International Diabetes Federation

How registries can help tackle the global diabetes burden

Online event







1 October 2024
14:30-16:00 CEST

HOW REGISTRIES CAN HELP TACKLE THE GLOBAL DIABETES BURDEN

WELCOME FROM THE MODERATOR

DR HERMELINDA PEDROSA

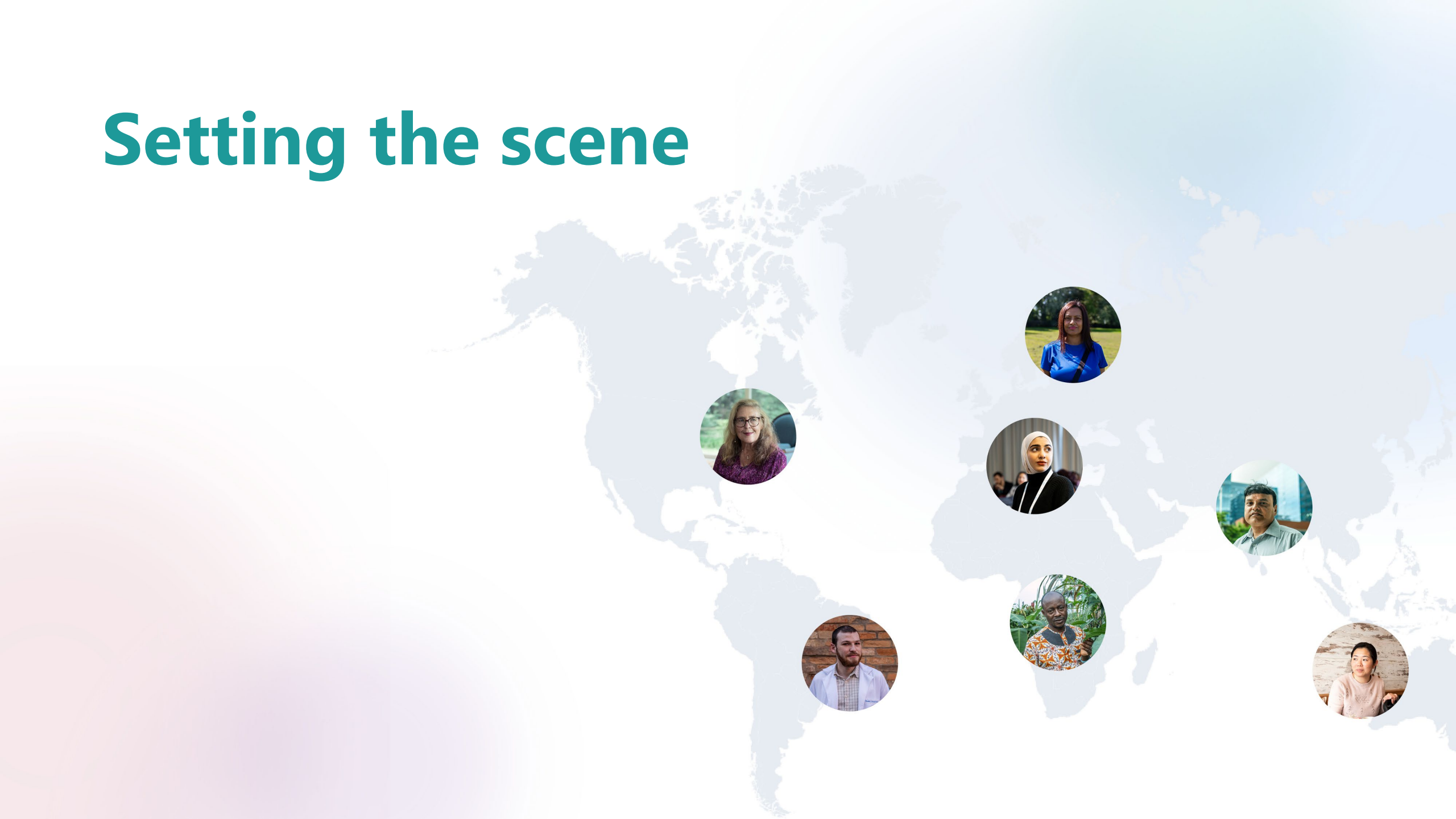
IDF Vice President Physician, Chair of IDF Women and Diabetes Committee, International Relations Advisor and Advocacy at SBD (Brazilian Diabetes Society), Coordinator at the Endocrinology Unit Research Centre HRT/FEPECS, Investigator at Fiocruz Biomanguinhos

Brasil

WELCOME FROM IDF

- This webinar will be recorded.
- You can activate Zoom-generated subtitles for this webinar by clicking on the closed caption (cc) button at the bottom of your Zoom window. Please note these subtitles are not 100% accurate.
- The recording, slides and feedback questionnaire will be sent to all registrants in a few days.
- Participants who attend at least 80% of this event live will receive an attendance certificate only if they complete a feedback questionnaire. Please check your spam folders if you have not received them by 20 October.
- **Please use the Q&A function to post your questions to speakers and panellists.**

Setting the scene



HOW REGISTRIES CAN HELP TACKLE THE GLOBAL DIABETES BURDEN

MESSAGE FROM THE IDF PRESIDENT

PROF PETER SCHWARZ

IDF President, Research group leader at the Paul Langerhans Institute Dresden (PLID)

Germany

HOW REGISTRIES CAN HELP TACKLE THE GLOBAL DIABETES BURDEN

REAL-WORLD EVIDENCE THE NEXT GENERATION OF CLINICAL EVIDENCE

PROF KAMLESH KHUNTI

Professor of Primary Care Diabetes & Vascular Medicine at the University of Leicester, iCaReMe Steering Committee Member

United Kingdom

HOW REGISTRIES CAN HELP TACKLE THE GLOBAL DIABETES BURDEN

EXPERIENCE IN IMPLEMENTING A NATIONAL DIABETES REGISTRY IN PAKISTAN

PROF ABDUL BASIT

Secretary General of the Diabetic Association of Pakistan (DAP), President of the Diabetes in Asia Study Group (DASG), and Vice Chairman at the Health Promotion Foundation (HPF).

Pakistan

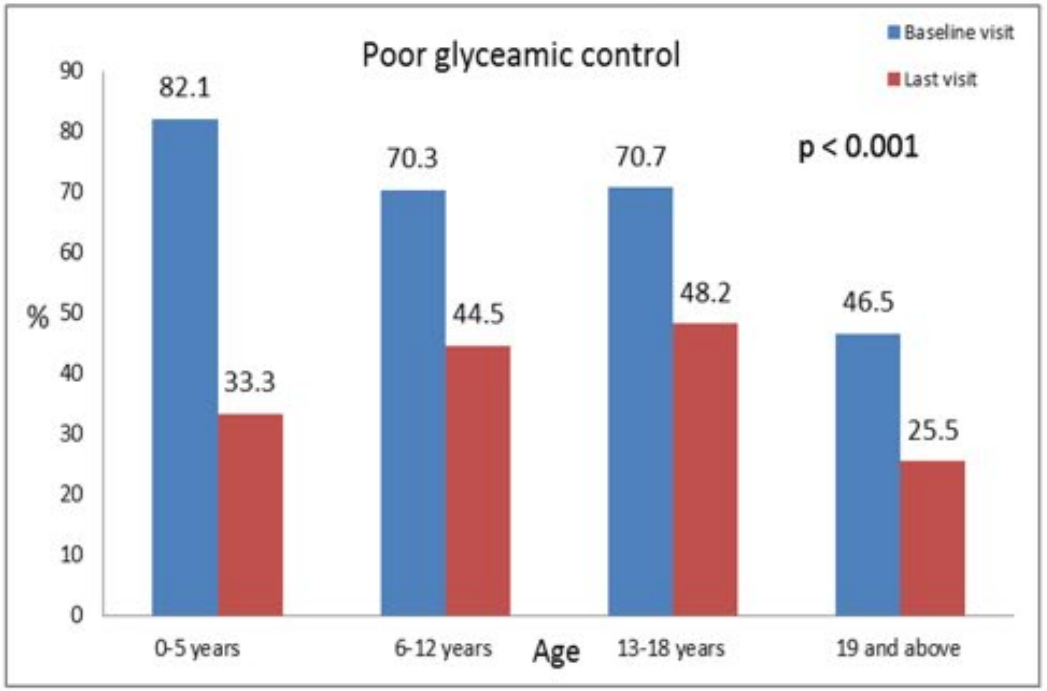
How did it start?

2010 Insulin My Life

LIFE FOR A CHILD
an International Diabetes Federation Programme

Centers established 34

Subjects registered 1900+

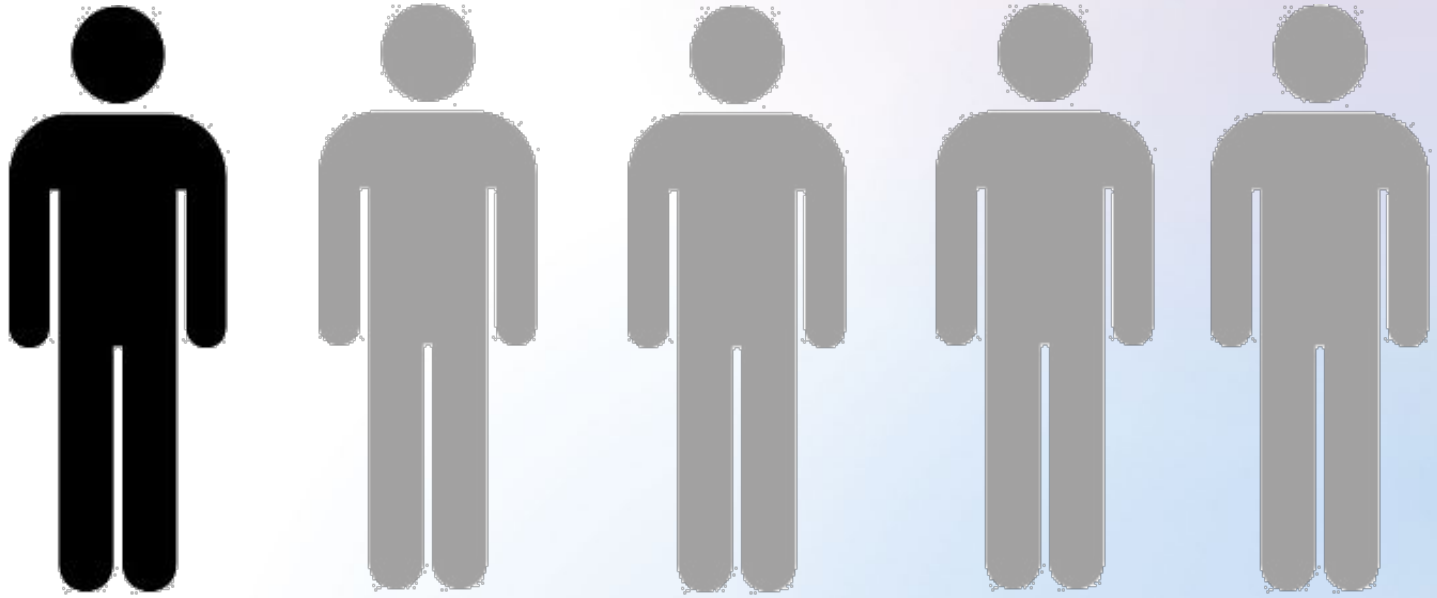


Comparison of abnormal HbA1c levels (according to age) from baseline to last visit

Ahmedani MY, et al. Optimized health care for subjects with type 1 diabetes in a recourse constraint society; A three-year follow-up study from Pakistan. World Journal fo Diabetes 2019;15:10:224

2019 Prevalence of T2DM and Associated Risk Markers

1 in 5 persons aged 20 and above have diabetes



33 million people with diabetes in Pakistan

	2021		2030		2045	
Rank	Country or Territory	Adults with diabetes, (million)	Country or territory	Adults with diabetes, (million)	Country or territory	Adults with diabetes, (million)
1	China	140.9	China	164.1	China	174.4
2	India	74.2	India	92.9	India	124.9
3	**Pakistan**	**33.0**	**Pakistan**	**42.9**	**Pakistan**	**62.0**
4	United States of America	23.7	United States of America	34.8	United States of America	36.3
5	Indonesia	19.5	Indonesia	23.3	Indonesia	28.6
6	Brazil	15.7	Brazil	19.2	Brazil	23.2
7	Mexico	14.1	Mexico	17.1	Bangladesh	22.3
8	Bangladesh	13.1	Bangladesh	16.1	Mexico	21.2
9	Japan	11.0	Egypt	13.8	Egypt	20.0
10	Egypt	10.9	Turkey	10.8	Turkey	13.4

IDF Diabetes Atlas 10th edition updates, Available from:
https://diabetesatlas.org/data/en/country/150/pk.html (Last accessed on November 12, 2021)

Aims and Objective of DROP

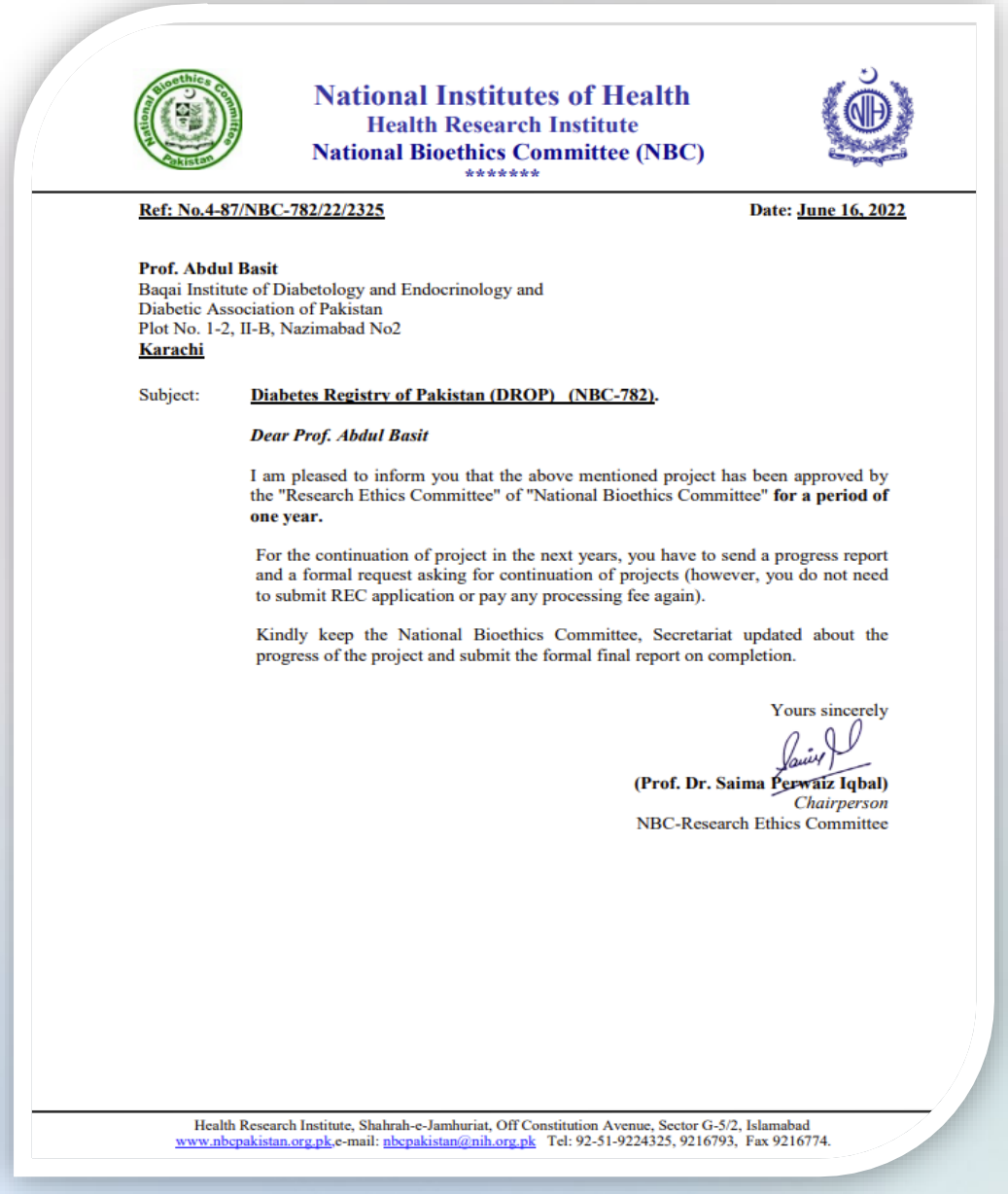
- Incidence and prevalence
- National action plan and prevention policy
- Structured and uniform clinical care
- Implementation of National Guidelines
- Specific post graduate teachings; Preventive managers
- Policy making and legislation
- Linking with Regions; e.g. DASG and IDF-MENA Region

How did it progress?

Stakeholders for DROP

- Ministry of National Health Services Regulations and Coordination
- National Institute of Health
- Health – Research Advisory Board (Health RAB)
- Health Promotion Foundation (HPF)
- Diabetic Association of Pakistan (DAP)

National Bioethics Committee (NBC) Approved



National Institutes of Health
Health Research Institute
National Bioethics Committee (NBC)
****

Ref: No.4-87/NBC-782/22/2325 Date: June 16, 2022

Prof. Abdul Basit
Baqai Institute of Diabetology and Endocrinology and
Diabetic Association of Pakistan
Plot No. 1-2, II-B, Nazimabad No2
Karachi

Subject: **Diabetes Registry of Pakistan (DROP) (NBC-782).**

Dear Prof. Abdul Basit

I am pleased to inform you that the above mentioned project has been approved by the "Research Ethics Committee" of "National Bioethics Committee" **for a period of one year.**

For the continuation of project in the next years, you have to send a progress report and a formal request asking for continuation of projects (however, you do not need to submit REC application or pay any processing fee again).

Kindly keep the National Bioethics Committee, Secretariat updated about the progress of the project and submit the formal final report on completion.

Yours sincerely

(Prof. Dr. Saima Perwaiz Iqbal)
Chairperson
NBC-Research Ethics Committee

Health Research Institute, Shahrah-e-Jamhuriat, Off Constitution Avenue, Sector G-5/2, Islamabad
www.nbcpakistan.org.pk,e-mail: nbcpakistan@nih.org.pk Tel: 92-51-9224325, 9216793, Fax 9216774.

Advocacy

Sindh Health Department – BIDE

- Primary prevention
- Diabetes Awareness
- Diabetes Registry of Pakistan(**DROP**)
- Conduct diabetes **research**

18th June 2021

Meeting with DDG Sindh for standardization of diabetes care in rural health centers of Sindh

Training Programs in rural and urban areas of Sindh

Murad Memon Goth, Matiari with Sindh Governement

MoU

Advocacy

MoU PPHI – BIDE

Meeting with CEO & COO of PPHI for standardization of diabetes care in PPHI HF

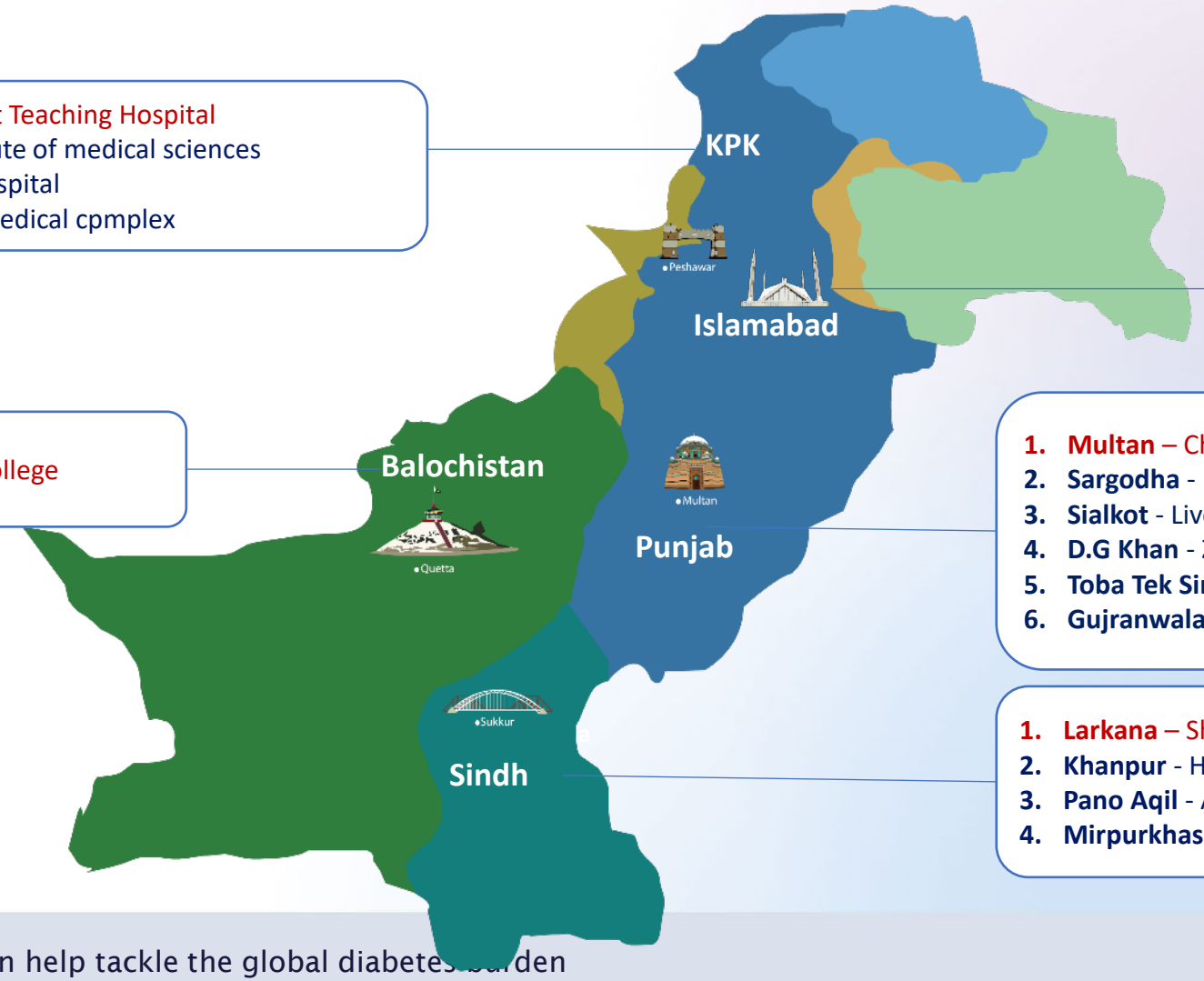
- Primary prevention
- Diabetes Awareness
- Diabetes Registry of Pakistan(**DROP**)
- Conduct diabetes **research**

26th November 2020

CDiC Centers – Pakistan

05 Main Centers
21 Satellite Centers
2250 children

1. **Peshawar** – Northwest Teaching Hospital
2. **Mengora** - Swat Institute of medical sciences
3. **Timergara** - Jasmin Hospital
4. **Abbottabad** - Valley Medical cpmplex



Islamabad – Yashfeen Trust

Quetta – Bolan Medical College

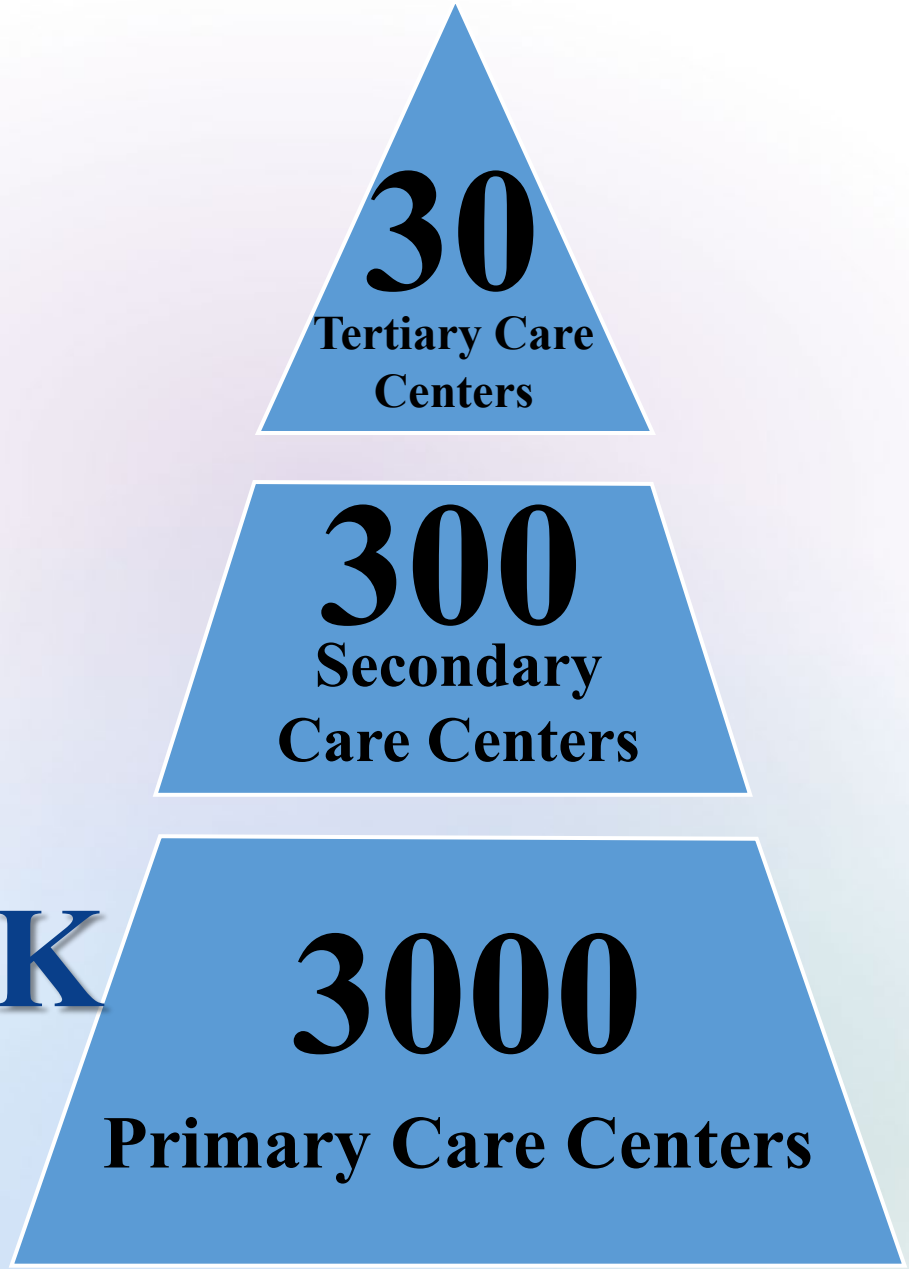
1. **Multan** – Childrens Hosp. and Inst of Child Health
2. **Sargodha** - Mubarak Medical Complex
3. **Sialkot** - Liver & Diabetes Clinic
4. **D.G Khan** - Zafar Diabetes and Endocrine Centre
5. **Toba Tek Singh** - Al Raheem Clinic
6. **Gujranwala** - Rasheed Medical Complex

1. **Larkana** – Shanzay Diabetes & Endocrine Clinic
2. **Khanpur** - Hassan Rasheed Hospital
3. **Pano Aqil** - Advance Diabetic & Cardio Clinic
4. **Mirpurkhas** - Rehman Medicare Clinic

How do we see its future?

NDN
NATIONAL DIABETES NETWORK

NATIONAL DIABETES NETWORK



How registries can help tackle the global diabetes burden

Barriers and Solutions

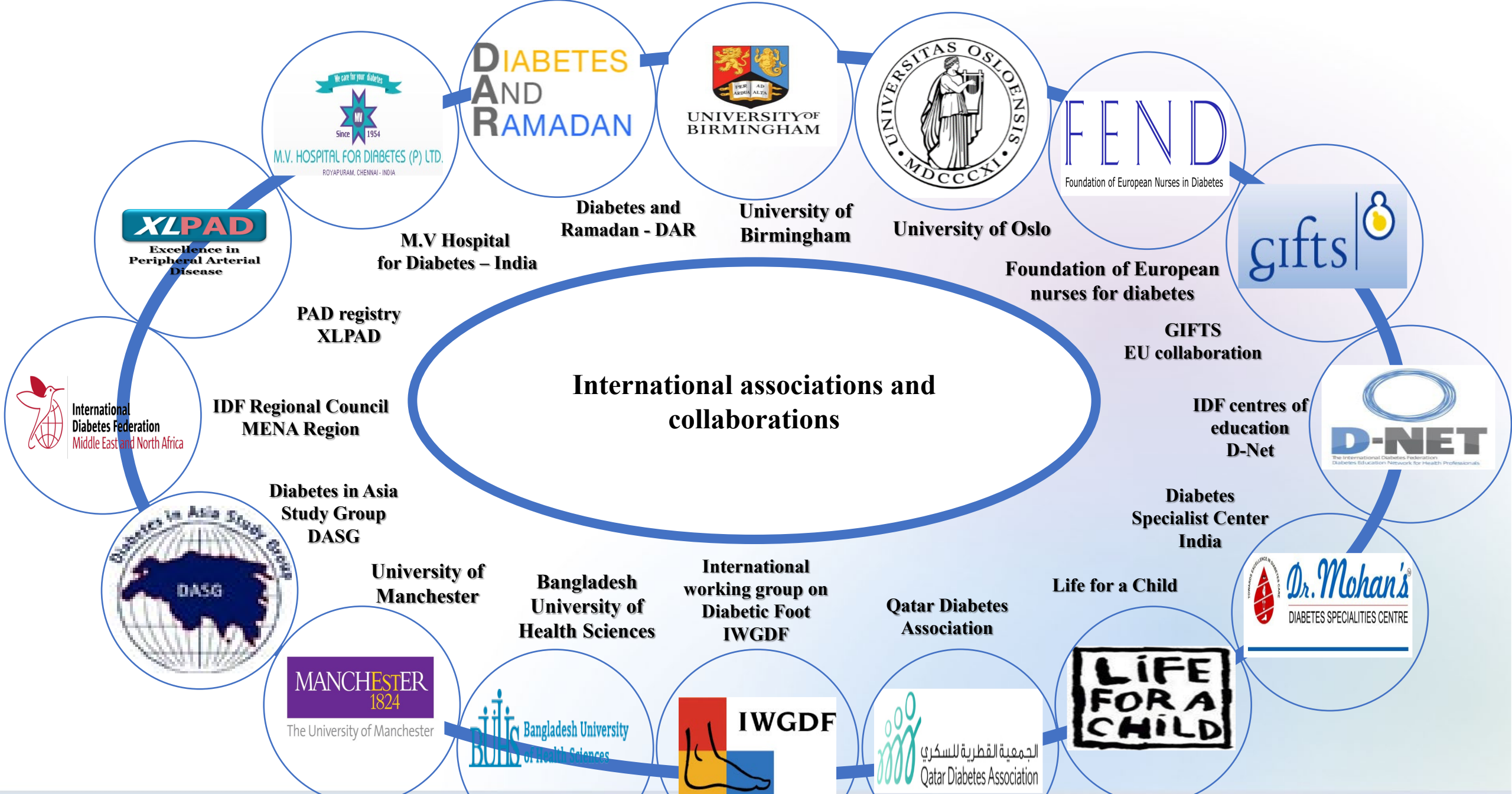
- Initiate the process and governments get involved.
- Capacity building.
- Minimal Model registries to make it time-effective.
- Adequate anonymization increases healthcare personnel's confidence and decreases the sense of insecurity.
- Private-public partnerships with cross-financing models ensure sustainability
- Implementation and surveillance gets stronger with government involvement. Bodies like WHO play a key role in its facilitation.

IDF has selected our DROP registry as an example for LMICs

How registries can help tackle the global diabetes burden

National Institutions

- Liaquat national Institute of PG Med & Health Sciences, Karachi
- Diabetic Association of Pakistan (DAP
- Sobhraj Maternity Hospital
- The Karachi Institute of Biotechnology and Genetic Engineering (KIBGE)
- University of Karachi (KU)
- Jinnah Sindh Medical University, karachi (JSMU)
- Fatima Jinnah Medical College, Lahore
- Dow University of Health Sciences (DUHS)
- King Edward Medical University, Lahore
- Jinnah University for Women (JUW)
- Bolan Medical College, Quetta
- National Institute of Diabetes & Endocrinology (NIDE)
- Khyber Medical University, Peshawar
- Liaquat Univeristy of Medicine and Health Sciences, Hyderabad
- Pakistan Endocrine Society (PES)
- PG Medical Institute, Hayatabad medical Complex, Peshawar
- Rana Liaquat Ali Khan Government College of Home Economics (RLAK)


International associations and collaborations
M.V Hospital for Diabetes – India
Diabetes and Ramadan - DAR
University of Birmingham
University of Oslo
Foundation of European nurses for diabetes
GIFTS EU collaboration
IDF centres of education D-Net
Diabetes Specialist Center India
Life for a Child
Qatar Diabetes Association
International working group on Diabetic Foot IWGDF
Bangladesh University of Health Sciences
University of Manchester
Diabetes in Asia Study Group DASG
IDF Regional Council MENA Region
PAD registry XLPAD
M.V. HOSPITAL FOR DIABETES (P) LTD.
ROYAPURAM, CHENNAI - INDIA
DIABETES AND RAMADAN
UNIVERSITY OF BIRMINGHAM
UNIVERSITAS OSLOENSIS MDCCCXI
FEND
Foundation of European Nurses in Diabetes
gifts
XLPAD
Excellence in Peripheral Arterial Disease
International Diabetes Federation
Middle East and North Africa
D-NET
Dr. Mohan's
DIABETES SPECIALITIES CENTRE
DASG
MANCHESTER 1824
The University of Manchester
Bangladesh University of Health Sciences
IWGDF
Qatar Diabetes Association
LIFE FOR A CHILD

THANK YOU ALL

HOW REGISTRIES CAN HELP TACKLE THE GLOBAL DIABETES BURDEN

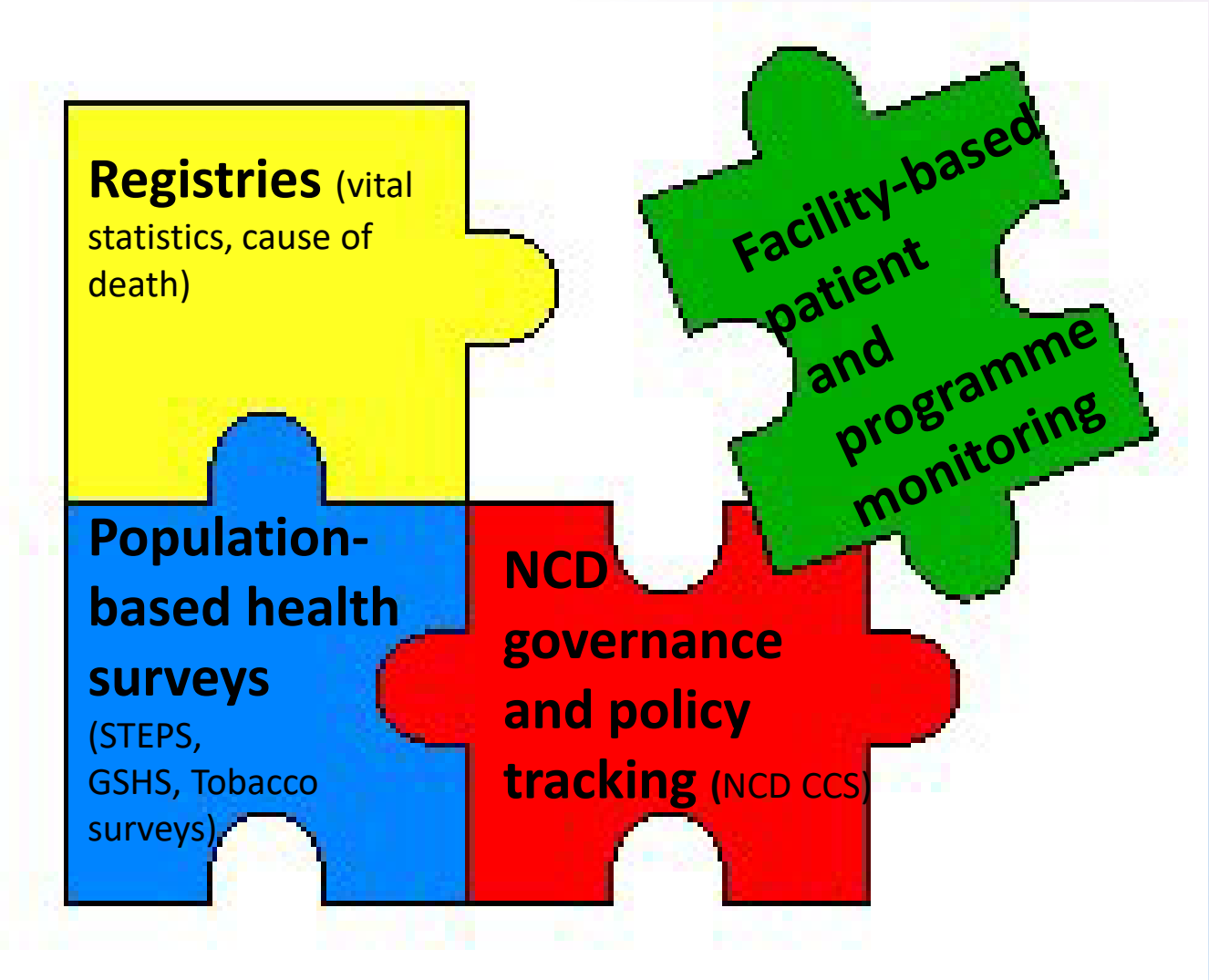
FROM DATA TO ACTION: THE ROLE OF FACILITY-BASED MONITORING IN DIABETES CONTROL

PROF FARSHAD FARZADFAR

Scientist, NCD department, WHO, HQ

Switzerland

NCD surveillance system components



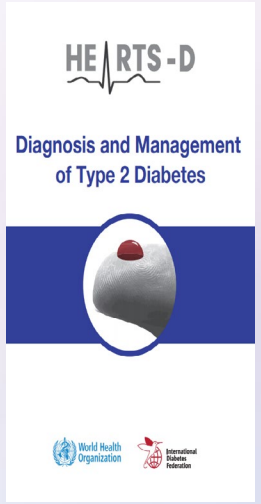
Facility-based monitoring Guidance

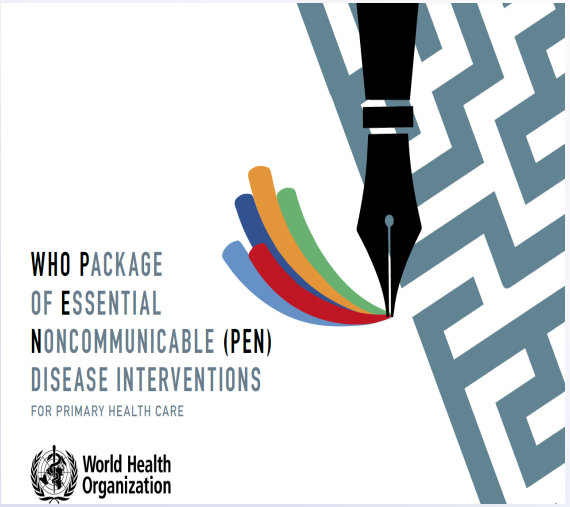
1. One of the NCD surveillance components
2. Provides data at the patient and facility levels
3. Targets improvement in healthcare and health status from bottom to up
4. Includes 22 core and 59 optional indicators
5. Provides details in metadata as standards for calculating the indicator

Noncommunicable disease facility-based guidance: scope and development process

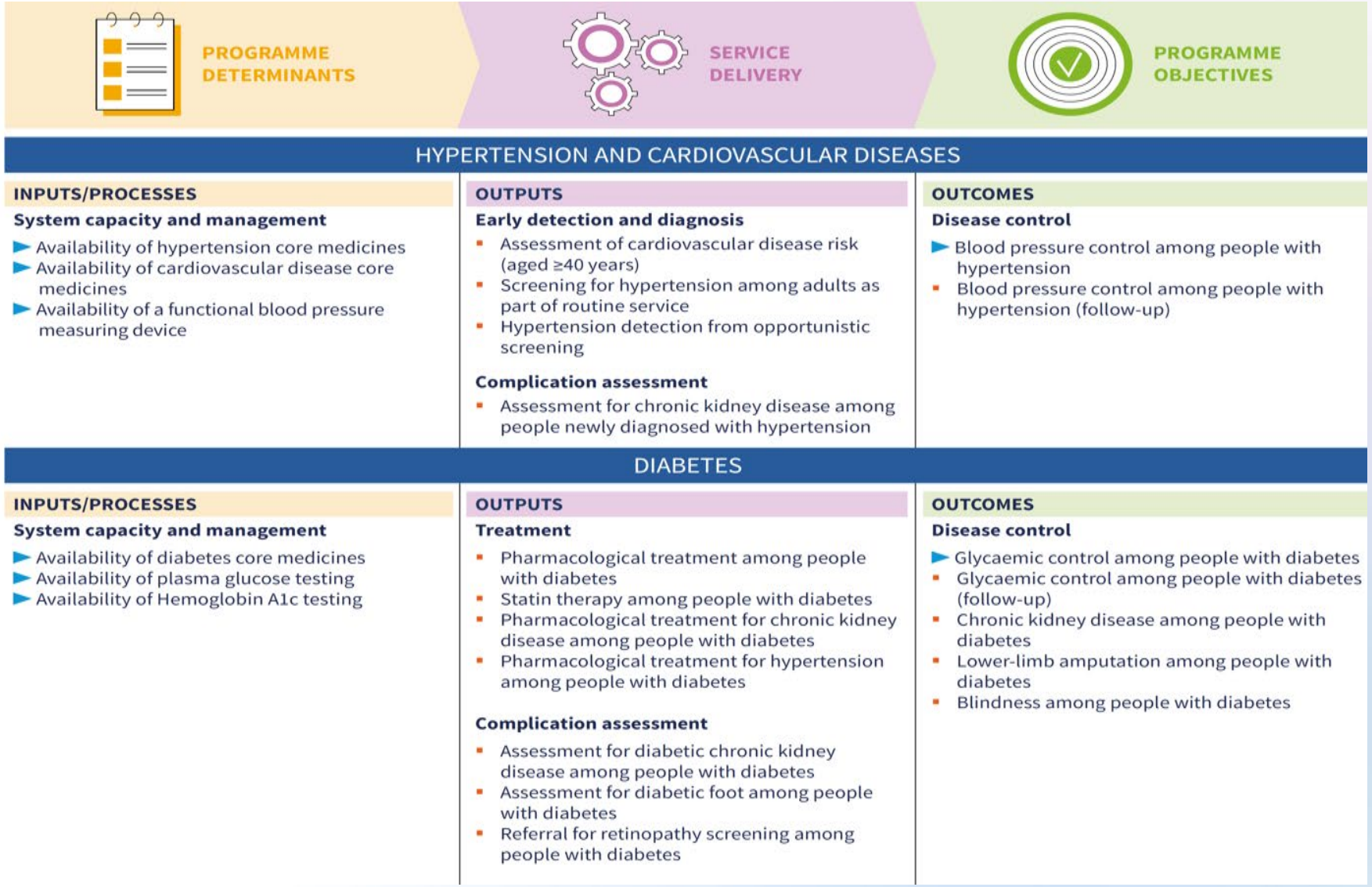
- Comprehensive monitoring for essential noncommunicable disease interventions at primary care settings
  - Cardiovascular diseases including hypertension
  - Diabetes
  - Asthma and chronic obstructive pulmonary disease
  - Breast cancer, cervical cancer, childhood cancers and general cancers

- Rigorous development and prioritization processes (experts' opinions, systematic reviews, global and regional priorities)





Facility-based patient and program monitoring framework



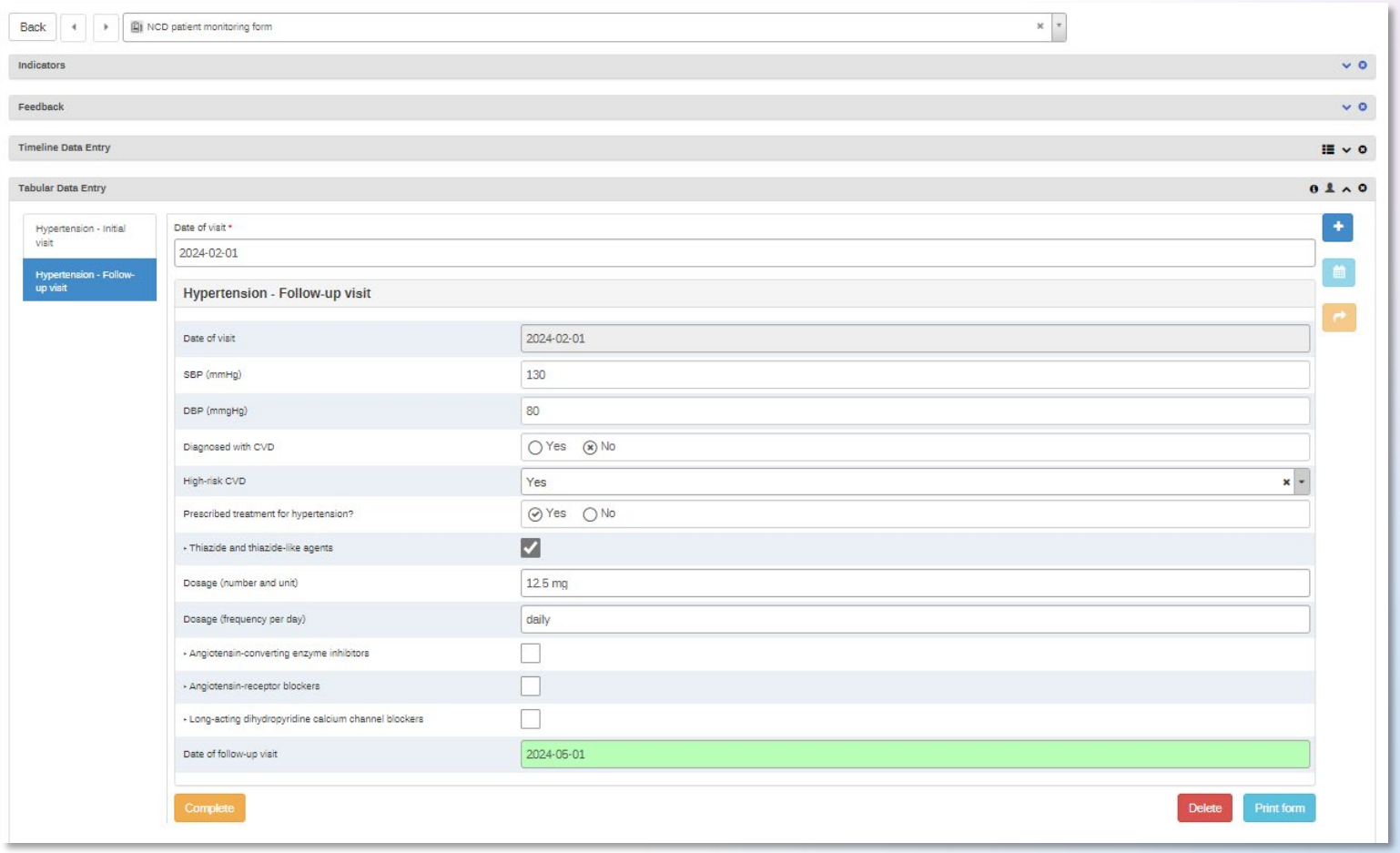
Indicator metadata

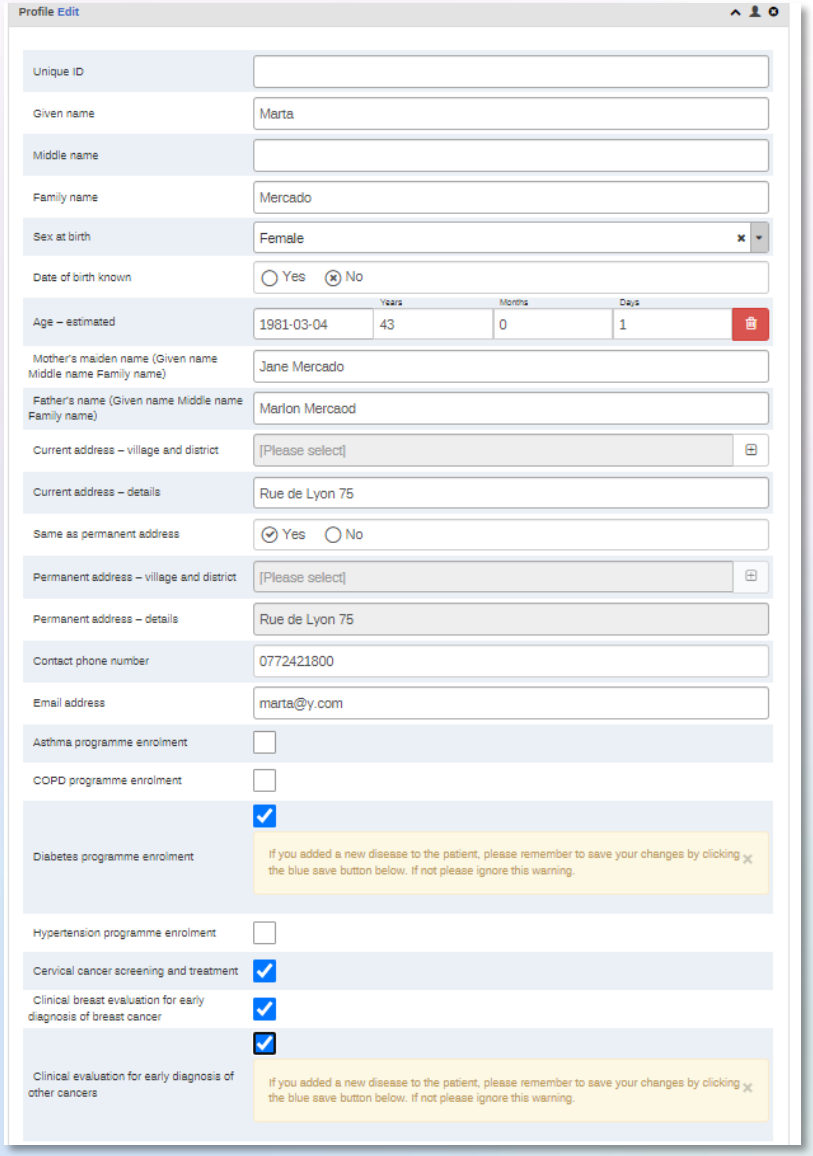
- Definition, purpose, numerator, denominator, calculation method, aggregation, disaggregation, sources of data, key data elements, frequency of reporting, users of data, limitations/comments and related links
- Comparability of data across geographical areas and across times

C2-Availability of plasma glucose testing

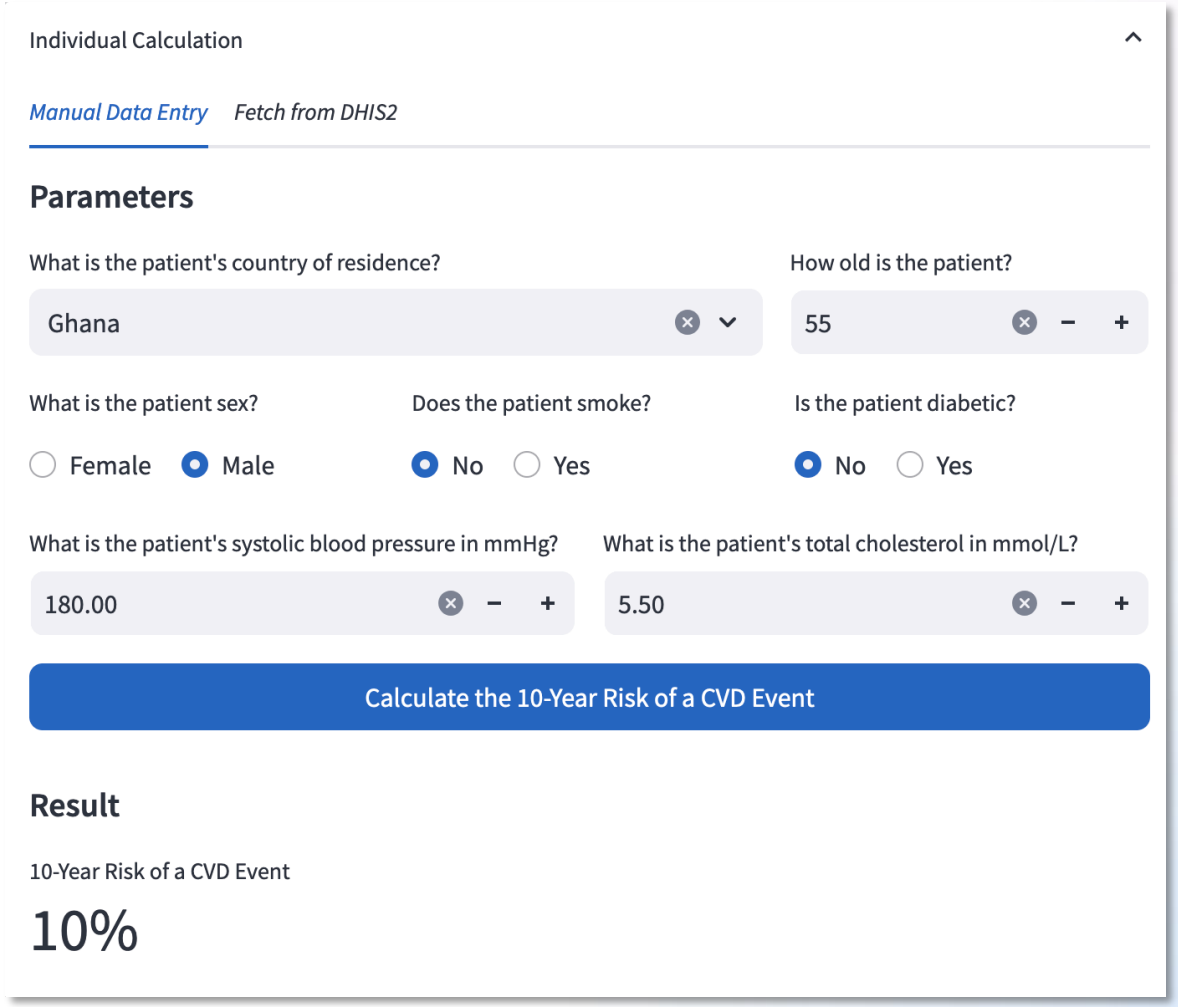
Indicator name	**Availability of plasma glucose testing**
Purpose	To ensure uninterrupted services to diagnose diabetes and assess glycemic control among patients with diabetes
Definition	Proportion of health facilities that have capability of laboratory or point of care plasma glucose (PG) testing
Numerator	Number of health facilities reporting capability of performing either laboratory or point of care PG tests in the reporting period
Denominator	Total number of health facilities
Method of calculation	Numerator ÷ denominator × 100
Aggregation	District, province, state, national
Disaggregation	Health facility, provider ownership type (public/private), facility location type (urban/rural), plasma glucose testing site (point-of-care or laboratory)
Sources of data	Health facility reports, regional logistics information system or survey
Key data elements	Count of number of facilities reporting "test capability"
Frequency of reporting	Quarterly
Users of data	District-, province- and state-level managers to focus supervision on health facilities reporting no lab capability, making facilities capable and strengthening health systems to ensure uninterrupted laboratory services
Limitations/ comments	In some settings the health facilities do not provide laboratory services so the reporting units will need to come from other laboratory service providers
Related links	Harmonized health facility assessment (HHFA): core questions https://www.who.int/publications/i/item/harmonized-health-facility-assessment-(hhfa)

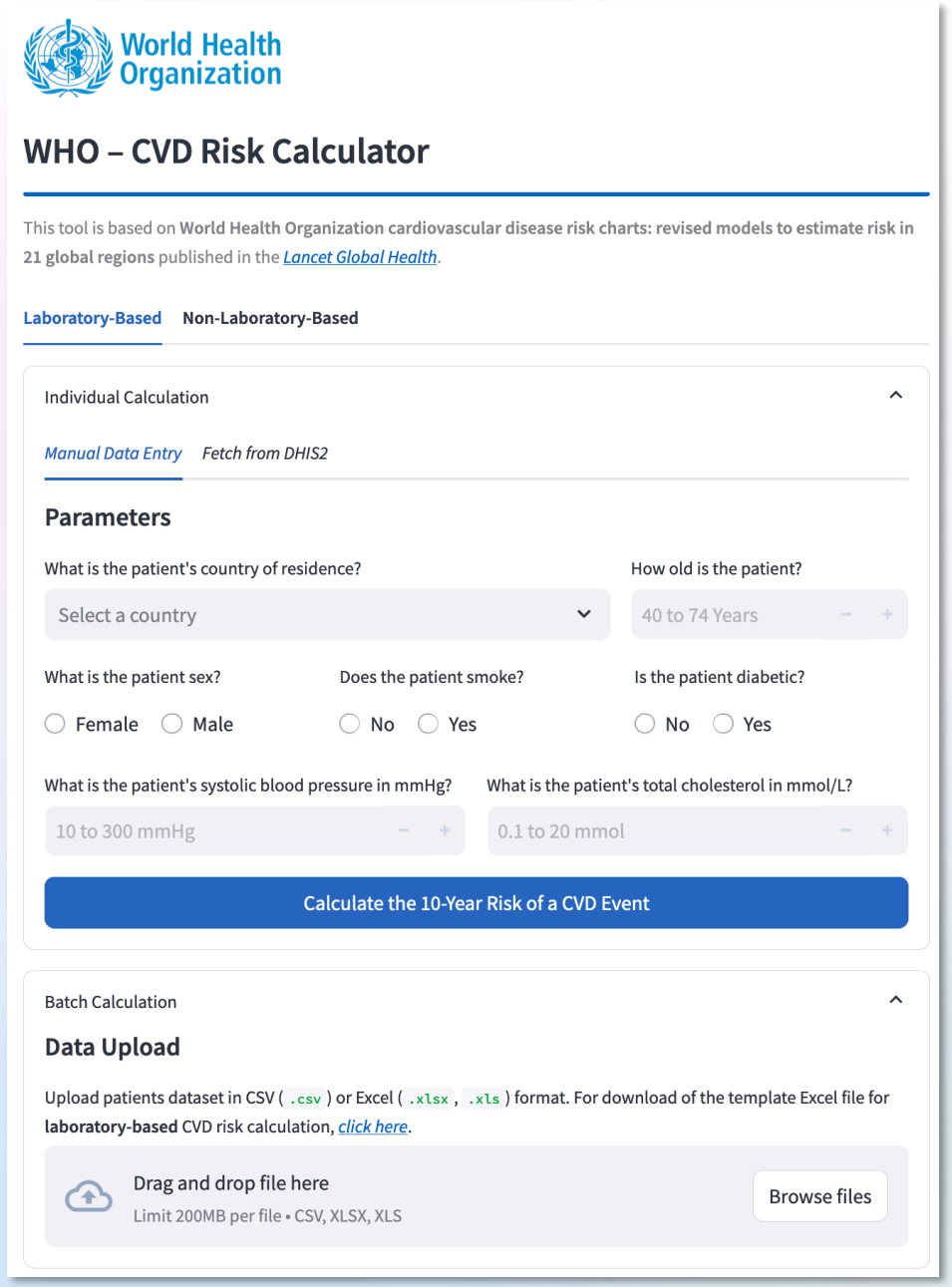
Digital Data Collection tool (NCD DHIS2)



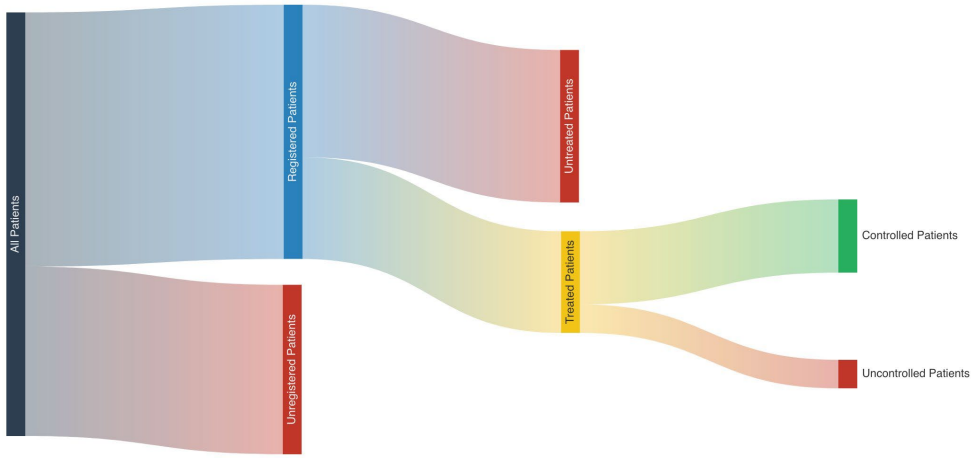


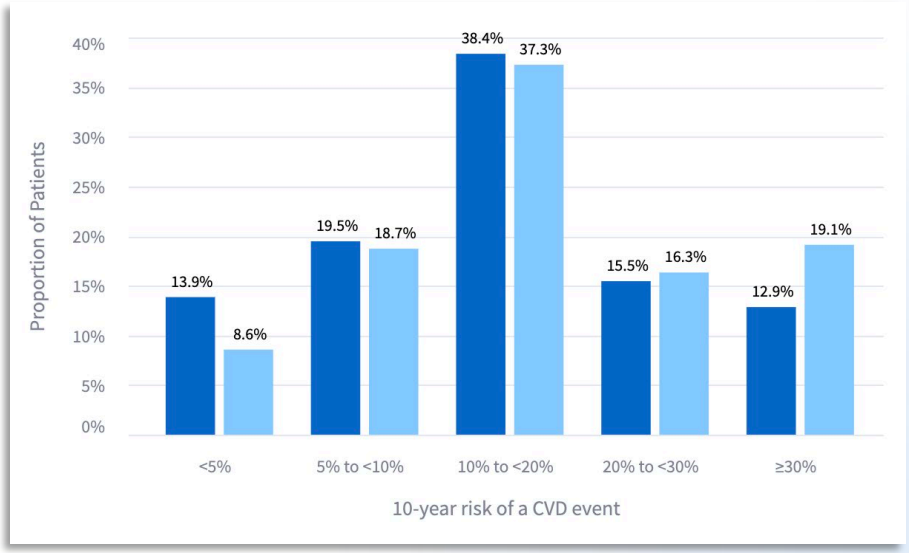
Cardiovascular Disease Risk Scoring

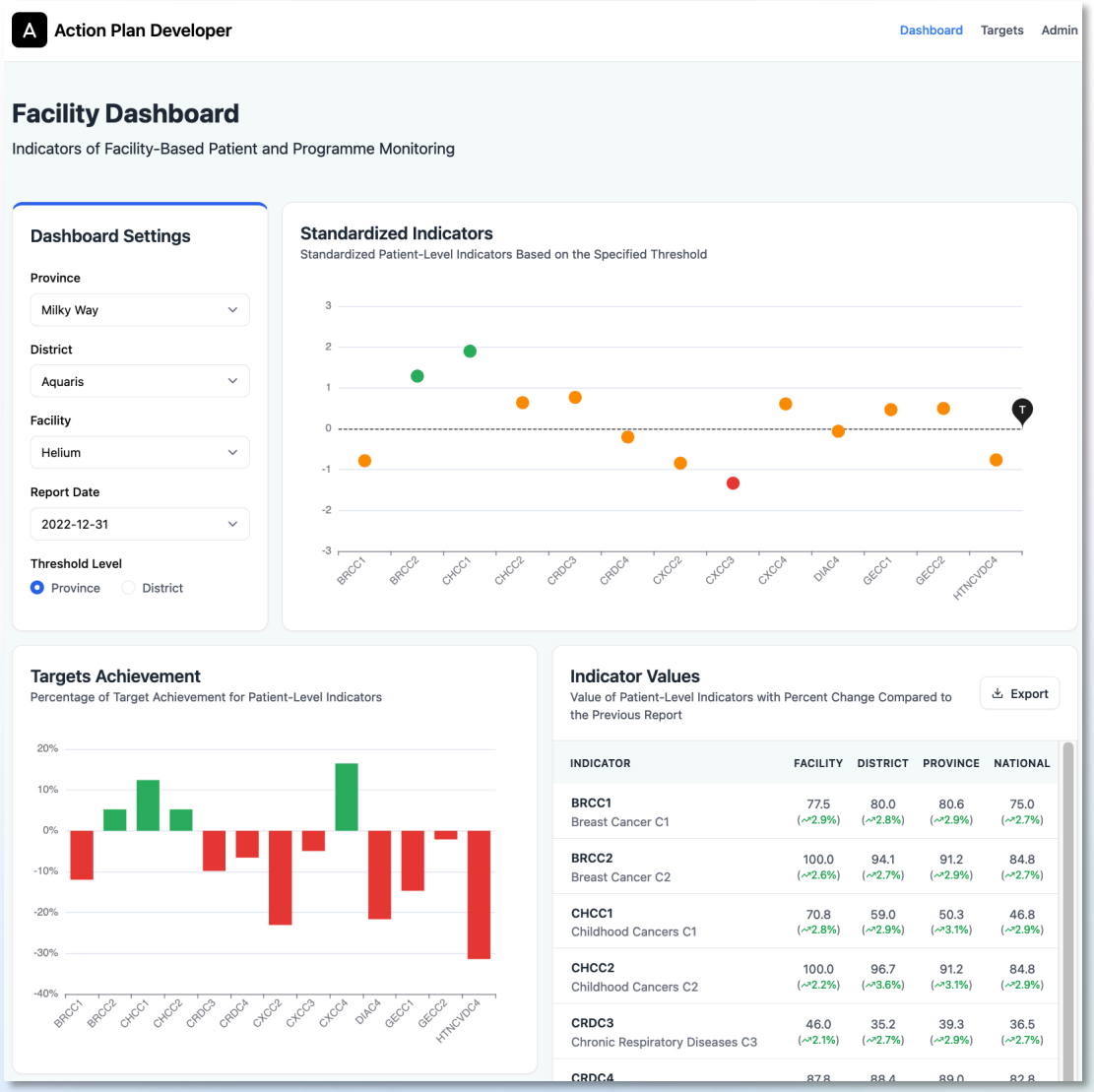




Universal NCD Dashboard and Action Plan Developer







How registries can help tackle the global diabetes burden

Facility-based monitoring stream work

Development of norms and standards		Development of tools			Advocacy, technical supports, and implementations
Facility-based monitoring guidance	Global monitoring framework	NCD and rehabilitation DHIS2 (aggregate and tracker)	E-registry	PROMs	End-user testing and adaptation process
Primary care settings	Global Diabetes Monitoring Framework	CVD risk scoring API/App			Training and advocacy sessions
Secondary and tertiary settings	Global Cancer Monitoring Framework	NCD Universal dashboard and action plan developer			NCD RHIS assessments
PEN-Plus	Global PEN-Plus Monitoring Framework	Digital adaptation kit			Evaluation of programme/projects/initiatives (e.g., NORAD, D-Card)
Patient reported outcome measures		Validating screening tool for rehabilitation needs			
		STEPS companion, facility level survey			

Published
Current/ongoing tasks
Future tasks

THANK YOU

farzadfarf@who.int

HOW REGISTRIES CAN HELP TACKLE THE GLOBAL DIABETES BURDEN

ASPECTS AND ANECDOTES AROUND A TYPE 1 DIABETES REGISTRY

DIANA NOVELO ALZINA

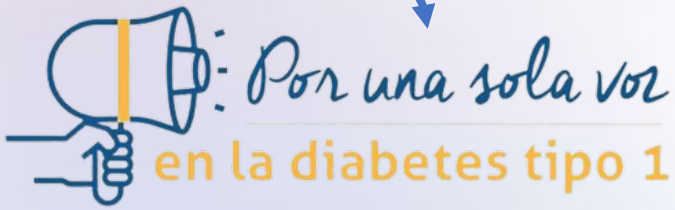
YLD Mentor and Council's Treasurer of the Diabetes Association of Southeastern Mexico (Asociación Mexicana de Diabetes en el Sureste)

Mexico

A TYPE 1 DIABETES REGISTRY

- A YLD project that joined forces with the National movement **"One Voice in Type 1 Diabetes"** for a national type 1 diabetes registry in Mexico.

Movement's logo:



- The intention of a national registry:

❖ **Reach the maximum goal** → complete access to treatment

❖ **Obtain statistical data** → advocate for policies that improve the quality of care

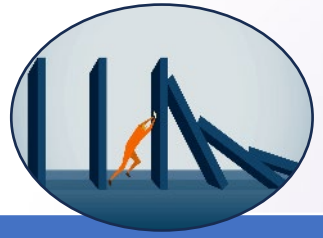
❖ **Appel for Budget** → a government budget specific for T1D

❖ **Assert rights to health** → better care, fewer complications, more lives saved.

COMMENTS BASED ON: THE REGISTRY OF PEOPLE LIVING WITH TYPE 1 DIABETES IN THE STATE OF YUCATAN, MEXICO.

ACHIEVEMENTS

- 130 registries in Yucatan
  2,279 registries nationally
- Statistical data provided



CHALLENGES

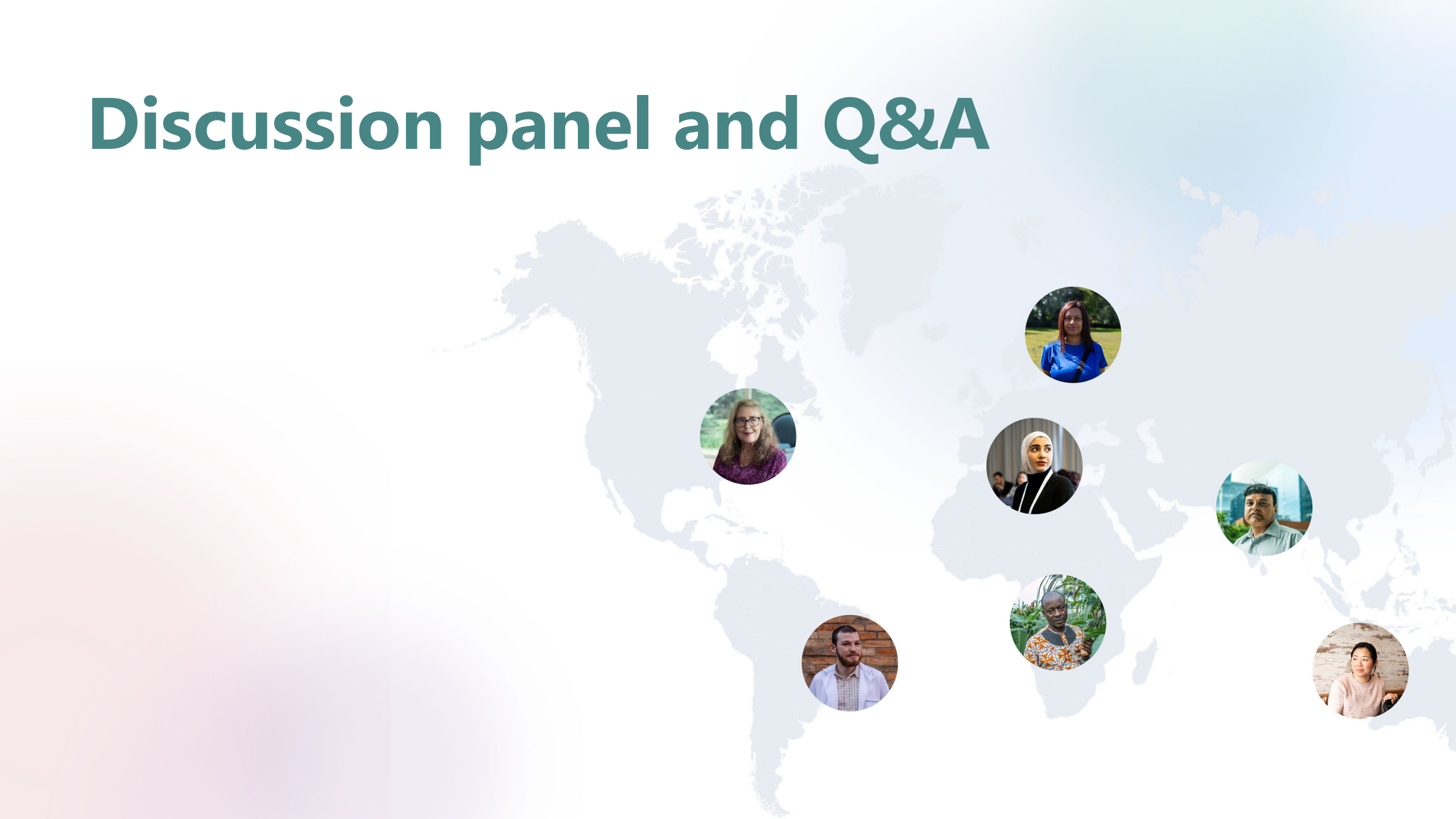
- Lack of participation
- Calls and manual filling of the database
- Lack of knowledge in the management of softwares

RECOMMENDATIONS

- Appeal for an official national registry
- Invest in a reliable software
- Have an expert in the area of technology and softwares.

THANK YOU

Discussion panel and Q&A



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CLOSING REMARKS AND THANKS

DR HERMELINDA PEDROSA

IDF Vice President Physician, Chair of IDF Women and Diabetes Committee, International Relations Advisor and Advocacy at SBD (Brazilian Diabetes Society), Coordinator at the Endocrinology Unit Research Centre HRT/FEPECS, Investigator at Fiocruz Biomanguinhos

Brasil

CLOSING REMARKS AND THANKS

- The recording, slides and feedback questionnaire will be sent to all registrants in a few days.
- Please respond to the feedback questionnaire to help us improve future IDF online events.
- Send any questions you may have to advocacy@idf.org or atlas@idf.org

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IDF 2025 BANGKOK 7-10 APRIL

Shape the future of diabetes

IDF World Diabetes Congress

Bangkok, Thailand, 7 – 10 April 2025

Why attend

- **10** programme streams
- **130** hours of scientific sessions
- **250** international speakers

Key date

- **31 Oct 2024** Early rate deadline

THANK YOU