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Fifth annual update on increasing transparency in Aotearoa New Zealand health care

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Purpose

This paper sets out the fifth and final annual update required by the Ombudsman from the Ministry of Health (the Ministry) and the Health Quality & Safety Commission (the Commission) on the sector's progress towards increasing transparency of health data in Aotearoa New Zealand by June 2021.

Background

In June 2016, Ombudsman Professor Ron Paterson ruled on a complaint by journalist Martin Johnston of the *New Zealand Herald*.

The Ombudsman ruled that district health boards (DHBs) were not required to provide the *New Zealand Herald* with requested rates and total, unadjusted numbers of mortality, readmissions and complications of individual cardiothoracic surgeons and neurosurgeons. Instead, the Ministry and the Commission must work together to provide: a publicly available, annual update (commencing in June 2017) on the sector's progress towards, in five years (ie, by June 2021), the selection, development and public reporting of a range of quality of care measures (including outcomes data) across specialties that meet certain criteria. Reported quality of care measures must:

- be meaningful to health care consumers;
- be meaningful to the clinicians who provide their care;
- be meaningfully attributable to the clinicians or service providing that care; and
- increase the availability of information to the people of New Zealand.

Four annual updates have been published in 2017, 2018, 2019 and 2020.^{1 2 3 4} Publication of this update has been delayed by the COVID-19 response.

Overview – transparency during a global pandemic

The COVID-19 pandemic has spurred massive activity and extraordinary efforts globally – it has also by necessity diverted focus, activity and resource from important issues. Transparency of health care data is one such issue. While in developed countries transparency of COVID-19 case, hospitalisation, fatality and vaccination data has progressed at pace, if unevenly (and indeed has spurred a massive rise in public health and data literacy), other work in increasing transparency of health care data has either progressed as business as usual, stalled or, in some major cases, collapsed utterly.

A key example is the fate of My NHS,⁵ the United Kingdom's transparency portal launched in 2014. It provided a curated view of public-facing data comparing the performance of individual UK consultants, as well as hospital or service data, across 27 specialties.

The service was suspended some time in 2020, and reporting of data has defaulted to a directory of websites reporting data from individual specialties' organising bodies,⁶ as well as a range of performance measures for NHS services and commissioners from different sources.⁷ The NHS England Clinical Outcomes Publication initiative, managed by the Healthcare Quality Improvement Partnership, reports:

In 2019 NHS Digital and NHSX reviewed the value of MyNHS. Although MyNHS has enabled a range of information to be available in one place for users including patients, health and care staff, and developers, it has not generated enough use to warrant the considerable resources that go into maintaining it. Consequently, MyNHS has been decommissioned.⁸

¹ Health Quality & Safety Commission. 2017. *First annual update on increasing transparency in New Zealand health care*. Wellington: Health Quality & Safety Commission. URL: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/2962 (accessed 19 August 2021).

² Health Quality & Safety Commission. 2018. *Second annual update on increasing transparency in New Zealand health care*. Wellington: Health Quality & Safety Commission. URL: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/3438 (accessed 19 August 2021).

³ Health Quality & Safety Commission. 2019. *Third annual update on increasing transparency in New Zealand health care*. Wellington: Health Quality & Safety Commission. URL: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/3801 (accessed 19 August 2021).

⁴ Health Quality & Safety Commission. 2020. Fourth annual update on increasing transparency in Aotearoa New Zealand health care. Wellington: Health Quality & Safety Commission. URL: <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/4118/> (accessed 19 August 2021).

⁵ NHS. My NHS. URL: <https://www.nhs.uk/mynhs/index.html> (accessed 19 August 2021).

⁶ My NHS. Data on speciality treatments. URL: <https://www.nhs.uk/mynhs/specialties.html> (accessed 19 August 2021).

⁷ My NHS. Data on services. URL: <https://www.nhs.uk/mynhs/services.html> (accessed 19 August 2021).

⁸ Healthcare Quality Improvement Partnership. National quality improvement programmes. Clinical Outcomes Publication. URL: <https://www.hqip.org.uk/national-programmes/clinical-outcomes-publication/> (accessed 19 August 2021).

Usage data from 2016/17 suggests the service did not have the consumer uptake expected, well before the effects of COVID-19.⁹ This abrupt suspension, whether related to the effects of the pandemic or not, has nonetheless occurred without any apparent discussion in the medical literature or other media and apparently without any coherent scheme installed to replace it.

This development points to the lack of a coherent conceptualisation of how transparency was intended to work in this form in the UK other than a general approach of ‘more is better’. Was My NHS intended to drive quality improvement on the provider side, inform the public or facilitate consumer choice? The suspension points to a lack of clarity in regard to the tensions surfaced in the Commission’s position paper and consumer consultation over what consumers of health care actually want,¹⁰ the projected usage and benefits of transparency of data and appropriate discussion of the mechanism involved,¹¹ the return on investment expected for this work in terms of use and improved quality of care and outcomes, and the vulnerability of this work to shocks to the system, of which the pandemic is now the signal example.

In effect, a coherent purpose of transparent health care data reporting, which is aligned with the unique local conditions of health care systems (and indeed with different parts of those systems), must be established early for schemes to be coherent and able to measurably deliver on what they are intended to do. An example here is the Australian MyHospitals portal, which, spurred by COVID-19 measures, has pivoted to a position of reporting on health system quality rather than informing consumers to aid them in their choice of vendor.¹² This returns us to Berwick’s seminal 2003 paper, which identified two mechanisms for improvement spurred by public reporting: selection or change.¹¹ In the first, ‘selection’, more and better data allows consumers (and funders, etc) to correctly choose better-performing providers, bringing market forces to bear on lower-performing providers to improve. In the second mechanism, providers become aware of low performance and address it to maintain or increase their ‘market share’ or protect or enhance the reputations of their institutions.^{13 14} Some authors now classify the reputation pathway as a third pathway in itself.¹⁵ In any case, the selection pathway has in a recent systematic review been largely discredited in terms of bringing market forces to bear on quality improvement via more informed patient choices, for varying and complex reasons.¹⁵ Furthermore, the assumption of choice that selection is predicated upon is simply not a mechanism available to the majority of Aotearoa New Zealand consumers of health care.

In Aotearoa New Zealand, responses to the COVID-19 pandemic have considerably affected some areas of progress in transparency of health care data. While on the one hand the Ministry of Health has provided clear, accessible updates on COVID-19 information via the Unite

⁹ Shuker C, Bohm G, Hamblin R, et al. 2017. Progress in public reporting in New Zealand since the Ombudsman’s ruling, and an invitation. *New Zealand Medical Journal* 130(1457): 11–22.

¹⁰ Health Quality & Safety Commission. 2016. *Position paper on the transparency of information related to health care interventions*. Wellington: Health Quality & Safety Commission. URL: <https://www.hqsc.govt.nz/publications-and-resources/publication/2463/> (accessed 19 August 2021).

¹¹ Berwick DM, James B, Coye MJ. 2003. Connections between quality measurement and improvement. *Medical Care* 41(1 Suppl): I30–8.

¹² Australian Institute of Health and Welfare. MyHospitals. URL: <https://www.aihw.gov.au/reports-data/myhospitals> (accessed 19 August 2021).

¹³ Hibbard JH, Stockard J, Tusler M. 2005. Hospital performance reports: Impact on quality, market share, and reputation. *Health Affairs* 24(4): 1150–60.

¹⁴ Bevan G, Evans A, Nuti S. 2019. Reputations count: why benchmarking performance is improving health care across the world. *Health Economics, Policy and Law* 14(2): 141–61.

¹⁵ Prang KH, Maritz R, Sabanovic H, et al. 2021. Mechanisms and impact of public reporting on physicians and hospitals’ performance: a systematic review (2000–2020). *PLoS One* 16(2): e0247297.

Against COVID-19 campaign and regular televised briefings in times of potential outbreaks, on the other hand some work has stalled as clinicians' and other health care workers' focus and efforts have been diverted. We report below on progress on transparency in different forms aside from specifically COVID-related communications, some of which however include work on COVID-19 effects on service provision.

Most central is a new system of transparent public reporting of health care performance of the New Zealand health care system.

Health Systems Indicator (HSI) framework – a new way of measuring and reporting health system performance

On 6 August 2021 Hon Andrew Little, Minister of Health, announced the new Health System Indicators framework, a new way of measuring and publicly reporting operation of the health system. Cabinet has agreed that the new framework will replace the existing national health targets from 2021/22. Development and implementation of the new framework are led by the Ministry and the Commission.

A two-tier system: high-level national measures and local contributory actions and measures
The new framework builds on the System Level Measures (SLM) programme philosophy that was co-designed with the sector.¹⁶ It recognises that while the Government wants to achieve the same health and wellbeing outcomes for everyone in New Zealand, every locality has its own operating environment and a unique set of challenges that require local solutions. The framework emphasises continuous improvement at a local level to lift overall health system performance, rather than achieving nationally set performance targets.

Thus the framework sets out 12 high-level, national measures that correspond with the Government's priorities for the health care system. Under the framework, local actions will be developed by localities to address the particular local conditions and manifestations of these priorities in their areas, thus contributing to improved and relevant performance locally, and on each high-level measure. DHBs and local providers will be supported during 2021/22 to partner with their stakeholders, including Māori/Iwi partnership boards and clinicians, to develop their sets of local actions and associated measures (publicly reported) that will contribute to national improvement on the publicly reported high-level measures. It is anticipated that all local actions will be in place by 1 July 2022 and once in place reported alongside their contribution to the national, high-level measures.

The emphasis in both high-level and local measures is on continuous improvement rather than achieving set performance targets. Targets set a minimum level of performance for processes (such as immunisation rates or wait times in emergency departments) and monitor performance against this. This approach has some virtues and some successes but also some limitations, which are well rehearsed elsewhere.¹⁷

¹⁶ Ministry of Health. System Level Measures Framework. URL: <https://www.health.govt.nz/new-zealand-health-system/system-level-measures-framework> (accessed 19 August 2021).

¹⁷ Shuker C. 2019, 5 November. The power, peril and promise of targets. *The Spinoff*. URL: <https://thespinoff.co.nz/society/05-11-2019/the-power-peril-and-promise-of-targets/> (accessed 19 August 2021).

These limitations relate to the:

- limited nature of the target measures themselves (which are imperfect representations of larger ideals)
- need to be able to hold one body to account for their achievement (which assumes a linear relationship between action and result, ignoring that health systems are complex adaptive systems where these linear relationships seldom apply)
- uniformity of required actions regardless of local circumstances, priorities and needs.

The alternative, which addresses these limitations while meeting the imperative to measure and report in a transparent way, is to use very broad rather than targeted aims, and use broader measures of these aims, to track system functioning at a very high level. To be sufficiently broad, such measures cannot be achieved by one body operating alone, project managing the achievement of a target. Rather, the actions required to achieve this:

- need a coalition of clinicians, consumers, communities and providers to work together
- are likely to vary between different communities.

What then follows is a two-level framework: national aims delivered by local action.

The intended audience of the framework is both the public and providers, with the purpose of quality improvement at a local level and accountability of services to Government and the public to deliver on Government priorities. The HSI framework proceeds from the assumptions that measuring and transparent reporting on the operating of the health system is simultaneously:

- a democratic obligation – voters, who pay for the system, should have assurance both that the system aims are reasonable, and that acceptable progress is being made towards these aims
- a management necessity – without identifying and measuring the right things, those responsible for providing, planning, funding and managing health services cannot know whether their efforts are benefiting the populations they serve.

The ‘framework’ element is essential to emphasise. The headline national indicators are not accountability metrics for local health system players but rather a way for the centre to provide an account to the public about progress of relevant, focused local work against high-level aims. They fulfil the first imperative, that of democratic obligation.

The second imperative (management necessity), and the focus of accountability for local services, lies in the local plans against each high-level aim, and the indicators chosen to track progress in achieving these. The rationale is that achievement of local plans will make the required local contribution towards the national aims.

For this reason, fixating on the top-level measures is a mistake. These need to be reliable, available and amenable to change, but cannot and should not be used as ‘key performance indicators’ to track quarterly progress using conventional tools. These top-level measures are critical measures of health system success that will take longer to see change but will have a meaningful impact on people’s lives.

The accountability for localities (as it will be in the new system) coming through the locally agreed plans and measurement thereof creates greater accountability (in the broad meaning of

the term). Primarily, localities will need to show that they have plans, actions and measurable goals that their local communities and other stakeholders agree meet local needs and aspirations. Then they will need to show that they have ‘done what they said’ in delivering these plans. Finally, over time, they will need to show that the local plans were the right thing to do, by assessing whether achievement of local plans ‘moves the dial’ on the high-level national indicators for the locality’s population.

This separation of accountabilities fits well with the redesigned health system. The high-level system indicators allow Health NZ to give an account to both the Minister of Health and the public of how well it is progressing national aims. The local plans and measures allow localities to provide accountability through Health NZ about how well they are implementing the national priorities in a way that is relevant to their population.

The current Government priorities shaping the selection of high-level measures are:

- improving child wellbeing
- improving mental health
- improving wellbeing through prevention
- a strong and equitable public health system
- better primary health care
- a financially sustainable health system.

One of the strengths of this framework is that it is adaptable and robust to those priorities changing or evolving, to completed or newly identified areas of focus locally or nationally, and to shocks to the system such as the COVID-19 pandemic represents. While indicators may be moved in and out as areas of focus evolve, what remains intact is the logic of central guidance with local freedom, an atmosphere of trust, cooperation and collaboration, local community and consumer involvement, and local, relevant quality improvement guided by national imperatives.

Alongside this new framework, other work in transparency of health care data has been conducted, as summarised below.

Updates on selected other work in transparency

Some of the work described below has been delayed by the response to the COVID-19 pandemic.

Ischaemic heart disease

The consumer-facing version of the All New Zealand Acute Coronary Syndrome Quality Improvement (ANZACS-QI) registry dashboard of key acute coronary syndrome care quality indicators is published via the Heart Foundation’s website (www.heartfoundation.org.nz/your-heart), in partnership with the Foundation, the Ministry, the Commission and ANZACS-QI. It was updated in March 2021 with new data from between 2018 and 2020 (as appropriate to the indicator).

A key new addition is publication of data for 30-day all-cause mortality after percutaneous coronary intervention (PCI) in New Zealand between 1 July 2017 and 30 June 2019. PCI is the optimal reperfusion strategy to manage ST-elevation myocardial infarction (STEMI) and mortality rates after PCI procedures are often seen as a marker of how well services are performing (and have thus been controversial).

This new data reveals overall mortality rates in New Zealand after PCI are comparable with those reported internationally. There were no statistically significant differences between individual New Zealand sites and national rates.

Dashboard of health system quality

The second iteration of the Commission’s dashboard of health system quality, presenting a complex array of comparative performance information by DHB visually, was published on the Commission’s website on 12 February 2021 and updated on 31 May 2021.¹⁸ This new national dashboard was created in partnership with Te Tumu Whakarae, the national General Managers Māori/Executive Directors Māori group across DHBs.

The dashboard brings together 70 indicators of quality across all 20 DHBs in one dashboard. Indicators are divided into domains structured by an Aotearoa New Zealand-specific permutation of the Institute of Medicine’s widely influential STEEP framework (care that is safe, timely, effective, efficient, equitable and patient-centred).¹⁹ The dashboard’s domains are safety, effectiveness, efficiency and patient-centredness and it includes a new specific Māori Health Equity Report, using distinct data, and a dashboard of ‘quality priorities’, which identifies emergent areas of quality issues revealed by the data. All indicators are regularly updated.

Orthopaedics

- Work on the hip fracture co-design workshop held in 2019 with consumers and whānau of those affected by hip fracture, along with clinicians and staff from the Australian & New Zealand Hip Fracture Registry (ANZHFR), resulted in a consumer discharge resource developed collaboratively and given to all patients discharged from hospital following a hip fracture.²⁰ The ANZHFR is a clinical registry that collects data on the care processes and outcomes of people admitted to hospital with a fracture of the proximal femur. The discharge tool was developed with consumers and a working group with specialised input from geriatric, nursing, orthopaedic surgery, physiotherapy, occupational therapy and Accident Compensation Corporation perspectives.
- Hard copies of the discharge booklet have been circulated to DHB hip fracture liaison staff and DHB quality and risk managers.
- Other work with the Joint Registry has been on hiatus since the COVID-19 response.

Cancer services – Te Aho o Te Kahu (Cancer Control Agency)

Background

Te Aho o Te Kahu (Cancer Control Agency) was established in December 2019 to provide leadership and oversight of all cancer-related activity in Aotearoa New Zealand. This leadership will strengthen and improve cancer control through prioritising and getting the best value from existing cancer care investment, monitor the quality of cancer services and guide improvement activities. Te Aho o Te Kahu is committed to accountability and transparency as it works

¹⁸ Health Quality & Safety Commission. Dashboard of health system quality. URL: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/quality-dashboards/dashboard-of-health-system-quality (accessed 19 August 2021).

¹⁹ Institute of Medicine. 2001. *Crossing the Quality Chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.

²⁰ Health Quality & Safety Commission and ANZHFR. *Recovering from a hip fracture | Pikinga ora i tētahi whainga hope*. Wellington: Health Quality & Safety Commission. URL: <https://www.hqsc.govt.nz/our-programmes/reducing-harm-from-falls/publications-and-resources/publication/4319/> (accessed 19 August 2021).

towards achieving the goals and outcomes of the New Zealand Cancer Action Plan 2019–2029.²¹

Te Aho o Te Kahu's website launched in 2020 to provide a source of reliable cancer-related information and to enable ongoing transparency for its work.

Activity towards transparency

1. Cancer Quality Performance Indicator Programme progress

Te Aho o Te Kahu took over the quality performance indicator (QPI) development and publication programme from the Ministry of Health on 1 December 2019. It is developing tumour-specific QPIs in partnership with sector-led working groups. Developing QPIs is an internationally accepted approach for measuring patient outcomes, illuminating and enabling opportunities to address any unwarranted variation across services.

Indicative information on timing and progress in the development of QPIs across the programme is available and updated as work continues.²²

Recent QPI-related work and publications include the following.

- The *Lung Cancer Quality Improvement Monitoring Report*, published on 3 March 2021, provides information about DHB performance against generic and lung-cancer-specific QPIs that were developed through a process of clinical engagement, consultation and consensus.²³ The associated data is also provided via the lung-cancer-specific Cancer Care Data Explorer, which users can interrogate at multiple levels (by DHB, region, ethnicity, age, etc).²⁴
- The *Prostate QPI Monitoring Report* was shared in draft (for feedback) with DHBs on 10 March 2021. This report provides information about DHB performance against generic and prostate-cancer-specific QPIs that were developed through a process of clinical engagement, consultation and consensus. It will be finalised and published on the Te Aho o Te Kahu website, and the associated data provided via a prostate-cancer-specific Cancer Care Data Explorer, in mid to late 2021.
- A national lung and prostate cancer QPI forum was held on 8 April 2021 with over 80 representatives in attendance, ranging from DHB representatives to primary care providers and consumers. The purpose of the forum was to discuss the results of the lung and prostate QPI monitoring reports and to develop quality improvement plans that will (when published in mid to late 2021) support DHBs to address unwarranted variation as part of their quality improvement programmes.

²¹ Ministry of Health. 2019. *New Zealand Cancer Action Plan 2019–2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029. Revised January 2020*. Wellington: Ministry of Health.

²² Te Aho o Te Kahu. Cancer Quality Performance Indicator Programme. URL: <https://teaho.govt.nz/about/our-work/qpi> (accessed 19 August 2021).

²³ Te Aho o Te Kahu. 2021. *Lung Cancer Quality Improvement Monitoring Report 2021*. Wellington: Cancer Control Agency. URL: <https://teaho.govt.nz/static/reports/lung-cancer-quality-improvement-monitoring-report-20210225.pdf> (accessed 19 August 2021).

²⁴ Te Aho o Te Kahu. 2021. Cancer Care Data Explorer 2021. URL: <https://minhealthnz.shinyapps.io/cancer-care-data-explorer/> (accessed 19 August 2021).

- Bowel cancer QPIs, which were first published in March 2019,²⁵ are currently being recalculated and the updated information will be provided in a published report and via the bowel-cancer-specific Cancer Care Data Explorer in mid to late 2021.

2. Radiation oncology collection

The Radiation Oncology Online Tool published on the Ministry of Health's website provides non-identifiable and aggregated information available to all DHBs and the general public.²⁶ The tool enables comparisons for performance for the six radiation treatment centres in New Zealand. It supports quality improvement activity through understanding and addressing unwarranted variation.

3. *He Pūrongo Mate Pukupuku o Aotearoa 2020: The State of Cancer in New Zealand 2020 Report*

Te Aho o Te Kahu released *The State of Cancer in New Zealand 2020* on 2 February 2021, as the first-ever comprehensive report of the cancer system in Aotearoa.²⁷ This report provides a detailed snapshot of the current performance across the system from cancer prevention, treatment and beyond. The report provides a benchmark for monitoring progress going forward to ensure all New Zealand receive the best-possible quality care and for monitoring work to establish whether what we are doing is making a difference to those who are disproportionately impacted by cancer. This will include our ability to monitor prevention activities, inequalities in care and access to diagnostics. This report will be reviewed, updated and republished biannually.

4. COVID-19 impact on services

During the COVID-19 response, Te Aho o Te Kahu initiated a programme of work monitoring the impact of COVID-19 on cancer services. As part of this work, monthly reports monitoring key diagnostic procedures, cancer registrations and cancer treatment (surgery, medical oncology and radiation therapy) were released. The first report was released at the end of May 2020 and reports were published on the Ministry of Health website. Once the Te Aho o Te Kahu website went live, all reports were made available there.²⁸

²⁵ Ministry of Health. 2019. *Bowel Cancer Quality Improvement Report*. Wellington: Ministry of Health. URL: <https://www.health.govt.nz/publication/bowel-cancer-quality-improvement-report-2019> (accessed 19 August 2021).

²⁶ Te Aho o Te Kahu. 2021. Radiation Oncology Online Tool. URL: <https://minhealthnz.shinyapps.io/radiation-oncology-online-tool-test-version-2/> (accessed 19 August 2021).

²⁷ Te Aho o Te Kahu. 2021. *He Pūrongo Mate Pukupuku o Aotearoa 2020: The State of Cancer in New Zealand 2020*. Wellington: Te Aho o Te Kahu, Cancer Control Agency. URL: <https://teaho.govt.nz/reports/cancer-state> (accessed 19 August 2021).

²⁸ Te Aho o Te Kahu. nd. Te tautiaki o te mate pukupuku me mate Korona – Cancer Care and COVID-19. URL: <https://teaho.govt.nz/reports/cancer-care> (accessed 19 August 2021).

Te Aho o Te Kahu also led the publication of two peer-reviewed articles published in *The Lancet Regional Health – Western Pacific Region*, describing the national response to COVID-19 and the impact it had on cancer services.^{29 30}

5. Planned release 2021–2022

Te Aho o Te Kahu plans to:

- complete further QPI monitoring reports and publication and quality improvement plans
- report against the *New Zealand Cancer Action Plan 2019–2029*.

Overarching work in transparency

- The Commission continued to update the clinical domains of the Atlas of Healthcare Variation this financial year, presenting comparative data by DHB.

Conclusion

The Ministry of Health and the Commission, in partnership with other agencies and organisations, will continue to work to increase transparency of health data across specialties and all aspects of Aotearoa New Zealand’s health care.

²⁹ Millar E, Gurney J, Beuker S, et al. 2021. Maintaining cancer services during the COVID-19 pandemic: the Aotearoa New Zealand experience. *The Lancet Regional Health-Western Pacific* 11: 100172.

³⁰ Gurney JK, Millar E, Dunn A, et al. 2021. The impact of the COVID-19 pandemic on cancer diagnosis and service access in New Zealand: a country pursuing COVID-19 elimination. *The Lancet Regional Health-Western Pacific* 10: 100127.