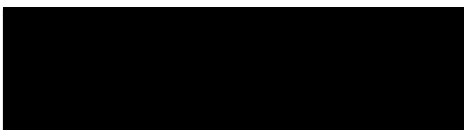


22 January 2021



Dear 

Re: OIA request – Patient information and data sharing at DHBs

Thank you for your Official Information Act request received on 14 December seeking information from Waitematā District Health Board (DHB) about data sharing at DHBs and how patient information is shared.

Before responding to your specific questions, it may be useful to provide some context about our services.

Waitematā is the largest and one of the most rapidly growing DHBs in the country, serving a population of around 650,000 across the North Shore, Waitakere and Rodney areas. We are the largest employer in the district, employing around 8,500 people across more than 80 locations.

In addition to providing care to our own resident population, we are the Northern Region provider of forensic mental health services and child rehabilitation services, plus the metro Auckland provider of child community dental services and community alcohol and drug services.

In response to your request, we are able to provide the following information:

1. Do you have a privacy officer and at what level of DHB leadership do they sit?

Waitematā DHB has two privacy officers who are our General Counsel and Senior Legal Counsel. The General Counsel reports to the Chief Financial Officer/Head of Corporate Services.

2. Do you have a chief data officer and if so, what is their responsibility in the organisation?

The duties of a chief data officer form part of our Chief Information Officer's role. A brief overview of the relevant key accountabilities of this role is as follows:

- health intelligence
- data warehouse management and information life cycle
- Enterprise patient management systems
- production planning systems
- clinical applications development and deployment
- clinical coding.

3. How do you gain patient consent for data sharing – i.e., via a consent form? (Please provide a copy of the form or statement that explains how patient data is shared).

It is important to be aware that the Privacy Act 2020 and Health Information Privacy Code 2020 do not require us to obtain consent to share data in all situations. Our patients are advised that information may be shared without consent for any of the purposes permitted by Privacy Principle 11 and Rule 11(2) of the Health Information Privacy Code 2020.

In some situations, patients will give verbal consent to their information being shared. Patients may also give written authorisation for release of their information to third parties, for example, to insurers, lawyers, etc.

We inform patients of our information-sharing guidelines by having 'Your Personal and Health Information' posters and brochures available in patient areas, as well as on our website: <http://www.waitematadhb.govt.nz/assets/Documents/patients-visitors/your-safety-in-hospital/POSTER-Personal-Health-Info.pdf>

In addition, sharing of patient information is mandatory under some statutes e.g., the Oranga Tamariki Act 1989, Section 22H Health Act 1956, the Land Transport Safety Act 1998 and under court orders. We also have discretion to disclose information under other statutes such as Section 22C Health Act.

Ways in which we gain patient consent currently are as follows:

- a) **Attachment 1** - patient registration form. This contains two privacy statements:
 1. General Privacy Statement – page 1.
 2. Point 5: Patient Privacy – page 2.
 - b) Privacy authorisations - some services (e.g. Community Alcohol and Drugs Service) provide a privacy authorisation for patients to sign when they first engage with the service. In some situations, patients will give verbal consent to their information being disclosed.
 - c) Data sharing for research – data may be shared with sponsors in clinical trials in a de-identified form. Patient consent to participation in clinical trials is gained via a consent form unless, under special circumstances, the Health and Disability Ethics Committee (HDEC) has waived the requirement for patient consent. The HDEC consent template provides instruction to researchers for the appropriate wording for information sheets/consent forms related to data sharing on pages 6-8: <https://ethics.health.govt.nz/updates/new-participant-information-sheet>
- 4. For what purposes are you sharing patient identifiable health information within the DHB?**
- **Clinical care**
 - **Analytics**
 - **Quality improvement**
 - **Planning**
 - **Research.**

We use identifiable patient information within our DHB for all of the purposes listed above.

We note that use of patient data within the DHB does not amount to sharing. Sharing under the Privacy Act 2020 and Health Information Privacy Code 2020 involves the disclosure of information outside the agency which collected the information.

- 5. Do you share patient identifiable information outside of the DHB and, if so, with what other entities? I.e., other DHBs, primary health organisations (PHOs), GPs, non-government organisations (NGOs), social services. If so, what agreements do you have in place to support this?**

Information about patients is shared with general practitioners, private specialists, rest homes, private hospitals and other providers involved in their care in the community. Information is also shared with other district health boards if patients move or are transferred out of Waitematā DHB's care or catchment area.

As previously mentioned, we are sometimes required to share information under various pieces of legislation with various government agencies and health providers and under court orders.

In September 2005, the metro Auckland DHBs - Waitematā, Auckland and Counties Manukau - established the Regional Privacy Advisory Group (RPAG) to assist the Regional Information Services Strategic Plan (RISSP) Governance Group to address privacy issues arising out of regional information sharing projects. The Regional Health Information Sharing Guideline was subsequently developed, advocating a robust and consistent approach to maintain the trust and confidence of all stakeholders and to ensure that information is properly valued, respected and protected. The intention of the guideline is to promote an environment where relevant information can flow efficiently and safely between treating healthcare professionals. As such, the guideline enables shared regional on-line access to clinical information.

In addition, the DHB is a signatory to the Metro Auckland Data Sharing Framework for sharing of data between the metro Auckland DHBs and PHOs in the region.

Sponsors of clinical trials must sign a Clinical Trial Agreement and an Indemnity Agreement which include requirements to keep the de-identified patient data that is provided to them in the course of clinical trials confidential.

- 6. Do you share any personal data directly with patients (appointment and discharge letters/ emails to patients should not be included in this definition of 'sharing personal data').
If yes, what data do you share and via what method?**

Our clinical teams share information with patients throughout the course of their treatment. In addition, all patients are entitled to request access to their patient records at any time under the Privacy Act 2020 and Health Information Privacy Code 2020.

- 7. Do you plan to let consumers access and contribute to their own health information online, via something like a patient portal, in the future? If so, when do you plan to implement and what info will be shared first?**

Some patients use third party clinical equipment which submits data to their DHB-held health record. For example, some pacemakers and implantable cardioverter defibrillator (ICDs) have home monitors which record particular events.

The DHB is planning to expand several aspects of “remote monitoring” which will allow a patient to submit data into their own medical record. The remote monitoring project is currently investigating options for this functionality. The DHB is also looking at providing an online booking function for patients which will enable them to book, amend and review their appointments with our hospital services.

8. How does your organisation govern data sharing?

Waitematā DHB governs data sharing through the following mechanisms and groups:

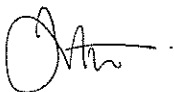
- Regional Data Design Authority (RDDA)
- Metro Auckland Data Sharing Stewardship Group
- Waitematā DHB Privacy and Security Governance Group (PSGG)
- Regional Privacy Advisors Group
- Waitematā DHB privacy policies
- Contracts with funded providers, suppliers and IT providers.

I trust that this information is helpful.

Waitematā DHB supports the open disclosure of information to assist community understanding of how we are delivering publicly funded healthcare. This includes the proactive publication of anonymised Official Information Act responses on our website from 10 working days after they have been released.

If you consider there are good reasons why this response should not be made publicly available, we will be happy to consider your views.

Yours sincerely



Jonathan Christiansen
Chief Medical Officer
Waitematā District Health Board



Stuart Bloomfield
Chief Information Officer
Waitematā District Health Board



Date: Time:

(PLACE PATIENT LABEL HERE)	
SURNAME:	NHI:
FIRST NAMES:	
DATE OF BIRTH: / /	SEX:

REGISTRATION FORM

1: WHY DO YOU NEED MY ETHNICITY INFORMATION?

Ethnicity data are part of a set of routinely collected administrative data used by health sector planners, funders and providers to design and deliver better policies, services and programmes. Better information will help improve every New Zealander's health by providing a sound basis for decision making.

In New Zealand, ethnic identity is recognised as an important dimension of health inequalities. The impact of those factors is particularly evident amongst Māori and Pacific peoples, whose health status is lower on average than that of other New Zealanders.

Ethnicity is self-perceived, so the person concerned should identify their ethnic affiliation wherever feasible. A person can belong to more than one ethnic group and the ethnicities with which a person identifies can change over time.

2: RELIGION

This information is made available to our chaplains. Complete this box if you are affiliated to a particular religious or cultural group. This will enable Waitemata District Health Board to provide appropriate support if (i) there are any religious considerations that you would like us to know about; (ii) if you would like or need religious support. Our Chaplains provide non-denominational support, friendship and counselling, as well as referral to other religious groups.

3: NEXT OF KIN AND ALTERNATIVE/ EMERGENCY CONTACTS

Waitemata District Health Board needs the name(s), addresses and telephone numbers of your preferred contacts. These contacts do not have to be a family member, but it is necessary that the person(s) that you list here knows that you have nominated them. This information allows the hospital to call them to support you, and/ or to accept interim decision-making in an emergency, or allow us to divert enquiries about your health to that person.

4: CHARGING POLICIES:

Only people meeting the eligibility criteria defined in the Government's 2003 Eligibility Direction policy are entitled to publicly-funded care in New Zealand. There is a detailed guide at <http://www.moh.govt.nz/eligibility> but essentially eligible people are New Zealand citizens and permanent residents; work permit holders here for two years or more; specific categories of students; refugee and asylum seekers; and Australian and UK citizens who become acutely unwell.

All patients will be asked to provide proof of eligibility before treatment or after urgent treatment - either a photocopy of:

- your passport (both the first page and the page showing any relevant visas or permits);
- a NZ birth certificate;
- a NZ Citizenship certificate; or
- a letter from Immigration of acceptance of refugee status.

No one will be refused urgent treatment, but ineligible patients will be billed for this afterwards.

In order to determine your eligibility we may disclose information to the New Zealand Immigration Service. Only the minimum information necessary to determine your eligibility (generally your name, gender and date of birth) will be disclosed, and only for the purposes of determining your eligibility.

For more information go to the MoH website <http://www.moh.govt.nz/eligibility> , or call the Eligibility Office on: 09 440 6920.

5: PATIENT PRIVACY

Waitemata District Health Board (WDHB) is required to protect your privacy and will only use your information 1) to provide you with care and treatment, 2) for reasons directly related to the provision of your health Services or 3) use your anonymised data to improve services for future patients. In certain circumstances WDHB may be legally required to provide some of this information to other government agencies e.g. **NZ Police, Oranga Tamariki, Work and Income or NZ Immigration Service.**