

SA Academic Health Science and Translation Centre and Health Performance Council

Data Access Workshop Output Report

Thursday, 16 March 2017

3.00 to 6.00pm

SAHMRI Auditorium, North Terrace, Adelaide

The question for this workshop:

What can the SA Centre do with you to promote and increase data access for audit and research so we'll know how well the new evidence-based models of care are working?

The SA Centre with Health Performance Council has produced this output report as a reminder of key elements of the workshop discussions, and is joining forces with delegates who volunteered as champions for this cause.

Key sections:

Executive summary page – slides 4 and 5

Discussion panel Q&A session page – slides 17 - 19

Parting words from Erma and Gerry – slide 22

This Data Access Workshop Output Report is designed to be most easily read on screen.



Executive Summary 1/2

- ▶ This workshop set out to explore the issues with data access for health audit and research with a group of 88 academics, clinicians, consumers and policy makers from public and independent sector in South Australia.
- ▶ Prof Steve Wesselingh, Executive Director of SAHMRI and A/Prof Gerry O'Callaghan from SA Centre welcomed delegates to the SAHMRI Auditorium, outlined the SA Centre's data access priority and why there is a focus on this now.
- ▶ The workshop program covered three main areas:
 1. showcasing SA public sector developments with contributions from the Commissioner for Public Sector Employment on cultural aspects of clinical data system developments and data sharing; introduction from the newly appointed SA Chief Data Officer; and SA Health on a clinical information strategy and new Clinical Data Hub platform;
 2. hearing from keynote speaker Dr Stephen Duckett, Director, Health Program at Grattan Institute and council member at HPC on advancing transparency in the health sector through data access and use to improve quality and safety of care; and
 3. contributing to the question and answer session with a panel of A/Prof Gerry O'Callaghan, Ms Tina Hardin for SA Health, Dr Stephen Duckett and Ms Jennifer Richter, a board member of Health Industries SA.

Executive Summary 2/2

There was agreement about what has been achieved to date in separate agencies and SA NT DataLink, and the urgency with which next steps need to be addressed.

Key topics for action include:

- ▶ Take an all-of-SA approach with linked data for audit and research – public and private sector, state and Commonwealth – so a multiplicity of outcomes can be assessed. Support this with an examination of the value proposition, relationship and trust between all sectors to complete the all-of-SA picture.
- ▶ Design data access service model/s that recognise different user needs from near real-time data locally to monitor quality of care to ‘big data’ epidemiology studies that inform health services planning, public health and policy.
- ▶ Foster culture and behaviours for collaboration and sharing.
- ▶ Involve consumers; discuss social values and public benefit.
- ▶ Value and build data analytics capability and training.
- ▶ Use current advances in information technology infrastructure to add to available dataset/s – SA Health Clinical Data Hub/ Business Intelligence; EPAS CPM; and others.
- ▶ Consider return on investment from these dataset/s and research with possible benefits of downstream commercialisation of outputs.
- ▶ Feed information about data access blocks to the Chief Data Officer.
- ▶ Document and publish the SA Centre data access & workshop outcomes to maintain momentum.

An anonymised summary of the pre-workshop survey was shared on arrival

Data Access Workshop - 16 March 2017 - Delegate Pre-survey

SA Academic Health Science & Translation Centre and Health Performance Council

To help us fine tune the agenda for the Data Access Workshop on 16 March, please consider giving us your thoughts on data access and experiences in your audit and research to feed into discussions. All responses will be anonymised, summarised and shared in the introduction to the Data Access Workshop on 16 March.

If you have any questions about this survey, please email healthhealthperformancecouncil@sa.gov.au

1. What experience have you had with accessing all-of-SA data for population-based research, policy development, and service monitoring/evaluation?

2. What experience have you had with accessing all-of-SA data for health system (public and private sector) research, policy development, and service monitoring/evaluation?

3. What frustrates you the most?

What about practical tips for SA Centre tackling this topic?

Keep up the good work

- > use and support the current network of SA Academic Health Science and Translation Centre members to develop principles for better access to data; supporting research; and harmonising governance processes within and between LHN, SAHMRI, PHN, all health service providers etc
- > challenge organisational leaders to articulate their vision for embedding applied research in decision making and performance evaluation

The SA Centre could do more to amplify communications

- > build awareness of SA Centre *"Who are SA Centre?" -respondent quote*
- > inform population with easy access and understandable information to support consumer confidence
- > involve consumers and consumer advocates at every stage

The SA Centre could consider options for...

- > listing datasets that are available in SA and the type of data collected.
- > suggesting a unique medical record number visible in the data bases or single identifier for each patient
- > setting up of current (SA Health) software platforms currently available for better data access use
- > developing shared protocols across SA Health, LHNs, PHNs, to access and link specific client group data across settings

"The plans seem to be heading in the right direction although not there yet." -respondent quote

We asked what one thing would increase confidence most...

More visible projects, better communication & awareness-raising

- > Seeing more projects based on data research
- > Seeing measurement based on patient experience data
- > More willingness from the 'big' agencies to share data. Governments and agencies articulating the value of data linkage and smart dedicated pioneers like SANT Datalink working on the practicalities to make it happen.
- > Government (SA and Commonwealth) commitments to support

Making best use of new technology

- > EPAS has the potential to make collecting and using data easier if the right amount of governance and structure is developed
- > Implementation of the data.sa.gov.au site



Health Performance Council

Any other comments for the Data Access Workshop?

There is a desire to make the workshop relevant to all, interactive and broad in its outlook

- > acknowledge pockets of success and positive movement in applied analyses, and capitalise on SA's strengths in our size and inter-connectedness with each other.
- > hope we take the opportunity to improve understanding of current issues & proposed means of addressing, and bring consumer representative into the discussion at a state level.
- > important to ensure with increasing access to data that privacy and security of information remains paramount and that consumers are confident about the processes (including legislative) that protects their privacy.



The workshop program

3pm	<p>Welcome, Introduction and Acknowledgement of Country</p> <p>Prof Steve Wesselingh</p> <p>A/Prof Gerry O'Callaghan to introduce the SA Centre's data access priority</p>
3.20pm	<p>Presentation – Cultural and Behavioural Domains of Data Access</p> <p>Ms Erma Ranieri, Commissioner for Public Sector Employment</p> <p>Introducing the State Government Data Agenda</p> <p>Mr Peter Worthington-Eyre, Chief Data Officer, Department of Premier and Cabinet</p>
3.50pm	<p>Presentation – SA Health Clinical Information Strategy</p> <p>Ms Tina Hardin for Ms Michele McKinnon, Executive Director, Quality, Information and Performance, SA Health</p>
4.30pm	<p>Presentation – Data access to improve quality and safety of care - learning from 'Targeting Zero', the Victorian Health Minister's review of quality and safety following the discovery of a cluster of potentially avoidable deaths at Djerriwarrh</p> <p>Dr Stephen Duckett, Director, Health Program at Grattan Institute and council member of Health Performance Council. Dr Duckett was chair of the review.</p>
5.15pm	<p>Discussion Panel – Chaired by Ms Erma Ranieri</p> <p>What can the SA Centre do with you to promote and increase data access for audit and research so we'll know how well the new evidence-based models of care are working?</p> <ul style="list-style-type: none"> - A/Prof Gerry O'Callaghan - Ms Tina Hardin - Dr Stephen Duckett - Ms Jennifer Richter, Board member, Health Industries SA
5.45pm	<p>Chair's review of the day, next steps and close</p>



A/Prof Gerry O'Callaghan outlined the aim for the afternoon

- ▶ To promote and increase data access for audit and research in health.
- ▶ Inform evidence based practice to achieve consistency in models of care.
- ▶ To make the most of the data we have.
- ▶ To improve health system performance and health outcomes for the community.



Gerry referenced SA Health's Data Collection & Management Senate Report as a starting point

Key recommendations of the 2014 Clinical Senate report:

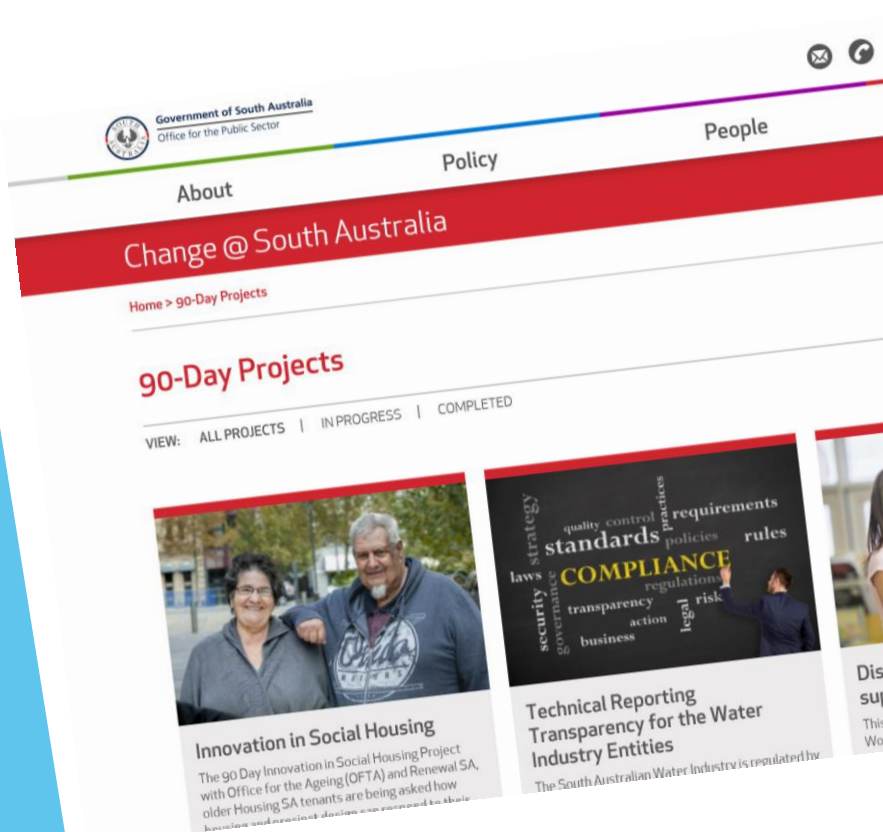
- ▶ SA Health engage with key external agencies such as the proposed Health Performance and Productivity Commission to develop a strategy for how comparative healthcare data can be presented, shared, and made more accessible to frontline health care professionals within the state.
- ▶ The ability for health services to measure and analyse data, and subsequently draw conclusions is limited.
- ▶ In collaboration with SA Health Data and Reporting Services, facilitate further discussion amongst SA Health clinicians about what information they require at a service/unit level and how it is best accessed across the system.
- ▶ Local Health Networks review and analyse how they can promote a shift in analytical capacity and resources from 'financial' to 'clinical' departments, encouraging employment of persons such as health economists, bio-statisticians or behaviour scientists across the system.
- ▶ Local Health Networks develop internal mechanisms and accountability frameworks for managing poor performance of health services/units, as measured against state, national and international benchmarks.
- ▶ SA Health commission a project which explores what health service data consumers want access to, and how, within the public domain.

Ms Erma Ranieri, Commissioner for Public Sector Employment, challenged delegates on what we can do to improve public sector collaborative culture

Erma argued public sector values support this priority on data access.

She challenged us to make data access and transparency the norm, rather than the exception.

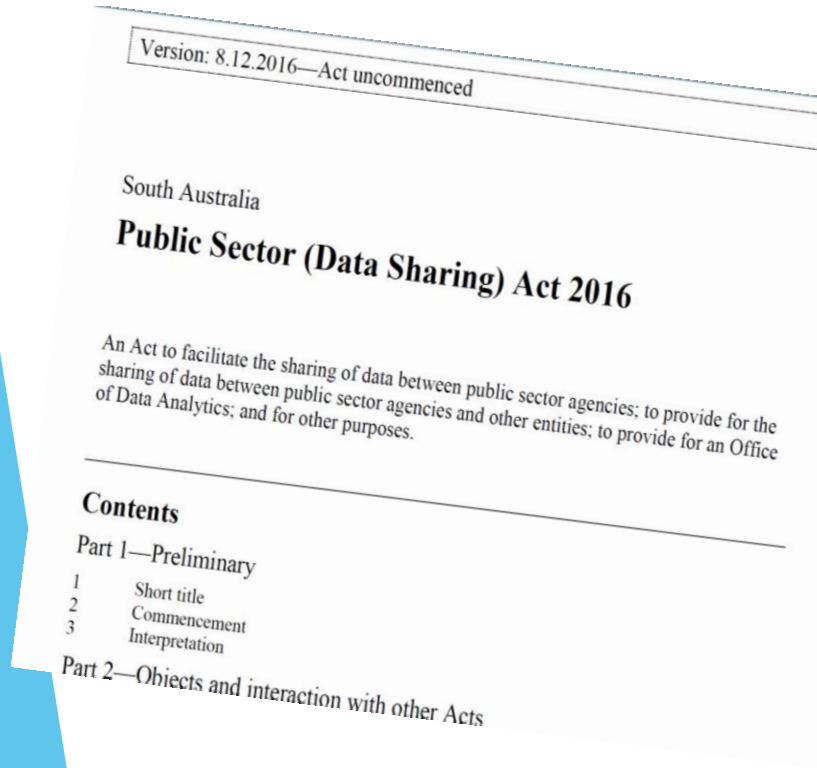
Could the next concrete step in data access be a 90 day project?



Mr Peter Worthington-Eyre, SA's new Chief Data Officer outlined how the *Public Sector Data Sharing Act (2016)* and the Office for Data Analytics will look for a 'biased yes' for collaboration & sharing

When regulations are in place for the Act, the Office for Data Analytics should be able to help operationalise research and tackle lag times between research findings and translation to practise.

The Office for Data Analytics is 'here to help break down barriers'.

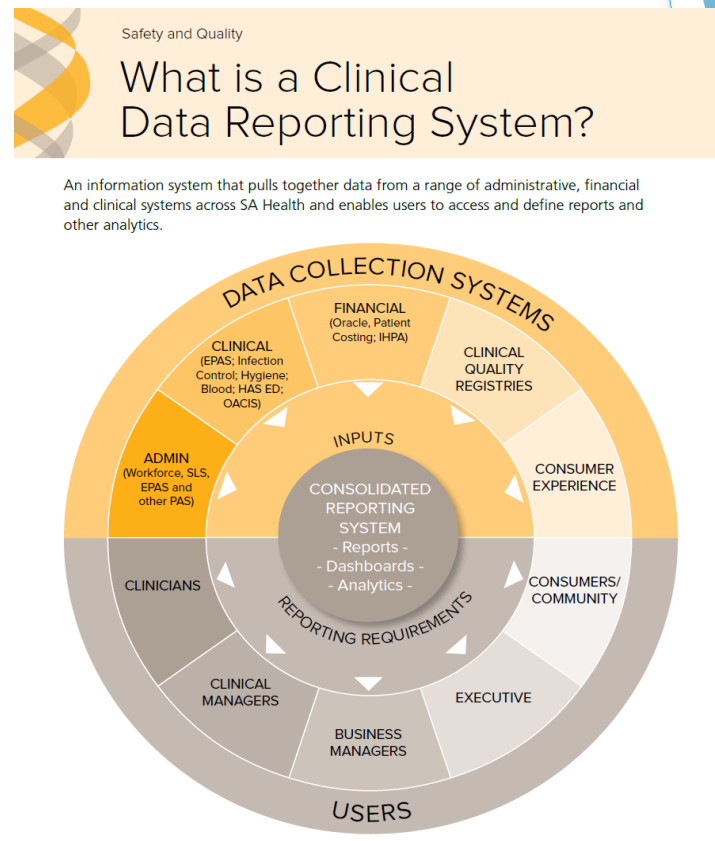


Ms Tina Hardin for SA Health shared progress towards a Clinical Data Hub – business intelligence platform - based on what was described by Clinical Senate Report on Data Collection and Management and links with the Quality and Safety Work Plan 2016-18

In 2015, SA Health reviewed business systems and enablers and took the 2014 recommendations from the Clinical Senate to build the concept for a new clinical data reporting system.

The department has procured a new business intelligence and analytics platform that should go-live in 2017, and add to other dashboards for use by those inside SA Health.

The clinical data strategy directly contributes to achieving the department's Safety and Quality Priority Areas, particularly commitment to deliver a quality healthcare system with quality, cost and value including Transforming Health; and supporting health professionals to provide safe and high quality care.



Delegates wanted to know whether the SA Health business intelligence platform would include private sector and Commonwealth health data, and how the department looks at the value proposition for private sector data linkage.

SA Health collates private sector admitted patient activity data (this is transferred to AIHW for routine hospitalisation reporting), but linkage in the new platform is not in the plans.

And yet, SA is part of the AHMAC review of health system performance and reporting frameworks that includes the principle there should be linkage and analysis across sectors and transparency of reporting and benchmarking.



Review of Australia's health system performance information and reporting frameworks. Final draft report

Keynote speaker Dr Stephen Duckett made the case for advancing transparency in the health sector through data access and use to improve quality and safety of care

Last year, Stephen chaired 'Targeting Zero', the Victorian Health Minister's review of quality and safety following the discovery of a cluster of potentially avoidable deaths at Djerriwarrh.

He set out the key themes for safety and quality reform under the theme of data access and use for investigating quality and safety of care. Importantly, not to blame.

Key themes for safety and quality reform

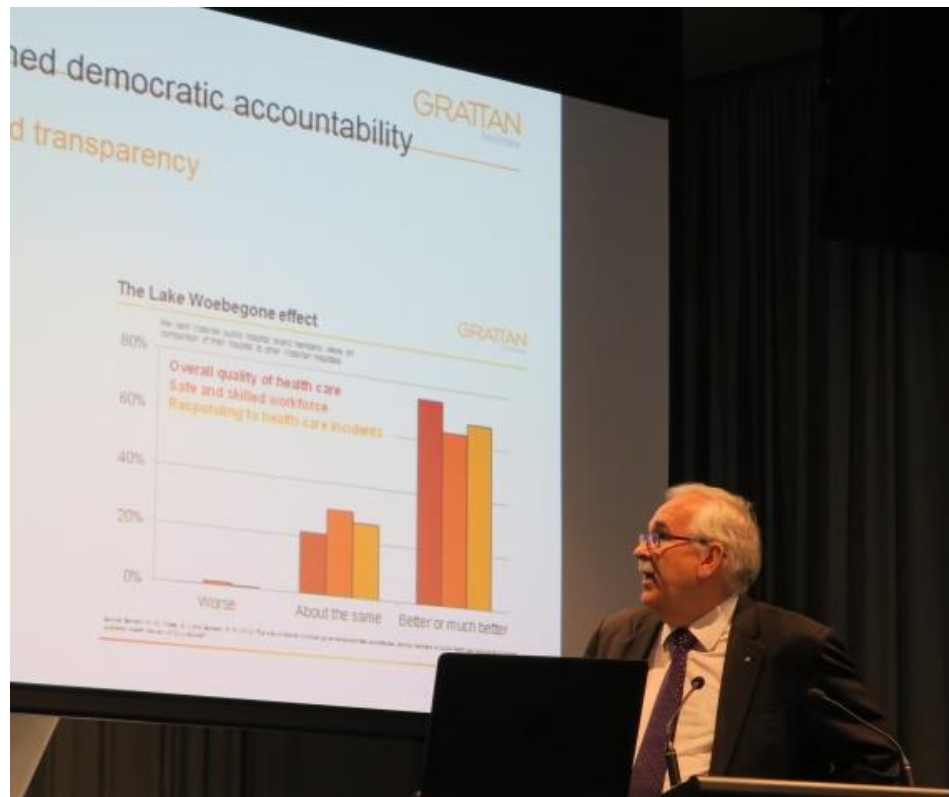
GRATTAN
Institute

1. Fostering a **culture** of continuous improvement and clinical excellence in the health sector, including by engaging and empowering clinicians in reform.
2. Strengthening **oversight** of both safety issues and clinical governance by the Department, so that warning signs are detected and acted upon in a timely manner.
3. Improving **governance** of hospitals, so that the public can be confident that all hospitals - big and small, public and private - are delivering safe care.
4. Advancing **transparency** within the health sector, so that communities can verify that their local hospital is rapidly identifying and rectifying important defects in care when they arise.

stephen.duckett@grattan.edu.au

<https://www2.health.vic.gov.au/hospitals-and-health-services/quality-safety-service/hospital-safety-and-quality-review>

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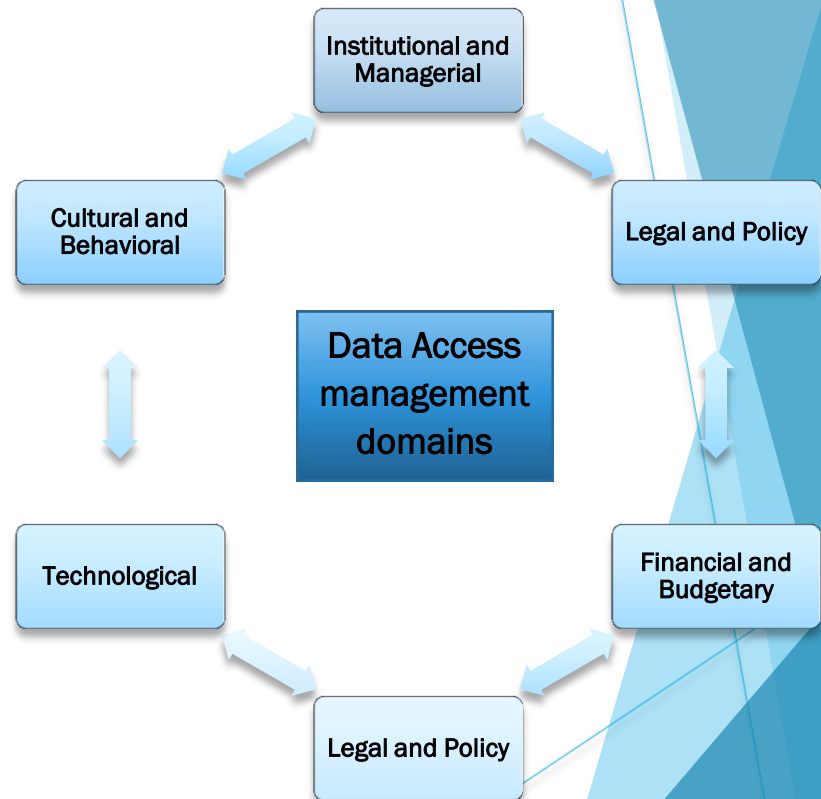


Erma set the scene for the panel discussion on what will address data access barriers

Agencies recognise the need to address the data access barriers and issues, and positive steps are being taken to address them.

But there is still some way to go before we have reached a point where we are in a position to freely share data to facilitate clinical service delivery and health research.

SA Centre is looking for suggestions and actions that will move us forward in each of the data access management domains.



Panel discussion of questions from the floor

(1/3)

Q: Where is the analytic capability in SA? Do we need more training?

- ▶ Important to consider what you're trying to communicate to end users, keep the presentation simple and consider standardised reporting
- ▶ Delegates identified that many, perhaps more younger, health professionals come to their professions with lots of analytical capability and expectation to use big data. Can foster this to fuel insights.
- ▶ Gerry and Jenny proposed SA Health's work should be expanded because it's current design weakness is lack of linkage key and private data then Commonwealth PBS/MBS
- ▶ Stephen referenced the Manitoba Population Research linked data repository, possibly cross-sectoral dataset nirvana Ref www.umanitoba.ca
- ▶ Erma encouraged delegates and the panel to see this discussion as part of contributing to the bigger SA (economic priorities) picture including engaging with other stakeholders. For example the challenge is probably not the data, as much as how we work together and willingness to unlock new practices: for example the SA Government's Multi-Agency Protection Service (MAPS) started in 2014 to share information from multiple sources to identify and act on mitigating risk to vulnerable victims or potential victims of domestic violence. It really took 1-2 years to change culture and share data and recognise widely how important that work is.

Panel discussion of questions from the floor (2/3)

Q: How is EPAS going to add to the richness of the dataset?

- ▶ EPAS clinical front end and clinical data entry has a mirror interface database that can be queried on a regular basis through extraction in LARS (see SA Health) or the clinical performance management tool built in (CPM) but it's a lot of work to get it up and running. What needs to happen:
 - ▶ Governance needs assurance patient level data will be used properly
 - ▶ Skill up
 - ▶ CPM set up 1-2 years implementation work that is NOT yet started

Q: Where is the community 'license' for data sharing and data access?

- ▶ Stephen reported the Consumer Health Forum, national representative organisation, has stated in general principle consumers are comfortable with data access for widespread purpose, and consumers hope they will not to have to repeat themselves every time they engage with health services.
- ▶ The panel recognised there hasn't been a local consumer discussion this topic.

Panel discussion of questions from the floor (3/3)

Q: Jenny Richter, from the panel, asked if given the ability to confidently deidentify data, is there a view that this could be commercialised?

- ▶ There appear to be examples. Stephen reported that Commonwealth PBS datasets are released to pharmaceutical companies as part of their monitoring processes, And Commonwealth release of PBS/MBS 10% was intended for common use

Q: When data access is blocked, who do I talk to?

- ▶ The Office for Data Analytics and the Chief Data Officer

The workshop closed with a review of the day

Review Card – Data Access Workshop 16/3/17

Name: _____ (optional)

- How do you rate the event in terms of its outcomes and outputs? 7/10
- How do you rate the event in terms of its design and running? 7/10
- What was best about the event?
D Stephen Puckett's presentation
- What would you like to have been different?
2) open discussion and enthusiasm of attendees for a collaborative approach to data.
- What will you tell others?
plans are afoot for better data access in SA
- What should happen next?
with

Review Card – Data Access Workshop 16/3/17

Name: _____ (optional)

- How do you rate the event in terms of its outcomes and outputs? 8/10
- How do you rate the event in terms of its design and running? 10/10
- What was best about the event?
high level of interest + enthusiasm for data collection + linkage, good representation + speakers.
- What would you like to have been different?
Someone who was in the room to get an understanding of the audience.
- What will you tell others?
SA Health data management & improving.
- What should happen next?
continue the momentum
- What one word summarises how you feel now? positive

Thank you for taking the time to complete this review card.

Queries relating to this workshop can be directed to:
Iris O'Rourke, Executive Officer SA Academic Health Science and Translation Centre
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Review Card – Data Access Workshop 16/3/17

Name: _____ (optional)

- How do you rate the event in terms of its outcomes and outputs? 8/10
- How do you rate the event in terms of its design and running? 9/10
- What was best about the event?
Good discussion
- What would you like to have been different?
- What will you tell others?
Yes
- What should happen next?
Follow up to see progress
- What one word summarises how you feel now? engaged

Thank you for taking the time to complete this review card.

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Selection of Review Card results

Workshop ratings

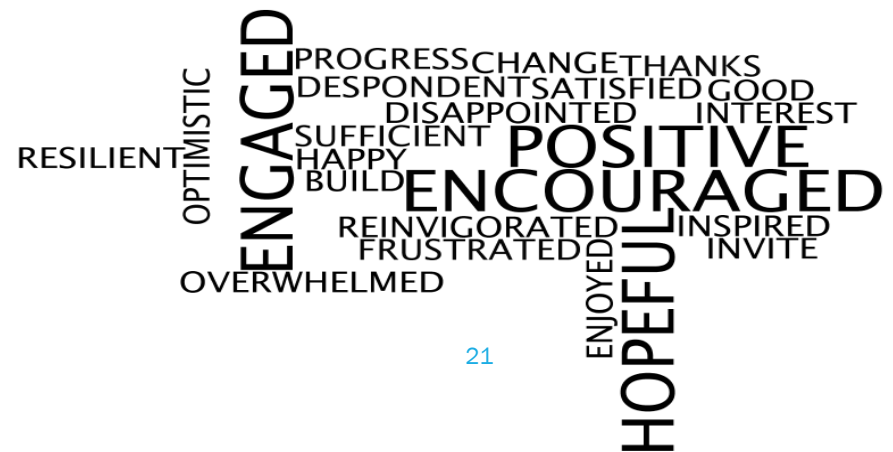
Outcomes and outputs: average 7.2 out of 10

Design and running of workshop: average 8.3 out of 10

Q What was best: Respectful, thoughtful facilitation; open discussion and enthusiasm of attendees for a collaborative approach; the panel, the talks and the cakes; update on what SA Health is doing; and Stephen Duckett

Q What should happen next: Actual outcomes; Better communication with clinicians; Collaborate more; Actual access to data rather than just talk about movement away from centralised data control and governance structure that facilitates; Regular forum; Engage consumers in this space; Report back on the 90 day project

Q: One word that summarises how you feel on leaving today's workshop:



Some parting words from Erma and Gerry

- ▶ Thank you all.
- ▶ This workshop has achieved a lot of thinking and working together.
- ▶ Our speakers have set the scene - outlining the work done to date and the latest thinking on the directions of data access in the SA Public Sector and elsewhere.
- ▶ We are listening to you. There are unanswered questions and barriers to data access. We've felt a movement in the room to advance our commitment to data access and data linkage in ways that are valuable for clinical practice, research, health policy development and strategic planning.
- ▶ The SA Centre is ready to use this information to commence the development of a framework for an effective state-wide data access strategy to increase data access for research and audit for improved health outcomes and public benefit.
- ▶ The challenge is keeping the momentum and tackling barriers. We can't do it alone. Use your passion and depth of feeling on this topic to volunteer as one of our champions.
- ▶ We are thinking of writing this up into a journal article.
- ▶ We'd like to put together a 90 day project.

Secretariat Contacts

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