Strengthening Mortality Surveillance for improved monitoring of HIV/ AIDS, TB and COVID-19 in South Africa

TeleVA Pilot Workshop Report
22 November 2021

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Abbreviations

ART	Antiretroviral therapy
COD	Cause of death
COVID-19	Coronavirus disease 2019
CRVS	Civil registration and vital statistics system
DOA	Death on arrival
DOB	Date of birth
DOD	Date of death
EMS	Emergency medical services
HDSS	Health demographic surveillance sites
HECTIS	Hospital and Emergency Centre Tracking Information System
HIV/AIDS	Human immunodeficiency virus/ acquired immune deficiency syndrome
MCCD	Medical certificate of cause of death
NCODV	National Cause of death validation
NOK	Next of kin
NPR	National Population Register
PHCIS	Primary healthcare information system
PLHIV	People Living with HIV
SA	South Africa
SAMRC	South African Medical Research Council
SARS CoV-2	Severe acute respiratory syndrome coronavirus-2
SMS	Strengthening Mortality Surveillance
Swiss TPH	Swiss Tropical and Public Health Institute
TeleVA	Telephonic verbal autopsy
TB	Tuberculosis
UCoD	Underlying cause of death
VA	Verbal autopsy
WCDoH	Western Cape Department of Health
WCPHDC	Western Cape Provincial Health data centre
WHO	World Health Organization

Contents

1 Workshop Overview

In order to respond to a gap in the district health information system with regard to access to timeous and accurate cause-of-death data, particularly for out-of-facility deaths during the COVID-19 epidemic, a project piloting telephonic Verbal Autopsy (teleVA), as part of the Strengthening Mortality Surveillance (SMS) project was undertaken in the City of Cape Town during the 3rd wave of the pandemic in June -August 2021.

1.1 Workshop Objectives

This workshop aimed to:
- provide feedback to stakeholders on the experience and lessons learned from the teleVA study;
- brainstorm how to strengthen Western Cape's mortality information systems; and
- discuss potential opportunities for Verbal Autopsy.

1.2 Workshop Participation

Participants:

1.	Pierre Dane	Western Cape Department of Health, Provincial Health Data Centre
2.	Andrew Boulle	Western Cape Department of Health, Provincial Health Data Centre and UCT Public Health and Family Medicine
3.	Adele Anthony	Western Cape Department of Health, Eerste River Hospital
4.	Erna Morden	Western Cape Department of Health, Epidemiology and Disease Surveillance
5.	Jamy-Lee Bam	Western Cape Department of Health, Provincial Health Data Centre
6.	Selwyn September	Western Cape Government Emergency Medical Services
7.	Theuns Jacobs	Western Cape Department of Health, Epidemiology and Disease Surveillance
8.	Nesbert Zinyakatira	Western Cape Department of Health and UCT Public Health and Family Medicine
9.	Oluwatoyin Awotiwon	South African Medical Research Council, Burden of Disease Research Unit
10.	Nadine Nannan	South African Medical Research Council, Burden of Disease Research Unit
11.	Monique Maqungo	South African Medical Research Council, Burden of Disease Research Unit
12.	Diane Morof	United States Centers for Disease Control and Prevention South Africa

Facilitators:

Ian Neethling	South African Medical Research Council, Burden of Disease Research Unit
Natasha Kallis	South African Medical Research Council, Burden of Disease Research Unit
Debbie Bradshaw	South African Medical Research Council, Burden of Disease Research Unit
Pam Groenewald	South African Medical Research Council, Burden of Disease Research Unit
Carmen Sant	Swiss Tropical and Public Health Institute
Daniel Cobos	Swiss Tropical and Public Health Institute

2. Workshop sessions

The workshop was structured in four sections:

1) Welcome and introductions;
2) Presentations by the SMS study team members to set the scene, outline the study and provide preliminary results;
3) Group work; and
4) Plenary and panel discussion.

Further detail and summaries of the presentations and discussion is provided in the following sections.

2.1 Setting the scene and Verbal Autopsy (VA)

Global Overview of VA - Daniel Cobos Munoz

Information about how many people die and the cause of death is essential for public health and policymaking, as has been demonstrated during the severe acute respiratory syndrome coronavirus-2 (SARS CoV-2) pandemic. However, fragmentation of mortality surveillance systems is a major limitation for accurate and timely mortality statistics that could inform policies. Multiple formal and informal subsystems capture mortality data but often remain unintegrated (see Figure 1).

As a result of this fragmentation, none of these subsystems have a full picture of mortality statistics of the population in the country since they capture information from different and partially overlapping population groups.

VA is emerging as a promising tool to increase the completeness of death registration and cause of death information, especially for those deaths occurring in the community. Great progress has been achieved during the last 15 years.[1]

Countries worldwide are finding different ways to use VA to strengthen their Civil Registration and Vital Statistics (CRVS) systems. Below are some examples:

- Cause of deaths (COD) in the community (more than 20 countries)[2]
- Validation of CRVS COD (South Africa)[3]
- Refine ill-defined deaths (Brazil)[4]
- Support to physicians (Philippines)[5]
- Dead on arrival COD determination (Sri Lanka)[6]
- Support post-mortem processes (Zambia)[7]
- Sample registration system (China, Bangladesh or India)[8]
- Health research (Health and Demographic Surveillance Sites)[9]
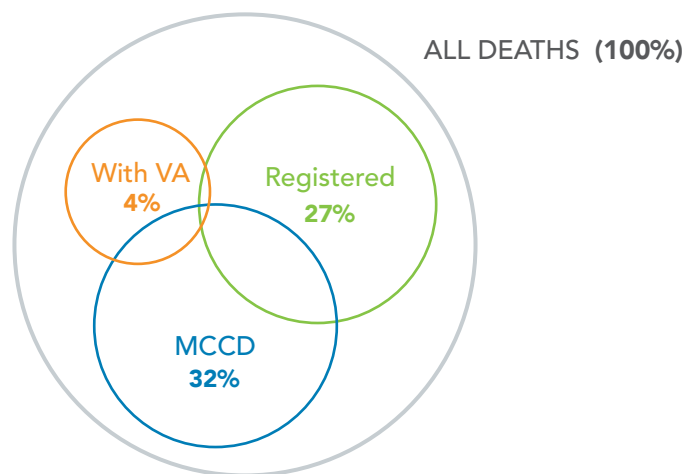

Figure 1: Generic representation of mortality silos. Example developed by Swiss Tropical and Public Health Institute for visualization purposes.
MCCD= Medical certificate of cause of death, VA= Verbal Autopsy

Several technical guidance documents and manuals have been developed emerging from these experiences. These are accessible on the World Health Organization's (WHO's) website.[10]

Furthermore, there is increasing evidence highlighting the importance to look at the whole mortality statistics system, when aiming to integrate VA. There are two steps in this process where increasing attention is needed, how to notify deaths occurring in the community and start the integration process, as well as how to combine the death statistics from VA and hospital settings.

Verbal Autopsy (VA)

- What is VA?

Verbal autopsy is a structured interview with relatives or a close caregiver of the deceased (see Annexure 1), to obtain information on the clinical symptoms, signs and events during the illness leading to death followed by a review of the verbal autopsy information to assign a cause of death (either by a clinician or using computerised software).[11]

VA is based upon three assumptions:
- The symptom complex for each disease of interest is unique (e.g., neonatal tetanus or motor vehicle accidents).
- Family members or other caregivers can accurately recall symptoms and their timing.
- Caregivers are willing to disclose this information (important where a death is stigmatized).

- History of VA in South Africa

VA has been used in health and demographic surveillance sites in South Africa since 1992,[12] to assign a cause of death to all deaths occurring in those communities. Previously all records were assigned a cause of death by a physician who reviewed the narrative and responses to the questions. More recently, automated coding software has been developed to assign causes of death making the process a lot quicker and less costly. This has enabled consideration to be given to implementing VA routinely within a CRVS for specific circumstances. The South Africa National Cause of Death Validation study[13] conducted VAs for a national sample of deaths to provide empirical data for correcting the cause specific mortality fractions from official CRVS data.

2.2 Strengthening Mortality Surveillance (SMS) study and preliminary results

South Africa has made considerable progress with strengthening its Civil Registration system and improving Vital Statistics, but the quality of COD data remains a challenge, particularly the underreporting of human immunodeficiency virus/ acquired immune deficiency syndrome (HIV/AIDS) deaths. PEPFAR SA works through South African partners and in collaboration with the Department of Health to prevent new HIV infections, link people living with HIV to lifesaving antiretroviral treatment, and ensure they can stay on treatment. This investment includes strengthening health information systems to monitor these goals. The National Cause of Death Validation[13] (NCODV) study funded by PEPFAR SA, aimed to validate the causes of death reported in the official statistics against verbal autopsy and medical records to derive best-estimates of cause-specific mortality patterns in South Africa for 2017. The study will provide correction factors that can be applied to the COD profiles to improve estimates of the cause-specific mortality, to monitor HIV and tuberculosis (TB) programmes. A national sample of 5,400 VAs identified that 22% of deaths were due to HIV compared with only 5% in the Stats SA 2017 data.[14] In addition, the verbal autopsy narratives identified HIV and TB cases who had discontinued their treatment prior to death. In South Africa, where only 66.9% of clients remain on anti-retroviral treatment (ART) and 10.5% of TB patients are lost to follow up[15] this information is invaluable for monitoring of the HIV and TB programmes. However, challenges with the identification of deaths and recruitment of informants suggest that there is room for further enhancement and clarification of approaches to incorporate VAs into health programmes.

The SARS CoV-2 pandemic raised concerns that people living with HIV would be more susceptible to severe disease and mortality from coronavirus disease 2019 (COVID-19).[16] Preliminary data suggested that HIV and TB might be risk factors for COVID-19 mortality but there is insufficient data to confirm this, and further exploration is needed. The pandemic has also highlighted the shortcomings of the current CRVS system in providing timely COD information, particularly for deaths occurring outside of health facilities. This limits the ability of the Department of Health to identify COD information to enable public health follow-up actions. The pandemic has provided an opportunity to identify longer-term solutions that improve the CRVS and the logical follow on from a previous interdepartmental evaluation of the CRVS conducted in 2014/2015 which highlighted some areas for improvement.[17]

The purpose of this project is to respond to a gap in the South African district health information system regarding access to timeous and accurate COD data, particularly for HIV/AIDS and TB during the COVID-19 epidemic. The project assesses the feasibility of implementing TeleVA data collection within a provincial health program and pilot test tools for mortality surveillance to serve the health service and improve the official CRVS system at a district level. The acceptability of TeleVA was assessed within the district of Cape Town and at two Health and Demographic Surveillance sites (SAPRIN nodes) located in the provinces of rural Mpumalanga (Agincourt) and rural Kwazulu-Natal (African Health Research Institute).

2.2.1 Ethics

We obtained ethics approval from the SAMRC and the Swiss Tropical and Public Health Institute and permission from the Western Cape Department of Health (WCDoH). This project was reviewed in accordance with CDC human research protection procedures and was determined to be non-research public health surveillance.

2.2.2 TeleVA pilot study

The pilot was conducted in the Cape Town metro which falls under the Western Cape and the City of Cape Town health departments. TeleVA had already been implemented in SAPRIN Health and Demographic Surveillance sites (HDSS) nodes, so only the acceptability component was investigated in these nodes.

Since information on COD is mostly available for people who died in hospital, this pilot focused on deaths that occurred outside health facilities during the SARS CoV-2 epidemic. The first step was to identify out-of-facility deaths where the name and contact details for relatives were available. This was done using three methods (see Annexure 2 for TeleVA process):

1) Out-of-facility deaths were retrospectively identified through linkage of the known COVID-19 cases and cohorts of known TB, HIV, and Diabetes cases from the Western Cape Provincial Health data centre (WCPHDC) with the National population register data held by the SAMRC. Contact information for relatives was sought from other available datasets in the data centre and those with information for relatives were included on a participant list.
2) The Emergency Medical Services (EMS) identified home deaths that they attended to during August 2021 and obtained contact details for the person who called EMS at the time of the death. These were added to the participant list.
3) Funeral undertakers were approached to assist with identifying home deaths and getting consent from relatives for the project to contact them to arrange an interview. These were added to the participant list.

A data system for electronic data capture and storage was set up using KoboToolbox installed on the WCPHDC server. The data capture form was installed on KoboToolbox and accessed using the KoboCollect app which was installed on the interviewer's android tablets.

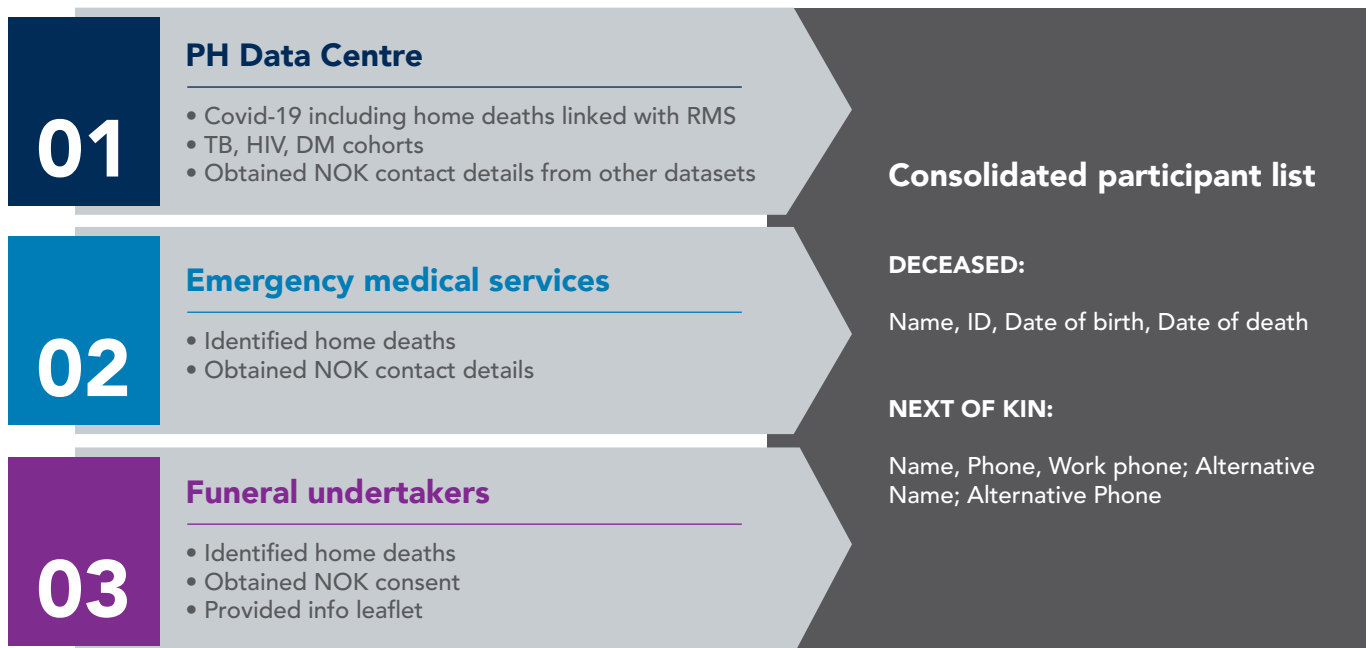*Figure 2: Overview of designed recruiting process for study participants. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa. September 2021*
COVID-19= Corona virus disease 2019, RMS= Rapid Mortality surveillance, TB= Tuberculosis, HIV= Human Immunodeficiency Virus, DM= Diabetes Mellitus, NOK= Next-of-kin, ID= Identity number, DOB= Date of birth, DOD= Date of death

A convenience sample of participants were selected from the deaths occurring during December 2020 through September 2021. The interviewer supervisor allocated the participants to fieldworkers who contacted relatives, informed them of the study, and requested consent to set up an interview for a VA interview. The interviews were conducted using android tablets and the data captured on the same device using KoboCollect. Consent was taken verbally and recorded using the android device.

2.2.2.1   Preliminary results

A total of 4342 potential study participants were identified, with the majority through the WCPHDC, see Table 1. Very few were identified through funeral undertakers. We selected 1570 participants who had complete information on name and contact details, for a target sample of 600 – 900 to accommodate non-response.

Table 1: Study participants by month and stakeholder. Strengthening mortality surveillance systems study, September 2021.

Study participants identified				
Month/Year	EMS	Funeral undertaker	PHDC	Total
Dec-20			531	531
Jan-21			529	529
Feb-21			296	296
Mar-21			292	292
Apr-21			265	265
May-21			326	326
Jun-21			360	360
Jul-21			594	594
Aug-21	358	5	602	965
Sep-21		2	182	184
Total	358	7	3 977	4 342

EMS= Emergency Medical Services, PHDC= Western Cape Provincial Health Data Centre, Dec= December, Jan= January, Feb= February, Mar= March, Apr= April, Jun= June, Jul=July, Aug= August, Sep= September

The TeleVA were conducted between August and October 2021. A team of 7 TeleVA interviewers were trained over 5 days by the SMS study team to conduct the phone interviews. The interviewers had all conducted face-to-face interviews for the NCODV project so had received previous training and had experience in face-to-face VA.

The final participant list contained the next of kin details for 1570 decedents. Of these, 112 were excluded as they were subsequently identified as deaths in hospitals, and 111 were not contacted due to time and budget constraints. A total of 1347 eligible respondents were contacted, with 229 successfully interviewed, 138 refused an interview, 373 had incorrect contact details and 607 did not answer the call. A total of 2735 calls were made in order to interview eligible respondents. Further details are shown in Table 2.

Table 2: Response rates and average number of calls required for a successful interview

Outcomes	N	%
Total sample identified	**1 570**	**100**
Total Exclusions	**223**	**14.2**
Hospital deaths excluded	112	7.1
Not called – time constraints	111	7.1
Respondents approached	**1 347**	**85.8**
Successful interviews	229	17.0
Refusal	138	10.2
Contact details incorrect	373	27.7
No answer	607	45.0
Calls	**N**	**%**
Total calls	2 735	100
Call success rate	229	8.4

The recruitment proved to be challenging among all stakeholders:

- Funeral parlors yielded very few recruits – it was a busy period due to the 3rd wave of SARS CoV-2 infections and a difficult time to approach grieving relatives
- EMS could identify the death on arrivals (DOAs) but had to obtain next-of-kin (NOK) contact details from the call logs – sometimes only a first name was available
- WCPHDC yielded the most recruits but also had to link deaths with various databases to obtain NOK contact details.

2.2.2.2   Acceptability and Feasibility

This was an exploratory study, using a parallel mixed methods design. The study combined a call log sheet in which all attempts were recorded, a survey to measure the technical performance of each TeleVA as well as the semi-structured interviews with the interviewers and respondents to further understand the acceptability of conducting TeleVAs. The survey was conducted after each interview.

On average, two attempts were needed before successfully completing the VA interview after NOK agreed to be interviewed.

We also recorded the experience of technical challenges. These included connectivity interruptions, lack of airtime, and battery running out of charge/empty. The details are shown in Table 3 below.

Table 3: Post-teleVA interviewer survey. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa, March 2022

Technical Challenges recorded	(%)
None	193 (84,3)
Poor/No connectivity	26 (11,4)
No airtime	1 (0,44)
Respondent's battery empty	2 (0,87)
Other	7 (3,1)

Semi-structured interviews were conducted with TeleVA interviewers as well as with respondents. The average time for each interview was 30 minutes. These interviews were conducted based on the question guide that had been developed for this study (see Annexures 3 & 4). Probes were used to elicit additional information based on the course of conversations and interviewer's observations.

The study sample included the respondents that had been recruited within the SMS study, as well as respondents from the SAPRIN nodes. In this section, we describe the preliminary results from all interviews.

The TeleVAs were generally very well accepted. We describe in the tables below the main advantages and disadvantages, as described by the interviewers and respondents.

The interviewers seemed to gain confidence and acceptability as they gained experience conducting TeleVAs. At the beginning, some struggled with enrolling respondents and were demotivated by this. However, with time they gained experience explaining and introducing the study and had more pleasant experiences. Further advantages and disadvantages can be found below in Table 4.

Table 4: Summary of TeleVA interviewer's perspectives. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa, November 2021

Perspectives of teleVA interviewers	
Advantages	**Disadvantages**
Less travel time	Feeling of more rejections – challenging
More flexibility to arrange interviews over the phone	Transition to phone was complicated – Especially when respondents were crying
Safer over the phone (COVID-19 and personal)	In some cases, the interviewed participants were distressed (crying) during the teleVA. The interviewers felt fear for them, as they couldn't follow up
TeleVA exceeded the expectations of most teleVA interviewers	It was harder to establish trust relationships with respondents over the phone than in person

COVID-19= Corona virus disease 2019

Similar to the TeleVA interviewers, the respondents were generally very positive about conducting the VA over the phone. Several reasons were given for this, as highlighted in Table 5 below. One important difference between the respondents in Cape Town and the SAPRIN nodes, was that all the Cape Town respondents received a R100 voucher for participating in the TeleVA interview whilst these were not offered in the SAPRIN nodes as this is not routine practice in these sites. Vouchers were disbursed from the interviewer's tablet using the Flash mobile application directly to the mobile device of the respondent, or someone nominated by the respondent. The respondent had a choice of receiving the following vouchers, i.e., airtime, cellular data, a prepaid electricity token, a prepaid water token, Netflix, Uber/Uber eats. A R50 shopping voucher were also sent to participants who completed the in-depth telephonic interviews.

We explored how the voucher may have influenced respondents to participate in the study. Mixed answers came from the Western Cape, for some this was rather important and for many this was not relevant, and they were rather intrinsically motivated to support the district health office.

Table 5: Summary of TeleVA respondent's perspectives. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa, November 2021

Perspectives of teleVA respondents	
Advantages	**Disadvantages**
Importance to have time to answer questions – establishing trust	For some respondents it was challenging to trust the person calling over the phone
Talking during VA helps with grieving process	Face-to-face interviews are more personal
More safety	
Appreciated contact of the government	
Mixed answers about importance of the voucher: some participants stated it did not make a difference for them, while others mentioned they would not participate without the voucher	

2.2.2.3   Learnings and suggestions

This study showed that TeleVA worked well in Western Cape and was generally accepted by respondents, as well as interviewers. The challenges that interviewers faced could be addressed by increasing the training provided on:

- Grief counseling (especially over the phone)
- How to engage people over the phone
- How to deal with rejection
- Patience, as explaining the concepts, questions required more time over the phone

The challenges experienced in the recruitment of respondents show the importance of establishing an integrated VA process. It will be crucial for the future of TeleVA to work within existing systems that push information about the next of kin, directly to the TeleVA program. This will require careful consideration of the process and stakeholder responsibilities since the occurrence of a death until the TeleVA is conducted. TeleVA shows promise as an alternative to face-to-face VA. The data show that there is potential for TeleVA to be used in combination with face-to-face interviews. When next of kin have concerns about discussing these issues over the phone, or where connectivity is a problem, a face-to-face interview could be offered as an alternative.

2.3   Group work – Improving processes

This workshop session consisted of 25 minutes of group work (see Annexure 5 for the workshop agenda). Attendees were divided in two groups and invited to brainstorm about the following questions:

- What data sources have information about deaths in Western Cape? (including NOK contact details and COD information)
- Which opportunities exist to integrate mortality information sources?
- If integrating TeleVA in the routine system, who would be most suitable to recruit NOK?

2.3.1   Mortality information sources

Both groups discussed the question of which information systems collect mortality information in Western Cape. Figure 3 compiles the information collected from both groups. We have organized these information sources by information system, i.e., health, other government and informal (see Annexure 6).

Figure 3: Brainstorming notes collected during the workshop. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa, November 2021

TB = Tuberculosis, HIV = Human Immunodeficiency Virus, DHA = Department of Home Affairs, SAMRC = South African Medical Research Council, N/A = Not applicable, UNHCR = United Nations High Commissioner for Refugees

Additionally, the groups also discussed which information is collected by which data information system. The information systems that were used in the SMS study to identify NOK have been compiled and complemented in Table 6.

Table 6: Information systems used in the SMS study to extract next-of-kin information. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa, March 2022

Information system	Main Institution or Sector	Purpose of the system	Individual vs Aggregate	Source of deaths captured	Next of Kin contact details
Clinicom	Health	Hospital patient administration system for in- and outpatients and emergency centres (EC)	Individual	All deaths that occur in the hospital and EC	Yes
Primary healthcare information system (PHCIS)	Health	Primary healthcare (clinic) patient administration system (including Midwife and obstetrics unit and 24hr Community Health Centres)	Individual	Deaths occurring at clinics (DOAs variable)	Yes
Hospital and Emergency Centre Tracking Information System (HECTIS)	Health	Patient management including tracking within the emergency centre. Phased roll out to all ECs	Individual	Deaths in selected emergency centers	Yes
Emergency Medical Service (EMS)	Health	Management of patients accessing EMS services	Individual	Deaths confirmed by EMC staff	Some
National Population Register (NPR)	Home Affairs	Identification system for South Africa citizens	Individual	Deaths of registered individuals with SA ID	No
Rapid Mortality Surveillance	SAMRC	To monitor trends in numbers of deaths	Individual	Deaths of registered individuals	No
Funeral undertakers	Community	Billing system	Individuals	Deaths processed at undertaker	Yes

2.3.2 Opportunities to strengthen mortality information in Western Cape

Both groups briefly discussed existing opportunities to strengthen the mortality information in Western Cape. The discussion was structured by two main topics as shown in Figure 4:

2.3.2.1 Opportunities for integration

As the SMS study has shown, there are several silos of information systems collecting information about the occurrence and COD, as well as NOK. There are several opportunities to integrate these systems and increase the completeness of the Western Cape mortality information system. Some examples that were discussed are:

- The EMS database currently collects information about the deaths that are assisted by the team. However, the data collected do not include all details that would be needed by the Department of Health to integrate in their system. The EMS team confirmed that there is an opportunity and willingness to change this.
- How can research mortality data be integrated and embedded in a routine system to inform decisions? The group discussed how research institutions, such as SAMRC or HDSS collect information about deaths and cause of death but this does currently not flow into the routine Civil Registration systems. There could be an opportunity to integrate these.

2.3.2.2 Opportunities for quality improvement

One of the groups identified quality improvement as one of the key dimensions to address when strengthening the mortality information system in the Western Cape. They described quality as a pending activity and of great importance to increase the usefulness of mortality statistics.

The participants described different initiatives ongoing in the region to increase quality of death data recorded in hospitals, such as the use of a probabilistic software to link the different datasets.

Furthermore, the group brainstormed about other potential activities to increase awareness of the importance of quality COD information. Two main ideas discussed were firstly, the creation of a mortality dashboard for hospitals that would provide an indication of when data are used, a second idea linked with the dashboard was increasing the visibility of mortality data more broadly within the hospital to reach its goal of increasing awareness among healthcare workers.

OPPORTUNITIES MORALITY INTEGRATION

EMS – details missing for Western Cape DoH. There's willingness and opportunity to add and complement information collected.

At the moment, very few systems collect next of kin information – it could be viewed as routine data – included in health information systems for example

Work with Home Affairs to include discharge diagnosis information into registration documents

There's an opportunity to integrate data coming from research studies (e.g. SAMRC) with routine data.

Obtain copy of DNF from DHA

HDSS – not linked to CR system

OPPORTUNITIES QUALITY IMPROVEMENT

Create hospital death dashboard – using existing data from mortality reports

Increasing quality of CoD – probability software

Visibility within hospital reporting

Figure 4: Brainstorming notes about opportunities to strengthen the mortality statistics in Cape Town. Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa, November 2021
EMS = Emergency Medical Services, DoH = Department of Health, CoD = Cause of Death, HDSS = Health Demographic Surveillance Site, DNF = Death Notification Form, DHA = Department of Home Affairs, CR = Civil Registration, SAMRC = South African Medical Research Council

2.3.3 TeleVA – who should recruit NOK?

One of the challenges identified by the SMS study for the future of TeleVA is the recruitment of the NOK. For this reason, we included a question to identify how this could be better addressed in the future. Unfortunately, due to time limitations this brainstorming fell a bit short; however, some ideas were suggested by the participants.

Participants agreed that there are two main groups of stakeholders with different mechanisms to collect this information. On one hand, there are some institutions which collect information about the deceased which often also includes information about the NOK. These include porters at healthcare facilities, who keep a register of all bodies transferred to funeral undertakers and the EMS, which also has a register and as shown in the SMS study can be an invaluable source of information for NOK details for deaths outside the hospital.

On the other hand, the Department of Home Affairs collects information on the NOK as part of the routine death registration process. The group agreed that in the ideal mortality surveillance system the NOK information should be provided by the Department of Home Affairs. However, as previous collaborations have shown this can be a tedious and long process.

One of the groups also added that when discussing about the NOK information, it is essential to guarantee confidentiality of information and achieve a process to ensure inquiries on NOK remain confidential.

The last session of the workshop consisted of a plenary discussion. This included the short inputs from four panellists: Nadine Nannan (SAMRC), Andrew Boulle (Western Cape Department of Health), Erna Morden (Western Cape Department of Health), and Diane Morof (U.S. Centers for Disease Control and Prevention South Africa). Below is a summary of points covered by each panellist.

- **Nadine Nannan, SAMRC**

The overview of the South African CRVS system and the quality of COD statistics found that an evaluation of CRVS was undertaken in 2014/15 with the view to develop a strategic plan for the country to improve CRVS but it remains incomplete. The evaluation identified the need for an inter-departmental committee to facilitate cooperation and provide updates in legislation and practical service improvement opportunities to the stakeholders – Department of Health, Stats SA and Department of Home Affairs.

Although the completeness of death registration has increased dramatically since 1994 from 50% to currently more than 90% for adults, there remain major challenges with the COD data. These are:

- Misclassification of HIV deaths to other causes such as TB, diarrhoea etc.
- Injury mortality profile is problematic due to the death notification form needing to be changed to include a field for manner of death
- There is a high proportion of ill-defined causes
- The quality of COD statistics is rated low and require doctors to be trained in medical certification.
- Improvement in the timeliness of COD statistics is needed, currently there is a 2-3-year lag in publication for the statistical report.

In terms of public health utility of COD data, the review revealed that under the present circumstances COD data in South Africa are not fit for purpose. This is largely due to an amendment to DHA-1663 in 2014 which introduced a self-sealing form for the page containing the medical certificate of cause of death with an instruction that the sealed document can only be opened by a Stats SA official. This halted the Western Cape Department of Heath mortality surveillance project from accessing the death notification forms. Prior to that, the local level mortality surveillance provided sub-district mortality statistics that were used for public health response such as diarrhea outbreaks, planning health interventions and monitoring health programmes.

Timely reporting of deaths is achieved through using data from the National Population Register but is limited since no COD information is provided. The Rapid Mortality Surveillance provides empirical estimates of key mortality indicators and weekly death reports have been used to monitor excess deaths during COVID-19 and highlights urgency of access to COD information.

Cause-of-death data provided by Stats SA are made relevant by addressing quality challenges to make sense of COD data. Burden of disease analysis makes national burden of disease estimates available by correcting for all deficiencies while the district barometer redistributes the large group of ill-defined causes to provide COD profiles for health districts. A NCODV Project is underway to estimate correction factors for COD profiles.

The review identified the importance for South Africa to develop a country roadmap for strengthening the reporting of births and deaths with stakeholders. The outstanding component of the review is to conduct interviews with key informants to identify current challenges in the CRVS system and plans to address them. A major consideration is how can DoH get timely information about COD in context of COVID-19.

- **Andrew Boulle, Western Cape Department of Health**

The Department has established a data exchange, the WCPHDC, as the vehicle of integration. Curating and consolidating mortality data is done based on several clinical data sets using a probabilistic multi-evidenced approach. Thus far, there has been no focus on fact of death or COD, but rather on clinical data that is being used to track their programmes. It would be ideal to add a link to the HANIS data from Home Affairs (see Figure 5). So far this has only been done in a collaborative research project which linked COVID-cases with the National Population Register data from Department of Home Affairs which is collated weekly by the SAMRC for monitoring of excess deaths.
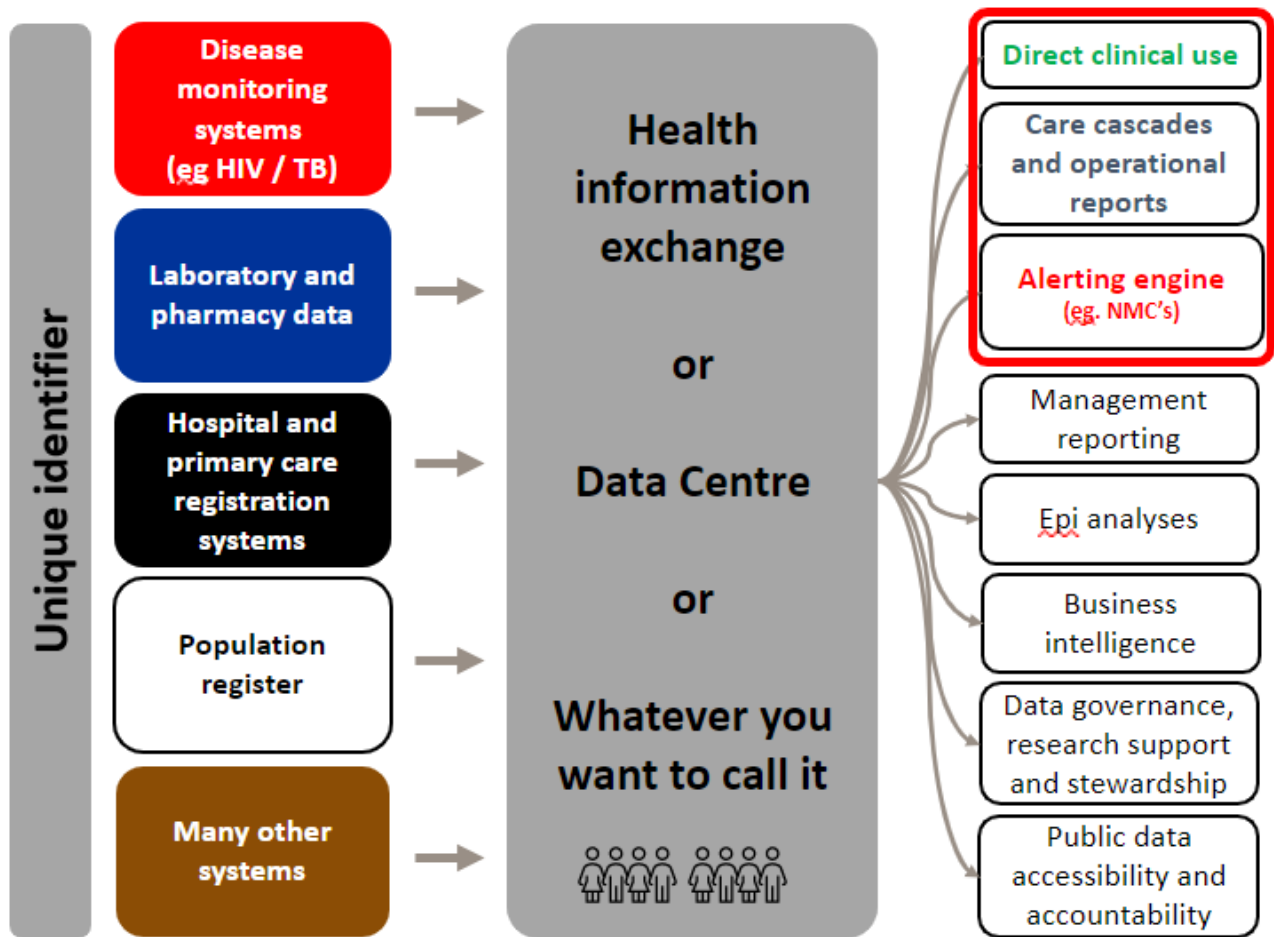
Figure 5: Western Cape Provincial Health Data Centre as vehicle for data integration (WCPHDC), November 2021
HIV = Human Immunodeficiency Virus, TB = Tuberculosis, NMC = notifiable medical conditions, Epi = Epidemiology

The immediate implementation of VA will be within the SAPRIN: C-SHARP node in 2 Cape Town sites, i.e., Bishop Lavis and Nomzamo (see Figure 6). Two clinical nurses will be appointed in the project and will conduct TeleVAs as part of the surveillance.

Cape Town Surveillance through Healthcare Action Research Project
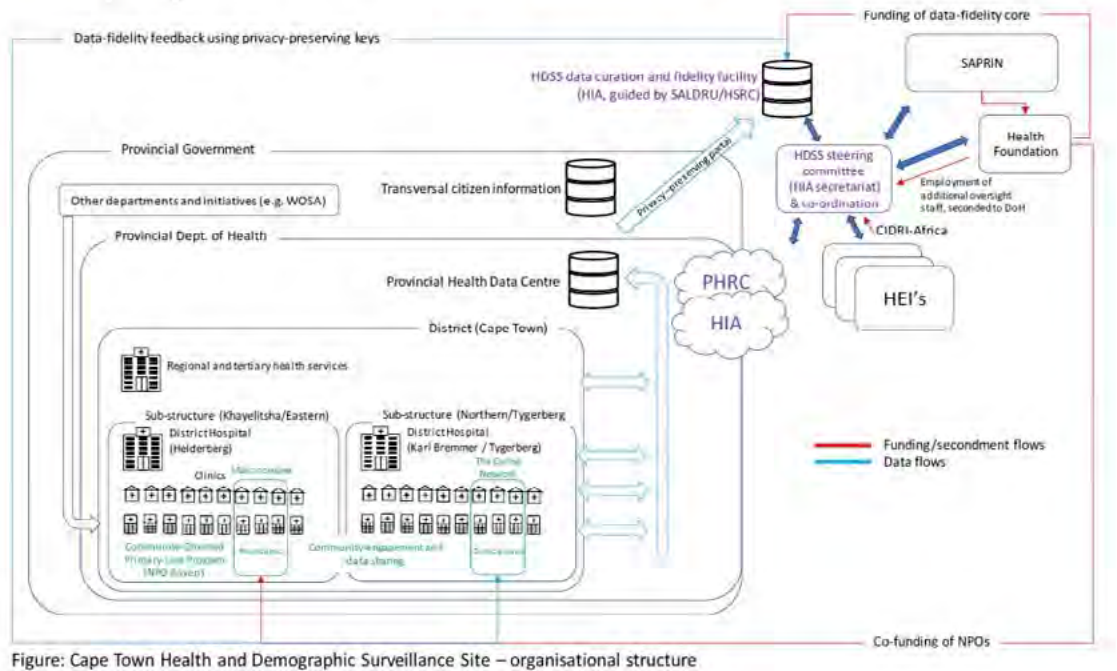
Figure: Cape Town Health and Demographic Surveillance Site – organisational structure

Figure 6: C-SHARP node. Developed by the Western Cape Provincial Health Data Centre, November 2021
WOSA= Whole of society approach, NPO= Non-profit organisation , HEI= Higher Education Institutions, HDSS= Health Demographic Surveillance Site, HIA= Health Impact Assessment, SALDRU= South African Labour and Development Research Unit, HSRC= Human Sciences Research Council, PHRC= Provincial Health Research Committee, SAPRIN= South African Population Infrastructure Network

Another possibility for implementation of TeleVA is within the Digital safety-net – initiative (see Figure 7). This is an ongoing telehealth project providing care to diabetic patients. It might be appropriate to incorporate TeleVA in the project.

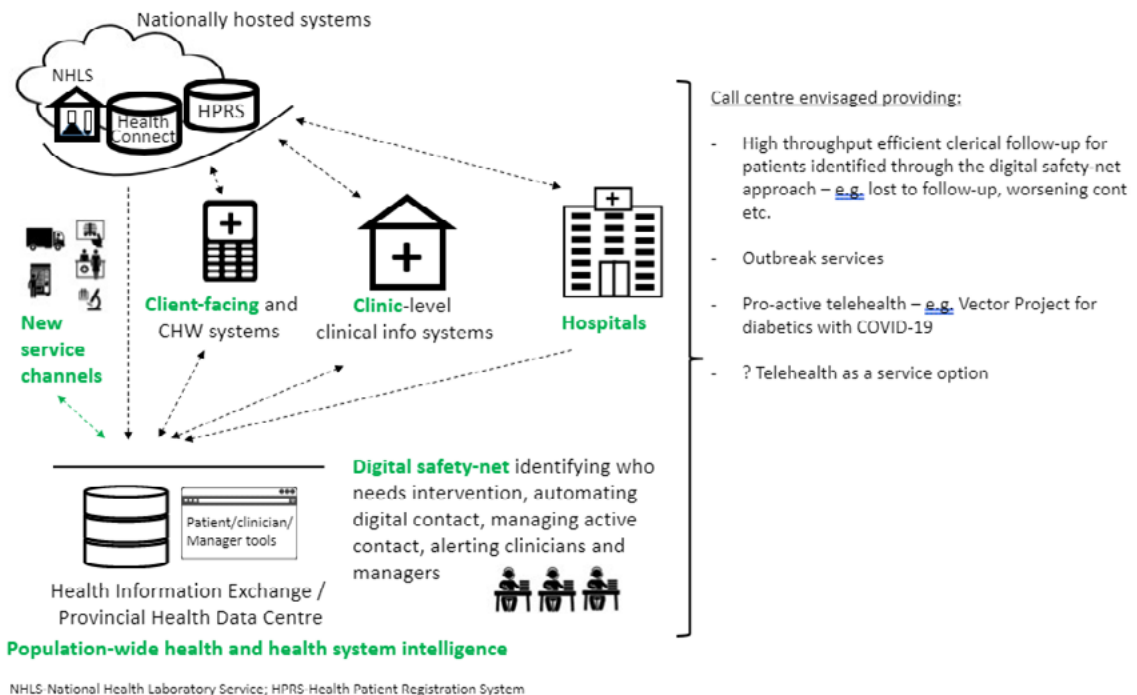Digital safety-net initiative as platform for TeleVA

Figure 7: Digital safety-net initiative as platform for TeleVA. Developed by the Western Cape Provincial Health Data Centre, November 2021

-   **Erna Morden, Western Cape Department of Health**

    •   Highlighted the current capacity constraints around data processing, providing a reality check around implementation of TeleVA. Highlighting the need for using underlying COD for determination instead of immediate cause, and the in-facility reliance on ICD-10 coding.

-   **Diane Morof, US Centers for Disease Control and Prevention South Africa**

    •   The project provides essential information that will define the potential contribution of using VA to provide mortality and COD data. Careful consideration is needed on how best to incorporate this system more broadly into death surveillance systems to ensure integration and integrity of mortality data capture in the future.

During the discussion after the plenary, the participants identified an important gap that could at least provide information on the COD for deaths occurring in hospitals. The Department of Health is currently not collecting or using the death data from health facilities. The participants discussed potential ways to address this including increasing awareness of the importance of death information among health personnel. It was suggested that a dashboard reporting the mortality statistics for deaths in health facilities could generate awareness about the importance of filling in the information, as well as how to do it.

Furthermore, the participants also discussed potential ways forward to curate the death data.

4   Conclusion and next steps

The results and discussions from the SMS study provided key learning and lessons for other programs in the country. Two specific programmes were discussed that could benefit from this experience: the work being conducted by the SAPRIN nodes which are being extended to the Western Cape where two new nurses will be enrolled and could be engaged to conduct VA, and the planned telehealth programme, which may benefit from the lessons of engaging with the community over the phone.

Lastly, the participants all recognized the importance of dedicating more time to understanding and designing recruitment methods for NOK in future VA projects.

All in all, everyone saw promising opportunities emerging from this work and engagement among stakeholders to strengthen the quality of mortality statistics in the Western Cape.

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Verbal autopsy

- Verbal Autopsy process, assumptions and principles
- Verbal Autopsy use in SA
- 2016 WHO Verbal Autopsy instrument structure and content
- Verbal autopsy cause list

Verbal Autopsy process

A structured interview with relatives/close caregiver of the deceased, to obtain information on the clinical symptoms, signs and events during the illness leading to death

followed by

A review of the verbal autopsy information to assign a cause of death (either by a clinician or using computerised software)

VA is used

*To provide cause of death information in areas with limited access to health care and poor civil registration and vital statistics systems*

Three key assumptions

- The symptom complex for each disease of interest is unique (e.g. neonatal tetanus or motor vehicle accidents)
- Family members or other caregivers can accurately recall symptoms and their timing
- Caregivers are willing to disclose this information (important where a death is stigmatised)

Health and Socio-Demographic Surveillance

- *Defining and registering* a population
- *Following* community over time
- *Recording* all vital events
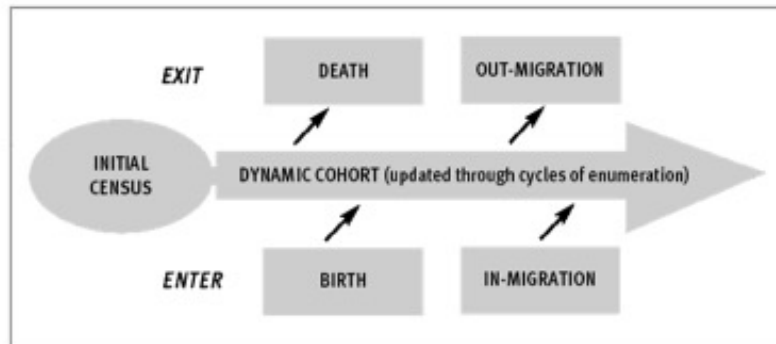
Health and demographic surveillance site research design

- Baseline census
  - Agincourt 1992; Dikgale (DIMAMO) 1996; Africa Centre (AHRI) 2000

- Annual household and vital events update

- Key information on vital events
  - pregnancy outcome, deaths, in/out migration, maternity history

- **Verbal autopsy on all deaths**

- **Validation study**

  Kahn K et al. 2000. Validation and application of verbal autopsies in a rural area of South Africa. *Trop Med & Int Health*; **5**(11): 824-31

- Migration reconciliation; Marital/union status; Special modules – e.g. assets (SES), health care utilisation, temporary migration

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Verbal autopsy

- Method of ascertaining cause of death especially in HDSS
- VA on all deaths recorded during annual HDSS update
- Trained lay fieldworkers to interview closest caregiver
- VA Questionnaire: signs and symptoms, lifestyle behaviours, treatment
- Open narrative and filtering questions
- Previously physician coded only; now automated software
- Largely used in research – now standardised tools developed for routine systems to fill the gaps – deaths occurring in the community
- Include questions on circumstances of death

Important principles for VA

- Identification of best respondent
- Optimal recall period
- Selection of fieldworkers
- Training of fieldworkers
- Fieldworker debriefing: managing self

South African Population Research Infrastructure Network (SAPRIN)
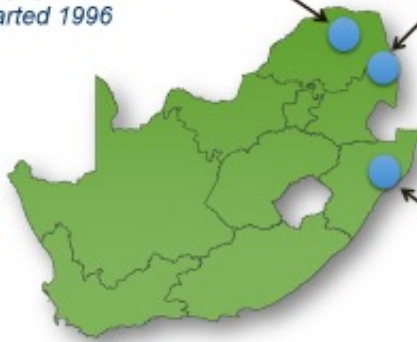
DIMAMO HDSS
Limpopo Province
Started 1996

Pop: 35 000

Agincourt HDSS   Pop: 120 000
Mpumalanga Province
Started 1992

Africa Health Research Pop: 165 000
**Institute**
KwaZulu-Natal Province
Started 2000

Agincourt area, Bushbuckridge

31 villages, 19,000 households, 120 000 people

Rural, densely settled former Bantustan

31% Mozambican immigrants (self-settled former refugees)

Established 1992 to:

- generate **valid, empirical information** on rural communities

- inform vital **health reforms**

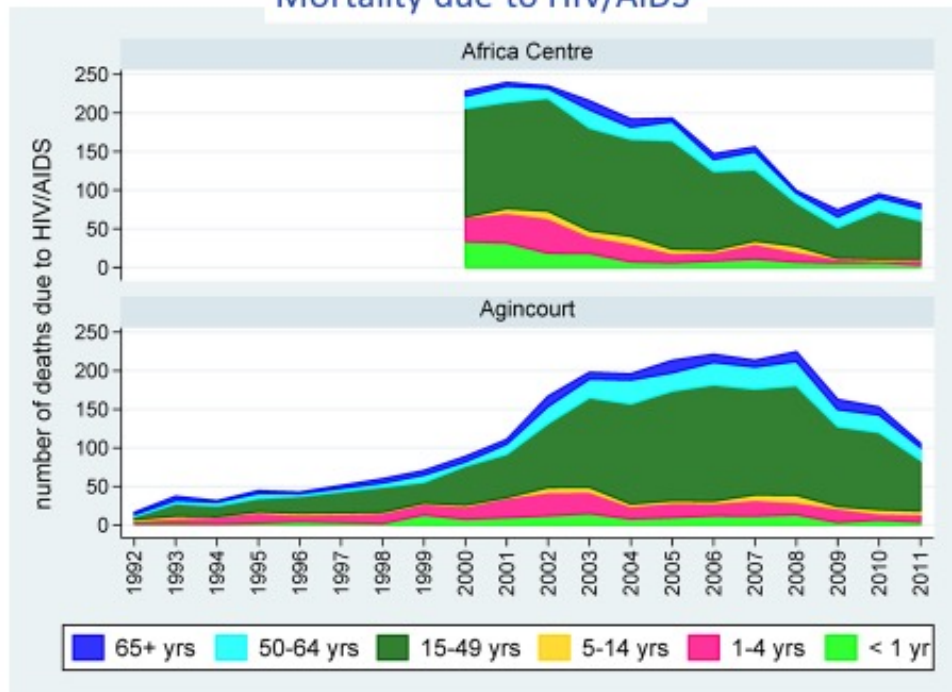- bring the **strongest science** to bear where needs are greatest

Kahn K et al. Profile: Agincourt Health and Socio-demographic Surveillance System. *IJE* 2012
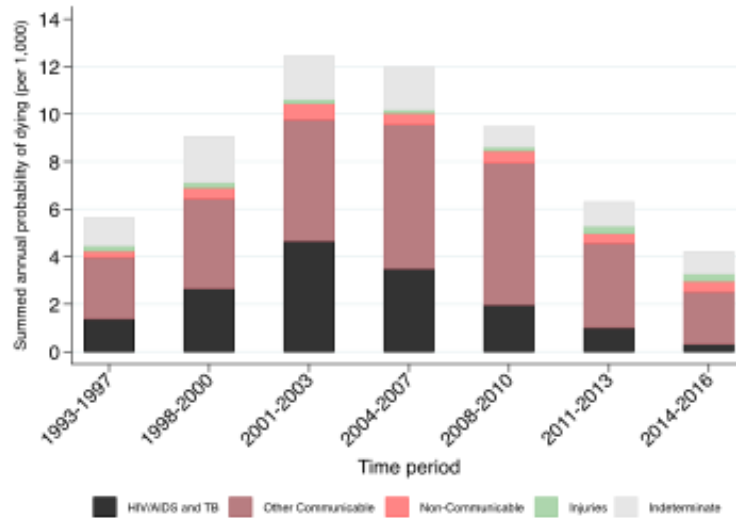
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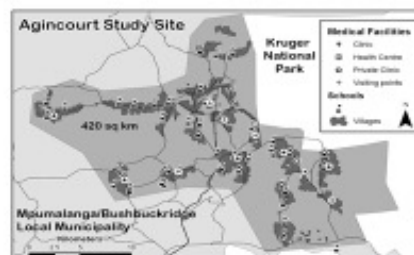
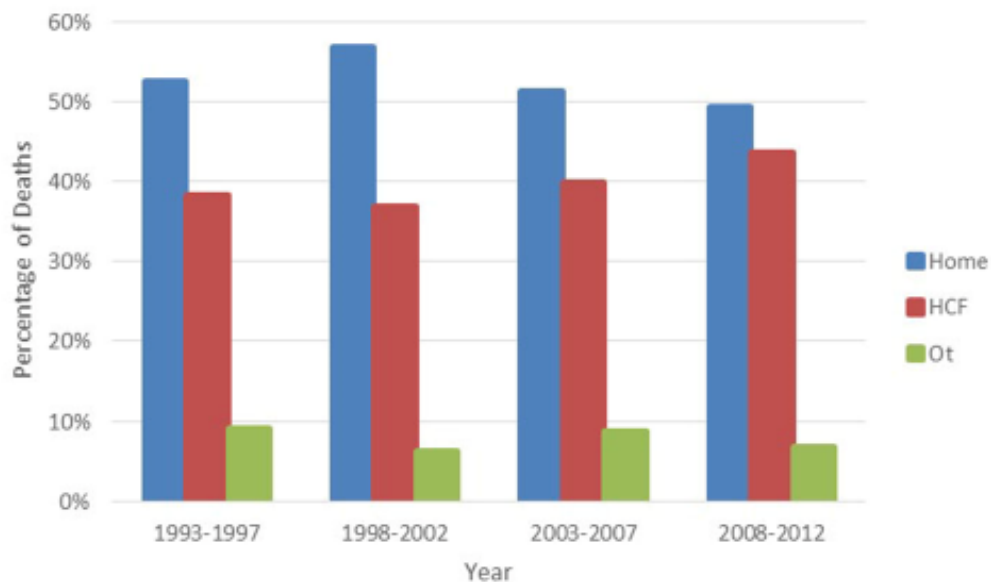Colliding epidemics: cause-of-death composition
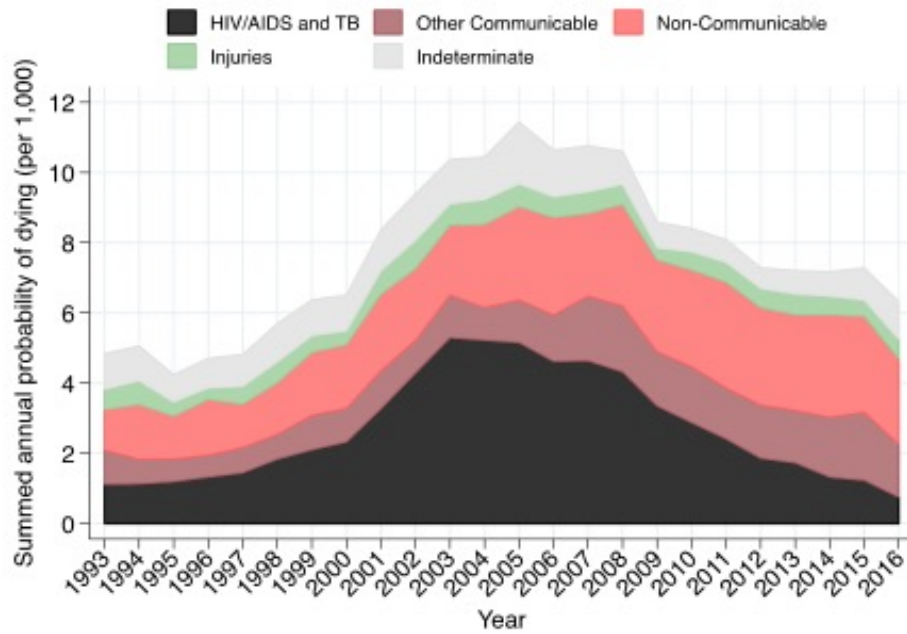
Mortality due to HIV/AIDS

"A successful failure": monitoring MDG targets
Cause-specific mortality: 0-4 years

Byass P et al, PLoS Med 2015

% DEATHS 0-4 YEARS BY PLACE OF DEATH, 1993-2012 (N=1992)

2016 WHO VA instrument
Basic structure

WHO 2016 verbal autopsy questionnaires

➢ Questionnaires and other resources are available for download on the World Health Organization (WHO) website at: http://www.who.int/healthinfo/statistics/verbalautopsystandards

- **WHO VA Questionnaire 1** —for neonatal, perinatal deaths and stillbirths (deaths of children aged less than four weeks or 0-27 completed days).

-

- **WHO VA Questionnaire 2** — for post-neonatal and child deaths up to 11 years (deaths of children aged four weeks (day 28) up to 11 years).

-

- **WHO VA Questionnaire 3** — for adolescent and adult deaths (death of a person aged 12 years and above).

Detailed structure of VA questionnaires

- All 3 questionnaires follow the same general structure across 5 broad segments
- "Skip patterns" facilitate the use of the questionnaires
  - When an answer to a specific question results in bypassing or "skipping" other irrelevant questions
  - "Entry level" questions always asked; Level 2 & 3 questions may be asked depending on response to entry level
- Skip patterns driven by:
  - Age
  - Sex
  - Maternal or perinatal death
  - Symptoms/signs
  - Constructs requiring more detail (e.g., duration, timing, severity, and location)

Detailed structure: broad segments

Segment/ depth	Neonate	Child	Adult (incl. maternal)
Personal	19	21	20
Entry level	15	17	16
Level 2	4	4	4
CRVS	13	18	18
Entry level	2	2	3
Level 2	11	16	15
CoD	122	161	184
Entry level	38	86	66
Level 2	65	72	96
Level 3	19	3	22
Context	23	23	19
Entry level	7	12	10
Level 2	10	10	8
Level 3	6	1	1
DeathCert	12	12	12
Entry level	1	1	1
Level 2	1	1	1
Level 3	10	10	10
Grand Total	**189**	**235**	**253**
Entry level	63	118	96

Sections of VA questionnaire

- Introduction
  - Interviewer details
  - Outcome (consent or refuse)
- eConsent (audio)
1. Preset HIV-Malaria mortality and season
2. Information on the respondent and background about interview
3. Information about the deceased and vital registration
   a. Socio-demographic information
   b. Civil registration information
4. History of injury/accidents
5. Health history on information required for assigning causes of death
6. Open narrative
   a. Text field (image of handwritten notes taken at beginning of interview)
   b. Check list of additional items to record in the narrative open space

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Health history on information required for assigning a cause of death

a. Duration of final illness

b. Medical history associated with final illness

c. General signs and symptoms associated with final illness

d. Signs and symptoms associated with pregnancy and maternal deaths

e. Neonatal and child history, signs and symptoms

f. Health service utilization

g. Background and context

h. Death certificate with cause of death

PEPFAR CDC saMRC Swiss TPH Western Cape Government BETTER TOGETHER GeoSpace

Open narrative

- Open text field that allows for comments and adding additional information. Captures key items such as signs and symptoms, timing of care seeking, and any points that need to be clarified.
- Respondent provides brief description of the illness and terminal events.
- Useful for quality control and for providing additional information for physician assessment of the cause of death if needed.
- Also used to complete a checklist of some indicators that are required for assigning causes of death using an automated algorithm.
- Critical for clinicians involved in interpreting VA.
- ➢ Asked near beginning of the questionnaire; recorded in notebook.
- ➢ Entered in tablet after interview.

Open narrative - importance

- Provides an opportunity to break the ice
- Informal recall of the circumstances of the death provides
  - a more holistic picture of the events
  - Opportunity to understand the sequence of events
- Often information relevant to the cause of death that is not captured by the standard questions is disclosed
  - Discontinuation of chronic treatment by the decedent (ARV and TB meds)
- Crucial information for clinical reviews
  - Usually provides a differential diagnosis
- Quality control
  - Be on the alert for contradictions between question responses and details given in narrative

HANDWRITTEN NARRATIVE IMAGE

Verbal autopsy analysis: Cause of death list

- VA cannot ascertain all causes of death & VA does not perform equally well for all causes that it can ascertain

- The WHO 2016 VA instrument includes a list of 64 causes that can be ascertained with reasonable accuracy from a well-administered VA interview

- Causes correspond with codes from the International Classification of Diseases (ICD-10)

- Cause of death assignment requires correct completion of questions

Verbal autopsy code	Verbal autopsy title	ICD-10 code (to ICD)	ICD-10 codes (from ICD)
VAs-01 Infectious and parasitic diseases			
VAs-01.01	Sepsis	A41	A40-A41
VAs-01.02	Acute respiratory infection, including pneumonia	J22/J18	J00-J22
VAs-01.03	HIV/AIDS related death	B24	B20-B24
VAs-01.04	Diarrheal diseases	A09	A00-A09
VAs-01.05	Malaria	B54	B50-B54
VAs-01.06	Measles	B05	B05
VAs-01.07	Meningitis and encephalitis	G03; G04	A39; G00-G05
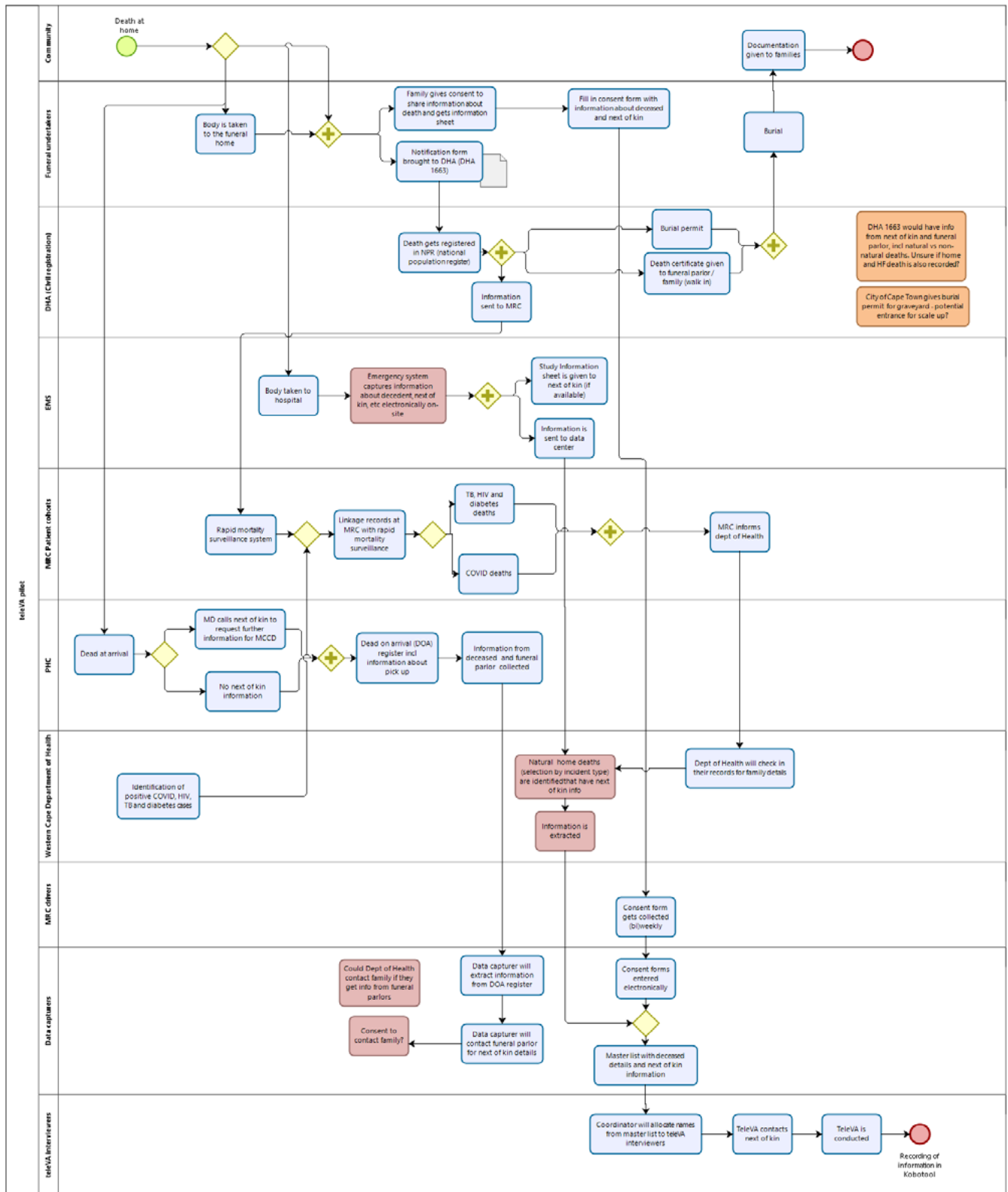
Participant ID No |__|__|__|__| Gender   Male / Female
Interviewer Initials |__|__|__| Date |__|__/__|__/__|__|
District: _____   Ward:_____   Country _____

Warm up [demographic & work history]

Can I ask some details about you and your job?
1.   Current Job Title _____
2.   Highest Educational Grade attained _____
3.   VA interviewer since _____
4.   Region of work_____
5.   How many VA interviews have you conducted since your enrolment in the program? _____

Feasibility

1.   How was the experience of reaching out to the families over the phone?
       a.   How many times did you have to call before finding an appointment?
2.   Did you find the right respondent? How did you identify he/she?
3.   Are there any advantages or challenges of conducting the interview by phone?
       a.   In terms of time? Costs? Quality of interview? Skills of interviewer?

Acceptability

4.   Overall, how was it for you to conduct TeleVAs compared to face-to-face VA?
5.   How would you describe the communication over the phone vs face-to-face?
       a.   Any important differences? What do you prefer? Why?
6.   How would you describe the respondent's attitude on the phone vs face-to-face interview?
       a.   Did you see any better/worse reaction towards the questions?
7.   When do you think the interviewee was more comfortable?
       a.   Why?
8.   How do you think any of the above influenced the quality of the interview?
9.   What kind of differences do you think will appear in the results of the VAs face-to-face vs TeleVA?
       a.   If you had to choose in the future, which kind of interviews would you choose? Why?
       b.   What would you do different if you were to do the TeleVAs again?
       c.   Do you have any advices for us?

Annexure 4: INTERVIEW GUIDELINE (VA RESPONDENT)

Participant ID No: |__|__|__|__| Sex: Male / Female
Interviewer Initials: |__|__|__| Date: |__|__/__|__/__|__|
Village: _____ Ward: _____
District: _____ Country: _____

Warm up [demographic & work history]

Can I ask some details about you?
6.   Highest Educational Grade attained _____
7.   Current occupation
8.   Relationship to the deceased?
9.   When did you conduct the phone interview?

Feasibility

10.   How has the experience of participating in this study been for you?
11.   Before the phone interview, do you remember how many times the interviewer had to call before talking to you?
    a.   What kind of delays did you have for this call?
12.   Was there a time that was more convenient for you to conduct the interview over the phone?
13.   Where did you do the phone interview?
    a.   Was it difficult to find a quiet and private space?
14.   How did the technology work during the interview?
    a.   Any connectivity problems? Was the sound quality acceptable? Did you understand well the interviewer? Did your battery last all the time?
15.   Would you describe any advantages of this method? And disadvantages?

Acceptability

1.   How did you know you could trust the person calling over the phone?
2.   How did you understand the interviewer's questions?
3.   How would you describe the communication over the phone?
4.   How did you feel to discuss that type of sensitive topics over the phone?
5.   If you could choose to repeat the interview, would you prefer to conduct a phone or in person VA?
    a.   Why?
6.   Do you have any suggestions or advice for us?
7.   Any other comments?

Annexure 5: WORKSHOP AGENDA

Date: Tuesday 23rd of November 2021
Start time: 11am SAST

Tuesday 23 November 2021		
11:00 – 11:10	Welcome remarks & Introductions	SAMRC – Pam
11:10 – 11:30	Verbal Autopsy 101	SAMRC
11:30 – 12:15	SMS study - Presentation	SAMRC & Swiss TPH
12:20 – 13:00	Discussion of improved processes Plenary (25 min Group work, 15 min Plenary)	Group work Swiss TPH & All
13:00 – 13:30	How could VA contribute to mortality surveillance in Western Cape?	Panel & Plenary SAMRC & All
13:30 – 13:40	Closing Remarks	SAMRC – Debbie

Information system	Main Institution or Sector	Purpose of the system	Individual vs Aggregate	Source of deaths captured	Next of Kin contact details
HIV register	Health	Management of patients with HIV	Individual	?recorded only if death notified	?
TB registers	Health	Management of patients with TB (different registers for XDR/MDR or DR-S TB)	Individual	?recorded only if death notified	?
Confidential enquiries into maternal deaths registry	Health	Recording in-facility maternal deaths and assessing causes and where preventative interventions required Maternal death audits to identify areas of improvement and at which level (health system, patient, individual healthcare worker)	Individual	In-facility deaths. Deaths due to other causes e.g. trauma or cancers excluded as a maternal death if pregnant	No
Private sector hospital deaths	Health				
Population register	Department of Home Affairs	Identification system	Individual	Deaths of registered individuals	No
Child death audits (Perinatal Problem Identification Programme, PPIP and Child Problem Identification Programme (Child PIP)	Health	Audits into neonatal or child deaths to identify causes and areas of improvement (health system, patient, individual healthcare worker etc.)	Individual	In-facility deaths on neonatal or pediatric units	Maybe
District health information system	Health	Capture of indicators as detailed in the National Indicator Dataset (NIDS)	Aggregate	Selected indicators capturing deaths at clinics or hospitals	No
Life insurance companies					
South African Police Service (SAPS)					
Social Security					
Forensic Pathology Services	Health	Electronic system for FPS operations, including evidence chain. Western Cape specific.	Individual	Deaths referred for postmortem investigation	Yes, if decedent identified
CoCT Invoicing systems – Burial homes	Community				
UNHCR					
Religious communities	Other				No
Tribal Headman	Community				Maybe

HIV = Human Immuno deficiency virus, TB = Tuberculosis, PPIP = Perinatal problem identification programme, Child PIP = Child problem identification programme, SAPS = South African Police Service, CoCT = City of Cape Town, UNHCR = United Nations High Commissioner for Refugees, XDR = Extensively drug resistant, MDR = Multi-drug resistant, DR-S = Drug resistant, NIDS = National indicator dataset, FPS = Forensic Pathology Services