



Lifelong Care for Children with Chronic Conditions: Session 2

Re-imagining the Package of Care for Children Subgroup

June 25, 2021

Series objectives

- Share and get feedback on UNICEF's working “*Integrated Chronic Lifelong Care for Children and Adolescents*” framework
- Present case studies on specific chronic conditions
- Draw lessons for broader programming and implementation

UNICEF's Integrated Chronic Lifelong Care for Children and Adolescents Framework

- Chronic Conditions affecting Children and Adolescents: HIV, Diabetes, Rheumatic Heart Disease, Asthma, Disabilities, Sickle Cell Disease, Cancers, Hep B, Syphilis
- In contrast with high-income countries, Chronic Care for children and adolescents is a less-developed area in low-and-middle-income countries
- These countries have typically focused on “episodic” management of common childhood illnesses that significantly contribute to child mortality
- With shifting epidemiologies, in part due to improving economies and gains in child mortality; and with UNICEF's focus on a survive, thrive and transform agenda, chronic conditions come more into focus



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Botswana Comprehensive Care and Support for Orphans and Vulnerable Children Project 2016 – 2022



USAID
FROM THE AMERICAN PEOPLE



Botswana Comprehensive Care and Support for OVC Project

Project Goal and Objectives

Strengthening community agency to seek, support, and provide HIV-related services to AGYW, OVC, and their families

IR 1: Strengthen household and community to support OVC and AGYW

IR 2: Increase uptake of HIV prevention, care, and treatment services among OVC households and AGYW

IR 3: Improve policy implementation for delivery of coordinated quality social service

IR 4: Strengthen capacity of local organisations to sustain program delivery and outcomes

Priority sub-populations

Children and adolescents living with HIV

HIV-exposed infants including infants of young mothers

Vulnerable adolescent girls and young women

Children of female sex workers

Survivors of violence

Lifelong care for children

Contributing to the clinical cascade for the chronic care of HIV+ OVC in Botswana

Providing linkages to HTS and ART treatment and monitoring retention and viral load suppression

OVC Project funded by:

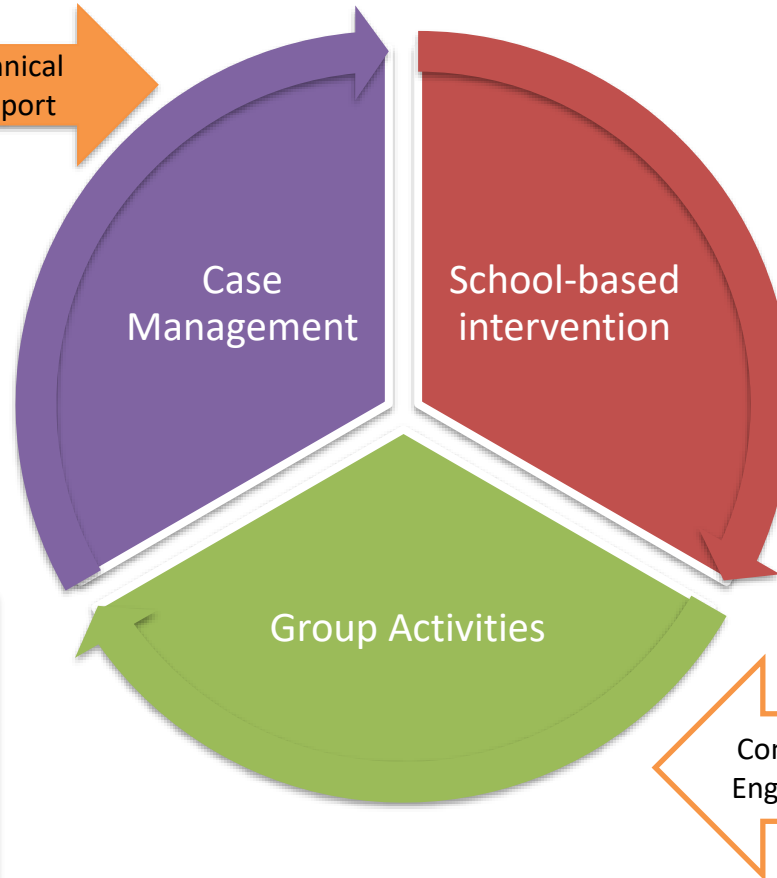


Botswana Comprehensive Care and Support for OVC Project

OVC Services



Technical
Support





Community
Engagement

HEALTHY SERVICES
SCHOOLED SERVICES
STABLE SERVICES
SAFE SERVICES

Botswana Comprehensive Care and Support for OVC Project

Geographic Locations



-  OVC and AGYW services
-  OVC services only

The HIV Management Approach

- **Approach used for client identification:** Referrals from clinics and community members, and through household assessments
- **Populations served:** HIV+ children, pregnant women, and HIV exposed infants
- **Model of delivery:** Household visits
- **Service providers:** Community Service Providers (CSPs)



The Service Package

Health services offered for HIV+ children:

- Age-appropriate HIV treatment literacy counselling and HIV disclosure support for children and families
- Provision of adherence counselling, care and support, including tracking of viral load suppression for HIV+ Orphans and vulnerable children as well as their Caregivers
- Age-adjusted care:
- Referral for early infant diagnosis (EID)
- Referral for developmental support for HEU and HIV infected children
- PLHA support through *Teen Clubs*
- Referral for HIV related testing (STI, TB)

Our partner Baylor University provides training and technical support for CSPs in children and adolescent HIV treatment management.

Baylor also runs a teen club model where HIV+ adolescents who know their HIV status meet regularly to support each other. They receive life skills training and group adherence counselling.



Identifying HIV+ clients during visits

CSP asks what client s/he knows about HIV and provides education where there are gaps

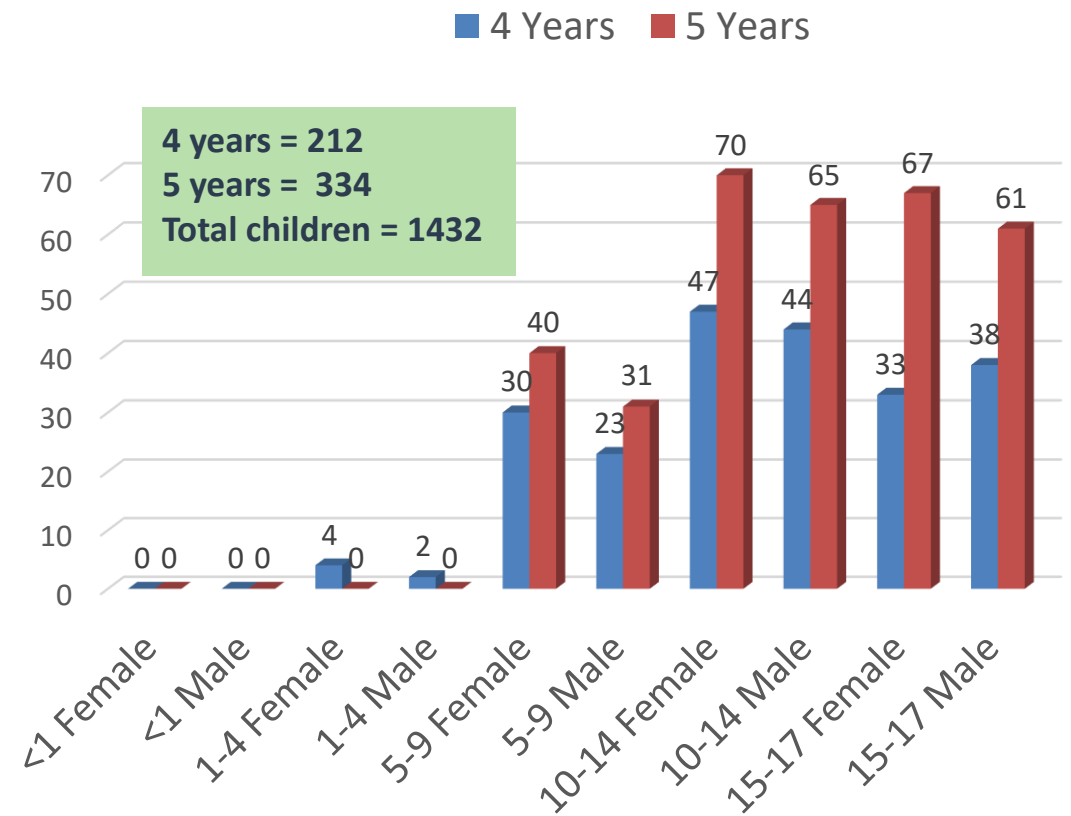
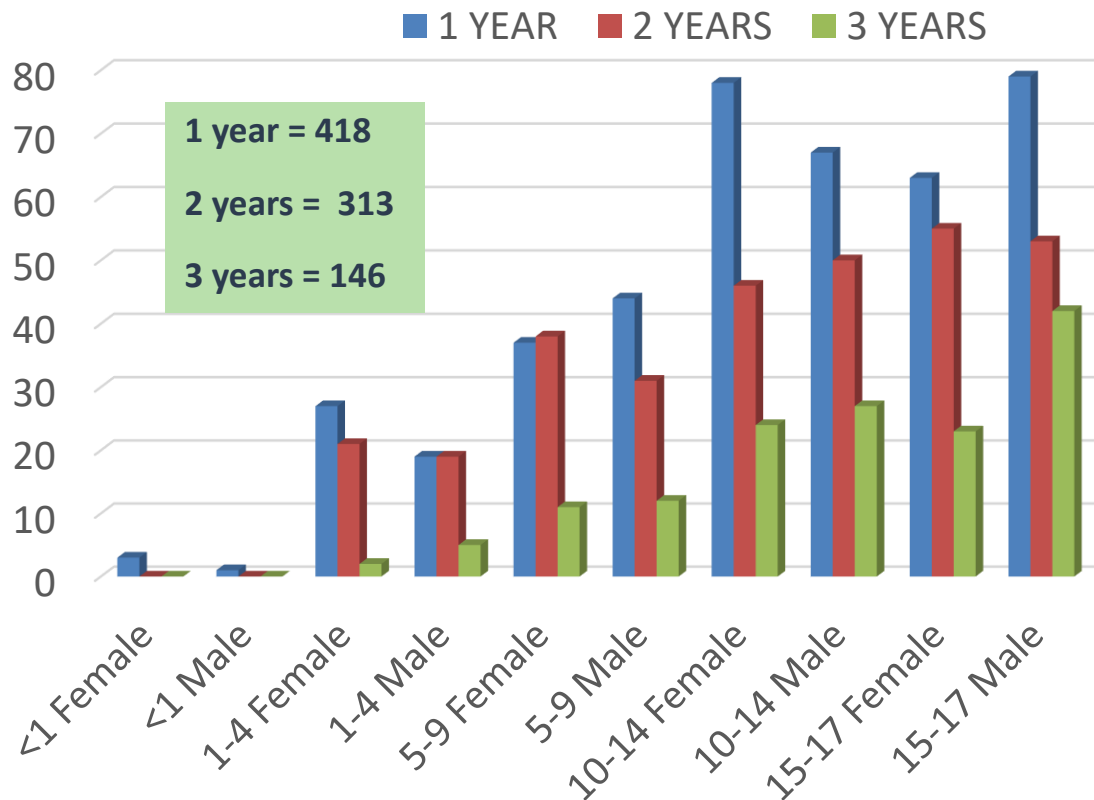
CSP asks client their HIV status and when they had their most recent HIV test

Where client is HIV+ CSP determines whether client is on treatment (if not, CSP links them to treatment) or is adhering to medication (supports viral load monitoring)

Where HIV- CSP continues with HIV education and works with the client to develop prevention strategy including linkage to DREAMS for AGYW

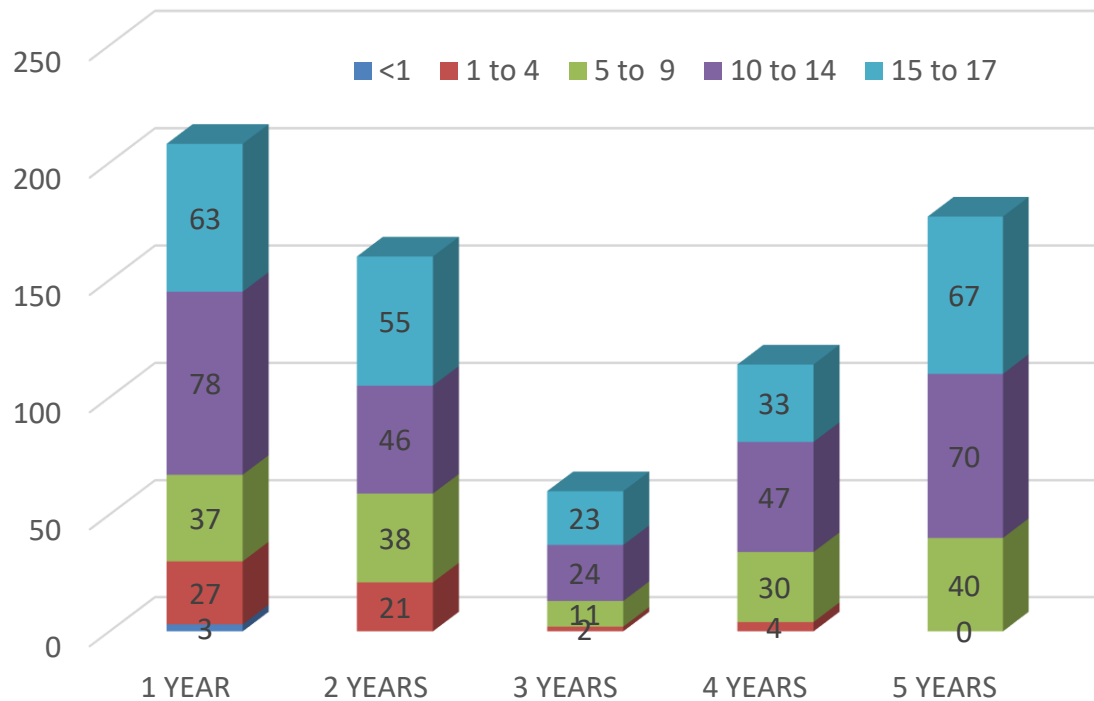
Where HIV status is unknown, CSP administers a risk assessment. Those at high risk for HIV are referred for HIV testing and followed up

Duration of Care for HIV+ Children

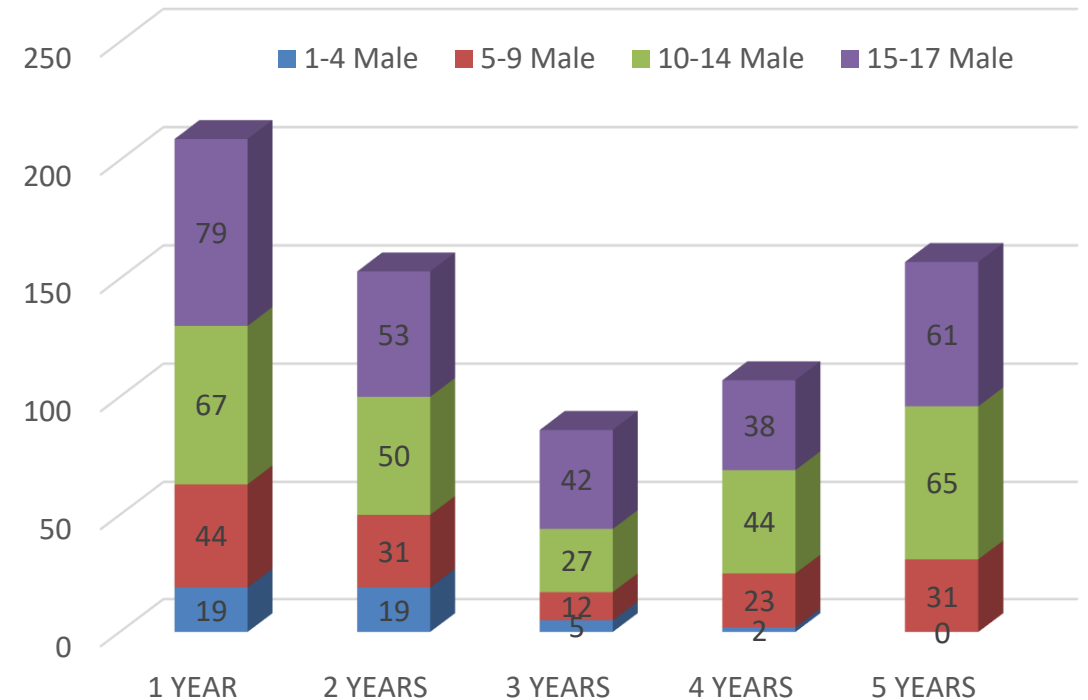


Duration of Care for HIV+ Children

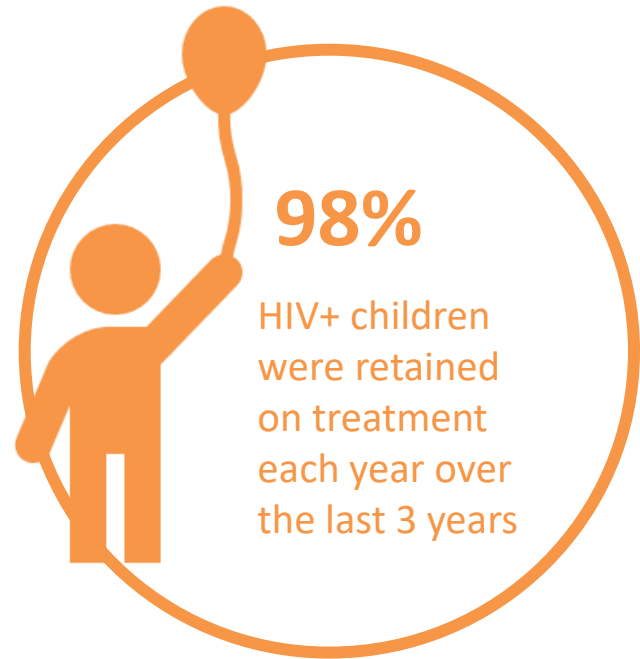
Female Participation by Age and by Year



Male Participation by Age and by Year



Working towards the 95-95-95



Source: PCI Global Communities Botswana database

Tracking of HIV retention amongst OVC over the past 3 years



Thank you





LIFELONG CARE OF CHRONIC DISEASE SCD – CASE STUDY

BY

Vivian Paintsil MD

Senior Lecturer-KNUST, Senior Specialist Paediatrician KATH

Overview



Overview of the burden

- SCD is an inherited disease in which there is the inheritance of 2 abnormal Hb, one of which is Hb S
- Over 400,000 newborns screened since 1995
- In Ghana, about 1.8% of newborns have SCD
- Routine clinic attendance of about 150 a week
- Hydroxyurea treatment offered to patient
- Paediatric, Adolescent Clinic and transition clinic (Mondays, Tuesdays, Thursdays, Fridays)
- Hydroxyurea clinic on Fridays

Overview of SCD

- High Incidence of SCD - similar to most sub-Saharan African Countries
 - *Est. 15,000 with SCD born annually*
 - *56% SCD-SS; 1% SCD-S β^0 *thal* - Severe*
 - *42% SCD-SC; - Moderate*
 - *1% SCD-S β *thal* - Mild*
- Major contributor to under-five mortality (9-16%)

Overview

- Newborn Screening for SCD
 - *National Policy in place since 2011; very slow scale-up*
 - *Only 3% of newborn screened annually*
 - *Newborn with SCD provided penicillin prophylaxis and comprehensive care*
- Hydroxyurea offered to patients currently through a partnership with Novartis where patients get free HU.



Government fulfils promise to absorb Hydroxyurea sickle cell therapy under NHIS

The Vice President, Dr Mahamudu Bawumia has announced that the www.ghanaweb.com

Available guidelines

- Training for healthcare workers on hydroxyurea use
- Guidelines for hydroxyurea use
- Guidelines for managing SCD at the different referral levels also in the process of being field tested prior to roll out

Case study

- Name : BO
- Gender : Male
- Age : 15 yrs
- School : JHS 3
- School Performance : Currently not doing well

CS 2/6

- Was diagnosed by newborn screening which showed a possible SCD FS
- Parents tracked by the screening office and results disclosed to them
- Both parents have Hb AS
- BO is the last of 2 children.
- 1st is a girl with Hb AS

CS 3/6

- Patient's 1st visit was at 4 mths of age and caregivers defaulted for their next appointment
- Caregivers were educated and given Folic acid and Penicillin prophylaxis
- Came back at 9 months of age with dactylitis and fever.
- Admitted and managed and parents recounselled and educated.
- Improved adherence to clinic visits and compliance to medications thereafter
- Patient managed severally on inpatient and OPD basis for varying degrees of Vaso-occlusive Pain events, hyperhaemolysis and recurrent infections.
- Hb was always around 6 - 7g/dl

CS 4/6

- At age 8yrs, had a generalized tonic clonic seizure with weakness on the Right side of the body.
- Power -0/5 on the Right LL and UL but 5/5 on the left UL and LL
- Reflexes was reduced with reduced tone.
- CT scan showed a left frontoparietal infarct
- Imp: SCD – SS with CVA (Infarctive stroke)

CS 5/6

- Admitted and transfused
- Continued on prophylactic medications
- Started on physiotherapy – patient currently able to walk but with a hemiplegic gait
- Issues identified
- Low Hb – 6 – 7g/dl g/dl (Reluctance of parents to have transfusions)
- Recurrent visits to hospital to pain episodes and loss of school hours

CS 6/6

- At 10 years of age, HU was introduced to the family
- Had baseline labs done and started on 20mg/kg.
- Dose Escalation done and currently on 30mg/kg
- Recurrent pain episodes and absence from school all subsided.
- Had episodes of staring gaze and tonic seizure.
- Scans still showed the old infarct – chronic left frontoparietal infarct with associated atrophy
- Seen by the neurologist and put on AEDs.
- No seizures subsequently and doing well

Lab data

date	Hb g/dl	WBC	Neut	MCV	Plt	Retics %
26/03/2021	9.3	5.85	2.04	97.4	261	
20/08/2020	9.4	6.98	3.18	91.5	342	3.01
07/05/2020	9.4	6.01	2.17	103.5	277	3.88
02/2019	8.0	7.82	3.22	82.8	523	6.59
02/2018	7.9	10.3	4.48	82.9	367	3.5
01/2017	7.7	10.6	6.56	86.8	298	6.9
04/2016	7.4	8.9	3.68	80.8	471	4.9
02/2015	6.3	9.2	3.17	78.5	513	3.17

Learning points/Implementation

- Importance of NBS program. This is not fully accessible for everyone in Ghana. 3% of popltn can access it
- Importance of enrolment in an SCD clinic for comprehensive care
- Patient / parents education is key for success of management
- Availability of prophylactic medications – folic acid, Pen V
- Availability of disease modifying medications – Hydroxyurea and other newer ones - NHIS
- Availability of facilities for screening – TCD, ECHO, Urine R/E,
- Support for mental health issues
- Management of acute and chronic complications – Guidelines

Acknowledgements

- Patient BO and family
- KATH SCD management team members





Child Health Task Force
18th June, 2021
Dr Graham Ogle

LIFE
FOR A
CHILD

Challenge of diabetes in children

- Mainly type 1 – autoimmune
- Quickly die without treatment
- Requires
 - insulin injections at least twice per day
 - Fingerprick blood glucose tests
 - HbA1c testing
 - Diabetes education
 - Expert care
- Tightrope each day
- Risk of life-threatening acute complications
- Social implications



Many cases die before
diagnosis

Many others die quickly of
ketoacidosis or
hypoglycaemia

Others develop early and
devastating complications

1.1 million children and
adolescents have type 1
diabetes

Around 300,000 of these are in
great need of help



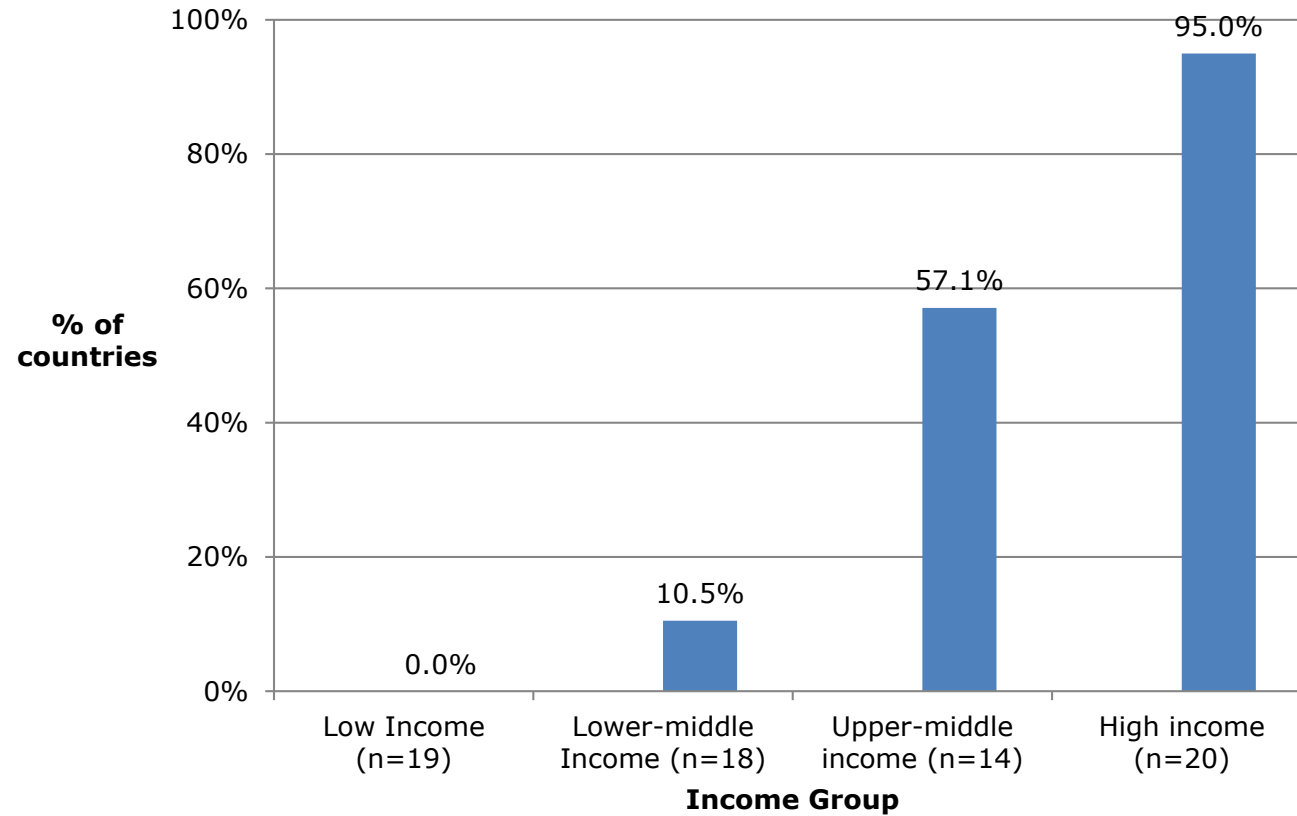
Mali

- 1999 publication (Sidibé et al.) + follow-up data:

18 of 20 children with type 1 died within three years



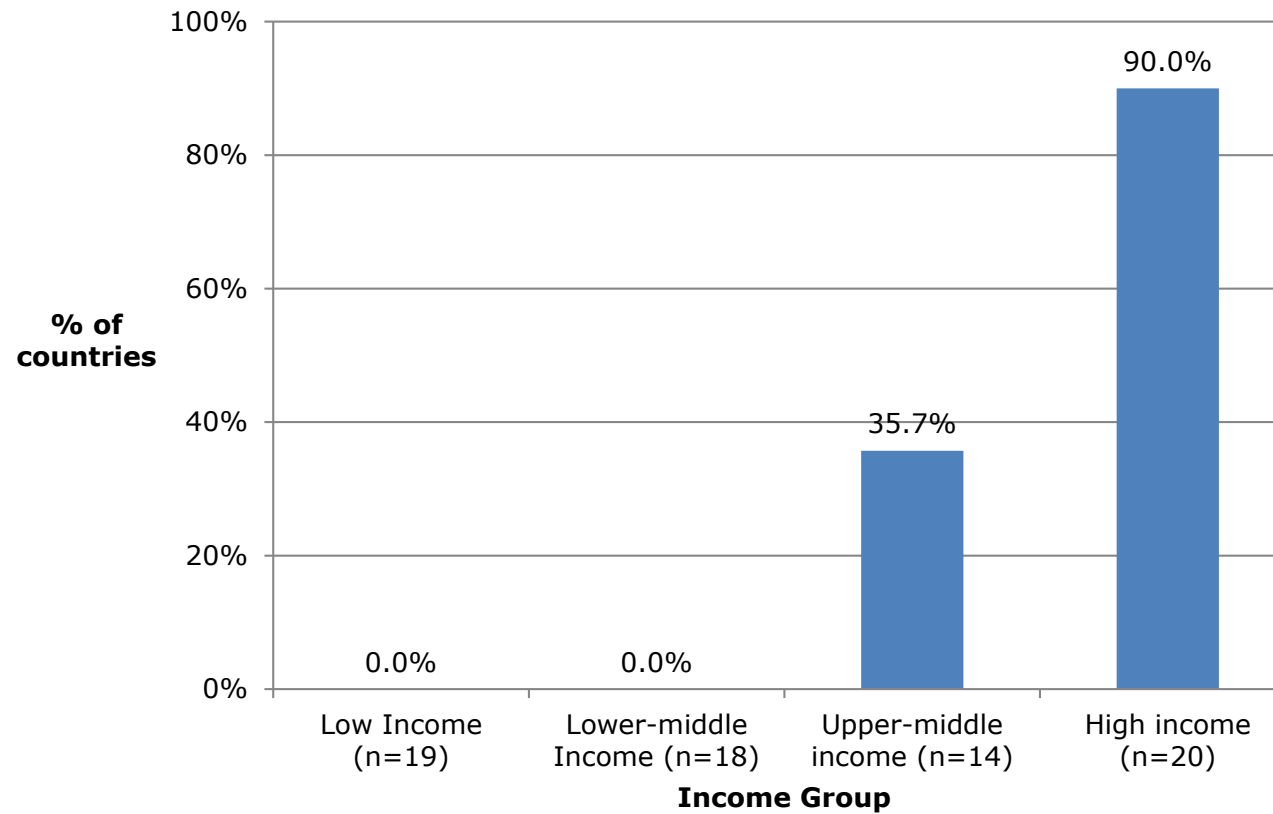
Full provision of insulin by Government for children <15 years



Ogle, Middlehurst, Silink. Pediatr Diabetes 2016;17:374-384



Full provision by Govt. of 2+ blood glucose strips per day for children <15 years



Ogle, Middlehurst, Silink. Pediatr Diabetes 2016;17:374-384



(After a period of illness when I was seven) I was finally labelled with type 1 diabetes. Me and my family literally felt shattered. Life stood stand still.

There came a time, when I along with my family started praying to God to put a full stop to my life. My family is not financially strong, on top of that expenses on insulin injections, meters and strips, lancets, and managing hypoglycemia.

Shirin, age 17, India

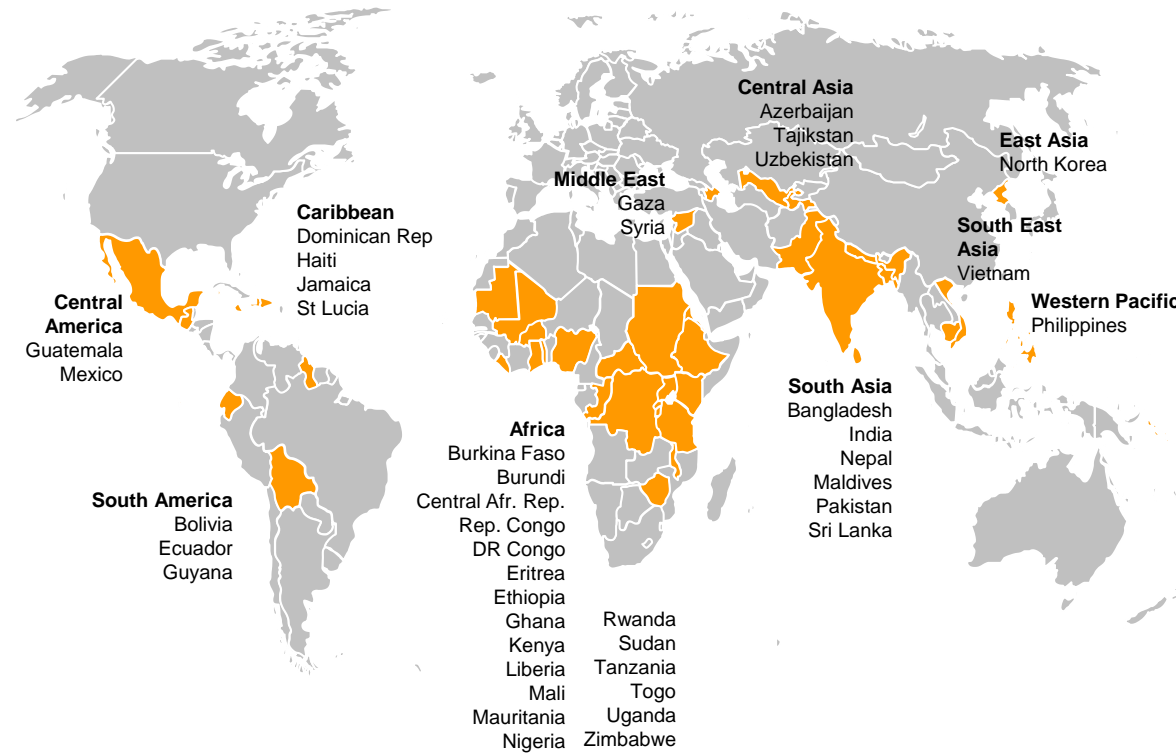


Life for a Child Program

- **Commenced** 2000
- **Vision** *No child should die of diabetes*
- **Mission**
Support the provision of the best possible health care, given local circumstances, to all children and youth (under 26 years of age) with diabetes in less-resourced countries, **through the strengthening of diabetes services in these countries.**
- Conduct clinical research and international advocacy, and where possible help both young adults and also recipient countries with **achieving sustainability.**



2021 Life for a Child Program – Over 23,000 children in 42 countries



Major Partners and Donors

- Diabetes NSW & ACT
- Leona M and Harry B Helmsley Charitable Trust
- JDRF
- Diabetes Australia
- Direct Relief
- ISPAD
- Insulin for Life
- International Diabetes Federation
- Eli Lilly and Lilly Foundation
- Becton Dickinson
- Siemens Healthineers
- LifeScan
- Trividia Health
- Many individual donors



Other Partners

- Children's Hospital Oakland Research Institute
- University of Pittsburgh
- University of Sydney
- University of Florida
- London School of Hygiene and Tropical Medicine
- Marjorie's Fund
- Team Type 1
- Barbara Davis Center
- Orbis International
- McGill University
- Caring and Living as Neighbours (CLAN)



Support

- **Insulin and syringes**
- **Meters and strips**
- **HbA1c**

- **Training of health professionals**
- **Diabetes education**

- Complications screening
- Assistance with transport costs, communications
- Capacity building
- Technical advice and mentoring
- Research
- Diabetes camps



Process

- Assist diabetes centres caring for children
- Request received, bona fides assessed, questionnaire sent
- Questionnaire reviewed, priorities (e.g. insulin, monitoring, HbA1c, education) are identified
- Joint decision made to support a specific list of the most needy children with specific costed supplies +/- funds, according to a pre-agreed budget
- MOU signed with requirement for clinical and financial feedback
- Ongoing monitoring and evaluation

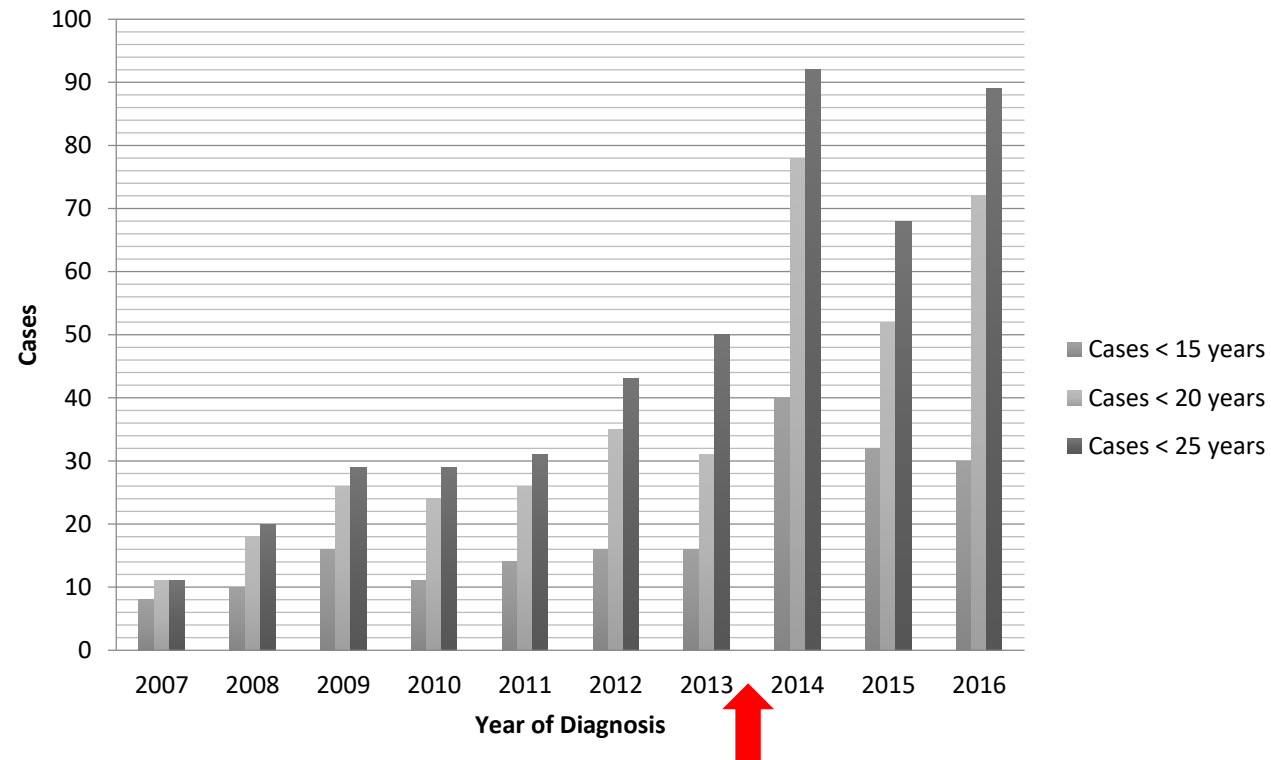


Mali

- 1999 publication (Sidibé et al.) + follow-up data:
18 of 20 children with type 1 died within three years
- Since 2007, numbers <26 years of age have grown
from 14 to >650



Mali – diagnoses per year



Sandy, Besançon et al. Pediatric Diabetes 2021



DIABÈTE DE L'ENFANT ET DU JEUNE ADULTE : CONNAITRE LES SIGNES PRÉCURSEURS DU DIABÈTE !

SOUKARO DOUN BANA BÉ DÛN TCHOGUODI MÔGUÔ KÔRÔBA LA ANI
DENMISSENI NA : DEMISSENOU KA SOUKORO TIAYA BANA DJOLILA TAMACHIN



Si un enfant ou un jeune adulte présente ces signes, vérifiez immédiatement si c'est le diabète. Le traitement est urgent.

Ni aw yé nin fenw djabatéminè denmissenni walima môguô kôrôba min na, a yé Soukaro doun bana testî kè. Soukaro doun bana kaka fourakè djona.

2013 awareness campaign

1,600 posters distributed



A campaign organised by the IDF Life for a Child Programme and Santé Diabète with funding from the Leona M and Harry B Helmsley Charitable Trust.



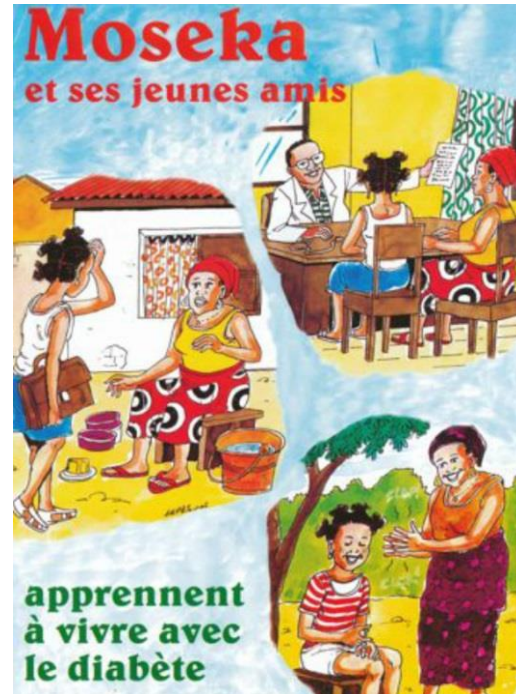
It was when I was in Primary School and 12 years old that it started and it was just like a joke. It started coming through urine until it became very critical.....

After some months in that hospital, they taught me how to inject myself and immediately I learnt that, we went back home.

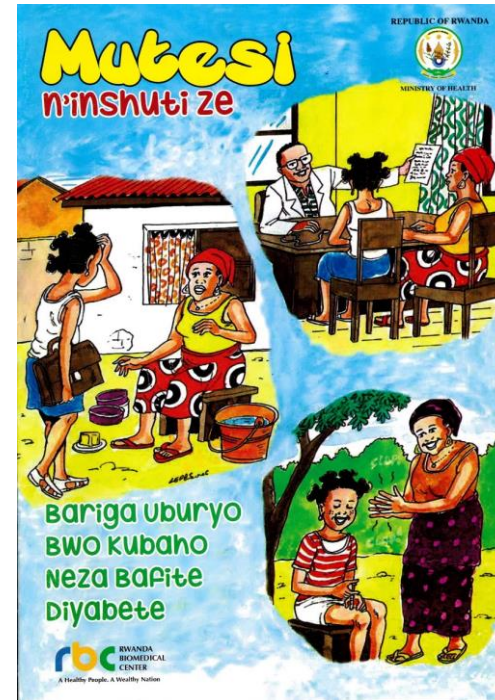
Awayo, aged 17, Nigeria



Moseka & her friends



French (DR Congo)



Kinyarwanda

also:

English

Bahasa
(Indonesian)

Swahili

Nepali



Amharic

Arabic العَرَبِيَّة

Azeri

Bahasa

Bangla

English

Español

Français

Hindi

Kannada

Kinyarwanda

Marathi

Português

Sindhi

Swahili

Tagalog

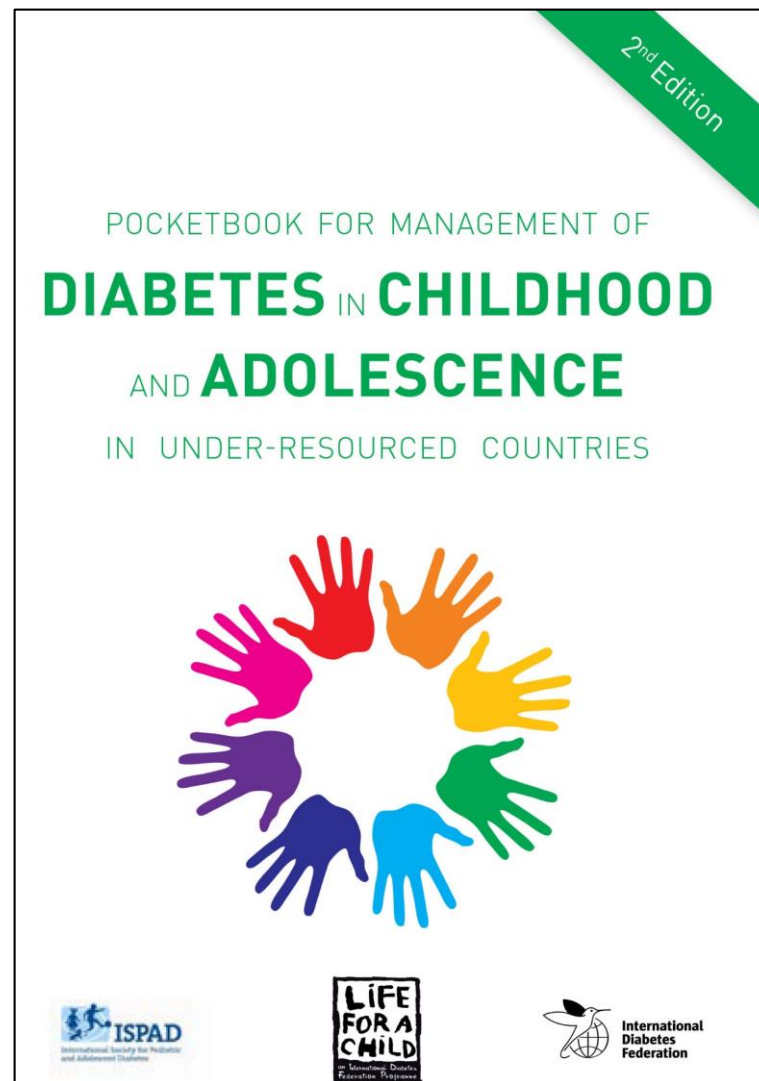
Tamil

Tiếng Việt

Urdu



Life for a Child / ISPAD Pocketbook Guidelines





LIFE
FOR A
CHILD

Tanzanian Diabetes Youth Alliance (TDYA)



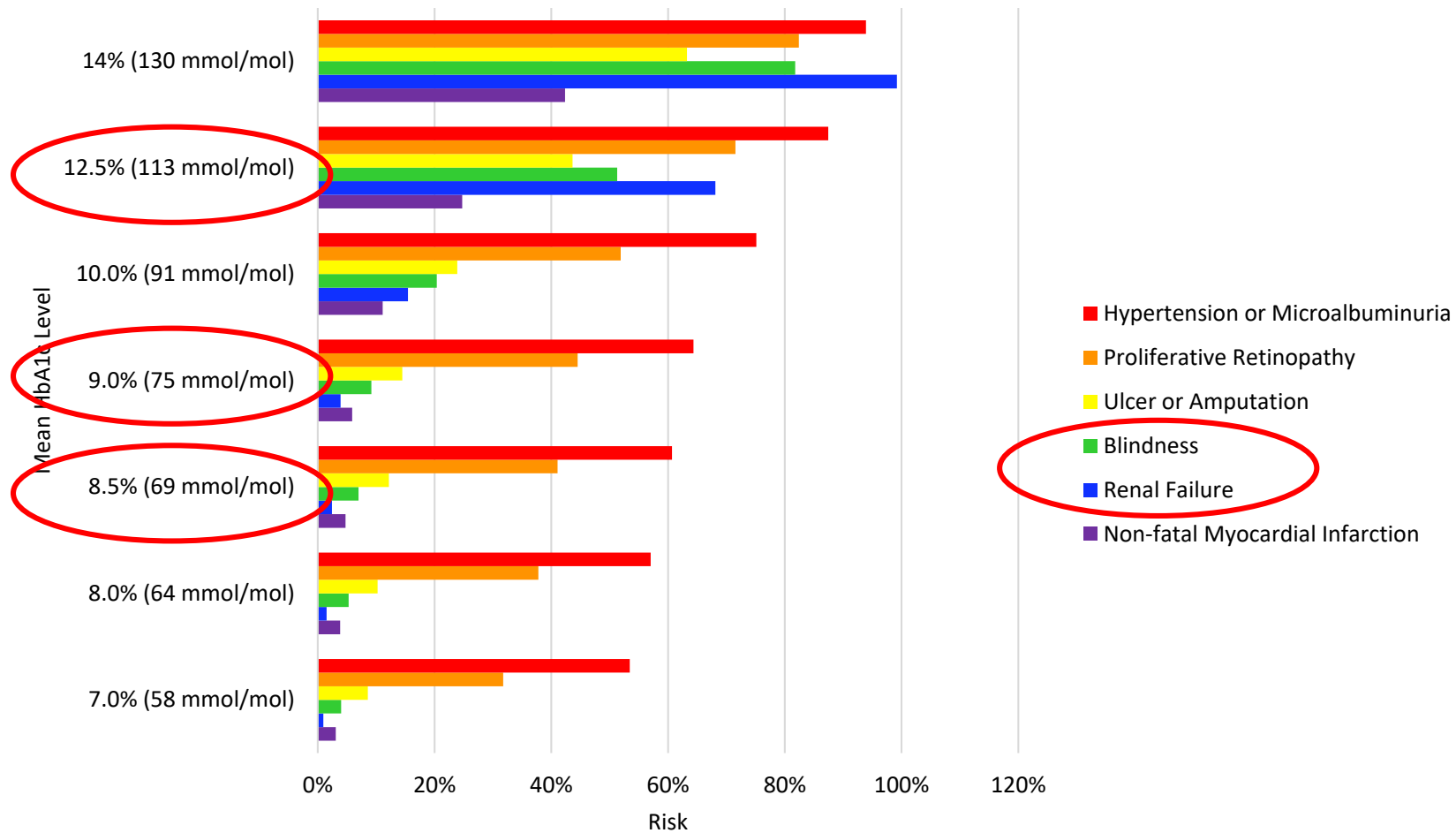
Importance of blood glucose control

Key metric – HbA1c. Measured every 3-4 months

- Target is <7.5%



Complications Rates



Estimated from Pittsburgh EDC data

Gregory, Guo et al. Pediatric Diabetes 2020; DOI: 10.1111/pedi.12988.



Research Article

Incidence and Mortality Rates and Clinical Characteristics of Type 1 Diabetes among Children and Young Adults in Cochabamba, Bolivia

Elizabeth Duarte Gómez,¹ Gabriel Andrew Gregory,^{2,3} Miriam Castrati Nostas,¹
Angela Christine Middlehurst,^{2,4} Alicia Josephine Jenkins,³ and Graham David Ogle^{2,3,4}

¹Centro Vivir con Diabetes, Av. Simón López, No. 375, Cochabamba, Bolivia

²International Diabetes Federation Life for a Child Program, Glebe, NSW 2037, Australia

³NHMRC Clinical Trials Centre, University of Sydney, Sydney, NSW 2006, Australia

⁴Diabetes NSW, Glebe, NSW 2037, Australia

DE GRUYTER

J Pediatr Endocrinol Metab 2019; aop

María Elena Mota-Oropeza^a, Hannah Elizabeth Bartley^a, Norma Daniela Hernández-Pérez,
Arely Gutiérrez Lara, Nancy Alejandra Vázquez-López, María Francisa Flores,
Mariana Marroquín Velázquez, María José Castañeda-Saldivar, Angela Christine Middlehurst,
Alicia Josephine Jenkins and Graham David Ogle*

Providing quality care for children and adolescents with diabetes from lower-income families in Mexico

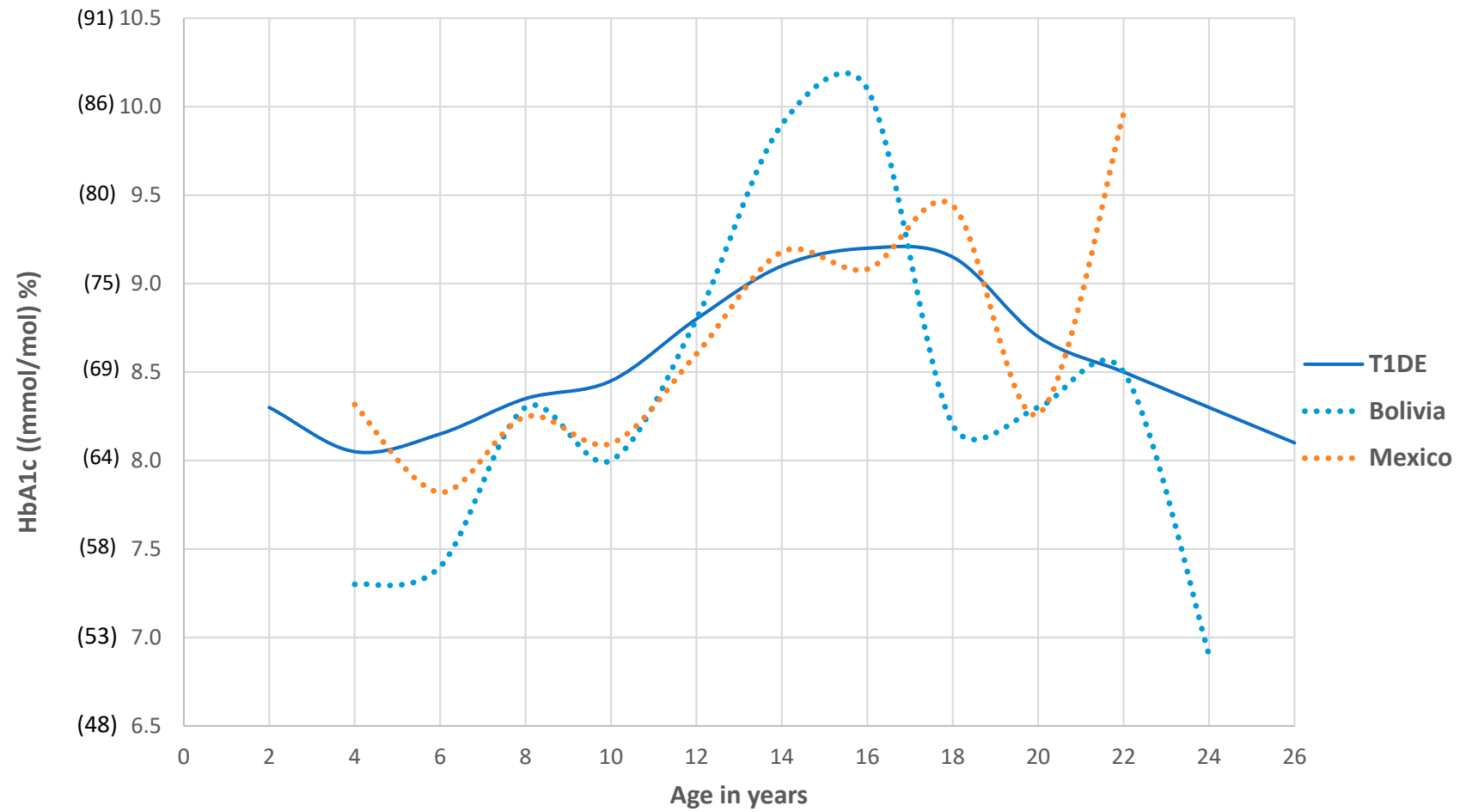
<https://doi.org/10.1515/jpem-2019-0363>

Received August 7, 2019; accepted August 8, 2019

Abstract

0.0–21.0 years), with a mean \pm SD subject age at check-up of 13.3 ± 4.3 years. Of the T1D subjects, 1.0%, 6.7%, 13.7% and 78.6% were receiving 1, 2, 3 and ≥ 4 insulin injections/day with a mean \pm SD daily dose of 0.92 ± 0.34 U/kg. The





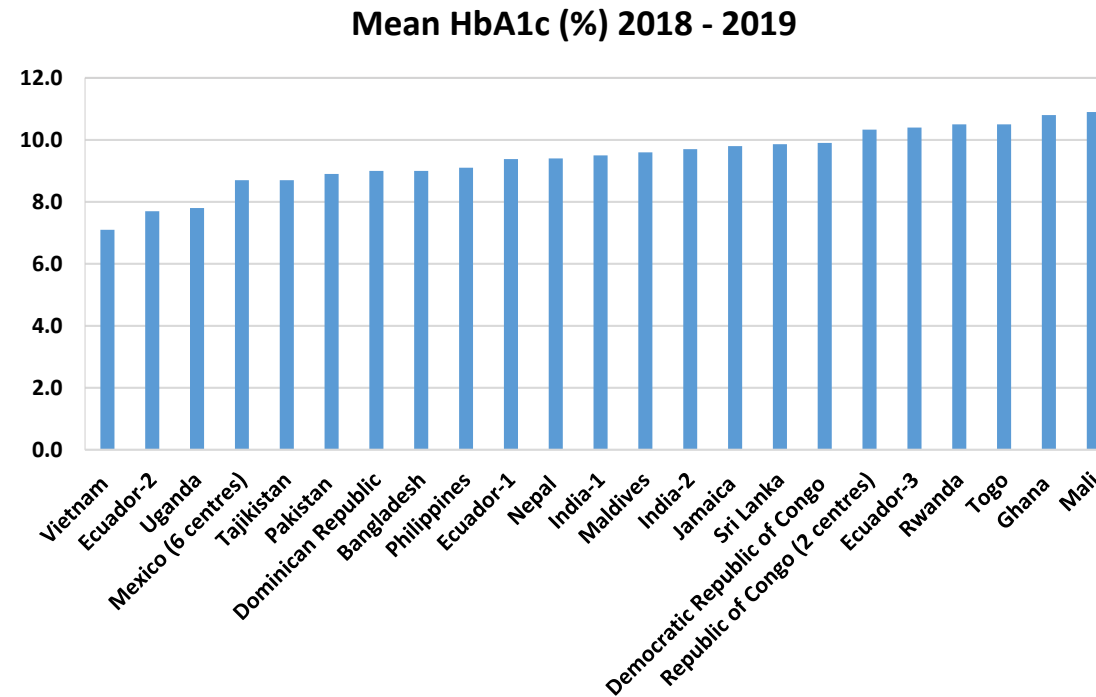
US data courtesy T1D Exchange

Bolivia data: Duarte-Gómez, Gregory et al. J Diab Res

Mexico data: Mota-Oropeza, Bartley et al. J Ped Endocrinol Metab 2019

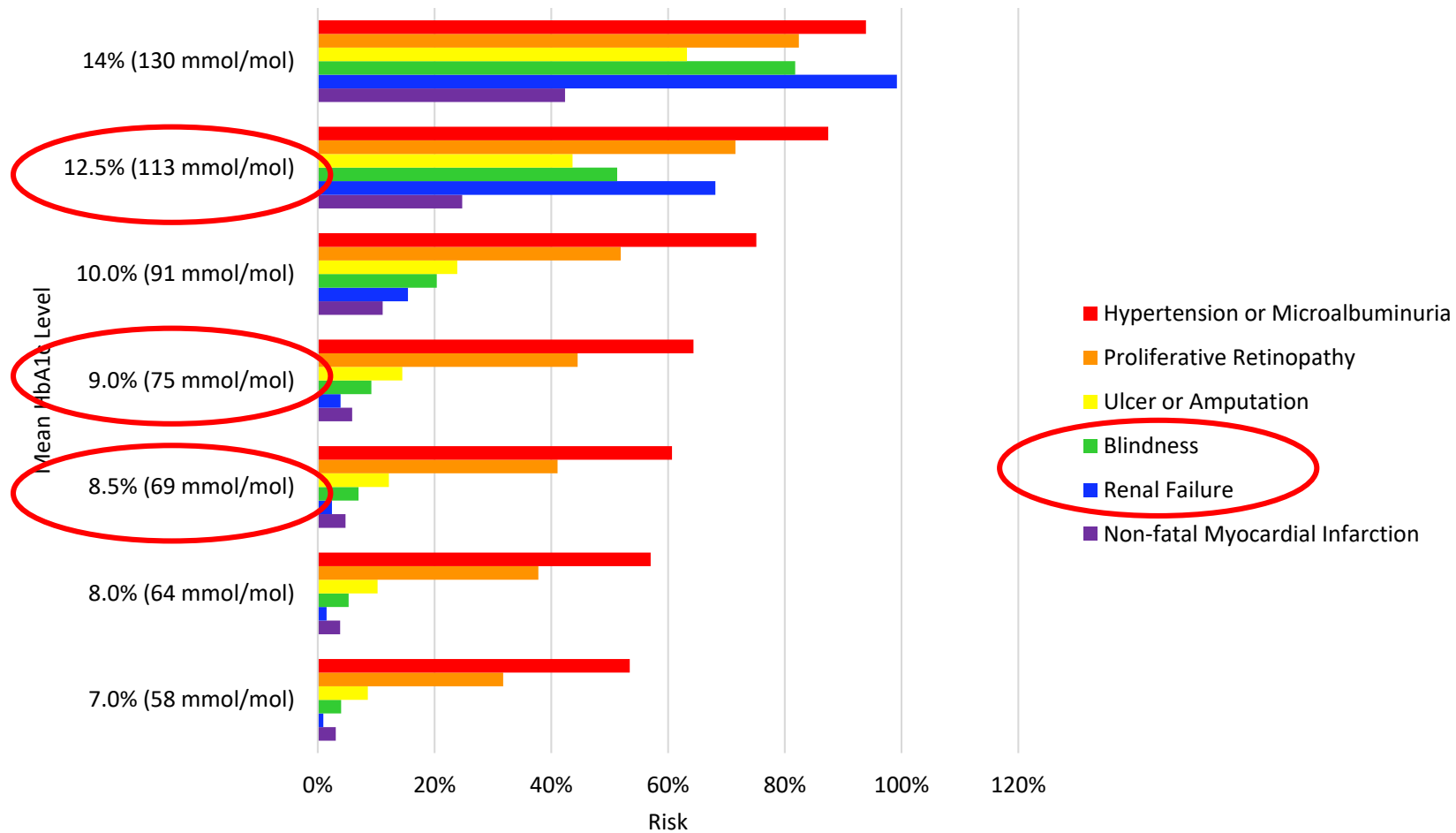


Mean HbA1cs in LFAC centres



<u>Tier</u>	<u>Level</u>	<u>Insulin</u>	<u>Blood glucose monitoring</u>	<u>HbA1c</u>	<u>Complications screening</u>	<u>Diabetes education and team care</u>	<u>Intra-clinic range of clinic mean HbA1c</u>	<u>Mortality and Complications</u>
<u>Minimal Care</u>	1A	Human premixed insulin only, twice daily injections	Only at clinic	None	None /just weight	Minimal or no diabetes education. Care from general physician or paediatrician.	12.0-14.0% (108-130 mmol/mol)	High mortality from misdiagnosis and acute complications. Serious early-onset long-term complications very common in survivors
	1B	Human premixed insulin only, twice daily injections	1-2 tests / day	Done in lab or point-of-care	Weight, height, blood pressure, visual acuity and light touch	Some diabetes education. Care by adult diabetologist or paediatrician.	9.5-12.0% (80-108 mmol/mol)	Substantial mortality, serious early-onset long-term complications common
	1C	Human short- and long-acting insulin, twice daily injections				Education about insulin dose adjustments.	9.0-10.5% (75-91 mmol/mol)	
<u>Intermediate Care</u>	2A	Human insulin, multiple daily injections (“basal bolus regimen”)	2-3 tests / day	Point-of-care	Weight, height, blood pressure, eyes, feet, urinary albumin, creatinine, lipids. Treatment as indicated. Access to glucagon if possible.	Diabetes education appropriate for age. Care by paediatric or adult diabetologist, nurse educator, + dietitian and social worker if possible. Diabetes camps. Peer & school support. 24-hour emergency call service.	8.0-9.5% (64-80 mmol/mol)	Infrequent mortality, serious long-term complications rare unless less-than-optimal blood glucose control.
	2B	Human insulin, basal bolus regimen +/- insulin pens	4+ tests / day					
<u>Comprehensive Care (ISPAD Guidelines)</u>	3A	Analog insulin, basal bolus regimen, insulin pens	5+ tests / day	Point-of-care	Full complications screening – including all above plus fundal photography, thyroid, coeliac – at frequency according to guidelines. Treatment as indicated. Access to glucagon.	Diabetes education appropriate for age. Multidisciplinary team with paediatric diabetologist, nurse educator, dietitian, social worker, psychologist. Diabetes camps. Peer & school support. 24-hour emergency call service.	6.5-8.5% (48-69 mmol/mol)	Mortality very rare, long-term complications long-delayed or prevented entirely except if blood glucose control is suboptimal.
	3B	Insulin pump + consumables						
	3C	Insulin pump + consumables	Continuous glucose monitoring (CGM) + consumables					
	3D	Artificial pancreas + consumables						

Complications Rates

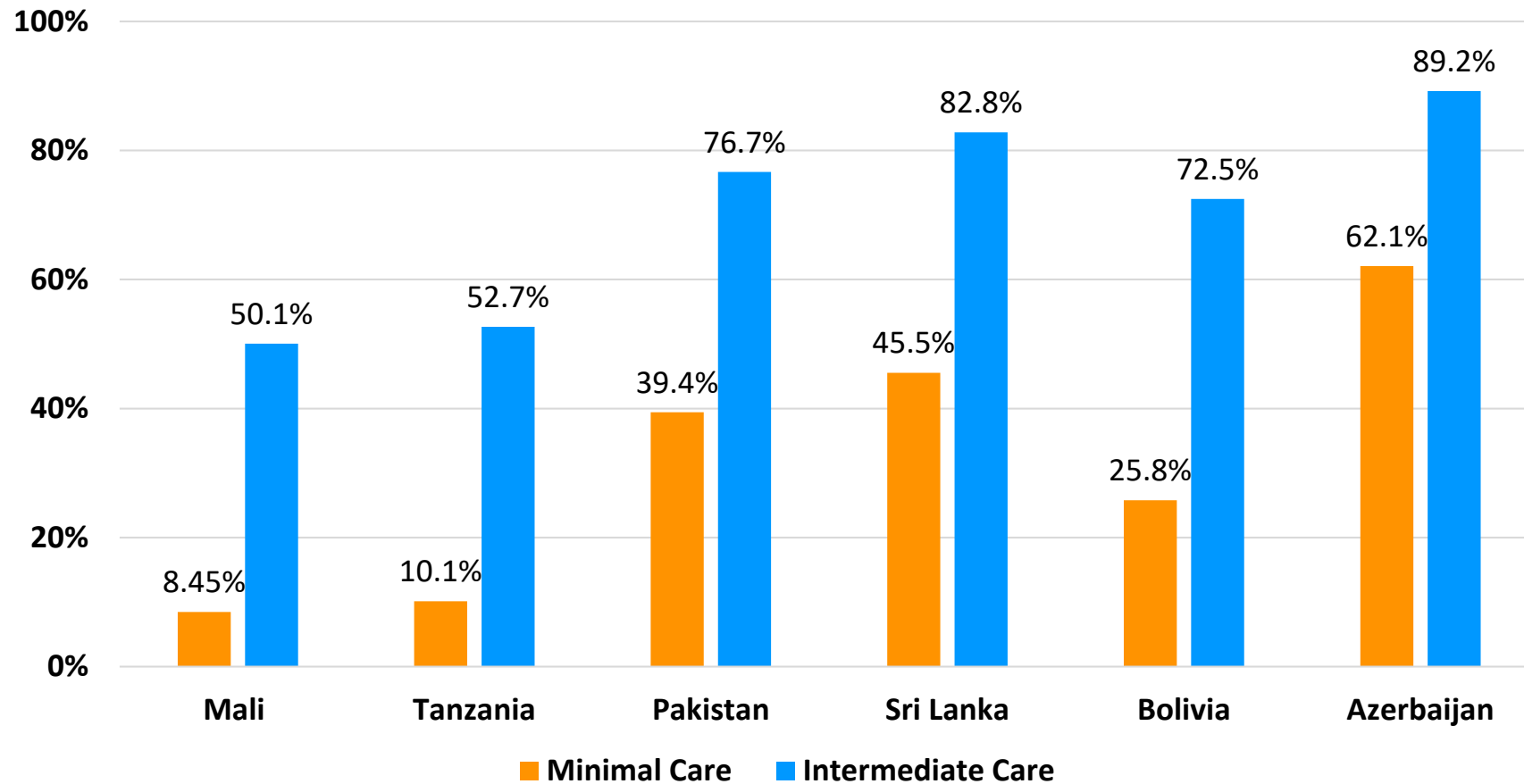


Estimated from Pittsburgh EDC data

Gregory, Guo et al. Pediatric Diabetes 2020; DOI: 10.1111/pedi.12988.



30 Year Country Survival Rates



Gregory, Guo et al. Pediatric Diabetes 2020; DOI: 10.1111/pedi.12988.



Cost of a Healthy Life Year as a percentage of country GDP

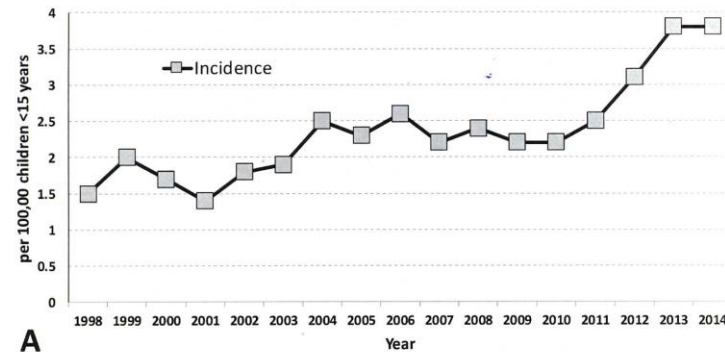
Countries	HLYs per individual (minimal/intermediate care)	Cost of HLYs gained as % GDP/capita (minimal/intermediate care)
Mali	12.4/21.1	141.1%
Tanzania	14.0/22.0	110.0%
Pakistan	19.3/24.9	52.3%
Sri Lanka	20.3/25.7	41.8%
Bolivia	17.1/24.4	17.0%
Azerbaijan	22.5/26.5	15.6%

as per the approach used in the WHO CHOICE framework

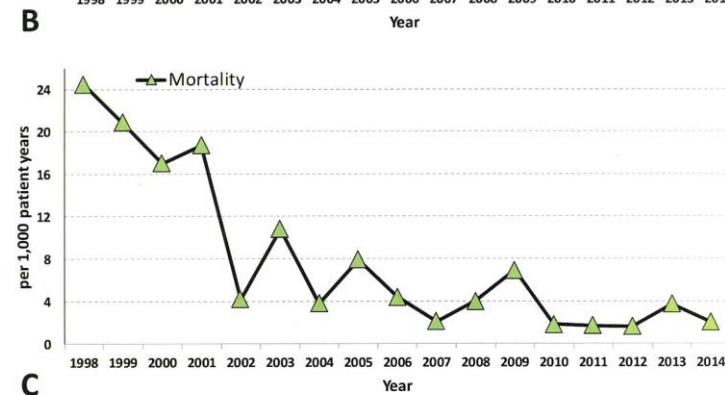
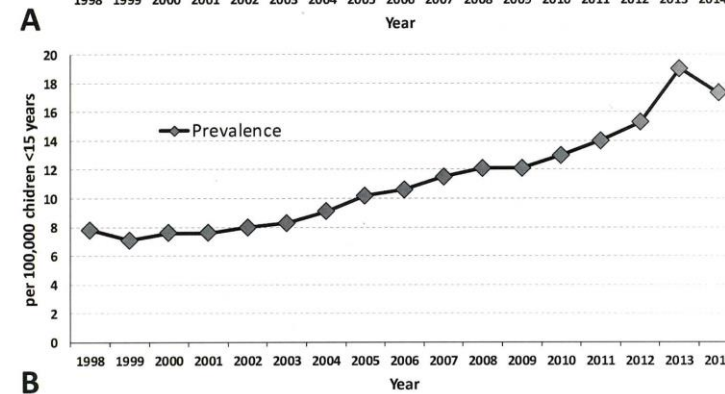
Gregory, Guo et al. Pediatric Diabetes 2020



Know the numbers – e.g. Uzbekistan



female > male
5.6% annualised increase



Rakhimova GN, Alimova NU, et al. *Pediatr Diabetes*, 2018;19:158-165.



Key components

- Build on what is there – local champions
- Engage Ministry of Health as much as possible
- Build expertise through a hub and spoke model
- Education – of children and their families, and health professions is critical
- Flexible approach

- Monitoring outcomes
- Internal and external evaluation
- Partner and network with other groups, pharma, and academic centres – expertise and supplies

- Collect data for health planning and advocacy
- Encourage governments to provide cost-effective care



Expansion: “Vision 2030”

Ten years 2021-2030:

- Number of children and youth helped: 23,000 to 150,000+
- Number of countries helped: 43 to 65+
- Expand footprint in large countries
- Help in ‘new’ countries
- Deepen support in all countries helped – education, training, quality of care, research, advocacy
- Supported by Eli Lilly, the Helmsley Charitable Trust, JDRF, and other donors





Leonard Thompson, Toronto, 1921-22, aged 14





LIFE
FOR A
CHILD



LIFE
FOR A
CHILD



For no child should die of diabetes





Lifelong Care for Children with Chronic Conditions Discussion Series



Engage with the co-chairs:

- Cara Endyke Doran - cendykedoran@globalcommunities.org
- Raoul Bermejo - rbermejo@unicef.org

Series Dates & Case Study Discussions:

May 14th: *Congenital heart disease*
June 25th: *HIV, type 1 diabetes & sickle cell disease*
July 9th: *Integrated NCD package of services*

Time: 9 - 10:30am EDT [GMT-4]

Check out the Child Health Task Force Website for important resources!

Subgroup information, recordings and presentations from previous webinars are available on the subgroup page of the Child Health Task Force website:

www.childhealthtaskforce.org/subgroups/expansion

Become a member of the subgroup: www.childhealthtaskforce.org/subscribe