



## Experience in action: Moderating care in web-based patient feedback



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### ABSTRACT

What does it take to mobilise experiences of care and make them useful for improving services? This article draws on ethnographic fieldwork with a UK-based patient feedback website to develop a critical perspective on patient experience as a contingent accomplishment and a focal point for eliciting, provoking, and respecifying relations of accountability. Following a single posting from the moderation room back to the author and into the wards and offices of the hospital, I show how moderators, carers, and clinical staff respond to and act upon a seemingly stable experience. Drawing on recent work in science studies and ethnomethodology, I suggest that the work of 'capturing the patient experience' is not so much a matter of accurate reporting or incontestable opining, but an exercise in testing versions of reality through the ongoing respecification of objects, audiences, and identities. Attending to the mundane practices of moderating accounts of care highlights the work of ordering *alongside* technologies of evaluation – the largely invisible labour that sustains the possibility of public patient feedback in the first place.

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### 1. Introduction

Asking patients to share their experience of care has become a widespread way of generating useful knowledge. Bolstered by patient activism, health consumerism, and concerns over standards of care, a range of devices for capturing experience have emerged, including customer satisfaction surveys, focus groups, and Patient Experience Trackers (PET). Especially digital technologies have been championed as an efficient way of sharing 'experiential data' (Adams, 2011; Lupton, 2014; Mazanderani et al., 2012; Wyatt et al., 2013). The UK-based website Patient Opinion is a good example (Fig. 1). Founded as a not-for-profit social enterprise in 2005, Patient Opinion solicits, publishes, and circulates web-based patient feedback with the goal of improving the National Health Service (NHS). In contrast to the commercial review schemes it has been modelled after, its mission aims entirely at public service. As the description of the website states, 'Patient Opinion is all about enabling patients to share their experiences of health care, and by doing so help other patients, and perhaps even change the NHS' (Patient Opinion, 2010). Yet, while interest in such feedback schemes has been growing, little is known about how they work in practice. So what does it take – apart from running a website – to mobilise experiences of care and make them travel?

In this article, I examine how moderators, authors, and hospital staff construct and construe a seemingly stable 'patient experience'. To do so, I shall reconstruct the journey of one specific posting – Dave's posting – and show how it is mobilised in the day-to-day interactions of not just people, but also institutions, editorial policies, libel law, databases, and an unspecified public. As participants orient themselves and others towards accounts of care, what counts as an 'experience' is constantly being respecified for practical purposes independent of the original events. This ongoing work of *moderation*, I suggest, is a key feature of the scheme and an important reminder of how notions of experience as a resource for inquiry are problematic – not just or primarily for external observers, but also for those who dedicate their careers and time to make it work.

The article thus speaks to a number of analytic and methodological concerns at the intersection of healthcare, governance, and patient engagement. First, I offer an in-depth ethnographic account of a phenomenon that is usually talked about in rather abstract or systemic terms. Adopting a strategy of 'following the posting', I foreground the everyday work of running and participating in a patient feedback scheme. Second, I shift the analytic focus from the *content* of patient feedback to the everyday *practices* that sustain it as a site of ordering and evaluation in its own right. Rather than understanding patient experience as 'data' or 'knowledge', I am interested in how this status is accomplished in the first place. Third, I explore the role of moderation in this process. Often

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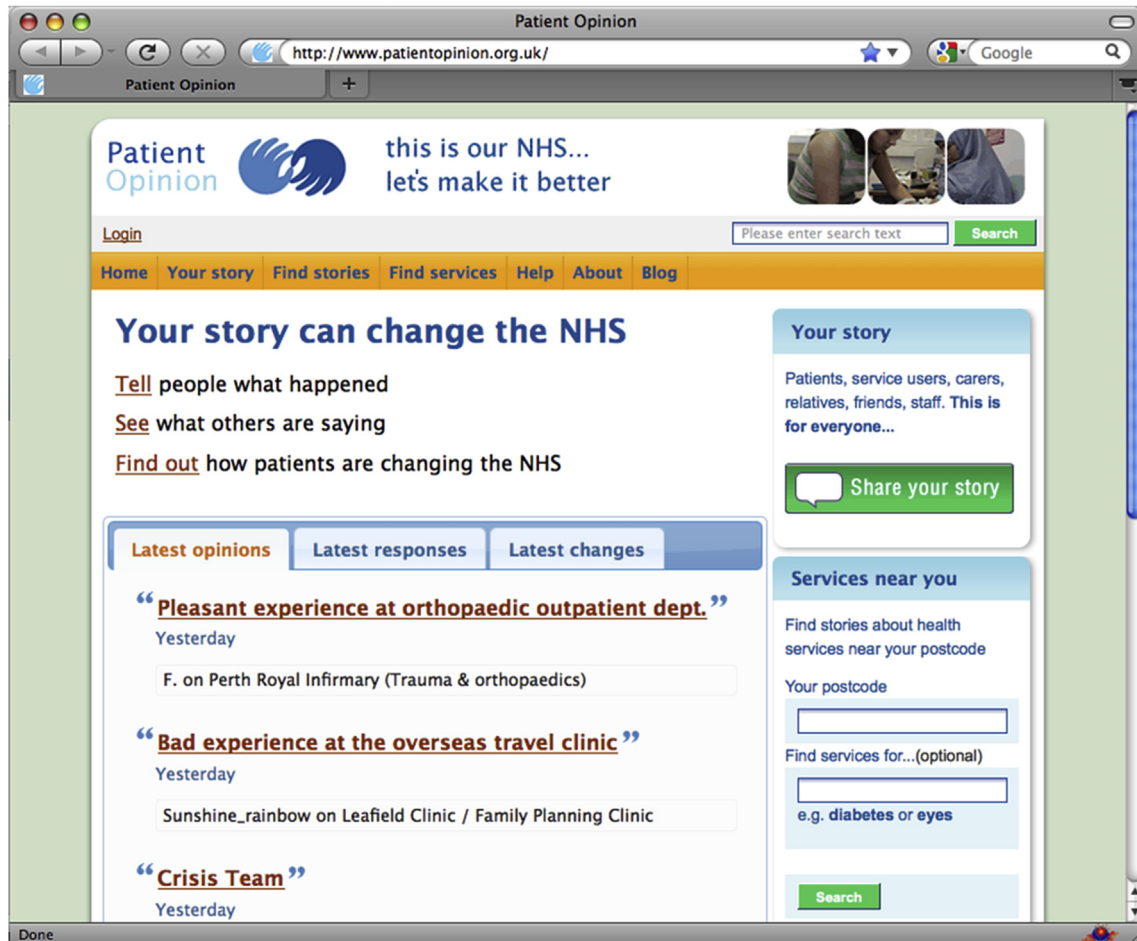


Fig. 1. Patient Opinion homepage (visited 5 January 2011).

regarded as a technicality at best or censorship at worst, moderation is a key feature of the scheme, highlighting the never quite accomplished struggle to adjust the range of possible readings for improving care.

The materials I draw on here derive from ten months of ethnographic fieldwork between 2009 and 2011 with Patient Opinion and its users, partners, and collaborators. After four months as a trainee moderator in the Patient Opinion office, I followed up with individual authors and interviewed them about their experience of 'sharing an experience'. I further tried to understand what happened to the postings in the offices and wards of hospitals and Trusts, visiting and interviewing managerial and clinical staff. Providing an account of this experience was itself an exercise in caring, adding another layer to the careful calibration of relations, audiences, and identities. After a brief note on the analytic and methodological challenges of accounting for patient experience, I shall introduce and follow the story of Dave's posting to explore and illustrate how one account of care became enacted during a tutorial in the moderation team, an exchange with the author, and a visit to the hospital. I conclude with a call to make web-based feedback schemes a proper site of ethnographic inquiry.

## 2. Accounting for experience

The idea of capturing experience for improving care is not exactly new. Already in the 1970s, Thomasina Borkman suggested the notion of 'experiential knowledge' to highlight the capacity of

self-help groups to generate 'truth based on personal experience with a phenomenon' (Borkman, 1976: 445). Since then, the role of experience in clinical decision-making has been analysed from a variety of angles (Caron-Flinterman et al., 2005; France et al., 2011; Frank, 2013; Mattingly, 1998). Especially the internet has been celebrated as a new technology for tapping the 'wisdom of patients' (Sarasohn-Kahn, 2008) and harnessing patient experience as 'the final arbiter in everything the NHS does' (Department of Health, 2011, p. 17). Yet, while enthusiasm for these new technologies of experience is widespread, a number of concerns have been raised specifically about web-based patient feedback. Among other things, scholars brought attention to the limited public awareness regarding these schemes (Terlutter et al., 2014), the potential for systematic misrepresentation and bias (Powell et al., 2015), the risk of deliberate gaming (Greaves et al., 2013), and a lack of integration with medical practice (Coulter et al., 2014).

Interestingly, this work assumes a rather stable notion of experience as an epistemic resource that is – at least in theory – available for capture. Mostly framed as a concern with 'data' or 'knowledge' as the basis of practical action, the currency and status of experience is taken for granted. However, as recent work in social studies of science, technology, and medicine has shown, this bracketing is problematic. In a content analysis of patient feedback websites in the Netherlands, the U.S., and the UK, Samantha Adams questions the idea of the 'reflexive patient', suggesting that 'reflexivity does not come from individual patients, but is promoted and encouraged by website creators' (2011: 1074).

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