Online Companion Document

Companion information to supplement the *Snapshot Report*
Capacity Assessments in Relation to Healthcare Decision Making: A Jurisdictional Scan
March, 2022

Overview

The purpose of this companion document is to provide a supplementary list of references for the *CHRSP Snapshot on Capacity Assessments in Relation to Healthcare Decision Making*. These references provide additional knowledge and support about decision-making capacity assessments from general guidance documents and research articles published from 2016-2021 and were gathered in the setup phase for the report but fell outside the inclusion criteria for the Snapshot format.

Description of References Included

The references included in this document explore several themes:

- They describe processes used to assess decision-making capacity;
- They provide recommendations on how to carry out and/or improve assessment of decision-making capacity; and
- They report on barriers and facilitators of recommended capacity assessment processes, among other outcomes.

The references are organized alphabetically by article type and are divided into two main sections:

1. **Guidance Articles** - These include 5 references that provide clinical guidance or guidance from experts in the field about aspects of decision-making capacity assessments; and
2. **Research Articles** – These include 16 research studies with particular methodologies and are subdivided into the following article types:
    - 2 Scoping Reviews,
    - 1 Systematic Reviews,
    - 3 General Reviews and
    - 10 Primary Research Studies.

Following each reference is a brief description or direct quotation of the key points or guidance given in the article as it relates to decision-making capacity assessments. Some text has been bolded to add emphasis to the description or quote.

Reference List

Guidance Articles on Decision-Making Capacity Assessment

Barstow C, Shahan B, Roberts M. Evaluating Medical Decision-Making Capacity in Practice. Am Fam Physician. 2018 Jul 1; 98(1):40–6. (LINK)

- Clinical guidance article that goes through some steps for evaluating capacity
- The evaluation involves a number of steps including starting with **initial steps**:
    - "Ensure that there are no communication barriers".
    - "Evaluate for reversible causes of incapacity".
    - "Consider the patient's values and culture".
- "The next step is a **capacity assessment with a quick and informal directed clinical interview**".
- "If the directed interview does not clearly demonstrate capacity, or if additional information is required, the **use of a formal assessment tool is the next step**".
- "Assessing cognition can be useful but is not required to determine capacity".

- **"Determining that a patient lacks capacity and restricting his or her autonomy require clear and convincing evidence that the patient's decision will cause unintended and irreparable harm. If there is uncertainty after conducting a full capacity evaluation, the final judgment should err on the patient's side".**

Bourgeois J, Tiamson-Kassab M, Sheehan K, Robinson D, Zein M. Resource Document on Decisional Capacity Determinations in Consultation-Liaison Psychiatry: A Guide for the General Psychiatrist [Internet]. American Psychiatric Association; 2019. (LINK)

- "Guide for general psychiatrists who have the occasional need to complete decisional capacity determinations when functioning in a consultation-liaison role."
- "The authors…have reviewed the classic and emerging literature on DC in a consultation-liaison context, including clinical methodology, specific psychiatric and neurologic illnesses affecting DC, use of standardized rating instruments, and modification of clinical examination techniques for DC determinations."
- "The authors of this resource document cover a sequence of nine topic areas pertinent to DC determinations, ordered in a way consistent with the conduct of a consultation-liaison interview of a DC case."
- "In each section, there is a review of the relevant literature for that topic, yielding a literature-informed and comprehensive proposed clinical methodology for DC determinations in the context of consultation-liaison psychiatric evaluations."

Ehrman SE, Norton KP, Karol DE, Weaver MS, Lockwood B, Latimer A, et al. Top Ten Tips Palliative Care Clinicians Should Know About Medical Decision-Making Capacity Assessment. J Palliat Med. 2021 Apr 1; 24(4):599–604. (LINK)

- Provides "expert guidance to PC clinicians on best practice for complex DMC assessment."
- "Tip 1: Decision-Making Capacity Implies That a Person Can Make an Autonomous Choice; Clinicians Should Use Specific Criteria to Determine If a Patient Has Capacity for a Medical Decision"
- "Tip 2: Capacity Assessments Performed by Clinicians Have De Facto Legal Standing, Can Subsequently Be Reversed by Clinicians If Patient Capacity Changes, and Should Be Documented Appropriately"
- "Tip 3: Capacity Is Decision Dependent and Can Change as a Patient's Condition Changes; a Patient May Have Capacity for One Decision But Not Another in the Exact Same Moment"
- "Tip 4: When a Patient Lacks Capacity, the Appropriate Surrogate Should Be Identified; Decisions Made by the Surrogate Should Reflect the Values of the Patient, and Not Necessarily the Values of the Surrogate"
- "Tip 5: Decision-Making Capacity Develops Over Time as the Brain Matures: Some Pediatric Patients May Be Ready to Make Complex Decisions Well Before They Turn 18, and Some Adults May Not Be Ready"
- "Tip 6: Patients with Capacity Have the Right to Make Decisions That Are Not Consistent with Clinician Recommendations; as Such, Clinicians Should Be Extraordinarily Attentive to Personal and Professional Biases During Assessments"
- "Tip 7: When Patient Actions Are Incongruent with Their Stated Values, Further Exploration Is Warranted and Should Include Assessment for Mental Health Disorders"

- "Tip 8: Patients with Chronic Mental Health Conditions Often Retain Complex Decision-Making Capacity"
- "Tip 9: Acutely Altered Emotional States Due to Trauma or Suicidal Ideation May Temporarily Affect Capacity"
- "Tip 10: Patients Who Lack Capacity May Still Have the Right to Refuse Treatment"
- See Table 1 in the article text titled "A quick guide to capacity assessment"

Stuart RB, Thielke S. Protocol for the Assessment of Patient Capacity to Make End-of-Life Treatment Decisions. J Am Med Dir Assoc. 2018 Feb 1; 19(2):106–9. (LINK)

- Special article proposing a protocol "for assessing capacity to make decisions about end-of-life interventions" in the absence of clear guidelines
- "General decision making capacity has been well studied, but few clear protocols exist for ascertaining capacity at the end of life. Without clear guidelines about how to assess capacity, medical staff may ignore assessment and operate from invalid assumptions. In the interests of protecting patients' agency, we propose a straightforward protocol for assessing capacity to make decisions about end-of-life interventions."
- See Fig. 1. "Protocol for Assessing Patient Capacity to Accept or Refuse Medical Procedures."

Wong SP, Sharda N, Zietlow KE, Heflin MT. Planning for a Safe Discharge: More Than a Capacity Evaluation. J Am Geriatr Soc. 2020 Apr; 68(4):859–66. (LINK)

- "In this article, we explore frameworks and models of care that can be utilized to improve transition-of-care outcomes and alleviate some of the ethical dilemmas surrounding decision-making capacity, safe discharge planning, and supporting older adults in the community."
    - See "Table 1. Applying Person-Centered Elements to Discharge Decision Making" p. 861
    - See Figure 1 for "a model representing a multidisciplinary framework for discharge planning, with discussions, evaluations, and observations performed longitudinally across a variety of clinical settings" p.862'
    - See "Table 2. Examples of Programs Promoting Person-Centered Care and Optimizing Independence" p. 864

Research Articles on Decision-Making Capacity Assessment

Scoping Reviews

Charles L, Parmar J, Brémault-Phillips S, Dobbs B, Sacrey L, Sluggett B. Physician education on decision-making capacity assessment: Current state and future directions. Can Fam Physician Med Fam Can. 2017 Jan; 63(1):e21–30. (LINK)

- Scoping review, and qualitative research methods (focus groups and structured interviews)
- "Based on the scoping review of the literature, **4 main themes emerged**: **increasing saliency of DMCAs owing to an aging population, suboptimal DMCA training for physicians, inconsistent approaches to DMCA, and tension between autonomy and protection."**
- "The findings of the focus groups and interviews indicate that, while FPs working as independent practitioners or with inter-professional teams are motivated to engage in DMCAs and use the DMCA model for those assessments**, several factors impede their conducting DMCAs**. **The most notable barriers were a lack of education, isolation from inter-professional**

teams, uneasiness around managing conflict with families, fear of liability, and concerns regarding remuneration."

- "Participants in this study appreciated having strategies and supports that assisted them in conducting DMCAs; these included a patient centered care approach, best practice processes, and tools to guide the use of the DMCA model, particularly the worksheets."
- "Participants offered a number of **recommendations** that might lead to facilitating better engagement in DMCAs**: enhanced training and education, access to inter-professional teams, consultative or mentoring support, and remuneration**."

Usher R, Stapleton T. Assessment of older adults' decision-making capacity in relation to independent living: A scoping review. Health Soc Care Community. 2021 [Internet]. [Cited 2021 Nov 18];n/a(n/a). (LINK)

- "This scoping review aimed to identify and map current knowledge on assessment of older adults' decision-making capacity in relation to independent living. A five-stage scoping review framework was followed."
- Six themes were identified:
    - Theme 1: Functional approach to DMC assessment for independent living
    - Theme 2: Values and Preferences
    - Theme 3: Components of DMC assessment for independent living
    - Theme 4: Maximizing and supporting DMC
    - Theme 5: Specific assessments for independent living DMC
    - Theme 6: HSCPs involved in assessment

Systematic Review Articles

Gasparini M, Moro V, Amato S, Vanacore N, Gambina G. The evaluation of capacity in dementia: ethical constraints and best practice. A systematic review. Ann 1st Super Sanita. 2021 Sep; 57(3):212–25. (LINK)

- "Firstly, **to date there have been no tests designed to measure capacity**: all of the tools available have been adapted from those used for clinical diagnostics, and they investigate specific functions rather than abilities, with the result that the scores do not provide any relevant information concerning any compensatory, adaptive strategies implemented by the patient to face the demands of daily life. Similarly, **there are no standards for assessing capacity**, probably due to the fact that patients vary greatly from one to another even though the diagnoses and levels of medical care are similar. There is also the question of the specificity of the various different contexts relative to each individual. This means that a case-by-case tailor made approach is required."
- "Secondly, the lack of a gold standard is now the greatest challenge since the complexity of assessments of capacity cannot be reduced to simple scores for cognitive tests or questionnaires but is a complex endeavor involving cross-disciplinary knowledge involving, for instance, ethics, law, neuropsychology and neuroscience."
- "In light of this, the following **ethical recommendations** for the neuropsychological evaluation of capacity are particularly important:
    i. the use of several tools and various different approaches to the evaluation of the patient's daily life functioning skills;
    ii. respect for his/her residual autonomy to whatever degree it is present and
    iii. a tailored approach to his/her emotional, functional and cognitive responses, as well as to clinical and socio-demographic condition."

- "Thirdly, an issue which we consider needs to be addressed emerged from the present review. This concerns the lack of emphasis on the concept of awareness within any assessment of capacity."

Review Articles

Kan JYL. Rethinking the Assessment of Decision-Making Capacity and Making Treatment-Related Decisions. J Clin Ethics. 2020; 31(1):60–7. (LINK)

- This article reviews current methods to assess mental capacity - understanding, appreciating reason, communicating a choice
- The authors suggest a more comprehensive framework for assessing decision-making capacity for medical treatment and making treatment-related decisions (see figure 1)
- "There are a variety of instruments that provide questions to guide a structured or semi-structured interview to measure capacity that have good inter-rater reliability. Four of these published instruments are designed to include information tailored to the individual's condition and the specific decision at hand during the assessment."
- "The proposed enhanced framework incorporates important considerations for more comprehensive assessments of patients' decision-making capacity. The simple algorithm also serves as a guide to give clinicians confidence that their decision to proceed in patients' best interests, or to delay treatment-related decision making, is an appropriate and well-calculated one. Furthermore, determination of incapacity should not be the end of the process, but should serve as an opportunity for intervention to enhance patients' capacity, in hope of restoring their decision-making abilities and rightful autonomy."

Palmer BW, Harmell AL. Assessment of Healthcare Decision-making Capacity. Arch Clin Neuropsychol. 2016 Sep; 31(6):530–40. (LINK)

- "Psychologists/neuropsychologists faced with evaluating a patient's capacity to consent to (or dissent/refuse) healthcare need to consider all four dimensions of this construct: Understanding, Appreciation, Reasoning, and Expression of a Choice."
    - "In a **low-risk or simple context**, it may be acceptable to have this assessment as part of the informal/unstructured interview, but that discussion and assessment should still be guided by consideration of these four components."
    - "In **higher risk populations or contexts**, explicit formal/structured assessment of healthcare decisional capacity should be considered. In many cases, this assessment may be best guided by inclusion of one of the published instruments reviewed earlier [MacCAT-T, Competency Interview Schedule, SICIATRI, Capacity Assessment Tool], with the interpretive limitations of each instrument held in mind."
    - "In some cases, wherein a patient seems to lack capacity to consent, the reasons for his/her difficulties may not be readily apparent. It is in those contexts where we believe neurocognitive assessment may be helpful in identifying specific cognitive strengths and weaknesses."

Wade DT. Determining whether someone has mental capacity to make a decision: clinical guidance based on a review of the evidence. Clin Rehabil. 2019 Oct 1; 33(10):1561–70. (LINK)

- See Appendix 2 for suggested forms to assess capacity

- "The most important messages from this review of assessing mental capacity are that assessment and especially documentation of capacity must be an integral part of all clinical practice, and there are no short-cuts. In many cases, the patient's capacity is in fact obvious, but it must be recorded. In difficult cases, clinical judgement taking all facts into account is the only method; there is no definitive test of capacity and disagreement between assessors will occur quite frequently. Assessment by different people over time probably reduces uncertainty Supplemental Appendix 2 suggests the level of detail needed in different circumstances."
- "The **recommendations** are as follows:
    1. Capacity should always be considered within the decision-making process, and the outcome should be documented, with sufficient information to understand the opinion given.
    2. Detailed assessment should be reserved for situations when
        a) A major decision is needed and
        b) There is time to assess and discuss the assessment."

Primary Articles

Brémault-Phillips SC, Parmar J, Friesen S, Rogers LG, Pike A, Sluggett B. An Evaluation of the Decision-Making Capacity Assessment Model. Can Geriatr J. 2016 Sep 30; 19(3):83–96. (LINK)

- Methodology: Evaluation (mixed methods, survey and focus group)
- "The Decision-Making Capacity Assessment (DMCA) Model includes a best-practice process and tools to assess DMCA, and implementation strategies at the organizational and assessor levels to support provision of DMCAs across the care continuum. A Developmental Evaluation of the DMCA Model was conducted."
- "Strengths of the Model include its best-practice and implementation approach, applicability to independent practitioners and inter-professional teams, focus on training/mentoring to enhance knowledge/skills, and provision of tools/processes. Post-training, participants agreed that they followed the Model's guiding principles (90%), used problem-solving (92%), understood discipline-specific roles (87%), were confident in their knowledge of DMCAs (75%) and pertinent legislation (72%), accessed consultative services (88%), and received management support (64%). Model implementation is impeded when role clarity, physician engagement, inter-professional buy-in, accountability, dedicated resources, information sharing systems, and remuneration are lacking. Dedicated resources, job descriptions inclusive of DMCAs, ongoing education/mentoring supports, access to consultative services, and appropriate remuneration would support implementation."

Cairncross M, Peterson A, Lazosky A, Gofton T, Weijer C. Assessing Decision-Making Capacity in Patients with Communication Impairments: A Case Study. Camb Q Healthc Ethics. 2016 Oct; 25(4):691–9. (LINK)

- Methodology: Case study
- "In this article, we present a general strategy for assessing decision-making capacity in patients with communication impairments. We derive this strategy by reflecting on a particular case. The strategy involves three steps: (1) determining the reliability of communication, (2) widening the bandwidth of communication, and (3) using compensatory measures of decision-making capacity. We argue that this strategy may be useful for assessing decision-making capacity and preserving autonomy in some patients with communication impairments."

Charles L, Torti JM, Brémault-Phillips S, Dobbs B, Tian PG, Khera S, et al. Developing a Decision-Making Capacity Assessment Clinical Pathway for Use in Primary Care: a Qualitative Exploratory Case Study. Can Geriatr J. 2021 Feb 18; 24(1):26–35. (LINK)

- Methodology: Qualitative exploratory case study with three focus groups
- "Use of a decision-making capacity assessment clinical pathway has the potential to standardize decision-making capacity assessment processes in primary care, and support least intrusive and least restrictive patient outcomes for community dwelling older adults."
- "**Presently, there is no standard approach to DMCA in the primary care setting**. The development of an inter-professional Primary Care Decision-Making Capacity Assessment Clinical Pathway in this setting has the ability to facilitate the DMCA process and improve the consistency of DMCAs."
- See Appendix A for: "Initial pathway for Decision-Making Capacity Assessments (DMCA) in primary care"

Jayes M, Palmer R, Enderby P. An exploration of mental capacity assessment within acute hospital and intermediate care settings in England: a focus group study. Disabil Rehabil. 2017 Oct 9; 39(21):2148–57. (*LINK*)

- "This article reports a focus group study which aimed to explore how health and social care staff assess mental capacity in acute hospital and intermediate care settings."
- "The study was designed to generate data to inform the user-centered development of a toolkit to facilitate multidisciplinary staff members' mental capacity assessments."
- "Participants in this study suggested the two most important groups of patients requiring capacity assessment were patients who have a diagnosis of stroke or who have cognitive impairment due to dementia or delirium."
- "Participants identified the main patient decisions implicated in capacity assessments as those relating to discharge arrangements and treatment planning."
- "Participants in this study identified that different multidisciplinary staff tend to be involved in capacity assessment."
- "The assessment process includes potentially overlapping phases of information gathering and both formal and informal assessments of patients' decision making abilities."

John S, Schmidt D, Rowley J. Decision-making capacity assessment for confused patients in a regional hospital: A before and after study. Aust J Rural Health. 2020 Apr; 28(2):132–40. (LINK)

- Methodology: Before and after study
- See Figure 1 for **"**Capacity assessments clinical algorithm"
- "In order to address the perceived persistent difficulties with the capacity assessment and guardianship application, a capacity testing procedure (CTP) including a clinical algorithm "a traffic-signal framework" (Figure 1) was developed and implemented in a regional hospital in New South Wales, Australia. The CTP was designed by the lead author in conjunction with a multidisciplinary team (MDT). The CTP guided clinicians to decide when to conduct capacity assessments and guardianship applications."
- "The introduction of CTP was associated with improvements in some aspects of DMCA conduct for CHOPs. Of note, MDT meetings and documentation of capacity assessment process improved. There was no significant change in the presence of a valid trigger when requesting

capacity assessment, organizing family meetings and contacting patient GP in the process of capacity assessment, demonstrating that not all process steps were positively impacted."

Jones S, Gill P, Kenkre J. Nurse managed patient focused assessment and care: A grounded theory of qualified nurses in acute and critical care settings assessing the mental capacity of adult patients. J Clin Nurs. 2020; 29(7–8):1254–66. (LINK)

- Methodology: Qualitative study with semi-structured interviews
- "Nurse Managed Patient Focused Assessment and Care explains how qualified nurses assess the mental capacity of acutely and critically ill patients. Five categories were identified as having explanatory power:
    - Factors informing nurse-led assessment
    - Nurse-Led Assessment
    - Influence of the role of others
    - Impact of clinical setting
    - Caring role of the nurse"
- "The role of the nurse in assessing mental capacity is a process which appears to be hidden and applied during day-to-day nursing activities. These processes may be regarded as having significance in supporting the decision-making abilities of patients across acute and critical care settings."
- "Figures 1 and 2, used together, represent the grounded theory of Nurse Managed Patient Focused Assessment and Care"

Kane NB, Keene AR, Owen GS, Kim SYH. Applying decision-making capacity criteria in practice: A content analysis of court judgments. PloS One. 2021; 16(2):e0246521. (LINK)

- Methodology: Qualitative content analysis
- "We analysed all published cases from courts in England and Wales [Court of Protection (CoP) judgments, or Court of Appeal cases from the CoP] containing rationales for incapacity or intact capacity (n = 131). Qualitative content analysis was used to develop a typology of capacity rationales or abilities."
- "We argue that our typology of capacity rationales should be considered as a set of practical anchors to guide those approaching capacity assessments. The typology constitutes a group of rationales for capacity judgments which have been found acceptable by experienced judges evaluating real capacity dilemmas in a specialist court. The judgments covered a wide range of diagnoses (most commonly dementia, intellectual disability and psychosis) and types of capacity decision (most frequently medical treatment, residence and care), and hence can be seen to have a wide applicability. Although the typology emerged from judgments in a specific jurisdiction, we contend that the capacity rationales are relevant to any capacity assessor applying functional capacity criteria across jurisdictions where such criteria apply."

Lamont S, Stewart C, Chiarella M. Documentation of Capacity Assessment and Subsequent Consent in Patients Identified With Delirium. J Bioethical Inq. 2016 Dec; 13 (4):547–55. (LINK)

- Methodology: Retrospective documentation review
- "This study of patients with delirium sought to determine the processes by which consent to medical treatment was attempted, how capacity was assessed, and any subsequent actions thereafter."

- "As a result of the findings within this study, the authors have developed a decisional guide for health professionals working within this jurisdiction, when undertaking processes relating to capacity assessment and subsequent consent."
- See Fig. 1 "Capacity assessment and consent to treatment decisional pathway"

Poppe C, Elger BS, Wangmo T, Trachsel M. Evaluation of decision-making capacity in patients with dementia: challenges and recommendations from a secondary analysis of qualitative interviews. BMC Med Ethics. 2020 Jul 6; 21:55. (LINK)

- Methodology: Secondary analysis of qualitative interviews
- "In this study, we present findings from a secondary analysis of a qualitative interviews with physicians. These interviews were initially used to assess usability of an instrument for the evaluation of decision making capacity. By looking at difficult cases of decision-making capacity evaluation in patients with dementia, we provide recommendations for such evaluations in clinical practice."
- "…decision-making capacity evaluations in patients with dementia were mainly perceived as challenging when they pertained to treatment refusals and treatment unrelated circumstances, such as psychiatric consultation, advance directives, and new living arrangements. Furthermore, the physicians reported training needs regarding situation-independent challenges with decision-making capacity evaluation."
- **"Recommendations to address decision-making capacity evaluations of patients with dementia**"
    - "Evaluation of decision-making capacity as part of the informed consent process"
    - "Psychiatric evaluation of decision-making capacity"
    - "Solution-focused decision-making while respecting the right to autonomy"
    - "Presence of relatives and the evaluation of decision making capacity"

Usher R, Stapleton T. Occupational therapy and decision-making capacity assessment: A survey of practice in Ireland. Aust Occup Ther J. 2020 Apr; 67(2):110–20. (LINK)

- Methodology: Cross-sectional online questionnaire
- "The assessment process section was answered by 89 therapists, with therapists typically using multiple approaches to assess DMC. Typical assessment approaches included: performance-based assessments, interview-based assessments and professional judgment."
- "Participants also reported using information from cognitive screening assessments such as the
    - Montreal Cognitive Assessment;
    - Addenbrooke's Cognitive Examination (ACE-III);
    - Mini Mental State Examination (MMSE) and
    - Rivermead Behavioural Memory Test (RMBT)"
- "Respondents reported that cognitive screening tools are used as part of typical practice and the scores can be useful in informing the assessment of decision-making capacity."
- "Respondents reported MDT members specifically request a particular standardised assessment or screening tool be carried out to inform the overall assessment of the client's DMC."
- "Occupational therapists primarily engaged with physicians, nurses and social workers when assessing DMC."