

## End-of-Life Services in Africa: A Pilot Stakeholder Mapping

Dr Bulelwa Maphela\*

Senior Lecturer/ Ethics Officer 0877 Ethics SA (TEI), School of Economics, University of Johannesburg, South Africa.

\*Corresponding author: Dr Bulelwa Maphela, Senior Lecturer/ Ethics Officer 0877 Ethics SA (TEI), School of Economics, University of Johannesburg, South Africa. Tel: 011 559 5725; Email: bmaphela@uj.ac.za

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### Abstract

South Africa operates according to the National Health Act (No. 61 of 2003), in which section 68(1)(b) speaks to the regulation of human remains. This articulation of the Health Act is specific to the processes of running an establishment that handles human remains. For this study, the management of human remains falls within the ambit of end-of-life services. In South Africa, a majority of establishments that manage human remains are in the hands of emerging funeral directors. Much of the population is served by emerging funeral directors, who are mostly survivalists. A few well-established sector service providers service the affluent, while most of the population relies on emerging funeral directors (EFDs). Though the sector falls under the National Department of Health, the management of human remains has a business wing that largely falls in the hands of emerging funeral directors. It was found that the end-of-life service sector has many stakeholders, the most notable interface of human remains management takes place between the funeral directors and the Environmental Health Practitioners. Since there is a dearth of evidence about the sector, the article first sought to understand the size and context of the evidence base on end-of-life services in South Africa to develop a pilot evidence map. Secondly to narrate the process of stakeholder engagement to supplement the pilot evidence map. The pilot evidence map strongly suggests that there is a lack of evidence in practices and guidelines around human remains management in resource-limited settings, such as those of emerging funeral directors. The current study reveals that, though the management of human remains is part of national health, policy planning does not say much about end-of-life services. A need for ongoing research was found to be necessary from the stakeholder engagement sessions, and regulations on human remains management were still found to be a challenge amongst the stakeholders.

**Keywords:** end-of-life services, emerging funeral directors, stakeholder mapping, scoping of evidence, death, pilot evidence, and stakeholder engagement.

### Key messages

- The dearth of evidence at the end of live services in South Africa exists as a by-the-way business activity, instead of being treated as part of a developmental agenda.
- Emerging Funeral Directors in end-of-life services play a critical role in communities, that the government is struggling to fulfil because of population growth.
- According to Regulation 363, end-of-life-services providers must be compliant to adhere to the SGDs' social, environmental, and economic activities.
- Compliance of the stakeholders that handle human remains management at the end-of-life services is in line with the Sustainable Development Goals, which ensures that future generations are afforded a chance to interact with a healthy environment.

### Introduction

The World Health Organization (WHO, 2021, Report EB148/24 page 1) [1] articulated that “opportunities to be healthy are closely linked to the conditions in which people grow, learn, live, work and age”. “Some groups are faced with poor housing conditions and education, fewer employment opportunities and compromised physical environment, water and air quality, food security, and health care”. In a nutshell, social, environmental, and economic circumstances remain compromised which is a fertile ground for health inequities. This has led to unfair differences in health status between groups are communities. National Health policies and the WHO are explicit on processes of ensuring progressive health standards for citizens, supported by vast literature in this regard. However, the end-of-life

services do not get enough scientific articulation for users of such evidence. Maphela (2021, 2022, and 2023) [2] also found that the body of literature on end-of-life services is known to be limited, especially when it comes to death services in the South African environment. The process of end-of-life services involves many stakeholders, such as hospitals, SAPS, Forensic Pathology, Emergency Services, Funeral Undertakers, Parks and Cemeteries, Home Affairs, Environmental health services, Port Health, and many more. For this study, the end-of-life is unpacked by the South African Law Reform Commission (SALRC, 2020, Report 147) [3] as a sector that involves the organizing and carrying out of various sets of activities. These activities involve the removal of human remains, holding the remains, registering the death, planning for the place of interment, preparation of the remains for viewing by the family, repatriation, and interment for the remains. The recent studies used in this inquiry only focused on two stakeholders i.e., the Emerging Funeral Directors (EFDs) and the Environmental Health Practitioners (EHPs). The EHP ensures compliance for an EFD's premises to be fully functional. Therefore, this relationship was found to be a catalyst in end-of-life services, particularly the management of human remains. Literature on the population growth of South Africa is not in unison, depending on the inquiry followed. In the year 2000, the Department of Social Development refuted the notion that SA's population is on a rapid increase [4]. It depends on how one sees the population changes. Malthus's theory on population growth already cautioned that there is a strong relationship between population growth and social change. If the population growth is not checked, it leads to poverty and misery [5]. In the year

2000, Stats SA (2000) [6] indicated that the SA population was at 47 million, whilst it also reported that in 2022, the population was at 62 million (Stats SA, 2023) [7]. The 24% change between 2000 and 2022, signifies that the population growth rates have been on a steady increase.

South Africa is plagued by high levels of unemployment, inequality, poverty, and a struggling Health System. The International Monetary Fund (IMF, 2020) [8] opined that the rising unemployment levels and poverty seemed to be a challenge for the government of SA, evidenced by the constant shifting of budgetary priorities. The tilting of government spending reduced the ability to effectively support education and health. It is interesting to find that the Millennium Development Goals (MDGs) Country Report (2015) found that South Africa demonstrated progress in expanding its healthcare infrastructure, thereby improving healthcare access for its citizens. Maphumulo and Bhengu (2019) [9] posit that despite several commendable endeavors to improve the health service, basic services were failing to meet basic standards of care. Ripseli (2016) [10] found that South Africa spends 8.5 percent of its gross domestic product on gross domestic product (GDP) on health care, but half of this expenditure goes to private health care to service the socio-economic elite. Leaving 84 percent of the population dependent on the under-resourced public sector. This is further exacerbated by moving the sector from being the second priority to the fourth priority in terms of funding. Makalane, Heunis, Chikobvu, Kigozi, and Kruger (2020) [11]. Whilst the government is struggling to provide certain services, such as human remains storage and burials, it has tacitly relinquished the duty to the hands of the funeral directors. Given the economic performance of the country, most of this sector is dominated by emerging funeral directors. The emerging funeral directors dominate the end-of-life services, they serve communities that live in poverty and with minimal employment opportunities, whilst death does not discriminate based on circumstances. They play a pivotal role in managing the traumas in the townships and doing so regardless of whether people have employment or not. The emerging funeral directors have never had a scientific platform where their views can be documented and used as a point of reference when they engage with the government on disputes.

The SALRC (2020) [3] found that a bulk of these businesses are made up of small businesses that serve mostly the struggling local communities. The challenge is they are unknown as they are not registered with the local government due to the onerous requirements of owning a funeral parlor. Upon searching for literature on this topic initially, during the initial inquiries it was established that the voice of the Emerging Funeral Directors (EFDs) was missing, though they played a pivotal role in the afterlife services [2]. All the activities in the end-of-life services fall under the guidelines of the National Health Act no. 61 of 2013, *section 3* Regulation of Human Remains. Given the Regulation of human remains management, Miller (2006) explained that the daily job of the environmental health practitioner (EHP) involves protecting public health from harmful elements in the environment. By law, the EHPs must be actively involved in local and regional response-planning efforts. Maphela (2021) [2] and Maphela (2022) reported that the EHPs act as the authority in human remains management to ensure that the process of handling human remains management by established and emerging funeral directors is free from harmful practices.

Countries are striving to ensure effective and accessible healthcare services. Essential services ranging from health promotion, illness prevention, treatment and rehabilitation, and palliative care, have been on the agenda of health regimes, though there is limited information regarding end-of-life services in South Africa and the rest of the continent. In the latest report of the South African Department of Health (DOH) (2022), it was also found that the priorities centre around preventative measures for diseases and preservation of life, except for the measures for end-of-life services.

End-of-life services are part and parcel of the developmental agenda, specifically the human well-being of all those who are involved in the process. The domain of end-of-life services has many stakeholders, who each play a role of prime importance in the process, especially that of human remains management. There is a nuanced understanding of the importance of end-of-life care and services. Darell (2017) [12] makes a distinction between the nuanced definitions by stating that end-of-life care refers to a process of providing comfort and support to the persons and their loved ones' living experience. End-of-life care includes palliative care and pain management. It is also an interdisciplinary specialized service that helps people manage symptoms and stress associated with serious illness and its treatment. However, end-of-life care continues beyond death, specifically for this inquiry in South Africa, we focus on the end-of-life services that are mostly administered by various stakeholders. Amongst these stakeholders, the EDFs play a major role in providing this service, herein known as the management of human remains. Although death and quality of life are two of the most common measures in impact studies across the fields of health and social policy, the quality of end-of-life services is massively under-researched. Therefore, the study seeks to explore end-of-life services through stakeholder engagement in the field of human remains management to generate evidence about the sector.

### Literature

Unlike the start of life, which has seen billions of dollars invested in maternal and child health, end-of-life public services are highly neglected globally [12,13,14]. While in the Global North, discussions focus on privileges such as 'good death' and ethical debates about assisted suicide to reduce suffering, the Global South fails to deliver essential public services. In the past, South Africa was hailed as having a decent public health system, though it marginalised the indigenous African population in favour of whites. Maphumulo and Bengu (2019) [9] and Brauns and Staton (2015) [15] found that in 1994, the majority government inherited a highly dysfunctional healthcare system due to the National Party's policy. As such, the Department of Health operated under a skewed policy regime that neglected the needs of blacks [16]. The growing population also meant that even the afterlife services were left in the hands of the marginalized black undertakers. Over time, the government has neglected to take decisive corrective action to improve the provision of these services, such as human remains removal and basic public and environmental health protection. The constraints of the government were clearly shown during the floods in KwaZulu-Natal in April 2022, where for the most part, black emerging undertakers were on the ground assisting families with burials [17].

The scant evidence on end-of-life services on the continent suggests a possible failure in service delivery which may adversely impact physical and mental well-being,

environmental services, and, perhaps most crucially, local economic development. Successful delivery of these services also requires a balance between three areas that are often in conflict with each other: the environmental, social, and economic costs and benefits. End-of-life public services include a range of stakeholders, including the communities, forensic pathology services, municipal health services, parks and cemeteries, crematoriums, port health (for repatriations), police, government departments of home affairs, the environment and health, emergency medical services (EMS), and funeral directors. The latter is a key stakeholder group that is perhaps most neglected, despite playing a pivotal role at the interface of these diverse groups [2]. Funeral directors are the first point of contact when there is a death, providing frontline public service to families. As mentioned, their role was highlighted when severe flooding struck KwaZulu-Natal between the 8th and the 12th of April 2022. At the time, the media reported on the storage capacity challenges experienced by the government mortuaries, leading them to rely on private undertakers to help store unidentified human remains. This is one of many examples of the crucial role undertakers play in communities. The challenges and the role of funeral directors are only discussed at the association level which is supposed to be a nationwide practice in all the provinces. These discussions are not documented and as such, any information that arises is not available for public consumption. The disjointedness in the research-policy-practice nexus has further led to conflicts, strikes, and situations where communities must negotiate with the undertakers for end-of-life services where the government is struggling to do so.

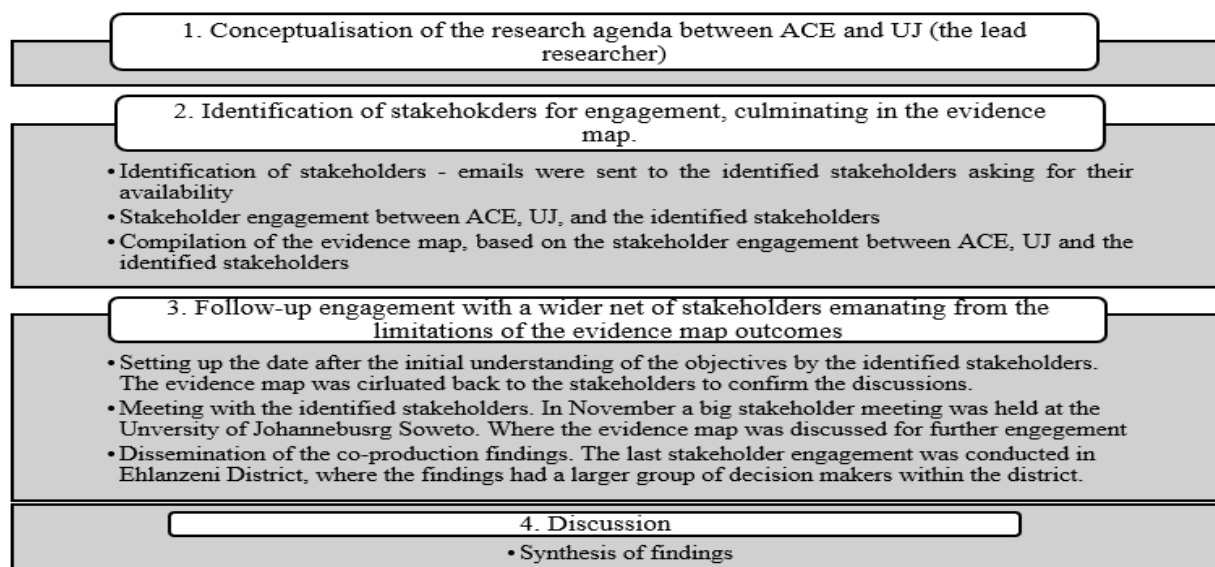
While there are economic benefits to the scientific articulation of the challenges in the industry, unearthing challenges through evidence-based inquiry helps articulate the importance of the activities that take place at the end of life [18]. Though this is not currently on the developmental agenda, it is part and parcel of the nation's ecosystems [19]. In this field, where investment has been so poor and the stakes for communities are so high, there is an urgent need to systematically collate the evidence base on public service interventions and outcomes for end-of-life public services to understand what we know and what we don't know. The preliminary research conducted by Maphela in 2021 [1] and 2022 pointed out to the need for an engagement with other research groups and stakeholders to contribute to the research agenda of this sector. This led to an identification of

stakeholders that could support and contribute to this research agenda.

**Methodology**

The study conceptualised stakeholder engagement from the studies done by Maphela in 2021 & 2022 [1]. In these studies, a qualitative reflexive methodology was followed. The 2021 study conducted interviews with the EHPs whilst the 2022 one engaged the EDFs. It transpired from both findings that the two stakeholders in the end-of-life were catalysts in human remains management and also struggled to find each other because of the Regulations contained in the National Health Act of No.61 of 2013. It also emerged from the synthesis of these findings that a further dialogue amongst stakeholders was necessary for the envisaged theory to emerge. The University of Johannesburg (UJ) as the lead researcher, and the Africa Centre for Evidence (ACE) met to set the agenda, where stakeholders were identified. Wilkonson et. Al. (2022) also advises that researchers should actively engage stakeholders in decision-making about the design and the conduct of the research. International guidelines on ethics in research also support stakeholder engagement as a method that is sound, ethically grounded, and inclusive of the voices of stakeholders that are directly involved. A few stakeholders between EHPs and EFDs were invited to set up the agenda for further engagement in June 2022. From this initial engagement, an evidence map emerged, which served to indicate where the gaps were. Haddaway, Kohl, da Silva, Schiemann, Stewart, Sweet, and Wilhelm (2017) defined a stakeholder as any person or organization who can affect or may be affected by the planning, conduct, results, and communication of a systematic review or map. Stakeholders at the end-of-life services provided insights into the human remains management research spearheaded by the researchers which improved the evidence base, creating greater public awareness, likelihood of informing literature, wider communication of findings, and increased likelihood of evidence-based decision-making process. Two stakeholder meetings were held in May and November 2022. The first stakeholder engagement was a pilot engagement where it was researchers from ACE and LED, two EFDs, and two EHPs. One of the EFDs was a chairman of the Funeral Directors Association from Mpumalanga Province and the second one was also a chairman of the funeral association from Gauteng Province.

**Figure 1:** Research agenda.



### **Adapted from the research agenda between ACE and LED**

#### *Conceptualisation of the research agenda between ACE and the lead researcher*

Figure 1 depicts the research agenda that was initiated between the Africa Centre for Evidence and the LED researcher from the School of Economics under the Local economic development cluster. The researcher knew nothing about ACE, its missions, and its objectives. During the hard lockdown due to COVID-19, senior academics delivered various lectures on various topics. The director of ACE, when introducing the cluster said the following “So much research is done on social issues, who benefits from this research, and does it attempt to solve the very social issues countries are facing?” It was about time that the scholarly rigor focusses on the co-production of evidence with the subjects so that the learning and the solutions are co-produced by all stakeholders involved”. This statement sparked interest and as the researcher from LED, I engaged with the centre (ACE) to introduce the inquiry on the management of human remains. As the lead researcher, I subsequently discovered that Among the possible stakeholders within the University of Johannesburg (UJ), the Africa Centre for Evidence (ACE) is committed to reducing poverty and inequality by increasing the use of research evidence, which was a challenge of the current research. The lead researcher chose to partner up with ACE for the purposes of this research since ACE prides itself in advancing the art and science of evidence-informed decision-making in Africa by building evidence capacities, supporting evidence communities, and conducting evidence synthesis. In 2019, ACE reportedly provided responsive evidence services that shaped national and international policy and practice. At the same time, inroads were made towards the evidence capacity agenda in Africa. This was achieved by mentoring, training, and supporting other communities, including researchers from various fields, such as the LED agenda in the generation and use of evidence. Upon the first day of engagement with ACE, the lead researcher unpacked the research agenda as follows as per the studies conducted in 2021 and 2022:

The initial engagement with the EFDs pointed out many challenges with various other stakeholders. The immediate stakeholder was the Municipal Health Service (Environmental Health Practitioners).

The EFDs complained about the process of obtaining a certificate of compliance, which is a crucial document that certifies the operations of the funeral house, herein referred to as a mortuary. To establish the facts around this complaint, there was a need for an unbiased inquiry.

To remove biases, the lead researcher first engaged with the EHPs of Ehlanzeni District in 2020 to understand the challenges they experience with EFDs when it comes to matters of compliance. Ehlanzeni District was accessible as it had a functional human remains forum that welcomed the research. Though the intention was to also engage with Gauteng Province, at the time of the 2020 inquiry, there was no functional forum in Gauteng.

The study found that the EFDs struggle with running compliant funeral businesses because of the amount of financial outlay needed to be fully compliant.

In 2022, another study was conducted with the EFDs, to establish their reasons for the struggle to be fully compliant with the National Health Act. The study revealed that, though EFDs provide a service that the government cannot provide for its communities, such as the storage of human remains, they do not receive the necessary support from the government toward being compliant. Most of the EFDs operate without Certificates of Competence (CoC). Both studies established that the services of EFDs are a catalyst to Local Economic Development in any given locality. Koma (2012), Elephant and Maphela (2018), and Radebe and Maphela (2019) argue that LED is one of the imperative developmental strategies articulated in the National Development Plan (NDP) of South Africa (2030 vision) and the National Framework for Local Economic Development (NFLED, 2019). The strategy of LED is to drive the economy and developmental trajectory with a special focus on the poor and marginalised component of the population, the main purpose being to encourage organic development that sprouts from within local spaces. Therefore, by encouraging organic development which sprouts within local spaces, EFDs thus act as a catalyst for Local Economic Development in any given locality. The after-life service sector is made up of a value chain, where all activities are interdependent for the completion of a burial, from death until interment. Thus, it was deemed necessary to delve into the process of stakeholder engagement for this study.

#### *Identification of stakeholders for engagement, culminating in the evidence map.*

ACE and the lead researcher met thrice a week to map out the journey of stakeholder engagement. After the discussion as per the previous section, two stakeholders were identified i.e. the EHPs and the EFDs, and communication was done telephonically and via emails. The purpose of this communication was to inform the identified stakeholders of the intentions of the researchers and how they can assist. The proposed date was dependent on the availability of the two stakeholders, which had to be between Tuesday and Thursday due to the nature of the sector, which is mostly busy from Friday until Monday for burials. From the agreed date, the engagement took place, where the evidence map was discussed.

On the 7<sup>th</sup> of June 2022, ACE convened a one-day evidence mapping workshop consisting of 10 people – five national and international academics and five guests from the community of practice. The guests were three representatives from the end-of-life services associations and two EHPs from regions D and G. The workshop was divided into two sessions, the first session aimed to introduce the funeral directors, EHPs, and visiting scholars to the evidence mapping methodology. During the planned stakeholder engagement, the EFDs felt that they were not supported by the existing policy and were only expected to follow stringent National Health Act guidelines. Whilst the EHPs were aware of their challenges, they confirmed that EFDs are struggling with compliance, which puts them in a challenging position as they are required to enforce the law. Regardless of these initial discussions, participants made contributions to inform the development of the framework for the evidence map by identifying high-level interventions and outcomes within the sector. The framework developed during the session was then created in Excel format and shared with stakeholders for further additions, an attempt was made to define the end-of-life services from an emerging funeral directors’ point of view.

In the follow-up to this session, stakeholders were asked to add to the inclusion criteria, which describes the characteristics of the studies to be included in the evidence map. They also suggested search terms to use on the two identified academic

databases. After completing the evidence mapping process, it was produced and shared with stakeholders for validation and comments. The evidence map is illustrated in Figure 2.

End of life services in Africa

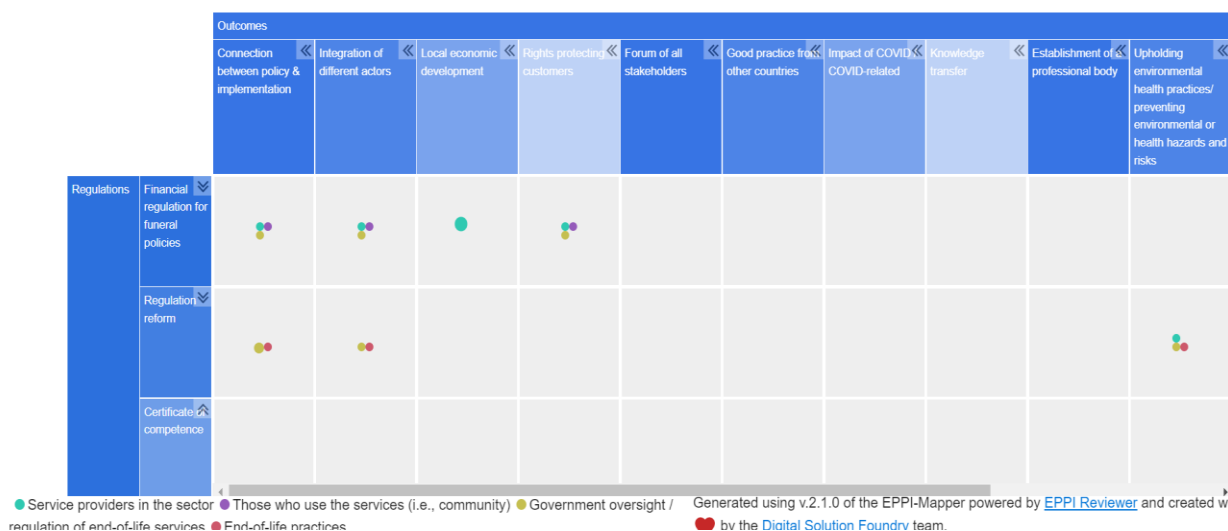


Figure 2: evidence map as an outcome of the engagement between ACE, UJ, and the identified stakeholders.

Seven academic databases and 18 grey literature databases were systematically searched supplemented by search engines for empirical evidence on end-of-life services across all African countries, with no date restriction. The topic areas and inclusion criteria were identified during a stakeholder session with two funeral directors, four academics, two visiting scholars, and two environmental health practitioners from Gauteng, South Africa. In total, 68 full-text academic articles and 33 grey literature pieces were included in the pilot evidence map. The evidence map attempted to give a picture of evidence synthesis in end-of-life services. It shows the dearth of literature in this sector. The search engine included service providers, the community that uses the services, and the regulation of the sector. The map was circulated back to the stakeholders for confirmation of the discussions that took place during the first engagement. The idea behind this exercise was to ensure that, the issues that needed urgent attention were in line with what the EHPs and the EFDs found to be common in their day-to-day engagements within the after-life service sector. Once the confirmation was received from the two stakeholders, preparations for wider stakeholder engagement were done with the City of Johannesburg (Municipal Health Service).

*Follow up engagement with a wider net of stakeholders*

Based on the limitations of the evidence map, the lead research and ACE saw it fit to conduct follow-up engagement with a wider net of stakeholders for purposes of sourcing out evidence in the discussions amongst the stakeholders.

On the 18<sup>th</sup> of August 2022, the Ehlanzeni Forum of Human Remains, based in Mpumalanga, invited the lead researcher to attend their quarterly engagement. The evidence map developed from the June session was presented to the stakeholders at the forum. These included Parks and Cemeteries, the Department of Home Affairs, Forensic Pathology, Municipal Health Services, the local tribal authority, funeral directors’ associations, and crematorium service providers. Other districts also attend, including the Gert Sibande and Nkangala districts. The third engagement was on 10 November at the Soweto Campus, with attendees representing a cross-section of the end-of-life service sector. This included nearly 60 emerging funeral directors, representatives from Parks and Cemeteries, Municipal Health, the Department of Home Affairs, and several academics. The evidence map was discussed with the attendees, who also focused on other pressing matters relating to compliance.

On 17 November, the lead researcher was invited back to the Ehlanzeni District of Mpumalanga. Local Economic Development was part of the engagement, welcoming the presentation of the evidence map and pledging to assist in addressing compliance issues for end-of-life services. Since the Local Economic Development is not in health science, they were prepared to take the lead from the EHPs in identifying the EFDs that are active in communities, who are also found to be struggling with minor issues, or who have been given a grace period to fix what was found to be a potential hazard if not addressed. From all these engagements, we attempted to synthesise all the outcomes from different stakeholders, as depicted in Table 1.

**Table 1:** Synthesis of the stakeholder and outcomes.

Stakeholder	Impact	Influence	Expectations	Contribution of the stakeholders	Challenges of the stakeholders with the engagement	Strategy of engagement
<i>Africa Centre for Evidence</i>	<i>Medium</i>	<i>High</i>	<i>Co-production of evidence</i>	<i>Presenting the preliminary systematic reviews</i>	<i>There was no literature relating to the objective of the engagement.</i>	<i>Call for a follow-up stakeholder engagement to present the evidence map from the initial engagement</i>
<i>Local Economic Development</i>	<i>medium</i>	<i>High</i>	<i>Co-production of evidence</i>	<i>Presenting the findings conducted in 2021 and 2022</i>	<i>The EHPs needed more time to understand their role in LED</i>	<i>Continuous engagement with the EFDs and EHPs</i>
<i>Funeral Directors</i>	<i>High</i>	<i>High</i>	<i>Solutions to compliance challenges</i>	<i>Day-to-day experiences of operating businesses in the management of human remains</i>	<i>They felt that the EHPs did not understand their role in the lives of communities. They felt that there was a need for policymakers in the stakeholder engagement.</i>	<i>They asked for further engagements that involve policymakers for them to articulate their challenges with the policy.</i>
<i>Environmental Health Practitioners</i>	<i>High</i>	<i>High</i>	<i>Solutions to alleviate environmental challenges</i>	<i>Narrating experiences of the day-to-day inspections of the funeral businesses</i>	<i>They also felt that the absence of policymakers in the engagement left them vulnerable in their duties</i>	<i>They asked for further engagements that involve policymakers for them to articulate their challenges with the policy.</i>
<i>Parks and Cemetery</i>	<i>High</i>	<i>Medium</i>	<i>Seamless burial process</i>	<i>Narration of experiences of the burial sites.</i>	<i>The absence of policymakers was a challenge as they are often vulnerable when dealing with communities.</i>	<i>They asked for further engagements that involve policymakers for them to articulate their challenges with the policy.</i>

**Adapted from the initial stakeholder engagement.**

Table 1 is a synthesis of the different findings from different stakeholders at different times. Different stakeholders had varying degrees of influence and impact. When it comes to influence, the academic conveners of the stakeholder engagement had a high influence. The expectations varied from the co-production of evidence and seeking solutions from the stakeholders’ side. All the stakeholders articulated their concerns about the end-of-life services value chain. It was ultimately agreed that the end-of-life services value chain stakeholder engagement needed to be an ongoing process to understand the regulation of human remains.

**Discussions**

In all of South Africa’s nine provinces, discussions about the challenges of this sector remain undocumented. Only the Mpumalanga province currently has a functional forum to discuss the concerns and proposed legislation with all the stakeholders in the after-life services. The challenge has been, in all these engagements, there were no scientific records of these quarterly meetings and the information shared during meetings. This was confirmed during the evidence mapping stage after the meeting between ACE and the lead researcher. We argue that documenting these discussions will potentially lead to scientific studies that can help inform policy. The initial visits by the lead researcher in the Mpumalanga forum meeting gave valuable insight into the sector’s challenges, including the

lack of knowledge sharing, undocumented data, access to information, political influence, and issues of policy implementation. These insights assisted in identifying the most accessible stakeholders, such as the EHPs and the EFDs. The evidence from the research conducted by Maphela (2021, 2022, and 2023) was extensively used because of the choice of the methodology used. The evidence was generated from qualitative primary data and most of the EHPs and the EFDs were part of these research activities.

The first engagement between ACE and the lead researcher revealed that not much has been done in end-of-life services, which are largely dominated by emerging businesses. It became necessary for the first engagement to call for EFDs and EHPs since they were accessible and looking for solutions. They confirmed the findings of the evidence map and the fact that the sector has many undocumented challenges. Their insights were documented, where they indicated that there is a need for a wider net of stakeholders as the sector is a value chain.

The Ehlanzeni District in Mpumalanga was willing to work with the University of Johannesburg but during the engagement, the stakeholders indicated that the budget allocation did not allow funds to be diverted to collate the available data. Gathering evidence within this sector would also be challenging as there are high levels of political play, mistrust, and disagreements among stakeholders. During the engagement with the forum, where the evidence map was presented, it was confirmed that no

research had been conducted in this sector, though the Local Government has a data repository. Despite this, they do not use this data as evidence to inform scientific reporting. Access to this information is impaired because loose pieces of evidence from the discussions have not been converted into meaningful evidence.

Undertakers rely on the academic community to document their stories and frustrations with the Department of Health and its policies. They are also protective of the space in which they operate and demonstrate high levels of mistrust towards outsiders, believing that people engage with them for personal gain rather than the benefit of the sector or the community. The evidence map corroborated by the stakeholder engagement showed no evidence of documented engagement amongst the stakeholders, though they do meet when there are pressing challenges.

In the first and the second stakeholder engagements, a plethora of challenges surfaced, which were unanticipated. It transpired that there was a standing issue, that of the compliance of the EFDs. This was further exacerbated by the proposed policy amendment of human remains Maphela (2023) [2]. It also transpired that The Department of Home Affairs was supposed to be among the stakeholders. During the forum, the issue of 'designation' was addressed. A death must be registered by the Department of Home Affairs, and a 'designation number' issued. Undertakers highlighted the logistical challenge with this practice as, for example, an undertaker's business may be in Mpumalanga, but when they are asked to collect a deceased's remains in Gauteng, Home Affairs in Gauteng will not register the death, because the undertake render taker designation was issued in Mpumalanga. Furthermore, within Mpumalanga (as in other provinces) each region is also given a 'designation', creating further ambiguities for a local undertaker moving remains from one region to another. The Department of Home Affairs was set to address the matter during the last Mpumalanga forum meeting of 2022, though this study has shown that although these issues are being discussed, there is no evidence synthesis or records to refer to.

Although the Department of Health has published a revised policy, undertakers felt excluded from a policymaking process that affects their day-to-day activities. The grievances they expressed at various engagements in recent years were ignored, and the lack of consultation is seen as another hindrance to their development. Ultimately, their aspirations and challenges were still not addressed in the revised policy. They are expected to follow the guidelines while being at pains to engage with the Department of Health to find solutions to the sector's problems. Information on the data used to inform the revised policy is also not forthcoming.

This has also led to the perceived unfairness of environmental health practitioners around cultural and religious burial practices. For example, tensions have arisen between Muslim and African undertakers because the latter group believes the policy is not as stringent on their Muslim counterparts. Though asserting their compliance, Islamic customary burial practice differs substantially from African culture, being conducted within hours and with a minimum requirement of cleaning the body. According to the burial practice in African culture, burials do not happen on the same day. As such, the body is kept in a refrigerator for several days and requires standardized preparation rooms, car wash bays, drainage, and secured loading and unloading of human remains.

It is argued that regardless of the manner or turnaround time of burial, Muslim undertakers are still part of the overarching afterlife services sector, and its guidelines should be universally applied. It was interesting to see that among the Muslim stakeholders, Black Africans operating in Muslim communities defended the application of the guidelines.

### Conclusion

The stakeholder engagement aimed to disseminate the findings of the two current studies and to engage further with the stakeholders, since the end-of-life- services have a value chain that lacks scientific evidence.

Though death and quality of life are two of the most common measures in impact studies in the fields of health and social policy, the quality of end-of-life services remains under-researched. The lack of essential public services has hindered efficient end-of-life service delivery by the EFDs. Several factors contribute to this inefficiency. Looking at South Africa's past, Brauns and Staton (2015) [15] found that the post-1994 democratic dispensation inherited a highly dysfunctional healthcare system due to National Party policy, which marginalised non-white South Africans in all spheres of life, whether political, economic, or social. End-of-life services for indigenous Africans were a matter for black undertakers, and little has changed since. The removal of human remains and basic public and environmental health protection remain understudied, given the scant evidence on the afterlife services on the African continent. This suggests a failure in the system that will not only impact physical and mental well-being and environmental services but local economic development too.

End-of-life public services include a range of stakeholders. Despite funeral directors being a key group, it is also the most neglected (Maphela, 2021) [1]. Although funeral directors are often the first point of contact for grieving families, they must contend with many challenges, including storage capacity. This was on full display during the 2022 floods in KwaZulu-Natal, resulting in conflicts within communities and grievances with the government for failing to provide the required services. It is understood that the economy will benefit from the scientific articulation of the challenges in after-life services. Evidence-based inquiry is used to articulate the importance of the activities that take place at the end of life (Stewart et al., 2018) [18], although not on the developmental agenda despite the distinguishable role within the natural ecosystem of a nation. Indeed, there is an urgent need to prioritise this area by collating the evidence based on public service interventions and outcomes and determining their impact on communities.

The stakeholders all agreed that there is little evidence of end-of-life services. For instance, no evidence exists on the role of LED at the municipal level, which could alleviate the challenges of EFDs and EHPs. The second last argument held in Soweto was more challenging, due to newly proposed regulations in 2022 which were even more stringent than the current set. The EFDs felt that the Department of Health was struggling to understand the significant role EFDs play in end-of-life services and that more engagements between the parties were necessary (Maphela, 2023) [1]. This was highlighted in the last stakeholder engagement in Ehlanzeni District, where for the first time the LED department was invited to the human remains forum. The takeaway from this engagement was that the Local Economic Development Department decided to assist EFDs upon the

guidance of the EHP. This help was dependent on their budgetary allocation.

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