

Health information as a catalyst for community health system engagement

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Introduction

This case study reviews lessons learned from an intervention bringing together two familiar but often un-connected domains, namely health information systems and community engagement. Health information is a fundamental building block in the health system, and community engagement is recognised as a critical foundation for the delivery of quality, people-centred and resilient health services.¹⁻³ While South Africa has made impressive progress in both domains over the last 20 years, challenges persist.

Health information systems are often fragmented, costly, inefficient, and based on data of uncertain quality.^{4,5} In South Africa, there is also little experience with effective use of health information in decision-making, especially at primary health care level.^{6,7} Efforts to promote community engagement also face various challenges, including a technocratic, hospital-centric and over-worked health system; community distrust and disenchantment with health staff; and lack of policies, models and resources for effective community engagement.^{2,3}

This case study reports on initial findings from the iALARM project (Using Information to Align Services and Link and Retain Men in the HIV Cascade) in a Cape Town sub-district. The project collects, synthesises and distributes health information and research to a diverse set of health system and community stakeholders to catalyse more effective forms of community engagement and to strengthen the local health system. A combination of ethnographic and action research methods were used to document lessons learned.

The iALARM project

The focus of the iALARM project is to improve men's poor performance in the HIV cascade.⁸ The project centres on the linkage and retention task team, which brings together people from different levels of the public-sector health system as well as community members, non-governmental organisation (NGO) staff, and local activists. New forms of health information are introduced at monthly task team meetings, and conversations are facilitated to catalyse new ideas, relationships and programmes to better support men's access to HIV prevention, treatment and care. The project is a collaboration between the University of Cape Town (UCT), Brown University (in the US), the South African Medical Research Council (SAMRC), the University of California, San Francisco (UCSF), and Sonke Gender Justice.

The linkage and retention task team

The task team consists of a core of 20 regular members who meet monthly at the Men's Wellness Centre (a project run by Sonke Gender Justice). Members include nurses, community health workers, sub-district managers, facility and programme managers, health information officers, HIV/AIDS, STI and TB (HAST) coordinators, NGO and community-based organisation (CBO) staff and volunteers, community members, and local health activists. Staff and students from the University of Cape Town, the SAMRC, and Brown University host the meetings and prepare the materials for each month's discussions.

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The original intention of the intervention was to use unique, 'harmonised' forms of routine health information available from the Provincial Health Data Centre (PHDC), which integrates clinical records across multiple municipal, provincial and national routine health information databases.⁹ However, at monthly task team meetings, it became apparent that other forms of information were also needed and the focus was expanded to include 'headcount' data from routine monthly reports (RMRs), local qualitative research on masculinity and HIV, published scientific literature, government and academic databases, and other sources of health information.

The first half of the meeting generally involves a presentation and discussion of health information: summaries of cascade performance, changes in headcount data, syntheses of qualitative research findings, and even testimonials from local HIV-positive men. The second half of the meeting addresses possible responses to this information. While UCT staff and students may, and do, get involved in carrying out some of the emerging ideas, the main objective of the meeting is for task team members to take the ideas forward.

Setting up the task team

In recruiting for the task team, recurring complaints were heard about both health information systems and community engagement. For example, health staff (especially at the frontline) expressed frustration with health information processes. Clinic staff described data as being generated in forms and registers, filtered 'up' the system, and never heard of again. Clinic managers spoke about routine data primarily in terms of monthly performance review meetings with their managers. At the same time, however, there was strong belief in the value of health information and its potential to inform and improve services.

Similar patterns emerged when asking those in the health system about community engagement. They described how community members and local NGOs were vocal in their complaints about the health services, but that there were few spaces where health system and community members could engage regularly on these issues. Clinic health committees were generally perceived as inconsistent and ineffective. The local Multi-Sectoral Action Team (MSAT), a sub-district-level body meant to coordinate health system and community responses to HIV, was also reported to be ineffective. Community actors reported similarly frustrating experiences, both with health information and attempts to engage with the health system. They too expressed desire for greater access to health information and better engagement with the health system to improve the health of their communities.

Creative conversations

Given these past experiences, there was uncertainty regarding how the first task team meetings would unfold. There was concern that health staff might feel judged or that some community members might struggle to understand and engage with health data. There was also uncertainty as to whether interest in working with new forms of health information and engagement would be more than a distant ideal.

From the start, however, what has been strongly and consistently apparent is the hunger task team members have for health information, and the enthusiasm and creativity they bring to discussions regarding what this information means and how it can be used. Health system staff have engaged positively with criticism

from community and NGO members and they have talked together about ideas to improve services and relationships. Health staff have in turn explained their frustration in delivering services to male patients who appear to them as reluctant to accept advice. These conversations have not always been easy, but they have been respectful and productive.

Lessons from the task team's first year

Several key lessons have emerged so far. The first is that bringing diverse actors together with novel forms of locally relevant health information can catalyse productive conversations and new ideas that improve the health system and coordination with community organisations. There seem to be few if any other collaborative spaces of this kind. The ability to engage not only across the health system/community divide, but also across different levels of the health system and with diverse NGOs and CBOs in the area, has also been an important element in the team's design.

A second lesson has been the value of open-ended forms of engagement in the task team's discussions and objectives. The task team is not a space for formal oversight or for the co-option of community members for service delivery. Instead, the task team functions as a flexible, responsive and creative space to generate discussion and ideas for solving problems. At the same time, not being part of a formal governance structure, or day-to-day operations limits its potential sustainability and impact. While the task team does not replace forms of community engagement that involve governance or service delivery, experience thus far has shown that this collaborative kind of engagement is possible and desired, and can be productive when properly supported.

What kind of information is most useful?

Valuable lessons have also been learned about what kinds of health information are useful and how to use them. The initial plan had been to bring regularly updated sub-district-level cohort data on the current performance of local men in the HIV cascade. This information is not currently available at this level of the system and across different services, and task team members were keen to review these data on an ongoing basis and to adjust their services accordingly.

There was concern that we (the authors) might not be able to receive, analyse and synthesise PHDC data on a regular enough basis given capacity constraints. We were also concerned about the meaning and quality of some of the data, largely because of concerns about the underlying data sources at the frontline. There was additional concern that the PHDC was still working out the details of its complex efforts to link individual records across multiple databases, and we were not always sure we understood enough about the data we were working with.

Two key learnings emerged in relation to these concerns. First, task team members were much more interested in working with a diverse and evolving set of health information than with the same monthly cascade report every meeting. For example, whenever a graph from the cascade report was reviewed, the ensuing discussion would raise possible explanations as well as gaps in knowledge and questions about appropriate responses. This led directly to requests for different forms of information that would support the developing brainstorming discussion.

What became clear was the importance of having a diverse 'ecology of evidence',¹⁰ combining not only cascade reports, RMR headcounts, qualitative research, and WHO reports, but also informal knowledge and experience such as personal testimonies, news reports, lists of local organisations and projects, personal and professional networks, etc. The mix of formal and informal bodies of knowledge has become a central feature in the task team meeting discussions, and an important source of the value team members ascribe to the process.

Another learning has been the value of 'good-enough' information in these discussions. Task team members occasionally raised questions about the accuracy or timeliness of the data, but for the most part, new ideas to support men have not required precise or up-to-the-minute information. Small-to-moderate errors in quantitative estimates have not been problematic. Instead, what has been valuable is the local relevance of the information. The ability to see one's own clinic or neighbourhood in the data sparked conversations about local dilemmas and solutions that would not have been likely if the information had been aggregated at district or provincial level.

Conclusions and recommendations

Below are some of the key lessons learned; which may be relevant to other efforts to improve data use and community engagement.

- There is a desire for new forms of health information and new forms of engagement (if effectively facilitated). People are willing to break out of conventional ways of thinking and doing when given the opportunity.
- It is important to promote conversations across different sectors of the community and different levels of the health system.
- Responsive and open-ended forms of engagement are generative. This does not diminish the important place of community-driven forms of accountability and oversight. Rather, the lesson here is that significant forms of community engagement can – and may need to – happen outside of existing spaces.
- It is effective to use a wide array of forms of health-information that are locally relevant and sufficiently trustworthy. In this intervention, concerns about data quality usually mattered much less than whether or not the data spoke to local contexts and experiences.

Recommendations for those working with health information and community engagement are as follows:

- Focus on a specific health problem around which a diverse set of actors can be mobilised. The actors should share a common set of interests and objectives and work towards concrete local actions.
- Think broadly about the types of information that might be relevant to the health problem at hand, and develop capacity (ideally among both health system and community actors) for finding and synthesising this information efficiently and in a manner that can be understood by all involved.

Insights from this case study may help to inform new ways of thinking about the production, circulation and use of health information as well as new forms of engagement between health systems and communities.

Acknowledgements

The authors are grateful to all who have participated in the iALARM task team as well as those who have been part of iALARM's broader research. Thanks also to Sonke Gender Justice for partnering in this work and serving as a platform for the task team. Time to write this chapter was supported by the US National Institute of Mental Health and the South African Medical Research Council [#R01 MH106600]. The content is solely the responsibility of the authors and does not necessarily reflect the official views of the US National Institutes of Health or the SA-MRC.

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