Developing and Implementing NICE Guidance on Patient Experience

Sophie Staniszewska, RCN Research Institute, University of Warwick, with Ian Bullock, Liz Avital, Norma O’Flynn, National Clinical Guidelines Centre, Royal College of Physicians

Introduction

Patient experience has become a key component of good quality care, reflecting a long tradition of research and policy initiatives, which have emphasised the importance of patient-centred care.

This article considers the research and policy context that have driven patient experience up the agenda, summarises the development of the Warwick Patient Experience Framework, before presenting the development and discussing the implementation of the NICE guidance and quality standards, which are published as Patient Experience in Adult NHS Services: Improving the Experience of Care for People Using Adult NHS Services.

The guidance and quality standards are the first of their type and as such represent a landmark in the history of patient experience initiatives, with potential international transferability to other health-care providers.

Background

The development of interest in patient experience has a long history, originating in the 1950’s and 1960’s in the United States, the UK and other countries. Early studies explored concepts such as patient satisfaction, less commonly used now to capture patient evaluations of care, with its limitations more fully understood. [1][2][3][4][5] The importance of patient perspectives was recognised as early as 1974 by the eminent epidemiologist Richard Doll, who emphasised the importance of evaluating the social acceptability of care, alongside evaluations of clinical effectiveness and economic efficiency. He stated ‘There is no point providing a health service that is effective and cheap, if no-one wants it,’ emphasising the importance of finding out what patients think about their care[6]. Early research gradually expanded into a significant body of international research, which now contains a range of approaches to evaluating patient experience[7]. As other papers in this Journal demonstrate, patient experience as a field of research and practice has truly come of age.

Although patient experience is recognised as important, conceptual and methodological challenges exist. A common problem is the normative effect, where patients evaluate their care positively, even when their care has been poor, leading to a possible underestimation of such care. There is still an important need to develop instruments, which are able to mitigate some of these social effects and so capture the full range of positive and negative evaluations of care.[8]

The need for guidance
The Department of Health asked the National Institute for Health and Clinical Excellence (NICE) to develop guidance on patient experience in the NHS, to add to a suite of existing and developing guidance, which primarily covers clinical topics. The ‘Patient Experience in Adult NHS Services: Improving the Experience of Care for People using Adult NHS services’ guidance was published in February 2012 (14). This guidance focuses on generic adult patient experience and is relevant for all people using adult NHS services (excluding mental health services – see guidance for service user experience in adult mental health) (15). The guidance differs from most other NICE work, as it is non population and non setting specific. The guidance will underpin future NICE Guidance by cross referral, and will only be augmented by topic specific recommendations where necessary. Collectively, the recommendations in the Guidance and Quality Standard aim to contribute to an individual, organisational and professional change in culture, attitudes, beliefs and practices at all levels, to truly create patient-centred care. It aims to achieve this by establishing clear standards for both clinicians and patients/carers to follow.

**Warwick Patient Experiences Framework**

The development of the guidance included a review of existing patient experience frameworks. It was not always clear how well patient experience frameworks were supported by research evidence, or the extent to which the frameworks reflect patient-identified experiences, as opposed to those identified by researchers and clinicians (14, 16). As a result, a scoping study was commissioned to develop a framework with very clear links to the evidence base, capturing generic themes and sub-themes of experiences (for example, different aspects of information provision). The framework was then tested for its validity and acceptability by the guideline development group, including six patient representatives.

The scoping study aimed to:

- Identify generic themes and sub-themes of patient experience in three clinical areas: cardiovascular disease, diabetes and cancer, all areas of significant disease burden.
- Use the themes and sub-themes identified in the three clinical areas to develop an overall generic patient experiences framework that has relevance for all patients.

NICE then produced an evidence table of generic themes and sub-themes for each clinical area. A thematic synthesis was carried out which drew the themes together into one overarching generic framework (16). It is important to recognise that this scoping study was a focused thematic qualitative overview, as a pragmatic review of the literature was needed given the timescale of guideline development. Some elements of systematic reviewing were adopted (for example, development of search strategies, identification of papers through inclusion and exclusion criteria and extraction of data from papers (Centre for Reviews and Dissemination Guidance 2009). The full methods and results are reported elsewhere (14,16). Table 1 shows the key dimensions developed for the Warwick Patient Experiences Framework.

**Table 1 The Warwick Patient Experiences Framework:**
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<table>
<thead>
<tr>
<th>Generic theme</th>
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<tbody>
<tr>
<td>Patient as active participant</td>
</tr>
<tr>
<td>Responsiveness of services - an individualised approach</td>
</tr>
<tr>
<td>Continuity of care and relationships</td>
</tr>
<tr>
<td>Lived experience</td>
</tr>
<tr>
<td>Communication</td>
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<tr>
<td>Information</td>
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<tr>
<td>Support</td>
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</tbody>
</table>

A full description of each dimension is included elsewhere (14,16). These themes provided an architecture around which the content of the patient experience guideline was developed. This is described more fully in the next section.

**NICE Guidance**

To develop the guidelines, NICE recruited a Guideline Development Group (GDG) consisting of healthcare professionals and patients. In developing the Patient Experiences Guidance, the GDG drew on a range of evidence and information in order to establish what is important to patients when considering their experience of healthcare (14). In addition to the scoping study which produced the Warwick Patient Experience Framework, key sources were:

1. Review of existing patient experience frameworks
2. Review of NHS survey results
3. Review of existing NICE recommendations related to patient experience
4. Systematic reviews of the literature on prioritised topic areas

Drawing on these sources, the GDG worked in collaboration to achieve consensus through the development of specific recommendations which took into account:

- Existing NICE recommendations related to patient experience in the area they wish to make generic recommendations
- Selected systematic literature reviews for specific interventions that may improve patient experience (14)

See Figure 1 for a graphical representation of the synthesis of evidence, taken from NICE Guidance.

**Figure 1 A summary of evidence sources for the development of the Patient Experiences Guidance**
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**Inputs**

- **Existing patient experience frameworks**
  - Systematic narrative review
- **Patient experience qualitative thematic review**
  - Qualitative review
  - Aims to identify key themes and subthemes
- **NHS surveys results**
  - What patients want
- **Existing NICE recommendations**
  - Systematic extraction of published NICE recommendations related to patient experience
  - Interpreted in context of patient experience framework and key issues
- **Literature reviews**
  - Focussed systematic reviews of published evidence
  - Clinical effectiveness and cost effectiveness
- **GDG**
  - Experience
  - Knowledge
  - Opinion
  - Consensus

**Outputs**

- **Patient experience themes**
  - High level categories describing the elements of patients experience
  - Based on key ‘themes’ identified
  - Used to guide development of recommendations and provide structure for outputs
- **Patient experience sub-themes**
  - Specific areas that are important in patient experience
  - Based on key ‘subthemes’
  - Used to guide where recommendations potentially need to be made

**Recommendations**

**Quality standards**
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Through a process of consensus, the GDG further refined the dimensions contained within the Warwick Patient Experience Framework to generate the final high level themes, which framed the Guidance to ensure it was structured in a way that focused on practical recommendations for professionals. The dimensions in the NICE Guidance are:

- Knowing the patient as an individual
- Essential requirements of care
- Tailoring healthcare services for each patient
- Continuity of care and relationships
- Enabling patients to actively participate in their care

Within each of these dimensions, a set of recommendations was developed.

A detailed description of each of these dimensions and their accompanying recommendations is contained in the Guidance (14). [http://guidance.nice.org.uk/CG138](http://guidance.nice.org.uk/CG138)

**NICE Quality Standard**

The quality standard defines best practice for the delivery of excellent patient experience. The intention is to deliver specific, concise statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care (14). By nature these statements are aspirational. The aim of this quality standard is to provide the NHS with clear commissioning guidance on the components of a good patient experience, embedding this as a key priority within the commissioning outcomes framework. The quality standard gives evidence-based statements for commissioners that provide the foundation for a cultural shift towards a truly patient-centred service.

**Table 2. NICE Quality Standard on Patient Experiences**

<table>
<thead>
<tr>
<th>No.</th>
<th>Quality statements</th>
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<tbody>
<tr>
<td>1</td>
<td>Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.</td>
</tr>
<tr>
<td>2</td>
<td>Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.</td>
</tr>
<tr>
<td>3</td>
<td>Patients are introduced to all healthcare professionals involved in their care, and are made aware of the roles and responsibilities of the members of the healthcare team.</td>
</tr>
<tr>
<td>4</td>
<td>Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.</td>
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</tbody>
</table>
Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.

Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.

Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.

Patients are made aware that they can ask for a second opinion.

Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.

Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.

Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.

Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.

Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.

Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.

### Importance of patient involvement in guideline development

The Patient and Public Involvement Programme (PPIP) at NICE provides advice and support to NICE on patient, carer and public involvement. The PPIP currently works with NICE to develop opportunities for involving patients, carers and members of the public across all NICE’s work programmes. The Patient Experience Guidance Development Group included six patient representatives, significantly more than usual in guideline development. While NICE processes were followed, some elements were adapted. Because of the particular focus of the guidance and the large number of patients involved, INVOLVE ways of working were
used to support the development of a collaborative and respectful working style, which valued all contributions to the process.

Implementing the NICE guidance on patient experience

The existence of NICE Guidance on patient experience does not automatically guarantee adoption and implementation. As Seers et al (17) state ‘despite significant investment, translating research in to healthcare decision making and practice remains a considerable challenge.’ Seers et al (17) point to numerous examples of attempts to implement evidence into practice; with mixed success.

Such uneven progress in implementing evidence in practice relates to the complexity of the process, which can involve change at many levels and depends on a range of factors that can influence uptake (18). The complexity of implementation can be even more challenging when, like the NICE Patient Experiences Guidance and Quality Standard, the guidance is complex and contains an extensive range of required changes, including those at individual, organisational and at professional level.

NICE Implementation Support

To support implementation, NICE has established a programme which works alongside guideline developers, the communications team and field based teams to ensure the guidance is disseminated throughout the NHS, local government and the wider community. The Implementation team also provide tools to support implementation of NICE Guidance. NICE produced a document which provides support for commissioners and others using the NICE guidance and quality standard on patient experience in adult NHS services (19). This provides information about patient experience, the policy context, why it is important, how it can be measured and how commissioners can incorporate it into all aspects of commissioning, including contract management, service delivery and incentive schemes.

NICE encourage commissioners to use the Patient Experience Guidance in a range of ways. For example, it can be used as one of the factors used to judge tenders for services (19). Commissioners could ask for evidence that demonstrates that the provider has systems in place for collecting and using information about patient experience. Commissioners could use some or all of the NICE guidance and quality statements in their contracts, and stipulate the frequency for gathering and reporting measures with providers (19). NICE also state that commissioners should audit local practice and can incentivise improvements to patient experience by using the CQUIN scheme. They should ensure that all CQUIN schemes have a focus on patient experience. Commissioners could also ensure that providers collect information about patient experience across the whole service pathway, from referral to post-discharge. Commissioners should also describe how to manage examples of poor patient experience. Providers and commissioners ought to be made aware of any problems so that they can take action to improve services (19).

Such support provides practical advice for embedding the NICE Guidance. Any commissioner or provider involved in embedding the NICE Guidance within their
organisation must draw on the implementation evidence base in developing their strategy, in recognition of the complexity involved in changing practice (17, 20-23). One way forward would be to draw on existing implementation frameworks to provide a context for thinking through key elements of an implementation strategy. A range of implementation frameworks exist (20). One of the key frameworks is the Promoting Action on Research Implementation in Health Services (PARIHS) framework, which demonstrates the complex interplay of a number of factors that influence the successful implementation of evidence in practice (20-23). Successful implementation is represented as a function of the nature of evidence being implemented, the context in which implementation takes place, and the way in which that process is facilitated. The PARIHS framework has been ‘used by others as a heuristic to guide implementation efforts at the point of care delivery’ (17) and so has important applicability for the NICE Patient Experiences Guidance. Ideally, the PARIHS framework would be used within a research study to test different ways of implementing the NICE Patient Experiences Guidance, order to identify the most effective forms of implementation. In the absence of such formal research studies, the core thinking which underpins the PARIHS framework may be useful for practitioners, commissioners and providers when they plan their implementation strategy. Even being aware of the three key concepts of the PARIHS framework, evidence, context and facilitation could provide an initial conceptual structure to underpin the development of an implementation strategy.

Collaborative patient and public involvement in implementation

The NICE Patient Experience Guidance was developed on the basis of collaborative involvement which aims to ensure true partnership and equal power in discussions and decision-making at a local level, ensuring everyone has the opportunity to shape thinking and debate. This approach can also be used in the implementation of research evidence or guidance. We would propose a collaborative form of patient and public involvement is used in the development of implementation strategies locally. Patients and patient organisations have a vital role to play in developing such strategies and in implementing them in a range of ways, including at an individual level when they have a consultation with their doctor or nurse.

Starting the debate

We would also like to use this opportunity to encourage debate among the health community, including patients and patient organisations, about the most effective ways of implementing the NICE Patient Experience Guidance into practice. There has already been some discussion at events and conferences, which has focused on implementation of NICE Patient Experience Guidance (Measuring and Monitoring Patient Experience, Healthcare Events, March 2012). We hope this article generates further debate, drawing on practitioner and patient knowledge about effective forms of implementation. We also hope it highlights the need for research to better understand what forms of implementation work, for whom, why and in what circumstances, when implementing the Patient Experience Guidance.

An opportunity for dialogue on ‘how best to implement the NICE Patient Experience Guidance’ will be set up with the NHSIII [to be confirmed].
Conclusions

The NICE Patient Experience Guidance and Quality Standard provides a unique opportunity to implement cultural, attitudinal and behavioural changes in health-care provision, in order to provide the best possible experience for all patients. We hope to encourage others to contribute to the debate about the most effective forms of implementation and to work together to create truly patient-centred care.

References