

e-Ethics Bits and Bytes

Patient/SDM Education and Decision-Making Aids

Tools to aid HCPs

Introduction

This e-Ethics Bits and Bytes can be used to locate quality educational material to give to patients/SDMs to enhance their understanding. Decision aids can be used to walk patients through the decision-making process. Most tools have been evaluated in clinical trials.

Patient/SDM Education Sites

One of the biggest challenges is providing patients/SDMs with clear, accurate, quality information.

Canadian

Health Canada. <http://www.hc-sc.gc.ca/index-eng.php>

Public Health Agency of Canada. <http://www.phac-aspc.gc.ca/index-eng.php>

A-Z Index. <http://www.phac-aspc.gc.ca/a-z/index-eng.php>

Health Gateway. <http://www.healthgateway.ca/>

This site lists over 600 decision aids that have been evaluated in clinical trials.

The Ottawa Hospital Research Institute. Patient Decision Aids.

<https://decisionaid.ohri.ca/index.html>

Toronto General & Western Hospitals. Patient Education.

Overview http://www.uhn.ca/PatientsFamilies/Health_Information/Patient_Family_Education/Search_for_Health_Information

http://www.uhn.ca/PatientsFamilies/Health_Information/Patient_Family_Education/Pages/search_health_information.aspx

Health Information List of Videos

https://www.youtube.com/user/UHNPatientEducation/videos?view=0&sort=dd&flow=list&live_view=500

United States

Some information may not be applicable to the Canadian context.

Centers for Disease Control. Patient Education. <http://www.cdc.gov/vaccines/ed/patient-ed.htm>

Agency for Healthcare Research and Quality. <http://www.ahrq.gov/> This site has a vast array of information including a section for “consumers & patients.” Patients & Consumers <http://www.ahrq.gov/patients-consumers/index.html>

National Institutes of Health. <http://nih.gov/>

Health Information. <http://health.nih.gov/> select topic

MedlinePlus. Health information. <http://www.nlm.nih.gov/medlineplus/>

MedlinePlus. **Easy-to-Read.** (low literacy level; many have interactive tutorial)

http://www.nlm.nih.gov/medlineplus/all_easytoread.html

Society of Critical Care Medicine. MyICUCare.org <http://www.myicucare.org/Pages/default.aspx>

ICU-USA. <http://www.icu-usa.com/>

Mayo Clinic. Diseases and Conditions. <http://www.mayoclinic.com/health-information/>

YouTube, Patient Education

http://www.youtube.com/results?search_query=patient+education&oq=patient+education&aq=f&aqi=g5&aql=&gs_sm=3&gs_upl=740216209101188571211212171011991128718.411210

UPMC Patient Education Materials

<http://www.upmc.com/healthAtoZ/patienteducation/Pages/patiented.aspx>

Ohio State Patient Education Home <https://patienteducation.osumc.edu/Pages/Home.aspx>

Literature

The following articles outline patient education strategies; tips on writing materials for patient learning.

Canada

Cancer Care Ontario. Patient Education. Evidence-based Series (EBS)

<https://www.cancercare.on.ca/cms/one.aspx?objectId=10376&contextId=1377>

Friedman, AJ *et al.* Cancer Care Ontario. Effective Teaching Strategies and Methods of Delivery for

Patient Education <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>

Jewish General Hospital. How to Create Effective Written Patient Learning Materials.

<http://www.jgh.ca/uploads/Library/HandbookEngJan20.pdf>

United States

Ward, J. How to educate patients. Nursing Times.net <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/educators/how-to-educate-patients/5030180.article>

A Guide For Nurses: Teaching Healthcare Effectively to Patients

<http://www.healthcareersjournal.com/a-guide-for-nurses-teaching-healthcare-effectively-to-patients/>

Huffman, M. Health Coaching: A New and Exciting Technique to Enhance Patient Self-Management and Improve Outcomes. *Home Healthcare Nurse*. April 2007. Volume 25, Number 4

<http://www.wholehealtheducation.com/news/pdfs/health-coaching-for-health-care-providers.pdf>

Nettles, AT. Patient Education in the Hospital <http://spectrum.diabetesjournals.org/content/18/1/44.full>

<http://spectrum.diabetesjournals.org/content/18/1/44.full.pdf+html>

Graham, S; Brookey, J. Do Patients Understand? *The Permanente Journal*. Summer 2008/ Volume 12, No. 3 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3037129/>

Weiss, BD. Removing barriers to better, safer care. Health literacy and patient safety: Help patients understand. Manual for clinicians. 2nd ed. AMA Foundation

http://www.med.fsu.edu/userFiles/file/ahc_health_clinicians_manual.pdf

Decision Making Capacity

The assessment of decision making capacity is fundamental whenever treatment is proposed. Using a standardized, evaluated tool is essential. The following tools have been evaluated in clinical trials.

Aid to Capacity Evaluation (ACE)

This tool is used for assessing capacity for treatment decisions. Questions can be altered to make them PAD specific.

Etchells, Ed. Aid to Capacity Evaluation (ACE). University of Toronto, Joint Center for Bioethics, Aid to Capacity Evaluation package can be downloaded @

<http://www.jointcentreforbioethics.ca/tools/ace.shtml>

Etchells, Ed. Aid to Capacity Evaluation (ACE) Training Presentation. Online Course

http://www.cw.bc.ca/onlinecourses/ace/ace_ace_instruction_p001.htm

Etchells, Ed. *et al.* Assessment of Patient Capacity to Consent to Treatment. *J Gen Intern Med* 1999

January; 14(1): 27–34 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1496441/pdf/jgi_277.pdf

Etchells, Ed. *et al.* Bioethics for Clinicians 3. *CMAJ* 1996 155: 657-661

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1335218/pdf/cmaj00102-0043.pdf>

Communication Aid to Capacity Evaluation (CACE)

This tool is for assessing capacity for admission decisions for patients with communication challenges. It is based on the ACE tool and uses pictures to communicate. Questions and pictures can be adapted to fit other questions.

Carling-Rowland, Alexandra. Communication Aid to Capacity Evaluation – CACE. 2012. Tool, documents, communication cards and training video are at. <http://www.aphasia.ca/home-page/health-care-professionals/resources-and-tools/cace/>

Carling-Rowland, Alexandra. Adaptation of the Capacity Evaluation Process to make Admission .Decisions: Increasing Access for People with Aphasia and other Communication Barriers
https://tspace.library.utoronto.ca/bitstream/1807/30035/1/Rowland_E_Alexandra_201106_PhD_thesis.pdf

Consent & Capacity

This is an excellent pocket tool for use by HCPs and or patients/SDMs.

National Initiative for the Care of the Elderly. Tool on Capacity & Consent: Ontario edition.
<http://www.nicenet.ca/files/Capacity.pdf>

Health Care Decision-Making Role

This is an excellent short video for patients and SDM regarding their respective roles in decision-making and decision-making standards.

Paula Chidwick and Jill Oliver. What is your Role in Health Care Decision-Making in Ontario? Video
<https://youtu.be/T7s9xOR-xo0>

End of Life Decision Making

CARENET CPR Decision Aid

The CARENET website has many resources to assist HCPs educate patients/SDMs.

Canadian Researchers at the End of Life Network. <http://www.thecarenet.ca/>

CPR Decision Aid – Video <http://www.thecarenet.ca/resource-center>

CPR Decision Aid – Print <http://www.thecarenet.ca/resource-center>

Goals of Care – Just Ask

Goals of Care. Just Ask: A Conversation Guide for Goals of Care Discussion. <http://thecarenet.ca/our-campaigns/just-ask-campaign>

or

http://www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_just_ask_booklet-rev-may8_final-web.pdf

You, J. *et al.* Just ask: discussing goals of care with patients in hospital with serious illness. *CMAJ* April 1, 2014 186(6): July 15, 2015
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3971028/pdf/1860425.pdf>

CPR/DNR Discussion, Decision-Making Aids

Taylor, RM. *et al.* Improving Do-Not-Resuscitate Discussions: A Framework for Physicians .

https://media.capc.org/filer_public/42/55/42551c57-0351-4509-94a6-a3992c01754c/the_ohio_state_taylor.pdf

Taylor, RM. *et al.* Improving Do-Not-Resuscitate Discussions: A Framework for Physicians . *J Support*

Oncol 2010;8(1). <http://www.oncologypractice.com/view-pdf.html?file=jso/journal/articles/0801042>

von Gunten, CF; Weissman, DE. Fast Facts and Concepts #23. Discussing DNR Orders – Part 1. Palliative

Care Network of Wisconsin. <http://www.mypcnow.org/#!/blank/tapnc>

von Gunten, CF; Weissman, DE. Fast Facts and Concepts #24. Discussing DNR Orders – Part 2. Palliative

Care Network of Wisconsin. <http://www.mypcnow.org/#!/blank/gqrzh>