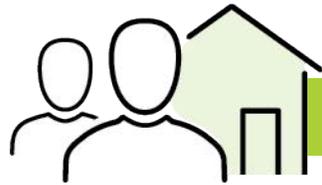


Environmental Scan

Additional Resources

This document is a list of existing and non-affiliate resources put together by our research team. We hope that these resources may be helpful to older adults living at home with frailty and their family caregivers, health-care providers, healthcare managers and leaders, or government leaders and decision-makers. Below you will find links to resources for these different groups. The titles of the resources are hyperlinked to live links on the internet that will bring you directly to the resource when clicked.

The links were last verified on January 20, 2020.



[Patients & Caregivers on pages 2-5](#)

[Healthcare Providers on pages 6-7](#)



[Healthcare Managers & Leaders on page 8](#)

[Government Leaders & Decision-makers on page 9](#)



Patients and Caregivers

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[C-DEMQOL: A measure of carer quality of life for those who live with someone with dementia Video](#)

About a quality of life assessment tool that was developed at the Brighton and Sussex Medical School that assesses the quality of life of family caregivers of people living with dementia.

[Manual for the Adult Carer QOL Questionnaire \(AC-QOL\) PDF](#)

Explains the specific use of the AC-QOL caregiver quality of life assessment tool.

[Agency for Clinical Innovation: What are PROMs and PREMs? PDF Presentation](#)

Created by the Agency for Clinical Innovation (ACI) of the government of New South Wales, Australia on patient reported outcome measures (PROMs) and patient reported experience measures (PREMs).

[Alberta Health Services Palliative & End of Life Care Webpage](#)

Contains information healthcare professionals on palliative and end of life care and the revised Edmonton Symptom Assessment Scale (ESAS).

General QOL Resources

[Australian Commission on Safety and Quality in Health Care: Patient-Reported Outcome Measures Literature Review PDF](#)

Accumulates more knowledge about the use of PROMs internationally in health systems similar to the one in Australia.

[BC SUPPORT Unit: BC Patient-Centred Measurements Data YouTube Video](#)

Shares patient centred measurement data in British Columbia (BC) to researchers.

[Canadian Institute for Health Information: PREM's Webpage](#)

Contains links to various resources on PREMs.

[Canadian Institute for Health Information Webpage](#)

Contains information on the use of PROMs, the CIHI's PROMs program, and the use of PROMs in the care of patients undergoing joint replacement surgery and those with renal disease.

(NOTE: general information but also mentions use in hip and knee replacements, and renal disease)

[Centers for Disease Control and Prevention: Policy and Practical Implications of HRQOL Surveillance Webpage](#)

Outlines the United States government Centers for Disease Control and Prevention (CDC) information and implementation initiatives of health-related quality of life (HRQOL) tools.

[Code Technology: Veterans RAND 12 \(VR-12\)](#)

Explains the background of the VR-12 health survey, how answers are scored, and what the strengths and weaknesses of the reporting tool are.

(NOTE: this is about the VR-12, history and development)

Patients and Caregivers

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[DREX Quality of Life Assessment YouTube Video](#)

Provides a step-by-step guide on how to complete a quality of life assessment.

[Durham Reading and Exploration Training: Quality of Life Assessment YouTube Video](#)

Provides a step-by-step guide of how to complete the DREX quality of life assessment tool.
(NOTE: teaches how to use a specific tool (DREX))

[E-Learning at Upskill: Demo – Professional Quality of Life Scale \(PROQOL\) YouTube Video](#)

Depicts a quality of life assessment being completed electronically.

[Hospital News: Putting the Focus on Patients Web Article](#)

Outlines how patient reported outcome and experience measures are shifting the focus to patients in the Canadian healthcare system.

[KCE \(Belgium Healthcare Knowledge Center\) Short Report on Use of Patient Reported Outcome and Experience Measures in Patient Care and Policy PDF](#)

Contains information on the implementation strategies and methods being used to implement PROMs and PREMs into the healthcare system.

[Progether – The Prostate Cancer Network YouTube Video](#)

Outlines a narrative example of the impact of patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) as well as the goals of a German company in a world-wide effort to track PROMs and PREMs in prostate cancer.

[Mass General Hospital: HUBweek Healthcare Innovations – Brigham & Women’s Hospital Patient Reported Outcome Measures YouTube Video](#)

Describes how patient reported outcomes are integrated into care at Mass General Hospital.

[NIHOD: National Institute of Health PROMIS YouTube Video](#)

Demonstrates the specific use of the Patient Reported Outcome Measurement Information System (PROMIS) quality of life assessment tool in the care of patients living with chronic illnesses.

[OBERD: Patient Reported Outcomes – Benefits to Patients and Providers YouTube Video](#)

Outlines the benefits of patient reported outcomes for patients and healthcare providers.

[Partners Healthcare PROMS: Patient Reported Outcome Measures Provider YouTube Video](#)

Explains a PROMs measurement screening tool that is used by a non-profit hospital in Boston, Partners Healthcare.

[Powell River Division of Family Practice: Edmonton System Assessment Scale \(ESAS\) YouTube Video](#)

Outlines how to complete the Edmonton System Assessment Scale (ESAS).
(NOTE: this tool teaches ESAS specifically)

Patients and Caregivers

Environmental Scan



[World Health Organization: Measuring Quality of Life Webpage](#)

Outlines the specific uses of the World Health Organization's quality of life instruments.

Hematology

[American Society of Hematology: The PROs of Patient-Reported Outcomes YouTube Video](#)

Describes the use of patient reported outcomes in hematology.

Bipolar Disorder

[CREST.BD: About the ORBIT Research Program YouTube Video](#)

Describes a research program that is aimed at improving the quality of life of people living with Bipolar Disorder through the development of new skills and the use of videos and interactive resources.

[CREST.BD: Applying the Quality of Life in Bipolar Disorder QOL.BD Assessment Scale – Patient Vignette 1 YouTube Video](#)

Features a vignette of a healthcare provider applying the results of a quality of life assessment to patient care.

[CREST.BD Research Website](#)

A multidisciplinary collaborative research team studies psychosocial issues in Bipolar Disorder.

Joints and Spine

[University of Oxford Keeping the Patient in the Picture: Patient Reported Outcome Measures YouTube Video](#)

Describes the use of patient reported outcome measures with patients undergoing joint replacement surgeries.

[Dartmouth-Hitchcock How Patient-Reported Outcomes are used at the Spine Center YouTube Video](#)

Describes the use of patient-reported outcomes at the Spine Center at the Dartmouth-Hitchcock Medical Center.

[OBERD: Specialty Society Recommendation Initiatives – AAOS YouTube Video](#)

Displays an example of standardized scores for specific tools.

[Canadian Institute for Health Information: PROMs Background Document PDF](#)

Contains detailed background information on PROMs and PREMs, values for stakeholders, a comparison of various tools, and the frameworks for national and international initiatives.

Pediatrics

[Cincinnati Children's: Patient Reported Outcomes YouTube Video](#)

Discusses the use of patient reported outcomes in the care of pediatric patients.

Patients and Caregivers

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[KidsPRO Introduction YouTube Video](#)

Describes the use of KidsPRO in relation to the care of pediatric patients with asthma.

[KidsPRO Patient Partners Recruitment YouTube Video](#)

Designed to recruit pediatric patients living with asthma in co-designing KidsPRO.

Cancer

[Canadian Partnership Against Cancer: Person Centred Perspective: Patient Reported Outcome Video for Patients YouTube Video](#)

Outlines the use of patient reported outcomes in person-centred care for patients with cancer.

[OnLiveTV: Jeannine Brant on the Benefits of Patient-Report Outcomes YouTube Video](#)

Discusses the benefits of patient reported outcomes in cancer care.

[Quality of Life Assessments in Clinical Practice – Journal Article](#)

Outlines the use and value of quality of life assessments in clinical practice when caring for oncology patients.

[MUSICUROLOGY: MUSIC \(PRO\) Patient Reported Outcomes YouTube Video](#)

Describes the use of a specific patient reported outcome tool in the care of patients living with prostate cancer.

**More resources in the other sections of this document may also be relevant.

Healthcare Providers

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[Alberta Health Services Palliative & End of Life Care Webpage](#)

Contains information for healthcare professionals on palliative and end of life care and the revised Edmonton Symptom Assessment System.

[Canadian Institute for Health Information: Program Information Sheet PDF](#)

Outlines the CIHI's PROMs program.

[Canadian Researchers at the End of Life Network Resource Centre Webpage](#)

Contains a description of why the Canadian Health Care Evaluation Project (CANHELP) questionnaire was developed, how the scoring works, and various versions of the tool.

[Canadian Virtue Hospice: Assessing Quality of Life YouTube Video](#)

Demonstrates the development of the McGill questionnaire.

[Family Caregiver Alliance: Selected Caregiver Assessment Measures: A Resource for Inventory for Practitioners \(2nd Edition\) PDF](#)

Provides healthcare practitioners with an inventory of tools they can use to assess the quality of life of caregivers.

[Manual for the Adult Carer QOL Questionnaire \(AC-QOL\) PDF](#)

Explains the specific use of the AC-QOL caregiver quality of life assessment tool.

[NIHOD: National Institute of Health PROMIS YouTube Video](#)

About the specific use of the Patient Reported Outcome Measurement Information System (PROMIS) quality of life assessment tool in the care of patients living with chronic illnesses.

[The Carer Support Needs Assessment Tool PDF Document](#)

Outlines what the Carer Support Needs Assessment Tool (CSNAT) is.

[The Carer Support Needs Assessment Tool Website](#)

Contains many different resources for using the Carer Support Needs Assessment Tool (CSNAT).

[CREST.BD's Quality of Life Tool: Video for Healthcare Providers YouTube Video](#)

For healthcare providers on the use of quality of life assessment tools and their utility in patient care.

[Healthcare Improvement Scotland: PROMs Clinician User Guide](#)

Outlines how to implement PROMs into practice and is designed for clinician use.

Healthcare Providers

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[Healthcare Improvement Scotland: PROMs Knowledge Transfer Partnership Project Webpage](#)

Contains information about a research project on the implementation of PROMs into clinical practice.

[Healthcare Improvement Scotland: PROMs Patient Information Leaflet](#)

Contains introductory information on patient-reported outcome measures and their use in clinical practice.

(NOTE: mostly a general source but makes mention to NHS – Scotland’s healthcare)

[Applying Quality-of-Life Data Formally and Systematically Into Clinical Practice – Journal Article](#)

Describes the integration of quality of life assessments into clinical practice and the barriers that prevent clinicians from doing so.

[Impact of Quality of Life Measurement in Daily Clinical Practice – Journal Article](#)

Outlines the use of quality of life measurement in daily clinical practice.

[Implementing Patient-Reported Outcomes Assessments in Clinical Practice: A Review of the Options and Considerations – Journal Article](#)

Outlines the implementation of patient-reported outcomes assessments in clinical practice.

[International Society for Quality of Life Research: User’s Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice PDF](#)

Provides an overview of how to implement patient-reported outcomes into clinical practice.

[OBERD Selecting Quality Measurement Tools YouTube Video](#)

Demonstrates how to select measures.

[OBERD Types of Quality Performance Measures YouTube Video](#)

Demonstrates how to select the correct tool depending on what a healthcare provider is aiming to measure.

[York Health Economics Consortium \(YHEC\) Patient-Reported Outcome Measures \(PROMs\): Implementation of PROMs YouTube Video](#)

Discusses the implementation of PROMs into clinical practice.

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Healthcare Managers & Leaders

Environmental Scan



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[OBERD: Global Standardization Initiatives YouTube Video](#)

Highlights the global efforts of standardized measurement sets, including PROMIS and ICHOM. OBERD: Measurement Standardization Efforts YouTube Video
Shows the issues surrounding the standardization of PROMs.

[Organisation for Economic Co-operation and Development \(OECD\): Patient-Reported Indicators Surveys \(PaRIS\) Webpage](#)

Contains information about the relevance of understanding patient perspectives on healthcare delivery and health systems.

[Recommendations to the Organisation for Economic Co-operation and Development \(OECD\) Ministers of Health from the High Level Reflection Group on the Future of Health Statistics PDF](#)

Outlines the importance and benchmarking of patient-reported indicators of health system performance and supporting countries in embedding patient-reported indicators into national health system performance assessment.

**More resources in the other sections of this document may also be relevant.

Government Leaders & Decision-makers

Environmental Scan



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