Health Quality & Safety
Commission New Zealand
Kupu Taurangi Hauora o Aotearoa

Position paper on the transparency of information related to health care interventions

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HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

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Contents

Recommendations

The Health Quality & Safety Commission (the Commission) has reviewed the evidence surrounding publication of outcomes data such as rates of surgical mortality and other complications. This review includes the practical effects of reporting the outcomes of individual clinicians and those of wider teams.

We recommend:

- the public reporting of judiciously chosen, adequately risk-adjusted measures at the team, unit or organisational level rather than the individual level
- development of agreed national standards of data collection, relevant definitions and measures across New Zealand, and agreed risk adjustment models to account for case complexity and risk
- publication should include clear explanations of context, and of the limitations and interpretation of the data, in different formats and media to ensure the information is accessible to people of all levels of health literacy
- further evaluation of the cost effectiveness of investment in clinical registries weighed against accelerated investment in IT systems that could capture the same information as part of routine care.

The Commission suggests:

- consumers, colleges, professional bodies and employers together define a simple group of outcome and process measures for each specialty group that will serve to assure safety and drive improvement. These measures should reflect the different needs of the interested parties: we suggest one outcome and process measure each that is consumer-focused, clinician-focused and organisation-focused.

The Commission supports:

- the work underway to strengthen and align the processes within organisations to demonstrate doctors' ongoing competence: we recommend these processes are made more transparent and that boards of health care organisations are asked to attest to their presence, and to their confidence that all practitioners are participating and achieving acceptable standards
- increased education and training focused on enhancing teamwork within organisations.

The evidence

Transparency

The Commission supports transparency – 'shining the light' – to assure and improve the quality and safety of health care. Feedback to the Commission confirms wide support in New Zealand for this position and the view is widely held in most comparable countries.

The balance of the positive and negative practical effects of transparency on quality of health care is less clear in the context of the publication of outcomes data (such as surgical mortality and complications rates). In particular, it seems there is an important distinction between reporting information on the performance of individual practitioners and reporting information on the performance of units, organisations or teams.

The following matters need to be considered when thinking about transparency of outcomes data:

1. the views of New Zealand patients and consumers
2. data considerations, appropriateness of measures, and registries
3. the requirements for informed consent (and the autonomy of patients)
4. how best to use data to drive improved outcomes and improve quality of care
5. how outcomes data may contribute to assuring the accountability of practitioners and organisations.

In this paper we summarise the evidence on these issues, and draw conclusions. We reviewed the literature, held a workshop with consumers, and consulted the sector (by seeking responses to a draft paper summarising the literature and the issues). More detail on the search strategy, cited publications, and reviewed submissions is provided in the evidence review and appendices document, available on the Commission's website: **www.hqsc.govt.nz**.

1. THE VIEWS OF NEW ZEALAND PATIENTS AND CONSUMERS

Patients and consumers should be included in the process of determining which outcome measures are reported and how the information is presented.[1-4] New Zealand consumers have stated that, because choice of individuals or hospital teams is generally not available, there is all the more reason for complete transparency to drive improvement across the sector.[5] Consumers appear to want simple things: trust and confidence in the system; to know that professionals are competent and meet or are above the acceptable standard and that this competence is publicly demonstrated; that the system is reliable and organisations have the right culture of openness and transparency; and that there are visible processes to improve quality.[5]

Reporting should be connected to consumer decisions and needs.[4, 6, 7] Many people may be more interested in functional and health-related outcomes than mortality data. Mortality rates are very abstract and often difficult to relate to – people find low frequencies difficult to interpret in relation to catastrophic events.[7] Patient reported outcome measures (PROMs) – defined as each individual's own assessment of his or her health or wellbeing, without interpretation by a clinician or anyone else – may be seen as particularly relevant and important.[8, 9] Patients value information about the experiences of other patients, including friends or family. For example, about whether their pain was controlled, whether they were listened to and whether the nurse came when called.[10, 11]

It follows that the profession, consumers and the specialty groups should work together to agree which outcomes should be reported, and at what level (eg, individual, unit, institution).

2. DATA CONSIDERATIONS, APPROPRIATENESS OF MEASURES, AND REGISTRIES

If we are to publish outcomes responsibly it is essential the data are accurate, valid and provide meaningful information on the outcomes measured. Measures should be specific, sensitive, timely, and easy to collect – ideally as part of routine care.[12] There should be agreed national standards of data collection and definition across New Zealand, and agreed risk adjustment models to ensure case complexity is accounted for. The benefits from this work should outweigh the potentially substantial costs.[13]

Having selected a suitable measure and approach to risk adjustment, the statistical requirements for identifying differences between the performances of individuals, or between the performance of one individual and a given standard, are:

1. a sufficiently high rate of the relevant outcome (eg, mortality)
2. a high enough case load for adequate statistical power
3. an understanding of the prior probability of the condition to be identified (eg, poor performance).

There are statistical challenges to public reporting of outcomes by individual clinicians because typical caseloads will not generate enough statistical power to reliably identify potential poorer performers.[14] The typical case loads and mortality rates for most procedures fall well below these requirements for most individual clinicians.

Cardiac surgery is more suitable for this type of reporting than most other specialties. In particular first-time coronary artery surgery is relatively common and relatively standardised. Mortality is one appropriate outcome, can be risk-adjusted and occurs at a relatively high rate. However, United Kingdom (UK) cardiac surgeons would have to annually perform three times the number of procedures they typically do to generate enough statistical power to detect eight in ten true poor performers. This problem is only exaggerated for other specialities. The New Zealand situation is essentially similar. There is a danger of injustice or conversely of false complacency if a poor performer is not identified. Lengthier reporting periods (one solution to the problem of insufficient statistical power) may miss recent deterioration, and measures collected over a long period risk losing relevance.[14]

The alternative solution is to aggregate to the team, unit or hospital level, which increases statistical power without losing immediacy.[14, 15] Even then, some units may be too small. For procedures that carry substantial risk (eg, >1% mortality rates), consideration should be given to amalgamation to ensure all units have sufficient volumes to provide reliable estimates of outcome. This view is further supported by data that suggest volume itself may be a factor in determining outcome.[16-18] This is one reason why the Commission recommends this level of publication.

Collection and registries

Clinical registries are a structured ongoing collection of personal health data from all patients in a clinically defined population. Once established, registries can provide benchmarked, risk-adjusted outcomes, and can be used as the basis of public reporting.[19] They are work-intensive and expensive.[10, 12, 19, 20] Currently New Zealand has a few established clinical registries but there is no consistent approach nationally. Most data currently available for public reporting are derived from administrative datasets and lack the depth and detail of registry data.

Bridging administrative data collection and clinical data collection is difficult, and has thus far failed in the UK National Health Service (NHS).[21, 22] Building more registries may address the medium-term need, but in the long run IT systems that capture the required information as part of routine care are needed, as some district health boards (DHBs) are pursuing, and investment in this approach may be more prudent. Discussion with the National Health IT Board must happen as part of the early stages of this process.

3. INFORMED CONSENT AND THE AUTONOMY OF PATIENTS OR CONSUMERS

There is no clear consensus on whether information about individual surgeons' performance, such as volume, casemix, mortality and complication rates is required to gain informed consent. In the United States (US), case law is evolving with conspicuous differences between states.[16, 23-27] In the UK and Australia the courts have lately moved away from a standard of adequate disclosure determined by the profession to one determined by what 'the prudent patient' would want to know in the given circumstances.[28, 29] The latter part of this test implies that context is important and the matter needs to be decided on a case-by-case basis rather than in a universal or general way.

In New Zealand the Code of Health and Disability Services Consumers' Rights 1996 ('the Code') is the key source of law on informed consent supplemented by other legislation and case law. Informed consent is typically viewed as a continuum and a process of information-sharing.[30] Under the Code a patient has the right to be fully informed but also to effective communication. Thus, the information that is best suited to help any particular patient in making a decision will depend on the patient's context.

There are grounds that there is no ethical obligation to provide performance information for informed consent because of imprecision of measurement: the individual surgeon's performance alters depending on the team and institution they operate in,[31] and measures are too late and not accurate enough.[27, 32]

Even if limited sets of data were provided on some specialities using statistical approaches such as funnel plots, as with cardiac surgery in the UK, many patients may have insufficient statistical knowledge to interpret the information correctly. The limitation in choice within our public hospitals is also relevant. Patients may decline treatment, but it would be unfortunate if misinterpretation of data that was presented too simplistically resulted in patients declining treatment that would in fact be of value to them.

The relevant information for most patients may simply be that adequate processes are in place to ensure the competence of all practitioners (see 'Accountability' below).

4. USING DATA TO DRIVE IMPROVED OUTCOMES AND IMPROVE QUALITY

To change outcomes, behaviour has to change. Public reporting may change behaviours by patients or providers.

Patients may:

- choose better quality providers and force lower-quality providers to improve or leave the market
- gain or lose trust and thus potentially respond with more or less compliance with treatment regimens
- access published information at different levels due to literacy, leading to increased inequities in outcomes.

Providers (whether individual or institutional) may:

- improve the quality of services
- cease to provide lower-quality services
- respond perversely – for example, by reorganising services to reduce exposure to riskier patients, or changing data recording practice to give the impression of a riskier casemix and thus better relative outcomes.

Changed behaviours by patients or consumers

The evidence is mixed but suggests consumer decision making is not substantially influenced by public reporting on health care quality.[33-35] Though consumers and the public are in favour of public reporting, in practice they tend not to know about[36] or search for the information.[11, 37] They sometimes fail to understand it[7, 38-40] and/or mistrust the source agencies.[41] They make little use of it in actual decisions as choice is not always a feasible option.[41-43] Indeed, consumer choice of physician has been described as a 'black box' – it could not be explained.[44] There is, however, some evidence of choosing better-rated providers when there is thoughtful presentation of the information.[15, 45-48] Differential access to such reports, perhaps because of differences in health literacy, may have led to inequities by race and socioeconomic status in certain jurisdictions.[12, 49-54]

Quality improvement and public reporting

Evidence shows public reporting of performance data stimulates quality improvement activity at the provider level, but not at an individual level.[52, 55] Public reporting is more likely to be associated with changes in health care provider behaviour than with selection of health services providers by patients or families.[39, 41, 42, 48, 52, 56] Improvement after public reporting seems to be driven by reputational concerns: institutions that report publicly rather than internally tend to put more quality improvement projects in place, and tend to improve, regardless of any efforts to game such systems.[45, 48, 56-61]

The New York State Cardiac Surgery Reporting System (NYS CSRS), the longest-running and most-studied such programme in the US, is a clinical registry with a quality improvement focus and a public reporting feature. Hospitals were the unit of reporting until a lawsuit forced reporting by individual surgeon. The NYS CSRS was associated with a 41 percent statewide fall in in-hospital mortality rates for coronary artery bypass graft (CABG) surgery in three years,[10, 12, 18, 62, 63] though the causes have been debated.[45, 64-67] Other similar statewide public reporting programmes, particularly in California, have been associated with improved outcomes for mortality following cardiac surgery.[68-73] Over the same period, mortality has steadily improved in many units around the world, in cardiac surgery and in surgery generally, so many factors may be at play.[74]

Public reporting of individual surgeons' outcomes in the UK was stimulated by the paediatric cardiac surgery scandal at Bristol Royal Infirmary and subsequent inquiry.[75] The Department of Health informed consultants of their intention to publish performance information at the level of consultant teams.[21] The Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS) responded quickly, having data systems in place.[58, 76] The Dr Foster organisation published mortality rates for coronary artery surgery by hospital in 2001, and a Freedom of Information Act request in 2005 led to publication of mortality data for coronary artery surgery for all UK surgeons, named individually. Outcomes have clearly improved in the NHS since then,[77-79] despite an increasing complexity of casemix, but a causal link has not been established. As indicated above, results have also improved in other countries over this time period. Concerns remain over the potential for surgeons to become risk-averse and avoid high-risk patients,[80] or for gaming to occur with patients scored as higher risk to ensure better outcomes.[81] Gaming behaviour has been considered a sign that incentives are strong and a measure is effective in discerning performance.[81] If systems of performance measurement are taken seriously, and are designed to have an effect, approaches to counter gaming ought to be integral to the design.[82]

Teams versus individuals in determining patient outcomes

There is increasing evidence that outcomes of surgery are less attributable to any single individual but instead depend on multidisciplinary teams and on the collaborative and institutional context in which surgery is done.[27] Failures in teamwork and communication underpin a high proportion of adverse events.[83, 84, 172-174] Outcomes have been shown to vary by the institution and team a surgeon performs in.[31] This is because many aspects of care other than the surgeon's performance are involved, and outcomes are dependent on failure to rescue rates, the influence of the anaesthetist, and postoperative care, among other considerations.[61, 85-89]

The US Veterans Health Administration has discouraged surgeon-specific outcomes as they believe that performance cannot be separated from the institution.[90] Teamwork and training significantly reduce both morbidity and mortality and improve processes.[90]

Enquiries into failures of care at Bristol Royal Infirmary and Stafford Hospital in the UK revealed lack of leadership, teamwork and the ability to work together effectively for the interests of patients as the key failings.[75, 91-93]

If outcomes are dependent on the team and organisational factors rather than the individual, accountability to the public would appear to require publication at team or organisation level. Publishing the results of individual surgeons seems likely to promote individualistic behaviour, rather than team-oriented behaviour. If it is team-based medicine that is to be encouraged, it does not seem sensible to publish data based on one team member (M Seddon, personal communication, 6 July 2015).[15, 55] Further, at a team level there may be sufficient data to reach meaningful statistical power and allow a timelier pick-up of issues.[14, 15]

5. ACCOUNTABILITY

Health care practitioners, providers and regulators, and professional bodies are accountable to the public for safe, high quality services. The public rightly expects staff to be technically competent, use evidence-informed treatments, work ably within teams, have good communication skills, be caring, and maintain these skills over time.[5] The relevant authorities should make the proper checks to ensure health care professionals remain competent and fit to practise.[5]

A number of varying processes are currently used to demonstrate doctors' ongoing competence continuously throughout their medical careers, from postgraduate training to specialist practice. The Council of Medical Colleges, the Medical Council of New Zealand and the Ministry of Health are working to better align and strengthen these processes.

These processes could be made more transparent with more visible evidence of participation and of the criteria used to assess acceptable performance. Appropriate data on the performance of individual practitioners may have a role in assuring standards within institutions or units. However, the interpretation of performance should be holistic and focused on early intervention to maintain standards rather than on waiting for red flags to identify problems after many patients have been harmed. There is evidence that publicly reported surgeon rankings of quality have not correlated with disciplinary rates and complaint rates, so some quality measures may not pick up disciplinary issues,[94] but the internal use of techniques such as variable life-adjusted CUSUM[95] to monitor outcomes on a case-by-case basis may be useful.

The Commission's view

Increased transparency and openness are among our core values. Most consumers and clinicians concur. We believe transparency and openness are best achieved by the public reporting of judiciously chosen, adequately risk-adjusted measures at the team, unit or organisational level. We discourage reporting at an individual level, as it is likely to be statistically unsound and counterproductive by undermining the teamwork we wish to encourage. Unit-level data would provide the necessary reassurance to the public and contribute to improvement in quality of our health care services. This view has been almost universally supported in feedback to our draft position paper.

Public reporting at the unit level would provide information needed for clinicians, organisations and central agencies to drive quality improvement. It could potentially lead to a meaningful national data set from which risk and benefit could be determined for common procedures, and assist in planning investment in health systems.

Publication needs to be in a manner that is meaningful and understandable to a wide range of people. Context must be explained. Results should be presented in different formats and media to ensure inequities are not increased through failure to address differences in health literacy and access to information.

We recommend that, through a co-design process, consumers, colleges, professional bodies and employers define a simple initial group of outcome and process measures for each specialty group.

These measures must reflect the different needs of the interested parties so all may agree separate or overlapping sets of consumer-, clinician- and organisation-focused measures. Once agreed, the information should be collected nationally in a standardised way. Reporting by DHB should be via their websites and annually in their quality accounts. These measures would complement the Commission's current suite of reporting, such as the quality and safety indicators and the New Zealand Atlas of Healthcare Variation. Measures should be kept under review and revised when necessary as part of the quality improvement journey.

Cost is important – money spent on this activity represents an opportunity cost in relation to other priorities for improving the quality of our health services. An assessment of what data are currently available and of what reporting could be undertaken currently from registries or other data sets should be made. Building more registries may address the medium-term need, but in the long run IT systems that capture the required information as part of routine care are needed, and investment in these may be more cost-effective. The National Health IT Board must be integral to this process.

The Commission supports the direction the Council of Medical Colleges, the Medical Council of New Zealand and the Ministry of Health are taking in strengthening and aligning processes to demonstrate doctors' ongoing competence, the outcomes of which we suggest should be made more transparent and publicly available. We also recommend strengthening of recertification and credentialing of health care practitioners. We suggest organisations should be asked to attest to the presence of such processes and to their confidence that all practitioners are participating and achieving acceptable standards.

Next steps

The Commission would like to work with the Ministry of Health to facilitate and help consumers, colleges, professional bodies and employers to define a simple initial group of outcome and process measures as described.

We propose the Commission facilitate this process by prototyping the development of measures, working with a few key DHBs and stakeholders in their development.

Public reporting is a complex and challenging area that is opened up by a seemingly simple and obvious request – to know. There are pitfalls and also opportunities ahead. The Commission supports increased transparency. But we must build, not destroy or divide. If we are to construct windows we must make the right decisions early on and proceed in a phased, consistent way, as architects and builders might, so those windows are well made, in the right places, and shine sufficient light upon the things that are useful to see.

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