

PEPFAR Public Health Evaluation: Palliative Care Newsletter

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Successful Phase I meetings



I would like to start this newsletter by thanking everyone who attended the

Phase I Results Sharing meetings held at the end of May. Nearly all Phase I facilities were represented and there were lively discussions. We enjoyed sharing results with those people who contributed most to the data—the facility staff. We also received

valuable feedback to help us to improve our reports for PEPFAR. We hope that those who attended found the sessions informative. In this newsletter we have squeezed in a few photos from the days, see page 4.

It's also time to say goodbye, of sorts, to one of our evaluation team members. Dr. Rick Berzon has left USAID but is still intending to work with us on the analysis of Phase 2 data.

Thanks to Rick for his enthusiastic support for this evaluation.

Our continued thanks go to all the facility staff and patients involved for providing us with the data for us to be able to conduct this study.

With best wishes on behalf of the team.

Dr Julia Downing,
Deputy Director, APCA

Added value: Post-graduate studies

The extensive data being collected in Phase 2 is a rich resource for further studies to complement the evaluation questions.

Vicky Simms is a research associate on the evaluation team who has recently registered at King's College London (KCL) to study for her PhD. She will be using Phase 2 data to explore the needs and experiences of

individuals newly diagnosed as HIV positive; an area where little information has been published to date. The design of Phase 2 provides an ideal opportunity to study this important area.

Vicky says, "I'm particularly interested in people who have just been diagnosed because I think the right care provided early on could

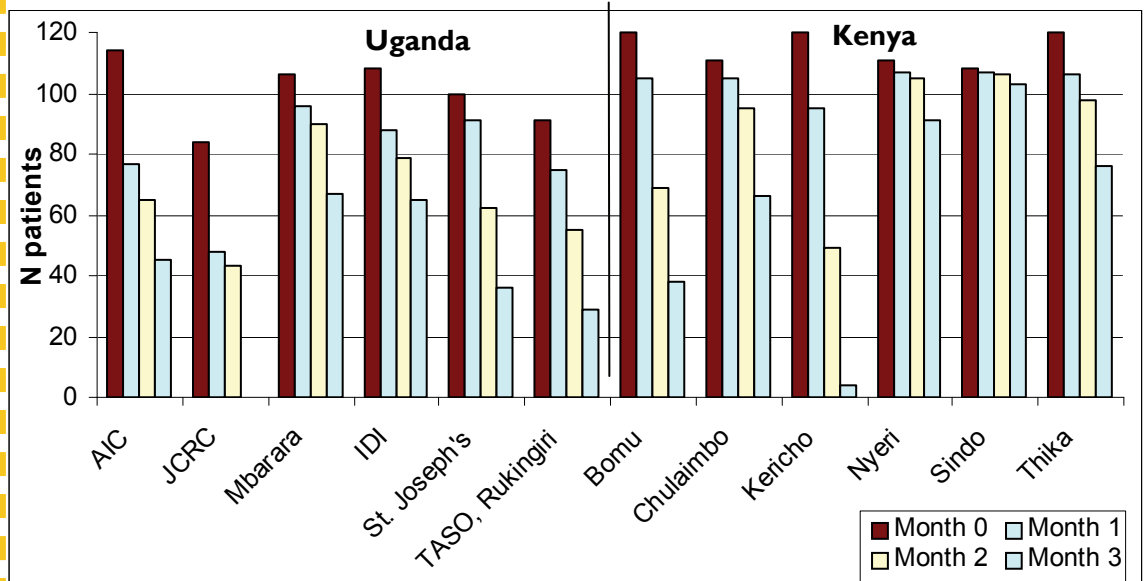
prevent potential future problems arising."

Vicky's studies show the added value of conducting such evaluations in a research setting and the outcomes of her work are eagerly awaited.



Phase 2 progress: longitudinal data collection

The table below shows the current status of data collection for the patient longitudinal study. As you can see, this part of the study is going very well; most sites have recruited 100 patients, and for all sites follow-up has been consistent. Congratulations to Sindo for being the first facility to complete the follow up for all their patients (103 patients completed all 4 time points). A special mention has to go to Kericho and JCRC for such rapid recruitment and sustained follow up after a delayed start.



Patients recruited for Phase 2 and follow up interviews, by facility — approx figures at June 13th



“It’s been great working with everyone involved in this PHE. I look forward to participating in the review of the analyses of the findings, especially from the costing data.”

Dr Rick Berzon

Evaluation: Next steps

Now that several patients have completed the questionnaires for the four time points in the longitudinal study, and their data have been entered into the database on site, the APCA researchers are beginning to bring these questionnaire packs back to the offices in Nairobi and Kampala.

Here the researchers are entering all the data for a second time. When this is

complete the two entries (the original entry done on sites and the one done by the researchers) will be compared and any discrepancies checked by referring back to the questionnaires. This double entry-method is considered to be the ‘gold standard’ in data entry procedures. It minimises typing errors, which occur for even the best typists! Most Phase 2 sites are nearing completion of

longitudinal data collection. Researchers at KCL are currently drawing up an analysis plan, so that when data collection is complete the analysis can be undertaken swiftly.

In addition, the in-depth interviews that have been undertaken with staff, patients and carers are being transcribed and translated, so we hope to begin analysis of these soon.

Spotlight on Mbarara

Mbarara ISS clinic, one of the phase two sites, is part of Mbarara Teaching Regional Referral Hospital and a regional centre of excellence for HIV care. Mbarara ISS clinic serves patients from great distances and from all walks of life. Clare Nsubuga has been the APCA contact for Mbarara Regional Hospital since Phase 2 started.

In June Dr. Suzanne Penfold from KCL accompanied Clare to Mbarara on a regular study visit. Suzanne gained insight into how data collection was fitting into the day-to-day running of the clinic. She also received valuable feedback on the questionnaires from the staff who had been us-

ing them; including examples of questions that were useful to the patient-clinician interaction, and

some which were tricky for respondents to answer. Such information will be useful for future studies involving these tools.

Clare summarised her thoughts on working with Mbarara: "We greatly appreciate the study's



Dr. Suzanne Penfold, Abdu S Kato, Kenneth Musenge
Dr. Ruth Mbabazi, Dr. Winny Omuut, Clare Nsubuga

team's commitment to the evaluation process and the support from the ISS clinic director, which has made the process a great success. Our prayer is that you continue with the same spirit so that we realize our goals."

Partner Profile: Measure Evaluation

MEASURE Evaluation is a global public health project funded by USAID and implemented by the University of North Carolina at Chapel Hill (USA) in partnership with Constella Futures, John Snow Inc., Tulane University and Macro International Inc.

MEASURE works in consultation with USAID Mission staff, local counterparts, cooperating agencies working in country, USAID Bureau of Global Health staff and other donors.

The objective of MEASURE is to improve the collection, analysis,

presentation and use of data in planning, policy-making, programme management and the monitoring and evaluation (M&E) of population, health, and nutrition programs. MEASURE provides technical assistance to health ministers, district caregivers and local trainees in successful data management for better informed programme planning and policy-making.

In this evaluation MEASURE is currently assisting in the implementation of Phase I findings and recommendations. Dr.

Scott Moreland is MEASURE's representative working as a member of this palliative care PHE team.



Phase 1 results sharing meetings

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There were lively discussions in both meetings!



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