



Palliative Care Workstream

Team members:

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Background and development of Workstream

- Met with the Jordanian Ministry of Health to facilitate a national strategy meeting for home palliative care
- Met with the National Palliative Care Committee within the Ministry of Health to review the availability of routine data
- Established an agreement with the Ministry to use routine death registration data in a joint analysis and publication
- Met with the multidisciplinary palliative care teams at King Hussein Cancer Centre and Al Bashir hospitals to plan the research activities
- Delivered a tailored seminar on psychosocial support to health care professionals targeting advanced cancer patients and families
- Appointed a post-doc in palliative care
- Developed protocol for phase 1

How will the Workstream build capacity in the region?

- Coproduction of protocol & ethics application
 - Jointly working on writing research protocols
- Focus on quality – strengthening health system and individual clinical capacity to undertake outcome-led care
- Embed outcome measurement for quality improvement through capacity building and routine collection of clinical outcome data
- Research methods training delivered locally for capacity building
- Delivered a seminar – building local capacity to affect and deliver psychosocial care

Overview of achievements in year 1

- Established a new Center for Palliative & Cancer Care in Conflict (CPCCC) under KHCC - appointed 2 staff at CPCCC 1 FTE and 0.5 FTE to work on R4HC
- Submitted R2HC Expression Of Interest with collaborators in Jordan & Palestine
- Developed proposal with Tezer to expand paediatric palliative care outcome work in Turkey
- Progressed well in phase 1
 - Co-developed a study protocol and literature review with Jordanian colleagues
 - Submitted this to KCL for ethical approval and full approval granted on 11.07.18
 - Completed the ethical review forms for KHCC. All forms translated and submitted in Arabic, awaiting IRB full board review since refugees are involved
 - Met Al Bashir Hospital staff to plan recruitment. Completed IRB application and ethical approval obtained from Al Bashir Hospital
 - National palliative care strategy meeting with Ministry of Health and developed strategy document
 - Delivered psychosocial seminar
 - Visited KHCC on 16.08.18 for study launch: successfully delivered local staff training on phase 1 research methods and had a productive meeting with people from Ministry of Health regarding death registration data extraction and transfer
 - Received approval from Ministry of Health in Jordan for phase 1

Reflection on year 1

- Progressed well as planned
- Established protocol and ethics application done for phase 1
 - Now can focus on mentorship delivery on partnership and capacity
- Discussed local training needs in Jordan
 - Now work together to develop training programmes to be delivered locally (e.g., data analysis, validation study methods training for phase 2, outcome measurement, psychosocial skills in phase 3 quality improvement, publication and dissemination)
- Enabled us to identify additional opportunities in this theme and partnership looking at sustainability
 - A new R2HC Expression of Interest application submitted, awaiting to hear back
 - To attend the World Cancer Congress, Kuala Lumpur, Malaysia, 1-4 Oct 2018
- Identify candidates for MSc palliative care: in discussion (funding issue)

Aims and objectives for year 2

- To complete high quality data collection for
 - a. Analysis of Ministry of health mortality data [month 1-6]
 - b. Qualitative study of refugees/displaced persons at end of life (KHCC/AI Bashir) [month 1-6]
- To finish data analysis and dissemination of the study results for a & b
- To seek ethics applications for KCL & Jordan for
 - c. Local validation of IPOS [month 7-18]
 - d. Local validation of CPOS [month 7-18]
- To arrange future visits for effective capacity building and training on research methods for c & d
- To develop and implement quality improvement strategy (KCL to Jordan to locally)

Longer term deliverables in years 3-4

- Continue building research capacity in the region through training, workshops, and primary research delivery
- Disseminate research findings through peer reviewed journals, national/international conferences, and policy briefs.
- Develop quality improvement strategy and conduct our outcomes-focused evaluation with quality improvement [months 19-36]
- Continue MSc degree training with KCL
- Plan local accreditation for KCL MSc course

Looking into the future

Steps to maximise capacity building and reach into the region:

- Identifying local needs and building on existing capacities
- Being clear about the shared objectives for capacity building
- Using a wide range of capacity building approaches (e.g., training, formal education, networking, and interactive workshops using exercises, case studies, field visits and other elements of experiential learning to actually build capacities)
- Targeting the right people to build a critical mass (key stakeholders groups to eventually build a critical mass of people that can initiate and sustain a process of change).
- Making the training-of-trainers approach work
- Securing the new programme grants to ensure sustainability of capacity building in the region