MINISTRY OF HEALTH
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Third annual update on increasing transparency in New Zealand health care

6 August 2019

Purpose

This paper sets out the third 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 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
    - 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 and 2018,[1,2] in response to the Ombudsman's ruling, the Ministry and the Commission, with the support of the Accident Compensation Corporation (ACC) and the Health and Disability Commissioner, developed a rationale and strategy for public reporting to be effective in the New Zealand context (*Guiding Principles: Towards the Publication of Clinical Performance and Outcome Data*[1]).

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[1] First annual update on increasing transparency in New Zealand health care. 28 June 2017. www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/2962.

[2] Second annual update on increasing transparency in New Zealand health care. 14 August 2018. www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/3438.

Work in 2018/19

Ischaemic heart disease

- Agreement has been reached with the Heart Foundation to present the consumer-facing version of the All of New Zealand Acute Coronary Syndrome Quality Improvement (ANZACS-QI) registry dashboard of key acute coronary syndrome (ACS) care quality indicators on the Heart Foundation's website, in partnership with the Ministry, the Commission and ANZACS-QI. ANZACS-QI is a large clinical registry of ischemic heart disease patients with ACS. The clinical dashboard showing variation by DHB on eight indicators was circulated to an internal clinical audience via the Cardiac Network, and then to DHBs in November 2018. The consumer-facing version will be a co-designed, accessible version of this, showing comparative quality data on emergency response, treatment and after care indicators.
- Alongside the data transparency work, the 'Open Heart' consumer co-design workshop, based on ANZACS-QI, was held in October 2017. The workshop identified discharge as a key point for improvement in consumers' experience of care, and initiated plans to assist with work on a standardised discharge tool to be co-designed by consumers and clinicians. This tool was developed by clinicians at Middlemore Cardiac Care Unit and tested with consumers, with support from the Ministry and the Commission. It is now in use at Middlemore Hospital and Auckland DHB. A generic version has been developed for other DHBs to adapt to their own service configurations (see Appendix 1).

Cancer services

A programme of quality performance indicator development and publication is underway across tumour streams. Tumour-specific quality performance indicators are being developed by the Ministry 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.

- On 5 March 2019 the Cancer Services team within the Ministry of Health and the National Bowel Cancer Working Group, using data from the New Zealand Cancer Registry and the Ministry of Health's National Collections, published the Bowel Cancer Quality Improvement Report 2019 (www.health.govt.nz/system/files/documents/publications/bowel-cancer-quality-improvement-report-mar19v1.pdf). This report presents the first release of results of investigation into the use of the Ministry's National Collections to calculate quality performance indicators for bowel cancer. The report presents six robust and validated quality performance indicators from patients diagnosed with colorectal cancer in New Zealand between 1 January 2013 and 31 December 2016, compares variation in these measures by ethnicity and other demographic variables, and between district health boards (DHBs) and provides recommendations for improving outcomes of New Zealanders with bowel cancer.

- The Ministry, the Southern Cancer Network and the National Urological Cancer Working Group have worked together to identify a set of proposed quality performance indicators for prostate cancer. Consultation feedback has been received and the Ministry has provisional dates for a draft report in November 2019, and publication in February 2020.
- The Ministry, the Midland Cancer Network and the National Lung Cancer Working Group have collaborated to identify a set of 19 proposed quality performance indicators for lung cancer. These will measure the quality of care and outcomes for people with lung cancer in New Zealand and support continuous quality improvement in lung cancer care. The proposed indicators have been sent out to the sector for clinical consultation and feedback by 22 July 2019. Provisional dates are a draft report ready in December 2019, with a view to publish in March 2020.
- The Commonwealth Neuroendocrine Tumour research collaborative (CommNETs), in collaboration with the Ministry, has used a modified Delphi process to achieve consensus on the best measures of diagnosis and service quality clinical indicators for neuroendocrine tumours (NETs). CommNETS brings together NET researchers, clinicians and consumers from Australia, New Zealand and Canada. The proposed indicators are currently undergoing review with a view to circulation to the wider sector for consultation provisionally in August 2019.

Orthopaedics

- Work with the Australian & New Zealand Hip Fracture Registry (ANZHFR) generated the hip fracture co-design workshop held on 2 April 2019. 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. Every year, more than 3,000 people sustain a hip fracture in New Zealand, incurring hospital costs of NZ$105 million. This number is projected to increase to more than 5,300 hip fractures by 2020. The purpose of the day was to ascertain the views of New Zealanders and their families and whānau affected by hip fracture on transparency of information contained in the ANZHFR. Six consumers and two whānau were recruited. Recruitment and retention of workshop participants underlined the challenges of co-design with a cohort characterised by ageing, challenges to mobility and in some cases neurocognitive impairment. Using ‘unconferencing’, a participant-driven process recently used in co-design projects in health care, consumers, family and clinical representatives developed four ideas that were key focuses for them in their experience of hip fracture. The focus quickly moved from transparency of registry data to prevention of hip fracture. Consumers were engaged by the data the ANZHFR contained and the picture it provided of hip fracture care in New Zealand. Some consumers wanted visibility of information and units to know who is doing well and if they as units were ‘wanting’. However, the acute nature of a hip fracture episode and the absence of choice or opportunity to engage with data on services, low engagement with technology in the cohort affected, and considerable residual trust in the system meant transparency of ANZHFR data was of lesser importance to this group than work on prevention and communication.
- Early engagement work is ongoing with the Joint Registry.

Overarching work in transparency

The Commission's dashboard of health system quality, bringing together 70 indicators of quality across all New Zealand DHBs, was published on the Commission's website in May 2018.[3] These indicators are regularly updated.

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

Appendix 1

My Heart Recovery Plan (generic version – contact info@hqsc.govt.nz for more information).

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