

This is a response from the UNZA team on the one-page paper from the Linkages Team entitled "Continuum of Care: Confluent Medical Records". You had lots of good ideas and we at UNZA generally saw our purpose in this case being to provide clarifying information and focus your potential solutions on something manageable and on the area where we felt we could have 1) the greatest impact (most likely to change something) and 2) the need is greatest.

Your identification of the two major components of the problem of information flow was good, especially based on the information you had. At this point there are at least some indicators that are suggested (see below) but that does not mean they are being tracked well.

Some of the statements you made in your one-page were a bit bold or too absolute. Most HBC programs have *some* form of record keeping. However, the quality and usefulness of these records varies widely and it is generally true that they do not make significant use of them, especially at the level of individual caregivers. It is also even more rare that it is passed on to other healthcare providers. The use of the data on the national level is also more than just epidemiological in nature, they can use information on services, finances, trainings, operations, etc.

Some things to note:

- 1) HBC caregivers are not trained healthcare professionals. They have no real clinical skills unless they happen to individually have that training.
- 2) There is something called the Health Management Information System (HMIS) in Zambia. It was created about 10 years ago in 1996 and it provides a means to collect aggregate indicators from the health facility level all the way up to the national MOH/CBoH level. There was an assessment of the HMIS system done in 2003, which you can read about in the attached paper. There was also an assessment of the HMIS system done this year by EuroHealthGroup. We only have a paper copy, but it may be available on the web somewhere. The authors were Arthur Heywood, Stanislaw Orszyszyna (sp?), and Erik Nielsen. The HMIS is old, out-dated, and not functioning that well. And it doesn't really provide any means of gathering HIV-related statistics because it was built so long ago. (see below for more description of the HMIS in Zamb)
- 3) The National AIDS Council has a Zambia-wide monitoring and evaluation system that is just becoming operational. It is called the NAC Activity Report Form (NARF) It is meant to reach below the health facility level to all community organizations doing HIV/AIDS related work. It is specific to HIV/AIDS and gathers only a very few indicators at community level. It is also meant only for national aggregation and not for program management or patient care at any other level. See the NARF guidelines sent with this document. In this document, there are indicators marked "National" which are passed up to NAC, and "Program" which are just recommended for program-level use.

The HMIS system extends from the Health Facility level up to the national level. The forms and personnel are there to gather, aggregate, and pass on the information collected. One important point is that this health information doesn't extend beyond the health facility (meaning it doesn't come from the community-based programs such as HBC). So, there is a definite gap here. When thinking about gathering and using this information, it is useful to make a distinction between the different ways information is used: patient management and program management are the two broad categories you can consider. The following table is our attempt at describing the use of information at the various levels of the Zambian healthcare system (public and private). Note, this is a not a direct description of the HMIS system, because it includes HBC which is not a part of HMIS.

Who does what, so why do they need information?

Level	Patient Care	Program Management
MOH/CBoH	No	Yes
Province	No	Yes
District	No	Yes
Health Facility	Yes	Yes
HBC	Yes	Yes

As a group, we tried to take this information and consider the two questions above: where can we create the most change, and where is the need greatest? We decided that the need is greatest at the HBC level, since that is not even included in the HMIS system. Further, we think we have the best chance of actually creating positive change at the level of HBC where there are smaller, more flexible programs for us to work with. Another factor directing us to HBC is that there are opportunities for both patient care and program management at this level. As HBC is at the bottom of this information pyramid, it is the foundation that a lot of the rest of the indicators are built on and is thus a very important part of the whole information management system. So, for these reasons we suggest a focus on home-based care information for this module.

The next questions are whether you want to focus on gathering patient-level data, such as individual charts/records for each patient, or project-wide indicators. And, do you want to focus on using these for patient management or program management? While there are dependencies within these two questions and they all overlap to a certain degree, trying to tackle the whole thing at once would be a bit too much for you and for any program you were to work with. Our advice is to start with something small and work up from there as you have success. It is tempting to think big, especially when you are on the other side of the world, but try to moderate this impulse and understand that to a HBC program here even an incremental change in their record keeping will potentially be both a big improvement and a big shock.

Taking all of this into consideration, we want to offer a suggestion that you choose one of the following two areas to focus your pitch on. Your next steps should be to do research in two areas: 1) questions you need to answer to understand doing this in the Zambian context and 2) how things like this have been done in other countries and what we can learn from that. We cannot stress enough the importance of this second piece. It has been suggested in the past, and seems to have been ignored. It is not easy, but it is vital to doing a responsible job of working in this space and not repeating the mistakes others have made.

Potential problems/solutions:

- 1) Something to help caregivers use the information they are gathering about patients in the care they provide. This is our interpretation of what you meant by a "patient monitoring chart." It would be better than a simple blank notebook and it would provide some tools for summarizing and following patient information in a useful way. You may have to deal with low-literacy and certainly low education levels. But we expect there is a lot out there to build on and you should be able to find prior art out there to get you started. So, this would fall under patient-level information for improving patient care. Be creative and think of possibilities such as focusing on ART support, etc. Perhaps the tool could help a caregiver distinguish between everyday symptoms and signs of serious side effects or treatment failure.
- 2) The other area that you might want to focus on is strengthening program management of HBC at the site level. This could be through some combination of patient-level information and aggregate indicators. The project would have to include recommendations on the information to be captured, how it could be used, and how it could be gathered effectively given the constraints of the HBC programs. The indicators listed in the included NARF guidelines should give you a place to start from.