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

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Purpose

This paper sets out the fourth 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 *NZ 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.

Establishing principles and rationale for transparency

As outlined in the annual updates of 2017, 2018 and 2019,[1] [2] [3] in response to the Ombudsman's ruling, the Ministry and the Commission, with the support of the Accident

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[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.

[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.

[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.

Compensation Corporation (ACC) and the Health and Disability Commissioner, developed a rationale and strategy for public reporting to be effective in the Aotearoa New Zealand context (*Guiding Principles: Towards the Publication of Clinical Performance and Outcome Data*).[1]

These principles informed the strategy of working with existing registries of robust data that clinicians trust and developing measures and publications through co-design with health service consumers and whānau.

Work in 2019/20

Some of the work described below has been delayed by the response to COVID-19, which began in February 2020.

Ischaemic heart disease

- On 7 July 2020, 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 was 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. The dashboard has been co-designed to be accessible and present complex registry data in a simple way. It shows comparative quality data by DHB on seven emergency response, treatment and after-care indicators.
- The dashboard was initially developed for and circulated to the clinical audience of cardiology teams around Aotearoa New Zealand via the Cardiac Network, and to DHBs in November 2018. It was then adapted to what is known as a 'stave chart' format, presenting indicators as a patient pathway. This reflects leading international work on presenting performance indicators in a legible, accessible, patient-friendly way. Agreement was met with the Heart Foundation, a trusted partner with mana, credibility and consumer faith, to present the dashboard via its website.
- A peer-reviewed paper in the *New Zealand Medical Journal* was published on 21 August 2020.[4] The paper announced the dashboard and described its background, rationale and what it shows. It also discussed the principles underpinning the presentation of responsible, ethical, open transparency of health care data in Aotearoa New Zealand that drives quality improvement and reductions in unwarranted variation.
- Alongside the data transparency work, use of the standardised discharge tool has spread to a number of DHBs. The tool was co-designed and developed by consumers and clinicians in response to poor discharge experiences. The format has been adopted for hip fracture (see next section).

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[4] Kerr A, Shuker C, Devlin G. 2020. Transparency in the year of COVID-19 means tracking and publishing performance in the whole health system: progress on the public reporting of acute coronary syndrome data in New Zealand. *NZ Med J* 133(1520). URL: www.nzma.org.nz/journal-articles/transparency-in-the-year-of-covid-19-means-tracking-and-publishing-performance-in-the-whole-health-system-progress-on-the-public-reporting-of-acute-coronary-syndrome-data-in-new-zealand.

Orthopaedics

- Work with the Australian & New Zealand Hip Fracture Registry (ANZHFR) resulted in a hip fracture co-design workshop being held on 2 April 2019 with consumers and whānau of those affected by hip fracture, along with clinicians and agency staff. 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 purpose of the day was to understand the views of consumers and whānau on transparency of information contained in the ANZHFR. Consumers were engaged by the ANZHFR data and the picture it provided of hip fracture care in Aotearoa New Zealand. The focus quickly moved to the desire for prevention and communication, particularly relating to disparate and confusing experiences on discharge.
- The workshop highlighted the need for a consumer discharge resource to be developed collaboratively and given to all patients discharged from hospital following a hip fracture. This information resource would prompt a conversation between patients, whānau and clinicians, and lead to the development of an individualised care plan (meeting Hip Fracture Clinical Care Standard 7).
- The Commission formed a working group with specialised input from geriatric, nursing, orthopaedic surgery, physiotherapy, occupational therapy and ACC perspectives.
- On 26 February 2020, a consumer workshop was held in Auckland, where a large group of consumers and whānau shared their experiences and gave feedback on what the resource should include. The workshop emphasised the need for simple, easy-to-follow written information. A draft resource is now in progress, and the content has been guided by (and amended following) feedback from consumers, whānau, members of the working group and Commission representatives. It will be shared with a wider consumer network for further consultation before being finalised.
- Work with the Joint Registry is ongoing. With the help of clinicians at the Registry and the New Zealand Orthopaedics Association, a preliminary questionnaire using questions adapted from a validated survey was appended to a sample of postoperative patient reported outcome measures (PROMs) sent out by the Joint Registry to patients six months after their hip or knee procedure. The questionnaire was designed to identify orthopaedic patients' need for and beliefs about more transparent data. It focused on whether performance varied between surgeons and/or hospitals, how consumers went about seeking information and what kind of information and data they sought and/or found. From 100 questionnaires there were 34 respondents.
- Most respondents agreed the hospital and surgeon they had had an important effect on their health outcome. Some felt there were large differences in quality between surgeons, but most did not seek or find data to understand this. About two-thirds of respondents sought more information about their surgeon from sources other than the surgeon or GP.
- Anecdotal information suggests the people who undergo these surgeries rely transfer significant information through in-person encounters in social situations for information; word of mouth is a strong factor in choice of surgeon.
- Shortly after the questionnaire responses were received, the response to COVID-19 paused work with the Registry.

Cancer services – Te Aho o Te Kahu, Cancer Control Agency

a) Quality performance indicator programme

Te Aho o Te Kahu took over the programme of quality performance indicator development and publication from the Ministry of Health on 1 December 2019. Tumour-specific quality performance indicators are being developed by Te Aho o Te Kahu in partnership with sector-led working groups, ultimately for public release. Key principles of the process are clinical engagement, consultation and consensus, and that indicators selected, developed and published are:

1. evidence-based (ie, supported by sound, current evidence that the indicator can drive quality improvement)

2. important (ie, address an area of clinical importance that could significantly impact on the quality and outcome of care delivered)

3. supportive of the goals of achieving Māori health gain, equity and national consistency.

- A national forum with representatives from most DHBs was held in September 2019 to discuss the results of the Bowel Cancer Quality Improvement Report. A national quality improvement plan for bowel cancer is being developed based on learnings from the forum.
- An agreed set of 13 quality performance indicators for prostate cancer have been identified. Work is progressing on calculating the indicators and a report is being drafted.
- A set of 11 quality performance indicators have been identified and agreed for lung cancer. Eight indicators have been calculated and a report has been drafted. The report and results will be circulated to DHBs for review and feedback in August 2020.
- A working group of neuroendocrine tumour experts met in December 2019. A set of 8 proposed indicators were sent out for sector feedback in February 2020.
- A working group of head and neck tumour experts was formed and met for the first time in October 2019. A set of 14 head and neck tumour indicators have been identified and sent out for sector review. Feedback is being collated for review before indicator results are calculated.
- A working group has been formed and met for the first time in June 2020 to identify pancreatic cancer indicators.

b) COVID-19 impact on cancer services

Te Aho o Te Kahu published an initial report on the national impact of COVID-19 restrictions on cancer diagnosis and treatment services in March and April 2020.[5] Reports are also being prepared for DHBs and will be updated monthly.

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[5] Te Aho o Te Kahu, Cancer Control Agency. 2020. *COVID-19 and cancer services: A Cancer Control Agency working report on the impact of COVID-19 and the lockdown on cancer services in New Zealand*. URL: www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-resources-health-professionals/covid-19-cancer-and-screening-services.

Overarching work in transparency

- The Commission's dashboard of health system quality was published on the Commission's website in May 2018.[6] The dashboard brings together 70 indicators of quality across all 20 DHBs in one dashboard. These are regularly updated.
- The Commission updated several clinical domains of the Atlas of Healthcare Variation this financial year, presenting comparative data by DHB. Domains included opioids, gout, diabetes, asthma, community antibiotics and health service access. A new domain presenting mental health in primary care indicators was also launched this year.[7]

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.

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[6] www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/quality-dashboards/dashboard-of-health-system-quality

[7] Health Quality & Safety Commission. Atlas of Healthcare Variation. Mental health in primary care domain. URL: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/mental-health.