

Scottish Government

Malawi Development Programme 2015-2018

End of Year Report – Part 1 of 3

This narrative report should be submitted together with your updated logframe and financial report.

PLEASE READ ATTACHED GUIDELINES BEFORE COMPLETING THE FORM

| 1. Basic Project Information | | |
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| Complete the information below for management purposes. Please indicate in the relevant section whether any changes to your basic project information (e.g. partners, geography, project dates or budget) have occurred during this reporting year. Explanations should be provided in section 3. | | |
| 1.1 | Project Reference Number | M/15/H/001 |
| 1.2 | Reporting Year | From: 01/04/2017 To: 31/03/2018 |
| 1.3 | Project Year (e.g. Year 1) | Year 3 |
| 1.4 | Name of Lead Organisation (Grant Holder)* | NHS Lothian |
| 1.5 | Name of Partner(s)* | Queen Elizabeth Central Hospital, Blantyre |
| 1.6 | Name of Project* | The Edinburgh Malawi breast cancer project |
| 1.7 | Project Description* | To achieve and demonstrate improvement in breast cancer treatment at Queen Elizabeth Central Hospital, Blantyre through development of multi-disciplinary care and enhanced pathology. |
| 1.8 | Project Country/ Region* | Malawi/ Blantyre region |
| 1.9 | Project Start & End Date* | Start: 01/10/2015 End: 31/03/2018 |
| 1.10 | Total Project Budget* | £185,340 |
| 1.11 | Total Funding from IDF* | £185,340 |
| 1.12 | IDF Development Priorities Please tick the box next to the development priority/priorities that your block grant aims to address | <input checked="" type="checkbox"/> Health <input type="checkbox"/> Education <input type="checkbox"/> Civic Governance <input type="checkbox"/> Sustainable Economic Development <input type="checkbox"/> Renewable Energy |
| 1.13 | Supporting Documentation Check box to confirm key documents have been submitted with this report | Up-to-Date Logical Framework (LF) summarising progress against relevant milestones for project activities, outputs, outcomes and impact. <input checked="" type="checkbox"/> |
| | | Please indicate (check box) if you have proposed amendments to your LF since your last report. If so, please detail any changes in Q3.2 <input type="checkbox"/> |
| | | Please indicate (check box) if the LF submitted has been approved by the Scottish Government. <input checked="" type="checkbox"/> |
| | | End of Year Financial Report <input checked="" type="checkbox"/> |
| | | Proposed Revised Budget (if applicable) <input type="checkbox"/> |
| | Please list any further | Annex 2: Oncology Nursing Education Report - Edinburgh |

1. Basic Project Information

Complete the information below for management purposes. Please indicate in the relevant section whether any changes to your basic project information (e.g. partners, geography, project dates or budget) have occurred during this reporting year. Explanations should be provided in section 3.

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| | supporting documentation that has been submitted | Malawi Breast Cancer Project Annex 3: Scottish Trainee Oncologist Review of the QECH Cancer Projects Annex 4: Malawi Breast Nurse Review of the Project Annex 5: Specialist Nurse Review of the Project Annex 6: November 2017 In-Country Visit Annex 7: Pathology report Annex 8: Breast Cancer Staff Questionnaire Feedback Report | |
| 1.14 | Response to Previous Progress Reviews | Scottish Government's comments on previous reports: None received from the September 2017 Report and anything outstanding from previous Reports are covered in this Report. | Action taken since received: We have successfully received a Project extension through to October 2018. This allows us to address in full previous issues raised. |
| 1.15 | Date report produced | 30/04/2018 | |
| 1.16 | Name and position of person(s) who compiled this report | Name, Position: [REDACTED] Project Lead Name, Position: [REDACTED] Project Co-ordinator | |
| 1.17 | Main contact details for project, if changed | | |

Signed by **[REDACTED]**

Date 30 April 2018

Designation on the Project: Project Lead

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| 2. | Project Relevance |
| 2.1 | <p>Project Beneficiaries Does the project remain relevant to the context and the beneficiaries with whom you are working? Please justify this in a short paragraph below.</p> <p>Yes it does, and a summary is as follows: Health support infrastructure: By end Year 3, the aim was to complete the oestrogen receptor testing and to further develop joint working. We can confirm that we have delivered all the identified Activities:</p> <ul style="list-style-type: none"> • ER testing protocol for appropriate patients with breast cancer is established; quality assured by Scottish partners; and confidence of the team to be strengthened during Extension Period • The breast cancer MDT, developed by the cross partner team, is now well embedded as normal working practice for all the health specialists • The IT system for managing follow up and collecting data is now working on internal LAN. The database now holds data on 81 breast cancer cases. • The Malawi National Breast Cancer Symposium on multi-disciplinary breast cancer management and treatment complications was undertaken in Year 2 and reached health specialists across Malawi. It was attended by 18 females, and 15 males. A further Symposium is planned for the Extension Period • A further 5 Staff Questionnaire Feedback Reports have been completed with results and feedback reported below. <p>Patients: 157 female and 3 male patients with breast cancer have been registered at the oncology unit to date. The numbers have increased from 44 in Year 1, to 55 during Year 2, and to 69 in Year 3.</p> <p>Staff: Specialist breast cancer nurse is fully trained and operationally effective. 2 pathology technicians have successfully completed their ER training and are seeking further training in the extension period. 19 oncology staff (3 males and 16 female) were successfully trained as part of the April 2018 oncology nursing education programme run jointly with northern and southern partners.</p> <p>Local region: The Project Team have identified differences between the easily accessible local urban (within 10km of QECH and with some 660,000 population) and the more remote regional rural (>10km from QECH and some 350,000 population). This has led to supporting the Cancer Association of Malawi's (CAM) regional rural sensitisation programme with the QECH team actively involved. The CAM Programme has reached village heads, group chiefs, and local churches. And the Project has assisted in translating breast cancer leaflets and posters into the local language. Up to 30% of the rural population has been reached in these ways. And in addition, 3 local radio stations run question & answer sessions about breast cancer which is likely to have reached up to 50% of the population. Taken together, all of this gives women the courage that breast cancer can be treated and to go to their local clinics for onward referral as appropriate.</p> <p>National Malawi: We have engaged with the National Cancer Registry re the sharing of data. A key outcome of the partnership was the National Breast Cancer Symposium of September 2016 and that planned for the Extension Period.</p> |
| 2.2 | <p>Gender and social inclusion Please describe how your project has worked to ensure that women and girls, and other vulnerable groups (as appropriate) benefit from the project. Describe any challenges experienced in reaching vulnerable people and how these have been overcome.</p> <p>Project aimed at females:</p> <ul style="list-style-type: none"> • 157 females with breast cancer have attended the MDT clinics in the Project to date. • We continue to contribute to the awareness programme with the Cancer Association of Malawi by making information more available to the local female population. |

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| | <ul style="list-style-type: none"> • Of the staff, 75% are female and 25% are male. <p>Local Sensitivity: Together with the Cancer Association of Malawi, the team continue to:</p> <ul style="list-style-type: none"> • Make Health Care workers in the Health Centres more aware of all cancers including Breast Cancer • Engage the local populations in awareness of cancer given the local cultural view that no cancer is treatable and is effectively a 'death sentence' • Specifically make women aware of breast cancer symptoms, give women the knowledge that breast cancer can be treated, and encourage them to go to their local clinics for onward referral to QECH as appropriate. |
| 2.3 | <p>Accountability to stakeholders How does the project ensure that beneficiaries and wider stakeholders are engaged with and can provide feedback to the project? What influence has this had on the project? What challenges have been experienced in collecting and acting on beneficiary feedback?</p> <p>Our stakeholders reportable feedback during Year 3 are set out below:</p> <ul style="list-style-type: none"> • Health Lead, Ministry of Health, Government of Malawi: the 2 Project Leads jointly communicate with her on the importance of cancer treatment. • Malawi Scotland Partnership (MaSP): During each North-South visit, the 2 Project leads communicate with the MaSP to discuss the Project. And the local team report into MaSP project meetings in Blantyre. • QECH management team: Are committed to the Project as evidenced by their recruitment of staff and in the continuous professional training of staff as part of the leadership culture of Dr [REDACTED] • NHS Lothian – local communications via the NHS Lothian bulletin; support trainee staff to undertake learning journey to QECH (see Annex 3 re trainee oncologist); and enable senior staff travel to Malawi twice per annum • Staff: 15 Breast Cancer Staff questionnaires are being completed providing feedback from staff as to the benefits and potential improvements to oncology treatments in QECH. • QECH-Edinburgh Team: In Year 1 the Team jointly prepared the Baseline Report and the training programme (for Blantyre and Edinburgh); and in Years 2 & 3 the Team jointly co-ordinated and delivered the 2016 National Breast Cancer Symposium and the bi-annual training programme. • QECH Team: In Year 3, the in-country team took the lead on the development of the needs side of the education programme. |

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| <p>3. Progress and Results</p> <p>This narrative report on project performance and results will be reviewed together with your revised and updated Logical Framework (or if not yet approved your original Logical Framework). See Guidelines (Annex 1) for details.</p> | |
| 3.1 | <p>Changes to Project Status Has the focus or delivery of your project changed significantly over the last financial year? If so, please explain how and why, and attach copies of all relevant correspondence with the Scottish Government.</p> <p>There is no change to focus of the Project.</p> |

3. Progress and Results

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3.2 Changes to the Logical Framework
 If changes have been made to the logframe since the previous financial year please describe these below. Please also provide evidence (e.g. copies of correspondence) that these changes have been agreed with the Scottish Government. If you would like to make changes to your logframe, but these have not yet been approved by the Scottish Government, please describe and justify in detail the requested changes below – and highlight the proposed changes in the revised logframe.

| Result Area/ Indicator | Proposed/ Approved Change (please clarify and evidence below) | Reason for Change |
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| Year 1 change: Output Indicator: Number of pathology staff at QECH trained in immunohistochemistry | We had assumed the existence of suitable lab facilities. However there was not enough space and Scottish Government agreed a £13k contribution to new facility | The existing facilities at QECH were not large enough to support the immunohistochemistry protocols – as provided in Scotland. The existing facilities were extended to enable appropriate functionality for a successful Project. |
| Year 2 change: Change to Output 3.2 Milestones 1 and 2. | Change to Output 3.2 Milestones 1 and 2 (contained in our Mid-Year Review): <ul style="list-style-type: none"> • <i>Patient and staff interview questionnaires designed and ethics application submitted: delete 'Patient and'</i> • <i>20 patient interviews held, transcribed and translated and results used to design follow up strategy: delete '20 patient' and replace with 'staff'.</i> | Following discussion with the Project Lead in Malawi in September 2016, it was agreed that the focus of ongoing work will be on staff interviews. The principal reasons for this change was firstly, the acknowledgment that a large body of published work had already identified and reported on the main factors that were associated with compliance and follow up; and secondly, it was more complex than initially anticipated in obtaining Ethics Committee approval and then recruiting appropriate staff to conduct and translate patient interviews. It was felt that by focusing on staff interviews we will still receive valuable data that may result in recommendations for promoting robust compliance and follow up for patients with breast cancer. The templates for staff questionnaires were set out in the Mid-Year Review and reported on in Year-end Reports 2 and 3 (below). |

3.3 Gaps in Monitoring Data
 If baseline or monitoring information is not available, please provide an explanation below. Where monitoring data has been delayed (since previous report), please provide an indication of when and how it will be made available to the Scottish Government.

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N/A

3.4 Project Outputs

In the table below, please list each of your project outputs, and provide further detail on your progress and results over this reporting period. Describe any delays or other challenges that you have experienced and how these have been addressed, and provide information about any unexpected results. Progress should be supported with evidence (such as links to monitoring data in line with logical framework, case studies, web-based information, reports etc) where possible.

Output 1: Implementation of oestrogen receptor (ER) testing to allow appropriate targeted use of anti-oestrogen therapy (tamoxifen).

Output Indicator

1.1 Number of pathology staff at QECH trained in immunohistochemistry.

Progress against Planned Milestone/ Target

Milestone (31/03/2016): Core pathology staff at QECH pathology department successfully trained in IHC.

Achieved: In order to facilitate this, the team extended the existing pathology facilities to provide sufficient space – agreed by Scottish Government.

Two technicians successfully completed their training on oestrogen receptor testing at Kamuzu Central Hospital, Lilongwe. Face-to-face discussions between [REDACTED] and the two technicians highlighted the importance and usefulness of this training (report previously included). The main learning point was to recognise the importance of sharing expertise within Malawi to ensure long term sustainability of pathology training.

Pathology training was received in September 2016 by [REDACTED] and the team were reviewed jointly by [REDACTED] and the Scottish team in April 2018. Report of the Extension Period recommendations are set out at Annex 7.

Milestone 2 (31/03/17): End of year 2 report confirms numbers of pathology staff competent to perform oestrogen receptor testing.

Achieved: 2 staff have gone through 2 levels of training and are better equipped to be confident in performing ER testing. Between Sep 16 and April 17 further modifications were made to the pathology protocols in collaboration with the Canadian team, in order to ensure that they are optimised for the Malawi setting.

Milestone 3 (31/03/18): In-house training of all pathology staff completed to ensure sustainability of development. Estimate is 6 members of pathology staff trained at QECH with capacity to extend training elsewhere.

Achieved: In-house training of all pathology staff completed to ensure sustainability of development. 4 members of pathology staff trained at QECH with capacity to extend training elsewhere. Quality also checked in Scotland leading

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| | | <p>to increased confidence and sustainability.</p> <p>Extension Target: ensuring international quality by Canadian [REDACTED] reviewing progress with review of quality of pathology testing and ensure adequate staff capabilities for delivering a sustainable service.</p> <p>On target: capacity building training to be provided in the Extension Period.</p> |
| | <p>1.2 Number of patients for which eostrogen receptor testing performed at QECH.</p> | <p>Milestone (31/03/2016): First cohort of 10 patients for testing identified.</p> <p>Achieved: 10 patients have been Identified and there is ongoing work on protocol development (by the northern and southern teams) and procurement of appropriate equipment in Malawi to enable the testing to be initiated.</p> <p>In collaboration with the pathology team from Toronto ([REDACTED]) we secured pathology immunohistochemistry equipment both from a supplier in South Africa and through a collaboration with the Pathology Unit in Lilongwe where it was felt that sharing of reagents was likely to be more economical. The main challenge was to try and keep to the Project schedule despite delays in the process of ordering and receiving equipment. We also recognised that extra equipment was required including a new refrigerator to ensure stability and security of some of the reagents (reported previously).</p> <p>Milestone 2 (31/03/17): Testing for first cohort of 10 patients successfully completed and routine testing for new cases established.</p> <p>Achieved: lab equipment use demonstrated and staff trained in the immunohistochemistry protocol. The first 10 patients with breast cancer had ER testing performed. Quality Control was performed by retesting the same samples in the pathology lab in Edinburgh which confirmed the results are valid.</p> <p>A second cohort of 10 patients has been identified in order to perform further testing and validation of the protocol which will confirm whether results are reproducible. Routine testing of cases will only be initiated once the pathology team are happy that the results are of a suitable standard for clinical use. Some challenges have been noted including ensuring that the reagents are kept at a constant temperature and that refrigeration and electricity supply remain secure.</p> <p>Milestone 3 (31/03/18): End of project review of pathology service confirms high quality assurance of results and sustainability of service. Estimate is 50 women with breast cancer in year 3.</p> <p>Partially achieved/ongoing: NHS Lothian have confirmed quality of pathology service and 15 women tested although there is ongoing work to optimise pathology service to ensure</p> |

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| | | <p>sustainability of enhanced service (See Annex 7)</p> <p>Extension Target: ensuring high quality <u>international</u> assurance of results and sustainability of service</p> <p>On target: capacity building training to be provided in the Extension Period.</p> |
| Output 2: Implementation of multi-disciplinary breast cancer care ensuring high quality, holistic patient care. | | |
| | <p>2.1 Number of staff taking part in breast cancer MDTs and joint clinics.</p> | <p>Milestone (31/03/2016): Recruitment and training of Malawian breast care nurse successfully completed and MDT formed.</p> <p>Achieved: Oncology breast cancer nurse has completed oncology training.</p> <p>Visit to Edinburgh Cancer Centre: 3 members of the team (2 male and 1 female) had a full hands-on programme of activities at ECC observing MDT breast cancer working and learning about the role of a breast care nurse (BCN). Their update was previously reported. One of the key learning points from this visit was the recognition of the central role of the pharmacy team as part of an integrated cancer team to ensure safe delivery of treatment and adequacy and stability of drug supplies.</p> <p>During the September 16 visit it was evident that the role of the breast care nurse was progressing well and there was an agreement for him to start attending the breast surgery clinics to ensure that patients are reviewed and supported at the earliest stage of the treatment pathway. It was also acknowledged that further work was required in order to clarify the specific priorities of the BCN role. Our intention was that this prioritisation would be driven by what aspects of the care pathway were thought to be most important from the BCN point of view but it became clear that the BCN was seeking specific guidance on this from the oncology lead in Malawi. A report on the BCN role was previously included.</p> <p>During the April 17 visit a meeting between the BCN and the surgical and oncology team took place to review recent progress. It was agreed that experience in the new role had provided valuable learning and experience across all areas of breast cancer care but that for the next 12 months the focus should be on supporting the oncology service, MDTs and the 'one stop' breast cancer clinic and that other areas of breast cancer nursing care (such as supporting the general breast surgical clinic) would be delegated to other members of staff.</p> <p>Throughout Year 3, the BCN has been concentrating his time on activities centered around multi-disciplinary care of patients with breast cancer.</p> |

3. Progress and Results

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| | | <p>Milestone 2 (31/03/17): Educational workshop on breast cancer MDT working and Malawi Breast Cancer Symposium completed with national representation and positive feedback.</p> <p>Achieved: The QECH Team planned the Malawi National Breast Cancer Symposium held in September 2016 for specialists in oncology, pathology, surgery, palliative care from both Blantyre and other parts of Malawi. In particular there was the opportunity to discuss integrated care of patients with breast cancer across all specialties which supports the partnership's MDT model of integrated breast cancer care and which will be a key development that will support the sustainability of our Project. Evaluation of the symposium was previously reported on.</p> <p>A nurse led programme of education on chemotherapy and management of breast cancer was completed in Year 2 as reported. An evaluation was completed and positive feedback was received both from attendees at the course and from the BCN; 'The week was fantastic. I have learnt a lot and I am looking forward to seeing you in Malawi next time'.</p> <p>Re the training undertaken during Year 2, one key positive outcome is that of the 5 day programme, the local team delivered 3 days of training. Helpfully [REDACTED] delivered complementary training in June and an agreement was been made to continue to co-ordinate a nursing education programme with [REDACTED] team from Dublin.</p> <p>Milestone 3 (31/03/18): All members of the breast cancer team (surgery, oncology, pathology, radiology, palliative care) take part in MDTs as part of the routine management of patients with breast cancer at QECH. Estimate is approximately 15 members of the MDT team.</p> <p>Achieved: All members of the breast cancer team (surgery, oncology, pathology, radiology, palliative care) take part in MDTs – as their availability allows. The Project Leaders have reviewed and amended staff workloads with a view to prioritizing them re contributing to MDTs.</p> <p>Extension Target: Added value national awareness raising via delivering a summer MDT Symposium in Blantyre to consolidate MDT practice and raise awareness of the benefits across Blantyre and Lilongwe health communities.</p> <p>On Target: MDT Symposium being arranged.</p> |
| | <p>2.2 Number of patients treated by the multi-disciplinary team.</p> | <p>Milestone: (31/03/2016): Format of breast cancer MDTs agreed.</p> <p>Achieved: The breast care nurse is well established as the MDT co-ordinator and he has initiated combined oncology/surgery clinics. These are now running weekly. This demonstrates staff capability development – part of our</p> |

3. Progress and Results

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Sustainability Strategy.

In Year 2, 21 patients were reviewed in the MDT with the patients themselves forming part of a 'second and patient stage' of MDT consultation. This is a local Malawi adaptation that includes the MDT discussing the case directly with the patient. This step does not happen in the UK.

A key learning point is the importance of collecting data for patients presenting with breast cancer to the surgical clinic in order to estimate whether there were potentially a large number of patients who may benefit from oncology input and weren't attending the oncology unit.

Milestone 2 (31/03/17): Breast cancer MDT established for all new cases at QECH facilitated by breast care nurse.

Achieved and continuing: To facilitate this Milestone, [REDACTED] from QECH and [REDACTED] from NHS Lothian jointly delivered the September 2016 training programme on MDT breast cancer care and safe chemotherapy delivery. They worked in advance of the day so that all on-site issues were identified upfront and addressed. The full report of the education programme and evaluation was previously included.

Although during the education programme there was further training regarding the use of a standardised chemotherapy prescription, the QECH ward staff felt that additional training was required before adopting this change of practice. This was the focus of further work in Year 3. It was agreed that modifications of the proposed chemotherapy prescriptions would be piloted to ensure that they could be reliably used in the Malawi setting.

We are continuing to build on the Oncology Project (Edinburgh Malawi Cancer Partnership Project (MW31)), by working alongside [REDACTED], Specialist Cancer Nurse Manager (Ireland) as part of our partnership on the education side. This has ensured that the education courses are delivered more regularly to ensure that existing staff are more confident in their delivery and new staff are trained as early as possible. This has a positive effect on the sustainability of the MDT approach.

It was also recognised via the Year 2 Staff Interviews that it would be good to have radiology and pathology representatives at the MDTs. This was immediately implemented.

Milestone 3 (31/03/18): All patients presenting to QECH with breast cancer treated after MDT discussion. Estimate is 120 women per year (based on 2013-14 presentation rate).

To accommodate the overall cancer caseload the MDT

3. Progress and Results

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| | | <p>process has been adapted so that the MDT considers difficult, complex and unusual cases rather than all cases. From November 2017 – March 2018 136 women (including 32 breast cancers) and 16 men have been reviewed in the MDT.</p> <p>Extension target: With the added value of using follow-up data for all patients and to chase up patients who have not returned for appointments/gone missing.</p> <p>On target: we continue to collect these data which will be presented in the end of project report.</p> |
| <p>Output 3: Development of systematic follow up for patients with all stages of breast cancer informed by qualitative work on compliance with treatment.</p> | | |
| | <p>3.1 Number of staff completing qualitative interviews on follow up and non-compliance.</p> | <p>Milestone: (31/03/2016): Staff interview questionnaires designed and ethics application submitted. (Please refer to Section 3.2 above)</p> <p>Achieved: Outline questionnaire had been agreed by the Team but after further discussion with the Project Lead in Malawi it was agreed that the focus of ongoing work will be on staff interviews only and not including patient interviews. The principal reasons for this change was firstly, the acknowledgment that a large body of published work had already identified and reported on the main factors that were associated with compliance and follow up. Secondly, it was more complex than initially anticipated to obtain Ethics Committee approval and then recruit appropriate staff to conduct and translate patient interviews. It was felt that by focussing on staff interviews we will still receive valuable data that may result in recommendations for promoting robust compliance and follow up for patients with breast cancer. Templates for staff questionnaires (previously reported) have now been completed and we are focusing on finalising the staff interviews in Year 3.</p> <p>Milestone 2 (31/03/17): staff interviews held, transcribed and translated and results used to design follow up strategy.</p> <p>Achieved: A full report on the 5 staff Breast Cancer Staff Questionnaires was previously submitted. In summary, for the completed Staff Questionnaire which covers both staff views of the Project AND their perceptions of patients' views. They:</p> <ul style="list-style-type: none"> • welcomed the Project and the opportunity to train in Breast Cancer • wished for more training (especially exchange visits) and for more drugs, equipment and facilities • were concerned about the transport costs for patients, many of whom they feel travel far to come to the Unit. As a result they tend not to attend follow-up clinics |

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- consider patients need to know more about cancers
- consider there needs to be more outreach/sensitisation or clinics held in some of the Districts
- consider the database has made it easier to find information about patients.

Milestone 3 (31/03/18): Staff interviews completed to gain their perspective on progress and to inform MDT development. Estimate is 15 (actual is 10) members of staff.

Achieved: We have completed 10 comprehensive interviews of staff members. A summary of the final 5 questionnaires provided by – 3 Doctor/Clinician, 2 Support staff; 4 males and 1 females) is that they:

- welcomed the Breast Cancer Centre, Path Lab, the new skills being learned and working as a team
- wished for more resources to ensure sustainability; and more exchange visits with Edinburgh
- future priority is increased material & human resources; collaboration & capacity building; training
- consider patients transport needs and unbearable side effects of chemo treatments
- consider patients poverty and knock on family issues; outreach clinics
- need internet re patient follow-up but database makes it easier to find information about patients.

The feedback and that of the previous year, supports our recent application for funding for additional MDT; training and education; and community engagement.

3.2 Number of patients for which robust follow up data obtained 6 and 12 months following diagnosis.

Milestone: (31/03/2016): NHS Lothian and QECH staff agree templates for use in data collection which will suit the emerging multidisciplinary ways of working.

Achieved: Templates have been agreed for data collection – through a north-south working exchange and drawing on the experience of the previous Oncology Project (Edinburgh Malawi Cancer Partnership Project (MW31)). The data clerk (**REDACTED**) is leading the collection of follow up data. The main challenge is to keep up to date with data entry in the face of increasing clinical workload and strategies for prioritisation of work have been agreed and implemented.

Milestone 2 (31/03/17): Data systems and user protocols established in QECH.

Achieved and continuing: The team are very aware of the need to have good quality data and work towards ensuring it is kept up to date despite the very busy clinics and schedules.

Reliable internet access continues to be an issue so upgrades were made early in Year 3 visit to the portal and database to make it more standalone and ensure it is available at all times.

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| | | <p>Back ups are taken on a daily basis and stored separately from the main systems to ensure integrity of the data.</p> <p>Upgrades to the reporting system have helped with analysis of the data and demonstrated again to the team the need for good quality data being entered into the system. It is clear that the importance of high quality clinical data is acknowledged by the QECH team which is evidenced by the increased quality of clinical record keeping and accessibility of medical records.</p> <p>In Year 3 the local team have focused on ensuring a working LAN network and with minimal/no wi-fi connectivity.</p> <p>The lessons learned are that we need to be pragmatic about the use of IT and that a working local LAN solution is a good compromise. This will also reduce the running costs of internet connectivity and therefore make the data systems more sustainable in the long run.</p> <p>Milestone 3 (31/03/18): End of project report confirms complete follow up data achieved for all patients at QECH oncology unit with breast cancer. Estimate is 60 patients in year 3.</p> <p>Achieved: Data collection continues and will be presented for new and recurrent patients and by stage of cancer in the final report.</p> <p>Extension Target: The added value of the Blantyre data team ensuring more complete follow-up data for all patients and chase up patients who have not returned for appointments/gone missing.</p> <p>On target: data systems under review</p> |
| | <p>3.3 Number of patients diagnosed with breast cancer across all specialties in QECH established for use by National Cancer Registry.</p> | <p>Milestone: (31/03/2016): Initial meeting with Cancer Registry Staff to discuss data strategy successfully completed. Data collection system successfully piloted.</p> <p>Achieved: In Year 1, at meeting with the National Cancer Registry, [REDACTED] established the strategic aim of having both the Cancer Registry and Breast Cancer data systems able to 'talk to each other' to provide richer and more usable data. Since then both teams worked together and in Year 2 linked the 2 data systems and specifically the capture of outcome data following treatment.</p> <p>Milestone 2 (31/03/17): Mid-point meeting with Cancer Registry staff to refine strategy successfully completed.</p> <p>Achieved: During the September 2016 visit it became apparent that Cancer Registry staff were still collecting data direct from oncology medical records rather than from the clinical database so a meeting was set up with the lead of the Cancer Registry to discuss and address this matter. The 2 data systems are now linked as set out above.</p> <p>Lesson learned: A key learning point from the September 2016 visit is the importance of collecting data for patients</p> |

3. Progress and Results

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| | | <p>presenting with breast cancer to the surgical clinic in order to estimate whether there were potentially a large number of patients who may benefit from oncology input that weren't attending the oncology unit at present. As a result of this a proposal has been submitted to other members of the breast cancer team for a breast cancer registry that will attempt to capture data from the whole hospital rather than simply for those attending oncology.</p> <p>Milestone 3 (31/03/18): End of project report confirming use of QECH cancer unit data for National Cancer Registry figures confirmed. Estimate is 120 patients with breast cancer across QECH in year 3.</p> <p>To be confirmed: Provisional data shows there were 87 presentations to oncology and the breast clinic during 2017. Data will be finalised and a report submitted.</p> | | | | |
|---|---|---|-------------------|--|---|---|
| Please add additional outputs/ indicators as required | | | | | | |
| 3.5 | <p>Project Outcomes In the table below, please list your project outcome, and provide further detail on your progress and results over this reporting period. Please describe any delays or other challenges that you have experienced and how these have been addressed, and provide information about any unexpected results. Progress should be supported with evidence (such as links to monitoring data, case studies, web-based information, reports etc) where possible.</p> <p>Outcome: To achieve and demonstrate improvement in breast cancer treatment at Queen Elizabeth Central Hospital, Blantyre through development of multi-disciplinary care and enhanced pathology</p> <table border="1" data-bbox="252 1256 1514 2031"> <thead> <tr> <th data-bbox="252 1256 703 1292">Outcome Indicator</th> <th data-bbox="703 1256 1514 1292">Progress against Planned Milestone/ Target</th> </tr> </thead> <tbody> <tr> <td data-bbox="252 1292 703 2031">1 Number of staff trained in MDT working and taking part in breast cancer MDTs and joint clinics.</td> <td data-bbox="703 1292 1514 2031"> <p>Milestone 1 (31/03/2016): Breast care nurse appointed, training undertaken and format of breast cancer MDTs agreed</p> <p>Achieved: Nurse appointed in February 2016 with good nursing skills, now upskilled in oncology and with skills expanding on the job. He has adopted a leadership role in further development of the MDT as discussed above.</p> <p>Further: During the Sep 2016 visit [REDACTED] spent time in the breast cancer surgical clinic which gave them a different perspective on the breast cancer pathway and emphasized the challenges around patient support and timelines for referrals to oncology and initiation of chemotherapy.</p> <p>The key learning point was the recognition that there are areas that the BCN should focus on and it was also agreed that the BCN will spend some time in the surgical clinic gaining experience of this part of the cancer care pathway.</p> <p>Milestone 2 (31/03/17): Educational workshop on breast cancer MDT working and Malawi Breast Cancer Symposium completed.</p> <p>Achieved: 3 staff (2 male and 1 female) were in Edinburgh in Year 2 and had a week's immersive training in MDT at the</p> </td> </tr> </tbody> </table> | | Outcome Indicator | Progress against Planned Milestone/ Target | 1 Number of staff trained in MDT working and taking part in breast cancer MDTs and joint clinics. | <p>Milestone 1 (31/03/2016): Breast care nurse appointed, training undertaken and format of breast cancer MDTs agreed</p> <p>Achieved: Nurse appointed in February 2016 with good nursing skills, now upskilled in oncology and with skills expanding on the job. He has adopted a leadership role in further development of the MDT as discussed above.</p> <p>Further: During the Sep 2016 visit [REDACTED] spent time in the breast cancer surgical clinic which gave them a different perspective on the breast cancer pathway and emphasized the challenges around patient support and timelines for referrals to oncology and initiation of chemotherapy.</p> <p>The key learning point was the recognition that there are areas that the BCN should focus on and it was also agreed that the BCN will spend some time in the surgical clinic gaining experience of this part of the cancer care pathway.</p> <p>Milestone 2 (31/03/17): Educational workshop on breast cancer MDT working and Malawi Breast Cancer Symposium completed.</p> <p>Achieved: 3 staff (2 male and 1 female) were in Edinburgh in Year 2 and had a week's immersive training in MDT at the</p> |
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3. Progress and Results

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| | | |
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| | | <p>Edinburgh Cancer Centre. Their update was previously reported. This visit helped to support a team approach to cancer care and emphasized the important role of the cancer pharmacist in supporting safe delivery of chemotherapy and stability of drug supplies.</p> <p>In Year 2, 20 staff attended the September education programme (previously reported), 33 attended the breast cancer symposium (full report was provided), 3 staff attended the UK visit and several ongoing clinical audit projects by members of the Malawi oncology team have been initiated in order to obtain further data on treatment pathways and outcomes for patients attending the oncology unit. These have been presented at both local and International meetings. A summary paper describing the development of multidisciplinary breast cancer care in Southern Malawi was published in the European Journal of Cancer Care.</p> <p>Milestone 3 (31/03/18): Self-sufficiency of team-based model of care established with assurance that the breast cancer programme is sustainable, can be adopted by other Malawian hospitals and meets international standards.</p> <p>Progressing into Extension period: As QECH team are now progressing towards leading the Education Programme we are en route to self-sufficiency of a team-based model of care; and external colleagues forming part of the Symposium means that MDT is already being adopted by other Malawian hospitals. Further training took place during our April 2018 visit (19 staff attended; 16 females, 3 males - see Annex 2) with ongoing discussions taking place with Kamuzu College of Nursing re developing a country wide, sustainable model of oncology nursing education.</p> <p>Extension Target: Building local & national capacity by:</p> <ul style="list-style-type: none"> • the Blantyre team delivering a 6-month nursing education training programme. • externally reviewing the team’s training delivery – adding quality assurance and making the MDT more resilient and ready for future growth. • holding MDT symposium with Blantyre and Lilongwe breast cancer colleagues, enabling us to gain information about the indirect benefits of the Project for patients throughout Malawi. <p>On target: Education Programme under review; and symposium currently being planned.</p> |
| | <p>2 Number of patients treated by the multi-disciplinary team (including use of enhanced pathology) with complete follow up.</p> | <p>Milestone (31/03/2016): Core pathology staff at QECH pathology department successfully trained in IHC and strategy for data collection agreed.</p> <p>Achieved: Two technicians successfully completed their training on oestrogen receptor testing in 2016 at Kamuzu</p> |

3. Progress and Results

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Central Hospital, Lilongwe. 4 pathology staff received further training from [REDACTED] team during the September 2016 and April 2018 visits.

Templates have been agreed for data collection – through a north-south working exchange and drawing on the experience of the previous Oncology Project (Edinburgh Malawi Cancer Partnership Project (MW31)).

At the April 2016 meeting with the National Cancer Registry, [REDACTED] discussed and agreed the linking of the 2 data systems and specifically the capture of outcome data following treatment. This has now been implemented.

(Milestone 2 31/03/17): ER testing and breast cancer MDT established at QECH.

Achieved: Staff from QECH and [REDACTED] from NHS Lothian have jointly delivered the September 16, April 17 and April 18 training programmes on MDT breast cancer care and safe chemotherapy delivery. Both teams work together in advance so that all on-site issues are identified upfront and addressed.

Reports of each education programme have been provided and the programme for April 2018 is set out at Annex 2. Positive evaluations have been received and suggestions for future content discussed.

The first cohort of breast cancer cases have been tested for ER with quality assurance given by NHS Lothian. And MDT continues to evolve and with representation from further departments including radiology and pathology.

Milestone 3 (31/03/18): End of project report confirms ER testing and robust follow up data achieved for all patients at QECH with breast cancer.

Achieved: ER testing currently assured by NHS Lothian as providing a quality controlled output. The team are also strengthening data to support follow-up being achieved for all breast cancer patients.

Extension Target: adding value by undertaking

- international quality path lab training specialized for breast cancer.
- the management use of data on patients who have failed to attend for follow up visits will bring the patient care pathway into line with best practice in the UK.

On Target: [REDACTED] engaged in path lab review; and management and data systems under review re patient follow up.

Please add additional indicators as required

3. Progress and Results

This narrative report on project performance and results will be reviewed together with your revised and updated Logical Framework (or if not yet approved your original Logical Framework). See Guidelines (Annex 1) for details.

3.6 Project Impact

In the table below, please list each of your project outcomes, and provide further detail on your progress and results over this reporting period. Please describe any delays or other challenges that you have experienced and how these have been addressed, and provide information about any unexpected results. Progress should be supported with evidence (such as links to monitoring data, case studies, web-based information, reports etc) where possible.

Project Impact: Improved healthcare for women in Malawi through multi-disciplinary treatment for patients with breast cancer.

Impact Indicator

Number of women in Malawi with breast cancer treated by multidisciplinary team with the use of a new clinical pathway including enhanced pathology.

Progress against Planned Milestone/ Target

Milestone 3 (31/03/18): QECH established as a 'centre of excellence' for team-based breast cancer treatment for other centres in Malawi to follow. End of project report confirms robust data on breast cancer clincopathological features including ER status and treatment outcomes available for all patients with breast cancer presenting in Southern Malawi.

In Year 1: we saw an added value approach to MDT emerging – the multidisciplinary team meet professionally to discuss the case; and then meet with the patient (at a 'second and patient stage') to discuss her/his condition. This is not something that currently happens in Scotland and is a lesson learned. It is an example of the Malawian team adapting UK oncology practice to suit local needs.

In Year 2: we saw the MDT evolving to include a number of other specialties including pathology and radiology which will help to ensure that clinical decisions are truly multidisciplinary. And we undertook a Malawi-wide MDT training session and a Breast Cancer Symposium at QECH.

In Year 3:

1. A focus on local team leading MDT training sessions at QECH with Scottish Partners reviewing and supporting to ensure quality team-based breast cancer treatment and ensuring training capable of being used in other centres in Malawi.
2. We now have robust data on breast cancer clincopathologic features including ER status and treatment outcomes will be developed for all patients with breast cancer presenting in the Extension period.

Extension Target: And shared MDT learning via a Blantyre-Lilongwe MDT Symposium.

On Target: Symposium being programmed.

3.7 Risk Management

If progress towards delivering activities and outcomes is slower than planned or there have been delays in the delivery of the project, please explain: a) What the issues have been and

3. Progress and Results

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| whether they were highlighted on your risk register? b) What actions have been taken in response to these issues? | | | |
|---|-------------------|-------------------------|---|
| Issue/ Risk | On risk register? | Action Taken | Outcome |
| <ul style="list-style-type: none"> • No identified risks emerging • Additional Issue: | | | |
| Year 1: Length of time taken to secure visas for team to come to Scotland in 2016 | No | Awaited issuing of visa | Knowledge Exchange visit slipped from March to June 2016. |
| Please add additional issues as required | | | |

4. Sustainability

| | |
|-----|---|
| 4.1 | <p>Partnerships Provide a brief description of the roles and responsibilities of all partners, including in M&E. Have roles and responsibilities changed or evolved? Please provide a brief assessment of your partnership, including its strengths, areas for improvement and how this will be addressed. This section should be completed by lead partners based in Scotland and Malawi.</p> <p>Partnership roles and responsibilities have not changed.</p> <ol style="list-style-type: none"> 1. [REDACTED] is the Project Lead in Scotland providing leadership for the team and along with [REDACTED] is responsible for M&E. [REDACTED] leads the oncology education programme and [REDACTED] and [REDACTED] is responsible for working with the Malawi team to further develop the new breast cancer oncology nursing role. 2. [REDACTED] is the Project Lead in Malawi and is responsible for leading Malawi team on all aspects of the project including M&E. 3. Good quality data is very important to demonstrate the Project's success and we are pleased by the close working relationship that has developed between the teams in QECH and Scotland ([REDACTED]). There is close working with the National Cancer Registry. This data partnership is crucial to providing the evidence base for the Project – and especially so with the IT wi-fi and user issues. By amalgamating data this will add a further professional level to the upkeep of the IT system and the sustainability of the data. 4. The main strengths of the partnership include the firm working relationships between Scotland and Malawi partners from which mutual benefit is achieved, and the focus on ensuring that all aspects of the project are based on local need and reflect local culture, all in support of the realities of building long term sustainability. 5. An ongoing challenge is the changing staffing situation which we try to reduce by ensuring that multiple staff members are trained across all aspects of the project; and that the programme of CPD (via the training provided) encourages staff to stay in Cancer Care at QECH and grow their skills and career opportunities. 6. [REDACTED] recruited as a new oncologist at QECH in April 17 is working well with [REDACTED] and [REDACTED]. Agreement was reached that it was important to develop increased pathology capability including a high quality immunohistochemistry service to guide clinical management for patients with breast and other cancers. If this is a successful part of the project, it is anticipated that future funding for this service would potentially become part of core pathology funding from the Ministry of Health. |
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4.2

Exit Strategy

Describe the key components of your exit strategy and outline progress towards achieving it. Provide any other achievements or progress towards ensuring that your project remains sustainable in the longer term (including in relation to local ownership and capacity, and resourcing). Describe any challenges and how these will be addressed.

In Year 3 of the Project, the exit strategy continues to evidence sustainability – and will be helped by the Extension Period added value work.

1. Economic – Hospital business model

- Cancer treatment has been absorbed as an integral part of the QECH service as evidenced by the recruitment and training of staff and the inclusion of chemotherapy drugs on the Essential Drug List funded by the Ministry of Health.
- Staff capability and capacity to deliver across the MDT teams is encouraging a sustainable collaborative approach to breast cancer care– and this forms the basis for the staff training programme.
- Joint working across the Scottish and Malawi teams is strongly in place and working well – evidenced by the staff training being led by the local team and reviewed for quality by the Scottish Team.
- The QECH team is developing and maintaining stand alone patient databases; with little day-to-day support required from the northern partners (helped by experience gained in the previous Cancer Partnership Project (MW31)). That said the QECH team still needs support from the Scottish Team to upgrade the systems. In Year 3 we put a mentoring system in place AND by linking with Cancer Registry data we are building more resilience to the IT function. The priority for the database is for it to be used to assist and evidence improved clinical care and patient follow through.

2. Environmental – Hospital facilities and actions:

- The extended pathology lab is providing a good and necessary facility for lab work
- Training of staff in the safe handling and delivery of chemotherapy has been completed which is encouraging a long term culture of safe practice with bio-hazardous material.
- We are proactively encouraging patients in a healthy lifestyle – in support of the Cancer Association of Malawi, we have provided cancer prevention/awareness and breast checking information (in the local language) and the local team has undertaken many talks about breast cancer.

3. Social – Blantyre, Southern Region and Malawi

- The project is aimed at promoting high quality, safe and effective treatment for patients with breast cancer within the Blantyre Region. This is of direct benefit to all of Blantyre’s population (at female and family levels) as QECH is referred cancer patients from the entire Southern Region of the country (population of around 6 million). We are working with our Southern partners to collect data on the urban-rural split; and the proposed sensitisation programme alongside the Cancer Association of Malawi should increase the number of females attending the clinics - as they will better understand the symptoms of breast cancer.

| | Total | Male | Female |
|------------------|--------------|-------------|---------------|
| Blantyre (Rural) | 340,728 | 164,766 | 175,962 |
| Blantyre (City) | 661,256 | 336,234 | 325,022 |

The data provides us with a Project reach as follows:

| | | | |
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| | <p> </p> | <p>Examining the district of residence of breast cancer cases shows 31% come from Blantyre District, 17% from Thyolo, 9% from each of Chiradzulu and Mangochi districts and 6% from both Mulanje and Zomba districts. The over representation of patients living near to QECH suggests that people from remote areas are having difficulty accessing the specialist cancer unit. Forty per cent of all cancer types come from Blantyre district – again suggesting distance decay effect.</p> | |
| | <ul style="list-style-type: none"> • The registration rate to the oncology database is 61/100,000 for Blantyre and not more than 7/100,000 for other districts - this will be further analysed for the final report and emphasises the importance of outreach work. • In the Extension Period we will explore how we measure the increased indirect benefit throughout Malawi as we share knowledge MDTs via the planned Symposium. | | |

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| <h2>5. Learning and Dissemination</h2> | |
| <p>5.1</p> | <p>Lessons Learned Describe briefly any lessons learned during this reporting period, and how it will influence the project and your work moving forward.</p> <p>During Year 1 the Project identified the need for strong local partners in pathology rather than dealing exclusively with Northern partners. We considered this to be the best way to build sustainability and where possible ensure that local collaboration to share expertise and reagents is enabled. During Year 2, the Project Leads have identified the Canadian Project as a valuable Northern Partner with expertise in the important issue of quality control of new pathology services. Details of this are contained at Annex 7.</p> <p>In Year 2 there are ongoing issues with reliability of WiFi and the clinical database which can sometimes take time to resolve. Despite this it is clear that the culture of improved clinical record keeping has meant that when the database is not operational the clinical service continues to function well due to the improved quality of the written clinical records.</p> <p>On the pathology side good progress was made although there was some frustration by clinical colleagues that ER testing is not ready for clinical use. Discussions took place to emphasise the importance of good quality control before routine testing could be considered.</p> <p>The BCN role has developed well although it became clear that the job description has been too broad and the workload unsustainable. Agreement was therefore been reached to focus the job description on aspects of the role that will support the breast cancer oncology service and the BCN's</p> |

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| | <p>own personal development.</p> <p>It became clear that it was nearly time to hand over leadership of the nursing education to the Malawi team given the success of the Malawi led teaching during the April 17 visit. The Edinburgh team (in collaboration with Paul Troy) will now have a supporting rather than a leadership role.</p> <p>In Year 3 and to resolve IT connectivity issues, the focus has been to ensure a strong LAN network within QECH. The internal data systems are now more robust. We are currently trying to work out how to get wi-fi connectivity for Skype meetings.</p> <p>Review of progress with the ER testing identified a number of important issues with the quality and capacity of the basic pathology service which need further exploration during the extension period (Annex 7).</p> |
| 5.2 | <p>Innovation and Best Practice</p> <p>Summarise briefly any examples of innovations/ innovative approaches or best practice demonstrated by your project during this reporting period. Please explain why these are innovative or best practice, and detail any plans to share these with others.</p> <p>We have successfully engaged with a range of organisations (in Malawi, UK and Canada) with the intent of ensuring long term sustainability of pathology testing by assessing new pathology testing techniques (such as gene expression technologies currently used in TB and HIV clinics). We plan to set up a pilot study to test in parallel with the ongoing traditional methods once the local ER testing has achieved adequate quality control. We have ongoing discussions with Kamuzu College of Nursing regarding becoming a formal partner in support of their new oncology nursing degree course in Malawi.</p> |
| 5.3 | <p>Dissemination</p> <p>Summarise briefly your efforts to communicate project lessons and approaches to others (e.g. local and national stakeholders in Scotland and Malawi, academic peers etc). Please provide links to any learning outputs.</p> <ul style="list-style-type: none"> • In Year 1 a publication setting out the progress of the Partnership to date (<i>The Edinburgh Malawi Cancer Partnership: helping to establish multidisciplinary cancer care in Blantyre, Malawi</i>) has stimulated other potential partners in expressing an interest in collaborating in the Project. • In Year 2 – the European Journal of Cancer Care published the article ‘<i>Development of multi-disciplinary breast cancer care in Southern Malawi</i>’ jointly authored by the north-south partnership. • In Year 2 the project team attended the SMP Health Links Forum where there was an opportunity to discuss the project with potential collaborators including the Glasgow project team who plan to develop a research hub in Blantyre. • In Year 3 a manuscript summarising the oncology nursing education programme has been drafted for submission to a global oncology nursing journal. It will be submitted during the Extension Period. • In the Extension Period the project team will lead a plenary session on Global Oncology at the Scottish Oncology Summit. |
| 5.4 | <p>Wider Influence</p> <p>Briefly describe any intended or unintended influence on development outcomes beyond your project. For example influence on local and national policy, contribution to debate on key development issues, uptake by other projects etc.</p> <p>We are building on existing collaboration with Kamuzu Central Hospital, Lilongwe as the northern</p> |

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| | <p>hub for cancer care and develop a collaborative approach to cancer care across Malawi. To date we have been successful in training oncology nurses from Lilongwe, training pathology staff in facilities in Blantyre and Lilongwe and several members of the oncology team in Lilongwe have attended the breast cancer symposium. This has resulted in discussion about a 'national' approach to cancer treatment in Malawi which we hope to be a subject of future project funding applications. This will be particularly important as the construction of a new cancer centre in Lilongwe should be completed in September 2018.</p> |
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| <p>6. Financial Report</p> | |
| <p>The narrative report below should be provided in conjunction with the Budget Spreadsheet report (see Annex 2). Please fill in the Budget Spreadsheet to: (a) confirm actual spend for the year and justify any significant disparities between programmed expenditure and actual expenditure within the financial year, (b) detail programmed spend for next year.</p> | |
| <p>Please note that any carry-over of funds to the next financial year should have been agreed with the Scottish Government by January 31st of the current financial year.</p> | |
| <p>6.1</p> | <p>Project Underspend Please note whether the project has reported a significant underspend, and whether the Scottish Government has agreed to this being carried forward. If this has been agreed, please provide copies of or links to relevant correspondence. Please indicate whether the underspend is the result of currency fluctuations or other issues with project delivery.</p> <p>A small underspend (<£2000) has been reallocated to part-fund a trip for one of the Malawi trainee oncologists to visit Edinburgh in Nov 18 in support of the Scottish Oncology Summit, Global Oncology session. This underspend came from the agreed change in Output 3 where interview costs for patients were no longer required and has already been approved in principle by email from the Scottish Government.</p> |
| <p>6.2</p> | <p>Cost Effectiveness and Efficiency Please detail any efforts by the project to reduce project costs, whilst maintaining the quality of the project – for example through managing projects costs, efficient resourcing, working with and learning from others etc.</p> <ul style="list-style-type: none"> • NHS Lothian travel service now used and flights are booked early to ensure best deals are accessed for flights and accommodation. • Working alongside Malawi Cancer Association, [REDACTED] (from Ireland) and the Canada Project to build cost saving synergies in sensitisation, nurse training and pathology respectively. |
| <p>6.2</p> | <p>Co-finance and Leverage Please provide details of any co-finance or leverage that has been obtained for the project during the reporting period, including how the funds/ resources will contribute to delivering more and/or better development outcomes.</p> <p>No co-finance at present</p> |

7. IDF Programme Monitoring

The list of IDF programme indicators are listed below. With reference to Q46 on your application form, please report on progress for the IDF programme indicators that you have committed to tracking in your original proposal, including the 'Poverty and Vulnerability Indicators', which are obligatory for all Scottish Government funded projects.

1. IDF Programme – Poverty and Vulnerability (compulsory)

| 1.1 Indicator 1.1 Total number of people directly benefitting from the project | | | | |
|--|----------------------|----------------------|-----------------------|--|
| Baseline | Female | Male | Total | Brief description (e.g. small-holders) |
| Staff: | | | | |
| At Baseline 0 | 0 | 0 | 0 | Oncology staff Potentially up to a total of some 40 staff would have the potential to benefit directly from the project. We have assumed 75% female and 25% male split in gender. |
| At 31/03/2016 | 7 | 9 | 16 | CPD, education courses and day to day experience |
| At 31/03/2017 | 9 18 27 | 6 15 21 | 15 33 48 | CPD, education courses, National Symposium and day to day experience |
| At 31/03/2018 | 16 0 16 | 3 4 7 | 19 4 23 | Year 3 Oncology nursing training Oncology in-house training |
| Patients: | | | | |
| At Baseline 0 | 0 | 0 | 0 | Anticipated patient numbers In the Year 1 report we set out the Direct and Indirect Patient data expected (by Globocan 2012) and the actual Breast Cancer patient data from QECH during 2012-2014. This demonstrated that QECH receives 20% of breast cancer patients presenting, rather than the expected 14% by Globocan. From this work we anticipate around <u>120</u> females attending QECH per annum (approx. <u>60</u> for the oncology clinic; and <u>60</u> for surgery). We have therefore used the '60 for the oncology clinic' as our target figure for those being treated via MDT (Multi Disciplinary Team). |
| At 31 March 2016 | 20 | 1 | 21 | For first 6 months of Project 21 patients – 20 female; 1 male received MDT treatment. The sensitisation programme with the Cancer Association of Malawi is aimed at raising awareness of breast cancer symptoms; and raising the numbers of women coming to QECH. |
| At 31 March 2017 | 56 | 1 | 57 | These figures are correct up until Oct 2016 with further data from Oct 16-April 17 to be confirmed. |
| At 31 March 2018 | 67 | 2 | 69 | Breast Cancer MDT attendees. |
| | | | | |

7. IDF Programme Monitoring

The list of IDF programme indicators are listed below. With reference to Q46 on your application form, please report on progress for the IDF programme indicators that you have committed to tracking in your original proposal, including the 'Poverty and Vulnerability Indicators', which are obligatory for all Scottish Government funded projects.

| | |
|--|---|
| | State the evidence that supports the progress described |
| | QECH Oncology data base. |

1.2 Indicator 1.2 Total number of people indirectly benefitting from the project

| Baseline | Female | Male | Total | Brief description (e.g. small-holders) |
|--|-----------|-----------|-----------|---|
| Staff: | | | | |
| As at 31/03/2016 | 0 | 0 | 0 | Oncology staff elsewhere in Malawi Potentially up to a total of 50 staff with the potential to be upskilled during the Project through 1-2-1 working directly alongside trained staff members of which we have assumed: 75% female and 25% male. |
| As at 31/04/2017 | 25 | 8 | 33 | The National Breast Cancer Symposium of September 2016 has enabled us to estimate the increased numbers of staff <u>indirectly</u> benefitting from the Project. It was attended by 33 staff: so we have assumed a 75% females; and 25% male split in indirect staffing benefit. |
| As at 23/04/2018 | 0 | 0 | 0 | National Symposium planned for the Extension Period. |
| Patients dependants: | | | | |
| As at baseline | | | | Patients' dependants: As set out above, we have used the '60 for the oncology clinic' as our MDT target figure. Assuming a family/social circle of 5 to 10 people, then up to 600 people [split equally between male:female] could indirectly benefit from the programme. |
| 0 | 0 | 0 | 0 | |
| At 31 March 2016: 21 total patients | Up to 105 | Up to 105 | Up to 210 | 21 went through the MDT approach in Year 1 (6 month period and increasing once programme is established), And from recent knowledge sharing with the Malawi Cancer Association we simply note at this stage the importance to small business owners within these figures. The local statistics are currently under joint review with the National Cancer Registry. |
| At 31 March 2017: 57 total patients | Up to 285 | Up to 285 | Up to 570 | 57 patients with breast cancer have been treated through the MDT then with a family/social circle of 5 to 10 people, then up to 570 people would be indirectly benefited – which we have split 50:50 by gender. |

7. IDF Programme Monitoring

The list of IDF programme indicators are listed below. With reference to Q46 on your application form, please report on progress for the IDF programme indicators that you have committed to tracking in your original proposal, including the 'Poverty and Vulnerability Indicators', which are obligatory for all Scottish Government funded projects.

| | | | | | | | |
|--|--|--------------|------------|-------------------------|---|-------|--|
| | At 31 March 2018: 69 total patients | Up to 345 | Up to 345 | Up to 690 | 69 patients with breast cancer have been treated through the MDT then with a family/social circle of 5 to 10 people, then up to 690 people would be indirectly benefited – which we have split 50:50 by gender. | | |
| State the evidence that supports the progress described | | | | | | | |
| Globocan (2012); QECH Oncology data base; and National Cancer Registry data. Year 1 and Year 2 figures are from hospital data. | | | | | | | |
| 2. IDF Programme – Health (optional) | | | | | | | |
| 4.1 | Indicator 4.1 Number of health professionals with up-to-date skills, knowledge and qualifications in essential healthcare | | | | | | |
| | Baseline | Female | Male | Total | Brief description (e.g. nurses) | | |
| | At Baseline | 0 | 2 | 2 | We anticipate having 15 health professionals with up-to-date skills, knowledge and qualifications about MDT Breast Cancer treatment. 2 staff had up to date skills at the start of the Project. | | |
| | At 31 March 2016 | 4 | 5 | 9 | In Year 1 the Breast Cancer nurse underwent training, 2 technicians have received ER pathology training, and 3 staff have planned training in Edinburgh, and 3 doctors had CPD | | |
| | At 31 March 2017 | 9 | 6 | 15 | 5 Doctors (3 male, 2 female) 10 nurses (3 male ,7 female) All had training/CPD with a strong programme in place for Year 3. | | |
| | At 31 March 2018 | 8 | 7 | 15 | 6 Doctors (4 male, 2 female) 9 nurses (3 male, 6 female) A strong training/CPD programme delivered during Year 3. | | |
| State the evidence that supports the progress described | | | | | | | |
| QECH data base | | | | | | | |
| 4.4 | Indicator 4.4 Number of people directly reached by improved essential health services | | | | | | |
| | Baseline | Adult Female | Adult Male | Child Female (< 18 yrs) | Child Male (< 18 yrs) | Total | Brief description (e.g. malaria) |
| | At Baseline 0 | 0 | 0 | 0 | 0 | 0 | 60 Breast Cancer patients per annum anticipated to have MDT treatment as set out above |
| | At 31 March 2016 | 20 | 1 | 0 | 0 | 21 | Treatment via MDT |
| | At 31 March | 45 | 1 | 0 | 0 | 46 | Treatment via MDT |

7. IDF Programme Monitoring

The list of IDF programme indicators are listed below. With reference to Q46 on your application form, please report on progress for the IDF programme indicators that you have committed to tracking in your original proposal, including the 'Poverty and Vulnerability Indicators', which are obligatory for all Scottish Government funded projects.

| | | | | | | | |
|---|----|---|---|---|----|-------------------|--|
| 2017 | | | | | | | |
| At 31 March 2018 | 69 | 0 | 0 | 0 | 69 | Treatment via MDT | |
| | | | | | | | |
| State the evidence that supports the progress described | | | | | | | |
| Originally Globocan 2012, then QECH Oncology data base | | | | | | | |

Annex 1: Guidance Notes: End of Year Report

| <ul style="list-style-type: none"> • This report is to be completed by all project managers/leaders at the end of the financial year. • Please complete this form electronically. • Once complete please send this reporting form, by email to your Scottish Government project manager. • The report should be submitted by the end of April following the financial year to which the report relates. | |
|---|--|
| Question | Guidance |
| Basic Project Information | |
| 1.1 | The project reference number was given to you by the Scottish Government in your grant offer letter – please refer to it in all correspondence. This is a number unique to your project and helps the Scottish Government track information relating to your project within the system. |
| 1.2 | Insert the financial year for which you are reporting |
| 1.3 | Insert the year of your project (i.e. Year 1, 2 or 3) |
| 1.4 | Insert the name of your lead organisation responsible for managing the grant (based in Scotland). Please make a note if this has changed during this financial year. Reasons for changes should be reported in section 3. |
| 1.5 | Insert the names of your partner organisations in Scotland and Partner countries. Please make a note if this has changed during this financial year. Reasons for changes should be reported in section 3. |
| 1.6 | Insert the name of your project in the space provided. This should correspond with the name given in your grant offer letter. Please make a note if this has changed during this financial year. Reasons for changes should be reported in section 3. |
| 1.7 | Provide a brief project description as per your grant offer letter. |
| 1.8 | Insert the geographical area in which your project is being implemented. Please make a note if this has changed during this financial year. Reasons for changes should be reported in section 3. |
| 1.9 | Insert start and end dates. The start date is the date you received your first tranche of funding. |
| 1.10 | Insert the total project budget (including funding from other sources). Please make a note if this has changed during this financial year. Reasons for changes should be reported in section 3. |
| 1.11 | Insert the total amount of funding received through the IDF for this project. |
| 1.12 | Indicate the theme that your project addresses (tick as many boxes that apply.) |
| 1.13 | Confirm that supporting documentation has been included with your report. Please tick those boxes that apply. Confirm whether any changes have been made to the logical framework, and whether the LF submitted has been approved by the Scottish Government (or is pending approval). Reports that do not include all required documentation will not be considered complete. |
| 1.14 | Please reference previous (actionable) feedback that you have received in your last MY and EY report, and describe any action that has been taken in response/ since then. |
| 1.15 | Insert the date that your report was produced. |

| | |
|-----------------------------------|---|
| 1.16 | Insert the names and positions of the key person(s) involved in preparing your report. |
| 1.17 | It is essential that you let us know if any of your contact details have changed, either in Scotland or in Malawi. |
| Project Relevance | |
| 2.1 | Provide a brief update on the context in which your project is working, and describe briefly how your project remains relevant to your project beneficiaries. |
| 2.2 | Working towards gender equity and social inclusion is considered essential to any projects funded through the IDF. Please describe briefly how your project is delivering this. |
| 2.3 | Please describe briefly how beneficiaries are engaging with the project (if at all) and what effect that is having, as well as any challenges in engaging with them. |
| Progress and Results | |
| 3.1 | If your Project has changed significantly in the focus of its delivery since your last report, please explain how and why, attaching copies of all relevant correspondence you have had with the Scottish Government about this. Please also describe and explain any changes to basic project information here. |
| 3.2 | If your Logical Framework has changed over the last Financial Year please detail and explain these here. This enables us to more quickly understand the changes and your progress, based on the most up-to-date information. |
| 3.3 | An update on any delays or challenges in monitoring will help us to understand the information presented in the report and logframe. |
| 3.4 | For this question you will need to refer back to your most up-to-date APPROVED logical framework. Looking again at the <i>output indicators</i> outlined, please comment on the progress made towards achieving these during the reporting period, including any challenges and how these were overcome. This should include a narrative (where relevant) as well as quantitative data – indicating clearly the milestones (including dates) and progress to date using the same measurement unit (e.g. number/percentage) provided for the baseline etc. should be outlined using a percentage or number. E.g. By end March 2016, 5 wells have been dug in the last year against a milestone target of 4. |
| 3.5 | For this question you will need to refer back to your most up-to-date APPROVED logical framework. Looking again at the <i>outcome indicators</i> outlined in your original application, please comment on the progress made towards achieving these during the reporting period, including any challenges and how these were overcome. |
| 3.6 | For this question you will need to refer back to your most up-to-date APPROVED logical framework. Please comment on the overall impact of the project to date, including any challenges and how these were overcome. |
| 3.7 | If progress towards delivering activity and outcomes has been slower than planned, please use this space to indicate the reasons why and whether any of the risks outlined in your application have impacted on the project. |
| Sustainability | |
| 4.1 | Provide a brief update on how your partnership is working and evolving. |
| 4.2 | Detail briefly your progress towards ensuring that your project will be sustainable in the longer term. We would like you to refer back to your exit strategy in your application form) as well as reflect on other elements of sustainability. |
| Learning and Dissemination | |

| | |
|---------------------------------|--|
| 5.1 | The Scottish Government is very interested to hear of lessons you may have learnt during any aspect of the project and may use your experience in future policy consideration. |
| 5.2 | The Scottish Government is very interested to hear of any innovations or examples of best practice, and how projects are sharing good practice more widely. |
| 5.3 | The Scottish Government would like to know how the work of the project is being communicated more widely to a range of stakeholders in Scotland and beyond. |
| 5.4 | The Scottish Government would like to know if your project (whether intended or unintended) is likely to have an influence on policy. |
| Financial Reporting | |
| 6 | For this question, you will also need to complete the summary page of the budget spreadsheet. Please use the budget headings on the spreadsheet to provide a detailed breakdown of actual expenditure incurred during the financial year to which this report relates, against expenditure planned as well as expected expenditure for the next financial year. Please outline any reasons for any discrepancy in the budget spend. <i>N.B If the budget spend is more than 10% different from the original estimate please use the additional tabs on the budget spreadsheet to provide more detail.</i> |
| 6.1 | It is important for us to understand and learn from how projects budget, including reasons for underspend. |
| 6.2 | The Scottish Government is interested in how projects are working efficiently and effectively. |
| 6.3 | Please detail if the project has succeeded in sourcing additional funds to enable it to extend its work. |
| IDF Programme Monitoring | |
| 7 | The Scottish Government needs to understand who is being reached by the IDF and how therefore it is essential that projects contribute to programme monitoring. |

Annex 1: Financial Report

Attached separately as Excel Spread sheet.

Annex 2: Oncology Nursing Education Report - Edinburgh Malawi Breast Cancer Project

April 2018

Report Edinburgh Malawi Breast Cancer Project

Report - [REDACTED] MBE C/N ECC / [REDACTED] Breast care Nurse ECC

Introduction

A partnership was established between the Edinburgh Cancer Centre and Queen Elizabeth Hospital in Blantyre in October 2013. The first 3 years of the partnership focussed on development and educational opportunities to facilitate a longer term move towards nurse led delivery of chemotherapy.

The partnership with QECH established relationships, guidelines and a framework to make what the project delivered sustainable in the medium to long term. This includes consistent approaches around the disciplines required for effective treatment of patients.

The initial project is viewed as a success from all teams that participated - the Edinburgh Cancer Centre, the Beaumont Oncology Hospital in Dublin and the Queen Elizabeth Central Hospital in Blantyre, Malawi.

Following the initial partnership protocols and processes within the oncology unit were reviewed.

The next phase of the link up with the QECH has a focus on the delivery of treatment for breast cancer, and development of the role of breast cancer nurse specialist. An initial visit in September 2016 and subsequent visit in April 2017 supported the introduction of breast cancer nurse specialist role to QECH.

This report follows a return visit to the QECH in April 2018 by the nursing team [REDACTED] ECC, [REDACTED], ECC and [REDACTED], Dublin. It will update on previous recommendations from the visit to QECH in April 2017.

These include :

- Ongoing development / support of breast cancer nurse specialist in Malawi
- Education feedback
- Ongoing work from previous visits
- Next steps / recommendations will be highlighted throughout
- Summary

Ongoing development / support of breast cancer nurse specialist in Malawi

The Breast Cancer Nurse Specialist ([REDACTED]) has now been in post for approximately 30 months and the role has developed significantly. It has expanded in terms of responsibilities and demands on time and resource. Recommendations from the previous visit have been taken up and put into practice effectively.

These recommendations were

- The CNS from ECC will provide ongoing support and mentorship to the CNS in relation to specialist knowledge and overall management skills.
- The CNS (QECH) will continue to explore avenues for dissemination of breast cancer awareness, utilising local support networks.
- Completion of the online oncology course and increased participation in delivery of education on breast cancer at a local level, with the support of the CNS from ECC.
- QECH Breast Cancer CNS to concentrate support of those patients with a cancer diagnosis due to limited time and other oncology commitments.

The CNS from ECC has provided continued ongoing support via e-mail and social media. Communication links established with the Breast Surgeon, who operates at QECH continue and the Breast surgeon has made a further visit to ECC. This has supported the aim of increasing the knowledge and management of Breast cancer for the CNS at QECH. During this latest visit increased confidence and improved management skills have been demonstrated by the BCN at QECH, evidenced by the introduction of a triage system which improves the patient pathway by identifying those patients at risk of sepsis .

The CNS at QECH continues to participate in raising awareness of breast cancer by supporting a local charity which visits rural communities, church groups and various other settings. Posters which were developed in the local language are still on display in clinic and generating interest. (**Figure 1**)

Further discussions have taken place during this visit around development of patient information in the local language and using visual aids for illiterate patients.



Figure 1 (Breast Self Examination poster – translated into local Language)

The BCN continues to develop his specialist knowledge and education by continued support of the breast triple assessment clinic, Multi disciplinary team co-ordination and data collection. He has also completed the specialist on-line oncology course (Alberta course) and has commenced a further specialist course (The De-Souza course, Toronto).

There has been further improvement in his ability to manage support staff and resources and in the absence of the ward charge nurse, has assumed a lead role in the co-ordination of ward and clinic activities.

He has had responsibility for the organisation of the nursing education sessions for this visit, including arrangement of speakers from both nursing and medical teams, along with delivering the session on breast cancer.

Recommendations

- The CNS from ECC will provide ongoing support and mentorship to the CNS in relation to specialist knowledge and overall management skills.
- The CNS QECH will continue to work with local agencies to improve the delivery of appropriate education and cancer awareness in the local communities.
- The CNS QECH will aim to complete the online De Souza Oncology Course on the administration of chemotherapy (supported by both the Irish and the Edinburgh Team)

- The CNS will provide support of breast cancer patients throughout referral, diagnosis , treatment and follow-up process.

Education

A weeks programme was developed and delivered to staff in the QECH. It involved daily education sessions and then practical clinical teaching in ward and clinic settings (see attached programme – **Appendix 1**). **[REDACTED]** (breast CNS Malawi) took a lead role in the organisation, development, co-ordination and delivery of the programme. The content was decided after discussion with the staff locally. The programme included chemotherapy safe handling and administration, an update on breast cancer services at QECH and oncology emergencies- as requested by local staff due to the recent introduction of an oncology HDU (**see figure 2**).



Figure 2 (Newly refurbished Oncology HDU QECH)

The breast specific session was delivered by the local BCN.(Figure 3)



Fig 3 **[REDACTED]** delivers lecture on breast cancer at QECH.

Safe delivery of chemotherapy, management of side effects and sepsis were key components of the workshop. Presentations were developed and delivered by the staff from Queens who have completed both the Alberta Course and the De- Souza course in chemotherapy administration. (This was an agreed action from the initial partnership project to ensure sustainability). The content included coverage around the reinforcement of basic guidelines on extravasation, spillage and safe handling and management of side effects.

The workshop was followed by practical sessions, in-patient chemotherapy was covered clinically by **[REDACTED]** (Charge Nurse EEC), **[REDACTED]** (Acting Charge Nurse QECH) and **[REDACTED]** (Dublin). Ongoing support and mentorship for the Breast CNS role in Malawi was provided by **[REDACTED]** (BCNS ECC). This was achieved by working alongside the breast CNS in the clinic setting. **[REDACTED]** supervised practical sessions in clinic.

The sessions were well attended by a variety of staff from Oncology QECH, and other institutions providing Oncology services throughout Malawi, including Mwaiwathu Hospital Blantyre, Adventist Hospital Blantyre

and Neno Hospital-Partners In Health, Malawi. A total of 19 staff attended, 4 males and 1 females. Attendees were all qualified nursing staff. The Breast Cancer CNS attended all sessions and contributed to teaching and practical sessions.

The workshop was positively evaluated – see **Appendix 2**



Fig 3 Eluby (QECH) and Catherine (Adventist) deliver chemotherapy training update sessions

Kamuzu College of Nursing have recently announced their intention to develop a BSc in Oncology Nursing. A meeting was held between [REDACTED] and the principal of Kamuzu College of Nursing, Malawi University to discuss the proposed plan for a degree programme. The University recognise within Malawi there is limited capacity to deliver specialist Oncology Modules. Potential exists for ECC/ BOH support in the development of the degree programme. Kamuzu College of Nursing are keen to accept any assistance that can be offered in the initial delivery of the degree course with a view to establishing a sustainable local delivery in the long term.

2 students who have previously completed the Alberta on line Oncology Course have also completed an internationally recognised Chemotherapy administration module with the De Souza Institute in Toronto. A further 4 students have now enrolled on this course. This initiative has been crucial to capacity building within the nursing service and the Irish and the Edinburgh teams have committed to ongoing support for this initiative.

Recommendations

- Continue collaboration with the Irish team to support the online students undertaking the on line De Souza Oncology course
- QECH to continue chemotherapy updates bi annually
- ECC/ Irish team will continue to support education with cancer site specific sessions
- Collaboration with Kamuzu College of Nursing, University of Malawi around support for their planned degree programme

Summary - Project Evaluation

Ongoing Work from previous visits

- **Collaboration with the team at Beaumont Oncology Hospital Dublin**
There is continued collaboration with the team at the Beaumont Oncology Hospital. The visiting team provided some individual teaching sessions during the 2018 visit to course participants. The Alberta on line learning course is no longer in existence and the Desouza course is being accessed as a suitable

alternative. Support is also now being provided locally to the De Souza course students by [REDACTED] Staff Nurse Adventist Hospital Blantyre and [REDACTED], Acting Charge Nurse QECH (both Alberta course and De - Souza on line graduates). A further 4 members have staff have been enrolled on the De-Souza chemotherapy course April 2018). The Scottish Malawi cancer Partnership and the Irish teams will continue to support this initiative, to increase nursing capacity in Oncology at QECH.

- **Work to embed the 'Guidelines for Safe Use of Chemotherapy Agents'**
The QECH team are following these guidelines and the basic principles, evident in their own teaching.
- **Work with the team in Malawi to address the issues identified around their use of master prescriptions and mitigate risks to patients' safety**
The trial of ECC master prescriptions has not progressed to general use but the use of local master prescriptions is embedded in practice.
- **Provide support for recommended (fully) in house delivery of a chemotherapy workshop**
The QECH delivered successfully the chemotherapy workshop in house in October 2017 and this has now been repeated in April 2018. Once again sessions were accurate, run entirely in house, using their own materials and were well evaluated. In terms of sustainability, the QECH continue to run refresher workshops bi-annually.

The initial project led to significant and positive improvements in patient care, delivered by the oncology unit at the Queen Elizabeth Central Hospital (QECH). The focus to date has been on the delivery of an education programme and aim for best practice in the form of guidelines and processes.

The project has been built around collaboration and partnerships. Close links have been built up with staff in the QECH and the team in Dublin. Other units in Malawi and research facilities have benefitted from the workshops and training programme that have been created and delivered. Within the QECH there is closer collaboration between teams who need to work together on delivering effective chemotherapy treatment to their patients. The program has encouraged other institutions (who have similar oncology services) to work together, providing the basis of peer support and cross site collaboration within Malawi, enhancing consistency of practice- an area that has potential for development.

This phase of the link up with the QECH has focus on the delivery of treatment for breast cancer and the development of the role of a breast cancer nurse specialist.

The breast cancer CNS who has now been in post for 30 months demonstrates an increased knowledge of breast cancer and general cancer management. He has made significant efforts to disseminate knowledge to patients and to other staff. This should become more evident, with increasing involvement as the role continues to develop.

It is clear that this role has impacted positively on patients with breast cancer and will continue to do so as other elements are added to the remit of the BCN.

Kamuzu College of Nursing University of Malawi are eager to engage with the Scottish Malawi Partnership should a further grant be awarded. It is clear opportunity exists for collaboration in the area of specialist Oncology nursing education. This could have significant national impact for development and sustainability of improved cancer care in Malawi.

Appendix 1

QECH EDUCATION
ONCOLOGY EMERGENCIES
 Monday 23th April to 27th April 2018
 Venue : QECH

| Date APRIL 2018 | Education Session | Speaker |
|----------------------------------|---|---|
| 23/4/18 0800-0930 | Welcome. Overview of the Programme: Administration of chemotherapy , including <ul style="list-style-type: none"> • Safe handling • Hypersensitivity reactions • Dose calculation • Documentation • Extravasation <p style="color: red;">Daily sessions will be followed with practical sessions within the ward and clinic</p> | [REDACTED] |
| 24/4/18 0800-0930 | Update on common regimes used in Queens and the management of toxic side effects of chemotherapy <ul style="list-style-type: none"> • Bone Marrow depression • Nausea and vomiting • Diarrhoea <p>Care of the critically ill patient and management of sepsis</p> | member of QECH medical staff <div style="text-align: center; color: red;">[REDACTED]</div> |
| 25/4/18 0800-0930 | Breast Cancer and its management within Queens (including common regimes in use for curative and metastatic disease) Patient Information needs | [REDACTED] |
| 26/4/18 0800-0930 | Blood parameters and the significance in relation to common chemotherapy regimes. Blood transfusion – safety issues | [REDACTED] |
| 27/4/18 0800-0930 1300 | Other oncology emergencies <ul style="list-style-type: none"> • Superior vena cava obstruction • Spinal cord compression • Tumour Lysis syndrome Exam | [REDACTED] |

Appendix 2 – Attendance List – 19 (16 females; 3 males)

[REDACTED]

Appendix 3

EVALUATION FORM SUMMARY (TOTAL RETURNED 15) – EDINBURGH/MALAWI CANCER WORKSHOP

23/4/17 – 27/4/17

| | | | |
|---|---|-----------------|----|
| 1 | Was the academic level | A) appropriate | 15 |
| | | B) too basic | 0 |
| | | C) too advanced | 0 |
| 2 | Were the teaching methods | A) appropriate | 12 |
| | | B) stimulating | 3 |
| | | C) dull | 0 |
| 3 | Please state any topics you feel were not useful for a chemotherapy update and explain why? | | |

Comments :

- None, all topics were relevant and useful

4 Please state any topics that should be included in any future chemotherapy update.

Comments :

- Chemotherapy protocols
- Further breast input
- Cervical cancer
- Lymphomas
- Patient information
- Counselling and palliative care
- Radiotherapy

5 What was the most valuable part of the workshop, explain why?

Comments :

- Practical preparation
- All
- Breast cancer sessions
- Oncology emergencies
- Chemotherapy side effects and management

6 What was the least valuable part of the workshop, explain why?

Comments :

- Every part was valuable , more time for theory would be beneficial

7 Please give an overall score out of ten

10/10 (4)

9/10 (6)

8/10 (4)

7/10 (1)

8 Comments:

- More time required
- All valuable
- Time keeping of attendees
- Relevant to the modern community/population, hope with what we have learnt will help to sensitise the population.
- It was good and more practical, managed to learn more information based on oncology update
- I feel I am now equipped with knowledge and skills which will help me in giving quality oncology care. I have acquired new knowledge in chemo administration, handling and management. I am eager to learn more!
- We need these trainings to be done frequently as we gain lots of skills knowledge and expertise.
- Our presenters from abroad really alight our brains – keep it up!
- I would like to learn more hence the duration was short. The introduction of the degree programme at KCN on oncology will be very important for deeper knowledge on the disease.

Annex 3: Scottish Trainee Oncologist Review of the QECH Cancer Projects

Report: [REDACTED]

Trip: November 11th – 19th 2017 Queen Elizabeth Central Hospital Blantyre, Malawi

Participants: [REDACTED]

Project Aims: Ongoing partnership aimed at improving cancer services in Malawi through education and health promotion as well as improving access to services.

My Aims: Since my elective at university I have been interested in being involved in projects aimed improving global health care. My frustrations on my elective came from not being more “useful” ie as I was not fully qualified there was a limit to how much I could provide. Now that I am specialising in Oncology this feels like the ideal time to be renewing g my aspirations whilst also feeling valuable to the community and able to provide assistance and ideas on how to engage and improver services.

For me the aim of this trip was to 1. See exactly how the project ran day to day and the services we are trying to impact upon and 2. To see how I could be involved in the long term – ideally looking for how I could be involved in a 3 month project/rotation.

Timetable:

| | Monday | Tuesday | Wednesday | Thursday | Friday |
|----|--|--|--|---|--|
| AM | 8am Educational Meeting (Medical student case presentations)/ Shadow SpR Ward reviews 9am New Patient Clinic | 8am Educational Meeting (Medical student case presentations)/ Shadow SpR Ward Reviews 9am Chemotherapy Clinic | 8am Educational Meeting (Medical student case presentations)/ Shadow SpR Ward Reviews 9am Chemotherapy Clinic | 8am Educational Meeting (Medical student case presentations) / Shadow SpR Ward Reviews 9am Consultant WR/ One Stop Breast Clinic | 8am Educational Meeting (Medical student case presentations) / Shadow SpR Ward Reviews 9am Return Patient Clinic |
| | Consultant talk through of difficult cases | Consultant talk through of difficult cases | Consultant talk through of difficult cases | | Consultant talk through of difficult cases |
| PM | Clinic at Private Hospital / Ward | Clinic at Private Hospital / Ward | Clinic at Private Hospital / Ward | Ward Round | MDT |

General Impressions: During the week, I met with 4 of the trainees – their experience was varied, some had just started working in Oncology, other were more senior and about to go to South Africa to complete their formal Oncology training – a coveted opportunity.

The first thing that struck me was the mix of pathology even in one clinic. In Edinburgh I spend the day prior to clinic prepping – I know exactly who I am seeing and pretty much what I am going to say and what the outcome will be. With often 60+ patients on the list for clinic at Queens this is impossible, and the range of ages and tumour types including haematological malignancies and also the advanced pathology was astounding and I have a lot of respect for the trainees. The overwhelming impression is lack of resources.

The ward was also quite a harrowing environment. Patients potentially septic, lie on the floors of the wards, and those in beds are crammed in next to each with no space. There is an attempt made at gender segregation but of course not always possible. The smell of fungating tumours is overpowering. It is difficult to justify how I complain about the four bedded bays at the ECC and that 8 people share a toilet when faced with this environment.

Example Clinic – Chemotherapy Clinic Wednesday 15th November 2017 (Sat in with Noel)

Patient 1: 40F C8 Docetaxel (neoadjuvant cervical ca – but still inoperable) plan to continue palliation with docetaxel

Patient 2: 53M HIV+ Oesophageal Ca C3 Gem/Tax – good clinical response plan to continue for ongoing palliation

Patient 3: 42F Stage IIB Ca Cervix C7 Palliative paclitaxel/carboplatin – plan to continue

Patient 4: 42F NR HIV NHL 6th CHOP. Hb 59 – plan to transfuse 1 unit then give chemo

Patient 5: 39F Stage IIA Ca Cervix – 4th cycle Neoadjuvant Gem/Paclitaxel – aim is surgery

Patient 6: 37F Breast Ca T3N0M0 Mx + ALND had neoadjuvant AC, squamous poorly differentiated with close margins, now getting 3rd cycle adjuvant gemcitabine – this was delayed as could not afford transport to hospital last month, openly said she won't afford it next month. Also on carbamazepine for peripheral neuropathy.

Patient 7: 48F Ovarian and Cervical Ca – C8 Neoadjuvant Carbo/taxol – plan to continue ??surgery. Hb 78 symptomatic – transfuse 1 unit and give chemo

Patient 8: 68F Ca Cervix 6th cycle paclitaxel. TAH 2013 – notes lost no idea of stage but has no had recurrence. Symptomatic benefit.

Patient 9: 45M NHL NR HIV C4 CHOP – good clinical response.

Patient 10: 22M Kaposi Sarcoma Extensive disease, HIV+. C5 paclitaxel – marked clinical improvement after just C1

Patient 11: 34M Lung Ca – stage IV adeno. Cis/paclitaxel with no response. Switched to gem/paclitaxel after 2 cycles effusion gone and no longer SOB.

Patient 12: 34F Oesophageal Ca – Gem/Taxotere – weight starting 30kg has now improved to 47kg, able to eat and drink. Hb 69 – for 1 unit then chemo.

Patient 13: 55M Myeloma – off Rx. Sent for CXR but only got half a film therefore sent back for repeat CXR, unable to make any other decisions.

Patient 14: 42F Met Breast Ca (dx 2011) HIV+ (6 AC then 3CMF then tamoxifen the follow up) Now C5 paclitaxel.

Patient 15: 34M HIV+ KS – 2nd line chemo. 1st line paclitaxel relapsed in July started ABV p cycle 6. TB negative.

Patient 16: 24F Choriocarcinoma – single agent MTX. bHCG 261-67. On cycle 5. bHCG test too expensive so has to be paid for privately so unable to have every cycle, Hospital lab does not offer testing.

Patient 17: 38F Vulval Ca – C9 cisplatin/taxotere – good response but inoperable continue to 11 cycles then list for surgery.

Pathology seen: Head and Neck SCC, Vulval Ca, Cervical Ca, KS, Conjunctival SCC, Breast, Lymphoma, Oesophageal, Rhabdomyosarcoma, Prostate, Lung, Oesophageal, AML, ALL, Choriocarcinoma.

Observations:

1. Understaffed – on the day of the chemotherapy clinic there was one chemotherapy nurse for 60 patients. There should normally be 7. Issues with pay.
2. Access to drugs - Ran out of dexamethasone. Every patient gets 20mg premed. Hospital pharmacy ran out. Patients had to travel (if well enough) or their advocate to source and buy and only then could they get treated.
3. Access to drugs - Ran out of doxorubicin and then gemcitabine.
4. Access to drugs - Ran out of morphine – certain preparations
5. Transport – patients cannot afford, or there is no access, or limited access to transport to bring them to the hospital. One patient told me there was 1 car every two weeks that arrived on the main road - a 2 mile walk from her house – that went in the direction of the hospital and she could afford to pay the journey sometimes.
6. Services - CT broke down. Patients had to travel to Lilongwe – an 8-hour round trip. There was no hospital transport to take them thought they had to make their own way.
7. Services - Lack of access to blood products. Patient with an hb 37 got 1 unit after 2 days but unable to access any more...reasoning unclear. Similar story with ALL/AML patients.
8. Services - Radiology/pathology – often would have to take the scans/samples themselves to get reported by someone different who had done the scan/biopsy. Often scans and even biopsies were then lost or even binned as they could not afford to pay for the report.
9. Time management - At clinic, there is lots of duplicate work, the chemo script is written in the notes by hand then in the patient's passport and often on another source.

Suggestions:

1. Utilise Master prescription charts – this could save on time for transcribing, reduce errors and help pharmacy whilst also helping the registrars standardise amendments or dose reductions based on blood counts or toxicity.
2. Health education. The majority of patients still present at a late stage. Early access to cancer services but also an understanding of what symptoms to look out for, how to access services. ? community reviews
3. Services – radiology, pathology, laboratory? any access to these/funding solely for cancer patients to relieve stresses from other areas. Blood machine for chemo bloods, one stop biopsy clinics like for breast.
4. Mentor/exchange programme for trainees? I have learnt so much in one week. It has allowed me to see first-hand pathology I would not have access to in western medicine routinely but also made me re-think my attitude to palliation. This should be symptom focussed and less reliant on scans and even perhaps OS. Equally the SpRs in Queens would relish the chance to learn at the ECC.
5. Global Oncology for trainees. I have started an email group of interested trainees across Scotland and had a great response so far from people wishing to engage and be interested in going out to see first-hand what it is like but also work out there. Lots of interest in developing an (optional) rotation or an end of training fellowship.

Personal Conclusions:

This has been an utterly invaluable and rewarding experience. I have learnt so much that I will take back to my daily practice and I actively wish to be encourage and enable others to have the same experience. I look forward to going back out to Queens and establishing my role in the Edinburgh-Malawi Cancer Partnership.

Annex 4: Malawi Breast Nurse Review of the Project

Report: [REDACTED], Breast care nurse

Date: 20/11/17

Hello [REDACTED], I would like to give a brief explanation of the breast project, in the first place I would like to thank you for the effort made to initiate this project, it's not an easy task. Management of breast cancer in Malawi like other cancer did not have proper strategy. I would not provide proper statistics but we had problems with recurrences because most of our breast cancer patients got surgery something without proper assessment whether the tumour is operable or not. In a nutshell patients were mismanaged. The coming of the project in Malawi with the guidance of [REDACTED] has been a very good strategy to manage breast cancers. Development of the multidisciplinary team meeting which is part of the project has provided proper direction to management of breast cancer and other cancers as well. Initially patients had limited choices, they could only have surgery and go home without proper assessment in case such patients needed chemotherapy as well, with the coming of the MDT, I am able personally to follow up patients who have had surgery in the surgical department, where I give suggestions to the surgeons to discuss the patient in the MDT, this has helped cancer patients to get maximum standard of care and has helped to development of proper patient follow up that never existed.

We have been working with the cancer association of Malawi (CAM), CAM has taken advantage of us in the breast project to do community awareness campaign, this has increased awareness and has helped in early detection for most cancers which leads to successful treatment for most cancers. We had had opportunities for further learning in the areas of oncology for example I have done the online oncology nursing assisted by some members of the breast project. We have managed to go further and develop the triple assessment breast clinic in Malawi, an initiative that has evolved from the same project. This clinic has helped even more in early detection and treatment of breast cancer.

The breast project was well funded so that we were able to help patients as needed, however we still have set backs which I believe if they are sorted, we will achieve the most desired patients needs. The project needs radiography and lab support services, Queens as a big hospital serving the whole Malawi, it's a challenge for us to share these services with other departments because there hasn't been any hope whether we can be prioritised in terms of helping our patients in such departments. We have our own scanning machine and that helps us have results in time than if the patients were sent to use the general scanner. So we currently have problems with the lab because it serves the whole Queens our samples take long time to be attended to and most of the times we have had situations where we only realise that the samples have gone missing at the lab. We have tried to find solutions to this problem but It hasn't been easier to sort this problem. My suggestion is that if the oncology department could have its own machines for a full blood count and chemistry, it would save many patients from hospital overstay and disappointments.

I have also noted that there is shortage of staff and if the the project plan includes employment of additional staff member it would bring a great change, though it might not be very sustainable but we are hoping the Malawian government would be able to learn from the Scottish government and would be able to proceed from where you stop. I am personally grateful for the employment I got due to the efforts you people made to your government. I am just challenged with inflation in Malawi, basic needs get high costs at regular intervals in Malawi, however I enjoy being part of the project, I am planning to do my carer development in two years time, I would wish to do proper breast care nursing and or masters degree in oncology just as my friend [REDACTED] has done.

The first two years (2018-2019) I would like to establish myself more on the ground in oncology so I would still concentrate on work that's why your continued support in this project is important to me as an individual because apart from helping patients I have also been helped in terms of employment because remember in Malawi we have big issue of high unemployment rate. Otherwise I am happy to work with [REDACTED] he's been a very good mentor I have ever seen and had excellent plans for us and Malawi at large.

The triple assessment clinic is okay with me but just discuss with [REDACTED] if he can give me the entire Thursday to the triple assessment clinic. Due to increase in number of oncology patients which is now at least 80 patients on average per clinic, it has made us to attend to some of the patients on Thursday which is the same day we do the triple assessment clinic and the ward round so the three things collide, you can help suggest what the best thing could be. So on Thursday it means I have three things to attend to, the ward round, the triple assessment clinic and organising the oncology clinic patients from the Wednesday clinic. It's not an issue for me, I do attend to all of them but the problem is people enjoy just quarter of my services this day as you can see it's not possible to be available in two places at the same time. I was born that fast when doing everything but sometimes I still think a work colleague will help sort out this problem so I can easily concentrate on the breast clinic on Thursday, it's easy I am already used to working with [REDACTED].

I emphasise that I will still need more knowledge and training be a breast care nurse, my coming to Western General Hospital has been so fruitful because I learnt several things on breast cancer. [REDACTED] and [REDACTED] have been supportive to me very much, provision of the breast prosthetic material has made counselling of breast cancer patients who underwent mastectomy easy. You have supported us more, the thermometers, BP, calfs, toniques that you bring are very important and they ease my work, it's not easy in Malawi to have even basic resources and you know it's stressful to work in an environment without resources. Another challenge facing our patients is non compliance to treatment, the greatest cause is transport, many patients cannot afford to come to the hospital ever month. [REDACTED] has tried to sort this out by involving the CAM, we have contacted the CAM to help our financially, only those that have been failing to come to the hospital because of transport. We have developed a tool that we are using to identity the needy in that area.

So generally I will be so glad to see the Malawi Scottish partnership continuing, it's a fruitful partnership.

Thanks.

Annex 5: Specialist Nurse Review of the Project

Report: [REDACTED]

Date: September 2017

Dear [REDACTED],

I hope this email finds you well. Apologies for the delay in emailing. I have to meaning to do so since my return from Malawi two weeks ago.

I have managed to secure a donation towards the tablets for the two nurses to undertake the online chemotherapy course with De Souza Institute, Toronto.

A brief summary of my thoughts/ in relation to cancer services in QECH

- There have been significant improvements in the delivery of medical oncology service at QECH over the last three years. This include but are not limited to pathology services are much improved with a much faster turn around time in terms of reports and most likely accuracy
- Access into the service has become better especially for breast cancer patients. This certainly has been assisted by the role of [REDACTED]. His presence in the clinic has improved logistics of getting All oncology patients into the system in a more timely fashion. His current role is a little "all encompassing". It would be worth considering if it could be streamlined or whether a second position if sustainable could be used especially if the next priority was a second cancer such as lymphomas
- The establishment of the MDT. This is a major achievement and although not working to its maximum (nothing does in QECH), has potential to deliver greater benefits.
- Overall safety in terms of chemotherapy preparation and administration has witnessed significant improvements. This is a result of trainings delivered by both Edinburgh and [REDACTED] and the distance learning programme with Alberta Cancer Centre. (Unfortunately this programme has now ended). There is now a small cohort of staff who are company in many aspect of cancer nursing
- Quality of care with inpatients although coming from a very low base, has witnessed improvements
- Improvements in IT and data capturing capability although it still is hindered by reported internet challenges
- Having dedicated NCHD's such as the registrars for the service with specific acres of work greatly contributes to the quality of the service.

Risks/Opportunities

- The increase in activity levels within the services threaten to erode all progress made. Currently there is an ethos of "treating everyone with everything" irrespective of the capacity to do so effectively or safely
- There is a lack of certain basics for the increased numbers ie chairs, drip stands etc. This is easily addressed
- Laboratory services in QECH are not providing the minimum for oncology devices with delays of up to 3 days to get Creatine levels. This causes delays in cisplatin administration for up to 5 days
- There are still serious safety issues with prescriptions. Frequently there are incorrect dosages, patients getting more dosages than standard as a result of poor prescribing but also as a result of knowledge and skills defects of all involved in the process. Standardised prescriptions may prove to be safer and more effective and in part addresses human resource challenges
- Prioritising a specific cancer such as lymphoma may yield significant benefits

- Many of the current regimes are too complicated to be delivered on the inpatient ward. Streamline and dose banding may be appropriate. For example it is not possible to accurately give 5FU or other chemotherapy over 22 hours as in patients.
- Delays in patients being referred from within QECH, but there are notable improvements. The role of a second nurse may prove invaluable here
- Absence of pharmacy oversight on chemotherapy prescribing. Furthermore pharmacy should be reconstituting the chemotherapy. With nursing staff in doing so, it compromises their ability to provide the necessary care to patients. There are many unnecessary deaths that could be prevented with more skilled nursing care on the ward
- The number of competent nurses within the service is too few. There is an urgent need to increase this both to match increasing patient numbers but also to mitigate for resignations etc. This can only be addressed currently with an alternative online education with extra support being provided by Edinburgh and [REDACTED]
- I am unsure of the educational support being offered to NCHD's but there is a knowledge deficit in many key areas (prescribing and reviewing during treatments). Is there any potential of addressing this?
- The return of the clinical officer has helped the service and he is less likely to move again. An established role for another?
- How informed is hospital management of what has been achieved? Frequently it appears that oncology is just a headache for them. Greater support is needed in light of planned cancer unit in Lilongwe

They are just some of my and [REDACTED] thoughts. I am very happy to discuss further.

Regards

[REDACTED]

Annex 6: November 2017 In-Country Visit

Present: **[REDACTED]**

High Level Key Messages

1. MDT cancer care

MDT continues to function weekly, involving oncology, surgery, gynae, plastic surgery.

Patient numbers between 4 and 12 per week.

Good records kept.

Action: **Ewan to discuss standardisation of guidelines to avoid repetition e.g. neoad breast chemo**

2. Clinical Data

Database working relatively well.

[REDACTED] working to chase up breast cancer follow up.

Dermot collected breast cancer data from 2014-2016 to explore impact of MDT on patient pathways.

Action: **[REDACTED] to draft papers on overall oncology unit numbers and breast cancer pathways**

Dermot to chase up outcome/follow up data and write report for March 18

3. Nursing Education

[REDACTED] planning to run abbreviated education course on 4th Dec.

Action: **[REDACTED] to chase up outcome of Dec course and make plans for 2018**

4. Breast Care Nursing Role

[REDACTED] continues to fulfill diverse role inc chemo nurse, breast care nurse and MDT co-ordinator.

Finding breast cancer surgical clinic rewarding.

Action: **[REDACTED] to review progress at next visit.**

5. Pathology

Little progress to report as **[REDACTED]** on maternity leave until Jan.

Leo agreed to chase up regents and ensure we are set to restart project in Jan.

Action: **[REDACTED] to liaise with [REDACTED] re. next visit plans**

6. Next Grant application

Discussed various proposals inc extending MDT working, extending nursing education programme, developing lymphoma service, cancer referral pathways, cross-specialty mentoring scheme, early palliative care proposal, training exchanges, support for labs.

Action: **[REDACTED]** to draft proposal and discuss with potential partners inc RCPSG, EMMS, Global Health Academy, NHS Fife Hospice, Glasgow Uni, CAM, **[REDACTED]** Maggies

Aim to have project meeting around 11th Dec

Annex 7:

Pathology summary April 2018

Background:

In response to a request from Oncology leads a team from Ontario visited the QECH pathology laboratory in late 2016 to train existing technical staff in oestrogen receptor (ER) immunohistochemistry (IHC) and quantitative PCR using the Gene Xpert system, the latter is currently in use within the laboratory for TB and HIV monitoring.

Following a three day visit staff were trained to perform IHC and qPCR and a plan instigated to allow future testing of IHC to proceed to accumulate a retrospective breast cancer cohort of approximately 100 cases with ER and qPCR data available. This was part of a development plan to assess the feasibility of introducing ER testing as part of a routine service.

In early/mid 2017 15 breast cancer specimens were identified by QECH and stained for ER in QECH and assessed by [REDACTED]. Subsequently, in April 2017 samples were shipped to Edinburgh and ER staining reassessed by [REDACTED], Consultant Histopathologist. Of the 15 samples tested 11 were confirmed as breast cancer, 2 were benign and 2 were “unsatisfactory” due to quality of fixation.

The quality of ER staining was high and there was good concordance between the results of ER testing in QECH and Edinburgh. The main issues identified during this process was the suboptimal quality of the tissue fixation and sectioning. Recommendations were made to further optimise the process.

In April 2018 a team from Edinburgh ([REDACTED]) and Toronto ([REDACTED]) visited QECH to review all pathology processes and operations with a view to identifying an action plan for quality improvements.

Summary

Initial enquiries determined that no further work on the immunohistochemistry project had been undertaken. This was due to multiple factors but mainly that [REDACTED] had been on maternity leave for the majority of the time since the initial pilot study and therefore there was no pathologist in the department for several months. In addition, the technicians do not feel comfortable using the IHC protocol and feel they have deskilled after initial training due to low number of cases. The low frequency of IHC use also means that many reagents have expired before being used.

We were, however, able to have lengthy discussions with both the pathologists ([REDACTED] and [REDACTED]) and technical staff in the laboratory.

Several key issues came to light which have hindered the implementation of the immunohistochemistry project and also limit the provision of the wider histology service in QECH. Constructive suggestions were made as to how, through continued partnership, these could be addressed. These issues are outlined below:

- There is a general lack of reagents and an inconsistent supply resulting in periods of time where there are no reagents. As a result the reagents for tissue processing and staining are used for longer periods than is recommended which limits the quality of staining.
- For each step in the tissue processing pathway there is only a single machine therefore if any one breaks the whole process grinds to a halt this is all the way through from tissue receipt/fixation to sectioning for H&E (At the time of the visit the sole microtome in the lab was broken therefore no tissue processing could take place).
- The management structure is complex and the histopathologists have no influence over the laboratory staff or departmental budget
- The technical staff do not receive training or practical support outside of that provided on the previous visit by the Toronto team and a recent visit of one technician to a laboratory in Spain.
- There is no immunohistochemistry staining which limits capacity of routine diagnostic work
- There is a lack of continuing professional development (CPD) or scope for further training opportunities leaving the pathologists feeling limited in their ability to keep up to date with developments in clinical pathology or research
- The pathologists are paid significantly less than consultant colleagues elsewhere in the hospital which adds to difficulties in ensuring retention of staff within the department.

Future

In view of the above review several opportunities have arisen that have the potential to improve the quality of routine tissue processing and provide a platform for the introduction of immunohistochemical staining. This will result in improved quality of the pathology service and increase diagnostic accuracy. The key areas are:

- Training of technicians in fixation, sample preparation and specimen processing as well as maintenance of equipment. Both remote (online) training and the possibility of visits from Edinburgh laboratory staff will be explored.

- Share good laboratory practice between laboratories to help minimise error and improve patient safety.
- Development of a process of external quality assurance between pathology laboratories to assess changes in slide quality.
- Support pathologists by development of remote teaching lectures from consultant histopathologists in Edinburgh
- Implement a pilot of providing second opinions on complex cases through the use of digital pathology in conjunction with consultant histopathologists in Edinburgh

**Annex 8: Breast Cancer Staff Questionnaire Feedback Report
(Final 5 Feedback Reports – 3 Doctor/Clinician, 2 Support staff; 4 males and 1 females)**

Summary

In summary, 5 staff completed the agreed Staff Questionnaire which covers both staff views of the Project AND their perceptions of patients' views. They:

- welcomed the Breast Cancer Centre, Path Lab, the new skills being learned and working as a team
- wished for more resources to ensure sustainability; exchange visits with Edinburgh
- future priority is increased material & human resources; collaboration & capacity building; training
- consider patients transport needs and unbearable side effects of chemo treatments
- consider patients poverty and knock on family issues; outreach clinics
- internet needed re patient follow-up but database makes it easier to find information about patients.

The full documents are attached below.



Staff Questionnaire on the Edinburgh Malawi Cancer Partnership: September 2016

| |
|--|
| Position in QECH: Clinician/Doctor <input type="checkbox"/> Nurse <input type="checkbox"/> Other <input checked="" type="checkbox"/> |
| What are the key benefits of the partnership between QECH oncology unit and the Edinburgh Cancer Centre? • Better working environment & treatment for patients • Clean database, this makes it easy to track patients & follow them up and analyse data easily. • Experience from our colleagues who have been to Scotland has made a big impact on the unit. good |
| What are the key challenges of the partnership? NONE |
| What could be done better? If we could have nurses in Malawi visiting Scotland to appreciate what and how nurses in Scotland operate for them to learn and practice here in Malawi. |
| Has the partnership changed your working practices in QECH? What do you now do differently? The partnership has changed our working practices also we work in a more conducive & better environment compared to other departments at QECH & we have resources. |
| What are the priorities for the future? -have our own labs and Radiology |
| What are the main challenges in ensuring compliance with treatment and attendance for follow up for patients at the oncology unit? We have no follow up team. There is no car time allocation for making follow up calls to patients. |
| What can be done to support patients to ensure better compliance and follow up? Have a person allocate car time for this purpose. |
| What difference (if any) has it made to the oncology unit to have a clinical database? Easier having a database has made it easy to find files quickly, collect data easily and make analysis. |
| Any other comments? If there was any chance that workers here would come to Scotland to learn more. |



Staff Questionnaire on the Edinburgh Malawi Cancer Partnership: September 2016

| |
|---|
| Position in QECH: Clinician/Doctor <input type="checkbox"/> Nurse <input type="checkbox"/> Other <input checked="" type="checkbox"/> |
| What are the key benefits of the partnership between QECH oncology unit and the Edinburgh Cancer Centre? - Skills training in oncology nursing which improves service delivery - Capacity builds / support which enhances smooth running of clinic |
| What are the key challenges of the partnership? None that I can point out really |
| What could be done better? Exchange visits should happen. Our nurses should also be coming to Scotland to see how oncology nursing is done there |
| Has the partnership changed your working practices in QECH? What do you now do differently? The introduction of a database which is slowly but surely enhancing data accessibility |
| What are the priorities for the future? Train more nurses in oncology nursing to cater for the ever increasing number of patients |
| What are the main challenges in ensuring compliance with treatment and attendance for follow up for patients at the oncology unit? We still have defaulters who stop coming for treatment once they start feeling well. |
| What can be done to support patients to ensure better compliance and follow up? We need to seriously follow them up perhaps by making phone calls to them or community visits in their homes |
| What difference (if any) has it made to the oncology unit to have a clinical database? one of the challenges we were facing is patients forgetting their oncology number. So if the patient has their details in the database, we easily just search by name and their number shows |
| Any other comments? None |



Staff Questionnaire on the Edinburgh Malawi Cancer Partnership: September 2016

| |
|---|
| Position in QECH: <u>Clinician</u> Doctor <input type="checkbox"/> Nurse <input type="checkbox"/> Other <input type="checkbox"/> |
| What are the key benefits of the partnership between QECH oncology unit and the Edinburgh Cancer Centre? Good collaboration system between the two groups and the establishment of the continued meetings on Friday. |
| What are the key challenges of the partnership? Very few visits from Malawi Cancer unit to Edinburgh unlike colleagues from the Edinburgh |
| What could be done better? Improve on the exchange visits so for more people from Malawi Cancer unit also has a chance of being exposed |
| Has the partnership changed your working practices in QECH? What do you now do differently? No we are able to discuss difficult cases with different specialities through the introduction and establishment of the MDT |
| What are the priorities for the future? ① Strengthen collaboration collaboration and improve on patient care ② Capacity building - staff trainings / upgrading |
| What are the main challenges in ensuring compliance with treatment and attendance for follow up for patients at the oncology unit? ① Financial problems - transportation ② Lack of essential drugs at times |
| What can be done to support patients to ensure better compliance and follow up? ① - Good transport systems - especially those that fail regularly ② - Re-establishing out reach clinics so patients don't need to travel long distances |
| What difference (if any) has it made to the oncology unit to have a clinical database? |
| Any other comments? Increase number of staff both clinical and nursing so patients do not wait longer hours due to staff shortages. |



Staff Questionnaire on the Edinburgh Malawi Cancer Partnership: September 2016

| |
|---|
| Position in QECH: Clinician/Doctor <input checked="" type="checkbox"/> Nurse <input type="checkbox"/> Other <input type="checkbox"/> |
| What are the key benefits of the partnership between QECH oncology unit and the Edinburgh Cancer Centre? Makes work easy in terms of Radiology scans and Pharmacy |
| What are the key Challenges of the partnership? |
| What could be done better? Having our own Laboratory, since most of the times lab clinics are delayed and some critical patients missed because results |
| Has the partnership changed your working practices in QECH? What do you now do differently? We do our scans / scans on our own scheduled dates by specialised Radiographers at our unit. |
| What are the priorities for the future? - Laboratory - |
| What are the main challenges in ensuring compliance with treatment and attendance for follow up for patients at the oncology unit? -Defaulting Due to Transport Issues. |
| What can be done to support patients to ensure better compliance and follow up? Giving Funds to the Needy Patients. For Transport and Shelter for those who come from far. |
| What difference (if any) has it made to the oncology unit to have a clinical database? We track files easily and progress / work progress is monitored. |
| Any other comments? |



Staff Questionnaire on the Edinburgh Malawi Cancer Partnership: September 2016

| |
|--|
| Position in QECH: Clinician/Doctor <input checked="" type="checkbox"/> Nurse <input type="checkbox"/> Other <input type="checkbox"/> |
| What are the key benefits of the partnership between QECH oncology unit and the Edinburgh Cancer Centre? - Development of the cancer unit which was not there before. - Sustainability of the project and provision of new knowledge and skills |
| What are the key challenges of the partnership? - We are still unable to reach an optimum level for availability of resources. |
| What could be done better? - If we we could have all the necessary resources like good internet signal then we will be able to use the data base here easily |
| Has the partnership changed your working practices in QECH? What do you now do differently? Very much, we used to work blindly in terms of team work spirit but now we are able to work as a team and work becomes easier |
| What are the priorities for the future? We should be able to have average resource level, both material and human resource. - we must be able to conduct the follow-up for patients |
| What are the main challenges in ensuring compliance with treatment and attendance for follow up for patients at the oncology unit? ① Financial constraints, many patients are poor and cannot afford to source transport - Side effects - some side effects of chemo are unbearable |
| What can be done to support patients to ensure better compliance and follow up? - Integrate other issues like family planning because poverty levels are also attributed to that and if possible provide support then financially |
| What difference (if any) has it made to the oncology unit to have a clinical database? - Able to track patient easily |
| Any other comments? - If exchange visits were continued it will help more because people learn more when they visit the WHH as well. |