
UNIVERSITY OF CAPE TOWN, FACULTY OF HEALTH SCIENCES,
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## Title

Health service utilisation prior to out-of-hospital natural deaths among children under five in Metro West, Cape Town in 2018: a retrospective analysis of data from the Child Death Review

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## Abstract

### Background

In the Metro West geographical service area within the City of Cape Town district the under-five mortality rate in the Metro West GSA decreased from 25 per 1000 live births in 2010 to 22 deaths per 1000 live births in 2013, but the rate of decrease slowed down in part because of the amount of child deaths outside of health facilities. Fifty-five percent of under-five deaths occur out-of-hospital in South Africa, with a similar percentage in the Metro West (49-52% in 2010 to 2015). Describing factors that enable or prevent health service usage among natural under-five deaths is an important precursor for effective interventions.

### Objectives and Methods

A retrospective cross-sectional design utilised secondary, routinely collected data from 1 January to 31 December 2018 on under-five out-of-hospital natural deaths reported to Salt River Mortuary. We used the data, which included routine interviews with the caregivers, together with social and medical data collated by the Child Death Review, to describe the cause of death, the socio-demographic profile, and the routine and prior-to-death health service usage. Dimensions of health service access according to the WHO and Anderson, respectively, were used as a heuristic lens to describe the applicable variables and to formulate *a priori* multivariable logistic regression models to compare those who did and did not seek care before death. These dimensions include physical accessibility, financial affordability, the health needs of the child as well as the existing health behaviour of the caregiver.

### Results

Of the 187 cases described, 68% died of lower respiratory tract infections and 8% of diarrhoea. Fifty four percent of cases were younger than 3 months, and 40% were born prematurely. In terms of the residential health sub-district, 37% resided in Mitchells Plain, 29% in Klipfontein, 18% in Western and 14% in Southern; 52% resided in needy or very needy areas. Mothers were single (69%), unemployed (73%) and lived in informal housing (46%). Of the cases who were alive at the time, immunisation coverage was 79%, 70% and 68% at the 6-, 10- and 14-week visits. However, only 23% of mothers sought health care prior to the child's death. Overall, 51% of the mothers recognised symptoms of illness prior to death and symptoms were recognised in 95% of the mothers who sought health care compared to 37% of the mothers who did not seek health care (p-value < 0.001). Multivariable logistic regression models showed the importance in recognising symptoms in seeking health care (aOR 18.28, 95% CI 3.67-90.93), and that, while not statistically significant, the recognition of symptoms was less likely at younger ages (aOR 0.28, 95% CI 0.07-1.14 for cases younger than 3 months compared to those older than 6 months)

### Conclusion

The study identified key risk factors implicated in the out-of-hospital deaths in Metro West and the need for mothers to identify and seek health care when their child is symptomatic. There should be focused support during the first 1000 days for mothers identified as being at-risk, namely: those who are single, unemployed, lack social support and abuse substances, and for babies with prematurity and HIV-exposure. Counselling should emphasise the recognition of LRTI symptoms and health care seeking to prevent child deaths and reduce the under-five mortality. Further research is needed to consolidate which provincial geographical areas should be prioritized for targeted interventions that impact on health care seeking behaviour, as well as the most effective child health education and messaging. Data paucity on medical history may be addressed by data augmentation from the Provincial Health Data Centre and improvements should be made for capturing children's anthropometry.

## Acknowledgements

Thank you to my supervisors, Prof Shanaaz Mathews, Prof Michael Hendricks, and Dr Tammy Phillips for their support, feedback, and insights. I am inspired by your passion for the well-being of children!

*"Childhood, after all, is the first precious coin that poverty steals from a child."*

— Anthony Horowitz

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SECTION 1: RESEARCH PROPOSAL

# Introduction and background

## Under five mortality, Millennium Development and Sustainable Development Goals

The Millennium Development Goals were launched in 2000 by the United Nations with four of the development goals directly relevant to the wellbeing of children.[1] One of the stated health targets was reducing the under-five mortality rate by two-thirds from 1990 to 2015. This set a goal of 20 deaths per 1000 live births for South Africa.[1] By 2015, this goal was not met, although the under-five mortality rate decreased from 66.9 deaths per 1000 live births to 34.3 deaths per live births during that time.[1] Since then, the Millennium Development Goals were replaced by the Sustainable Development Goals. The Sustainable Development Goals set 17 goals with 169 targets to be achieved by the year 2030. The target set for under-five mortality is to achieve a mortality rate of less than 25 deaths per 1000 live births by 2030. [2]

## Under-five mortality rate in Sub-Saharan Africa and South Africa

*1. Mortality rates in Sub-Saharan Africa and South Africa*

Though great progress has been made with child mortality in the last twenty years around the Millennium Development and Sustainable Development Goals, a child or adolescent still died globally every five seconds in 2018. [3] Of these deaths, 85% occurred within the first five years of life. [3] Sub-Saharan Africa is the global region with the highest under-five mortality rate, with an estimated 78 deaths per 1000 live births in 2018. [3] This equates to 1 in 13 children dying in the region before they turn five. [3] The difference between this rate and the target set by the Sustainable Development Goals is marked. The Second Triennial Report of the Committee on Morbidity and Mortality in Children Under 5 Years [4] reported that the under-five mortality rate in South Africa decreased from 56 deaths per 1000 live births in 2009 to 41 deaths per 1000 live births in 2012. This translates to a decrease from 60 000 annual deaths in 2008 to 38 000 annual deaths in 2012. [4]

*2. Under-five deaths in health facilities and at home or in communities.*

An important and overlooked modifiable aspect of the under-five mortality is the place of death. [5,6] In South Africa, 36% of deaths occurred at a health facility from the age of one month to five years in 2014. But a high figure of 55% of under-five deaths occurred outside of health facilities — either at home or within the community.[4] This proportion of children younger than five dying outside health facilities in South Africa is comparable to the situation in the Sub-Saharan Africa. In another systematic review on verbal autopsies for child death in the Sub-Saharan Africa, it was estimated that approximately 50% of deaths (53.2% of neonates and 53.1% of infants and young children) were reported to be out-of-hospital deaths. [6]

## Tracking mortality rates of children younger than five in South Africa

*1. Fragmented health information systems*

One of the problems with granular tracking of the under-five mortality rate in a South African context is the fragmentation of various health information systems. There is also a lack of data on deaths outside of health facilities.[7] For example, the ministerial Committee on Morbidity and Mortality in Children Under 5 Years report had to draw from various sources to compile a national estimate of the under-five mortality rate.[4] This included the Rapid Mortality Surveillance (RMS), the Vital Registration System, the District Health Information System (DHIS), Census 2011, and the national Child Healthcare Problem Identification Programme (Child PIP) database.

Each of these databases serve divergent purposes. The Rapid Mortality Surveillance (RMS) database is collated from the National Population Register which is administered by the Department of Home Affairs (DHA) and is based on deaths registered at DHA. [1-4] The Vital Registration System are annually compiled by Statistics South Africa and provides provincial and district statistics of child births and deaths. The District Health Information System (DHIS) collects routine data taken by the National Department of Health from public health facilities and records deaths, and cause of death, for in-hospital cases.[1] Census 2011 compiled statistics on deaths in households based on surveys in various communities.[4] Lastly, the Child PIP database compiles the audits of in-facility deaths among children. The Perinatal Problem Identification Programme (PPIP), which is also a health facility based auditing system of neonatal deaths developed by the Medical Research Council, was not utilised by the Committee on Morbidity and Mortality in Children Under 5 Years.[6] Though an estimated 55% of deaths occurs outside of health facilities [4], details on cause of death and the modifiable factors of these deaths, are sparse compared to health facility-based dataset, including the DHIS and Child PIP databases.

*2. The Child Death Review*

In 2014, the Child Death Review (CDR) was piloted under the auspices of the Children's Institute and the Forensic Pathology Services (FPS) at both the Salt River Mortuary (Cape Town) and Phoenix Mortuary (Kwazulu-Natal).[7] The CDR has since been expanded to cover all health districts across the Western Cape, with five functional CDR teams in the Western Cape and two teams in Kwazulu-Natal. The CDR sets out to review unexpected natural deaths and unnatural deaths among children up to seventeen years of age and follows an inter-disciplinary approach to compile data on child and adolescent deaths to better understand and respond to the local context of the phenomenon. Disciplines include law enforcement and prosecution, social services, forensic pathology, and health services. CDR teams meet monthly to review cases of unexpected deaths of children younger than seventeen. Data collection forms are used to collate demographic variables, cause of death and medical history of cases.[7] In the Metro West geographical service area (GSA) in Cape Town such cases are reported to the Salt River Mortuary and reviewed by the CDR. The Metro West GSA consists of Klipfontein, Mitchells Plain, Southern and Western health sub-districts. Some of the patterns of reported deaths in various age groups includes infanticide among neonates, respiratory tract infection deaths among infants, neglect and abuse related deaths among children younger than five, road traffic deaths as children get older, and homicide and suicide among older children aged fifteen to seventeen. [7]

## Situational analysis of under-five mortality rate in the Metro West GSA, Cape Town

*1. A plateau in under-five mortality rate*

For 2018, the under-five population in the Metro West was 172 368.[8] The under-five mortality rate in the Metro West GSA decreased from 25 per 1000 live births in 2010 to 22 deaths per 1000 live births in 2013.[9] This rate is in line with the Sustainable Development Goals for 2030 and lower than the current national and Sub-Saharan under-five mortality rate. The recent decrease in under-five mortality rate is attributed to better immunisation coverage for children younger than a year; improved coverage of the pneumococcal, measles second dose and rotavirus immunisations; improved treatment of gastroenteritis; maternal antiretroviral coverage, HIV testing in babies and a reduction to perinatal transmission of HIV. [9,10] However, the under-five mortality rate has also effectively plateaued from 2010 to 2015 in the Metro West GSA in Cape Town. [7,12] This plateau in under five-mortality in the Metro West effectively mirrors a similar national plateau from 2011. [8]

*2. Prevalence of unexpected natural deaths at home or in the community in the Metro West GSA*

A high rate of out-of-hospital deaths of children contributes to this plateau.[7] In the period of 2010 to 2015, out-of-hospital deaths of children younger than five continued to hover at the 50% mark (49-52%) of all deaths.[11] It is estimated that 45% of out-of-hospital deaths are attributable to respiratory tract infections and 21% to gastroenteritis.[10] Furthermore, 83% of respiratory infection deaths in 2011 occurred outside of health facilities. In contrast, in-hospital deaths attributable to respiratory tract infections only amount to 0.6% in the Metro West in the same period.[10] This implies that gains could be made in decreasing the under-five mortality rate should effective interventions be successfully geared to reach at-risk households.

*3. Prevalence of unexpected natural infant deaths in the Metro West GSA*

A more recent five-year retrospective study (2013–2017) of infant deaths in the Metro West GSA (children younger than a year, excluding neonates) examined 1608 cases admitted to Salt River Mortuary with an emphasis on sudden unexpected deaths.[13] Of all recorded cases, 86% died due to natural causes. Most of the cases categorised as sudden and unexpected (SUDI cases) due to natural causes died before they turned 4 months old (73.56% of cases) with a peak age at death of one to two months of age.[13] Post-mortem results indicated that of these natural deaths, 52% died due to respiratory related infections, 11% of gastroenteritis and/or dehydration, and 11% of other unspecified natural causes.[13]

## Health service utilisation among children younger than five in South Africa

The situational analysis above suggests that health service utilisation, among other possible interventions, may be a modifiable factor to address under-five mortality. Health service utilisation is a complex social phenomenon that requires various research methods to adequately study within the local context.[14] The concepts of health service utilisation are also not always well understood and defined. This complicates their operationalisation in research.[15] The approach of Rutherford et al will be used in this study to narrow the scope of definition of health service utilisation around the concept of health care access and what influences access: “impaired access resulting from any intra or extra household influence that hinders health service”.[14] The World Health Organisation (WHO) defines access to health services as the opportunity and ability of patients to “obtain the health services they need”.[16] Defining and measuring influences within households and outside of households that promote or hinder access to health service is central to the proposed study.

According to WHO, access to health services has three dimensions (or categories), namely: physical accessibility, financial affordability, and acceptability.[16]

1. Physical accessibility contains variables that describe the availability of good quality health services within reasonable geographical reach for those that need it. This also includes system and service aspects of the health facilities such as operating hours, availability of the applicable services and appointment systems.
2. Financial affordability contains variables that describe the ability of those that need health services to afford it. This may include items such as out of pocket costs, but also more indirect factors such as travel costs and opportunity costs with time away from employment.
3. Acceptability contains variables that describe the willingness of people to seek health services. This may include variables such as the quality of care at facilities, health beliefs, the autonomy of caregivers to decide to seek health care and socio-cultural factors (such as language barriers). Due to the nature of the secondary routine data for this study, this dimension is unmeasured.

Additional dimensions or categories applicable to under-five mortality and health access is a description of health needs and health behaviour of cases. This originates from the concept of health care access from Anderson. [17,18] For Anderson, health care access is, *inter alia*, a result of realised health needs and health behaviour. In other words, the extent of health needs, together with existing health behaviour, in a specified area, drives how health services are accessed. This may include variables such as premature birth (or low birth weight), age of the child and HIV status. Health needs and behaviour are not the only dimensions described by Anderson, but due to its overlapping nature with the WHO criteria, only health needs and behaviour are included here. These four dimensions, coupled with available and imputed variables available from CDR and the Forensic Pathology Services (FPS), provide a suggested heuristic lens to describe health care access for the study.

## Methods of recent research of health service utilisation for under-five mortality in South Africa

Recent research into health service utilisation among children in South Africa leveraged the following methods to describe these intra and extra household influences that promote or hinder access to health services:

*1. Pathways of health care seeking for natural out-of-hospital deaths*

Price et al [6] notes a lack of studies that disaggregate under-five mortality by place of death in South Africa. In response, they launched a longitudinal study utilising verbal autopsies at two rural health and demographic surveillance sites (Agincourt and African Health Research Institute) and made the place of death (out-of-hospital or in-facility) the primary outcome.[6] Of the 3760 deaths tracked, 53% died at home and 41% in health facilities — including neonatal deaths.[6] In 92% of all cases (regardless of the place of death) it was reported that the caregivers sought care from formal health care providers. In 84% of cases where children died at home it was reported by the mother (or caregiver) that formal health services were sought prior to death. In another study in the same two sites for the year of 2017, Price found that in 42% of the cases children died outside a health facility.[19] A further breakdown of pathways of care showed 31% of the deaths were at home, 8% were on route to health services and 2% died elsewhere.

*2. The use of verbal autopsies for research into health seeking behaviour*

The WHO international standard verbal autopsy is a health surveillance instrument that uses structured interviews with the mother or caregiver especially in low and middle-income countries to study contributing factors for causes of death outside health facilities or without registration.[20] Increasingly verbal autopsies are used to understand factors relating to place of death and health seeking behaviour among children.[19-22] The CDR, together with the FPS form 006(b), utilises a similar instrument to gain understanding of the contextual factors around child deaths. "The CDR investigates each child death using a set of questions that include the medical factors together with the social contributors to each child's death, particularly in sudden unexpected and injury-related deaths. This process requires an understanding of the context or environment in which each death occurred, including factors at each level – individual (biological and psychological), family, social, cultural, health and social welfare system – that influence access to care and the care the child received". [7,12] In supplementary material for protocol, see appendix 1 for a blank copy of the CDR data collection form as well as appendix 2 for the interview form used by the FPS.

## Influences that inhibit under-five health care utilisation in Sub-Saharan Africa and South Africa

In the context of Sub-Saharan Africa, Rutherford et al [15] notes in a systematic review of under-five mortality that physical accessibility such as longer distance to health facilities and long travel time are associated with decreased health care utilisation. Travel may be complicated and unsafe afterhours which causes delays in seeking health care. This links to the time it takes to receive health care which plays a role in health service utilisation.[15] Financial affordability to visit health facilities (like the cost of travel) and the performance of health workers also impacted health seeking behaviour. [23,24] Here social networks and social capital play an important role. Social capital in the form of familial relationships and relationships with others in a community, as well as integration into social networks enables a person to seek care if they are unable to afford travel or care on their own. Female autonomy in making decisions about seeking.[15] Similarly, Sharkey et al in 2011 found in a qualitative study on what impacted health service utilisation among infant deaths in rural South Africa that important contextual factors were limited autonomy of mothers and caregivers in making decisions about the care of their infants, the health of the caregivers themselves, how the caregivers understood the disease according to a local explanatory model of disease (their health beliefs), as well as how well the mothers and caregivers understood what the child's symptoms signified about the severity of the illness.[23]

In the context of rural South Africa, Price et al [6] notes that demographic and socio-economic factors such as low maternal education and household sizes (above 15 people) were associated with out-of-hospital deaths. Child factors such as age category (such as late neonates) and the cause of death (such as HIV) were associated with out-of-hospital deaths.[6] In the context of the Metro West GSA in Cape Town, Hendricks et al [11] notes that the bulk of respiratory tract infection out-of-hospital deaths were preterm infants whose parents had limited social support. Reid et al [10] remarks that access to health services were problematic for this group, but also notes that in 2011, in 15% of out-of-hospital deaths, the caregiver and child visited a health facility within a week of the death. Mathews et al notes that substance abuse in households contributed to out-of-hospital deaths since it negatively impacts timeous decisions to seek health care. [7] Another influence is the possibility of health system failures to timeously refer and treat the cases where parents or caregivers sought health care.[7]

## Research Question

The primary research question is: What was the health service usage prior to death among children younger than five who died out-of-hospital due to natural causes in the Metro West GSA in Cape Town? The secondary research question is: What are the barriers, within household and outside of households, that hindered health service utilisation and access among children younger than five dying due to natural causes in the Metro West GSA in Cape Town?

## Aims of the Study

The aim of this study is to describe health service usage, describe factors influencing health service utilisation and access, and describe the relationship between these factors for out-of-hospital natural deaths in the Metro West GSA in Cape Town for the year 2018, using secondary data compiled by the CDR and FPS for that year.

## Study Objectives

The main objective of the research is to formulate a descriptive analysis of health service utilisation for reported natural deaths of children younger than five out of hospital using data compiled by the CDR and FPS in Metro West for the year 2018. Three objectives will be set out for the study to achieve this.

1. Among reported cases of under-five out-of-hospital natural deaths in 2018, describe:
    a. The causes of death.
    b. The sociodemographic profile of the children who died.
    c. The health service seeking behaviour prior to death.
2. Categorise and describe the dimensions of health care access of cases of under-five out of hospital natural deaths in 2018 according to WHO criteria, and health needs and behaviour according to Anderson.
3. Compare cases that sought health services prior to death and those that did not along the dimensions of health care access of cases of under-five out-of-hospital natural deaths in 2018 according to WHO criteria, and health needs and behaviour according to Anderson.

## Methodology

### Study Design

The study will utilise a retrospective cross-sectional design using secondary data as collated for the year of 2018 by the CDR and the FPS.

### Study Period

The respective study period is from 1 January 2018 to 31 December 2018. The rationale for the period of 2018 is that the cases of 2019 might still have missing data e.g., histology results and cause of death being under investigation.

# Study Setting

## Study Setting and Population

The study population is reported for cases of children, younger than five, residing in the Metro West GSA in Cape Town, who died of natural out-of-hospital causes as reported to Salt River Mortuary. The Metro West GSA consists of Klipfontein, Mitchells Plain, Southern and Western subdistricts in Cape Town. These subdistricts serve as the drainage area for reported cases to Salt River Mortuary. The Metro West GSA has an estimated population of 172 368 children younger than five years.[9]

## Inclusion Criteria

The inclusion and exclusion criteria of cases for the study are cases of out-of-hospital deaths among:

1. Children younger than five years of age.
2. Natural deaths due to respiratory tract infections, gastroenteritis and other natural pathologies will be included.
3. Cases occurring in 2018.
4. Cases residing within the Metro West GSA in Cape Town as reported at Salt River Mortuary.

## Exclusion Criteria

1. No cases where the cause of death was due to unnatural causes such as abuse, unintentional injuries (e.g., road traffic injuries, burns, falls, drowning, poisoning etc.), homicide, procedure related deaths or suicide will be included.
2. No cases where the death occurred in a health facility will be included (excluding dead-on-arrival cases).
3. No cases from outside the Metro West GSA will be included.

# Research Procedure

## Data Collection

The study will not generate primary data and there will be no contact with the children's families. The study will utilise routine data from the CDR data collection forms as well as form FPS006(B). See appendix 2 in supplementary material for protocol for a blank copy of form FPS006(B). This part of the form FPS006(B) contains a description of health seeking behaviour as well as health service providers consulted before death. For each case the applicable CDR data collection form indicates whether form FPS006(B) has also been completed. The secondary data will be requested from the Children's Institute and the FPS upon ethics approval for the study. Approval will be sought from the CDR principal investigators - Professor Shanaaz Mathews of the Children's Institute, and Professor Lorna Martin, Division Head, FPS, UCT. The CDR data is available in Excel format from the Children's Institute. FPS folders for the year 2018 must be drawn at the Salt River FPS.

## Data Management

CDR data are already captured into an Excel database. Missing data will be collected between CDR and FPS006(B) forms as well as cause of autopsy reports. Each case will be tagged with the existing research number on the CDR data collection form. This is done to de-identify the data and protect privacy. Addresses or geo-location of homes or the place of incident will be abstracted separated to protect the privacy of the cases and kept unlinked. New variables of interest that has been calculated from this data (such as distance from nearest public health facility and travel time) will be linked back to the main data frame.

## Data Analysis

The following variables will be abstracted or calculated from the CDR data collection form, form FPS006(B), Census 2011, City of Cape Town, Department of Health, Western Cape, and Google Application Programming Interface (API).

**Table 1: Demographic, spatial, socio-economic, temporal, and health variables**

| |
|---|
| **Demographic variables** |
| Age of mother (in years) |
| Number of children of mother |
| Number of individuals in household |
| Type of housing (formal, informal) |
| Biological sex of child (male, female) |
| Caregiver (mother, grandmother, other) |
| |
| **Spatial variables** |
| Suburb |
| Socio-economic index of suburb (City of Cape Town) |
| Place of death (home, dead on arrival health facility, elsewhere) |
| Travel distance to nearest health facility (Google API, kms) |
| Travel time to nearest health facility (Google API, minutes) |
| Operating hours of nearest health facility (workday, 24hrs with EC) |
| |
| **Socio-economic variables** |
| Employment of mother (employed, unemployed) |
| Educational status of mother (highest level) |
| Relational status of mother (married, single) |
| |
| **Temporal variables** |
| Gestational age of child (weeks) |
| Date of birth |
| Date of death |
| Age of child (in days) |
| Age category of case (< 3, 3-6, > 6) |
| Duration of illness according to caregiver (< 24 hrs, < 48 hrs, > 48 hrs, < 2 weeks, > 2 weeks) |
| |

| **Health variables** |
|---|
| Cause of death |
| Did caregiver note symptoms of illness prior to death (yes, no) |
| Were health services sought prior to death? (yes, no) |
| Reasons why health care was not sought prior to death (answers to be coded) |
| First providers for cases where health care was sought (clinic, hospital, other) |
| Antenatal care recorded (yes/no) |
| Vaccination status (birth, 6 weeks, 10 weeks, 14 weeks, 6 months, 18 months \| completed (yes, no)) |
| Birth weight (grams) |
| HIV status of child (positive, negative, unknown) |
| Nutritional status of infant (breast, breast/bottle, bottle, weight to age) |
| |

The data analysis will follow the study objectives and will be performed in R (version 4.1.2).

*Objective 1: Among cases of under-five out of hospital natural and unexpected deaths in 2018, describe:*

*a. Cause of death*

A summary of causes of natural deaths of out-of-hospital child deaths for 2018 will be provided from CDR data. The summary will consist of count data and percentages.

*b. The sociodemographic profile of the children who died*

Socio-demographic description of the cases will include all the variables from the demographic, spatial and socio-economic variables. Temporal variables included will be age of mother as well as age of the child at death. Where data takes on a non-normal distribution, measures of central tendency and spread will be reported as median and interquartile range. Categorical variables will be reported as frequencies and proportions.

*c. The healthcare seeking behaviour prior to death.*

A summary description of symptom recognition and health service usage prior to death will be done. Both the CDR data collection form and Part 2 Section C Question 6 of the FPS006(B) form (where available) describe health seeking behaviour of each case before death.

*Objective 2: Categorise and describe the dimensions of health care access of cases of under-five out of hospital natural and unexpected deaths in 2018 according to WHO criteria and health needs according to Anderson.*

Dimensions of health service access will be constructed using the available data in the CDR and FPS006(b) forms, according to the WHO criteria of the dimensions of health services access (physical accessibility and financial affordability) and health needs and behaviour according to Anderson. Variables that describe acceptability will not be included as the available datasets do not measure this directly or indirectly. Acceptability is an important dimension, and this is noted as a limitation of this proposal, and as a possibility for future research.

Objective 2 is a descriptive objective that will not attempt to make any causal conclusions. However, the causal assumptions concerning the dimensions of health service access and the various variables that directly or indirectly describe those dimensions, will serve as a heuristic lens to critically discuss health service utilisation among cases. Figure 1 presents a Directed Acyclic Graph (DAG) of the causal assumptions concerning health services access that will be made in this study. Variables that are measured in this study (in the smaller blocks with a solid outline) are grouped together according to dimensions of health service utilisation (in the larger blocks with outlines of dashes). The various dimensions are colour coded. Acceptability is unmeasured in this study. Existing health service use prior to death are noted through antenatal care and immunisation. Socio-economic status is presented as a common antecedent that impacts both the various dimensions of health service use (and concomitant variables) and health service utilisation.

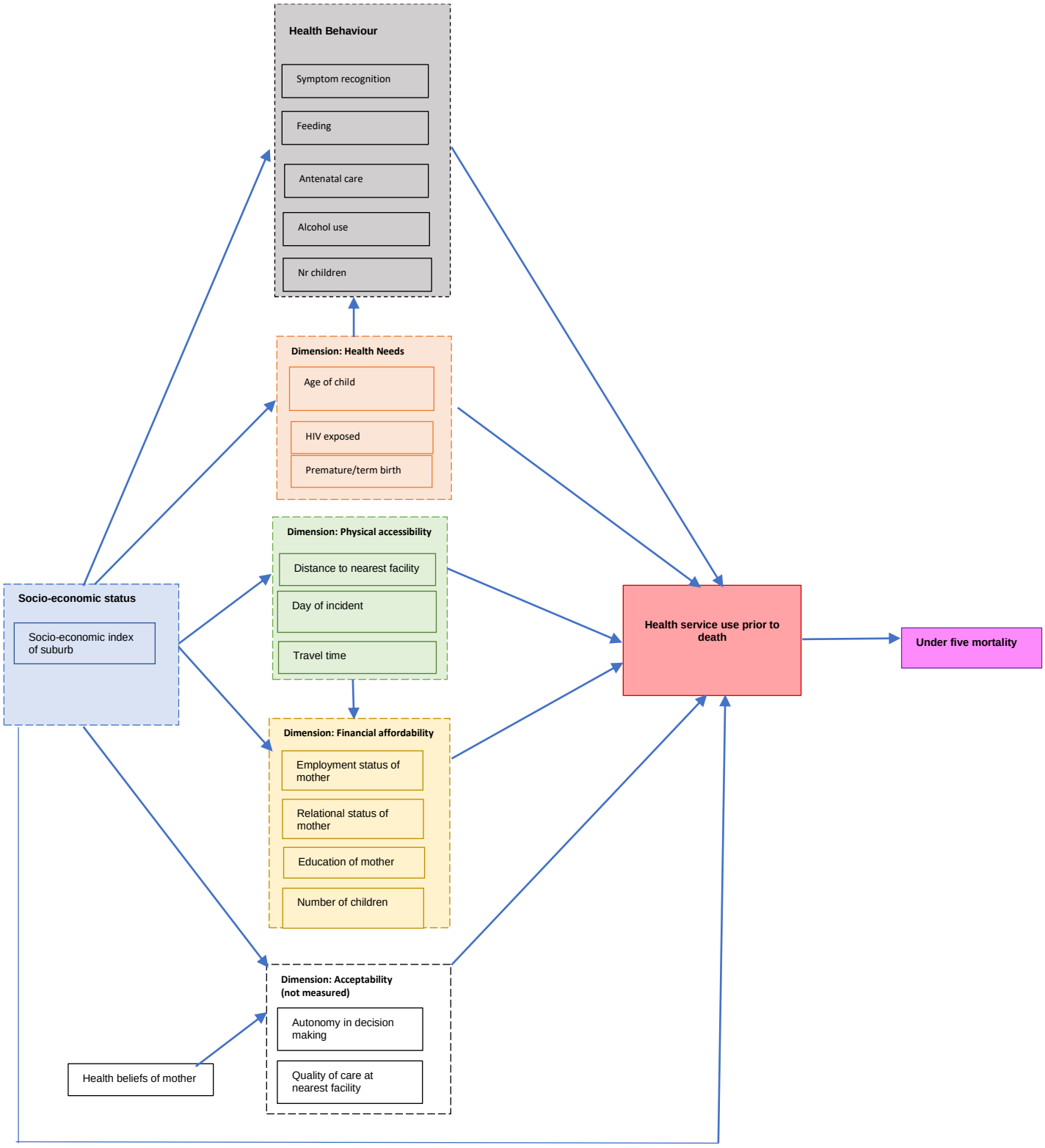


*Figure 1: DAG of causal assumptions made concerning dimensions of health services access*

In this objective, the dimensions will be constructed as the proposed DAG, the dimensions will be described, and differences will be explored by key characteristics. Since socio-economic status is an

antecedent for all the dimensions of health service access, it is expected that suburbs with a lower socio-economic index will have higher numbers of out-of-hospital deaths. These dimensions of heath service access (health needs, physical accessibility, and financial affordability) will be compared between suburbs with a lower socio-economic index and higher counts of out-of-hospital deaths. To do this, the socio-economic index from the City of Cape Town will be used as a measurement. This index is based on Census 2011[24] and gives a weighting of variables from Census 2011 that describes the socio-economic status of various suburbs. This can be used a measure to compare the relative socio-economic status between various suburbs. It also is expected that a higher proportion of cases will be infants compared to older age categories. Differences in dimensions of health service access will also be compared by case age. If the sample size allows statistical significance between groups may be tested using the Pearson $\chi^2$ test or Fisher exact test for categorical variables, and the Wilcoxon rank sum test for numerical variables.

*Objective 3: Compare cases that sought health services prior to death to those that did not in terms of the dimensions of health care access of cases of under-five out-of-hospital natural deaths in 2018 according to WHO criteria and health needs according to Anderson.*

It is expected that some cases sought health care prior to death in relation to the child's illness. It is also expected that this number of cases will be lower than those that did not seek health services prior to death. According to Reid et al only 15% of out-of-hospital natural deaths in 2011 in the Metro West GSA visited a health facility a week prior to death. [10] It is important to describe the characteristics of cases of those that sought health services prior to death and those that did not to understand the differences between these groups (if there are any differences) and describe any modifiable factors to prevent death among those that did use health services prior to death.

Multivariable logistic regression will be used to analyse the difference between those that sought health care prior to death and those that did not. Regression models will be built based on the variables in each dimension of health service access in Objective 2 above (health needs, health behaviour, physical accessibility, and financial affordability). The binary outcome is health service used prior to death (yes/no). Results will be presented as odds ratios with 95% confidence intervals and p-values.

### Data Safety and Monitoring

The data is captured on Excel sheets and will be anonymised according to CDR research number. The Excel sheets and data analysis in R will be stored on a flash drive kept in a secure access-controlled office in a locked cabinet. The flash drive will be encrypted, and password protected. Due to the sensitive nature of the research topic, the raw data will not be published. The data used for the analysis in R will be deleted two years after publication by the author.

## Potential Bias

Information bias in the form of social desirability bias is a possibility for this study. Social desirability bias is when participants are under social pressure when interviewed concerning a sensitive topic or social taboo and therefore change an answer to what is assumed to be more acceptable.[26] The death of a child falls

under this category and may create a situation where the participant is afraid of recriminations. Part of the CDR data collection form and form FPS006(b) are based on interviews with the caregiver of the deceased child. Since the data is secondary, no changes can be made on the existing data to decrease the risk of social desirability bias. Since cases are reviewed monthly by CDR, recall bias should not feature with the interviews.

Another source of potential bias is missing data. Missing data may decrease statistical power and introduce bias if the missing data is differential by key variables.[27] Random errors with the recording of data during interviews are also possible. A comparison between CDR data collection forms and FPS006(b) forms will be made where possible to minimise missing data. Multiple imputation will be used to account for missing data where appropriate. [28,29]

## Limitations

The limitation of the study includes unmeasured confounding, generalisability, and missing data. There is potential for unmeasured confounders beyond the scope of the study and the data gathered, since health service utilisation lies on the intersection of human behaviour, health needs, physical accessibility, financial affordability, and acceptability. Because of this, the study will not attempt to make causal inferences, but rather will attempt to describe dimensions and the associations between dimensions that influences or impede health service access.

There are also limitations to the generalisability of the study. Although all the reported cases of out-of-hospital deaths due to natural causes for the period of a year for the Metro West GSA are included, the study does not cover health seeking behaviour among cases that survived (or those not reported). Nor are variables that describe the dimension of acceptability available for this study. This may limit the external validity of the findings concerning health service utilisation. It may also be that the social and economic structures of the Metro West GSA differ from other regions in Cape Town and the larger South Africa. This limits generalisability beyond the study population. Missing data is also a potential limitation to the study, and contingency plans are discussed in the section on potential bias.

## Ethical Considerations

### Ethics approval and registration

Ethical clearance of this study will be sought from the Human Research Ethics Committee of the University of Cape Town. CDR data is part of the part of the autopsy database registered with Faculty of Health Sciences Ethics (REF NO: R036/2014). Approval from Department of Health, Western Cape will be sought on the National Health Research database. The protocol follows the principles and guidelines of the Declaration of Helsinki (2008) and the Department of Health's Ethics in Health Research (2004) principles, structures, and processes.

### Description of risks and benefits

There is minimal risk and benefits to the families of the deceased due to adherence to the privacy of the families. See the section on privacy below. The families will not be contacted, nor will their details be recorded or disseminated to other parties. This also means that there are no direct benefits to the families of the deceased as such.

Social risks include public perception and cultural mores around out-of-hospital deaths of children. More specifically, a social risk is that the study may reinforce a notion that bad parenting leads to these deaths and that those parents are deserving of denigration. The study mitigates this risk in several ways. Geographical areas will be analysed on a higher aggregate level such as the subdistricts. The social benefit of the study consists of how the study aims to provide the Metro West GSA health system with information that will enable better interventions, including educational programs, for at-risk groups and areas. This will benefit the future patients, communities, and households of at-risk children.

### Informed consent process

This study will make use of data that are routinely collected by the CDR in the event of a child death therefore no informed consent will be obtained for this study. The primary risks are loss of confidentiality. The families of cases will not be contacted, nor will their details be recorded or disseminated to other parties. The protocols to ensure privacy and confidentiality are described below.

## Privacy and confidentiality

Privacy and confidentiality are of importance in all research and particularly in this study due to the sensitive nature of the topic. The first type of data that may breach confidentiality are variables that contain personal identity data. The following steps will be taken to protect this data: The data will be anonymised by using the research numbers of the CDR data collection form. No names of the deceased, parent or caretaker will be recorded from the secondary data. No contact details will be acquired such as mobile number or email. Addresses at the time of death will be collected as this data will be used to describe spatial variables. Analysis of the data will occur on a higher aggregate level such as subdistricts. Addresses or geo-location of the place if incident will be abstracted separated to protect the privacy of the cases and kept unlinked. New variables of interest that has been calculated from this data (such as distance from nearest public health facility and travel time) will be linked back to the main data frame.

## Logistics, Time Schedule, and Action Plan

| Actions | Aug 2020 | Sept 2020 | Oct 2020 | Nov 2020 | Jul 2021 | Aug 2021 | Sep 2021 | Oct 2021 | Nov 2021 |
|---|---|---|---|---|---|---|---|---|---|
| Literature review | X | | | | | | | | |
| Research proposal | | X | X | X | | | | | |
| Data collection | | | | | X | X | | | |
| Data analysis | | | | | | X | | | |

| Actions | Aug 2020 | Sept 2020 | Oct 2020 | Nov 2020 | Jul 2021 | Aug 2021 | Sep 2021 | Oct 2021 | Nov 2021 |
|---|---|---|---|---|---|---|---|---|---|
| Report writing | | | | | | | X | X | |
| Dissemination | | | | | | | | | X |

## Budget/ Resources

The study is self-funded.

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SECTION B: MANUSCRIPT


## Abstract

### Background

Fifty-five percent of under-five deaths occur out of hospital in South Africa, with a similar percentage in the Metro West geographical service area within the City of Cape Town district. Describing factors that enable or prevent health service usage among natural under-five deaths is an important precursor for effective interventions.

### Objectives and Methods

A retrospective cross-sectional design utilised secondary, routinely collected data from 1 January to 31 December 2018 on under-five out-of-hospital natural deaths reported to Salt River Mortuary. We used the data, which included routine interviews with the caregivers, together with social and medical data collated by the Child Death Review, to describe the cause of death, the socio-demographic profile, and the routine and prior-to-death health service usage. Dimensions of health service access according to the WHO and Anderson, respectively, were used as a heuristic lens to describe the applicable variables and to formulate *a priori* multivariable logistic regression models to compare those who did and did not seek care before death.

### Results

Of the 187 cases described, 68% died of lower respiratory tract infections and 8% of diarrhoea. Fifty four percent of cases were younger than 3 months, and 40% were born prematurely. In terms of the residential health sub-district, 37% resided in Mitchells Plain, 29% in Klipfontein, 18% in Western and 14% in Southern; 52% resided in needy or very needy areas. Mothers were single (69%), unemployed (73%) and lived in informal housing (46%). Of the cases who were alive at the time, immunisation coverage was 79%, 70% and 68% at the 6-, 10- and 14-week visits. However, only 23% of mothers sought health care prior to the child's death. Overall, 51% of the mothers recognised symptoms of illness prior to death and symptoms were recognised in 95% of the mothers who sought health care compared to 37% of the mothers who did not seek health care (p-value < 0.001). Multivariable logistic regression models showed the importance in recognising symptoms in seeking health care (aOR 18.28, 95% CI 3.67-90.93), and that, while not statistically significant, the recognition of symptoms was less likely at younger ages (aOR 0.28, 95% CI 0.07-1.14 for cases younger than 3 months compared to those older than 6 months)

### Conclusion

The study identified key risk factors implicated in the out-of-hospital deaths in Metro West and the need for mothers to identify and seek health care when their child is symptomatic. There should be focused support during the first 1000 days for mothers identified as being at-risk, namely: those who are single, unemployed, lack social support and abuse substances, and for babies with prematurity and HIV-exposure. Counselling should emphasise the recognition of LRTI symptoms and health care seeking to prevent child deaths and reduce the under-five mortality. Further research is needed to consolidate which provincial geographical areas should be prioritized for targeted interventions that impact on health care seeking behaviour, as well as the most effective child health education and messaging.


## Introduction

Place of death is an important factor in under-five mortality [1] with an estimated 55% of natural deaths occurring outside health facilities (out-of-hospital deaths) in South Africa.[2] Likewise, in the Metro West geographic service area (GSA) of Cape Town, out-of-hospital deaths account for approximately 50% of

under-five deaths.[3] Though the under-five mortality rate decreased from 25 deaths per 1000 live births in 2010 to 22 deaths per 1000 live births in 2013, the rate of decline has effectively plateaued from 2010 to 2015 in Metro West. [3] Reid et al [4] found that in 2011, 45% of under-five out-of-hospital deaths in the Metro West GSA were due to lower respiratory tract infections (LRTI) and 21% to diarrhoea. Furthermore, 83% of LRTI deaths occurred outside of health facilities, and only 0.6% of in-facility deaths were due to LRTI in the same year. Of infant deaths reported to Salt River Mortuary from 2013 to 2017, 52% of natural deaths were found to be due to LRTI and 11% to diarrhoea.[5] Since in-facility death rates are much lower for LRTI and diarrhoea in this age bracket, health service utilisation remains an important modifiable factor in reducing the under-five mortality rate from these causes.

Health service utilisation is a complex social phenomenon that requires various research approaches to describe within a local context.[6] According to the WHO, health service access is shaped by the dimensions of physical accessibility, financial affordability, and acceptability.[7] Additionally, in the model of Anderson[8], health service usage is a realization of the dimension of health needs and existing health behaviour – the higher the health need and the better the personal health practices, the higher the potential for health service usage. These dimensions describe factors that enable, or conversely, decrease utilisation.[9] Interviews with caretakers in the form of verbal autopsies are often used in low to middle income countries to describe these dimensions.[10] In 2014, the Child Death Review (CDR) team was established at the Salt River Mortuary under the auspices of the Forensic Pathology Services (FPS) and Children's Institute (CI), University of Cape Town, to better understand "the medical factors together with the social contributors to each child's death, particularly in sudden unexpected and injury-related deaths" [11] and was since established at various sites within the province.

## Objectives

This study describes the cause of death, the socio-demographic profile of the children who died, as well as the caregiver health service seeking behaviour among the under-five children who died out-of-hospital from natural causes in Metro West in 2018, as reported to the Salt River Mortuary and collated by the CDR team. Applicable variables in the CDR and Forensic Pathology Services (FPS) dataset were categorized to describe health service usage along the dimensions described by the WHO [7] and Anderson.[8] Lastly, cases that sought health services prior to death in this group were compared to those that did not along the same dimensions.

## Methods

### Study design

A retrospective cross-sectional design was used with secondary, routinely collected data compiled from 1 January 2018 to 31 December 2018 by the CDR and the FPS, on under-five out-of-hospital natural deaths reported to Salt River Mortuary. Out-of-hospital deaths refer to deaths occurring outside health facilities and include reported dead-on-arrival cases reported to Salt River Mortuary for an autopsy to determine cause of death. These natural causes of deaths do not involve external causes such as poisoning, accidents, trauma, or abuse.

### Study site, population, and data sources

Metro West is one of the five geographical service areas in the Western Cape and consists of the Klipfontein, Mitchells Plain, Southern and Western health subdistricts in Cape Town.[4] Reported out-of-hospital deaths in Metro West are routinely reported to Salt River Mortuary for further investigation and serves as one of the sites from which CDR teams operate in the province.[11] The Metro West GSA had an

estimated population of 172 368 children younger than five years old in 2018.[12] Data collection forms based on verbal interviews with the caregivers were completed by Forensic Pathology Officers for the CDR to gather patient level data on all under-five deaths. These cases were reviewed, and the medical and socioeconomic data were collated by an inter-disciplinary team comprised of law enforcement and prosecution, social services, forensic pathology, and health services. This study reviewed the routine data from the CDR data collection forms as well as additional data from FPS (form FPS006(b)) of cases reported to Salt River Mortuary. Where available, the child's Road to Health Book (RTHB) was also reviewed. The RTHB serves as patient health record for children in South Africa and contains information on elements such as immunization, growth and nutrition, development, previous illness, birth history and hospitalisation.

## Data collection

Cause of death and the socio-demographic profile of cases was described including age, sex, race, maternal age, marital status, education, employment, type of housing and health subdistrict. Additionally, dimensions of health service utilisation were used as a heuristic lens to describe and explore related variables. Variables were grouped along dimensions of health service utilisation, namely: physical accessibility, which included day of incident, minimum distance to nearest 24-hour facility, and socio-economic indicator of the suburb; financial affordability, which included education, marital status, employment status, and number of children in the household; the health needs of the mother and child, which was based on whether the child was born at term or prematurely, the birthweight, and HIV exposure; and existing health behaviour, which included symptom recognition prior to death, type of infant feeding, antenatal care attendance, the use of alcohol and substances by the mother. Socio-economic indicator categories were assigned per suburb as estimated by the Development Information and GIS Department, City of Cape Town.[13] The index is a composite of the Census 2011 Household Services, Education, Housing and Economic indices per suburb, and formulated both as a numerical index and categorical variable (very needy, needy, average, good, very good). To assess physical accessibility, the minimum driving distances, and time to drive to 24-hour public health facilities as well as weekday facilities were estimated using Google Distance Matrix Application Programming Interface (API) and the de-identified geolocation of cases. Where street addresses were specified in small informal settlements but could not be identified on Google API, a centre point in the settlement was chosen.

Two outcome variables regarding health seeking behaviour are described, namely: how cases engaged in routine health care and how cases engaged health services directly before death. Attendance of antenatal care, utilizing a health facility for birth, and immunization visits were used to assess routine care. Where data were missing on immunization visits (after reviewing the CDR data, the FPS006(b) forms and RTHB), it was assumed that the relevant visit did not happen. Symptom recognition prior to death was recorded in the FPS006(b) form by asking the caregiver if child was ill before death and when symptoms appeared. Health service usage directly before death was similarly recorded in the FPS006(b) form by asking the caregiver if, when, and which type of health services were accessed before death if the child was recognized to be ill. Date of death and dates of health service usage, as well as additional free text information in the FPS006(b) forms and CDR forms were used to compile how cases engaged health services prior to death.

The dataset was anonymised and kept in a secure access-control office. Contact details of cases were not recorded, and addresses used for Google API matrix was performed in R with a separate de-identified dataset. No contact was made with cases since the study used secondary data. Ethics approval for the study was obtained from the Human Research Ethics Committee from the University of Cape Town (approval number HREC 806/2020) as well as Health Research Department of the Western Cape (approval number WC_202101_001).

### Statistical analysis

All analyses were conducted in R (version 4.1.2). All variables were described using frequencies and proportions for categorical variables, and medians and interquartile ranges (IQR) for numeric variables. Pearson's Chi-squared test and Fisher's exact test were used to test for significant differences between categorical variables and the Wilcoxon rank sum test for numerical variables. Z-scores for anthropometry were calculated in R according to the WHO Child Growth Standard and were corrected for gestational age. *A priori* multivariable logistic regression models were used to compare those that utilised health services prior to death and those that did not, using variables categorised by the dimensions of health service discussed above (accessibility, affordability, health needs and existing health behaviour). Both complete case analysis and multiple imputation was performed with the logistic regression models, using the mice package in R. [14] A thousand multiple imputations were performed on a dataset containing all variables used in the multivariable logistic regression models, and the output pooled from each model to create adjusted estimates. Due to a potential conflation of deaths occurring *en route* to health facilities or before, for the purpose of the multivariable models, cases where health care was sought in 24 hours and less prior to death were allocated as not sought (13 cases). In effect the models describe health service usage more than 24 hours prior to death. Where symptom recognition was used as independent or dependent variable, additional models were built where symptoms appearing in less than 24 hours was changed to having no symptoms to adjudge the effect thereof on health service utilisation. Multiple imputation was also performed on these models.

## Results

The original data set provided by the CDR consisted of 256 cases but 187 were included in this analysis. A total of 69 cases were excluded: 6 duplicates, 5 died in hospital, 9 still births, 5 non-viable foetuses, 19 suspected of being unnatural deaths, 7 post-operative deaths, 3 cases were terminal ill, and 15 cases were undetermined but not confirmed to be natural causes of death. Notably, missing data of more than 50% of values appeared in HIV exposure, growth charts and weight at immunization visits. Appendix 1 shows percentage of missing data for all variables considered for the multivariable models.

### Cause and location of natural out-of-hospital under-five deaths

Of 187 natural out-of-hospital under-five deaths reported in Metro West in 2018, the main causes of death were LRTI (68%), diarrhoea (8%), other causes such as sepsis (8%) and undetermined causes (6%) (Figure 1). Of the LRTI deaths, 13 were reported in July, and 16 each in August and September, respectively.

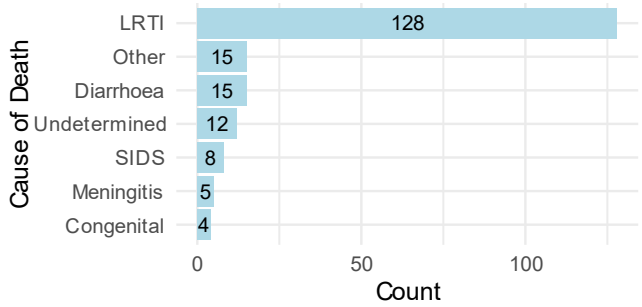


*Figure 1: Count of causes of death among natural out-of-hospital deaths in the Metro-West in 2018.*

Mitchells Plain health sub-district had 37% of the cases residing in the area, Klipfontein 29%, Southern 14%, Western 18% and 2% were unknown. Cases were highly clustered within the Mitchells Plain and Klipfontein subdistricts (Figure 2).

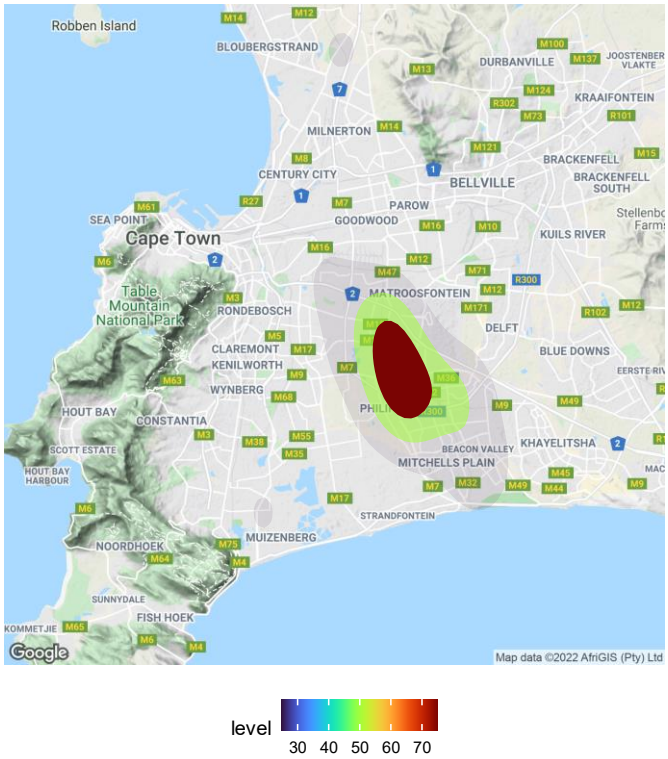


*Figure 2: Density map of natural out-of-hospital deaths in the Metro-West in 2018*

## Sociodemographic profile of the mothers and their children

The median age of cases at death was 77 days (IQR 41-150 days, Table 1). The median age at death among LRTI and diarrhoea cases were 67 days and 178 days, respectively, and 113 for all other causes of death (with a statistically significant difference between grouped causes of death). Fifty four percent (101/177 cases) died younger than 3 months. For LRTI this percentage increased to 62% (79/121 cases). There was a predominance of males (55%) and African children (68%) among the cases (Table 1). In terms of socio-economic status, 24% of cases lived in average areas, 30% in needy areas, and 22% in very needy areas. The median age of mothers was 27 years (IQR 24-32). Most mothers had qualifications up to late secondary school (74% or 94/127 completed later secondary school, namely: grade 10, 11 or 12), were unemployed (73% or 116/159) and were single (69% or 120/175). A high percentage of households lived in informal housing (45% or 45/98).

*Table 1: Socio-demographic characteristics of natural out-of-hospital deaths in the Metro-West, Cape Town in 2018*

| | | Cause of Death | | | |
|---|---|---|---|---|---|
| **Characteristic** | **Overall, N = 187** | **Diarrhoea, N = 15** | **LRTI, N = 128** | **Other Causes, N = 44** | **p-value** |
| **Age in days, Median (IQR)** | 77 (41 – 150) | 178 (103 – 296) | 67 (41 – 119) | 113 (51 – 335) | <0.001 |
| Unknown | 10 | 0 | 7 | 3 | |
| **Age category, n (%)** | | | | | 0.001 |
| 3 months | 101 (54) | 4 (27) | 79 (62) | 18 (41) | |
| 6 months | 42 (22) | 5 (33) | 29 (23) | 8 (18) | |
| Above 6 months | 34 (18) | 6 (40) | 13 (10) | 15 (34) | |

| | | | | | |
|---|---|---|---|---|---|
| Unknown | 10 | 0 | 7 | 3 | |
| **Sex, n (%)** | | | | | 0.059 |
| Female | 83 (45) | 4 (27) | 64 (50) | 15 (34) | |
| Male | 103 (55) | 11 (73) | 63 (50) | 29 (66) | |
| Unknown | 1 | 0 | 1 | 0 | |
| **Race, n (%)** | | | | | 0.38 |
| African | 124 (68) | 12 (80) | 86 (69) | 26 (60) | |
| Coloured | 59 (32) | 3 (20) | 39 (31) | 17 (40) | |
| Unknown | 4 | 0 | 3 | 1 | |
| **Socio-economic category, n (%)** | | | | | 0.87 |
| Very needy | 41 (22) | 3 (20) | 31 (25) | 7 (16) | |
| Needy | 56 (30) | 6 (40) | 34 (27) | 16 (36) | |
| Average | 44 (24) | 3 (20) | 30 (24) | 11 (25) | |
| Good | 36 (19) | 2 (13) | 25 (20) | 9 (20) | |
| Very Good | 8 (4.3) | 1 (6.7) | 6 (4.8) | 1 (2.3) | |
| Unknown | 2 | 0 | 2 | 0 | |
| **Age of mother, Median (IQR)** | 27.0 (24.0 – 32.0) | 31.0 (26.0 – 35.0) | 27.0 (23.0 – 32.0) | 28.0 (26.0 – 31.0) | 0.11 |
| Unknown | 20 | 2 | 11 | 7 | |
| **Education of mother, n (%)** | | | | | 0.18 |
| Early Secondary | 13 (10) | 1 (11) | 7 (7.7) | 5 (19) | |
| Late Secondary | 94 (74) | 7 (78) | 67 (74) | 20 (74) | |
| Primary | 14 (11) | 1 (11) | 13 (14) | 0 (0) | |
| Tertiary | 6 (4.7) | 0 (0) | 4 (4.4) | 2 (7.4) | |
| Unknown | 60 | 6 | 37 | 17 | |
| **Employment status of mother, n (%)** | | | | | 0.15 |
| Employed | 43 (27) | 6 (46) | 31 (27) | 6 (18) | |
| Unemployed | 116 (73) | 7 (54) | 82 (73) | 27 (82) | |
| Unknown | 28 | 2 | 15 | 11 | |
| **Marital status of mother, n (%)** | | | | | 0.67 |
| Married | 55 (31) | 6 (40) | 36 (30) | 13 (33) | |
| Single | 120 (69) | 9 (60) | 85 (70) | 26 (67) | |
| Unknown | 12 | 0 | 7 | 5 | |
| **Type of dwelling, n (%)** | | | | | >0.99 |
| Formal | 53 (54) | 2 (50) | 39 (54) | 12 (55) | |
| Informal | 45 (46) | 2 (50) | 33 (46) | 10 (45) | |
| Unknown | 89 | 11 | 56 | 22 | |

## Health service usage prior to death

Data on whether health services were sought and on symptom recognition were available for 183/187 cases.[1] Fifty one percent of mothers (93/183 cases, Appendix 2) indicated that they recognized some form of illness before death irrespective of using health services before death. Among the 23% (43/183 cases) that sought health care prior to death, 95% of cases recognized symptoms (Appendix 2, Figure 2). Among the 75% (140/183 cases) that did not seek services, 37% still recognized symptoms of the child being ill. There was a statistically significant difference in the recognition of symptoms in those who sought health care and those who did not (p-value < 0.001). Of those who used services, 30% and 24% recognized symptoms in ≤24 hours and ≤ 48 hours, respectively. Services were mostly sought ≤ 1 week and ≤ 24 hours by 30% and 20%, respectively.

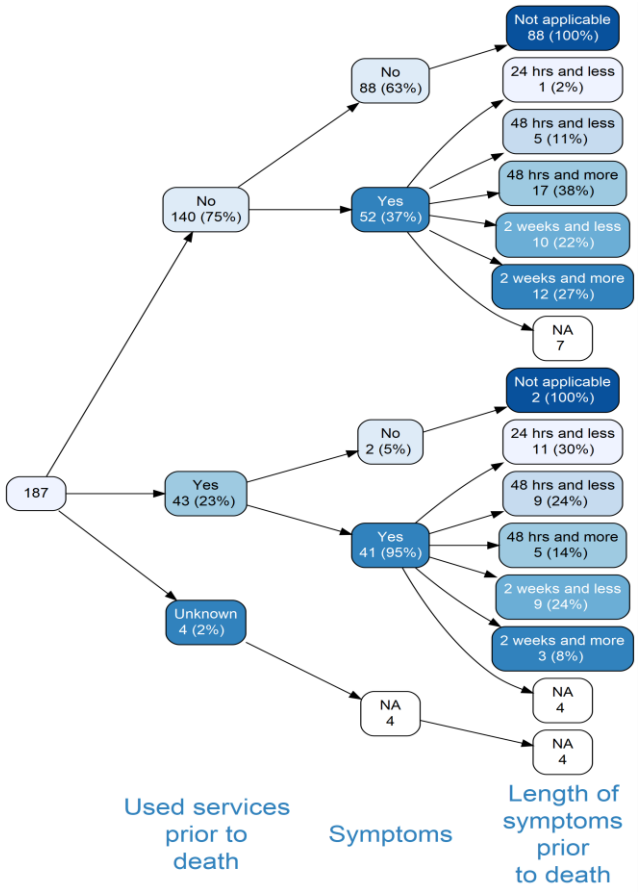


*Figure 2: Variable tree of health service use prior to death*

Health care was sought prior to death in 20% of cases (20/101) of mothers with infants younger than three months; 24% (10/41 cases) with infants aged three to six months; and 35% (12/34 cases) with children older than six months (with a non-significant p-value of 0.2). Mothers who recognized symptoms before death included 45% of cases (45/101) with infants younger than three months, 51% (21/41) with infants between three to six months and 71% (24/34) with children six months and older (with a significant p-value of 0.03). Among cases with LRTI as cause of death, symptoms were recognized in 46% of cases (58/125) but in only 23% of cases (24/101) were health services used.[2] Over half (55%; 67/121) of LRTI cases were younger than three months. Among diarrhoeal cases, 100% (15/15) of mothers recognized symptoms, but

[1] Results in the text are reported as a % of those with symptom recognition data (n=183).
[2] Denominators differ due to missing values in the different categories.

only 53% (8/15) sought health services. In this group, 47% of mothers recognised symptoms 48 hours and less before death; 40% (6/15) were older than 6 months at death. Twelve cases (7%) where time of seeking health care before death was known died after discharge from a hospital: three within 24 hours, two within 48 hours, three within three to four days, three within two weeks and one more than two weeks later. Of these cases nine died due to LRTI, one of SIDS and two had an undetermined cause of natural death. Eight of these cases were born prematurely and nine were less than three months at death.

## Routine health service usage

Overall, 54% of mothers attended at least one antenatal care session. In terms of immunisations, 87% of cases were immunized at birth. Of those who survived but succumbed later 79%, 70% and 68% were immunized at 6, 10 and 14 weeks, respectively (Figure 3).

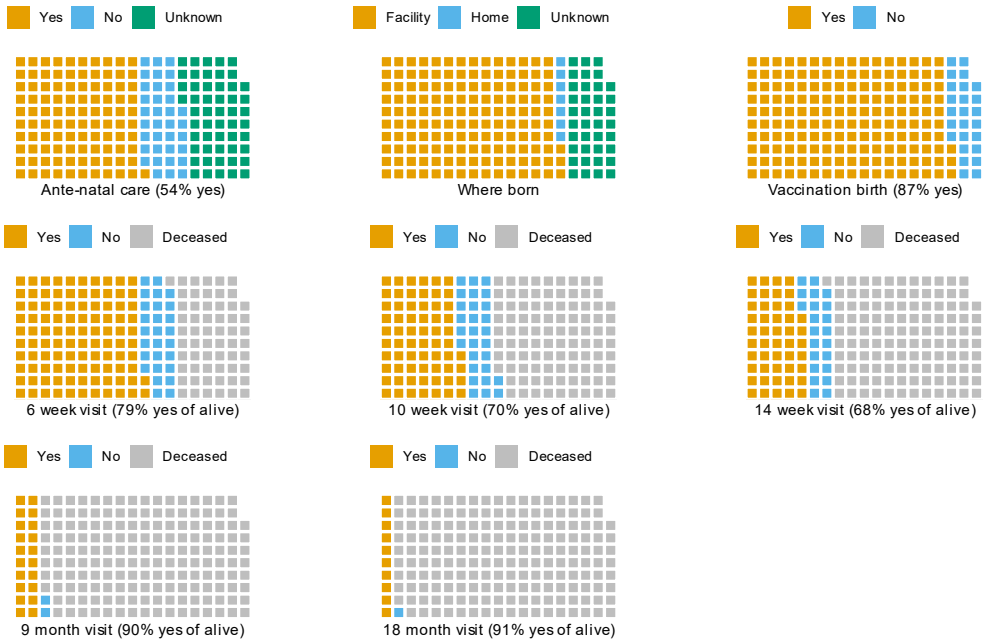


*Figure 3: Health service encounters for ante-natal care, birth, and immunization*

## Dimensions of health service usage

### *Accessibility and affordability*

Most deaths occurred on a Wednesday (19%) and a Thursday (18%) during the week. The median minimum driving distance to 24-hour health facilities was 3060 meters (m) (IQR 1868-4443m). Driving time, taking the shortest route according to Google API, was a median of 7.9 minutes to 24-hour health facilities (IQR 5.6–9.9 minutes). The median shortest driving distance to weekday facilities was 1207m (IQR 825–2074m). When comparing those that sought health services in this group to those that did not, the group that sought health services before death resided slightly closer to a 24-hour facility (median 2888m, IQR 2129–4356m) compared to those that did not (median 3060m, IQR 1788–4449m) but this was not a statistically significant difference (p-value 0.7).

*Health needs*

Of 176 cases with data for gestational age, only 106 (60%) were born full term. Most premature births occurred in Klipfontein (35%) and Mitchells Plain (32%) health sub-districts. The median gestational age among premature births was 31.5 weeks (IQR 29–35) and the median birth weight 1940 grams (g) (IQR 1220–2325g). Among the 70 cases that were premature births, 51 (73%) died due to LRTI, 6 cases were undetermined (9%), 5 from other causes (7%), 4 from diarrhoea (6%), 3 from SIDS (4%) and 1 from congenital causes (1%). Cases from birth prematurity also died younger on average (median 69 days, IQR 44–124 days) than those born full term (median 77 days, IQR 37–190) but this was not statistically significant (p-value 0.21). Less cases with birth prematurity used health services before death (17% or 12/70) compared to full-term cases (25% or 27/106), but the difference was not statistically significant (p-value 0.21). Recognition of symptoms was similar between those born prematurely and full term (48% and 52% respectively).

In terms of birth weight categories ≥ 2500g, 2000–2499g, 1500–1999g, 1000–1499g and 500–999g, there were 102 (59%), 29 (17%), 17 (10%), 17 (10%) and 7 (4%) cases, respectively. Cases with a birthweight above 2500g had the lowest proportion of deaths due to LRTI (59%). Conversely, all cases with a birth weight of 500–999g died due to LRTI. Fifty of 128 mothers (39%) indicated that they experienced medical difficulty during pregnancy. Twenty-five (19%) of mothers had hypertension; 35/111 (31%) of mothers were known to be living with HIV. For the births with the lowest birth weight these factors increased substantially. Among cases with a birth weight of 500 to 999g, 75% (3/7) were HIV exposed, and 67% (4/7) of the mothers had hypertension during pregnancy.

In the 156 RTHBs available, weight was charted for 3 cases at 4 weeks, 34 cases at 6 weeks, 25 cases at 10 weeks, 14 cases at 14 weeks and 2 cases at 6 months. After correction for gestational age, cases were removed with negative values for age at week 6, 10 and 14. Of 29 cases corrected for gestational age at week 6, the median weight-for-age (WFA) z-score was -0.21 (IQR -1.19–0.35), with 4 cases below 2 standard deviations (SD) (14%). Of the 23 cases corrected for gestational age at 10 weeks, the median WFA z-score was -0.19 (IQR -1.05–0.81), with 3 cases below 2 SD (13%). Of the 14 cases corrected for gestational age at 14 weeks, the median WFA z-score was 0.44 (IQR -0.96–1.71), with 2 cases below 2 SD (14%). Length was not sufficiently recorded in the RTHBs to estimate the weight-for-length z-scores.

Thirty-five cases were recorded to be HIV exposed, 17 cases were recorded to have a PCR test at 6 weeks with 3 positive results (9% of those recorded HIV exposed), and 11 cases received a PCR test at 10 weeks with 2 positive results. All the tests at 10 weeks were repeats of week 6 tests with no change in result.

*Health behaviour*

Data relating to infant feeding was available for 131 (70%) of the mothers. Of these, 46% (60 cases) exclusively breastfed, 27% (35 cases) exclusively formula fed and 28% (36 cases) mixed fed their babies. Twenty-nine percent (46/156) of mothers indicated they used substances at the time of their child's death, and of this group only 26% used services prior to death. Twenty one percent (28/132) mothers used alcohol during pregnancy and 29% (38/133) smoked during pregnancy. The proportion who sought health services before death decreased to 14% (4/28) among mothers who used alcohol during pregnancy compared to those that did not drink (23%; 24/104; p-value 0.21).

## Multivariable models for health service usage and symptom recognition

A model describing health service usage along the dimension of accessibility (Appendix 3, Table A), which contained day of incident, minimum driving distance to the nearest 24-hour public health facility and socio-economic indicator categories, showed that compared to the end of the week (Fridays), cases that died on Wednesdays were more likely to seek health care prior to death (aOR after multiple imputation 8.34, 95%

CI 1.34 to 51.91, p-value 0.02). Those in the very needy SEI category were less likely to seek health services than those in the average category (aOR after multiple imputation 0.56, 95% CI 0.15-2.15, p-value 0.40). The finding was not statistically significant. Proximity to nearest 24-hour public health facility made no difference to how health care was sought before death (aOR after multiple imputation 1.00, 95% CI 1.00-1.00, p-value 0.15).

A multivariable model describing affordability contained variables on education level, marital status, employment status and number of children (Appendix 3, Table B). Those cases where the mother had tertiary education were more likely to seek care than those with early secondary school education but only six mothers attained this level of education, and the estimate was not statistically significant (aOR after multiple imputation 6.17, 95% CI 0.38-99.74, p-value 0.20). A model describing health needs contained variables on whether cases were born premature or full term, birth weight categories, age categories and exposure to HIV at birth (Appendix 3, Table C). None of these variables had a statistically significant effect on health service usage in the group. Those aged less than 3 months were less likely to use services compared to infants 6 months or older (aOR after multiple imputation 0.5, 95% CI 0.11-2.24, p-value 0.36). A multivariable model describing existing health seeking behaviour contained variables on symptom recognition, breast and bottle feeding, attendance of ante-natal care and drinking and smoking categories (Appendix 3, Table D), illustrates the overwhelming importance of symptom recognition on health service use prior to death. Even though 37% of those that recognized symptoms did not seek health care prior to the death, those that recognised symptoms compared to those that did not were more likely to seek health care (aOR after multiple imputation in model where only symptoms longer than 24 hrs before death are considered, 18.28, 95% CI 3.67-90.93, p-value < 0.001)

A multivariable model for available factors that may be related to symptom recognition (Appendix 3, Table E) shows that among cases aged less than 3 months symptoms were less likely to be recognized than those age 6 months and older (aOR after multiple imputation in model where only symptoms longer than 24 hrs before death are considered, 0.28, 95% CI 0.07-1.14, p-value 0.08) adjusted for premature births, birth weight, number of children in the household, substance abuse, antenatal care attendance and education status. In the complete case analysis model, the aOR decreases to 0.08 and is statistically significant (95% CI 0.00-0.60, p-value 0.03). However, this effect was not statistically significant when multiple imputation was used or in a model that excluded symptoms recognised less than 24 hours prior to death.

## Discussion and recommendations

Among cases of out-of-hospital under-five deaths in the Metro West GSA in 2018, most of the deaths were in infants younger than 3 months of age and a greater proportion of premature infants compared to term infants died of LRTI. The proportion of LRTI cases (68%) was higher than previous studies in the same area [4,5], but the sample size of this study was smaller than prior studies. Fifty-two percent of the mothers and children lived in needy and very needy areas according to the City's socioeconomic indicators, and mothers were generally single and unemployed.

In terms of seeking routine care after birth, immunisation coverage among cases in this study was in line with the District Health Barometer estimates for the City of Cape Town.[15] Notably routine visits after birth becomes less important as most deaths occurred at a young age. This makes the timing of intervention before or at birth of greater importance for intervention strategies. Despite more than 79% using routine health care services at the six weeks immunisation visit, only 23% of mothers sought health care prior to death and only 51% recognized symptoms in their child (irrespective of seeking care). More cases with children older than 6 months sought heath care prior to death, and less infants younger than 3 months had recognition of their symptoms.

Proximity to the healthcare facility made no difference in seeking health care. Travel time to nearest facilities has been found to be a key component in maternal service usage in some sub-Saharan countries

[17] but among cases in the Metro West GSA in 2018, driving distance and time to the nearest 24-hour facilities appeared low and homogenous. This may be indicative of the social and spatial arrangement of cases with most cases occurring in Philippi and Mitchells Plain and residing close to 24-hour facilities. The number of available facilities, the capacity of those facilities, or the perceived acceptability of facilities were not measured. For those in very low socio-economic areas, even nearby facilities may not be easily accessed, particularly after hours, for impoverished households during a medical crisis. Safety concerns in high crime and violence areas may also be a barrier in accessing health services after hours.

The number of premature births and the intersection of premature births and other maternal health risks (e.g., hypertension during pregnancy) also stand out as a feature of health need in the group. This is in line with prior findings that 44% of LRTI deaths in CDR sites in Cape Town and Durban were among premature infants.[16] A lack of hospitalisation data of premature babies in the dataset may confound the health service usage among these cases since they may have died shortly after initial discharge. Interventions like a post-natal care package, including linkage to community health workers (CHWs), especially in the light of the impact of premature births on neonatal deaths has been advocated for in the South African context. [18]

Recognition of symptoms prior to death was the best predictor of health service use among cases in this study. Symptom recognition was best among cases who died after 6 months of age and decreased for deaths at younger ages. Typically, caregivers face a myriad of decision points when neonates and young infants exhibit signs of illness. And whilst recognition of signs is the first step, this may be difficult for caregivers of neonates due to decreased specific symptoms in this age bracket.[19] Other research shows that caretakers respond in four stages to signs of illness by gradually moving from inside to outside the household during illness, namely: symptom recognition, seeking advice in the family, engaging community-based treatment options, and then accessing formal medical services.[20] An attitude of waiting is often accepted by the caretakers if symptoms are not understood to be linked to severe illness. [20] This underlines the complexity around decision making in a household and that continued education and support is necessary to improve decision making with child illness. More attention to recognition and importance of symptoms by mothers and caregivers of LRTI in high-risk infants should be emphasized at birth and postnatal visits. This upskilling HCWs and CHWs on how to educate and support mothers of high-risk infants with regards symptom recognition. Bhutta et al [21] highlights research into contextual and cultural factors that impact health service seeking behaviour as well as the effectiveness of culture-appropriate health education and messaging as two of the top 10 research priorities in delivery categories to curb LRTI and diarrhoea child deaths. Colbourn et al [22] showed that the use of pulse oximeters aided in diagnosing hypoxia in 30% of episodes that were not identified by clinical symptoms in outpatient and community health settings in Malawi. Distributing pulse oximeters among CHWs and mothers of infants may aid in identifying serious LRTI cases among infants in high-risk areas.

Another area of concern is that according to the mothers interviewed, 7% of infants died shortly after discharge from a hospital. It may be that these cases depict poor outcomes of premature infants following discharge. It may also be that some mothers conflated a visit to a clinic with a hospital admission, but this should be compared in future studies with recorded health service encounters among natural out-of-hospital deaths. All this points to the need for more focused support for mothers who are identified as being at-risk (viz. single, unemployed, poor social support and substance abuse) with premature, low birth weight and HIV-exposed infants during the first 1000 days (FTD). Though FTD is an apex provincial priority [23] and broad in intersectoral scope and reach [24], our findings show that targeted support antenatally, during birth and postnatally focused on the recognition of symptoms of illness could reduce infant and under-five mortality in Metro West. An example would be linkage of high-risk mothers and infants in pregnancy and the first 1000 days to CHW's with special emphasis on symptom recognition of LRTI and other illness and access to health services. A higher CHW-to-population ratio in wards has been advocated for with a broadening of their scope of practice beyond support and advice to mothers at risk.[16] Additional measures may lie in focused support and messaging utilizing mHealth initiatives such as MomConnect.[24] Bhutta et al [26] estimated in a meta-analysis of the impact of various interventions on child death that community-

based interventions could lead to 13% increase (RR 1.13, 95% CI 1.08-1.18) in care-seeking for LRTI and a 9% increase (RR 1.09, 95% CI 1.06–1.11) for diarrhoea, with an overall reduction of 32% (RR 0.68, 95% CI 0.53–0.88) in LRTI mortality. In a Cochrane Review by Lassi et al [27] a potential 25% reduction in overall neonatal deaths from robust CHW intervention packages was estimated.

The findings of this study should be interpreted with the following limitations in mind. Social desirability bias is likely with interviews done shortly after the death of a child, and the high number of missing values hold potential to introduce bias into the study. The sample size was small and missing data further decreased the effective sample size of the data which had a negative impact on statistical power to detect small associations in the multivariable models. It is not clear if post-mortem diagnosis of LRTI cases were based on LODOX scans only, or also included macroscopic and microscopic pathology. This may create misclassification of LRTI as cause of death since the use of LODOX scans only potentially have decreased diagnostic prediction sensitivity for LRTI. [28] This makes no difference in the findings around health service usage. Given the importance of malnutrition and HIV status in under-five mortality, [29] missing data for WFA and HIV status of cases proved to be a barrier for describing this aspect among cases. To improve data completeness, accuracy, as well as accessibility to data, it is recommended that CDR data is integrated with existing electronic patient records within the Provincial Health Data Centre (PHDC). The PHDC consolidates person-level clinical data across government services in the Western Cape via patient registration systems and administrative and clinical digital health systems to be used for epidemiological purposes, clinical care, and public health planning.[30] This will provide a more thorough view of the longitudinal use of health services among cases as well as the applicable medical history for this highly vulnerable group. For routine data on malnutrition, solutions on improvements of capturing children's anthropometry as outlined in the RTHB at clinic visits especially in high-risk areas must be explored. Cases reviewed in this study are highly homogenous in terms of cause of death and age. Cases were concentrated within the Mitchells Plain-Klipfontein substructure and within the catchment area of Salt River Mortuary, which implies that they are likely to have shared the same social and environmental stressors that may be problematic for comparisons of health service usage dimensions within group. Acceptability of health services was unmeasured in the study and would best be described with qualitative study methods.

Further research, comparing a cohort of children that survived LRTI after being admitted in facilities, compared to LRTI out-of-hospital deaths should be prioritized for the Metro West GSA to derive a better understanding of risk factors that influence health service usage among LRTI cases. Similar studies for other areas of the City of Cape Town (as well as the Western Cape) where the CDR operates should be done to highlight priority wards for intervention and to arrive at a more granular understanding of this vulnerable group. Research into the current effectiveness of child health education and messaging, including training to HCWs, is needed. The effectiveness of such interventions ought to be piloted and evaluated in high incidence areas such as Mitchells Plain.

## Conclusion

Natural at home deaths in the Metro West GSA in 2018 as reported at Salt River mortuary were mostly due to LRTI, among children younger than 3 months at time of death and infants born prematurely in the Klipfontein-Mitchells Plain substructure. Targeted support for high-risk infants, particularly premature babies residing in high-risk areas with an emphasis on maternal LRTI symptom recognition and facilitation of health service usage is needed in further reducing under-five child mortality in the Metro West GSA. Further research is needed to consolidate which provincial geographical areas should be prioritized for targeted interventions and contextual and cultural factors that impact health service seeking behaviour, as well as the effectiveness of child health education and messaging. Ongoing assessment of the scope of CHW activity and implementation studies on local CHW interventions are needed.

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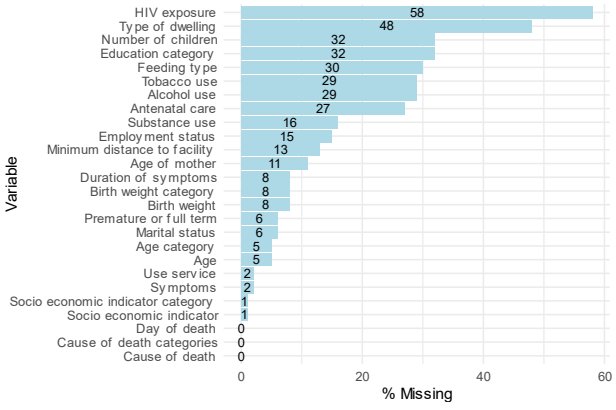
# Supplementary Material for Manuscript

## Appendix 1: Plot of Missing Data




*Plot of percentage missing data per variable used in multivariable logistic regression models*

## Appendix 2: *Health Service usage prior to death among natural out-of-hospital deaths in the Metro-West, Cape Town in 2018*

*Table 2: Health Service usage prior to death among natural out-of-hospital deaths in the Metro-West, Cape Town in 2018*

| | | Used Services | | |
|---|---|---|---|---|
| **Characteristic** | **Overall, N = 187** | **No, N = 140** | **Yes, N = 43** | **Unknown, N = 4** |
| **Symptoms before death, n (%)** | 93 (100) | 52 (56) | 41 (44) | 0 (0) |
| Unknown | 4 | 0 | 0 | 4 |
| **Age category, n (%)** | | | | |
| 3 months | 101 (100) | 81 (80) | 20 (20) | 0 (0) |
| 6 months | 42 (100) | 31 (74) | 10 (24) | 1 (2.4) |
| Above 6 months | 34 (100) | 22 (65) | 12 (35) | 0 (0) |
| Unknown | 10 (100) | 6 (60) | 1 (10) | 3 (30) |
| **Cause of death, n (%)** | | | | |
| Diarrhoea | 15 (100) | 7 (47) | 8 (53) | 0 (0) |
| LRTI | 128 (100) | 101 (79) | 24 (19) | 3 (2.3) |
| Other | 44 (100) | 32 (73) | 11 (25) | 1 (2.3) |
| Unknown | 0 | 0 | 0 | 0 |

| | | Recognised Symptoms | | |
|---|---|---|---|---|
| **Characteristic** | **Overall, N = 187** | **No, N = 90** | **Yes, N = 93** | **Unknown, N = 4** |
| **Used Services, n (%)** | | | | |
| No | 140 (100) | 88 (63) | 52 (37) | 0 (0) |
| Yes | 43 (100) | 2 (4.7) | 41 (95) | 0 (0) |
| Unknown | 4 (100) | 0 (0) | 0 (0) | 4 (100) |
| **Age category, n (%)** | | | | |
| 3 months | 101 (100) | 56 (55) | 45 (45) | 0 (0) |
| 6 months | 42 (100) | 20 (48) | 21 (50) | 1 (2.4) |
| Above 6 months | 34 (100) | 10 (29) | 24 (71) | 0 (0) |
| Unknown | 10 (100) | 4 (40) | 3 (30) | 3 (30) |

| **Cause of death, n (%)** | | | | |
|---|---|---|---|---|
| Diarrhoea | 15 (100) | 0 (0) | 15 (100) | 0 (0) |
| LRTI | 128 (100) | 67 (52) | 58 (45) | 3 (2.3) |
| Other | 44 (100) | 23 (52) | 20 (45) | 1 (2.3) |
| Unknown | 0 | 0 | 0 | 0 |

## Appendix 3: Regression Tables

*Table A: Univariable, multivariable models, pooled multivariable models from multiple imputation focused on accessibility*

| | | Univariable: Complete Case Analysis | | | | Multivariable: Complete Case Analysis | | | | Multivariable: Multiple Imputation | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Accessibility*** | Term | Estimate OR | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high |
| Outcome: Used services | **Day of incident** | | | | | | | | | | | | |
| | Friday | Ref | | | | Ref | | | | Ref | | | |
| | Monday | 0.50 | 0.58 | 0.02 | 5.52 | 1.05 | 0.97 | 0.04 | 27.90 | 0.54 | 0.62 | 0.04 | 6.49 |
| | Saturday | 3.37 | 0.15 | 0.74 | 24.03 | 10.03 | 0.04 | 1.50 | 200.96 | 3.97 | 0.12 | 0.70 | 22.51 |
| | Sunday | 5.28 | 0.05 | 1.21 | 37.02 | 13.57 | 0.02 | 2.14 | 267.44 | 5.33 | 0.05 | 1.00 | 28.47 |
| | Thursday | 0.71 | 0.79 | 0.03 | 7.94 | 1.19 | 0.91 | 0.04 | 32.37 | 0.62 | 0.71 | 0.05 | 7.79 |
| | Tuesday | 3.00 | 0.23 | 0.53 | 23.31 | 5.21 | 0.18 | 0.58 | 113.26 | 3.12 | 0.23 | 0.48 | 20.27 |
| | Wednesday | 7.36 | 0.03 | 1.45 | 55.88 | 16.52 | 0.02 | 1.97 | 360.08 | 8.34 | 0.02 | 1.34 | 51.91 |
| | **Min driving distance** | | | | | | | | | | | | |
| | Minimum distance | 1.00 | 0.23 | 1.00 | 1.00 | 1.00 | 0.08 | 1.00 | 1.00 | 1.00 | 0.15 | 1.00 | 1.00 |
| | **SEI categories** | | | | | | | | | | | | |
| | Average | Ref | | | | Ref | | | | Ref | | | |
| | Very needy | 1.09 | 0.88 | 0.34 | 3.51 | 0.26 | 0.09 | 0.05 | 1.16 | 0.56 | 0.40 | 0.15 | 2.15 |
| | Needy | 0.89 | 0.84 | 0.29 | 2.77 | 0.94 | 0.93 | 0.26 | 3.44 | 0.91 | 0.87 | 0.27 | 3.00 |
| | Good | 1.03 | 0.96 | 0.30 | 3.42 | 0.45 | 0.26 | 0.11 | 1.76 | 0.75 | 0.66 | 0.21 | 2.73 |
| | Very Good | 1.71 | 0.56 | 0.22 | 9.44 | 1.39 | 0.76 | 0.14 | 11.32 | 1.74 | 0.59 | 0.23 | 13.50 |

*Table B: Univariable, multivariable models, pooled multivariable models from multiple imputation focused on affordability*

| | | Univariable: Complete Case Analysis | | | | Multivariable: Complete Case Analysis | | | | Multivariable: Multiple Imputation | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Affordability*** | Term | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high |
| Outcome: Used services | **Education categories** | | | | | | | | | | | | |
| | Early Secondary | Ref | | | | Ref | | | | Ref | | | |
| | Primary | -0.08 | 0.96 | -3.38 | 3.22 | 1.31 | 0.87 | 0.04 | 43.81 | 1.19 | 0.91 | 0.06 | 24.01 |
| | Late Secondary | 0.56 | 0.60 | -1.20 | 3.51 | 1.18 | 0.89 | 0.15 | 26.39 | 1.73 | 0.62 | 0.19 | 15.56 |
| | Tertiary | 1.79 | 0.19 | -0.78 | 5.02 | 3.26 | 0.48 | 0.09 | 126.35 | 6.17 | 0.20 | 0.38 | 99.74 |
| | **Marital status** | | | | | | | | | | | | |
| | Married | Ref | | | | Ref | | | | Ref | | | |
| | Single | 1.26 | 0.61 | 0.54 | 3.22 | 1.99 | 0.44 | 0.40 | 15.28 | 1.22 | 0.76 | 0.33 | 4.53 |
| | **Employment status** | | | | | | | | | | | | |
| | Employed | Ref | | | | Ref | | | | Ref | | | |
| | Unemployed | 1.08 | 0.87 | 0.44 | 2.96 | 2.14 | 0.39 | 0.43 | 16.30 | 1.04 | 0.95 | 0.31 | 3.49 |
| | **Children in household** | | | | | | | | | | | | |
| | Nr children | 0.87 | 0.49 | 0.56 | 1.28 | 0.68 | 0.25 | 0.31 | 1.21 | 0.78 | 0.41 | 0.43 | 1.42 |

*Table C: Univariable, multivariable models, pooled multivariable models from multiple imputation focused on health needs*

| | | Univariable: Complete Case Analysis | | | | Multivariable: Complete Case Analysis | | | | Multivariable: Multiple Imputation | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Health Needs*** | Term | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high |
| Outcome: Used services | **Term** | | | | | | | | | | | | |
| | Full term | Ref | | | | Ref | | | | Ref | | | |
| | Premature | 0.73 | 0.48 | 0.30 | 1.70 | 0.90 | 0.91 | 0.13 | 5.40 | 0.96 | 0.97 | 0.17 | 5.56 |
| | **Birth weight categories** | | | | | | | | | | | | |
| | 1000-1499g | Ref | | | | Ref | | | | | | | |
| | 500-999g | 1.5 | 0.76 | 0.06 | 19.30 | 3.96 | 0.41 | 0.11 | 150.35 | 2.29 | 0.62 | 0.08 | 62.86 |
| | 1500-1999g | 1.61 | 0.63 | 0.23 | 13.60 | 2.19 | 0.62 | 0.07 | 70.81 | 2.32 | 0.60 | 0.10 | 54.72 |
| | 2000-2499g | 0.87 | 0.88 | 0.13 | 7.10 | 1.85 | 0.65 | 0.15 | 45.92 | 2.03 | 0.59 | 0.14 | 28.51 |
| | 2500g + | 1.33 | 0.50 | 0.43 | 11.50 | 1.44 | 0.80 | 0.10 | 39.04 | 1.55 | 0.75 | 0.10 | 23.79 |
| | **Age categories** | | | | | | | | | | | | |
| | 6+ | Ref | | | | Ref | | | | | | | |
| | < 3 months | 0.62 | 0.35 | 0.23 | 1.78 | 0.45 | 0.30 | 0.10 | 2.14 | 0.50 | 0.36 | 0.11 | 2.24 |
| | 3 to 6 months | 1.08 | 0.89 | 0.36 | 3.40 | 0.67 | 0.68 | 0.09 | 4.50 | 0.78 | 0.80 | 0.11 | 5.36 |
| | **HIV exposed** | | | | | | | | | | | | |
| | No | Ref | | | | Ref | | | | | | | |
| | Yes | 0.65 | 0.48 | 0.18 | 2.11 | 0.60 | 0.41 | 0.16 | 2.01 | 0.61 | 0.44 | 0.17 | 2.18 |

*Table D: Univariable, multivariable models, pooled multivariable models from multiple imputation focused on health behaviour, as well as model describing symptoms recognised > 24 hrs prior to death from multiple imputation*

| | | Univariable: Complete Case Analysis | | | | Multivariable: Complete Case Analysis | | | | Multivariable: Multiple Imputation | | | | Multivariable: Symptoms > 24hrs | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Health Behaviour*** | Term | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high |
| Outcome: Used services | **Recognised symptoms** | | | | | | | | | | | | | | | | |
| | No | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| | Yes | 18.95 | 0.00 | 5.43 | 120.03 | 29.87 | 0.00 | 5.68 | 552.34 | 23.13 | 0.00 | 2.82 | 190.01 | 18.28 | 0.00 | 3.67 | 90.93 |
| | **Feeding** | | | | | | | | | | | | | | | | |
| | Bottle fed | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| | Breast fed | 0.64 | 0.46 | 0.19 | 2.15 | 0.92 | 0.91 | 0.23 | 3.79 | 0.95 | 0.95 | 0.21 | 4.24 | 0.94 | 0.94 | 0.20 | 4.37 |
| | Mixed | 0.97 | 0.96 | 0.27 | 3.42 | 1.34 | 0.68 | 0.33 | 5.55 | 1.29 | 0.73 | 0.29 | 5.74 | 1.13 | 0.87 | 0.25 | 5.05 |
| | **Antenatal care** | | | | | | | | | | | | | | | | |
| | No | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| | Yes | 0.97 | 0.95 | 0.34 | 3.19 | 0.57 | 0.37 | 0.16 | 1.99 | 0.85 | 0.81 | 0.23 | 3.15 | 1.02 | 0.98 | 0.26 | 3.95 |
| | **Drinking** | | | | | | | | | | | | | | | | |
| | No | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| | Yes | 0.71 | 0.61 | 0.16 | 2.37 | 0.35 | 0.24 | 0.05 | 1.72 | 1.04 | 0.96 | 0.22 | 4.98 | 1.05 | 0.95 | 0.20 | 5.38 |
| | **Children in household** | | | | | | | | | | | | | | | | |
| | Nr children | 0.87 | 0.49 | 0.56 | 1.28 | 0.68 | 0.25 | 0.31 | 1.21 | | | | | 0.93 | 0.79 | 0.52 | 1.65 |

*Table E: Univariable, multivariable models, pooled multivariable models from multiple imputation with symptoms recognition as outcome, as well as model describing symptoms recognised > 24 hrs prior to death from multiple imputation*

| | Univariable: Complete Case Analysis | | | | Multivariable: Complete Case Analysis | | | | Multivariable: Multiple Imputation | | | | Multivariable: Symptoms > 24 hrs | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high | Estimate | P.value | Conf.low | Conf.high |
| **Age categories** | | | | | | | | | | | | | | | | |
| 6+ | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| < 3 months | 0.62 | 0.35 | 0.23 | 1.78 | 0.08 | 0.03 | 0.00 | 0.60 | 0.26 | 0.07 | 0.06 | 1.11 | 0.28 | 0.08 | 0.07 | 1.14 |
| 3 to 6 months | 1.08 | 0.89 | 0.36 | 3.40 | 0.09 | 0.06 | 0.00 | 0.82 | 0.36 | 0.21 | 0.07 | 1.80 | 0.28 | 0.12 | 0.06 | 1.42 |
| Term | | | | | | | | | | | | | | | | |
| Full term | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| Premature | 0.73 | 0.48 | 0.30 | 1.70 | 0.82 | 0.80 | 0.15 | 3.96 | 0.76 | 0.67 | 0.22 | 2.65 | 0.56 | 0.42 | 0.14 | 2.32 |
| **Birth weight categories** | | | | | | | | | | | | | | | | |
| 1000-1499g | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| 500-999g | 1.50 | 0.76 | 0.06 | 19.35 | 0.50 | 0.71 | 0.01 | 24.51 | 3.55 | 0.39 | 0.19 | 65.41 | 6.97 | 0.22 | 0.30 | 164.12 |
| 1500-1999g | 1.61 | 0.63 | 0.23 | 13.61 | 0.79 | 0.86 | 0.05 | 12.51 | 0.80 | 0.84 | 0.08 | 7.48 | 0.75 | 0.86 | 0.03 | 17.93 |
| 2000-2499g | 0.87 | 0.88 | 0.13 | 7.13 | 0.83 | 0.89 | 0.06 | 11.74 | 1.56 | 0.66 | 0.20 | 11.97 | 2.81 | 0.43 | 0.21 | 37.49 |
| 2500g + | 1.72 | 0.50 | 0.43 | 11.47 | 0.30 | 0.38 | 0.02 | 4.55 | 0.57 | 0.59 | 0.07 | 4.51 | 1.47 | 0.78 | 0.10 | 21.12 |
| **Children in household** | | | | | | | | | | | | | Ref | | | |
| Nr children | 0.87 | 0.49 | 0.56 | 1.28 | 0.74 | 0.23 | 0.44 | 1.17 | 0.84 | 0.43 | 0.54 | 1.30 | 0.74 | 0.27 | 0.42 | 1.28 |
| **Substance use mother** | | | | | | | | | | | | | | | | |
| No | Ref | | | | Ref | | | | | | | | Ref | | | |
| Yes | 0.82 | 0.70 | 0.28 | 2.14 | 0.43 | 0.22 | 0.10 | 1.58 | 0.46 | 0.15 | 0.16 | 1.33 | 1.54 | 0.44 | 0.51 | 4.69 |
| **Antenatal Care** | | | | | | | | | | | | | | | | |
| No | Ref | | | | Ref | | | | | | | | Ref | | | |
| Yes | 0.97 | 0.95 | 0.34 | 3.19 | 0.70 | 0.61 | 0.17 | 2.80 | 0.66 | 0.46 | 0.22 | 1.98 | 0.92 | 0.88 | 0.28 | 3.05 |
| **Education categories** | | | | | | | | | | | | | | | | |
| Early Secondary | Ref | | | | Ref | | | | Ref | | | | Ref | | | |
| Primary | 0.92 | 0.96 | 0.03 | 25.12 | 1.12 | 0.92 | 0.12 | 11.04 | 0.83 | 0.85 | 0.12 | 5.94 | 0.67 | 0.71 | 0.08 | 5.73 |
| Late Secondary | 1.76 | 0.60 | 0.30 | 33.42 | 0.41 | 0.33 | 0.06 | 2.57 | 0.63 | 0.52 | 0.15 | 2.58 | 0.64 | 0.53 | 0.15 | 2.67 |
| Tertiary | 6.00 | 0.19 | 0.46 | 151.95 | 0.81 | 0.89 | 0.04 | 26.62 | 0.81 | 0.87 | 0.07 | 9.69 | 1.63 | 0.70 | 0.13 | 20.10 |

# Appendix 3: SAMJ Journal Submission Guidelines

**Research**

*Guideline word limit: 4 000 words*

Research articles describe the background, methods, results and conclusions of an original research study. The article should contain the following sections: introduction, methods, results, discussion and conclusion, and should include a structured abstract (see below). The introduction should be concise – no more than three paragraphs – on the background to the research question, and must include references to other relevant published studies that clearly lay out the rationale for conducting the study. Some common reasons for conducting a study are: to fill a gap in the literature, a logical extension of previous work, or to answer an important clinical question. If other papers related to the same study have been published previously, please make sure to refer to them specifically. Describe the study methods in as much detail as possible so that others would be able to replicate the study should they need to. Results should describe the study sample as well as the findings from the study itself, but all interpretation of findings must be kept in the discussion section, which should consider primary outcomes first before any secondary or tertiary findings or post-hoc analyses. The conclusion should briefly summarise the main message of the paper and provide recommendations for further study.

Select figures and tables for your paper carefully and sparingly. Use only those figures that provided added value to the paper, over and above what is written in the text.

Do not replicate data in tables and in text .

*Structured abstract*

- This should be 250-400 words, with the following recommended headings:
  - **Background:** why the study is being done and how it relates to other published work.
  - **Objectives:** what the study intends to find out
  - **Methods:** must include study design, number of participants, description of the intervention, primary and secondary outcomes, any specific analyses that were done on the data.
  - **Results:** first sentence must be brief population and sample description; outline the results according to the methods described. Primary outcomes must be described first, even if they are not the most significant findings of the study.
  - **Conclusion:** must be supported by the data, include recommendations for further study/actions.
- Please ensure that the structured abstract is complete, accurate and clear and has been approved by all authors.
- Do not include any references in the abstracts.

*Main article*

All articles are to include the following main sections: Introduction/Background, Methods, Results, Discussion, Conclusions.

The following are additional heading or section options that may appear within these:

- Objectives (within Introduction/Background): a clear statement of the main aim of the study and the major hypothesis tested or research question posed
- Design (within Methods): including factors such as prospective, randomisation, blinding, placebo control, case control, crossover, criterion standards for diagnostic tests, etc.
- Setting (within Methods): level of care, e.g. primary, secondary, number of participating centres.
- Participants (instead of patients or subjects; within Methods): numbers entering and completing the study, sex, age and any other biological, behavioural, social or cultural factors (e.g. smoking status, socioeconomic group, educational attainment, co-existing disease indicators, etc)that may have an impact on the study results. Clearly define how participants were enrolled, and describe selection and exclusion criteria.
- Interventions (within Methods): what, how, when and for how long. Typically for randomised controlled trials, crossover trials, and before and after studies.
- Main outcome measures (within Methods): those as planned in the protocol, and those ultimately measured. Explain differences, if any.

*Results*

- Start with description of the population and sample. Include key characteristics of comparison groups.
- Main results with (for quantitative studies) 95% confidence intervals and, where appropriate, the exact level of statistical significance and the number need to treat/harm. Whenever possible, state absolute rather than relative risks.
- Do not replicate data in tables and in text.
- If presenting mean and standard deviations, specify this clearly. Our house style is to present this as follows:
- E.g.: The mean (SD) birth weight was 2 500 (1 210) g. Do not use the ± symbol for mean (SD).
- Leave interpretation to the Discussion section. The Results section should just report the findings as per the Methods section.

*Discussion*

Please ensure that the discussion is concise and follows this overall structure – sub-headings are not needed:

- Statement of principal findings
- Strengths and weaknesses of the study
- Contribution to the body of knowledge
- Strengths and weaknesses in relation to other studies
- The meaning of the study – e.g. what this study means to clinicians and policymakers
- Unanswered questions and recommendations for future research

*Conclusions*

This may be the only section readers look at, therefore write it carefully. Include primary conclusions and their implications, suggesting areas for further research if appropriate. Do not go beyond the data in the article.

# Supplementary Material for Protocol

## Appendix 1: CDR Data Collection Form


| | | | | | |
|---|---|---|---|---|---|
| **Review date** | | **Research study number** | | **Mortuary name** | **SALT RIVER** |
| **PM number** | / 2 0 2 0 | **Autopsy date** | | **Pathologist** | |
| **Police station**<br>**CAS number** | ..... / ..... / 2020 | **Hospital case**<br>**Hospital name**<br>**Folder number** | ..... | | |
| **I/O details** | **Name:** ..... \| **Force number:** ..... \| **Telephone number:** ..... | | | | |

| **SECTION 1: LAB 27/SCENE SCRIPT - CHILD INFORMATION/DEMOGRAPHICS** | | | | | |
|---|---|---|---|---|---|
| **1.1 Race** | | **1.2 Gender** | | **1.3 Estimated age** | ..... |
| **1.4 Date of incident** | | **1.5 Day of incident** | | **1.6 Time of incident** | ..... |
| **1.7 Place of incident** | ..... | **1.8 Scene address** | | **Specify:** | |
| **1.9 Scene attended** | | **1.10 If yes, who attended the scene?** | ☐ Police ☐ Forensic Officer ☐ Forensic Pathologist ☐ EMS ☐ Other (Specify) ..... | | |

**1.11 NARRATIVE: PROVIDE MORE DETAIL ON THE CIRCUMSTANCES OF DEATH AND OTHER RELEVANT INFORMATION**

Source of the information (mainly to be able to pick up Health System Failures) (please select all that apply):

☐ Lab 27; ☐ FPS 100; ☐ SAPS Annex A; ☐ SAPS A1 Statement; ☐ Other (Specify) .....

Brief history of events:

**1.12 FPS 006b**

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Completed** | | **Who is interviewed** | | ..... | | | |
| *Information about the Mother:* | | | | | | | |
| **Marital status** | | **Employed** | | **Age** | ..... years | **Education** | Grade ..... |
| **Number of children** | ..... | **Age(s)** | ..... | **Who looks after child** | | ..... | |
| **Substance abuse** | ..... | **Dwelling** | | **Number of occupants:** Adults: ..... ; Kids: ..... | | | |

# CHILD DEATH REVIEW DATA COLLECTION FORM

| 1.13 RTHC: TO BE COMPLETED IN SUDDEN DEATHS OF CHILDREN <5 YEARS OLD | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **RTHC Available** | | **Clinic number** | ..... | **Place of birth** | ..... | | | | |
| **Date of birth** | | **Home Address** | | **Specify:** | | | | | |
| **Clinic visits recorded** | | **Immunisations** | ☐ Birth ☐ 6 weeks ☐ 10 weeks ☐ 14 weeks ☐ 6 months ☐ 9 months ☐ 12 months ☐ 18 months | | | | | | |
| **ANC received** | | **Delivery mode** | ..... | | | | | | |
| **Birth weight** | ..... kg | **Birth length** | ..... cm | **Gestational age** | ..... weeks | | | | |
| **HIV exposed** | | **RPR result** | | **Nevirapine received** | | **PCR test** | ☐ 6 weeks ☐ 10 weeks | **Result:** | |
| **Growth charted in RTHC** | | **Describe growth** | | **PM weight** | ..... kg | **PM length** | ..... cm | | |
| **Health systems failure** | | **High risk infant** | | **Premature** | | **RVD exposed** | | **Neonate** | |

**Other comments:**

| SECTION 2: Autopsy | | | | | |
|---|---|---|---|---|---|
| **2.1 Autopsy done** | | **2.2 Manner of death** | | **2.3 Circumstances of death** | |
| **2.4 Cause of Death** | ..... | | | | |
| **2.5 Suspicion of sexual assault?** | | **2.6 Were x-rays taken?** | | **2.7 Were specimens collected?** | |
| **2.8 If yes, what test was requested? *Please indicate tissue/fluid taken.*** | ☐ Alcohol - ..... ☐ Histology - ..... ☐ Chemistry - ..... ☐ Genetic studies - ..... ☐ Research - ..... | | ☐ Formal Toxicology - ..... ☐ Microbiology - ..... ☐ DNA - ..... ☐ Pharmacology - ..... ☐ Other (Specify) ..... - ..... | | |
| **2.9 Specify any results** | ..... ..... ..... ..... ..... ..... | | | | |

# CHILD DEATH REVIEW DATA COLLECTION FORM

| Section 3: Other | | | |
|---|---|---|---|
| **3.1 Did death occur during another crime?** | | **3.2 If yes, which crime?** | ..... |
| **3.3 Was any of the following done:** | i) Case reported to **Social Services** | ☐ | |
| | ii) **Form 22** completed (to report suspected non-accidental injury) | ☐ | |
| | iii) **Diarrhoeal** death notified | ☐ | |
| | iv) **TB** death notified | ☐ | |
| | v) **Organophosphate** death notified | ☐ | |

**Other comments:**

**Submit Form**

## Appendix 2: Form FPS 006(6)

**FPS 006(b)**

Western Cape Government

**Forensic Pathology Services**

**SUD Questionnaire**

### FORENSIC PATHOLOGY SERVICE

**To be completed in all individuals 5 years of age and younger who have died suddenly and unexpectedly.**

FPS laboratory_____ WC _____

Name of baby _____

**Part 1: Scene Questionnaire and Observations**

**Date:**_____ **Time:**_____

**Name of Forensic Pathology officer:**_____

| **1. A: Who gives the history/ information in this case e.g. mother / father / granny / grandpa / other relative (give details)** | |
|---|---|
| Name: | Relationship: |
| Address: | Contact telephone number: |
| ID Number or Date of Birth: | |
| **1. B: Deceased's Details** | |
| Full name: | |
| Home Address: | |
| Age: | Date of birth: |
| Race: | Gender: |

| **1. C: Person(s) at/called to the scene and relationship** | | |
|---|---|---|
| Name/relationship | Date | Time |
| Name/relationship | Date | Time |
| Name/relationship | Date | Time |
| Police response/name | Date | Time |

WC_____ FPS006(b)

| | | | |
|---|---|---|---|
| Paramedic response/name | | Date | Time |
| When was the death certified/by whom | | Date | Time |
| Was the deceased taken to hospital? If yes, provide name of hospital | | Yes | No |
| Name of hospital:<br>Date of arrival: | Time of Arrival: | | |
| Name of doctor seen / declared death:<br>(Comment: Get copies of doctors notes) | | | |
| Was the deceased's resuscitated or treated by the paramedics? If Yes, get copies of the ambulance voucher | | Yes | No |

**1. D: Household environment at scene:**

| | | | |
|---|---|---|---|
| Place (dwelling) where the deceased lived at time of death: | House | Shack | Other (specify) |
| Number of rooms and bedrooms within household? | | Bedrooms | Total rooms: |
| Number of individuals living in household? | Adults: | Children: | Total: |

| | | |
|---|---|---|
| Is there enough fresh air circulating through the room in which the deceased was found? | Yes | No |
| Are there odours present in the room where the deceased slept? If Yes, specify | Yes | No |
| Was there peeling paint in the room in which the deceased slept? | Yes | No |
| Was the peeling paint anywhere near the deceased's food? | Yes | No |
| Was the room damp and/or fungal (mould) present within household? | Yes | No |
| Did people smoke cigarettes within the household? | Yes | No |
| Are there any pets in the household? If Yes, provide type and number | Yes | No |

Provide a brief history of the events leading up to death:

| | | |
|---|---|---|
| Is there any suspicion of foul play? If Yes, please describe below | Yes | No |

WC_____ FPS006(b)

| List items retained by FPO at scene (e.g. medications, syringes, clothing etc.) |
|---|
| |
| |
| |
| |
| Comments by FPO who attended scene: |
| |
| |
| |
| |
| |
| |

| Date: | Signature of deponent: |
|---|---|

I certify that the above answers to the questionnaire at the scene was taken down by myself and that the deponent has acknowledged that he / she knows and understands the contents hereof.

Date _____ Time: _____ Place: _____

Signature of Forensic Pathology Officer: _____

WC_____ FPS006(b)

**Part 2: Facility Questionnaire**

**Date:**_____ **Time:**_____

**Name of Forensic Pathology officer:**_____

| **2. A: Who gives the history/ information in this case<br>Ideally to be provided by mother, legal guardian or primary caregiver** | | |
|---|---|---|
| Name: | Relationship: | |
| Address: | Contact telephone number: | |
| ID Number or Date of Birth: | | |
| **2. B: Deceased's Details** | | |
| Full name: | | |
| Home Address: | | |
| Age: | Date of birth: | |
| Race: | Gender: | |
| **2. C: Circumstances of death / details about events before death** | | |
| 1. When was the baby last seen alive? | Date | Time |
| 2. Who last saw the baby alive? Name and relationship | | |
| 3. When was the baby found dead? | Date | Time |
| 4. Who found the baby dead at the scene? Name and relationship | | |
| 5. Was the deceased's body moved when found dead? If Yes, provide details below | Yes | No |
| | | |
| | | |
| | | |
| | | |
| 6. Was the deceased ill prior to death? | Yes | No |
| a) If Yes, Was the deceased taken to doctor, hospital, clinic, pharmacy or traditional healer for treatment? Indicate which option(s) and dates below | Yes | No |
| | | |
| | | |
| | | |
| | | |
| | | |

WC_____ FPS006(b)

| | | | | | |
|---|---|---|---|---|---|
| b) If deceased was ill and not taken to doctor or clinic, provide reasons why? | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| c) Provide names of medication given to deceased (including traditional). FPO to retain all medications for pathologist. | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| 7. Where was the baby found dead | Bed | Cot | Couch | Floor | Other |
| Other: | | | | | |
| 8. Did the baby sustain any injuries – e.g. by falling or being hit:<br>If yes: | | | | Yes | No |
| a) When did it happen? | | | | | |
| b) How did it happen? | | | | | |
| | | | | | |
| | | | | | |
| c) Where did it happen? | | | | | |
| d) What did the caretaker do about it? | | | | | |
| | | | | | |
| | | | | | |
| 9. a) On what surface was the baby placed to sleep? | Bed | Couch | Cot | Floor | Other |
| b) Specify Other: | | | | | |
| c) If Bed/cot, Indicate mattress type. | Foam Rubber | Inner Spring | Other (specify): | | |
| 10.a) Was there a pillow present under the head? | | | | Yes | No |
| b) If Yes, was the face pressed against pillow | Yes | | | No | Don't know |
| 11.a) In what position was the deceased's body found? | Back | Stomach | Side (R/L) | Other | |
| b) Specify Other: | | | | | |
| c) In what position was the deceased's face found? | To side (R/L) | Face up | Face down | Other | |
| d) Specify Other: | | | | | |
| e) Was there anything covering the deceased's head or face? | Yes | | No | Don't Know | |
| f) If Yes, provide details. | | | | | |

WC_____ FPS006(b)

| | | | |
|---|---|---|---|
| 12. Was the head, neck or chest squashed or wedged between any objects? | Yes | No | Don't know |
| If Yes, provide details | | | |
| 13. Did the deceased use a dummy (pacifier)? | Yes | No | Don't know |
| 14.a) Did the deceased sleep in the same bed as the mother, father or another person? | Yes | No | Don't know |
| b) If Yes, describe position | In the arms | Alongside | On Chest |
| c) Number of people that slept in same bed with deceased? | | | |
| d) Was anyone found laying on top of deceased (overlay)? | Yes | No | Don't know |
| 15. Did the mother or anyone in the house smoke while the deceased slept on the night/day of death? | Yes | No | Don't know |
| 16.a) Did the mother/caregiver use alcohol before going to bed with the baby on the night/day the baby was found dead? | Yes | No | Don't Know |
| b) If Yes, Indicate what and how much? | | | |
| 17.a) Did the mother/caregiver use drugs before going to bed with the baby on the night/day the baby was found dead? | Yes | No | Don't know |
| b) If Yes, Indicate what and how much | | | |
| 18.a) Did the mother/caregiver give the baby medication on the night/day of death? | Yes | No | Don't know |
| b) If Yes, Indicate what medication and how much. | | | |
| 17.a) When was the deceased last fed? | | Date | Time |
| b) What was the deceased fed? | | | |

**2. D: About the baby**

| | | | | |
|---|---|---|---|---|
| 1.a) Where was the baby born? | Hospital | Clinic | Home | Other |
| b) Name of clinic/hospital, or specify other | | | | |
| 2.a) How was baby born? | Normal Vaginal delivery | Caesarian Section | Forceps or Ventouse | |
| b) Indicate reason for Caesarian Section or assisted delivery | | | | |
| 3. Birth weight | | 4. Birth Length | | |
| 5. Specify number of weeks gestation and indicate term | Weeks: | Preterm | Full Term | Post-dates (overdue) |
| 6. Did the deceased receive Kangaroo care (skin to skin contact)? | | | Yes | No |
| 7.a) Was the baby | Exclusively Breast fed | Exclusively Bottle fed | Mixed Bottle and Breast fed | |
| b) Provide name of Formula Milk | | | | |
| c) Was boiling water used to make the bottle? | | | Yes | No |
| d) Provide names of any other foods used to feed deceased. | | | | |
| 8. Does the mother have the clinic card? If Yes, make copies for pathologist. If No, ask family to bring to facility. | | | Yes | No |
| 9.a) Are the immunizations up to date for age? | | | Yes | No |

WC_____ FPS006(b)

| | | | | |
|---|---|---|---|---|
| b) If No, provide reasons | | | | |
| 10. Was the deceased sick before it died? | < 24 hours | 1 day to 2 weeks | > 2 weeks | Never |
| Cold or Runny Nose | | | | |
| Coughing | | | | |
| Diarrhoea (Runny tummy) | | | | |
| Unusually restless or irritable | | | | |
| Crying more than usual | | | | |
| Change in appetite or feeding | | | | |
| Vomiting | | | | |
| Seizures or fits | | | | |
| Fever or Warm to touch | | | | |
| Lethargic, floppy, no energy | | | | |
| Cyanotic (Blue) or suddenly stop breathing | | | | |
| 11.a) Did the deceased come into contact with someone who was sick in the past 2 weeks? | | | Yes | No |
| b) if Yes, provide details of sickness and who the person was: | | | | |
| 12.a) Is the deceased known to be allergic to anything? | Yes | No | Unknown | |
| b) If yes, what? | | | | |
| 13.a) Did the deceased visit another province or country prior to the death? | | | Yes | No |
| b) If yes, provide details of where and when. | | | | |
| 14. What did the baby wear when it died? (list clothing) | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| **2. E: About the mother** | | | | |
| 1. Is the mother | Single | Married | In relationship | |
| 2.a) Is the mother employed? | | | Yes | No |
| b) If Yes, what works does she do? | | | | |

WC_____ FPS006(b)

| | | |
|---|---|---|
| 3. Age of the mother? | | |
| 4. What standard of schooling did she achieve? | | |
| 5.a) Is the mother the primary caregiver | Yes | No |
| b) If No, who is caregiver and why? | | |
| 6. Was she on contraception before she fell pregnant? | Yes | No |
| 7. Did she take iron and vitamin tablets during her pregnancy? | Yes | No |
| 8. Did she receive antenatal care? | Yes | No |
| 9. Did the mother have diabetes in the pregnancy? | Yes | No |
| 10. Did the mother have high blood pressure in pregnancy | Yes | No |
| 11. Did the mother gain weight adequately in pregnancy? | Yes | No |
| 12.a) Was she diagnosed with any illness during the pregnancy e.g. HIV? | Yes | No |
| b) If Yes, What? | | |
| 13.a) Was the mother on any medication during the pregnancy? | Yes | No |
| b) If yes, what medication: | | |
| 14.a) Were there any difficulties during the delivery? | Yes | No |
| b) If yes, what? | | |
| 15.a) Were there any problems with the baby after the delivery? | Yes | No |
| b) If yes, what? | | |
| 16.a) Was any specific instruction given about specific health care for the baby? | Yes | No |
| b) If yes, what? | | |
| 17.a) Was she depressed after the pregnancy? | Yes | No |
| b) If Yes, is she on any treatment? | | |
| 18.a) How many children does she have? | | |
| b) How old are they? | | |
| c) Do they all have the same father? | Yes | No |
| d) If No, provide details | | |
| e) Do they all live with her? | Yes | No |

WC_____ FPS006(b)

| | | | | | | |
|---|---|---|---|---|---|---|
| f) If No, Provide reasons why? | | | | | | |
| g) Are they all healthy? | | | | | Yes | No |
| h) If No, provide details | | | | | | |
| i) Do any of the children have learning disability? | | | | | Yes | No |
| 19.a) Did the mother smoke during the pregnancy? | | | | | Yes | No |
| b) If yes, how many cigarettes per day? | | | | | | |
| c) Does the mother smoke after the pregnancy? | | | | | Yes | No |
| d) Does the mother know that smoking harms the unborn baby? | | | | | Yes | No |
| 20.a) Did the mother drink alcohol during the pregnancy? | | | | | Yes | No |
| b) What did she drink? | Beer | Wine | | | Spirits | Other |
| c) Other: | | | | | | |
| d) How often did she drink? | Daily | Weekly | Occasionally | | | |
| e) How much did she drink? | | | | | | |
| f) Does the mother drink after the pregnancy? | | | | | Yes | No |
| g) Does the mother know that alcohol harms the unborn baby? | | | | | Yes | No |
| 21.a) Did the mother use drugs? | | | | | Yes | No |
| b) What drugs did she use? | Cannabis | Cocaine | Heroin | Mandrax | Tik | Other |
| c) Other: | | | | | | |
| d) How often does she use drugs? | Daily | Weekly | Occasionally | | | |
| 22. Does the husband/partner drinks? | | | | | Yes | No |
| 23. Do the parents of the mother drink? | | | | | Yes | No |
| 24.a) Did the mother have a previous baby that died suddenly? | | | | | Yes | No |
| b) If yes, how many died? | | | | | | |
| c) At what age did they die? | | | | | | |
| d) Was a PM done? | | | | | Yes | No |
| e) If yes, Provide details as to when it was done, where it was done and what the cause of death was. | | | | | | |
| 25.a) Did the mother have a previous stillbirth? | | | | | Yes | No |
| b) If Yes, provide details | | | | | | |

WC_____ FPS006(b)

| **2. F: Household environment** | | | | |
|---|---|---|---|---|
| 1.a) Was the following in the room where the deceased slept to heat the room? | Electric heater | "Galley" | Fire | Other |
| b) Describe other: | | | | |
| 2. Number of people in dwelling | Adults: | Children: | Total: | |
| 3. Estimated monthly income? | | | | |
| 4. Number of smokers in the dwelling? | | | | |
| 5. Are there mentally retarded/ challenged people in the dwelling? | | | Yes | No |

| Comments from the FPO who conducted the interview: | |
|---|---|
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| List any items retained at the interview | |
| | |
| | |
| Date: | Signature of deponent: |

I certify that the above answers to the questionnaire at the facility was taken down by myself and that the deponent has acknowledged that he / she knows and understands the contents hereof.

Date _____ Time: _____ Place: _____

Signature of Forensic Pathology Officer: _____

Department of Health
Forensic Pathology Laboratory

## Appendix 3: HREC Approval

**UNIVERSITY OF CAPE TOWN**
**Faculty of Health Sciences**
**Human Research Ethics Committee**

**Room G50- Old Main Building**
**Groote Schuur Hospital**
**Observatory 7925**
**Telephone** [021] 406 6492
**Email:** hrec-enquiries@uct.ac.za
**Website:** www.health.uct.ac.za/fhs/research/humanethics/forms

07 December 2020

**HREC REF: 806/2020**

**Dr T Phillips**
Division of Epidemiology & Biostatistics
Public Health & Family Medicine-FHS
Email: - Tammy.phillips@uct.ac.za
Student: jcbsol002@myuct.ac.za

Dear Dr Phillips

**PROJECT TITLE: HEALTH SERVICE UTILISATION PRIOR TO OUT-OF-HOSPITAL NATURAL DEATHS AMONG CHILDREN UNDER FIVE IN THE METRO WEST, CAPE TOWN IN 2018: A RETROSPECTIVE ANALYSIS OF DATA FROM THE CHILD DEATH REVIEW MASTERS CANDIDATE-DR THEUNS JACOBS**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.**

**Approval is granted for one year until the 30 December 2021.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

***The HREC acknowledge that the student: - Dr Theuns Jacobs will also be involved in this study.***

**Please quote the HREC REF in all your correspondence.**

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

**PROFESSOR M BLOCKMAN**
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

## Appendix 4: WC DoH Approval

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 0866; fax: +27 21 483 6058
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_202101_001
ENQUIRIES: Dr Sabela Petros

**University of Cape Town**
**Anzio Road**
**Observatory**
**Cape Town**
**7925**

For attention: Dr Theuns Jacobs, Prof Shanaaz Mathews, Prof Michael Hendricks, Dr Tammy Phillips

**Re: Health service utilization prior to at-home natural deaths among children under five in the Metro West, Cape Town in 2018: a retrospective analysis of data from the Child Death Review**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.
Please contact the following people to assist you with any further enquiries in accessing the following sites

| | | |
|---|---|---|
| **Forensic Pathology Services** | **Vonita Thompson** | **021 928 1501** |

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

**DR M MOODLEY**
**DIRECTOR: HEALTH INTELLIGENCE**
**DATE:** 25/08/2021
**CC**

## Appendix 5: Turnitin Report

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