

# Setting the research agenda. involving women living with HIV in research on children born HIV-free in the UK

Laurette L. Bukasa<sup>1\*</sup>, Angelina Namiba<sup>2\*</sup>, Matilda Brown<sup>2</sup>, Estelle Ndu'ngu<sup>2</sup>, Mercy Nangwale<sup>2</sup>, Gillian Letting<sup>2</sup>, Patricia Chirwa<sup>2</sup>, Claire Thorne<sup>1</sup>, Shema Tariq<sup>3,4</sup>

<sup>1</sup> UCL Great Ormond Street Institute of Child Health, London, United Kingdom  
<sup>2</sup> 4M Network of Mentor Mothers, London, United Kingdom  
<sup>3</sup> UCL Institute for Global Health, London United Kingdom  
<sup>4</sup> Mortimer Market Centre, Central and North West London NHS Foundation Trust, London, United Kingdom



## INTRODUCTION

- The **research agenda for children born HIV-free** (commonly referred to as children who are HIV-exposed and uninfected, CHEU) has **mostly been determined by researchers**, funders and policy makers **with little involvement from parents living with HIV**
- We sought to **engage mothers living with HIV to elicit their feedback on research plans** utilising population-level data on pregnancy, birth and long-term outcomes of their children

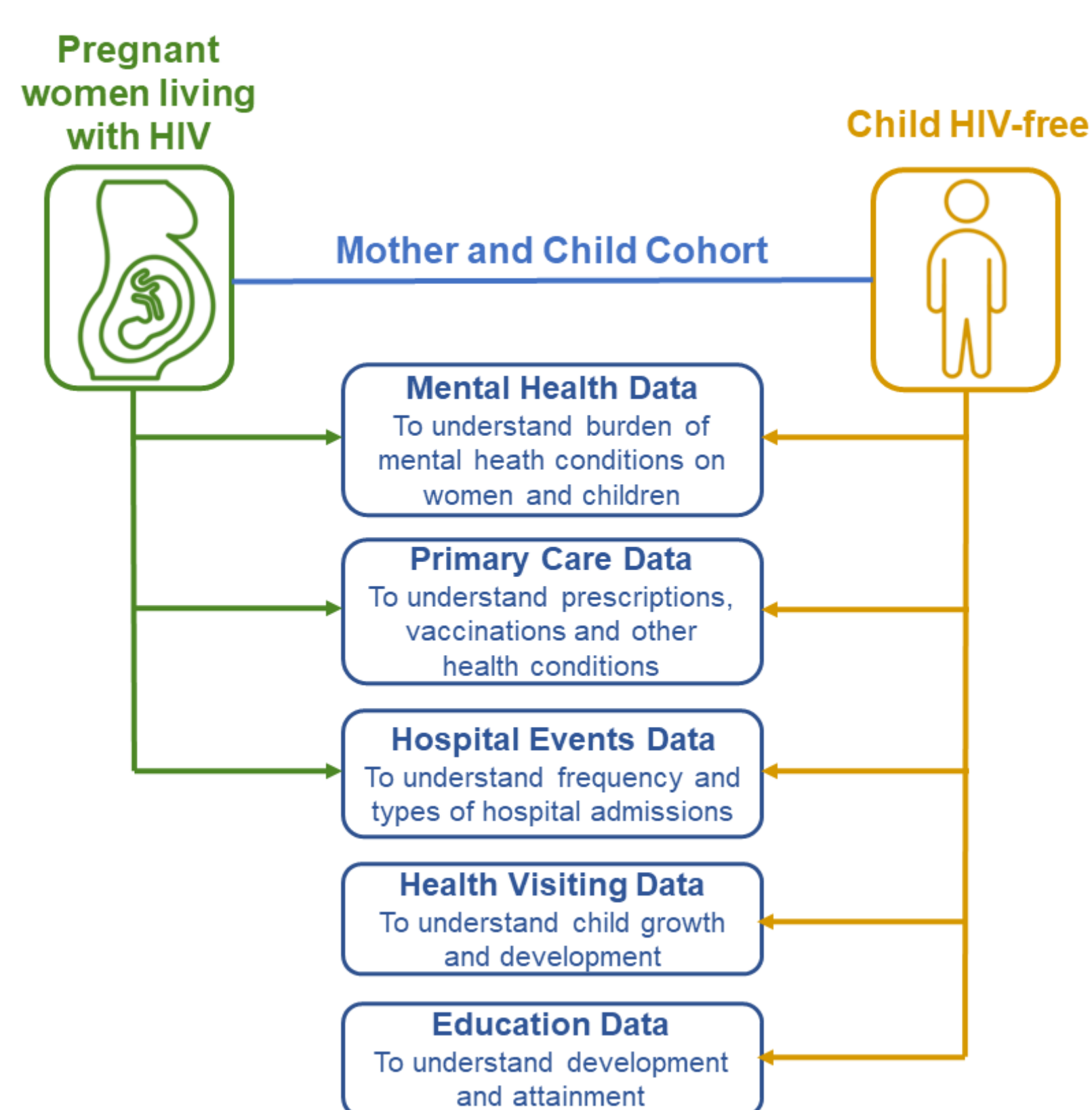
## METHODS

- In **partnership with 4M Net**, a national community-based peer-support network for mothers living with HIV, we co-designed and held **two online workshops in March 2022**
- **Workshops were supported by a supplementary booklet** which participants received prior to the workshops that comprised questions, activities and space for reflections
- Participants were **also prompted to discuss research priorities with peers and/or family members**

## RESULTS

### Reflections on research in the UK

Figure 1: Schematic for data linkage



- Women were concerned about **potential adverse effects of antiretroviral drug exposure** during pregnancy
- They recommended the team look at a **wide range of outcomes**, beyond severe outcomes, e.g., dental conditions (Fig. 1)
- Investigating the **health effects/benefits of breastfeeding** were also deemed a priority

**“For a healthy pregnancy, birth and child, a woman must be physically and mentally well.”**

— Mothers favoured a woman and pregnancy-first approach to research

### Language and terminology

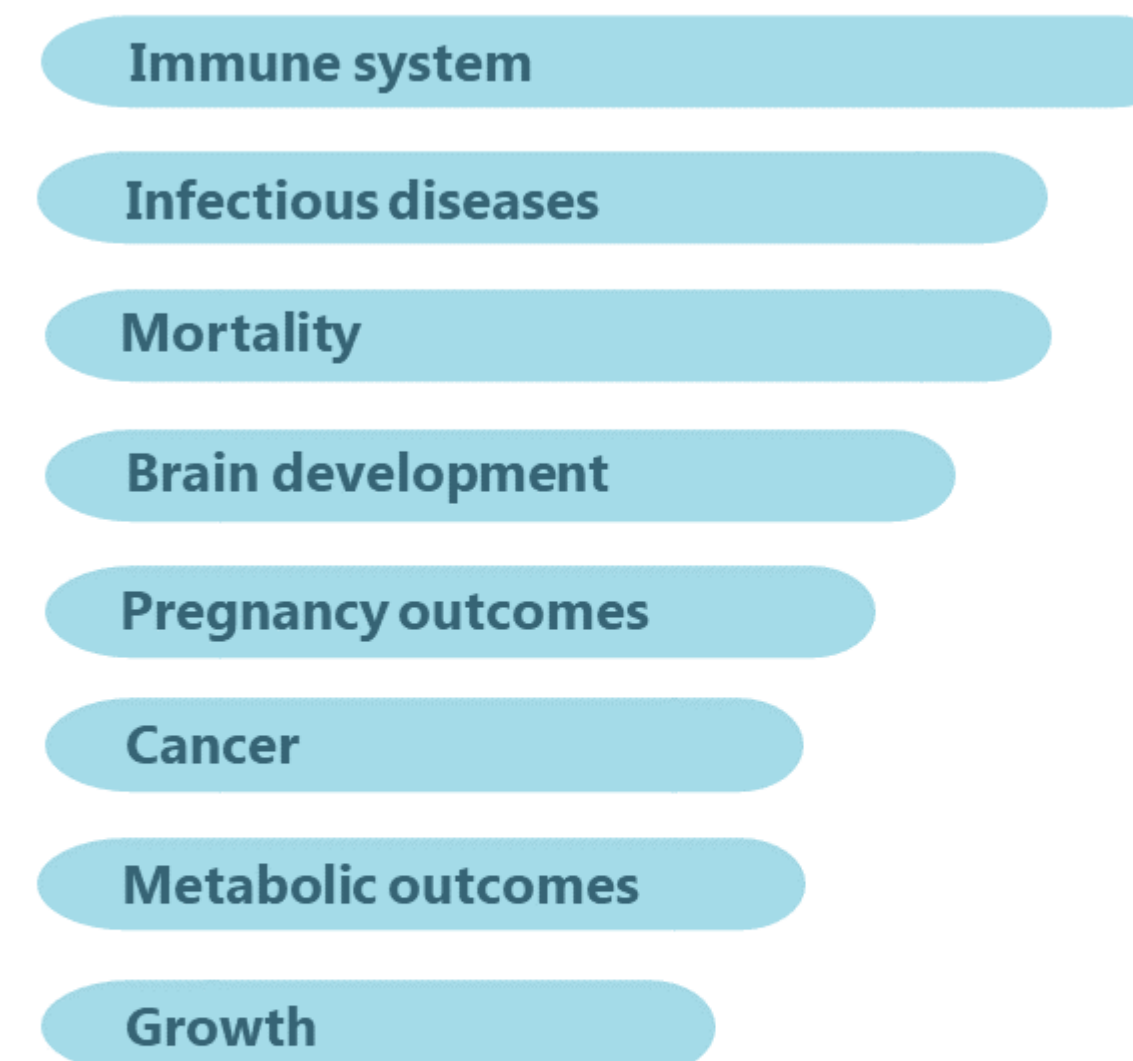
- Terms such as **“uninfected”** were seen as **clinical and stigmatising**, and acronyms such as **“CHEU”** (child who is HIV-exposed but uninfected) were **considered dehumanising**
- **Women preferred “child born HIV-free”**

## CONCLUSIONS

Women have an appetite for this research and it is important to work with partner organisation embedded in the community to ensure their perspectives are centred. They have invaluable insights into their children’s health often as primary caregivers, and could be instrumental in engaging wider affected communities, including families, peers and children born HIV-free themselves.

## The research agenda

Figure 2: The research agenda determined by mothers



- Understanding the **burden of infectious diseases** and possible **links to immune system development** were a priority for mothers (Fig. 2)
- Mothers were also interested in research on **metabolic outcomes**, as they had observed weight-related issues in their cohort

## Thoughts from the affected communities

- Participants approached individuals affected by HIV in their wider network to get their opinion on research on children born HIV-free

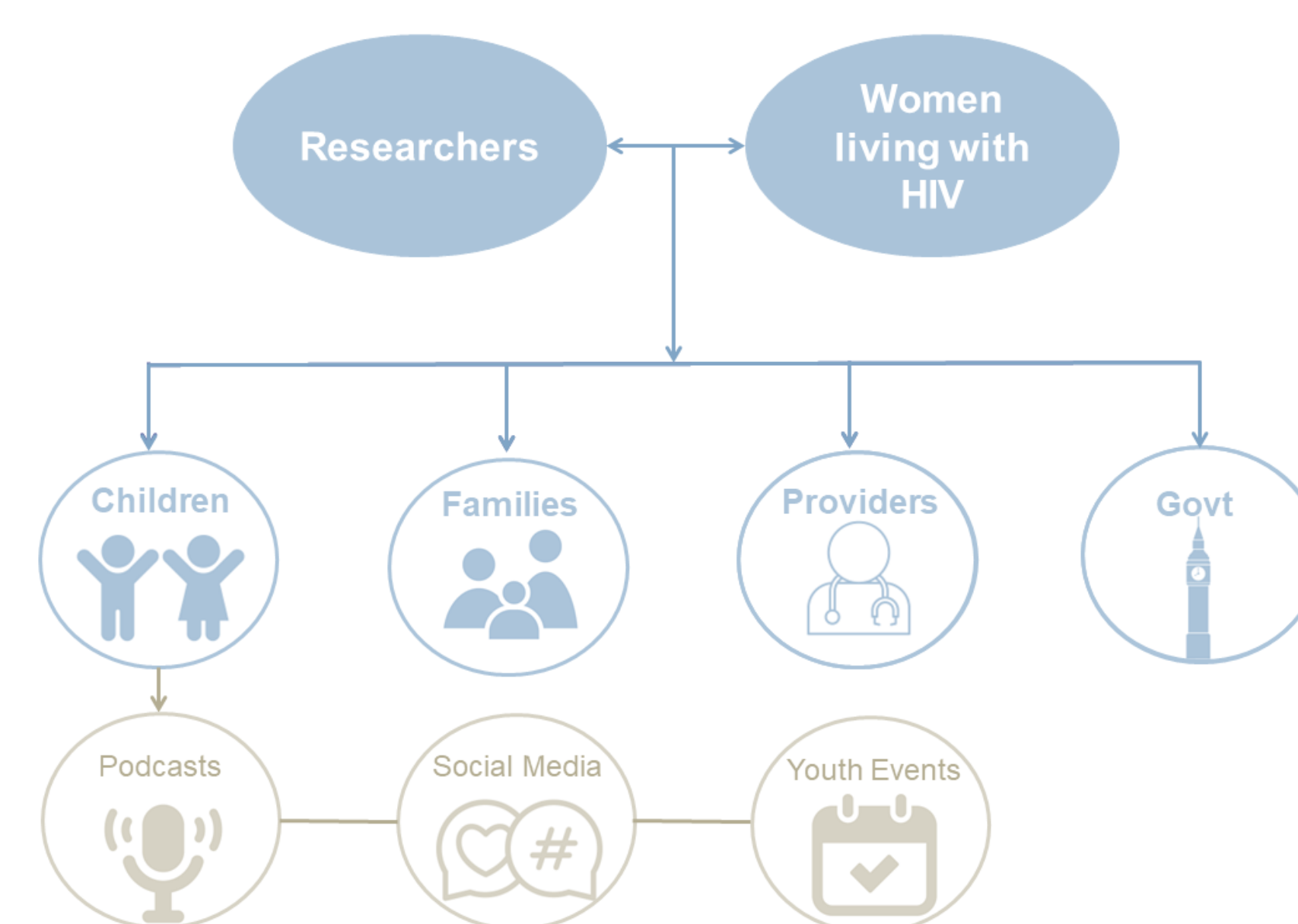
Other mothers	Family members	Children
<ul style="list-style-type: none"> <li>• Concerns about <b>lack of follow-up</b></li> <li>• Experiences of bullying and stigma</li> <li>• <b>Discrimination or stigma directed towards children</b> born HIV-free by healthcare providers</li> <li>• No concerns</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Mental health</b> of children, more prone to develop conditions, <b>developmental delay</b>, behavioural problems</li> <li>• Concerns about <b>immunity</b> at the beginning of their lives</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Don't consider themselves as born HIV-free</b> but could be affected by factors that affect children with HIV</li> <li>• <b>Afraid of being bullied</b> if people find out mother is living with HIV</li> </ul>

**“I’m just like any other kid, there’s nothing wrong with me.”**

— Child born HIV-free when discussing research on possible health inequalities

## Maximising research impact

Figure 3: Dissemination and communication strategy



- **Women should be involved in communicating research findings** and identified a number of key stakeholders (Fig. 3)
- **Children should be made aware of research** with efforts made to **tailor communications**

## FUTURE WORK

Findings from this project has informed the objectives of current and future research. Future plans will involve women and families.