

Social Licence for HealthOne

“When people trust that their data will be used as they have agreed, and accept that enough value will be created, they are likely to be more comfortable with its use. This acceptance is referred to as a social licence.”¹

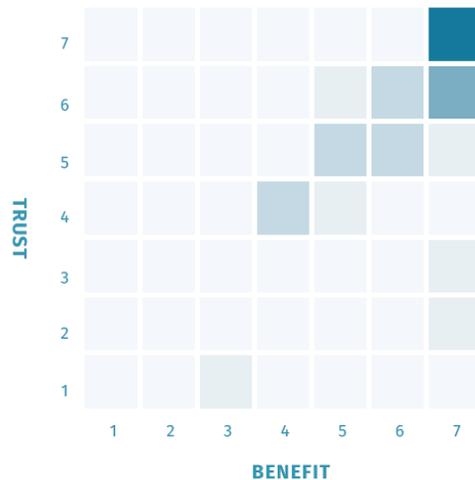
HealthOne relies on ‘social licence’ by ensuring value through having informed clinicians while safeguarding the privacy of individual’s data. Only clinicians involved in the individual’s care are provided with this data.

Data Futures Partnership’s report in Community Comfort Assessment: HealthOne

HealthOne has worked with the Data Futures Partnership (along with Massey University) to evaluate social licence for HealthOne. The Data Futures Partnership report shows strong trust and benefits were identified by both public and clinical (provider) communities.

The concerns about social licence and HealthOne’s responses are outlined below.

Public engagement results



¹ <http://datafutures.co.nz/our-work-2/talking-to-new-zealanders/social-licence/>

Key Issues and Responses

1	<i>A. Benefit</i>	<i>Response (and further development)</i>
	Security and privacy	
1.1	"Need to ensure that all privacy laws are strictly adhered to and data well protected."	<p><i>HealthOne adheres to the Health Information Privacy Code (HIPC) and has a strong and ongoing communication with the Office of the Privacy Commissioner, which has expressed support for the privacy controls implemented by HealthOne.</i></p> <p>Future development: <i>Review of HealthOne Privacy Framework pending.</i></p>
1.2	"There is a trade-off between personal privacy and community benefit which requires clear protocols and reassurance to the individual."	<p><i>HealthOne implements strict protocols to ensure personal privacy while maximising the benefits to patients, clinical teams and the system. Patients benefit through having:</i></p> <ul style="list-style-type: none"> <i>• More informed clinical teams – leading to safer care from understanding the patient and their usual care</i> <i>• Plans designed with the patient inform care teams in different locations</i> <i>• Less duplication of repeated questions and diagnostic tests.</i> <p><i>Personal privacy is protected:</i></p> <ul style="list-style-type: none"> <i>• A clinician must be delivering care to the person and ask permission to access HealthOne</i> <i>• Guaranteeing a relationship between the patient and clinician delivering care through proactive fortnightly auditing</i> <i>• Signed 'User Agreement' outlines expectations and obligations.</i> <p><i>HealthOne currently doesn't store clinical notes/patient's personal conversations with their health provider. Diagnosis, allergies, health warnings, medications and test results from authorised healthcare providers are recorded from people directly involved in care e.g. general practitioners, practice nurses, community nurses, pharmacists and hospital doctors and nurses.</i></p> <p><i>Patients can choose to mark certain information as confidential (after discussion with their primary health provider to ensure health risks are considered). Patients can choose to 'opt off' HealthOne – after discussion with their primary health provider. The choice always remains with the patient.</i></p>

		<p><i>For access to HealthOne, proactive auditing protocols establish if a clinician is delivering care to a patient and patients are asked permission. If this relationship can't be established, a formal audit is initiated which asks the clinician about this relationship.</i></p> <p><i>There are consequences if clinicians break 'Access Agreement' rules:</i></p> <ul style="list-style-type: none"> • <i>Immediate removal of access to HealthOne</i> • <i>Reporting to clinician's governing body</i> • <i>Possible strike from the medical register.</i>
1.3	<p>"I feel health workers who do not have an understanding about the privacy act are a real issue when you are a health professional trying to access information regarding a mutual client. I think all professionals working with a client/patient should have access in this way. This is especially important in the mental health sector where safety can be a concern."</p>	<p><i>The design of HealthOne provides extra support to clinicians to protect them from unintentionally breaching patient's privacy.</i></p> <p><i>Using HealthOne requires both training and an Access Deed – highlighting privacy, especially for patients with mental health issues (https://privacy.org.nz/further-resources/online-privacy-training-free/)</i></p>
1.4	<p>"Information re: protection, storage and backup of health records."</p>	<p><i>Information is protected as all users must be part of the restricted Connected Health Network (this is not open to the internet, nor stored in the 'cloud'). In addition HealthOne users must use a unique log-in to identify them.</i></p> <p><i>As above, the signed User Agreements along with proactive fortnightly auditing provide protection.</i></p>
1.5	<p>"I am concerned that friends, family, or anybody may access the file to just be nosey."</p>	<p><i>There is no public access to HealthOne. In the future, HealthOne may become part of a patient portal that allows people to see their own records, however, this would require individual passwords for each person.</i></p>

	Availability of HealthOne	
1.6	"...unless this system covers the whole country the level of benefit will remain constrained and not fully realised."	<i>We agree that a single electronic shared health record across the entire country would be beneficial. Currently North Island clinicians cannot see shared health records of South Island patients.</i>
1.7	"Only of full benefit to NZ if fully available in NZ."	<p>Future development: <i>The Ministry of Health is conducting a process to ensure New Zealand has a shared health record.</i></p> <p><i>A number of North Island DHBs have expressed interest in adopting HealthOne.</i></p> <p><i>There are also initiatives to develop shared health records e.g. midlandclinicalportal.health.nz which covers Waikato, Bay of Plenty, Lakes, Taranaki and Tairāwhiti DHBs.</i></p>
1.8	"Visibility and accuracy."	<i>The information in HealthOne is reliant on the electronic recording of patient's care records by each health professional. HealthOne contains a copy of information from each partner, e.g. General Practice and Pharmacy. By having this information available to other health professionals, records are more likely to be recorded accurately and corrected.</i>
1.9	"I am concerned about the accuracy of these records. One simple mistake and correct medical treatment could be severely endangered. This would be disadvantageous to both the patient, the medical staff and the Community. Once these records have been entered it is essential that the data is checked regularly and is available for the public to check as well as Medical Practitioners."	<p>Future development: <i>Ongoing education will reinforce the importance of entering information in a way that will assist other health professionals.</i></p>
1.10	"Understanding the information will be difficult for a member of the public, with little medical knowledge. Thus, it will be easy for an overly dominant medical practitioner to ride rough shod over a patient."	<i>Currently patients only have access to their information when they are with a health professional. The emergence of patient portals will create a need to ensure patients can understand and interpret their information.</i>
2	<i>B. Trust</i>	<i>Response</i>
2.1	"One question concerned midwives. As a male I cannot see that it is relevant they know my medical details, but recognise it may be useful in the event of an emergency."	<p><i>HealthOne is designed to provide access where there is a clinical relationship. If a midwife accessed a male patient's record in HealthOne it would be identified in audit and the midwife asked to explain.</i></p> <p><i>Currently, community midwives do not have access to HealthOne.</i></p>

	Security and privacy	
2.2	"I have no problem health professionals accessing the records but would not want commercial organisation such as drug companies, health insurance providers and marketing organisation getting or demanding access."	<p><i>The commercial organisations mentioned don't have access. Under the current HealthOne privacy framework and rules of the Health information Privacy Code - the information is "collected for lawful purpose, connected with what the agency does, and it is necessary to collect the information for that purpose"; and "Agencies must use health information for the same purpose for which they obtained that information."</i></p> <p><i>HealthOne uses the information collected to support the best possible care.</i></p>
2.3	"The issue is more about potentially unauthorised access by medical personnel rather than whether I can access and correct my records."	<p><i>There is potential for unauthorised access by medical personnel, with any electronic or paper clinical information. HealthOne reduces those risks and the audit safeguards mean that unauthorised access will be detected and followed up.</i></p>
2.4	"If HealthOne has the capability to ensure the security of patient record, the full trust will build up from the patient."	<p><i>We agree.</i></p>
2.5	"Not sure all the data are visible in one place."	<p><i>HealthOne provides summary patient information in one place (on different tabs) – this information does not currently include clinical notes from providers. HealthOne has a number of tabs including prescribed and dispensed medications, service summary, observations, diagnosis, alerts/warnings.</i></p>
2.6	"It is accessible by parties who could undertake 'research' with varying degrees of institutional and/or ethical approval."	<p><i>Clinical information in HealthOne cannot be used for 'research.'</i></p> <p><i>However, a patient's clinical information may be used if that patient is part of a trial/research project in which the health professional accessing HealthOne is delivering care, e.g. taking vitals, bloods, prescribing medication. If the user is not accessing the clinical information for delivering care, they will be asked to refrain from further access and their access will be monitored.</i></p>

	Visibility, accuracy and correcting of data	
2.7	"Is there a patient portal available or being developed that would allow me as a patient to view and update personal information? Can I also see when a referral had been sent out by my GP and when or if I have any upcoming appointments at the hospital?"	<p><i>HealthOne does not currently have a patient portal.</i></p> <p>Future Development: <i>The HealthOne infrastructure is being developed to allow patient portal access in the future. Using HealthOne for this purpose would require clinical and public consultation.</i></p>
2.8	"Data only as good as is entered."	<i>We agree – see 1.8 and 1.9.</i>
2.9	"I am a little worried that access to change things may not be as easy as advertised. It would depend a lot on the software."	<i>Currently patients do not have the ability to change their information in HealthOne. This information is drawn from each health providers' records; it is these systems that would require changing.</i>
2.10	"More trust in ability to see data, that in ability to correct."	Future Development: <i>The development of patient portal functions will consider the ability for people to make notes on their record to address incorrect information.</i>
	Consent	
2.11	"I was with my GP and had to explain it to him to show me my record as when I asked he didn't know. Also, no Dr or Pharmacy has even mentioned Opting off to me ever."	<p><i>When HealthOne is rolled out in a region, health professionals must receive training (and supporting documents) before they have access. Posters and pamphlets are visible at each facility and inform patients they can opt off. Pharmacy receipts highlight to patients who they should call if they don't wish to share their information.</i></p> <p>Future Development: <i>Enhance and promote the training material available on-line to users including privacy so that clinicians are well informed when treating patients.</i></p>
2.12	"Presumably, consent will be verbal. So, there is no proof that consent was given."	<i>We encourage clinicians to record conversations about HealthOne consent in their patient management systems. If clinicians don't have consent they need to explain why they accessed information (e.g. the patient was unconscious).</i>

Key Issues and Responses

4	<i>A. Benefit</i>	<i>Response</i>
4.1	"Can't see benefit for community — isn't this about personal, individual records?"	<i>HealthOne saves clinicians time providing opportunities for more informed, better quality of care across the entire patient population. HealthOne also impacts on resource utilisation with less duplication of diagnostic testing, freeing up resources for improved care.</i>
4.2	"In the comment at the start you state that HealthOne has your medical record. It doesn't, it has selected parts. It doesn't include your consultation notes but it may have medications and problems and various communications to and mainly from the hospital sector."	<i>Correct. HealthOne only stores selected parts of the general practice record: encounters, diagnosis, medications, allergies, observations.</i>
4.3	"This is a small, incremental piece of work. Awesome sharing records, but actually makes very little practicable difference most of the time."	<i>A number of benefits identified across the health system have saved clinicians time and led to safer clinical care for patients (see 4.1). We will continue to identify, measure and publish these benefits.</i>
5	<i>B. Trust</i>	<i>Response</i>
5.1	"The data is still accessible without consent and relies on the integrity of each individual that has access to the system."	<p><i>HealthOne relies on the professional integrity of clinicians, however there are a number of measures to protect patient privacy:</i></p> <ul style="list-style-type: none"> <i>• Each clinician uses a unique log-in and can only access the system from the Connected Health Network</i> <i>• Clinicians sign an Access Deed</i> <i>• Access is defined by role</i> <i>• Auditing for proximity is proactively completed</i> <i>• If consent is not given, follow-up of reasoning.</i>
5.2	"Potential time consuming updating for some patient types, especially psychiatric."	<i>Recording patient information and establishing consent for information sharing may be more time consuming for some patients.</i>

5.3	"Not all providers contribute to the shared record and some might get my identity wrong so my info isn't in the right place for me to see it."	<i>HealthOne is reliant on the information captured in each clinician's patient management system. The advantage of a shared record is that other clinicians may question errors, leading to better quality information.</i>
5.4	"It is not a common procedure to ask to view, let alone review/modify information."	<i>HealthOne captures information from each clinician's patient management system meaning changes should be made in these which would be replicated in HealthOne.</i> Future Development: <i>The development of patient portal functions will consider the ability for people to make notes on their record to address incorrect information.</i>
6	<i>C. Ongoing control and direction</i>	<i>Response</i>
6.1	"GPs are not good at keeping my information safe and at big practices there can often be mistakes."	<i>The design of HealthOne provides extra support to clinicians to protect them from unintentionally breaching patient's privacy.</i>
6.2	"The use of the information is again dependent on their own commitment to good healthcare for each of their patients, sometimes the system may be inaccessible and the person may not be bothered using HealthOne as they do not realise its use. Others may not be trained well enough to use it to its full effect."	<i>Measurable benefits from using HealthOne have been identified and there is ongoing education to ensure clinicians understand and have the ability to use HealthOne to its full extent.</i>
6.3	"I would like to be able to access my own health records."	<i>HealthOne does not currently have a patient portal.</i> Future Development: <i>The HealthOne infrastructure is being developed to allow patient portal access in the future. Using HealthOne for this purpose will require clinical and public consultation before agreement.</i>
6.4	"A tool is only as good as the quality of information provided in it, consistently by key medical professionals. People want the best for their health."	<i>Each clinical role has differing access to information based on the needs of that role. This role-based access was established through consultation and robust discussion with clinical</i>

	<p>GPs, ER consultants, nurses and Pharmacists should, in my opinion, have the same access to information for seamless health care support to a person, including sensitive disclosures. Health professionals are bound by ethics and there is an audit process to track those who 'wander' for accountability purposes. Increased transparency required!"</p>	<p><i>leaders when HealthOne was developed. There are processes for reviewing the access each profession has and we expect this will develop over time.</i></p>
<p>6.5</p>	<p>"Just have no experience with yet, not as a physio nor a client, so no idea how to "build up my trust."</p>	<p><i>The advantages of HealthOne are well recognised and there have been many requests for different patient management systems to be 'integrated' into HealthOne. There is an active program of integrations for these systems which are limited by the development team's capacity. Each patient management systems must meet technical criteria such as having unique log-ins (each clinician can be identified for audit) and being on the Connected Health Network.</i></p> <p><i>It is our vision that any health professional will be able to access relevant information about their patients to provide good care in a way that protects patient's privacy</i></p>