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# Second annual update on increasing transparency in New Zealand health care

### 31 June 2018

## Executive summary

### Purpose

This paper sets out the 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. Specifically this means selecting, developing and publicly reporting a range of quality of care measures (including outcomes data) across specialties.

### Background

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

The Ombudsman ruled that DHBs were not required to provide the *NZ Herald* the requested rates and total, unadjusted numbers of mortality, readmissions and complications of individual surgeons. 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

In response to the Ombudsman's ruling, the Ministry and the Commission 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* (see Appendix One) were established by the Ministry and the Commission in May 2016, with the support of the Accident Compensation Corporation (ACC) and the Health and Disability Commissioner.

The rationale for transparency based on these principles is premised upon:

- utilising existing registries for robust, trusted data by specialty or clinical domain
- co-design of tailored specialty-specific measures for publication, both consumer-facing AND clinically relevant for quality improvement
- consumer-focused data presentation with best-practice visualisation practices
- publication at statistically robust aggregation levels to incentivise teamwork, initially internal to clinical stakeholders, with open, transparent publication to follow
- encouraging providers to improve, engage, learn for quality improvement.

**Work to date**

- Early co-design work with the All New Zealand Acute Coronary Syndrome Quality Improvement registry (ANZACS-QI), a clinical registry of ischemic heart disease patients with acute coronary syndrome (ACS), has produced a dashboard of key ACS care quality indicators. Public release after a consumer co-design project is scheduled for late 2018.
- The “Open Heart” co-design workshop held in October 2017 has initiated plans for work on a standardised discharge checklist to be co-designed by consumers and clinicians. Work continues on understanding and addressing the gaps in care that occur after discharge, including loss of patients from cardiac rehabilitation programmes, and variation in access, availability and structure of such programmes across the country.
- A national dashboard of health system quality bringing together 57 indicators of quality across all New Zealand DHBs in one dashboard was published on the Commission’s website in May 2018.
- Early conversations have commenced around application of the above approach with cardiology to orthopaedic practice in New Zealand, with the support of the New Zealand Orthopaedic Association (NZOA), and the Australian & New Zealand Hip Fracture Registry (ANZHFR).

**Conclusion**

The Ministry of Health and the Commission will continue to work to increase transparency of health data with the orthopaedic community and other registries via a co-designed publication regime derived from mature registry data and findings from co-design workshops.

Currently, a co-design project is in progress to produce an accessible public-facing version of the ANZACS-QI dashboard to complement and follow the internal clinical release, and to supplement the discharge work derived from findings during the workshop. Public release of the ANZACS-QI and supplementation of the dashboard is scheduled for later this year. Monitoring implementation of quality improvement activity in response to publication, and the effects of public reporting on the overall performance we wish to improve, will follow.

Increasing transparency of health care for all New Zealanders through an holistic, co-design process using robust registry data that clinicians trust published in ways consumers want and can understand is the core of this process.

# Second annual update on increasing transparency in New Zealand health care

## Background

In June 2016, the Ombudsman Professor Ron Paterson ruled on a complaint by Martin Johnston of the *New Zealand Herald*.[1] Johnston had requested the volumes and types of operations performed by individual surgeons at five district health boards (DHBs) under the Official Information Act (the Act). He also requested rates and total, unadjusted numbers of mortality, readmissions and complications by individual surgeon, and was either turned down or provided with numbers at abstracted levels by DHBs.

The Ombudsman noted in his opinion that one of the purposes of the Act is "to progressively increase the availability of official information to the people of New Zealand." The Ombudsman has also suggested, in his 2014 opinion, that "New Zealand lags behind [international] developments" in the "proactive disclosure of performance and outcome information."[2] For these reasons, the Ombudsman appended to his opinion the following new recommendation:

> "that the Ministry of Health and Health Quality & Safety Commission [the Commission] 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:[1]
>
> - are meaningful to health care consumers;
> - are meaningful to the clinicians who provide their care;
> - are 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

The literature suggests that a coherent rationale, a clear conceptual framework, and a strategy of public reporting is essential to the success of any regime of public reporting, and for any assessment or evaluation of the effects of such a regime.[2]

In May 2016, "Guiding Principles: Towards the Publication of Clinical Performance and Outcome Data" (see Appendix One),[3] based upon a thorough evidence review and environmental scan conducted by the Commission,[4] were established by the Ministry and the Commission, with the support of the Accident Compensation Corporation (ACC) and the Health and Disability Commissioner.

These principles were designed to form a common platform from which to operate consistently to achieve effective public reporting of clinical performance and outcome information. They reflect the points in the process of public reporting: purpose; design; data capture and treatment; and publication. Subsequently, a rationale for effective publication of health data (transparency of health information), based on the current evidence, was elaborated on in papers published in the *New Zealand Medical Journal*.[3] [5]

This rationale is premised upon:

- utilising existing registries (see Appendix Two) for robust, trusted data by specialty or clinical domain
- co-design of tailored specialty-specific measures (one measure, i.e., mortality, does not fit all) for publication, both consumer-facing AND clinically relevant
- consumer-focus with good data presentation practices
- publication at statistically robust aggregation levels to incentivise teamwork, initially internal to clinical stakeholders, with open, transparent publication to follow
- encourage providers to improve, engage, learn for quality improvement

### Work to date: transparency in cardiology in New Zealand using the ANZACS-QI registry and co-design

On the basis of the above findings, a pilot project was initiated by the Ministry and the Commission with the All New Zealand Acute Coronary Syndrome Quality Improvement registry (ANZACS-QI).[6]

ANZACS-QI is a clinical registry of approximately 73,000 patients, with an acute coronary syndrome (ACS) form opened, and approximately 92,000 patients with a cardiac catheterisation laboratory form opened, for hospitals across New Zealand. The registry currently covers 46 public and private hospitals across New Zealand where acute cardiac patients are admitted and have coronary angiography. As at June 2018, 117,518 episodes of care for patients with suspected ACS and patients referred for coronary angiography, were registered in the ANZACS-QI database. ANZACS-QI was selected based upon the maturity of the registry, and the high burden of disease and cost to New Zealanders of ischaemic heart disease.

A day-long *Open Heart Transparency Co-design Workshop* co-design workshop was convened on October 12 2017 with 14 consumers and consumer representatives with experience in different forms of ACS, clinicians representing the registry, and Ministry and Commission staff. The workshop gave clinicians and consumers the background to calls for transparency, examples of public reporting from other jurisdictions, and an introduction to the registry and its contents. Through an holistic co-design process called “Unconferencing”, consumers and clinicians focused on aspects of consumer experiences that would provide opportunities for improvement. Consumers were asked what measures they saw merit in reporting, and how they felt that might be gone about.

*Findings*

- Consumers were not in favour of US-style public reporting schemes to help consumers to find and choose doctors based on individual clinician mortality and other ratings.
- Notwithstanding the lack of choice available to New Zealand patients in the public system, the idea of “choosing” a provider based on quality information during an acute emergency such as ACS was seen by the group as a clear non sequitur.
- Attendees trusted that New Zealand clinicians and services were auditing services in relation to variation and were monitoring quality and outcomes data. A consensus gathered around shared problematic discharge processes and the life-changing effects of their condition after the initial episode of acute care.

- Some described their cardiac journey as “like a miscarriage” – a trauma that was not spoken of again. Many did not fault their initial episode of care, but barely remembered it. After discharge consumers described feeling alone and vulnerable and unsure how to begin a new life with a chronic condition. Some described leaving hospital and returning to an empty home. Others felt their families and whānau were more scared and unsure than they were. “The aftercare treatment was lacking,” said one.

*Open Heart co-design resulting projects*

These findings informed a tailored approach to transparency in terms of ACS and the data held in the ANZACS-QI registry.

1. Discharge

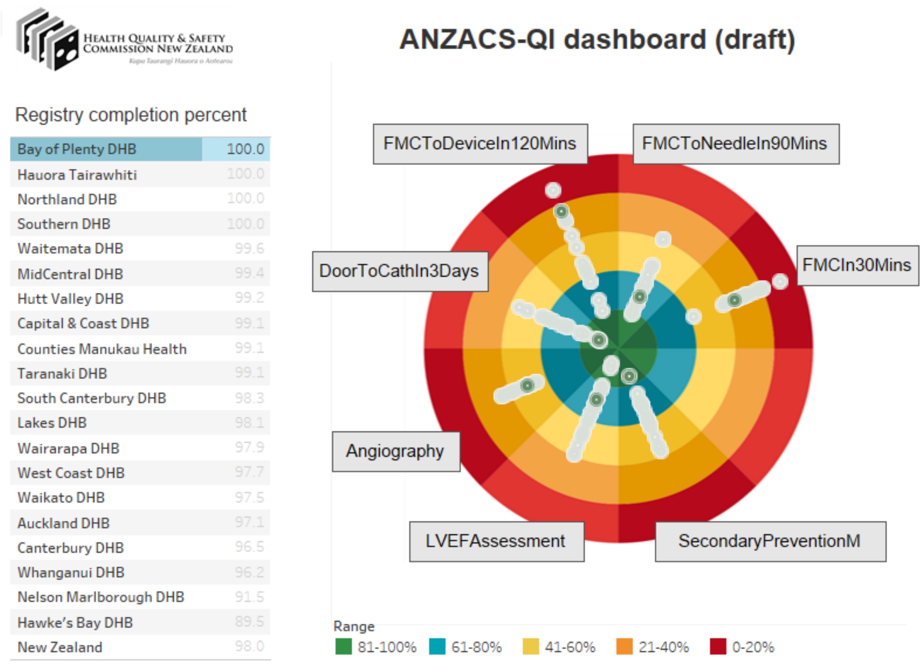
The workshop developed plans for work to begin on a standardised discharge checklist to be co-designed by consumers and clinicians. Work continues on understanding and addressing the gaps in care that occur after discharge, including loss of patients from cardiac rehabilitation programmes, and variation in access, availability and structure of such programmes across the country. Existing research programmes in nursing at Middlemore around discharge have been engaged with, with a view to Commission and Ministry support for a discharge checklist project and pilot. An immediate goal is linking up rehabilitation unit data with the ANZACS-QI database to report on patients as they progress on their journey, in particular using structured questionnaires at discharge and post-discharge.

2. Cardiology quality dashboard

With registry data and in consultation with registry leadership and governance the Commission has developed a dashboard of key ACS indicators comparing DHB performance. The first ANZACS-QI dashboard was finalised in May 2018 and circulated internally to the Cardiac Network. Favorably received, the dashboard is to be used in a co-design project with a consumer group augmented from the original Open Heart group, to develop a consumer-facing version in parallel with the discharge checklist project. International evidence suggests a consumer-facing release of comparative performance data engages reputational effects generating quality improvement activity otherwise not seen after internal-only releases of the same information. A staggered release is planned, with the internal release to the Cardiac Network complete and external public release scheduled for late 2018 after completion of a co-design project of the presentation of the consumer dashboard.

The dashboard (seen below in Figure 1) shows DHBs’ relative positions in terms of performance on each indicator. The draft live dashboard can be used here: https://public.tableau.com/profile/hqi2803#!/vizhome/ANZACS-QIV2_0/Home. Clicking on a DHB highlights their position on the dartboard (green dot). Registry completion is included, and plans are in place for inclusion of outcome data presenting 30-day mortality after percutaneous coronary intervention (PCI) in New Zealand public hospitals adapted from registry data published previously in 2017 in the *New Zealand Medical Journal*.[7]

FIGURE 1: DRAFT DASHBOARD FOR ANZACS-QI INDICATORS



ANZACS-QI dashboard (draft)

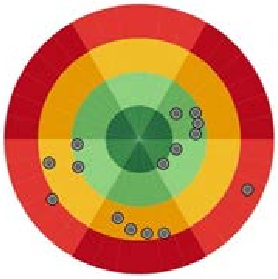
Registry completion percent

| | |
|---|---|
| Bay of Plenty DHB | 100.0 |
| Hauora Tairawhiti | 100.0 |
| Northland DHB | 100.0 |
| Southern DHB | 100.0 |
| Waitemata DHB | 99.6 |
| MidCentral DHB | 99.4 |
| Hutt Valley DHB | 99.2 |
| Capital & Coast DHB | 99.1 |
| Counties Manukau Health | 99.1 |
| Taranaki DHB | 99.1 |
| South Canterbury DHB | 98.3 |
| Lakes DHB | 98.1 |
| Wairarapa DHB | 97.9 |
| West Coast DHB | 97.7 |
| Waikato DHB | 97.5 |
| Auckland DHB | 97.1 |
| Canterbury DHB | 96.5 |
| Whanganui DHB | 96.2 |
| Nelson Marlborough DHB | 91.5 |
| Hawke's Bay DHB | 89.5 |
| New Zealand | 98.0 |

### *National dashboard of health system quality*

The Commission continues to publish over 250 quality of care indicators for each DHB. Many of these indicators link to the Ministry's SLM framework. These indicators are now presented as a dashboard of health system quality (https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/quality-dashboards/dashboard-of-health-system-quality/). The 'dartboard' format of the dashboard, in line with the ANZACS-QI cardiology dartboard format, brings a range of measures together in one place, placing many different measures on the same scale and allows click-through to measures for the local system presented in time series and statistical process control format.

The visual of a target or dartboard allows two things:



1. put measures that use unique units (percentages, rates per thousand, individual counts, days, scores out of 10) on the same scale
2. use individual segments (or slices of the pie to use a different analogy) to group related measures by theme. This has the effect of creating clusters on the dartboard which actually are related to each other.

### *Colour: performance in relation to national average*

The different colours ranging from red on the outer ring through to dark green at the bullseye have meaning.

| **Colour** | **Meaning** |
|---|---|

| | | | |
|---|---|---|---|
| 🟩 | 🟩 | Centre of the dark green bullseye | the best possible result (3 standard deviations better than national average, For example, this might be 0 for a harm such as a fractured neck of femur, or 100% for a process measure like practicing good hand hygiene.) |
| 🟩 | 🟩 | Boundary between the two green zones | 1 standard deviation better than national average |
| 🟩 | 🟨 | Boundary between light green and amber rings | the national average for any given measure. |
| 🟨 | 🟥 | Boundary between orange and red | 1 standard deviation worse than national average |
| 🟥 | 🟥 | Outer rim of the red ring | 3 standard deviations worse than national average |

*Dots: the measures*

Each measure is plotted by means of a dot along a straight line running from the bullseye through to the outer rim of the red ring. On rare occasions the measure will be more than three standard deviations away from the national average. In this case the point will literally miss the target and be in the white space outside of the dartboard.

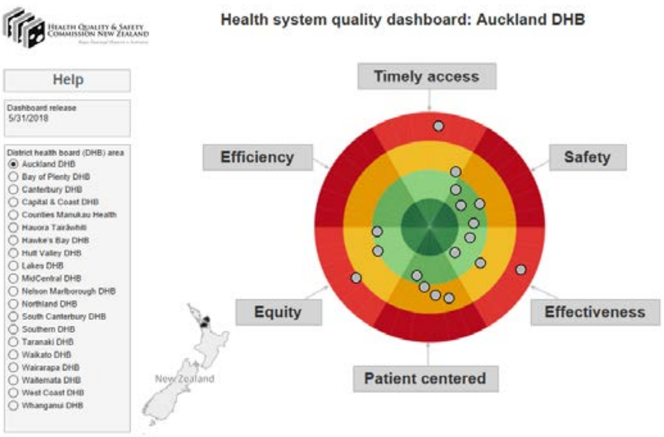
*Slices: the dimensions of quality*

At the ‘Home’ page the dartboard is arranged into six slices which correspond to the six dimensions of quality identified by the Institute of Medicine:

1. timely access
2. safety
3. effectiveness
4. patient centredness
5. equity
6. efficiency.

Currently there are no measures for efficiency (these are in discussion with other agencies) and measures of equity have been withdrawn following concerns raised about the potential for this presentation to be misleading. Within each of these slices some key outcome measures are presented.

The positioning of indicators is deliberate. Related measures are placed next to each other so that apparent clusters actually have some meaning. For example, if three measures concerning infection control are all at a consistent position within the dartboard, indicating a consistent level of success or otherwise in preventing and controlling infections, a natural ‘cluster’ of dots will form on the face of the dartboard.



Health system quality dashboard: Auckland DHB

Dashboard release
5/31/2018

District health board (DHB) area
● Auckland DHB
○ Bay of Plenty DHB
○ Canterbury DHB
○ Capital & Coast DHB
○ Counties Manukau Health
○ Hauora Tairāwhiti
○ Hawke's Bay DHB
○ Hutt Valley DHB
○ Lakes DHB
○ MidCentral DHB
○ Nelson Marlborough DHB
○ Northland DHB
○ South Canterbury DHB
○ Southern DHB
○ Taranaki DHB
○ Waikato DHB
○ Wairarapa DHB
○ Waitemata DHB
○ West Coast DHB
○ Whanganui DHB

*Different levels*

Since there are so many measures to put on one dartboard, a second domain specific level, has been added. These can be reached by clicking on the arrow next to the domain title. The lower level dartboards work in exactly the same way as the 'Home' page on the top level summary. In this instance process measures (denoted by the yellow squares) and outcome measures (blue circles) are shown together.

This shows a comparison of these measures against the national average, but full understanding of the situation needs us to know how things are changing. This can be reached by clicking on the arrow next to the subject titles. The lowest level pages show various time series and statistical process control presentations.

## Other registry opportunities in early-phase discussion

### *Orthopaedics*

In May 2018 representatives of the Commission met with representatives of the New Zealand Orthopaedic Association to begin discussions of applying the approach used with ANZACS-QI to orthopaedic practice in New Zealand. New Zealand has two key orthopaedic registries, the New Zealand Joint Registry[8] and the Australian & New Zealand Hip Fracture Registry (ANZHFR).[9] Initial discussions over increasing transparency have now begun with the ANZHFR with the support of their leadership.

There are approximately 22,000 new hip fractures in Australia and 4,000 in New Zealand annually, incurring hospital costs of AU$579m and NZ$105m, respectively. The ANZHFR is a clinical registry that collects data on care provided, and outcomes of care, to older people in Australia and New Zealand, admitted to hospital with a fracture of the proximal femur. The registry is a collaborative project between several professional societies and is one of a number of complementary initiatives designed to improve hip fracture care bi-nationally. There is known variation in practice models within and between states and territories (Australia) and DHBs (New Zealand) and that much of what happens in the acute and rehabilitation settings impacts directly on the longer term outcomes for the person with the fracture.

The stated aims of the ANZHFR are to use data to improve performance and maximise outcomes for older people who have sustained a hip fracture. The registry states this will be achieved by:

- Reporting annually on the current state of hip fracture care;
- Identifying variation between hospitals in care and the outcomes of care and across the health care systems and using this information to drive system-level improvements in care;
- Monitoring secondary prevention interventions to reduce the likelihood of future falls and fractures;
- Addressing barriers to the use of the best available evidence and therefore standardising hip fracture care across Australia and New Zealand;
- Evaluating the care provided by hospitals with the Australian and New Zealand Hip Fracture Care Clinical Care Standard and its Quality Indicators;
- Enabling participating hospitals to access data that can be used to improve the hip fracture care they provide to their communities;

- Providing opportunities to answer research questions that address high quality and safe care for people suffering a hip fracture.[8]

The registry's data align with the Hip Fracture Care Clinical Care Standard agreed upon by the Commission and the ACSQHC. The Clinical Care Standard divides its indicators of quality care into seven "Quality Statements" alongside a selection of outcomes indicators. These, representing a pathway of high-quality care, are presented below and represent a likely opportunity for public reporting of hip fracture care quality.

**Hip Fracture Care Clinical Care Standard Quality Statements and associated indicators derived from the Hip Fracture Registry**

| Care at presentation | Pain management | Orthogeriatric model of care | Timing of surgery | Mobilisation and weight-bearing | Minimising risk of another fracture | Transition from hospital care | Indicators of effectiveness (outcomes) |
|---|---|---|---|---|---|---|---|
| • 1a: Evidence of local arrangements for the management of patients in ED. | • 2a: Evidence of local arrangements for timely and effective pain management for hip fracture. | • 3a: Evidence of orthogeriatric management during an admitted patient's hip fracture episode of care. | • 4a: Proportion of patients receiving surgery within 48 hours of presentation. | • 5a: Proportion of patients mobilised on day one post hip fracture surgery. | • 6a: Proportion of patients receiving bone protection medicine. | • 7a: Evidence of local arrangements for the development of an individualised care plan prior to discharge. | • Re-operation within 30-day follow-up |
| • 1b: Proportion of patients who have had their preoperative cognitive status assessed. | • 2b: Proportion of patients assessed for pain within 30 mins of ED presentation and receive analgesia within this time or do not require it. | | | • 5b: Proportion of patients with unrestricted weight-bearing status immediately post surgery. | • 6b: Proportion of patients readmitted to hospital with another femoral fracture in 12 months. | • 7b: Proportion of patients living in a private residence prior to their fracture returning to private residence within 120 days post discharge. | • 30-day mortality following hip fracture |
| | | | | • 5c: Proportion of patients experiencing a pressure injury during hospital stay. | | | • Discharge to usual place of residence |
| | | | | • 5d: Proportion of patients returning to pre-fracture mobility. | | | 3-month outcome indicators: survival status, place of residence, living alone status, quality of life. |

## Dissemination of work/knowledge: building momentum

Our findings and the approach to transparency being undertaken here have been shared at invited presentations to the Royal Australasian College of Medical Administrators (RACMA) conference in Melbourne and the Victorian Agency for Health Information (VAHI) in 2017, and will be presented at the International Hospital Federation's 42nd World Hospital Congress in Brisbane in October 2018.

## Conclusion and next steps

The Ministry of Health and the Commission will continue to work to increase transparency of health data with the orthopaedic community, specifically with an initial focus on the ANZHFR, and other registries via a co-designed publication regime derived from mature registry data and findings from co-design workshops.

Currently, a co-design project is in progress to produce an accessible public-facing version of the ANZACS-QI dashboard to complement and follow the internal clinical release, and to supplement the discharge work derived from findings during the workshop. Public release of the ANZACS-QI dashboard is scheduled for later this year. The dashboard will be supplemented with further measures as they come online. Monitoring implementation of quality improvement activity in response to the measures selected and published, and the effects of public reporting on the overall performance we wish to improve, will follow.

Increasing transparency through an holistic, co-design process using trusted, robust registry data clinicians trust published in ways consumers want and can understand is the core of this process.

**Appendix One**

## Guiding Principles: Towards the Publication of Clinical Performance and Outcome Data

These guiding principles form a common platform from which to operate consistently to achieve effective public reporting of clinical performance and outcome information. They reflect the points in the process of public reporting: purpose; design; data capture and treatment; and publication.

Public reporting of clinical performance and outcome data is currently under development in New Zealand and these principles for such reporting are based on current evidence. Through consultation, these principles have the support of consumers, regulatory and professional bodies, and key groups in the sector. The principles are aligned with key themes of the Health Strategy: ‘people-powered, value and high performance, one team, and smart systems’ and they align with the strategic directions of other key healthcare organizations, and with processes that oversee professional competency. The principles will be regularly reviewed to ensure they remain current with changing strategic and legislative documents. Innovations or changed models in healthcare should, where possible, incorporate these principles prospectively as part of implementation.

### Our purpose is quality improvement and patient safety

The aim of publication of clinical performance and outcome information is to facilitate continuous improvement in the quality and safety of health services. Focuses for improvement include better service experience for consumers; practitioner learning and performance; and accountability to the public.

### Co-designed publications and measures

Consumers, colleges, professional bodies, clinicians and employers have an important role to play in defining and selecting relevant outcomes and process measures. Strong measures reflect the different needs of the interested parties, are outcomes-focused, reflect consumer experience, and serve to assure quality and safety and drive improvement. Meaningful data should promote a culture of continuous improvement, stimulate clinical focus and encourage open and honest reporting.

### Data capture and treatment using national standards

Digital technology supports the management of clinical performance and outcome information via electronic capture and as part of routine care. In a smart system, wherever possible and appropriate there are agreed national standards of data collection, and consistent definitions and measures across New Zealand.

Where possible, data should be risk-adjusted and/or accompanied by relevant contextual information to account for case complexity and risk. Resulting measures should be meaningfully attributable to the clinicians or service providing care, to ensure that they are clinically credible and reliably inform the public, clinicians, healthcare providers, administrators and policymakers.

### Publish accessible, clear and contextualised information

Data should be published in different formats and media to ensure that the information is accessible to people of all levels of health literacy and acceptable and comprehensible to target audiences.

Data can be analysed and reported at multiple levels (national, regional, service, individual). Choice of level is, where appropriate, related to purpose and audience, to facilitate understanding of causes, contributing factors, and opportunities for improvement.

**Quick Look**

- Co-designed measures
- Co-designed publications
- Outcomes-focused
- Consumer-focused
- Data capture part of routine care
- Electronic capture
- Agreed national standards of data collection
- Consistent national definitions and measures
- Risk-adjusted
- Contextualised
- Meaningfully attributable to clinician/s or service
- Accessible formats and media
- Related to purpose and audience

## Appendix Two

### What are registries?[10]

Clinical registries are databases that systematically collect granular health-related information at clinical level in the form of a clinical audit, within an overall governance and management structure, on individuals who are:

- treated with a particular surgical procedure, device or drug, eg. joint replacement;
- diagnosed with a particular illness, eg. stroke; or
- managed via a specific healthcare resource, eg. treated in an intensive care unit.

Registries have greater capacity than administrative data collections to measure and monitor effectiveness of treatments and track patients over time. They also have the capacity to show variations in treatment and risk-adjusted outcomes at a national level. Registries are usually developed by clinicians, with mixed funding structures, sometimes from central agencies due to evidence for benefits in quality improvement and positive returns on investment (ROI) (ranging from 2:1 to 7:1 in a recent evaulation by the Australian Commission on Safety and Quality in Health Care (ACSQHC) of five sufficiently mature registries).[11]

The ACSQHC established a prioritised list of clinical domains where registries were likely to have the most impact. Criteria included high cost burden, high disease burden, and a priority for quality improvement by clinical, consumer and jurisdictional stakeholders.[12] The first three prioritised clinical domains were ischaemic heart disease, musculoskeletal disorders, and trauma, all with serious consequences of poor quality care, high burden of disease and cost to the health system.

*Types of clinical registries*

Clinical quality registries

- The primary purpose of a clinical quality registry is to monitor outcomes and report on quality of care.

Condition / Disease registries

- The primary purpose of a condition / disease registry is to collect diagnostic details on patients with specific diseases or conditions.

Drug/Device/Product registries

- The primary purpose of a drug / device / product registry is to monitor the medium to long-term safety of devices, drugs or products such as blood.

Currently operational registries in New Zealand that are at least partially supported by the Ministry of Health include:

1. Cardiac Interventional Registry (All New Zealand Acute Coronary Syndrome Quality Improvement registry (ANZACS-QI))
2. Cardiac Surgical Registry
3. New Zealand Joint Registry
4. Major Trauma Registry
5. Australia and New Zealand Dialysis and Transplantation Database (ANZDATA)
6. Spinal Cord Impairment (Rick Hansen) Registry
7. New Zealand Cancer Registry
8. New Zealand Breast Cancer Registry
9. New Zealand Child Cancer Registry
10. Intestinal Failure

There is also a number of Australasian registries supported by the Australian Commission on Safety and Quality in Health Care and based in Monash University:

11. Australian and New Zealand Massive Transfusion Registry
12. Australian and New Zealand Thyroid Cancer Registry
13. Bariatric Surgery Registry
14. Burns Registry of Australia and New Zealand
15. Prostate Cancer Outcome Registry Australia and New Zealand

In addition, the Australian and New Zealand Intensive Care Society runs:

16. Australian and New Zealand Adult Patient Database
17. Australian and New Zealand Paediatric Intensive Care Registry

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[1] Office of the Ombudsman. Request for Complications data by named cardiothoracic surgeon and neurosurgeon. Case numbers 402136/402138/402140/402142/402144. 2016. http://www.ombudsman.parliament.nz/system/paperclip/document_files/document_files/1635/original/402136_etc_-_request_for_surgical_complications_data.pdf?1467187036 (accessed 9 June 2017).

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[4] Health Quality & Safety Commission. Position paper on the transparency of information related to health care interventions. https://www.hqsc.govt.nz/publications-and-resources/publication/2463/.

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[6] Kerr A, Williams MJ, White H, et al. The All New Zealand Acute Coronary Syndrome Quality Improvement Programme: Implementation, Methodology and Cohorts (ANZACS-QI 9). N Z Med J. 2016 Aug 5;129(1439):23-36.

[7] Kerr A, Williams MJ, White H, et al. 30-day mortality after percutaneous coronary intervention in New Zealand public hospitals (ANZACS-QI 18). N Z Med J. 2017 Jul 21;130(1459):54-63.

[8] New Zealand Joint Registry. https://nzoa.org.nz/nz-joint-registry.

[9] Australian & New Zealand Hip Fracture Registry (ANZHFR). http://anzhfr.org/about-us/

[10] Adapted from https://www.monash.edu/medicine/sphpm/registries and elsewhere.

[11] Australian Commission on Safety and Quality in Health Care. Economic evaluation of clinical quality registries: Final report. Sydney: ACSQHC; 2016 https://www.safetyandquality.gov.au/wp-content/uploads/2016/12/Economic-evaluation-of-clinical-quality-registries-Final-report-Nov-2016.pdf.

[12] Australian Commission on Safety and Quality in Health Care. Prioritised list of clinical domains for clinical quality registry development: Final report. November 2016.