

**The 2nd Annual Measuring, Monitoring & Managing
Outcomes in Health Conference**

**Developing Measures to Monitor the Impact of
Outcomes on a Specific Cultural Group such as
Māori**

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Introduction

The measurability of health or treatment efficacy is not a new concept nor is there any clear agreement as to how this can be done. During the early 1800s, for example, Florence Nightingale made some initial attempts to improve the quality of British hospital records. She suggested that a third category of outcome “relieved” be added to the existing options of “discharged” or “dead”. She had come to the conclusion that while both “discharge” and “death” were identifiable outcomes of care they lacked a degree of sensitivity, and, while generating data that was comparable, and relatively easy to gather, did not account for the full range of outcomes experienced.

More contemporary ideas on outcome measurement have similarly been shaped by the need to consider, in some meaningful way, the outcomes of treatment and care. And while considerable progress has been made, the fundamental challenges have remained unchanged. What to measure? , how to measure? , who to measure? , and perhaps most importantly, why to measure?.

This paper intends to consider all these issues, albeit superficially, but in a way which highlights cultural perspectives and concerns – the needs and expectations of Māori, as well as the difficulties of measuring culturally derived outcome preferences. A rationale is also offered and provides some justification as to why outcome measurement must include an assessment of cultural factors.

The paper and presentation is divided into six main parts and considers.

- Definitions of Outcome
- The levels of outcome measurement
- How is outcome measured
- Cultural considerations
- Implications for services
- Concluding comments

Defining Outcome

The problem of defining 'health' and 'health outcome' has bedevilled attempts to set priorities based on effectiveness and outcomes, in New Zealand and elsewhere. They continue to do so today. A decades-long debate has surrounded the definition of 'health' and has failed to provide consensus on this issue.ⁱ

Previous presenters have already provided excellent definitions of outcome and the challenges associated with this. However, I have always found it useful to describe, more precisely, what I consider an outcome and how this inevitably shapes ones ideas and theories. I remember a number of years ago giving a paper on the measurement of outcome and thinking (as I was presenting) how well it was going, until the end at least, and when the opportunity to ask questions was provided. A hand was raised at the back of the room and the question came forward “what’s and outcome”. Going by the expression on the faces of others in the audience (frowns and subtle nods) – I don’t think he was alone.

I have no doubt that today’s audience will be significantly better informed, however, outlining key concepts, criteria, or parameters is a useful exercise and at least clarifies my perspective and position. Unfortunately, and despite some considerable effort and research, no single definition of health outcome has been produced.ⁱⁱ Just as various measures of outcome have been developed so have different explanations for the concept of outcome – what this means and what is implied.

The dictionary, for example, states that an outcome is “the result of an action or process”. The American Institute of Medicine defines it as an “achievement in relation to realistic expectations or targets”. McCallum provides a more comprehensive definition and concludes that “an outcome is a natural or artificially designed point in the care of an individual or population suitable for assessing the effect of an intervention, or lack of intervention, on the natural history of a condition”.ⁱⁱⁱ

Perhaps the most well-known definition of health outcome, however, is the so-called *Sunshine Statement* – “A health outcome is a change in the health of an individual, or

a group of people or population, which is wholly or partially attributable to an intervention or series of interventions”.^{iv}

There are obvious differences in the way in which the notion of outcome is perceived and indeed there are many more examples which could have been used, though which would further complicate the discussion. Nevertheless, and despite these conflicting perspectives, the examples reveal a number of “high-level” similarities – features consistent enough to draw three important conclusions.

The first is the implicit relationship between outcome and intervention. The *Sunshine Statement* illustrates the point and makes it clear that an outcome is of little consequence unless the cause or intervention is also known. Within the health sector in particular (and as mentioned yesterday), the identification of an intervention can be difficult, and since a multitude of factors/interventions contribute, the health intervention may be only one of many factors leading to the result. Regardless, and again as illustrated in the examples given, there appears to be some agreement on the relationship between an outcome and an intervention, so that identifying the intervention becomes as important as determining the outcome.^v

A second issue concerns the measurement of outcome and the fundamental need to determine what change (in terms of health) has occurred. In this sense, an outcome measurement should enable comparative assessments of health status and interventions to be made. Measures of outcome are typically designed to do so and will most often include mechanisms through which nil or negative change can be considered. It should not be assumed that an intervention will automatically lead to a consequential improvement in health.

A third and final feature concerns the health outcome focus (i.e. the purpose of measuring outcome). Within each of the given examples is the assumption that an outcome must measure change as it affects either an individual, group of individuals or a defined population. A health outcome (and I stress - in this context at least) is not concerned with epidemiological illness patterns, prevalence rates, or what policies have been most effective. Neither should it be confused with measuring economic or fiscal performance. Rather, the focus is directed toward the examination of more

fundamental health components, the consumer or a larger group at which an intervention is directly targeted.^{vi} Other definitions of outcome may not prescribe to this view. However, within the context of health outcomes research, a focus on people is a generally accepted principle.^{vii}

FEATURE	INTERPRETATION
The Relationship between Outcome and Intervention	An outcome is a consequence of an identifiable intervention or series of interventions. The intervention must therefore bear a relationship to the outcome. Likewise the outcome should be attributable to the intervention
Measurement and Relevance	Health outcome is concerned with the measurement of change, both positive and negative, and in a manner relevant to the those under examination
A Consumer Focus	Health outcomes and outcome measures are consumer focused and are designed to measure outcome as it relates to the health status of an individual or group of individuals

Levels of Outcome

The frequent and ongoing difficulties associated with measuring outcome have led, in part, to the use of proxy measures of outcome – indicators, that while described as outcomes, may not entirely satisfy conventional criteria. Inputs, for example, are sometimes used as outcome indicators, an assumption based on the idea that an input (e.g. staff or resources) will lead to a consequential an inevitable improvement in health. These suppositions are as much based on faith as they are on science. The health sector is in fact funded on this basic premise – a belief that funding, resources, or equipment, will lead to health gains/outcomes. Such beliefs are not without justification and indeed system inputs (staff and other resources) are a fundamental

component of achieving positive outcomes. However, inputs are an imperfect measure of outcome – the anticipated outcomes of inputs are not always achieved or considered, inputs may only describe what happened and what is expected, rather than what actually occurred.

Process indicators are also used as a proxy for outcome and typically describe the activity of people within a service setting. Again, the assumption is that this activity will lead, by default, to an outcome. As with input based measures these kinds of expectations are flawed and similarly describe activity rather than outcome or consequence.

Another common proxy measure of outcome is “output”. Output measures may include data such as the number of patient consultations, bed nights, or perhaps vaccinations. However, this information lacks precision in that an expectation of health gain is assumed, further, individual views and perspective may not be afforded adequate attention.

A number of simple analogies have been used to describe the difference between input, process, output, and outcome. A favourite of mine describes a ship setting out on a voyage. The “inputs” are seen as fuel and provisions, the engines and hardware. “Processes” describe the activities of the people on board, the stewards, engineers, the captain and first mate. “Output” is obviously movement – all the systems are working in unison and functioning in the manner intended.

“Outcome” however, describes the “direction” of the ship, and, importantly, is the ship moving in the direction intended, and will it dock at the port desired. If you expect a tropical cruise but end up in Siberia then obviously the outcomes are not positive – this despite appropriate inputs, processes, and outputs.

The example also highlights the relationship between input, process, output, and outcome. Certainly, outcomes cannot be achieved without input, process and output activity. Furthermore, non-outcome based measures can provide information which is comparable, timely, and collectable. The abandonment of activity measures (such as those described) is therefore unwise. However, outcome measures will provide a

more accurate impression of health service efficacy – data which will at the very least complement existing information sets.

“The operation was a complete success, the facilities were adequate, the surgeon and support staff were well qualified....Unfortunately the patient died”

How to Measure Outcome

The measurement of outcome, and how this is achieved, is fundamentally reliant on one's definition of outcome and the parameters which are set. The three criteria given previously are often used to guide the development of consumer focused measures of outcome. For the most part these are schedule or questionnaire based instruments designed for a specific purpose or condition and which give some indication as to the health status of an individual. By comparing pre vs post care results treatment efficacy can be determined, comparisons between various population groups can be made, or the identification of certain outcome deficits or problems – mobility (for example) may be good but levels of pain unacceptably high.

Measures such as SF-36, or the WHOQOL attempt to measure a range of different health domains through the use of a simple questionnaire. Mental, physical, or emotional health may be considered, a grade or score is often produced, giving a simple, and relatively unobtrusive impression of health status. (click until all SF 36 questions come up)

The various problems with consumer focused measures of outcome (SF-36, HoNos, Basis, HoNosCa the list is endless) continue to generate research interest, and, as importantly, research funding. To date, no single measure of outcome has been shown to be appropriate in every situation – nor is it likely that this type of generic instrument will ever be constructed. To date, more than 1500 measures of outcome have been developed, a number which continues to grow. Different conditions and varying consumer expectations mean that no schedule based tool will ever provide the degree of specificity required, by some at least, and hence the number of condition specific measures has grown. Questionnaires or schedules designed to measure the outcome of a specific intervention or condition.

Measures such as SF-36 will give an overall impression of health status. However, this data may be too broad for use in a mental health or disability setting. As a consequence various mental health instruments have been produced, further, instruments which target particular mental health problems (the Hamilton Rating Scale for Depression for example). Despite this, the need for even greater precision has driven the construction of more and more tools, especially as the validity and reliability of measures come under increased scrutiny. Tool for the young, for the old, for men for women, healthy and disabled – the list seems endless.

Another problem with outcome measures concerns the accuracy of the data which is gathered. Most measures are self-reporting and require the respondent to offer an assessment of their own health status. The validity of this approach is fundamentally based on the notion that the individual is able to provide an informed and accurate response. For the most part this is true; however, research has shown that Māori can rate their health high, despite suffering from a multitude of ailments – is the impression gathered, therefore, accurate. Mental health conditions pose similar challenges in that the reliability of consumer outcome impressions are often questioned. Proxy measures are sometimes used in mental health settings and provide a means by which clinicians are able to rate (by proxy) the perceived consumer outcome. This approach is also problematic in that a clinician may similarly provide a biased or ill-informed assessment. A clinician may also be inclined to offer a more enhanced result – particularly when the tool considers the efficacy of their own treatment and care.

When to measure outcome is another issue for consideration. If a schedule based outcome tool is developed, when should it be administered? Outcomes from treatment may not manifest for days, months, weeks, or even years. It makes little sense, therefore, to administer an outcome measure immediately following treatment. While for some conditions outcomes may be expected soon after treatment (a dislocated shoulder for example) for others the delay may be lengthy (surgery to repair a ruptured Achilles tendon). Regardless, a point at which to measure outcome is an important consideration.

The possibility of an optimal outcome is also unrealistic. A questionnaire cannot, for example, ask “as a result of the intervention are you now cured”. That is of course unless cure is the most probable or expected outcome. A compromise may be “as a result of the intervention have you now returned to your previous level of function”. However this may also be unrealistic – one wonders if Jonah Lomu will ever recover from his recent health problems and return to the form of 1995 – certainly as a Hurricanes supporter – I hope so. “As a result of the knee surgery, can you now walk 400 meters” – I couldn’t before, I can’t now, was the operation a waste of time ?

Obviously, there are numerous and complicated issues which need to be considered when developing consumer measures of outcome. They will, most probably, be only as useful as their limitations permit. For this reason outcome measures are not a panacea, but will nevertheless provide useful, informative, and timely data – especially when combined with they types of input, process, or output measures described previously.

Why are Cultural Issues Important

As mentioned one of the more obvious problems with outcome measurement concerns “what to measure”. An outcome questionnaire or schedule is loaded with assumptions; that the questions posed are meaningful and relevant to the target group of consumers, that the questions are fully understood, and are un-ambiguous in their interpretation.

As described measures need to consider what is important or relevant to the individuals completing the assessment. Relevance is determined by many factors, however, population sub-classification allows many of these common features or characteristics to be identified with greater precision; but without the need to account for every potential variable. Obviously measures designed for geriatric use will differ to those intended for children, the same can be said for both men and women – the fundamental issue is that the questions asked will be meaningless unless they measure what is valued or important.

Culturally derived outcome preferences represent another sphere of sub-classification. The assumption being that those of a similar cultural background or experience may favour a unique set of outcome preferences; concepts, concerns, or domains which are not always considered by more generic instruments. Other issues may also arise. Outcome instruments frequently (and sensibly) use the language, and colloquialism, familiar to the tools designers. Instruments developed in the United States for example, may assess emotional states by considering whether or not an individual felt “blue”. Likewise, an assessment of alcohol or drug dependence may include references to “hard liquor”. Obviously cultures and nationalities unfamiliar with these terms will find the interpretation of the questionnaire problematic – the questions become confusing or ambiguous.

Other useful examples can also be cited. The results or outcomes of a hip-replacement surgery may be determined by a series of questions, and perhaps include a phrase like “as a result of the hip-replacement are you now able to walk around the block?”. The question, at first, appears to make perfect sense – obviously it attempts to measure mobility and physical function. By our definition of outcome a link to the intervention is established and we should assume that the question is asked at the point at which the desired outcome is expected. However, on closer inspection a number of interesting questions are raised. As an illustration I asked this very question to an elderly Māori man “e koro, imagine if you had just had an operation (on your hip) and I wanted to see how well it worked. What would you think if I asked this question. “As a result of the hip replacement are you now able to walk around the block ?”.

His response was as expected, he certainly understood the question, and was well aware of the type of outcome sought – the reason for this. However, he made further comment. “Why would I want to walk around the block for though, I’ve got my car for that”. Further, and after additional prompting I discovered that the “block” where he lived was a round trip of some 22 kilometres – certainly the idea that “a block” represents some standard measure of distance is flawed. Other issues are also apparent. Is it hot or cold when walking around the “block” are there hills or other obstacles, is it wet or windy. All these issues influence the way in which the question is perceived and interpreted and therefore it’s validity.

To the koro the question made sense but, as well, did not measure what was important to him. A more appropriate question, perhaps, would have been to ask him “ as a result of the hip-replacement are you now able to stand in one place for 30 mins”. This scenario is familiar and important to him as it describes something he is often required to do on the Marae and when welcoming visitors. If he could walk around the block but not fulfil his customary obligations the outcome to him would be unfavourable. Although to the designers of outcome measure a positive result would have been noted.

For Māori, culturally derived outcome preferences will inevitably impact on the way in which outcomes are measured and the types of issues that are considered. Māori and holistic models of health, such as Te Whare Tapa Wha highlight this. Here, the concept of health is described along spiritual, physical, mental, and whanau domains. From a Māori perspective all four dimensions are intertwined and mutually-inclusive. That is, a healthy state requires positive results in all four domains – a deficit in one creates imbalance, a lack of synergy, and therefore a deficit in overall health status.

The difficulties of measuring culturally derived outcome preferences are numerous. A model of Māori health, such as Te Whare Tapa Wha, provides some guidance as to what outcomes may be preferred. However, Māori are not a homogenous population, diversity of cultural experience means that not all prescribe to single view of health, not all speak Māori or are comfortable in cultural settings. Nevertheless, and regardless of language proficiency or cultural familiarity, the desire to be Māori and to identify as such is often consistent. The problem, therefore, is how to measure or consider cultural outcomes that reflect the diversity of cultural experience ?

As touched on previously, part of the problem with outcome measurement stems from the fundamental realities of health care provision – the difficulty of constructing a tool which is appropriate, reliable, and valid, in every type of clinical situation. This impossibility has led to the construction of condition specific measures of outcome. These issues are no less important from a cultural perspective. Will a holistic, culturally valid instrument, developed through the disability sector, work as well in a public health or health promotion setting. The answer is “unlikely”, however, the

need to design a cultural measure, suited to every imaginable type of clinical setting may be avoided – the reason being, that while Māori and non-Māori outcome preferences may be different, numerous similarities also exist. Outcomes such as the absence of pain or reduced disability are common to all cultures, not just Māori. Generic or clinical measures of outcome will often, therefore, consider issues which are important to Māori and necessary. The problem, however, is not so much as to what they measure – but what they do not.

This raises an interesting possibility. The idea that an existing clinical measure of outcome may be enhanced through the application of a more culturally aligned tool. The absence of hallucinations or maladaptive behaviour, for example, is a useful measure of mental health outcome. However, for Māori patients, a complementary tool, one which also considered physical or spiritual outcomes, may provide a more complete and therefore accurate assessment. The cultural measure, if generic enough, could be applied across a range of mental health conditions and therefore avoid the need for an endless array of cultural measures, instruments which are only valid in certain settings or situations. For patients with depression the Hamilton Rating Scale may provide accurate and useful outcomes data. If they are Māori another “cultural” measure may also be required and applied as a complement.

The point is that both cultural and clinical measures of outcome are neither contradictory or in conflict. They may in fact work in a complementary and mutually beneficial manner. The important thing is that the outcomes desired are adequately considered and that these (for Māori at least) are likely to be both culturally and clinically related.

Implications for Health Service Provision

Consumer measures, such as those described, are used for a variety of purposes, but are typically applied at a service level. Instruments which measure treatment efficacy have obvious potential to improve the quality of care provided and the outcomes produced. For policy makers and health funders the potential to enhance monitoring and purchasing arrangements is also obvious. Again, these opportunities are fundamentally reliant of the quality of the tool used and their capacity to accurately measure what is produced.

For Māori health service providers some interesting issues arise. Again, the perspective that I offer is that existing generic or clinically focused measures of outcome provide valuable, important, and necessary outcomes related data. However, questions should be asked as to their ability to measure the full range of outcomes produced by Māori health service providers.

Dedicated Māori health service providers have been around for almost 20 years. However, there is no clear agreement as to what constitutes a Māori health service – other than the provision of care to Māori. Diversity of service operation is often the rule. Many are operated for Māori, by Māori. However, many employ non-Māori staff, are located in mainstream settings, and function along clinical lines. Yet all affirm their function as dedicated Māori health service providers. This paper is not designed to invite debate on the precise characteristics of a Māori health service, rather to highlight that fact that amidst this diversity certain features or qualities exist – ideals and concepts which provide broad parameters and overall guidance as to what constitutes a Māori health service.

One of the more common characteristics is the notion of holism – care which is provided within a holistic context. The implication here are that services will be delivered in a way which caters to more than just the clinical symptoms of illness and have often led to innovative and unique approaches to health promotion, health protection, and health service delivery. Care is usually provided within a cultural context and in ways which utilise traditional concepts, mechanisms, and methodologies. The overall aims are to improve access, treatment, recovery, and rehabilitation.

In considering the implications of these approaches two important issues arise. First, Māori health services often administer treatments or interventions which are different to their mainstream counterparts – even though the client base may be the same. Second, the outcomes sought may also be different, guided both by the interventions administered as well as the expectations of their Māori patients. As a consequence, the more usual measures of outcome are often ill-equipped to capture the full range of outcomes produced by Māori health service providers. Nor, do they appreciate or recognised the types of interventions which are administered.

The implications are that an imperfect assessment of service efficacy is made, and, potentially, that Māori health services do not receive full credit for the outcome produced. The relationship to monitoring and funding issues are obvious. Assessment tools which are based on narrow, clinical parameters, are likely to underestimate the value of services which operate in a cultural paradigm. As well, Māori approaches to health service delivery may go unrecognised. Interventions designed to enhance cultural or spiritual health dimensions may go unfounded, regardless of the fact that they make a significant contribution to health gains and health outcomes. An outcome tool can only measure what it is designed to and often not the full range of outcomes produced.

Moves toward an outcomes based approached to funding makes sense but is hampered by the need for tools which are valid as well as practical. That is, instruments appropriate for routine clinical use. There has been considerable debate as to the types of measures which could be used and how this can be done. However, less attention has been given to cultural issues and implication. Further and on-going debate is therefore required not only to establish how and in what form outcome measures fit within the business of health service provision. But also, how the needs and expectations of Māori health services are to be met.

Conclusions

At the beginning of this paper I mentioned some important issues which needed to be considered, the most critical being “why” to measure outcome. The issues so far discussed go some way to answering this question. An obvious response to this question would be “so that we know what we do works”. Alternatively, to ensure the most effective use of every health dollar spent, to aid service development, monitoring, the identification of health deficits, or for planning and staff deployment. All these decisions are enhanced through the use of health outcome measures. However, the rationale I prefer is much more pragmatic in that health outcome measure should contribute (fundamentally) to an improvement in health. Quantifying or measuring this improvement is the essential quandary, however, we must remember the measurement is not the endpoint rather an indicator of whether or not the prime objective (health) has been satisfied.

This paper has discussed, somewhat, the difficulties associated with measuring outcome. Several definitions of outcome were presented as well as some broad outcome parameters and requisites. The various levels of outcome were also discussed as were the differences between input, process, output, and outcome. How to measure outcome was further considered along with some of the numerous pitfalls, hazards, and concerns. Leading on from this was the issue of culture, a significant problem in terms of health outcome measurement, but which has received relatively little attention. Though I must admit that New Zealand, at least, is making some excellent progress here.

In an attempt to rationalise the need for cultural consideration in outcome measurement a reasonable case has been put forward. However, the foundation of this case is derived not from political, social, moral or even treaty grounds but from the position that it makes sense, is good practise, and will contribute to positive health gains for Māori.

In terms of outcome measurement the challenges faced by health researches, policy makers, funders and service providers are significant. We know well the benefits of

outcome measurement but are less certain as to how these opportunities can be realised. Outcomes research must lead to pragmatic solutions, outcome tools or instruments. Policy makers should appreciate the advantages presented as well as the inevitable limitations. Funders may see the opportunity to more effectively monitor, however, without buy-in from service providers the whole process may be perceived as a cost-cutting exercise designed to reduce and rationalise existing budgets. A coordination, considered, and integrated approach is therefore required a process which facilitates gradual development and allows for input from a range of key stakeholders (including Māori). As well, we should recognise that outcomes measures cannot operate in isolation nor are they an ultimate panacea for the health system. Health service delivery is much too complex and the value of input, process, and output measures should also be considered.

No reira...ki a koutou katoa...kia ora (good health to you all)

ⁱ Health Funding Authority, (1998), *op cit.*, p. 7.

ⁱⁱ Borman and Wilson, (1998), *op cit.*, p. 2.

ⁱⁱⁱ J. McCallum, (1993), 'What is an Outcome and Why Look at Them?', in *Critical Public Health*, vol. 4, no. 4, p. 4.

^{iv} Australian Health Ministry's Advisory Council: *Health Outcomes Bulletin*, no. 1, February 1994, p. 5.

^v G. Andrews, L. Peters, and M. Teesson, (1994), *The Measurement of Consumer Outcomes in Mental Health*, Australian Government Printer, Australia.

^{vi} J. Sansoni, (1997), 'Health Outcomes - Made to Measure', in *Australian Private Hospitals Association Caring with Skill Conference, July 1999 Proceedings*, Sydney, Australia.

^{vii} Eagar, (2000), *op cit.*, p. 142.