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## A Measurement Framework for Quality Health Care for Adolescents in Hospital

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#### ABSTRACT

**Purpose:** Despite growing interest in measurement of health care quality and patient experience, the current evidence base largely derives from adult health settings, at least in part because of the absence of appropriately developed measurement tools for adolescents. To rectify this, we set out to develop a conceptual framework and a set of indicators to measure the quality of health care delivered to adolescents in hospital.

**Methods:** A conceptual framework was developed from the following four elements: (1) a review of the evidence around what young people perceive as "adolescent-friendly" health care; (2) an exploration with adolescent patients of the principles of patient-centered care; (3) a scoping review to identify core clinical practices around working with adolescents; and (4) a scoping review of existing conceptual frameworks. Using criteria for indicator development, we then developed a set of indicators that mapped to this framework.

**Results:** Embedded within the notion of patient- and family-centered care, the conceptual framework for adolescent-friendly health care (quality health care for adolescents) was based on the constructs of experience of care (positive engagement with health care) and evidence-informed care. A set of 14 indicators was developed, half of which related to adolescents' and parents' experience of care and half of which related to aspects of evidence-informed care.

**Conclusions:** The conceptual framework and indicators of quality health care for adolescents set the stage to develop measures to populate these indicators, the next step in the agenda of improving the quality of health care delivered to adolescents in hospital settings.

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# IMPLICATIONS AND CONTRIBUTION

There is increasing interest in quantitative information about the quality of health care, including patient experience. This article describes the development of a conceptual framework and a set of indicators to measure the quality of health care delivered to adolescents in hospital to provide a quantitative basis for quality improvement.

Across the world, pediatricians are managing growing numbers of adolescent patients [1,2]. About one in five adolescents has a severe chronic health condition including physical, developmental, and mental disorders that requires them and their families to actively engage with current health care while concurrently

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preparing for future engagement in adult health services [1,3]. Many more adolescents experience health risk behaviors (e.g., unsafe sexual behaviors and substance use) and health states (e.g., mental disorders, overweight, and obesity) that could benefit from brief interventions that too often remain hidden from health professionals, whether in the community or in hospitals [4,5]. All adolescents could benefit from respectful communication with caring professionals who deliver high-quality health care.

There is growing interest from health care providers, regulators, purchasers, and consumers about having access to quantitative information about the quality of health care

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services [6,7]. This includes measurement of patient experience that is now well appreciated to be an important index and driver of health system performance [8,9]. This perspective is relevant for health services across the lifespan, including for children and adolescents whose experience of illness and health care differs from that of adults [10]. Indeed, many aspects of child and adolescent health care have no parallel in adult health services. For example, the UN Convention on the Rights of the Child affirms that young people should be involved in decision making around their health care in line with their developing capacities for understanding and participation [11]. Yet at the same time, clinicians must balance this with the known benefits of continuing to engage parents in their children's health care [12,13]. Patient-centered care has been shown to result in improved patient satisfaction with some evidence for improved health outcomes [14,15]. However, just like evidence-informed practices vary between individual clinicians and institutions, so too do measures of patient experience and patient-centered care [6,7,16]. Despite growing interest in measuring patient experience, the current evidence base largely derives from adult health care settings, at least in part because of the absence of appropriate measurement tools for children and adolescents [17].

Indicators provide a quantitative basis for improving health care quality. Repeated measures of quality indicators can, for example, be used to track the progress of specific quality improvement initiatives, while comparisons of quality measures from different institutions can be used to help establish quality benchmarks [16,18]. While the importance of young people's involvement in the process of health service development, monitoring, and evaluation is well appreciated [19–21], little attention has been paid to either measurement frameworks for quality adolescent health care or the development of indicators of quality health care for adolescents, whether in the community or in hospital [22,23].

The World Health Organization (WHO) emphasizes the value of "adolescent-friendly" health care as an approach to better orientating health services to the needs of young people [21]. Having emerged out of concerns about the lack of developmentally appropriate primary health care for adolescents in low- and middle-income countries, the approach of adolescent-friendly health care is appreciated to be equally relevant for providing quality health care to adolescents in high-income countries, including specialist health settings [24,25].

This article describes the development of a conceptual framework and a set of indicators to measure the quality of health care delivered to adolescents within a hospital setting.

#### Setting and context

This research was undertaken as part of a hospital-wide approach to improving the quality of health care delivered to adolescent patients of the Royal Children's Hospital (RCH), a tertiary children's hospital in Melbourne, Australia. The research was approved by the RCH Human Research Ethics Committee. The study was led by an evaluation subcommittee of a hospital steering committee that was established to oversee the implementation of adolescent-friendly health care at the RCH. Members of the evaluation subcommittee (the authors) had expertise in adolescent health and medicine, quality improvement, and research. The project also involved extensive consultation with the RCH Youth Advisory Committee, a group of experienced

consumers of health care at the hospital aged between 13 and 19 years.

#### Development of the conceptual framework

A conceptual framework for quality health care for adolescents in hospital was developed from the following four elements: (1) a review of the evidence around "adolescent-friendly" health care from young people's perspectives; (2) an exploration of the principles of patient-centered care as they relate to young people; (3) a scoping review of policies and guidelines from professional associations to identify core clinical practices around working with adolescents; and (4) a scoping review of conceptual frameworks for quality health care for adolescents. The processes for deriving each of these elements and their integration within a conceptual framework are described in more detail below.

Young people's perspectives of adolescent-friendly health care. We undertook a systematic review of young people's perspectives of health care with a view to defining possible domains of what they view as youth-friendly care [25]. From 22 studies (both quantitative and qualitative), we identified a set of eight domains around which there was striking overlap about what young people viewed as important to youth-friendly care. These domains were accessibility; staff attitude including respect and friendliness; communication; medical competency; guideline-driven care; age-appropriate environment; involvement in health care; and health outcomes including attention to issues such as pain relief.

This systematic review also identified marked overlap of these domains within a number of different constructs that were variously referred to in the literature as experience of care, satisfaction with care, patient- and family-centered care, adolescent-friendly health care, and quality care (i.e., a single domain could sit within a number of different constructs).

Young people's perspectives of patient-centered care. The construct of patient-centered care is based on the view that as consumers, regardless of age, patients deserve health care that is respectful of and responsive to their preferences, needs, and values, and that they should be encouraged to play an active role in all aspects of their health and health care, consistent with their level of development, capacity, and interest [26,27].

Articulation of how the principles of patient-centered care relate to adolescent patients was achieved through a consultative process with young people. At that time, the hospital's Youth Advisory Committee consisted of 8-10 young people aged 13–19 years led by two peer mentors. The members and peer leaders (whose health care was no longer managed at the hospital) had experience of different departments and programs at the hospital. Consultation took place on four occasions. Most members participated on each occasion, with the addition of some new members for the latter part of the process. Each consultation was led by the peer mentors in collaboration with two members of the research team, one of whom was engaged in the discussion by gently seeking clarification and refinement of the points discussed, while the other took notes. The initial consultation was set up as a free flowing focus group to explore what elements young people valued and did not like about their experience of the hospital. In effect, the intent was to understand what they felt constituted an adolescent-friendly hospital. No topic was viewed as "out of scope." The subsequent three focus groups built on this but were more directive about seeking feedback about how we had grouped their

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