

# Data availability and Use

## Joint Councils of Social Service Network submission to the Productivity Commission

August 2016



# About the Councils of Social Service

The nine Councils of Social Service (COSSes) are the respective National, State and Territory peak bodies of the community services sector and a voice for the needs of people affected by poverty and inequality. The Councils are:

- The Australian Council of Social Service (ACOSS)
- The Australian Capital Territory Council of Social Service (ACTCOSS)
- The Council of Social Service of New South Wales (NCOSS)
- The Northern Territory Council of Social Service (NTCOSS)
- The Queensland Council of Social Service (QCOSS)
- The South Australian Council of Social Service (SACOSS)
- The Tasmanian Council of Social Service (TasCOSS)
- The Victorian Council of Social Service (VCOSS)
- The Western Australian Council of Social Service (WACOSS)

This submission has been prepared for the COSS Network with the assistance of WACOSS and VCOSS. It has been authorised by the Chief Executive Officer of each Council.

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## Recommendations

1. Make improving outcomes from publicly funded and supported service delivery a central goal of improved data collection and use
2. Develop a centralised mechanism for data integration and dissemination to inform policy and program development and collaboration
3. Develop clear and consistent measurements of service outcomes, underpinned by a capacity-building strategy to enable the community services sector to engage in data sharing and analysis
4. Reinstate production of the Socio-Economic Index for Individuals (SEIFI) by the ABS
5. Increase availability of local area data and improve collection of demographic information for disaggregation
6. Investigate the benefits and risks of a shared consumer record
7. Invest in IT platforms that encourage information sharing between community agencies, and in building the capacity and expertise of the community sector in information sharing
8. Ensure any data integration, linkage and utilisation activity only occurs after evaluation of the potential positive and negative impacts for the individuals whose data is being used
9. Allow consumers to consent to what data is shared and with whom, providing them with choice and control in protecting their privacy
10. Increase consumer access to their own data, to empower them to make informed choices about services and care

## Introduction

The nine Councils of Social Service (the Councils) welcome the opportunity to provide comment on the Productivity Commission Issues Paper *Data Availability and Use*.

The community services sector is a unique and valuable component of Australia's economy and society. It offers programs and services to help people overcome disadvantage and poverty, advocates for policy solutions, supports a wide range of people with multiple and complex needs, and generates significant income, employment and social capital.

Authoritative and reliable sources of data are fundamental to developing the programs and service delivery undertaken by the community services sector. Good use of data makes it possible to tackle complex, intergenerational and entrenched disadvantage and inequality.

The Councils are particularly interested in the potential of better data sharing, data quality and data analysis to improve the capacity of community services to deliver better long-term outcomes for vulnerable and at-risk groups within our community, while ensuring appropriate safeguards to manage associated risks.

This requires improved data sharing and linkages involving our tax and transfers system, and Federal and State data on community need and service outcomes. Achieving this means more data sharing with the community services sector, and mechanisms to improve social service data quality and comparability. There is significant public sector data on community need and service outcomes, including data generated from contracted social services reporting requirements.<sup>1</sup> The inquiry is concerned with ensuring the availability and use of data providing 'the maximum net benefit to society'. This clearly encompasses making better use of existing data to improve the well-being, economic participation, and life outcomes for some of our most disadvantaged, at-risk and vulnerable citizens.

Better data sharing and analysis can improve the design and efficiency of community services delivery, and more effectively target prevention or early intervention services to individuals and cohorts most at risk of poorer life outcomes, which could reduce service costs in the long term. Given the potential positive impacts, we are concerned the framing of this inquiry (and to a lesser extent of the Commonwealth's *Public Data Policy Statement* and the *National Innovation and Science Agenda*) risks missing an opportunity for improved economic and social outcomes due to their primary focus on government and private sector data and lack of due consideration of human services.

We note that these issues are also of direct relevance to the Productivity Commission's current *Human Services: Identifying sectors for reform* inquiry.<sup>2</sup> Without the ability to quantify outcomes and accurately calculate long-term systemic costs, there can be no informed discussion as to the impact that greater competition, contestability and user choice would have within the human services sector and on service users.

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<sup>1</sup> Much of this data relates to state funded and joint-funded and state managed services.

<sup>2</sup> Productivity Commission (2016), *Human Services: Identifying sectors for reform*  
<http://www.pc.gov.au/inquiries/current/human-services/identifying-reform/issues/human-services-identifying-issues.pdf>

# Use data for social purposes

## Use data to drive better social outcomes

### Recommendation

Make improving outcomes from publicly funded and supported service delivery a central goal of improved data collection and use

A significant benefit likely to arise from improved data sharing, quality and analysis is transforming social services design and delivery to dramatically improve service outcomes and reduce long-term costs. This is identified as one of the three priorities of the Commonwealth's *Public Data Policy Statement*<sup>3</sup> and also in the discussion paper on *Public Sector Data Management*,<sup>4</sup> but is not included as a priority in this inquiry's terms of reference.

Using better data linkage for improved social service outcomes depends upon the ability to:

1. Identify risk factors and quantify the probabilities of poor life outcomes, to more accurately target people most likely to face poor long-term life outcomes
2. Design and deliver transformative wrap-around services to specific cohorts facing complex need or entrenched disadvantage
3. Quantify integrated service model outcomes, to compare costs and benefits of service models and service user targeting to maximise benefits of earlier intervention approaches based on known risk factors
4. Confidently and accurately calculate and compare the long-term system costs and community benefits in a manner that allows quantification of long-term savings.

The discussion paper identifies the long-standing issue of how governments can improve their service provision, which arguably includes the provision of services they commission, fund or subsidise through charitable tax concessions. However, it appears to dismiss this in favour of considering how developments in data-management might help 're-shape markets' or 'alter previously-accepted paradigms of disadvantage and societal need.'<sup>5</sup> The meaning and intent of these comments is not entirely clear in the discussion paper and we recommend they be clarified in the report.

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<sup>3</sup>

[http://www.dpmc.gov.au/sites/default/files/publications/aust\\_govt\\_public\\_data\\_policy\\_statement\\_1.pdf](http://www.dpmc.gov.au/sites/default/files/publications/aust_govt_public_data_policy_statement_1.pdf)

<sup>4</sup> [https://www.dpmc.gov.au/sites/default/files/publications/public\\_sector\\_data\\_mgt\\_project.pdf](https://www.dpmc.gov.au/sites/default/files/publications/public_sector_data_mgt_project.pdf)

<sup>5</sup> Data Availability and Use, Productivity Commission Issues Paper (2016), p5.

## Use data to support social investment

### Recommendations

Develop a centralised mechanism for data integration and dissemination to inform policy and program development and collaboration

Reinstate production of the Socio-Economic Index for Individuals (SEIFI) by the ABS

Data needs to be at the centre of policy development and evaluation in Australia. For this to occur, clear leadership is needed to set priorities for social and public good outcomes and provide a mechanism for commissioning research and analysis to achieve them. There is no whole of sector mechanism to evaluate data and no central database of social research data in Australia. This means organisations, agencies and universities cannot draw upon in a central data repository for policy development, in turn siloing research and actively discouraging data sharing.

We would like to raise our concerns about funding cuts to the Australian Bureau of Statistics (ABS) which have led to the decision to not continue to produce the Socio-Economic Index for Individuals (SEIFI) data set. The development of this data set in 2011 enabled accurate mapping of disadvantage in local areas, particularly in small jurisdictions such as the ACT and the NT. Its loss is of significance at all levels of the policy making process. Accurate data is imperative to our sector, to the policy making process and, most significantly, to achieving positive outcomes for people experiencing disadvantage in our community. Implementing a data integration, linkage and utilisation strategy without addressing the significant gap in accurate data on poverty, especially in small jurisdictions, will put at significant risk the accuracy and relevance of decisions made based on that data.

The Issues Paper refers to increasing the availability of public and private (including NGO) data, and to the benefits and costs of standardisation. There is little explicit consideration given to opportunities arising from better integration across public and private (community services sector) data sets. There is some relevant discussion of economies of scale and scope in linking diverse sources of data to generate greater value than the sum of the parts.

Good data sources and integration are necessary for the development and implementation of a 'social investment' model, as seen in the approach to integrated data infrastructure developed in New Zealand.

### Data sources for New Zealand's Social Investment model

As part of their Social Investment approach the Government of New Zealand have set up an independent statutory authority called the Social Policy Evaluation and Research Unit which has responsibility across government to increase the use of evidence by people across the social sector so that they make better decisions about funding, policies or services to improve the lives of New Zealand's communities, families.

The Unit's role is to grow the quality, relevance and quantity of evidence base for social priorities and to facilitate the use of evidence for best practice decision making in the social sector. The Unit identifies research priorities (to achieve the Government's objectives – linked to the Social Investment model), commissions and manages contracts for social science research, sets standards and maintains databases.<sup>6</sup>

It is important to note its role extends beyond data collection, protocols and analysis to the promotion and interpretation of research outcomes and analysis to ensure its use in public policy.

The NZ Social Investment model uses an actuarial analysis of the predicted lifetime welfare and support service costs of specific disadvantaged cohorts as a means to target increased up-front investment into intensive wrap-around service delivery to reduce long-term costs (for instance to assist a young person from a background of intergenerational unemployment to secure and maintain a job). This work has been done in conjunction with payment reform, including imposing extra conditions on payment receipt. The investment model has resulted in reduced access of welfare payments, but the cause of this shift (whether it was the upfront investment or the increased conditionality) is ambiguous.

The Councils advocate for data linkage capacity and capability to allow implementation of social investment and other innovative models. Identified data weaknesses currently include the:

- **comparability** of existing data sources
- **ability to link** personal data at the level required to identify those at risk
- individuals and groups missing, under-represented or poorly counted, including people experiencing homelessness, people renting, Aboriginal people in remote communities and people not receiving social assistance
- **quality** of service data on outcomes (given the lack of rigorous measurement protocols and outcome frameworks).

Significant activity is underway within DSS and DHS in data linkage, actuarial analysis and the development of experimental interventions as part of the *Try Test and Learn Fund* announced in the 2016 Budget.<sup>7</sup> Collaboration is also taking place with the NSW Government to use data linkage to identify risk factors and target assistance to reduce the number of children being taken into out of home care.

The Issues Paper identifies five areas of potential benefits across public and private sectors: efficiency, empowerment of consumers, competition, innovation, and accountability of governments<sup>8</sup>. Improved collaboration, producing greater collective impact, is another area of significant benefit not included. Some areas where the social services system is currently failing are 'wicked problems' spanning the 'siloes' of existing programs, portfolios and

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<sup>6</sup> <http://www.superu.govt.nz/about-us/our-role>

<sup>7</sup> [Federal Budget 2016-17](#)

<sup>8</sup> Issues Paper, Page 9.



disciplines. These areas of co-morbidity, complex need, and multiple disadvantage are not effectively addressed by any one service, service system, discipline or level of government and require greater levels of service integration and 'wrap-around'. In response, systemic reform in health, education, employment and social services has increasingly looked to integrated service models, place-based approaches and collective impact initiatives to address escalating costs and the failure of existing approaches.

## Use data for comparability and productivity improvements

### Recommendation

Develop clear and consistent measurements of service outcomes, underpinned by a capacity-building strategy to enable the community services sector to engage in data sharing and analysis

The capacity to collect and analyse data in increasingly complex ways has shaped the current direction of community service design and commissioning and the development of social policy. With the development of more powerful tools and the commitment to greater data openness, data linkage is set to play an increasingly central role.

The 2014 Harper Review proposed that the community services sector and the community more broadly would benefit from increased levels of competition. This is despite recognising that some markets would not have sufficient depth to support multiple providers, and the overarching objectives of equity of access, universal service provision and minimum quality, which often conflict with a competition model.<sup>9</sup>

The Panel noted that it did not wish to discourage or crowd out the important contributions of not-for-profits and recommended Government allow room for providers to innovate. Without a serious approach to enabling not-for-profit providers to engage in data analysis, they will not only have no room to innovate, but are liable to being squeezed out by for-profit organisations that can monetise the use of data.

In the absence of clear and consistent measurement of service outcomes, which can only be achieved through better data sharing and analysis, it is not clear how there can be meaningful competition between service providers on anything other than price. In the joint COSS submission to the Harper Review, it was noted that the “lack of consistency and validity in the reporting and regulatory requirements on community services has long been a barrier to productivity within this sector.”<sup>10</sup>

Currently the accountability of governments and community service providers is limited by the lack of clear and consistent outcomes measures and frameworks across services and programs. In the absence of a consistent approach, individual service providers have developed and invested in a range of different outcomes measures and models, such as social return on investment, or results-based accountability. However, the resulting service outcome measures are not consistent and comparable across services or programs, and in the absence of shared outcome frameworks in service contracts, reporting is likely to produce incommensurate data. This poses the risk that the choice of reporting outcomes is driven more by competitive advantage than the desire to accurately report population and cohort outcomes.

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<sup>9</sup> Competition Policy Review (2015) [http://competitionpolicyreview.gov.au/files/2015/03/Competition-policy-review-report\\_online.pdf](http://competitionpolicyreview.gov.au/files/2015/03/Competition-policy-review-report_online.pdf)

<sup>10</sup> Joint COSS Network Submission to Competition Policy Review, [http://www.acoss.org.au/images/uploads/COSS\\_Competition\\_Review\\_submission\\_november\\_2014.pdf](http://www.acoss.org.au/images/uploads/COSS_Competition_Review_submission_november_2014.pdf)

## Include local level and demographic data

### Recommendation

Increase availability of local area data and improve collection of demographic information for disaggregation

Data at a community or local level is crucial to effectively implementing place-based approaches to tackling complex disadvantage. Place-based approaches can be a powerful way of connecting people right across the community and of connecting communities, organisations and government. This can reduce the social isolation people can experience when marginalised through poverty or disadvantage, and empower people right across the community to develop and deliver solutions. By connecting and bringing people together, place-based approaches can help 'join up' and improve the coordination of policy, services and their delivery in a way that will work best in local communities.

What constitutes a place can vary depending on the needs and characteristics of the local community. It may be a region, local government area, a town or suburb, or a community within a town, such as a public housing development. Effective place-based approaches need quality, local level data to inform planning and build a case for change. Without meaningful community and local level data, it is difficult for communities to identify a baseline and measure change over time.

However community organisations report that it is often difficult to access local level data below local government area. This restricts their ability to implement and evaluate programs that tackle disadvantage at a town or even street block level. Community organisations report that government departments or agencies, like police, often have some of the data they need, but can be reluctant to make it available to external organisations. The negotiations to access data can be long and time consuming, creating a barrier for organisations looking to implement collective impact, justice reinvestment or other collaborative, place-based models. It can also be difficult to get data disaggregated by gender, cultural background, health or disability status, or income source or level at a local level, which can be useful for specialist agencies or those working with particular population groups. As a result, community organisations are often reliant on small-scale studies or anecdotal information about the experiences of different population groups. We recognise, however, that the need to obtain detailed local data must be balanced with protecting individuals' privacy.

Data can fail to depict the complexities and the lived experience of the lives of people experiencing disadvantage. Community organisations warn against becoming overly reliant on 'quantitative' approaches that focus on numbers, and losing sight of the 'qualitative' stories that focus on people, and illustrate the diversity of disadvantage.

It is also important that we are mindful of the limitations of the data we collect and the systemic biases that might underpin it. Data about vulnerable groups is collected by individuals, and errors are inevitable; they must be accounted for when the data is analysed and used. For example, there is a significant risk that particular cohorts are not 'counted' effectively in our data sets. Disadvantaged population groups like people who are homeless and people with mental illness are often underrepresented in responses to questionnaires

and surveys, including the census, due to challenges researchers face in engaging with these groups.

Information about demographics and socio-economic characteristics are important in developing social policy and monitoring people's journeys through complex health and social service systems. However collection of demographic information such as lesbian, gay, bisexual, transgender and intersex (LGBTI) status, health and mental health status, disability, Aboriginality and culturally and linguistically diverse (CALD) status is often inconsistent. The Victorian Crime Statistics Agency identifies Aboriginal and Torres Strait Islander status, culturally and linguistically diverse indicators and health and disability indicators as 'data items with varying quality', which are 'of a high priority for decision makers.'<sup>11</sup>

The Victorian Royal Commission into Family Violence found that the reason socio-economic and demographic data is 'patchy' is because this demographic information may be:

- Not provided for on forms and databases
- Not be mandatory
- Reliant on unsolicited self-identification by individuals
- Reliant on a service provider's judgement, perceptions or assumptions
- Not cross-correlated with other demographic data.<sup>12</sup>

Aboriginal people are underrepresented in many data sets. There are many reasons for this underrepresentation. A person may choose not to identify as Aboriginal and Torres Strait Islander, often because they distrust government and the legal system and are reluctant to disclose their status. Some staff recording data continue to feel uncomfortable asking about Aboriginal identity or make assumptions based on physical appearance. Others may expect that Aboriginal people will disclose their Aboriginality without being prompted.

*Almost 50 per cent of Victorian Police Family Violence Incident Reports have an unknown Aboriginal status. Unless we fully understand the data we can't be confident our service responses are hitting the mark.*<sup>13</sup>

The Victorian Crime Statistics Agency is considering options for improving the quality of their data about Aboriginal and Torres Strait Islander people. Options under consideration include adoption of an 'ever-identified' rule, where a person has identified on one occasion as Aboriginal and Torres Strait Islander, this identification is carried across all their other records in the database. Another option is the 'most-frequent' rule, where the most frequently appearing identification is carried across all records.<sup>14</sup>

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<sup>11</sup> Royal Commission into Family Violence, *Volume IV: Data Research and Evaluation*, March 2016, p 142.

<sup>12</sup> Royal Commission into Family Violence, *Volume IV: Data Research and Evaluation*, March 2016, p 142.

<sup>13</sup> Victorian Aboriginal Legal Service, *Submission to the Royal Commission into Family Violence*, 2015.

<sup>14</sup> Crime Statistics Agency, *Consultation Paper: Improving recorded crime statistics for Victoria's Aboriginal community*, 2016.

A particular challenge in obtaining high quality data about people's cultural background is that the methodologies of data collection differ. This makes it difficult to compare data across agencies and data sets. For example, agencies may collect information about:

- nationality
- language spoken at home
- need for an interpreter
- proficiency in English
- belonging to a cultural or ethnic group
- country of birth.

Additional work could be done to standardise CALD data items to make sure all data collected is using the same definitions and is comparable across datasets.

The Councils also suggest that the ABS income surveys have higher sample sizes (or over-sample populations) to allow disaggregation in small states and territories as well as specific population groups (for example, Aboriginal and Torres Strait Islander and CALD populations).

### **Make data accessible and useable**

Community organisations collect and provide government with large amounts of information about their services and service users. This information is not often analysed and provided back to them in a useful format that would inform planning and evaluation. When data is provided back to community organisations it is sometimes in formats that are difficult to work with or require specialised software. This is a barrier to more widespread use of data and evidence in program design and evaluation. Critical administration data of special value to program design and evaluation across portfolios, (eg. social security data) should be shared (at no cost) with independent researchers subject to appropriate protocols (regarding privacy, academic use, etc). This requires investment in data preparation and 'cleaning' to ensure the data is fit for use. Another area where data sharing could be improved is evaluations of social programs. Evaluations should be made public within a short period (for example, four weeks) of delivery to Ministers. Governments should also report regularly, especially in Budget documents, on the impact of major policies (for example social security and tax) on households with different income levels and demographic characteristics.

Some COSS member organisations reported suspicions that the information they provide is never used at all, disappearing into a great 'data-hole'. Collecting information and data from service users places an administrative burden on frontline community sector workers. It can take time away from providing other kinds of support that help people move out of poverty and disadvantage. The administrative burden on organisations is already high; some community sector workers estimate they spend up to half their time on data entry and reporting. We emphasise the importance of only requiring organisations to collect and submit data that is going to be used in some way to improve the lives of Australians.

### **Community Indicators Victoria**

Community Indicators Victoria aims to support the development and use of local community wellbeing indicators in Victoria with the purpose of improving citizen engagement, community planning and policy making. Community Indicators Victoria presents data and reports on the wellbeing of Victorians using an integrated set of community wellbeing indicators.

Community Indicators Victoria's website includes an interactive mapping and analysis tool Instant Atlas™ that allows for visual communication of wellbeing indicators across selected geographic regions. This tool makes the data accessible for organisations and individuals without less expertise and background in data analysis.

### **Australian Charities and Not-for-profit Commission**

The ACNC is the national regulator of charities in Australia. Australian charities submit data to the ACNC about their activities, financial status, workforce and purpose. In 2015 the ACNC began publishing this information online in an interactive data cube.

The data cube allows organisations to compare data across geographic area, sector and charity size. It is user-friendly and visually simple.

### **Justice Data Lab (UK)**

The Justice Data Lab is run by the UK Ministry of Justice and gives organisations working with offenders access to re-offending data. The information helps organisations to assess the impact of their work on reducing re-offending and also helps develop an understanding of effective rehabilitation.

Organisations submit details of offenders they have worked with and statisticians find them in the Police National Computer and report back the aggregate rate and frequency of recidivism. The Data Lab also provides a re-offending rate for a statistically-matched control group, to show more robustly if the intervention has made a difference.<sup>15</sup>

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<sup>15</sup> Thinks NPC, *Justice Data Lab*, accessed 15 July 2016 <http://www.thinknpc.org/our-work/projects/data-labs/justice-data-lab/>

# Increase data linkage and integration

## Assess barriers and limitations of data linkage

Statistical linkage is a process by which a person's identifiable details are combined to create a de-identified unique key which can be used across multiple data sets. This already occurs in some data sets, such as the AIHW Homelessness data set. The Victorian Crime Statistics Agency describes this as a 'way of connecting disparate datasets to create a more useful source of information without significant investment in system upgrades or significant data manipulation.'<sup>16</sup>

Linked data sets can help us understand how different issues and systems interact and affect people over time. It can also help us to track people's journey through the system and identify risk factors that can predict when people might require support, providing opportunities for early intervention.

We note, however, that analysing groups across multiple data sets can be a difficult proposition, as individuals are not identified in consistent ways. For example, the Victorian Royal Commission into Family Violence found that there was no common identifier to allow a Magistrate to discern whether a person before them had active matters in other court jurisdictions.<sup>17</sup> Similarly, within hospitals, data from emergency departments, outpatient and inpatient are often not linked to an individual patient, so there is no way to track the different hospital services a person might use across a year.

The Victorian Crime Statistics Agency has said:

*... it is currently difficult, for example, to identify through the data which individuals have come into contact with police, homelessness services and victims assistance programs and which services they first contacted.*<sup>18</sup>

There are serious gaps in our knowledge about the characteristics and experiences of people accessing health and community services systems. Improving linkages between health and community sector data sets would help us to more effectively respond to disadvantage, identify system failures, plan for the future, and intervene early with people at risk.

There is also a significant risk with the development of data driven social policy in relation to 'who counts' and who or what does not get included or effectively measured within our data sets.<sup>19</sup> This remains, for example, a critical issue in relation to the number of Aboriginal people who are not being counted in our population and health data sets, or the number of people who are breached and subsequently drop out of our social security system. We need to be conscious of the limitations of the data we collect and the analytical tools we employ to

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<sup>16</sup> Royal Commission into Family Violence, *Volume IV: Data, research and evaluation*, March 2016, p 162.

<sup>17</sup> Royal Commission into Family Violence, *Volume IV: Data, research and evaluation*, March 2016, p 140.

<sup>18</sup> Crime Statistics Agency, 'An overview of family violence in Victoria: Finding from the Victorian Family Violence Database 2009-10 to 2013-14' January 2016, provided to the Royal Commission into Family Violence.

<sup>19</sup> There is a more detailed discussion of this issue by Sue Ash in the chapter "The Role of Not for Profits and Active Citizenship" in the recent book [The Three Sector Solution: Delivering public policy in collaboration with not-for-profits and business](#) (2016) ANU Press.

derive meaning from it, and ensure that there are no gaps or systematic biases in our approaches that disadvantage particular groups, cohorts or populations. We need to be aware that the complexities of the lives and the lived experience of those who we are measuring can't always be captured in the approximations and generalisations we need to make to enable our analysis.

There is otherwise a significant risk that the uncritical application of data collection and analytical approaches may lead us astray if we are not mindful of the gaps, assumptions and biases that may unwittingly shape the conclusions of our analysis, however powerful our analytic tools. To this end it is crucial that service user and service provider engagement in 'ground-truthing' any measurement and analysis is built into our processes of co-evaluation and co-design of services, systems and policies.

## Share consumer data across organisations and system

### Recommendation

Investigate the benefits and risks of a shared consumer record

People accessing community services often experience multiple and complex disadvantages, affecting many different parts of their lives. Many people will come into contact with numerous different agencies across the health and social services systems. However people's journey through these systems is often hampered by disjointed communication and limited access to quality information. As a result, people can sometimes 'fall through the cracks' or decisions can be made by agencies based on incomplete or out-of-date information.

*About one in six medical errors are due to inadequate patient information.<sup>20</sup>*

*The lack of information sharing and care management for chronic disease sufferers costs the healthcare system up to \$1.5 billion a year.*

The consequences of these information gaps can be dire. They can result in medical errors or inappropriate treatment. They can cause people to become frustrated, or lose trust in services. They can put people's safety at risk, where the information is related to family violence or other victimisation.

### Inquest of Luke Batty

When State Coroner, Judge Ian Gray, handed down his findings from the inquest into the tragic death of 11-year-old Luke Batty in February 2014, he identified a number of gaps and flaws in Victoria's criminal justice and family violence processes and systems that need to be addressed.

Judge Gray found that although Luke's mother, Rosie Batty, had contact with numerous agencies, actively seeking and receiving assistance from them, each agency's involvement was "episodic, limited and not integrated with other agencies".

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<sup>20</sup> Australian Institute of Health and Welfare, *Australia's Health 2002*.



“The evidence in this case is that no single agency held or assessed all of the information for the purposes of conducting risk assessments, and managing the risks posed by Mr Anderson. There was no 360° information sharing, uniform approach to risk assessment, or coordinated approach to risk-management and safety planning.”<sup>21</sup>

Sharing information across systems and organisations can help provide safer, more effective and holistic care. One of the challenges for consumers in the community services system is the need to tell their story and provide their information to many different services and workers. As well as being frustrating and potentially re-traumatising for individuals, this is an inefficient use of consumer and community workers’ time.

Some COSS members indicated support for a single consumer record that can be shared across agencies and systems. This would reduce time spent on data input and information collection for agencies, increasing the time that can be spent providing help and support to people.

There are, however, significant risks in the introduction of a single record system. It is important that mechanisms are in place to ensure only people and agencies requiring information have access to it. For example, family violence services flagged concerns about safety arising from too many agencies having unnecessary access to data about victims of family violence. Other community sector agencies were concerned that advising vulnerable and marginalised people their information would be shared with organisations with which they have no relationship or established trust may be a disincentive to engaging with any support service.

There are lessons to be learnt from the implementation of personally controlled electronic health records (PCEHR). The PCEHR was a special electronic personal health record where the consumer controlled his or her record content and record access, which meant only nominated health practitioners were able to access nominated information in the record. Update and utilisation of the system was low, resulting in a decision by the Australian Government to trial an opt-out system, instead of an opt-in system.

COSS members reported that some services were unable to access the e-health records, or were unwilling to upload data. Numerous reports on the system have highlighted the need for adequate workforce training, incentives for healthcare providers to use the system and information for people to encourage meaningful use. In particular, it is necessary to target vulnerable and marginalised people who may be less likely to engage with the system, but could potentially gain the most benefit.

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<sup>21</sup> Coroners Court of Victoria, *Finding – Inquest into the death of Luke Batty*, 28 September 2015.

## Address barriers to interoperability in the community sector

### **Recommendation**

Invest in IT platforms that encourage information sharing between community agencies, and in building the capacity of expertise of the community sector in information sharing

One of the major challenges for sharing client level data is the technological barriers to sharing across different information technology platforms. Many community organisations are small organisations operating with limited budgets. They have limited capacity to invest in new IT systems that support information sharing. They may also have invested in training their staff in their existing IT system, and be reluctant to introduce new systems that require different expertise and additional training.

There are technological solutions to addressing many issues related to interoperability. For example, there are third party products currently available that support information sharing between existing IT systems. However, community organisations need support and training in how these systems work and financial support to purchase them. Information sharing across IT platforms also requires development of shared standards for recording information.

Organisations like the Victorian Primary Care Partnerships and Primary Health Networks are already engaged in addressing interoperability and supporting information sharing, especially in the health sector, but investment is needed to ensure community organisations across a range of sectors are able to implement appropriate systems.

# Prioritise people's needs

## Consider risks for consumers

### **Recommendation**

Ensure any data integration, linkage and utilisation activity only occurs after the potential positive and negative impacts for the individuals whose data is being used are assessed

There is also significant concern about the potential abuse of data and its potential to underpin punitive and paternalistic approaches, as well as the risks to privacy.

Integration of data has potentially positive impacts but also presents significant risks to people. To ensure the impacts are positive we recommend adoption of an independent process through which any data integration, linkage and utilisation activity only occurs after the potential positive and negative impacts for the individuals whose data is being used are assessed. This process could build on the theory and practice that guides the ethical approval processes used in research institutions conducting research involving human participants.

This data collected by community agencies is incredibly valuable to policy makers, government and the community. It also has value to private providers and businesses. Some community organisations are concerned that a move to integrate data and make it more openly accessible will enable private-sector businesses to use the data they collect to develop programs that compete with the non-profit sector without delivering additional value or disadvantage vulnerable consumers.

Community organisations have suggested scenarios where information about communities experiencing high levels of disadvantage could lead to insurance companies charging higher premiums, banks offering less attractive loan conditions and gambling venues targeting people from those communities. They also warn private businesses are already using retail and other data to predict consumer behaviour. While this can be an effective marketing strategy, it could have detrimental consumer impacts, when people can be misled or advantage taken of their vulnerabilities.

At the same time, the Councils welcome a broader discussion on how community organisations themselves could use and understand this type of private sector data, including retail data. Most community organisations have not considered how data about shopping or spending habits could be useful in identifying risk factors and points of intervention for vulnerable people. There are significant ethical and privacy related concerns for community organisations about using private sector data in this way. There are also likely to be costs involved for community sector organisations that will put the option out of reach for many.

## Prioritise consent to protect privacy

### Recommendation

Allow consumers to consent to what data is shared and with whom, providing them with choice and control in protecting their privacy

A wider discussion is needed about how to balance the protection of privacy versus the provision of social support so the best interests of the individual and the community are served. In the absence of clear privacy laws and protocols, claims or concerns about individual privacy limit personal data sharing that may assist in service delivery. This can happen even in circumstances where individuals have actively sought assistance and could provide or are providing consent for their data to be shared.

For example, the absence of privacy laws in Western Australia potentially creates a barrier to data sharing, as Commonwealth agencies and other jurisdictions can be reluctant to share and link data in the absence of clear assurances of privacy protection and compliance. State or Territory government agencies may be reluctant to link data sets in the context of a lack of clear guidelines and protocols about data protection.

On the other hand, it can be difficult for community organisations to obtain informed consent from consumers to share data with other agencies. This can be because people are reluctant to give consent, lack of trust in the system, or because they do not have capacity to consent as a result of age, disability, mental illness, drug and alcohol addiction or other reason.

Often consent is viewed as a yes or no question. However, people may be unwilling to consent to all their information being shared but may feel comfortable sharing some of their personal data with some agencies. For example, some health consumers report a desire to seek second opinions that are not biased by previous diagnoses. The PCEHR allowed people to provide consent to sharing some information with some health practitioners, but not share other information. This provided people with an additional level of control over their own information. There is room for further exploration of this more nuanced understanding of consent in the social services sector. Some community organisations report a growing number of people refuse consent for their information to be shared at all. This means their information cannot be provided to government agencies through reporting processes. In some circumstances, government funding bodies own client files managed by community organisations. If a person refuses consent for their information to be shared, organisations are forced to either refuse service to a vulnerable person or search for a 'work-around.' Governments need to work with the community sector to identify more realistic alternatives when consent to share information is refused.

In this light, protocols should be developed for government bodies who are the custodians of significant data sets to maintain their integrity and privacy as appropriate. Government should ensure such datasets are used appropriately for evaluation purposes. With the appropriate protections, these datasets could (and often should) be shared with others within and outside government as appropriate. This is usually a better option than centralizing *control* of government data, as distinct from aggregating key data sets in a single website for *ease of access*, or the establishment of new bodies to aggregate and administer certain data

sets that cut across portfolios. Over-centralisation will result in double handling, loss of expertise, weaker links between data use and program administration, and (ironically) could limit external access.

The Western Australian government is currently undertaking a data linkage review<sup>22</sup>, overseen by an expert advisory committee. Its [terms of reference](#) seek to build upon past population health research data linkage and extend it into other areas of social policy. The focus is on building on the states data linkage capabilities and capacities; addressing the barriers and impediments to data linkage; examining and improving on data linkage infrastructure, processes and systems; and governance and funding arrangements. The Councils suggest that the Commission should liaise with the expert advisory group to determine where analysis of issues of mutual interest can be shared.

### **Improve consumer access and control over their own data**

#### **Recommendation**

Increase consumer access to their own data, to empower them to make informed choices about services and care

Effective and timely access to data about their health, wellbeing, finances and behaviour can help people to make informed choices about their services and care. For example, health consumers have long sought access to their personal health information to empower them to be active partners, prevent ill-health and make informed choices about their healthcare. Access to data about energy consumption and patterns can help people manage their bills, optimise energy efficiency and switch providers to the most appropriate plan. As well as helping individuals, informed consumers promotes effective competition between providers and services.

While technology is providing community organisations and consumers with greater access to data, this will only be of value if the community can understand and make use of it. Consumers need to be supported and provided with skills and understanding to be able to interpret the huge amount of information available. It is important that consumers be continually engaged in the design and monitoring of data and record systems. If consumers are not engaged, systems risk developing in a way that is not user-friendly or does not meet the needs of people using them. See for example, the example below related to Victorian energy companies.

#### **Case Study: Victorian Smart Meter Data**

While Victoria has self-service capabilities for access to meter data across the state, in practical experience this does not yet translate to easy access for all consumers. As at May 2016, three out of five<sup>23</sup> of the Victorian distribution network businesses have introduced web-portals through which consumers can access their energy consumption data. However these portals require the customer to have a level of understanding of the electricity industry and a degree of technical sophistication that many consumers do not have.

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<sup>22</sup> [WA Data Linkage Review](#)

<sup>23</sup> Jemena, UED, AusNet

Many consumers who are interested in obtaining their energy consumption data for purposes of price comparison are unable to easily do so. Even technologically savvy consumers find the process confusing and prone to error.

Information should also comply with relevant standards for document accessibility. Making information physically accessible is not enough. Nearly one in five Australians have a disability, and many of these are 'print disabilities.' Infrastructure challenges are apparent in rural and remote areas of Australia and there is still a significant number of Australians who do not have internet access or computer literacy. Only making data available online risks further marginalising people already experiencing vulnerabilities.

## **Conclusion**

Data can provide the community services sector with the tools it needs to improve services in order to deliver long-term outcomes for vulnerable and at-risk groups within our community. Without the necessary enabling environment created by government, the sector risks being left behind by private for-profit organisations that are able to use that data in ways that do not necessarily provide the greatest benefit to the community as a whole. Through better data linkage between Federal and State governments and with the not-for-profit sector, it is possible to deliver wrap-around services that will reduce long-term costs and drive better community outcomes.

The Councils would welcome the opportunity to discuss these issues in more detail with the Commission.