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**Title:** Developing a roadmap for cancer patient experience initiatives in Saudi Arabia: lessons from health care settings in the United States and England

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**Abstract:**

Patient experience is now widely used as a measure of healthcare quality. In Saudi Arabia, the public healthcare system is being transformed at a national level to improve the health care services provided. Patient experience assessment initiatives have started across many care settings including cancer care. Gathering data on cancer patients' experiences of care has been introduced nationally in the United States (US) and England and continued to be used for over two decades. This resulted in a considerable amount of literature on what patient experience is, how to measure it, and how it can be applied within cancer care settings. In this paper we aim to set out lessons learned from the US and England in assessing and using cancer patient experience data in order to inform current patient experience initiatives in Saudi Arabia. These lessons include how to define patient experience, explain its different aspects and their measurement, and maximize both the value and use of the data gathered. Several methodological and implementation challenges have been found in the US and English literature that need to be taken into account in order to meet the patient experience goals in Saudi Arabia. These include developing specific patient experience definition and its different aspects, using the appropriate data collection methods, gathering representative patient perspectives, and overcoming resistance among health professionals.

**Keywords:** Patient experience, cancer, Saudi Arabia

## Introduction:

Patient experience has emerged over many years as an important research area and is now widely considered as an aspect of care quality alongside patients safety and clinical effectiveness[1–3]. It is conceptualized as the full range of patients’ interactions with the health workforce and health care system[4] and as part of a process of moving towards patient-centered care. A considerable international literature on patient experience has grown in response to the increasing emphasis on, and measurement of, patients’ perspectives on healthcare systems[1, 5, 6]. Recent research has now linked better patient experience to improved clinical effectiveness, patient safety and disease outcome in many care settings including cancer.[7, 8] Presently, patient experience measures are being used widely in cancer care within many international health care systems [6, 9–12].

Cancer is a major public health problem in Saudi Arabia. The health care system in Saudi Arabia has been given a high priority by the government in the last three decades. This is shown through infrastructure building, offering education and training opportunities for health professionals to travel to Asia, North America and Europe, and the implementation of effective care policies and strategies [13]. Specialized oncology care settings are currently located in big cities where about 80% of the Saudi population live, with oncology care recently being established in other less populated areas [14]. The Ministry of Health (MOH)- the national healthcare regulator and provider - has also recently introduced many initiatives to gradually transform and promote the health sector as part of both the 2020 National Transformation Program and Saudi Vision 2030[15]. The Patient Experience Measurement Program (PEMP) was introduced as part of these initiatives to improve patient experience and care quality across the national healthcare system. Health care institutions such as King Fahad Medical City (KFMC) and King Faisal Specialist Hospital and Research Centre (KFSH&RC), have recently introduced a patient experience survey to measure and improve their healthcare system using a modified version of the US Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey [16]. A specific cancer patient experience survey has also been developed to assess cancer patients’ experiences at the National Guard Health affairs Health system in Riyadh [17].

Cancer patient experience as a concept has been used in the US and England health systems for over two decades. This has allowed the development of research and improvement initiatives to better use the data gathered to assess, monitor and improve the quality of cancer care. In this paper, we aim to introduce some important lessons and practices in assessing cancer patients that were learned in the US and England to develop a road map for future patient experience initiatives in Saudi Arabia.

### History and definition of patient experience:

Improvements in scientific, clinical and epidemiological knowledge in recent decades along with advances in healthcare technology have offered a significant opportunity to deliver effective patient-centered care. This shift in the focus of the healthcare system has resulted in increasing attempts to gather patients' feedback with the aim of understanding their experiences[5]. Efforts to investigate and understand patient's experiences are not new and can be traced back to the 1990s when Cleary and others in the United States introduced the methodology with the Picker Institute for assessing patients' experiences using patient surveys[5]. In the US, CAHPS was introduced in 1995 in response to concerns about the measurements of quality of health in US healthcare system [18]. Since then, it has been widely used across US healthcare settings to assess patients' experiences of health care plans with a modified version developed for cancer care [19]. In England, two national surveys of cancer patient experience were conducted in collaboration with Picker Europe between 1999-2004 [20] which led to several improvements in some aspects of patients' experiences [20, 21]. The National Cancer Patient Experience Survey (CPES) is an annual English survey since 2010 that invites patients to report their experiences of NHS cancer care [9].

Previous literature has identified a large confusion and overlap between the concept of patient experience and that of patient satisfaction. Although the two concepts are closely linked, they differ in their purpose and measurement. Patient satisfaction is generally accepted as referring to whether patients' expectations are met, while patient experience refers to the interaction between patients and the healthcare system and what actually happened [4, 22]. Patient experience definitions, however, vary widely from one healthcare system to another with no unique or common definition [4]. For example, The Agency for Healthcare Research and Quality in the US defines patient experience as "the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities" [22]. The National Health Services (NHS) in England, on the other hand, defines patient experience as "what the process of receiving care feels like for the patient, their family and carers" [23]. The first step towards improving cancer patients' experiences in Saudi Arabia will be to come up with a definition of patient experience in relation to its specific health system structure and expectations of its patients. A standardized definition that consists of a set of standards and measurable indicators would identify the essential components of patient experience and its boundaries in the Saudi healthcare system [24]. While there is no current study on patients' experiences in Saudi, previous published international definitions can be assessed for validation such

as those by Wolf and colleagues [4], The Agency for Healthcare Research and Quality in the US [22], or by the NHS [23]. These can then be used to tailor patient experience initiatives to customize a set of tools rather than use off-the-shelf tools developed for different national healthcare systems.

### **Cancer patient experience aspects**

There are several dimensions of patients' experiences of healthcare introduced by the Institute of Medicine (IOM), and the NHS in England (Table 1) [2, 23]. These aspects have also been used in systematic reviews focused on cancer patients' experiences [7, 8, 19]. For example, Saunders and others investigated the available instruments used to measure cancer patients' experiences of health care, and their review revealed a lack of studies measuring cancer patient experience in systematic and consistent ways [25]. Another scoping review of cancer patient experience focusing on the aspects used in CAHPS to measure patient experience summarized the literature in this subject and identified possible future directions for research including the relationships between patients' experiences, their healthcare utilizations, and their subsequent care outcomes [19]. The aspects of patient experience investigated vary widely by health system structure and location. Cancer patient experience initiatives should distinguish between these concepts, to evaluate and develop aspects of care that are relevant to patients' expectations and their health system, and validate these aspects on a wide range of populations.

### **Patient experience measurements**

Cancer patient experience data can be gathered using several methods which may be broadly categorized into quantitative and qualitative measures. The first include audit data, and ward level and national surveys, while the second include small focus groups or interviews, online comments, and formal or informal comments in national patient surveys [1, 19, 26, 27]. However, each method has its advantages and disadvantages. For example, focus group or ward-level survey can be useful to assess patient experience within particular cancer care services or specific clinics, but limits the reporting of experiences for other aspects of cancer care journey [1]. Post-discharge surveys on the other hand can cover these aspects but may be limited with respect to their representation of poor prognosis patients who might go to palliative care or die before receiving the survey [28–30]. Determining the available budget, staff resources, purpose, and the use of gathered data are important aspects to consider before steps are made to collect patient experience data so that their value and use is maximized.

**Table 1:** Patient experience aspects in Institute of Medicine (IOM), and NHS reports

IOM aspects of patient centred care [2]	NHS England patient experience aspects [23]
Compassion, empathy and responsiveness to needs, values and expressed preferences Co-ordination and integration Information, communication and education Physical comfort Emotional support, relieving fear and anxiety Involvement of family and friends	Choice of provider Access and waiting times Confidence and trust in health professionals Information and communication Involvement in treatment decisions Availability of staff when needed Hygiene, cleanliness and handwashing Food and physical environment Access to records and medical communications Being treated with dignity and respect Overall satisfaction

### Variations in cancer patients' experiences

Cancer populations in different areas vary by many demographic aspects including gender, age, and socioeconomic status. In addition, cancer patients differ in terms of their care pathways, which involve varying organizational and treatment factors and so affect their experiences of care. Patients' experiences should therefore be assessed meaningfully by all population subgroups in order to highlight actionable items, improve cancer care, and prioritise care policies [27, 31]. Variations in experiences with cancer care have been documented for patients from different socioeconomic groups, those with different cancer types, and different patterns of health services utilization. For example, published studies from US and England showed that, overall younger patients report less positive experience than older ones [32, 33], and females report less positive experiences than males [32]. Moreover, non-white patients have been shown to report less positive experiences than those from the white population [32–35], and patients diagnosed with advanced stage disease or through emergency presentation are less positive than others [36].

### Data linkage of cancer patients' experiences

Cancer patient experience data sets in US and England have each been recently been linked to patient demographic and disease characteristics at cancer registry level to maximize their value [37]. Several years of collated surveys data for CAHPS in US and CPES in England and have recently been linked to population-based cancer registry data. As a translated version of CAPHS is being used in Saudi Arabia

to assess patients' experiences of healthcare, efforts to link patient experience data with demographic and disease characteristics data can meaningfully help to understand patient experience and prioritise policies as well as allow for international comparisons.

**Table 2:** Comparison between the US and English cancer patient experience data linkage with national registry datasets

<b>Variables</b>	<b>US linkage [16] (n= 150,750)</b>	<b>English linkage [37] (n= 233,445)</b>
Data source	CHAPS, SEER, and Medicare	CPES and NCRAS
Time period	CAHPS (1998–2010) SEER (1973+) Medicare (2002–2011)	2010– 2017
Patient age	>= 65 years	>= 16 years
Survey methods	By mail (telephone follow-up for non-respondents)	By mail (two reminders for non-respondents)
Response rate	71% (49% - 82%)	67% (64% - 68%)
Inclusion/linkage method	US linkage criteria included: being cancer patient, resident in SEER region, and enrolled in Medicare. Matching percentage was 24%	CPES was sent only to cancer patients and linked with NCRAS. Linkage matching percentage was 80-85%
Linkage Identifier	A unique identifier across all datasets	NHS number and ICD-10 code 4 digits and 3 digits
Survey themes	Getting needed care Getting care quickly Doctor communication Health plan customer service Global ratings of personal doctor, specialists, Patient characteristics overall healthcare and health plan	Seeing the general practitioner, Diagnostic tests Deciding best treatment Clinical Nurse Specialist Support for cancer patients Communication Home care & support Hospital and outpatient care Overall NHS care

**Abbreviation:** ICD-10 = The 10th revision of the International Statistical Classification of Diseases and Related Health Problems; CPES = The National Cancer Patient Experience Survey; CHAPS = The Consumer Assessment of Healthcare Providers and Systems; NCRAS = The National Cancer Registration and Analysis Service in England; SEER = The Surveillance, Epidemiology, and End Results in US; GP = General practitioner.

### Future of cancer patient experience in Saudi Arabia beyond cancer care:

The healthcare system in Saudi Arabia is undergoing a major transformation with the aim of improving access to care, care quality, as well as containing cost. Excellence in patient experience is emerging as a strategic target for healthcare organizations [38]. Consumers’ voices now play a major role in defining care policies, leadership actions, grant funding, and care budgeting [38, 39]. There is strong evidence on the effectiveness of patients and policy makers co-designing healthcare transformations [40]. In Saudi Arabia, measuring patients’ experiences is important during this transformational era at both national and local levels as it can help reshape the healthcare system to meet consumers’ needs. Patients therefore can and should take a direct role in identifying, implementing, and evaluating improvement initiatives to healthcare services transformation. In addition, in order for patient experience measurement to succeed and translate into care policies, it requires a committed and engaged leadership with clear goals, engaged patients and families, trained workforce to assess patients’ experiences using wide range of methods, budget allocation, and measured performance and feedback (table 3) [31, 41]. Furthermore, health policy makers in Saudi Arabia might consider making the survey results available online on a regular basis and feed these back to each hospital. This is expected to engage care providers in identifying areas for improvements and care consumers to ask for better care experiences.

**Table 3:** Strategies and challenges to improve patients’ experiences

<b>Elements to improve patients’ experiences: adapted from Coulter et al. 2014 [31]</b>	<b>Challenges against improving patients’ experiences: adopted from Raleigh et al. 2015[41]</b>
Leadership commitment Staff at operational level commitment Consumer involvement Patients and family engagement Clear goals Trained staff Budget resourcing Performance measurement and feedback	Lack of support from leadership and organisational culture Scepticism among clinicians Lack of coordination Lack of patient experience understanding Lack of the ability to translate patient experience data to measurable actions Pressure on financial and operational resources Conflict of executive responsibilities of patient experience results

**Conclusion:**

Patient experience is an important measure of care quality. The health care system in Saudi Arabia is being updated and transformed to improve care quality across many settings including cancer care. Gathering patient experience data is an important part of meeting this ambitious transformation plan. However, several methodological and systematic challenges have been highlighted in the US and English literature that need to be considered in order to meet the patient experience goals. These challenges include defining patient experience, developing specific patient experience aspects, using the appropriate data collection methods, gathering representative patient perspectives, and overcoming resistance among health professionals who might be skeptical of the new measurement systems.

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