Using online patient feedback to improve NHS services: the INQUIRE multimethod study

John Powell,[1]* Helen Atherton,[2]
Veronika Williams,[1] Fadhila Mazanderani,[3]
Farzana Dudhwala,[1] Steve Woolgar,[4,5]
Anne-Marie Boylan,[1] Joanna Fleming,[2]
Susan Kirkpatrick,[1] Angela Martin,[1]
Michelle van Velthoven,[6] Anya de Iongh,[7]
Douglas Findlay,[7] Louise Locock[8]
and Sue Ziebland[1]

[1]Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK
[2]Unit of Academic Primary Care, Warwick Medical School, University of Warwick, Coventry, UK
[3]School of Social and Political Science, University of Edinburgh, Edinburgh, UK
[4]Saïd Business School, University of Oxford, Oxford, UK
[5]Department of Thematic Studies, Linköping University, Linköping, Sweden
[6]Department of Paediatrics, University of Oxford, Oxford, UK
[7]Lay representative, UK
[8]Health Services Research Unit, University of Aberdeen, Aberdeen, UK

*Corresponding author john.powell@phc.ox.ac.uk

Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Scientific summary

The INQUIRE multimethod study

Scientific summary

Background

A new challenge for the NHS is to know how to interpret online patient feedback in relation to other sources of data on patient experience, and if and how to act on this content to improve services. Online feedback may have advantages, such as timeliness and transparency, but anecdotally it is sometimes seen as providing unrepresentative information from just a few users and, at the extreme ends of feedback, from overly negative and very positive experiences. The overarching aim of this study was therefore to provide the NHS with the evidence required to make best use of online patient feedback to improve health-care delivery in combination with other local qualitative and quantitative information on patients' experiences.

Objectives

We had four objectives:

1. to identify the current practice and future challenges regarding online patient feedback, and to determine the implications for the NHS
2. to understand what online feedback from patients represents and who is excluded, and with what consequences
3. to understand the potential barriers to and facilitators of the use of online patient feedback by NHS staff and organisations, and the organisational capacity required to combine, interpret and act on patient experience data
4. to use the study findings to develop a toolkit and training resources for NHS organisations, to encourage appropriate use of online feedback in combination with other patient experience data.

Methods

The study comprised five projects:

1. stakeholder consultation and evidence synthesis (scoping review) regarding use of online feedback in health care
2. questionnaire survey of the public on the use of online comment on health services
3. qualitative study of patients' and carers' experiences of creating and using online comment
4. survey and focus groups of health-care professionals
5. ethnographic organisational case studies with four NHS secondary care provider organisations.

Project 1. A scoping review and stakeholder consultation charting the current landscape of the evidence on online patient feedback

As the initial project, this scoping review and stakeholder consultation aimed to identify and synthesise the current practice and future challenges in the field of online patient feedback. We searched electronic bibliographic databases and conducted hand-searches up to January 2018. We included primary studies of internet-based reviews and other online feedback (e.g. from social media and blogs), from patients, carers or the public, about health-care providers (individuals, services or organisations). Key findings were extracted and tabulated for further synthesis, guided by the themes arising from a consultation with

15 stakeholders with online feedback expertise from a range of backgrounds, including health-care policy, practice and research. We found that, as with much digital innovation, research is lagging behind practice. The current literature was able to address some key issues, such as identifying the extent of the use of comments and challenging the false assumption that feedback is usually negative, when, in fact, most is positive. It also shows that there are clear gaps in the evidence base, which can guide future work, especially in understanding how organisations can use feedback to deliver health-care improvement.

Project 2. A cross-sectional survey of the UK public to understand use of online ratings and reviews of health services

We conducted a face-to-face cross-sectional survey of a representative sample of the UK population to investigate the self-reported behaviour of the public in reading and writing online feedback in relation to health services. Descriptive and logistic regression analyses were used to describe and explore the use of online feedback. A total of 2036 participants were surveyed. Of the 1824 internet users (90% of the sample), 42% ($n = 760$) had read online health-care feedback in the last year and 8% ($n = 147$) had provided this feedback in the same period. People more likely to report reading feedback were younger, female, with a higher income, experiencing a current health condition, urban-dwelling and more frequent internet users. For providing feedback, the only significant association was more frequent internet use. The most frequent reasons for reading feedback were finding out about a drug, treatment or test; and informing a choice of treatment or provider. For writing feedback, they were to inform other patients, praise a service or improve standards of services. Ninety-four per cent of internet users in the general population said that they had never been asked to leave online feedback by their health-care provider.

Project 3. Cross-sectional surveys of doctors and nurses to identify UK health-care professionals' attitudes to and experiences of online feedback

We conducted cross-sectional self-completed online questionnaires of 1001 registered doctors and 749 nurses or midwives involved in direct patient care in the UK, and a focus group with five allied health professionals. A total of 27.7% of doctors and 21% of nurses were aware that patients or carers had provided online feedback about an episode of care in which they were involved, and 20.5% of doctors and 11.1% of nurses had experienced online feedback about them as an individual practitioner. Feedback on reviews or ratings sites was seen as more useful than social media feedback to help improve services. Both types of feedback were more likely to be seen as useful by nurses than doctors, and by hospital-based professionals than community-based professionals. Doctors were more likely than nurses to believe that online feedback is unrepresentative and generally negative in tone. The majority of respondents had never encouraged patients or carers to leave online feedback. The findings from the focus group and from free-text comments in the survey showed concerns about representativeness and a reported lack of communication from management about what feedback is for, whether or not it is received and how it should be used.

Project 4. Interview study with patients and their family members to explore their perspectives on and experiences with online feedback about NHS services

We explored how and why patients and their family members provide and use online health-care-related feedback in the UK. We conducted 37 qualitative semistructured interviews with people who had read others' health-care service reviews and/or provided their own. A thematic analysis of the data was carried out, focusing on interviewees' self-reported motivations for reading others' health-care experiences and sharing their own.

Interviewees described multiple overlapping motivations. In spite of this diversity, online feedback was persistently framed as a means of improving health-care services, supporting staff and other patients; this is conceptualised here as 'caring for care'. The metaphor of engaging in a 'conversation' with health-care services providers was frequently evoked as the key mechanism through which online ratings, reviews and feedback could be used to improve health-care services.

Framing online feedback as 'care' opens up new ways of thinking about the meanings and consequences of these practices from the patient perspective in the context of public health-care services and the NHS specifically. Moreover, it adds an important dimension to academic work on online feedback, which typically conceptualises rating, reviews and feedback in terms of 'choice' or 'voice'. We suggest that thinking of feedback in terms of 'care' and 'conversation' opens up productive ways of engaging with the sharing of health-care experiences online.

Project 5. Responsibility, response-ability and responsivity: the new characteristics of accountability in the face of online patient feedback – ethnographic case studies in four NHS trusts

Ethnographic case studies were carried out at four NHS trust sites across the UK to examine individual- and organisational-level issues in relation to online patient feedback on health services, focusing on various NHS staff groups. The insights from this work show how online patient feedback has, in various ways, shifted the ways in which trusts are held accountable and to whom. We show how online patient feedback and expectations around it are changing work practices, and shifting the locus of responsibility to include new forms of response-ability (having the infrastructure in place to deal with multiple channels of, and increasing amounts of, online feedback) and responsivity (ensuring that responses are swift and publicly visible and, thus, accountable).

Conclusions and implications

Digital health is fast becoming a new determinant of health. Access and use of digital services will soon influence both the care options available to individuals and the outcomes they gain from them. The idea of a digitally sophisticated health consumer at the centre of a technology-enabled health system, actively engaged in managing their own care, which elsewhere we have characterised as the 'digital health citizen', has caught the imagination of policy-makers seeking to address the challenges of twenty-first century health care. At the same time, our findings show that providing online feedback is a minority activity, there is professional scepticism and there is a lack of organisational preparedness.

The area of online patient feedback (and its use for improvement) is undoubtedly an emerging field for policy-makers and practitioners seeking to deliver patient-centred health services that make best use of technology. We are not suggesting that online patient feedback should replace all other forms of patient experience data, but we believe that it can provide a valuable and timely adjunct to existing sources. Online feedback data are not perfect, the people who engage with online feedback are not representative of the general population (tending to be more frequent internet users, younger, female, less deprived, more educated and urban-dwelling) and taking averages from the online feedback content is not helpful, as people tend to comment when they have something to say about a particularly good or bad experience, so the distribution of the tone of content is not a normal one, but is skewed towards either end. However, those working in policy or practice roles need to understand that reading online feedback from other patients is becoming a more mainstream activity for many people and has wide reach with the potential to influence other patients' behaviour. Writing online feedback is increasing, but still remains an infrequent activity. Many people provide feedback because they want to give praise. Previous work confirms that the content of most online feedback is positive in its tone. In our interviews, people describe caring about the

NHS and wanting to help it. They also report wanting their feedback to form part of a conversation rather than to be a one-way street.

Despite the above, medical professionals are sceptical and cautious about the usefulness of online patient feedback. They are becoming aware that patients are providing feedback online, but have concerns about non-representativeness, negative comments and the anonymity of most online mechanisms. Nursing staff are less sceptical, although share some of these reservations. It is perhaps not surprising that very few patients report being encouraged to provide online feedback and few doctors or nurses ask their patients to do so. NHS trusts have varying approaches to capturing and using online patient feedback. A significant finding from our work is that, varying by trust, different online channels are seen as 'sanctioned' or 'unsanctioned' by the organisation, and, in general, only the sanctioned channels get monitored and responded to (even though patients use a multiplicity of routes to give feedback). Staff working within trusts are aware that the public visibility of online patient feedback makes response important for reputation management, as well as service improvement. However, trust staff are often unsure where the responsibility to respond to online feedback lies, and they also do not always have the resources to be able to respond to feedback (either to provide direct responses or to act on the information provided) or feel powerless to do so, as anonymous (or anonymised) comments restrict what response can be made (this is also constrained by patient confidentiality concerns).

Recommendations for research

Our findings open up some key questions for future research.

Intervention research could examine the extent to which online patient feedback can deliver service improvements in settings such as general practice, residential homes or secondary care. Further observational studies could take a longitudinal perspective to understand how staff and organisations deal with online patient feedback over time. Observational work would also be useful to determine what proportion of contacts with the health service (such as consultations) lead to an online comment being made and what the predictors of this are (e.g. by patient characteristics, service characteristics or other factors).

Policy research could examine how regulators could use feedback as part of their inspections and quality control of organisations or individuals. This could be done in a cross-sectional way (e.g. what does the online feedback say about this organisation?) or in a predictive way (e.g. can monitoring online feedback predict when a quality problem is emerging in an organisation?).

Another area of focus in the future could be examining patient comments about particular treatments or diagnostics and, especially, whether or not this could be used for vigilance of safety issues. This is more likely to be useful for device or procedure vigilance, which are less developed than the area of pharmacovigilance.

Finally, methodological work is needed to determine the best approaches to analysing comments to provide the most useful data to the NHS. In our literature review work, we found papers that used both traditional qualitative analysis and machine learning techniques, like sentiment analysis. The latter approaches have attracted a lot of interest, as have all areas of 'big data' analysis, but previous work has tended to conclude that computational approaches to online patient feedback are generally too insensitive to the nuanced nature of many comments, and that just categorising comments as being positive, negative or neutral in tone is not always that helpful for services seeking actionable feedback on which to base improvements. Future research could determine how best to derive actionable comments from large amounts of online feedback.

Study registration

The ethnographic case study work was registered as ISRCTN33095169.

Funding

Health Services and Delivery Research

Criteria for inclusion in the *Health Services and Delivery Research* journal
Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme
The HS&DR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HS&DR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-services-and-delivery-research.htm

This report