

Meaningful engagement of youth: from research prioritization to clinical trials, implementation science and policy development



Carlo Andre Oliveras Rodriguez
Adolescent HIV Treatment Coalition

The background of the slide is a close-up photograph of a honeycomb. The hexagonal cells are filled with a golden-yellow substance, likely honey, and are surrounded by several bees. The bees are scattered across the frame, with some in the foreground and others in the background. The lighting is bright, highlighting the texture of the honey and the details of the bees.

Defining engagement

why is it important?

Meaningful engagement in research

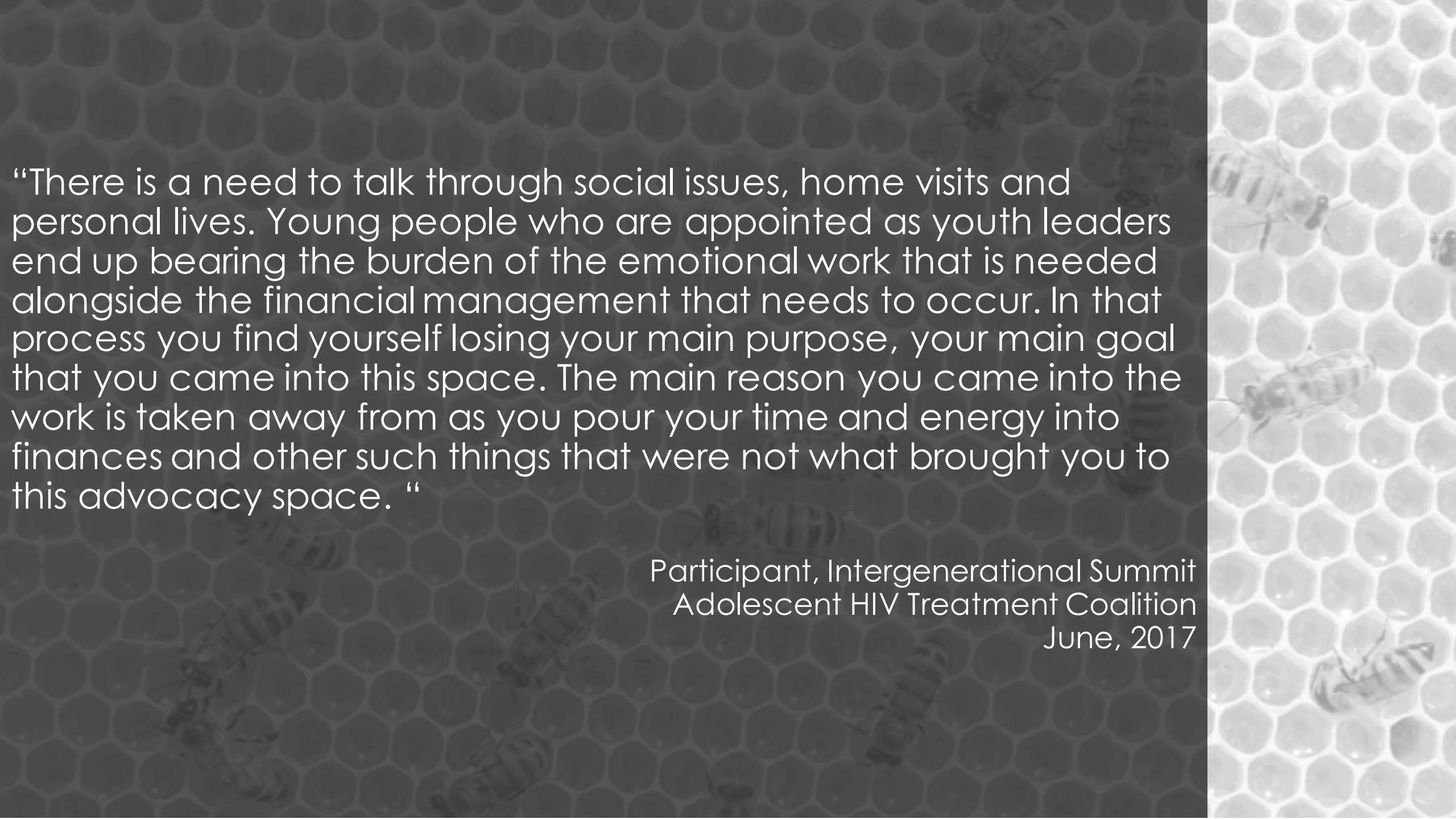
The following principles are central to young people's meaningful engagement in research to move beyond tokenistic participation towards citizenship.

1. They understand the intentions of the project;
2. They know who made the decisions concerning their involvement and why;
3. They have a meaningful (rather than 'decorative') role;
4. They volunteer for the project after the project was made clear to them.

"From tokenism to citizenship", Dr. Hart 1992

The background of the slide is a close-up photograph of a honeycomb. The hexagonal cells are a warm, golden-yellow color. Several bees are visible, scattered across the frame. Some are in sharp focus, showing their striped abdomens and wings, while others are blurred in the background. The lighting is soft, creating a natural and textured appearance.

How **well** do we know the
young people we are
engaging?

The background of the slide features a dark, textured honeycomb pattern. Several bees are visible, some in flight and others on the cells. The text is overlaid on the left side of this pattern.

“There is a need to talk through social issues, home visits and personal lives. Young people who are appointed as youth leaders end up bearing the burden of the emotional work that is needed alongside the financial management that needs to occur. In that process you find yourself losing your main purpose, your main goal that you came into this space. The main reason you came into the work is taken away from as you pour your time and energy into finances and other such things that were not what brought you to this advocacy space. “

Participant, Intergenerational Summit
Adolescent HIV Treatment Coalition
June, 2017

What now? Going **beyond** dissemination

- **Connecting** researchers with youth
- Assessing **the involvement/engagement** of young people in order to document best practices for engagement
- Establishing **standards of practice** for projects and programs impacting the lives of YPLHIV

Contributions and support

- Youth Trials Board team
 - Dr. Sarah Bernays, PhD
 - Magda Conway
- Professor Lucie Cluver, PhD
- Adolescent HIV Treatment Coalition and all the participants at the Intergenerational Summit for Positive Youth Leadership



**ADOLESCENT
HIV TREATMENT
COALITION**



Global research agendas for paediatric & adolescent HIV

Marissa Vicari, Alice Armstrong, Cadi Irvine, Diddie Schaaf and
Martina Penazzato



Policy briefs

- Paediatric and Adolescent briefs
- In English and French
- Available online:

<https://www.iasociety.org/CIPHER>



World Health
Organization

CIPHER
PAEDIATRIC HIV MATTERS



CIPHER
CHILDREN IN PAEDIATRIC HIV EDUCATION AND RESEARCH



RESEARCH FOR AN AIDS FREE GENERATION:

A GLOBAL RESEARCH AGENDA FOR ADOLESCENTS LIVING WITH HIV

Worldwide, there were an estimated 2.1 million [1.4 million - 2.6 million] adolescents (10-19 years old) living with HIV in 2016, with 150 adolescents dying from AIDS-related causes every day¹. Between 2000 and 2015, annual AIDS-related deaths declined for all age groups except adolescents, where mortality more than doubled from 18,000 to 41,000².

In 2016, there were an estimated 260,000 [150,000-340,000] new HIV infections among adolescents. In sub-Saharan Africa, two out of three newly infected adolescents aged 15-19 years were girls³. With the successful scale up and effectiveness of antiretroviral therapy (ART), children living with HIV are surviving and growing into adolescence. This increasing population requires ongoing support to remain in care and adhere to ART, as well as to manage the changes related to adolescence.

Adolescents living with HIV are in urgent need of improved approaches to address their specific health needs. Evidence indicates higher rates of loss to follow up^{4,5}, and poor adherence⁶, as well as increased needs for psychosocial support⁷. This population group continues to be underserved by current HIV services and have significantly worse access to and coverage of ART⁸. Despite a rapidly growing area of HIV research, a considerable amount of effort is still needed to inform the understanding of what works for this population. Improving outcomes for adolescents and reaching global targets for an AIDS FREE generation by 2030⁹ will require evidence-based interventions and policies. These should take into consideration the developmental stage of adolescence while comprehensively addressing the multiple needs of adolescents living with HIV and actively engaging them in their own healthcare. To overcome these barriers and challenges in a context of increasing funding constraints, targeted research is urgently required to bridge identified research gaps and inform policy on adolescent HIV.

The World Health Organization (WHO) and the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) of the International AIDS Society

(IAS) have undertaken a global research prioritization process. Through broad engagement with stakeholders, a global research agenda has been established, which is aimed at guiding work and maximising available resources. The agenda is comprised of priority research themes in the areas of testing, treatment and service delivery for informing global policy change, and improving outcomes for adolescents living with HIV.



Targeted research is urgently required to bridge identified research gaps and inform policy on adolescent HIV.

WHO/CIPHER 2017/33



CIPHER
CHILDREN IN PAEDIATRIC HIV EDUCATION AND RESEARCH



RESEARCH FOR AN AIDS FREE GENERATION:

A GLOBAL RESEARCH AGENDA FOR PAEDIATRIC HIV

An AIDS FREE generation is within reach with 'super-fast-track targets'¹ developed to accelerate prevention and treatment of HIV among infants and children and contribute to ending AIDS by 2030. To achieve these targets, evidence is needed to inform global policy change and ensure better outcomes for infants and children across the HIV cascade.

In 2016, 2.1 million [1.4 million - 2.6 million] children were estimated to be living with HIV globally², 88% of whom were living in sub-Saharan Africa. Around 50% of perinatally infected children die within the first two years of life if not started on treatment³. In 2016, only 43% [36%-54%] of all children living with HIV were accessing antiretroviral treatment⁴. While the expansion of provision of mother-to-child transmission interventions has led to fewer infants being born with HIV, many children continue to go undiagnosed and only 43% [37%-54%] of HIV-exposed infants are tested by the recommended age of two months⁵.

Critical barriers to scaling up paediatric HIV treatment and care remain, including the complexity of existing approaches to testing and treating children, lack of age-appropriate formulations to provide the most effective and tolerable drugs, and lingering difficulties around decentralizing and integrating HIV services into the broader maternal, child and reproductive health platforms. Innovative testing, treatment and service delivery strategies are needed to simplify and expand paediatric services, but evidence to support this is currently lacking.

New and better data are required to accelerate the introduction of innovations, overcome existing implementation challenges, and inform the development of normative guidance that will set the standard of care for children around the world. To overcome these barriers and challenges in a context of increasing funding constraints, efforts must be focused on generating targeted evidence that improves HIV programme implementation through a better understanding of what works for infants and children.

The World Health Organization (WHO) and the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) of the International AIDS Society (IAS) have undertaken a global research prioritization process. Through broad engagement with stakeholders, a global research agenda has been established, which is aimed at guiding research efforts and maximizing available resources. The agenda is comprised of priority research themes in the areas of testing, treatment, and service delivery for informing global policy change, and improving outcomes for infants and children living with and affected by HIV.



Efforts must be focused on generating targeted evidence that improves HIV programme implementation through a better understanding of what works for infants and children.

WHO/CIPHER 2017/32



Outline



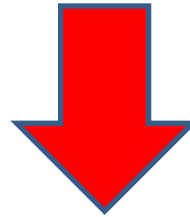
- Rationale
- Objective
- Methods
- Process
- Results



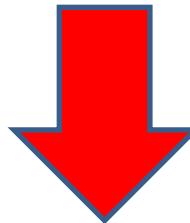
Rationale



Challenges persist to scale up timely HIV testing, treatment and quality care for children and adolescents worldwide



Evidence-based policy



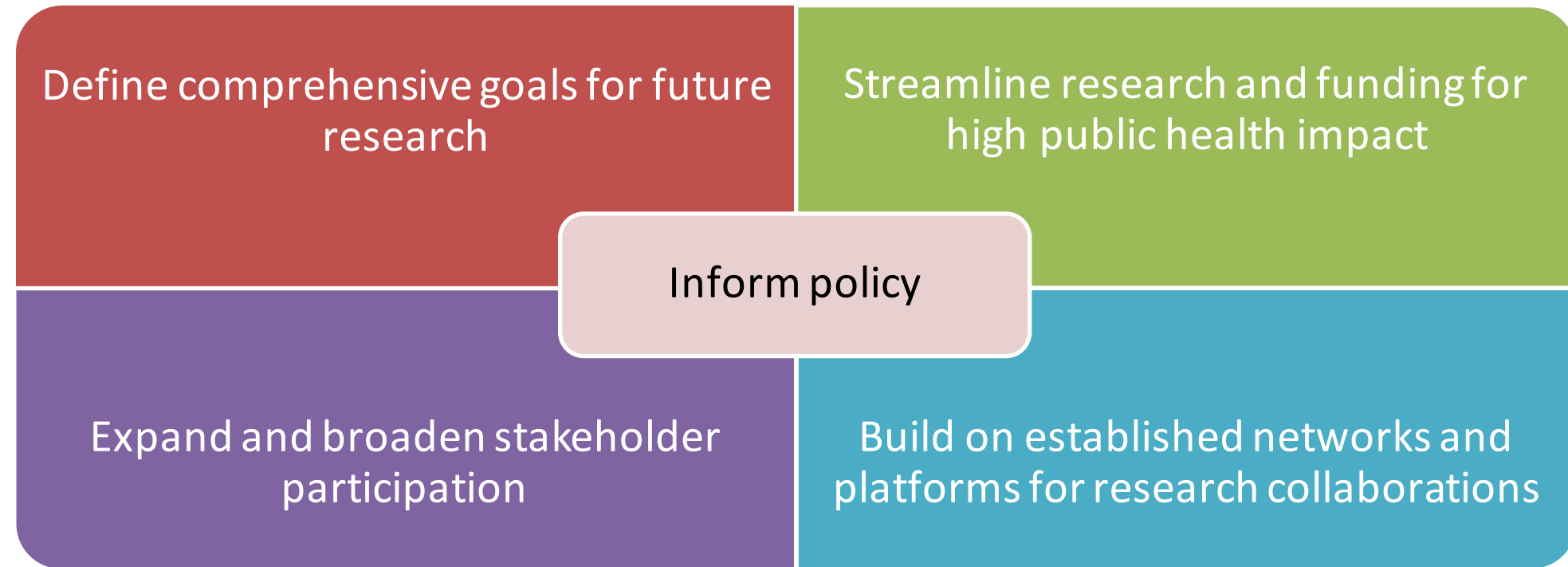
Reaching ambitious targets to reach AIDS FREE generation by 2030



Rationale



Challenges persist to scale up timely HIV testing, treatment and quality care for children and adolescents worldwide



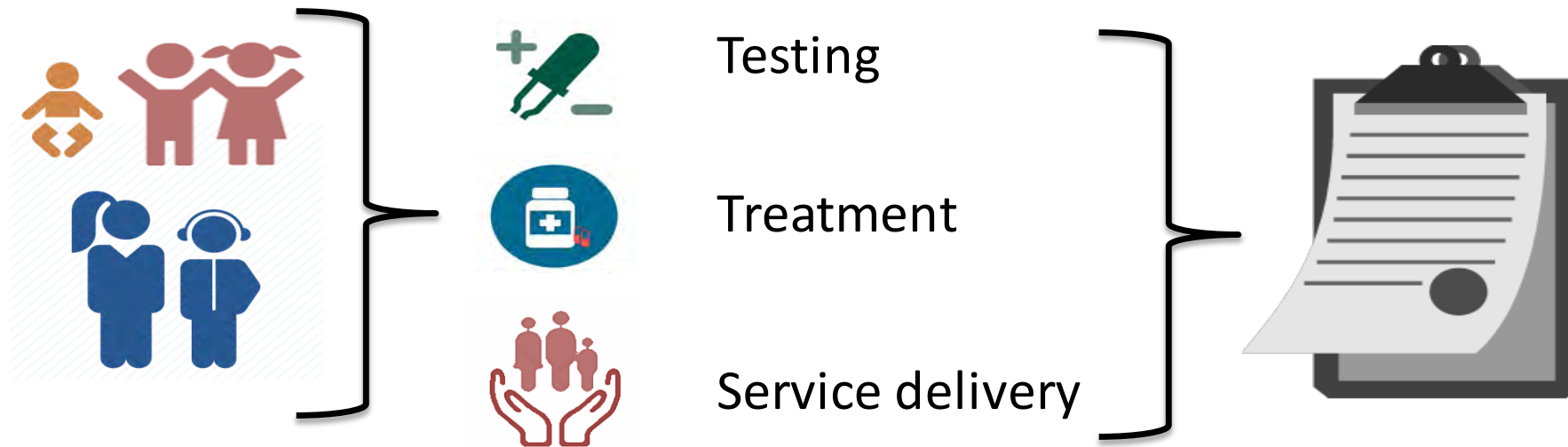
Reaching ambitious targets to reach AIDS FREE generation by 2030



Objective



Develop a prioritized global research agenda for **children and adolescents** living with HIV



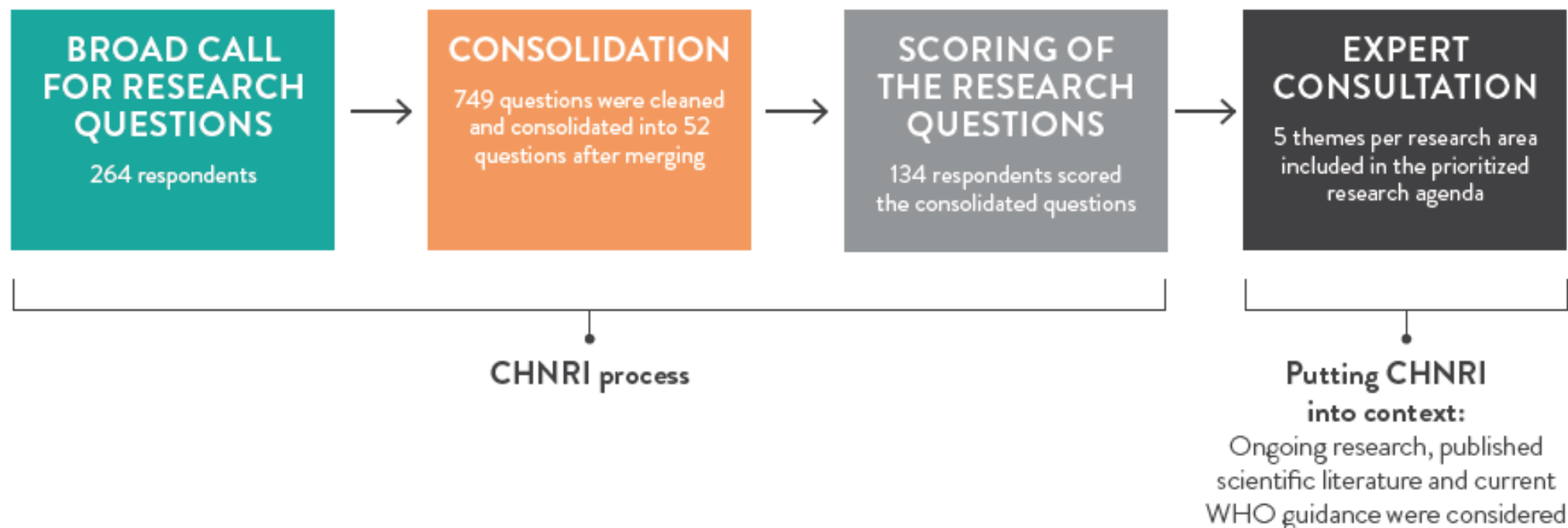
Intended audience: ALL STAKEHOLDERS (Funders, researchers, programmers, policy makers, community)



Methods



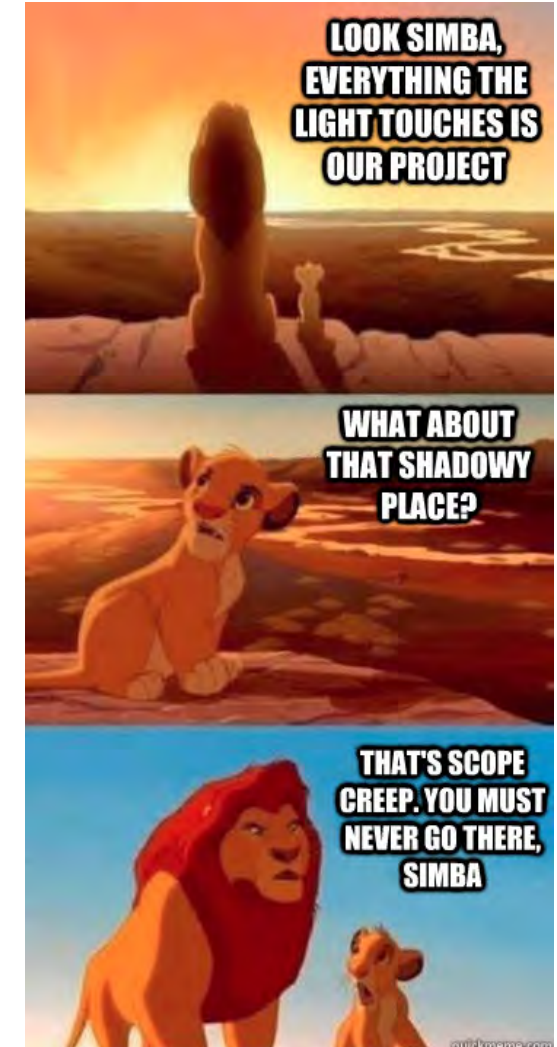
- Child Health and Nutrition Research Initiative (CHNRI, www.chnri.org) systematic method for setting priorities in health research
- Adopted by numerous WHO processes, especially in MCAH





Phase 1: Definition of scope

- In consultation with expert working group
- Testing, treatment and service delivery (and HEU for paediatrics)
- Excluded: prevention
- Timeframe for implementation: current – 2030
- Inclusion of clinical and implementation research







Phase 2: Call for research questions



- **Survey 1:** Stakeholders asked to submit priority research questions and ongoing research
 - CIPHER network, IAS membership lists, call for submissions on WHO and IAS website, working group networks, snowballing encouraged

Survey 1	No.
Adolescent HIV only	106
Paediatric HIV only	52
Both populations	217 (58%)

Share your view: research priorities for paediatric and adolescent HIV

13 September 2016 – The World Health Organization (WHO) and the International AIDS Society's Collaborative Initiative for Paediatric HIV Education and Research are developing a prioritized research agenda on HIV services for children and adolescents.



WHO

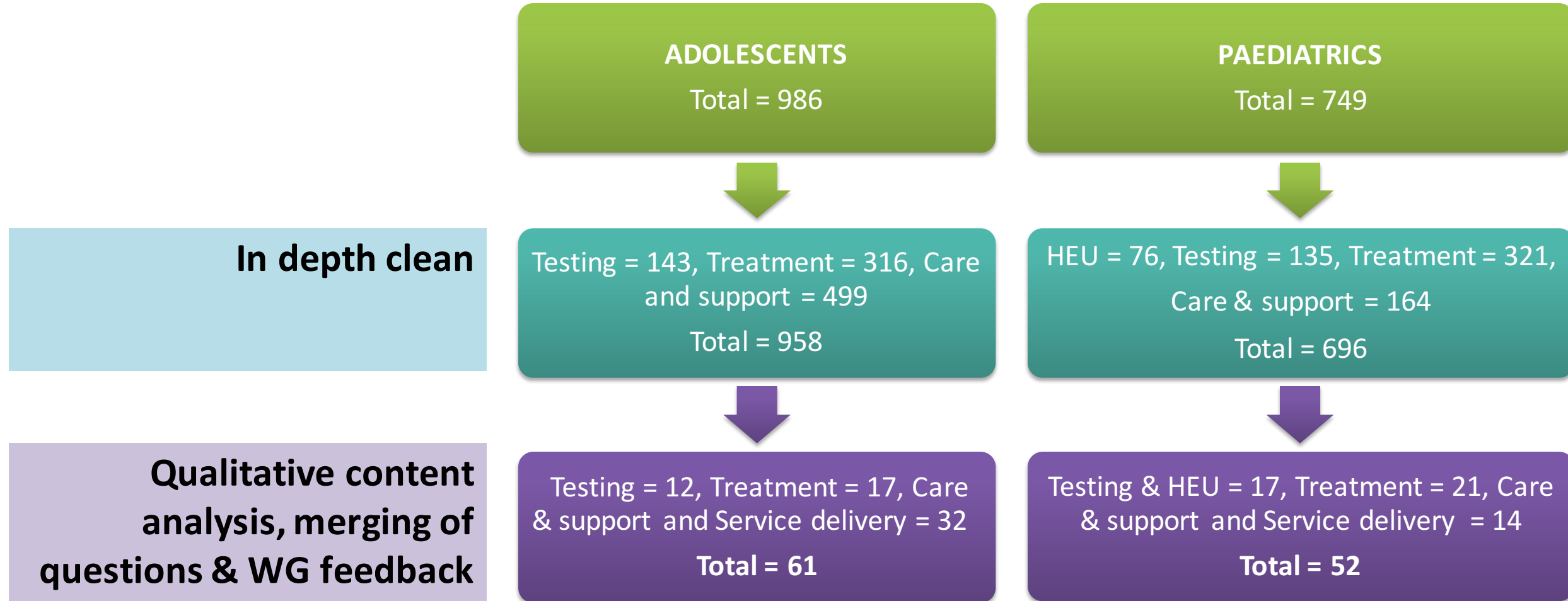


Phase 3:

Analysis and consolidation



World Health
Organization





Phase 4:

Prioritization of research questions (Survey 2)



World Health
Organization



Numbers per research area

Population	Testing (+HEU)	Treatment	Service delivery
Children	83	66	62
Adolescents	66	75	107

n=181/375; 48%
response rate

Numbers per role of respondents



All CHNRI ranked questions available at
www.iasociety.org/CIPHER



Phase 5: Putting in context





Phase 5:

Research questions in context



Expert
consultation

- Virtual **expert consultation** to complement the CHNRI process and ensure that the prioritized questions are relevant in the **current research context**.

Context considerations:

- WHO existing recommendations
- Existing evidence from systematic reviews
- Upcoming and ongoing research
- Recently published literature (from June 2015)



Results



Top 5
themes
for HIV
testing

Top 5
themes
for
treatment

Top 5
themes
for service
delivery



HIV TESTING



Top 5: HIV Testing Children



POTC Optimal **placement and timing of novel diagnostic tools** for point-of-care use



Interventions to ensure **timely linkage** between HIV diagnosis, treatment and care



Interventions or strategies to improve **access and uptake** of HIV testing for infants and children, particularly community-based approaches



Factors that **enable or hinder linkage** to care and timely initiation of ART



Effective, feasible and acceptable testing strategies (including routine testing at birth) at **entry points** other than antenatal care (ANC) for identifying undiagnosed HIV-positive infants and children in different epidemic settings



Top 5: HIV Testing Adolescents



Strategies and interventions to improve **access and uptake** of HIV testing and factors that impact success



Strategies and interventions to improve **linkage** of newly diagnosed adolescents to HIV treatment and factors that affect success



Safe and acceptable strategies or interventions to improve **access and uptake** of HIV testing services for adolescents from **key populations**



Consent policies and practices to facilitate access and uptake of HIV testing services in adolescents



Safety, acceptability, feasibility and effectiveness of **self-testing**

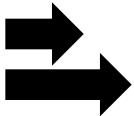


HIV TREATMENT



Top 5: Treatment Children



-  Safety, efficacy, acceptability, pharmacokinetics and optimal dosing of **existing and new antiretroviral drugs and formulations**, particularly with novel drug delivery systems
-  Strategies or interventions to improve **adherence** and factors that affect success
-  Optimal prevention and clinical management of **co-infections**, particularly tuberculosis
-  Impact of HIV infection and ART on **short- and long-term outcomes**, in particular non-communicable disease
-  Short- and long-term virologic and immunologic outcomes of **starting very early treatment** in infants living with HIV (impact on functional cure)



Top 5: Treatment Adolescents



Effective monitoring approaches and strategies to improve **adherence** among adolescents and factors that impact success



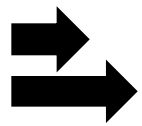
Safety, efficacy and acceptability of **novel drug delivery systems**



Prevention and clinical management of **co-infections**, particularly tuberculosis



Optimal **sequencing of ART** in adolescents



Impact of HIV infection and ART on **short- and long-term outcomes** in particular non-communicable diseases



SERVICE DELIVERY



Top 5: Service delivery Children



Strategies or interventions to improve **access, uptake and retention** in care and factors that impact their success



Service delivery models to improve individual and programmatic outcomes along the HIV cascade, including integration of comprehensive HIV treatment and care into the MCH platform



Psychosocial and family support strategies or interventions to improve individual and programmatic outcomes



Strategies or interventions to improve and support parents, caregivers and health care providers to facilitate **HIV disclosure** to children as well as factors that impact success



Strategies or interventions to reduce **stigma and discrimination** experienced by children and their caregivers



Top 5: Service delivery

Adolescents



Interventions to improve **retention** in care and factors that affect their success



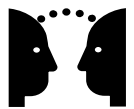
Strategies or interventions to improve **sexual and reproductive health outcomes** in adolescents living with HIV



Strategies or interventions to **support pregnant adolescents** living with HIV and improve maternal and child health outcomes



Service delivery models to improve outcomes along the HIV cascade, including peer interventions and differentiated service delivery models



Psychosocial support strategies or interventions to improve individual and programmatic outcomes

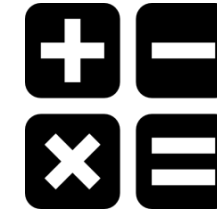


Key considerations



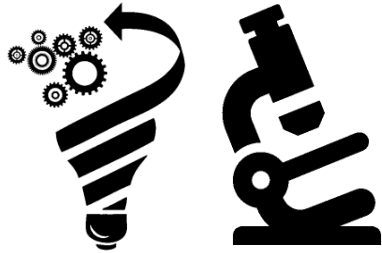
Participation of key stakeholders

Overcoming
consent barriers



Modelling to optimize
data and bridge gaps

Innovative
trial designs



Key
considerations



Strengthen
national M&E to
obtain
disaggregated
data

Observational
& big data



Age disaggregation



Better programmatic
data



Call to action



**WE ALL HAVE A
ROLE!**



Acknowledgements



Project team

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WHO staff

Shaffiq Essajee
Rachel Baggaley
David Ross
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Lara Vojnov

Working group

Rohan Hazra
Laura Guay
Elaine Abrams
Aditi Sharma
Angela Mushavi
Lucie Cluver
Annette Sohn
Carlo Oliveras
Georgina Caswell
Jane Ferguson
Dorothy Mbori-Ngacha

Resource group

Lynne Mofenson
Chewe Luo
Diana Gibb
Pim Brouwers
Valeriane Leroy
Thanyawee Puthanakit
Lucy Wanjiku
Nicola Willis
Jason Nagata
Mo Archary
Sabrina Bakeera-Kitaka



SURVEY 1 & 2 RESPONDENTS



11/9/2017

ENGAGING WITH MINISTRIES OF HEALTH ON IMPLEMENTATION SCIENCE RESEARCH

Anjuli Wagner, MPH, PhD
University of Washington

Reasons why engagement is mutually beneficial

- ◆ Reasons why engagement is mutually beneficial
- ◆ Researchers test interventions that could be scaled
 - ◆ Appropriate staffing & level
 - ◆ Intervention in line with priorities and policies
- ◆ Scientific inference is appropriate
 - ◆ Especially important in absence of parallel control
 - ◆ Changing background and landscape
- ◆ Build enthusiasm and buy-in for scaling effective interventions



How can researchers go about engaging?

- ◆ Engage across the lifecycle of a project
 - ◆ Planning, implementation, post-results dissemination
- ◆ Engage with wide range of MOH
 - ◆ National, county, in-charges, front line health care workers
- ◆ Long term investments in partnerships
 - ◆ Building capacity with MOH to interpret, design, and collaborate on operations research and IS through long-term training programs
 - ◆ Fund attachments of scientists to MOH posts

