

# Primary Care Dataset Governance Group

## Terms of reference

23 June 2025

### Purpose

1. The purpose of the Primary care Dataset Governance (PCDG) group is to support the development of a national administrative primary care data repository hosted by Health NZ and supported by primary care providers.

### Background

2. Health NZ intends to establish a new administrative national primary care data repository alongside the other national collections such as the hospital national minimum data set and the national non admitted patient collection (listed in Appendix 2). The data will include clinical information (such as conditions) but is intended to enable monitoring of health system performance, track trends in primary health workforce, and monitor health service utilisation, capacity, provider performance, timely access and clinical outcomes. The dataset will not be used for clinical purposes, in contrast to the shared electronic patient record.
3. The purposes of the dataset are to improve the performance of the health system by enabling Health NZ to:
  - a) monitor health system performance and contracted provider performance
  - b) inform the planning, funding, monitoring, and evaluation of services
  - c) inform policy development
  - d) monitor health system capacity and workforce disposition
  - e) track population health trends
  - f) understand and improve people's experience of health services
  - g) monitor access to primary care services.
4. PHOs and Contracted Providers collect and hold a wide range of data from Service Users and therefore have a critical role to play in the provision of data to support these functions, and in maintaining the confidence of clinicians and patients that the data set is being appropriately specified, extracted, stored, reported, safeguarded, and interpreted.

### Primary Care Dataset Governance group functions

5. To determine a Data Framework for the primary care data set that complies with the Data Principles set out in Schedule G1 of the PHO Services Agreement by 31 October 2025 (listed in Appendix 1) and relevant legislative data privacy requirements.
6. To determine ongoing changes to the Data Framework as appropriate.
7. To advise on improvements to the manner in which Service Users consent to and are informed about information collection and use.

8. To advise on socialisation campaigns and communications strategies.
9. To advise on ways to minimise the compliance burden on contracted providers.

## Data Framework

10. The Data Framework shall include:

- a) the Specified Data that Participating Practices must provide to Health NZ;
- b) how the Specified Data is to be provided, including its format;
- c) data extraction, transformation, and transmission arrangements;
- d) parameters around how the Specified Data will be shared, the purposes for which it will be used, and who will have access to, and use of the Specified Data; and
- e) how privacy breaches will be managed.

## Specified Data Scope

11. The following key parameters will inform the work of the PCDG group:

- (a) the dataset/repository will be an administrative national data asset held by Health NZ in trust for New Zealand, alongside other national collections (see Appendix 2)
- (b) data will be supplied at an individual transactional level with NHI included where applicable and will be encrypted by Health NZ (in common with other datasets) to protect privacy
- (c) the data is not collected for the purpose of creating a shared health record or clinical decision making
- (d) Health NZ is responsible for the operational management of NZ health datasets including the primary care data repository that holds the Specified Data
- (e) encounter notes and financial information shall not be included in the primary care national dataset/repository Specified Data.

12. The Specified Data shall include at a minimum the following domains:

Domain	Indicative data set
<b>Workforce</b>	Clinical staff: FTE, work dates, profession, registration number
<b>Consultations / clinical encounters</b>	Data to allow calculation of metrics for routine and urgent access and balancing measures – including time between booking and appointment, type of consult, continuity of care metrics, clinical provider identity, Read or Snomed codes associated with consult. Mode of delivery (online, in person, etc).
<b>Health Status</b>	Patient measurements (such as blood pressure, height, weight, Smoking status) Long term conditions coded (e.g. diabetes)

<b>Screening</b>	CVRA score, screening status.
<b>Diagnostics</b>	Lab tests & results. Radiology referrals & reports. (note these will be excluded when Health NZ has separate repositories for this data)
<b>Patient experience</b>	Patient experience survey results at practice level. (sourced from HQSC)

## Membership

13. The PCDG group shall be made up of nine members, being:
- (i) two members appointed by Contracted Providers;
  - (ii) one member appointed by Te Kāhui Hauora Māori;
  - (iii) one member appointed by PHOs;
  - (iv) four members appointed by Health NZ; and
  - (v) one consumer member nominated by the Health Quality Safety Commission.
14. The appointing parties will work together to ensure that the PCDG group has the appropriate skills, capabilities, and experience required.
15. A Chair shall be appointed by the members annually. The Chair's responsibilities include facilitating meetings of the group and ensuring that the group is focused on carrying out its functions.

## Roles of the parties

16. Health NZ
- Operational management of the Specified Data and primary care national dataset/repository collection in line with the Data Framework and its statutory roles and functions.
  - Secretarial support to the PCDG group.
  - Administration of the Data Framework.
17. PHOs
- Primary care data expertise
  - Provider and sector engagement related to the use and application of the data and information
18. Contracted Providers
- Primary care data expertise
  - Patient engagement related to the collection, use and application of the data and information.

## Decision making

19. The group shall aim to reach agreement by consensus. In the absence of that, a 2/3rds majority (six members) is required for a decision.
20. A quorum is two thirds of the members including at least two members appointed by Health NZ and two members appointed by PHOs or contracted providers.

21. Members may designate alternates.
22. The group shall review these TOR annually and may make recommendations to PSAAP negotiators to amend them (at any time) provided they remain consistent with the Data Principles set out in the PHO Services Agreement.

## **Reserve powers**

23. As set out in clause 4.4 of Schedule G1 of the PHO Services Agreement, if Health NZ considers (acting reasonably) that the PCDG group is unable to reach a timely decision on the Data Framework or other matters within its scope, Health NZ may make such a decision. Before doing so, Health NZ must:
  - a. advise the PCDG group that Health New Zealand intends to make a decision on the relevant matter, and provide reasons why;
  - b. if the decision relates to the Data Framework (including changes to the Framework), Health NZ must:
    - i. provide the PCDG group with the proposed Data Framework or proposed changes, and provide an opportunity for comment; and
    - ii. take into account any comments received before making a final decision.
24. If Health NZ makes a decision under reserve powers then it shall formally notify the PSAAP Group, and Participating Practices shall have the opportunity to opt out prior to the change being implemented.

## Appendix One – Data Principles

As set out in the PHO Services Agreement, Part G1, Clause 3:

- (a) Health New Zealand requires good quality, accurate data about primary health systems and services, in order to carry out its statutory functions;
- (b) PHOs and Contracted Providers have a legitimate interest in understanding how data about practices and Services Users that is provided to Health New Zealand might be used;
- (c) Specified Data must be used, collected, stored, and disclosed in accordance with the requirements of the Privacy Act and the Health Information Privacy Code;
- (d) each Party must use, access, store, transfer or disclose the Specified Data in accordance with the Data Framework, and comply with the requirements of the Data Framework;
- (e) each Party will implement and maintain security measures in accordance with industry best practice (including without limitation that Health New Zealand will encrypt the Specified Data) to prevent the loss of, unauthorised access, use, processing, modification, disclosure, accidental loss or destruction of or damage to, and any other misuse relating to, the Specified Data;
- (f) except as required by law, Health New Zealand will not make the Specified Data publicly available in a manner that identifies individuals, practitioners or Contracted Providers (except as part of an agreed performance programme);
- (g) the Specified Data will not include financial information or consultation notes;
- (h) to avoid duplication of work and to reduce risks of a data breach, the Specified Data will not include data that is already being shared with, or otherwise collected by, Health New Zealand as part of a national data set (unless there are good reasons for this); and
- (i) except as expressly provided in the Data Framework, the Specified Data will not be used, disclosed, transferred, stored or made available, outside New Zealand.

## Appendix Two - Current national data collections managed by Health NZ

Data Repository	Data
NHI	National health index data
National Enrolment System	PHO and General practice Enrolment information
General Practice Qualifying Encounter Data ED	General Practice Qualifying encounter data – registers every daily contact with an enrolled patient, by provider.
Pharmaceutical collection / Medicines Data Repository	Prescribed and dispensed medicines.
PHO enrolment collection	Longitudinal information on PHO and provider enrolment
National Minimum dataset	Public Hospital admissions and discharges.
National Non-Admitted Patient Collection	National data set for non-admitted (outpatient and emergency department) activity
NZ Mortality Collection	Information on all deaths.
NZ Cancer Register	Register of all cancers
Aotearoa Immunisation Register	Immunisation data
National surveillance system	Notifiable diseases register.
MHINC / PRIMHD	Mental Health Service Use
Virtual Diabetes Register	Virtual Diabetes Register
National Booking Reporting System	Planned care waiting lists and times
General medical subsidy collection	Payments under GMS.
National maternity collection	Statistical, demographic and clinical information about selected publicly funded maternity services
Laboratory claims collection	Contains claim and payment information for community laboratory tests