



Lifelong Care for Children with Chronic Conditions: Session 3

Re-imagining the Package of Care for Children Subgroup

July 9, 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 UNICEFs focus on a thrive and transform agenda, chronic conditions come more into focus



Ana Mocumbi

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*Bridging a Gap
in Universal Health Coverage
for the Poorest Billion*

Care delivery systems for children and adolescents with severe or complex chronic NCDs

Ana Mocumbi, Co-Chair

UNICEF Series: Lifelong Care for Children with Chronic Conditions
July 9, 2021

Outline



- Current NCD paradigm
- PEN Plus Origins
- Lifelong Care for Children with Chronic Conditions
- Opportunities and Ways Forward

The current NCD paradigm focuses on 4 main diseases and modifiable risk factors

Current NCD
Paradigm*

Noncommunicable Diseases 4 Diseases, 4 Modifiable Shared Risk Factors

	Tobacco Use	Unhealthy diets	Physical Inactivity	Harmful Use of Alcohol
Cardio-vascular				
Diabetes				
Cancer				
Chronic Respiratory				

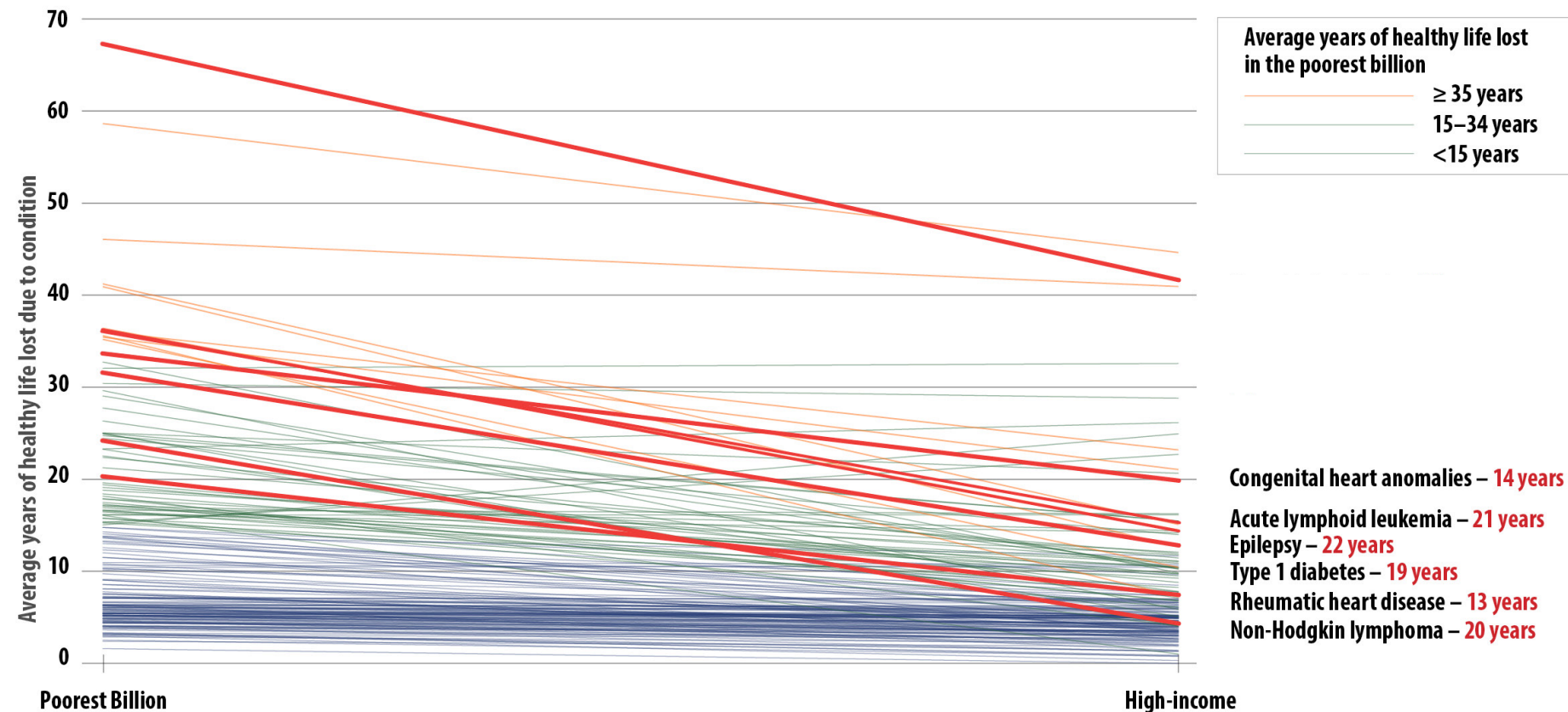
* Mental Disorders and Road Traffic injuries have more recently been included as well (i.e., "5x5")

The Lancet Commission on Reframing NCDs and Injuries was launched in 2013



LANCET NCDI POVERTY COMMISSION MEMBERS WITH REPRESENTATIVES OF NATIONAL NCDI POVERTY COMMISSIONS, ADVISORS AND STAFF
KIGALI, RWANDA IN 2016

Some of the steepest gradients in years of life lost are for NCDs affecting the poor



Other NCDs affecting the poorest

Sickle Cell Disease
Rheumatic heart disease
Type 1 diabetes
Cervical Cancer
Pediatric Cancers
Congenital heart disease
Household air pollution
Schizophrenia
Injuries
Epilepsy

The Lancet NCDI Poverty Commission report



- NCDI Poverty is a huge gap in achieving UHC
- NCDI Poverty cause annually 800,000 deaths among <40y
- There's a major gap in health financing for NCDIs

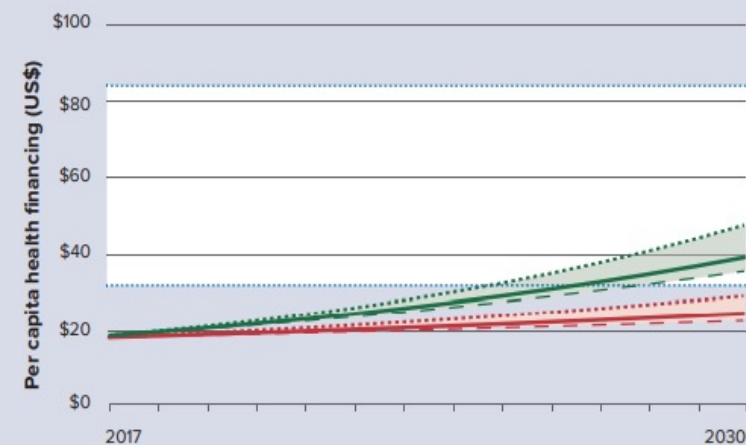
Financing Universal Health Coverage in Low-Income Countries

Range of projected health financing capacity

Linear increases in revenue/ expenditure for health

Constant levels of revenue/ expenditure for health

Projections model annual per capita GDP growth of 6%, 4% and 3%



Essential universal health coverage (UHC) costs

\$84—All conditions including NCDs and injuries

NCDI Poverty UHC gap

\$32—Infectious, maternal, child and reproductive health

NCDI Poverty Network Member Countries

National
Commissions
2016 - 2019



NCDI Poverty Network – Strategic Initiatives



Strategic Initiative	Expanding the NCDI Poverty Network	Integration Science	PEN-Plus Partnership	NCDI Poverty Fund
Major Category	Policy & Awareness	Research & Design	Implementation, Service Delivery, & Training	Financing & Scale-up

PEN-Plus: A march towards UHC

Characteristics of Package of Essential NCD Interventions (PEN) -Plus clinics

- Decentralized, integrated, person centered
- **Severe diseases:** lethal, disabling, disproportionately affect the poorest and youngest
- **Rural majority:** Increased access to care by overcoming geographic and financial barriers
- **Promote decentralization:** training, supervision and mentorship of health center and community staff

Lifelong Care for Children with Chronic Conditions

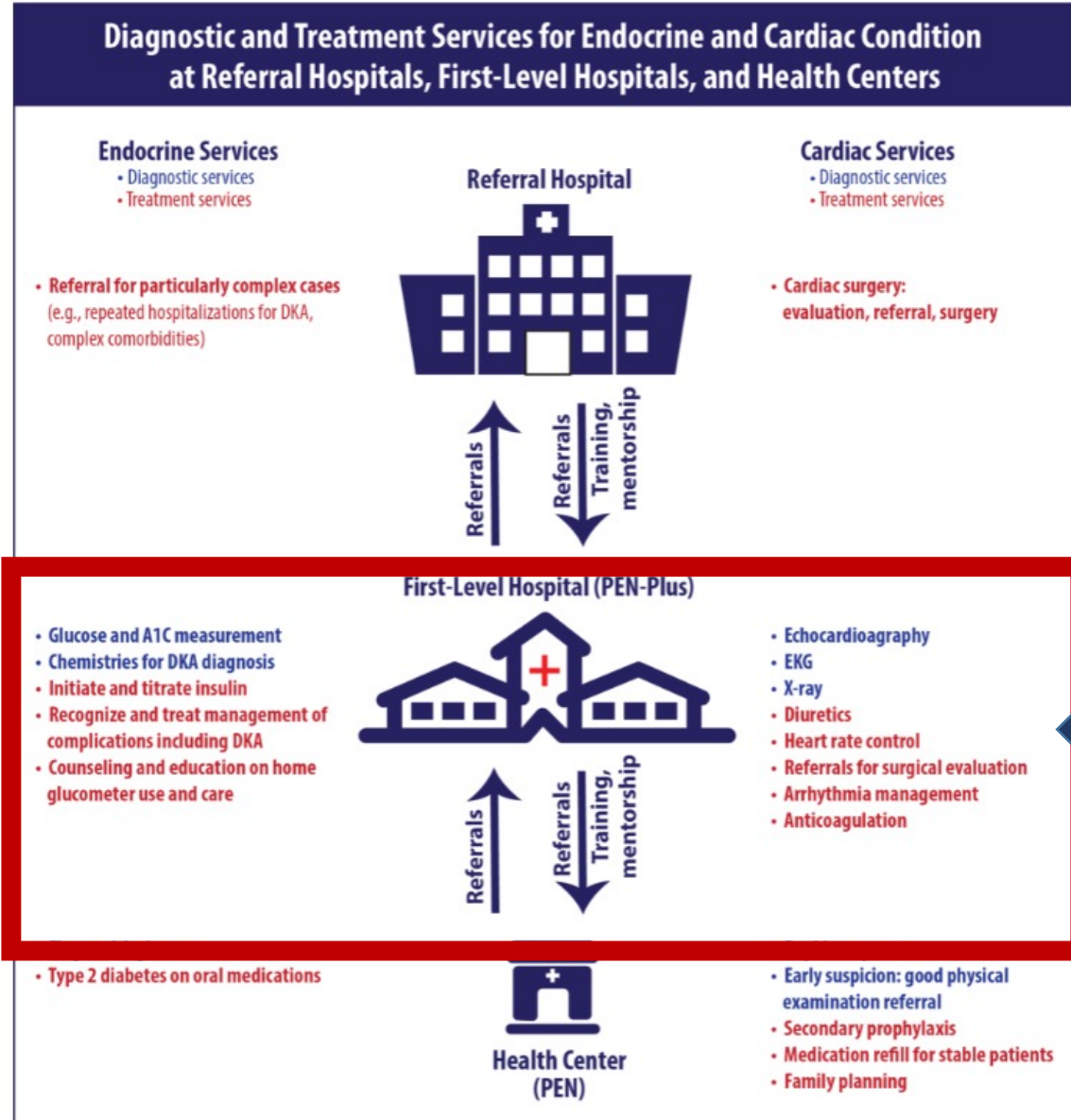
PEN-Plus is an integrated delivery strategy for chronic care of severe NCDs at first-level hospitals (e.g. district hospitals)

- . builds on the WHO PEN for common NCDs
- . seeks to increase coverage of high-quality care for less common but more severe conditions by decentralizing services normally available only at tertiary referral centers.
- . provides mid-level health workers (e.g. nurses, clinical officers) with the shared competencies needed to deliver integrated care for groups of related conditions, including psychosocial support and palliative care.
- . strengthens WHO PEN services at lower-level facilities by providing training, mentorship, and supervision

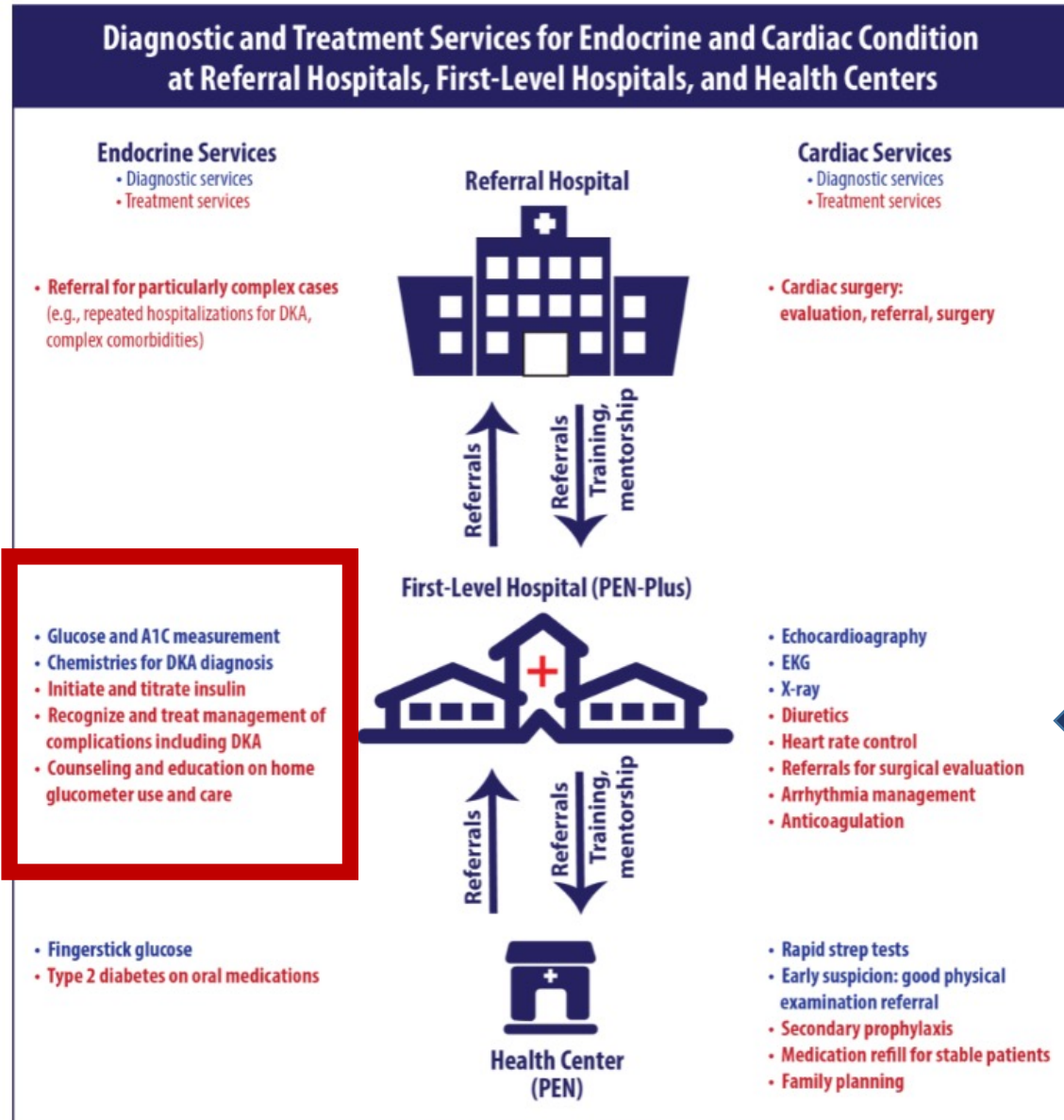
PEN-Plus addresses gaps in care for severe NCDs among the poor



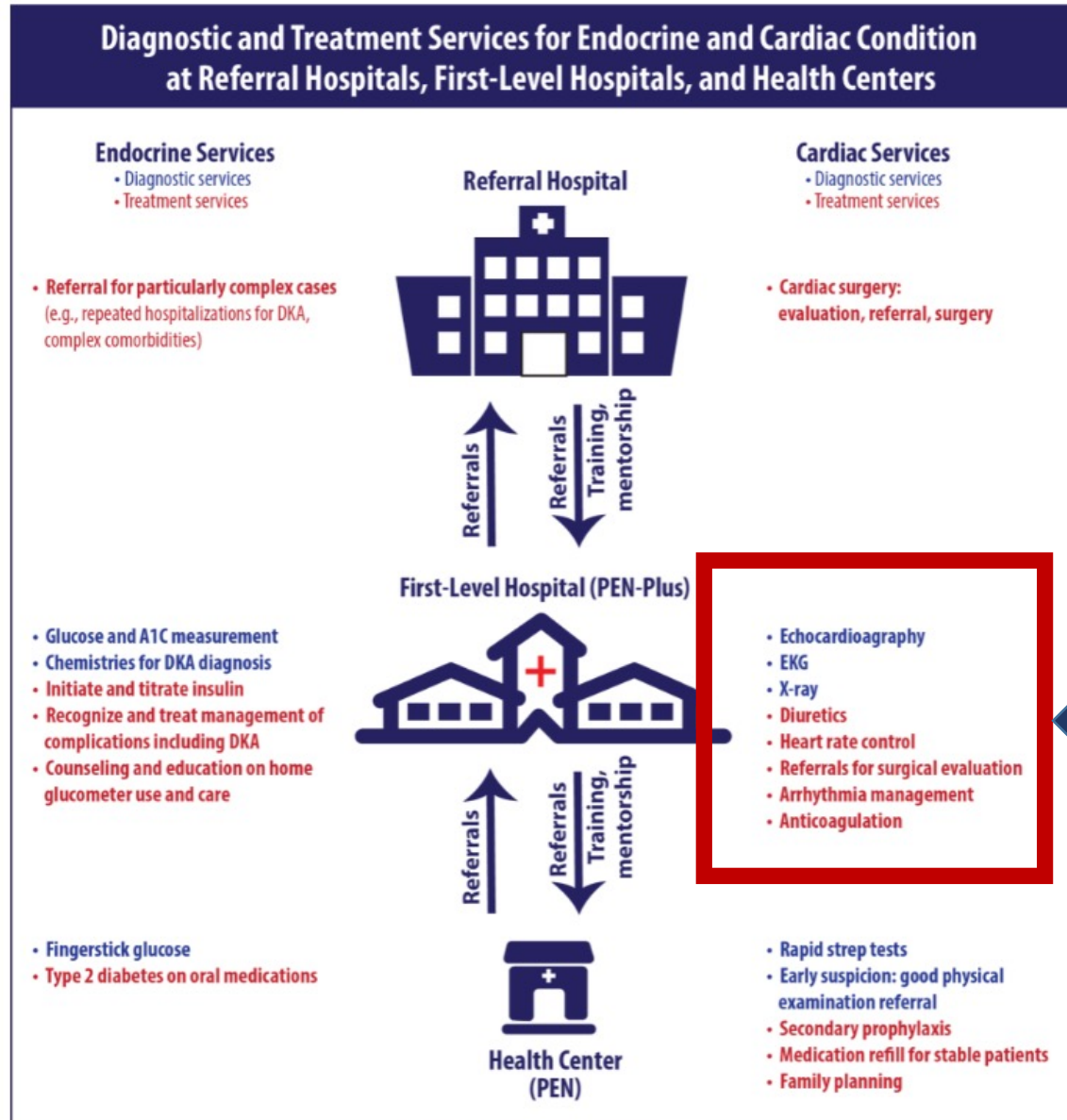
	WHO PEN	PEN-Plus
Sample list of conditions	<ul style="list-style-type: none">Type 2 Diabetes, Stage 1 and 2 Hypertension, Asthma and COPD, asymptomatic rheumatic heart disease	<ul style="list-style-type: none"><u>Sickle Cell Anemia</u>, <u>Type I and Insulin-dependent diabetes</u>, <u>Malignant Hypertension</u>, <u>Advanced Rheumatic and Congenital Heart disease</u>, <u>Cirrhosis</u>, <u>Malignancies</u>
Facility level	<ul style="list-style-type: none">Most peripheral	<ul style="list-style-type: none">First-Referral
Disease prevalence	<ul style="list-style-type: none">High	<ul style="list-style-type: none">Low
Disease severity	<ul style="list-style-type: none">Low	<ul style="list-style-type: none">High
“Therapeutic window”	<ul style="list-style-type: none">Wide	<ul style="list-style-type: none">Narrow
Training model	<ul style="list-style-type: none">Short, didactic	<ul style="list-style-type: none">Longer, didactic + clinical practice



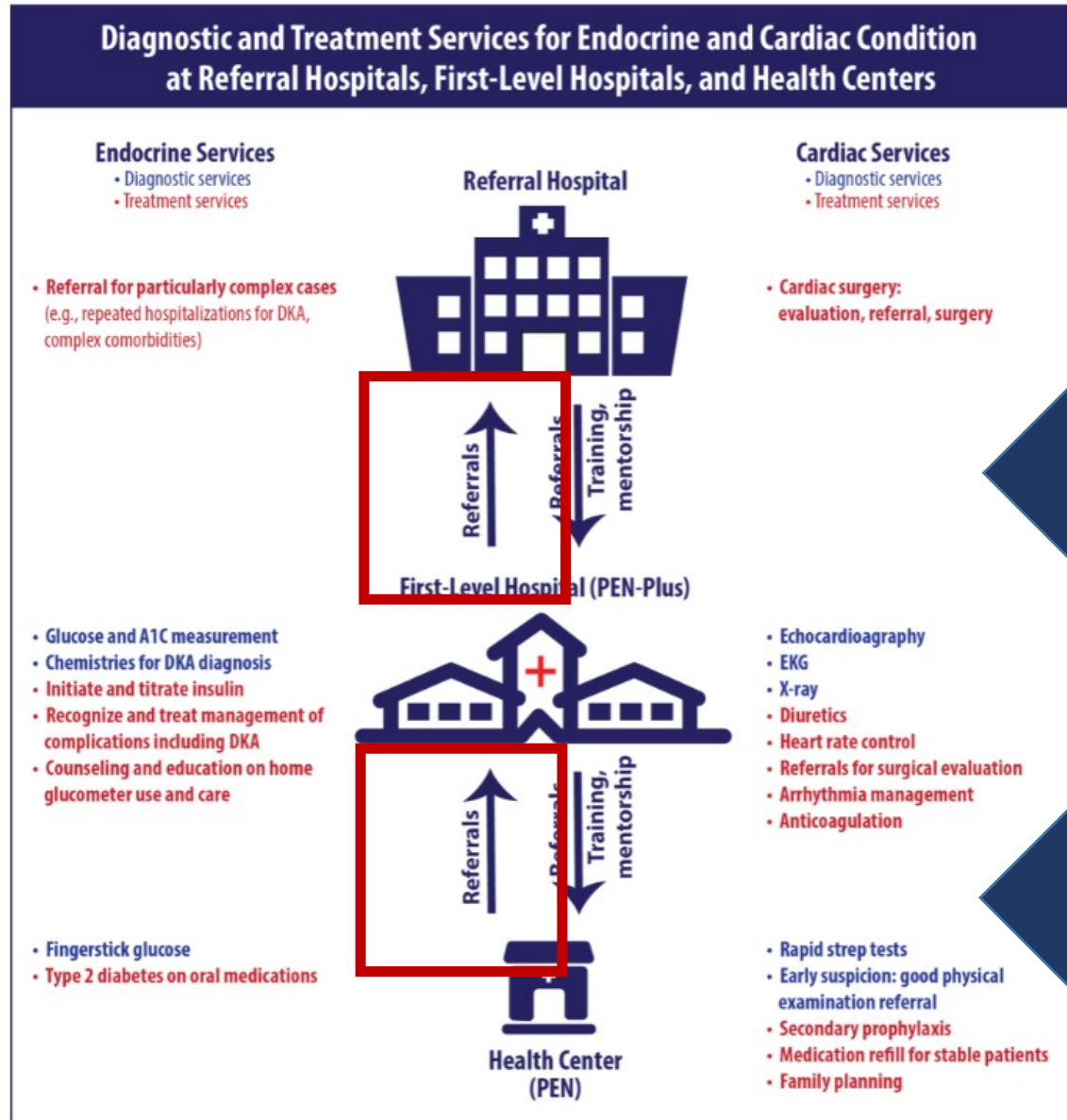
PEN Plus is part of an ecosystem of chronic care – the piece where care and treatment is provided at first level hospitals (e.g. district hospital)



For example, adolescents with Type 1 Diabetes can receive diagnosis, insulin titration, laboratory monitoring, and treatment of complications such as DKA

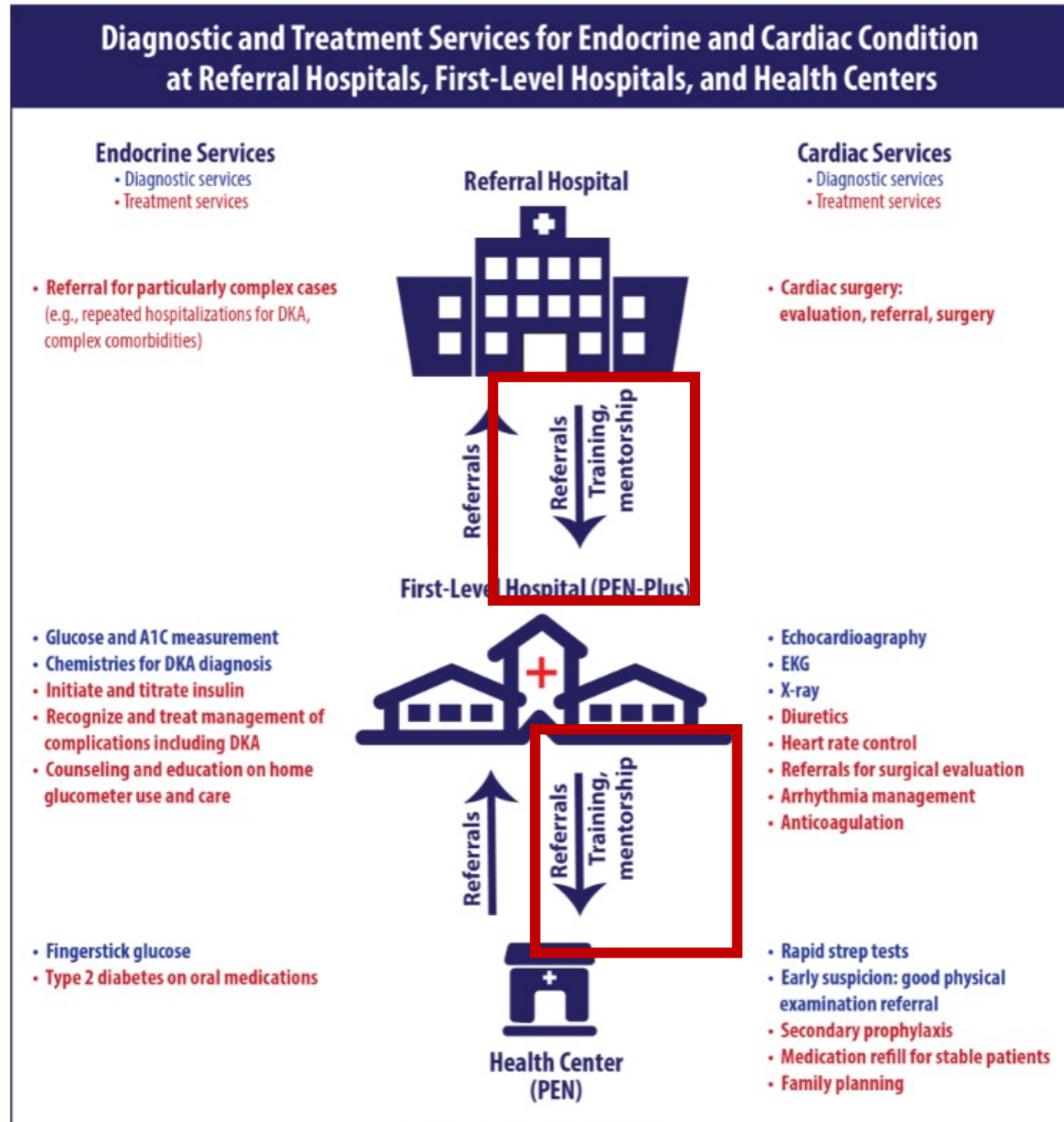


Or, a child with congenital heart disease can receive diagnosis, echocardiography, follow up clinical monitoring and treatment, and referral for surgical evaluation



The PEN Plus model allows for referral to central or tertiary hospitals when needed

And primary care clinics can escalate care to PEN Plus for new patients or complex conditions



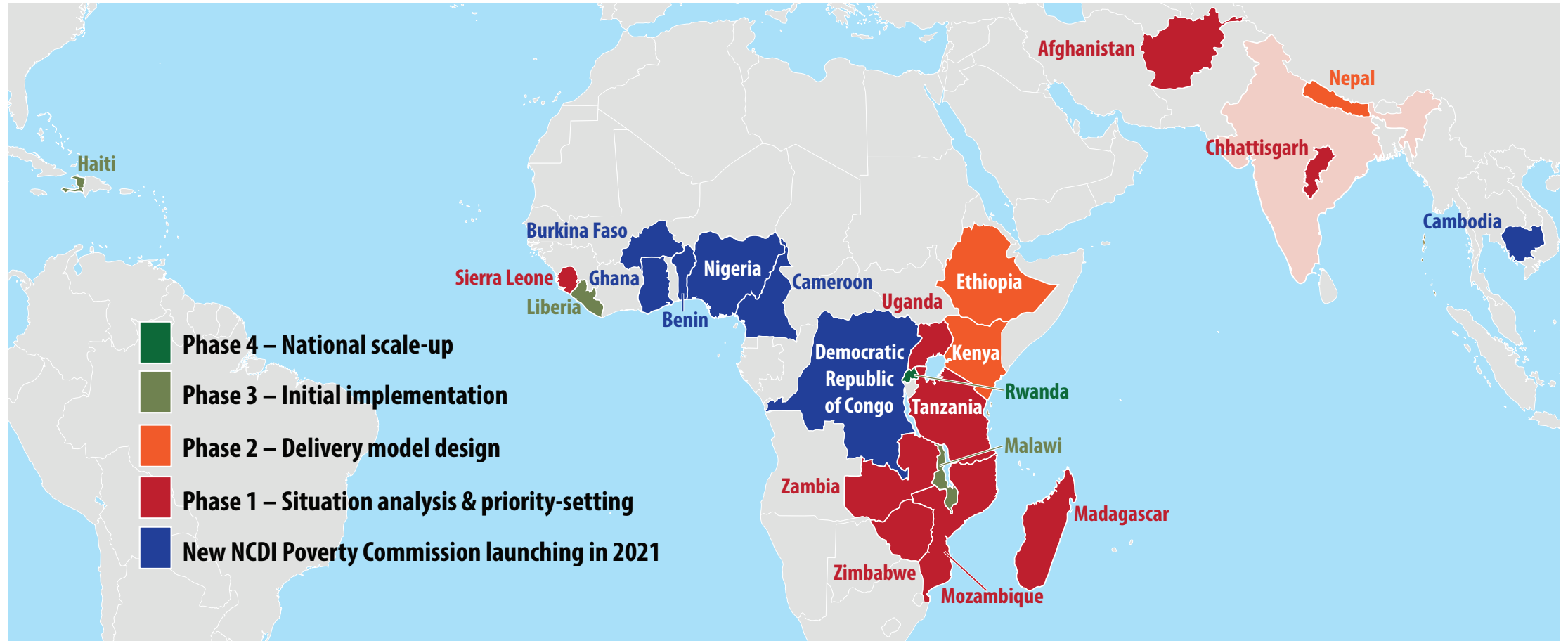
In addition, the relationship between levels of care provides a platform and opportunity for training and mentorship

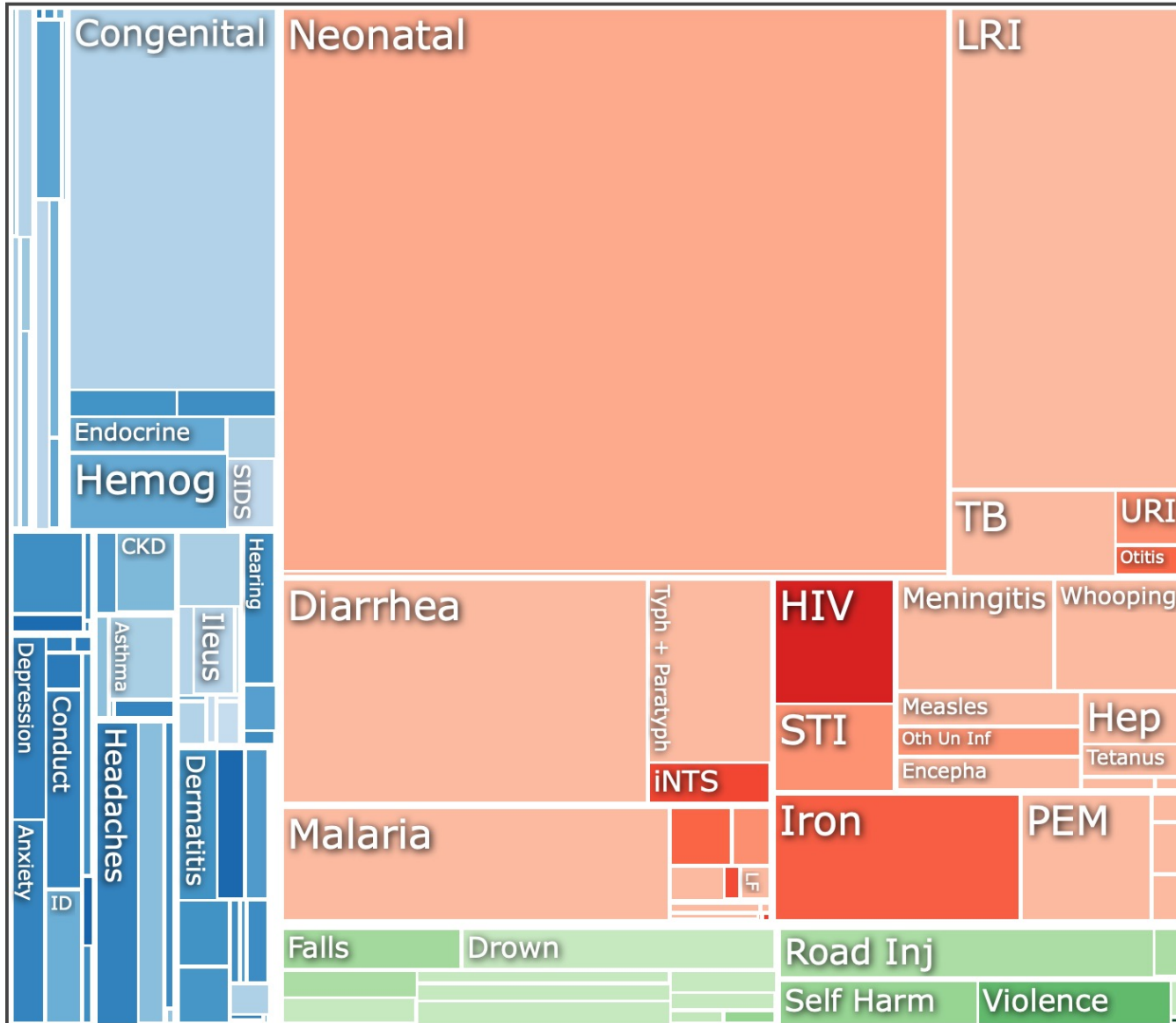
Which also strengthens primary health care

Opportunities & Ways Forward

PEN Plus implementation contributes to address the lack of NCD policy for children

PEN Plus Implementation & Expansion





DALYs in LMICs in people under 20 years (*GBD 2019*)

NCDs (blue) = 23% of DALYs

Very diverse set of conditions

SUPPLEMENT ARTICLE

WILEY **obesityreviews**

Narrative review of reviews of preconception interventions to prevent an increased risk of obesity and non-communicable diseases in children

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Summary

Evidence for the effect of preconception and periconceptional risk factors on childhood outcomes such as obesity and other non-communicable diseases (NCDs) in later life is growing. Issues such as maternal malnutrition need to be addressed before pregnancy, to prevent a transgenerational passage of risk of NCDs. The aim of this



Review

Personalized Nutrition Approach in Pregnancy and Early Life to Tackle Childhood and Adult Non-Communicable Diseases

Shaikha Alabduljabbar , Sara Al Zaidan, Arun Prasath Lakshmanan  and Annalisa Terranegra * 

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Abstract: The development of childhood and adult non-communicable diseases (NCD) is associated with environmental factors, starting from intrauterine life. A new theory finds the roots of epigenetic programming in parental gametogenesis, continuing during embryo development, fetal life, and finally in post-natal life. Maternal health status and poor nutrition are widely recognized as implications in the onset of childhood and adult diseases. Early nutrition, particularly breastfeeding, also plays a primary role in affecting the health status of an individual later in life. A poor maternal diet during pregnancy and lack of breastfeeding can cause a nutrient deficiency that affects the gut microbiota, and acts as a cofactor for many pathways, impacting the epigenetic controls and transcription of genes involved in the metabolism, angiogenesis, and other pathways, leading to NCDs in adult life. Both maternal and fetal genetic backgrounds also affect nutrient adsorption

SPECIAL ARTICLE

Obstetrics

WILEY




Do the concepts of “life course approach” and “developmental origins of health and disease” underpin current maternity care? Study protocol

Chandni Maria Jacob^{1,2,3,*} | Wendy T. Lawrence^{2,3,4} | Hazel M. Inskip^{2,3,4} | Fionnuala M. McAuliffe⁵ | Sarah Louise Killeen⁵ | Mark Hanson^{1,2,3}

BMJ Global Health

Delivering non-communicable disease interventions to women and children in conflict settings: a systematic review

Shailja Shah,¹ Mariella Munyuzangabo,¹ Michelle F Gaffey,¹ Mahdis Kamali,¹ Reena P Jain ,¹ Daina Als,¹ Sarah Meteke,¹ Amruta Radhakrishnan,¹ Fahad J Siddiqui,^{1,2} Anushka Ataullahjan,¹ Zulfiqar A Bhutta^{1,3}

To cite: Shah S, Munyuzangabo M, Gaffey MF, et al. Delivering non-communicable disease interventions to women and children in conflict settings: a systematic review. *BMJ Global Health* 2020;5:e002473. doi:10.1136/bmjgh-2020-002473

ABSTRACT

Background Non-communicable diseases (NCDs) are the leading cause of death worldwide. In the context of conflict settings, population displacement, disrupted treatment, infrastructure damage and other factors impose serious NCD intervention delivery challenges, but relatively little attention has been paid to addressing these challenges.

How we synthesise the available evidence and apply

Key questions

What is already known?

- Conflict imposes long-term and intergenerational effects on the health of children that place them at higher risk of future non-communicable diseases (NCDs).

TASK SHIFTING/SHARING Shared competencies for NCD care

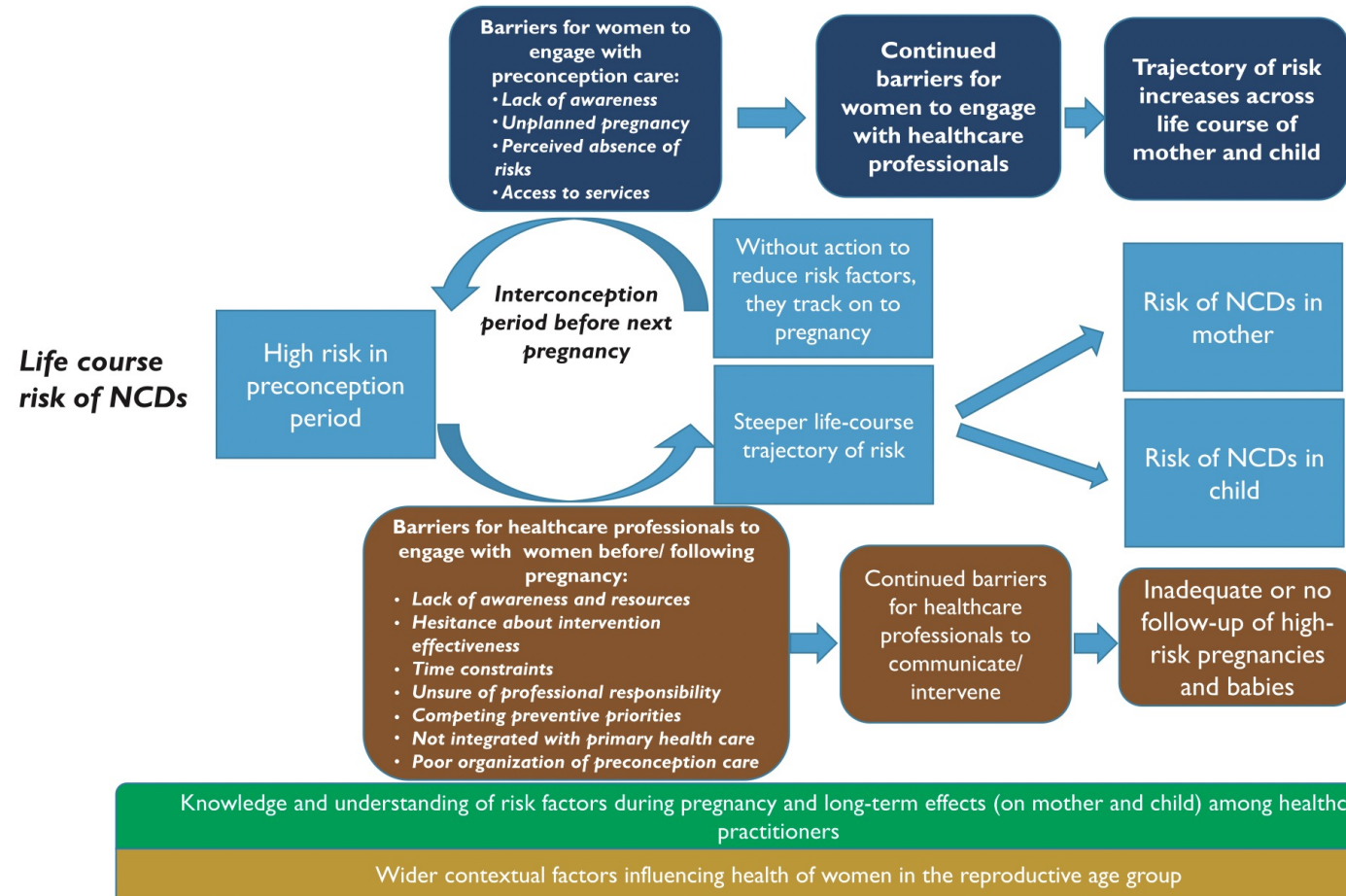
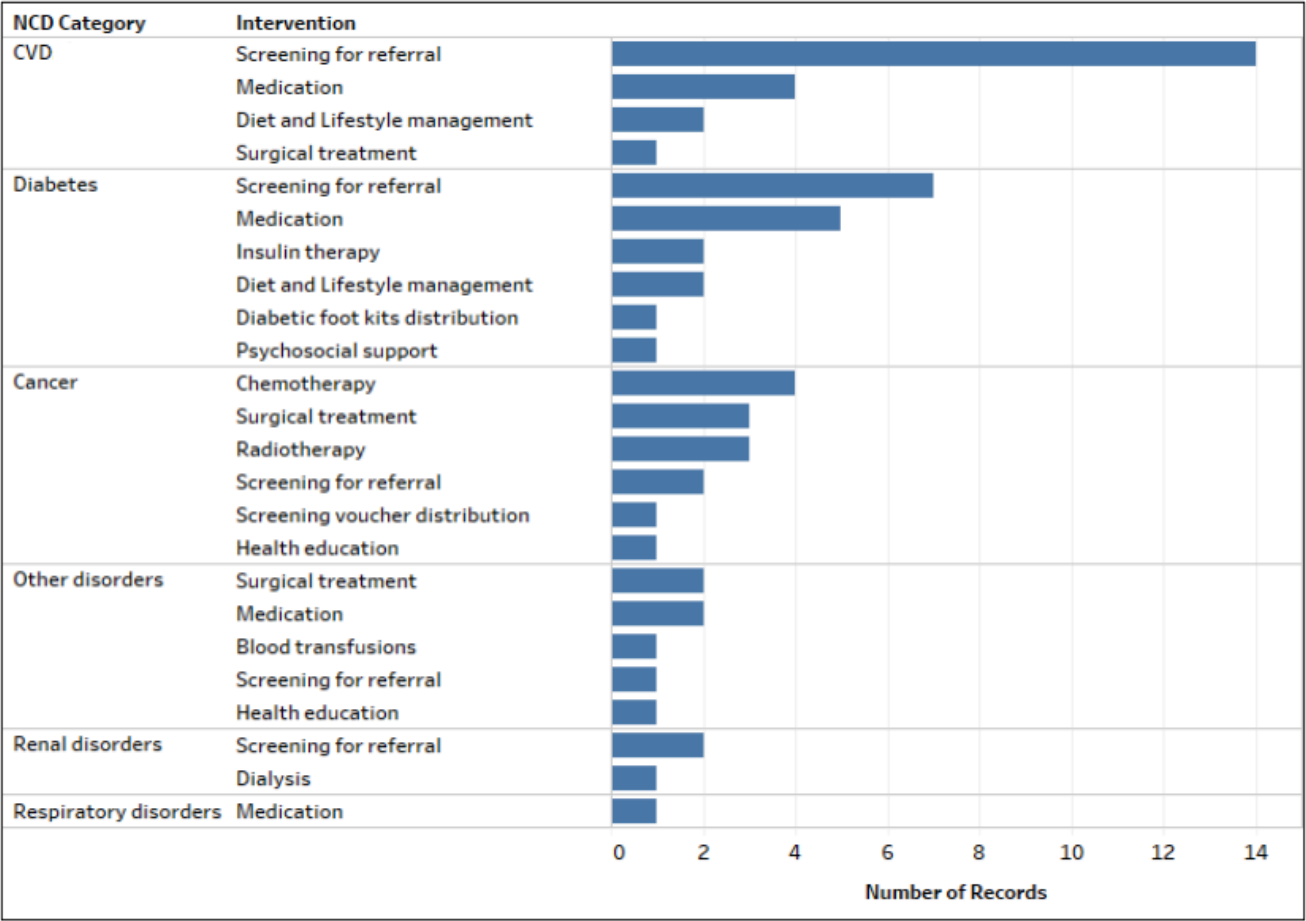


FIGURE 1 Conceptual framework of factors affecting the intergenerational transmission of risk for NCDs. The life course model of NCDs and DOHaD both suggest that the mother's nutritional status and health behaviors, before and during pregnancy, can have effects on fetal growth and development. This has further long-term consequences on the health of the mother and child. For example, pre-pregnancy BMI is a risk factor for both gestational diabetes and future type 2 diabetes in the mother and childhood obesity for the baby. OBGYNs and midwives are stakeholders who come in contact with women during these stages most frequently. Knowledge and understanding of DOHaD among healthcare practitioners will determine the extent to which these issues are communicated with women or couples.

SHARED NCD PACKAGES packages & integrated care



“ Absence of national NCD policy for children is a major challenge. The burden of care rests mainly on the parents/caregivers. A national strategic intervention on the importance of awareness generation on the causes, risk factors, prevention and treatment of NCDs for families and communities is essential. Government support through national health and social policy initiatives are essential.”

URI: <http://ugspace.ug.edu.gh/handle/123456789/25285>

Anarfi J et al. Digital Collections 2016

Figure 3 Frequency of reported interventions delivered, by NCD condition. CVD, cardiovascular disease; NCD, non-communicable disease.

For children and adolescents prevention alone is not enough!

- Many PEN Plus conditions occur in young children and adolescents, and many of these cannot be addressed with prevention alone:
 - Type 1 Diabetes
 - Sickle Cell Disease
 - Congenital Heart Disease
 - Nephrotic Syndrome
 - Childhood Cancer
- Many may benefit from prevention but also need treatment once they occur:
 - Rheumatic Heart Disease
 - Severe or complicated epilepsy
 - Congenital anomalies
 - Injury

Leveraging prevention + treatment

- Severe chronic NCDs in children and adolescents may be each individually rare --> However, as a group, we see a lot of illness and suffering
- PEN-Plus is a piece of the puzzle for comprehensive prevention and treatment for children and adolescents
 - Complementary to prevention agenda
 - A platform for care delivery for complex conditions
 - Supports mentorship and quality for primary care
 - Opportunity for integrating other primary and preventive services

Acknowledgments

- Dr. Emily Wroe
- NCDI Poverty Co-Secretariat
- NCDI Poverty Network Members

Thank you ver much for your attention!

Wrapping up

- **Key messages**

- Low case numbers is a challenge- rationale for an approach to chronic lifelong care that bundles chronic conditions and looks at critical health system inputs to integrate some elements of care at Primary Health Care level.
- An integrated approach and multidisciplinary teams seem to be a more cost-efficient and practical way to achieve this, this includes connections to tertiary care.
- A life-course approach will be needed to adjust care as children enter adolescence and adulthood.
- A better understanding of pediatric experience of care and support for chronic illness to be recognized and addressed.
- Patient and family engagement and advocacy is needed for inclusion of NCDs, chronic care in LMICs in UHC and PHC initiatives- including inclusion in national health sector plans, policies, and ultimately integrated budgets



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

Reach out to the Child Health Task Force at
childhealthtaskforce@jsi.com

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 Task Force Child Health 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