

## Measuring patient experience in the primary care sector: Does a patient's condition influence what matters?

Measuring patient experience has become increasingly central to assessing and improving the performance of healthcare systems worldwide and has been identified as a priority for many national healthcare systems. Little previous research has focused on what matters to patients beyond hospital contexts. Systems for measuring and improving patient experience in the community sector are relatively underdeveloped. For example, there is no national survey programme for primary care patients. A recent NNRU/King's Fund study, commissioned by the Department of Health, focused on investigating patient experience in primary care settings. The aim was to identify the features of care that mattered most to patients and whether what patients want from their care varies depending on their condition.

### Why look at patient experience?

A better understanding of patient experience could help to develop services and deliver the care patients, families and carers need[1][2] Patients' views on their experiences can be used for several purposes:

- as part of systems for monitoring the performance of health care organisations (accountability)[3]
- to improve patient choice and make healthcare organisations more accountable to their local populations (transparency)[4]
- as a mechanism to improve patient experiences in - and satisfaction with - specific health care services (local quality improvement)[5]

The problem is that important dimensions or domains of patient experience are largely derived from research on the experience of patients in acute settings, such as the Institute of Medicine's domains of Patient-Centred Care and Picker framework[6,7]. Do these frameworks adequately reflect what is important to patients receiving primary care?

### Does 'what matters' to patients in the primary care setting depend on their condition?

Fifty narrative based interviews were conducted with patients with one or more of the following five conditions: stroke, Chronic Obstructive Pulmonary Disorder (COPD), depression, diabetes and elective hip replacement. The five conditions were purposively selected to represent:

- A long term condition in which effective self-management contributes to better clinical outcomes (COPD)
- Very intensive use of primary, community and acute services by patients with complex needs and co-morbidities (diabetes)
- A condition for which significant aspects of care are transferred away from acute hospitals and into the community (stroke)
- A mental health condition (depression)
- An elective surgical procedure either requiring or not requiring an overnight stay in hospital (hip replacement)

Interview transcripts were analysed thematically. Initially the researcher looked for emerging themes and patterns that were specific to each of the conditions. Only themes that were mentioned more than three times for each condition were highlighted; these themes across all conditions were then compared to determine whether they were generic or condition-specific. Amongst the fourteen themes that emerged, seven were generic and seven were condition-specific.

Generic themes of aspects of care that mattered to all patients included:

- being treated as a person, not a number
- staff who listen and spend time
- individualised treatment and no labelling
- feeling informed, receiving information and given options
- patient involvement in care-efficient processes
- emotional and psychological support

Whilst the following themes were related to patients with specific conditions:

- using language that's easy to understand – mattered especially to *COPD patients* who often were trying to come to terms with their condition
- finding out about latest technologies/innovations/medication - mattered most to *diabetic and COPD patients*
- more public awareness about condition - mattered most to *COPD and hip replacement patients*
- knowledgeable health professionals - *patients with diabetes and depression* emphasised knowledge of their condition, available treatment and care options
- aftercare support –*hip replacement and stroke patients* often felt 'lost' at the end of their treatment
- positive clinical outcomes - *hip replacement* patients stressed this theme
- continuity of care- *patients with diabetes and depression* stressed the importance of ongoing relationships with the same health professionals.

A key overall finding across the 50 interviews was the strong emphasis patients placed on the relational aspects of their experience, such as dignity, empathy and emotional support which were very significant in terms of overall patient experience. Thus experiences that support the ongoing relationship with the patient and family need to be taken into account alongside the more often measured 'functional or transactional' aspects of care experienced e.g. access, waiting times[5].

### Conclusions and Implications

Providing a good patient experience in primary care settings is similar to acute care in that it is multi-dimensional: comprising of the what (functions or transactions) - and the how (relational) of interactions with patients[8]. Whilst some aspects of patients' experience are condition specific (or condition sensitive) our findings revealed that it is commonly the relational aspects of care which mattered most to all patients in primary care settings.

Tools for measuring these relational aspects of care are in development, (for example, see Williams and Kristjanson, 2008[9] for description of development of the 'Patient Experience of Emotional Care in Hospital (PEECH)' scale) which have recently been validated in the acute setting and extended to the primary care sector (as part of a NNRU study that is exploring the links between patient experience and staff wellbeing).

Our overall conclusion is that a generic framework can be applied to a wide range of conditions, treatments and settings; the Institute of Medicine or Picker frameworks are both broadly appropriate for 'what matters most' to patients in both acute and primary care sectors however further work is required to include acute mental health conditions.

### Key points for policy

- Policymakers can apply a generic framework of 'what matters' to patients to a wide range of clinical conditions in different sectors – including primary care
- Much of what has been measured to date in terms of patient experience has focused on functional aspects of service provision (access, waiting, food, noise etc). Policymakers should also attend to relational aspects of patient experience such as compassion, empathy, emotional support, and so on, which can only be collected from patients themselves
- Commissioners and service providers need to work together to capture patient experience data across organisational and service boundaries in order to improve access, transition and continuity of care

## References and information

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