

Better Data – the benefits to the profession and public

Purpose

1. This paper highlights the key themes from the submissions the Medical Council of New Zealand (Council) received on its discussion paper *Better Data – the benefits to the profession and the public*.

Background

2. On 26 March 2015, Council released a discussion paper titled *Better Data – the benefits to the profession and the public* (*Better Data*). The purpose of the paper was to generate debate within the profession and wider stakeholders including the public on the value of performance and outcome data, and how such data promotes the competence of doctors. The paper addressed two separate but related issues:
(1) The role performance data can play to assure competence; and
(2) The public release of any outcome data.
3. Several months before *Better Data*, Ombudsman (and former Health and Disability Commissioner) Professor Ron Paterson ruled that Tairāwhiti DHB should release surgeon-specific case volume data. This was in response to Fairfax Media seeking information under the Official Information Act after Tairāwhiti DHB declined to release information on the volume for various surgical procedures performed by a particular surgeon because the DHB considered that such data on its own had little value. In his Final Opinion,¹ Professor Paterson argued that there was public interest among members of the community and the media in being able to access data on the work carried out by specialists in New Zealand's public hospitals, and highlighted the availability of such data in other jurisdictions, particularly in the United Kingdom's National Health Service (NHS).
4. In light of the Ombudsman's findings, Council decided to take a proactive approach by engaging the profession and public on the two questions mentioned above so that whatever information that is ultimately collected and provided to the public is led by the profession rather than imposed by the media or by some external body.
5. Since its release, the consultation has generated a large number of responses. No deadline to respond was specified. To date, Council has received a total of 57 submissions of which:
 - Forty six were from individual doctors from primary care as well as from private practice and public hospitals;
 - Four from vocational colleges;
 - Four from professional associations;²
 - One from a government agency;
 - One from a private sector health organisation;
 - One from a consumer group.

¹ Please refer to Final Opinion 371760 by the Office of the Ombudsman (<http://www.ombudsman.parliament.nz/search?q=surgeon>).

² This includes a submission from the Association of Salaried Medical Specialists (ASMS). Owing to the timing it was received, feedback from ASMS has not been incorporated in this paper.

In addition, feedback was sought from the Consumer Advisory Group (CAG) when CAG met in June 2015 (discussed below).

Widespread support for better data collection and transparency

6. Overall, there was widespread support amongst individual doctors, vocational colleges and other health stakeholders on the views that Council expressed in *Better Data*. Many of the submissions commended Council on the helpful and constructive points the paper raised, and agreed that better data collection and transparency would facilitate improvements in patient care and patient outcomes. Some doctors who had previously worked in the United Kingdom detailed their experience of the less-than-positive effect of data collection within the NHS (discussed below) and cautioned New Zealand against going down the same path. The small handful of doctors who expressed disagreement with *Better Data* were concerned that any information collected would be used negatively to compare and rank individual doctors which was not something our consultation paper had advocated.

Common themes from submissions received

7. The following are common themes from the submissions we received from individual doctors, vocational colleges and various health stakeholders:

The importance of good quality performance data

8. Several submissions including that of the Royal Australasian College of Surgeons (RACS) and the Council of Medical Colleges in New Zealand (CMC) emphasised the importance of good quality performance data in that it is crucial to a high performing health system and a high performing health system in turn increases confidence amongst the public in New Zealand's health system. The New Zealand Medical Association (NZMA) agreed that quantitative data down to the individual clinician that is gathered accurately, used correctly and explained well could benefit clinicians and administrators but queried the value of releasing performance outcome and outcome data to the public. RACS recommended not limiting any public reporting of outcome data to surgical specialties but to include all sectors of health care delivery.
9. There was acknowledgement that outcome and performance data are being collected nationwide in some areas. For example, it is a legal requirement that annually, DHBs publish reports on serious adverse events and open disclosure of adverse events to patients; and that the Perioperative Mortality Review Committee³ publishes annual mortality reports with the aim of reducing the number of perioperative deaths in New Zealand, and to support quality improvement within the health sector.

Purpose of collecting data

10. Several submissions including the New Zealand Society of Anaesthetists (NZSA) agreed that there was a need to examine the basis for collecting and publicising performance data.⁴ This entails asking questions about the purpose of the data collection and its release: Is it to increase public safety? To reassure the public? To give patients choice? (Note: Choice is not a feature of the public health system as discussed below.) In other words, there must be a sound basis for collecting and releasing patient outcome data beyond merely responding to media

³ Part of the information that the Perioperative Mortality Review Committee reviews includes anaesthesia data provided by the New Zealand Society of Anaesthetists.

⁴ NZSA indicated a preference for the term "patient outcome data" as "performance data" gives emphasis to an individual doctor's performance when care is in fact provided by a team.

requests. Several submissions expressed concerns that owing to the complexity of performance data, both the media and public risk misinterpreting it. There is also a risk that the media could disregard the context and sensationalise the information that is provided.

11. There was support for data collection where it yields useful information for learning, reflection and improvement in performance. Many submissions discussed the benefit of using performance data for ongoing medical education with the aim of reducing risks and improving quality, safety and patient outcomes. In addition, several submissions cited the value of having an organisation such as the Health Quality and Safety Commission to interpret data and encourage quality improvement.

The importance of context

12. Many of the submissions (such as from ACC, RACS, CMC, Perioperative Nurses College of the New Zealand Nurses Organisation, and Southern Cross Healthcare Group) agreed that context is essential for any meaningful debate about data particularly as populations that DHBs serve are not homogenous. Publishing uncontextualised data is misleading and risks misinterpretation. It could also create unwarranted fear and concern amongst the public.
13. However, some doctors were concerned that even if data were published with context, the public are still unlikely to understand it and the data could end up being misused by the media and by individual members of the public.
14. Collecting contextualised data include taking into account factors such as volume (frequency in which a particular procedure is performed), geography / locality of the patient and the health provider, case mix, types of procedures performed, seriousness of the patient's condition as well as their age, fitness and lifestyle. Both CMC and RACS noted that each patient undergoing treatment or a procedure bring with them their individual set of risk factors that invariably influence the likely success of treatment (discussed further in 'Confounding factors and the need for risk adjustment'). It is important that these pre-treatment risk factors are identified, measured and included in the outcome data so that accurate and valid conclusions are drawn.
15. It is also important that data are collected on the same basis nationwide yet takes into account local conditions. For this reason, several submissions commented that simply publishing surgeon/proceduralist specific data as recommended by Ombudsman Ron Paterson are unhelpful as that does not take into consideration the environment in which the care was provided. CMC noted that the case load of some doctors may be skewed and their patients' outcomes biased by the uneven distribution of chronic conditions in certain parts of the country (for example, the prevalence of diabetes amongst the population that Counties Manukau DHB services).

Confounding factors and the need for risk adjustment

16. Confounding factors refers to a situation in which two or more causal factors are associated and contribute towards a particular patient outcome. Along with patient co-morbidity, there are other confounding factors that influence patient outcome which extend beyond the skill and ability of an individual doctor. Confounding factors can be classified as follows:
 - Patient factors (for example age, co-morbidities, ethnicity, socio-economic deprivation, health literacy, diagnostic validity, and complexity / severity of condition. When applying generalised truths of biomedical science to the unique context of the individual patient's life and circumstances, there will always be a degree of uncertainty and acceptance of this concept needs to be more embraced by medicine and the public. A Wellington anaesthetist commented that the dominant factor in perioperative risk is the patient themselves.)
 - System factors (for example diagnostic / interventional facilities, health care team factors

such as supervision, available resources versus competing demands, management and clinical governance.)

- *Clinician factors* (for example volume of procedures performed, training of clinicians, a clinician's skill and level of experience, and case-mix.)

17. Because there are confounding factors in every clinical procedure, it is important to view them collectively so that whatever data that is ultimately recorded depicts the situation accurately. In that respect, NZMA commented that failure to consider confounding factors could distort the actual competence and skill-level of individual clinicians.
18. To ensure that data are collected and reported accurately, several doctors as well as CMC and NZMA highlighted the need for risk adjusted to reflect certain particularities. For example, the best clinicians may be those who manage the most complex and difficult patients. Therefore, higher instances of adverse patient outcomes or mortality may not be reflective of their actual clinical skill. It is also important to bear in mind that the most urgent cases are usually dealt with in the public health sector. As such, the outcome for this group of patients would not be comparable with the population group that the private sector services. In addition, data that is reported must be statistically robust and representative of the clinical group being reported. This means that institutions with too few procedures to accurately characterise their performance should not be included in the reporting, and reports should include an explanation that inadequate number of procedures do not allow a meaningful analysis.

Adopting a systems approach

19. A number of submissions commented that because that health care is delivered by teams and across various disciplines, data that is collected and reported should focus on the team or the organisation in which the team is based rather than on the work of individual doctors. Adopting a systems approach reduces the risk of using data inappropriately (discussed below) and a defensive approach in clinical decision-making. Instead, it encourages transparency and information sharing. As a result, team members are more inclined to disclose events and review their own performance as well as that of the team all of which go some way towards improving patient outcomes.
20. Several submissions (including that of NZMA and CMC) cautioned against reporting raw clinician-specific data as this could obscure wider failings that might exist. It could also be misleading in that it creates an impression that the outcome of a medical procedure is dependent on the work of an individual medical professional when most clinicians work in multi-disciplinary teams. In addition, reporting outcome data at an individual clinician level could impact team work negatively by driving individualistic and competitive behaviour. For example, individuals would be less likely to support their peers or embrace a team culture if they are striving for results that will outperform their colleagues. For this reason, there was little support for the concept of league tables and the reporting of individual surgeons' performance that presently occur in the UK and USA. RACS noted that the publication of surgeon-specific data in the UK has coincided with a decrease in both the proportion and variety of cases performed by trainees, and a disincentive for consultants to provide surgical training. Several doctors also observed that overseas league tables have produced spurious outcomes. It has led to doctors gaming the system to their own advantage by opting for less complicated cases and avoiding areas of practice where there are higher risks of poorer outcomes. Ultimately, this affects patients' access to care.

Data collected should be used appropriately

21. Many submissions (including that of RACP and NZMA) agreed that it is for the profession and stakeholders to determine the nature and context of the data collected, and that data collection should be used for learning and quality improvement rather than for punitive

measures. A surgical registrar noted that the best judge of a clinician's performance is the oversight of their peers as that is multi-faceted, and it should be this system that is strengthened and used to reassure the public rather than providing a ranking system of simplified data which the public are unlikely to understand. This view was shared by a GP who commented that improvements in care are more effectively achieved by direct observation and colleagues working alongside peers who are deficient as well as through Regular Practice Reviews. In addition, it is important to bear in mind the limitations of using performance data to assess and evaluate the quality of care because performance data are unable to reflect certain aspects of care such as how effectively a doctor communicates or monitors patients with chronic conditions.

Managing risk and the need for good governance

22. Appropriate use of data and safeguarding it require good governance. RACP recommended that data collection be situated within a protected quality improvement system and housed in a trusted space. There is also a need for strong clinical governance to ensure that outcome measures are consistent, reliable and valid across the health sector and that meaningful comparative data are produced. In addition, good clinical governance is needed in managing the risks that could arise from collecting and making data available to the public.

The challenges in collecting (meaningful) data

23. Several DHB doctors commented that DHBs are already collecting vast amounts of data on many aspects of patient care but they queried the veracity and reliability of the data collected. Ultimately, data collection is dependent on who gathers and records the data, and if this task is assigned to non-clinicians, there could be issues of bias, inaccuracy as well as a lack of understanding of the data and its context. A Wellington paediatrician cited his 20-year experience of discharge coding in that non-clinical coders often relied on written records rather than asking doctors what the patient's actual final diagnoses was, and tended to make significant errors in the process. Other challenges include hospital managers' inability to understand the results of the data collected and the need to involve clinicians in interpreting and explaining the results.
24. Both the PNC and CMC shared the view that meaningful data collection is resource-intensive. In a busy clinical setting, responding to patients' clinical needs will often be accorded a higher priority compared to data collection. Both PNC and CMC suggested collecting data as part of the process of care and identifying patterns from each patient's journey through the health care system.
25. Doctors from some specialties such as general practice, internal medicine, psychiatry and neurology commented on the difficulties in identifying and collecting data that can provide a meaningful picture of an individual practitioner's overall performance. Many outcomes in medicine are qualitative rather than quantitative so it is difficult to measure the former in a meaningful way. For example, a GP's scope of practice is broad and health outcomes are often linked to the socio-economic status of the local community they serve. At an organisational level, a PHO with a model of care that does not require patients to make appointments may see a larger number of patients compared to other PHOs but it would be difficult for patients in that PHO to have any continuity of care.
26. Several doctors observed that it is easy to collect data that is relatively easy to measure (such as surgical outcomes) and this is often not well understood by the public. However, data that is easy to measure is rarely an index of quality and may not be important or meaningful for patients. For example, patients may not necessarily remember or value having their blood pressure recorded on a regular basis but they will value the time a doctor took to help care for a dying family member. However, care in that respect is difficult to measure. There is also a

risk that because some aspects of quality are easier to measure, those measures will become more “important”. RNZCGP cited the example of prescribing data which is relatively easy to collect and analyse but there is a risk that the quality of general practice could start to be measured by the quality of prescribing. Consequently, a GP who prescribes within acceptable limits but who is unable to develop a relationship of trust with his/her patients could be perceived as a “better” GP compared to one who has earned the trust and respect of his/her patients, but who is identified as prescribing an older (but still effective) medicine.

27. A Waikato anaesthetist observed that there is a tendency to collect vast amounts of data which in turn leads to meaningless debates and generates spurious conclusions about apparent variations. Spurious outcomes could include attempts to identify and single out certain doctors and concluding that they are not sufficiently skilled. This in turn affects the reputation of the doctor and creates unnecessary angst and concern amongst the public.
28. To minimise the risk of producing poor quality data, it would be vitally important to involve clinicians with statistical expertise in the collection and interpretation of performance and outcome data. Specifically, such clinicians should assist with identifying appropriate and reliable variables for specialty-specific outcomes and to critique any process that purports to assess performance. In addition, raw data should be reviewed before it is used to inform decision-making.

The need for robust audit systems

29. Having robust audit systems improves the quality of data collected. A general surgeon at North Shore Hospital observed that while larger hospitals in metropolitan centres have good paperless audit systems that are regularly reviewed, this may not be the case for smaller centres in New Zealand. As such, before publishing any outcome data, it is imperative that audit systems across New Zealand institutions are universal, robust, objective and verifiable. Ideally, surgeons practising in private hospitals should also participate in audit programmes that enable them to review their outcomes but it is often the case that surgeons in private practice are not part of any audit programme.
30. Part of a sound audit system includes institutions and teams having adequate opportunity to review any report, provide feedback and to re-work the content before it is circulated. Reports should also be evaluated to ensure that they fulfil their stated purpose and that any unintended consequences are identified. To promote transparency, reports should also outline the methodology used in collecting and reporting the data.

The impact of collecting data

31. A number of doctors commented on the impact of collecting data. In particular, several GPs who have worked in the UK highlighted being mindful of how data collection can impact on doctors’ workload, stress levels, mental health, and motivation. This is because the very act of measuring a system invariably changes the dynamics of working relationships in it especially if the results are associated with a reward or a perceived punishment. These GPs observed that data collection and the obsession with meeting targets within the NHS have been detrimental to patient care as it has shifted the focus from caring for patients to meeting targets. It has also contributed to widespread burnout and low morale particularly amongst GPs, and led to instances of falsifying data.
32. Doctors should be striving for high standards of care and safety, and appropriate performance analysis and reflection are key aspects of achieving this. However, analysis and reflection involve consciously setting aside time during a working week so that work schedules are not squeezed in the same way it has been in the UK.

The concept of choice

33. Several doctors queried the concept of choice for patients within the public health system since patients are usually treated at their nearest DHB so they do not actually choose their clinician or the facility they will receive care from. Choice is even more limited for patients in rural areas.
34. Owing to the lack of choice, colleges such as RACP recommended working with clinicians and stakeholders to devise more effective ways of providing information to help the public make decisions about their care. However, being informed could also result in instances where patients opt for a high risk intervention. This in turn raises questions such as whether a patient's informed choice to undergo a riskier intervention should be allowed to proceed, and whether the doctor would be inclined to provide full and frank advice about higher risk interventions if the doctor knows that outcomes from higher risk procedures are being used to measure that doctor's performance.

Executive managers to be held accountable

35. Along with clinicians, organisations such as NZMA commented that executive managers should also be held accountable for health outcomes. This would ensure a system-wide responsibility for outcomes that impact on fiscal constraints. Mid Staffordshire NHS was cited as an example in that the failings of hospital management and overall systems were major contributors to adverse health outcomes and high mortality rates amongst patients.⁵

Cost considerations

36. NZMA noted that *Better Data* did not allude to cost considerations which is an inevitable aspect of generating and managing performance and outcome data. They and several doctors recommended carrying out a cost-benefit analysis to ascertain whether our health dollar could be put to better use to improve health outcomes and reduce health disparities rather than by spending it on providing data that the public are unlikely to understand.

Suggestions for improving data collection and the provision of information to patients

37. Several submissions included suggestions for improving the way in which data are collected and circulated.

(1) Central repository

At present, no one organisation is in a position to provide a full picture of the quality of health care across New Zealand. Southern Cross commented that it would be ideal if one organisation acted as the central repository for co-ordinating, collecting, analysing and disseminating the data in a manner that is agreed by stakeholders.

A Christchurch psychiatrist suggested that Colleges (with branches in New Zealand) work together with relevant consumer groups to decide on and devise a set of service outcome metrics that are readily reportable, meaningful and aligns with what the Ministry of Health already collect (or aims to collect) and what sister Colleges or professional groups overseas have done. Several submissions considered that the Health and Safety Quality Commission

⁵ The Mid Staffordshire NHS scandal came to national attention in the UK following an investigation in 2008 by the Healthcare Commission. The Commission was alerted to the high mortality rate in patients admitted as emergencies in that between 2005 and 2009, up to 1,200 patients at two Mid Staffordshire hospitals died through neglect. When queried by the Commission, Mid Staffordshire NHS failed to provide an adequate explanation. In November 2010, a full public inquiry was held. The key findings released in February 2013 recommended the need for greater transparency amongst health care professionals, greater supervision of health care assistants and hospital managers, and the move away from a culture of meeting targets to a culture of compassion.

would be the most appropriate body to drive this.

(2) Development of a “patient charter”

The development of a “patient charter” for those undergoing surgical procedures was suggested by a general surgeon at North Shore Hospital. The charter would be in addition to informed consent procedures and would provide the means for patients to enquire about a surgeon, for example, the surgeon’s results for a particular procedure, and how often the surgeon has performed that procedure. However, a patient charter entails a very sound database and that could be costly. There may be little benefit in having a patient charter where there is only one surgeon available or skilled to perform a particular procedure.

Feedback from consumer groups

38. Unlike many of the submissions from doctors and vocational colleges, consumer groups tended to favour providing outcome data to the public. As such, their feedback is discussed separately in this paper:

(1) Palmerston North Women’s Health Collective

Palmerston North Women’s Health Collective (the Collective) agreed with the Ombudsman’s ruling that Tairāwhiti DHB should release surgeon-specific case volume data to the public as such information is potentially useful for health consumers, and noted that similar data was available within the NHS. The Collective considered it beneficial for consumers to be informed of the number of procedures a surgeon has performed as most consumers would prefer to undergo an operation with an experienced surgeon.

The importance of context and representing data accurately were also acknowledged. In particular, the Collective noted that procedures with very high risks of complications could skew performance and outcome, and it was important that any data reported does not disincentivise surgeons from performing high risk surgeries.

(2) Consumer Advisory Group

Key points from *Better Data* were presented to the Consumer Advisory Group (CAG)⁶ when the group met on 11 June 2015. CAG were asked to consider 6 questions and the following was their response:

Q1. What role do you think data about doctor performance can play in patient choice?

It is important for patients to be able to trust the doctors who provide care to them and to know which doctors they can trust. For patients who live in rural areas, there may not be a wide range of doctors to choose from. Choice may also be limited in some specialties. Patient choice includes personal decisions patients make in terms of managing their own health.

Q2. What performance data (the data about an individual doctor) do you or the groups you represent want to know?

CAG considered that it was important for doctors to have regular performance appraisals, and for the health system to be more accountable to patients and the public. Having doctors who understand the patient’s condition (for example, disability) matters. There is also a need for PHOs to have access to performance data of doctors in the PHO’s catchment area.

⁶ The Consumer Advisory Group provides representative consumer advice to Council on strategic and operational health and disability issues. Established in 2003, CAG comprises consumer stakeholders appointed from the health and disability sector who act as a sounding board.

Q3. What outcome data (the data about the impact of treatment on the patient) do you or the groups you represent want to know?

CAG considered it important to know the following:

- Is the doctor competent and a good communicator?
- Does the doctor listening well to his/her patients?
- Is the doctor someone who is trustworthy and who respects patients especially if the patient has a disability?
- In instances where the patient has a long-term condition, how effective is the doctor in managing chronic illnesses?
- How can doctors encourage patients towards getting the best quality of life possible in the patient's circumstances?
- Are the practice systems that the doctor works with cohesive and their work environment conducive?
- The cost of treatment and consultation – for those on lower incomes, medical costs could be off-putting such that they delay seeing a doctor and by the time they do, the condition has worsened. How could a doctor address this?

Q4. Do you think the changes suggested in the discussion paper should apply only to the public health system or include the private sector for example Southern Cross hospitals / GPs?

CAG considered that the discussion paper should apply to both the public and private health system. It is important that doctors do not focus primarily on acute conditions but also on chronic conditions.

Q5. How and in what form would you like to receive data, for example would you like your doctors to tell you or would you like to read it in the newspaper?

CAG members commented that any data that is provided to the public needs to be meaningful and easy to understand. Publication on a wide scale through nationwide advertisements are effective as it means that everyone is given the same message. It is important for the information to be received in writing so that the recipient is able to discuss it with someone else. It is also important for information to be presented in its context.

Q6. Do you have any other suggestions or comments on this issue?

Health literacy is an important aspect as it helps patients to understand the health system better and how certain health information applies.