Where to from here? Posthumous healthcare data, digital e(lectronic)-mortality and New Zealand’s healthcare future

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ABSTRACT

Ongoing improvements in digital data acquisition and storage has led to the phenomenon of e(lectronic)-mortality, where digital data can now exist for a potentially infinite period. Globally, many countries are facilitating the acquisition and researcher-led access to large-scale, population-based digitised healthcare data sets. Their utilisation has led to numerous positive advances in healthcare. New Zealand’s medical record system is becoming increasingly digitised, and as a consequence there will be an ever-increasing resource of posthumous healthcare data stored digitally, including genomic information. Such data could be utilised for research purposes, and developing such a consolidated resource could improve healthcare outcomes in our own nation and allow us to parallel global progress in healthcare research trends.

This viewpoint article explores the issues surrounding, and potential for utilisation of, a national resource of posthumous digital healthcare data. Currently, there appear to be no legal barriers to the large-scale acquisition and utilisation of posthumous healthcare data in New Zealand, however, previous legislation may not have been developed with developments in technology or e-mortality in mind. Ethically, culturally and socially there are many challenges to address, including issues surrounding obtaining consent, respecting privacy, management of incidental findings, maintaining anonymity and ensuring community support for such a resource. Despite the potential for widespread health benefits that utilisation of posthumous healthcare data in this country may facilitate, wide and ongoing consultation is required to examine how such a precious resource can be enabled for the downstream benefit of all New Zealanders.

Digitisation of health data, including medical records and genomic information, is becoming common practice in many countries around the world. With this improvement in digital technology, a new phenomenon has emerged because of the indefinite period that information can now be stored: an era of ‘e(lectronic)-mortality’ has arrived, where digital information can potentially exist, and be accessed, for an infinite period. As a consequence of these new developments there are major ramifications in many different areas, and particularly in regard to health research where large data sets are a rapidly developing reality.

Coinciding with recent advances in digital technology and information storage is the development and utilisation of genomic medicine. The parallel growth within both domains has serendipitously provided the foundation for large-scale studies involving digital health data. Globally, many studies are being conducted that allow scrutiny of health data from large populations to further an understanding in such areas as disease processes, drug interactions and epidemiology.1–3

New Zealand’s medical record system is increasingly becoming digitised in order to increase efficiencies in our health system. It is therefore timely to reflect...
on the choices available in the context of the posthumous use of digital healthcare data. New Zealand’s digitised healthcare data, and in particular digitised genomic data, could be used posthumously and has useful potential to advance the diagnosis and treatment of diseases. Healthcare data digitisation has allowed large-scale genomic sets of data to be used for research that has societal benefit at a personal, community and nationwide level. Although large digitised healthcare sets are being developed and used in other countries, this is a ‘new’ resource in our country, and its potential adoption, utilisation and implementation as a resource in a specifically ‘New Zealand’ context requires consideration.

Science and medicine: current technology and the utility of digitised health data

Genomic data is derived from examination of a person’s DNA, with the information stored via digital file. Genome-wide studies can uncover associations between genetic variation and medical conditions that cannot be diagnosed from the bedside. It follows that the use of this technology has great potential to advance the diagnosis and treatment of diseases. Scientific progress using genomic information will develop most rapidly through widespread access to genomic data that is linked to healthcare information gathered by agencies and biobanks. Furthermore, this data has the potential to be shared across research projects in order to address a wide range of research questions.

Digitisation of healthcare records can potentially allow genomic data sets to be used for collaborative research, and this has potential for wider societal benefit. In order for this information to be widely applicable across multiple research fields and retain its value in the future, data is required to be presented in a standardised format. This may include information such as nutrition, medications and illness outcomes. Information that is presented in such a format can then be processed, collated and examined in a similar manner to produce high-quality outcomes. The subsequent use of digital, post-mortem health information in research could then be utilised to reveal genetic links to specific diseases and explore how effective different medications might be for different individuals. Expanding this technology to large-scale genomic data sets sequenced from entire genomes may elucidate secondary associations when pooled with data from other individuals, and has a direct medical application. This could mean potential improvements in selecting drugs to maximise their efficacy for individual patients, or advances in the diagnostic accuracy of rare conditions, which would translate to improvements in New Zealand’s healthcare, including research that specifically examines and provides benefits for Māori and Pacific populations. The use of human data in this digitised manner will also allow scientific and medical advances in New Zealand to parallel global progress.

Utilisation of digital healthcare data: global trends

Globally, many countries have initiated large-scale digitisation of healthcare records, and are using these for research purposes. Numerous research successes from investigations via genomics have been seen in many countries, with collaborative digital databases revealing genetic associations with multiple cancers, identified mechanisms for cancer development, revealed genetic causes of smoking behaviour and identified genes involved in body fat distribution. Over the last two decades, Iceland has used a large database to advance population genetics and uncover genes involved in various diseases. This project has been supported within the community, with half the population participating in research projects. The UK Biobank collects prospective lifestyle information, medical information and biological samples from 500,000 consenting adults, with consent permitting the use and retention of posthumous data.

In Estonia, the Human Genes Research Act (2000) was implemented to encompass the use of genotypes, phenotypes, health and geographical information, with participants giving broad informed consent. The national genetics research database in Iceland integrates genealogical and genetic...
data under the Health Sector Database Act (1998), with existing medical records of citizens computerised and integrated into the database without requiring consent from the individuals. However, individuals can opt out of this project to withhold their medical information.13

The Biobank Act (2012) in Finland supports research using human biological material and technical records of the material, including global collaborations. Similarly, existing clinical and research samples can be transferred to the biobank provided the individual does not opt out, and there has so far been no indication that the person, if they were alive, would object to the use of the samples.14 In Poland, collection of human tissues and cells is governed under the Cell, Tissue and Organ Recovery, Storage and Transplantation Act, which also reversed the system of acquiring consent; consent is presumed and prospective donors can opt out of this system to retain their autonomy.15

In countries where an opt-out system is implemented, the relatives of the deceased are also entitled to oppose donation at the time of death to avoid additional psychological stress.16 While there have been many positive outcomes from large-scale utilisation of digitised healthcare information presented above, there are also issues that have generated debate on the nature of the informed consent and of appropriate use of the acquired data from large-scale and national healthcare-information databases.

Legal and ethical considerations

A major challenge associated with posthumous healthcare research is ensuring that the data is used in an appropriate way. The legal perspectives on the use of human data were established at a time when digital technology was in its infancy and e-mortality was not a relevant consideration, before digital storage and widespread genomic investigations were common. Current research policies address the use of genetic material of living participants, but few consider what happens to this data following the death of the individual and subsequent information disclosure for further research. It is therefore relevant to examine some of the issues surrounding the use of posthumous, digitised healthcare in New Zealand. These include the legal and ethical rights to use, consent, anonymity and issues underpinning the ethical right to use.

Considerations surrounding legal right to use

There are currently no legal barriers to the posthumous use of digitised healthcare information in New Zealand. Use of posthumous, digitised healthcare information may seem, at face value, to be a breach of privacy. However, the Privacy Act (1993), which aims to promote and protect individual privacy, defines an individual as a natural person other than a deceased natural person.17 Therefore, legally, a deceased individual cannot have their privacy breached when they are no longer alive to be harmed.18

The duration for which posthumous healthcare data can be used following acquisition is not specifically legally restricted. The Health (Retention of Health Information) Regulations apply to health information of an identifiable individual, and define an individual as a natural person, including a deceased natural person.19 The regulations state that health information must be kept for 10 years (Section 5). However, in the context of using posthumous health information for research, the maximum duration for which data can be stored and used is not specified in the above regulations or in the Standard Operating Procedures for Health and Disability Ethics Committees.20

The HIPC (Rule 9) states “A health agency that holds health information must not keep that information for longer than is required for the purposes for which the information may lawfully be used”.21 The Code acknowledges that there may be plausible reasons for which records can be retained after they are no longer relevant to their primary purpose, as long as there is still some lawful purpose. Information which is stored by health agencies is covered under the rules of disclosure under the HIPC for 20 years beyond the death of an individual. There is a further acknowledgement that health information can still be sensitive after a person has died. Therefore, healthcare information is currently held by health boards
and healthcare providers, who have a duty of care that encompasses use of the information. However, there is no legal barrier to the use of such information for research purposes, and no restriction to the length of time that such information can be used.\(^2\)

Comprehensive collation of healthcare information increases the likelihood of discovering incidental findings, particularly when examining genetic data. The identification of incidental findings has impact on family members and relatives who may be affected, such as when diseases and heritable disorders are recognised. Procedures regarding disclosure of information and providing treatment to those individuals who are then classified as ‘at-risk’ should be established to manage this information, with decisions made in regard to how incidental findings would be used. In a survey conducted in Australia, the majority of citizens stated they would like to be informed of any incidental findings in their data, although the extent of desired information differed between individuals.\(^2\)

**Consent**

An inherent difficulty with posthumous data is that patients are unable to consent after their death. While many legal and ethical guidelines exist regarding the acquisition and use of healthcare data for individuals that are alive, it is unclear how this applies to the use of posthumous digitised healthcare data. In the case of utilisation of public healthcare records, discussion with the wider public and consumer groups is required as to determine how consent processes should be implemented, with this including consideration of options such as opt-in and opt-out consent processes.

There is also the question of who has the authority to consent to the acquisition of genomic data on behalf of the deceased. The deceased have no way of implementing an action unless they have explicitly stated their wishes prior to their death, and people do not tend to make decisions regarding the posthumous applications of their medical information.\(^2\) The wishes of an individual regarding the course of action for their body after their death may differ from those of the family, yet as it stands the family has the final say.\(^1\) Currently in the US, a biospecimen can be used in a research capacity without explicit consent, provided the sample has already been collected for another purpose.\(^2\) Similarly, The Royal Liverpool Children’s Inquiry recommended that once informed consent has been obtained for a tissue specimen, consent should remain valid, provided the specimen is used for ethically approved research projects.\(^2\) This would prevent repeated requests to the next of kin for consent, and allow data to be used for new projects.

The above examples provide a consent pathway for downstream posthumous tissue use, however, this is only for current or previous research projects and does not provide the benefit of gaining access to data from a larger cohort. It does, however, suggest a precedent for gaining one consent during a person’s lifetime and having this support posthumous information use. Wide consultation is therefore required to examine what sort of consent framework could be implemented that would satisfy New Zealand’s culturally and ethnically diverse community.

**Anonymity**

Anonymity is difficult to adhere to as much genetic data is correlated with medical (and therefore personally identifiable) information. The HIPAA (Rule 10) states “A health agency that holds health information obtained in connection with one purpose must not use the information for any other purpose unless the health agency believes... that the information is used in a form in which the individual concerned is not identified; or... is used for research purposes and will not be published in a form that could reasonably be expected to identify the individual concerned.”\(^2\) To effectively utilise digitised healthcare data, some elements of personal and medical information are required, however, issues surrounding the security and privacy of digital healthcare resources have been raised.\(^2\) The specific issues were in regard to the implementation of digitisation and integration of a large number of health records, and with particular reference to anonymisation. Anonymous data implies it has been collected and used without any associated personal identifiers, and useful genomic data may never be truly anonymous.
In addition, with the increase in publicly available databases, large-scale data linkage between healthcare data and personal information also becomes more possible, further decreasing the potential for ‘true’ anonymisation. Data linking in New Zealand is already possible by use of the Information Data Infrastructure, a digital resource which stores data from a range of government and non-government organisations. There is therefore the necessity to differentiate between data being sufficiently anonymous for the purposes of legal and ethical standards, and data being ‘truly’ anonymous in a scientific sense, in order to inform guidelines for utilisation of digital healthcare information.

The development of a controlled, digitised database where medical records are integrated across the population provides an elegant solution to attenuate challenges associated with anonymity. Data is separated from any identifying information and coded in a secure database to ensure privacy to the individual in the future.

Protection of electronic data is important, particularly when data may be shared globally. In Estonia, a chief processor only releases data in a coded form and any identifiable data cannot be accessed through an external network to ensure secure use and storage of genomic data. Similarly, digital data collected by the UK Biobank is separated from any identifying information by coding it in a restricted-access database.

Issues underpinning the ethical right to use

As presented, there appears to be no legal barrier to the use of posthumous, digitised healthcare information in New Zealand, though this does not mean it should be performed. The way scientific research is conducted and how findings are disseminated into the community influence the support or objection of the public. The Royal Liverpool Children’s Inquiry was conducted following the revelation that organs and tissues were being retained from deceased children and babies without the knowledge of the parents. During this inquiry, parents expressed that they would have considered donating tissue from their children for education or research if they had been approached in an open manner. However, the betrayal of trust without permission reduced the faith they have in the medical profession, signalling the important role of communication in generating support for healthcare research.

Community support and acceptance of an accessible digital healthcare database is essential to prevent ethical repercussions, with transparency and communication between researchers, healthcare professionals and the public regarding the acquisition and intended use of digitised healthcare data paramount to maintaining social support. Sharing information of the deceased without prior consent may violate their pre-mortem wishes, yet withholding such information from medical research may prevent a potential benefit that could be delivered to society. Therefore, the decision to allow use of healthcare information of the deceased must be weighed carefully, with full consideration of the range and scope of the potential benefits and risks associated with such access.

Conclusion

New Zealand has a history of being a pioneering country that brings about change through public, community and cultural support, and has already proven itself capable of undertaking large-scale research projects that span over decades. A small nation with an established health system coupled with the technology to support a digital database presents an ideal opportunity to develop a unique platform for biomedical research using posthumous, digitised healthcare data. Such a resource would assist our understanding of the relationship between genetics, environment and disease, facilitate improved drug administration and create new opportunities for prevention and treatment in healthcare, including those that benefit European, Māori and Pacific populations.

There are currently no apparent legal barriers prohibiting the utilisation, for research purposes, of posthumous digital healthcare data in New Zealand, and the barriers to its use appear largely ethical. However, this does not necessarily mean it should proceed on an organised basis, with decisions on consent, anonymity and ethical use requiring further consideration. Establishing and accessing such a resource will require strict oversight in order to prevent
misuse or exploitation, and to establish trust between those gathering the data, those utilising the information, and the public who will be contributing to it. Further discussion is required in order to explore the idea of utilising digitised healthcare data on a national scale in order to discover whether and how such utilisation should occur. If a decision to proceed is forthcoming, the implementation and introduction of appropriate systems to regulate e-mortal healthcare data in New Zealand's unique cultural, social and ethnic environment can then be planned through appropriate consultation. Failure to undertake consultation and implement frameworks that are appropriately informed has the potential to undermine any trust in the relationship between those giving and those utilising digitised healthcare information. Undertaking wide and thorough consultation is therefore necessary to establish a robust and evidence-based platform that can guide stakeholder behaviour.

New Zealand currently has the opportunity to establish a system that effectively and efficiently utilises posthumous digitised healthcare data. Implementing a system that does this in an ethically and culturally appropriate manner will enable New Zealand to provide more effective healthcare for its citizens and remain at the forefront of healthcare research. There are inherent problems associated in the utilisation of such digital information following death, and undoubtedly new legal and ethical situations will continue to unfold with advancing technology. However, these should not be seen as permanent barriers to the implementation and use of a successful and effective system that allows posthumous digital healthcare data to be sensitively and effectively utilised. Similarly, the risks of allowing posthumous digital healthcare information to be utilised must also be considered in any decision about information use, including the potential range and scope of any proposed benefits. Wide and appropriate consultation should be undertaken in order for participants and end-users to contribute perspectives on a collective way forward and guide appropriate utilisation of this precious resource. The development of such a uniquely ‘New Zealand’ resource will likely provide benefit for all New Zealanders over time, with its establishment echoing global trends in healthcare research.

**Competing interests:**
Miss Hoeksema reports grants from University of Otago Centre for Society, Governance and Science during the conduct of the study.

**Acknowledgements:**
KH was the grateful recipient of a summer student scholarship from the Centre for Society, Governance and Science at the University of Otago.

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