Health and public sector data sharing requires social licence negotiations

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Over the past two decades, Australian governments and researchers have invested in building the infrastructures and legal frameworks to enable public sector data linkage. For public health researchers, securely and safely shared anonymised population-based data – as enabled by data assets such as the Australian Bureau of Statistics' MADIP[1] – is akin to a collective resource managed as a public good.[2-4] Among its diverse applications (e.g. health systems efficiencies, treatment innovations and medicine safety monitoring), the analysis of linked public sector data (such as health, disability, welfare, taxation, education, census) offers a powerful new lens into the social and political drivers of health.[5] Although the public good that can ensue from public sector data seems clear, it is not inevitable. In this commentary, we argue that building a social license will be fundamental to ensuring that data integration operates as a public good.

Widening access to public sector data has diverse trajectories, one being to facilitate information sharing between jurisdictions, government departments, researchers and industry.[6,7] Public sector data are also envisaged as an economic asset, as illustrated by the *2021 National Data Strategy* and the Productivity Commission's *Data Availability and Use* report.[8] The report highlights the role of the private sector in wealth creation and cites estimates of the annual economic value of public sector data ranging from AU$625 million to AU$64 billion: "data can create commercial value … It enables firms to create new products and services, enhance existing ones, and introduce entirely new business models".[8] Beyond advancing healthcare and medical research, public sector data integration can drive social transformations, such as economic growth with or without redistribution of benefits arising from a public asset,[9] over-surveillance of or poor policy pertaining to already disadvantaged or socially excluded groups.[10] Shaping the social transformations arising from data integration may be beyond the remit of ethics committees.[11] Work on Indigenous Data Sovereignty suggests that genuine Indigenous ownership of data governance matters for shaping the outcomes of data integration.[12] As emphasised in the Australian Medical Association's 2019 submission to the Office of the National Data Commissioner (ONDC), the specific details of both legislation and professional practices that regulate data infrastructures matter. So too does public engagement. The ONDC has consulted across government jurisdictions, with the research sector and with key stakeholders, and has invited public submissions on draft legislation. Some other developments in public sector data integration have entailed public consultation or the inclusion of consumer representatives in decision-making forums. Yet without broad, sustained public dialogue, it is difficult to gauge public awareness, concerns or hopes regarding data integration.

This paper examines the importance of a social licence for public sector data integration to realise these public goods. While a social licence has been used and conceptualised in different ways, there is agreement that it is distinct from legal or economic legitimacy and that it foregrounds the – often contested – values that publics bring to social changes which may ensue from new developments.[13] Moreover, there is clear evidence that social licences granted by publics are effective in supporting and shaping technological developments when they are co-produced through an ongoing process of public engagement, dialogue and negotiation.[14] Neither passive public acceptance nor closed discussions with select community representatives indicate the existence or form of a social licence.[14] We examine the risk of advancing public sector data integration without establishing a process for gauging and calibrating data integration development with its social licence: i.e. the risk of undermining public trust in the government agencies and health services involved in collecting, curating and sharing data.

What do Australians think about public sector data sharing?

The July 2021 *Intergovernmental Agreement on Data Sharing between Commonwealth and State and Territory Governments* states that data access requests "may be refused if … sharing is inappropriate from a … social licence perspective, *despite* the proposed public interest" (emphasis added). This is clear governmental acknowledgement of the importance of aligning data use with its social licence. But what are the Australian public's – or diverse and differently situated publics' – hopes for and concerns about governments, researchers and industry gaining access to public sector data? We have useful indications of public sentiment about *some* aspects of data sharing. Of respondents to Research Australia polls conducted in 2016 and 2019, 79% and 78%, respectively, indicated they would agree to share their own de-identified health information to "advance medical research".[15] A survey to examine Australians' thinking about private sector access to health data found that 51% disagree with allowing the private sector to profit from data access and 24% are neutral.[16] Office of the Australian Information Commissioner surveys on Australian attitudes to privacy suggest a shift in public thinking towards affirming data sharing between government agencies, albeit a minority support the practice (30% in 2017, 36% in 2020).[17] Such surveys offer an estimate of some aspects of public sentiment, but they cannot tease out people's awareness of existing data infrastructure, regulation or practice, their reasoning, or – most importantly, regarding the development of a social licence – their specific concerns or hopes regarding the roles data sharing may play in social change.

Trust, transparency and values

What people want matters. If developments in the use of public sector data do not align with the social licences granted we risk losing public trust, not only in data systems and analysts, but in government, and even in the public facing healthcare workers and professionals who gather data while delivering healthcare or government services. Existing research gives us useful entry points into some fundamentals we can anticipate. Firstly, private sector involvement is a fraught issue for Australians.[18] A review of research undertaken in the UK, US, Canada, Japan and Sweden identified widespread conditional support for health data access for research purposes – one of the common conditions being to regulate private profit.[19]

Secondly, decades of research into public trust of the regulation of technology demonstrates that publics often know technology entails fundamental uncertainties and mistrust actors who fail to acknowledge this or who claim certain knowledge of the future.[20,21] Beyond interest in the safety of new technologies, people are commonly invested in the values manifesting in social transformations triggered by technological change.[20,22] Likewise, research suggests that publics care about the role of data integration in social change. A report for the UK National Data Guardian identified that trust hinges on transparency to the public across "the full cycle of data collection, assessment, use and impact".[23] The report found that people care that data analysts have domain expertise, about possibilities for fuelling negative views of marginalised groups, and that data are used to inform equitable health and welfare policies.[23] This illustrates the importance of acknowledging potentially different values that publics and other stakeholders bring to negotiations of social licence.[20]

The importance of transparent calibration of the public interest with a social licence

One of the important recent reforms, the *Data Availability and Transparency Act 2022*, involves measures for transparency over some parts of the data lifecycle – access and use. The legislation's explanatory memorandum stated (in 2020) that it aims to regulate access to public sector data for "the delivery of government services, to inform government policy and programs and for research and development purposes". The purposes may encompass private sector profit-making but exclude compliance activities. Public transparency measures include registers of accredited users and information about which data is accessed, by whom, the safeguards in place, the benefits anticipated and how a specific data request is in "the public interest". Consideration of the public interest could, potentially, entail deliberation over how specific data uses might contribute to wider social transformations as public interest assessments are to consider "the potential benefits and risks to the economy, public health, the environment and overall social wellbeing".[24] In developing the bill it was decided that the meaning of "public interest" be kept open because it will "evolv[e]" with technological transformation and because "[c]ommunity expectations around public interest are subjective and change over time".[24] Yet, there is no clear mechanism for the transparent assessment of evolving "community expectations". In 2018, the National Data Advisory Council were envisaged as being responsible for advising the Data Commissioner on "social licence", however, this specific role was no longer in the terms of references endorsed at their first meeting in 2019.[25] Estimations of the public interest by professionals involved in deliberating over data requests may or may not align with social licences. The *Intergovernmental Agreement* suggests that the social licence for data-sharing should be treated as the bedrock for transparent decisions about the public interest. However, in the absence of sustained publicly transparent processes for acknowledging public hopes, concerns and values and for negotiating how these can shape developments in data integration and its uses, there is a risk that professionals' estimations of public interest will stand in for, or even obscure, what people care about.

A shifting, working consensus

Some agencies have consulted with nominated community representatives or courted wider opinion via public consultations. However, if the consultation processes themselves are not publicly accessible, and if decisions about public interests are not clearly connected with public concerns and hopes – such that all can see, debate, contest – opportunities for democratically shaping the social transformations ensuing from data integration are effectively closed. Some suggest that using public sector data for economic growth is incommensurable with the values of people whose data is being shared.[26] Others are less fatalistic, but identify that "innovation" using public sector data can yield private profit without resulting in public good, highlighting the need to ensure that data governance is developed in ways that attend to, rather than undermine, democratic citizens' active involvement in shaping their social worlds.[27] An effective social licence is always a context-specific process, which centres on acknowledging rather than decentring diverse public values.[14] The glimpses we have about Australians' concerns indicate that people may value differently, differences likely shaped by current and historical experiences of inclusion, access to public goods, and trust in government and in researchers and industries interested in accessing public sector data, as well as different visions of social futures. Given the diversity of interests, uses and potential outcomes envisaged in Australian data reform – from private profit and economic growth through to equitable policies designed to improve the well-being of socially excluded groups – we can reasonably anticipate that the concerns of Australians will diverge depending on proposed uses and users. With so much already invested, the prospect of an ongoing process of public negotiation to establish and monitor a social licence may seem daunting. Yet, the challenge of seeking out, acknowledging and transparently navigating potentially fractious differences in public values is by no means unique to data integration, and similar challenges have been met before. Research on regulating medical technologies suggests that with extensive public dialogue it is possible to hear and acknowledge starkly different perspectives and, over time, build trust and transparently establish a workable consensus,[28] a consensus that may shift with ongoing engagement and time. This requires an enduring, transparent process for public involvement in the regulation and use of public sector data – a process that tracks differences and shifts in the social licence Australian publics grant for data integration, and underpins decisions that reflect that licence.

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