

A Review of Paediatric Quality Measures

Development, Testing and Endorsement in the United States of America, Australia, United Kingdom and European Union.



Date: 15 May 2017

Report title Version 2.0

Prepared by:

Assistant Professor Sue Woolfenden Professor Gary L. Freed, MD, MPH

This report was undertaken by the Centre for Community Child Health at the Royal Children's Hospital and the School of Population and Global Health at the University of Melbourne.

This work is copyright. To request permission to reproduce any part of this material or communication of, please contact the Centre for Community, Health.

The Centre for Community Child Health is a research group of the Murdoch Children's Research Institute and a department of The Royal Children's Hospital, Melbourne.

Centre for Community Child Health

The Royal Children's Hospital Melbourne 50 Flemington Road, Parkville Victoria 3052 Australia Telephone +61 9345 6150 Email <u>enquiries.ccch@rch.org.au</u> www.rch.org.au/ccch

Contents

List of figures	iv
List of tables	iv
Glossary (If glossary short, insert here. If glossary long (more than 1 page) insert after references, be	fore
appendices)	iv
Acknowledgments	v
Executive Summary	6
Introduction	8
1. What is quality in the health system context?	8
2. How do we measure quality?	9
3. Why do we need paediatric quality measures?	9
4. What is a quality measure?	10
5. How do quality measures differ from guidelines and indicators?	11
5.1 Clinical Practice Guidelines	11
5.2 Indicators	11
5.3 Quality Measures	12
6 What are the special challenges of measuring quality in children?	12
7. How are guality measures used?	12
8. How are quality measures developed and tested for reliability and validity?	13
8.1 Development of quality measures	13
8.2 Testing of quality measures for reliability and validity	14
9. How are quality measures assessed in the USA. Australia, UK. and EU?	15
9.1 United States of America	16
9.1.1 National Quality Forum (NQF)	17
9.1.2 The American Medical Academy - Physician Consortium for Performance Improvement (AMA-PCPI)	18
9.1.3 Agency for Health Care Research and Quality (AHRQ) and National Quality Measures Clearinghouse	
(NQMC)	18
9.1.4 Centres for Medicare and Medicaid services (CMS)	18
9.1.5 National Committee for Quality Assurance (NCQA)	19
9.1.6 Paediatric Quality Measures in the USA	19
9.2 Australia	19
9.2.1 Australian Commission on Safety and Quality in Health Care (the Commission)	20
9.2.2 Australian Council on Health care standards (ACHS)	20
9.2.3 Children's Healthcare Australasia (CHA)	21
9.2.4 Royal Australasian College of General Practice (RACGP)	21
9.3 United Kingdom (UK)	22
9.3.1 The National Health Service	22
9.4 The European Union (EU)	26
9.4.1 Organization for Economic Cooperation and Development (OECD)	۲۵ مد
9.4.2 Health Systems Performance Assessment (HSPA)	۲۵ مر
9.4.5 Health Systems Ferrormance Assessment (HSFA)	22
9.4.5 Netherlands	رد∠ ∩2
9.4.6 Ireland	02 مد
9.4.7 Norway	
9.4.8 Denmark	31
9.4.9 Sweden	32
9.4.10 France	33

10.Discussion3411.Conclusion3412.Recommendations3512.1 Recommendation 13512.2 Recommendation 23512.3 Recommendation 33512.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613.ReferencesAppendices42Appendix 1: Examples of validity and reliability testing of quality measures42	51 HI Cernary	
11.Conclusion.3412.Recommendations3512.1 Recommendation 13512.2 Recommendation 23512.3 Recommendation 33512.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613.References36Appendices42Appendix 1: Examples of validity and reliability testing of quality measures.42	10. Discussion	34
12.Recommendations3512.1 Recommendation 13512.2 Recommendation 23512.3 Recommendation 33512.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613.References42Appendices42	11. Conclusion	34
12.1 Recommendation 13512.2 Recommendation 23512.3 Recommendation 33512.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613. References36Appendices42Appendix 1: Examples of validity and reliability testing of quality measures42	12. Recommendations	35
12.2 Recommendation 23512.3 Recommendation 33512.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613. References36Appendices42Appendix 1: Examples of validity and reliability testing of quality measures42	12.1 Recommendation 1	35
12.3 Recommendation 33512.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613. References36Appendices42Appendix 1: Examples of validity and reliability testing of quality measures42	12.2 Recommendation 2	35
12.4 Recommendation 43512.5 Recommendation 53512.6 Recommendation 63512.7 Recommendation 73613. References.36Appendices42Appendix 1: Examples of validity and reliability testing of quality measures42	12.3 Recommendation 3	35
12.5 Recommendation 5	12.4 Recommendation 4	35
12.6 Recommendation 6	12.5 Recommendation 5	35
12.7 Recommendation 7	12.6 Recommendation 6	35
13. References36Appendices42Appendix 1: Examples of validity and reliability testing of quality measures42	12.7 Recommendation 7	36
Appendices42Appendix 1: Examples of validity and reliability testing of quality measures42	13. References	36
Appendix 1: Examples of validity and reliability testing of quality measures	Appendices	42
	Appendix 1: Examples of validity and reliability testing of quality measures	42
Appendix 2: Examples of quality measures	Appendix 2: Examples of quality measures	44
Quality measures - USA	Quality measures - USA	44
Quality measures - UK	Quality measures - UK	56
	Quality Measures - Denmark	56

List of figures

Figure 1 The relationship between quality frameworks, NICE and indicator sets	. 22
Figure 2 NICE development and assessment of quality measures	. 25
Figure 3 Assessment of validity by the National Quality Forum	. 42
Figure 4 Assessment of reliability by the National Quality Forum	. 43
Figure 5 NHS system of development, evaluation and endorsement	. 44

List of tables

Table 1 Quality measure assessment in the USA	. 17
Table 2 Quality indicators in Australia	. 19
Table 3 Quality measures and indicators in the UK	. 23
Table 4 Quality measures and indicators in the EU	. 27

Glossary

ACHS	Australian Council on Health care standards
ACSQHC	Australian Commission on Safety and Quality in Health Care
AMA-PCPI	American Medical Academy - Physician Consortium for Performance Improvement
BHVQ	Barnhälsovårdsregistrets
BQS	Federal Office for Quality Assurance
CCG	Clinical Commissioning Groups
СНА	Children's Healthcare Australasia
CHILD	Child Health Indicators of Life and Development
CHIPRA	Children's Health Insurance Program Reauthorization Act
CMS	Centers for Medicare and Medicaid Services
HAS	French National Authority for Health
HCQI	Health Care Quality Indicators
HEDIS	The Healthcare Effectiveness Data and Information Set
HSPA	Health Systems Performance Assessments
NCQA	National Committee for Quality Assurance
NDMG	National Disease Management Guideline
NICE	National Institute for Health and Care Excellence
NQIS	The Norwegian Quality Indicator System
NQMC	National Quality Measures Clearinghouse
NHS	National Health Service
NQF	National Quality Forum
OECD	The Organisation for Economic Co-operation and Development
PATH	Performance assessment tool for quality improvement in hospitals
PNE	National Outcome Evaluation Program
PQMP	Pediatric Quality Measures Program
PQRS	Physician Quality Reporting System
QOF	Quality Outcomes Framework
RACGP	Royal Australasian College of General Practice
RIVM	Dutch National Institute for Public Health and the Environment
WHO	World Health Organization

Acknowledgments

We thank Prof Sharon Goldfeld, Prof Harriet Hiscock, Prof Mitch Blair ADD, Prof Anders Hjern who provided assistance in the preparation of this report. This work was funded by the Australian National Health and Medical Research Council.

Executive Summary

There is an urgent need for an evidence base in the quality of current child health care services in the United States of America (USA), Australia, United Kingdom (UK) and European Union (EU). For this, *paediatric quality measures* – clearly defined, validated and robust tools that can be used to assess the performance of health care providers and systems are required. A paediatric quality measure provides a reference point against which data on child health care service provision can be assessed and quantified against clear criteria in terms of its quality domains (safety, effectiveness, patient centeredness, timeliness, equity and efficiency). Their use can identify quality gaps and where improvements need to be made.

Paediatric quality measures need to be differentiated from quality indicators. A quality measure includes the methods required to determine the performance of a quality indicator. In the international literature, the term indicator and measure are used interchangeably but a valid quality measure has been rigorously developed and tested with evidence of *importance, scientific soundness (reliability, and validity), usability* and *feasibility*. It must have detailed technical specifications and a clear description of the link between structure, process and/or outcome. In addition, once the quality measure has been tested there needs to be a clear mechanism for dissemination, implementation and where possible endorsement by a central agency that monitors the quality of health care for that country.

This report is a comprehensive review of the published and grey literature on national and international initiatives for quality measure development, testing and endorsement in the USA, Australia, UK and EU. Country level specific information on quality measures was collected on:

- 1. Testing of reliability and validity of quality measures.
- 2. Technical specifications of the quality measure.
- 3. Availability of paediatric quality measures.
- 4. Whether these quality measures examined structure, process and outcomes.
- 5. The process of quality measure endorsement.

Where further information was required after examining the online and published data, professional organisations and governmental bodies were contacted directly. National and international experts in the USA, Australia, the UK and EU also were consulted. Paediatric quality indicators from countries with no link to measuring the quality of health care and no description of being developed in a scientifically sound manner, including assessment and testing of their validity and reliability, were excluded from this report.

Key Findings from this report include:

- 1. Issues with interchangeable terminology of quality indicators and measures across countries.
- 2. Variable criteria across countries for development of quality measures.
- 3. For most countries, there was a lack of testing of quality measures for validity and reliability.
- 4. When testing of quality measures was performed, there was significant variation in testing for validity and reliability.
- 5. For almost all countries, there is a lack of a central agency or specific respected organizations(s) for endorsement of quality measures
- 6. Across all countries, there is a lack of broad/universal use of paediatric quality measures.

Recommendations

It is clear from this report that a standardised international approach to terminology, definition, development, testing and endorsement is required. The recommendations from this report are as follows:

Recommendation 1

Develop uniform definitions for quality measures and quality indicators.

Recommendation 2

All quality measures should be developed with the following minimum criteria

- 1. Relevance/importance
- 2. Scientific soundness validity/reliability
- 3. Feasibility
- 4. Usability/acceptability

Recommendation 3

An expert working group should be formed which conducts an evidence review for the importance/relevance of the quality measure and develops detailed technical measure specifications for obtaining data and calculating the measure. This includes a clear definition of variables to be measured with a denominator and numerator, inclusion/exclusion criteria (e.g., age, gender; health condition; setting (primary vs tertiary)); a data source and time frame for collection and a rationale for why it is important to collect the data.

Recommendation 4

All quality measures should be pilot tested for *reliability*. This should include one or more of the following depending on the specific measure:

- 1. Testing inter-rater (inter-abstractor) and intra-abstractor reliability between those doing the data extraction.
- 2. Parallel form (form equivalence) reliability
- 3. Checking for internal consistency
- 4. Ensuring test- retest (sampling variation) reliability over time

Recommendation 5

All quality measures should be pilot tested for *validity.* This should include one or more of the following depending on the specific measure:

- 1. Content validity
- 2. Face validity
- 3. Construct validity
- 4. Criterion validity
- 5. Discriminant validity

Recommendation 6

Develop and test new paediatric quality measures across primary to tertiary and across taking into account the 4Ds of quality measurement in childhood - developmental change; dependency; differential epidemiology and demographic patterns including child and family reported quality of care

Recommendation 7

Governments should have a central agency that endorses quality measures using a rigorous and impartial evaluation of the components of the measure.

Introduction

Quality health care means that the right care is provided to the right person at the right time, every time.(Morris & Bailey, 2014a) There are two main challenges to ensure that the health needs of children are adequately and equitably addressed by high quality health care services.(Hodgson, Simpson, & Lannon, 2008) These include:

- 1) A lack of documentation on how paediatric conditions are treated and if there is variation in care between health care providers. (3) and:
- A consideration of children's changing developmental needs, dependency on others, differential epidemiology, and demographic patterns as they grow into adulthood. (Forrest, Simpson, & Clancy, 1997; McDonald, 2009)

In order to determine if quality child health care is provided, it is necessary to both measure and provide an evidence base in the domains of safety, timeliness, effectiveness, equity, efficiency and/or patient-centeredness.(Hodgson et al., 2008; IOM (Institute of Medicine), 2001) To accomplish this on behalf of children, one needs *paediatric quality measures* – clearly defined and robust tools that can be used to assess the performance of health care providers and systems in terms of their structure, process and outcomes in a valid, and reliable manner.(Morris & Bailey, 2014b) As most quality measures have been focused on adults, there has been a recent focus internationally on the expansion of the number and reach of paediatric quality measures for preventive and clinical care. Where possible, these measures have also attempted to include the patient perspective.(IOM (Institute of Medicine), 2011; Raleigh & Foot, 2010) The purpose of this project is to undertake a systematic assessment of paediatric quality measure development, testing and endorsement across the United States of America (USA), Australia, the United Kingdom (UK) and European Union (EU). This is vital in order to address standardisation of data comparison internationally and to better measure and understand variation in health care and in perceptions of quality.

The aims of this report are to;

- 1) Identify and compare information in the USA, Australia, UK and EU on development, testing and endorsement of paediatric quality measures.
- 2) Develop recommendations for best practices for paediatric quality measure development, testing and endorsement.

1. What is quality in the health system context?

In 2001 in the document *Crossing the Quality Chasm: A new health system for the 21st century*, the Institute of Medicine defined 6 domains of quality for health care;(Hodgson et al., 2008; IOM (Institute of Medicine), 2001)

- 1. Safety: avoiding missed and incorrect diagnosis; medication errors; injury in health care settings.
- 2. **Effectiveness**: ensuring appropriate use of health services by avoiding overuse or underuse in preventive, chronic or acute care.
- 3. **Patient-centeredness**: effective partnerships between providers, patients, and their families and a focus on the patient experiences of care.
- 4. **Timeliness**: prompt access to care without delays within a health care system and delays in coordination of care.
- 5. **Equity**: the provision of health care does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.
- 6. Efficiency: avoidance of waste in equipment, supplies, ideas, energy and financial resources

There are international differences in how quality of health care is conceptualised.(Raleigh & Foot, 2010) In the USA, the National Quality Strategy states that for quality health care to exist:

- 1. Health care must be *patient centred, reliable, accessible and safe*.
- 2. There are evidence based interventions that tackle the social determinants of health to ensure a healthy population.
- 3. Health care costs are *reduced* for individuals, families, communities, and government.(National Quality Strategy)

In the UK, the National Health Service (NHS) uses the quality domains of *access, timeliness, effectiveness, equity, patient-centeredness, safety and system capacity*. The Organisation for Economic Co-operation and Development (OECD) defines quality in terms of effectiveness, safety and patient-centeredness. (Arah, Westert, Hurst, & Klazinga, 2006; E. Kelley & Hurst, 2006; Raleigh & Foot, 2010) The Australian Commission on Safety and Quality in Health Care defines quality in terms of safety, appropriateness and evidence base of care, and consumer-provider partnership.(ACSQHC, 2016). In summary, common international quality domains that are examined in health care systems are safety, patient-centeredness and effectiveness.

2. How do we measure quality?

To measure the domains of quality in health care we need tools called "*quality measures*" that we can apply to health system data. Donabedian identified that although the most important measure of quality is outcome, one needs to understand the pathway to this outcome in the system.(Byron et al., 2014; Donabedian, 1966; Hodgson et al., 2008; Morris & Bailey, 2014b; Palmer & Miller, 2001) Thus he posited that there is a need to assess quality in three domains:

- 1. The system within which health care occurs, also known as the <u>structure</u> of the health care system including resources, financing, standards, data systems and workforce (e.g. availability of trained nursing staff).
- 2. The *process* of health service delivery such as assessment, diagnosis and treatment (e.g. provision of care plans for asthma, organisation of services).
- 3. Changes in *outcome* in the health status and function as a result of health care delivery (e.g. representations to hospital with asthma).

In addition, we need *measures of the patient experience* (e.g. patient report that doctor provided information on asthma that was easy to understand). All these dimensions are required to truly assess the quality of a health care system.(Byron et al., 2014; Hodgson et al., 2008; Morris & Bailey, 2014b; Palmer & Miller, 2001)

To actually assess these domains, we require validated and reliable quality measures to identify the "performance gap" in what evidence indicates *should* be done and what *actually* is done as assessed by the measures.

3. Why do we need paediatric quality measures?

The vast majority of quality measures have been developed for adult rather than paediatric care. (Byron et al., 2014; Palmer & Miller, 2001) Less than 5% of children are affected by the 3 most common chronic conditions that are the primary foci of quality measurement in the adult population (Type 2 diabetes, cardiovascular disease, arthritis). (Bordley, 2002) Further, adult measures are not designed to address the differences in care provided to children with these same conditions. In addition, although chronic diseases in children are increasing in prevalence (due mostly to increased survival of previously fatal illnesses and the rise in the "new morbidities" of obesity and developmental/ behavioural issues), most children are healthy. Thus, quality measures for children must also include the ability to assess preventive services. (Schuster, 2015)

This paucity of paediatric quality measures reflects the fact that in developed countries adults are the more dominant consumers of health care and are able to advocate for high quality health services. (Forrest et al., 1997) In contrast to adults, children are over-represented in vulnerable, socioeconomically disadvantaged uninsured populations in both user pay and universal health systems. Their health needs are neither adequately nor equitably prioritised across and within national boundaries, budgets and organisation of services. (AIHW, 2011; Berry, Bloom, Foley, & Palfrey, 2010; Goldfeld, Woolfenden, & Hiscock, 2016; Hodgson et al., 2008; Schuster, 2015; Turrell, Stanley, de Looper, & Oldenburg, 2006) For example, evidence suggets that 30-40% of children do not routinely receive standard care for many common paediatric conditions in the primary health care systems of both the US and Australia. (Goldfeld et al., 2016; Schuster, 2015; Starfield et al., 1994; Woolfenden et al., 2016). To truly improve the morbidity and mortality of the adult population and reduce health care costs over the life course one must concentrate on improving the measurement of the quality of health care children receive. It is during childhood that the foundations for good health are laid for a lifetime. (IOM (Institute of Medicine), 2011)

Quality measurement can improve the health care of children through; (IOM (Institute of Medicine), 2011; Morris & Bailey, 2014a, 2014b; Schuster, 2015)

- 1. The prevention the overuse, underuse, and misuse of health care services.
- 2. Ensuring patient safety.
- 3. Identification of where there is an evidence to performance gap in quality to drive health care improvement.
- 4. Provision a mechanism for monitoring the health of populations;
- 5. Holding those that provide health care accountable for its quality.
- 6. Measurement of disparities in health care delivery and in health outcomes to inform intervention and policy.
- 7. Accreditation and certification of health care services.
- 8. Giving children and their families the data they need to make informed choices so that children receive the best care. For this the quality measure data must be publicly available.

External government and non-government bodies need quality measures to assess how health care services are performing for their patients and purchasers and to determine if they are providing "value for money".(Barker & Field, 2014; Kuhlthau, Mistry, Forrest, & Dougherty, 2014; Palmer & Miller, 2001)

4. What is a quality measure?

The National Quality Forum (NQF), the most respected quality measure endorsement agency in the USA, defines a quality measure as a *"standard: a basis for comparison; a reference point against which other things can be evaluated"*. (NQF) A paediatric quality measure is therefore a measure that provides a reference point against which data on child health care service provision can be assessed and quantified against clear evidence-based criteria in terms of its quality domains (safety, effectiveness, patient centeredness, timeliness, equity and efficiency). (IOM (Institute of Medicine), 1990) It will identify where improvements need to be made and help identify who is responsible for specific components of child health care. To accomplish these goals, paediatric quality measures need to be developed and assessed using the following rigorous criteria:(Ed Kelley, Moy, Stryer, Burstin, & Clancy, 2005; Nolte, 2010)

- 1. Importance: the quality measure has a focus on an area of health/health care that is important to measure and report for policy makers and consumers. There is evidence of current variation in, or less-than optimal, performance in the area and potential to make gains in quality and/or improve outcomes.
- 2. Scientific soundness of the measure properties: the quality measure has been rigorously assessed to ensure validity (*it measures what it is intended to measure about the quality of care*) and reliability (*it*

gives consistent and repeatable results across populations and circumstances) and there is scientific evidence to support that its measurement will improve quality of health care.

- **3.** Usability: the information produced by the measure is meaningful, understandable and useful for intended audiences to understand results and find them useful.
- **4. Feasibility**: the data (from electronic medical records, national datasets and/or manual data collection) needed for the quality measure is easily available/already in use, accurate and its collection is not excessively burdensome on the system in terms of time, scale or cost.

Despite these clear criteria there is a paucity of robust paediatric quality measures with demonstrated reliability and validity which address important aspects of child health, and are able to be implemented at the payer, delivery system or provider levels. (Kavanagh, Adams, & Wang, 2009) This reflects the historic limitations of quality assessment, with many paediatric quality measures having evolved based only on data availability rather than child health care priorities. This has resulted in rather simplistic measures such as whether care has been received (e.g. the percentage of the population who attend a primary health care provider), the quantity of care (e.g. the number of visits) and when care was received (e.g. time of visit). There is greater difficulty in focusing on potentially more meaningful assessments such as the actual content or outcome of care (e.g. did the patient actually understand and act on the advice given at the consultation rather than just receive it).(Nolte, 2010)

5. How do quality measures differ from guidelines and indicators?

5.1 Clinical Practice Guidelines

To guide best practice, professional, government and academic bodies must identify and examine the best available evidence base for treatments that result in improved health and patient experience of healthcare. This evidence is summarised into clinical guidelines for health professionals and serve to guide clinical decision-making (e.g. clinical guideline for use of steroids in asthma). Some aspects of guidelines are difficult to measure as many components of guidelines may have variable specificity. For example, some guidelines recommend that clinicians "consider" certain treatments in specific situations. It is difficult, if not impossible, to measure where "consideration of a treatment option" has occurred. Guidelines also may often lack specificity in either determining case definitions or firm inclusion and exclusion criteria for specific recommendations. Further, the existence of a guideline does not automatically translate into its adherence. Studies have shown that even guidelines from authoritative sources are implemented less than 30% of the time.(Morris & Bailey, 2014b; Palmer & Miller, 2001). Therefore, quality measures are vital in measuring whether health care providers are providing care based on the best available evidence and on evidence-based clinical recommendations from authoritative professional bodies.(Morris & Bailey, 2014b; Palmer & Miller, 2001)

5.2 Indicators

An indicator is a tool that can be used to assess components of the structure, process or outcome of a health care system that are deemed to be important for quality.(Hibbert, Hannaford, Long, Plumb, & Braithwaite, 2013; Mainz, 2003) Ideally, indicators have a numerator and a denominator. Although indicators may suggest what care should be delivered, many lack specificity in terms of their rationale, accuracy and process for measurement. This variable rigour in indicator development can undermine any assessment of a health system's performance in the quality domains identified by the indicator.(Arah et al., 2006; Nolte, 2010) As a result, many indicators can only be used to identify broadly, that is "indicate", if health care services are high or poor quality rather than accurately measure the outcome to be addressed.

5.3 Quality Measures

A quality measure assesses whether an indicator has indeed been met. A quality measure requires rigorous development and testing with evidence of importance, scientific soundness (reliability, and validity), usability and feasibility.(CMS (Centers for Medicare and Medicaid Services), 2016) It must have detailed technical specifications and a clear description of the link between structure, process and/or outcome. Unfortunately, in the international literature the term indicator and measure are often used interchangeably. (Barker & Field, 2014) As such, it is essential to examine the process by which an indicator is derived, particularly in terms of testing its validity and reliability, before it can be classified as a quality measure.(Mangione-Smith, Schiff, & Dougherty, 2011)

6 What are the special challenges of measuring quality in children?

Paediatric quality measures must take into account Forrest's *4 D's (distinguishing characteristics)* of childhood (Forrest et al., 1997):

- 1. **Developmental change**: the rapid developmental changes in childhood affect functioning, cognition, health care needs, recommended preventive services and utilisation patterns
- 2. **Dependency**: children depend on parents/carers to access care and parental report on outcomes and experiences when they are young which may confound quality assessments. In addition, quality measures must not only reflect child- centeredness but family centeredness and partnership.
- 3. **Differential epidemiology**: most children do not have chronic diseases or disabilities. Most of their interactions with the health system are for prevention or treatment of acute illness. It is difficult to measure absence of disease and their paucity of chronic illness creates data challenges.
- 4. **Demographic patterns**: many children living in poverty with rates increasing, they are vulnerable to health care policy change around financing and come from diverse communities.(Forrest et al., 1997)

These 4 D's have a significant impact on both children's health and health care as children progress across their life course trajectory from birth to adulthood.(IOM (Institute of Medicine), 2011; Palmer & Miller, 2001) For example a 2 year old who presents with a wheeze to emergency department is very different to the 12 year old who presents with similar symptoms. The 2-year-old may have viral induced wheeze, and is dependent on its parents for history giving and medication. The 12 year old is more likely to have asthma, can administer their own medication, and attends school. (Palmer & Miller, 2001)

Children and their families are also more vulnerable to health and health care *disparities* – *the fifth D* due to greater exposure to socioeconomic disadvantage which has its greater impact during sensitive periods in early childhood development.(Forrest et al., 1997) It is therefore essential that paediatric quality measures be developed and tested so that they may be used in "at risk " or vulnerable populations. Paediatric quality measures must also be able to examine differential access to and quality of effective interventions through disaggregation of data by socioeconomic status and race/ethnicity,

Current quality measures vary in their ability to address these issues. A recent review by the Institute of Medicine and National Research Council of the National Academy in the USA (IOM (Institute of Medicine), 2011) reports: a lack of standardisation on how disparities are identified and measured; and a lack of capacity to measure across developmental stages.

7. How are quality measures used?

Quality measures can be used for accountability and quality improvement of health systems and providers, as well as monitoring the health of populations. (Hodgson et al., 2008; Panzer et al., 2013; Raleigh & Foot, 2010)

Accountability of health systems, governments and providers includes:

1. Monitoring performance of health care delivery.

- 2. Certification, credentialing and accreditation of services and providers.
- 3. Payment (including incentives and funding of services).
- 4. Public disclosure, advocacy and reporting.

Once a quality measure determines the "performance gap" in the delivery of services, quality improvement programs can be developed to address the gap and improve care.

Monitoring the health of populations includes:

- 1. Identifying priority areas for health care change for services providers, clinicians, children and their families and to track progress after policy change.
- 2. Health service research such as longitudinal tracking of health care quality.(Hodgson et al., 2008; Panzer et al., 2013; Raleigh & Foot, 2010)

8. How are quality measures developed and tested for reliability and validity?

A poor quality measure is worse than no measure at all as it can result in inaccurate and misleading information regarding the quality of care being provided and thus guiding actions with potentially negative consequences. Therefore, there must be clarity and standards regarding paediatric quality measure development and testing.(Byron et al., 2014)

8.1 Development of quality measures

The process undergone in developing a quality measure is as follows (Barker & Field, 2014; Byron et al., 2014; CMS (Centers for Medicare and Medicaid Services), 2016; Mangione-Smith et al., 2011; Morris & Bailey, 2014b; NQF., 2016b):

- 1. An *expert working group* is formed which:
 - a. Identifies the concepts to be measured.
 - b. Develops a clinical algorithm and/or measurement framework that reflects consensus on how a condition is best managed.
 - c. Assesses the scientific literature to find any quality measures currently existing on the topic. (CMS (Centers for Medicare and Medicaid Services), 2016)
 - d. Prioritises the measure concepts identified using consensus based approaches. These include the Delphi method, nominal group technique, consensus development conference, iterated consensus rating procedure, and the RAND-UCLA appropriateness method. (Byron et al., 2014; S. M. Campbell, Braspenning, Hutchinson, & Marshall, 2003; Stephen M. Campbell et al., 2011; Fitch, Bernstein, Aguilar, Burnand, & LaCalle, 2001)
- 2. The working group conducts an *evidence review* for the importance/relevance of measurement of this area of health care. This includes:
 - a. The level of evidence available. Evidence may be an existing clinical guideline or systematic review but if these are missing then a systematic review should be undertaken.
 - b. An examination of the known or existing quality performance gap.
 - c. An examination of the link between structure, and/or process and/or or outcome of health care.(Hodgson et al., 2008; Mangione-Smith et al., 2011)
- 3. The working group develops *detailed technical measure specifications* for obtaining data and calculating the measure. These are necessary for programmers to acquire administrative data, the programming of medical record abstractor tools and measure implementation. These specifications have:

- a. A clear definition of variables to be measured with a denominator and numerator, inclusion/exclusion criteria (e.g., age, gender; health condition; setting (primary vs tertiary)).
- b. A data source and time frame for collection.
- c. A rationale for why it is important to collect the data.

8.2 Testing of quality measures for reliability and validity

After a quality measure is developed it must be field tested to determine its reliability and validity both in terms of data elements and the measure score that is computed. (CMS (Centers for Medicare and Medicaid Services), 2016; Hodgson et al., 2008; NQF., 2016a; Palmer & Miller, 2001) With regards to sampling for testing, the sample should: (CMS (Centers for Medicare and Medicaid Services), 2016)

- 1. Represent the full spectrum of health care services across populations where the quality measure will be used.
- 2. Have an adequate sample size to support statistical analysis of reliability and validity analyses using the planned statistical methods.
- 3. Be randomly selected.

For a measure to be **reliable** it must produce the same results when used in the same population over the same time period.(CMS (Centers for Medicare and Medicaid Services), 2016) It must have minimal intra and inter observer variation, have a reliable data source and be statistically rigorous. (Booth & Collopy, 1997; IOM (Institute of Medicine), 2011; Palmer & Miller, 2001; Wollersheim et al., 2007) Methods of testing for reliability include:(CMS (Centers for Medicare and Medicaid Services), 2016; Fitch et al., 2001; NQF., 2016a)

- Testing inter-rater (inter-abstractor) and intra-abstractor reliability between those doing the data extraction. This level of agreement between information manually collected by 2 abstractors (S. M. Campbell et al., 2003) can be statistically tested using concordance rates and Cohen's Kappa with 95% confidence intervals or intra-class correlations. (CMS (Centers for Medicare and Medicaid Services), 2016)
- 2. Parallel form (form equivalence) reliability where multiple formats of the test are compared and assessed for their yield of the same result (i.e. EHR measurement vs manual review). This can be assessed statistically using correlation coefficients of equivalence. (CMS (Centers for Medicare and Medicaid Services), 2016)
- 3. Checking for internal consistency when there are multiple items in the quality measure. (NQF., 2016a)
- 4. Ensuring test– retest (sampling variation) reliability over time to test variation across repeated samples. This can be assessed using a co-efficient of stability or Monte Carlo simulation it only should be used when the condition is expected to remain stable over time. (CMS (Centers for Medicare and Medicaid Services), 2016)

For a measure to be **valid** it needs to truly measure what is states it is measuring and be free of bias (random and systematic error).(IOM (Institute of Medicine), 2011; Palmer & Miller, 2001) Reliability is necessary, but not sufficient, to achieve validity. A *valid quality measure:*

- 1. Is based on the best available evidence (content validity).
- 2. Has expert consensus that it supports links between structure, processes and/or outcomes in the health care system (*face validity*).
- 3. Can quantify what it in theory is measuring (*construct validity*)(CMS (Centers for Medicare and Medicaid Services), 2016).
- 4. Can accurately predict outcomes in the future where appropriate (*predictive validity*)(S. M. Campbell et al., 2003; IOM (Institute of Medicine), 2011).
- 5. Correlates well with the gold standard when different sources of data are compared (*criterion validity*).
- 6. Can differentiate between the concept it is supposed to measure and other concepts measured by other tools (*discriminant validity*).(CMS (Centers for Medicare and Medicaid Services), 2016)

Testing of validity includes: (Byron et al., 2014)

- 1. Content validity: rating of validity by members in the expert working group and how it correlate with known results from evidence base is undertaken. (S. M. Campbell et al., 2003; Fitch et al., 2001)
- 2. Face validity: a panel of objective clinicians not involved in the working group examine the measure specifications and rate the degree to which data that has been flagged as a variation in care.(CMS (Centers for Medicare and Medicaid Services), 2016; LAWTHERS, 1996)
- 3. Construct validity: there is statistical analysis of components of the measure such as confirmatory factor analysis.(CMS (Centers for Medicare and Medicaid Services), 2016)
- 4. Criterion validity: using cases to confirm against a gold standard what is observed from a range of information sources including administrative data, medical records and parent surveys.(CMS (Centers for Medicare and Medicaid Services), 2016; NQF., 2016a)
- 5. Discriminant validity: applying measure specifications to multiple populations where the measure should be able to distinguish between different groups who are known to have different quality scores as measured by another quality measure. (CMS (Centers for Medicare and Medicaid Services), 2016)

There are a number of additional challenges in testing quality measures which include an assessment of feasibility including:

- 1. The availability and quality of data.
- 2. The cost and complexity of data collection
- 3. Variation in how data are defined in different data sets. There may be a lack of coordinate data standards, including terminology standards (how terminology used), messaging standards (how data are packaged for transmission); functional standards (how data systems operate in a clinical environment) and mixing of information sources (electronic medical records versus paper.(Nolte, 2010)

Measuring disparities can also pose problems including:

- 1. Difficulties disaggregating socioeconomic status, race and ethnicity.
- 2. Differentiating whether a disparity in utilisation reflects cultural norms or lack of access.
- 3. Defining underlying risk status of populations and subsequent risk adjustment that is required. (NQF., 2016a)
- 4. Defining differential access to effective interventions.(Hibbert et al., 2013)

Once testing is complete then the expert working group reviews and finalises measure specifications (although repeat testing may be required before this can occur). It then approves the quality measure for dissemination, implementation and where possible endorsement by a central agency that monitors the quality of health care for that country. (Barker & Field, 2014; Byron et al., 2014; CMS (Centers for Medicare and Medicaid Services), 2016; Morris & Bailey, 2014b; NQF., 2016b)

9. How are quality measures assessed in the USA, Australia, UK, and EU?

To identify and compare information in the US, Australia, UK and EU on paediatric quality measures, a comprehensive review of the published and grey literature on national and international initiatives for quality measure development, testing and endorsement was undertaken.

We conducted an iterative search of Pubmed, bibliographies of review articles, common worldwide web search engines (Google, Google Scholar), and specific government and agency websites, the Kings Fund and Nuffield Trust, Families USA. Content experts within the areas of interest were contacted. Search terms used to identify initiatives included "quality" "measures" "indicators" "assessment", "endorsement", "child health ", and country specific labels such as "USA", "Australia", "EU", "UK" were used. Text box 1 has search strategy used for Pub Med for articles. The search was limited to English language and papers published in the last 10 years and was run December 2016.

Text Box 1- Search Strategy

PubMed

Search ((((((child health service[MeSH Terms]) OR child health services[MeSH Terms]) OR pediatrics[MeSH Terms]) AND ("last 10 years"[PDat] AND Humans[Mesh] AND English[lang] AND (infant[MeSH] OR child[MeSH] OR adolescent[MeSH]))) AND ((((quality indicator, healthcare[MeSH Terms]) OR healthcare quality indicators[MeSH Terms]) OR healthcare quality indicators[MeSH Terms]) OR healthcare quality indicators[MeSH Terms]) OR quality measures[Other Term]) AND ("last 10 years"[PDat] AND Humans[Mesh] AND English[lang] AND (infant[MeSH] OR child[MeSH] OR adolescent[MeSH]))) AND ("last 10 years"[PDat] AND Humans[Mesh] AND English[lang] AND (infant[MeSH] OR child[MeSH] OR child[MeSH] OR child[MeSH]))) Filters: Humans; English

Country level specific information on quality measures was collected on:

- 1. Testing of reliability and validity of quality measures.
- 2. Technical specifications of the quality measure.
- 3. Availability of paediatric quality measures.
- 4. Whether these quality measures examined structure, process and outcomes.
- 5. The process of quality measure endorsement

Where further information was required from organisations after examining the online and published data, organisations were contacted directly.

National and international experts in the area of quality measurement were also contacted in the USA, Australia, the UK and EU gain additional information regarding their countries in the following areas:

- 1. Whether quality "indicators" are differentiated from quality "measures"?
- 2. Are there any quality measures specifically for children? If so,
 - a. have these measures been tested for reliability and validity? Have they been applied broadly?
- 3. Is there mandatory reporting of quality measures to a central body?
- 4. Are existing measures focused on outpatient as well as inpatient care?

As stated previously, an indicator is not equivalent to a quality measure. For the purposes of this report, if in a given country only paediatric quality indicators were identified with no link to actual measurement of quality of health care and no description of development in a scientifically sound manner, including assessment and testing of their validity and reliability, they were excluded from this report. If the indicator was reported as having been "tested" but the details of testing of validity and reliability were not provided, the indicators were not excluded but the lack of supporting documentation was noted and a comment was made on whether these were quality indicators or quality measures.

9.1 United States of America

In the USA, there are a number of agencies, organisations and other entities that develop and test quality measures (including paediatric quality measures).(Morris & Bailey, 2014b) These include the Agency for Health Care Research and Quality (AHRQ)(AHRQ, 2015), the Centers for Medicare and Medicaid Services (CMS)(CMS (Centers for Medicare and Medicaid Services), 2016), the American Medical Academy - Physician Consortium for Performance Improvement (AMA-PCPI)(Association, 2010), the National Committee for Quality Assurance (NCQA)(NCQA, 2016) and the National Quality Forum (NQF., 2016a).

Once a quality measure is developed and tested it is ready to be assessed for potential endorsement. Quality measures can be endorsed through the AHRQ National Quality Measures Clearinghouse (NQMC)(NQMC, National Quality Measure Clearinghouse AHRQ. https://www.qualitymeasures.ahrq.gov/ accessed September 2016), the National Quality Forum (NQF)(NQF., 2016a) and professional groups such as the AMA.(Morris & Bailey, 2014b) Endorsement involves a rigorous review process of the measure and all of its supporting evidence. If a measure passes this review, it is eligible to be endorsed by one of these bodies. This is outlined in Table 1

Table 1 Quality measure assessment in the USA

Agency	Source	Terminology	Testing of validity and	Role
NGO (private not for profit)	National Quality Forum (NQF)	Measures	reliability Yes	Assessment and endorsement
Department of Health and Human Services (HHS)	Agency for Health Care Research and Quality (AHRQ)' National Quality Measures Clearinghouse (NQMC)	Measures	Yes	Assessment and endorsement
Professional	The American Medical Academy - Physician Consortium for Performance Improvement (AMA-PCPI)	Measures	Yes	Assessment and endorsement
Department of Health and Human Services (HHS)	Centres for Medicare and Medicaid services (CMS)	Measures	Yes	Assessment
NGO (private not for profit)	National Committee for Quality Assurance (NCQA)/ HEDIS (The Healthcare Effectiveness Data and Information Set)	Measures	Yes	Assessment

9.1.1 National Quality Forum (NQF)

The NQF is a not-for-profit, non-government organisation in the USA. The role of the NQF is to assess and endorse health quality measures developed by others that have been submitted to NQF. It is the most rigorous quality measure endorsement agency in the USA. The NQF's assesses quality measures on: (Ed Kelley et al., 2005; NQF)

- 1. Importance,
- 2. Scientific soundness (reliability, validity, evidence base),
- 3. Feasibility

4. Usability

The NQF uses the following guide for assessment - Measure Evaluation Criteria and Guidance for Evaluating Measures for Endorsement- August 2016). This guide clearly outlines a system of rating the level of reliability and validity as outlined in *Appendix 1*.

9.1.2 The American Medical Academy - Physician Consortium for Performance Improvement (AMA-PCPI)

The AMA is the key founding member of the Physician Consortium for Performance Improvement (PCPI). The PCPI includes health professionals, patients and health care organisations and has approved quality measures. For a quality measure to be PCPI approved it needs to meet standards in the PCPI "Measure Testing Protocol". (Association, 2010) This includes an assessment of:

- 1. Scientific evidence of a performance gap in health care needs from peer review publications and secondary analysis of current health care data. Evidence does not include quality improvement research that has used the measure being assessed.
- 2. Validity through testing of face and content validity is undertaken by the working group, however construct validity does not need to be assessed. For measures that are not supported by a strong evidence base, predictive validity testing is recommended. Validity should be evaluated across different types of data, providers and populations.
- 3. Reliability through testing of technical specifications including inter-abstractor and parallel form reliability across different types of data, providers and populations.
- 4. Feasibility through an implementation study that describes the strategy to use the assess the ease of data collection, barriers, resources and costs
- 5. Harm through monitoring for unintended consequences of using the quality measure.

The Working Group for assessment of a quality measure is comprised of a multidisciplinary expert panel from a number of specialties. The PCPI work with other quality measure organisations such as the NCQA.

9.1.3 Agency for Health Care Research and Quality (AHRQ) and National Quality Measures Clearinghouse (NQMC)

The purpose of the US Department of Health and Human Services' Agency for Health Care Research and Quality (AHRQ) is to produce evidence that will improve all the quality domains of health care including the development of quality measures. It reports on the quality of health care in the USA at a national level. (Hibbert et al., 2013)

The National Quality Measures Clearinghouse (NQMC) is a free and publicly available repository organised and funded by AHRQ that holds summaries of quality measures.(NQMC, National Quality Measure Clearinghouse AHRQ. https://www.qualitymeasures.ahrq.gov/ accessed September 2016) For a quality measure to be listed in the NQMC there are clear inclusion criteria regarding its definition, currency (i.e. last 3 years), rationale/importance, evidence base, technical specifications, data source, evidence of testing of reliability and validity and that an international, national, regional, state or local health organisation has "developed, adopted, adapted, or endorsed" the measure. The AHRQ NQMC has a "Template of Measure Attributes" tool that it asks submitters to use to demonstrate the process of quality measure development and testing for reliability and validity and to give evidence of endorsement.(NQMC, 2016)

9.1.4 Centres for Medicare and Medicaid services (CMS)

CMS uses standardised criteria to assess quality measures that may be used in its Physician Quality Reporting System (PQRS). For a quality measure to be used by CMS it need to be shown to be important/relevant, scientifically sound (valid and reliable), feasible, and usable. It is preferable if it is already endorsed by the NQF. The CMS's recommended process in developing quality measures in terms of importance/relevance and testing for reliability and validity is outlined in the document, "A Blueprint for the CMS Measures Management System" (the Blueprint). This Blueprint is also used by CMS to evaluate quality measures.(CMS (Centers for Medicare and Medicaid Services), 2016)

9.1.5 National Committee for Quality Assurance (NCQA)

The National Committee for Quality Assurance is a non-governmental, private, not-for-profit organization. It endorses organisations with a "NCQA seal" for quality if they meet its standards and continue to meet them annually. Assessment of organizations is done by reporting their performance on specific NCQA quality measures. These measures are listed in the Healthcare Effectiveness Data and Information Set (HEDIS). For a quality measure to be developed and/or included in HEDIS it must meet be relevant/important; scientifically sound (valid and reliable), and feasible. There is an in-depth manual for the quality measure development and assessment process entitled the HEDIS Volume 1: Narrative available for a cost at http://store.ncqa.org/index.php/catalog/product/view/id/2271/s/hedis-2016-volume-1-epub/.

9.1.6 Paediatric Quality Measures in the USA

The Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 has galvanised investment in paediatric quality measure development and testing in the USA. AHRQ and CMS have set up the Pediatric Quality Measures Program (PQMP). Seven centres of excellence in paediatric quality measure development and testing - were established using CHIPRA funds. (Mangione-Smith et al., 2011; Schuster, 2015) These measures will be used across the USA. Initially there were 24 Core "CHIPRA measures" in 2011. (Mangione-Smith et al., 2011) These have been re-examined in 2014 as part of their three yearly review of their importance, scientific soundness, feasibility and usability. Through the PQMP program, over 100 additional paediatric quality measures have been developed and tested, most of which are listed in the NQMC and some endorsed by the NQF Examples of quality measures are listed in *Appendix 2*.(Brooks, 2016; Dougherty et al., 2014; PQMP, 2016)

9.2 Australia

In Australia, there are a number of bodies that are involved in the assessment of quality in its health care system. However as recently as 2014 international reviews of Australia's quality indicator systems described a lack of overall systematic approach to developing and testing indicators with no central system of endorsement or warehousing. (Hibbert et al., 2013; OECD)

The Australian Commission on Safety and Quality in Health care (The Commission) was established in 2006 and is funded by the Australian Federal, State and Territory Governments. The National Health Reform Act (2011) require the Commission to develop National Safety and Quality Health Service (NSQHS) Standards that direct the improvement of quality in the Australian Health Care System in both the hospital and community. Indicators are being developed by the Commission that reflect these standards.(ACSQHC, 2016) The Commission works with non-government organisations that accredit health care providers such as Australian Council on Health care standards (ACHS), and professional bodies around the development of quality indicators. This is outlined in Table 2.

Agency	Source	Terminology	Details on testing of validity and reliability?	Role
Government	Australian Commission on Safety and Quality in Health care	Indicators	No (Toolkit to be published in future)	Development and Assessment
NGO	Australian Council on Health care standards (ACHS)	Indicators	Unclear	Development and Assessment

Table 2 Quality indicators in Australia

NGO	Children's Healthcare Australasia (CHA)	Indicators	No	Assessment and endorsement
NGO	Royal Australasian College of General Practice (RACGP	Indicators	No	Assessment and endorsement

9.2.1 Australian Commission on Safety and Quality in Health Care (the Commission)

The Commission has a role in developing quality indicators to enhance the implementation of the NSQHS. These quality indicators are recommended by the Commission to be used for quality improvement and accountability at a local level. It is a requirement that health care services regularly use these to monitor their safety and quality. At present, there is no mechanism for the Commission to independently assess the reliability and validity of the quality indicators. As such these indicators cannot be regarded as quality measures. However, the Commission has made the first step in being able to facilitate this in the future with a recent review of quality indicator development and a corresponding toolkit being produced. (Shaw.T, McGregor. D, & C, 2017). The report/toolkit are in press and will be available on ACSQHC

website<u>https://www.safetyandquality.gov.au/(ACSQHC, 2016)soon.</u>

On *personal communication* with Commission staff during the writing of this report, the Commission plans to "'Scope and develop neonate and paediatric safety and quality indicators". This is likely to commence in 2018.

9.2.2 Australian Council on Health care standards (ACHS)

The Australian Council on Health care standards (ACHS) is an independent NGO that is the lead provider of assessment and accreditation of the quality of health care organisations in Australia, including public and private hospitals.(ACHS, 2015) The Performance and Outcomes Service (POS) coordinates the development, collection, collation, analysis and reporting of the ACHS Clinical Indicators that are used in this accreditation process. ACHS accreditors will question the health care organisation on any action/s taken where a significant variation from their peer group's results on the indicators is evident.

The ACHS clinical indicator program was commenced in 1989 in consultation with Medical and Nursing Colleges, the Australian Private Hospitals Association (APHA), University of Newcastle statisticians and a consumer representative. Working parties are formed by these groups for indicator set development to focus on the importance and, face and content validity of the indicators. It is reported that validity and reliability are tested through extensive field testing, feedback and review (including indicator modification/deletion) by the working party of the indicator sets on a national basis before their release. The ACHS also tests validity by the qualitative feedback from health services in its usefulness post release (Booth & Collopy, 1997) (i.e. their ability to induce action for change and improvement). Therefore, it appears there is some testing of face and content validity but there is no documented mechanism for testing of construct, criterion or discriminant validity.

The ACHS indicator set technical specifications include a rationale, description, numerator and denominator as well as exclusions and notation whether the indicator is a process, outcome or structure indicator.(ACHS, 2014) Reliability of the indicator is also monitored post release by examining the consistency of the rates of the indicators over time. (Booth & Collopy, 1997) There does not appear to be a documented mechanism for testing of interrater reliability, internal consistency, form equivalence or sampling variation. The feasibility and usability are examined by the qualitative information the ACHS receives from hospitals in the first few years of the program. (Booth & Collopy, 1997)

Of note the above details apply broadly to all ACHS indicator sets, not specifically to the paediatric ones. Therefore, it is unclear if these are quality indicators or quality measures as per this report's definition.

The Royal Australasian College of Physicians (Paediatric and Child Health Division), CHA, University if Newcastle, Australian College of Children and Young People's Nurses, paediatric clinicians and consumers worked with ACHS to develop paediatric indicators which have a focus on hospital based child health care, structure and process. They include:

- 1. Completed asthma action plan paediatrics (paediatric patient separations with a primary diagnosis of asthma who are discharged with a completed asthma action plan)
- 2. Paediatric surgery post-procedural report (paediatric patients where the post-procedural instructions are documented on the Surgeon's/Operation Report)
- 3. Physical assessment completed by medical practitioner and documented (paediatric patients with a completed documented physical assessment conducted by a medical practitioner within 4 hours of admission, over a consecutive 7-dayperiod in May or November.)
- 4. Physical assessment completed by registered nurse and documented (paediatric patients with a completed documented physical assessment conducted by a registered nurse within 4 hours of admission, over a consecutive 7-day period in May or November)
- 5. Medical discharge summary completed paediatrics (paediatric patients with a completed medical discharge summary in their medical record, within the time specified in your healthcare organisation's guidelines)

These indicators are endorsed by The Royal Australasian College of Physicians. There are no paediatric quality indicators for out of hospital care in the ACHS set.(ACHS, 2014)

9.2.3 Children's Healthcare Australasia (CHA)

CHA is an international not-for-profit organisation that is the peak body for health care services for children and young people in Australia and New Zealand. (CHA, 2017) CHA has a number of dashboard indicators collected from its member paediatric hospital and health care services that it uses for benchmarking. These were selected by a multidisciplinary team who reviewed current indicators used in the USA, UK and Canada based on their importance, feasibility and scientific soundness. For each indicator a description with a rationale and recommendations of criteria for both numerators and denominators are provided. (CHA, 2010) The indicators include

- 1. rates of an event e.g. rate of re-presentation to Emergency Department with repeat diagnosis of asthma (within 8 days of departure from ED) or,
- 2. proportions e.g. of all reported incidents for known food allergy aged less than 19 years

<u>However, there is no formal testing of validity or reliability of these indicators described.</u> From the information available, the lack of specificity and testing of the measurement process indicates that these CHA indicators act as <u>guality indicators, not quality measures.</u>

9.2.4 Royal Australasian College of General Practice (RACGP)

The Royal Australasian College of General Practice (RACGP) has developed a set of quality indicators for Australian general practice that are a voluntary quality improvement tool that can be used by general practice.(RACGP, 2015, 2017) To develop the indicators an expert advisory group was established, conducted a literature scan, and developed indicators that were important, have face and content validity, feasible and supported by an evidence base.(RACGP, 2017) Stakeholder consultation was undertaken and the indicators were piloted. Technical specifications include a description, numerator, denominator, rationale and level of evidence from the literature that supports the indicator.(RACGP, 2015) <u>The only paediatric indicator available</u> <u>online and from the published literature is *childhood immunisation rates*, and there is no further detail of the <u>testing of its validity and reliability, thus it acts as a quality indicator rather than measure.</u></u>

9.3 United Kingdom (UK)

9.3.1 The National Health Service

The UK has an overarching National Health Service (NHS) Outcomes Framework that outlines goals for the quality of health services provided by the NHS. The Secretary of State holds NHS England, in particular the NHS Commissioning Board, to account for improvements in health outcomes outlined in the NHS Outcomes Framework. (Hibbert et al., 2013; NHS, 2017a, 2017b) Clinical Commissioning Groups (CCG), are responsible for buying and delivering most local NHS services. The NHS Commissioning Dutcomes Framework.(Raleigh, 2012) In addition to the NHS and CCG outcomes framework there is the Quality Outcomes Framework. This is used to guide the contracting of GP services by the NHS as part of a voluntary annual reward and incentive programme with the vast majority of GP surgeries in England participating. (Hibbert et al., 2013; NHS, 2012)

Linked to these frameworks are three sets of overarching quality indicators - (a) the NHS Outcomes Framework Indicator Set, (b) the Clinical Commissioning Group (CCG) Outcomes Indicator Set and (c) the Quality Outcomes Framework (QOF) Indicator Set.(Darzi, 2008; Gill, O'Neill, Rose, Mant, & Harnden, 2014; Hibbert et al., 2013; Macbeth) The indicators are stored on the NHS Digital Indicator Portal. (NHS, 2017a) The National Institute for Health and Care Excellence (NICE) has been commissioned by the NHS Commissioning Board to develop quality indicators to be used by CCGs and the NHS for the QOF. These link to 150 quality standards (including child health) that support the NHS Outcomes Framework and inform the CCG and QOF Outcomes Framework.(Raleigh, 2012) These quality standards are endorsed by NHS England and the Care Quality Commission which is the main independent regulator of health and social care in England (CQC, 2016) and have a list of supporting organisations such as professional colleges and support the delivery of outcomes.(Macbeth; NICE, 2014, 2016)

The relationships between the frameworks, NICE and the indicator sets is outlined in Figure 1 from a presentation on the topic by the King's Fund in 2012 and Table 3.

Figure 1 The relationship between quality frameworks, NICE and indicator sets (Raleigh, 2012)

The NHS Outcomes Framework



Table 3 Qualit	y measures and	indicators in the UK	
----------------	----------------	----------------------	--

Agency	Source	Terminology	Details on testing of validity and reliability?	Role
Government and	NHS/NICE	Indicators	Yes	Assessment and
NGO				endorsement
NGO	NICE	Indicators and	Yes	Assessment and
		Measures		endorsement

The NHS Outcomes Framework indicator set acts as an overarching national indicator set for the CCG and QOF indicators. Examples of the national child health indicators listed for the NHS Outcomes Framework include:(NHS, 2017a)

- 1. Potential years of life lost (PYLL) from causes considered amenable to healthcare (i.e. those that are treatable) children and young people.
- 2. Five-year survival from all cancers in children.
- 3. Emergency admissions for children with lower respiratory tract infections (LRTIs).
- 4. Tooth extractions due to decay for children admitted as inpatients to hospital, aged 10 years and under.

From the available published and online information these act as quality indicators rather than quality measures. This is because there is no description of testing of validity or rigour of the indicators.

The CCG Outcomes Indicator set is used by the CCGs, the public, patients and local government to monitor the quality of health care at the local level and drive local improvement. (Hibbert et al., 2013; NHS, 2017b) The CCG Outcomes indicator set includes (Raleigh, 2012):

- 1. NHS Outcomes Framework indicators measured at the level of the CCGs.
- 2. Indicators based on NICE quality standards that link to the Framework.

3. Other indicators linked to the Framework where standards are not available.

The CCG Outcomes paediatric quality indicators are listed in *Appendix 2*. The QOF indicator set changes annually.(Hibbert et al., 2013; NHS, 2012) It is used in the UK and Wales. Current examples of paediatric QOF indicators are listed in *Appendix 2*. (QOF, 2017)

In addition, all NHS service providers are required to publish annual Quality Accounts on their service through reporting on 15 mandatory indicators chosen by the National Quality Board (NQB).(Darzi, 2008) <u>It is important</u> to note that none of the Quality Account indicators for providers are specifically focused on children.(NHS, 2017a) There is no formal central reporting of paediatric quality indicators.

NICE has a key role in the development of the CCG Outcome Indicator Set and the QOF Indicator Set. This includes selecting indicators to be used, reviewing existing indicators and recommending if they should be part of the NHS frameworks. (Hibbert et al., 2013; Macbeth)

There is a clear process guide to the development of NICE CCG Outcome and QOF indicators. (NICE, 2014). There is a clear description of inclusions, exclusions, a rationale, a denominator and numerator.

The process for developing and testing the NICE quality indicators is in Figure 2.

Figure 2 NICE development and assessment of quality measures (NICE, 2014)



This process is overseen by an appointed NICE advisory committee and undertaken by a NICE indicator team. Testing of the indicator is led by the NHS Information Centre to assess validity, reliability and testing of feasibility, acceptability and unexpected consequences. Post testing there is a review by NICE and approval by the NHS Commissioning Board via a defined process.(Hibbert et al., 2013; Macbeth; NICE, 2014). Further details of testing of reliability and validity are not given in the NICE indicator process document.(NICE, 2014) However, a publication outlining the protocol for development and pilot testing of QOF indicators gives much more detail. In this document, the word *quality indicator was used interchangeably with quality measure*.

The steps for development and pilot testing of the QOF quality indicators include the formation of an expert working group whose role is to:(Stephen M. Campbell et al., 2011)

- 1. Undertake public consultation on the topic to assess its importance
- 2. Ensure the definition is clear and accurate and reflects the content as rated by the RAND/UCLA Appropriateness Method

- 3. Ensure that it is within the control of an area of healthcare as rated by the RAND Appropriateness Method
- 4. Test for content validity through a comprehensive evidence review and the measure needs to be underpinned by a review of national guidelines for England (NICE) and Scotland (SIGN).
- 5. Test for face validity by consensus as rated by the RAND Appropriateness Method.
- 6. Test for discriminate validity through assessment in a nationally representative sample of health care providers
- 7. Test for reliability through the application of detailed technical specifications to health care system data and generation of reproducible results when applied to this data through test retest (sampling variation) on health care data.
- 8. Test for feasibility through the application of detailed technical specifications to health care system data and generation of data reports within reasonable time frame and budget.
- 9. Ensure there is no harm through unintended consequences

Detailed methodology for testing for the Quality Outcomes Framework Indicators for British General Practice with a rigorous process for testing reliability and validity is outlined in *Appendix 1*. (Stephen M. Campbell et al., 2011)

The working group then makes recommendations which are considered by the NICE Advisory Committee. NICE then validates this decision on which potential QOF indicators have passed pilot testing by reviewing the testing data. The recommended indicators are then reviewed by the British Medical Association General Practitioners Committee and NHS and the process of assigning payments to the tested and validated indicators takes place if both bodies agree to their use.(Stephen M. Campbell et al., 2011) It is not clear from what is published and is available online if this testing protocol is used in the development of all CCG Outcome and QOF indicators not developed by NICE

The CCG and QOF indicators developed by NICE are linked to the NICE quality standards which have corresponding quality measures. (Macbeth; NICE, 2016) Of note the NICE Health and Social Care Directorate Indicators Process Guide states "Indicators from the NICE programme differ from quality measures within NICE quality standards because they have been through a formal process of testing against agreed criteria to ensure they are appropriate for national comparative assessment. Quality measures are not formally tested and are often intended to be adapted for use at a local level for local quality improvement. The term 'NICE indicator' is used in this guide to describe outputs of this formal process." (NICE, 2014)

From this statement, it appears that the terms quality indicator and quality measure <u>have opposite definitions</u> <u>compared to the USA</u>. It appears from the above methodology and their design that the QOF quality indicators and the CCG quality indicators which are designed following the NICE protocol are similar to what would be called <u>quality measures in the US</u>.

There are also a number of paediatric Patient Reported Experience Measures (PREMS) and Patient Reported Outcome Measures (PROMS) that are being developed, validated and piloted in the NHS in the areas of sickle cell disease, (Chakravorty et al., 2015) asthma (Soyiri, Nwaru, & Sheikh, 2016) and atopy (Gore et al., 2016), however they are not currently in the CCG Outcomes or QOF indicator sets.

9.4 The European Union (EU)

There is a range of initiatives in the EU to develop systems of quality measurement. These are outlined in Table 4.

Table 4 Quality measures and indicators in the EU

Agency	Source	Terminology	Details on testing of validity and reliability?	Role
OECD	1	1	ſ	I
OECD countries	Health Care Quality Indicators Project	Indicators	No	Assessment
CHILD				
EU	CHILD project	Indicators	No	Assessment
WHO - Europe				
WHO - Europe	WHO – PATH project	Indicators	No	Assessment
HSPA – Malta, Bel	gium, Italy and Portugal			
Government	Health system performance assessment (HSPA)	Indicators	No	Development and Assessment
Netherlands				L
Government	Dutch Health Care report	Indicators	No	Development and Assessment
Ireland				
NGO	The Health Information and Quality Authority	Indicators	Yes	Development and Assessment
Government	National Healthcare Quality Reporting System	Indicators	Yes	Development and Assessment
Norway		•		•
Government	Norwegian Knowledge Centre for the Health Services	Indicators	Yes	Development and Assessment
Denmark				
Danish Government	Clinical quality development program	Indicators	Yes	Development and Assessment
Sweden				
The Swedish National Board of Health and Welfare and the Swedish Association of Local Authorities and	Clinical indicators	Indicators	No	Development and Assessment
Regions				
France	I	1		I
Government	French National Authority for Health (HAS)	Indicators	Yes	Development and Assessment
Germany				

Government	Federal Office for	Indicators	No	Development
	Quality Assurance			and Assessment
	(BQS)			

9.4.1 Organization for Economic Cooperation and Development (OECD)

The Organisation for Economic Co-operation and Development Health Care Quality Indicators (HCQI) Project led by the OECD commenced in 2001. It was overseen by an expert group made up of representatives from 23 countries (Australia, Austria, Canada, Czech Republic, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Japan, Mexico, Netherlands, New Zealand, Norway, Portugal, Slovak Republic, Spain, Sweden, Switzerland, United Kingdom, United States.(Arah et al., 2006; E. Kelley & Hurst, 2006) Since 2010, 37 countries have been involved. The HCQI criteria for the development of quality indicators include: (Arah et al., 2006; E. Kelley & Hurst, 2006)

- 1. Importance.
- 2. Scientific soundness including reliability, face and content validity
- 3. Feasibility

An Expert Group in the HCQI has developed quality indicators that were selected based on research reviews, have been tested for data collection and comparison in existing country databases.(Arah et al., 2006) The HCQI indicators were reviewed by the expert group in 2015. (Carinci et al., 2015) They are described by numerator/denominator/exclusions/quality domain

From the information published and online there was not sufficient detail be clear if these indicators are able to detect variations in quality across the range of child health care are occurring, why and who is accountable. <u>This precludes them being regarded as accurate and reliable quality measures, rather they appear to be quality indicators.</u> In addition, although it is stated that all indicators were chosen through systematic selection, pilot testing and refinement, details on testing procedure are not given. (Klazinga, 2014) <u>The only indicators specific to paediatrics are vaccination coverage.</u>

9.4.2 The World Health Organisation PATH project- Europe

In 2003 the World Health Organization (WHO) Regional Office for Europe launched the performance assessment tool for quality improvement in hospitals (PATH). This involved workshops with worldwide experts, an extensive literature review, evaluation of existing indicators and a survey of health professionals in 20 European countries. As part of the PATH project there was a selection of core performance indicators to use to assess quality. The criteria for indicator selection included criteria on:(Veillard et al., 2005).

- 1. Relevance and importance.
- 2. Scientific soundness including demonstrated validity (including face, content, and construct validity) and reliability.
- 3. Feasibility.

These were then piloted and revised in Belgium, Denmark, France, Lithuania, Poland, Slovakia. (Groene, Klazinga, Kazandjian, Lombrail, & Bartels, 2008). PATH quality indicators are used at a National and International level. There is a PATH coordinator in each participating country who reports on the countries performance against the indicators and hospital coordinators. Participating countries include Albania, Bosnia and Herzegovina, Croatia, Czech Republic, Estonia, France, Germany, Greece, Hungary, Lithuania, Malta, Poland, Slovakia, Slovenia, Spain and Turkey.(PATH, 2017)

The only clear paediatric indicator is percentage of infants being exclusively nurtured with breast milk (including expressed milk) from birth to discharge. (Guisset, 2009) Although these indicators exist, there is no detail of testing for reliability or validity or detailed technical specifications being used once an indicator is selected, thus these appear to be quality indicators rather than quality measures.

9.4.3 Health Systems Performance Assessment (HSPA)

In Malta, Belgium, Italy, Portugal and Finland there are indicators used for Health Systems Performance Assessments (HSPA).

In 2015 Malta's first Health system performance assessment (HSPA) was published by the Ministry for Energy and Health. A working group was formed to select the indicators.(Grech K., Podesta M., Calleja A., & N., 2015) Belgium publishes HSPA every three years with intermediate reports every two years. In Italy, there is a set of quality indicators from The National Outcome Evaluation Program (PNE) used to evaluate the outcomes of health care in the Italian Health Service. In Portugal, the Ministry for Health has a national system of indicators to monitor health care quality. <u>However, there are no paediatric indicators</u>. In all these countries, a description of indicator selection for HSPA is given as follows;

- 1. Formation of an expert working group
- 2. A literature review, a review of international indicators including the OECD HCQI(E. Kelley & Hurst, 2006)
- 3. Selection of indicators through a consensus method. In Malta, this includes a description of selection criteria of usefulness, scientific soundness (reliability and validity) and feasibility. Indicators are assessed using a survey method with external scoring using a criteria matrix and algorithm adapted from OECD HCQI with 60% as the cut off mark for further inclusion in the HSPA.(Commission, 2016)

<u>No description of testing of validity and reliability is given for any of the countries</u>.(Commission, 2016; Grech K. et al., 2015)

The paediatric indicators used in the HSPA include child mortality (Malta), Annual Incidence of Type 1 Diabetes in children between 0-14 years of age at diagnosis (clinical) per 100,000 children (Malta), vaccination coverage in children (Malta, Belgium); proportion of low-birth-weight infants (Finland) and hospitalisation for paediatric gastroenteritis (Italy).

It is noted in a review of these countries by the European Commission in 2016 that these are indicators, in that they indicate issues with quality, they are not quality measures. (Commission, 2016)

9.4.4 The Child Health Indicators of Life and Development (CHILD) project

The Child Health Indicators of Life and Development (CHILD) project was undertaken between 2000 and 2002 as a collaboration between the then 15 EU Member States, plus two (Iceland and Norway) of the European Economic Area (EEA) countries to identify key population level child heath indicators of health and illness, health determinants and challenges to health, quality of healthcare support and health-promoting national policies for children aged between 1 week and 15 years. (Rigby, Köhler, Blair, & Metchler, 2003) Each nation involved nominated an expert to be on the working group

The group had a systematic approach to identifying indicators. This included a structured search of published evidence to identify indicators. The following criteria were used to assess if indicators would be considered by the group:

- 1. Validity -Face validity; content validity and construct validity.
- 2. Reliability
- 3. Feasibility
- 4. Sensitivity (can register appropriate change)
- 5. Definition topic; measure; measurement and data capture

Potential indicators were then further filtered through a process of consensus within the group and external consultation based on:

- 1. The evidence base for the indicator being underpinned by research
- 2. The indicator measures a condition that has a considerable burden to society, family and the individual
- 3. The indicator has representativeness of significant population groups

- 4. The regularity and repeatability of the indicator
- 5. Data availability
- 6. The topic amenable to effective action
- 7. The indicator being understandable to broad audience.

There is a final list of 38 population level indicators that span childhood. The indicators of quality of health services in the finalised set are:

1. Immunization rates for childhood immunisation, expressed as children aged 24–35 months inclusive having completed primary courses of immunization as a percentage of all children in that age-group, separately for the following antigens: Diphtheria, pertussis, tetanus, poliomyelitis, haemophilus influenza type b, measles, mumps, rubella, hepatitis B, meningococcus C

2. Five-year survival rate for acute lymphatic leukaemia, in age-groups at diagnosis 0–4; 5–9; 10–14; 15–19

There is also an indicator for access to services:

1. Percentage of inpatient bed days of children aged under 16 occurring in hospitals where accompanying by 'parents' day and night is offered

Significant gaps in knowledge were identified and work is now being undertaken to develop indicators in these areas in the RICHE project. These indicators have also been used in to support and monitor the WHO Child and Youth strategy for Europe in 2005. From published and online sources there is no further detail on the pilot testing for validity or reliability, detailed technical specification or endorsement process by which central agencies in which countries use them. (Rigby et al., 2003)<u>Therefore, it appears that these are quality indicators rather than quality measures as per this report's definition.</u>

9.4.5 Netherlands

The Netherlands uses the OECD HCQI quality indicator framework in its biennial "The Dutch health care performance report" for the Dutch Ministry of Health. This is produced by the Dutch National Institute for Public Health and the Environment (RIVM) to assess the health care system quality over time and in comparison, to other countries.(Arah et al., 2006; M. van den Berg, Heijink, Zwakhals, Verkleij, & Westert, 2011; M. J. van den Berg, Kringos, Marks, & Klazinga, 2014)

<u>The paediatric quality indicators in these reports only include vaccinations, infant mortality, preventive health</u> <u>care attendance, prevalence of obesity, and survey data on experience of care</u>.(Westert, van den Berg, Zwakhals, De Jong, & Verkleij, 2010) Although there is a clear description of indicator testing for reliability and validity of quality indicators used in the Dutch health system in the areas of head and neck tumours; diabetes mellitus and pneumonia, it is not clear if this is universal or if it applies to child health.(Wollersheim et al., 2007) <u>Therefore at</u> <u>present these appear to be quality indicators rather than measures at least for paediatrics.</u>

9.4.6 Ireland

Ireland has The Health Information and Quality Authority, established under the Health Act 2007 by the Irish Government to drive safety and quality in health and social care. The Authority reports directly to the Minister for Health and Children.(Health Information and Quality Authority, 2013)

The process for development of indicators involves the establishment of an advisory group whose selection criteria for quality indicators includes (Health Information and Quality Authority, 2013):

- 1. Face and content validity
- 2. Inter-rater, test retest reliability and internal consistency
- 3. Explicit evidence base including grading of evidence, Delphi and RAND techniques with an expert advisory panel.
- 4. Relevance

- 5. Acceptability
- 6. Feasibility
- 7. Sensitivity/specificity
- 8. Harmonisation existing indicators that have been tested are examined and no duplication in development
- 9. Safety (i.e. no unintended adverse consequences)

For testing there is a detailed guide from the Authority outlining the need for detailed technical specifications and a clear plan to validate the indicators against the above selection criteria. (Health Information and Quality Authority, 2013)

The National Healthcare Quality Reporting System has been established by Ireland's Minister for Health.(An Roinn Slainte, 2013) Its first annual report was in 2015. The Authority contributes to this report. The selection of indicators used in the report takes into account the recommendations of the Health Information and Quality Authority on selection of indicators (An Roinn Slainte, 2013, 2015; Health Information and Quality Authority, 2013) There is no clear process of endorsement described.

It appears from the above methodology and their design that these quality indicators are similar to what would be called quality measures in the US. However, there are no paediatric quality measures other than vaccination coverage. (An Roinn Slainte, 2013)

9.4.7 Norway

In Norway, the Norwegian Knowledge Centre for the Health Services has made recommendations for the development and testing of quality indicators for the Department of Health for the purposes of accountability, governance and quality improvement.(Rygh et al., 2010) The NQIS - The Norwegian Quality Indicator System indicator development is based on the OECD HCQI method.(European Commission, 2016; E. Kelley & Hurst, 2006) Indicators must be relevant, scientifically sound (valid and reliable), feasible and applicable. The recommendations outline a structure and process for developing and testing indicators including formation of a consensus group, systematic examination of the literature and indicator sets and a test phase (piloting and evaluating the selected indicators for validity, precision and bias in current data sets). It is advised that risk adjustment occur if systematic biases are detected and that there should regular updating and re-evaluation of indicators using the consensus process. (Rygh et al., 2010)

From the data published and available online in English no paediatric quality indicators were able to be identified. There was no clear process for endorsement described. It appears from the above methodology and their design that these quality indicators are similar to what would be called quality measures in the US. However, there are no paediatric quality measures described in the published and online material available in English.

9.4.8 Denmark

The Danish Institute for Quality and Accreditation in Healthcare is the peak body for health care quality in Denmark. The Danish National Indicator project was commenced in 2000 but is now merged with the Clinical Quality Development Program. (Hibbert et al., 2013) The indicators were developed with multidisciplinary expert groups including doctors, nurses, physiotherapists, occupational therapists, the Ministry of Health, the National Board of Health, the County Counsellors' Association and Scientific Societies. (Mainz, Krog, Bjørnshave, & Bartels, 2004) The principals underpinning indicator development were that the indicators include importance, relevance, scientifically sound (valid and reliable), and useful.

The indicators were pilot tested nationwide and validated by inter-rater reliability assessments. Data specifications were also reviewed. (Mainz et al., 2004) All hospitals and associated clinical departments must use these clinical indicators. Data on these indicators are examined at a local, regional and national level with

monthly feedback to clinical teams and health care organisations. There is an audit process every 6 months after which the data are released to the public.(Hibbert et al., 2013)

It appears from the above methodology and their design that the quality indicators are similar to what would be <u>called quality measures in the US.</u> There is no clear process of endorsement described. The paediatric quality measures are outlined in *Appendix 2*.

9.4.9 Sweden

Sweden has developed national health care quality indicators. All County Councils (CC) in Sweden make their own decisions about reporting to national quality registers. There exist written statements that all CC should report to national quality registers but it is not mandatory. The indicators are published on a yearly basis on a local authority level and as a national snapshot in the Regional Comparisons report which is based on available national healthcare statistics. The Swedish National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions conduct the project on a joint basis.(Heurgren, Åberg, Köster, & Ljung, 2007; Swedish Association of Local Authorities and Regions, 2013) The last available report online was for 2012.(Swedish Association of Local Authorities and Regions, 2013)

Indicators reported have a description, numerator, denominator, method of measurement, data sources and sources of error defined. This report states that the indicators used should be feasible, well defined, valid (determined by whether the indicator is generally accepted and preferably part of other established sets), relevant, and useful. Indicators should include outcome and process measures. It states however that "the report uses some indicators that do not fully meet these criteria". No further detail of testing of validity and reliability is given.(Swedish Association of Local Authorities and Regions, 2013)

The Swedish Diabetes Register for children, swediabkids, https://swediabkids.ndr.nu/ which is run by a group of pediatric endocrinologists in Sweden collects:

 Percentage of child and adolescent diabetics 18 years and younger who reached the treatment goal for HbA1c levels in the year being reported (The treatment goal was an HbA1c level of 6.5 percent or below.) (National Diabetes Register)

Additional indicators that are collected for the regional comparisons include:

- Children age 6 and younger treated with penicillin V as a percentage of all children treated with respiratory antibiotics. (The indicator assesses the percentage of children who received penicillin V as first-line treatment when prescribing respiratory antibiotics.) (Prescribed Drug Register, Swedish National Board of Health and Welfare)
- 2) Vaccination of children measles-mumps-rubella (MMR) (Swedish Institute for Infectious Disease Control -vaccination based registers)
- 3) Appointments at child and adolescent psychiatric clinics percentage of patients with waiting times longer than 30 days of everyone on the waiting list, 31 March 2012.

The Barnhälsovårdsregistrets (BHVQ) is a suite of quality indicators for preventive child health services for ages 0-5 years that is in the process of being set up for all of Sweden. It is based on the experience of two regional quality indicator sets. This register has not yet collected any data. The register has defined measures of indicators of risk factors amenable for prevention such as breastfeeding, vaccination and parental smoking, and early intervention indicators such as home visits and participation in parent education groups. This will form continuous quality improvement activities in child health.(BHVQ, 2017) None of these indicators have been formally tested for their validity and reliability at a national level, although this is an area for future development. In Sweden, the term quality measure applies to an indicator sare operationalised (*personal communication*). Further details on how these indicators are operationalised in terms of validity, reliability

testing, and technical specifications are not available in published or online sources. <u>Therefore, these must be</u> <u>considered to be quality indicators rather than quality measures as per this report's definition.</u>

9.4.10 France

Health care quality in France is overseen by the French National Authority for Health (HAS). HAS has developed health care quality indicators with health professionals. These are used for accreditation, public reporting, financial incentives, contracting of services and policy development at the regional and national level. (Commission, 2016) The methodology for quality indicator development includes

- 1. Formation of a working group (healthcare professionals, coders, and consumers of the healthcare system).
- 2. A literature review and selection of indicators by healthcare professionals using a two-round Delphi technique.(Commission, 2016) To be selected indicators must have clinical relevance, feasibility and be scientifically sound in terms of:(HAS, 2017b)
 - a. Reliability, which is assessed by inter-observer stability and internal consistency.
 - b. Face and content validity, which is assessed as all users having a mutual understanding of the indicator and the indicator's "ability to represent all important dimensions of an assessed clinical situation", respectively.
- 3. Pilot testing on 50 to more than 100 hospitals depending on the quality indicator to assess feasibility, reliability and discriminant validity.(Commission, 2016)

A published example of the method of developing and testing these quality indicators describes pilot testing for feasibility in 23 hospitals followed by larger scale testing in 60 hospitals for internal validity, reliability and relevance. (Ferrua et al., 2012)

It appears from the above methodology and their design that these quality indicators are similar to what would be called quality measures in the US. No specific paediatric measures were found in the available published and online information.(HAS, 2017a)

9.4.11 Germany

The Federal Office for Quality Assurance (BQS) measures quality at the regional level using indicators in hospitals and ambulatory services. Results are fed back to individual hospitals in an annual report that is made publicly available. Quality indicators are derived by medical staff and from administrative data. (Busse, Nimptsch, & Mansky, 2009) Since 2008 the development of quality Indicators is mandatory for every new German National Disease Management Guideline (NDMG). The NDMG has an NDMG Quality Indicators expert panel and assessment of the NDMG indicators is done using the QUALIFY instrument, which was developed by the BQS.(M. Nothacker & Reiter, 2010; Reiter et al., 2007) The QUALIFY instrument assesses the following:

- 1. Relevance and importance of the quality indicator.
- 2. Scientific soundness including validity and reliability.
- 3. Feasibility.

The quality indicators are developed in cooperation with the NDMG guideline authors. It is recommended that they meet the QUALIFY criteria and that there is a pilot testing. No further details of testing are given. There is no clear description of endorsement provided (M. Nothacker & Reiter, 2010)

However, in an analysis of criteria for quality indicators in 2010 not all were assessed for scientific soundness and feasibility and few were piloted. (Monika Nothacker, Bunk, Weinbrenner, & Ollenschläger, 2010) <u>Therefore, it appears that these are quality indicators as per this report's definition. No specific paediatric indicators are apparent from the published and online information that is available.</u>

10. Discussion

Thirteen countries/collaborations of countries were able to provide information on paediatric quality measure development and testing. In only six countries (the USA, UK, Ireland, Norway, Denmark and France) are there clear descriptions of some type of testing for validity and reliability and thus could be classified as quality measures. However, of these six countries:

- 1. Not all paediatric quality indicators could be considered to be quality measures as the testing is not uniform.
- 2. Only four (the USA, UK, Ireland and Denmark) had a clear description of testing of paediatric quality measures for validity and reliability
- 3. Only two countries (USA and UK) have a clear process of quality measure endorsement by a central agency or respected organisations described online in English speaking websites.

Key Findings from this report include:

- 1. There are issues with interchangeable use of terminology with quality indicators and measures <u>across countries.</u> Only in the USA was the term *quality measure* used to refer to clearly defined, validated and robust tools that can be used to assess the performance of health care providers and systems. Also in the USA, quality indicators referred to tools that are used to identify broadly, that is *"indicate"*, whether health care services are high or poor quality rather than accurately measure the outcome to be addressed. In the UK, the definition of a quality measure and indicator appeared to be the opposite to that of the USA. In all other countries, there was no differentiation in the terminology between quality indicators and measures.
- 2. There are variable criteria across countries for the development of quality measures. Although all study countries provided a listing of criteria for measure development which included importance, relevance, scientific soundness (including validity and reliability) and feasibility, for many there was no further or only limited details of these criteria. For example, the agencies in the USA provided detailed descriptions of the components of validity and reliability including the multiple dimensions of validity and reliability that must be considered, while other countries gave only a partial or no description of these components of measurement.
- 3. In most countries, there was a lack of testing of quality measures for validity and reliability. For only six countries (the USA, UK, Ireland, Norway, Denmark and France) was there clear descriptions of testing for validity and reliability. In the UK and France, it appeared that this testing was not uniformly applied across all measures promulgated by government bodies.
- 4. When testing of quality measures was performed, there was significant variation in testing for validity and reliability. In only the USA was there a detailed description of testing of all the components of validity and reliability (see *Appendix 1*)
- 5. For almost all countries, there was a lack of a central agency or specific respected organizations(s) for endorsement of quality measures. In only the USA and UK was there a clearly described process of endorsement which followed a rigorous and impartial evaluation of the components of the quality measure by a government or non-profit organisation.
- 6. <u>Across all countries, there is a lack of broad/universal use of paediatric quality measures</u>. Only four countries (the USA, UK, Ireland and Denmark) had paediatric quality measures. In Ireland, this was limited to childhood vaccination. In only the USA with the PQMP there are clearly documented paediatric quality measures that extend from preventive to tertiary paediatrics.

11.Conclusion

Quality measurement can inform and encourage improvement in child health care. Outside of the USA, there is a paucity of paediatric quality measures used outside of the USA that have been rigorously developed, assessed and endorsed. An international effort is required to address this issue. Without this there is no way to accurately measure how child health services are used, if they are safe, and where are the performance gaps.

Such information is essential to hold health services accountable for their quality, measure disparities in their provision and for parents and children to make informed choices about their care.

12. Recommendations

It is clear from this report that a standardised international approach to terminology, definition, development, testing and endorsement is required. The recommendations from this report are as follows:

12.1 Recommendation 1

Develop uniform definitions for quality measures and quality indicators.

12.2 Recommendation 2

All quality measures should be developed with the following minimum criteria:

- 1. Relevance/importance
- 2. Scientific soundness validity/reliability
- 3. Feasibility
- 4. Usability/acceptability

12.3 Recommendation 3

An expert working group should be formed which conducts an evidence review for the importance/relevance of the quality measure and develops detailed technical measure specifications for obtaining data and calculating the measure. This includes a clear definition of variables to be measured with a denominator and numerator, inclusion/exclusion criteria (e.g., age, gender; health condition; setting (primary vs tertiary)); a data source and time frame for collection and a rationale for why it is important to collect the data.

12.4 Recommendation 4

All quality measures should be pilot tested for *reliability*. This should include one or more of the following depending on the specific measure:

- 1. Testing inter-rater (inter-abstractor) and intra-abstractor reliability between those doing the data extraction.
- 2. Parallel form (form equivalence) reliability
- 3. Checking for internal consistency
- 4. Ensuring test- retest (sampling variation) reliability over time

12.5 Recommendation 5

All quality measures should be pilot tested for *validity.* This should include one or more of the following depending on the specific measure:

- 1. Content validity
- 2. Face validity
- 3. Construct validity
- 4. Criterion validity
- 5. Discriminant validity

12.6 Recommendation 6

Develop and test new paediatric quality measures across primary to tertiary and across taking into account the 4Ds of quality measurement in childhood - developmental change; dependency; differential epidemiology and demographic patterns including child and family reported quality of care

12.7 Recommendation 7

Governments should have a central agency that endorses quality measures using a rigorous and impartial evaluation of the components of the measure.

13. References

- ACHS. (2014). Paediatrics Version V Clinical Indicator User Manual. The Australian Council on Healthcare Standards.
- ACHS. (2015). The Australian Council on Healthcare Standards. <u>http://www.achs.org.au/</u> accessed September 2016.
- ACSQHC. (2016). http://www.safetyandquality.gov.au/national-priorities/goals/ accessed October 2016.
- AHRQ. (2015). National Healthcare Quality and Disparities Report <u>http://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/nhqdr15/2015nhqdr.pdf</u> accessed Sept 2016.
- AIHW. (2011). Headline indicators for children's health , development and wellbeing. Australian Institute of Health and Welfare. Canberra. Cat. no PHE 144.
- An Roinn Slainte. (2013). An Roinn Slainte. Health Care Quality Indicators in the Irish Health System: Examining the Potential of Hospital Discharge Data using the Hospital Inpatient Enquiry System available at http://www.rte.ie/documents/news/hcqi.pdf accessed September 2016.
- An Roinn Slainte. (2015). An Roinn Slainte, Department of Health, National Healthcare Quality Reporting System First Annual Report.
- Arah, O. A., Westert, G. P., Hurst, J., & Klazinga, N. S. (2006). A conceptual framework for the OECD Health Care Quality Indicators Project. *International Journal for Quality in Health Care, 18*(suppl 1), 5-13. doi:10.1093/intqhc/mzl024
- Association, A. M. (2010). Measure Testing Protocol for Physician Consortium for Performance Improvement (PCPI) Performance Measures.
- Barker, L., & Field, D. (2014). Neonatal quality measures: time to show developmental progress? Arch Dis Child Fetal Neonatal Ed, 99(6), F505-509. doi:10.1136/archdischild-2013-305623
- Berry, J., Bloom, S., Foley, S., & Palfrey, J. (2010). Health Inequity in Children and Youth With Chronic Health Conditions. *Pediatrics, 126 Suppl 3*, S111-119.
- BHVQ. (2017). Barnhälsovårdsregistrets (BHVQ). <u>http://rcso.se/register/anslutna-register/bhvq/</u>. accessed February 2017.
- Booth, J. L., & Collopy, B. T. (1997). A national clinical indicator database: issues of reliability and validity. *Australian Health Review, 20*(4), 84-95.
- Bordley, W. C. (2002). Outcomes research and emergency medical services for children: domains, challenges, and opportunities. *Ambul Pediatr, 2*(4 Suppl), 306-310.
- Brooks, T. (2016). Measuring and Improving Health Care Quality for Children in Medicaid and CHIP: A Primer for Child Health Stakeholders. Robert Wood Johnson Foundation . Georgetown University, Health Policy Institute. available at <u>http://ccf.georgetown.edu/wp-</u> <u>content/uploads/2016/03/Measuring Health Quality Medicaid CHIP Primer.pdf</u> accessed December 2016.
- Busse, R., Nimptsch, U., & Mansky, T. (2009). Measuring, monitoring, and managing quality in Germany's hospitals. *Health affairs, 28*(2), w294-w304.
- Byron, S. C., Gardner, W., Kleinman, L. C., Mangione-Smith, R., Moon, J., Sachdeva, R., . . . Scholle, S. H. (2014). Developing measures for pediatric quality: methods and experiences of the CHIPRA pediatric quality measures program grantees. *Academic pediatrics*, *14*(5), S27-S32.

Campbell, S. M., Braspenning, J., Hutchinson, A., & Marshall, M. N. (2003). Research methods used in developing and applying quality indicators in primary care. *BMJ : British Medical Journal, 326*(7393), 816-819.

- Campbell, S. M., Kontopantelis, E., Hannon, K., Burke, M., Barber, A., & Lester, H. E. (2011). Framework and indicator testing protocol for developing and piloting quality indicators for the UK quality and outcomes framework. *BMC Family Practice*, *12*, 85-85. doi:10.1186/1471-2296-12-85
- Carinci, F., Van Gool, K., Mainz, J., Veillard, J., Pichora, E. C., Januel, J. M., . . . Raleigh, V. (2015). Towards actionable international comparisons of health system performance: expert revision of the OECD framework and quality indicators. *International Journal for Quality in Health Care, 27*(2), 137-146. doi:10.1093/intqhc/mzv004
- CHA. (2010). Children's Healthcare Australasia . A presentation from CHA Benchmarking Meeting done in April 2010 by Elizabeth Chatham (CEO of CHA at the time) and Aarthi Ayyar-Biddle.
- CHA. (2017). Children's Healthcare Australasia <u>https://children.wcha.asn.au/</u> accessed September 2016.
- Chakravorty, S., Tallett, A., Hay, H., Chisholm, A., Warner, J., Sathyamoorthy, G., & James, J. (2015). Assessing the care experiences of people living with sickle cell disease to inform the development of a patient reported experience measure (prem). *British Journal of Haematology, 169*, 25-26.
- CMS (Centers for Medicare and Medicaid Services). (2016). CMS Measures Management System Blueprint (the Blueprint) v 12.0. <u>https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/MMS-Blueprint.html</u>.
- Commission, E. (2016). SO WHAT? Strategies across Europe to assess quality of care available at http://ec.europa.eu/health//sites/health/files/systems performance assessment/docs/sowhat en.pdf accessed November 2016.
- CQC. (2016). Care Quality Commission available at (<u>http://www.cqc.org.uk/</u>) accessed September 2016.
- Darzi, A. (2008). High quality care for all: NHS next stage review final report (Vol. 7432): The Stationery Office.
- Donabedian, A. (1966). Evaluating the quality of medical care. *The Milbank memorial fund quarterly, 44*(3), 166-206.
- Dougherty, D., Mistry, K. B., Lindly, O., Desoto, M., Llanos, K., & Chesley, F. (2014). Systematic Evidence-Based Quality Measurement Life-Cycle Approach to Measure Retirement in CHIPRA. *Academic pediatrics,* 14(5, Supplement), S97-S103. doi:<u>http://dx.doi.org/10.1016/j.acap.2014.06.015</u>
- European Commission. (2016). SO WHAT? Strategies across Europe to assess quality of care available at http://ec.europa.eu/health/sites/health/files/systems performance assessment/docs/sowhat en.pdf accessed November 2016.
- Ferrua, M., Couralet, M., Nitenberg, G., Morin, S., Serin, D., & Minvielle, E. (2012). Development and feasibility of a set of quality indicators relative to the timeliness and organisation of care for new breast cancer patients undergoing surgery. *BMC Health Services Research*, *12*(1), 167. doi:10.1186/1472-6963-12-167
- Fitch, K., Bernstein, S. J., Aguilar, M. D., Burnand, B., & LaCalle, J. R. (2001). *The RAND/UCLA appropriateness method user's manual*. Retrieved from
- Forrest, C. B., Simpson, L., & Clancy, C. (1997). Child health services research. Challenges and opportunities. JAMA, 277(22), 1787-1793.
- Gill, P. J., O'Neill, B., Rose, P., Mant, D., & Harnden, A. (2014). Primary care quality indicators for children: measuring quality in UK general practice. *The British Journal of General Practice, 64*(629), e752-e757. doi:10.3399/bjgp14X682813
- Goldfeld, S., Woolfenden, S., & Hiscock, H. (2016). Access to Quality Health Services. Section 5.2 in Chapter 5 Health CRC 25. Australian Child Rights Progress Report. Australian Child Rights Taskforce, 2016.
- Gore, C., Griffin, R., Rothenberg, T., Tallett, A., Hopwood, B., Sizmur, S., . . . Warner, J. O. (2016). New patientreported experience measure for children with allergic disease: development, validation and results from integrated care. *Arch Dis Child*, *101*(10), 935-943. doi:10.1136/archdischild-2015-309598
- Grech K., Podesta M., Calleja A., & N., C. (2015). Performance of the Maltese Health System. Ministry for Energy and Health (Health), Valletta, Malta

- Groene, O., Klazinga, N., Kazandjian, V., Lombrail, P., & Bartels, P. (2008). The World Health Organization Performance Assessment Tool for Quality Improvement in Hospitals (PATH): an analysis of the pilot implementation in 37 hospitals. *International Journal for Quality in Health Care, 20*(3), 155-161.
- Guisset, A.-L. (2009). PATH Preview of Indicators. World Health Organisation regional office for Europe. Available at <u>http://www.pathqualityproject.eu/upLoad/file/path09_ljubljana_workshop__part2.pdf</u> accessed November 2016.
- HAS. (2017a). Haute Autorite De Sante. <u>http://www.has-sante.fr/portail/jcms/c_2044563/en/healthcare-guality-and-safety-indicators</u> November 2016.
- HAS. (2017b). Haute Autorite De Sante. <u>http://www.has-sante.fr/portail/jcms/r_1455081/Home-page</u> accessed November 2016.
- Health Information and Quality Authority. (2013). Health Information and Quality Authority. Guidance on Developing Key Performance Indicators and Minimum Data Sets to Monitor Healthcare Quality:February 2013 (Version 1.1). Dublin: Health Information and Quality Authority.
- Heurgren, M., Åberg, A., Köster, M., & Ljung, R. (2007). Performance indicators in Swedish Health Care. *BMC Health Services Research*, 7(1), A10. doi:10.1186/1472-6963-7-s1-a10
- Hibbert, P., Hannaford, N., Long, J., Plumb, J., & Braithwaite, J. (2013). Final report: performance indicators used internationally to report publicly on healthcare organisations and local health systems. *Australian Institute of Health Innovation, University of New South Wales*.
- Hodgson, E., Simpson, L., & Lannon, C. (2008). Principles for the development and use of quality measures. *Pediatrics*, 121(2), 411-418.
- IOM (Institute of Medicine). (1990). Medicare: A Strategy for Quality Assurance, by the Committee to Design a Strategy for Quality Review and Assurance in Medicare Volume I. Lohr KN, ed. Washington, DC: National Academies Press.
- IOM (Institute of Medicine). (2001). Crossing the quality chasm: a new health system for the 21st century by the Committee on Quality of Health Care in America: National Academy Press.
- IOM (Institute of Medicine). (2011). Committee on Pediatric Health and Health Care Quality Measures Board on Children, Youth, and Families, Board on Health Care Services; Institute of Medicine and National Research Council of the National Academy. Child and Adolescent Health and Health Care Quality: Measuring What Matters. National Academies Press, Washington, DC; 2011.
- Kavanagh, P. L., Adams, W. G., & Wang, C. J. (2009). Quality indicators and quality assessment in child health. *Archives of disease in childhood, 94*(6), 458-463.
- Kelley, E., & Hurst, J. (2006). Health care quality indicators project. OECD Health Working Papers, No. 23, OECD Publishing. <u>http://dx.doi.org/10.1787/440134737301</u>.
- Kelley, E., Moy, E., Stryer, D., Burstin, H., & Clancy, C. (2005). The national healthcare quality and disparities reports: an overview. *Medical care, 43*(3), I-3-I-8.
- Klazinga, N. (2014). Update on OECD's Health Care Quality Indicator Project Measurement, Information Systems, Policies and Governance in OECD countries Patient Safety and Quality of Care Working Group, Brussels, March 13
- Kuhlthau, K. A., Mistry, K. B., Forrest, C. B., & Dougherty, D. (2014). Advancing the Science of Measurement in Pediatric Quality of Care. Academic pediatrics, 14(5, Supplement), S1-S3. doi:<u>http://dx.doi.org/10.1016/j.acap.2014.06.016</u>
- LAWTHERS, A. G. (1996). III Validity Review of Performance Measures. *International Journal for Quality in Health Care, 8*(3), 299-306.
- Macbeth, F. NICE Quality Standards and the Commissioning Outcomes Framework: A work in progress available at <u>https://www.kingsfund.org.uk/sites/files/kf/Fergus-Macbeth.pdf</u> accessed September 2016.
- Mainz, J. (2003). Defining and classifying clinical indicators for quality improvement. *International Journal for Quality in Health Care, 15*(6), 523-530. doi:10.1093/intqhc/mzg081
- Mainz, J., Krog, B. R., Bjørnshave, B., & Bartels, P. (2004). Nationwide continuous quality improvement using clinical indicators: the Danish National Indicator Project. *International Journal for Quality in Health Care, 16*(suppl 1), i45-i50. doi:10.1093/intqhc/mzh031

Mangione-Smith, R., Schiff, J., & Dougherty, D. (2011). Identifying children's health care quality measures for Medicaid and CHIP: an evidence-informed, publicly transparent expert process. *Acad Pediatr, 11*(3 Suppl), S11-21. doi:10.1016/j.acap.2010.11.003

- McDonald, K. M. (2009). Approach to improving quality: the role of quality measurement and a case study of the agency for healthcare research and quality pediatric quality indicators. *Pediatr Clin North Am*, *56*(4), 815-829. doi:10.1016/j.pcl.2009.05.009
- Morris, C., & Bailey, K. (2014a). Measuring Health Care Quality: An IntroductionPublication. FamiliesUSA.<u>http://familiesusa.org/sites/default/files/product_documents/HSI%20Quality%20Measure_ment%20Intro_factsheet_final_web.pdf</u> ID: 018HSI031914.
- Morris, C., & Bailey, K. (2014b). Measuring Health Care Quality: An Overview of Quality Measures ISSUE BRIEF . Health Service Improvement. FamiliesUSA. Publication ID: 024HSI050114<u>WWW.FAMILIESUSA.ORG</u> accessed Oct 2016.
- National Quality Strategy. National Strategy for Quality Improvement in Health Care March 2011. http://www.ahrq.gov/workingforquality/nqs/nqs2011annlrpt.pdf accessed sept 2016.
- NCQA. (2016). Desirable Attributes of HEDIS available at <u>http://www.ncqa.org/tabid/415/Default.aspx</u> accessed September 2016.
- NHS. (2012). Quality and Outcomes Framework 2011-12. NHS Digital. http://content.digital.nhs.uk/catalogue/PUB08135 accessed October 2016.
- NHS. (2017a). National Health Service (NHS) NHS Digital Indicator Portal. <u>https://indicators.hscic.gov.uk/webview</u> accessed November 2016.
- NHS. (2017b). NHS England. CCG outcomes indicator set. available at <u>https://www.england.nhs.uk/resources/resources-for-ccgs/ccg-out-tool/ccg-ois/</u> accessed February 2017.
- NICE. (2014). NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE; Health and Social Care Directorate Indicators Process Guide.
- NICE. (2016). NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE). Standards and Indicators available at https://www.nice.org.uk/standards-and-indicators accessed September 2016.
- Nolte, E. (2010). International benchmarking of healthcare quality. A review of the literature. *RAND Corporation, Technical Report*.
- Nothacker, M., Bunk, T., Weinbrenner, S., & Ollenschläger, G. (2010). S121–Quality indicators (QI) in German evidence-based guidelines. *Otolaryngology--Head and Neck Surgery*, 143(1 suppl), 76-77.
- Nothacker, M., & Reiter, A. (2010). National Program for Disease Management Guidelines Responsible Agencies: German Medical Association;National Association of Statutory Health Insurance Physicians;Association of the Scientific Medical Societies.National Disease Management Guidelines-Quality Indicators- A Manual for Authors-- Short Version -Version 1.0.
- NQF. National Quality Forum. The ABC's of Measurement accessed August 2016 at http://www.qualityforum.org/measuring_performance/abcs_of_measurement.aspx.
- NQF. (2016a). National Quality Forum. Measure Evaluation Criteria and Guidance for Evaluating Measures for Endorsement. Available at NQF <u>http://www.qualityforum.org/</u>.
- NQF. (2016b). National Quality Forum. The consensus development process. Available at .<u>http://www.qualityforum.org/Measuring_Performance/Consensus_Development_Process.aspx</u> accessed Nov 2016.
- NQMC, A. (2016). NQMC Template of Measure Attributes. Available at <u>https://www.qualitymeasures.ahrq.gov/help-and-about/summaries/template-of-measure-attributes</u> accessed September 2016.
- NQMC, A. (National Quality Measure Clearinghouse AHRQ. <u>https://www.qualitymeasures.ahrq.gov/</u> accessed September 2016).
- OECD. OECD Reviews of Health Care Quality: Australia 2015: OECD Publishing.
- Palmer, R. H., & Miller, M. R. (2001). Methodologic challenges in developing and implementing measures of quality for child health care. *Ambulatory Pediatrics*, 1(1), 39-52.

- Panzer, R. J., Gitomer, R. S., Greene, W. H., Webster, P. R., Landry, K. R., & Riccobono, C. A. (2013). Increasing demands for quality measurement. *JAMA*, *310*(18), 1971-1980. doi:10.1001/jama.2013.282047
- PATH. (2017). PATH Performance Assessment Tool for Quality Improvment in Hospitals.http://www.pathqualityproject.eu/path-organized,pcc.html accessed November 2016.
- PQMP. (2016). CHIPRA Quality Measures available at https://www.ahrq.gov/policymakers/chipra/factsheets/quality-measures.html accessed March 2017.
- QOF. (2017). Guidelines in practice QOF 216/2017 available at <u>https://www.guidelinesinpractice.co.uk/qof</u> accessed February 2017.
- RACGP. (2015). Clinical indicators for Australian general practice. Melbourne: The Royal Australian College of General Practitioners, 2015. .
- RACGP. (2017). Royal Australasian College of General Practice (RACGP)- Clinical indicators available at www.racgp.org.au/your-practice/business/tools/support/indicators accessed February 2017.
- Raleigh, V. (2012). Pick 'n' mix: an introduction to choosing and using indicators. The King's Fund available at https://www.kingsfund.org.uk/sites/files/kf/field/field_document/Outcomes-choosing-and-using-indicators-the-king's-fund-aug-20121.pdf accessed October 2016.
- Raleigh, V., & Foot, C. (2010). Getting the measure of quality. *Opportunities and challenges*.
- Reiter, A., Fischer, B., Kotting, J., Geraedts, M., Jackel, W., Barlag, H., & Dobler, K. (2007). QUALIFY: Instrument for the Assessment of Quality Indicators. *Dusseldorf: Bundes Geschafts Stelle Qualitats Sicherung*.
- Rigby, M. J., Köhler, L. I., Blair, M. E., & Metchler, R. (2003). Child health indicators for Europe: a priority for a caring society. *The European Journal of Public Health*, *13*(suppl 3), 38-46.
- Rygh, L. H., Helgeland, J., Braut, G. S., Bukholm, G., Fredheim, N., Frich, J. C., . . . Nguyen, K. N. (2010). Forslag til rammeverk for et nasjonalt kvalitetsindikatorsystem for helsetjenesten.
- Schuster, M. A. (2015). Measuring quality of pediatric care: where we've been and where we're going. *Pediatrics*, *135*(4), 748-751. doi:10.1542/peds.2014-3082
- Shaw.T, McGregor. D, & C, K.-C. (2017). Report Development and Review of Indicators for Safety and Quality in Health Care. Research in Implementation Science and eHealth, University of Sydney in consultation with the Australian Commission on Safety and Quality in Health Care: Sydney; 2017.
- Soyiri, I. N., Nwaru, B. I., & Sheikh, A. (2016). Patient-reported outcome measures for allergy and asthma in children. *Pediatr Allergy Immunol, 27*(8), 779-783. doi:10.1111/pai.12603
- Starfield, B., Powe, N. R., Weiner, J. R., Stuart, M., Steinwachs, D., Scholle, S. H., & Gerstenberger, A. (1994). Costs vs quality in different types of primary care settings. *JAMA*, *272*(24), 1903-1908.
- Swedish Association of Local Authorities and Regions. (2013). Swedish Association of Local Authorities and Regions Quality and efficiency in Swedish health care: regional comparisons
- Turrell, G., Stanley, L., de Looper, M., & Oldenburg, B. (2006). *Health Inequalities in Australia: Morbidity,health behaviours, risk factors and health service use.Health Inequalities Monitoring Series*. Retrieved from Canberra:
- van den Berg, M., Heijink, R., Zwakhals, L., Verkleij, H., & Westert, G. (2011). Health care performance in the Netherlands: Easy access, varying quality, rising costs. *European Union law and health, 16*(4), 27.
- van den Berg, M. J., Kringos, D. S., Marks, L. K., & Klazinga, N. S. (2014). The Dutch health care performance report: seven years of health care performance assessment in the Netherlands. *Health research policy and systems*, *12*(1), 1.
- Veillard, J., Champagne, F., Klazinga, N., Kazandjian, V., Arah, O., & Guisset, A.-L. (2005). A performance assessment framework for hospitals: the WHO regional office for Europe PATH project. *International Journal for Quality in Health Care*, *17*(6), 487-496.
- Westert, G. P., van den Berg, M. J., Zwakhals, S., De Jong, J., & Verkleij, H. (2010). *Dutch health care performance report 2010*: Rijksinstituut voor Volksgezondheid en Milieu RIVM.
- Wollersheim, H., Hermens, R., Hulscher, M., Braspenning, J., Ouwens, M., Schouten, J., . . . Grol, R. (2007). Clinical indicators: development and applications. *Neth J Med*, *65*(1), 15-22.
- Woolfenden, S., Eapen, V., Jalaludin, B., Hayen, A., Kemp, L., Dissanyake, C., . . . Watch Me Grow' study, g. (2016). Prevalence and factors associated with parental concerns about development detected by the

Parents' Evaluation of Developmental Status (PEDS) at 6-month, 12-month and 18-month well-child checks in a birth cohort. *BMJ Open, 6*(9), e012144. doi:10.1136/bmjopen-2016-012144 Text size is smaller than normal

Appendices

Appendix 1: Examples of validity and reliability testing of quality measures. Figure 3 Assessment of validity by the National Quality Forum

Algorithm 3. Guidance for Evaluating Validity (including eMeasures)



Figure 4 Assessment of reliability by the National Quality Forum

Algorithm 2. Guidance for Evaluating Reliability (including eMeasures)



Figure 5 NHS system of development, evaluation and endorsement



Source Campbell et al 2011(Stephen M. Campbell et al., 2011)

Appendix 2: Examples of quality measures

Quality measures - USA

National Quality Forum endorsed paediatric quality measures

National Quality Forum (NQF) endorsed Paediatric Quality Measures that are available. For information on specifications, reliability and validity testing by the NQF please go to <u>http://www.qualityforum.org</u>

- 1) Accidental Puncture or Laceration Rate
- 2) Acute Otitis Externa: Systemic Antimicrobial Therapy Avoidance of Inappropriate Use
- 3) Acute Otitis Externa: Topical Therapy
- 4) Admit Decision Time to ED Departure Time for Admitted Patients
- 5) Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care
- 6) Ambulatory Care Sensitive Emergency Department Visits for Dental Caries in Children
- 7) Antipsychotic Use in Children Under 5 Years Old
- 8) Appropriate Treatment for Children with Upper Respiratory Infection (URI)
- 9) Asthma Admission Rate (PDI 14)
- 10) Asthma: Pharmacologic Therapy for Persistent Asthma
- 11) Audiological Evaluation no later than 3 months of age
- 12) CAHPS Clinician & Group Surveys (CG-CAHPS)-Adult, Child
- 13) Child and Adolescent Major Depressive Disorder (MDD): Suicide Risk Assessment
- 14) Child Hospital CAHPS (HCAHPS)
- 15) Child Overweight or Obesity Status Based on Parental Report of Body-Mass-Index (BMI)
- 16) Childhood Immunization Status (CIS)
- 17) Children Age 6-17 Years who Engage in Weekly Physical Activity
- 18) Children Who Are Exposed to Secondhand Smoke Inside Home
- 19) Children Who Attend Schools Perceived as Safe

- 20) Children Who Had Problems Obtaining Referrals When Needed
- 21) Children Who Have Dental Decay or Cavities
- 22) Children Who Have Inadequate Insurance Coverage for Optimal Health
- 23) Children Who Live in Communities Perceived as Safe
- 24) Children Who Receive Effective Care Coordination of Healthcare Services When Needed
- 25) Children Who Receive Family-Centered Care
- 26) Children Who Receive Preventive Medical Visits
- 27) Children Who Received Preventive Dental Care
- 28) Children with a Usual Source for Care When Sick
- 29) Children with Inconsistent Health Insurance Coverage in the Past 12 Months

30) Children with Special Health Care Needs (CSHCN) who Receive Services Needed for Transition to Adult Health Care

31) Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey, Version 5.0 (Medicaid and Commercial) (AHRQ)

- 32) Developmental screening using a parent completed screening tool (Parent report, Children 0-5)
- 33) Diagnostic Imaging: Stenosis Measurement in Carotid Imaging Reports
- 34) Failure to Rescue 30-Day Mortality (risk adjusted)
- 35) Failure to Rescue In-Hospital Mortality (risk adjusted)

36) Family Experiences with Coordination of Care (FECC) -3: Care coordinator helped to obtain community services

37) Family Experiences with Coordination of Care (FECC) -5: Care coordinator asked about concerns and health

- 38) Family Experiences with Coordination of Care (FECC) -7: Care coordinator assisted with specialist service referrals
- 39) Family Experiences with Coordination of Care (FECC) -9: Appropriate written visit summary content
- 40) Family Experiences with Coordination of Care (FECC)-1 Has Care Coordinator

41) Family Experiences with Coordination of Care (FECC)-15: Caregiver has access to medical interpreter when needed

- 42) Family Experiences with Coordination of Care (FECC)-16: Child has shared care plan
- 43) Family Experiences with Coordination of Care (FECC)-8: Care coordinator was knowledgeable, supportive and advocated for child's needs
- 44) Follow-Up after Emergency Department Visits for Dental Caries in Children
- 45) Follow-Up After Hospitalization for Mental Illness (FUH)
- 46) Follow-Up Care for Children Prescribed ADHD Medication (ADD)
- 47) Gastroenteritis Admission Rate (PDI 16)
- 48) Hearing screening prior to hospital discharge
- 49) Hepatitis B Vaccine Coverage Among All Live Newborn Infants Prior to Hospital or Birthing Facility Discharge
- 50) HIV/AIDS: Pneumocystis jiroveci pneumonia (PCP) Prophylaxis
- 51) HIV/AIDS: Sexually Transmitted Diseases Screening for Chlamydia, Gonorrhea, and Syphilis
- 52) Human Papillomavirus Vaccine for Female Adolescents (HPV)
- 53) Influenza Immunization in the ESRD Population (Facility Level)
- 54) Initiation and Engagement of Alcohol and Other Drug Dependence Treatment (IET)
- 55) Immunizations for Adolescents
- 56) Influenza Immunization
- 57) Late sepsis or meningitis in Very Low Birth Weight (VLBW) neonates (risk-adjusted)
- 58) Measure of Medical Home for Children and Adolescents
- 59) Measurement of nPCR for Pediatric Hemodialysis Patients
- 60) Median Time from ED Arrival to ED Departure for Discharged ED Patients

- 61) Metabolic Monitoring for Children and Adolescents on Antipsychotics
- 62) Minimum spKt/V for Pediatric Hemodialysis Patients
- 63) Monthly Hemoglobin Measurement for Pediatric Patients
- 64) National Healthcare Safety Network (NHSN) Antimicrobial Use Measure

65) National Healthcare Safety Network (NHSN) Catheter-associated Urinary Tract Infection (CAUTI) Outcome Measure

66) National Healthcare Safety Network (NHSN) Central line-associated Bloodstream Infection (CLABSI) Outcome Measure

- 67) Neonatal Blood Stream Infection Rate (NQI 03)
- 68) Number of School Days Children Miss Due to Illness
- 69) Operative Mortality Stratified by the 5 STAT Mortality Categories
- 70) Oral Evaluation, Dental Services
- 71) Otitis Media with Effusion: Antihistamines or decongestants Avoidance of inappropriate use
- 72) Otitis Media with Effusion: Systemic antimicrobials Avoidance of inappropriate use
- 73) Participation in a National Database for Pediatric and Congenital Heart Surgery
- 74) Pediatric All-Condition Readmission Measure
- 75) Pediatric Cardiac Surgery Stratified Mortality and Volume Pair (Paired Measure)
- 76) Pediatric Computed Tomography (CT) Radiation Dose
- 77) Pediatric Kidney Disease : ESRD Patients Receiving Dialysis: Hemoglobin Level < 10g/dL
- 78) Pediatric Lower Respiratory Infection Readmission Measure
- 79) Pediatric Peritoneal Dialysis Adequacy: Achievement of Target Kt/V
- 80) Pediatric Psychosis: Screening for Drugs of Abuse in the Emergency Department
- 81) Percentage of low birthweight births
- 82) Perioperative Temperature Management
- 83) PICU Severity-adjusted Length of Stay
- 84) PICU Unplanned Readmission Rate
- 85) Potassium Sample Hemolysis in the Emergency Department
- 86) Pressure Ulcer Rate (PDI 2)
- 87) Prevention of Central Venous Catheter (CVC)-Related Bloodstream Infections
- 88) Prevention: Dental Sealants for 10-14 Year-Old Children at Elevated Caries Risk
- 89) Prevention: Dental Sealants for 6-9 Year-Old Children at Elevated Caries Risk
- 90) Prevention: Topical Fluoride for Children at Elevated Caries Risk, Dental Services
- 91) Preventive Care and Screening: Influenza Immunization
- 92) Preventive Care and Screening: Screening for Clinical Depression and Follow-Up Plan
- 93) Promoting Healthy Development Survey (PHDS)
- 94) Proportion of infants 22 to 29 weeks gestation screened for retinopathy of prematurity
- 95) RACHS-1 Pediatric Heart Surgery Mortality Rate (PDI 06)
- 96) RACHS-1 Pediatric Heart Surgery Volume (PDI 7)
- 97) Retained Surgical Item or Unretrieved Device Fragment Count (PDI 03)
- 98) Risk-Adjusted Operative Mortality for Pediatric and Congenital Heart Surgery
- 99) Signed Part C Individual Family Service Plan (IFSP) before 6 months of age
- 100) Standardized adverse event ratio for children < 18 years of age undergoing cardiac catheterization
- 101) Tobacco Use and Help with Quitting Among Adolescents
- 102) Transcranial Doppler Ultrasonography Screening Among Children with Sickle Cell Anemia
- 103) Transfusion Reaction Count (PDI 13)
- 104) Unexpected Complications in Term Newborns
- 105) Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics
- 106) Utilization of Services, Dental Services
- 107) Ventriculoperitoneal (VP) shunt malfunction rate in children
- 108) Weight Assessment and Counseling for Nutrition and Physical Activity for Children/Adolescents (WCC)

- 109) Well-Child Visits in the First 15 Months of Life
- 110) Well-Child Visits in the Third, Fourth, Fifth, and Sixth Years of Life

111) Young Adult Health Care Survey

Agency for Health Care Research and Quality (AHRQ)/National Quality Measures Clearinghouse (NQMC) quality

measures that are endorsed by the NQF

Agency for Health Care Research and Quality (AHRQ)/National Quality Measures Clearinghouse (NQMC). For information on specifications, reliability and validity please go to https:// www.qualitymeasures.ahrq.gov

1) Access to referrals: percentage of children who needed referrals and had a problem obtaining them.

2) Accidental puncture or laceration: percentage of accidental punctures or lacerations during a procedure per 1,000 discharges for patients ages 17 years and younger.

3) Acute otitis externa (AOE): percentage of patients aged 2 years and older with a diagnosis of AOE who were prescribed topical preparations.

4) Acute otitis externa (AOE): percentage of patients aged 2 years and older with a diagnosis of AOE who were not prescribed systemic antimicrobial therapy.

5) Anticipatory guidance and parental education (AGPE) about development and behavior of the child from doctor(s) or other health provider(s): proportion of children whose parents had their informational needs met.

6) Anticipatory guidance and parental education (AGPE) about the physical care of the child from doctor(s) or other health provider(s): proportion of children whose parents had their informational needs met.

7) Anticipatory guidance and parental education (AGPE) from doctor(s) or other health provider(s): average percentage of recommended topics discussed by a child's doctor(s) or other health provider(s).

8) Anticipatory guidance and parental education (AGPE) about injury prevention from doctor(s) or other health provider(s): proportion of children whose parents had their informational needs met.

9) Anticipatory guidance and parental education (AGPE) from doctor(s) or other health provider(s): average percentage of topics for which parents had their informational needs met.

10) Anticipatory guidance and parental education (AGPE) from doctor(s) or other health provider(s): proportion of children whose parents had their informational needs met on all recommended anticipatory guidance and parental education topics assessed.

 Anticipatory guidance and parental education (AGPE) from doctor(s) or other health provider(s): proportion of children whose health care provider(s) discussed at least 80% of the recommended AGPE topics.
 Antipsychotic use in children: percentage of children under age 5 using antipsychotic medications during the measurement period.

Appropriate treatment for children with upper respiratory infection (URI): percentage of children 3
 months to 18 years of age who were given a diagnosis of URI and were not dispensed an antibiotic prescription.

14) Appropriate treatment for children with upper respiratory infection (URI): percentage of children 3 months to 18 years of age who were given a diagnosis of URI and were not treated with an antibiotic medication.

15) Ask about parental concerns (developmental surveillance): proportion of children whose parents were asked by their child's health care provider if they have concerns about their child's learning, development and behavior.

16) Assessment of psychosocial well-being of parent(s) in the family: proportion of children whose parents were assessed for one or more topics related to psychosocial well-being.

17) Assessment of psychosocial well-being of parent(s) in the family: average percentage of recommended topics assessed.

18) Assessment of smoking, substance abuse, safety, and firearms risks in the family: average percentage of recommended topics assessed.

19) Assessment of smoking, substance abuse, safety, and firearms risks in the family by a child's doctor(s) or other health care provider(s): proportion of children whose parents were assessed for one or more risk factors.

20) Asthma admission: percentage of admissions with a principal diagnosis of asthma per 100,000 population, ages 2 through 17 years.

21) Asthma medication ratio: percentage of members 5 to 85 years of age who were identified as having persistent asthma and had a ratio of controller medications to total asthma medications of 0.50 or greater during the measurement year.

22) Asthma: the relative resource use by members with persistent asthma during the measurement year.

23) Care coordination communication: percentage of children who needed care coordination

communication but were not satisfied with the coordination communication that they received.

24) Care coordination (CC): proportion of children needing more than one health care service who received coordinated care.

25) Care coordination: percentage of children who needed care coordination help but did not receive all that they needed.

26) Child and adolescent major depressive disorder (MDD): percentage of patient visits for those patients aged 6 through 17 years with a diagnosis of MDD with an assessment for suicide risk.

27) Childhood immunization status: percentage of children 2 years of age who had four diphtheria, tetanus, and acellular pertussis (DTaP); three polio (IPV); one measles, mumps, and rubella (MMR); three haemophilus influenza type B (HiB); three hepatitis B (HepB); one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (HepA); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday.

28) Childhood immunization status: percentage of children 2 years of age who had four diphtheria, tetanus, and acellular pertussis (DTaP); three polio (IPV); one measles, mumps, and rubella (MMR); three H influenza type B (HiB); three hepatitis B (HepB); one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (Hep A); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday.

29) Communication and experience of care: mean score on seven items asking about helpfulness of office staff, overall rating of care and whether doctor/other providers listen carefully, explain things clearly, respect you, spend enough time.

30) Communication climate: mean score for the "Performance Evaluation" domain on the Patient (or Pediatric) Survey and Staff Survey.

31) Communication climate: mean score for the "Language" domain on the Patient (or Pediatric) Survey and Staff Survey.

32) Communication climate: mean score for the "Leadership Commitment" domain on the Patient (or Pediatric) Survey and Staff Survey.

33) Communication climate: mean score for the "Health Literacy" domain on the Patient (or Pediatric) Survey and Staff Survey.

34) Communication climate: mean score for the "Individual Engagement" domain on the Patient (or Pediatric) Survey and Staff Survey.

35) Communication climate: mean score for the "Workforce Development" domain on the Patient (or Pediatric) Survey and Staff Survey.

36) Communication climate: mean score for the "Socio-Cultural Context" domain on the Patient (or Pediatric) Survey and Staff Survey.

37) Cost of care: total cost of care population-based per member per month (PMPM) index.

38) Dental care: percentage of enrolled children in the age category of 10 to 14 years at "elevated" risk (i.e., "moderate" or "high") who received a sealant on a permanent second molar tooth as a dental service within the reporting year.

39) Dental care: percentage of enrolled children who are at "elevated" risk (i.e., "moderate" or "high") who received (1, 2, 3, 4 or more) topical fluoride applications as a dental service within the reporting year.

40) Dental care: percentage of enrolled children under age 21 who received at least one dental service within the reporting year.

41) Dental care: percentage of caries-related ED visits among children 0 through 20 years in the reporting year for which the member visited a dentist within 7 days of the ED visit.

42) Dental care: percentage of caries-related ED visits among children 0 through 20 years in the reporting year for which the member visited a dentist within 30 days of the ED visit.

43) Dental care: percentage of enrolled children in the age category of 6 to 9 years at "elevated" risk (i.e., "moderate" or "high") who received a sealant on a permanent first molar tooth as a dental service within the reporting year.

44) Dental care: percentage of enrolled children aged 1 to 21 years who are at "elevated" risk (i.e., "moderate" or "high") who received at least 2 topical fluoride applications as a dental service within the reporting year.

45) Dental care: percentage of enrolled children under age 21 who received a comprehensive or periodic oral evaluation as a dental service within the reporting year.

46) Dental care: number of ED visits for caries-related reasons per 100,000 member months for all enrolled children.

47) Effect of care provided on parental confidence: proportion of children whose parents reported care had a positive influence on their confidence in parenting their child and managing their responsibilities.

48) Emergency department (ED): median time from ED arrival to time of initial oral, intranasal or parenteral pain medication administration for ED patients with a principal diagnosis of long bone fracture.

49) End stage renal disease (ESRD): percentage of patient months for all pediatric (< 18 years old) in-center hemodialysis patients in which the delivered dose of hemodialysis (calculated from the last measurement of the month using the UKM or Daugirdas II formula) was spKt/V \geq 1.2.

50) End stage renal disease (ESRD): percentage of ESRD patients aged 6 months and older receiving hemodialysis and/or peritoneal dialysis during the time from October 1 (or when the influenza vaccine became available) to March 31 who: 1) receive an influenza vaccination, or 2) were assessed and offered an influenza vaccination but decline, or 3) were assessed and determined to have a medical contraindication(s) to the influenza vaccination.

51) Epilepsy: all female patients of childbearing potential (12 to 44 years old) diagnosed with epilepsy who were counseled or referred for counseling for how epilepsy and its treatment may affect contraception OR pregnancy at least once a year.

52) Family-centered care (FCC): average percentage of recommended aspects of family-centered care regularly received.

53) Family-centered care (FCC): proportion of children whose parents routinely received all aspects of family-centered care.

54) Follow-up after hospitalization for mental illness: percentage of discharges for patients 6 years of age and older who were hospitalized for treatment of selected mental health disorders and who had an outpatient visit, an intensive outpatient service, or partial hospitalization with a mental health provider within 30 days of discharge.

55) Follow-up after hospitalization for mental illness: percentage of discharges for members 6 years of age and older who were hospitalized for treatment of selected mental illness diagnoses and who had an outpatient visit, an intensive outpatient encounter, or partial hospitalization with a mental health practitioner within 30 days of discharge.

56) Follow-up after hospitalization for mental illness: percentage of discharges for members 6 years of age and older who were hospitalized for treatment of selected mental illness diagnoses and who had an outpatient visit, an intensive outpatient encounter, or partial hospitalization with a mental health practitioner within 7 days of discharge.

57) Follow-up after hospitalization for mental illness: percentage of discharges for patients 6 years of age and older who were hospitalized for treatment of selected mental health disorders and who had an outpatient

visit, an intensive outpatient service, or partial hospitalization with a mental health provider within 7 days of discharge.

58) Follow-up for children at risk for delays: proportion of children who were determined to be at significant risk for developmental, behavioral, or social delays who received some level of follow-up health care.
59) Follow-up care for children prescribed ADHD medication (continuation and maintenance [C&M] phase): percentage of patients 6 to 12 years of age as of the index prescription start date with an outpatient ADHD medication who remained on the medication for at least 210 days and who, in addition to the visit in the initiation phase, had at least two follow-up visits with a practitioner within 270 days (9 months) after the initiation phase ended.

60) Follow-up care for children prescribed ADHD medication (initiation phase): percentage of members 6 to 12 years of age with an ambulatory prescription dispensed for ADHD medication who had one follow-up visit with a practitioner with prescribing authority during the 30-day initiation phase.

61) Follow-up care for children prescribed ADHD medication (initiation phase): percentage of patients 6 to 12 years of age as of the index prescription start date with an outpatient ADHD medication who had one follow-up visit with a practitioner with prescribing authority during the 30-day initiation phase.

62) Follow-up care for children prescribed ADHD medication (continuation and maintenance [C&M] phase): percentage of members 6 to 12 years of age with an ambulatory prescription dispensed for ADHD medication who remained on the medication for at least 210 days and who, in addition to the visit in the initiation phase, had at least two follow-up visits with a practitioner within 270 days (9 months) after the initiation phase ended.

63) Frequency of ongoing prenatal care: percentage of Medicaid deliveries between November 6 of the year prior to the measurement year and November 5 of the measurement year that received less than 21%, 21% to 40%, 41% to 60%, 61% to 80%, or greater than or equal to 81% of the expected number of prenatal care visits.

64) Gastroenteritis admission: percentage of admissions for a principal diagnosis of gastroenteritis, or for a principal diagnosis of dehydration with a secondary diagnosis of gastroenteritis, per 100,000 population, ages 3 months through 17 years.

65) Health information: proportion of children whose parents received all health information.

66) Health insurance coverage: percentage of children who do not meet the criteria for having adequate insurance for optimal health.

67) Health plan enrollees' satisfaction with care: parents' or guardians' overall rating of their child's specialist.

68) Health plan enrollees' experiences: percentage of parents or guardians who reported how often it was easy to get needed care for their enrolled child.

69) Health plan enrollees experiences: percentage of parents or guardians who reported how often they were satisfied with their enrolled child's health plan information and customer service.

70) Health plan enrollees' satisfaction with care: parents' or guardians' overall rating of their child's personal doctor.

71) Health plan enrollees' experiences: percentage of parents or guardians who reported how often their enrolled child's personal doctor communicated well.

72) Health plan enrollees' satisfaction with care: parents' or guardians' overall rating of their child's health plan.

73) Health plan enrollees' satisfaction with care: parents' or guardians' overall rating of their child's health care.

74) Health plan enrollees' experiences: percentage of parents or guardians who reported how often their enrolled child got care quickly. Hospital inpatients' experiences: percentage of parents who reported how often nurses communicated well with their child.

75) Helpfulness of care provided to parents: proportion of children whose parents reported care provided was helpful or very helpful on core aspects of preventive and developmental health care.

76) Helpfulness of counseling: mean score on six items asking about the helpfulness of counseling among young adults who received counseling on selected topics.

77) Home health care: percentage of home health episodes of care during which the patient's frequency of pain when moving around improved.

78) Hospital inpatients' experiences: percentage of parents who reported whether providers communicated about their child's medicines.

79) Hospital inpatients' experiences: percentage of parents who reported whether providers helped their child feel to comfortable.

80) Hospital inpatients' experiences: percentage of parents who reported how often doctors communicated well with their child.

81) Hospital inpatients' experiences: percentage of parents who reported whether the provider prepared them and their child to leave the hospital.

82) Hospital inpatients' experiences: percentage of parents who reported whether they were kept informed about their child's care in the emergency room.

83) Hospital inpatients' experiences: percentage of parents who reported how often providers kept them informed about their child's care.

84) Hospital inpatients' experiences: percentage of parents who reported how often their child's nurses communicated well with the parent.

85) Hospital inpatients' experiences: percentage of parents who reported how often their child's doctors communicated well with the parent.

86) Hospital inpatients' experiences: percentage of parents who reported whether providers asked about their child's pain.

87) Hospital inpatients' experiences: percentage of parents who reported how often they had privacy with providers when discussing their child's care.

88) Hospital inpatients' experiences: percentage of parents who reported how often providers prevented mistakes and helped them to report concerns.

89) Hospital inpatients' experiences: percentage of parents who reported whether providers involved teens in their care.

90) Hospital inpatients' experiences: percentage of parents who reported how often they got prompt help when they pressed the call button.

91) Hospital inpatients' experiences: percentage of parents who reported how often the area around the room was quiet at night.

92) Hospital inpatients' experiences: percentage of parents who reported whether they would recommend this hospital to their family and friends.

93) Hospital inpatients' experiences: percentage of parents who reported how often the room and bathroom were kept clean.

94) Hospital inpatients' experiences: parents' overall rating of hospital.

95) Hospital-based inpatient psychiatric services: the percentage of patients discharged from a hospitalbased inpatient psychiatric setting on two or more antipsychotic medications with appropriate justification.

96) Hospital-based inpatient psychiatric services: the percentage of patients admitted to a hospital-based inpatient psychiatric setting who are screened within the first three days of admission for all of the following: risk of violence to self or others, substance use, psychological trauma history and patient strengths.

97) Hospital-based inpatient psychiatric services: the total number of hours that all patients admitted to a hospital-based inpatient psychiatric setting were held in seclusion.

98) Hospital-based inpatient psychiatric services: the total number of hours that all patients admitted to a hospital-based inpatient psychiatric setting were maintained in physical restraint.

99) latrogenic pneumothorax: percentage of iatrogenic pneumothorax cases per 1,000 discharges for patients ages 17 years and younger.

100) Immunization: percent of acute care hospitalized inpatients age 6 months and older who were screened for seasonal influenza immunization status and were vaccinated prior to discharge, if indicated.

101) Immunizations for adolescents: percentage of adolescents 13 years of age who had one dose of meningococcal vaccine and one tetanus, diphtheria toxoids and acellular pertussis vaccine (Tdap) or one tetanus, diphtheria toxoids vaccine (Td) by their 13th birthday.

102) Information about resources for parents in the community: proportion of parents who had their informational needs met.

103) Information to address parental concerns: proportion of children whose parents had concerns about their child's learning, development and behavior and they received information to address their concerns.
104) Medical home: percentage of children and adolescents who meet the threshold for having a medical home according to a subset of questions from the 2011-12 National Survey of Children's Health.

105) Medication management for people with asthma: percentage of members 5 to 85 years of age during the measurement year who were identified as having persistent asthma and who were dispensed an asthma controller medication that they remained on for at least 50% of their treatment period.

106) Medication management for people with asthma: percentage of members 5 to 85 years of age during the measurement year who were identified as having persistent asthma and who were dispensed an asthma controller medication that they remained on for at least 75% of their treatment period.

107) Missed school days: number of school days that children missed in the past 12 months due to illness or injury.

108) Neonatal blood stream infection: percentage of discharges with healthcare-associated bloodstream infection per 1,000 discharges for newborns and outborns with birth weight of 500 grams or more but less than 1,500 grams; with gestational age between 24 and 30 weeks; or with birth weight of 1,500 grams or more and death, an operating room procedure, mechanical ventilation, or transferring from another hospital within two days of birth.

109) Otitis media with effusion (OME): percentage of patients aged 2 months through 12 years with a diagnosis of OME who were not prescribed systemic antimicrobials.

110) Otitis media with effusion (OME): percentage of patients aged 2 months through 12 years with a diagnosis of OME who were not prescribed systemic corticosteroids.

111) Otitis media with effusion (OME): percentage of patients aged 2 months through 12 years with a diagnosis of OME who were not prescribed or recommended to receive either antihistamines or decongestants.

112) Pediatric kidney disease: percentage of calendar months within a 12-month period during which patients aged 17 years and younger with a diagnosis of ESRD receiving hemodialysis or peritoneal dialysis have a hemoglobin level less than 10 g/dL.

113) Perioperative care: percentage of patients, regardless of age, who undergo central venous catheter (CVC) insertion for whom CVC was inserted with all elements of maximal sterile barrier technique, hand hygiene, skin preparation and, if ultrasound is used, sterile ultrasound techniques followed.

114) Perioperative care: percentage of patients, regardless of age, who undergo surgical or therapeutic procedures under general or neuraxial anesthesia of 60 minutes duration or longer for whom at least one body temperature greater than or equal to 35.5 degrees Celsius (or 95.9 degrees Fahrenheit) was recorded within the 30 minutes immediately before or the 15 minutes immediately after anesthesia end time.

115) Pressure ulcer: percentage of stage III or IV pressure ulcers per 1,000 discharges for patients ages 17 years and younger.

116) Preventive and developmental health care for young children: proportion of children who received all individual care components measures in the Promoting Healthy Development Survey (PHDS).

117) Preventive and developmental health care for young children: average percentage of individual care components (assessed in the Promoting Healthy Development Survey [PHDS]) a child received.

118) Preventive screening and counseling on emotional health and relationship issues: average proportion saying "yes" to six items about whether provider(s) discussed/screened for feeling sad or depressed, school performance, friends, suicide and sexual orientation.

119) Preventive screening and counseling on risky behaviors: average proportion saying "yes" to ten items about whether provider(s) discussed/screened on smoking, alcohol use, helmet use, drunk driving, chewing tobacco, street drugs, steroid pills, sexual/physical abuse, violence, guns.

120) Preventive screening and counseling on sexual activity and sexually transmitted diseases (STDs): average proportion saying "yes" to four items about whether provider(s) discussed/screened on birth control, condoms and prevention of human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) and STDs.

121) Preventive screening and counseling on weight, healthy diet and exercise: average proportion saying "yes" to three items.

122) Private and confidential care: average proportion reporting that they had a private and/or confidential visit.

123) Standardized developmental and behavioral screening: proportion of children whose health care provider administered a parent-completed standardized developmental and behavioral screening tool.

124) Safe communities: percentage of children who live in neighborhoods or communities perceived as safe.

125) School safety: percentage of children who attend school perceived as safe.

126) Timeliness of prenatal care: percentage of deliveries that received a prenatal care visit as a member of the organization in the first trimester or within 42 days of enrollment in the organization.

127) Weight assessment for children/adolescents: percentage of patients 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of BMI percentile documentation during the measurement year.

128) Weight assessment and counseling for nutrition and physical activity for children/adolescents: percentage of members 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of counseling for nutrition during the measurement year.

129) Weight assessment and counseling for nutrition and physical activity for children/adolescents: percentage of members 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of counseling for physical activity during the measurement year.

130) Weight assessment and counseling for nutrition and physical activity for children/adolescents: percentage of members 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of BMI percentile documentation during the measurement year.

131) Well-child visits in the third, fourth, fifth and sixth years of life: percentage of members 3 to 6 years of age who had one or more well-child visits with a PCP during the measurement year.

132) Well-child visits in the first 15 months of life: percentage of members who turned 15 months old during the measurement year and who had the following number of well-child visits with a PCP during their first 15 months of life: zero, one, two, three, four, five, six or more.

133) Ventriculoperitoneal (VP) shunt malfunction: percentage of initial VP shunt placement procedures performed on children between 0 and 18 years of age that malfunction and result in shunt revision within 30 days of initial placement.

National Committee for Quality Assurance (NCQA)/ HEDIS (The Healthcare Effectiveness Data and Information

Set) NQF endorsed paediatric quality measures

National Committee for Quality Assurance (NCQA)/ HEDIS (The Healthcare Effectiveness Data and Information Set) For information on specifications, reliability and validity please go to

http://store.ncqa.org/index.php/performance-measurement.html#vol1

1) Appropriate treatment for children with upper respiratory infection (URI): percentage of children 3 months to 18 years of age who were given a diagnosis of URI and were not treated with an antibiotic medication.

2) Appropriate treatment for children with upper respiratory infection (URI): percentage of children 3 months to 18 years of age who were given a diagnosis of URI and were not dispensed an antibiotic prescription.

3) Asthma medication ratio: percentage of members 5 to 85 years of age who were identified as having persistent asthma and had a ratio of controller medications to total asthma medications of 0.50 or greater during the measurement year.

4) Asthma: the relative resource use by members with persistent asthma during the measurement year.

5) Childhood immunization status: percentage of children 2 years of age who had four diphtheria, tetanus, and acellular pertussis (DTaP); three polio (IPV); one measles, mumps, and rubella (MMR); three haemophilus influenza type B (HiB); three hepatitis B (HepB); one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (HepA); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday.

6) Childhood immunization status: percentage of children 2 years of age who had four diphtheria, tetanus, and acellular pertussis (DTaP); three polio (IPV); one measles, mumps, and rubella (MMR); three H influenza type B (HiB); three hepatitis B (HepB); one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (Hep A); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday.

7) Engagement of alcohol and other drug (AOD) treatment: percentage of patients who initiated treatment and who had two or more additional services with a diagnosis of AOD within 30 days of the initiation visit.

8) Engagement of alcohol and other drug (AOD) treatment: percentage of members who initiated treatment and who had two or more additional services with a diagnosis of AOD within 30 days of the initiation visit.

10) Follow-up care for children prescribed ADHD medication (initiation phase): percentage of patients 6 to 12 years of age as of the index prescription start date with an outpatient ADHD medication who had one follow-up visit with a practitioner with prescribing authority during the 30-day initiation phase.

11) Follow-up care for children prescribed ADHD medication (initiation phase): percentage of members 6 to 12 years of age with an ambulatory prescription dispensed for ADHD medication who had one follow-up visit with a practitioner with prescribing authority during the 30-day initiation phase.

12) Follow-up care for children prescribed ADHD medication (continuation and maintenance [C&M] phase): percentage of patients 6 to 12 years of age as of the index prescription start date with an outpatient ADHD medication who remained on the medication for at least 210 days and who, in addition to the visit in the initiation phase, had at least two follow-up visits with a practitioner within 270 days (9 months) after the initiation phase ended.

13) Follow-up care for children prescribed ADHD medication (continuation and maintenance [C&M] phase): percentage of members 6 to 12 years of age with an ambulatory prescription dispensed for ADHD medication who remained on the medication for at least 210 days and who, in addition to the visit in the initiation phase, had at least two follow-up visits with a practitioner within 270 days (9 months) after the initiation phase ended.

14) Follow-up after hospitalization for mental illness: percentage of discharges for patients 6 years of age and older who were hospitalized for treatment of selected mental health disorders and who had an outpatient visit, an intensive outpatient service, or partial hospitalization with a mental health provider within 30 days of discharge.

15) Follow-up after hospitalization for mental illness: percentage of discharges for patients 6 years of age and older who were hospitalized for treatment of selected mental health disorders and who had an outpatient visit, an intensive outpatient service, or partial hospitalization with a mental health provider within 7 days of discharge.

16) Follow-up after hospitalization for mental illness: percentage of discharges for members 6 years of age and older who were hospitalized for treatment of selected mental illness diagnoses and who had an outpatient visit, an intensive outpatient encounter, or partial hospitalization with a mental health practitioner within 30 days of discharge.

17) Follow-up after hospitalization for mental illness: percentage of discharges for members 6 years of age and older who were hospitalized for treatment of selected mental illness diagnoses and who had an outpatient

visit, an intensive outpatient encounter, or partial hospitalization with a mental health practitioner within 7 days of discharge.

18) Frequency of ongoing prenatal care: percentage of Medicaid deliveries between November 6 of the year prior to the measurement year and November 5 of the measurement year that received less than 21%, 21% to 40%, 41% to 60%, 61% to 80%, or greater than or equal to 81% of the expected number of prenatal care visits.

19) Immunizations for adolescents: percentage of adolescents 13 years of age who had one dose of meningococcal vaccine and one tetanus, diphtheria toxoids and acellular pertussis vaccine (Tdap) or one tetanus, diphtheria toxoids vaccine (Td) by their 13th birthday.

20) Initiation of alcohol and other drug (AOD) treatment: percentage of patients who initiate treatment through an inpatient AOD admission, outpatient visit, intensive outpatient service or partial hospitalization within 14 days of the diagnosis.

21) Initiation of alcohol and other drug (AOD) treatment: percentage of members who initiate treatment through an inpatient AOD admission, outpatient visit, intensive outpatient encounter, or partial hospitalization within 14 days of the diagnosis.

22) Medication management for people with asthma: percentage of members 5 to 85 years of age during the measurement year who were identified as having persistent asthma and who were dispensed an asthma controller medication that they remained on for at least 75% of their treatment period.

23) Medication management for people with asthma: percentage of members 5 to 85 years of age during the measurement year who were identified as having persistent asthma and who were dispensed an asthma controller medication that they remained on for at least 50% of their treatment period.

24) Timeliness of prenatal care: percentage of deliveries that received a prenatal care visit as a member of the organization in the first trimester or within 42 days of enrollment in the organization.

25) Postpartum care: percentage of deliveries that had a postpartum visit on or between 21 and 56 days after delivery.

26) Weight assessment for children/adolescents: percentage of patients 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of BMI percentile documentation during the measurement year.

27) Weight assessment and counseling for nutrition and physical activity for children/adolescents: percentage of members 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of counseling for nutrition during the measurement year.

28) Weight assessment and counseling for nutrition and physical activity for children/adolescents: percentage of members 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of counseling for physical activity during the measurement year.

29) Weight assessment and counseling for nutrition and physical activity for children/adolescents: percentage of members 3 to 17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of BMI percentile documentation during the measurement year.

30) Well-child visits in the third, fourth, fifth and sixth years of life: percentage of members 3 to 6 years of age who had one or more well-child visits with a PCP during the measurement year.

31) Well-child visits in the first 15 months of life: percentage of members who turned 15 months old during the measurement year and who had the following number of well-child visits with a PCP during their first 15 months of life: zero, one, two, three, four, five, six or more.

Quality measures - UK

The CCG Outcomes paediatric quality indicators include:(NHS, 2017a)

- 1) Emergency admissions for children with lower respiratory tract infections
- 2) Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s

The QOF indicator set examples of paediatric QOF indicators used include:(QOF, 2017)

- 1) The contractor establishes and maintains a register of patients with asthma, excluding patients with asthma who have been prescribed no asthma-related drugs in the preceding 12 months
- 2) The percentage of patients aged 8 or over with asthma (diagnosed on or after 1 April 2006), on the register, with measures of variability or reversibility recorded between 3 months before and or anytime after diagnosis
- 3) The percentage of patients with asthma, on the register, who have had an asthma review in the preceding 12 months that includes an assessment of asthma control using the 3 RCP questions
- 4) The percentage of patients with asthma aged 14 or over who have not attained the age of 20, on the register, in whom there is a record of smoking status in the preceding 12 months
- 5) The contractor establishes and maintains a register of patients with learning disabilities

Quality Measures - Denmark

Quality measures are available on http://www.kcks-vest.dk/kliniske-kvalitetsdatabaser/ and include those for Attention Deficit Hyperactivity Disorder **ADHD** (http://www.kcks-vest.dk/siteassets/de-kliniske-databaser/adhd/indikatorskema_bup-adhd_marts-2016.pdf) such as

- 1) The proportion of patients where there has been somatic investigation within 90 days of ADHD elucidation start
- 2) The proportion of patients of 6-18 years, undergoing a manualized diagnostic interview concerning differential diagnosis and comorbidity either Kiddie-Sad, PSE-SCAN or DAWBA within 90 days of ADHD investigation
- 3) The proportion of patients as assessed by environmental observation in school, home, or institution within 90 days of ADHD elucidation start

and Diabetes in children and youth (http://www.kcks-vest.dk/siteassets/de-kliniske-databaser/borne--og-ungdomsdiabetes/dandiabkids_indikatorsat2016_rev-27092016.pdf) such as

- 1) The proportion of patients with diabetes who have an HbA1c of \leq 59 mmol / mol
- 2) The proportion of patients with diabetes who have had severe hypoglycemia
- 3) The proportion of patients with diabetes who have had severe ketoacidosis
- 4) The proportion of patients with diabetes at least once a year have been measured blood pressure
- 5) The proportion of patients with diabetes who have undergone foot examination by applicable guideline









The Royal Children's Hospital Melbourne 50 Flemington Road Parkville Victoria 3052 Australia www.rch.org.au/ccch

The Centre for Community Child Health is a department of The Royal Children's Hospital and a research group of Murdoch Childrens Research Institute.