

editorial

Numbers and narratives: approaches to understanding patients' experiences.^A**Helen Ward, Pr**

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I decided to use the title of numbers and narratives because if you're thinking about patient experience and feedback there are many different ways of finding that. But for me, as a clinician, researcher and as a patient, I think the most important thing is to understand, not just count. So that's going to be the theme of my presentation.

Twenty or thirty years ago we never talked about patient experience. We certainly didn't measure it. We might have measured patient satisfaction, but not patient experience. In the last two decades there's been an explosion of interest in this area, so why? The social context is that it comes out of many social movements. I started my medical career working in HIV and sexual health, and HIV patients - certainly at the beginning of the epidemic - demanded that we paid more attention to their needs. They were already - as gay men, as Black Africans - mobilized and actively seeking rights, and that activism translated over into demanding better healthcare. We also have, and still have, the disability rights movement which has been very important in putting patients and disabled people's rights onto our agenda. Taken together, I think there's been a shift from paternalism, where doctors tell patients what's best for them, towards a more partnership way of working and towards empowerment of patients. At the same time there's been a shift, certainly in the UK and most of Europe, of responsibility for health from state public health in particular - from the state protecting your health - to you being personally responsible for eating better, avoiding harmful behaviours and so on. And there's been a growth in markets in healthcare, it's a very big business now. All of these factors have come together to focus attention on measuring and understanding patient experience.

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So why is it important? In 2002 Don Berwick wrote that patients' experiences should be the fundamental source of the definition of healthcare quality. It should be all about the patients, and research has shown that patient experience measured in many different ways is associated with better adherence to medication, self-measured health outcomes, some improvement in objective measures of health outcomes, efficient use of healthcare resources, and a little bit - not very good evidence - of most safe healthcare¹. So if you can improve experience these things should improve. Or is it because you improve those things, you get better experience?

What Is Patient Experience?

So what is patient experience? It's a subjective experience of the process of care. My scientific background is as an epidemiologist, and whenever you mention to a very quantitative scientist like me the fact that something is subjective, that's seen as a little bit of an insult. Subjectivism is not a good thing in science, but experience is subjective and there's no point in saying "because it's subjective, it's not valid". It is subjective. But because it's subjective, it's also different. If I go out for a meal, I may enjoy it very much, I may have a great experience. You may go for the same meal, the same restaurant, and yet you hate it. You didn't enjoy the experience either because you didn't like the food, you thought you had to wait too long, or maybe you thought it was too expensive. Neither of us is right or wrong. We just experienced it differently and drew different conclusions. That's the challenge we have here in understanding patient experience because it's not a thing. It's not a single thing that you can get right for everybody because people have varying expectations and varying subjective experiences. But you can look at some of the components that lead to having a good or bad experience. And the ones that have been suggested are:

- A. respect - people like to be treated with respect
- B. good information, communication - several of these were mentioned in the first session
- C. physical comfort
- D. emotional support
- E. access to care - not having to wait too long for your care

Can you Measure Patient Experience?

So, if you have some idea of what it is, can you measure it? There's been a huge debate over the last 20 years about how to measure it. Before the term patient experience was a widely used term, discussion focused on patient satisfaction: how satisfied are you, which is a summary, purely subjective view. Questions might be, "were you satisfied? Yes. No", or "how satisfied were you on a scale of 1 to 10". But that doesn't tell you very much about why, what might be going right or wrong. Between about 2000 and 2010, there was a shift towards using much more experience-based measures which focused on the different elements that shaped experience. Rather than simply asking about overall satisfaction, specific questions were asked, such as: "how long did you have to

wait?” “Did the nurse treat you with respect?” “Did somebody send you a follow up appointment when they said they would?” These are more factual and less subjective. That means that you can measure them, and you can compare them. Many people liked that because it seems more familiar to science, but to include some of the subjective part we also asked, in addition to “how long did you wait”, “did you wait too long?” Now one person might think waiting half an hour is too long, while someone else would be happy to wait for up to six hours. So that started to build in an extra complexity; they are different but both valuable ways of measurement. But more difficult to compare. Once we started to collect more data, what we actually used most of the time - if we’re honest – were the summary measures such as, “Overall, how did you rate your care?” That of course goes back to the issue of satisfaction. I’m going to come back to this because I think it’s a very important observation that comes from - actually there’s a debate as to who first said this - but basically, what gets measured gets done. If you measure something, you do something about it. If you can’t measure it, it’s more difficult to motivate people to do something. So what we decide to measure is what we will then focus on. It’s the audit culture; if we decide it’s waiting times that are important and we measure them, efforts will be put into trying to reduce them.

I’m going to give two examples from the UK which I hope will be of interest to you.

One is the friends and family test, which is probably the biggest data collection on patient experience that there’s ever been, and the second is some more detailed work on a cancer patient experience survey that we did at a hospital where I work.

Briefly, the policy context. In the late 1990s under Tony Blair’s Labour Government, there was a drive to improve the quality and equity of healthcare in the National Health Service (NHS). It’s a very large, publicly funded organization, it is still mostly free at the point of use and covers almost all healthcare services. However, the quality varies considerably between hospitals and areas. There was a drive to try and make quality better across the board, and patient experience was defined as one of the three key elements of healthcare quality, alongside clinical outcomes and patient safety. So patient experience was placed as a key factor alongside things like mortality and adverse events, and people started to develop more sophisticated ways of measuring it.

The focus on patient experience was further increased in the subsequent decade by a scandal at one local hospital in Staffordshire, England; between 400 and 1200 premature deaths were attributed to poor quality care at the hospital². The inquiry into the deaths identified major problems of culture, including that staff and the leadership did not listen when people said things weren’t working. One of the key recommendations of the inquiry was the need to use patient feedback more effectively. Results and analysis, including qualitative information, need to be made available to all stakeholders in as near real time as possible. And the aim was to improve that culture, to make people open to listening to criticism.

The Prime Minister at that time was David Cameron, and he announced that in every hospital and NHS service, patients are going to be able to answer a simple question in order to provide better feedback.

“In every hospital, patients are going to be able to answer a simple question: whether they’d want a friend or relative to be treated there in their hour of need. By making those answers public we’re going to give everyone a clear idea of where to get the best care – and drive other hospitals to raise their game.” (David Cameron, 2012)

His justification was that this “Friends and Family Test” would produce a simple metric that could be made available very quickly, and that the public could then see where to get the best care and drive other hospitals to raise their game. The measure was closely linked to the drive towards greater competition between hospitals, which was a policy of the coalition government: increasing competition and with it a greater marketization of healthcare.

So what is this Friends and Family Test (FFT)? Everyone using an NHS service is asked, “How likely are you to recommend us to friends and family if they needed similar care or treatment”. The response is a from extremely unlikely to extremely likely. Interestingly, this method comes directly from marketing and not from any health research. In marketing this question is the foundation of the Net Promoter Score. If you want to drive up sales of a new product, for example a mobile phone, you need people who buy it to be so pleased with it that they promote it to family and friends - that’s how you drive up market share. The FFT question is designed to test that. You want people who are extremely likely to recommend it to be much more than people who are neutral or detractors. There is also a question if you notice on the bottom of this: “what is the main reason you feel this way?” which is just open free text.

The latest data are from two months ago, July 2017. There were 1.2 million responses in that month alone, and there have been 34 million responses since it was first introduced. For hospital inpatients, 96% of responses are positive, i.e. likely or very likely to recommend, and only 2% are unlikely or very unlikely to recommend. Over the years it’s been collected those headline figures have hardly changed at all from month to month or between services of similar types. So we are collecting millions and millions of data points that we can confidently predict will not change from one month to the next.

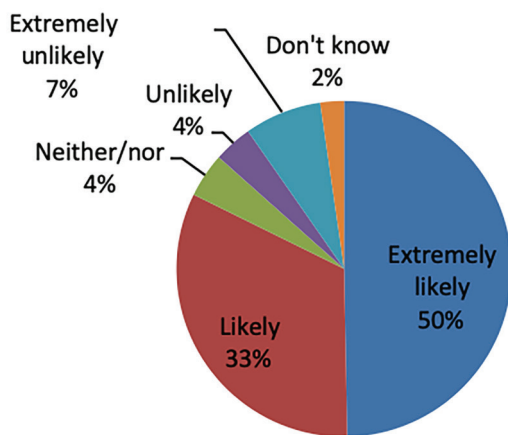
We analyzed 3.7 million responses from hospital patients from 2014 and 2015^B. The data are all publicly available. There was very little variation between hospitals or overtime. Using statistical process control charts, a technique that is used to detect spikes in relatively rare events³ - we did identify a small number of hospitals that had higher than expected numbers of those who would “not recommend”. There were around 20 negative spikes in 500 hospitals over 2 year, so it did not seem very useful. In another analysis of one local hospital, we found that there was variation in response rates, with some groups systematically underrepresented in this dataset. Patients under 35yrs old or over 80, and people black and minority ethnic groups were less likely to complete the survey. That is consistent with many similar surveys, but it is important if you’re trying to generalize from patient experience surveys.

^B Unpublished data.

We also tried to use the free text comments to see if that provided more useful feedback. We took a sample of 800 responses from one trust and compared the rating that people gave to the comments they left. We were surprised to find that 28% of people who said they were unlikely to recommend, actually gave positive comments, suggesting some misunderstanding of the question. When we have interviewed people about patient experience, some explained that they would never recommend anyone to go to hospital, for example for cancer care. Others said that their friends and family don't live nearby so of course they would not recommend.

So has this massive exercise in collecting patient feedback been useful? It might be useful for detecting some really poor quality care, but locally the numbers each month by ward or by hospital are too small to compare. Despite this, it is used in every single hospital, every ward, every clinic as a key metric for feedback. It is often regarded by staff, particularly nurses, as a way of checking up on them, asking them to account for minor fluctuations. It does not seem to be encouraging staff to listen to patients, it's seen as a stick to say if you go down slightly then you have to do something about you. So it's been introduced as an external monitoring audit in which the score in particular hasn't been particularly useful.

The most useful bit by far are the comments but few staff have the time to really analyze them. You can't analyze 1.2 million text comments every month and feed them back in a meaningful way. We have been promised that natural language processing will be able to automate this, and there is ongoing work to explore this, but at the moment we are still waiting. It's very difficult for computers to distinguish between "It was very nice that someone gave me a cup of tea" or "it would have been nice for someone to give me a cup of tea" so it's challenging. Briefly I will look at a manual analysis of 400 comments from an emergency department.



FFT responses, CXH A&E, April 2013



Figure 1. Analysis of the FFT Numeric responses and comments.

The figure shows that 83% were likely or extremely likely to recommend. And

at the top on the right is a word cloud from the comments of those who responded that they were highly likely to recommend. You can see the kind of words: staff, service, good, care friendly; the size of the words shows their frequency. In contrast, the bottom of the right side shows comments from those who were unlikely or extremely unlikely to recommend. It very clearly shows the challenges of the service: waiting, hours, long, time. That shows that the qualitative feedback can be helpful. But as I said earlier, what gets measured gets done, and my complaint about this metric approach to measuring patient experience is that the numbers don't tell you much and they certainly don't help you to improve care; if your score goes up and down you don't know why. So it might be a signal but it's not helpful in terms of why. I recommend that teams pay more attention to the comments than the scores.

My second example is a smaller study of cancer patient experience. Now if you remember the quote at the beginning from Don Berwick was that good quality care is about good patient experience. We worked in a cancer service which had some of the best patient outcomes in the country, but scored really badly on patient experience surveys. As one member of staff in the hospital commented, 'you'll have a good outcome if you survive the experience'. My research group was asked to investigate why there was this disparity between clinical outcomes and experience and to suggest ways to improve the latter? We carried out a rapid evaluation of the cancer services in 2012-2013, using both statistical and ethnographic methods. We took the patient experience survey data and analyzed it in detail, including comments, and also conducted observation in the services, interviews with patients, staff, researchers, companions, etc.

First on the statistical analysis of the survey, which included around 60 questions about experience plus an overall rating of care. Although poor relative to cancer services in other hospitals, 79% of patients rated their care positively overall, and 6% said it was fair or poor. We explored the demographic and clinical characteristics of those who rated it poorly, and also looked for internal correlations between the different questions and overall experience. We found that women were more likely to give a negative rating as were Black, Chinese and other ethnic minority groups, people with mental health conditions. Psychometric analysis showed that the question that best predicted overall rating was "Were you able to discuss any worries or fears with staff during your visit?". If you said no to that question, you were far more likely to give a bad rating. This is an indication of what people valued and what they were missing. When we first presented these results back to managers they immediately tried to address that problem; they tried giving staff badges with, "Do you have any worries or fears? Talk to me". I was horrified by that approach, To my mind the issue of worries and fears is about relationships: people didn't feel they had a relationship with a member of staff that they could confide in.

^c Unpublished data.

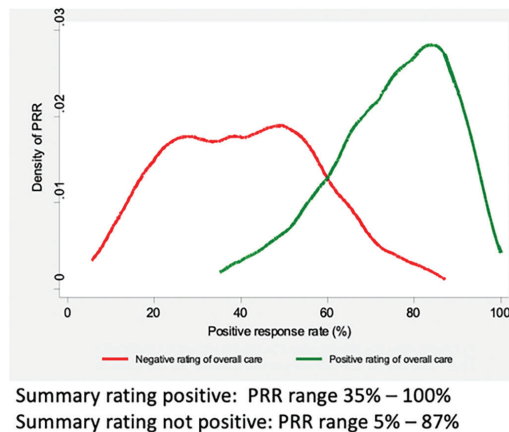
Positive response rate (PRR: % of all questions answered positively)

Figure 2. Positive item response rate by overall rating of care

One final bit of data is shown in the next figure^c. We worked out a positive item response rate for each person – what proportion of all questions were answered in a positive way indicated a good experience, and then looked at how this related to their summary rating of care as positive or negative. This chart shows the distribution positive item response rate to those who were positive about their care overall (in green) and negative overall (in red). It shows that for people who rated their care as good, the number of items they were positive about ranged from as low as 35% to 100%. And for those who had a bad overall rating, their responses ranged from 5% to 87%. That shows that some people scored over 80% of the individual parameters of patient experience positively, still rated their overall experience as poor. I think this underlines the fact that an overall experience - not just patient experience - is a subjective judgement of a whole, not just a numeric addition of individual factors. We also did a thematic analysis of the comments on this survey, and almost all the positive comments were about the staff, and all the negative comments were about the system. I think patients are very aware of the stresses the staff are working under, and are mostly reluctant to criticize them. They say that staff are exceptional but they are let down by the system.

Briefly, what about our more ethnographic approaches? Myself and my colleague, an anthropologist, visited different parts of the cancer service, including the chemotherapy unit, the outpatient department, the wards and the diagnostic services. We observed, talked to and interviewed patients, carers, volunteers and a range of staff; echoing the comments in the survey, the overwhelming feeling we got was the staff were good but the system wasn't working: it was underfunded, there weren't enough staff, there was too many patients. That's why things were not working. One patient I spoke to said "it's like I'm in a play with a cast of thousands, and the play is about me, but nobody can see me". She had breast cancer and a complicated clinical history, and was seeing a clinical oncologist, a medical oncologist, a radiologist, a surgeon, a plastic surgeon and an infectious disease specialist. That was just the doctors; she also described the many different specialist nurses, therapists, pharmacists and oth-

ers who were involved. She felt nobody had the whole picture and there was this general concern about, “who is thinking about me when I’m not here?”. These different people thinking about bits of me but nobody’s thinking about me. We have heard echoed by patients in other services – they value it when they have a relationship with at least one professional who is interested in them as a whole, not their constituent parts and problems. That is very important when you are living with a chronic long-term condition and that was sometimes missing.

Another thing that I was interested in is how different people would relate quality of care. And this particular man who was having chemotherapy I interviewed, he had to have repeated chemotherapy for a chronic blood condition. “This is a fantastic hospital. You can quote me on that”. So I do quote him on that. He compared it to other trusts which is something other patients say when you ask them, how likely would they be to recommend it, they will have no experience anywhere else. And he was concerned. He thought that in other trust the staff were rushed and didn’t take time. And he said nursing is all about care taking time and doing it well. And he insisted that I take a photograph of his cannula that he had in the back of his hand because he thought it was very beautifully sited and beautifully protected and neat. And for him that was a sort a sign of the fact that the whole experience was good because people cared. That’s not the sort of thing you can get in a survey by writing a question, you know, “how neat was your dressing?”, it’s something that you have to talk to people and then try and understand, and it doesn’t mean that that becomes your priority, but it means you talk and feed back to the nurses quite how much little - what apparently little - things make a difference. So the main thing we really concluded from this was that the system had become so complex that patients couldn’t navigate it. The nurses and others were not really given the power to navigate it. And that patients really valued having one or more very strong relationship.

We related that in a more in-depth analysis to what is generally called personalized medicine: the introduction of ever more refined biologically personalized treatment pathways. So you have a very precise set of treatments and monitoring that you have to have, based on the type of cancer, your responses, and so on. That’s great in terms of biological and it may be great in terms of outcome but it feels very unstable to the patients because nobody knows ahead of time which path you’re going along because it’s constantly changing. So we related this, that the personalized medicine that is growing can lead to less personalized care if you’re not aware of it and don’t put in the systems to support patients.

Concluding thoughts

So is it numbers or is it narratives? Surveys and their numbers can be useful. But I’m not a great fan as you can probably tell, as they are generally used to rate institutions and services using predefined categories that someone else said are important, They don’t always capture what’s important to a patient. And I think they can sometimes silence patient voices, because if you’ve got 95% of people who are very happy, nobody says you’ve got to work on the 5%, or that you should see whether that 95% have ideas about making services even better. So I think you have to be wary of just taking a summary figure. Qualitative methods such as I’ve described can give voice to patients, but it is difficult to compare and to generalize. I think that improving patient experience requires

you to have staff and patients who can work to manage improvement together which is what the first session today was about. So whether the government can rank or rate you is less important to me as to whether or not the staff, the patients and the managers can work together to improve care and be given the power to do that in a process of co-production.

I wanted to say something about staff because we talk about patient experience and one of the strongest predictors statistically of patient experience outcomes is staff experience surveys. They're very closely aligned. If the staff are not happy, patients won't be happy. So working on staff experience and using them as people who can hear what's going on is a very useful way of moving forward.

So my conclusion is first of all that patient experience isn't a thing. By measuring it, I think we've started thinking there is good patient experience, and there is bad patient experience. It's an experience, it varies. For most people, it lasts for years and it's important that we find ways of tracking patient journeys and not just asking at a point in time. We can measure elements, we can rate and rank, but the title of my talk was about understanding numbers and narratives they use in understanding patient experience. And I would strongly argue that narratives are much better if you want to understand something, And therefore we need mixed methods of approach and more than anything we need to foster conversations between patients and those providing the care so that they can work to improve patient experience together.

Thank you.

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