



You've collected data: what now?

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What is data?

First let's reflect on what we mean by 'data'. In our research centre we believe that the world spins on data—data from research studies, data synthesised into systematic reviews or clinical guidelines, data produced from clinical endeavours. We are interested in data that helps clinicians understand their patients better, and treat them better, for better outcomes. However clinicians consider data with different eyes and therefore this presentation is an opportunity to reflect on how you perceive data, and the purposes for which you can use it.

The underlying intent of this presentation is to discuss data use in terms of quality improvement in health care. My PhD¹ examined physiotherapy and chiropractic service quality from different stakeholder perspectives, and the data we collected consistently supported the framework proposed by Donabedian in 1980²—that service quality could be appropriately considered in terms of structure (how a service was organised), process (what care was provided) and outcome (whether the care produced health outcomes for reasonable cost). The inter-relationship between these quality elements is still being debated, and this is why discussions on quality practice continue to be challenging.

One of things that my PhD established was that clinics can have terrific structures, but poor practices and variable outcomes, or that clinics can have ordinary structures, but great processes and good outcomes. The current theory in quality improvement is that good structures do not automatically indicate good processes and outcomes, as these are very different constructs, and require different investments in time and resources to achieve them. Conversely good outcomes do not necessarily indicate good structures or processes, as good outcomes can occur by chance. The most important element to consider at the moment for therapies is the delivery of consistently good processes (based on available research interpreted in local settings), which are underpinned by appropriate and supportive structures, and from which there are measurable outcomes.

There has been an enormous amount of work conducted in Australia over the last 20 years by allied health professionals trying to come to terms with what constitutes a minimum set of data which reflects allied health activity. There hasn't yet been a resolution about minimum data sets because consensus has not been arrived at, on the purpose of data collection, and what 'data' actually means³. The lack of consensus reflects unresolved issues of differences between allied health disciplines' training and focus, their service delivery patterns, and the way different disciplines manage their patients, as well as differences between the public and private sectors.

Data in allied health clinical practice is most often collected on throughput or activity. In the quality improvement sense this information provides very little information on structure, processes or outcomes.

Clinicians, particularly those in private practice, often record information relevant to billing purposes and related to one patient. They use database software which records details such as patient identifier (name, DoB), insurance status, how many visits were consumed, dates of visits etc. They may also record the length of the visit (if there are different costs for different service types) and whether consumables were provided (tape, splints, books etc). They may note which therapist consulted the patient, in instances where there were differential costs for therapists (specialist therapists vs new graduates etc) What this data does it provide a cost-centred view of service provided to one patient, from which an account can be generated.

Hospital-based clinicians often record throughput data for administrative purposes. They record how many patients were seen in a week, how much time was spent in direct and indirect patient contact, how much time was spent in administration etc. Waiting list data may also be collected—time delays between making an appointment and the first consultation. The therapist status may also be recorded (new graduate, senior etc).

Diagnosis and outcome data

Rarely in clinical settings is useful information on diagnosis or outcome measures collected. In our research centre we have long asked ourselves why? Information on diagnosis and outcome provides immediate information on effectiveness of care for specific groups of patients. Diagnosis coding has been around for a long time in hospitals, where the ICD codes are in place for casemix purposes. As they have grown in sophistication, these codes now reflect





many allied health conditions, although they are rarely used directly by allied health clinicians for their own quality improvement purposes. Other attempts have been made to develop codes for diagnosis, but their successful implementation has been tempered by practicality and application. There are convincing clinical arguments not to use diagnostic codes, in that many codes that have been developed to date are perceived to be insensitive in recording specific diagnostic/clinical reasoning markers that will identify a specific patient, or a homogenous set of patients for quality improvement purposes. The one reason for recording standard diagnosis codes is to have the capacity to retrieve information for a specific group of patients on their management and outcome. Diagnosis codes can be recorded electronically along with other information on patients, or a simple register can be kept of key diagnoses linked to patient identifiers, so that records can be identified for quality improvement purposes.

So a diagnosis needs to be a standard set of numbers or letters that is understood by everyone using it, to mean exactly the same thing. I well recall an evaluation that I undertook some years ago of an electronic patient record system at a local hospital which had a diagnosis field⁴. I was understandably excited by this because it was in the middle of the period of debate on usefulness of diagnosis coding. How disappointed was I to find the field mostly blank, or with one code in it (9999 meaning diagnosis not specified). Discussions with clinicians at this hospital identified that diagnosis was too hard to assign using the list with which they had been provided, as the list was either not handy to their computer for data entry, it was seen as too generic, they had not actually recorded a diagnosis on the patient notes, or they were reluctant to record a diagnosis because they might be wrong and therefore considered to be legally liable.

Certainly many diagnostic coding systems that we have seen incorporate information what is often not a determinant of a diagnosis, rather it reflects useful adjunct descriptive information of events that may impact on outcome of care (for instance patient age, chronicity of condition, severity of condition, nature of injury/trauma). Diagnoses are integrally related to clinical reasoning and problem solving, and because this is becoming a therapy art-form it may well indicate the diagnostic codes will never be arrived at!!!! When we talk about diagnosis data, we require an allied health think tank to understand in epidemiological terms the purpose of what we assess and collect, and how we collect it.

Let's consider a common diagnostic term, low back pain. To start with, is this a diagnosis, or is it a descriptor only of pain location? Yet this 'diagnosis' is common across clinical and research projects. What is 'low back pain'? It is a phenomenon produced by one or more poorly functioning structures presumably in the lumbar spine area.

Low back pain has a range of descriptive elements. We have discussed the value of this term in describing body part or location. The other element of the descriptor is 'pain'—that is the presenting problem. Pain is an amazing phenomenon related to irritation of body structures sufficient to trigger pain signals. So it is pain reflecting something going on in the structures in the low back, or in central pain pathways that have been sensitised by something in the low back that is our diagnostic focus. The next logical question is its chronicity—the length of time low back pain has been a problem—is it a recent event or is it a long term problem? If it is a long term problem, how often has it been a problem? (remembering too that there are different definitions of chronicity in the literature!!!!) Over the period of time in which the patient has suffered the condition, has it occurred daily, monthly, infrequently, always in association with a specific event?

Now let's focus on this current presentation—what is the pattern of the pain? Pain can be intermittent, related only to doing a specific activity. Or it can be consistent, being present throughout the day and night and related to no specific activity. Its severity may be the next logical question—how bad is it? Is it that bad all the time, or are there degrees of 'bad'? Linked to questions of pattern and severity are often questions related to restriction of usual activity, which describe the impact of the pain in the low back on daily lifestyle. Then there are the clinical diagnoses issues—using specific tests, can the presenting pain be isolated to a structure, which can give the diagnosis more biomechanical meaning? Is the pain related to poor performance of a disc? A facet joint? A muscle tear? A ligament sprain? Is the pain not related to anything in the low back, is it more a behavioural presentation incorporating psychosocial factors that need to be treated? Being cynics, we could ask how important is it that a body structure is identified—how valid and reliable are any of our clinical tests? How useful are medical imaging in determining affected body structures? Does information about an injured structure truly direct the clinical management?

And then there is clinical information on the patient which could contribute information on potential risk factors for the onset of the problem and/or the likelihood that the problem will resolve—BMI, gender, age, occupation, personality, fitness, motivation, financial position, satisfaction with work and home life etc

Now let's look at what we could record for diagnostic purposes.





Presenting patient = male, 54 years, high BMI, unfit, truck driver, works 6 days per week 18 hours per day, dissatisfied with job, suspects problems at home but never there long enough to bond with family, gets little exercise, eats poorly when driving truck

Location of problem = Low back

History of problem = pain in the low back which has occurred regularly over at least 10 years, related to sitting for long periods, each pain episode lasting for longer, can be minimised with tablets and alcohol and rest

This presentation = 3 days of niggling pain all the time, severe pain on extension, interferes with sleep, postural deformity in sitting and standing, cant drive truck as he cant get out of bed without pain, wife not happy with him being at home, no money coming in because he has used up all his sick leave and is waiting for insurance claim to come through. On examination he is acutely tender over the paraspinal muscles, anxious and angry.

How can you use this information to make a diagnosis? What diagnosis would you record?

More importantly from the perspective of data handling is how this information contributes to diagnosis. Basically if you had the opportunity to record information electronically or in a practice register, all you would probably be recording in order to retrieve records for this patient and any others like him (homogenous group), is that he presented with chronic low back pain. On his records you would then expect to find all of the factors recorded which could provide you with information that could be used for risk identification, or for calculation of the outcome of care.

Risk factors

Personal factors (male, 54 years, high BMI, unfit, truck driver, works 6 days per week 18 hours per day, dissatisfied with job, suspects problems at home but never there long enough to bond with family, gets little exercise, eats poorly when driving truck)

History of problem = pain in the low back which has occurred regularly over at least 10 years, related to sitting for long periods, each pain episode lasting for longer, can be minimised with tablets and alcohol and rest

Possible outcome factors

Reduction in severe pain on extension, reduction in tenderness over paraspinal muscles, reduction in interference with sleep, decreased postural deformity in sitting and standing, return to driving truck, improved home situation (wife happier, income return), reduced anxiety and anger.

Outcome measures

In our research centre we have undertaken a number of projects which have collected and reviewed standard outcome measures for use in clinical settings. Outcome measures can be usefully classified into the World Health Organisation⁵ framework of impairment (assessment of restrictions in movement, swelling, pain etc), assessment function capacity (which estimates capacity to operate at usual (expected) functional levels) and participation (assistance required for the patient to operate to capacity). There is a plethora of published outcome measures, which have variable psychometric properties (meaning content and construct validity, sensitivity to change, reliability of administration etc). An outcome measure used in one context may well not be appropriate in another, and choice of outcome measures requires some knowledge of what constructs should be measured. Most outcome measures produce a number, which is a proxy measure for the extent of the patient's problem. There are two other issues to consider—whose outcome is being measured, and the clinical utility of the outcome measure.

Considering the question of 'whose outcome' requires an understanding of ownership. Whilst impairment and participation can be measured by a therapist of a patient, pain and functional capacity can be really only measured by the patients themselves. Therapists can use a goniometer, tapemeasure, stopwatch etc to estimate the extent of impairment. They can also measure the use of a splint, medication, restricted duties etc as measures of participation. However functional capacity needs to be measured in terms of how the patient's problem influences his/her life. Thus validity questions relating to functional scales need to address the content of questions and the way they are asked. If the questions are designed by clinicians to find out elements of what they think are important, without asking patients whether the questions are relevant to them, then the functional measure is invalid.





Considering clinical utility requires answers to questions such as who administers the outcome measure, how appropriate is it for your patient group, how is the data recorded, how is it analysed etc? Many of the projects that we have undertaken have highlighted that clinicians are often confused by outcome measures (particularly in their choice of them), and that there are few guides around that point clinicians towards collecting cost-effective appropriate information on their patients. Many outcome measures are linked to diagnosis, which does offer some hope when attempting to record appropriate diagnosis and appropriate outcomes.

The most important clinical aspect to collecting outcome measures is that an outcome measure needs to be applied more than once in order to demonstrate change—most usually at first contact with the patient, and then on at least one further contact (usually discharge). Taking one number away from another provides a measure that possibly reflects treatment effectiveness.

Why do you collect data?

Many clinicians collect data on everything that moves, hoping that the mere construction of datasets will improve their practice. The take-home message from this talk is why are you collecting data (have a reason for each piece of data that you collect), how are you collecting it, how accurate is it, and how are you using it? Collecting and analysing data takes time, and should only be undertaken when there is a purpose to it.

Let's think about data uses. If you collect administration or cost-related data, all it basically tells you is how much money you have made, from how many patients, with your currently staffing complement. It tells you of the value to you, per therapist working in your practice and how much profit you made. It doesn't tell you why the patients consulted you, whether they were returning for treatment (and whether this is for the same condition, or another one), whether the patients were treated appropriately (i.e. using guidelines), whether treatment produced a good outcome, and whether the outcome was valuable in terms of cost effectiveness and patient satisfaction. If you collect data electronically, is your program providing you with the most useful outputs (i.e. data that answers your questions?) How readily can you manipulate the data to answer quality assurance questions? Whose responsibility is it to input the data, and who retrieves it for reporting purposes? Does anyone care? Are poor reports acted upon?

We became aware about seven years ago of legislation regarding Reasonably Necessary Treatment (*defined by legislation for NSW WorkCover*). The requirements of the Act were that clinicians should be able to justify their treatment choices based on the following concepts:

- ▷ Is treatment appropriate for the condition, the patient, the likely extent of improvement?
- ▷ Does treatment consider the known degree of effectiveness (actual or potential) and the potential cost?
- ▷ Is the treatment choice the best of all alternative treatment options?
- ▷ Has treatment been used previously in similar cases?
- ▷ Is it acceptable to peers?

To respond to a query about reasonably necessary treatment clinicians need to have access to their own treatment data, and also to data produced by others for comparison (research data or other clinical data). Clinicians cannot operate in isolation any more or put their heads in the sand about their patient care. Information on patient throughput, or patient costs to the system provides none of the answers to questions on reasonably necessary treatment.

CAHE Outcomes calculator (www.unisa.edu.au/cahe)

This software provides one way in which clinicians can readily collect data on individual patients, per diagnosis, to demonstrate change in chosen outcome measures over time. The CAHE calculator is free to download from our website and it offers a patient by patient opportunity to collect relevant outcome information. Clinicians are not restricted to using one outcome measure for one patient, as the current version of the calculator for musculoskeletal conditions contains about 14 measures of outcome that have good evidence for psychometric properties. The chosen outcome measure reflects the condition with which the patient presents and the most appropriate measures for the patient. The outcome measures range across pain, function and satisfaction. A graph can be printed at the end of the episode of care to demonstrate outcome change and to allow reflection by therapist, patient and referrer on patient





progress. What the calculator also provides clinicians with is the opportunity to consider expected improvement in outcome over an episode of care, and to consider whether the risk factors with which the patient presents, are impacting on the expected outcome. This requires the application of research knowledge to clinical practice, and we see the Outcomes Calculator as a bridge between the two. Lets take this example.

Clinical practice and research findings

The recent National Health and Medical Research Council-endorsed Evidence Based Management of Acute Musculoskeletal Pain guidelines⁶ provide guidance for clinicians in terms of treatment choices for low back pain, and the expected timeframe of recovery for patients with different risks. Treatment effectiveness information is gleaned from the research literature in terms of findings of RCTs, other experimental studies and systematic reviews. The research evidence findings are scored in terms of consistency, volume, clinical impact, applicability and generalisability, and are outlined in the guidelines in terms of what treatment choices are sound, based on strong evidence of effectiveness, what treatment choices may or may not be applied because of equivocal evidence of effectiveness, and what treatment choices should not be applied because of evidence of harm. The literature also provides strong evidence of risk factors for poor prognosis gleaned from epidemiological research—in the instance of low back pain, risks of poor outcome include psychosocial factors, poor physical fitness, high BMI, middle age, gender=male and sedentary occupations. Time frames for recovery have less robust evidence underpinning them and are often based on consensus opinion rather than good research evidence. The timeframes suggest that patient should obtain significant improvement within the first 2–3 treatments and should be considering discharge from care by about treatment 6–7. The question remains as to what is ‘significant improvement’—is this statistically significant improvement which few clinicians would be in the position to calculate, or is it significant for the patient? It also begs the question of the choice of outcome measure- some outcomes may show different types of change to others across the episode of care.

Using the CAHE Outcomes Calculator (or similar software) clinicians can chart the treatment-by-treatment progress of their patient, using a specific measure of outcome. If the patient fails to achieve expected outcome change over specific time frames (as outlined in the guidelines), the therapist can ask informed questions about why? Does this patient have risk factors for a poor outcome, and if so, perhaps treatment should be oriented to dealing with these? Has ineffective treatment been provided (as per the guidelines) and perhaps treatment choices could be adjusted? Perhaps after one-two treatments with no discernable change in outcome, patients could be directed to other types of care, rather than continue to consume care which is ineffective.

Summary

Clinicians should collect data. What data and why, are the moot points. It is important in any clinical setting to take time to establish what data elements are currently collected routinely (either on electronic databases or on patient records). Think about the purpose of each piece of data—what does it actually measure, is it measured properly (is there the possibility of error?), how is the data used for reporting purposes, and is it acted upon? If you didn’t collect this data, would there be a problem from anyone’s perspective? What are the current gaps in data collection (identified by asking the question ‘what more do you want to know about what you do, and what it achieves?’) If new data items are required, think again about their purpose. How will the data be used to inform quality improvement processes? If the data allows you to reflect during, and after treating a patient, about whether he/she received the best care for the presenting problem, whether the outcome reflected the care, and whether the patient’s needs were reflected in the outcome measure, then you are on the right track!

References

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