

The Ethical Conundrums of a State-wide study of Medical Practice Efficiency

Introduction

Technical advancements over the last century have made it easier than ever to accumulate and store data. Gone are the days where a civil servant takes hours or longer to sort through paper records to look back on a decade worth of information. Data input is now far simpler, and so too is data accumulation. In fact, many data-producing systems also produce data by-products; data that was never intended to be collected in the first place. Such is the nature of the world we find ourselves in. For example, most people have a medical record that encompasses information of every blood test, x-ray, medical procedure, or even doctors/telehealth appointment. All these things include information about times, places, interactions, durations, complexity of treatment, duration of treatment etc. With so many systems relying on it, the datafication of our world is unavoidable. The datafication has its advantages and disadvantages. For example, the availability of this data creates a unique opportunity to identify correlations, find trends in health across hundreds of attributes, and to improve the efficiency of our medical systems. However, although the data is available, its use necessarily raises multiple ethical questions. Questions of autonomy or ownership, privacy, security, objectivity, profiling and surveillance, and even epistemology. These concerns are all valid and need to be ethically addressed so that research can withstand peer review, even on an international stage.

After recent success investigating the efficiency of a long-serving medical clinic with numerous patient records, the state government has requested an investigation of the efficiency of all medical practices within its jurisdiction. While such a study has merits, there are multiple ethical issues with aspects of the request itself, and many more that are not as explicit. In this report we will discuss some of the ethical factors that accompany such an undertaking.

Detailed answer covering issues, defection, and solutions

Discussion

The first ethical issue is one of data ownership. These practices are not all state funded, but are all expected to contribute to the study; giving a totalitarian image. To avoid this and the risk of taking away patient autonomy and privacy, informed consent should be obtained from all participants prior to commencement; noting that they will need to assist in gaining consent from their patients when it comes to sharing private information (Mittelstadt & Floridi 2016; Nijhawan et al. 2013). No one should have their data used against their will or without their knowledge (Nijhawan et al. 2013).

Informed consent should include:

- An explicit participation invitation
- Aims/ benefit to society and methods of the study
- A risk management plan and hazards of the study
- Disclosure of who will have access to confidential information
- A contact method for further queries
- An indication that it is requested, and run, by the state-government
- An indication that participation is voluntary and can be discontinued at any time (FDA 2014)

Furthermore, non-compliant practices should not be penalised with a ranking of 0; this would give the perception they lack efficiency. These practices may refuse for good reason. For example, they may have taken years to build a rapport with an aboriginal/Torres strait islanders' community and just want to protect that relationship, or worry about the implications of profiling. We could take a forceful approach and risk damaging the community's trust in their practitioners and government but we suggest negotiating because their response is understandable; we should endeavour to meet them halfway so the study can truly benefit all (Mittelstadt et al. 2016). Practices and patients may have some attributes that they feel uncomfortable providing (e.g., appointment durations, regularity, condition, gender, etc), we must respect that and replace it with the average value (**see below**). In some cases, like the deceased or lost contacts, the cost/risk to the unknowing individual is minimal compared to the study's potential benefits; a contention supported by the literature (Floridi 2018; Mittelstadt & Floridi 2016).

Detailed briefing based on code of conduct

This company has 100 employees working as programmers, software team leaders, data scientists, and business development managers. Something we need to consider is how cultures and ethical views across each team will converge on this study. Conflict between individuals, teams, and stakeholders on their moral and ethical responsibilities is inevitable (Kohls & Buller 1994). In this section, we provide some clear guidance so staff can come together with a clear ethical framework that minimizes dispute. A link will also be provided so that disputes, or breaches of the code, can be anonymously sent to HR and upper management for swift resolution as other companies have done (Hassink, De Vries & Bollen 2007). As this study is a government project, and because we want it to be easily reconstructed for peer review (upholding the high ethical standards of this states scientific community) we have elected to use '*the Australian Code for the Responsible Conduct of Research*' to guide the company's ethical approach:

<https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018#block-views-block-file-attachments-content-block-1>(NHMRC 2018).

The key principles of this code are:

- Honesty – present true and accurate information at every stage of the study
- Rigour – ensure methods are well grounded and free from bias
- Transparency – ensure traceability and accountability
- Fairness – act fairly and give recognition of authorship when necessary
- Respect – respect each other and those this study will influence as well as the environment
- Recognition – recognition of country and the benefits of diversity
- Accountability – take responsibility and be proud of your contribution
- Promotion – engage with others and ensure they follow these principles

We have highlighted a few clauses in particular that have guided our suggested alterations and expect our staff to adhere to (table 1).

Table 1: A reference guide for specific aspects of the code that staff and study must adhere to.

Clause	Explanation
R8 <i>“Provide access to facilities for the safe and secure storage and management of research data, records and primary materials and, where possible and appropriate, allow access and reference.”</i>	Provides guidance for the company’s selection of cloud service for the collection and protection of private data.
R18 <i>“Ensure that the ethics principles of research merit and integrity, justice, beneficence and respect are applied to human research.”</i>	Our company will adhere to the principles of the Belmont report outlined in this clause to protect and respect all.
R19 <i>“Engage with Aboriginal and Torres Strait Islander peoples and respect their legal rights and local laws, customs and protocols”</i>	This clause protects the original custodians of this land and hopes to protect them from bias and include them in the process.
R21 <i>“Adopt methods appropriate to the aims of the research and ensure that conclusions are justified by the results.”</i>	Ensures our staff considers how their work can lead to transformative effects and profiling.
R22 <i>“Retain clear, accurate, secure and complete records of all research including research data and primary materials. Where possible and appropriate, allow access and reference to these by interested parties”.</i>	Encourages traceability, accountability, security, and integrity from our staff.
R28 <i>“Participate in peer review in a way that is fair, rigorous and timely and maintains the confidentiality of the content.”</i>	Encourages responsible practices and integrity.

(NHMRC 2018)

There are also issues of data protection and privacy to consider. We must ensure that the cloud-based server can protect the data just as well as it can store it; that means protecting it from intruders and keeping it confidential from third parties (Mittelstadt & Floridi 2016). Sensitive data is being collected and therefore security must be rigorous and redistribution limited to peer review or other consensual government studies on the health care system. Anonymization is a good start, but (in combination with other data sets) a person can be identified through inference, or abused through profiling; common security problems with big data (Choudhury et al. 2014; Mittelstadt et al. 2016; Mittelstadt & Floridi 2016). According to clause R8, we have a responsibility to participants and must consider the security of the cloud-based server (NHMRC 2018).

As R22 of the code states, we must retain accurate and complete records of all the data with the necessary traceability markers even after the study has concluded (NHMRC 2018). This demonstrates integrity (as raw data sources can be scrutinized) and allows the work to be reconstructed for peer review (Matthias 2004). Blockchain technology shows promise in enabling mistakes to be addressed by specific teams or perpetrators of foul play to be identified long after the studies completion (Sahoo & Halder 2021).

Our work will be recognised internationally after peer-review, and there are bound to be cultural clashes and conflicting ethical principles on an international stage. For example, in Australia we have a dual system, public and private. It enables everyone to get the care they need. This is not the case in the United States where private practices and insurance companies are paid handsomely for the privilege of efficient care (Donelan 1996; Shi & Stevens 2021). This study represents our medical system, it must uphold our ethical principles now and in the future. That means the privacy and security of the participants must remain protected here and abroad, even in places that may allow the data to be repurposed without consent. For example, it would be a failure if our data was repurposed for a study of the correlation between ethnicity/socioeconomics and 'silly' medical accidents; consequently, profiling groups and creating negative transformative effects. To defend against these issues, we must:

- Select a country that values autonomy and privacy, such as America, Canada, the EU, or New Zealand (Merchant 2016; Rumbold & Pierscionek 2017; Yogarajan, Mayo & Pfahringer 2018; Zhang et al. 2021). We have selected America (California) because:
 - It gives us more options in server providers
 - Individual state laws provide a range of security levels protected by law. California is leading the way in data privacy with the California Consumer Privacy Act of 2018 (Baik 2020).
 - The Federal Trade Commission will enforce the laws and protect consumers from negligence or rights abuses (Wilson & Commissioner 2020). Failing that, there is the option of a class action lawsuit (Poyraz et al. 2020).

- All state laws dictate breaches must be disclosed to us in the event of a breach, these laws have also been found to reduce cases of identity theft over time (Bisogni & Asghari 2020).
- The shared language reduces miscommunication.
- The data they collect as a result of our operations will be used ethically and with our informed consent.
- Ensure the laws and customs of that country reflect these values as is the case for America, and those mentioned above (Merchant 2016; Rumbold & Pierscionek 2017; Watts & Casanovas 2019; Yogarajan, Mayo & Pfahringer 2018).
- Ensure the cloud storage provider does not allow access to the data by third parties, and that we maintain ownership.

Furthermore, we must carefully consider issues of profiling, particularly in rural areas or places with large populations of a specific nationality (Mittelstadt & Floridi 2016). The image we give these groups will develop inaccurate and harmful profiles through inference; for example, Springvale has a large Asian population (Forrest et al. 2017). this study could create a social stereotype that they are less/more efficient. These profiles will be inaccurate because the study is about systems, not people. As Australia's medical systems are among some of the best in the world, we have influence when it comes to potential conflict (Schneider et al. 2021). As such, we have a responsibility to produce this report in a manner that can educate, foster collaboration, and even infiltrate other systems for the improvement of efficiency here, and abroad (Mittelstadt et al. 2016).

Identify misuse of the ranking number with explanation and evidence

Finally, there are the human factors to consider – factors enabling improved quality/design for humans. The outcomes of this study could provide tools and highlight practices that could benefit from optimization with a few alterations. We would like to suggest a better ranking system in line with clause R21 (NHMRC 2018). The current system does not consider the number of practitioners, the size/location of the practice, or the type of medical practice. This definition will incorrectly show that 'bigger is better' as a result of 'misguided evidence' (Mittelstadt et al. 2016). It also leads to profiling issues because it makes smaller medical clinics appear less efficient without the context behind the data, bringing their reputation into question. Instead, efficiency could be measured as the average number of patients seen per hour, per working practitioner for each class of practice. Some practitioners are specialized and require longer appointments to give proper care. Additionally, many practices may operate outside of the defined working day hours. This way practices with more working practitioners aren't interpreted as being more efficient, and comparisons can be made between classes of practice in a more meaningful way. For example, a 9am-5pm immunology practice with three practitioners cannot see as many people as a bulk billing clinic that operates 9am-9pm with 25 practitioners; nor would there be any meaning in comparing the efficiency of the two. This would also improve pre-processing because now **missing values** can be more accurately estimated; using instead a more reliable average number of patients seen for a practice of that size and class.

We would also like to suggest an improvement to the ranking. Currently, an efficiency of 21% is given the same numerical rank as one at 40%. We suggest a bell curve as it is a better interpretation of the data and more accessible to stakeholders (Reeves 2001). Practice efficiency can then be measured in terms of percentiles and the states mean efficiency and deviation can be quickly identified; thus, removing inaccuracies in readers perception of ranking from 'response bias' (Greenwald & Krieger 2006). However even then, it does not ensure that patient care improves with efficiency. As only the number of appointments is recorded, and not data on the degree of care received/ patient satisfaction, it is entirely possible that practices improve their perceived efficiency by increasing the number of appointments in a day without actually providing the care required. This study already assumes practices are giving appointments close to the time of first contact and that adequate care is given at that appointment. Both assumptions will require separate studies to verify the findings of the report.

Furthermore, the data doesn't include context of time and place or any of the changes that influence townships or communities (e.g., culture, diversity, population size, events, etc). Therefore, it doesn't accurately show changes in efficiency over time, it leads to 'inconclusive evidence' (Mittelstadt et al. 2016). For example, over the last few decades it might appear as though one practice drastically improved its efficiency, when in fact the population simply grew or the practice started offering blood tests, etc. The addition of other contextual attributes (e.g., population growth factors, changes to staff, addition/reduction of available classes of care like blood tests, x-rays, therapy, etc) would allow the output to show a more accurate efficiency over time that provides better advice to the administration.

We also advise caution when it comes to using the report in other systems. We are concerned it may result in detouring ambulances to practices further away than necessary because they appear more efficient; a 'transformative effect' (Mittelstadt et al. 2016). But this assumes that emergency cases don't get priority and unnecessarily increases the time between first contact and treatment. It is therefore important we are concise and clear about what the report does and does not show, ensuring the report supports objectivity and encourages careful examination.

Conclusion

The request from the state government shows promising benefits to our health system. We have indicated a few alterations to bolster the benefits available to its readers locally, nationally, and internationally while minimizing the hazards to the participants. We have outlined the ethical framework that will govern our company's behaviour and practices in the production of the report, and discussed in detail how internal and external conflict may materialise and how it should be managed or avoided. We have also indicated a few ergonomic factors that the report itself can benefit from, but also what we can do to ensure accurate conclusions and stories are drawn from our work.

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