VIEWPOINT: What counts as online patient feedback, and for whom?

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Online patient feedback is quickly becoming pervasive enough to warrant serious attention. For many decades, patients have been asked and encouraged to fill out paper-based questionnaires to give feedback on the care that they received. These have been used for a number of reasons, including to measure how the service has been rated by the patients, and to suggest areas for improvement. They were seen as a good alternative to face-to-face feedback because their impersonal nature can allow patients to more comfortably give feedback about the staff who care for them whilst minimising social desirability effects.[1] As well as this, the usual power dynamics between health professionals and patients were thought to be diminished, and patients could, in theory at least, offer honest critique without fearing pushback, or negative consequences on their subsequent care.[2]

More recently, with the advent of digital technologies and an increasing connectivity to the web, online patient feedback has been flung into the spotlight, stimulating research into how this might change current practice and whether it can lead to an increase in quality of care.[3,4] In theory, patients can now leave feedback using a website or app at a time and place of their choosing, with or without anonymity, rather than doing so in person at the hospital or local general practice. Consequently, within healthcare organisations, the jobs of patient experience leads, quality outcome and assurance managers, and data analysts, amongst others, are changing to assimilate feedback gathered online alongside more traditional methods, and with this there are new things to learn about how best to harness and use this online patient feedback to improve quality and outcomes for patients.[5,6]

There is, however, a fundamental gap in the understanding of what constitutes online patient feedback. Generally it is referred to in monolithic terms, abbreviated to OPF in some sources, implying a universally acknowledged and understood phrase. However, as this field advances in research and practice, we need to deconstruct this, and consider more carefully what counts as its three facets: 'online', 'patient' and 'feedback'. When describing online patient feedback there are often a number of different assumptions at play (see Table 1 below).

These different assumptions exist not only *between* researchers, the public, clinicians, and staff in the NHS, but also *amongst* these different groups — and which assumptions are held matters beyond just semantics. It could potentially affect many aspects of service delivery: who is able to give feedback (the patient? Their relative? An observer?); what content counts as legitimate feedback, and what gains attention from the healthcare provider (formal complaints? Recommendations for action? All comments?); and how health services may unwittingly shape the system in favour of certain people or certain types of feedback (are certain channels permitted or excluded? Are particular resources and skills required to access and use the channel?).

We need to be much clearer in articulating what exactly we mean by online patient feedback. Early observations from an ethnographic study at various organisational sites in the UK (NHS Trusts) conducted by the author (FD) as part of a larger programme of work in this area, suggest that from an institutional perspective, there is a difference between feedback that is sanctioned (feedback obtained through a medium that is approved by the Trust as an official feedback channel), solicited (consistently asked for from patients or carers) and sought (actively searched for and used), and feedback that is unsanctioned (not officially approved), unsolicited (not asked for), and unsought (not searched for). We refer to these as SSS feedback and UUU feedback, respectively.

SSS feedback is that which is actively solicited by organisations, teams, services and localities. Here patients may be encouraged to give feedback through a designated weblink, or asked to leave feedback

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Table 1. Different assumptions underlying the use of the terms 'online', 'patient', and 'feedback'.

What counts as 'online'?	What counts as 'patient'?	What counts as 'feedback'?
As a synonym for digital	Patient currently undergoing treatment	Comments
Point of feedback entry is 'online'	Patient who recently had treatment	Complaints
Point of feedback analysis is 'online'	Anyone who's ever had treatment	Gratitude/praise/thanks
Communication of feedback is 'online'	Carer of patient	Recommendations for action
Connected to the web	Parent of patient	Narrative accounts of experience
Publicly available on the web	Family/friends of patient	Numerical ratings of experience
All of the above	All of the above	All of the above
None of the above	None of the above	None of the above
Other	Other	Other

through a sanctioned provider at the time (examples of such sites in the UK are iWantGreatCare and Care Opinion), by giving patients electronic tablets with the survey pre-installed onto the device, asking for paper questionnaires to be filled out so that they can be transcribed later, or asking for face-to-face feedback, which is then re-reported elsewhere. This feedback is then used to assess the state of the service and understand the experience of patients. In contrast, UUU feedback is that which patients leave without any prior prompting or solicitation. It includes feedback from patients who post on Twitter, Facebook or YouTube, from those who write their own blogs, and also from those who leave feedback on public sites such as NHS Choices in the UK.

This distinction matters because SSS feedback is much more likely to be picked up and included in narratives about how the organisation is doing. These are the sources that are relied upon to populate 'patient experience' meetings with vignettes, or to derive the proportions of satisfied patients to inform board meetings. UUU feedback, on the other hand, will often stay somewhere 'out there' in the web-ether, not gathered and not considered. Healthcare organisations may have neither the resources nor the ability to deal with these multiple sources of feedback — and often may not even be aware of their existence.

It is important to note that these two types of feedback are not mutually exclusive. There are instances, for example, where feedback has been solicited through unsanctioned means for 'practical' reasons — staff asking patients on Twitter for permission to use their tweet as 'official' feedback, for instance. There are also instances where feedback from sanctioned sources has not been solicited since it was deemed inappropriate in that situation — for example asking for feedback when a patient is distressed. However, despite the occasional deviation from this rather crude classification, for the most part this SSS/UUU divide appears to play out in practice, and we believe is a useful heuristic.

For researchers, there is a need for greater awareness regarding what is being studied: the benefits and pitfalls of SSS feedback, for example, are likely to be very different from those of UUU feedback, and will no doubt also vary depending on whose perspective we are examining. A local healthcare organisation may only use SSS feedback, since this is the feedback that they can control, access, and set up systems for, from which to learn. Their patients, on the other hand, may not even be aware that certain feedback routes may be seen as more legitimate, or may be more likely to have influence, or that certain ways of leaving feedback may increase or decrease the chances of receiving a response, if that is what they were looking for. It is therefore crucial for healthcare organisations seeking to harness the benefits and mitigate against the pitfalls of 'online patient feedback', to understand the scope of online patient feedback, the SSS/UUU distinction, and the implications of this in how they capture feedback. Organisations need to be explicit about what is included and excluded as online patient feedback in service provision, and communicate this to their users. Patients who provide online comments to give voice to their experiences, to inform the choices of others, and ultimately to drive quality improvement, need to understand the constraints on what forms of feedback are likely to make an impact.

References

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