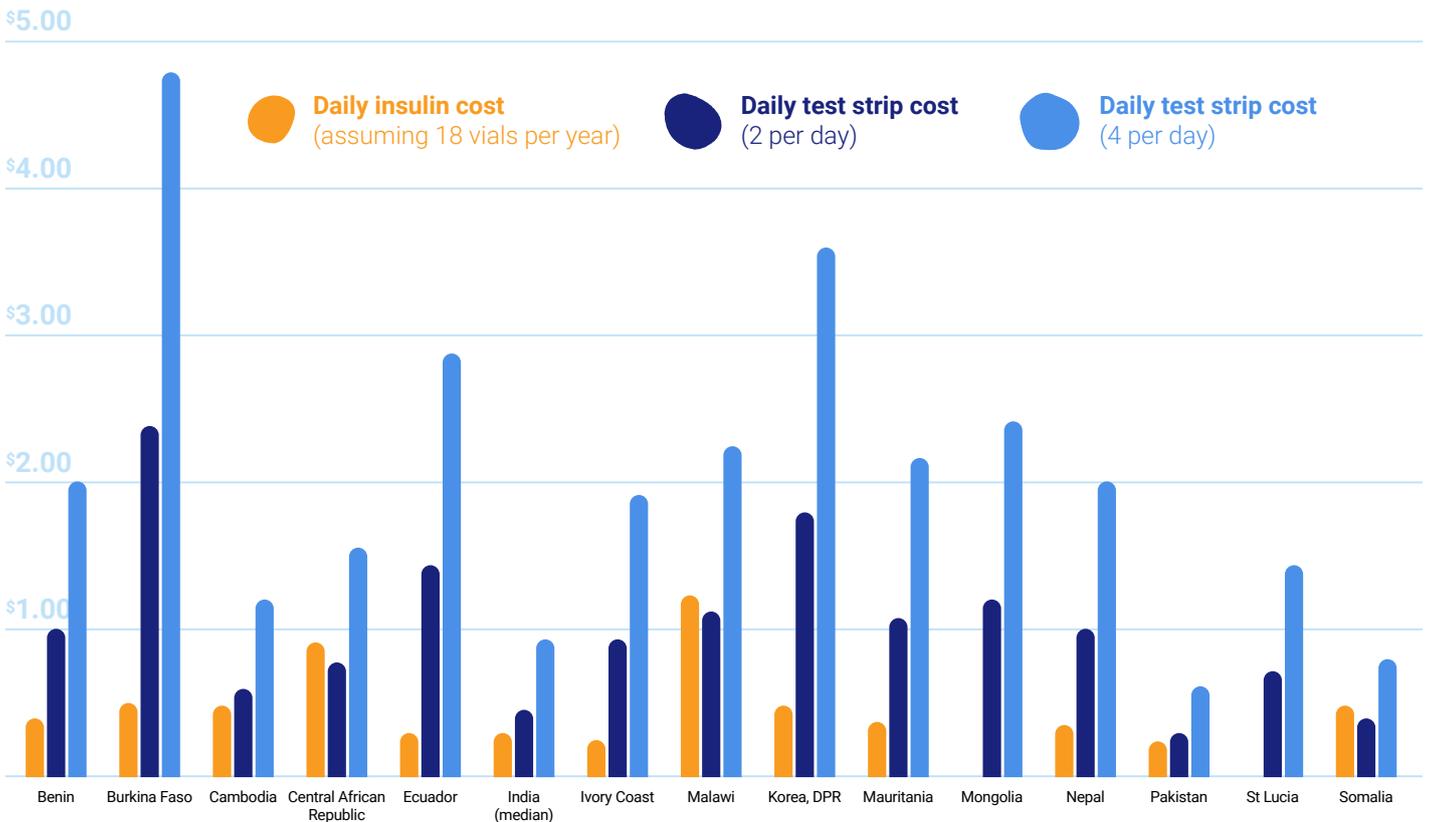
Access to diabetes care in less-resourced countries is inadequate for many reasons. The chart below shows the financial impact to patients and their families if they are forced to purchase items, like insulin and test strips, out-of-pocket. These additional, unexpected costs often hit families hard giving them long-term financial hardship.

Case Study: Luis

Luis is a 13-year-old boy in Ecuador. He has Type 1 diabetes. He has a job and, as such, has mandatory general insurance managed by the national Institute of Social Security. In recent years the quality of its service has deteriorated. Practically, the concerns for Luis are delays in receiving specialist review, unreliable supplies of insulin and no access to glucose meters or test strips. As a result, patients are forced to contribute to expensive private health insurance.

Case study from Fundacion Diabetes Juvenil Ecuador.

Daily costs: Insulin, blood glucose meter, blood glucose test strips



Klatman EL, Jenkins AJ, Ahmedani MY, Ogle GD. Blood glucose meters and test strips: global market and challenges to access in low-resource settings. *Lancet Diabetes Endocrinol.* 2019 Feb;7(2):150-160. doi: 10.1016/S2213-8587(18)30074-3. Epub 2018 Jul 30. Erratum in: *Lancet Diabetes Endocrinol.* 2018 Aug 30; PMID: 30072234.

National constitutions and rights

All countries have constitutions. Constitutions contain the rules of a nation, and they are the source of power of the government, the executive (the President or Prime Minister and Cabinet), the parliament and the courts.

Some, although not all, national constitutions contain a set of rights.

Those rights may include:

- a right to health care, goods and services.
- a right to life; and/or
- a right to be treated without discrimination.

A constitution may express the right to health broadly, universally and without limits. In the constitutions of Nicaragua, Vietnam and the Philippines, for example, there is a focus on the poor and disadvantaged members of society.²⁶ In South Africa, the constitution expresses an obligation of governments to fulfill the right to health depending on the availability of government resources.

Case Study: Brazil

The Constitution of Brazil contains a right to health.²⁹

Under this right there is a Universal Health System for comprehensive preventative and curative health care. For years, people living with diabetes reported that they were unable to receive adequate treatment and that costs compromised a significant part of the family budget. In 2001 the State of Sao Paulo enacted a law guaranteeing the provision of all necessary treatment for people living with diabetes. In 2006, the national government enacted a law which provides for the free distribution of medicines and supplies to people living with diabetes.³⁰

Paraguay followed Brazil approving a federal law on full coverage of diabetes care, including medical consultations, medications and supplies.

Case Study Source: ADJ Diabetes Brasil

In the latter situation, therefore, a challenge based on a constitutional right to health may be met with the national government saying: "We simply do not have the resources for what is being asked."

Four national constitutions expressly include an obligation to ensure a universal access to medicines: Panama, Mexico, the Philippines and the Syrian Arab Republic.²⁷

The constitutions of Ecuador and Panama specify that national medicine policies shall be established and implemented to achieve the broad constitutional obligations.²⁸ The provisions of the above constitutions are relevant to access to insulin in those nations.

Let us look at some examples of national constitutional rights as they relate to health and how they have been interpreted by courts.

Case Study: Venezuela

In the Bermudez³¹ case a group of people living with HIV/AIDS challenged the Venezuelan national government for not providing sufficient anti-retroviral medications to them.

Their argument was based on several rights: health, life and access to scientific advances. The Venezuelan Supreme Court concentrated on the right to health. This right was expressed in two ways in Venezuelan law – expressly in the national constitution and secondly, under national law, the government had an obligation to fulfill their treaty duties under international conventions (including the international right to health). This is an example of the right to health being expressed both under the national constitution and through international treaty obligations.

The Venezuelan Supreme Court held that the Ministry of Health was not fulfilling its duty under the right to health. Whilst it acknowledged the budgetary constraints of the government, it held that Ministry could lawfully seek further funds to provide these medications to all patients living with HIV/AIDS.

*Scales of Justice,
Dublin Castle, Ireland.
Photo taken by Graham Ogle*



Case Study: South Africa

The South African Constitution states:

Section 27.

(1) Everyone has the right to have access to:

a. Health care services...

(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.

Mr Soobramoney, a 41-year-old man, had kidney failure. He needed dialysis (a machine to do the job of kidneys and rid the body of toxins) and applied to the local health authority. They had limited dialysis machines and had strict criteria for entry onto their dialysis program. Mr Soobramoney did not meet these criteria and

was informed that it was not possible for him to receive dialysis. He challenged this decision based on the South African constitutional right to health. In *Soobramoney vs. Minister of Health, Kwazulu Natal*³², the Constitutional Court rejected his argument.

The Court held that the constitution states that the right to health is limited by the available resources of the government and, further, that it is the government that ultimately decides what priorities it sets for its health budget.

Case Study: South Africa

The shocking HIV/AIDS pandemic struck sub-Saharan Africa grievously. International evidence showed that Nevirapine, an anti-retroviral medication, significantly reduced the risk of mother – child transmission of HIV. Under government policy, Nevirapine could not be administered in the public hospital system to pregnant women with HIV except in certain designated sites. A coalition of activists challenged this policy based on the constitutional right to health

The South African Constitutional Court in *Minister of Health v Treatment Action Campaign (2)*³³, held that the policy violated the health rights of women and newborn babies. They held that the government policy was not reasonable, primarily due to its rigidity and inflexibility. The Court ordered the government to provide this medication in all hospitals.

Case Study: Colombia

The right to health is protected under the Constitution of Colombia. The right is supported by the availability of a tutela action, which allows any individual or group to bring an action for their constitutional rights to any court. Colombia is also party to both international and regional Human Rights instruments that include the right to health.

An indigent man was losing his vision and could not afford an eye operation that would restore that vision. In *Sentencia T-533/92*³⁴, an action was taken to the Colombian Constitutional Court based on the man's rights to health, life and work and, thereby, his dignity. The Court accepted this argument and ordered the eye operation for the man.

The role of Colombian courts, insurance companies and the government in managing the expectations flowing from the constitutional right to health have, over years, been the subject of controversy, protests and crises.³⁵





Taking action against national courts.

What factors can help with success?

Experts concluded that success in bringing an action based on the right to health before national courts is higher³⁶ when:

1. The national constitution contains a right to health care. That argument, alone, may be sufficient.
2. The national constitution states that international Human Rights conventions ratified by the government are embedded in, and are part of, the national law. This is significant. Rather than needing to argue the relevance of such international Human Rights to a country, they are automatically incorporated in the law of the nation. Currently, 31 national constitutions state this. Interestingly, this argument alone was successful in a case in Argentina, a nation without a constitutional right to health.³⁷ Where the argument is related to access to a WHO essential medicines especially where that medicine is on the nation's essential medicine list. This is relevant to insulin.



Aminatou hands a CLAN Child Friendly Rights Flyer, explaining the rights of the child with Type 1 diabetes to an advisor to the Ministry of Health in Mali.

3. In a large percentage of successfully argued cases, the right to health was linked to the right to life. This was especially so in the case of a life-threatening illness where treatment was potentially lifesaving. A relevant example is Type 1 diabetes and access to insulin.

Holding national governments to account: a checklist

When working to improve access to diabetes care in your country, understand that facts really matter. To have a clear understanding of where your government may be falling short of diabetes care provision, that is concurrent with their international Human Rights law obligations, it can be helpful to start here by first assessing the current

provision of diabetes care in your country. (See the first column in the 'How well is my country fulfilling their Human Rights obligations for diabetes care 'walkthrough' and compare it with the 'Rating' column to understand to what degree your government is fulfilling their obligations under international Human Rights conventions.

Human Rights obligations checklist

NATIONAL ACTIVITY	RATING
National Diabetes Policy	Yes / No
Are diabetes medicines, including insulin on the National Essential Medicine List?	Yes / No
Access to insulin – availability	1. Available for majority of patients and families. [^] 2. Not available for majority of patients and families.
Access to diabetes monitoring equipment - availability	1. Available for majority of patients and families. 2. Not available for majority of patients and families.
Access to insulin and diabetes care - affordability	1. Affordable for majority of patients and families. 2. Not affordable for majority of patients and families.
Quality of medicines and equipment	Grade 0 - 10 Where 0 = very poor; 10 = excellent
Use of quality data to monitor preventable mortality and morbidity (e.g. national patient registers)	Yes / No
Diabetes training, education and professional development for health professionals. This includes relevant information for health workers in local languages.	Grade 0 - 10 Where 0 = very poor; 10 = excellent
Monitor and address discrimination – direct e.g. Denying access based on religion, ethnicity etc.	Yes / No
Are there any government policies making access to diabetes care more difficult? e.g. favouring services to metropolitan versus rural areas; restricting access to services of refugees or prisoners.	Yes / No
Access to information on diabetes to the public, that is culturally safe, available in local languages, and accessible to people with varying levels of health literacy.	Yes / No

[^] We acknowledge the CLAN (Caring and Living as Neighbours) Snapshot Survey 2019 for the idea of characterising availability and affordability according to whether these metrics are present or absent for most patients and families.

How are the 'national activities' listed on the previous page, justified in international Human Rights law?



National Diabetes Policy

- The international right to health. A national public health policy is a “core obligation” irrespective of national resources.

Are diabetes medicines, including insulin on the National Essential Medicine List?

The existence of diabetes medicines on National Essential Medicines Lists relate to the right to health and the right to life. Access to Essential Medicines is a “core obligation” irrespective of national resources.

Access to insulin – availability

- The international right to health includes 4 “inter-related and essential elements” including availability. Access to Essential Medicines is a “core obligation” irrespective of national resources.

Access to diabetes monitoring equipment – availability

- The international right to health includes 4 “inter-related and essential elements” including availability of “facilities, goods and services”. (General Comment No. 14, Article 12(a))

Affordability of diabetes care

- The international right to health includes 4 “inter-related and essential elements” including accessibility – which includes economic accessibility. (General Comment No. 14, Article 12(b))

Quality of medicines and equipment

- The international right to health includes 4 “inter-related and essential elements” including quality.

Use of quality data to monitor preventable mortality and morbidity (e.g. national patient registers)

- The international right to health. One of the “core obligations” irrespective of national resources is the adoption of a national public health policy reflecting the importance of epidemiological evidence.

Diabetes training, education and professional development for health professionals. This includes relevant information for health workers in local languages.

- The international right to health – “obligations of comparable priority”. (General Comment No. 14 Article 44 (e)).

Monitor and address discrimination – direct. (e.g., Denying access based on religion, ethnicity etc.)

- The international right to health. Access to Essential Medicines is a “core obligation” irrespective of national resources.

Monitor and address discrimination – indirect (e.g., No or limited access on the basis of geographic location.)

- The international right to health. Access to Essential Medicines is a “core obligation” irrespective of national resources.

Are there any government policy making access to diabetes care more difficult? e.g. favouring services to metropolitan versus rural areas; restricting access to services of refugees or prisoners.

- The international right to health should be “progressively realized”, not restricted. “States are under an obligation to respect the right to health by... refraining from denying or limiting access for all persons” (General Comment No. 14 Article 34.)

Access to information on diabetes to the public, that is culturally safe, available in local languages, and accessible to people with varying levels of health literacy.

- The international right to health – “obligations of comparable priority”. (General Comment No. 14 Article 44 (d)).

Regional Human Rights

In addition to the provisions of international law, some geographic regions of the world have Regional Human Rights Conventions. In this section, we will look at these that are specific to The Americas, Africa, and Europe.

These regional instruments can further support your advocacy to mount an argument for improved diabetes care in your country. By having a regional Convention, this is another hook to government to indicate its responsibilities to its citizens. In some cases, depending on the regional Convention, individuals can raise issues around access to diabetes care with their own governments directly, or if not satisfied (and the legal process complete), take a complaint to the courts or commissions overseeing these conventions. For a list of the regional Human Rights conventions and the body overseeing them see the table on page 26.

Let us now look at some of those conventions and see how they may apply to diabetes care.

The Americas

The regional Human Rights conventions of the Americas (North, Central and South America) are:

- *American Declaration of the Rights and Duties of Man*
- *American Convention on Human Rights*

- *Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights ("Protocol of San Salvador", which has been* ratified by Argentina, Bolivia, Brazil, Columbia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Surinam and Uruguay)*

1. Article 10. Right to Health

- Everyone shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental and social well-being.
- To ensure the exercise of the right to health, the State Parties agree to recognize health as a public good and, particularly, to adopt the following measures to ensure that right:
 - Primary health care, that is, essential health care made available to all individuals and families in the community.
 - Extension of benefits of health services to all individuals subject to the State's jurisdiction...
 - Education of the population and the prevention and treatment of health problems.
 - Satisfaction of the health needs of the highest risk groups and those whose poverty makes them the most vulnerable.

EXERCISE

You are a 22-year-old living with Type 1 diabetes. You live in a South American nation that has ratified the Protocol of San Salvador.*

The national government announces that, in six months' time, it will cease providing free insulin and diabetes care consumables to people over 21 years of age. After approaching the Department of Health and local politicians and receiving no response, you decide to take your complaint to the Inter American Court of Human Rights.

How would you make your case?

*<https://www.oas.org/juridico/english/treaties/a-52.html>



Brandon and friends in Bolivia

Africa

The regional Human Rights convention of Africa is:

- *African Charter of Human and Peoples' Rights (ACHPR)*

The ACHPR includes several components applicable to diabetes care:

- Right to health.³⁸
- Right to life.³⁹
- Right to information.⁴⁰
- Right to non-discrimination and equality.⁴¹

The case study opposite is a real-life look at a case under this Charter.

Case Study: Purohit and Moore vs. The Gambia

This case was heard by the African Commission on Human and Peoples' Rights. The applicants alleged the Gambian laws for mental health violated the right to health and the right of people living with a disability to special measures of protection in keeping with their physical and moral needs (Articles 16 and 18(4) of the African Charter of Human and Peoples' Rights (ACHPR) respectively).

The Commission agreed. It stated that the right to health includes the right of all to health facilities, as well as access to goods and services, without discrimination.

Additionally, it stated that the enjoyment of the right to health is crucial to the realisation of other fundamental rights and freedoms. The Commission stated that mental health patients should be accorded special treatment to enable them to attain and sustain their optimum level of independence and performance.

EXERCISE

How could this decision be used to argue for universal access to diabetes care in an African nation that is signatory to the Charter?

Europe

In Europe, there are two main regional conventions on Human Rights. As they relate to diabetes care they are:

- *European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)*
 - Article 2(1): The right to life.
- *European Social Charter (ESC)*
 - Article 11: The Right to Protection of Health

1. To remove as far as possible the causes of ill-health;
2. To provide advisory and educational facilities for the protection of health and the encouragement of individual responsibility in matters of health...

EXERCISE

You are a Diabetes Association in a European nation signatory to the European Charter.

You are concerned about access to diabetes care in your country. After approaching your domestic Department of Health and receiving no response you decide to take your complaint to the European Court of Human Rights.

How shall you make your case?

Bringing it all together. From theory to practice

We are now able to bring this information together and plan an advocacy campaign based on Human Rights.

Step one

Learn more about your rights! Hopefully, this Toolkit and such documents including the CLAN Child Friendly Rights Flyer⁴² will build your confidence and understanding.

Step two

Carefully examine a nation's needs in diabetes care and evaluate the extent to which the nation preserves, protects and fulfills these needs. See the checklist on page 17 and the associated definitions on page 18. This includes whether the nation has a National Essential Medicines List that includes insulin and glucagon and the equipment needed to manage diabetes.

Step three

Research to see whether the nation:

- Is signatory to International Human Rights documents that contain rights relevant to diabetes care – the rights to health, right to life, information and nondiscrimination.
- Is signatory to Regional Human Rights Charters or Conventions that contain rights relevant to diabetes care – the rights to health, right to life, information and nondiscrimination.
- Has a constitution that contains rights relevant to diabetes care – the rights to health, right to life, information and nondiscrimination.

Step four

Meet with, petition and advocate to the national government with the above information from Steps 2 and 3, reminding them of:

- a. The deficits in diabetes care in the nation, and
- b. Their obligations under Step 3.

At this point it would also be appropriate to summarize the commitments of governments in Universal Health Coverage and UN Sustainable Development Goals as they relate to non-communicable diseases, including diabetes.



Ana asks the National Assembly of Ecuador to lower the cost of insulin.

Ideally, this should be tied to an express statement of openness to assist the government in any way possible, including facilitating the role of regional and international diabetes associations. **Step 4 may involve many attempts.**

Step five

Where there is no or inadequate response by the government, the Toolkit gives you choices in your next action. Depending on the commitments made by the individual government in Human Rights, the next steps could be one or several actions. These are set out in the table on page 26.

Step six

In addition to advocacy based on Human Rights, another path of advocacy is Universal Health Coverage. Here to remind nations of their commitment to UHC as part of the UN Sustainable Development Goals to be achieved by 2030.

Step seven

At all points in advocacy, expressly aid government in any way possible, including facilitating the role of regional and international diabetes associations.

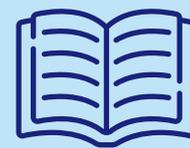
Possible rights-based actions you could take when your government is failing to improve access to diabetes care.

	INTERNATIONAL HUMAN RIGHTS	REGIONAL HUMAN RIGHTS	CONSTITUTIONAL RIGHTS
ACTION	Submission to Committees overseeing the conventions, especially the ICESCR and the Convention on the Rights of the Child.	Bring a case before the appropriate Regional Human Rights Court or Commission	Bring a case before the responsible national court. Usually, this is the national constitutional court.
BASIS OF ARGUMENT	<ol style="list-style-type: none"> 1. Analysis of current national deficits in diabetes care. 2. A clear analysis of the national obligations relating to the international rights to health, life, information, and non-discrimination as they relate to diabetes 	<ol style="list-style-type: none"> 1. Analysis of current national deficits in diabetes care. 2. Careful analysis of the relevant regional Human Rights convention and case law as they relate to rights to health care, life, information, and non-discrimination. 	<ol style="list-style-type: none"> 1. Analysis of current national deficits in diabetes care. 2. Careful analysis of the national constitution and case law as they relate to rights to health care, life, information, and non-discrimination. <p>Where relevant connect the right to health with the right to life.</p> <p>Strengthen the argument though the nation's international Human Rights obligations.</p>

An education workshop in Mali.



Reminding ourselves of the progress made to prioritize diabetes care within the global health agenda:



- In 2008 the *Global Strategy for the Prevention and Control of Non-Communicable Diseases (NCDs)*, including diabetes, was endorsed by the WHA, the governing body of the WHO. One of its central objectives was to encourage nations to formulate policies and plans for NCD prevention and control.
- In 2010, WHO released a *Package of Essential Non-Communicable (PEN) Disease Interventions for Primary Health Care in Low-Resource Settings*. This document set out the essential, minimum elements of a national NCD policy. One of those essential elements was the provision of affordable and effective medicines, including insulin. It is worth noting such NCD policies could include an explicit National Diabetes Policy that helps deliver strategies geared towards improving access to diabetes care.
- In 2013 WHO released its *Global Action Plan for the Prevention and Control of Non-Communicable Disease 2013-2020*. The overall objective was to attain nine global targets by 2025 known as the NCD Global Monitoring Framework. The Framework allows global tracking of progress in preventing and controlling major NCDs, including:
 - A 25% reduction in premature mortality from NCDs, including diabetes;
 - An 80% availability of essential medicines and affordable basic technologies required to treat NCDs. These include insulin and the necessary equipment for glucose measurement and diabetes management.
- In 2013 the World Health Assembly approved the *Omnibus Resolution on NCDs* which stated that:
 - *Children can die from treatable noncommunicable disease, such as ...Type 1 diabetes...if health promotion, disease prevention, and comprehensive care is not provided.*⁸
 - This was a pivotal acknowledgement by Member States that children, adolescents, and young adults are affected by, and are at risk of, NCDs. This statement can serve as a useful advocacy reference.
- In 2016, the WHO published the WHO Diabetes Global Report. This seminal document stated that all nations should *"make essential medicines such as human insulin available and affordable to all who use them."*²⁰
- In 2021, the WHO made two important initiatives. The first was an adoption by the Executive Board of a Decision on Addressing Diabetes as a Public Health Problem.²¹ The second was the launch of the WHO Global Diabetes Compact to identify ways to support nations to develop and implement programs to prevent and support the management of diabetes.²²
- In 2022, Member States voted for the adoption of the WHO diabetes recommendations and coverage targets at the 75th World Health Assembly. These targets include:
 - 80% of people with diabetes are diagnosed
 - 80% of people with diagnosed diabetes have good control of glycaemia
 - 80% of people with diagnosed diabetes have good control of blood pressure
 - 60% of people with diabetes 40 years or older with diabetes receive statins
 - 100% of people with Type 1 diabetes have access to affordable insulin treatment and blood glucose self-monitoring
- In 2023, the UN High-Level Meeting (HLM) on Universal Health Coverage will be convened.
- In 2025, the UN HLM on non-communicable diseases (NCDs) and action to achieve Sustainable Development Goals (SDGs) by 2030 will be convened.

Change is never static. Further prioritization of diabetes care into the global health agenda is possible.



Bushra checks her blood glucose level, Bangladesh.

Further resources

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- ¹⁰ United Nations General Assembly (1989) Convention on the Rights of the Child (CRC), Article 24. United Nations, New York.
- ¹¹ United Nations General Assembly (1979) Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), Articles 11.1(f) and 12. United Nations, New York.
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- ¹³ United Nations General Assembly (2006) UN Declaration on the Rights of Indigenous Peoples, Resolution 61/295. Article 24(2). United Nations, New York.
- ¹⁴ United Nations Committee on Economic SaCR (2000) General Comment No. 14. The Rights to the Highest Available Standard of Health. 22nd Session, April-May 2000. E/C 12/2000/4. United Nations, New York.
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⁴¹ *African Charter of Human and Peoples' Rights* (ACHPR). Article 2.

⁴² CLAN Child Friendly Rights Flyer. [https://www.clanchildhealth.org/uploads/8/3/3/6/83366650/clan_child-friendly_diabetes_rights_flyer_-_english_\[e\].pdf](https://www.clanchildhealth.org/uploads/8/3/3/6/83366650/clan_child-friendly_diabetes_rights_flyer_-_english_[e].pdf)





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