Vertical Interventions and Parallel Structures: A Case Study of the HIV and Tuberculosis Health Information Systems in South Africa

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ABSTRACT: South Africa is plagued by severe HIV and tuberculosis (TB) epidemics. Despite integration policies, health services’ reporting follows largely disease-specific vertical patterns, resulting in parallel data flows. This qualitative case study investigated how the health information system (HIS) is engaged with and perceived by health system employees. We conducted in-depth interviews with individuals (n=28) working in key roles at different levels of the health system in Cape Town, South Africa. Data from direct observation and document review complemented the interviews. All data were coded and analysed using thematic analysis. The key challenges reported included large amount of reporting in general, duplication of data elements, health governance and tensions over data collection tools. The vast amount of collected data was not considered holistic or fit-for-purpose. In conclusion, the HIS in South Africa causes work duplication and waste of efforts in times of scarce resources, and does not sufficiently support integration policies. Holistic approaches to studying, developing and implementing HIS are needed.

Keywords: HIV, TB, health information systems (HIS), monitoring and evaluation (M&E), South Africa

1. INTRODUCTION

Every day, several data is acquired at different levels of any health system so that actors within the health system and beyond can use it for their purposes. Health professionals generate, collect and utilise information in the context of clinical decisions; at manager-level, data is required to increase efficiency, effectiveness and accountability; those whose job is to plan services consult statistics for operational decisions; and policymakers on local, national and international levels rely on information for setting priorities and allocating resources [1]. However, research in resource-limited settings indicates that the quality of health data is inconsistent [2-4] often leading to limited use of the collected data [3, 5, 6]. In addition, in many low and middle income countries (LMIC) health services are often organised in a disease or programme-specific, i.e. vertical manner [7] that may weaken health information systems.
(HIS) [5] as monitoring and evaluation (M&E) tends to follow a largely similar vertical pattern causing excessive and parallel reporting efforts [8-11, 57]. This results in multiple reports with different formats and deadlines [12, 14] and added burden for site level staff, often responsible for data collection [12]. This approach may cause gaps in the data [12-13] and poor data quality, especially if the amount of data required is large [15]. As data is seldom shared across vertical programmes, planning and reporting of collaborative activities and productive utilisation of the data becomes difficult [16-18].

While the consequences of inefficient reporting systems are already known, the complexities in HIS entities causing the inefficiencies are not often described in the academic literature in a detailed manner. Holistic approaches to HIS research [19] including investigating the underlying factors, HIS performance and the impact of organizational and contextual issues [21, 22] has been called for among researchers and professionals [20]. Health information systems are not developed, implemented and used in a vacuum. We present a case study from the Cape Town Metropolitan District, which is one of the health districts of the Western Cape Province in South Africa. In the Cape Town Metropolitan District, two health authorities, City Health by the City of Cape Town, and a provincial Western Cape Department of Health deliver primary health care (PHC) services in the area. While there have been efforts to strengthen and integrate the provision of PHC across the two health authorities over the last two decades [23] the dual, overarching responsibility of two operators contributes to making the system highly complex and hierarchical [24].

Research in LMIC context [25-26] as well as in developed setting [27] suggest that the sustainability of HIS can be affected by the lack of attention to the notion that there are multiple stakeholders who may have different logics, rationalities, and interests. Hence, it is important to recognize the parallel structures created not only by the vertical disease-specific programmes but also local policy hierarchies. Against this background, addressing this gap in the literature, our study sets out to analyse key challenges in the South African HIV and TB related information systems stemming from vertical interventions and parallel structures. We identify, analyse and describe all key data flows within one specific thematic area in a particular geographic context:

1. HIV or TB related data flows (i.e. data flows that have HIV or TB data elements) in public health
2. Originating from one case study clinic in an under-privileged township, which is a part of the City of Cape Town, in Cape Town Metropolitan District of the Western Cape Province in South Africa.
2. METHODS

2.1 Research setting

This research was conducted in South Africa, which suffers from a double epidemiological burden of TB [28] and HIV [29] that is one of the worst in the world [30]. The rate of TB-HIV coinfection is particularly high [28]: more than 60% of patients have HIV-associated TB [31]. This makes efficient reporting and M&E systems between programmes a priority.

The particular setting of this descriptive case study, conducted in 2012, is a large, under-privileged township, initially created as a racially segregated residential area by the apartheid government. The township is located on the outskirts of Cape Town in the Western Cape Province, South Africa. The population is predominantly black African. High levels of poor health, unemployment, poverty, crime and violence are present. The township is also greatly affected by dual epidemics, exceeding the national averages in estimated antenatal HIV prevalence (35%) and TB incidence rate (a massive 1,164/100,000 population) [47] making it a global hotspot for HIV, TB and co-infection. Like in many LMIC in South Africa much of the collection of data at the facility level is assigned to the health professionals (including doctors and nurses), who are expected to do it alongside their care work. The questions around workload are therefore particularly important in the most under-privileged health care settings.

2.2. The HIS landscape in South Africa

The South African government has encouraged primary health care policy and service integration since the end of the apartheid era, but particularly HIV services have traditionally been developed in a vertical manner [32]. Accordingly, the information systems for M&E of HIV and TB have been developed and implemented as vertical programmes and have historically tracked the epidemics independently [17, 33]. Therefore, while the government has made progress in integrating HIV and TB activities across a range of policy areas and settings [32] there has been little progress in achieving integration of disease-specific programmes within the district health system, including the target of district managers assuming the authority for the M&E of these programmes [34].

Studies on South African HIS [13, 34-44] have identified weaknesses and strengths in the systems for antiretroviral therapy (ART), TB, Prevention of Mother to Child Transmission (PMTCT) or the District Health Information System (DHIS). Unlike the single disease systems, DHIS is used to compose monthly or quarterly reports on routine health service data
from immunisation to mental health as part of the nationally required essential dataset. The current ART information system has been described as a top-down, over-sized vertical system [36]. Although a more recent study [38] perceives the system as an improvement to the paper-based system. The TB information system has been assessed “strong” with users being very accepting of the system, but with concerns regarding the system’s rigidity (39).

Further challenges in South African HIS landscape include legislative, policy and governance/management issues, [36, 45] data quality issues, [37, 43-44], human resource limitations, including duplication of work and shortage of skilled staff such as data capturers [30, 36, 40-41] and deficiencies with data utilisation [6, 41, 45-46]. However, with a few exceptions [17, 39], research on systems for routinely collected data in South Africa have typically focused on one electronic or paper based information system or data around one specific health programme. Since the challenges are not usually specific to one particular system, research that analyses HIS landscape through the investigation of several information systems is needed, as this approach has a potential to identify gaps and caveats that may not be found otherwise.

2.3 Theoretical background

Our study follows an approach where an information system is seen as ‘a socio-technical system of managing information within an organization; a purposeful systemic entity which consists of people, processes, information and technologies (manual and computer-based ones)’ [48]. Therefore, the contribution of the local health professionals from various cadres related to data collection, reporting, and use is perceived as an integral part of the HIS. Research on holistic HIS analysis and development [19] emphasises that health professionals use information entities, information tools, and information systems within their daily work activities, and so, the entities and systems should address their needs. Accordingly, our investigation analyses how the central challenges are perceived by those who work and engage with the data flows as a part of their profession. More information is needed about how health workers in LMIC experience programme specific systems and their limitations, as better understanding of the strengths and weaknesses of the different components within HIS can lead to improved system functioning and better data [20].

2.4 Data Collection & Sampling

At the case study setting, public health HIV and TB data flows through four organizations, operating on four levels of the health system: facility, sub-district, district and
provincial levels. Data were collected through in-depth interviews from 28 key informants working in these organizations with TB or HIV data. A mixture of purposive and snowball sampling was used to identify informants: some of them were asked to provide recommendations for other individuals to be included in the study.

At the facility level, our investigation focused on the case study clinic, which is one of eight City Health’s primary healthcare facilities in the township, operating alongside three provincially-led clinics and a district hospital. The township forms one of the eight sub-districts in Cape Town Metropolitan municipality and has a sub-district office, which has the authority to manage the services and data flows that fall under its jurisdiction. Therefore, the sub-district office, located at the heart of the township, was chosen for our research site at the sub-district level. The selection of the case study clinic and sub-district was based on purposive and convenience sampling: while we sought and were allowed to investigate an underprivileged site, the final selection had to be negotiated in cooperation with the local health and health research authorities. At the district and provincial levels, the data flows through the City of Cape Town (CoCT) Health Department (i.e. City Health) and the Western Cape Department of Health, which were respectively included in our study. The data flows do not actually stop at the provincial level but flow all the way to the national, regional (for instance ‘Africa’ level) and global level, however, for the purpose of this research they were only followed to the provincial level.

2.5 Informants

The informants in the studied organizations worked in various roles ranging from clinical to clerical, and from monitoring and evaluation (M&E) to and management health governance. Although there are 6 informants in the reporting / M&E category, all of the informants are involved in one way or another in HIV and TB HIS entity, as illustrated in Table 1. In other words, their professional roles require production, management or use of HIV or TB related data.

Table 1. Informants’ professional roles and relation to HIV and TB HIS [n=28]
2.6 Interviews

We used semi-structured interviews with an interview guide that serves as a checklist of topics and a default wording and order for the questions, as guided by Robson [49]. Table 2 shows a sample of interview questions. Since the informants had particular expertise in different areas around HIS, not all informants were asked all / the same questions. Both wording and order were often substantially modified based on the flow of the interview. Interviews were conducted face-to-face and their duration varied from half an hour to more than two hours. The original interview template was piloted, but that had only limited use since each of the interviewees had their own specific occupational role and the interview situations were different in terms of the physical, social and contextual surroundings.

Table 2. Sample interview questions.

<table>
<thead>
<tr>
<th>Sample interview questions</th>
<th>Intended purpose of the question</th>
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<tbody>
<tr>
<td>What TB and HIV related information are you currently regularly collecting / reporting /</td>
<td>To obtain specific information on particular data flows to identify duplicative efforts and</td>
</tr>
<tr>
<td>If you consider your daily work in a role of X, what are the main challenges? Why?</td>
<td>To obtain information on the key challenges in HIS as a part of the health system, as well as</td>
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<tr>
<td>If you had a magic wand and you could change anything in the current collection, reporting</td>
<td>their root causes, as experienced first-hand by the local stakeholders.</td>
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<tr>
<td>and use of HIV and TB information, what would you change? Why?</td>
<td></td>
</tr>
<tr>
<td>Is there anything else that you want to tell me about the register/HIS/etc. X? Is there</td>
<td>To give each interviewee an opportunity to discuss areas that they believe to be important.</td>
</tr>
<tr>
<td>anything else I should know?</td>
<td></td>
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With permission from the informants, the interviews were recorded and transcribed resulting in 410 pages of data (150,923 words).

2.7 Document Review and Observation

A number of reference materials, including clinical stationery; printed pages and screen captures of registers, tools and electronic systems; and written data flow and other policies and procedures were collected during the interviews. These reference materials, along with publicly available documents and literature were reviewed to triangulate and contextualise findings from the interviews. Additionally, observation was used to collect data. The
observations took place throughout the field visits to obtain especially contextual evidence about the case (to notice, for instance, that the waiting room of the clinic is extremely crowded). Observation provided also useful additional data to the interviews when informants showed the particular computer programs and information systems they worked with. All accounts and observations were recorded as field notes.

2.8 Data Analysis

To interpret different aspects of the research topic, the data was analysed following the guidelines for thematic analysis by Braun & Clarke [50]. The researcher read through the entire data set. Data was coded, collated in themes and interpreted to answer the research question.

2.9 Ethical Approval

This research was carried out in compliance with the Helsinki Declaration. All pertinent ethical issues, including privacy and confidentiality, were addressed. All interview participants were asked to give their informed consent in writing and they were given an information sheet about the research in English, Afrikaans or Xhosa, a local language. The protocol and consent procedures were approved by the Trinity College Research Ethics Committee in Dublin and the Western Cape Provincial Research Health Committee in South Africa, as well as the health authorities at provincial, district, sub-district and facility level.

3. RESULTS

Data from the analysis of the in-depth interviews, documents and observations demonstrate that the complexity of the HIV and TB related HIS entity contributes to various challenges in the daily work of health professionals on different levels of the health system.

3.1 Data Flows Including HIV or TB Elements

We found that HIV and TB data elements are collected and reported within 7 major data flows that originate from the case study clinic. These data flow in various ways via sub-district, district and provincial level but not always straightforwardly through all levels. Moreover, it is not just the HIV programme and TB programme, but management of HIV is divided into the pre-ART programme (HIV counselling and testing, HCT) and the medication steered ART programme, which form their own silos under the umbrella of HIV/AIDS.
flow of TB data is further complicated by the fact that MDR-TB (Multidrug-Resistant Tuberculosis) is reported as its own separate entity. Similarly, PMTCT, Sexually Transmitted Diseases (STIs) and primary healthcare operate at least partially as their own programmes. All these programmes have their own agendas to a large extent, staff and management hierarchies, reporting lines and information systems. Therefore HIV and TB data elements are collected and reported within:

- HCT data flow
- ART data flow
- TB data flow
- MDR-TB data flow
- PMTCT data flow
- STI data flow
- RMR data flow (Routine Monthly Reporting)

The data relating to HIV, TB and STIs are often called ‘HIV/AIDS/sexually transmitted infections/TB’ (HAST) data flows. Routine Monthly Reporting (RMR) data flow is not technically one of them. The RMR dataflow, however, includes HIV and TB data elements in addition to primary health care and service data.

In the context of the data flows, HIV and TB related data is collected, captured in various paper-based and electronic health information systems, reported, used and fed back. Specifically, the data is collected with and reported via various paper form documents such as registers, and tally sheets, it is kept and transferred with memory sticks, CDs or Excel sheets and so on. While much of the data is in paper form at the clinic level it also entered into different electronic health information systems including (at the time of the study)

- ETR.Net (Tuberculosis)
- EDRWeb (Multidrug-Resistant Tuberculosis)
- Tier.Net (ART data, also known as Electronic HIV Register)
- Sinjani (aggregated HCT, PMTCT, STI, RMR data)
- PREHMIS (Patient Record and Health Management Information System for City of Cape Town clinics)

In addition, in the case study province, eKapa is used to report ART in some clinics (instead of Tier.Net or the paper-based equivalent), the Primary Health Care Information System (PHCIS) is used instead of PREHMIS in provincially run community health centres, and DHIS2 is used in place of Sinjani in the rest of the country. This list is not exhaustive as
there are various other registers and tools not examined in this study in detail. Most often the data is entered in electronic form at the sub-district level.

Stemming from the analysis of the HIV and TB related data flows, we identified four areas of key challenges arising from vertical interventions and parallel data flows.

3.2 Large Amount of Reporting and Duplication of Collected Data

The South African health system has, through the vertical health governance structures around health priorities, resulted in largely vertical reporting ‘silos’, term ‘siolo’ being picked up from the interviews and referring to disconnected systems. While this is already reported in literature, our study illustrates what is means in practical terms. For instance, there is TB data, which is largely collected by the TB nurse. The nurse writes it in the TB register from where it is entered by a clerk to whom the TB data responsibility is assigned, into a TB specific HIS (ETR.Net) to be reported to the TB manager at the higher level. Some data use and coordination surpasses the TB programme limits, but basically, much of the reporting is very programme-specific. As described by two participants working on different levels of the health system:

...we tend to work in little silos and- and terribly vertically... I’m sitting here with just my TB and I’ve got blinkers on and I’m just looking at TB, and I’ve got doctor [name removed] who’s got an ARV, um, focus, and I’ve got somebody else who’s got a different focus.

There is a lot of silo approach: when a particular programme comes up with something they don’t look to see what’s out already that we can build on. They always start as if it was tabula rasa. There’s nothing: “Let’s come up with monitoring and evaluation system”. They don’t see what elements are already being collected and how does that fit in what the other programmes are doing.

Since many of the programmes were established by external funders or stakeholders with specific information needs, each programme has its own reporting requirements. Additionally, each level of the health system (facility, sub-district, district, provincial and national) has their own information needs and the lower levels usually have to adapt to these requirements, which may not always be in line with their own needs. The observed HIS, registers and tools, as well as the analysis of the data flows and the reference materials (clinical stationery etc.) showed that reporting requirements pile up, resulting in a large amount of mandatory reporting. This came up repeatedly also in the interviews:
we are collecting a lot of data and registers which we don’t report on, and then we are not collecting data which we need to report on. So as protocols change, policies change, the registers were adapted, but often things were only added, very seldom were things taken out.

The informants perceived reporting as time-consuming and laborious. It puts a strain particularly on the facility level staff who do the majority of the manual collecting alongside care delivery. As stated by a participant working in a clinical role:

...to write all that information ...it takes up lots of valuable time, I would say, that you could’ve seen more clients.

Relatedly, our analysis identified unnecessary replication of data elements in HIV and TB data flows. TB indicators are being collected from HIV patients and vice versa but this is only a small part of the phenomenon. Our observations are in line with those of Loveday & Zweigenthal [15]: even facilities that promote integration use separate stationery for ART and TB care, and for co-infected patients the health professionals consult at least two sets of notes in order to see the full clinical and other history of the patient. Many patients in the under-privileged case study community suffer from multiple health conditions. Consequently, their personal details are captured over and over again in several systems. The patient’s name and basic information, such as gender, address and telephone number, are captured in PREHMIS. If the patient has TB, this same data is also captured in the TB system. If the patient is then offered an HIV test in line with testing policy, the same data is entered into HIV Counselling and Testing Client Records. If he is HIV positive and eligible for ART, also this information is captured again in the TB system and PREHMIS while his basic information is captured again in the ART system and so on. Some of the data is further replicated in the process of compilation of data in slightly more aggregated form or digitised form. Our analysis showed that one CD4 count of a HIV/TB co-infected pregnant patient, or the record of the fact that the count has been taken, would be hand written at least 6 times, captured in electronic form another 6 times and otherwise managed in more aggregated form at least twice at the case study setting.

3.3 Complexities Created by Parallel Health Governance Structures

In addition to following the programme-specific silos, the data flows are also dictated by the authorities that are involved in providing services. The case study clinic and sub-district are under the dual authority of the Western Cape Department of Health and the City of Cape
Town health department. It is publicly recognised in the official documents that the fragmentation of the delivery of PHC services in the Cape Town Metro District between provincial and local government (i.e. the Western Cape Government and the City of Cape Town) remains a challenge, is inefficient and ultimately compromises the quality of care [56]. However, less attention has been paid to what it does to the flow of routine health information. As indicated by an informant:

_You have a large Metro within the Province. And that you have this parallel thing...I think it makes it very difficult._

The abnormal HIV and TB related M&E structures in the Metropolitan area (in comparison to rural districts) have contributed to the situation, which can be called ‘a fight between the two authorities to amalgamate data’, according to a provincial level interviewee. Particularly, the presence of two health authorities makes it more difficult to streamline the M&E process and opens up risks of gaps and errors. Extra work may be required to make sure that accurate and appropriate versions of data sets are reported. A key informant explained:

_At the sub-district level there has to be communication between the City and the Provincial side and the same got to happen at the district level. Because there are authorities that are sitting on the City and on the Provincial side at the same level on the health in the system. The complexities are [about] making sure that only one dataset comes out at the each level otherwise you start getting different data being reported to high-level authorities. ... but who’s gonna sign it off before it travels up? And what’s gonna happen before that? That’s the complexity when there are two authorities._

At the time of the study, M&E SOP (standard operating procedure) had recently been created around the ART data flow in order to address the gaps, ambiguity with lines of accountability and other challenges created by the situation where there are multiple stakeholders working with data at each level. Two informants from different levels of the health system respectively indicated that creating an SOP with arrows indicating data flows, was not a smooth process:

_It took us I can’t tell you how many months to agree on in the Metro what the flow of data should be ...and the person in the Provincial Office, when we finally came up with this version said to me “now I’m sorry we can’t have this because there are too many arrows, it’s too confusing” And I said “well unfortunately_
it is too confusing to have two authorities but that is the reality, so we have to have all those arrows because otherwise it doesn’t reflect the reality on the ground.”

I think the painful part of this was …the local government reporting, to gel with the provincial government reporting system

There did not appear to be SOPs regarding other data flows.

3.4 Barriers to Obtaining Holistic Data

While on one hand vast amounts of data are being generated at the facility level of our case study setting and reported to higher levels, our analysis showed that sometimes holistic and joint information on HIV/TB was not available for those who need it. The close connection between HIV and TB aggravates the information needs, since these illnesses may advance each other and negatively impact on each other’s health outcomes, and the optimal timing of interventions for each disease may require awareness of the other illness and its medication. At the case study setting, the clinical staff had to sometimes make additional phone calls or leave the room to look for appropriate patient folders in order to obtain the required data, which was not easily available because it ‘belongs’ to another programme. However, also the authorities at the local and provincial level had to expend extra effort to achieve joint or holistic information, such as estimating local or provincial HIV/TB co-infection rate. Since each stakeholder is responsible for a particular programme they need to triangulate data from different sources to make the estimations. As indicated by a participant working in the TB programme:

[The way TB data is collected] …serves a purpose for the TB programme. …But it doesn't serve the purpose for wider than the TB programme because … your inclusion criteria is you... must have TB to be......on the system. And then once you're off the system, we don't have an idea in the general half information system of, of where you are. So we can only track our management of co-infected patients while they are TB patients. ....And that's the actual limitation...
The vertical and programme-specific data flows were not the only contributor to gaps in data. The presence of two health authorities also made it difficult for the authorities to have complete information, i.e. to be able to look at the ‘big picture’. An informant said:

we have to work very closely together to make sure that the data, when it’s finally used and presented and fed back to people, that it reflects the dataset of all the services in that specific geographical area. ...that is where some of the gaps happen, in the combining, and some of the tasks in terms of everybody, it’s not only around the relationship between the different levels of healthcare and the different levels of service we provide but also a lot at the same level, backwards and forwards in terms of how that should happen.

In other words, if each authority examines only its own services, it sees only a partial truth. Hence, the presence of two health authorities makes it more laborious to examine the coverage and roll-out of programmes, as well as estimate the whole disease burden as the required data needs to be collected from various sources over the authority limits.

3.5 Tensions over Routine Health Data Reporting

A further key challenge suggested by our findings, is that there were persistent tensions over routine health reporting. South Africa, except for the Western Cape, uses the District Health Information System (at the time of the study DHIS, currently DHIS2) to collect aggregated routine data from all public health facilities in the country. However, the Western Cape Department of Health (WCDoH) had developed its own health information system to collect routine health data, called Sinjani. The data in both of these systems include HIV and TB elements. According to an informant, the DHIS’s reported inadequacy to meet the information needs in the Western Cape Province and increasing dissatisfaction with insufficient technical support for DHIS had contributed to the decision to begin developing their own HIS instead of using the nationally prescribed one:

...they could not support the growing needs for information of the Western Cape. Because when they needed changes – and there were a lot of version changes, and when somebody needed them to assist, they were just not there. They were either in China, or Nigeria or somewhere. People had to wait about two months, three months before the person is able to come and assist with the changes. So there were really no support for version changes, or hardware or software
problems when it concerns the DHIS. That’s why the Western Cape developed their own system called Sinjani.

The health facilities in the Western Cape (including the City run facilities) are required to use Sinjani to report routine health data. However, with DHIS it is possible to change the data set collected according to local needs, whereas in Sinjani the data elements are standardised, which may feel like a limitation for local decision-making. An informant said:

...Sinjani, it is sort of, you can only capture the data that they want at the provincial level. So it becomes provincial collection tool rather than facility collection tool.

Sinjani was argued to be slow and less user-friendly than the DHIS. A district level informant remarked that the problems were with the technical deficiencies of Sinjani but that they also had an impact on how stakeholders perceived each other:

I think at the moment Sinjani has left such a bad taste in our mouths because when we want, when we ask for anything to be added that was in DHIS, it's like the City of Cape Town is... anti new systems, we’re resistant to change. And it's not that.

Because of Sinjani’s perceived limitations, an interviewee reported that there were sub-districts that enter the required RMR data into both Sinjani (because they have to) AND into the DHIS since they are more familiar with and prefer the pivots and the tools provided by DHIS. Obviously, capturing the same data twice is a waste of resources. Moreover, this may have adversely affected data quality in Sinjani in terms of accuracy, completeness or timeliness. As elaborated by the informant:

...so some people are still doing dual capturing which is a big danger... Because they start in DHIS and then capture in Sinjani... They see that DHIS is more of an accurate system because that is what they used to go and report on and kind of – I am making a big statement here - and kind of: “Well, they want it in Sinjani, I've captured it in Sinjani”

In other words, it appears that the tensions around the electronic systems to collect health data may contribute to acceptability of HIS, its usage and data quality. A further acceptability and usability related issue regarding Sinjani was reported by another informant.
At the time of the study, the HCT data was meant to be reported through Sinjani. However, due to the lack of data validation mechanisms in Sinjani, the data was also sent in Excel format with build-in validation formulae. In the process of correcting errors, one spreadsheet was often sent back and forth several times from the clinic to sub-district and district levels. With multiple people working on the document, the formulae in the Excel spreadsheet can be corrupted. While recognising the problem, the district level was reluctant to let go of the Excel sheets due to the perceived inadequacy of Sinjani. An informant in a decision-making role reported:

So some of the challenges around that is in our Excel versions we had validations built in, but Sinjani when they set it up, they had not set in a validation. So we were reluctant to drop one system until the next system was actually as equipped to deal with those things and for various reasons that haven’t happened. So it’s hampered, and we’ve been dragging on too long running a parallel system which is not helpful to anybody. You know it’s not efficient, it leads to different data sets coming out… So there has been a little pressure to be able to drop the Excel version, but on the other hand Sinjani hasn’t been ready to start doing it.

These accounts, which seemingly concern HIS functions and features have a long history. Braa and colleagues [13] have depicted the development of the minimal data set in South Africa, i.e. the data that is reported through Sinjani in the Western Cape and DHIS elsewhere. Several revisions have been made on the indicator data set since the work was started in 1994 in the Western Cape, term ‘indicator’ denoting information obtained from data elements, and which is used to measure the extent to which health targets are met. The study describes how at each revision, ‘the debate rages as to which data elements get included and which do not get included’ [13]. At the time of current study, the provincial authority had decided to reduce the number of indicators to be aligned with the requirements of the national level. Several interviewees objected, which suggests that tension over which indicators to collect continues to be a somewhat volatile issue. Two interviewees respectively said:

I always feel that they are important, you cannot leave them out. I would have preferred that at the provincial level we have the same; because there are a lot of indicators at the provincial level that were left out.
I don’t know what they’re going to use for intervention at the facility level… [what] the poor facility manager is going to say.
One district level interviewee indicated that the City has even considered leaving Sinjani and returning to DHIS because of that.

4. DISCUSSION

Our analysis of the South African HIV and TB HIS entity suggests that it does not sufficiently support the Government’s policies towards integration of health services. Considering that the critical shortage of health workers is a significant barrier to the delivery, implementation and sustainability of health services in South Africa [51] the large amount of reporting and unnecessary replication of data elements can be seen as a poor use of limited human resources. Since the global health worker crisis is an increasingly pressing challenge in the developed but particularly in the developing context, we argue that a holistic analysis pinpointing inefficiencies and duplication of work is a worthwhile exercise probably for any health system. Central to such analysis is that it should not concentrate on the workload and information replication within one programme (for instance TB programme) or one level (for instance field level) but recognize the overall burden and costs for the health system as whole in order to find the best synergies.

A well-functioning HIS entity requires efficient overall coordination and co-operation between different actors, albeit that they might have conflicting agendas. This concerns stakeholders on different levels of the system (facility, sub-district, district, provincial, etc.); different health programmes and different health authorities (for example provincial and local government, as in this case research). While tools, such as SOPs are useful in aligning data flows, our findings reinforce the message of previous LMIC research [26] in that it is the various institutional influences and different, sometimes competing, rationalities that should to be aligned when harmonizing and integrating HIS and programmes. However, as argued by Chilundo & Aanestad [26], this can be ‘a complex and politically charged activity’, which is reflected in our findings.

Our case study identified persistent tensions at the case setting, which seemingly revolve around the tools and their features developed for the reporting of the routine health data, as well as around the questions on which indicators should be collected and which not. These tensions may reflect deeper issues on power, control and flexibility and are therefore not likely to be solved by merely by improving the technical features of a HIS. The requests from a stakeholder that operates at a higher level of the health system or within a different health programme or health authority, to collect more (or less) data when it is contrary to one’s own
priorities may result in feelings of resentment. Obviously, the requests to collect more data contribute also to the discussed issues, such as workload and duplication of efforts.

Our study made an analogy to the advent of post-apartheid South Africa when Braa and colleagues began the HISP project in the Western Cape and elsewhere. At that time, as a legacy of the health system that had been organised to provide health services separately to the different racial groups, the health information reporting systems ‘were equally fragmented and incompatible’ [13]. To put it another way, much of reporting took place in race-related disconnected silos, and Braa and colleagues wanted to address that challenge. Now, approximately 20 years later, this study shows that the vertical and parallel health governance structures and consequent programme-specific health information silos are very much today’s challenge. While the silos are not connected to the different racial groups, in South Africa, this kind of vertical single-programme reporting has contributed to various challenges that limit the optimal functioning of the HIS. Therefore, a change in approach is needed in South Africa and in many other LMICs that have similar, persistent issues and a limited amount of resources to tackle them. A good starting point is to place the patient as the focal point of the HIS, not a disease, as indicated by an informant:

    Researcher: ‘if you had a magic wand... how would you change the current TB and HIV data collection ...and use and reporting in the Western Cape?’

    Informant: ‘Have all health data on as, one system. ....Have the patient reflected on the system and not the disease. So wherever I will go... my HIV, my TB my everything will be there.’

This is not an easy undertaking. Different takes on addressing this challenge, such as cloud computing [52] and integrated data warehouse approach [12, 53] have been reported in the LMIC setting but so far many key issues have been resistant to unilateral solution. Our analysis, based on data flows rather than a particular HIS, illustrated the profound complexity of a HIS entity in its equally complex local health governance context in a LMIC setting. This complexity creates interlinked challenges and requires new approaches for tackling them. The growing but still limited body of work on health system complexity calls for dynamic and holistic approaches, such as systems thinking, that appreciate ‘the multifaceted and interconnected relationships among health system components, as well as the views, interests and power of its different actors and stakeholders’ [54]. Since systems thinking invite us to stand back from a fixation on the individual components and being aware of the whole system when designing and evaluating innovations [54-55] applying this approach in the field of HIS
as well as in service might be a good starting point in understanding, developing and implementing more sustainable health information systems.

5. CONCLUSION

In conclusion, South Africa has made progress in integrating HIV and TB related policies and services, however systems set up to track epidemics have remained largely vertical. Much of the reporting is very programme-specific, and the health professionals working within the HIS consider this as a major challenge itself, as well as a root cause for other deficiencies. The identified parallel health governance structures further complicate the functioning of the HIS. Our study reports several consequences of a HIS entity that is on the one hand hampered by vertical structures and on the other hand further complicated by parallel health governance structures. These challenges make it difficult to obtain joint or holistic information and may result in fragmented and error-prone data. Our study highlights the challenges in complex political power-relations that can potentially affect the optimal functioning of the HIS. New more holistic approaches, such as systems thinking, is needed to address these challenges of which some have remained unsolved for more than two decades. Since the burden of HIV, TB and co-infection remains enormous additional strategies are required to strengthen the health system, and the time of caregivers in the system need to be optimised through well-functioning HIS.

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Disclosure statement / Declaration of interests: The authors declare that they have no competing interests.
7. REFERENCES


8. APPENDICES

8.1 Ethics, consent and permissions

The protocol and consent procedures were approved by the Trinity College Research Ethics Committee in Dublin and the Western Cape Provincial Research Health Committee in South Africa, as well as the health authorities at provincial, district, sub-district and facility level. This research has been carried out in compliance with the Helsinki Declaration. All pertinent ethical issues, including privacy and confidentiality, were addressed. All interview participants were asked to give their informed consent in writing and they were given an information sheet about the research.
### 8.2 List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>CoCT</td>
<td>City of Cape Town</td>
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<tr>
<td>DHIS</td>
<td>District Health Information System</td>
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<tr>
<td>HCT</td>
<td>HIV Counselling and Testing</td>
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<tr>
<td>HIS</td>
<td>Health Information System</td>
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<tr>
<td>HISP</td>
<td>Health Information Systems Programme</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>LMIC</td>
<td>Low and Middle Income Countries</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring &amp; Evaluation</td>
</tr>
<tr>
<td>MDR-TB</td>
<td>Multidrug-Resistant Tuberculosis</td>
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<tr>
<td>PHC</td>
<td>Primary Healthcare</td>
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<tr>
<td>PHCIS</td>
<td>Primary Health Care Information System</td>
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<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
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<tr>
<td>PREHMIS</td>
<td>Patient Record and Health Management Information System</td>
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<tr>
<td>RMR</td>
<td>Routine Monthly Reporting</td>
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<tr>
<td>SOP</td>
<td>Standard Operating Procedure</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Disease</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>WCDoH</td>
<td>Western Cape Department of Health</td>
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