

# References

## Used in All Resources

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This document provides the references for statements made in the following resources:

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## Older Adults and Family Caregivers – Live Your Best Life Possible

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If you're an older adult, living at home, and have an ongoing health condition – or you're caring for an older family member – your healthcare team cares about your quality of life (1, 2).

### Quality of Life Assessments

- How are you doing?
- How is your care?
- What matters to you?

### Proven Healthcare Tools Can Help

Tools for quality of life assessments have been shown to help:

- Older adults to work with their healthcare providers to live comfortably at home as long as possible (1, 3-17).
- Family members who are coping with the demands of caring for a loved one at home (5, 8, 9, 18)

These tools are a series of simple-to-answer questions about **your** health, **your** care, and **your** life (21).

### Sample Quality of Life Assessment Questions

The answers to these questions are about you – even if someone helps you fill it out. What's more there are no "right" or "wrong" answers. It's the "right" answer if it's what you really think or feel.

- *A: Over the past two days 48 hrs), emotionally I felt (19):*
  - For example, if you felt:
    - Very Bad, you might circle a 0 or 1.
    - Poor, you might circle a 2 or 3.
    - Moderate, you might circle a 4, 5, or 6.
    - Good, you might circle a 7 or 8.
    - Excellent, you might circle a 9 or 10.
- *B: In general, how satisfied are you with the quality of your care (20)?*

### Why These Questions Matter

- Your **healthcare providers** will be able to better understand how you are doing (1, 2, 22).
- If you're an **older adult**, the healthcare team can help you find the support you need to live comfortably at home (1, 3-17).
- If you're a **family caregiver**, the healthcare team can help you find the resources you need to support you and your loved one (1, 5, 8, 9, 18).

### What to Do

- **ANSWER** the quality of life assessment questions online each time before you have an appointment with your healthcare provider (23-25).
- **ASK** your healthcare provider if you can talk about the answers you provided when you're at your appointment (22, 26, 27).
- **LEARN** more at: [healthyqol.com](http://healthyqol.com)

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# Older Adults and Family Caregivers – Frequently Asked Questions (FAQs) About Quality of Life Assessments

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These frequently asked questions are about quality of life assessments for: **older adults** living with an ongoing health condition, or their **family caregivers**.

## What are quality of life assessments?

These assessments help support you in living your best life possible (1, 2). They include questions about many different parts of your life, such as your thoughts and feelings about your:

- They help your healthcare team understand what matters most to you (21), make better decisions about your care (2, 28), and get valuable information that might otherwise get missed in routine healthcare visits (21, 29-32)
- Your answers can help improve the healthcare system (28)

## Frequently Asked Questions (FAQ) About Quality of Life Assessments

### What are quality of life assessments?

- These assessments help support you in living your best life possible (1). They include questions about many different parts of your life, such as your thoughts and feelings about your:
  - Physical and emotional health
  - Healthcare experiences
  - Independence
  - Social support and relationships
  - Living situation and finances (21, 33, 34).
- These questions can be for older adults living with an illness or for their family caregivers (14, 18).

### How do I answer the questions?

You can answer the questions:

- On the internet
- Over the phone
- In person
- On paper (23, 24).

It's best if you answer these questions by yourself, so that other people don't influence your answers. But it's sometimes helpful to have a family member, friend, or healthcare provider help you log on to the internet or read the questions to you.

### How do I give my quality of life a number?

There are no right or wrong answers to these questions. It's the "right" answer if it's what you really think or feel.

### Why do these assessments matter?

Your answers can help you:

- Receive better care (2, 28),
- Keep track of your overall health and wellness (21)
- Get the support you need to continue to live comfortably at home (1, 3-17).
- Enhance your relationship with your healthcare providers (2, 27).

They help your healthcare team:

- Understand what matters most to you (21).
- Make better decisions about your care (2, 28).
- Get valuable information that might otherwise get missed in routine healthcare visits (21, 29-32).

Your answers can help improve the **healthcare system** (28).

In sum, you can live your best life possible.

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## Healthcare Providers – Start the Conversation About Quality of Life Assessments

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This brochure is for healthcare providers. It focuses on Quality of Life (QOL) assessments for two populations: **older adults** living with frailty, and their **family caregivers**.

QOL assessments are tools that ask these people about what matters to them about their health and their healthcare experiences.

### Quality of Life Assessments

- How are you doing?
- How is your care?
- What matters to you?

To see sample QOL questions, please refer to the “Living Your best Life” brochure for older adults and family caregivers.

### How QOL Assessments Make a Difference

The responses to an assessment have been shown to:

- Empower patients and family caregivers
- Guide more meaningful conversations with you
- Improve participation in making care decisions with you
- Promote person- and family-centred care (1, 2, 22, 29, 31, 35-38).

Regularly assessing a person's QOL saves healthcare providers time in the long run by focusing on what matters to patients and family caregivers.

As a healthcare provider, consider these talking points when introducing quality of life (QOL) assessments to two groups: **older adults** living with frailty, and their **family caregivers**.

### For engaging older adults living with frailty:

1. I want to be sure the care we're providing addresses your needs and helps you live your best life possible by discovering what matters most to you.

To help with that, could you please answer these questions on this *[tablet, computer, form]*?  
(Provide assessment.)

2. Could we go through a few questions together? It will help us to better address your concerns.

### For clerical staff to use with patients and caregivers:

1. Your healthcare provider would like to know more about what's important to you regarding **your** health and **your** current quality of life.

Could you please answer these questions on this *[tablet, computer, form]*? (Provide assessment.)

### For engaging family caregivers:

1. Can you please complete these questions about living your best life possible? It will help me understand what matters most to **you** in **your life** as you care for *[patient's name]*.

### For engaging older adults living with frailty or family caregivers:

1. Your answers will help us to work together to make decisions about your care.

I also have some information you can keep about why these questions are important. (Provide patient/family caregiver resources).

### What to Do

- **INCORPORATE** the use of QOL assessments in your practice.
- **ENGAGE** both older adults living with frailty and their family caregivers in QOL assessments.
- **USE** QOL assessment responses to inform care decisions.

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## Healthcare Providers – The Truth About Quality of Life Assessments

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These truths can help healthcare professionals correct any common misconceptions about the use of quality of life (QOL) assessments for **older adults** living with frailty, and their **family caregivers**.

MYTH	TRUTH
QOL assessments take away from the relational side of healthcare.	QOL assessments <b>promote relational care</b> by uncovering unsaid needs and providing an opportunity to facilitate a therapeutic relationship (27, 29-32).
QOL assessments are only for patients.	Some QOL assessment tools specifically assess the QOL and healthcare experiences of <b>family caregivers</b> (18, 19, 39, 40).
Healthcare providers are not able to respond to the needs revealed by the QOL assessments.	Together with patients, you can <b>determine the next steps of care</b> , involving other members of the healthcare team and resources in the community (22, 29, 31, 35, 37, 41, 42).
Older adults living with frailty do not perceive QOL assessment tools as valuable.	QOL assessment tools enable older adults living with frailty to share <b>what matters to them about their healthcare and their experiences of care</b> (1, 22).
There is no need for another assessment tool. Patients and family caregivers will tell you when they have concerns and unmet needs.	While some <b>patients</b> might discuss their needs, most will wait for you to ask. Many <b>family caregivers</b> won't voice their own needs because they want the patient's concerns to take priority (22, 26).
QOL assessments take too much time out of already busy days.	QOL assessments help to direct attention to health-related issues that might otherwise get missed, and can potentially save time by <b>identifying problems early</b> (29-32, 43).
It is too difficult for patients living with frailty to answer questions about their QOL due to decreased cognitive function, language barriers, or vision or hearing problems.	QOL assessments can be delivered in <b>various forms and languages</b> . Even incomplete information you gather about a patient's QOL can be valuable (23, 24).
QOL assessments undermine your clinical expertise.	Patients can provide you with <b>information that can't be assessed otherwise</b> . This can be used to enhance decisions made with your clinical expertise (2, 29, 42).

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## Healthcare Managers and Leaders – Start the Conversation About Quality of Life Assessments

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These talking points focus on quality of life (QOL) assessments for two groups: **older adults** living with frailty, and their **family caregivers**. These conversation starters may help healthcare managers and leaders when they talk to other healthcare managers and leaders.

**1. “I’d like to discuss the use of QOL assessments in order to:**

- Enhance healthcare performance and accountability.
- Better meet the needs of older adults and their family caregivers.”

QOL assessments include questions that can help us to measure what matters to them regarding:

- Life
- Healthcare experiences
- Physical, mental, and social health (38, 44).

**2. “QOL assessment data help ensure that our organisation is providing person- and family-centred care by revealing the needs of individuals (29, 45).”**

Healthcare viewpoints of older adults living with frailty and their family caregivers:

- Provide unique information regarding healthcare performance.
- Allow us a more complete picture of what matters to individuals.

These powerful data need to be routinely collected for analysis.

**3. “QOL assessment data provide important information for evaluating and optimizing quality of care for our organisation (14, 42, 45-58).”**

We can use these data to evaluate, monitor, and improve the quality of care and experiences of older adults and their family caregivers (1, 36).

These data provide the best available evidence to make decisions about person-centred quality improvement initiatives and changes we may choose to implement (28, 38).

**4. “QOL assessment data may help us demonstrate accountability for person-centred healthcare services.”**

QOL assessment results provide powerful information that demonstrate how patients’ voices are integral in evaluating healthcare service delivery and future improvement (28).

### What to Do

- **START** the conversation with other healthcare managers and leaders.
- **ACCESS** reports on QOL assessment data.
- **USE** QOL assessment reports to inform healthcare decisions.

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## Healthcare Managers and Leaders – Making a Difference With Quality of Life Assessments

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This resource is for healthcare managers and leaders. It focuses on quality of life (QOL) assessments for two groups: **older adults** living with frailty, and their **family caregivers**.

**Quality of life (QOL) assessments include questions that help to measure what matters to individuals about their:**

- Life
- Physical, mental, and social health
- Healthcare experiences (38, 44).

**Many tools are available for measuring QOL (38, 59, 60). These are often referred to as:**

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs)

The term “patient” refers to all people who have experience with health challenges, including family caregivers.

### How are QOL assessment results used

#### at the individual level?

**Healthcare providers** use QOL assessment results to help make better-informed, person-centred healthcare decisions (42).

#### at the population level?

The routine use of QOL assessment results can help **healthcare management leaders**:

1. Optimize quality improvement initiatives to better meet the needs of older adults and their family caregivers (30, 36, 61).
2. Demonstrate accountability in providing person-centred healthcare services (e.g., accreditation requirements) (30, 36, 61).

The results can also help government leaders identify needs and make policy and budget decisions (1).

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## Government Leaders and Decision Makers – Fact Sheet About Quality of Life Assessments

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Quality of life (QOL) assessments include questions that help to measure what matters to individuals about their: quality of life, healthcare experiences, physical, mental and social health.

This Fact Sheet focuses on QOL assessments for two populations: **older adults** living with frailty, and their **family caregivers**.

**Fact: QOL assessments are tools for everyone who lives with health challenges, including family caregivers (67).**

QOL assessment tools for older adults living with frailty and those for their family caregiver include:

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs) (68).

**Fact: QOL assessment results provide powerful data that are as valid as clinical and administrative data.**

QOL assessments offer insights into the healthcare system from a person-centred viewpoint.

**Fact: QOL assessment results can help inform healthcare decisions.**

Consistent collection of QOL assessment data can help inform a range of decisions, regarding:

- **Healthcare system priorities** for different regions, facilities, and populations.
- **Quality improvement (QI)** when used before, during, and after QI initiatives, health system changes, or new policies.
- **Budgets and policy**, focusing on those services that make the greatest positive impact on healthcare (36, 59).

**Fact: Rigorous testing of QOL assessment tools is necessary; assessments must be administered consistently (69).**

Many different types of QOL assessment tools exist.

The best tools undergo rigorous cognitive and psychometric testing to ensure that the questions are:

- Meaningful and understood by older adults and family caregivers (70).
- Effective in allowing for comparisons of results across time (71) and between different groups (72).
- Useful in providing actionable insights for healthcare providers and government decision makers (60, 65).

**Fact: Resources are available to help understand and use QOL assessment tools and data.**

Some of these resources include organisations, such as:

- International Society for Quality of Life Research (ISOQOL)
- The Professional Society for Health Economics and Outcomes Research (ISPOR)

Peer-reviewed bibliography available at: [healthyqol.com/additionalresources](https://healthyqol.com/additionalresources)

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# Government Leaders and Decision Makers – Frequently Asked Questions (FAQs) About Quality of Life Assessments

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The FAQs in this resource focus on quality of life (QOL) assessments for two populations: **older adults** living with frailty, and their **family caregivers**.

## What are quality of life (QOL) assessments?

QOL assessments include questions that measure what matters to people regarding their:

- Physical, mental, and social health
- Quality of life
- Healthcare experiences (21, 33, 34, 44).

## How is QOL measured?

There are many tools available for measuring QOL. These are often referred to as:

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs)

The term “patient” refers to all people who have experiences with health challenges, including family caregivers.

## What do government leaders need to know about QOL assessments and results?

It’s important to know that:

- QOL assessment tools were rigorously tested to ensure validity (36, 60, 62).
- Those who analyse and interpret these QOL assessment data need to be experts in measurement.
- QOL assessment data can be combined with existing clinical and administrative data to better inform decisions about health system performance, quality, and policy (47, 63).

## How are QOL assessment results used

### at the individual level?

Healthcare providers use QOL assessment results to make better-informed, person-centred healthcare decisions (1, 2, 22, 29, 31, 34-38, 64).

### at the population level?

Government leaders can use these QOL assessment results for older adults living with frailty, and their family caregivers in three important ways:

#### Monitor Performance

QOL assessment results can help government leaders:

- Compare regions, facilities, and populations.
- Monitor healthcare system performance.
- Identify areas for healthcare system improvement (14, 28, 47).

#### Improve Quality

QOL assessments can reveal changes in healthcare experiences and outcomes of older adults and their family caregivers associated with:

- Health system changes
- Quality initiatives
- New policies (65).

#### Make Policy and Budget Decisions

QOL assessments can help government leaders and decision makers measure what matters most to older adults living with frailty, and their family caregivers. Combined with clinical and/or administrative data, these data can inform person-centred policy-making and budget decisions (66).

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