



NIHR Global Health Research Group
on Stillbirth Prevention and Management in Sub-Saharan Africa



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Foreword

The NIHR Global Health Research Group on Stillbirth Prevention and Management in Sub-Saharan Africa is the first programme of its kind aimed at reducing stillbirths, identifying best practices, and supporting bereaved families.

It is a challenging area of investigation, particularly because of the traditional taboos, myths and practices associated with stillbirth. However, it is also the most rewarding, as it has the potential to have great impact for all those affected. Therefore, we planned this research to explore stillbirth from several vantage points; uniquely we researched the best way to support women physically, psychologically, and socially.

Although this programme of research was multi-disciplinary, it was led by midwives, both in the UK and in Africa (Kenya, Malawi, Uganda, Tanzania, Zambia and Zimbabwe).

Midwives, as primary caregivers during childbirth, are best placed to identify and address important research questions related to stillbirth. Taking on this work has been an empowering experience, giving midwives the confidence to make a real difference to women and their babies in the future. It has also enabled capacity development across the various settings.

Working with communities through the Community Engagement and Involvement (CEI) groups was a real highlight of this work. It allowed those most affected by stillbirth to have their voices heard and help us frame our research and questions in culturally sensitive ways.

The CEI groups have been instrumental in ensuring we asked the right questions and answered them in the most appropriate way and for the biggest impact. There have been many examples of their important contribution, such as influencing questionnaire design, advising on recruitment strategies, contributing to dissemination activities, and informing policy.

For example, the CEI members from Zambia presented research findings to the Ministry of Health resulting in 'stillbirth' being tabled in parliament.

The research team has a shared vision to change the lives of women, babies, and families. Everyone involved can be so proud of the huge strides this work has made towards raising the profile of stillbirth across Africa, encouraging conversations and engagement with a topic that would often be viewed as taboo, and building the capacity for research in each country so that its legacy can continue long after the funding comes to an end.

I feel honoured to be part of this team.

The changes we have already started to see are paving the way for real improvements in care for all those affected by stillbirth, and on behalf of all those families, thank you.



Dame Tina Lavender, Professor of Maternal and Newborn Health and Director of the Centre for Childbirth, Women's and Newborn Health at Liverpool School of Tropical Medicine, UK

LAMRN – the Lugina Africa Midwives Research Network – is a unique partnership of midwives across Kenya, Malawi, Uganda, Tanzania, Zambia and Zimbabwe committed to transforming maternal and newborn health outcomes by increasing evidence-based practice in midwifery.

LAMRN has established an enduring collaboration with the UK team since 2012, together delivering successful research and capacity strengthening programmes involving more than 1,000 midwives.

Most importantly the work has made important strides towards raising the profile of stillbirth across Africa, encouraging conversations and engagement with a sensitive topic.

The LAMRN network comprises a unique group of midwives who have trained in research methods and evidence-based care, enabling them to carry out this important programme of work to prevent and manage stillbirths.

Although this programme of work was multi-disciplinary, it was developed, led and delivered by midwives.

The six countries have also actively engaged with parents who have experienced a stillbirth, ensuring that the right research questions are asked and answered in the most appropriate way.

Over the course of this four-year programme our team has disseminated research findings in order to help to raise the profile of stillbirth and improve care. We have done this in many ways – at a local level within hospitals and communities, at a country and regional level through events and conferences, and on a global scale through working groups.

Midwifery, nursing and medical schools are incorporating our findings and interventions into course curriculums, so we have influenced the training of nurses, midwives and doctors to give better care to women and families.

Across the network, we have attracted the attention of the media on a subject which was neglected and for which women were stigmatised. Through our work we have reached our communities, starting discussions and encouraging a change in behaviours.

Reflecting on the four years, I believe that midwives, as primary caregivers, are well placed to address important healthcare issues, and as Chair of LAMRN I want to thank everybody involved for their passion and commitment.



Professor of Nursing (Reproductive Health), Kamuzu College of Nursing, University of Malawi





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Introduction

NIHR Global Health Research Group on Stillbirth Prevention and Management in Sub-Saharan Africa

Of the 2 million stillbirths occurring every year, 98% happen in low and middle income countries (LMICs) with sub-Saharan Africa bearing an unacceptable burden of 64% of these deaths.

Despite modest progress in recent years, parents in Kenya, Malawi, Uganda, Tanzania, Zambia and Zimbabwe are still around eight times more likely than those living in high-income countries to experience the death of their baby through stillbirth. Every death is a tragedy, with profound and long-lasting health, social and economic costs, not only for parents and families, but also for wider society.

“Around the globe, one baby dies every 16 seconds before, during or soon after birth.”

It is recognised that most deaths could be prevented with access to high quality maternity and childbirth care. The UN Sustainable Development Goals (SDG) and Every Newborn Action Plan (ENAP) have set ambitious international targets for stillbirth reduction to less than 12 per 1,000 births for all countries by 2030. However, it is widely recognised that without increased momentum these targets will not be met in most countries in sub-Saharan Africa.

Beyond the numbers, too many women and families will also continue to suffer the grief and trauma of stillbirth. In many communities, baby death is not recognised as equivalent to other deaths, mourning is limited and stigma and isolation particularly impacts women.

The NIHR Global Health Research Group on Stillbirth Prevention and Management in Sub-Saharan Africa, established in 2017, is a unique midwife-led research partnership between the UK's Liverpool School of Tropical Medicine / University of Manchester (until 2020), and the Lugina Africa Midwives Research Network (LAMRN).

Our research has focused on addressing the critical lack of meaningful insights surrounding preventable stillbirths and providing appropriate support to bereaved parents in sub-Saharan Africa.

98%
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countries

Parents in sub-Saharan Africa are
8 times
more likely to
experience
a stillbirth



Our work

This research programme, involving 33 researchers working across six countries, addressed two main themes:

1. Stillbirth prevention

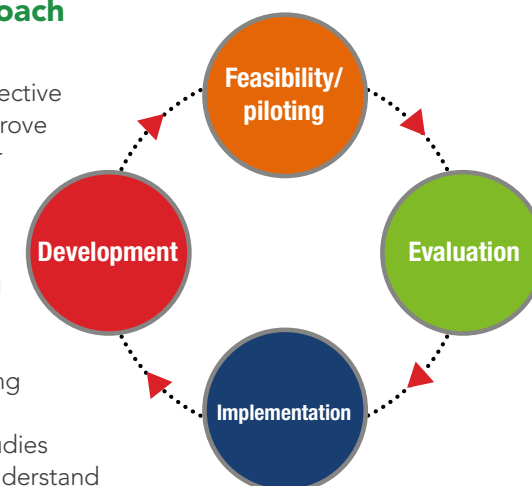
- a. Understanding the risks and associated factors of increasing stillbirth and improving care for women with risk factors in pregnancy.
- b. Exploring maternity and childbirth care to improve access, uptake and quality for all.

2. Developing bereavement care and support for parents

- a. Understanding the needs of parents and support for health workers to ensure appropriate support when a baby dies.

Research approach

We aim to develop sustainable, cost-effective interventions to improve maternity, and wider health care across sub-Saharan Africa. Our approach is systematic following a phased cycle of **development**, including synthesising existing evidence, undertaking new studies where needed to understand issues and context and co-developing solutions (interventions). **Feasibility** involves testing the research design and processes needed to test interventions, ensuring robustly designed large **evaluations** in clinical trials, which can demonstrate real world effectiveness. During the process we also gather data to understand how effective interventions might be scaled up and **implemented** as clinical practice in the future.



Research and Country Leads at the annual meeting of the Stillbirth Group in Uganda

Research themes

Theme 1 Stillbirth prevention

1. Better care for women at risk

Many stillbirths could be prevented using existing maternity and childbirth interventions and strategies. However, for the most effective use of resources it is crucial to be able to identify the women who would most benefit i.e. those who are at highest risk of having a stillbirth. This would allow health workers to target interventions, for example increased antenatal surveillance, induction of labour and caesarean section delivery for those women who will benefit. Minimising unnecessary intervention is also increasingly important, this consumes scarce resources for no benefit and is increasingly recognised as a cause of harm to women and babies in LMICs. Understanding of the medical, pregnancy, individual and social factors increasing the risk of stillbirth in sub-Saharan Africa is currently incomplete.

PHASE 1 DEVELOPMENT WORK

Identification of factors associated with stillbirth (cross-sectional cohort study, Zimbabwe)

Our prospective study of 1,779 postnatal women birthing in Mpilo Hospital, Bulawayo, demonstrated that stillbirth in the index pregnancy had a strong association with previous history of stillbirth, maternal medical complications and fewer than four antenatal visits. Women experiencing stillbirth tended also to have lower socio-economic status and less formal education.

Having a previous stillbirth increases the risk of recurrence

Embedding clinical audit of stillbirths: Malawi

The recently developed WHO audit tool was used to review the care provided to 478 women who experienced stillbirth at Bwaila District Hospital, Lilongwe and Queen Elizabeth Central Hospital Blantyre during July 2018 – Nov 2019. The audit cycle identified inconsistent performance in several important standards. These included antenatal assessment of baseline blood pressure and

haemoglobin, recording of blood pressure and urinalysis during labour and auscultation of fetal heart prior to caesarean section. Lack of consistent, contemporaneous record-keeping during admissions was also noted.

The subsequent action plan included mentorship, training, introduction of checklist/aide memoires and improving supply of equipment. Re-audit demonstrated improved performance across most standards and increased understanding, capabilities, and willingness amongst health workers to continue to audit.

Outcomes

- Having a previous stillbirth increases the risk of recurrence, therefore increasing antenatal monitoring and support for women with history of stillbirth is a potential strategy to reduce poor outcomes.
- Audit demonstrated that simple, low-cost changes can improve quality of maternity care. Taking part in the process developed local health workers' skills and audits are continuing in the included facilities as part of strategies to prevent stillbirth.



Research assistants Sikhululekile Mremi (left) and Grace Danda (right) organised the paperwork to collect data

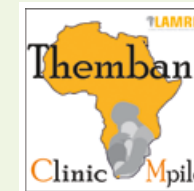
It has been a great experience following through the audit cycle in the stillbirth audit. [...] I love it when midwives call me 'checklist' or 'partograph' because I knew how familiar they are to the quality indicators we were pushing to achieve. Today, I am happy for the progress we have made so far in improving care for women giving birth, and I encourage all players to continue their great work.

Chisomo Petross, Research Assistant, Malawi

PHASE 2 INTERVENTION TESTING

Feasibility of a specialist antenatal clinic for women in subsequent pregnancy following stillbirth: Thembani Clinic

Women who become pregnant after a previous stillbirth are at greater risk of having another poor outcome, therefore increased antenatal visits, continuity of care and psychological support may be particularly beneficial for this group.



With support from the clinical team at Mpilo Hospital and the Zimbabwe CEI group, 'Thembani' (meaning hope) was developed. The intervention involved women with a previous stillbirth being offered regular access to a dedicated antenatal clinic, run by the same team of midwives, review by an obstetrician and opportunity for regular ultrasound assessment of fetal wellbeing.

27 out of 28 women who attended Thembani Clinic birthed a live baby.

To assess the feasibility of a large-scale trial, 28 women who had previously experienced a stillbirth and were currently pregnant were recruited and offered care in Thembani. Their care and outcomes were compared to a similar group (n=24) of women experiencing usual care in the hospital, before introduction of the clinic. The primary outcome for feasibility was willingness to participate and stay in the research until completion. Recruitment targets were met and 96% of participants were retained until study completion. All but one woman who attended Thembani birthed a live baby. The midwives and doctors involved expressed feeling more satisfied by the care they were able to give to women and felt that the service would improve outcomes.

Outcomes

- A wider evaluation of the effectiveness of the Thembani clinic appears feasible, the intervention was acceptable to staff and women. The hospital management have confirmed their intention to continue the clinic following the research.

Unique antenatal clinic for women in pregnancy after stillbirth piloted in Zimbabwe

Midwives and doctors are more alert in the identification and monitoring of women with previous history of stillbirth; mothers with previous stillbirths were given an opportunity to meet and discuss their experiences when they lost their babies, while midwives and obstetricians were able to identify nursing gaps and act on them for positive birth outcomes.



Locadia Gotora
Maternity Matron, Mpilo Central Hospital, Bulawayo

2. Improving access and uptake of high-quality maternity care for all

It is widely recognised that most stillbirths could be prevented and the impact of other serious pregnancy and childbirth complications – which blight the lives of millions of women and newborns worldwide – can be reduced with universal access to good quality antenatal and childbirth care.

Whilst a lack of resources to provide services undoubtedly impacts availability and quality in some settings, evidence suggests a more complex picture. Women in LMICs, including sub-Saharan Africa, do not always engage with available antenatal care early or regularly and may delay presentation in labour until severe complications arise. The move to high rates of facility births has not been accompanied by a sustained improvement in outcomes, suggesting quality of care is not consistent. Greater understanding of the barriers and facilitators influencing uptake and delivery of high-quality childbirth care is needed to improve engagement and quality leading to improved outcomes.

PHASE 1 DEVELOPMENT WORK

Influences on antenatal experiences and engagement (qualitative study, Tanzania and Zambia)

Interviews with 96 women, male partners, health workers and stakeholders (including service managers and policy makers) revealed a complex interplay of factors influencing antenatal attendance, including individual motivation and external influences, and health worker behaviour. Where conscious decisions to attend or not were involved, balancing of perceived 'losses' with 'gains' was key.

Intrapartum transfers, experiences and outcomes (mixed methods study, Tanzania and Zambia)

Transfer of women during labour between facilities for specialist care is undesirable, but often necessary when complications arise in sub-Saharan Africa. Good outcomes depend on minimising delays and smooth transfer processes, but few studies have examined practice and experiences in these settings.



Flora Kuenza, Research Assistant, Tanzania (left) coordinating data collection with support from CEI lead Prisca Ringa (right)

A consecutive case note review of 2,000 pregnant women attending for labour care at two health facilities, qualitative interviews and observations of clinical practice were conducted in Tanzania and Zambia. Intrapartum transfers were more common in Zambia and among women living with HIV, with fewer antenatal visits and residing a distance from the referral hospital. Delays were common and transfers were associated with poor outcomes. Qualitative data illuminated the contribution of inefficient processes, geographical distance, transport delays, limited birth preparedness, financial constraints and previous poor experiences of care.

Respectful maternity care: exploring intrapartum experiences (qualitative study, Tanzania and Zambia)

Labour experiences were explored from the perspective of women, male partners, health workers and stakeholders. Although positive relationships were valued by service users and providers, women did not equate respect with quality care and were often prepared to tolerate disrespect and abuse to receive services.

Outcomes

- Antenatal attendance could be improved by addressing disrespect and abuse, engaging women and communities to communicate benefits. However, further research is required to clarify women's needs and preferences.
- Intrapartum transfers are inevitable, but outcomes could be improved by developing transport infrastructure, support for health worker decision-making and better communication and support for affected women and families.
- Disrespect and abuse have significant direct and indirect impacts on uptake of maternity care in facilities in Tanzania and Zambia. There is a need to develop effective strategies to eliminate disrespectful care through changing behaviour and creating positive supportive environments for care.

PHASE 2 INTERVENTION TESTING

Women's preferences for antenatal care: A discrete choice experiment (Tanzania)

Our qualitative data surrounding antenatal experiences informed the development of a discrete choice experiment (DCE). This has determined the most important attributes affecting choices and priorities for antenatal care amongst 254 local women. Proximity to the clinic, perception of a friendly welcome and respectful care were priority influencers. Interviews revealed that lack of engagement of younger, less educated women and those living in rural areas compromised decision making, birth preparedness and understanding of complications. Relational care was not prioritised and communication between clinical teams was often suboptimal.

A new educational game, 'Dignity', helps midwives promote respectful care

Intervention testing: 'Dignity' educational game (Malawi and Zambia)

Following previous successes with game-based learning for labour monitoring, called 'Progression' and response to pregnancy complications called 'Crisis', the team developed a board game called 'Dignity' to enhance health workers knowledge and skills to deliver respectful maternal and newborn care. Initial testing with 111 midwives and 120 student midwives confirmed this was an enjoyable experience for learners, enabled reflection on practice and led to motivation to change behaviour.



Africa Research Coordinator Sabina Wakasiaka (left) playing the Dignity game with research assistants from Zambia, Kutemba Lyangenda (centre) and Khuzuet Tuwele (right)

WHO Labour Care guide: Rapid evaluation (LAMRN)

This recently developed tool supports the delivery of high-quality evidence-based care during birth, with a new focus on respectful care. In collaboration with the World Health Organisation (WHO), interview and focus groups were conducted with 43 midwives practicing across six countries. These captured initial reactions and views of the proposed changes and implications for uptake in Africa.

Outcomes

- Exploratory and DCE data, CEI and stakeholders' input have confirmed the need for a context appropriate intervention to increase antenatal engagement to reduce stillbirth and other adverse outcomes. A protocol for intervention development and testing has been developed.
- Despite wide recognition of the impacts of disrespect and abuse in maternity care there are no effective strategies to strengthen the health system's response and protect women's and newborns' rights in this area. We propose to develop and test a respectful care bundle to address this gap.
- WHO intrapartum guidance has not been universally recognised, implemented or followed in sub-Saharan Africa, and we plan further work to explore more effective mechanisms to implement, sustain and evaluate the impact of best practice guidelines into local health systems.

LAMRN Malawi and UK colleagues meeting the vice-principal of Kamuzu College of Nursing, University of Malawi. From left: Valentina Actis Danna (research associate), Chisomo Petross (research assistant), Dr Belinda Gombachika (vice-principal), Prof Angela Chimwaza (LAMRN Chair), Dr Rebecca Smyth (senior lecturer), Isabella Chisuse (research assistant).



Africa Research Coordinator Sabina Wakasiaka (left) with a traditional birth attendant (centre) and Kutemba Lyangenda, Research Assistant from Zambia (right) after conducting an interview



Stakeholders from Tanzania with UK colleagues

Theme 2 Developing bereavement care

Around 70% of women suffer depressive symptoms and 30% will develop prolonged grief which can seriously affect their mental health. Partners are also impacted, with an increased risk of relationship and family breakdown. In high income countries (HICs), good support from health workers families, and friends in the period following the baby's death helped parents to adjust. However, not all parents received the care or support they would have wanted. In LMICs, culture and traditions may increase stigma and isolation and women may also experience physical morbidity from traumatic births eg obstetric fistula which is rare in HICs. There is very little understanding of parents' experiences and care and support offered in sub-Saharan Africa.

PHASE 1 DEVELOPMENT WORK

Parents' and health workers' experiences of care and support after stillbirth (qualitative study, Kenya and Uganda)

A study of the lived experiences of 195 mothers and fathers who had experienced the death of their baby and health workers who provided care in five facilities in urban and more rural areas in Kenya and Uganda. Despite some positive reports, women and families were not adequately supported by health workers after the baby's death. Health workers felt unprepared for this aspect of their work and did not receive adequate support from organisations. Some beliefs and cultural practices in communities compounded trauma and increased isolation and stigma, particularly for women.

Women's experiences of stillbirth complicated by obstetric fistula (qualitative study, Kenya)

We explored the lived experiences of 20 women affected by the 'double tragedy' of stillbirth and obstetric fistula.

Experiences of communication after stillbirth (qualitative study, Malawi, Tanzania and Zambia)

We explored how health workers shared the news of the baby's death and subsequent communication including views around acceptability of post-mortem investigations, with 33 women, 18 partners, 20 family members and 24 community leaders. Health workers did not always communicate effectively or compassionately. Lack of candour and privacy caused considerable distress to women and their families.

Outcomes

- Parents were not always treated with compassion and lacked the care and support they needed after the death of their baby. Context and culturally appropriate interventions are required to improve support in facilities and communities.

“The death of a baby before or during birth is recognised as among the most traumatic life events for parents.”

- Women experiencing obstetric fistula and stillbirth face additional psychological, social and economic challenges. Specific and targeted strategies are required to reduce stigma and assist in reintegration.
- Health workers have a key role in supporting bereaved parents and families. Service improvement should target improved education, development of communication skills and awareness of parents' needs.

PHASE 2 INTERVENTION DEVELOPMENT AND TESTING

Improving bereavement care and support (feasibility study, Kenya and Uganda)

With input from CEI and stakeholder groups in Kenya and Uganda, we identified improving care in facilities and postnatal community support as target areas for improvement. The intervention included training health worker volunteers from maternity and neonatal units as 'bereavement champions' who would work to identify areas for development and promote good practice in facilities. Women with previous experience of stillbirth willing to provide support to others would be trained as peer supporters, enabling women to be offered access to telephone support in the first few weeks after the death of their baby.

The feasibility of research to evaluate the intervention was assessed with 44 women in Kenya and Uganda, recruited after the bereavement champion group was introduced, who were offered peer support. Their experiences and outcomes were compared with 56 women cared for in the same hospitals, before the change was introduced. Despite COVID 19 interrupting the research, women were willing to take part and stay in the study until completion. Initial data suggests overall positive experiences of the intervention and a few improvements which could be made in a larger trial.

44
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Sabina Wakasiaka, Africa Research Coordinator, meets Catherine, a service user in Kisii



Bereavement champions and peer supporters from Kenya

Development of a support package for women experiencing obstetric fistula and stillbirth (participatory action research, Kenya)

The research team engaged with local women, stakeholders and clinicians to explore the issues around these co-morbidities. Exploratory data identified challenges around care immediately following stillbirth, communication surrounding stillbirth and diagnosis of the fistula, access to follow up and treatment, lack of health worker knowledge and understanding, social and economic consequences of fistula including relationship breakdown, isolation, stigma and economic consequences including loss of livelihood and poverty.

A co-production process is underway to develop a package of interventions in five main areas: communication, capacity development for health and community workers, accountability and facility environment, support and sensitisation. Examples of interventions being considered include training packages, information campaigns for partners and communities, and peer support groups.

“This project has opened the door to higher learning and dissemination of study outcomes. Midwives in Kenya are now on the first track, conducting midwifery research led by midwives. They are unstoppable and I feel so privileged to have been part of this team’.”

Dr Sabina Wakasiaka, Africa Research Coordinator, Stillbirth Group

Advancing bereavement care: Africa (feasibility study, Malawi, Uganda, Zambia and Zimbabwe)

Lack of preparation and education for health workers was a major theme arising from exploratory work across settings. Therefore, we developed a one-day training workshop to improve health workers' understanding of the impact of baby death on parents. The workshop also introduces the evidence-based care covering good communication, supporting choices, making memories and information giving. The importance of self-care for staff is also covered. We have also developed an educational film called The Heartbeat, with Nabwiso Films in Kampala, Uganda, to support the training. An accompanying preparatory workshop prepared local midwife trainers to deliver the course in person.

The feasibility of a large-scale evaluation of the training package is currently being assessed with 132 midwives and nurses and 63 students across four sites. Initial feedback has been extremely favourable with more sites requesting to take part in the programme across the network.

Outcomes

- A large-scale evaluation of a multicomponent bereavement care intervention to improve care and support for parents is feasible and a protocol for a cluster randomised trial in Africa is being developed.
- The 'Advancing Bereavement Care in Africa' (ABC) package will form part of the wider intervention to support development of health worker knowledge and skills to support parents and be evaluated in the planned trial.
- Following the conclusion of development, a feasibility study will establish whether it is possible to conduct an evaluation of the intervention to improve support for women experiencing obstetric fistula and stillbirth. A protocol for the study is in development.

Developed and tested the first bereavement care training package for sub-Saharan Africa

Research capacity strengthening

Midwives and nurses manage and provide most of the front-line maternity and childbirth services across the globe and are committed to providing the best care possible to women and families.

However, compared to other professional groups (for example doctors), lack of investment and opportunity has hampered their ability to generate evidence needed to advance practice and quality through research. This failure is now seriously hampering the drive to improve outcomes, particularly in resource-limited settings where change is most urgently required.

A key focus of the NIHR Global Health Research Group on Stillbirth was to improve researchers' capability to develop, lead and deliver programmes and to further embed global health expertise in the UK team.

Activities spanned individual and organisational levels, drawing on previous programmes (THET).

Individual capacity

- Researchers from Kenya and Zambia undertook formal research training through the prestigious Master's in Clinical Research course at The University of Manchester.
- A programme of study-specific blended activities in each country supported delivery of the programme, including training in research methods, analysis and data management.
- The Country Lead from Tanzania, Dr Rose Laisser, strengthened her leadership skills by leading the study piloting the WHO Labour Care Guide in Mwanza.
- Training needs analyses were conducted for all staff at annual reviews, and additional resources provided to address gaps in knowledge e.g: an academic English language course sourced for research assistants in Tanzania.
- During the COVID 19 pandemic training was moved online with regular sessions focusing on research methods, dissemination skills and clinical updates making effective use of project downtime resulting from restrictions.
- South-to-south engagement and whole group meetings facilitated networking.
- Developing a new collaboration with Dr Paschal Mdoe, an early career researcher, obstetrician and gynaecologist at Haydom Lutheran Hospital in Manyara, Tanzania, to support future proposals.

Organisational capacity

- Access was provided to resources strengthening transferable skills in research governance, and Good Clinical Practice.
- UK programme management team worked with local finance and governance teams to develop processes and reporting structures.
- Engagement including clinical updates with the UK team strengthened relationships with partner health facilities.

Outcomes

- Activities have supported delivery of high-quality research throughout the programme.
- LAMRN partner researchers have authored publications and are developing independent proposals for further funding.



Country Leads and Africa Research Coordinator at research planning workshop in Uganda

I'm so grateful to be part of this NIHR group whose desire is to see midwives develop as good scholars and practitioners. It has opened doors for me within the maternal and newborn health care sector through our stakeholder engagement and I have grown as a researcher and academic thanks to the mentorship and collegiality provided by the knowledgeable UK team.

Elizabeth Ayebare, LAMRN Uganda Stillbirth project lead



Community engagement and involvement

Meaningful involvement of service users and communities in the research process, from identification of priorities to dissemination of findings, is considered fundamental to impact and relevance in UK research.

However, Community Engagement and Involvement (CEI) in maternal and newborn health research was virtually unknown in sub-Saharan Africa at the outset of Group activities. Stillbirth is often a hidden trauma in Africa, seldom discussed and highly stigmatised. Involving parents with experience of the death of a baby to shape the direction of the programme from the start was prioritised, to include their voices and reflect the local culture and context across the included settings.

Following international principles for CEI in research, training and guidance was provided for local research teams in identifying and supporting CEI in each country. Groups were recruited through networking and word of mouth. Given the taboos surrounding stillbirth in these settings, initially these groups functioned as a safe space for members to share their own experiences. Training and support from the local and UK team developed their understanding of the research process. Despite some challenges, the groups rapidly evolved. By the end of the programme they had provided insight into optimal recruitment processes, reviewed participant facing information, supported interpretation of research findings and dissemination at all levels. CEI Leads have co-authored several publications.

As the research programme advanced beyond exploratory work, CEI groups have contributed to intervention development. Members have also developed interests in advocacy, raising awareness of stillbirth as a public health issue, highlighted service gaps and need for further research.

Outcomes

- Functional cohesive CEI groups have been sustained in each country across the programme.
- Ongoing learning from CEI activities is helping to embed this concept in research across the six LAMRN countries and beyond.

It's so important for families to have someone to talk to who is not medical and knowing that I have been through the same thing and understand their feelings and beliefs, can really help.

Milcah Mwamadi, CEI Lead for Malawi



Involving parents with experience of the death of a baby to shape the direction of the programme from the start was prioritised, to include their voices and reflect the local culture and context.

Research impact

Wider dissemination and raising the profile of stillbirth

Increasing awareness of the impacts of stillbirth for parents, families and society has been a priority. We have published nine papers in peer reviewed journals, 12 publications are currently under review or in preparation, and we have presented findings at conferences across Africa and beyond:

- The Zimbabwe Confederation of Midwives.
- The Tanzanian Catholic University of Health and Allied Science Scientific Conference.
- The Association of Obstetricians and Gynaecologists in Uganda Conference.
- The East, Central and South Africa College of Obstetricians and Gynaecologists.
- The Regional Conference of the International Confederation of Midwives.
- Annual meeting of the International Stillbirth Alliance (ISA) in Madrid
 - Our Uganda Lead was invited as keynote speaker, we had a 'top 5' abstract and two posters were highly commended.
- Global Women's Research Society (GLOW).
- The Conference of the NIHR Group on Preterm birth, University of Sheffield – Poster prize awarded.
- LAMRN Conference.
- The Zambia Health Research Conference.
- NIHR Global Health Training Forum – Poster prize awarded.

The Group has contributed to the ISA Stillbirth Advocacy Working Group, providing evidence to support international recognition of stillbirth in the WHO and UNICEF strategies. Our presence within hospitals and health facilities has raised the profile of stillbirth across the region with one hospital Clinical Director reporting "it created a huge awareness amongst healthcare workers and patients about preventing stillbirths".

Impacts on practice in participating facilities

- In Malawi, stillbirth audits are now regularly conducted in two main facilities.
- In Tanzania, women with a previous history of stillbirth are seen by an obstetrician in a shorter time than before.
- In Kenya, stakeholder advocacy work has led to four private rooms being set aside and a dedicated counsellor for bereaved women. Bereavement champions created a cabinet to facilitate parents having contact and saying goodbye to their stillborn baby before going home.
- Increased interest in peer support following the feasibility study in Kenya and Uganda.
- Engagement with service managers has sustained improvements beyond the research including a commitment to continue the Themban Clinic, Zimbabwe.
- In Mansa, Zambia, supportive care is now offered to women who have a stillborn baby.

Wider impact and policy

Challenging stigma and taboos

- Connected with local parent-led organisations such as StillAMum (Kenya) and developed community engagement and involvement (CEI) groups in all partner countries.
- CEI groups provided a platform for parents to join together, share feelings and experiences. CEI group participants have built self-esteem through the process, grown in confidence and developed new skills.
- For the first time, we have given voice to women who had a stillborn baby.

Engagement with policymakers

- We have engaged with Ministries of Health (MOH) and relevant non-governmental organisations across the region.
- In Uganda, our findings have been disseminated to the MOH to inform strategies for stillbirth reduction.
- In Tanzania, the finding of high numbers of stillbirth led the MOH to conduct inquiries in several hospitals to understand the reasons. We are also contributing to the national Respectful Maternity Care policy.
- In Kenya, we have been involved in the formulation of National Guidelines on Maternal Health.
- In Zambia, the MOH is using our approach to design data collection for better estimates of numbers of stillbirths in other parts of the country.

Recognised lack of training for health workers and developed specific bereavement care education for sub-Saharan Africa.

A unique midwife-led and delivered research programme addressing preventable stillbirth and better support for bereaved parents across sub-Saharan Africa.



Zimbabwe: Identified increased risks of recurrence for women with previous stillbirth and piloted a special antenatal clinic for women offering better care in next pregnancies.



In Kenya and Uganda, identified gaps in support for women after stillbirth and tested 'Bereavement champions' in facilities and telephone peer support in communities to address these issues.



Tanzania and Zambia: Explored barriers to access and uptake of quality care, identified women's preferences for antenatal care.

Developed the 'Dignity' game to help midwives promote respectful care and assessed responses to new WHO Labour Care Guide.



Community engagement groups of bereaved parents supported the research in each country.



Malawi: Embedded clinical audit of stillbirth in two facilities to improve childbirth care quality.



Conclusion

Accelerating progress through sustainable partnerships

The NIHR Global Health Research Group on Stillbirth Prevention and Management in sub-Saharan Africa has successfully delivered a programme of research and capacity development focused on stillbirth.

This programme has catalysed acceleration of progress in preventing stillbirth and improving bereavement support, through building equitable sustainable partnerships with researchers in sub-Saharan Africa and generating high quality evidence. These have underpinned the development of solutions to key issues in strengthening maternal and newborn care in LMICs.

We are particularly proud of our collective achievements in increasing research expertise amongst midwives and nurses, who are working in challenging situations in sub-Saharan Africa. Our midwife and nurse researchers have unique passion, skills and insight which will lead to meaningful change in health outcomes for women and babies.

Our work with communities has started important conversations which will contribute to empowering parents to make their voices heard and challenge stigma and marginalisation.



Our Partners

With grateful thanks to all of those partners who have worked with us on this programme.



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**REPUBLIC OF ZAMBIA
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