DEPARTMENT OF HEALTH **RESEARCH BRIEF**

Verbal Autopsy with Participatory Action Research (VAPAR)
Expanding the knowledge base through partnerships for action on health equity
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'Setting the Scene': Persons lost to follow up with HIV/TB treatment

VAPAR promotes evidence generate and use with services and rural communities. Our current work focusses on building community health worker (CHW) capacities in rapid evidence generation for HIV and TB, as a main health problem in partner villages. This brief presents - Part 1: mortality data from MRC/Wits- Agincourt Unit's Health and socio-Demographic Surveillance System (HDSS); Part 2: evidence generated by communities to better understand how local action could address issues identified; and Part 3: a literature review.

1: Verbal Autopsy

(a) Burden of disease

Verbal autopsy (VA) is a survey method to measure levels and medical cause(s) of all deaths (occurring inside and outside facilities) in populations. Wits/Agincourt HDSS exhaustively covers district populations, supporting generalisability. We analysed VA data to quantify the burden of HIV/AIDs and TB over time (Fig. 1).

- **Significant improvements** in HIV/TB burden over the period 2012-19
- **20-49-year-olds largely affected -** account for 61% HIV, 66% TB deaths (2019)
- **72% TB deaths in males** (2019). HIV-related deaths 42%:58% (M:F) (2019)

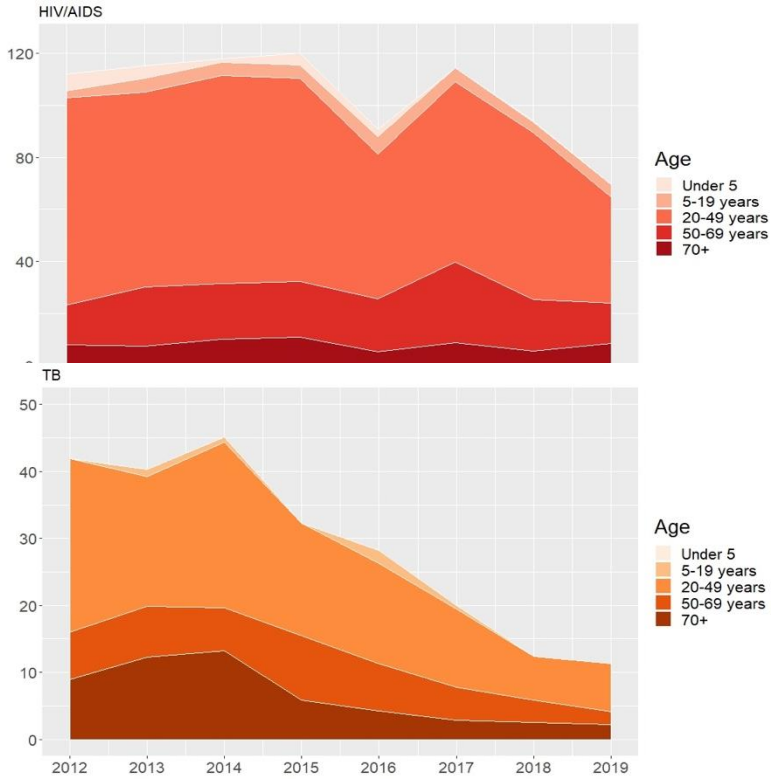

Figure 1: Number of HIV/AIDS and TB related deaths in Agincourt HDSS 2012-19

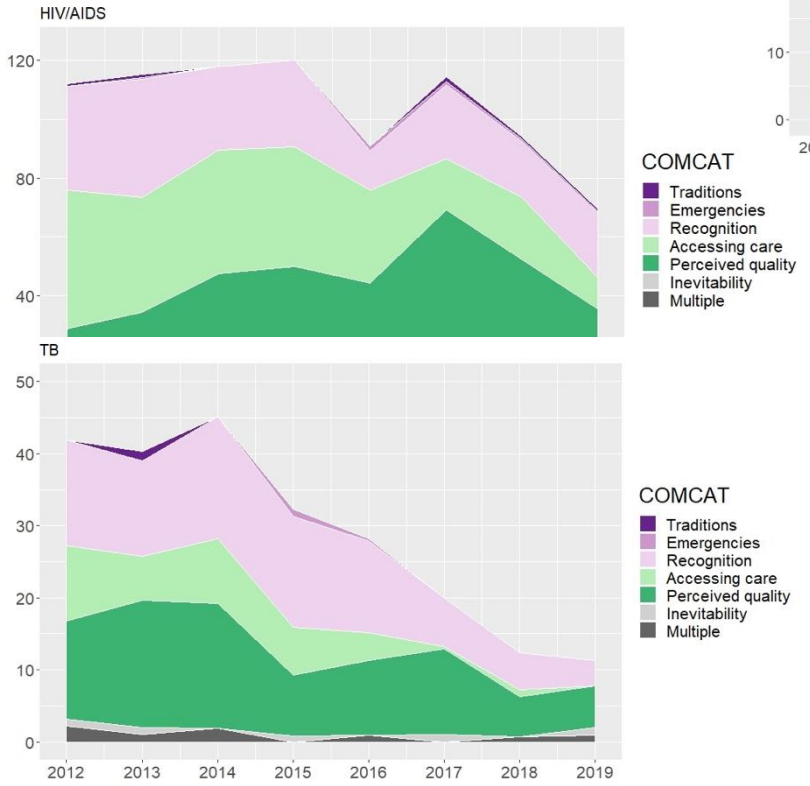

Figure 2: Circumstances of Mortality Categories (COMCATs) by year for HIV/AIDS and TB related deaths in Agincourt HDSS 2012-19

(b) Circumstances of mortality

We produced a method to assess individual needs and behaviours at and around time of death, and health system responsiveness, for inclusion with burden of disease data. The main circumstantial categories corresponding to the HIV/TB burden are: (Fig. 2).

HIV (2019)
- 32% reported failures to **recognise severity**
- 29% reported problems with **perceived quality**

TB (2019)
- 54% reported problems with **perceived quality**
- 28% reported failures to **recognise severity**

2: Participatory Action Research

We identified local health priorities using PAR supporting active involvement of CHWs and building capacities in rapid research methods. CHWs, with clinic committee members, clinic outreach team nurses and community stakeholders, identified **persons lost to follow up with HIV/TB treatment to understand service delivery issues: negative attitudes** referring to behaviours such as intolerance and disrespectful conduct on the parts of health workers and patients – affecting communities and the health system.



Figure 3: Skipping medication collection dates described as the cause of persons lost to follow up with HIV/TB treatment

(a) Causes of loss to follow up

- General negative attitude towards the health system, by health workers and communities
- Disclosure and stigma
- Migration
- Missing medications and clinic appointments
- Long waiting time at facilities
- Lack of food due to poverty



Figure 4: Long queues at health facilities described as causes of persons lost to follow up with HIV/TB treatment

(b) Impacts of loss to follow up

- Drug resistance, posing further health threats associated with weakening of the immune system
- Increased numbers perceived to be associated with CHWs incompetence/lack of effort
- CHWs' other responsibilities neglected in attempt to trace/re-initiate every patient lost to follow up

Along with other PAR methods, stakeholders were trained in Photovoice, where cameras and cell phones are used to collect and interrogate **visual evidence** from the local environment. This was challenging because of stigma associated with these conditions and restriction of the use of visual recording devices such as cameras in health facilities. A few participants were able to apply this method regardless of the challenges (Figs. 3-4).

(c) Local action

Following exploration of the health concern and key actors, an **action agenda** was developed. The action agenda includes 14 items, which range from CHWs-led actions such as local awareness campaigns, drawing patients' medication schedules, establishing local support groups and encouraging patients to utilise local clinics. It also focuses on the health system, including improving patients tracing systems, training CHWs, improving food supplementation, addressing issues of employment of CHWs, and verifying patients' information.

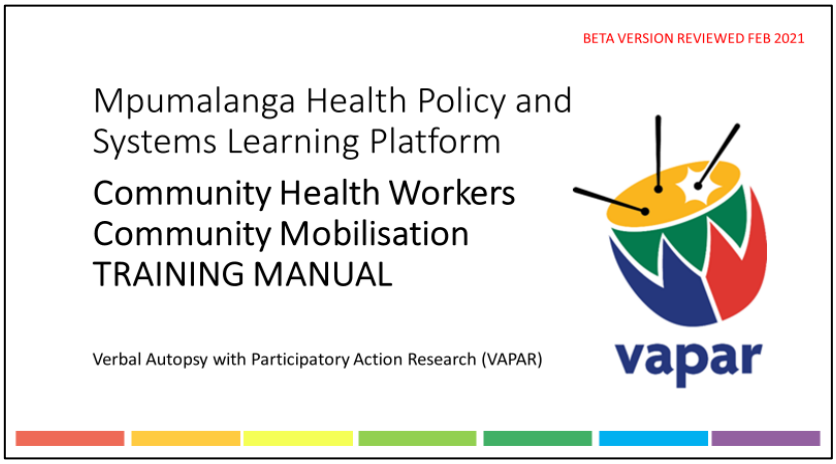

Figure 5: CHW Community Mobilisation Training Manual

(d) Refections

CHWs reported that the Community Mobilisation Training (Fig. 5) has had **multiple, positive impacts**. PAR skills have been acquired, they have increased confidence in public speaking and engaging with communities and clinic staff. CHWs indicated they are more determined to be involved in communities as demonstrated by their commitment to lead the community awareness campaigns. Clinic operational managers and clinic outreach nurses were engaged in and supportive of the process.

Collective Local Action Agenda

Action	Actors	When	Monitoring
Community (including CHWs)			
1. Drawing up patient medication schedules	- CHWs - Patients	Ongoing as of May	Increased in number adhering patients
2. Establishing community-based support groups for HIV/TB patients	- CHWs - Lay counsellors - Induna - Nurses	As soon as possible	Increased in number of people accessing and attending support group
3. Check clinic cards and regularly encourage patients to collect their medications during households	- CHWs - Family members	Ongoing as of May	Increase in number of patients whose medication schedule is up to date
4. Re-initiating and continuous monitoring of patients/persons lost to follow up HIV/TB	- CHWs - Nurses	As soon as possible	Improved patient adherence
5. Community awareness campaigns	- CHWs - Induna - OTL	As soon as possible	CHWs becoming more visible during community wanes campaigns
6. Encourage patients to collect their medications at their respective villages	- Induna - Clinic health committee - Nurses - CHWs	As soon as possible	Reduced number of persons lost to follow up
Government Departments			
7. Improving food supplement coverage for HIV/TB patients	- Social workers - Nurses - CHWs	As soon as possible	Increased in number of people receiving food parcels
8. Training of all CHW on CCMDD (Dablapmeds)	- DoH	As soon as possible	Clear understanding of the feasibility of water harvesting
9. Verify patient's information while they are still at the clinic premises	- Clinic data captures	As soon as possible	Improve tracing of persons lost to follow up for HIV/TB treatment
10. Linking patients to CHWs during treatment initiation while they are still at the clinic	- Nurses - Lay counsellors - Family	As soon as possible	Reduced number of of persons lost to follow up for HIV/TB treatment
11. Reducing waiting period that results in long ques at clinics	- Clinic health committee	As soon as possible	Reduced waiting times
12. Improving the tracing system of persons lost to follow up	- DoH - OTLs	As from August	Increase in number of traced patients
13. Permanent employment of CHWs	- DoH	End of 2022	Progress towards getting all CHWs permanently employment
Researchers			
14. Investigating why patients give wrong incorrect personal information at the clinic	- Wits/Agincourt	Anytime from now	Report illustrating why patients give incorrect information

3: Literature review on loss to follow up with HIV/TB treatment and role of CHWs

(a) Epidemiological and impact analysis

→ *High burden, successful treatment campaigns*

South Africa has the greatest number of people living with HIV, with 7.52 million of the estimated 36.9 million people living with HIV and AIDS in the world being in South Africa (1). Furthermore, TB remains in the top causes of death in South Africa with an estimated incidence of 567 cases per 100,000 population in 2015 (2). Concerns over the growing threat of multi-drug resistant TB are growing and South Africa reported the second highest number of MDR-TB (4,5). Levels of HIV and TB co-infection are very high, with as many one third of people with HIV are also infected with TB and TB accounting for 1 in 4 HIV deaths (4).

South Africa has the largest ART programme with approximately 4.3 million individuals on treatment (6, 7). One study describes the increase in life expectancy (LE) in KZN from 2003-14 by 15.2 years and 17.2 years (males and females respectively), 79.7%, and 90.7 % of these increases were attributed to reductions in HIV and TB related mortality (9). In terms of treatment for TB, South Africa adopted the STOP TB campaign, which intends to successfully treat at least 90% of notified TB cases and meet the WHO target of ending TB by 2035 (10).

→ *Uptake and adherence sub-optimal*

Despite improvements in treatment, uptake and adherence remains suboptimal. In order for HIV and TB treatment to be successful, individuals must adhere to strict medication schedules (11, 12). In 2018, it is thought that of the 13.8 million individuals living with HIV in East and Southern Africa, only 58% were virally supressed (13) although official rates of loss to follow up for HIV treatment are not nationally documented. In 2018/19, Mpumalanga Department of Health (MDoH) documented 6.6% of the population with TB are lost to follow up, (42). However, for those that test positive with TB and never initiate treatment, rates are expected to be between 15-18% (2).

→ *Loss to follow up for HIV treatment linked to health systems <u>and</u> individual challenges*

Adherence is defined as individuals abiding to a prescribed treatment regime (14, 15). Not only is adherence to treatment protocols important in treating HIV and TB, it reduces the likelihood of drug resistant strains (3, 5). Non-adherence, more recently termed ‘persons lost to follow up’, has been described as the most critical factor in the failure of treatment for HIV (16). Reasons appear to stem from two broad areas, healthy facility and or individual constraints. Although these often overlap, individual constraints are largely due to stigma, poor understanding of treatment and forgetfulness. Whereas health system constraints are problems associated with accessing care, such as having large distances to travel, long waiting times and poor clinic operating hours (2). This is evidenced further by findings that adherence is greater in urban areas, in females and older populations, as these populations describe less barriers in accessing care and loss of time away from work (17, 18, 19, 20).

(b) Policy and strategy

→ *Loss to follow up recognised in policy and strategy*

The South African Government is motivated to increasing the availability of HIV and TB treatment. The National Strategic Plan for HIV, TB and STIs 2017-2022 states that of the R23 billion that funds the HIV and TB services, the South African Government pays for 80% (21). Department of Health recognises the issue that those not engaged in treatment pose, this is reflected in key priorities; ‘Improving long-term retention in care of both HIV positive and TB patients’; ‘Integrated services to improve access to services’; and ‘Community outreach’ (21,22).

→ *CHWs critical service delivery mechanism*

As services have evolved to become more community-based and the focus of access to and retention in care have increased, community health workers (CHWs) have been key in this transition (33, 37). CHWs, who in 2011 outnumbered nurses in primary health clinics by 7:1 (43) now performs many roles within the community that were previously performed by nurses (33).

In South Africa, a large proportion support to individuals with HIV and TB is provided by Ward-Based Primary health Care Outreach Teams (WBPHCOTs). WBPHCOT’s consist of an enrolled or professional nurse, 6 community health workers (CHW), a health promotor and an environmental health officer (41). This shift has been seen across other countries as care has progressed from facility to community-based (37). The Department of Health plans to continue utilising the WBPHCOT teams to trace and retain individuals with TB and/ or HIV (42). The support provided by CHWs within the WBPHCOTs fall into two broad roles: (1) tracing and attempting to re-establish individuals back into care after loss to follow up and (2) supporting and providing assistance to those on treatment for HIV and or TB.

→ Stigma, trust, and mobile populations challenges adherence

CHWs carry out tracing of persons lost to follow up and provide support to retain individuals in the treatment of HIV and TB. 90% of the tracing carried out by CHWs was for individuals who had been lost to follow up from treatment for HIV and/ or TB (32). CHWs are provided with lists of patients who had been lost to follow up from treatment and are responsible for visiting their homes to establish them within care (2). In a study of individuals lost to follow up from HIV treatment, CHWs were able to trace in 2016-17, 62% later reported to clinic for treatment after successful tracing and re-referral from CHWs, this dropped to 51% in 2018-2019 (32). For TB, those traced and re-referred, 73% reported to clinic in 2018-19, an increase from 52% in 2016-17(32). In terms of tracing, one of the main problems appears to be in located those who have been lost to follow up. Reports of false addresses, names and contact details coupled with the fact that there is a high migrant population who move regularly for work are reported often as a barrier to tracing individuals (32, 33).

→ 'Adherence clubs' a promising intervention to improve trust relationships and adherence

In 2007, adherence clubs were introduced in the Western Cape for those HIV positive, and later rolled out more widely by MSF in 2011 (23, 40). The clubs, largely run by CHWs, enhance patient retention and treatment adherence. Individuals are included in clubs after their conditions are defined as stable, with their viral load being supressed for at least 3 months (23). Inclusion in adherence clubs allows medication to be dispensed in larger quantities, less frequent monitoring, and opportunities for peer support. Evaluations have shown improved retention rates and treatment adherence to 97% opposed to 85% to those in standard ART programs (24, 25, 26). Success has been attributed to the ease of accessing medication to invaluable social support (27-29).

Trusted relationships of support are associated with greater patient autonomy and improved self-efficacy and reduce stigma and psychological distress due to more discrete treatment (34-35). Furthermore, treatment in the community and at home reduces barriers such as long waiting times, overcrowded clinics and financial stress (35, 36). This is supported by findings that show that those with community support have better health outcomes and are more likely to be adhere to treatment than those in facility-based support (12,33,35,37-39).

→ CHWs perform many vital roles, and in the face of many challenges

CHWs perform many roles in the community previously performed by nurses in clinics such as monitoring symptoms, home visits and monitoring treatment adherence through pill counts (33). Furthermore, they often provide additional support by reminding individuals of medication and appointments and collecting prescriptions (32, 33). CHWs in Gauteng area and Limpopo, described carrying out directly observed therapy (DOTS) for TB patients, where they monitored patients taking required medication (40). CHWs also play a critical role in supporting families of individuals by cooking, cleaning, and performing daily tasks (33). These relationships of support are key in overcoming barriers that may lead to being lost to follow up in treatment.

While CHWs through WBPHCOTs are pivotal to reduce persons lost to follow up for HIV and TB treatment, WBPHCOTs are not appropriately supported or resourced and rely on goodwill and personal motivation from CHWs (43,44). Despite government efforts to formalise and integrate CHWs into the public health system, multiple obstacles exist. Implementation of WBPHCOTs has been slow and uneven and there is low coverage. By 2017, only 42% of the required teams had been established, with many inadequately staffed. There is also relatively low awareness of the expanded CHW roles and functions in communities. Moreover, despite recognition of the potential for WBPHCOTs to promote local action, these roles are not well-defined, valued or supported (45).

(c) Conclusion: CHWs "the backbone for accessible care and support"

Despite progress, HIV and TB pose deep challenges. Treatment is well-established and available. However, ensuring adherence is challenging, there is clear evidence of many causes that lead to loss to follow up in treatment for both HIV and TB. CHWs carry out essential roles in tracing and re-establishing individuals in the care system, as well as providing critical support to individuals to prevent loss to follow up occurring. Trusted relationships of support are key to counteracting problems associated with loss to follow up. It is apparent that CHWs are the trusted bridge between individuals and the health system, and are key to reducing the numbers of persons lost to follow up, and enable vulnerable individual's greater access to care. Without proper support and investment, sustainability is not guaranteed.

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