Informing the development of NICE (National Institute for Health and Care Excellence) quality standards through secondary analysis of qualitative narrative interviews on patients' experiences

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

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Plain English summary

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Plain English summary

What do people with health problems value about their health care, and do different groups with different experiences have different priorities? We studied a modern archive of interviews with people who had experienced a heart attack, or had rheumatoid arthritis, diabetes or asthma. We identified eight consistently important aspects of care: involving the patient in decisions; a friendly and caring attitude; understanding how life is affected; seeing the same health professional; guidance through difficult conversations; taking time to explain; identifying further support; and efficiently sharing health information across services. We tested these in focus groups with people with learning disabilities, migrant workers, illegal-drug users (some of whom were also homeless), Irish Travellers, young men and older people. We found that they valued the same things but that their expectations about their health care varied considerably, in line with their experiences and health-care relationships.

We worked with the National Institute for Health and Care Excellence (NICE) to see if our findings (presented as a series of tailored reports) might inform their guidelines (which set out clear recommendations for treatment and care) and 'quality standards' (which identify priority areas for quality improvement). We observed their meetings and interviewed staff. One report contributed to a 'quality statement', but not all teams valued the reports. Reports based on interviews from a modern archive may be more likely to contribute to NICE products when there is little published evidence. Uncertainty remains about the status of (unpublished) analysis. The potential contribution of qualitative research needs to be better understood and recognised.

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