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## OPINION FOR THE SOUTH AFRICAN MEDICAL RESEARCH COUNCIL ON TIMELY ACCESS TO CAUSE OF DEATH DATA

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- 1 My advice is sought by the South African Medical Research Council (“the MRC”) on access to cause of death data collected by the Department of Home Affairs (“the DHA”), and thereafter processed – and eventually published – by Statistics South Africa (“Stats SA”). In particular, the MRC seeks advice on identifying the legal barriers that stand in the way of health departments getting timely access to such data, and how these barriers may be overcome.
  
- 2 I am advised that health departments at all three spheres of government need access to cause of death data at the time of death registration, and that the current time lag from registration to the publication of death data by Stats SA (of about three years (on average)) undermines their work. Such information is required for a variety of reasons, including (but not limited to) –
  - 2.1 enabling swift interventions necessary to deal with public health crises;
  
  - 2.2 facilitating timely programme evaluation so as to establish whether public health interventions are working; and
  
  - 2.3 updating disease registers on the basis of which follow-up services are ordinarily provided to individual patients, and population-wide monitoring of certain diseases is undertaken.

- 3 As matters stand, health departments only get access to cause of death data many years later. For example, the most recently-published cause of death data are contained in the report published by Stats SA on 15 June 2021 entitled *“Mortality and causes of death in South Africa: Findings from death notification”*. That report *“presents information on mortality and causes of death in South Africa for deaths that occurred in 2018.”*<sup>1</sup>
- 4 The next report to be published, in or about early 2023, will only deal with 2019. What this means is that although the COVID-19 pandemic was declared two-and-a-half years ago,<sup>2</sup> we can only expect to gain access to cause of death data for the first year of the pandemic at some point in 2024. Insofar as our response to COVID-19 is concerned, such data will be quite useless by that stage.
- 5 In what follows, I deal with two issues in turn: first, the legislative framework governing the collection of, and control over, cause of death data in South Africa; and second, the lawfulness of this framework to the extent that it precludes health departments from accessing such data when needed.

## THE LEGISLATIVE FRAMEWORK

- 6 Two statutes govern the data in question: the Births and Deaths Registration Act 51 of 1992 (“the Registration Act”); and the Statistics Act 6 of 1999 (“the Statistics

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<sup>1</sup> Statistical release P0309.3, available at [https://www.statssa.gov.za/publications/P03093/P030932018.pdf\\_at\\_page\\_i](https://www.statssa.gov.za/publications/P03093/P030932018.pdf_at_page_i)

<sup>2</sup> See <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020>

Act”). The Director-General of the DHA (“the DG”) administers the Registration Act;<sup>3</sup> the Statistician-General (“the SG”) – who is appointed by the President to head Stats SA – administers the Statistics Act.<sup>4</sup> Insofar as the Registration Act is concerned, the relevant political head is the Minister of Home Affairs (“the Minister”); insofar as the Statistics Act is concerned, it is the Minister of Finance.<sup>5</sup>

- 7 Subject to the provisions of section 14 of the Statistics Act, which deals with statistical co-ordination among organs of state, the power to collect and control cause of death data vests in the DG. In terms of section 5(1)(a) of the Registration Act, the DG *“shall be the custodian of all ... documents relating to births and deaths required to be furnished under [the Registration] Act or any other law”*. Sections 14 and 15 of the Registration Act deal with the completion and furnishing of prescribed death certificates.
- 8 The DG does not act alone, but is empowered by section 4 of the Registration Act to authorise others to exercise and/or perform any power or duty imposed by or in terms of the Registration Act. Amongst others, the DG’s powers include *“furnish[ing] any information in relation to a person submitted in terms of [the Registration] Act to ... any department of State, local authority or statutory body for any of the statutory purposes of that department, authority or body”*.<sup>6</sup>

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<sup>3</sup> Section 3 of the Registration Act

<sup>4</sup> Section 7(1)(a) of the Statistics Act

<sup>5</sup> According to section 1, the relevant political head may also be *“such other Minister as the President may assign to be the executing authority for purposes of th[e] Act”*.

<sup>6</sup> Section 29(2)(a) of the Registration Act (my emphasis)

- 9 Absent such a power, the information furnished in prescribed death certificates could not be shared with any organ of state, including – for example – Stats SA.

This is because of section 29(1), which provides as follows:

*“Subject to the provisions of subsection (2), no person shall publish or communicate to any other person any information obtained from documents or records mentioned in section 5 (1), and which he or she acquired by virtue of his or her functions in terms of this Act or any other law, except for the purposes of this Act, judicial proceedings or the performance of functions in terms of any other law, and no person who has come into possession of any such information shall publish the information or communicate it to any other person.”*

- 10 The power to make regulations under the Registration Act vests in the Minister, who may make regulations relating (amongst other things) to –

10.1 *“the certificates which may be issued under [the Registration] Act and the requirements for the issuing of certificates”;*

10.2 *“any matter that may be prescribed under [the Registration] Act”;* and

10.3 *“any ancillary or incidental administrative or procedural matter that it is necessary to prescribe for the proper implementation and administration of this Act.”<sup>7</sup>*

- 11 Understood in light of section 29(2)(a), in terms of which the DG may grant access to cause of death data to any organ of state, the Minister’s regulation-

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<sup>7</sup> Sections 32(a), (d), and (e) respectively.

making power does not extend to determining with which organ(s) of state cause of death data may be shared, and/or the conditions attached to any such sharing. Importantly, the regulation-making power cannot be used to limit the DG's discretionary powers. To the extent that any regulation purports to do either, it falls to be reviewed and set aside.

- 12 According to section 14(7)(a)(ii) of the Statistics Act, the SG *“may designate as official statistics any statistics or class of statistics produced from statistical collections by ... other organs of state, after consultation with the head of the organ of state concerned.”* Section 1 of the Statistics Act defines a statistical collection to include *“the process of ... collating administrative records or data for statistical purposes”*. The collection of cause of death data by the DHA would appear to fall within this definition.
  
- 13 According to section 3(1) of the Statistics Act, *“[t]he purpose of official statistics is to assist organs of state, businesses, other organisations or the public in ... planning; ... decision-making or other actions; [and/or] monitoring or assessment of policies, decision-making or other actions.”* Put differently, the designation of statistics produced from statistical collections as official statistics ought not to result in organs of state being unable to discharge their statutory obligations; it must facilitate the purposes identified in section 3.
  
- 14 In terms of section 3(2) of the Statistics Act, *“[o]fficial statistics must protect the confidentiality of the identity of, and the information provided by, respondents”*. Who is a respondent? Section 1 defines a respondent to include *“any individual*

*... in respect of whom ... any information is sought or provided for purposes of a statistical collection in terms of [the Statistics] Act".* Such information would include, for example, all cause of death information obtained by the DHA which is provided to and/or shared with Stats SA.

- 15 Section 17 of the Statistics Act controls the disclosure of *"information collected by Statistics South Africa for the purpose of official or other statistics that relates to ... [amongst others] an individual"*. Subject to subsections (2) and (3), and *"[d]espite any other law"*, no such information may be disclosed to any person. While the two subsections make provision for a range of exceptions, neither appears to contemplate the sharing of information such as the raw cause of death data collected by the DHA and provided to Stats SA.

- 16 Of particular relevance to this opinion is section 17(5), which provides:

*"Information collected by any person, organ of state, business or other organisation for his, her or its own purposes and communicated to Statistics South Africa is subject to the same confidentiality requirements as information collected directly by Statistics South Africa, irrespective of any other confidentiality requirements to which it may have been subject when it was collected."*

- 17 As it currently reads, the legislative framework prevents the DHA from sharing raw cause of death data with anyone other than Stats SA, which in turn cannot share the data with anyone else. And the sole reason why the DHA is precluded from sharing such raw data with anyone other than Stats SA is Form DHA – 1663B, which requires the data to be sealed and provided to Stats SA for its use

only. Absent that form, as it currently reads, the DG would be able to share the data in the manner contemplated by section 29(2)(a) of the Registration Act.

## THE LAWFULNESS OF THE LEGISLATIVE FRAMEWORK

- 18 In promulgating the Regulations on the Registration of Births and Deaths, 2014 (“the Regulations”), the Minister did two things that he is not empowered to do: first, he determined with which organ(s) of state cause of death data may be shared, and the conditions attached to such sharing; and second, he effectively limited the DG’s power – in terms of section 29(2)(a) of the Registration Act – to share such information with an organ of state other than Stats SA.
- 19 According to Form DHA-1663 (the prescribed death notice),<sup>8</sup> section 5 (the medical certificate of cause of death) is to be “*sealed after completion to ensure confidentiality*”, and may only be opened by Stats SA officials.<sup>9</sup> Not only does this have the effect of determining that such information may be shared with Stats SA, but, once shared, it prevents the DG from sharing such information with anyone else, including – for example – any health department.
- 20 In the result, I submit that Form DHA-1663 is unlawful because the Minister had no legal authority to promulgate it in its current form. But unless and until the form has been amended in the manner contemplated by the Registration Act, or

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<sup>8</sup> Annexure 14 to the Regulations

<sup>9</sup> See Form DHA – 1663B

a court has pronounced on its lawfulness in review proceedings, it remains in force, and must be given effect.<sup>10</sup>

## CONCLUSION

- 21 Should the *status quo* remain unchanged, any interested party – including a non-profit organisation acting solely in the public interest – could approach the High Court for appropriate relief, including the grant of an order declaring Form DHA-1663 unlawful to the extent that it effectively precludes the DG from sharing cause of death data needed by organs of state such as departments of health.
- 22 Of course, a change to the form – in and of itself – will not guarantee that the DG exercises his power under section 29(2)(a) of the Registration Act to ensure that health departments have timely access to cause of death data. That said, a failure to exercise the power in this manner, in appropriate circumstances, may itself be reviewable under the Promotion of Administrative Justice Act 3 of 2000.

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<sup>10</sup> See, for example, *MEC for Health, Eastern Cape and Another v Kirland Investments (Pty) Ltd* 2014 (3) SA 481 (CC) at paras 101 and 103, citing *Oudekraal Estates (Pty) Ltd v City of Cape Town and Others* 2004 (6) SA 222 (SCA) with approval.