

## Editorial

### When service users' support obscures problems with care: the need for rigorous research into patients' experiences

Policy makers and health service leaders often justify changes to health care provision with claims that the changes reflect what matters to citizens and service users. But the basis for their claims is sometimes unclear or weak. Two papers in this issue of *Health Expectations* illustrate how new health service arrangements that appear to attract patients' support can fall short of delivering key aspects of care that matter. These papers highlight the danger that superficial assessments of service users' opinions may obscure important concerns. They remind us of the importance of well-designed and well-conducted research into patients' experiences of care – and of the need for those who influence the development of health services to make good critical use of this.

In the first paper, Gillian Hunt *et al.* focused on the length of time that patients spend in hospital after hip replacement surgery.<sup>1</sup> They identified one hospital that had pioneered short post-operative stays of 3–4 days and one that retained a more traditional discharge regimen of 6–7 days. The researchers interviewed people who had recently undergone hip replacement in these hospitals. They asked them first to describe their experiences of surgery and recovery. Only two of the 35 participants spontaneously mentioned length of stay: both noted their uncertainty about how long they would be in hospital for. When the researchers prompted participants to comment on their readiness for discharge and/or their care after discharge, two people

from the hospital with the early discharge policy questioned their length of stay, but both also suggested reasons that might justify it being short. At the end of the interviews, the researchers told participants about the usual length of stay for hip replacement in the other hospital, and asked what they thought of this. None of the participants from the hospital with the shorter stays explicitly criticized the earlier discharge policy that they had been treated under, and some gave reasons for thinking that shorter stays could be a good thing.

Many researchers and research users who consider patients' views tend to stop at this kind of point and conclude that the new way of doing things (in this case the shorter post-operative stay) is acceptable from patients' perspectives. But Hunt *et al.* probed further. They undertook a careful comparison of the accounts of patients treated under different discharge policies and practices, and because they were alert to the fact that patients are often guarded in the ways they express concerns about health services, they looked carefully at any implied evaluations in what patients said. This let them see that although patients from the hospital with the shorter stays tended to accept and refrain from criticizing these, they had some problematic experiences that were associated with their earlier discharge. Nine of the 13 patients who were interviewed after being discharged from the hospital with the shorter stays disclosed that they had felt unwell, been unsure how to deal

with their pain or other symptoms, and/or not known what or how much activity to engage in to help their recovery after they left hospital. In contrast only one of the 12 patients who were interviewed after discharge from the hospital with the longer stays mentioned feeling ill and needing more support than was received after going home. Also, all the participants from the hospital with the longer stay expressed surprise that patients were discharged earlier elsewhere. They thought their own experience justified the need for the time they had spent in hospital, and they were not convinced they would have recovered sufficiently for an earlier discharge.

In the second paper, Julia Lawton *et al.* interviewed 22 people with type 2 diabetes four times over a 4-year period during which much diabetes care provision was moved from specialist hospital clinics into primary care (general practice) settings.<sup>2</sup> The participants all expressed general support for the idea that diabetes reviews and care should be provided from general practice. Again, however, the research team's careful investigation suggests that such expressions of support should not be interpreted complacently.

Their longitudinal study design allowed Lawton *et al.* to see that the views patients expressed about the revised service arrangements became "more complex and ambivalent" over time. Not all patients experienced well integrated care within general practice, and some were inclined to doubt that their care under the new arrangements was as good as it had been under the old. Their interpretations of the contrasts between what happened in secondary and primary care varied. Some did not realise, for example, that a decision to reduce the frequency of their review appointments reflected attention to their own situation (e.g. achievement of good control of their blood glucose levels) rather than general system changes (e.g. reducing the frequency of all patients' reviews to save money).

In general terms, the aspects of health care that these two studies suggest might warrant some quality improvement attention will not surprise people with an interest in patients'

experiences of care. Variable but often poor access to appropriate professional support for people discharged from hospital<sup>3</sup> (or moving between services more generally),<sup>4</sup> and variable but often poor provision of the kinds of information and advice needed to help people to contribute effectively and confidently to their post-operative care (or self-management more generally)<sup>5</sup> are clearly evident in patients' stories. We also know that people may start to doubt the quality of their care if they are not offered interventions that they think might be appropriate and if their health care professionals do not explain why.<sup>6</sup>

Addressing these issues seems to be more challenging than uncovering them. But careful research – and careful use of research – into patients' experiences could be better integrated with good health service development. Even if the people who work on the (re)organization and improvement of health services are aware of the types of problem that are generally known to recur, and even if they include patient representatives who bring valuable personal experiences to bear and strive to keep issues that matter to patients at the forefront of considerations, it is unlikely that all the important issues and implications associated with particular care arrangements and transitions (including the information, capacity and capability development and communication needs that emerge with shifting distributions of responsibility) will be identified without careful, context-specific investigations of patients' experiences in practice. The ongoing nature of developments in health-related knowledge and technology, and of change in health care systems and broader societies, generates a need for continual attentiveness to these experiences.

The two papers featured in this Editorial warn us that superficial investigation of service users' views is likely to generate unduly optimistic evaluations of services. People's experiences of health care, and their views about what matters in health care contexts, are not always clearly and directly reflected in what they say about the care they have received. Poor experiences of care – and experiences of poor care – are particularly

likely to be obscured.<sup>7</sup> Good health service development requires an ongoing programme of rigorous research that is sensitive to these issues. It also requires that the people who shape policies and service provision make use of this research and interrogate claims about service users' views critically to avoid reaching oversimplistic conclusions.

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## References

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