CHAMPS

Child Health and Mortality Prevention Surveillance

Navigating Informed Consent in Child Health and Mortality Prevention Surveillance Involving Minimally Invasive Tissue Sampling (MITS): The Kenyan Experience

White Paper April, 2026

Peter Otieno, Peter Nyamthimba

Summary

The Child Health and Mortality Prevention Surveillance (CHAMPS) is a program of The Taskforce for Global Health with its Program Office in the United States, and supported by the Gates Foundation. CHAMPS is designed to generate accurate, timely data on the leading causes of death in children under five years and stillbirths, particularly in high-mortality settings. Its goal is to inform and improve child health programs and policies by filling the gap in reliable cause-of-death data. The data supports targeted interventions, better resource allocation and stronger health systems.

CHAMPS surveillance sites are located in sub-Saharan Africa: Kenya, Mozambique, Ethiopia, South Africa, Sierra Leone, Nigeria, and South Asia: Bangladesh, Pakistan. These sites represent regions with some of the highest rates of child mortality. In Kenya, CHAMPS operates in Siaya (Karemo) and Kisumu Counties (Manyatta) and is being implemented by the Kenya Medical Research Institute (KEMRI) and the Liverpool School of Tropical Medicine, in close collaboration with the departments of health for the two counties.

The Kisumu CHAMPS site, Manyatta, is a peri-urban area located on the eastern side of Kisumu, Kenya's third largest city. The settlement is characterized by informal, semi-permanent rental housing, primarily inhabited by individuals who migrated from rural areas in search of economic opportunities. Many residents culturally do not consider the rented houses in Manyatta to be their primary homes. Rather, "home" typically refers to their ancestral villages where their parents or extended families still live. For this group of people, if a family member dies in town, they are more likely to transport the body to their village home for burial. However, Manyatta also includes some landowners who have built homes in the area. Despite discouragement by urban authorities, it remains common for some residents to bury their loved ones within their home compounds. The Manyatta population is ethnically diverse, though the majority are of Luo ethnic origin. Christianity is the dominant religion, followed by smaller communities of Muslims and believers of African traditional religion.

The Karemo site in Siaya is located approximately 70 kilometers from Kisumu town. It is more rural and expansive than Manyatta, and with a larger population. The majority of the residents belong to the Luo ethnic group. Unlike in Manyatta, the majority of people in Karemo live in their own homes and practice subsistence agriculture on family land. Rented housing is also common mainly in the local markets or trading centers. Christianity is the predominant religion in the area, but there are also small communities of Muslims, as well as followers of the African traditional belief system.
CHAMPS implementation follows a structured pathway that begins with community engagement and a death notification system that identifies stillbirths and under five deaths. Once a death notification is received, parental consent is sought. Following consent, samples are collected from the child's body using the MITS procedure. The collected samples are then analyzed and presented before a cause-of-death expert panel to determine a cause of death. Finally, the program emphasizes results delivery to families and using the data to inform public health interventions aimed at preventing future child deaths.

The CHAMPS program places a strong ethical emphasis on obtaining voluntary informed consent from bereaved families before postmortem investigations can begin. This aligns well with KEMRI's regulations and guidelines on ethical health research practices. Since CHAMPS engages with communities that have long been involved in KEMRI research activities, the concept of providing consent is already familiar to sections of the population.

> *"With compassionate consent, CHAMPS turns loss into evidence that strengthens health systems, guides policy, and helps prevent future child deaths."*

01 The death notification process

The Kenyan site has put in place a robust death notification system for both health facility and home/community deaths through continuous and extensive community mobilization and sensitization. This system involves healthcare workers, morgue attendants, cleaners and security guards in the various wards, community health promoters, local chiefs, motorbike taxi drivers, KEMRI field personnel, and all community members including relatives or household members of the bereaved families. To ensure timely reporting, mobile phone numbers of the CHAMPS mortality surveillance team have been shared widely across the community, health facilities, and morgues within the catchment area. Anyone who learns of a child's death, including family members, is encouraged to notify the team via a phone call or a text message.

02 Twenty-four-hour Death Notification and Rapid Response System

Notifications of deaths can be received from either the community or health facilities anytime- day or night, including weekends and public holidays. To ensure that all notified cases are responded to, and promptly screened for eligibility, the site surveillance team has to be on call 24 hours. If a death notification is received during the night, the team initiates the consent process early the following morning. This entails asking a few eligibility screening questions about age, location, time of death etc. If the case qualifies, the team arranges to meet the family, parents or next of kin- usually at their home (community death) or hospital (health facility death), although other locations may also be suggested for the consenting process. To enable swift and efficient response, some members of the surveillance team are equipped with motorbikes for field operations.

03 Complexities in the Consenting Process

The location where consent is sought— whether in a hospital or community (typically at home)— can present distinct challenges. Several nuanced factors influence the process and outcome, including:

- Who is Present: the availability of key family members or decision makers at the time of approach. If the key decision makers are away, the consenting process may take a long time because their opinions have to be sought.
- Age of the parents: younger parents may require additional emotional support from relatives or close friends during the process. While this support can provide comfort during grief, it does not diminish their autonomy, as the final decision must remain theirs alone.

- Inherent dependencies: emotional, financial, or social dependence within the family can affect decision-making. In our experience, relatives with higher socioeconomic status often hold considerable influence in decision making. There have been instances where the engagement process proceeded smoothly and consent was obtained, only for a relative to later intervene and persuade the parents to withdraw their consent. On the other hand, when a relative is supportive of KEMRI and CHAMPS activities, they can add a positive voice to the discussion, helping to dispel misconceptions. This supports informed family deliberations while respecting individual autonomy in final decision-making. For married couples, we ensure that both parents are involved in the decision-making process.
- Circumstances of the child's death: the nature and timing of the death- whether sudden, expected, or prolonged, can deeply impact the family's readiness to engage.

04 Community Based Consenting: Navigating Social Dynamics and Sensitivities

Conducting the consenting process within a home or community setting often presents unique challenges, particularly due to the presence of groups of people who come to condole with the bereaved family. These gatherings typically consist of a blend of people, some of whom are familiar with CHAMPS and others who have never heard of the program. In these kinds of scenarios, the CHAMPS staff must first introduce themselves to the group and begin with an education session which involves, explaining the reason for their coming and giving a broad overview of the CHAMPS program and addressing questions or concerns. This initial engagement sometimes results in longer conversations or critiques, particularly from community members who, for whatever reason, want to voice their support or frustrations over what they perceive as past shortcomings by KEMRI. However, engaging with the wider group during such moments is crucial. Individuals present when CHAMPS staff visits may become sources of misinformation if they do not fully understand the aim of CHAMPS. In the past, some bereaved families have faced accusations from community members, claiming that they had traded their child's body to CHAMPS for financial gain.

While addressing the group, the CHAMPS staff also quietly observe the emotional and psychological state of the parents to assess whether they can engage in a consent conversation. If the death has just occurred, emotions may still be raw. Sometimes the atmosphere is filled with loud wailing and various expressions of deep sorrow. These are profoundly emotional and painful moments. Approaching the family with information about MITS at such a moment can be delicate and complex. It takes great care, timing, empathy and cultural sensitivity to avoid appearing intrusive or disrespectful during their grieving. The consenting team has received training in grief counseling to help them manage such situations. When the right moment presents itself, the staff member asks to talk with the parents or a designated relative. In this closer setting, the contents of the consent form are read and questions addressed. Sometimes, the parents can independently make the decision to consent or decline participation. In other cases, they can choose to consult other family members who are present or even those at a distance through phone calls, to seek guidance and support. While such input can be valuable, the authority to consent or decline participation ultimately rests with the bereaved parent(s) or caregiver(s) present, whose autonomy in decision-making must be upheld. For example, a death may occur in Manyatta while a senior or trusted family member, often expected to be present during family discussions related to consent, is in Nairobi. When senior or trusted family members are not physically present, the CHAMPS staff must place a phone call— often on loudspeaker— so that the bereaved family can be part of the discussion. Usually, these senior or trusted family members are the parents to the bereaved couple, elder siblings, or other respected figures such as religious leaders.

Regardless of who is involved, the study staff responsible for obtaining consent must carefully balance the importance of research participation with the sensitivity to the family's emotional needs and respect for the grieving process. They ensure that the bereaved family and more so the individual providing final consent is given ample time to understand the risks and benefits, and to reflect on the request without feeling pressured.

05 Consenting for MITS at the Health Facility

When the death occurs in a health facility, the notification may be received while the body of the child is still in the ward or already in the mortuary. Close family members and neighbours will still come to view the body. However, in an institutional setting, interactions usually involve smaller, controlled groups. This can help manage the flow of information and reduce the risk of misunderstandings, but it also takes careful planning to ensure that key family voices are heard and respected. If the body has been moved to the morgue, an urgent action is to alert the mortuary attendants to hold off on preservation because the body qualifies for CHAMPS, and consent for MITS is being sought. Although the morgue attendants have been made generally aware of CHAMPS procedures, this is a necessary step of caution to ensure that the body remains in a suitable condition before the MITS procedure. The next step is to locate the child's parents or primary guardians. In some cases, the notification is received while the family is still present at the hospital, which makes the process more straightforward. However, if the family has already left the facility, it requires CHAMPS staff to follow up with them at their place of residence. In cases of stillbirths or neonatal deaths, the mother may remain hospitalized and too weak to engage in the consenting process. In such situations, CHAMPS staff often have to look for the father/partner, if available. This can sometimes delay the start of the consenting process.

As with community-based consenting, health facility consenting may also come with the additional challenge of needing to consult senior or trusted family member who may not be physically present. This may necessitate phone calls and extra work to bring them into the conversation before any agreement is reached with the parents or caregivers present.

06 General Factors Influencing Consent for MITS

While the decision to consent for MITS is formally made by the bereaved parents or primary guardians, the decision is not as straightforward and often involves consultation beyond bereaved parents or primary guardians which includes extended family members, neighbors, religious leaders and community elders. In the course of our work, we have learned that a number of contextual and emotional factors can influence the outcome of the consent-seeking process. These factors include:

- Burial Timelines: In each case, the family and relatives set the timelines for funerals, often aligned with cultural or religious practices. Muslims are particularly very observant of burial timelines, often aiming to bury before sundown on the same day. Any delay caused by the MITS procedure can be a point of concern.
- Time between Death and MITS Procedure: Minimizing delays ensures that burial timelines are respected. The Kenya site has put in place mechanisms to ensure the MITS procedure can be done on the same day that the case is consented, allowing the child's body to be handed back to the family without delay. The introduction of the mobile MITS van has further streamlined the process. Families who might otherwise be concerned about transporting the body to a distant morgue are now more open to consenting, knowing that the MITS procedure can be performed closer to the place of death. This reassurance that the child's body will not need to be moved far from the home compound can inform decision-making around consenting.

- Availability of Results: Families are more willing to provide consent if they believe that the results will be shared in time to help them gain clarity or closure. We have learned that timely feedback is essential to maintain credibility and foster continued participation.
- Maternal History: The history of a mother, for instance, having previously lost a child, having experienced complicated pregnancies, or suffering from emotional distress, may influence her ability or willingness to consent to MITS.
- Nature of Illness: When a child's illness was sudden, severe or poorly understood, families may feel a stronger need to understand the cause of death, which may affect their openness to the MITS procedure. We observed that in situations where a mother feels that she is being blamed for the death of her child, whether linked to cultural beliefs about curses, perceived shortcomings in caregiving or suspicions of unfaithfulness, the desire for diagnostic clarity takes on added social significance. In such cases, MITS findings may be perceived as a means of providing objective explanations that can help address harmful assumptions and support social reconciliation within the family or community.
- The role of compensation in motivating research participation is debatable and can raise ethical concerns. At the Kenya CHAMPS site, however, compensation is intended to offset practical and financial burdens associated with participation rather than to incentivize consent. We observed that the compensation provided to participating families helps cover funeral expenses and enables them to take part in the program in a less burdensome way, especially for families who wish to bury their children in ancestral homes located far away, which often requires substantial resources. Overall, the compensation package functions as a form of logistical support during a period of acute vulnerability.

06 General Factors Influencing Consent for MITS

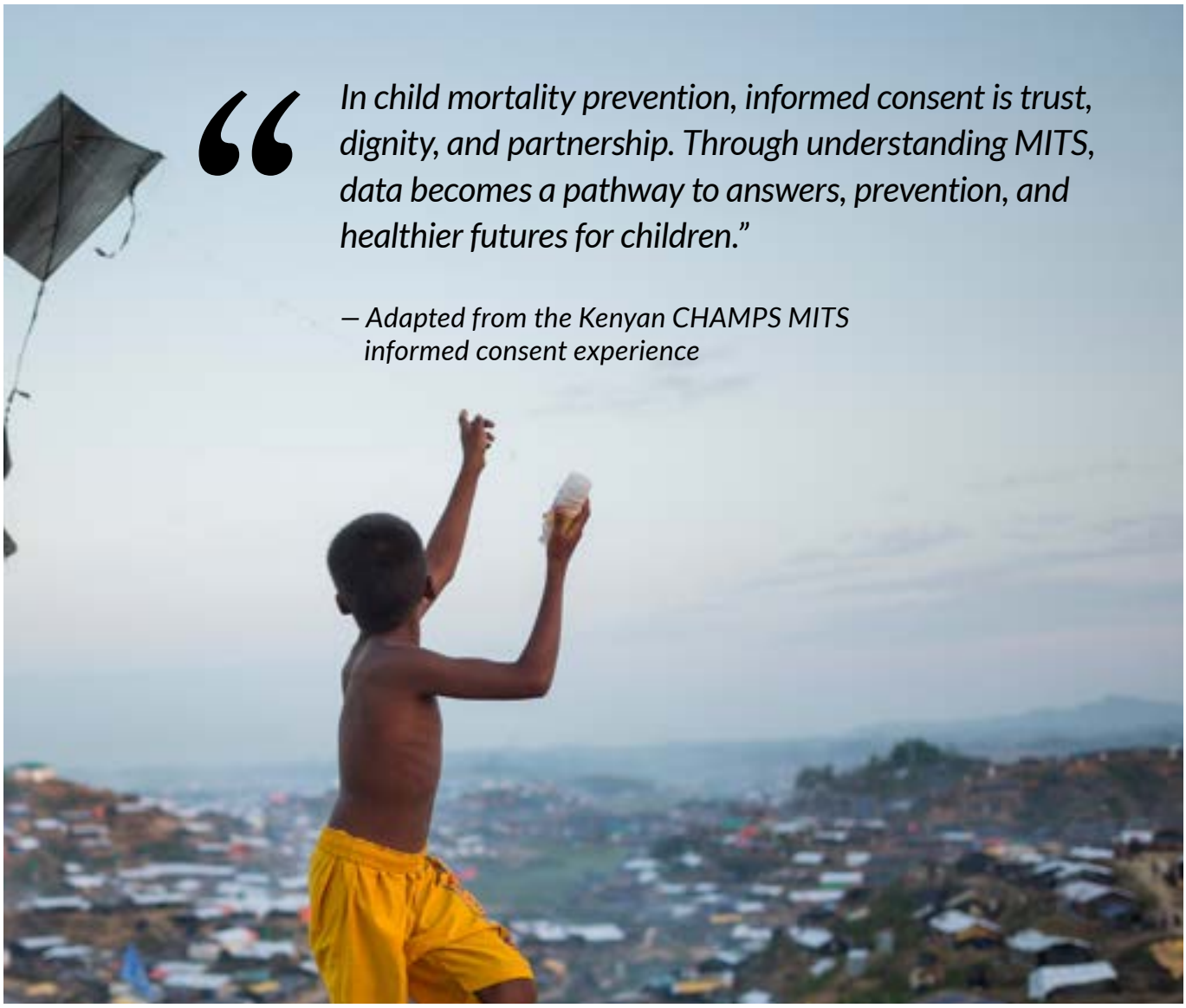
We have observed that the social bond formed between CHAMPS staff and bereaved families often endures well beyond the families' participation in CHAMPS. Many participants remember them as the team that approached them during their most painful moments, shared in their grief, and promised to help them understand the cause of their child's death. The trust and connections established during the consenting process have proven invaluable later, when challenges arise in following up with families to deliver results. Re-engaging families through the original consenting staff has been particularly effective in re-establishing contact. Moreover, when results are finally delivered, families often view this as a promise fulfilled, which further strengthens trust.

Beyond the official scope of work, members of the consenting team have reported being invited to family events and community gatherings such as "harambees" (fundraising). While accepting such invitations, the CHAMPS field staff maintain professional boundaries at all times, ensuring that their participation in community events is a gesture of respect and voluntary rather than an obligation, and that it does not present any potential conflict of interest. These gestures reflect the lasting trust and respect that families have for the CHAMPS team, highlighting the profound impact of compassionate engagement.

07 General Factors Influencing Consent for MITS

Finally, the trust and relationship built during the consenting process can be harnessed to support uptake of data-to-action (DtA) activities at the grassroots level. Community members who feel genuinely connected to CHAMPS through its staff are more likely to engage with follow-up interventions. The emotional bond and credibility established during grieving can become a powerful foundation for long-term engagement and community-driven change.

Overall, our experience is that the consenting process for MITS is complex and rarely follows a predictable path. It unfolds within a delicate atmosphere marked by grief, the pain of child loss and the fact that MITS is still not widely practiced or understood. Despite these challenges, the time-sensitive nature of MITS necessitates that the process continues, often in the midst of sorrow and grief. On some days, conversations flow more smoothly, even when consent is declined. On other days, the process can be prolonged and emotionally draining. What keeps the team going through these moments is their commitment to serving the community and their firm belief in the CHAMPS agenda that no child should die from preventable causes.



CHAMPS

Child Health and Mortality Prevention Surveillance (CHAMPS)

CHAMPS Health

@CHAMPS_Health

@CHAMPSHealth

Child Health And Mortality Prevention Surveillance

The CHAMPS network uses innovative approaches to generate and share knowledge that improves understanding and prevention of child mortality.

CHAMPS | A program of THE TASK FORCE FOR GLOBAL HEALTH