A Focus on Breast Cancer Project: Stakeholder Visit Report for Uganda and Zambia

NOVEMBER 17 – 23, 2024

FUNDED BY SANOFI

Report by Charles Omofomwan

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Overview of the project

The breast cancer care project titled 'A Focus on Breast Cancer', is a collaborative initiative led by Global Health Partners (formerly THET) in partnership with the Association of Breast Surgery (ABS) and Blended Learning UK (BLUK), with funding from Sanofi. The project focuses on addressing the disparities in breast cancer care in Zambia and Uganda, where women often face late diagnoses and limited access to timely treatment. By decentralising breast cancer care, the project aims to empower healthcare workers at the primary and community levels with the skills and knowledge needed to improve early detection, diagnosis, and management of breast cancer.

Objectives

1. **Develop a Global Breast Cancer Training Package**:
    - Create standardised tools and training materials tailored to the needs of primary and community health workers in low- and middle-income countries (LMICs).
2. **Strengthen Health Worker Capacity**:
    - Train Master Trainers and support them in cascading knowledge to Primary Healthcare Workers (PHWs) and Community Health Workers (CHWs).
    - Equip healthcare workers to raise awareness, screen, diagnose, and manage breast cancer cases effectively.
3. **Enhance Community Awareness**:
    - Promote early detection and self-examination through awareness campaigns integrated with existing community health structures.
4. **Support Healthcare Systems**:
    - Collaborate with Ministries of Health to decentralise breast cancer care, aligning with national health strategies and priorities.
    - Establish robust data collection systems to track project outcomes and inform policy improvements.

Implementation Approach

The project employs a phased approach:

- **Phase 1** focuses on developing the training package with input from local and international experts, conducting baseline assessments, and establishing a technical oversight group.
- **Phase 2** involves rolling out the training package through a cascade model, starting with Master Trainers, followed by training PHWs and CHWs in Uganda and Zambia.

Expected Impact

- Improved awareness and earlier detection of breast cancer.
- Enhanced skills and knowledge among healthcare workers.
- Strengthened referral systems and community engagement for breast cancer care.
- Development of a sustainable, scalable training model for replication in other LMICs.

Summary of the visit

Purpose of the Visit

The visit to Uganda and Zambia was a key component of the project, designed to advance its goals and ensure alignment with local healthcare systems and stakeholders. The objectives of the visit included:

- **Engaging with key stakeholders** at various healthcare levels to understand current breast cancer care challenges and opportunities.
- **Assessing the capacity and needs** of healthcare workers to inform the development of the project's training manual and implementation strategy.
- **Exploring existing healthcare systems** to align the project's activities with national priorities.
- **Laying the groundwork** for awareness campaigns and training rollouts in 2025.

The visiting team comprised:

- **Charles Omofomwan**: Programmes Coordinator, Global Health Partnerships (GHP) and UK Lead for the project.
- **Dick Rainsbury**: Representative of the Association of Breast Surgery (ABS).
- **Jerome Pereira**: Representative of Blended Learning UK (BLUK).

Timeline

- **Departure from the UK:** Saturday, 16th November 2024.
- **Uganda Visit:**
    - Arrived in Entebbe, Uganda on Sunday, 17th November 2024.
    - Activities spanned from Monday, 18th November to Wednesday, 20th November 2024.
- **Zambia Visit:**
    - Arrived in Lusaka, Zambia on Thursday, 21st November 2024.
    - Activities continued from Thursday, 21st November to Friday, 22nd November 2024.
- **Departure from Zambia:** Saturday, 23rd November 2024.

Key Activities

The visit encompassed stakeholder engagements, facility visits, and comprehensive debrief sessions. Highlights included:

1. **Stakeholder Meetings**:

   Discussions with government officials, healthcare leaders, and community representatives to align the project with national cancer care priorities.

2. **Health Facility Visits**:

   Observations at primary, secondary, and tertiary healthcare facilities in both countries to assess readiness, capacity, and gaps in breast cancer care.

3. **Community Engagements**: Insights into cultural and systemic barriers to breast cancer awareness and care delivery.

4. **Debrief Meetings**:

   Consolidation of findings and development of an action plan for the project's next phases.

Figure 1: Touring Mbarara Regional Cancer Referral Centre in Uganda.

Day 1 Report: Uganda

Date: Monday, 18th November 2024

Locations: Mbarara Regional Cancer Referral Centre, Bwizibwera Health Centre IV, Kampala

Figure 2: Group phot with the TOTS at the regional centre

Overview: The team, consisting of Charles Omofomwan (Global Health Partnerships Programmes Coordinator and UK Lead for the project), Prof. Dick Rainsbury (Association of Breast Surgery - ABS), and Prof. Jerome Pereira (Blended Learning UK - BLUK), began their official activities in Uganda on Monday, 18th November 2024, after arriving in Mbarara on Sunday evening, 17th November 2024 from Entebbe. The day featured three key engagements: a meeting and tour at the Mbarara Regional Cancer Referral Centre, a session with Trainers of Trainers (ToTs), and a site visit to Bwizibwera Health Centre IV. The day concluded with travel to Kampala.

Activities Conducted

Engagement and Tour at Mbarara Regional Cancer Referral Centre

- Met with Dr. Nixon Niyonzima, Head of the Centre, alongside Dr. Alfred Jatho, one of the project's focal persons at UCI.
- Held discussions about the current state of breast cancer care in Uganda and identified key challenges and opportunities.
- Conducted a tour of the facility to understand the range of services offered, including diagnostic capabilities, treatment services, and community outreach activities.
- Reviewed data on cancer cases and service utilisation at the centre.

Figure 3: Tour of the centre

Key Insights from the Visit:

- Cancer Prevalence in Mbarara (FY 2023/2024):
  - New Adult Oncology Cases: Male: 550, Female: 476
  - New Pediatric Oncology Cases: Male: 62, Female: 83

    - New Sickle Cell Cases: Male: 45, Female: 47

- Top New Adult Cases:
    - Prostate cancer: 146
    - Cervical cancer: 124
    - Esophageal cancer: 117
    - Stomach cancer: 103
    - Breast cancer: 90
    - Other prevalent cases include lymphoma (NHL), colorectal cancer, and Kaposi's sarcoma.
- Services Offered:
    - The centre provides diagnostic and treatment services for various cancers, including chemotherapy and palliative care.
    - Limited surgical capacity for breast cancer management due to a shortage of specialised surgeons.
- Gaps in Breast Cancer Care:
    - Surgery has been a critical missing component in managing breast cancer in Uganda.
    - There are only four surgeons currently managing cancer care across Uganda.
    - There are fewer than ten oncological surgeons nationwide, which severely limits surgical capacity.

Proposed Action:

- Explore the possibility of sending an additional master trainer to the UK for advanced breast surgery training to address the acute shortage of surgical expertise.

Meeting with the Trainers of Trainers (ToTs)

- Met with a group of 13 ToTs, comprising diverse professionals, including nurses, medical doctors, and radiologists.
- Prof. Jerome delivered a short but detailed presentation about the project, giving the ToTs a better understanding of its objectives and expectations.
- Reviewed cancer statistics from the Mbarara Centre to contextualise their training needs.

Figure 4: Meeting with the TOTs

Key Observations from the Engagement:

- The ToTs demonstrated significant interest in the project and expressed eagerness to support its implementation.
- The team learned that the ToTs are well educated and suited for online training modules, which aligns with the project's blended learning approach.
- Despite their high workload, the ToTs confirmed their willingness to participate in the training programmes to be designed.

Visit to Bwizibwera Health Centre IV

- Met with Dr. Alinda Albert, Head of the Health Centre, along with four Community Health Workers (CHWs) and two Primary Health Workers (PHWs) (Dr. Albert and a Nurse).
- Assessed the capabilities and challenges faced by the centre in delivering breast cancer awareness and care.

Figure 5: Meeting with some PHWs and CHWs in Bwizibwera

Key Findings:

- **Community Health Workers:**
  - The CHWs have limited education and no access to smartphones, necessitating face-to-face training delivery.
  - CHWs lack knowledge about breast cancer but are keen to receive training to raise awareness in their communities.
- **Breast Cancer Awareness:**
  - There is a significant gap in breast cancer information compared to cervical cancer.
  - Many women are aware of cervical cancer and routinely attend screenings, but awareness and education on breast cancer are severely lacking.
- **Workload:**
  - The health centre faces a high workload, with only two doctors and nine midwives managing care for a large population.

Proposed Action:

- Design a face-to-face training programme for CHWs to build capacity for community-based breast cancer awareness campaigns.
- Provide breast cancer informational materials for both CHWs and the health centre to address the knowledge gap.

End of Day: After completing the engagements, the team departed Mbarara at approximately 2:00 pm, arriving in Kampala at around 8:30 pm.

General Notes: Day 1 provided valuable insights into Uganda's breast cancer care landscape. The engagements, including the tour of Mbarara Regional Cancer Referral Centre and meetings with ToTs, highlighted significant opportunities for impact through targeted training and awareness initiatives, particularly at the community level.

Figure 6: From left - Vincent, Jerome, Alfred, Dick & Charles at Bwizibwera Health Centre IV

Day 2 Report: Uganda

Date: Tuesday, 18th November 2024

Location: Uganda Cancer Institute (UCI) and Ministry of Health, Kampala

Figure 7: From left (front): Alfred, UCI ED-Jackson, Jerome, GHP Uganda CD – Sheba, (back) Charles, Dick & Vincent at UCI.

Overview:

The second day of the Uganda visit focused on engagements at the Uganda Cancer Institute (UCI) and the Ministry of Health (MoH) in Kampala. The team met with key stakeholders, master trainers, and MoH officials to discuss existing systems, challenges, capacity-building opportunities, and the integration of breast cancer care into Uganda's health system.

Activities Conducted

Meeting with the Project Focal Persons at UCI

- Met with Dr. Nixon Niyonzima, Head of Education and Training at UCI, and Dr. Alfred Jatho, Head of Public Health Department who are both the focal persons for the project at UCI.
- Discussed UCI's role and its preparedness for managing the anticipated demand created by the project.

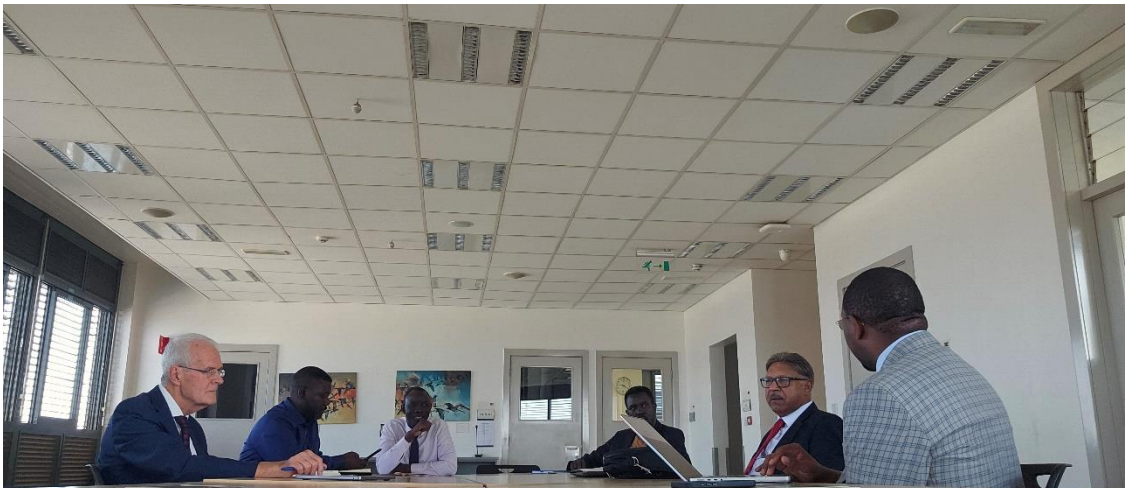

Figure 8: Meeting with Nixon & Alfred at UCI.

Key Insights from the Meeting:

- **System Strengths:**
  - Uganda has an effective system for transporting blood and samples from lower-level health facilities to UCI, enabling better diagnostic and treatment coordination.
- **Pathology Workforce Challenges:**
  - UCI currently has only 5 pathologists, significantly lower than the expected 28 to meet optimal operational capacity.
  - The Mbarara Regional Cancer Centre, another key facility, has 4 pathologists.
  - The gap in pathology services underscores the need for workforce development to support the growing demand for cancer diagnostics.
- **Role of Regional Centres:**
  - Regional cancer centres are structured to handle routine cases, with complicated cases referred to UCI for specialised care.

Proposed Action:

A half-day workshop to be facilitated by ABS and BLUK tentatively in early 2025 was proposed. This workshop aims to enhance UCI's capacity to manage the anticipated demand created by the project, particularly through workforce development and improved systems for breast cancer care.

Meeting with Master Trainers

- The team met with 7 master trainers, comprising various health professionals such as oncologists, medical doctors, radiologists, and nurses.

Presentations:

- Prof. Dick delivered a presentation on ABS's ongoing project in Zimbabwe and shared lessons that could be applied to the breast cancer project in Uganda.
- Prof. Jerome gave a presentation on the breast cancer project in Uganda and Zambia, detailing the role of master trainers and how they fit into the broader implementation framework in Uganda.

Figure 9: From left: Dick & Jerome (making a presentation during the meeting with master trainers at UCI.

Agreed Action:

The master trainers will undergo a 12-week online training programme in January 2025 consisting of:

1. Introduction to Breast Cancer Care
2. Introduction to Breast Ultrasound
3. A workshop on breast cancer ultrasound

Discussion Highlights:

- **Challenges Identified:**

- Delayed Patient Presentation: Many patients present at late stages of breast cancer (stage 3 or 4), reducing treatment success rates.
- Bureaucratic Delays: Delays in the referral system, such as the lack of radiologists at regional centres despite the presence of CT scan machines, further exacerbate late presentations.
- Resource Shortages: There is an urgent need for basic supplies to support breast cancer care delivery.

- **Existing Resources:**
  - UCI has an unpublished draft of a Breast Health Guideline manual to provide primary care guidance on breast cancer.
- **Recommendations and Solutions:**
  - Managing Workload: Rotating radiologists weekly across centres could help address delays in reporting scans.
  - Training Format: While face-to-face training is preferred, a blended approach will also work effectively for PHWs and ToTs.
  - Supply-Side Support: As part of the project implementation, consider providing basic supplies (e.g., hand gloves) to improve care delivery.
  - Master Trainers' Role: Master trainers will conduct face-to-face training for ToTs, ensuring practical and direct knowledge transfer.

Figure 10: Meeting with master trainers at UCI.

Courtesy Meeting with UCI Executive Director (ED), Dr. Jackson Orem

The meeting served to formally introduce the team to the Executive Director and discuss potential collaboration on breast cancer care.

Key Outcomes from the Meeting:

- **Breast Surgery Capacity:**
  - Currently, there is no focus on breast surgery due to limited capacity.
  - However, the ED emphasised that surgery will be a major component in the regional cancer centres within the next two years, as funding has been secured for three additional centres.
- **Future Partnership:**

- UCI is open to working with partners on breast cancer care specialism.
- The ED proposed the development of a jointly written blueprint to guide the implementation of strategies to upscale breast cancer care in Uganda.

- **Regional Cancer Centres Plan:**
  - UCI plans to establish four regional cancer centres, one of which is operational, while funding for the remaining three has been secured.

Figure 11: Courtesy meeting with UCI ED.

Meeting with Ministry of Health (MoH)

- The team met with Dr. Frank Mugabe, Acting Head of the NCD Department at MoH, and Dr. Akia Charles, MoH focal person for the project.

Key Outcomes from the Meeting:

- **Referral Pathway:**
  - Cancer referrals follow a hierarchical system from villages to regional centres and then to central facilities.
- **Awareness and Screening Challenges:**
  - There is a lack of awareness and information about breast cancer in communities.
  - Cervical cancer screening has increased, but breast cancer screening remains underutilised.
- **MoH Priorities:**
  - The MoH aims to integrate breast cancer screening into routine check-ups and cervical screening activities.
  - Breast cancer is already a policy priority, with the main focus on prevention and early detection.
- **Support for the Project:**
  - The MoH expressed strong support for the project and emphasised the need to keep them informed and engaged at every stage, not just during approval processes.

- Their goal is to reduce the percentage of late-stage breast cancer cases (currently ~80% at stage 4) to at least 50%.

Next Steps:

1. Finalise the 12-week online training programme structure and schedule for master trainers.
2. Draft a joint blueprint with UCI leadership for implementing strategies to upscale breast cancer care.
3. Develop a plan for integrating breast cancer screening into routine check-ups in line with MoH priorities.
4. Collaborate with MoH and UCI on addressing community-level awareness gaps and improving early detection rates.
5. Ensure consistent engagement with MoH throughout the project.

General Notes:

Day 2 highlighted critical gaps in awareness, screening, and diagnostic capacity for breast cancer in Uganda. The team's meetings with UCI and MoH laid the groundwork for impactful collaborations, with clear commitments to addressing late-stage presentation rates and strengthening breast cancer care systems.

Day 3 Report: Uganda

Date: Wednesday, 19th November 2024

Location: Uganda Women's Cancer Support Organization (UWOCASO) and Uganda Cancer Institute (UCI), Kampala

Figure 12: Jerome with UWOCASO CEO & team.

Overview:

The final day in Uganda included a meeting with the Uganda Women's Cancer Support Organization (UWOCASO), a debrief session with UCI leadership and GHP's Uganda

Programme Manager, and discussions on next steps for the project. The day's activities provided critical insights into cultural and systemic barriers to breast cancer care and refined the approach for the project's next phases.

Activities Conducted

Meeting with Uganda Women's Cancer Support Organization (UWOCASO)

- The team met with the co-founder and CEO of UWOCASO, a breast cancer survivor who serves as a board member at UCI and a member of the Breast Cancer Care Guidelines Development Committee.
- Discussed UWOCASO's activities, challenges, and how the organisation can support the project.

Figure 13: Jerome & Charles meting with UWOCASO CEO in her private consultation office.

Key Outcomes:

- **Cultural and Awareness Challenges:**
  - Breast cancer is often seen as a death sentence, attributed to spiritual causes like witchcraft.
  - Many women delay treatment, seeking help from herbalists or religious leaders, which worsens outcomes.
  - There is a significant demand for alternative options to mastectomy and information about breast reconstruction.
- **Recommendations for the Project:**
  - Awareness campaigns should target churches, herbalists, and traditional leaders to encourage accurate information and referrals.
  - Include guidance on navigating the healthcare system and understanding the treatment process in the training materials.
  - Address fear during awareness activities to reduce misinformation and exploitation.
  - Train Primary Health Workers (PHWs) to perform basic examinations, take biopsies, and refer patients for clinical screenings.
- **UWOCASO's Role:**
  - Their survivor-led network and expertise in community engagement make them a strong partner for the project's awareness phase.
  - They can contribute live testimonials to dispel myths and provide evidence of successful breast cancer treatment.

Figure 14: Public viewing of UWOCASO poster display

Debrief at Uganda Cancer Institute (UCI)

- The team, along with Vincent Katungi (GHP Uganda Programme Manager), met with Dr. Alfred Jatho to debrief on the visit and plan next steps.

Key Discussion Points and Agreements:

- **Lead Master Trainer Identified:**
  - Dr. James, a surgeon and newly added master trainer, will serve as the lead master trainer. He will travel to the UK in 2025 for a 6-week learning visit.
- **Leveraging Existing Programmes:**
  - The project will build on the established cervical cancer awareness programme, using it as a foundation for breast cancer awareness activities.
- **Project Focus:**
  - The project will remain focused on awareness and early detection through community awareness, self-examination, and capacity building.
- **Training Package Development:**

  The training package will focus on:

  - Breast cancer detection, referral, signs, symptoms, and self-examination.
  - Developing a Training Manual and Training Guides, including activity ideas, pre/post questionnaires, and mentorship tools.
  - PowerPoint slides will be created from the training manual for cascading training.
  - The package will align with feedback from the needs assessment questionnaires and IRB-approved areas.
- **Next Steps:**
  - Stage 1 Ethical Approval: Await the first-stage approval before administering the needs assessment questionnaires to selected PHWs and CHWs.
  - Develop the training package based on existing ABS and BLUK content and incorporate findings from the needs assessment questionnaire (include findings from Uganda if questionnaires feedback is received on time).
  - Master Trainer Online Course: Begin a 12-week online course for master trainers in January 2025.
  - Field Visits by ABS and BLUK:
    - Sue (BLUK) and Ruth (ABS) will visit Uganda in early 2025 to:
      - Train master trainers on using the manual.
      - Observe the master trainers delivering training to PHWs.
      - Conduct a half-day workshop for surgeons interested in breast cancer surgery during their visit.
  - Finalise the 6-week UK learning visit for Dr. James (the selected lead master trainer), ensuring alignment with project objectives.
  - Engage UWOCASO in awareness activities and include their input in the training materials.

General Notes:

Day 3 marked the conclusion of the Uganda visit, solidifying partnerships and aligning stakeholders on the project's focus. The debrief at UCI provided clarity on the next steps, particularly the training package development and the role of master trainers. The inclusion of UWOCASO and leveraging existing cervical cancer programmes further strengthen the project's foundation for success.

Day 4 Report: Zambia

Date: Thursday, 21st November 2024

Location: Cancer Diseases Hospital (CDH), Lusaka, Zambia

Figure 15: The team at CDH. From left: Ndekeela (GHP Zamba Programme Coordinator), Charles (GHP UK Programmes Coordinator), Dr Mwala (UCI), Muleba (GHP Zambia CD), Dick (ABS), Jerome (BLUK), Ethel (GHP Zambia Project Officer), Dr George (UCI), & Nurse Jennipher (UCI).

Overview

The fourth day of the visit focused on engaging with the master trainers in Zambia, discussing the challenges and opportunities in breast cancer care, and exploring actionable strategies to enhance the project's impact. Dr. Kabisa Mwala, the Head of Clinical Care at CDH, delivered a comprehensive presentation outlining the current status of breast cancer care in Zambia and the hospital's role in combating NCDs. The meeting also included a comparative presentation by Prof. Dick on lessons learned from a similar project in Zimbabwe and a presentation by Prof. Jerome on the responsibilities of master trainers and the methodology of the project.

Activities Conducted

Master Trainers' Meeting

The meeting was attended by six master trainers from various medical specialties, including surgeons, nurses, oncologists, and public health practitioners.

Key Presentations:

1. Dr. Mwala:

Dr. Mwala provided an overview of CDH's services, Zambia's cancer burden, and the project's alignment with national cancer care goals.

Highlights from the Presentation:

- **Cancer as NCD:**
  - Verbal autopsy data reveals a high NCD mortality rate in Zambia, with cancer cases contributing significantly.
  - Incidence of breast cancer is expected to rise, with LMICs bearing the brunt of this burden.
- **Breast Cancer Current Status in Zambia:**
  - Among 15,296 new cancer cases reported in 2022, breast cancer accounted for a significant proportion, with 519 cases diagnosed via clinical breast exams.
  - Delayed referrals from lower levels and limited awareness are key barriers to early detection.
- **Infrastructure:**
  - CDH is part of Zambia's cancer care ecosystem and is supported by nine pathologists (three at CDH) and three radiologists nationwide.
  - Plans are underway to establish two new cancer centres by 2027 to decentralise care.

Figure 16: Meeting with master trainers at CDH.

2. Prof. Dick:

Prof. Dick presented on a similar project in Zimbabwe, highlighting operational challenges, lessons learned, and how these could be applied to the Zambia project.

Key Insights:

- Zimbabwe's cervical cancer programme has been instrumental in building community trust and infrastructure, which can be replicated for breast cancer care.
- Collaboration with traditional leaders and community health workers was critical for awareness and referrals.

- Challenges in Zimbabwe included the need for better data systems and sustained funding for training.

3. Prof. Jerome:

Prof. Jerome provided an in-depth presentation on the role and responsibilities of master trainers, focusing on the project's methodology and structure.

Summary of Key Points from Jerome's Presentation:

- **Primary Aims:**
  - Develop an online training package for healthcare workers on breast cancer detection.
  - Establish a sustainable model for breast cancer awareness and care.
- **Methodology:**
  - Master trainers will undertake a Training of Trainers (ToT) programme, mentor primary care and community health workers, and monitor project outcomes.
  - Cascade training will involve master trainers educating health workers and community health volunteers at regional and community levels.
- **Training Structure:**
  - Online courses will cover breast cancer care, breast ultrasound, and practical skills.
  - Training materials will focus on early detection, self-examination, and awareness of red flags.
- **Core Principles:**
  - Empower health workers to teach and support community-based breast cancer care.
  - Ensure that patients and communities are equipped with knowledge for self-examinations and early referrals.

Figure 17: Jerome presenting during the meeting with master trainers.

Tour of CDH and University Teaching Hospital (UTH)

The team toured CDH (housed within UTH) and UTH facilities and discussed the use of online training platforms like the Echo Platform for breast cancer care knowledge dissemination. The

hospital leadership emphasised the need to integrate the breast cancer care training into existing systems like the Echo platform. World Continuing Education Alliance (WCEA) platform was also cited as an alternative that could be explored.

Key Insights:

- Breast cancer care has been historically neglected but is now receiving attention due to initiatives like this project.
- The major challenge remains the lack of referrals from lower-level facilities due to limited awareness and accessibility barriers.

Discussion Points:

- The cervical cancer programme's robust operational model could be leveraged to include breast cancer awareness and screening.
- CHWs play a crucial role but are limited to sharing information and referrals without conducting clinical tests.
- A strong data collection and management system is vital to measure the project's impact and ensure sustainability.
- Master trainers expressed the need for continued virtual collaboration and capacity building through regular meetings and group platforms like WhatsApp.
- The 12-week online course for master trainers (to begin in January 2025) will cover key topics such as breast cancer awareness, ultrasound techniques, and early detection strategies.

Figure 18: The team with a key stakeholder at UTH during the tour.

Recommendations and Agreed Actions:

The project will focus on:

- Raising awareness through community education campaigns targeting the general public, traditional leaders, and healthcare workers.

- Leveraging the cervical cancer programme's infrastructure for breast cancer screening and awareness.
- Enhancing the training manual to incorporate clinical pathways, signs and symptoms, referral protocols, and treatment expectations.
- Administration of PHWs training needs assessment questionnaires will commence in the week of November 25, 2024, via digital platforms like WhatsApp groups and professional associations, while CHWs' questionnaires will be administered offline.
- Establish a robust data collection framework to monitor project outcomes and inform future interventions.

Conclusion:

Day 4 in Zambia provided a thorough understanding of the challenges and opportunities in breast cancer care. The insights from Dr. Mwala's presentation, Mr. Dick's lessons from Zimbabwe, and Prof. Jerome Pereira's methodology will guide the development of targeted strategies to improve awareness, early detection, and care delivery in Zambia.

Day 5 Report: Zambia

Date: Friday, 22nd November 2024

Locations: Chainda Urban Health Facility, Chelstone Regional Hospital, Levy Mwanawasa University Teaching Hospital (Levy Hospital), and GHP Zambia Office, Lusaka, Zambia

Overview

The final day of the Zambia visit was packed with key engagements at multiple levels of the healthcare system, including visits to Chainda Urban Health Facility, Chelstone Regional Hospital, and Levy Mwanawasa University Teaching Hospital (Levy Hospital). Each visit offered valuable insights into the healthcare infrastructure, challenges, and opportunities for implementing and sustaining breast cancer care interventions. The day concluded with a debrief meeting at the **GHP Zambia Office**, where stakeholders reflected on the visit and aligned on next steps to move the project forward.

Activities Conducted

Visit 1: Chainda Urban Health Facility

Figure 19: Meeting with the In-Charge at Chainda Urban Health Facility.

Key highlights from the visit and meeting with the Nurse in Charge, Bridget Mwape:

- **Facility Overview:**
  - Serves an estimated population of 65,000 people.
  - Operates 24/7, with 103 staff members: 65 nurses, 11 clinical officers, one medical doctor, and other support staff.
  - Offers cervical screening services (2-5 screenings daily), managed by nurses.
- **Community and Data Management:**
  - Works with ~100 CHWs, conducting awareness activities through churches, business centres, community leaders, and MPs.
  - Record-keeping is online and offline, though internet connectivity is affected by erratic power supply.
  - CHWs meet monthly for updates and training.
- **Breast Cancer Awareness and Referrals:**
  - Cases are referred to Levy Mwanawasa Hospital, CDH, or UTH.
  - Self-assessed levels of breast cancer knowledge:
    - Nurses: 6/10
    - Clinical Officers: 8/10
    - CHWs: 4/10
- **Key Suggestions:**
  - Leverage existing maternal and child health clinic activities for spreading awareness.

- Use the centre's youth-friendly space for project activities.
- Collaborate with Zambian Cancer Society and Breakthrough Cancer Trust for national awareness.
- Create IEC materials in English, Nyanja, and Bemba, incorporating visuals like TV infographics.
- Develop awareness activities alongside training and select local champions to lead initiatives.

Figure 20: Group photo at Chainda

Visit 2: Chelstone Regional Hospital

Figure 21: Meeting with Nurse Rose, standing in for the facility manager.

Key highlights from the meeting with RN Rose Khunga (in charge of OPD):

- **Facility Overview:**
    - Serves a population of about 97,000 people.
    - Staff includes 26 nurses, 8 clinical officers, 4 medical doctors (1 on duty daily), and 1 medical licensure.
    - Cervical cancer clinic has 4 nurses attending to 14 patients daily, with referrals to Levy Mwanawasa Hospital.
    - Works with CHWs who are trained and collaborate on community awareness activities.
- **Breast Cancer Care and Data Management:**
    - No formal record-keeping system for breast cancer screening.
    - High interest in developing monitoring tools and data collection systems, including templates for breast cancer.
    - Recommended integrating breast cancer variables into the existing cervical screening data system.
- **Training Preferences and Opportunities:**
    - PHWs preferred blended learning with live sessions, while CHWs require face-to-face training.
    - Nurses expressed interest in training and emphasised the need for IEC materials with patient pathways outlined.
- **Key Suggestions:**
    - Establish monthly catchups at different levels (master trainers, PHWs, CHWs).

- Utilise IEC materials for awareness and consider partnerships with churches for community outreach.
- Leverage the centre's stable power supply and internet access for virtual training sessions.

Cervical Clinic Visit at Chelstone Regional Hospital

Figure 22: The team interacting with some nurses in training at the cervical clinic

Key highlights from the meeting with Naomi Bulenge, Nurse and Cervical Cancer Service Provider:

- **Clinic Operations:**
  - Four nurses serve 8-13 patients daily, with up to 18 on busy days.
  - Nurses undergo online training on cervical cancer, 1-3 hours daily.
- **Training Needs and Suggestions:**
  - Strong interest in breast cancer training and the development of data collection tools.
  - Suggested IEC materials include patient pathways:
    - **Awareness** → **Triage** → **Screening** (cervical/breast) → **Referral or treatment**.
  - Highlighted the need to support visiting nurses with accommodation, feeding, and logistics during training.

Visit 3: Levy Mwanawasa University Teaching Hospital (Levy Hospital)

Key highlights from the meeting with Dr. Changwe and Dr. Songiso, general surgeons (with Dr. Songiso having a special interest in breast cancer surgery):

- Breast Cancer Trends:
  - The hospital has observed an increasing number of breast cancer diagnoses, but most cases are diagnosed at late stages (3 and 4).

- Challenges in Care Provision:
    - High demand for care far exceeds the available resources, creating a significant supply-demand gap.
    - The centre does not have any surgical oncologist, which limits the scope and specialisation of care.
    - Surgeons are overburdened due to the increasing number of cases; for example, Dr. Songiso performs about 20 surgeries monthly, with 2 being breast cancer surgeries weekly.
- **Referral System:**
    - Unlike primary health centres, Levy Hospital primarily handles referrals rather than walk-in patients.
- **Opportunities for Skill Development:**
    - It was suggested to identify and support general surgeons interested in breast cancer surgery, enabling them to receive specialised training or upskilling.
    - Empowering regional centres with the necessary skills for breast cancer diagnosis and surgery will help:
        - Increase the number of locations where breast cancer care can be accessed.
        - Reduce the workload on surgeons at Levy Hospital.
- **Government Priorities:**
    - The Ministry of Health (MoH) has prioritised primary health care, making it essential to align project efforts with this focus.

Figure 23: Group photo at teh ened of the visit at Chelstone Hospital

Debrief Meeting at GHP Zambia Office

The final activity of the day, and the entire visit, was a debrief meeting at the GHP Zambia Office. Attendees included:

- Charles (GHP UK), Dick (ABS), Jerome (BLUK), Muleba (GHP Zambia), Ndekeela (GHP Zambia), Ethel (GHP Zambia), and Dr. Mwala (CDH).
- Jennipher Kombe Mulonda, Chief Nursing Officer at CDH.
- Dr. George Pupwe, Oncologist from CDH.

These attendees were part of the day's earlier visits and contributed to the discussions.

Figure 24: Ongoing debrief at GHP Zambia office

Key Highlights from the Debrief:

1. Planning Awareness Activities

- It was agreed that awareness activities planning should begin by January 2025, even before the finalisation of the training manual because of the amount of work required.

2. Data Management Tools

- The team discussed the need to either develop a new data management tool or adapt an existing system to monitor project outcomes. CDH will engage MoH to explore integration possibilities.

3. Training Manual Approval Process

- The training manual will need to be submitted for approval, a process that may take up to six weeks. Early submission of the training manual is critical to avoid delays on project's timeline.

4. Permissions for Training PHWs and CHWs

- Approvals for training PHWs and CHWs will need to be secured in advance to avoid any project setbacks.

5. Decentralising Cancer Care

- From the visits and engagements, it is evident that decentralising cancer care is a priority for the government, aligning with the project's objectives.

6. Accessing Existing Guidelines

- The team resolved to obtain the **existing breast cancer care guideline manual** from CDH to align training content with national standards.

7. Training needs assessment questionnaires

- Data collection for PHWs and CHWs is scheduled to commence urgently in the week of November 25, 2024. An action plan will be drafted the following Monday (November 25, 2024) to guide the distribution and collection process.
- The target sample size includes responses from 50 PHWs and 50 CHWs.

8. Incentives for CHWs

- To encourage participation and sustain engagement, incentives for CHWs were proposed. A mini budget will be developed to accommodate this.

9. Mentorship and Sustainability

- The team considered creating a WhatsApp group to support and mentor PHWs and CHWs, ensuring quality and sustainability of the project.

10. Regular Catch-Up Meetings

- Periodic catch-up meetings were proposed between the GHP Zambia team and CDH team to track progress and address emerging challenges.

11. UK Trip Plans

- It was agreed that two people will be selected for the UK trip to maximise impact.
    - Selected: Dr. Mwala and Nurse Jennipher Kombe Mulonda.
    - The trip duration will be reduced to three weeks instead of six, and additional funding will be sought for airfare for the second person.

Conclusion

Day 6 provided comprehensive insights into Zambia's healthcare system, from primary and secondary health facilities to tertiary-level care at Levy Hospital. The enthusiastic response from stakeholders at all levels emphasised the readiness and urgent need for breast cancer care interventions. Key opportunities include leveraging existing community systems, improving data management frameworks, and addressing the specific needs of CHWs and PHWs through tailored training and awareness materials.

The day concluded with a debrief meeting that consolidated the visit's findings and outlined clear next steps, including early planning for awareness activities, securing approvals, and

developing data management tools. These efforts, coupled with capacity-building initiatives such as upskilling surgeons and engaging CHWs, will align with Zambia's government priorities to decentralise cancer care and strengthen primary health care. The visit has laid a strong foundation for impactful, sustainable breast cancer care interventions in the country.

Figure 25: Official end of the visit group photo.

Reflections and Learnings from the Stakeholder Visit

1. **Late Diagnosis and Limited Awareness**
    - **Challenge:** Most breast cancer cases are diagnosed at late stages (3 and 4), with low levels of awareness in communities.
    - **Learning:** Leveraging existing community systems, such as churches and schools, and integrating awareness campaigns into cervical cancer programmes can help address these gaps.
2. **Resource Constraints**
    - **Challenge:** Insufficient numbers of specialised staff (e.g., surgical oncologists, radiologists, pathologists) and inadequate infrastructure for breast cancer screening and treatment.
    - **Learning:** Training general surgeons in breast cancer surgery and equipping regional centres can decentralise care and reduce burdens on tertiary facilities.
3. **Cultural Barriers**
    - **Challenge:** Persistent reliance on traditional and religious solutions delays patients seeking medical care.
    - **Learning:** Collaborating with community leaders, religious organisations, and CHWs can dispel myths and encourage timely medical intervention.
4. **Data Management Gaps**
    - **Challenge:** Lack of robust systems for tracking breast cancer cases and outcomes limits effective monitoring and decision-making.
    - **Learning:** Adapting existing data collection systems, such as those used for cervical cancer, and training data officers can enhance data quality and accessibility.
5. **Training and Logistics**
    - **Challenge:** Blended learning for PHWs and face-to-face training for CHWs require significant resources and careful planning to avoid service disruptions.
    - **Learning:** Training in batches, providing logistical support for participants, and using digital tools like WhatsApp for mentorship can address these challenges.
6. **Stakeholder Engagement**
    - **Challenge:** Securing approvals for training and aligning with government priorities requires proactive engagement.
    - **Learning:** Early collaboration with Ministries of Health and consistent communication with stakeholders are crucial for project success.

Recommendations

1. **Training and Capacity Building**
    - Roll out the 12-week online course for master trainers in January 2025, ensuring alignment with local needs in Uganda and Zambia.
    - Develop a robust training manual, submit it for approval promptly, and align it with existing national guidelines where available. The training manual should be structured into three sections to address the specific needs and roles of the different tiers of trainers and healthcare workers, for example:
        - **Section 1: Master Trainers**
            - Focus: Advanced knowledge of breast cancer care, including:
                - Comprehensive understanding of breast cancer (causes, progression, diagnosis, and treatment).
                - Advanced clinical techniques like biopsies and ultrasound imaging.
                - How to train PHWs effectively using mentorship tools and activity-based learning.
            - Purpose: Equip master trainers to train PHWs and provide technical support.
        - **Section 2: Primary Healthcare Workers (PHWs)**
            - Focus: Mid-level knowledge and skills required for breast cancer screening and early detection, including:
                - Conducting clinical breast exams.
                - Recognising signs and symptoms of breast cancer.
                - Counselling patients on self-examination and referral pathways.
                - Recording and reporting cases accurately.
            - Purpose: Prepare PHWs to cascade training to CHWs and provide frontline care.
        - **Section 3: Community Health Workers (CHWs)**
            - Focus: Basic awareness creation and community engagement skills, including:
                - Explaining the importance of breast cancer awareness and early detection.
                - Teaching women how to perform self-examinations.
                - Identifying cases for referral to healthcare facilities.

        - Using IEC materials to conduct community awareness campaigns.
    - Purpose: Enable CHWs to educate communities, promote self-examinations, and refer potential cases to PHWs or higher levels of care.
- Train selected clinical officers to perform biopsies and ultrasound imaging to expand diagnostic capacity.

2. **Awareness Campaign Planning**
    - Begin planning awareness activities in January 2025. Awareness activities should leverage existing community systems like maternal and child health services, churches, and schools.
    - Develop IEC materials in local languages (e.g., Luganda, Nyanja, Bemba) and English, incorporating visuals like TV infographics and printed guides.
3. **Data Management**
    - Design or adapt data collection tools, integrating breast cancer variables into existing systems (e.g., cervical cancer data platforms).
    - Provide training for data officers to ensure proper use and management of these tools.
4. **Decentralisation of Care**
    - Equip regional centres with skills and resources for breast cancer diagnosis and surgery, reducing burdens on tertiary facilities like UCI and CDH.
5. **Support for CHWs**
    - Provide incentives for CHWs to encourage participation and sustain engagement in awareness activities and data collection.
    - Establish WhatsApp groups for mentorship and support of PHWs and CHWs, ensuring quality and continuity.
6. **Collaboration and Stakeholder Engagement**
    - Maintain periodic catch-up meetings with project teams, healthcare facilities, and stakeholders at different levels.
    - Proactively engage Ministries of Health to align project activities with national health priorities, including approval processes for training.
    - Partner with local organisations like the Uganda Women's Cancer Support Organization and the Zambian Cancer Society to amplify outreach efforts.