Memo

Primary Health Dataset Programme Recommendations September 2022

Date:	1 September 2022
To:	Primary Health Dataset Governance Group
From:	Tony Cooke, Stephen Lavery, PHDP Co-leads
For your:	Decision

Post-memo Note (Dated 16/01/2023):

*The Summary of Recommendations provided at the end of this document are the **final agreed recommendations** after some adjustments to wording agreed post PHDP Governance Group meeting on 06/09/2022. The wording differs from the recommendations contained in the main body of the memo text (Paragraphs 1 – 43) for Recommendations 1 and 5.*

Purpose of memo

This memo presents a series of recommendations to the PHDP Governance Group regarding the proposed next steps in the programme. The Co-leads are seeking review and approval of these recommendations.

Background and context

1. Over July and August 2022, the Primary Health Dataset Programme team engaged widely with primary and community sector representative groups and analysed the data management approaches of the sector with a particular focus on access, curation and use of primary care data by Primary Health Organisations (PHOs).

2. The current state analysis of the data extracted and utilised, and the tools and capabilities used to do this, is described in the Primary Health Dataset Programme – Current State Analysis Report (Current State)[1]. This is based on two surveys which were responded to by PHOs and Managed Service Organisations (MSOs) in July and August 2022[2].

Overarching Observations

3. There is almost universal support for primary health data not currently available nationally to be joined up with other nationally held datasets to create a rich data resource for use by the whole health system.

4. Expectations by the primary care and Te Whatu Ora analytical networks are aligned with respect to what the essential primary health data elements should be. It is recommended that we also engage with analytical networks representing Māori.

---

[1] Fernando, Primary Health Dataset Programme – Current State Analysis, August 2022
[2] Note that as of 25/08/22 the PHOs who have responded to the first survey represent 89% of the enrolled PHO population
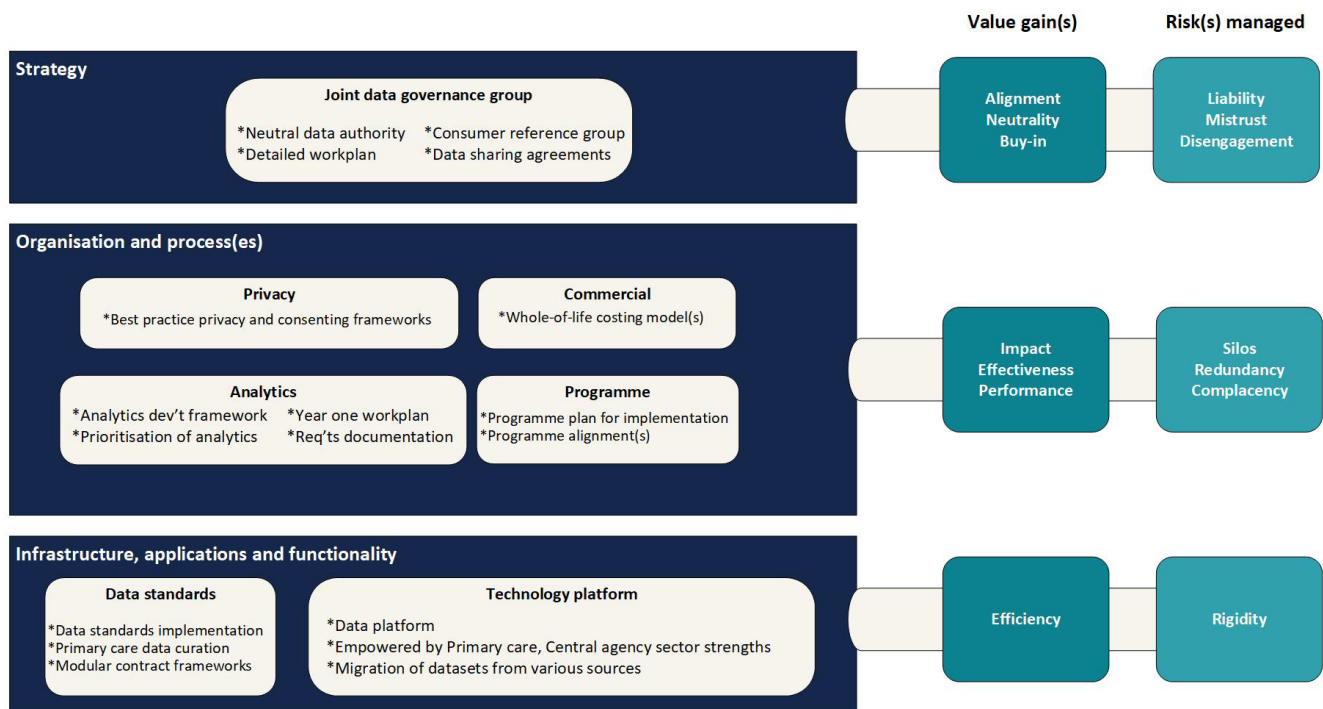
5. All parties want to progress the work in partnership.

6. The feedback has demonstrated that all PHOs are engaging in some level of population health analysis as well as their other core activities.

7. Key concerns:
   - how the dataset will be governed, noting that this is also a key concern for Māori representatives
   - resourcing and the additional workload this programme presents on top of what general practice and PHOs are currently coping with
   - timeframes are ambitious.

8. Key opportunities:
   - greater leadership from Te Whatu Ora in the implementation of data standards. This was also identified in the Health and Disability Services Review 2020 (refer to Figure 10 in Current State Analysis)
   - standardise privacy code processes and privacy statements and link these to the way analytical data will be governed
   - make it easier for primary and community organisations to access National Collection.

Design principles

9. Core design principles were outlined in the original approval memo entitled *Primary Health Dataset Proposal dated 9 February 2022*. From the work to date these principles remain intact:

   1.1 data governance to define and agree how the Dataset will be used and maintained;

   1.2 ongoing engagement with primary and community care providers;

   1.3 improved standardisation and quality of data at the point of creation;

   1.4 straightforward tools and processes to store and use the Dataset in a repeatable manner;

   1.5 technology to support virtual data warehousing so that data is not unnecessarily moved around or transformed;

   1.6 improved efficiency and ease of access for legitimate end-users; and

   1.7 ability to "add value" to the Dataset by linking and combining it with other data.

10. This demonstrates strong alignment of the PHDP work to date, expectations of the sector and the design principles initially agreed at the initiation of the PHDP programme.

Key Recommendations

11. Using the findings from the current state analysis and primary sector engagement a series of recommendations are offered for PHDP Governance Group consideration:
    - Data governance including Māori data sovereignty
    - Data standards and requirements
    - Analytics framework
    - Technology platform
    - Commercial model

Value gain(s)   Risk(s) managed

Strategy

Joint data governance group

*Neutral data authority   *Consumer reference group
*Detailed workplan   *Data sharing agreements

Alignment
Neutrality
Buy-in

Liability
Mistrust
Disengagement

Organisation and process(es)

Privacy
*Best practice privacy and consenting frameworks

Commercial
*Whole-of-life costing model(s)

Analytics
*Analytics dev't framework   *Year one workplan
*Prioritisation of analytics   *Req'ts documentation

Programme
*Programme plan for implementation
*Programme alignment(s)

Impact
Effectiveness
Performance

Silos
Redundancy
Complacency

Infrastructure, applications and functionality

Data standards
*Data standards implementation
*Primary care data curation
*Modular contract frameworks

Technology platform
*Data platform
*Empowered by Primary care, Central agency sector strengths
*Migration of datasets from various sources

Efficiency

Rigidity

Data governance including Māori data sovereignty

12. Data governance is about how data is acquired, maintained, secured and made available to end users.

13. A joined-up approach under one national data platform will require systematic, transparent and consistent data governance processes. A whole of sector co-governance approach is recommended – the concepts of ownership and control over data should be discussed and agreed there.

   - It is proposed that Te Whatu Ora's role is to provide trusted custodianship and protection of PHDP data on behalf of both the data consumer and the data provider and to ensure that data governance frameworks support the taonga that has been entrusted to them.
   - Data governance should be simple, nationally consistent and respectful and will evolve and change over time as this data becomes available.
   - Te Aka Whai Ora's role is to guide the Māori data governance framework to include Māori data sovereignty provisions in the access, curation and use of data related to Māori.

14. The data governance provisions for PHDP will be common across other data management programmes. If data is to be used safely and respectfully as a shared resource for national, regional and local purposes then data warehouse standardisation, data access procedures, definitions of classes of end-user, constraints on usage of certain data, quality assurance of outputs and data sovereignty rights need to be enhanced and made consistent for all national data collections.

15. It is clear that PHOs have worked with their affiliated general practices over a long period of time and have built up trust over that time as to how patient data collected by them is used.

16. Under the PHO Services Agreement (PHOSA), a PHO will have "back-to-back" agreements with its affiliated general practice providers for the sharing of data applicable to the obligations of the agreement. These may be updated as new data items or reports are required. It is noted that all PHOs use their data for population health purposes, and therefore the national use of this data will already be consistent with the local data governance provisions. Further work is required to understand these agreements in relation to PHDP.

17. PHOs and other primary health representative groups have expressed their concerns about how Te Whatu Ora will use primary health data once they receive it and want strong safeguards around its use – as there is for PHOs currently. There is an inherent distrust of central health agencies from past experience and past impositions of requirements without consultation or recognition of the associated costs of compliance. Similar concerns have been raised by Māori stakeholders.

18. It is noted that PHDP is currently focussed on general practice and PHO data sets and during the engagement process a key question was asked about how other primary and community care provider networks will align to the programme. Given the challenges of working with just general practice and PHO data, it is recommended that a dataset is implemented first and acts as an exemplar for further development in the use, access and curation of data from other primary and community care providers.

19. It is recommended to establish an independent primary and community care Health Data Governance Group which will have representatives from the key representative of the sector (general practice, PHOs, consumers and Māori).

20. In this way data can be treated as a health sector asset or taonga – treasured, protected and respected. As other primary and community care sectors participate they can also be represented on the group.

Recommendations

1. To establish an independent data governance authority which will work with the Data Tripartite Agreement, Māori data framework and primary health data governance provisions to build consistent and transparent data governance processes across the sector.

2. To co-design the data governance provisions for primary health data with expertise from primary care clinicians, general practitioners, PHO data managers, analysts, National Collections staff, Māori data sovereignty designers, and privacy specialists.

   Noting that access to a consumer reference group is recommended – potentially the same one used by HQSC.

3. To develop a best practice privacy and consenting framework through a review of existing privacy statements and data sharing agreements.

   Noting that a Privacy Impact Assessment on the agreed approach to data collection and governance of the primary health dataset will need to be undertaken.

Data standards and requirements

21. This analysis confirms that there is a wealth of data that is captured in primary and community care settings which will add to overall knowledge of the health system and how it can best operate. The goal to provide joined up care in primary and community health services will be enabled by the addition of primary health data to the population health intelligence of the whole system.

22. For this to happen efficiently and effectively, data needs to be consistent and standardised across the whole system. This happens most effectively when there are real time data interfaces between systems because system to system interfaces have a low tolerance for variability. A higher degree of tolerance is possible when data is extracted after the fact and massaged to produce a like-for-like data repository but this requires continual maintenance and responsiveness to variation.

23. A lack of consistency in the way data is collected and collated in primary care makes this a complex and time-consuming task. PHOs have invested significant knowledge and capacity in extracting and curating structured data from primary sources within practice management systems and building data repositories which are used for multiple purposes – from supporting specialised care directly to patients to better service planning.

24. To build a national view of primary care data which can be joined up with other national datasets of both primary and secondary data will require one data standard to be agreed. Adherence to an agreed set of data standards could be built into service contracts and capitation-based funding to support general practice and PHOs. These should be seen as enablers and features of a joined-up health system and not separate from it.

25. It is very important also that the general practitioners and practice staff themselves, see some benefit in collecting higher quality structured data. What is in it for them? It is possible that, with better data on the needs of patients, more targeted investment and comprehensive understanding of the realities and pressures of general practice will be accepted by planners and funders.

Recommendation

4. To implement agreed current data standards (based on approved HISO standards) for the curation of primary care data captured locally and held nationally, to **ensure that the work of general practice and PHOs is recognised and aligned nationally.**

Noting that work on developing a new standard for the transfer of primary care data is in progress and has been circulated for consultation (NZ International Patient Summary[3]), and that the Hira programme preference is for this data standard to support its development of real time interfaces.

Analytics Framework

26. Health data analytics is most advanced in those districts where data from primary and secondary care have been brought together for that purpose. Where there are economies of scale, as in the larger PHO/MSOs and the Health and Disability Intelligence unit in the Ministry of Health, a good level of analytics knowledge and application of peer-reviewed methods is available. However, the methodologies and learnings from these units are not more widely available or consistently utilised across the motu.

27. Small and medium sized PHOs are limited by scale and location leading to resource constraints or the lack of suitably skilled staff available – this is especially acute in rural districts. PHOs in Northland and East Cape, for example, have high Māori and rural populations – a population where equity needs are well-known – but their capability to use data and use of comparative data could be improved significantly.

28. The establishment of a consistent nationwide analytics framework where methodologies are peer-reviewed, problem solving is shared and analytics expertise is available regardless of postcode, would lift performance and enable the application of repeatable knowledge and actions across vulnerable populations.

---

[3] https://consult.health.govt.nz/hiso/hiso-10099-2022-nzips/

29. This dovetails well with the potential development of a population health intelligence platform[4] in which the analytics framework is embedded and data from National Collections is joined-up with the primary care dataset on the one platform. This would not take over the work that is currently being done by PHOs, districts, regions or, in future, localities – but it would enhance and streamline much of the analytics work done in those organisations.

Recommendation

5. To establish a whole of sector analytics framework to develop and apply consistent standards of analytic outputs and methodologies on a standardised set of data that includes primary and community data for use by health sector participants.

   Noting that analytics to improve equity of health outcomes for priority populations and to meet obligations under the Te Tiriti o Waitangi is critical.

Technology Platform

30. Data for analytical purposes will need to be consolidated on to a technical platform designed to manage multiple related datasets and to allow real-time joined-up views of data selected by population – this will allow analytical use at scale and precision.

31. A cost effective and cloud-based data warehouse platform has been selected by Te Whatu Ora to house national datasets and join them up under consistently controlled governance provisions (enforced at the technical level). This is the Snowflake platform that could serve as a cost effective, secure, auditable, shareable and scalable solution with in-built controls for handling access rights and governance provisions for the primary care sector, Te Whatu Ora and Te Aka Whai Ora.

32. The platform will need to be able to handle daily updates of data from multiple sources. It is preferred that primary care data will be curated and standardised outside the national data platform and that clean data will be provided in a standardised format.

Recommendation

6. To set up the technology platform to support the primary health datasets allowing it to be part of a wider data ecosystem which will be available for authorised analytical users from primary care, Manatū Hauora, Te Whatu Ora and Te Aka Whai Ora.

   Noting that migration of National Collections to the Snowflake platform is already a Data & Digital committed programme of work (the first 10 collections to be migrated by December 2022).

Commercial model

33. A commercial model to support the development and on-going upkeep of the primary health dataset will be required. It will need to be commercially viable, scalable and sustainable for general practice, PHOs, Te Whatu Ora and Te Aka Whai Ora. Te Whatu Ora Data & Digital currently does not have the expertise or capacity to handle primary care data. However, there is expertise available through trusted providers already working in the primary and community sector.

---

[4] "to develop a national data platform that will connect data and information to reduce duplication, accelerate access, and support local, regional and national decision-making" – Data and Digital ELT Paper (draft), August 2022

34. It is recommended that commercial arrangements are established jointly between parties to ensure that this occurs equitably.

35. A better understanding of the costs of provisioning an end-to-end data extraction, curation and analytics service will need to be undertaken.

36. A costing model is required for Te Whatu Ora costs to cover key data management aspects of the programme (this excludes existing programme management costs)

    a) Costs of exchange, transformation, loading and storage of data on the national data platform
    b) Costs of maintaining data governance, access rights, change management and support services
    c) Costs of providing software-as-a-service analyst usage on the national data platform, including for primary health users

37. A costing model is also required for primary and secondary data providers to cover their data management services

    a) Costs of data transformation and standardisation for loading the dataset to national data platform
    b) Costs of preparing and modifying data governance provisions through all organisations and providers involved in collecting or handling primary health data
    c) Costs of project management, change management and data analyst capability support

38. The approach to procuring and/or funding the data management services required will need to be agreed. It may involve payments to data providers, vendors or third-party data management specialists. In the short term, this may best be done on a time and materials basis, but in the longer term, the preferred model would be to pay for a managed service (potentially from multiple suppliers or a consortium).

Recommendation

7. To develop a costing model for the provision of data management services to support the primary dataset for (a) Te Whatu Ora platform and support costs and (b) primary health data providers costs to supply the data. Following that to select, procure and contract data providers appropriately.

Programme Implications

39. The decisions arising from these recommendations will have implications on the cost, timeframe and scope of the Primary Health Dataset Programme.

40. Once a set of recommendations has been agreed, then the programme plan will be updated to include the right sequencing, resources and dates.

41. The PHDP programme is now incorporated into the Early Actions Programme and so some adjustment in approach and resourcing may be required to align it with overall strategic direction.

Next steps

42. The PHDP team is seeking feedback from the governance group on the recommendations. The acceptance of a set of recommendations will enable further planning, budgeting and implementation steps.

43. Key planning considerations

- work required to co-design consistent data governance provisions including Māori data sovereignty, linking with other governance work and set up of an independent data authority
- Process to reach final agreement to data standards and what data elements will be included in the first version and then to negotiate data supply agreements
- Develop analytical framework and obtain agreement from the sector that it will be fit for purpose
- Develop options for technology platform and extrapolate costs based on use of that platform
- Develop commercial arrangements, including costings for central health agencies and the primary sector based on above planning assumptions to prepare a transparent and fair cost model.

Summary of Recommendations

Using the findings from the current state analysis and primary sector engagement a series of recommendations are offered for PHDP Governance Group consideration:

1.	Approve	To establish a data governance authority which will be governed in partnership with the sector, and which will work with the Data Tripartite Agreement, Māori data framework and primary health data governance provisions to build consistent and transparent data governance processes across the sector.	Yes/No
2.	Approve	To co-design the data governance provisions for primary health data with expertise from primary care clinicians, PHO data managers, analysts, National Collections staff, Māori data sovereignty designers, and privacy specialists.	Yes/No
	Note	Access to a consumer reference group is recommended – potentially the same one used by HQSC.	
3.	Approve	To develop a best practice privacy and consenting framework through review of existing privacy statements and data sharing agreements.	Yes/No
	Note	A Privacy Impact Assessment on the agreed approach to data collection and governance of the primary health dataset will need to be undertaken.	
4.	Approve	To implement agreed current data standards (based on approved HISO standards) for the curation of primary care data captured locally and held nationally, to ensure that the work of general practice and PHOs is recognised and aligned nationally.	Yes/No
	Note	Noting that work on developing a new standard for the transfer of primary care data is in progress and has been circulated for consultation (NZ International Patient Summary[5]), and that the Hira programme preference is for this data standard to support its development of real time interfaces.	
5.	Approve	To establish a whole of sector analytics framework to create a community of practice that combines the strengths of all parties to develop and apply consistent standards of analytic outputs and methodologies on a standardised set of data that includes primary and community data for use by health sector participants.	Yes/No
	Note	Analytics to improve equity of health outcomes for priority populations and to meet obligations under the Te Tiriti o Waitangi is critical.	

---

[5] https://consult.health.govt.nz/hiso/hiso-10099-2022-nzips/

|			
6.	Approve	To set up the technology platform to support the primary health datasets allowing it to be part of a wider data ecosystem which will be available for authorised analytical users from primary care, Manatū Hauora, Te Whatu Ora and Te Aka Whai Ora.	Yes/No
	Note	Migration of National Collections to the Snowflake platform is already a Data & Digital committed programme of work (the first 10 collections to be migrated by December 2022).	
7.	Approve	To develop a costing model for the provision of data management services to support the primary dataset for (a) Te Whatu Ora platform and support costs and (b) primary health data providers costs to supply the data. Following that to select, procure and contract data providers appropriately.	Yes/No

Appendix 1 - Primary health dataset – current and future data sources

Version 1 of the primary health dataset is intended to focus on high value, easily obtainable data – mostly data that is already being used at local and regional level for population health purposes.

Later versions may change the source of the data as national solutions are expanded or created. These can be done in a modular way – one data class at a time. Later versions may also include more data elements, and take advantage of increasing standardisation where possible.

The following illustration shows a future national data platform with data sourced from primary health and existing or future national datasets.

Primary health dataset – current and future data sources
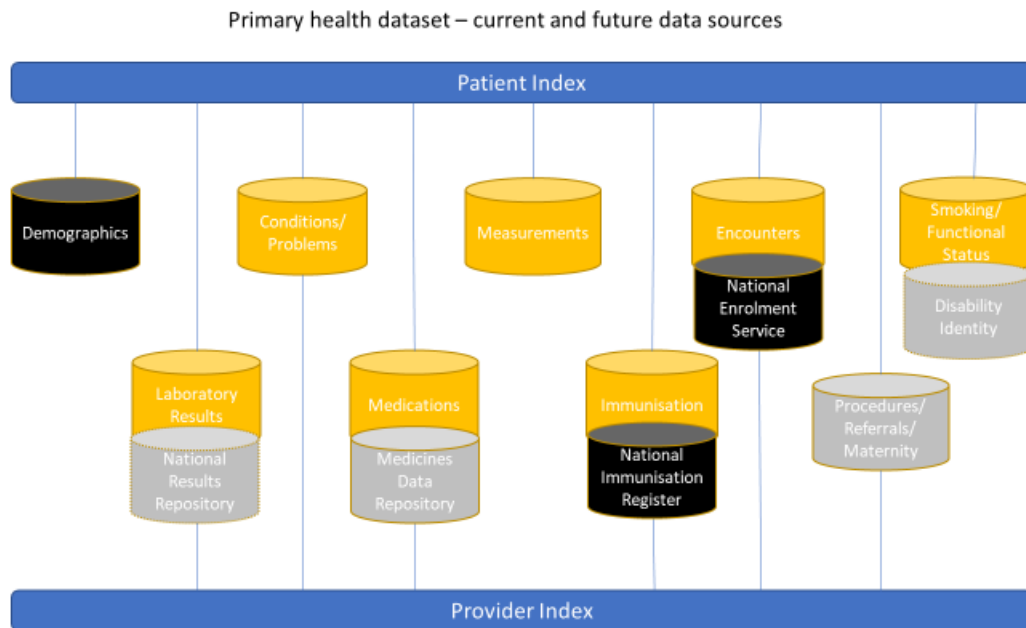
Each item of data within these datasets can be linked to the patient through the National Health Index, and to the provider person, location and organisation through the Health Provider Index.

The orange cylinders represent the primary dataset. The grey cylinders represent new collections or work-in-progress. The black cylinders represent data already present in National Collections.

Appendix 2 – Stakeholder value diagram / table
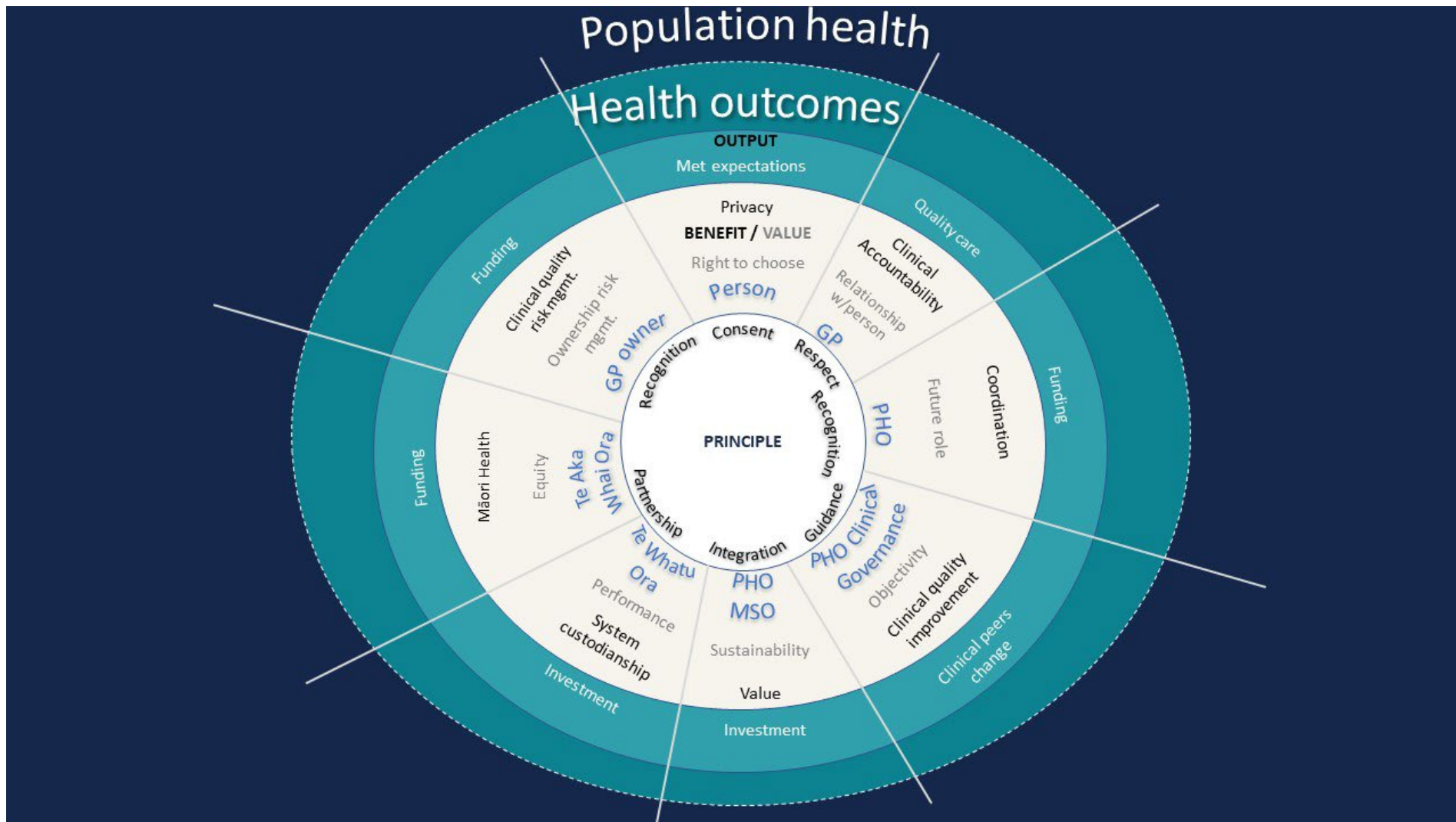
Stakeholder	Principle	Benefit	Value	Output	Result
Person	Consent	Right to choose	Privacy	Met expectations	Health outcome
General Practitioner	Respect	Relationship w/person	Clinical accountability	Quality care	Population health
General Practice Owner	Recognition	Future role	Clinical risk management	Funding	Population health
PHO	Recognition	Objectivity	Coordination	Local response	Population health
PHO clinical governance	Guidance	Clinical quality improvement	Clinical quality improvement	Clinical peers change	Population health
PHO MSO (in-house and external)	Integration	Sustainability	Value	Investment	Population health
Te Whatu Ora	Partnership	System custodianship	Performance	Investment	Population health
Te Aka Whai Ora	Partnership	System custodianship	Equity	Investment	Population health