



Health Issues Centre
Consumer voices for better healthcare

Will sharing improve caring?

A Clinical Information Sharing System
The Consumer Perspective



Report from Public Consultations

Health Issues Centre

November 2020

Level 1
255 Bourke Street
MELBOURNE VIC 3000

(03) 86769050
www.hic.org.au
info@hic.org.au

“There is a false dichotomy between ‘system’ and ‘people’. Healthcare is a socio-technical system. People ARE the system. Healthcare is a set of human behaviours facilitated by technology. People generate data, people collect data, people input data, people decide how data is presented, people access data, people interpret data, people make treatment decisions from their interpretation of data.” – Irith Williams

*“I agree that confidentiality needs to be respected and privacy is utmost but best practice care of every individual in society is important too and we’ve got to get some kind of middle line between respecting consumer rights and enabling our health professionals to deliver best practice care.”
- Robyn Abrahams, Board member, Post Polio Victoria*

Executive Summary

Despite a constrained timeframe providing consumers less than a week to respond to our invitation to participate, 150 consumers registered for Health Issues Centre (HIC)'s public forum to consider the Department of Health and Human Services (DHHS)'s proposed Clinical Information Sharing system. A further 30 consumers registered for a restricted-participant deeper discussion. This turnout indicates a high level of community interest and engagement with the theme of clinical information sharing.

Participants reflected a broad cross-section of the community. They included consumer representatives, consumers representing condition specific community groups, consumers experiencing special circumstances that increased the complexity of data sharing, former (and some current) healthcare workers and consumers who were simply curious and concerned about digital health data sharing.

While there was general acceptance among participants that clinical information sharing could improve patient health outcomes this was by no means considered inevitable.

Some consumers pointed out that data systems were socio-technologic rather than simply technology systems and, as such, no better than the imperfect data uploaded by subjective or error-prone operators. They shared their own personal experiences of misdiagnosis, inconsistent test results and inaccurately transcribed information to make the point that comprehensive records did not necessarily equate to quality records.

Conversely, others pointed out that the justification for the initiative, that comprehensive records ensured better personalised care, was undermined by the fact that the system would not include data from the private health sector, primary or allied health, nor from non-allopathic health care services and therefore could not fulfil the scheme's core value proposition.

Some consumers argued that the non-contextual disclosure of sensitive information could lead to overt discriminatory practice or at least unconscious bias in treatment decisions thereby negating any potential benefits of information sharing.

Among those who saw the virtue of clinical information sharing were those with specific conditions that were likely to trigger adverse reactions to common emergency procedures.

Some consumers proposed that any system should be confined to non-contentious data such as pathology tests, imaging, allergy and other potential adverse response risks and medication history and that interpretive data, particularly regarding socially sensitive health conditions should not be part of the record.

Several people queried why existing data sets, including My Health Record, could not be extended and improved to address unmet needs.

Apart from reservations about the reliability of data, many consumers voiced concerns about data security, whether in the circumstance of unauthorised access or data piracy.

While consumers accepted that there is no such thing as absolute data security, it increased their reluctance to support comprehensive records when these could include potentially compromising information.

Despite this range of reservations, the majority of participants agreed that sharing clinical information could potentially improve health treatment. However, there was universal concern that any such gains should not be at the expense of basic consumer property rights including the right to opt for or against participation, the right to withhold consent to access and the right to curate what information the records should hold and the accuracy of that information.

Overwhelmingly consumers believed that at least some data sharing was warranted but that any system design should be predicated on the principle that patients “owned” and should be left in control of their personal health history.

Methodology

All participants received the DHHS consultation paper as pre-reading. Two sessions were conducted using the Zoom on-line platform. Both sessions were addressed by the DHHS Chief Digital Health Officer, Neville Board, (the second via a pre-taped presentation), followed by a Q&A session and then small break-out group discussions.

The perspectives presented in this report (and the direct quotes associated with them) are derived from transcripts of the sessions (including break-out groups), chat room comments, notes taken by break-out group scribes and submissions received both before and after the sessions from individuals who could not attend but wished to express a point of view.

This report does not represent a policy position by Health Issues Centre but is an attempt to authentically reflect the disparate views of the forum attendees. As such, the report refrains from editorialising these views but simply arranges them into a coherent and logically sequenced collective narrative.

Forum participants will have the opportunity to correct any inaccuracies or misrepresentations arising from the transcribing process.

This process is consistent with the standard methodology known as Social Listening, developed and applied by Health Issues Centre through all its public consultation processes.

Analysis

While the majority of consumers supported the premise that sharing data could eliminate unnecessary test duplication and improve patient treatment, not everyone believed this was necessarily consequential. In particular, some participants challenged the notion that health records were always a reliable guide to treatment.

Some people cited instances of disputed diagnosis.

"I've been misdiagnosed several times in public hospital. I've had information documented about me which is incorrect and quite concerning. I cannot turn up at public hospitals as I'm seen as too complex due to the rarity of my illnesses and their complex nature. I have to take responsibility for my information but at the same time I would rather take that responsibility than put my information into a system ..." – A. Jordan

Others questioned the reliability of some information sources.

"(There's) lots of reasons why data can be wrong - patient confused at 1st presentation, lack of time/rushed, cognitive bias, family providing misinformation, doctor not asking right questions etc... Assumption is that what is entered will be correct... And that if you share access all will be better - I don't think it is this straightforward..." - Judith Drake

Some made the point that auditing standards would need to be dramatically improved before shared records could be trusted as reliable.

"If doctors are going to share information about any patient the information should have a mandatory requirement to be correct and accurate and the only way to ensure this is to allow the patient to be notified about all content as the patient is the major stakeholder." - Juell Young

Some consumers referred to data systems as socio-technical systems that were *"no better than the imperfect data uploaded by error-prone operators"*.

"It seems to me that what's been presented is that there is going to be this very sophisticated technical system that will do a great job in supporting our health care workers giving the data they need when they need it. The reality is that it's not a technical system, it's a socio-technical system. Human beings are involved in capturing and entering data and in interpreting data and therefore a lot of the risks introduced into the system are because it's a human technical system... technical solutions don't address the risks of human behaviour and human attitudes." – Irith Williams

"This is more than an IT system. It's a psychosocial system. And that has the risk of human error. There is an assumption that our medicos, our allied health professionals, and all our support folks, are 100% capable all the time. And (being one of them) we're not...And therefore it is flawed from the beginning... It must have a capacity for people to opt out and for information to be appropriately deleted. Otherwise, it is a social control mechanism that is feeding a completely different agenda and we have every good reason to believe it might be heading in that direction especially with the indication that it may head to include 'wellbeing' psychosocial information. There needs to be a very strong 'send this back to the beginning' message. Otherwise it shouldn't happen." - Barb

Others voiced scepticism as to whether, even setting aside human error, the system could overcome inherent technical challenges such as interoperability between IT systems.

"I'm an advocate at Breast Screen Vic and currently we can't share mammograms between public and private facilities in Victoria because they can't read each other's data. And that's within the state. So I really question how are they going to share data when we can't do it now." – Kylie

Will the system provide a comprehensive record?

Some consumers queried whether the objective of providing complete patient history was even valid given the boundaries restricting the type of data collected. They pointed out that data would not include information from the private health system, from primary or allied health, or from non-allopathic health care services and could therefore not deliver the complete picture that predicated the system's core justification.

"What is the use of this limited system as the private sector is not involved? - Christine

"This makes the assumption that allopathic medicine is the only valid system of medicine. There are many other highly qualified, accredited practitioners who look after people. If there is no capacity to include that as well, there is no point in going ahead because you will always have a potential interplay between allopathic medicine and other medicine." – Barb

"I have records in Perth WA at four public hospitals (multiple admissions but same UMRNo.) and one private hospital. I also have inpatient medical records in four hospitals (4 public, two private) in Victoria and a further three records of (outpatient) private consultations in SW Victoria. There are also additional medical records for me in NSW, Scotland (Edinburgh) and while aboard three cruise ships.

My question is would it be the intention of the treating doctor to consult all of or selected health services in these health care agencies?" - Jeanette Robertson

Can data sharing prevent adverse outcomes?

Many of those who supported a data sharing system lived with conditions that placed them at potential high risk in emergency circumstances.

"I am a retired Physio and suffer from epilepsy. I need medical personnel to be aware of my condition, my allergies and my medical history. If I was to have a seizure in a public place, I would like the paramedics or attending medics to be aware of my health conditions." - Andree Ernst

"I've worked in ED in medical units and it's very difficult to treat people when you don't know what's wrong with them. My concern for polio in particular, for those who don't know we get a secondary condition in our later years called post-polio syndrome which makes us huge anaesthetic risks. What happens to us under anaesthetic is that often we don't wake up. So we need a huge alert on our medical records and to that end I'm advocating that medical records are shared.

I agree that confidentiality needs to be respected and privacy is utmost but best practice care of every individual in society is important too and we've got to get some kind of middle line between respecting consumer rights and enabling our health professionals to deliver best practice care." -Robyn Abrahams, Board member Post Polio Victoria

Can data sharing lead to perverse consequences?

Some consumers argued that the non-contextual disclosure of sensitive information could lead to overt discriminatory practice or at least unconscious bias in treatment decisions thereby negating any potential benefits of information sharing.

"I feel this may lead to some people not seeking much needed medical attention due to fear of having possibly disadvantageous records accessible to parties they do not feel comfortable with." – Patrick

"I am concerned about diagnostic overshadowing of mental health patients by health clinicians as this is already a huge issue for consumers... For example, a patient who is given a diagnosis of BPD without proper assessment or the persons consent then (has that diagnosis) follow that patient around a health service and is used to belittle or discriminate against that person" - Neil Turton-Lane, VMIAC

"People experiencing substance dependence suffer high levels of discrimination and stigma, including systemic stigma emerging from the health sector. In many cases such people will choose to have multiple doctors, not to source additional substances, but rather (to avoid) discomfort in disclosing substance use and dependence to all health professionals." - Dave Taylor

"I have had vastly different experiences when clinicians know I have a MH history to when they don't.... diagnostic overshadowing is very real! Especially in EDs, big hospitals etc... I want someone to meet me first before they form prejudices and assumptions about me." - Judith Drake

How will this impact consumer rights?

Irrespective of their level of support or discomfort with a CIS system, many participants expressed concerns regarding the impact the current proposal would have on consumer rights.

"(I am) concerned with privacy, freedom to choose and cyber security" - Pamela Aldridge, former RN and Dementia Educator

"Its worth noting that the WA Health Dept (or possibly CAHS specifically) aimed for a vastly more limited contact information database and still eventually rejected the possibility based on the same privacy issues raised here." - Christopher Antonini

"... where is freedom of choice to participate in such an information sharing system? This cannot be mandatory in a person centred health care system." – Nora F

"Whilst I am aware that some people have a fear of government or shared access to their health records, I am in favour of shared access as long as privacy conditions are observed." - Andree Ernst

“The one constant through all the health interactions whether that be community healthcare, primary healthcare, secondary healthcare, tertiary, quaternary healthcare or even with different providers at different levels - the one constant is the patient. If you give the patient access to their own information they can share as they determine with whichever provider. It will however require the health system giving up power and information and that will take leadership and courage.” - Keren Pointon

“I do not agree to our health information being shared. It is my information that is private and I should have maximum control over who it is shared with. What has happened to the privacy legislation? (Is there) no respect for our individual rights?” - Jodi Campbell

Opt-out and controls

Comparisons were made between the proposed model and My Health Record, which, while criticised for adopting an opt-out model, at least allowed some measure of patient control.

“My Health Record at least gives me the option as to whom I share the records with, and to be notified when someone accesses my record. I can also choose to delete my record at any time, including whatever backups that may have existed. I don't see anything like that here.” - Catherine

Informed prior consent

Some consumers felt that the case for NOT including prior informed consent provisions had been inadequately made.

“As things stand at the moment, a hospital I enter today, whilst they may well be able to access my information from a hospital I have visited previously (which I view as grossly bad manners), they cannot do so unless I tell them about the fact that I had indeed visited that hospital. This scenario is totally different when a centralized system is involved.” - John

Review and redact:

Some consumers cited concerns over discrimination as a consequence of unfiltered access to their records.

“My interest is where people have stigmatised diagnoses (that may or may not be correct), who don't want their treatment impacted by those diagnoses (e.g. HIV (with undetectable viral load), BPD, other mental illnesses) - who want to be able to disclose that when safe.” - Rebecca

“How will CIS protect the upload of sensitive health service notes & results collection such as those delivered by CASA??” - mcdonaja

“If a patient has had an abortion, or been prescribed the morning after pill - they may not want any clinician treating them to know this... If someone is experiencing family violence, privacy is critically important! I also worry about diagnostic overshadowing particularly for people with mental health issues. These complexities seem to be being ignored with the presumption that all health providers are competent, have time to provide comprehensive

notes/update, and won't bring their own prejudices. It's possible some people go to a different service as they weren't satisfied with their experience at the first one! The more 'players' the more important informed consent is!! It also has to be easy for people to correct any mistakes, and to know exactly who has accessed their record, when, and for what purpose!" - Judith Drake

There was also concern that unscrupulous health services/clinicians could modify health records where they were potential evidence in a dispute, complaint or legal action.

"What stops a dishonest health provider from changing your records to avoid a court case where there has been bad treatment?" - Susan Housego

Security and safeguards

In general, many consumers accepted that there could be no ultimate guarantee of data security. People were well aware that the most secure sites in the world had proven to be susceptible to determined hacking; some consumers believed that data security would be improved by securing domestic data storage servers. People also understood the intrinsic value of health data for the purposes of identity theft, blackmail and other illegal activity, so rather than ask for ironclad but meaningless assurances, their attention turned to ensuring adequate punitive measures were in place and that potentially compromising data could be redacted.

"I feel there is great benefit in data sharing, but consent and safety are essential. Having had my ATO hacked recently, I also feel having all that comprehensive data online and connected puts consumers at risk in a myriad of ways." - Patrick

Some participants expressed concern regarding the proposed level of deterrence to unauthorised data access, with the penalties for disclosing someone's health information of no consequence.

"The proposed penalties for inappropriate access to information in this system are significantly different from My Health Record. I believe the proposed penalty for an individual is \$9,900 for this system, but up to \$315,000 and potential imprisonment for My Health Record." - Lynette de Valle

"Health information is extremely valuable to a range of malicious players." - Patrick

Some consumers expressed concern that apart from the potential for piracy, the system could be used "legally" for more than individual case management.

"I also have concerns around what the data will be used for apart from my health." - Peter Wood

The fact that DHHS officers would have access to the data fuelled this suspicion.

"(I) challenge the need for DHHS Officers to have access not just clinicians." - Kylie Jones

Conclusions

Many participants were not convinced that a Clinical Information Sharing system could fulfil its objective of delivering better health outcomes because current standards of data verification were not adequate to ensure data hygiene. Furthermore, given the limited sources of data to be included, the proposed system could not deliver on its promise of providing the comprehensive records that predicated its core purpose.

Many of those who acknowledged the value of information sharing recommended that data should be restricted to pathology and imaging (along with standardised reports), allergy/adverse reaction information and medicines.

Some consumers were reluctant to share data where subjective interpretation was possible, particularly for conditions that are commonly stigmatised or highly personal (drugs usage; infectious diseases, mental health conditions, pregnancy termination, sexual assault, family violence).

A number of participants expressed a firm view that consumers “owned” their medical histories and that it was their prerogative to determine whether to participate in a data sharing scheme, to curate the information that comprised their record and to determine to whom and in what circumstances access should be granted. Some participants acknowledged the need for an “override” mechanism enabling non-consensual access to records in the event of a catastrophic circumstance (unconsciousness, severe cognitive trauma etc). They proposed that a “break-the-glass” option could be adopted without negating the general principle of access through consent.

These sentiments are summarised as the following set of statements that should be adopted as the guiding principles underpinning the design of any Clinical Information Sharing System:

Consistent with patient centred care and consumer health rights, consumers are the owners of their own health data records. As such it follows that:

1. Consumers should have the right to determine whether or not they will participate in any information sharing system.
2. Consumers should have the right to review a record for both accuracy and sensitivity and consequently add to it, amend, confirm or redact it.
3. Access to a health record should be subject to obtaining the informed prior consent of the record owner.
4. The potential for misuse or unauthorised access of data should be protected through legislation incorporating significant punitive consequences for breaches.
5. There is a need for accompanying legislation protecting consumers from discrimination and bias resulting from information disclosure.

A number of participants expressed a strong sentiment that before any further modelling of a CIS system occurs (and certainly before legislative changes are made that will impact privacy and confidentiality protections), these principles should be adopted as overarching system commitments in conjunction with a commitment to co-design future iterations of the system together with consumers.