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The Warwick Patient Experiences Framework: patient-based evidence in clinical guidelines

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Abstract

Objective. This paper presents the development of the Warwick Patient Experiences Framework (WaPEF) and describes how it informed the development of the NICE Guidance and Quality Standard, 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services'.

Design. The WaPEF was developed using a thematic qualitative overview that utilized a systematic review approach. Search strategies were developed, inclusion and exclusion criteria developed and data extracted from papers.

Results. The WaPEF identifies seven key generic themes that are important to a high-quality patient experience: patient as active participant, responsiveness of services, an individualized approach, lived experience, continuity of care and relationships, communication, information and support.

Conclusions. The WaPEF is the first patient experiences framework with an explicit link to an underpinning patient evidence base, linking themes and sub-themes with specific references. The WaPEF informed the structure and content of the NICE Patient Experiences Guidance. The guidance, published in February 2012, will form a key part of the NHS Outcomes Framework in the UK for the future evaluation of health and social care. The proposed framework could be adapted to other country contexts and settings.

Keywords: patient experiences, clinical guidelines, quality, NICE, Warwick Patient Experiences Framework

Introduction

The National Institute for Health and Clinical Excellence (NICE) produces clinical guidelines, quality standards, public health and health technology appraisal guidance for the National Health Services in the UK. NICE commissioned the National Clinical Guideline Centre (NCGC) to produce clinical guidance and a quality standard on patient experience in adult NHS services. The evidence utilized in the production of clinical guidelines and quality standards predominantly consists of clinical and economic data, although the Patient Experiences Guidance drew heavily on patient-based evidence [1] and NICE will be considering future opportunities for using this form of evidence. Guidelines have an important role in influencing the provision of high-quality, effective and appropriate health care. A recent editorial [2] highlighted the Institute of Medicine criteria for guidelines [3], arguing that

trustworthy guidelines are key to achieving improvements in health quality and outcomes.

The acknowledgement of the importance of patient experiences reflects the philosophy proposed by the epidemiologist Richard Doll [4]. Doll advocated that health care should be evaluated according to three criteria, clinical effectiveness, economic efficiency and social acceptability. Building on Doll's work, a broader term has more recently been proposed, namely 'patient-based evidence [1]'. This term encompasses the diversity of information that patients provide in evaluating different aspects of care, including patient narratives, data on health-related quality of life (which is sometimes already included in NICE assessments in the form of quality-adjusted life years) and patient experiences survey data. The conceptualization of evidence proposed by Doll [4], Staniszewska et al. [1] and Rycroft-Malone et al. [5] provides a strong case for including patient-based evidence when developing clinical

guidelines that aim to improve the effectiveness, acceptability and appropriateness of care. As Doll [4] argued, 'there is no point providing a health service that is clinically effective and economically efficient, but no-one wants'.
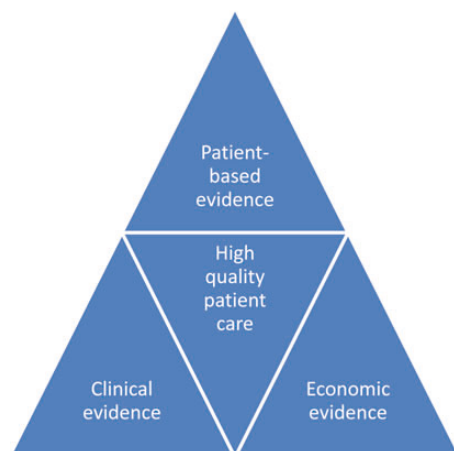
Conceptualising evidence for evaluating health care

While clinical and economic evidence is well developed conceptually and methodologically, patient-based evidence as a concept has received much less attention. There are fewer agreed ways in which such data can be integrated alongside clinical and economic evidence in the evaluation of care and more ambiguity about its role and contribution. There is an important need for such conceptual and methodological clarity in the next decade to ensure full synthesis of all three evidence components, clinical, economic and patient-based evidence. Some progress has already been made. For example, studies have started to explore the integration of qualitative experiences data with systematic review data [6]. The POPPY study provides an example of the way systematic review data have been synthesized with qualitative experiences data, collaboratively with patients, to develop acceptable, appropriate and effective models of care (Fig. 1) [7].

This focus on patient-based evidence reflects the recent White Paper on the organization of health care in the UK 'Equity and Excellence: Liberating the NHS' [8]. This emphasizes the importance of patient experiences in the evaluation of care and states that patient experiences surveys are not used widely enough at present and plans for an expansion of their use in the future.

Commissioning of the Warwick Patient Experiences Framework

NICE referred as a clinical guideline topic 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services,' to the National Clinical Guidelines Centre (NCGC) [9]. The intention was to highlight the issues of importance to patients using health care services in a guideline for those who deliver NHS services. Uncertainty about the robustness of published frameworks, explained in the next section, determined the need for a qualitative evidence synthesis that would provide themes that would shape the guidance. The NCGC commissioned a scoping study to be undertaken by the Royal College of Nursing Research Institute at the University of Warwick, which in collaboration with the NCGC identified the existence of qualitative evidence of patient experience in adult cancer, diabetes and cardiovascular disease populations. It was acknowledged *a priori* that findings would be used to inform and underpin the development of guidance recommendations, from which a set of quality standards would be synthesized to guide practice in the NHS [10]. This paper reports the findings of a scoping study that developed the Warwick Patient Experiences Framework (WaPEF) and describes the integration of the WaPEF into the guidance development process.

Patient experiences frameworks

A number of generic frameworks that aim to capture key dimensions of patient experiences already exist, including Institute of Medicine framework and the Picker principles (developed from the work of Gertis and colleagues, 11), Institute of Medicine framework, Picker principles and the National Health Council (2004) and International Alliance Patients' Organisations [11–16]. The NCGC undertook a review of these frameworks as part of the development of the Patient Experiences Guidance. The frameworks presented provided a useful overview of important patient experiences themes, with significant overlaps. They were helpful in demonstrating the potential range of experience dimensions. However, there were a number of limitations including uncertainty about how the dimensions had been extracted from a wide and diverse body of research, the extent to which patients and the public had been collaboratively involved in developing or selecting the dimensions and the extent to which the dimensions reflected patient-identified experiences, as opposed to those identified by researchers and clinicians. In addition, their utility in a UK context was questionable. Ideally the frameworks should have been based on evidence that considered preventative and community care settings and included areas where patient education and self-management are important. However, this was difficult to judge with available evidence.

Due to these uncertainties, a framework was developed to capture generic dimensions of patient experiences and to provide a strong evidence base for each theme and sub-theme by linking each back to the originating paper with detailed evidence tables. Patient experiences in cardiovascular disease, diabetes and cancer were chosen as the focus. These are conditions associated with significant disease burden, which include chronic and acute patients likely to have a wide range of health care experiences. The NHS also published a new patient experiences framework on the same day as the NICE Guidance in February 2012. The robustness of the evidence base underpinning this parallel framework was not reviewed as part of this study. https://www.gov.uk/government/news/a-framework-for-nhs-patient-experience.

Figure 1 Conceptualizing evidence for evaluating health care.

Methods

The WaPEF was developed through a search of existing literature, selection of papers, data extraction, development of themes and sub-themes and development of the WaPEF.

The patient experiences literature is vast and complex. It was not possible to include all potentially relevant studies within the available timescale. Instead the scoping study sampled a range of patient experiences studies, with the intention of reaching a level of data saturation, in terms of the generic themes being identified for each group. Data saturation describes the point at which no new generic themes are being identified from studies [17]. It is not an absolute measurement but a judgement made by the researcher. The intention was to use this concept of data saturation to identify all relevant generic themes from the evidence reviewed.

Search strategy

The search strategies were developed and refined by an information specialist for each of the following key electronic databases: Medline, Cinahl, Assia, Embase and Psychinfo. Additional papers were identified from reference lists and specialist journals. Additional searches were carried out on PubMed and UK PubMed Central.

Inclusion criteria. Research papers that focus on exploring or identifying patient experiences in adult services in three clinical areas: cardiovascular disease, diabetes and cancer. English language papers. 'Search dates': 1995–2011.

Exclusion criteria. Papers that primarily focus on interventions to enhance patient experiences. Papers that report development, testing or application of patient-reported outcome measures. Opinion articles or editorials about patient experience. Non-English language papers. Children's experiences. Carer's experiences. Grey literature.

Challenges in developing search strategies

In undertaking this study, a number of challenges were identified with the development of search strategies. A key difficulty was the lack of MESH headings that relate to patient experiences, necessitating the use of free text searching, which can rely on poorly defined terminology often used inconsistently across studies. The necessary use of many potentially relevant keywords initially produced a huge number of irrelevant hits that required refinement. The search strategy was then adapted for use with other databases. Keywords used in developing the search strategies are included in Appendix.

Selection of papers

Titles and abstracts were read for relevance, and papers judged to meet inclusion criteria were included in the study. The research team discussed ambiguous papers, and a decision was reached about their inclusion. Both qualitative and quantitative papers were included. A number of key steps were followed in the identification and analysis of themes.

Data extraction of sub-themes and themes

Each paper that met the inclusion criteria was read in full by one researcher. As each paper was read, sub-themes were identified. A sub-theme was defined as an aspect of patient experience, for example, 'patients experiencing poor information provision when making decisions'. Each theme was interpreted according to the way in which the original paper reported it. The researchers' interpretation focused on linking the sub-themes to a main theme—for example, a sub-theme focusing on communication style was interpreted by the research team as belonging to the broader communication theme. These analytical interpretations were made by each researcher and then presented to the team and discussed, to ensure consistency in the ways sub-themes were grouped into main themes. Although both qualitative and quantitative papers were included, qualitative papers formed the majority of studies selected because of the depth of data they provided for a scoping study. In contrast, quantitative papers rarely provided the required depth. Quantitative papers frequently corroborated the qualitative papers thematically but rarely offered new insights into key themes.

In a small number of cases, the same or very similar sub-themes would relate to more than one generic theme. For example, in the 'responsiveness of services—an individualised approach' theme, a corresponding sub-theme was 'being known as a person not as a number'. A similar sub-theme appeared under 'continuity of care and relationships,' which was 'needing to be seen as a person within the healthcare system'. In the theme communication, the sub-theme 'needing to be seen as a person' was included. Researchers tried to maintain the integrity of the original interpretations. These themes and sub-themes were identified by each researcher reading a paper, then recorded using a data extraction form, which provided a structured way of organizing the information and an audit trail for the construction of linkages between sub-themes and evolving generic themes. The inductive approach meant researchers focused on the data presented in the paper and built up their condition-specific frameworks using the sub-theme data to build the themes. All possible themes relating to any aspect of patient experiences were identified. A key challenge in developing the themes and sub-themes was the varying level of detail provided in papers when describing sub-themes. Researchers undertook this analysis individually, but ambiguous or conflicting sub-themes and their relationships to generic themes were discussed within the research team. The research team did not use a formal quality assessment tool to assess the quality of each selected paper, but each study was appraised for flaws that might justify its exclusion. Finally, a summary evidence table of generic themes and underpinning sub-themes was produced for each clinical area, with the references listed alongside each sub-theme, reported in the NICE Guidance.

Developing the overall patient experiences framework

To develop the overall generic experiences framework and to manage the process of synthesizing data extracted from

studies, the next stage utilized the widely-used Institute of Medicine (IoM) [18] framework as a model against which to compare and contrast the themes identified in this study. The IoM framework includes the themes of compassion, empathy and responsiveness, co-ordination and integration, information, communication and education, physical comfort, emotional support, relieving fear and anxiety and involvement of family and friends. Each element of the IoM framework was examined for each clinical area, to review its validity, that is, whether there is evidence to support its inclusion in an overall framework. Each dimension of the IoM framework was divided when appropriate. For example, information and communication were considered separately rather than amalgamating them into one category, in order to explore whether they should stand alone as themes. Once this process was complete, the research team then examined what generic themes might be missing from the IoM framework. The themes appear in the appendix to the NICE Guidance with the detailed evidence tables. Patient experiences varied across and within each clinical area.

Results

Generic framework of patient experiences

Analysis of IoM framework. The IoM framework provided a useful starting point for the analysis of the themes and sub-themes identified in this study as it provided a point of comparison from which evidence-based revisions could be made. Table 1 lists the themes in the IoM framework and provides a narrative commentary of how the IoM themes were adjusted and developed in the WaPEF. Table 2 lists the themes in the Warwick Framework with a narrative description of each theme.

An important difference between the IoM framework and the framework developed from this scoping study was a consideration of the role of patients as potentially active participants in their care and the importance of lived experience as underpinning health service experiences.

Utilizing the WaPEF in the guidance development process

The WaPEF supported and informed the NICE development process in a number of ways at different stages.

Providing an underpinning philosophy. The WaPEF includes seven dimensions of patient experiences. Taken together, the descriptions of the themes provided a summary of the philosophy or essence of the WaPEF, which focuses on potentially active patients, who have an important role in managing their health care experiences (if this is what they would like to do) and whose individuality should be recognized within a system established to provide health care. This tacit philosophy imbued the Guideline Development Group (GDG) discussions from the outset and helped shape some of the recommendations and accompanying guideline wording, for example, by ensuring active language was used to emphasize participation, rather than passive acceptance.

Structuring the guidance. Patient experiences of health care are complex and wide-ranging. The WaPEFs' seven generic dimensions and the accompanying descriptions of the content of each dimension provided a strong 'architecture' for the GDG discussions about what should be included in the Patient Experiences Guidance. Each dimension was discussed in turn and its relevance and utility considered by the Guidance Group. While most generic themes were supported as relevant by the GDG, some changes were made as discussion progressed to ensure the Guidance focused on practice-based recommendations. The guidance group decided that the term 'lived experience' was too technical and research orientated. This theme was renamed for the purpose of developing recommendations and became 'knowing the patient as an individual'. The theme lived experience was kept

Table 1 An analysis of the IoM framework

IoM theme	Narrative commentary
Compassion, empathy and responsiveness	Compassion and empathy were both important themes but appeared in more subtle forms within a number of wider generic themes, e.g. communication. Responsiveness emerged as a generic theme but was focused on the responsiveness of the service and the need for an individualized approach.
Co-ordination and integration	These themes were important but fitted more appropriately into the wider generic themes of continuity of care and responsiveness.
Information, communication and education	Information and communication emerged as two key themes but were separated to reflect the different content of the sub-themes identified. Education appeared in a number of the generic themes in different ways, including within support and information.
Physical comfort	Physical comfort was important but appeared in other more substantive generic themes, including responsiveness and lived experience.
Emotional support, relieving fear and anxiety	Emotional support was included in a much larger category of support. Elements of fear and anxiety were more subtle and appeared as part of a broader lived experience.
Involvement of family and friends	The role of family and friends was important and appeared in broader themes of lived experience and support.

Table 2 The Warwick Patient Experiences Framework

Generic theme	Narrative description
Patient as active participant	Reflects the role of patients as potential active participants in their health care, co-creators and co-managers of their health and use of services; responsible for self-care, participators in health care, shared decision-makers, self-managers, risk managers and life-style managers. Confidence in self-management is critical. Associated with issues of power and control.
Responsiveness of services—an individualized approach	Needing to be seen as a person within the health care system. The responsiveness of health services in recognizing the individual and tailoring services to respond to the needs, preferences and values of patients, taking into account both shared requirements and individual characteristics (such as individuals' expectations of service cultural background, gender, subtle issues such as preferences for humour). Includes how well clinical needs are met (e.g. pain management) and evaluation of how well services perform from a patient perspective.
Lived experience	The recognition that individuals are living with their condition and experiencing it in a unique way, that family and broader life need to be taken into account and that all of these aspects of lived experience can affect self-care. Taking into account individual physical needs and cognitive needs because of condition. Everyday experiences, hopes, expectations, future uncertainty, feelings of loss, feelings of being morally judged and feelings of blame. Some of these experiences originate 'outside' of the health care system but are brought with the patient into the health system; other experiences may be affected by attitudes and expectations of health professionals.
Continuity of care and relationships	Initiating contact with services, interpretation of symptoms, co-ordination, access (barriers to), and availability of services, responsiveness of services and feelings of abandonment (when treatment ends or support is not made available). Being known as a person rather than 'a number'. Trust in health care professional built up over time. Recognition/questioning of expertise of health care professional. Respect, including respect for patient's expertise. Partnership in decision-making. Issues of power and control.
Communication	Needing to be seen as an individual; communication style and format (e.g. over telephone or in person); skills and characteristics of health care professional; body language (which can convey different information from that spoken); two-way communication and shared decision-making; compassion, empathy; the importance of the set-up of consultation (e.g. appropriate time for questions, appropriate physical environment and number of peoples present). Listening and paying attention to the patient. Enabling questions and providing answers.
Information	Information to enable self-care and active participation in health care, importance of information in shared decision-making, tailored information to suit the individual, patient wanting/not wanting information and timely information. Sources of information, including outside the health service (e.g. peer-support, internet). Quality of information. Sources of further information and support. Developing knowledge and understanding, and making sense of one's health.
Support	Different preferences for support: Support for self-care and individual coping strategies. Education. Need for emotional support, and need for hope. Responsiveness of health care professionals to individual support needs (may vary according to gender, age and ethnicity). Importance of peer-support, groups and voluntary organizations. Practical support. Family and friends support. Role of advocacy. Feeling over-protected, not wanting to be a burden.

intact within this paper to reflect the results of the scoping study of evidence on which the WaPEF is based and demonstrates how the consensus process can develop the underlying evidence.

Comparison with other existing frameworks. As the WaPEF provides strong linkages to the underlying evidence base, with evidence tables linking themes and sub-themes to specific papers, it was used by the GDG as a comparator for other existing frameworks, in order to compare and contrast the themes across the frameworks. This helped to confirm the importance of the WaPEF dimensions in underpinning the

NICE Guidance and added confidence that GDG discussions were focusing on the appropriate dimensions of patient experience throughout the process.

Developing recommendations

The generic dimensions of the WaPEF provided an architecture and strong rationale for developing recommendations in specific areas. For example, the importance of the patient as an active participant in their care was a key generic theme. It included a number of sub-themes such as the role of patients

as potential active participants in their health care, co-creators and co-managers of their health and use of services; responsible for self-care, participators in health care, shared decision-makers, self-managers, risk managers and life-style managers. Both the generic and the sub-themes were utilized for developing specific recommendations through GDG discussion, and in conjunction with evidence reviews provided a robust basis for the development of recommendations. For example, NICE recommendations within the theme of the patient as an active participant were as follows:

- offering support to the patient when considering options. Using the principles of shared decision-making:
- ensuring that the patient is aware of the options available and explain the risks, benefits and consequences of these
- checking if the patient understands the information and
- encouraging the patient to clarify what is important to them and check if their choice is consistent with this [9].

Grouping existing recommendations from previous NICE guidelines relevant to patient experience. In providing the architecture for the guidance development, the WaPEF also provided a rationale for the identification of other NICE recommendations from previous guidelines, which were relevant to the Patient Experience Guidance. Thorough recommendations were discussed by the GDG and relevant ones utilized within the Patient Experience Guidance.

Identifying additional key areas. Utilizing the WaPEF to structure the GDG discussion also provided an opportunity to identify other areas that had not emerged as strongly in the scoping study. While basic needs such as diet and hydration had emerged in the scoping study, they did not become key generic themes. However, the GDG felt these should be included as key parts of the NICE Guidance as part of the 'essential requirements of care' theme.

Discussion

This paper has described the development and use of the WaPEF in the development of the NICE guidance and quality standards 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. Patient experience in generic terms'.[9] This NICE guidance and quality standards document could be utilized in the development of future guidelines that focus on specific clinical areas and develop condition-specific recommendations for particular patient groups.

The use of patient-based evidence in guideline development is still a relatively 'young' area, conceptually and methodologically. It will require significant enhancement in the future. NICE is actively exploring this.

The WaPEF has potential utility for international use, with additional work to ensure conceptual equivalence and the potential addition of country- or population-specific components. The WaPEF summarizes a complex patient experiences evidence base. The narrative description of each theme in Table 2 is thus illustrative, rather than exhaustive with further detail contained in the appendices provided within the main

NICE Guidance evidence tables. The themes and sub-themes contained in the generic framework are complex, and many connections exist between them. Themes such as 'responsiveness of service—an individualised approach' cut across other themes. Patients value health care professionals' consideration of their individuality and the unique way in which they experience their condition in the context of their own lives. Patients' values, beliefs and circumstances all inform their expectations of, as well as their needs for, services. Continuity of care and the establishment of trusting, empathetic and reliable relationships with competent and insightful health care professionals are key to patients receiving such individually orientated services and enable patients to become active participants in their own care, in partnership with health care professionals. The framework also suggests that patients' experiences of health services and their experiences of living with the condition are often closely linked to their interpretations of how effectively the service meets their needs.

Content validity refers to a judgement about whether all relevant or important content or domains have been included in an instrument [19]. While an assessment of the content validity of the WaPEF was not included in the scoping study, it has subsequently undergone extensive scrutiny by the Guidance Development Group, which included six patient representatives (in addition to clinicians and researchers) and a comparison with other existing patient experiences frameworks through the work undertaken as part of guidance development by the NCGC. The GDG group judged the framework to have greater content validity than the other frameworks when a comparison was undertaken, particularly for ambulatory care and chronic conditions, possibly because it included more recent studies, and chronic conditions, where patients had varied interaction with health services.

Limitations

While the WaPEF is a generic framework, only three clinical areas were included in the scoping study. Other patient experience themes may have relevance to other clinical areas that have not been included. The extensive scrutiny provided by the GDG offers some assurance of content validity, but it is not comprehensive. The future use of WaPEF internationally should incorporate separate reviews of themes and sub-themes in particular country settings or populations. WaPEF has a particular relevance for the UK setting, although some of the studies were international. Other organizations and countries considering using the WaPEF internationally should conduct an assessment of the conceptual equivalence of the content of the model for a particular country setting. In addition, future studies should include a more rigorous quality assessment of the studies included in the evidence base.

Conclusions

The WaPEF represents a synthesis of a wide and complex evidence base, building on the IoM framework, but changing and adding important themes that emerged in this scoping study.

It is the first international patient experiences framework with an explicit patient experiences evidence base that links themes and sub-themes to the underpinning papers so explicitly. The generic themes included in this framework are purposefully broad, in order to capture the complexity of patient experiences that lies beneath them. The WaPEF worked well in informing the structure and content of the NICE Patient Experiences Guidance. It provides future international guideline developers with a model and an approach for integrating patient-based evidence into the development of clinical guidelines and a suggestion for considering country or population-specific themes and sub-themes. This approach will mean that the three key forms of data relevant to evaluating health care, clinical, economic and patient-based evidence start to become more fully integrated in the consensus process, thus addressing the challenge Professor Richard Doll [4] posed: to provide care that people want, as well as care that is clinically effective and economically efficient.

Funding

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Appendix

Key search terms

(Table A1)

Table A1

Patient
Expectations
Preference
Need
Attitude
View
Opinion
Choice
Satisfaction
Choice
Information