



SUBMISSION

GENERAL PRACTICE DATA AND ELECTRONIC CLINICAL DECISION SUPPORT

CONSULTATION REGULATION IMPACT STATEMENT

28 Feb 2023

CONTACT US

W [Calabash Solutions](https://www.calabashsolutions.net/) | <https://www.calabashsolutions.net/>

E info@calabashsolutions.net

M +61 (0) 430 231 184

CONTEXT

Australia's Department of Health and Aged Care (the **Department**) has invited stakeholder feedback on the General practice data and electronic clinical decision support Consultation Regulation Impact Statement (**CRIS**)¹ in the second part of its two-stage consultation about general practice (**GP**) data and electronic clinical decision support (**eCDS**) software. The CRIS expands on the matters outlined in the initial General practice data and electronic clinical decision support Issues Paper (**Issues Paper**)², and outlines a range of potential regulatory options for GP data and eCDS software.

Calabash Solutions welcomes the opportunity to respond to the CRIS, and we are available for additional discussion, questions, and comments on our submission.

Calabash Solutions consents to the publication of all or part of our submission responses to public fora.

Donna-Leigh Jackson

FIP, CIPP/US, CIPM, CIPT, BSc (Biology, Psych), BSc (Software Eng)

Director, Calabash Solutions

Carey-Ann Jackson

MA Psychology, MA English

Director, Calabash Solutions

¹ Australian Government Department of Health and Aged Care (2022) [General practice data and electronic clinical decision support Consultation Regulation Impact Statement](#), Australian Government Department of Health and Aged Care website

² Australian Government Department of Health and Aged Care (2021) [General practice data and electronic clinical decision support - Issues Paper consultation](#), Australian Government Department of Health and Aged Care website

INTRODUCTION

Improved sharing of GP data and increased uptake of eCDS in GP settings have been assumed, by the Department in its CRIS, to be the nostrum to a healthcare system facing *'ongoing and growing opportunities and challenges'*, and capable of transforming it into one delivering improved health outcomes and system functioning. Equitable, coordinated and effective care in Australia, the Department writes, faces *'opportunities and challenges'* from an ageing population, workforce pressures, chronic disease prevalence and incidence changes, *'recent public health emergencies'*, technological advancements and complexities, issues of trust and quality, and the demand for *'connected care'*. It's not entirely clear, from the unbundled list of issues, which particular issues are considered, by the Department, as *'opportunities'*, and which are *'challenges'*. Undaunted, the Department claims that *'good quality and appropriately shared'* GP data and eCDS will improve the quality of care delivered across all healthcare settings, *and* drive research and innovation, *and* ensure the healthcare system's sustainability. (A nostrum, indeed.)

Four broad reform options presented in the CRIS for GP data and eCDS are:

- **Option 1:** Retain the status quo.
This retains the status quo and proposes no changes, legislative or otherwise.
- **Option 2:** Facilitate stakeholder-led regulation
This option seeks to use collaboration and co-design to develop agreed standards and processes which stakeholders voluntarily agree to follow.
- **Option 3:** Establish incentive-based regulation.
This option seeks to encourage and induce compliance with agreed standards and processes.
- **Option 4:** Introduce legislation and establish a new regulatory scheme.
This option seeks to mandate data sharing and standards for GP data and eCDS.

In our submission, Calabash Solutions challenges the assumption that collecting and sharing more health data will improve health outcomes and health system functioning. We argue that collecting and sharing more health data via technological systems, such as shared eCDS, will present new and complex challenges not contemplated in the CRIS and, absent a rigorous legislative framework regulating the use of Artificial Intelligence (AI), the increased uptake of eCDS in GP settings runs the risk of reinforcing existing human biases in technological systems, with the potential to diminish health outcomes among certain cohorts of the population – especially those who have been or still are marginalised, ignored, misdiagnosed or mistreated in medical and healthcare discourse and practice. We also challenge the assumption that,

without addressing implicit biases in medical and healthcare training and practice, shared GP data (a misnomer) can drive research and innovation systems – historically undertaken in universities and science councils, but shifting significantly to unregulated, for-profit companies (e.g., Microsoft and OpenAI, Alphabet, Meta, etc.) – and also deliver sustainability, however defined. Assuming shared data, of whatever quality, can improve healthcare quality is a formidable ask. But the Department goes further: it assumes that shared data can also deliver sustainability, drive innovation and foster integration. This is unrealistic and the fever-dream sales pitch of the Technorati.

CONSIDERATIONS

WORDS MATTER – WHEN IS A CONSUMER *REALLY* A ‘CONSUMER’?

The CRIS, in its description of the various stakeholders in the GP data ecosystem, uses the term ‘*consumer*’ to refer to an individual who ‘...*provide(s) GPs with information of their reasons for visiting and their needs.*’ (Australian Government Department of Health and Aged Care, 2022, p. 13)³.

The term ‘*consumer*’ suggests a transactional relationship, where a person has agency to purchase goods or services for personal use. When describing a doctor-patient relationship, it is our view that the exchange is dissimilar to a buyer-seller interaction. The need for an individual to engage the services of a GP is more likely necessitated because of a health (physical and /or psychosocial) requirement, then a desire to purchase a GP’s service.

As such, Calabash Solutions questions the use of the term ‘*consumer*’ to describe the patient in the doctor-patient relationship. We have, however, continued to use this term in our submission, to ensure consistency with CRIS terminology. We suggest that a more appropriate term to describe this cohort of stakeholders in the GP data ecosystem is ‘*individual*’ or ‘*patient*’.

QUESTIONING THE PREMISE THAT MORE HEALTH DATA IS NEEDED TO IMPROVE AUSTRALIAN HEALTHCARE

The opening paragraph of the CRIS executive summary states:

‘The improved sharing of general practice data and increased uptake of electronic clinical decision support (eCDS) within general practice settings present opportunities to improve the health of consumers and the functioning of the health system.’ (Australian Government Department of Health and Aged Care, 2022, p. 2)⁴

Data and technological systems, specifically eCDS, are identified by the Department as the levers of control of effective, equitable, coordinated care:

³ Australian Government Department of Health and Aged Care (2022) [General practice data and electronic clinical decision support Consultation Regulation Impact Statement](#), Australian Government Department of Health and Aged Care website

⁴ *ibid.*

‘These pressures for change illustrate the need to better utilise existing sources of information, such as general practice data and eCDS, to improve quality of care, health system interoperability across all healthcare settings and to drive research and innovation to ensure the sustainability of Australia’s healthcare system.’ (Australian Government Department of Health and Aged Care, 2022, p. 11)⁵

Calabash Solutions questions the assumptions behind these claims.

The CRIS presents no evidence to show a clear, direct link between the shared GP data plus the uptake of eCDS by GPs and the outcomes of improved health of consumers and functioning of the health systems. Sharing of GP data will make more GP data available, but that this will result in (or will potentially result in) improved consumer health and an improved functioning health system remains unsubstantiated in the CRIS.

To these points, Calabash Solutions questions whether more data will get Australia any closer to addressing challenges facing GPs and the broader healthcare system. To support our objections, we consider the broad expanse of health data repositories currently available to inform policy, and we present evidence that while Australia has an *ageing* population, Australians’ longevity reflects a health system with already successful health outcomes for most (but not all).

Current and existing treasure troves of health data

There is a treasure trove of Australian health data accessible to those who need it and/or want to make use of it. A rudimentary internet search on health data yields vast data repositories that are currently being collected and available to inform government policy and public health research. For example:

1. The Department currently holds different types of data about the health of Australians of all ages and from across the country. The Department’s population health data holdings⁶ currently include:
 - a. immunisation coverage for children and adults.

⁵ Australian Government Department of Health and Aged Care (2022) [General practice data and electronic clinical decision support Consultation Regulation Impact Statement](#), Australian Government Department of Health and Aged Care website

⁶ Australian Government Department of Health and Aged Care (2022) [Population health data](#), Australian Government Department of Health and Aged Care website

- b. Australia's health workforce.
 - c. Medicare use from 1984 onwards.
 - d. hospital use, including non-admitted patient care, admitted patients, and elective surgery and emergency department waiting times.
 - e. patient, medical and financial casemix for public and private hospitals.
 - f. medicine use and the cost of the Pharmaceutical Benefits Scheme.
2. The Australian Bureau of Statistics maintains data on health conditions and risks, mental health, causes of death, disability, and health services⁷.
 3. The Australian Institute of Health and Welfare publishes reports and data on a broad range of topics, including a biennial report on health of Australians⁸.
 4. Services Australia publishes a range of statistic information about Medicare, including Medicare Benefits Schedule statistics, Pharmaceutical Benefits Schedule (PBS) and Repatriation Pharmaceutical Benefits Scheme (**RPBS**) statistics, Australian Immunisation Register statistics, Australian Organ Donor Register statistics, Practice Incentives Programme statistics, and Division of General Practice statistics⁹.
 5. The Pharmacy Benefits Scheme (**PBS**) publishes an annual report on aggregate community use of prescription medicine in Australia¹⁰. The PBS also makes available a range of reports on the PBS medicine use (for example, Pharmaceutical Benefits Scheme (PBS) | PBS and RPBS Section 85 Date of Supply Data)¹¹.
 6. The Cancer Council Victoria conducts a survey on substance use among secondary school students every 3 years¹².

⁷ Australian Bureau of Statistics [Health](#), Australian Bureau of Statistics website

⁸ Australian Government Australian Institute of Health and Welfare (2022) [Australia's health 2022](#), Australian Government Australian Institute of Health and Welfare website

⁹ Australian Government Services Australia (2022) [Medicare statistics](#), Australian Government Services Australia website

¹⁰ Australian Government Department of Health and Aged Care The Pharmaceutical Benefits Scheme [Australian Statistics on Medicines](#), Australian Government Department of Health and Aged Care website

¹¹ Australian Government Department of Health and Aged Care The Pharmaceutical Benefits Scheme (2023) [PBS and RPBS Section 85 Date of Supply Data](#), Australian Government Department of Health and Aged Care website

¹² Cancer Council Victoria [Australian secondary school student alcohol use](#), Cancer Council Victoria website

7. State and territory health departments publish a suite of population health data, data sets and health statistics, in a demonstration of their commitment to Open Data Strategies. For example:
 - a. HealthStats NSW is a public website bringing together data from many sources to produce statistical information about the health of the NSW population¹³.
 - b. Queensland Health’s Chief Health Officer report includes data visualisations of population and health indicators for Hospital and Health Services (HHSs) and Primary Health Networks (PHNs)¹⁴.
 - c. Tasmanian Government Department of Health maintains a Health system dashboard where it provides access to statistical information on Tasmania’s health system¹⁵.

Recognising the current troves of health data available to anyone with access to the internet, Calabash Solutions rejects the premise that **more** health data (collected in time-poor GP practice settings, by GPs who, themselves, spend mere minutes their patients (Irving et al, 2017)¹⁶) is needed to improve quality of care, to improve health system interoperability across healthcare settings, and to drive research and innovation to ensure the sustainability of Australia’s healthcare system. What **more** data will result in, is the accumulation of **more** data. And with more data comes increased risks and challenges. We explore some of these risks and challenges below, in [Section Risks associated with holding more health data](#).

The counterargument that it’s not the pursuit of more data, but better data, that’s the Department’s goal, is also problematic. Data collected from patients (and captured in handwritten notes or coded in an eCDS) are not neutral, but constructed by human beings and within human-made discourses about who is human, who is “deserving” of the allocation of healthcare resources, and who isn’t. These discourses and their associated implicit and explicit biases (which we, including GPs and nurses and Practice Managers, have) mean that some individuals / groups are perceived as either malingerers undeserving of a GP’s attention or pathological and in need of interventions (medical or religious or community) that strip them of their rights and dignity. Transgender activists and LGBTQIA+ health professionals, such as Dr Clara Tuck Meng Soo, as

¹³ NSW Government HealthStats NSW [Population health data at your fingertips](#), NSW Government HealthStats NSW website

¹⁴ Queensland Government Queensland Health [Population health data and statistics](#), Queensland Government Queensland Health website

¹⁵ Tasmanian Government HealthStats (2023) [Health system dashboard](#), Tasmanian Government HealthStats website

¹⁶ Irving G, Neves AL, Dambha-Miller H, et al. International variations in primary care physician consultation time: a systematic review of 67 countries. *BMJ Open* 2017;7:e017902.

just one example, are bringing more attention to transphobia among GPs, the lack of acceptance of trans people in healthcare settings, and the biases towards them (Liotta, 2021)¹⁷. Collecting data from a transgender person in a GP setting, coding that data, along with all its implicit biases, into a PMS which is then shared across an entire healthcare system will not lead to better health outcomes for that person. All that data, no matter how well it is coded and captured in a PMS, will not lead to improved health outcomes if transphobia among GPs persists or the biases towards transpeople aren't addressed. An eCDS can't transform implicit biases in healthcare; it reinforces them.

What health outcomes need improving?

A common thread in the CRIS is the insistence on the need to improve Australia's current health system. The CRIS states that an objective behind using shared GP data and eCDS is to feed insights back to GPs to 'improve health outcomes for their community' (Australian Government Department of Health and Aged Care, 2022, p. 62)¹⁸. This statement assumes that current health outcomes need improving.

Calabash Solutions challenges the premise that health outcomes for all Australians need improving:

- Australians are living longer:
 - o In the last 100 years, the life expectancy of Australians has increased by 20 years¹⁹.
 - o In 2011, Australia has 3,700 people aged over 100. By 2050, it is predicted that Australia will have over 50,000 people aged 100 and over²⁰.
 - o At June 2020, one in six Australians are aged 65 or over, with an estimated 4.2 million older Australians (aged 65 and over) and older people comprising 16% of the total Australian population²¹.

¹⁷ Liotta, M. (2021, April 7). Healthcare a peak risk for transgender people. *newsGP*.

<https://www1.racgp.org.au/newsgp/clinical/barriers-to-accessing-care-peak-risk-times-for-tra>

¹⁸ Australian Government Department of Health and Aged Care (2022) [General practice data and electronic clinical decision support Consultation Regulation Impact Statement](#), Australian Government Department of Health and Aged Care website

¹⁹ Australian Government The Treasury (2011) [Australians Living Longer and Living Better](#), Australian Government The Treasury website

²⁰ *ibid.*

²¹ Australian Government Australian Institute of Health and Welfare (2021) [Older Australians](#), Australian Government Australian Institute of Health and Welfare website

- The number of older Australians has increased from 1.0 million (8.3% of the total population) in 1970 and 2.1 million (12%) in 1995 (ABS 2019)²².
- Further, more Australians are dying of Dementia, and fewer are dying of heart disease:
 - Dementia, including Alzheimer's disease, was the second highest leading cause of death in the period 2017-2021²³; in the period 2012-2021, deaths due to Dementia, including Alzheimer's disease increased by 53.8% (5,573 deaths)²⁴.
 - Ischaemic heart disease was the leading cause of deaths in the period 2017-2021; in the period 2012-2021, deaths due to Ischaemic heart diseases decreased by 13.8%²⁵.
- Fewer people are dying from potentially avoidable causes^{26, 27}:
 - The mortality rate for people who died from potentially avoidable causes is the lowest in ten years.

What the data shows is that **some** Australians are living longer, with more people dying from old age (or dying from more complex and more expensive diseases), and fewer people dying from potentially avoidable causes. According to the ABS, Australia's ageing population is a result of sustained low fertility and increasing life expectancy²⁸. Many Australians are living longer for a combination of reasons, some of which include advances in health care and lifestyle choices.

For other Australians, in particular Indigenous Australians, particularly those living in remote areas, health outcomes lag those of non-indigenous Australians. The National Agreement on Closing the Gap (Closing the Gap In Partnership, 2020)²⁹, an agreement between the Coalition of Aboriginal and Torres Strait Islander

²² *ibid.*

²³ Australian Bureau of Statistics (2022) [Causes of Death, Australia](#), Australian Bureau of Statistics website

²⁴ *ibid.*: While the number of dementia deaths has increased over the 10-year period, the age-standardised death rate for dementia has been more stable. This reflects the ageing population in Australia.

²⁵ *ibid.*

²⁶ *ibid.*: Potentially avoidable deaths are defined in [Causes of Death, Australia](#) as 'deaths from conditions that are potentially preventable through individualised care and/or treatable through existing primary or hospital care. They include both natural diseases, including many types of cancer, ischaemic heart disease, diabetes and infectious diseases, and external causes of death (e.g., suicide, assault) of people aged under 75'.

²⁷ *ibid*

²⁸ Australian Bureau of Statistics (2022) [Twenty years of population change](#), Australian Bureau of Statistics website

²⁹ Closing the Gap in Partnership. (2020, July). [National Agreement on Closing the Gap](#). Closing the gap website

Peak Organisations, and all Australian Governments, includes a set of targets to assess how Governments are tracking against the objectives and outcomes of the agreement. Some of the Closing the Gap targets recognise the need to improved health outcome for Indigenous Australians:

1. Close the Gap in life expectancy within a generation, by 2031.
2. By 2031, increase the proportion of Aboriginal and Torres Strait Islander babies with a healthy birthweight to 91 per cent.
3. A significant and sustained reduction in violence and abuse against Aboriginal and Torres Strait Islander women and children towards zero.
4. Significant and sustained reduction in suicide of Aboriginal and Torres Strait Islander people towards zero.

There is a need to refer to reviewed data on outcomes among Indigenous Australians (as well as migrants), along with WHERE people live. What the data shows is that Indigenous Australians living in remote areas have the lowest health outcomes (Australian Institute of Health and Welfare, 2022)³⁰. In general, life expectancy is lower in remote areas, and Indigenous males and females living in major cities are expected to live around 6 years longer than those living in remote and very remote areas.

Australia's GP crisis

Calabash Solutions does acknowledge that, despite improvements in health outcomes over time, there is currently a GP access crisis.

We recognise that demand for GPs in Australia is growing at the same time as the forecasted GP workforce supply is diminishing. In their General Practitioner workforce report³¹, Deloitte found that:

- With an ageing and growing population, demand for GP services is projected to increase by 38% by 2032 (and by 47% in our cities).
- Despite this significant increase, supply of GPs will decrease by 15% in cities and by 4% overall.
- This will result in a shortfall of 11,392 GPs by 2032, or almost 1 in 3 (28%) of the GP workforce.

³⁰ Australian Government Australian Institute of Health and Welfare. (2022, July 07). [Indigenous health and wellbeing](#). Australian Government Australian Institute of Health and Welfare website

³¹ Deloitte. (2022, May). General Practitioner workforce report 2022. Deloitte. <https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-cornerstone-health-gp-workforce-06052022.pdf>.

Compounding the GP shortage issue is the fact that it is more difficult for an individual to see a GP. In 6 *reasons why it's so hard to see a GP*, Stone and May (2023)³² claim that:

- GP clinics are less financially viable than they used to be. 48% of surveyed GPs said their practices were no longer financially sustainable.
- The Medicare rebate has increased much more slowly than inflation and was frozen from 2014 to 2020.
- GPs experience increasing pressure from administrative and compliance activities for Medicare, aged care, disability, social security, health, and workplace sectors.
- The rate of physical and mental illness among GPs is rising, due in part to the stress of increasing workloads, the cumulative effects of exposure to traumatic events and stories, administrative overload, and financial worries.
- The suicide rate for female doctors is more than twice the national average, and rates of depression are high.
- Fewer junior doctors (around 15%) are choosing general practice as a career, driven in part by the more than AUS \$100,000 in Higher Education Contribution Scheme (**HECS**) debts.
- Rural GPs are leaving rural areas, in part due to increased workloads, personal isolation, and more challenging work environments.
- With a global shortage of all health-care workers, fewer overseas-trained doctors are arriving on Australian shores.

Calabash Solutions acknowledges this complex, multifaceted crisis and believes it will exacerbate unless intervention is made now that will result in long-term and permanent fixes. We do not agree that making more health data available to and from GPs will have an impact in remediating the current GP crisis; rather it may be the case that what is being proposed in the CRIS will deepen existing issues faced by GPs by adding to the administrative overhead, capital expenditure (e.g., better IT infrastructure) and costs of trained staff (with better salaries) in GP settings.

Interventions targeted at addressing *real* GP issues will be more beneficial than investments made in GP data and eCDS. To this point, we support efforts to:

³² Stone, L. & May, J. (2023, February 9). 6 reasons why it's so hard to see a GP. *The Conversation*. <https://theconversation.com/6-reasons-why-its-so-hard-to-see-a-gp-199284>.

- Incentivise medical students to pursue general practice as a career, or at least making it more affordable to study medicine.
- Reduce the friction and cost for overseas-trained doctors to work in Australia (for example, by subsidising their assessments).
- Reduce the administrative burden and paperwork required of GPs or their Practice Managers and practice staff.
- Increase the Medicare rebate, to reduce the gap between the cost of care and the rebate, costs which are borne by the GP or their patients.

We offer a perspective borne out of our work with Australian health care providers. Our experience with small- and medium-sized health care clinics shows that in under-resourced clinical practices, it is the Practice Manager (where one exists) who is responsible for managing all aspects of the practice, including triaging medical expertise and resources, while also being the human resource manager, workplace health and safety officer, privacy and security manager, IT support consultant, finance officer, and office manager. In this environment, it is neither reasonable nor fair to add additional responsibilities to an already overburdened job role, even where financial incentives are provided. We have also observed, in our work with specialist clinics, attempts to outsource practice management, in full or in part, to third party companies, with disastrous results to patient satisfaction and staff retention.

RISKS ASSOCIATED WITH HOLDING MORE HEALTH DATA

We do not contest that fact that GPs should, and must continue to, collect and hold information in their patient consultation notes, handwritten or digital. However, it is critical to fully understand the risk associated with making this data available to others in the GP and health-tech ecosystem. It is our view that these risks are not fully explored nor articulated in the CRIS, and in this section of our submission, we put forward what we see as the biggest risks associated with collecting and holding more health data on individuals.

Cost of securing health data

Keeping data safe and secure is expensive. While it is not easy to obtain a dollar value on cybersecurity spending habits, Gartner estimates that, worldwide, organisations spent \$81.6 billion in 2016 on

information security, which was an increase of 7.9 percent from 2015 (CloudMask)³³. Compounding these cybersecurity costs is that fact that the data in scope of the CRIS, being health data, is afforded a higher level of protection under the *Privacy Act 1988 (Privacy Act)* than other types of non-sensitive personal information. The fact that the health data is de-identified in no way diminishes the requirement for robust security and privacy protections, a concept that we explore in more detail below in [Section Commercialising health data](#).

Adding to cybersecurity expenses are the costs associated with a data breach. In their 2022 Cost of a data breach report (IBM, 2022)³⁴, IBM and the Ponemon Institute estimate the average total cost of a breach in the healthcare industry to be US \$10.10M. Cybersecurity and data breach expenses are not the only costs to be considered. Insights for Professionals, in their post *The Cost of Cyber Insurance is Rising. Here's How to Reduce Yours*³⁵ (Insight For Professionals, 2022), writes that the rise in ransomware attacks is one of the reasons why cyber insurance coverage is harder to get and more expensive to retain.

In short, it costs a lot of money (1) to keep data safe and secure, (2) to recover from a data breach, and (3) to insure data. These expenses need to be absorbed by some or all actors in the GP ecosystem; what is not evident in the CRIS is who will foot these costs. If it's to be borne by a GP practice, these additional costs will be most likely to be passed on to consumers (i.e., patients).

What should never be contemplated is a scenario where consumers are expected to pay for expensive, previously unbudgeted-for, cyber protections. Our concern is that where costs are borne by PMS companies and/or extraction software companies, they will be passed downstream to GPs, through increased subscription fees for PMS usage or other such service charges. In turn, consumers may be expected to foot some of the bill.

The non-trivial, increased cyber costs must be absorbed somewhere in the GP data daisy chain, and it is our view that a more robust accountability of costs must be provisioned in the final Regulation Impact Statement (RIS).

³³ CloudMask. *The cost of data security: Are cybersecurity investments worth it?*

<https://www.cloudmask.com/blog/the-cost-of-data-security-are-cybersecurity-investments-worth-it>

³⁴ IBM. (2022). *Cost of a data breach 2022. A million-dollar race to detect and respond.*

<https://www.ibm.com/reports/data-breach>

³⁵ Insight For Professionals. (2022, December 12). *The Cost of Cyber Insurance is Rising. Here's How to Reduce Yours.*

<https://www.insightsforprofessionals.com/it/security/how-to-reduce-cyber-insurance-cost>

Environmental cost of holding more data

Collecting and holding more data contributes to global warming. In 2016, The Independent reported that the amount of energy consumed by the world's data centres will *treble* in the next decade, putting an enormous strain on energy supplies, and dealing a hefty blow to efforts to contain global warming. In Global warming: Data centres to consume three times as much energy in next decade, experts warn (Bawden, 2016)³⁶, The Independent reports that the 416.2 terawatt hours of electricity the world's data centres used in 2015 was far higher than UK's total consumption. The Guardian's How viral cat videos are warming the planet | Greenhouse gas emissions (Vaughan, 2015)³⁷ cites datacentre web servers, such as those used by Google (Alphabet) and Facebook (Meta), are to blame for 2% of greenhouse gas emissions, which is about the same as air travel.

Considering the scale of health data being contemplated by the CRIS, Calabash Solutions questions whether the benefits of collecting and storing more data outweighs the resultant environmental impacts. Further, we argue that resultant environmental impacts associated with storing more data will in turn worsen health outcomes for Australians.

'Climate change is the single biggest health threat facing humanity, and health professionals worldwide are already responding to the health harms caused by this unfolding crisis.' (World Health Organization, 2021)³⁸

³⁶ Bawden, T. (2016, January 23). *Global warming: Data centres to consume three times as much energy in next decade, experts warn*. <https://www.independent.co.uk/climate-change/news/global-warming-data-centres-to-consume-three-times-as-much-energy-in-next-decade-experts-warn-a6830086.html>

³⁷ Vaughan, A. (2015, September 25). *How viral cat videos are warming the planet*. <https://www.theguardian.com/environment/2015/sep/25/server-data-centre-emissions-air-travel-web-google-facebook-greenhouse-gas>

³⁸ World Health Organization. (2021, October 30). *Climate change and health*. <https://www.who.int/news-room/fact-sheets/detail/climate-change-and-health>

The World Health Organization's Climate change and health report (World Health Organization, 2021)³⁹ notes that:

- Climate change affects the social and environmental determinants of health – clean air, safe drinking water, sufficient food, and secure shelter.
- Between 2030 and 2050, climate change is expected to cause approximately 250,000 additional deaths per year, from malnutrition, malaria, diarrhoea, and heat stress.
- The direct damage costs to health (i.e., excluding costs in health-determining sectors such as agriculture and water and sanitation), is estimated to be between US \$2-4 billion per year by 2030.
- Areas with weak health infrastructure – mostly in developing countries, and within Australia, this means remote, rural areas – will be the least able to cope without assistance to prepare and respond.
- Reducing emissions of greenhouse gases through better transport, food and energy-use choices can result in improved health, particularly through reduced air pollution.

Against the bleak picture painted in the WHO report, it is our view that there will be an environmental impact associated with collecting and storing more health data, and that this impact is not offset by any purported health benefits articulated in the CRIS. Rather, the resultant environmental impact associated with storing more health data may be more likely to impair health outcomes for Australians.

COMMERCIALISING HEALTH DATA

There is huge value in health data. In *The economic value of health care data (2013)*⁴⁰, Harper argues that:

'The amount of health care data in our world has been exploding, and the ability to store, aggregate, and combine data and then use the results to perform deep analyses have become ever more important. "Big data," large pools of data that can be captured, communicated, aggregated, stored, and analyzed, are now part of every sector and function of the global economy. While most research into big data thus far has focused on the question of their volume, there is evidence that the business and economic

³⁹ *ibid.*

⁴⁰ Harper EM. (2013, June). *The economic value of health care data.*
<https://pubmed.ncbi.nlm.nih.gov/23454988/>

possibilities of big data and their wider implications are important for consideration. It is even offering the possibility that health care data could become the most valuable asset over the next 5 years as "secondary use" of electronic health record data takes off.'

(Harper, 2013)⁴¹.

The assertion that GP data will be de-identified makes it no less valued, valuable, prized and sought-after. It is a fact that technology companies need big data to build AI and Large Language Model (LLM) solutions, to train and inform their algorithms. It is not only private companies that recognise the commercial value associated with having access to 'big health data'. Governments, too, have recognised the commercial opportunities associated with commoditising health data, as was evidenced by the sentiment of former-US President, Donald Trump, in his efforts to gain access to NHS data (see US wants access to NHS in post-Brexit deal, says Trump ally, Elgot, 2019⁴²). In a frank on-air admission, the US ambassador, Woody Johnson, advised that the US would want its healthcare firms to be able to bid for NHS contracts as part of a post-Brexit trade deal with the UK.

Absent guardrails to either prevent the commercialisation of health data, or severely restrict it through regulated controls (such as consent provisions, consumer opt ins, and the like), the temptation exists for stakeholders in the GP ecosystem to on-sell deidentified health data principally to improve their profits. The potential exists for more than one actor in the GP ecosystem (for example, both the PMS company and the extraction software company) to commercialise and profit from the health data under its control.

And today, with LLM and AI solutions already integrated into online search engines (e.g., Bing-Sydney), we believe it is a matter of weeks and months, not years, before AI and LLMs are present in practice management software, online healthcare booking systems, online symptom checking websites, and mobile phone apps. We have been catapulted into the AI era, and regulation has not kept pace with these technological changes. From what journalists interacting with ChatGPT and Bing-Sydney have experienced,

⁴¹ *ibid.*

⁴² Elgot, J. (2019, June 3). US wants access to NHS in post-Brexit deal, says Trump ally. *The Guardian*. <https://www.theguardian.com/politics/2019/jun/02/us-wants-access-to-nhs-in-post-brexit-deal-ambassador-to-uk-says>.

we have been completely caught out by the arrival and (disturbing) performance of AI and LLMs in the past months^{43 44}.

Stakeholder ethics

Even where robust regulation exists, the possibility remains for actors to not do the right thing: to engage in illegal and/or unethical conduct. Consider, for example, the case of the online health booking platform HealthEngine Pty Ltd (**HealthEngine**), which engaged in misleading and deceptive conduct relating to the sharing of consumer information with insurance brokers. The Australian Competition & Consumer Commission (**ACCC**) alleged that ‘...HealthEngine gave information such as names, phone numbers, email addresses, and date of birth of over 135,000 patients to private health insurance brokers for a fee without adequately disclosing to consumers it would do so⁴⁵’. Their conduct occurred despite a rigorous legislative framework in place to prevent such practices.

In the context of the CRIS, and considering GP data, there is nothing preventing any number of players in the data ecosystem from engaging in illegal and/or unethical conduct, or harnessing any technology – including AI and LLM – to achieve maximum profits.

Seeking consumer consent for the commercial use of their de-identified health data

A policy objective articulated in the CRIS reads:

*‘The department is seeking to protect arrangements for access to de-identified general practice data so that it continues to be shared with relevant stakeholders to facilitate quality improvement in general practice, regional health system planning, analysis of population health needs, public health policy development and research. This sharing should align with the principles that Australia’s public health data should be secure, have appropriate consent and security arrangements, and only be used for **commercial***

⁴³ Roose, K. (2023, February 16). Why a Conversation with Bing’s Chatbot left me deeply disturbed. *The New York Times*. <https://www.nytimes.com/2023/02/16/technology/bing-chatbot-microsoft-chatgpt.html>.

⁴⁴ Siemens, G. (2022, December 22). Not everything we call AI is artificial intelligence: Here’s what you need to know. *The Conversation Australia*. <https://theconversation.com/not-everything-we-call-ai-is-actually-artificial-intelligence-heres-what-you-need-to-know-196732>.

⁴⁵ Australian Competition & Consumer Commission. (2019). [*HealthEngine in court for allegedly misusing patient data and manipulating reviews*](#), Australian Competition & Consumer Commission website.

purposes where there is clear consumer consent for that purpose.' (Australian Government Department of Health and Aged Care, 2022, p. 17)⁴⁶

This proposal would require at least one actor in the ecosystem, most pragmatically the GP, in our view, to seek consumer consent for the use and disclosure of their de-identified health data for commercial purposes. In this solution, the GP will not necessarily be the stakeholder profiting from the commoditisation of the consumer's health data. The consumer will likely have no relationship with those upstream stakeholders (e.g., PMS companies, extraction software companies) who are engaged in commercial pursuits.

In this context, Calabash Solutions rejects the proposal, and argues that consumers cannot provide meaningful, informed, and valid consent, nor can they easily withdraw their consent and be assured that their request has been actioned by an upstream stakeholder so far removed from them. The degrees of separation between the consumer and the profiteering benefactors impede any meaningful consent obligations that are needed to opt in to, or opt out of, commercial arrangements associated with one's health data.

Challenges of consent

A further complication to be factored into consent considerations is *who* has capacity to give consent. As provided in Paragraph B.53 of the Office of the Australian Privacy Commission (OAIC) *Australian Privacy Principles guidelines*⁴⁷, issues affecting an individual's capacity to provide consent include:

- age
- physical or mental disability
- temporary incapacity (such as dementia)
- limited understanding of English

Who can provide consent on behalf of another individual?

⁴⁶ Australian Government Department of Health and Aged Care (2022) [General practice data and electronic clinical decision support Consultation Regulation Impact Statement](#), Australian Government Department of Health and Aged Care website

⁴⁷ Australian Government Office of the Australian Information Commissioner. (2019, July). [Australian Privacy Principles Guidelines Privacy Act 1988](#), Australian Government Office of the Australian Information Commissioner website

Where an individual does not have capacity to provide their consent (even with the support of resources such as enlarged font sizes, text-to-speech options, translation services), consent can be obtained from an authorised representative. Paragraph B.54 of the OAIC *Australian Privacy Principles guidelines*⁴⁸ provides the following examples of who can act on an individual's behalf:

- a guardian
- someone with an enduring power of attorney
- a person recognised by other relevant laws, for example in NSW, a '*person responsible*' under the *Guardianship Act 1987* (NSW) (this may be an individual's spouse, partner, carer, family member or close friend), or
- a person who has been nominated in writing by the individual while they were capable of giving consent.

Calabash Solutions notes that consent provisions are not the same across Australian states and territories. For example:

In NSW, the *Health Records and Information Privacy Act 2002* (**HRIP Act**) defines an '**authorised representative**' to mean (HRIP Act (s8)):

- (a) *an attorney for the individual under an enduring power of attorney, or*
- (b) *a **guardian** within the meaning of the *Guardianship Act 1987*, or a **person responsible** within the meaning of Part 5 of that Act, or*
- (c) *a person having **parental responsibility** for the individual, if the individual is a **child**, or*
- (d) *a person who is otherwise empowered under law to exercise any functions as an agent of or in the best interests of the individual.*

where a '**child**' refers to an individual under 18 years of age,

and where '**parental responsibility**', in relation to a child, means '*all the duties, powers, responsibility and authority which, by law, parents have in relation to their children*' (HRIP Act, s8).

The *Guardianship Act 1987* (s3) defines '**guardian**' to mean:

⁴⁸ *ibid.*

'a person who is, whether under this Act or any other Act or law, a guardian of the person of some other person (other than a child who is under the age of 16 years), and includes an enduring guardian.'

where a **'person responsible'** means:

'(2) Person responsible for child: The person responsible for a child is the person having parental responsibility (within the meaning of the Children and Young Persons (Care and Protection) Act 1998) for the child. However, the person responsible is the Minister if the child is in the care of the Minister or the Secretary if the child is in the care of the Secretary.'

(3) Person responsible for person in care of Secretary The person responsible for a person in the care of the Secretary under section 13 is the Secretary.

(4) Person responsible for another person There is a hierarchy of persons from whom the person responsible for a person other than a child or a person in the care of the Secretary under section 13 is to be ascertained. That hierarchy is, in descending order—

(a) the person's guardian, if any, but only if the order or instrument appointing the guardian provides for the guardian to exercise the function of giving consent to the carrying out of medical or dental treatment on the person,

(b) the spouse of the person, if any, if—

(i) the relationship between the person and the spouse is close and continuing, and

(ii) the spouse is not a person under guardianship,

*(c) a person who **has the care of the person**,*

*(d) a **close friend or relative of the person'** (Guardianship Act 1987, s33A).*

A person **'has the care of another person'** where the person regularly provides domestic services and support to the other person, or arranges for the other person to be provided with such services and support (Guardianship Act 1987, s3D).

A person is a **'close friend or relative'** if they maintain a close personal relationship through frequent personal contact and a personal interest in the other person's welfare (Guardianship Act 1987, s3E).

s85 of Victoria's *Health Records Act 2001* (**HR Act**) provides that an individual is incapable of giving consent where they are '*incapable by reason of age, injury, disease, senility, illness, disability, physical impairment or mental disorder*' (s 85(3), HR Act).

The HR Act defines an '*authorised representative, in relation to an individual*' as a person who is:

- (a) '*a guardian of the individual; or*
- (b) '*an attorney for the individual under an enduring power of attorney; or*
- (c) '*the individual's medical treatment decision maker within the meaning of the Medical Treatment Planning and Decisions Act 2016;*
- (d) '*an administrator within the meaning of the Guardianship and Administration Act 2019; or*
- (e) '*a parent of an individual, if the individual is a child; or*
- (f) '*otherwise empowered under law to perform any functions or duties or exercise powers as an agent of or in the best interests of the individual—*

except to the extent that acting as an authorised representative of the individual is inconsistent with an order made by a court or tribunal' (s85(6), HR Act).

ACT HR (PA) Act considerations

In s26 of the ACT *Health Records (Privacy and Access) Act 1997* (**HR (PA) Act**), a 'guardian' is defined to mean:

- (a) '*a person who is—*
 - (i) '*a legally appointed guardian of the legally incompetent person; or*
 - (ii) '*an attorney, appointed under an enduring power of attorney that has become operative, of the legally incompetent person; and*
- (b) '*a person who has power to make decisions about the medical treatment or health care of the legally incompetent person*'.

What is evident from these three legislative frameworks is inconsistent consent provisions across Australian states and territories. It is our view that these inconsistencies in consent provisions will provide for a complex framework, where the potential exists for actors in the GP data ecosystem engaging in unintentional, non-compliant conduct if they do not comply with local laws when seeking consent from consumers.

Consent considerations are complex and complicated when considering historically marginalised individuals' right to consent. In 'Parental rights' lobby puts trans and queer kids at risk (2022)⁴⁹, Gilbert and Rawlings show that conservative parents and politicians invoke 'parental rights', and, in doing so, deny transgender children and young people the right to information and support, including health care, necessary for well-being, arguing that doing so is equivalent to 'grooming' and 'abuse'. The parental rights lobby in the USA has had 'Don't say gay' legislation passed in Florida, thereby restricting conversations about gender and sexuality in schools, while in Texas, parents seeking out gender-affirming care for their children are being investigated for child abuse. Rights have been thoroughly politicised in a 'hostile, political climate' (Gilbert and Rawlings, 2022), and with that, so has consent.

WHAT LESSONS CAN WE LEARN FROM THE MY HEALTH RECORD SYSTEM

The My Health Record System, which launched in 2012 to provide individuals with a My Health Record and which is administered by the Australian Digital Health Agency (**ADHA**) as the System Operator, provides individuals with an online summary of their key health information. The My Health Record System collates electronic summaries of individuals' health information so it can be accessed by the individual and different healthcare professionals involved in their care.

In understanding how My Health Record data is used, ADHA's December 2022 My Health Record Statistics and Insights report⁵⁰, cites the following in relation the usage statistic:

- 23.5M My Health Records.
- 98% (or almost 23M) My Health Records have records in them.
- Over 830M documents have been uploaded by consumers or healthcare providers (e.g., hospitals, pathologists, GPs, pharmacists).
- In the 12-month period ending December 2022, 1.28M documents were uploaded by GPs which were viewed by other organisations.
- In the 12-month period ending December 2022, 2.03M documents were viewed by GPs which were uploaded by other organisations.

⁴⁹ Gilbert, J. & Rawlings, V. (2022, June 22). 'Parental rights' lobby puts trans and queer kids at risk. *The Conversation*. <https://theconversation.com/parental-rights-lobby-puts-trans-and-queer-kids-at-risk-184804>

⁵⁰ Australian Government Australian Digital Health Agency My Health Record (2022, December). [My Health Record Statistics and Insights December 2022](#). The Australian Digital Health Agency My Health Record website.

Responding to the Australian Digital Health Agency Annual Report 2021-22 (Australian Digital Health Agency, 2022)⁵¹, The Gurdian's My Health Record: after 12 years and more than \$2bn, hardly anyone is using digital service (Davey, 2022)⁵² reports that:

- Twelve years after the introduction of My Health Record, Australians are struggling to access their medical information.
- Clinicians report frustrating difficulties uploading and finding vital health details such as pathology results and diagnostic tests.
- Just 2.69 million of the 23 million people registered for a My Health Record accessed it in 2020-21. While this is an increase of 14% from the previous year, it was largely driven by people accessing Covid-19 vaccination records and Covid-19 test results.
- Day-to-day health records from consultations, emergency department visits, hospital discharges, pathology, and diagnostic testing were still missing from many records.
- More than \$2bn has been spent on the system since it launched in 2012.

What's more, the My Health Record System, a system that already exists, has been touted as having '*the potential to revolutionise the quality and continuity of healthcare in Australia*' (Parliament of Australia, 2018, Paragraph 5.39)⁵³. If this claim made in Senate Estimates is to be believed, we ask (1) what is preventing the My Health Record System from realising this potential and revolutionising the quality and continuity of healthcare in Australia?, and (2) does Australia really need another, new digital system to '*revolutionise the quality and continuity of healthcare in Australia*'.

Further, the Final Report – Parliament of Australia (Parliament of Australia, 2018)⁵⁴ concludes that the My Health Record System needs '*a high degree of support from both the public and medical practitioners. For*

⁵¹ Australian Government Australian Digital Health Agency (2022, June). [Australian Digital Health Agency Annual Report 2021-22](#). Australian Government Australian Digital Health Agency website

⁵² Davey. M. (2022, June 6). My Health Record: after 12 years and more than \$2bn, hardly anyone is using digital service. *The Guardian*. https://www.theguardian.com/australia-news/2022/jun/06/my-health-record-after-12-years-and-more-than-2bn-hardly-anyone-is-using-digital-service?CMP=Share_iOSApp_Other

⁵³ Parliament of Australia. (2018, August 18). [Final Report My Health Record system](#). Parliament of Australia website

⁵⁴ *ibid.*

this to happen, both the public and medical practitioners need to have a high degree of confidence in the integrity of the system' Parliament of Australia, 2018, Paragraph 5.1)⁵⁵.

It is Calabash Solutions' position that instead of investing in a new system to '*revolutionise the quality and continuity of healthcare in Australia*', the Department would be better placed to consider ways to improve the existing My Health Record System, to fully harness its potential and revolutionise the quality and continuity of healthcare in Australia.

DE-IDENTIFICATION DIFFICULTIES AND RE-IDENTIFICATION RISKS

As proposed in the CRIS, GP data will be de-identified, aggregated and shared to benefit the planning and design of health programs. To this end, Calabash Solutions echoes the concerns raised by the OAIC in the Privacy Act Review – Discussion Paper (OAIC, 2021)⁵⁶, that while de-identification is an important and necessary privacy protective measure, it must be considered against the risks of re-identification and the difficulties in robustly and permanently de-identifying personal information in some circumstances.

In support of our concerns, we highlight the breach of myki user's privacy via de-identified information. In their compliance notice issued against Public Transport Victoria (OVIC, 2019)⁵⁷, the Office of the Victorian Information Commissioner (OVIC) found that Public Transport Victoria (PTV) breached the *Privacy and Data Protection Act 2014* by releasing data that exposed myki users' travel histories. This occurred when, in July 2018, PTV released a large dataset which it claimed to have de-identified, containing information from 15 million myki cards to support a datathon event. The dataset recorded 1.8 billion myki 'tap on' and 'tap off' events between July 2015 and June 2018.

In September 2018, academics from the University of Melbourne notified OVIC that they had located the dataset online and identified their own and others' travel histories. In Consultation with OVIC, data experts at CSIRO's Data61 found personal information could be obtained from the PTV dataset without expert skills or resources.

⁵⁵ *ibid.*

⁵⁶ Office of the Australian Information Commissioner. (2021, December 23). [Privacy Act Review – Discussion Paper](#). Office of the Australian Information Commissioner website

⁵⁷ Office of the Victorian Information Commissioner. (2019, August 15). [Information Commissioner investigates breach of myki users' privacy](#). Office of the Victorian Information Commissioner website

As noted by Dr Paul Tyler, Data Privacy Team Leader at CSIRO's Data61, "so-called 'de-identified' data can still carry re-identification risk, especially in linked transactional data".

OVIC's investigation found that PTV failed to address the possibility that individuals in the dataset could be re-identified by combining information in the dataset with information from other sources such as social media.

What the myki breach demonstrates is the difficulty of permanently de-identifying data sets.

Further, and as noted above in [Section Cost of securing health data](#) in relation to cyber security expenses, at least one actor in the GP data ecosystem will need to bear the costs associated with de-identifying GP data, and also with ensuring the data cannot be re-identified. This will most likely fall to extraction software companies, with the possibility that these expenses will flow downstream to PMS companies, to GPs and to consumers. De-identification expenses need to be accounted for in the final RIS.

Risk of re-identification

If we contemplate risks to consumers if their health data is re-identified, we only need to look to the recent Medibank data breach (OAIC, 2022)⁵⁸ to consider risk of serious harm for individuals whose health information is published on the dark web. Consider all risk faced by those whose own history of substance abuse, family violence, family planning procedures, mental health conditions, chronic ailments, sexually transmitted diseases, and the like, are published online, or with their increased risks of experiencing ongoing identity theft and scams.

It is our view that the process of permanent de-identification of data, where there is no risk of re-identification, is a difficult and very expensive one, and these difficulties need to be examined in more detail in the RIS.

⁵⁸ Australian Government Office of the Australian Information Commissioner. (2022, December). . [OAIC opens investigation into Medibank over data breach](#). Australian Government Office of the Australian Information Commissioner website

THE PROBLEMS WITH AI

The CRIS espouses the benefits of adopting eCDS software to assist GPs with *'staying up-to date with the most current advice or guidelines on medicines, disease treatments, referrals and testing'* (Australian Government Department of Health and Aged Care, 2022, p. 30)⁵⁹.

'eCDS, when used by primary healthcare practitioners, bring together a range of information and data to generate recommendations and supporting clinical information. The information and tools included in eCDS can range from clinical guidance information to options for practitioners (including prescribing of pharmaceuticals, requests for pathology and diagnostic imaging services, and referrals for specialist advice).'
(Australian Government Department of Health and Aged Care, 2022, p. 30)⁶⁰

It is our view that the use of 'data to generate recommendations and supporting clinical information' is fraught with risks, and none of the risks are clearly articulated in the CRIS. In this section of our submission, we highlight some of the risks associated with promoting eCDS uptake to improve health outcomes.

The inherent bias of AI solutions

A major concern with the development of machine learning technologies is the issue of bias (implicit or otherwise) and ensuring that programs work equitably for all patients, regardless of age, gender, ethnicity, nationality, and other demographic criteria. It is widely reported that there are instances of bias in AI and machine learning, as demonstrated in just a handful of cases below:

- In Upheaval at Google signals pushback against biased algorithms and unaccountable AI (2020)⁶¹, Walker reported on how ex-Google employee Timnit Gebru showed that *'facial recognition technology was highly inaccurate for Black people.'*

⁵⁹ Australian Government Department of Health and Aged Care (2022) [General practice data and electronic clinical decision support Consultation Regulation Impact Statement](#), Australian Government Department of Health and Aged Care website

⁶⁰ *ibid.*

⁶¹ Walker, M. (2020, December 10). Upheaval at Google signals pushback against biased algorithms and unaccountable AI. *The Conversation*. <https://theconversation.com/upheaval-at-google-signals-pushback-against-biased-algorithms-and-unaccountable-ai-151768?>

- In an experiment undertaken by the US National Bureau of Economic Research, and reported on in *Are Emily and Greg More Employable than Lakisha and Jamal? A Field Experiment on Labor Market Discrimination* (Bertrand & Mullainathan, 2003)⁶², results showed that:
 - o There was significant discrimination against African American names.
 - o White names receive 50 percent more call-backs for interviews.
 - o Race affects the benefits of a better resume.
 - o Applicants living in better neighbourhoods receive more call-backs but, interestingly, this effect does not differ by race.
 - o The amount of discrimination is uniform across occupations and industries.
 - o Federal contractors and employers who list 'Equal Opportunity Employer' in their ad discriminate as much as other employers.
 - o Racial discrimination is still a prominent feature of the US labour market.

The World Economic Forum found that these inequalities are not only perpetuated by human error, but that the algorithms increasingly used by recruiters are not neutral; rather, they reproduce the same human errors they are supposed to eliminate (World Economic Forum, 2019)⁶³.

- Reuters reported in *Amazon scraps secret AI recruiting tool that showed bias against women* | Reuters (Dastin, 2018)⁶⁴ how Amazon's AI recruiting tool was not rating candidates for software developer jobs or other technical posts in a gender-neutral way, because '*computer models were trained to vet applicants by observing patterns in resumes submitted to the company over a 10-year period. Most came from men, a reflection of male dominance across the tech industry.*'

⁶² Bertrand, M. & Mullainathan, S. (2003, July). *Are Emily and Greg More Employable than Lakisha and Jamal? A Field Experiment on Labor Market Discrimination*. *National Bureau of Economic Research*. <https://www.nber.org/papers/w9873>

⁶³ World Economic Forum (2019, May). *AI-assisted recruitment is biased. Here's how to make it more fair*. *World Economic Forum*. <https://www.weforum.org/agenda/2019/05/ai-assisted-recruitment-is-biased-heres-how-to-beat-it/>

⁶⁴ Dastin, J. (2018, October 11). *Amazon scraps secret AI recruiting tool that showed bias against women*. *Reuters*. <https://www.reuters.com/article/us-amazon-com-jobs-automation-insight/amazon-scraps-secret-ai-recruiting-tool-that-showed-bias-against-women-idUSKCN1MK08G>

- In Your Gender and Race May Determine Which Facebook Ads You See (northeastern.edu) (2019)⁶⁵, Thomsen reported how a team at Northeastern University tested Facebook’s algorithm and found its delivery of advertisements is skewed by race and gender. Lead researcher Alan Mislove, an associate dean, director, and associate professor at Northeastern’s Khoury College of Computer Sciences, was quoted:

“Increasingly, our lives are being mediated by large online algorithm-based platforms,” Mislove says. “But there are other domains where that controlling of the flow of information could lead to significant negative outcomes for society at large. The most obvious of those are credit, housing, and employment, which, in addition to being very important domains, also have special legal protection.” (Thomsen, 2019)⁶⁶.

- In the MIT Technology Review’s The coming war on the hidden algorithms that trap people in poverty (2020)⁶⁷, Hao argues that *‘(C)redit-scoring algorithms are not the only ones that affect people’s economic well-being and access to basic services. Algorithms now decide which children enter foster care, which patients receive medical care, which families get access to stable housing. Those of us with means can pass our lives unaware of any of this. But for low-income individuals, the rapid growth and adoption of automated decision-making systems has created a hidden web of interlocking traps.’*

⁶⁵ Thomsen, I. (2019, April 11). A Northeastern University team tested Facebook’s algorithm and found its delivery of advertisements is skewed by race and gender. *Northeastern Global News*.

<https://news.northeastern.edu/2019/04/11/a-northeastern-university-team-tested-facebooks-algorithm-and-found-its-delivery-of-advertisements-is-skewed-by-race-and-gender/>

⁶⁶ *ibid.*

⁶⁷ Hao, K. (2020, December 4). The coming war on the hidden algorithms that trap people in poverty. *MIT Technology Review*. <https://www.technologyreview.com/2020/12/04/1013068/algorithms-create-a-poverty-trap-lawyers-fight-back/>

- In Poverty-Lawgorithms-A Poverty Lawyer's Guide to Fighting Automated Decision-Making Harms on Low-Income Communities (2020)⁶⁸, Gilman explains how to deal with issues raised by algorithms and other data-driven technologies within the scope of existing laws.
- In Michigan's MiDAS Unemployment System: Algorithm Alchemy Created Lead, Not Gold (2018)⁶⁹, Charette reports on what happens when AI systems get things wrong, with a more egregious malfunction occurring in Michigan in 2013, when the state used AI technology to automate their unemployment benefits system. The Michigan MiDAD Unemployment System incorrectly flagged over 34,000 people for fraud, which resulted in personal trauma, ruined reputation and credit scores, home foreclosures, homelessness, bankruptcies and for some, suicides.

WHAT ABOUT BIASES IN HEALTHCARE AI SYSTEMS

Examples of biases in healthcare abound. Consider the following:

- In The Royal College of Surgeons of England report on Bias in medical artificial intelligence (2021)⁷⁰, Al Hasan opines on the **bias cascade**.

'The bias cascade starts with the data collection process. Disparities are known to exist in the recruitment of research subjects, where certain populations (e.g., women) are underrepresented. Since data form the technology's backbone, biased or skewed data fed into AI algorithms will eventually result in biased and therefore inaccurate clinical performance. Machines are only as impartial as the data that have been fed into them. Experts using these data to construct algorithms may also carry their own prejudices and these may further compound inherent bias in the technology. Finally, access to

⁶⁸ Gilman, M. (2020 September 15). Poverty-Lawgorithms-A Poverty Lawyer's Guide to Fighting Automated Decision-Making Harms on Low-Income Communities. *Data & Society*. <https://datasociety.net/wp-content/uploads/2020/09/Poverty-Lawgorithms-20200915.pdf>

⁶⁹ Charette, R. (2018, January 24). Michigan's MiDAS Unemployment System: Algorithm Alchemy Created Lead, Not Gold A case study into how to automate false accusations of fraud for more than 34,000 unemployed people. *IEEE Spectrum*. <https://spectrum.ieee.org/michigans-midas-unemployment-system-algorithm-alchemy-that-created-lead-not-gold>

⁷⁰ Al Hasan. AJMS. (2021, August 31). Bias in medical artificial intelligence. *Royal College of Surgeons of England*. <https://publishing.rcseng.ac.uk/doi/full/10.1308/rcsbull.2021.111>

healthcare facilities and medical technology suffers its own forms of inequalities, culminating in a compound interest of bias.' (Al Hasan, 2021)⁷¹,

- The article cites examples of a range of biases, including:
 - o Racial bias (e.g., how plastic surgery AI designed to detect features of attractiveness on patient photographs would make detrimental decisions on Asian patients if it were programmed to recognise only White features for signs of beauty, and AI taught to detect skin cancer on images of fair skin may not be able to reliably diagnose lesions on darker skin)
 - o Gender bias (e.g., how AI driven software used to read chest X-rays underperformed in the diagnosis of various thoracic diseases whenever it was confronted with data from underrepresented genders)
 - o Socioeconomic bias (e.g., how socioeconomic disparities, originally driven by racial disparities, resulted in an underestimation of sickness in Black patients when a hospital AI algorithm designed to identify patients who will benefit most from extra care to reduce their future healthcare costs, overlooked all the socioeconomic and racial barriers Black patients face, from difficulties in accessing hospital care in poverty stricken communities to the inability to afford insurance premiums and treatment, and the general distrust in healthcare and fear that Black communities may hold based on unpleasant past experiences of racial discrimination. Consequently, the sicker and poorer patients, on whom less money was already being spent, were unlikely to be offered the extra care they required based on the algorithm's inherently biased choices.)
 - o Linguistic bias (e.g., University of Toronto used an AI algorithm to identify language impairment as an early sign of Alzheimer's disease. In practice, however, the algorithm was best at identifying Canadian English, putting French speakers and those who used other dialects at a disadvantage and, therefore, at risk of being misdiagnosed).

⁷¹ Al Hasan. AJMS. (2021, August 31). Bias in medical artificial intelligence. *Royal College of Surgeons of England*. <https://publishing.rcseng.ac.uk/doi/full/10.1308/rcsbull.2021.111>

- The Gender bias in healthcare: Examples and consequences (Villines, 2021)⁷², reports on some of the consequences of gender bias, including: knowledge gaps, lack of women in leadership, delayed diagnosis, inadequate system management, avoidance of medical care, and abuse, neglect and death.
- As was reported above, in Algorithmic Bias in Health Care Exacerbates Social Inequities — How to Prevent It (2021)⁷³, Igoe argues that '*algorithms in health care technology don't simply reflect back social inequities but may ultimately exacerbate them*'.

What we know is that AI and LLM technologies are fed by big data, and that these big data feeding machines are not always representative the whole population. As such, AI technologies perpetuate the data inequalities and data gaps that feed them, resulting in biases. As highlighted above, the risk of harm when biases perpetuate stereotypes may be the misdiagnosis of serious illness, undertreatment as a result of a misdiagnosis, overtreatment resulting in expensive but necessary procedure, or death. The psychological consequences may be equally harmful or deadly.

A consumer visiting their GP is more than the sum of their symptoms, or the sum of the symptoms they choose to disclose to their GP. They present complex symptomology, made no less complicated by familial, genetic, lifestyle, dietary, socioeconomic, cultural, ethnic factors that cannot reduce a consumer to their health-related data points.

Do consumers have a right to appeal an AI decision: Don't blame me, the algorithm made me do it

Australia does not currently have specific laws regulating AI, big data or algorithmic decision making. However, as reported in Artificial intelligence can now be recognised as an inventor after historic Australian court decision (Jones, 2021)⁷⁴, the Australian Federal Court set a ground-breaking precedent when it decided that AI systems can be legally recognised as an inventor in patent applications. DABUS, or Device for the Autonomous Bootstrapping of Unified Sentience, was recognised as an inventor after its inventor

⁷² Villines, Z. (2021, October 25). What to know about gender bias in healthcare. *Medical News Today*. <https://www.medicalnewstoday.com/articles/gender-bias-in-healthcare>

⁷³ Igoe, K. (2021, March 12). Algorithmic Bias in Health Care Exacerbates Social Inequities — How to Prevent It. *Harvard T. H. Chan School of Public Health*. <https://www.hsph.harvard.edu/ecpe/how-to-prevent-algorithmic-bias-in-health-care/>

⁷⁴ Jones, A. (2021, August 1). Artificial intelligence can now be recognised as an inventor after historic Australian court decision. *ABC News*. <https://www.abc.net.au/news/2021-08-01/historic-decision-allows-ai-to-be-recognised-as-an-inventor/100339264>

demonstrated how, over time, the AI system was able to independently generate new and inventive outputs.

At Calabash Solutions, we argue that if the Australian Federal Court has recognised an AI system as an inventory, with an ability to independently generate new and inventive outputs, what happens when one of the new and inventive outputs is the wrong output. The fact that there is neither laws regulating AI, nor legal precedent in this regard, makes it impossible to understand a consumer's right to challenge a decision made by an AI system, such as eCDS software, in their diagnosis or treatment.

Compounding this is the issue that, globally, the problem appears not to have been resolved. As reported in *Medical Malpractice And Artificial Intelligence: Can You Sue An AI For Malpractice?* (Med Gadget, 2020)⁷⁵, AI systems cannot be held liable for medical malpractice, because ultimate responsibility resides with the GP. However, in *Can an artificial intelligence algorithm be sued for malpractice? (2020)*⁷⁶, Jha puts forward the case that, in some instances, the AI vendor can be sued, where the vendor is not shielded from liability (in USA, the shield of pre-emption would prevent a vendor being sued where the product has FDA approval and meets federal, but not all state, legislative regulations).

General mistrust of AI systems by GPs

Absent AI laws in Australia, it is also not clear whether GPs who use eCDS software can blame misdiagnoses or poor health outcomes (and treatment non-adherence) on the eCDS software. The Royal Australian College of GPs (**RACGP**) outlines potential problems and unwanted outcomes associated with AI in primary care (RACGP, 2021)⁷⁷. As reported by the RACGP, a major impediment to the uptake of AI within primary care is likely to be a lack of trust in the technology. There is scepticism about AI's ability to deliver care, and many GPs believe that patients will not accept a technological substitute for face-to-face human care.

⁷⁵ Med Gadget. (2020, June 16). *Medical Malpractice And Artificial Intelligence: Can You Sue An AI For Malpractice?* *Med Gadget*. <https://www.medgadget.com/2020/06/bmedical-malpractice-and-artificial-intelligence-can-you-sue-an-ai-for-malpractice.html>

⁷⁶ Jha. S. (2020, March 9). *Can you sue an algorithm for malpractice? It depends.* *STAT*. <https://www.statnews.com/2020/03/09/can-you-sue-artificial-intelligence-algorithm-for-malpractice/#:~:text=The%20answer%20is%2C%20%E2%80%9CIt%20depends.%E2%80%9D%20If%20Innovative%20C%20are,assumes%20the%20risk%20of%20letting%20AI%20fly%20solo.>

⁷⁷ Royal Australian College of General Practitioners. (2021, March). *Artificial intelligence in primary care Position statement – March 2021*. Royal Australian College of General Practitioners website

Further, the lack of collaboration between professionals from the fields of medicine , nevermind between medicine and the social sciences, and AI contributes to this lack of trust and acts as a barrier to uptake.

‘Without clinicians involved in the design, implementation and regulation of AI technologies, there is a risk that the healthcare system will inherit products that not only fail to solve existing problems, but create new and unforeseen ones in their wake.’

(RACGP, 2021)⁷⁸

GPs have voiced their concerns that failure to engage in this process could result in systems or products that do not benefit either clinicians or patients, where value to technology company shareholders might be prioritised over patient outcomes.

The CRIS does not shy away from this concern; instead, it leans into the debate, about a lack of peer reviews and transparency in black box functioning, by articulating that *‘stakeholders have expressed concerns that they do not know how the software has come to the recommendation provided to the practitioner. Limited transparency can result in a lack of trust in eCDS recommendations and a reluctance of GPs to rely on eCDS recommendations.’*

A potential to lose or diminish GP knowledge and skills

Calabash Solutions supports the arguments made in the CRIS that the reliance on eCDS could result in a perception of de-skilling GPs, where GPs rely too heavily on the recommendations provided by the eCDS software, and not use their knowledge and experience to make clinical decisions. While the consensus of the medical community is that eCDS should not be used to replace GPs’ autonomous decision making, and should be a support tool only, until such time as guidance and guardrails are in place, at best it is up to the individual GP; at worse, it is left to eCDS software companies to dictate.

⁷⁸ *ibid.*

AN UNDERFUNDED AND UNDER RESOURCED REGULATOR

It is widely reported that the Australian Information Commissioner is chronically underfunded and under-resourced (H, 2020)⁷⁹. In Privacy office is still ‘severely underfunded’ (2020)⁸⁰, Sadler reports that the OAIC missed all but one of its performance goals in the last year, leading to concerns the agency is “severely underfunded” and will be unable to effectively perform its role without a substantial resourcing boost.

Against this backdrop, and knowing regulator resourcing issues are not unique to the OIAC, Calabash Solutions voices concern with any proposal that requires regulatory oversight without significant investment in funding to that regulator by the Australian government.

Proposals that promote stakeholder-led regulation or incentive-based regulation have learnt nothing from cases - from a range of sectors as diverse as casinos, energy, banks, supermarkets - where self-regulation and incentive-based regulation have not worked.

The problem with stakeholder-led regulation

Of concern to Calabash Solutions are reform options that promote stakeholder-led regulation. Our main concern is that key stakeholders in the GP data and eCDS ecosystems will not likely put consumer interests first. Absent the voice of the consumer, their rights, obligations and interests will not be prioritised or serviced. Profits may be prioritised over ethics, considering the cohorts of stakeholders (e.g. eCDS vendors) in the ecosystem.

In Self-regulation carries an array of potential dangers - Ascend Magazine Website (2021)⁸¹, Milian reports on some of the pitfalls associated with self-regulations, some of which include:

- Giving rise to conflicts of interest
- Betraying public interest
- Abuse of power

⁷⁹ H, S. (2020, October 17). Understrength and underfunded: the state of private sector privacy law enforcement in Australia. *My Privacy Officer*. <https://myprivacyofficer.com.au/understrength-and-underfunded-the-state-of-private-sector-privacy-law-enforcement/>

⁸⁰ Sadler, D. (2020, October 13). Privacy office is still ‘severely underfunded’. *InnovationAus.com*. <https://www.innovationaus.com/privacy-office-is-still-severely-underfunded/>

⁸¹ Milian, J. (2021, September 24). Self-regulation carries an array of potential dangers. *Ascend A Magazine by Thentia*. <https://ascend.thentia.com/process/dangers-self-regulation/>

- Lack of transparency

The problem with incentive-based regulation

Equally concerning to Calabash Solutions are reform options that incentivise stakeholders to share GP data and/or use eCDS software. As articulated in Harvard Business Review's Why Incentive Plans Cannot Work (Kohn, 1993)⁸², there is growing evidence that rewards typically undermine the very processes they are intended to enhance, and that the failure of any given incentive program is due less often to a glitch in that program than to the inadequacy of the psychological assumptions that ground such plans.

'Rewards do not create a lasting commitment. They merely, and temporarily, change what we do.' (Kohn, 1993)⁸³

Reasons cited in the article regarding why rewards fail include:

- Pay is not a motivator.
- Rewards punish.
- Rewards rupture relationships.
- Rewards ignore reasons.
- Rewards discourage risk-taking.
- Rewards undermine interest.

Calabash Solutions rejects a proposal that would incentivise eCDS software companies' compliance. Rather, we support efforts to penalise non-compliance with heavy fines used to disincentivise non-compliant conduct.

⁸² Kohn, A. (1993, October). Why Incentives Cannot Work. *Harvard Business Review*. <https://hbr.org/1993/09/why-incentive-plans-cannot-work>

⁸³ *ibid.*



OUR VISION

Healthy. Safe. Respected. Free.

We believe in a world where all people are healthy, safe, free, and respected.

OUR MISSION

Helping Others.

The best versions of ourselves emerge when we help others to be the best versions of themselves.

OUR APPROACH

Listen. Support. Analyse. Discover

- We value patient privacy, and work with health service providers to assure and implement compliant privacy programs.
- We listen to patients and carers as they talk about their journeys through all systems of care.
- We develop and deliver Continuous Professional Development (CPD) for clinicians, support staff, and practice managers.
- We work with small and medium datasets to understand what inhibits or enables treatment compliance within unique patient cohorts.
- We embrace solutions that work, from technology to the creative arts, to cultivate health systems that deliver patient-centred care.

CONTACT

W www.calabashsolutions.net

E info@calabashsolutions.net

M +61 (0) 430 231 184

OUR PRIVACY SERVICE OFFERINGS

Online Privacy Training

Designed specifically for private sector health care workers. Offers a commonsense, practical view of the Australian Privacy Principles. Demonstrates how to apply the Australian Privacy Principles in Australian private health care sector.

Face-to-Face Training

Register for face-to-face training delivered at your practice, for your team.

Face-to-face training lets you and your team discuss your practice-specific privacy questions, concerns.

Privacy Compliance Assessment

Does your practice comply with the Australian Privacy Act?

We assess your practice's compliance with the privacy principles using our privacy compliance assessment tools.

Onsite visit and review of your privacy systems, processes, and practices against the thirteen Australian Privacy Principles contained in the Privacy Act.

Privacy Compliance Heat Map

After the privacy compliance assessment, we produce your unique privacy compliance heat map showing areas of strong and weak compliance against the thirteen Australian Privacy Principles.

Templated Privacy Processes

Use our privacy compliance heat map to uncover your areas of weak compliance. We work with you to strengthen the gaps and create privacy processes for your practice

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