

The duty of confidentiality towards deceased patients - the Mandela book

Kyknet recently released a news report ([click here](#) for the Youtube video) where they interviewed Paul Esselaar on the right of privacy of Nelson Mandela as well the right of privacy of his relatives. The book, which is written by Dr Vejay Ramlakan and published by Penguin Random House, has been removed from the shelves, but not before several copies of the book had been purchased. All of this raises a number of questions, and as always we need to make sure we ask the right questions before we look to the answers. Some of the questions are:

- 1) Does a doctor have an ethical duty to keep any patient interaction confidential even after the patient is dead?
- 2) Does a doctor have a legal duty to preserve the privacy of the doctor - patient relationship even after the patient is dead?
- 3) Does a doctor have a legal / ethical duty to the patient's next of kin to preserve their privacy and confidentiality?

ETHICAL DUTY TO DECEASED PATIENT

The answer to this is actually quite simple. Rule 13 of the Ethical Rules of the HPCSA states that a 'practitioner may divulge information regarding a patient only if this is done...(i)n the case of a deceased patient with the written consent of the next of kin or the executor of the deceased's estate'. Note that the consent must be in writing and so the onus lies on the doctor to prove that written consent was provided. It is likely that this consent should be (as the Protection of Personal Information Act (POPI) states): informed, specific and voluntary. It appears that this consent was not obtained at the time, but this should be a fairly simple question of fact - either the written consent was obtained or it was not...

LEGAL DUTY TO THE DECEASED PATIENT

Does a deceased person have personal information? The answer in terms of POPI is 'no' for the simple reason that the definition of 'personal information' requires that the data subject (i.e. the person) be 'living'. This in turn means that the entire of POPI does not apply any more to the information about deceased people. However, this is not the end of the question.

LEGAL / ETHICAL DUTY TO THE NEXT OF KIN

Of course POPI would apply to the people who are still alive, and specifically to the next of kin. In this particular case it seems clear that not only confidential information of Mandela but also personal information of the next of kin (remember that 'personal information' even includes opinions and preferences) is also in the book. Although POPI is not yet in force it is

highly likely that the Information Regulator (the body set up to police POPI) would be able to object to the use of the personal information of the next of kin on several different grounds, such as:

- a) The personal information that was collected was not collected for the purposes of writing a book, but to assist with the treatment of the patient,
- b) The purpose of using the Personal Information (which was to write a book and sell it to the public) does not comply with section 11 of POPI (which requires that PI can only be used for a purpose that meets the test of section 11),
- c) A data subject (in this case the next of kin) can object to the processing (i.e. use of the their PI in a book) in terms of section 11(3) of POPI and this in turn means that the PI cannot be used.

WHAT ABOUT THE 'LITERARY' EXCEPTION IN POPI?

On the other hand, (and it is important to realise that there is always 'another hand' when it comes to privacy) POPI provides a specific exclusion for literary works (such as books) in section 7 where it states that POPI does not apply to a book 'to the extent that such an exclusion is necessary to reconcile, as a matter of public interest, the right to privacy with the right to freedom of expression'. While there is tremendous public interest in the book, the real question here is whether the right to freedom of expression should trump the right to privacy of the next of kin. Some help in this regard can come from the Promotion of Access to Information Act (PAIA) which indicates (in section 34 for public entities and in section 63 for private entities) that a request for personal information – even about a deceased – must be refused if the next of kin have not provided consent (obviously this excludes situations where the personal information is required by a law).

WHY 'PRIVACY BY DESIGN' IS SO IMPORTANT

Confused?

More than anything this case shows how difficult it is to deal with privacy and personal information. There are always many rights that need to be considered and a careful and systematic approach to dealing with these thorny issues should always be done (preferably before you publish a book). In fact this is the whole point of 'privacy by design' which underpins the global approach to the protection of personal information. Essentially the idea of 'privacy by design' is that an investigation into the personal information used and the privacy of the individuals should be done routinely by all organisations. Perhaps if Penguin Random House had done this the book may well still be on the shelves...

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